

2015

Existential Suffering and Cura Personalis: Dilemmas at the End-of-Life

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Recommended Citation

George P. Smith II, Existential Suffering and Cura Personalis: Dilemmas at the End-of-Life, CUA Columbus School of Law Legal Studies Research Paper No. 2015-3 (2015).

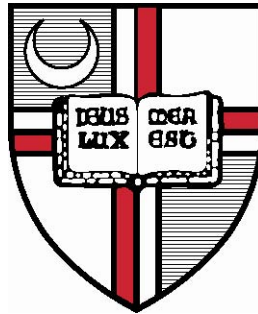
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THE CATHOLIC UNIVERSITY OF AMERICA

COLUMBUS SCHOOL OF LAW

Legal Studies Series

Accepted Paper No. 2015-3 Date: 2015



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at the End-of-Life**

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A paper presented at the International Congress on Law and Mental Health

Vienna, Austria

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The Columbus School of Law – <http://law.cua.edu/>

Existential Suffering and *Cura Personalis*: Dilemmas at The End-of-Life

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Abstract

Existential, or non-somatic suffering, is often associated with the management of refractory pain at the end-stage of life. Because of misleading sympathologies, this condition is often either misdiagnosed or even ignored. When diagnosed as a part of a futile medical condition, this Paper argues that deep, palliative, or terminal sedation be offered to the distressed, dying patient as an efficacious and ethical response to preserving a semblance of human dignity in the dying process. Not only is this option of care humane and compassionate, it is consistent with the ideal of best patient care. The notion of care should not only address and include somatic issues of intractable pain management, but—as well—non-somatic or existential suffering occurring in the absence of physical symptoms. Interestingly, sound holistic medicine traces its very province to the foundational value, or chrism of *cura personalis* which in turn directs respect be given to all individuals and to their souls. The importance of preserving human dignity should, thus, be recognized correctly as a human right. In sum, the doctrine of medical futility is a proper template for evaluating degrees of end-of-life care. Acceptance of this principle allows—in turn—for a greater openness to utilize palliative sedation.

INTRODUCTION AND OVERVIEW

Long before Dame Cicely Saunders inspired and led the modern hospice movement in 1967,¹ which was founded on “total pain management” of physical, psychological, and spiritual suffering,² the Society of Jesus, founded by St. Ignatius of Loyola in 1541, embraced the principle of *cura personalis* as a foundational value or *chrism*.³ Within this faith-based value system, is a significant acknowledgment that “attention and respect must be given to the care of an individual person and that person’s soul.”⁴ In antiquity, Scribonius, a Roman physician, *circa* 47 A.D., is attributed as the progenitor of the notion that the profession of medicine should espouse “a commitment to compassion or clemency in the relief of suffering.”⁵

Today, the World Health Organization chooses to define the contemporary goal and use of palliative care as that which “improves the quality of life for patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life, and bereavement.”⁶ Palliating the whole person—then—requires medicine to attend more fully to existential suffering. For this type of palliation to be efficacious, health care decision makers must regularly reassess patient treatment goals in order to not only learn how their patients define and experience pain, but the patients’ thresholds for tolerating various sources of distress.⁷ 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.⁸

Existential, or non-somatic suffering, is often associated with the end-stage of life and is considered generally to be refractory.⁹ Because of misleading symptomologies, this condition is often either mis-diagnosed or even ignored. When diagnosed, as part of a futile medical condition, this Paper argues that deep, palliative (or terminal) sedation be offered to the

distressed (*e.g.*, dying) patient as an efficacious and ethical response to preserving a semblance of human dignity in the dying process¹⁰—a state of dignity which surely must be recognized as a human right.¹¹ As used in this context of death management, dignity or well-being is not seen as the dignity that philosophers debate routinely.¹² Rather, it is to be taken as the term is used in everyday conversation and shaped ideally from the lived experience of a patient throughout his life. Commonly, dignity—for the average person—then, would mean an avoidance of helplessness, incontinence, incoherency, dependency, being a burden to others, and of poor general deportment.¹³

I.

MANAGING END-STAGE ILLNESS

“Managing” death at the end-stage of life when a futile medical condition exists, presents linguistic, moral, and philosophical ambiguities regarding the voluntary cessation of nutrition, hydration, palliative or terminal sedation, physician-assisted suicide and voluntary euthanasia.¹⁴ Although these actions are distinct, there is a central and unifying commonality among them—specifically, their common purpose of hastening a humane death and thereby showing compassion to those suffering refractory pain and existential suffering.¹⁵

The purpose of this Paper is to argue, and to advance the notion, that existential suffering is as valid a consideration as physical pain is at the end-stage of life. Because of this relationship, greater attention must be given by medicine to palliating the “whole person” and to accepting the validity of palliative sedation. As efficacious and compassionate treatment when appropriate,¹⁶ laws should—similarly—accommodate the necessity for this procedure as its use becomes warranted under a theory of adjusted care.¹⁷ The law should, further, validate palliative sedation as humane end-of-life medical treatment and should not complicate, and thereby hinder, what are

sound medical responses—consistent with patient values—to alleviating conditions deemed medically futile.¹⁸ Legislation allowing for death with dignity as enacted in the state of Oregon,¹⁹ Washington,²⁰ and Vermont²¹ is—outside of state judicial action validating assistance in dying when a futile medical condition exists²²—the most sensible approach toward achieving Social Justice.²³

Best Patient Care

The President’s Council on Bioethics in the United States concluded in 2005 that the basic standard for clinical decision-making should be one which promotes the best patient care.²⁴ This standard obviously must be adjusted continually as a patient’s case history progresses,²⁵ and to promote patient care anchored in mercy, compassion, beneficence, and loving charity—care which recognizes that relief of pain is the most universal moral obligation that a physician must uphold and that there is, indeed, a right not to suffer.²⁶

Psychological distress, or existential pain, however, is usually difficult to assess because evaluation requires special training and continual contact with the patients’ and their families.²⁷ There is a general societal aversion to the obstacles faced in proving a patient’s emotional distress at end-of-life care.²⁸ Distinguishing between depression and psychological morbidity is difficult because the symptomology of disrupted sleeping patterns, loss of energy, and lack of appetite are not exclusive response mechanisms to psychological distress, but appear in cancer and other terminal illnesses as well.²⁹ Because of these difficulties and uncertainties, the palliative management of existential pain has been largely neglected.³⁰

While no general “solutions” exist for meeting the existential needs of terminally ill patients, attempts to meet these needs require careful listening skills and defined lines of communication between health care providers, patients, affected families, and proxy or surrogate

decision makers. Valid existential concerns are often obscured during palliative care treatment.³¹ Even though a patient may have no absolute control over the wide and varied spectra of suffering, the patient still has freedom to choose what attitude is taken toward that suffering.³² 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 needs³³—a more complete, compassionate, and realistic approach to managing terminal illness and end-stage suffering would be implemented.³⁴

II.

ASSESSING PAIN

While pain is properly seen as biological and as measurable, it is—inherently—subjective, individual and variable.³⁵ Consequently, there is no clear understanding whether mental suffering and mental pain are, indeed, “equivalent or identical concepts and experiences.”³⁶ Interestingly, some research has even suggested that the same brain regions involved in assessing physician pain are also found similarly in a number of forms of actual emotional distress.³⁷ The central issue confronting law is how to deal with the “externally verifiable reality” of pain.³⁸ What level of exculpation should be granted by the state to those attending to the anguish and suffering of those at the end-stage of life.³⁹ Can pain and suffering in death be likened to the state’s responsibility to safeguard its citizens from suffering cruel and unusual punishment?⁴⁰

Although existential pain has been defined as suffering “with no clear connection to physical pain,” it has been recognized—nonetheless—as suffering,⁴¹ which in fact, can be expressed as physical pain. Today, existential pain is seen, commonly, as an important clinical factor either reinforcing existing pain or, serving as the root cause of it.⁴²

Existential Suffering

The desire to hasten death arises because of a number of conditions: inadequate pain management, psychological conditions ranging from depression and hopelessness, to fears of loss of autonomy and physical functioning,⁴³ to futile and unbearable suffering, and avoidance of humiliation.⁴⁴ All of these conditions conduce to one overriding fear: loss of human dignity,⁴⁵ which brings with it a fear of being forced to become but a “passive bystander” to all of the normal functions of life.⁴⁶

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur.⁴⁷ Yet, interestingly, few receive pharmacological aid through antidepressant prescriptions.⁴⁸ As this Paper shows, the main obstacle to a more liberal response to these patients’ needs is the lack of clarity in determining when a distressed, terminal patient is suffering from clinical depression or, instead, exhibiting a “normal grief response” to the dying process.⁴⁹ The components of both of these syndromes are often vague, imprecise, and difficult to evaluate.⁵⁰ Commonly, when patients are obsessed with feelings of worthlessness, they lose their ability and desire to interact socially, and—indeed—lose their sense of hope, they are properly assessed as suffering from clinical depression⁵¹ and should be given whatever dosage of analgesics is deemed necessary to alleviate that condition—because, pharmacotherapy is ultimately the principal tool for symptom control.⁵²

Another drawback to accurate and prompt evaluations of psychological distress or existential suffering is often the inability of a physician or palliative care management team to understand patient views about suffering. As a spiritual phenomenon, suffering is often accepted in Christian communities as a meaningful and authentic community response to Jesus Christ’s own suffering.⁵³ In some faith communities, cultural efforts are expanded in order to view suffering—physically and mentally—as a positive, reinforcing value. Merely accepting suffering

as authentic, however, does not mean that it is also meaningful.⁵⁴ It remains for the physician to ascertain and then listen carefully to the spiritual parameters within each patient's character⁵⁵ in an attempt to treat those seriously ill as "whole persons."⁵⁶ In this way, the therapy is truly patient-centered.⁵⁷

Refractory existential suffering—or those symptoms which defy adequate control despite all efforts to provide relief—is difficult to distinguish during the end stages of life from physical distress.⁵⁸ Those additional refractory symptoms most commonly reported as requiring palliative sedation are: various degrees of agitation, restlessness or distress, confusion, respiratory distress, pain, and myoclonus (*e.g.*, severe twitching, jerking or uncontrollable shakes).⁵⁹

Existential care is more often than not left to the nursing staff.⁶⁰ Even in the daily hospital bed environment, however, the nursing staff must possess a special level of sensitivity to understand patients' indirect questions regarding the depth and severity of their distress over their terminal illness. Once understood, it typically falls upon the nurses to devise a procedure for providing empathetic support.⁶¹ Palliative sedation therapy is thus defined as "the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness."⁶² When patient suffering—physical or existential—becomes refractory to standard palliative therapies, the human, compassionate and merciful response is to offer palliative or terminal sedation.⁶³ This approach to medical treatment may be seen as consistent with sound principles of adjusted care.⁶⁴

Cancer Pain Management

The management of pain in cancer patients is very often a significant challenge—this, because of the sub-optimal use of opioids. Studies conducted from 2008 through 2011, have shown conclusively that upwards of 43% of patients having cancer pain, received inadequate

care.⁶⁵ Poor pain assessment, patient reluctance to report pain and to access opioids, physician reluctance to prescribe opioids and a perception of excessive-regulation of controlled substances, combine to serve as high barriers for easy access by oncologists seeking to effectively manage pain.⁶⁶

Not only does poorly managed pain care compromise emotional and cognitive functions, but it curtails the activities of daily living as well as family and professional functioning.⁶⁷ Feelings of depression can also result from inadequate pain control to a point where at least one-third of cancer patients with refractory pain feel that they want to die.⁶⁸ Although the past twenty years have shown a remarkable frankness and openness in the oncology community about pain management, surveys from 1990 and 2009 have shown real gaps in knowledge and comfort levels among oncologists in their use of opioids to manage pain.⁶⁹ A 2009 survey found 60% of oncologists gave incorrect responses to questions concerning clinical scenarios for management of break-through pain.⁷⁰

Normal responses for patients with cancer—even among mentally healthy patients are—hopelessness, anxiety, and fear. Termed the six D's, the universal fear of cancer patients have been classified as: death, dependency, disfigurement, disability interfering with normal life functions, disruption of relationships, and discomfort or pain resulting from the disease itself.⁷¹

The extent to which a patient copes with these fears is a function of a number of factors including: the nature and progression of the disease itself; the individual patient's level of psychological adjustment prior to the onset of the disease; the extent to which the disease threatens to impair the normal activities of the patient; the culture, ethical perspective and religion of the patient; the patient's support network; the patient's potential for rehabilitation;

and the patient's personal style for coping.⁷² Critically ill patients are seen coping with similar psychological reactions.⁷³

III.

COGNITIVE IMPAIRMENT

Depending upon the physiological nature of a patient's illness and the medical treatments provided to cure the illness, cognitive impairment may well result. With cancer patients, oftentimes, "fatigue, recovery from surgery and radiation," together with toxicity from drugs—including antibiotics and pain medicines—may alter thinking abilities, going so far as to "dampening the sharpness, rapidity, and productivity of the thought processes of a patient."⁷⁴

For the terminally ill patient hospitalized for extended periods of time, additional physical as well as psychological responses to "coercive" hospital environments may—additionally—hamper cognitive capacity to make informed, rational health choices and decisions.⁷⁵

Unfamiliar health care environments—together with increased sensory inputs found commonly at all hospitals, result in sleep deprivation—which, in turn, not only exacerbate the physical and emotional trauma of terminal illness, but often lead to lassitude, lethargy, hallucinations, irritability, poor judgment, paranoid ideation, and hostility.⁷⁶

With a diagnosis of medical futility from a terminal illness, comes—oftentimes—a profound psychological patient response, which in turn causes a variety of psychopathologies.⁷⁷ Indeed, psychological symptoms may well be exacerbated by the physiological symptoms of disease. Compounding this situation may be the reluctance of patients to question the very authority of their treating physicians which has the effect of compromising a terminally ill patient from engaging in autonomous, rational decision-making.⁷⁸

There is no consensus among psychologists regarding both the emotion and psychological process which occur, normally, when a terminal diagnosis is given. While Freud hypothesized that the general human fear of death was rooted actually in a fear of the unknown,⁷⁹ others have opined that “death anxiety does not pertain to physical death, but to the primordial feelings of helplessness and abandonment; thus, “the fear of the unknown or death is the fear of the unknown of annihilation of self, of being, of identity.”⁸⁰

What is agreed upon, however, is that diagnosis of terminal illness, makes death imminent and quite often forces a patient’s realization of the inevitable and the need to address what, in the past, had been suppressed anxieties and fears.⁸¹ This “crisis of diagnosis” often triggers latent psychological issues of “dependency, passivity, and narcissism.”⁸²

“Therapeutic misconceptions” are common when patients participate as subjects in Phase 1 cancer research. One study found patient motivation to participate was because, almost exclusively, a hope of being cured from their illness. While expressing subjectively an understanding of the potential risks and benefits of the research, in fact, “they were unaware that the purpose of the research was to study dose schedules and toxicity levels of drugs, not to cure them.”⁸³

European Approaches to Psychogenic Pain

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 disease (*e.g.*, manic/depression or bipolar disorder) after years of “debilitating anxiety” or even possibly the “agonies of arthritis.”⁸⁴

In 1995, the Royal Dutch Medical Association determined that no valid distinction is drawn between physical and mental suffering.⁸⁵ Yet, the Association cautioned that in making medical evaluations of non-somatic illnesses, great care and caution should be exercised in assessing both the gravity and the depth of hopelessness consequential to the primary medical condition.⁸⁶

CONCLUSIONS

The whole person care paradigm is, perhaps, the greatest challenge to health care management in the twenty-first century; and, at the same time, holds the greatest promise for realization.⁸⁷ Death anxiety and existential concerns challenge not only patients, but—as well—health professionals,⁸⁸ and patients’ families.⁸⁹ Indeed, non-somatic suffering is just as significant as somatic pain at all levels of society.⁹⁰ Physicians and other healthcare providers “need to recognize how their own non-conscious death fears, combined with the abundant reminders of death that are typical of medical practice . . . influence how they diagnose and treat patients.”⁹¹

The psycho-social and the spiritual aspects of healthcare become more prominent with every biotechnological advance⁹²—this, essentially because of their interconnectedness⁹³ and goal-sharing of alleviating pain and suffering at all levels⁹⁴ and the further growing realization that scientific research is revealing some “specific biological pathways, notably in the brain, mediating social and psychological processes.”⁹⁵ Practical effectiveness of good clinical medicine today requires “establishing a genuinely human relationship between patient and doctor.”⁹⁶ Achieving this can only be accomplished by “considering all facets of the person, including their beliefs (faiths) and spiritual understanding.”⁹⁷

Rather than being completely socialized into a Western medical culture which predisposes them to “do more” (e.g., investigations, interventions and uses of new medical technologies),⁹⁸ and thus emphasizing “curing and fixing” rather than “healing/bearing witness/being with,” contemporary healthcare professionals need to be more intellectually honest and forthcoming in acknowledging when “death is imminent, inevitable, and perhaps timely.”⁹⁹ Patient adjusted care demands—first and foremost—a standard of total honesty between patient and physician¹⁰⁰—for, without it, there can be no conscious opportunity for informed consent to be operative.¹⁰¹ When both the healer and the patient are capable of confronting, specifically, their existential fears regarding a terminal medical condition and the mortality that attaches to it,¹⁰² whole person care and the very integrity of “*cura personalis*” are validated; an appropriate measures may be undertaken in order to alleviate the conditions. Proportional humane medical responses to patient suffering—of whatever character—at the end-stage of life, should be given medically and allowed legally.¹⁰³

Praxis

Chronic disease and illness is multi-dimensional.¹⁰⁴ Late middle to old age brings multiple, life-limiting co-morbidities that will lead, ultimately, to a downward spiral to death itself.¹⁰⁵ Rather than emphasizing survival at all costs, quality and functioning should—ideally—be the goals of medical care during this final phase of life.¹⁰⁶ Realizing the meaning of the word, “health,” to make whole again, cannot be achieved at the end-stage of life does not mean nothing can be done to restore harmony or physiological and psychological function.¹⁰⁷ Rather, it should be realized that, “to care, comfort, be present, help with coping, and to alleviate pain and

suffering are healing act as well as cure. In this sense, healing can occur when the patient is dying even when cure is impossible.”¹⁰⁸

All too often, deficiencies in clinical practice, which mar the treatment and care of advanced chronic disease patients, can be traced to a core deficiency in clinical praxis.¹⁰⁹ Praxis, then, should mean more than the application of theory or of philosophy. Rather, praxis means action informed and shaped continuously by critical reflection on the end of action, on the means to the end, and on salient dimensions of the context within which action unfolds.¹¹⁰ In cases of terminal illness, “existential preparedness” or the ability to shepherd a patient (or the patient’s family) along a course accepting the eventuality of the dying process is a noble principle of clinical practice.¹¹¹

Taxonomical “purities” often compound, as seen, confusion over the issue of assistance in dying from a terminal illness or—alternatively—committing assisted suicide.¹¹² This “ongoing confusion,” in turn, contributes directly to “a cluttered moral and legal matrix.”¹¹³ Rather than continue the quest to establish a constitutional right to assisted suicide, perhaps the time-honored Common Law right to refuse treatment should be seen as the cornerstone for building a more compassionate and enlightened ethics of understanding when managing end-of-life issues. This right of refusal is not a right to hasten death, but merely a right to resist unwanted physical invasions.¹¹⁴

Whether operable normative standard for policy-making in managing death is termed agape, charity, compassion, love or mercy, the common unifying denominator in palliative care is a humane, morally responsible approach to dealing with intractable suffering at the end-stage of life.¹¹⁵

Ongoing Dialogue

A national dialogue must continue over how best to “manage death” at its end-stage.¹¹⁶ An integral part of this discussion must evaluate humane, compassionate, approaches, together with efficacious medical treatments which seek to balance vitalism, or sanctity of life, with quality of life as consistent with established or sound medical practices.¹¹⁷

As well, wise consideration should be expanded in this dialogue which allows for acceptance of the notion that old age is—in actuality—a terminal illness. The key, then, is to be informed and educated to this eventuality and thus be prepared for what is to come.

A compassionate and a logical option for those in advanced age who do not wish to continue their lives in a terminal or futile condition should be early terminal sedation.¹¹⁸

Inspired by the concept of Death Cafes, or places where individuals could meet, casually, and discuss all issues of death management (*e.g.*, cemeteries, hospital care, funerals, hospices) first seen in France and Switzerland, in 2010, a Web programmer in England, Jon Underwood, introduced this notion to Great Britain.¹¹⁹ Presently, there are 750 death cafes in 17 countries, with more than 500 in the U.S. since they were introduced there in 2012.¹²⁰

These are positive frameworks for promoting end-of-life planning and surely will go far toward setting the ultimate standard of medical care and assuring autonomous decision making for those dying.

In the United States, it is estimated that spending on end-of-life care is between ten to twelve percent of overall spending for healthcare.¹²¹ Between 25 to 30 percent of all Medicare benefits are expended for end-of-life care.¹²² There is a significant volume of evidence which substantiates the conclusion that, in multiple health care settings such as hospitals and in nursing homes, hospices are cost effective.¹²³

The central ethical question in death management remains: namely, the extent to which “marginally beneficial” treatment should be offered and then maintained.¹²⁴ Because of the inherently subjective nature of weighing costs versus benefits and considering over-utilization or under-utilization of medical care and treatment, a “just right” mean between these options will be exceedingly difficult to set or establish.¹²⁵

The doctrine of medical futility is an efficacious framework for principled decision making within the medical profession.¹²⁶ Acceptance of this doctrine as a construct for medical decisions allows—in turn—for a greater openness to utilize palliative sedation. When necessary to accommodate the best interests of a patient and to alleviate refractory pain and suffering, compassion and common sense, then, become the cornerstones of end-of-life management, care or treatment.¹²⁷

ENDNOTES

¹ See Cicely Saunders, *Hospice*, MORTALITY 317, 320 (1996).

² GEORGE P. SMITH, II, PALLIATIVE CARE AND END-OF-LIFE DECISIONS, Ch. 1 (2013).

See also HOSPICE, THE LIVING IDEA (Cicely Saunders, *et al.*, eds. 1981); Sam Halabi, *Selling Hospice*, 42 J. L. MED. & ETHICS 442 (2014).

³ CATHERINE RANDALL, BLACK ROBES AND BUCKSKIN 21 (2011).

See IMAGO DEI: HUMAN DIGNITY IN ECUMENICAL PERSPECTIVE (Thomas Albert Howard ed. 2013).

⁴ RANDALL, *id.*

⁵ Robert L. Cruess & Sylvia R. Cruess, *Whole Person Care, Professionalism and Medical Mandate* in WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY 201 (Tom A. Hutchinson ed. 2011).

See generally George P. Smith, II, *Cura Personalis: A Healthcare Delivery Quandary at The End of Life*, 7 ST. LOUIS U. J. HEALTH L. & POL'Y 311 (2014).

⁶ *Palliative Care*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/en> (last visited Aug. 20, 2014).

⁷ See Martin J. Fegg *et al.*, *Personal Values and Individual Quality of Life in Personal Values and Individual Quality of Life Palliative Care Patients*, 30 J. PAIN & SYMPTOM MGMT. 154 (2005).

⁸ *Id.*

See generally FIONA RANDALL & ROBIN DOWNIE, END OF LIFE CHOICES: CONCERNS AND CONTROVERSY (2009).

⁹ SMITH, *supra* note 2.

¹⁰ *Id.* at Ch. 3.

Viewed by some as far more inflammatory than palliative or terminal sedation, ETS (or early terminal sedation), is seen by others as humane treatment. Under this procedure, a patient—with consent—is sedated before “actively dying.” Victor Cellarius, *Early Terminal Sedation is a Distinct Entity*, 25 BIOETHICS 47 (2011). The distinction between ETS and palliative sedation is that in the former, patients are capable of receiving alimentation and hydration orally or parenterally but exercise their right to refuse this treatment. In causing palliative or terminal sedation, however, sedation is administered to those for whom nutrition and hydration are no longer life-sustaining. Often analogized—incorrectly to assisted suicide—ETS should be viewed as but “translating” the choice of a patient to refuse nutrition and hydration by the patient with deep, continuous sedation. *Id.*

¹¹ Jordan J. Paust, *The Human Right to Die with Dignity: A Policy-Oriented Essay*, 17 HUMAN RIGHTS Q. 463 (1995).

¹² JANET L. DOLGIN & LOIS L. SCHEPHERD, BIOETHICS AND THE LAW 484 (3d ed. 2013).

¹³ *Id.*

The avoidance of drooling is also listed as an undignified act and one to be avoided. *Id.*

¹⁴ See generally STEVEN LUPER, THE PHILOSOPHY OF DEATH (2009).

Society may be seen as moving from an absolute sanctity of life view to a standard of quality of life when it accepts the Principle of Double Effect, refusals of treatment, and palliative or terminal sedation. JOHN B. MITCHELL, UNDERSTANDING ASSISTED SUICIDE: NEW ISSUES TO CONSIDER 23 (2007).

¹⁵ See George P. Smith, II, *Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being*, 20 CORNELL J. L. & PUB. POL'Y 469, 479 (2011).

¹⁶ See George P. Smith, II, *Terminal Sedation as Palliative Care: Revalidating a Right to a Good Death*, 7 CAM. Q. HEALTHCARE ETHICS 382 (1998).

¹⁷ A continuum of adjusted care commences from the initial diagnosis through the end-stage of illness and is modified, then, medically and palliatively, as deemed necessary to accommodate the best interests of the patient to avoid pain and suffering and thus receive compassionate care. See *infra* note 24.

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

¹⁸ See JENNIFER RUGER, HEALTH AND SOCIAL JUSTICE at 183-84 (2009).

¹⁹ ORE. REV. STAT. §§ 127.800 (12), 127.805 (2005).

²⁰ WASH. REV. CODE ANN., Ch. 70.245 (West 2009).

²¹ VT. STAT. ANN. Ch. 113, §5281 (2013).

²² See *Baxter v. State*, 2009 Mont. LEXIS 695 (Dec. 31, 2009) where, while declining to declare a constitutional right to die with dignity, the Montana Supreme Court held that physicians aid in dying was not violating the Rights of the Terminally Ill Act, nor against any state public policy forbidding such conduct.

²³ See GEORGE P. SMITH, II, DISTRIBUTIVE JUSTICE AND THE NEW MEDICINE CH. 2 (2008).

See also Katy Butler, *A Full Life to the End*, WALL ST. J., Sept. 7, 2013 at C1 (urging autonomous health care decisions be made in anticipation of medical crises so that use of medical technologies given routinely to individuals over 80 facing health care emergencies in intensive care units can be forestalled).

²⁴ PRESIDENT'S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 217 (2005), available at http://bioethics.georgetown.edu/pcbe/reports/taking_care. Best patient care is adjusted to the developing medical needs of the patient. Essential to the standard of best care is acceptance of the "intrinsic dignity of persons" which, in turn, mandates that the goal of providing care must be to enhance total patient well-being (somatic and non-somatic) and, at the end of life demonstrate beneficence, compassion, or charity in managing pain and suffering. DAVID C. THOMASMA, HUMAN LIFE IN THE BALANCE 165, 184 (1990).

²⁵ DAVID C. THOMASMA & GLENN C. GRABER, EUTHANASIA: TOWARD AN ETHICAL POLICY 129 (1991).

²⁶ *Id.* at 192, 194 (quoting Dr. Edmund D. Pellegrino).

²⁷ Manish Agrawal & Ezekial J. Emmanuel, *Attending to Psychological Symptoms and Palliative Care*, 20 J. CLINICAL ONCOLOGY 624 (Feb. 1, 2001).

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

³¹ Ingrid Bolmsjo *et al.*, *Meeting Existential Needs in Palliative Care—Who, When, and Why?*, 18 J. PALLIATIVE CARE 185 (2002).

³² William Breitbart, *et al.*, *Psychotherapeutic Interventions at The End of Life: A Focus on Meaning and Spirituality*, 49 CAN. J. PSYCHIATRY 336 (June, 2004).

³³ See HOSPICE *supra* note 2.

See Fife, *infra* note 61 (reporting that hospice and palliative care can improve existential well-being in addition to overall psychological and physical sympathologies).

³⁴ Breitbart *et al.*, *supra* note 32 at 371.

³⁵ Amanda C. Pustilnik, *Pain as Fact and Heuristic: How Pain Neuroimaging Illuminates Moral Decisions of Law*, 97 CORNELL L. REV. 801, 805-6, 810-11 (2012) (discussing pain assessments through magnetic imaging, the limits of pain detection and the proper inferences made regarding the degrees of acute pain).

³⁶ *Id.* at 825, n. 93.

³⁷ *Id.*

³⁸ *Id.* at 803.

Pain and neuroimaging, or more precisely functional magnetic resonance imaging (MRI), is being used to measure pain. *Id.* at 846.

³⁹ *Id.* at 817-25.

See Keating & Bridgeman, *infra* note 113.

⁴⁰ See JONATHAN HERRING, *CARING AND THE LAW*, Ch. 3 (2013); GEORGE P. SMITH, II, *PALLIATIVE CARE AND END-OF-LIFE DECISIONS* (2013).

See also George P. Smith, II, *Utility and The Principle of Medical Futility: Safeguarding Autonomy and The Prohibition Against Cruel and Unusual Punishment*, 12 J. CONTEMP. HEALTH L. & POL'Y 1 (1996); George P. Smith, II, Monograph, *FINAL EXITS: SAFEGUARDING SELF-DETERMINATION AND THE RIGHT TO BE FREE FROM CRUEL AND UNUSUAL PUNISHMENT* (1997) (Northwestern Univ. Medical School).

⁴¹ Peter Strang *et al.*, *Existential Pain—an Entity, or Provocation, or a Challenge?*, 27 J. PAIN & SYMPTOM MGT. 241 (Mar. 2004).

⁴² *Id.* at 241.

⁴³ Helene Stacks *et al.*, *Why Now? Timing and Circumstances of Hastened Deaths*, 30 J. PAIN & SYMPTOM MGMT. 212, 215 (2005).

⁴⁴ Gerrit Van der Wal & Robert J. M. Dillman, *Euthanasia in the Netherlands*, 308 BR. MED. J. 1346 (1994).

⁴⁵ DEREK HUMPHREY, *FINAL EXIT* at 135-36 (1991).

⁴⁶ Richard B. Gunderman, *Is Suffering the Enemy?*, HASTINGS CTR. REP. 40, 42 (2002).

⁴⁷ Karel E. Miller *et al.*, *Antidepressant Medication Use in Palliative Care*, 23 AM J. HOSPICE & PALLIATIVE MED. 127 (No. 2, Mar. -April 2006).

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.*

See generally Siow Ann Chong *et al.*, *Authorizing Psychiatric Research: Principles, Practices and Problems*, 25 *BIOETHICS* 27 (2011).

⁵¹ *Id.* at 128.

⁵² Arthur G. Lipman, *The Scream by Edvard Munch: A Profound Portrayal of Existential Pain*, 19 *J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 1-2 (2005).

⁵³ Stan Van Hooft, *The Meanings of Suffering*, 28 *HASTINGS CTR. REP.* 13 (1998).

⁵⁴ *Id.* at 14.

⁵⁵ *Id.* at 15.

See John Harding, *Spiritual Issues at The End of Life: A Call for Discussion*, 30 *HASTINGS CENTER RPT.* 28 (2006).

⁵⁶ See Seth M. Holmes, *et al.*, *Screening the Soul: Communication Regarding Spiritual Concerns Among Primary Care Physicians and Seriously Ill Patients Approaching the End of Life*, 23 *AM. J. HOSPICE & PALLIATIVE Med.* 25, 30 (2006).

⁵⁷ Alton Hart Jr., *et al.*, *Hospice Patients': Attitudes Regarding Spiritual Discussion with Their Doctors?* 20 *AM J. HOSP. PALLIATIVE CARE* 135 (2003).

⁵⁸ Holmes, *et al.*, *supra* note 56 at 30.

⁵⁹ Paul Rousseau, *Existential Suffering and Palliative Sedation: A Brief Commentary with a Proposal for Clinical Guidelines*, 18 *AM. J. HOSPICE & PALLIATIVE MED.* 151 (2001).

⁶⁰ Bernard Lo & Gordon Rubinfeld, *Palliative Sedation in Dying Patients: "We Turn to It When Everything Else Hasn't Worked,"* 294 *J. AM. MED. ASS'N* 1810, 1811 (2005).

⁶¹ Robert Hoatpen & David Hendriks, *Nurses and The Vicissitudes of Dealing with Euthanasia Questions in Terminal Palliative Care*, 10 *NURSING ETHICS* 377 (2003).

See Richard B. Fife, *Are Existential Questions the Norm for Terminally Ill Patients?*, 5 *J. PALLIATIVE MED.* 815, 817 (2002) (concluding that patient symptom control should be stabilized before attempting to deal with spiritual and psycho-social issues).

⁶² Tatsuya Morita *et al.*, *Definition of Sedation for Symptom Relief: A Systematic Literature Review and a Proposal for Operational Criteria*, 24 *J. PAIN SYMPTOM MGMT.* 447 (2002).

⁶³ Paul Rousseau, *Existential Suffering and Palliative Sedation: A Brief Commentary with a Proposal for Clinical Guidelines*, 18 *AM. J. HOSPICE & PALLIATIVE MED.* 151 (2001).

A study released by the University of Toronto Joint Center for Bioethics, an international medical ethics think-tank in September 2002, regarding how pain and suffering were palliated at the end-of-life, found that: regardless of so-called maximum dosages of narcotics and sedations which might, by custom, be recognized, each patient must receive whatever drug dosages remediate sympathologies; pre-emptive dosing in anticipation of pain and suffering

is good palliative care. So long as the intent of intensivists is to deal with a patient's refractory pain—even if the treatment may foreseeably cause the hastening of death—terminal sedation should be recognized as sound palliative care and not as euthanasia.

Laura A. Harvryluck *et al.*, *Consensus guidelines on analgesia and sedation in dying intensive care unit patients*, 3 BMC MEDICAL ETHICS 3 (2002). This article is available from: <http://www.biomedcentral.com/1472-6939/3/3>.

⁶⁴ See THOMASMA, *supra* note 24, regarding adjusted care.

See also Roger Magnusson, *The Devil's Choice: Re-thinking Law, Ethics, and Symptom Relief in Palliative Care*, 34 J. L., MED. & ETHICS 559 (2006) (arguing for a legal defense of necessity be allowed when symptom relief is ineffective and palliative interventions shorten the life of a patient).

⁶⁵ Steven M. Simon, Lee S. Schwartzburg, *A Review of Rapid-onset Opioids for Breakthrough Pain in Patients with Cancer*, 10 J. OPIOID MGT. 207, 208, 213 (June, 2014).

⁶⁶ *Id.*

Interestingly, Colorado, Missouri, and Louisiana are the first three states in the Nation to allow terminally ill patients the right to try experimental drugs without the heretofore required approval of the Food and Drug Administration. Termed “*Right to Try*” laws, these new laws create a set of two new complex issues: who should decide whether a drug is too risky to be administered and, secondly, the extent to which legislation of this nature compels cooperation from drug makers who are often reluctant to allow distribution of unapproved drugs. Brady Dennis, Ariane E. Cha, ‘*Right to Try*’ laws spur debate over dying patients’ access to experimental drugs, WASH. POST, May 17, 2014, at A3; Janon Milman, *New Arizona law gives terminally ill increased access to unproven drugs*, WASH. POST, Nov. 6, 2014, at A22.

⁶⁷ Simon & Schwartzburg, *supra* note 65.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

Citing H. Breivik, N. Cherney *et al.*, *Cancer-related Pain: A pan-European Survey of Prevalence, Treatment, and Patient Attitudes*, 20 ANN. ONCOL. 1420 (2009).

A relatively new class of rapid-onset opioids (ROO’s) is proving itself to be an effective agent for pain management which enables therapy to be administered to alleviate breakthrough pain (BTP) and thereby avoid total opioids burdens and reduce the level of their effect on patients.

A recent study found that only some ten percent of oncologists—however—would utilize this analgesic tool; preferring, instead, to refer their patients having cancer pain syndromes to pain specialists or to palliative care. In many cases, oncologists who practice in rural, small practice groups simply have limited access to pain specialists. In other situations, oncologists practicing in large community practices, make easy patient referrals to specialists in pain management or consult with them for deciding individually with their patients. Simon & Schwartzburg, *supra* note 65.

⁷¹ Lynna M. Lesko, *et al.*, *Oncology*, at 7 in PSYCHIATRIC CARE OF THE MEDICAL PATIENT (Alan Stoudemine & Barry S. Fogel eds. 1993).

⁷² *Id.*

See E. MANSELL PATTISON, *The Living-Dying Process* in PSYCHOLOGICAL CARE OF THE DYING PATIENT at 133-34 (Charles A. Garfield ed. 1978).

⁷³ Sharon L. Roberts, BEHAVIORAL CONCEPTS AND THE CRITICALLY ILL PATIENT at 197-222 (2d ed. (1996).

The critically ill frequently suffer also from sleep deprivation, hopelessness, anger or hostility, avoidance and denial, feelings of powerlessness, loneliness and depression. *Id.*

See Kenneth K. Dolka, *When Illness is Prolonged: Implication for Grief* in LIVING WITH GRIEF: WHEN ILLNESS IS PROLONGED at 6-7 (Kenneth J. Dolka & Joyce Davidson eds. 1998).

Generally, patients with a diagnosis of medical futility progress through six psychological stages: shock, denial, anger, bargaining, depression, and in the end, acceptance. ELISABETH KÜBLER-ROSS, ON DEATH AND DYING (1969).

⁷⁴ D. Christian Addicott, *Regulating Research on The Terminally Ill: A Proposal for Heightened Safeguards*, 15 J. CONTEMP. HEALTH L. & POL'Y 479, 500 (1999).

Cognitive impairment is also an inherent component of the aging process—with 50% of all Americans, by age 85—being diagnosed with dementia. By 2030, 76 million will suffer from this disease. Kent Russell, *No Exit*, NEW REPUBLIC, Sept. 15, 2014, at 18.

⁷⁵ *Id.* at 501.

⁷⁶ *Id.*

For a fascinating analysis of the early Roman view of cognition, see Danuta Mendelson, *Roman Concept of Mental Capacity to Make End-of-Life Decisions*, 30 INT'L J. L. & PSYCHIATRY 201 (2007).

⁷⁷ Addicott, *supra* note 74 at 496.

⁷⁸ *Id.*

⁷⁹ See generally SIGMUND FREUD, *Thoughts for the Times, on War and Death* in SIGMUND FREUD, 4 COLLECTED PAPERS 273-300 (1915).

⁸⁰ Adicott, *supra* note 74 at 496.

⁸¹ *Id.* at 497.

⁸² *Id.*

⁸³ *Id.* at 504, fn 138, citing Christopher K. Dougherty *et al.*, *Perceptions of Care Patients and Their Physicians Involved in Phase I Trials*, 13 J. CLIN. ONCOL. 1062-72 (1995).

⁸⁴ See Joachim Cohen *et al.*, *European Public Acceptance of Euthanasia: Socio-demographic and Cultural Factors Associated with the Acceptance of Euthanasia in 33 European Countries*, 63 SOC. SCI. & MED. 743 (2006).

See also 1998 Zurich Declaration on Assisted Dying which endorses the notion that all competent adults, “suffering severe and enduring distress, to receive medical help to die” (*e.g.*, by assisted suicide and euthanasia). See www.internationaltaskforce.org/Zurich.htm (accessed Aug. 5, 2014); ELIZABETH PRICE FOLEY, THE LAW OF LIFE AND DEATH 182-83 (2011).

See generally Jon D. Feldhammer, Notes, *Medical Torture: End-of-Life Decision-Making in the United Kingdom and United States*, 14 CARDOZO J. INT'L. L. & COMP. LAW 511 (2006).

On February 6, 2015, a unanimous decision by the Supreme Court of Canada voided laws which had prevented physicians from providing direct assistance to those dying under “grievous and unremediable medical conditions.” The High Court determined that present prohibitions on physician assistance in cases of this nature infringed on not only the right to life, liberty, dignity and security, but were not in accordance with fundamental principles of justice. *Carter v. Canada (Attorney General)*, 2015 SCC5. See Ian Austen, *Canada Court Strikes Down Ban on Aiding Patient Suicide*, N.Y. TIMES, Feb. 6, 2015, at page 4.

Presently, some twenty-five states are considering right-to-die with dignity legislation. See also Josh Sanburn, *How Canada's Right-to-Die Ruling Could Boost Movement in U.S.*, TIME, Feb. 6, 2015 at <http://time.com/3699464,feb6015>.

⁸⁵ Smith, *supra* note 15 at 481.

⁸⁶ *Id.*

See generally ROGER S. MAGNUSON & PETER H. BELLIS, *ANGELS OF DEATH: EXPLORING THE EUTHANASIA UNDERGROUND* (2002).

⁸⁷ Sheldon Solomon & Krista Lawlor, *Death Anxiety: The Challenge and The Promise of Whole Person Care*, Ch. 9 at 98 in Tom Hutchinson, *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21st CENTURY* (Tom A. Hutchinson ed., 2011).

See Edmund D. Pellegrino, *Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship*, 10 J. CONTEMP. HEALTH L. & POL'Y 47 (1994).

⁸⁸ Solomon & Lawlor, *id.*

See ATUL GAWANDE, *infra* note 91.

⁸⁹ See generally MARK EPSTEIN, *THE TRAUMA OF EVERYDAY LIFE: A GUIDE TO INNER PEACE* (2013).

See Mark Epstein, *The Trauma of Being Alive*, N.Y. TIMES, Aug. 4, 2013, at 8.

⁹⁰ See Susan Chater, *et al.*, *Sedation for Intractable Distress in The Dying—a Survey of Experts*, 12 PALLIATIVE MED. 255 (1998).

⁹¹ Solomon & Lawlor, *supra* note 87 at 101, 105-06.

See ATUL GAWANDE, *BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END* (2014).

⁹² See SAM PARINA, *ERASING DEATH: THE SCIENCE THAT IS REWRITING THE BOUNDARIES BETWEEN LIFE AND DEATH* (2013).

See generally GEORGE P. SMITH, II, *THE NEW BIOLOGY: LAW, ETHICS, AND BIOTECHNOLOGY* (1989).

⁹³ See generally Stephen Liben, *Empathy, Compassion, and The Goals of Medicine*, Ch. 6 at 63 in Hutchinson, *supra* note 87.

⁹⁴ See GEORGE P. SMITH, II, LAW AND BIOETHICS: INTERSECTIONS ALONG THE MORTAL COIL 138-60 (2012); *supra* note 23.

⁹⁵ John Cox, Alastair V. Campbell & Bill Fulford, Introduction: *At The Heart of Healing* in MEDICINE OF THE PERSON: FAITH, SCIENCE IN HEALTH CARE PROVISION 24 (John Cox *et al.*, eds. 2007).

⁹⁶ *Id.* at 24.

⁹⁷ *Id.*

See Antje Du Bois-Pedain, *The Duty to Preserve Life and Its Limits in English Law*, Ch. 13 at 305-09 in THE SANCTITY OF LIFE AND THE CRIMINAL LAW: THE LEGACY OF GLANVILLE WILLIAMS (Dennis J. Baker & Jeremy Horde eds., 2013) (observing a “morality of care” is imposed upon a physician to accept patients as “concrete individuals.”)

⁹⁸ See STANLEY J. REISER, TECHNOLOGICAL MEDICINE: THE CHANGING WORLD OF DOCTORS AND PATIENTS (2009); GAWANDE *supra* note 91.

⁹⁹ Solomon & Lawlor, *supra* note 87 at 104.

See Jessica Nutik Zitter, M.D., *A Code Death for Dying Patients*, N.Y. TIMES, April 10, 2014, at (asserting physicians, and especially those in ICU’s, need to “release the ancient art of dying” and—as such—disclose, honestly, when a patient is dying and assist/help that patient to die with dignity and without life-prolonging treatments) at http://well.blogs.nytimes.com/2014/04/10/a_better_way_to_help_dying_patients/.

¹⁰⁰ See *supra* note 24.

See generally EDMUND D. PELLEGRINO & DAVID C. THOMASMA, A PHILOSOPHICAL BASIS FOR MEDICAL PRACTICE: TOWARD A PHILOSOPHY AND ETHIC OF THE HEALING PROFESSION (1981).

¹⁰¹ George P. Smith, II, *The Vagaries of Informed Consent*, 1 IND. HEALTH L. REV. 111 (2004).

See Jay Katz, *Informed Consent—Must it Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL’Y 69 (1994).

¹⁰² See generally Edmund D. Pellegrino, *Character, Virtue and Self Interest*, 5 J. CONTEMP. HEALTH L. & POL’Y 53 (1989).

¹⁰³ See generally EDMUND D. PELLEGRINO & DAVID C. THOMASMA, THE PATIENT’S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE (1988).

¹⁰⁴ F. Daniel Davis, *On the Critical Potential of Pellegrino’s Philosophy of Medicine*, at 7, First Annual Edmund D. Pellegrino, M.D., Symposium, March 21, 2014, Georgetown University Medical School, Washington, D.C.

¹⁰⁵ *Id.*

See Ezekiel J. Emmanuel, *Why I Hope to Die at 75*, THE ATLANTIC, Oct. 2014, at 74.

But see Ruth Marcus, *Why set a deadline on life?*, WASH. POST, Sept. 28, 2014, at A21.

¹⁰⁶ See Charles Ornstein, *Deciding When to Let Mom Die*, WASH. POST, Mar. 3, 2013, at B1.

See generally EDMUND D. PELLEGRINO & DAVID C. THOMASMA, THE PATIENT’S GOOD: THE RESTORATION OF BENEFICIENCE IN HEALTH CARE (1988).

¹⁰⁷ Davis, *supra* note 104.

¹⁰⁸ Davis, *id.* at 13.

¹⁰⁹ See Letter, E. L. Lloyd, observing that protocols often have taken priority over clinical judgment, and uses the example of the unsound notion that opiates cannot be given immediately because they would obscure a diagnosis and, before their administration, electrocardiography and blood tests must first be given. 316 *BMJ* 390, 395 (Jan. 31, 1998).

¹¹⁰ Davis *supra* note 104 at 11.

¹¹¹ *Id.*

See Du Bois-Pedain, *supra* note 97.

See also PELLEGRINO & THOMASMA, *supra* note 106; GAWANDE, *supra* note 91.

¹¹² Danuta Mendelson & Mirko Bagaric, *Assisted Suicide Through the Prism of The Right to Life*, 36 *INT'L J. L. & PSYCHIATRY* 406 (2013) (arguing for retention of the criminality of assisted suicide).

But see Marcia Angell, *From 'assisted suicide' to 'death with dignity,'* *WASH. POST*, Nov. 2, 2014 at B3.

¹¹³ *Id.*

But see Heather Keating & Jo Bridgeman, *Compassionate Killing: The Case for a Partial Defense*, 75 *MOD. L. REV.* 697 (2012) (arguing for a new defense to murder—namely, of compassionate killing—which would have the effect of reducing a murder charge to recognition of a compassionate killing as a reasoned, caring, responsive, relational (*e.g.*, familial) act of care to the suffering of a loved one).

¹¹⁴ See generally Smith, *supra* note 15; Angell, *supra* note 112.

See also George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Suicide or Merely Enlightened Self-Determination?*, 22 *U. CAL.-DAVIS L. REV.* 275 (1989).

Doyal has maintained that, for competent persons, a right to die is linked to an exercise of autonomy rather than a right to privacy. Len Doyal, *Human Need and The Right to Patients to Privacy*, 14 *J. CONTEMP. HEALTH L. & POL'Y* 1, 10, 19-20 (1997).

¹¹⁵ Smith, *supra* note 15 at 529.

See generally Thomas L. Hafemeister, *End-of-Life Decision-Making, Therapeutic Jurisprudence and Preventive Law: Hierarchical v. Consensus-Based Decision-Making Model*, 41 *ARIZ. L. REV.* (1999).

¹¹⁶ See generally SMITH, *supra* note 2.

¹¹⁷ PARTNERS IN PALLIATIVE CARE: ENHANCING ETHICS IN CARE AT THE END OF LIFE (Mary Beth Morrissey & Bruce Jennings eds., 2013).

See HOSPICE ETHICS: POLICY AND PRACTICE IN PALLIATIVE CARE (Timothy W. Kirk & Bruce Jennings eds. 2014).

See generally IN DEFENSE OF HUMAN DIGNITY: ESSAYS FOR OUR TIME (Robert P. Kraymack & Glenn Tinder eds. 2013).

¹¹⁸ See Cellarius, *supra* note 10.

¹¹⁹ Tara Bahrapour, *Let's talk about it: 'Death cafes' focus on a difficult time*, WASH. POST, May 4, 2014, at C1.

¹²⁰ *Id.*

See the websites: Death Café.com; Death over Dinner; Ask a Mortician.

The National Institute of Aging web page on decision making and end-of-life cases is notable as well.

¹²¹ PARTNERS IN PALLIATIVE CARE, *supra* note 117.

¹²² *Id.* at 112.

¹²³ *Id.* at 119.

A growing number of hospices—particularly new, for-profit companies—are allowing up to 30% of its patients to be discharged. Some end-stage patients are simply released to hospital ER's—this, is an attempt to save money and avoid intensive continuous care. And—contributing to further economic stress, a number of hospices enroll patients who are not dying and thus generate high Medicare outlays. Peter Whoriskey & Dan Keating, *Rising exodus puts hospice care spotlight*, WASH. POST, Aug. 7, 201, at A16.

See Peter Whoriskey, *Congress approves closer scrutiny of growing hospice industry*, WASH. POST, Sept. 20, 2014, at A14 (discussing the effect of Public Law 113-185, Improving Medicare Post Acute

See also Halabi, *supra* note 2; HOSPICE ETHICS, *supra* note 117.

¹²⁴ PARTNERS IN PALLIATIVE CARE, *supra* note 117 at 119.

The prototype of state futility statutes is found at CAL. PROB. CODE §4735 (West 2007). Under this statute, and approximately 12 other similar statutes, health care providers are given the option to decline a health care instruction (e.g., advance directive) or health care decisions which require “medically ineffective care or health care contrary to generally accepted health care standards applicable to the health care provider or institution.” See also TEX. ADVANCE DIRECTIVES ACT, TEX. HEALTH & SAFETY CODE ANN. §166.001—166.166 (West 2010).

The other states which have legislated futility statutes are to be found in Meir Katz, *When Is Medical Care “Futile?” The Institutional Competence of the Medical Profession Regarding The Provision of Life-Sustaining Care*, 90 NEB. L. REV. 1, 6 at fn 39 (2011).

See generally George P. Smith, II, *The Ethics of Ethics Committees*, 6 J. CONTEMP. HEALTH L. & POL'Y 157 (1990).

But see Robert D. Truog, M.D., *Medical Futility*, 25 GA. STATE U. L. REV. 985, 1002 (2009) (concluding support for “a fair process approach to futility determinations” and arguing that “in some circumstances it is ethical to unilaterally withdraw life support from patients” against family wishes but concluding the Texas statutory approach is flawed).

¹²⁵ PARTNERS IN PALLIATIVE CARE, *supra* note 117 at 119.

See generally Meir Katz, *id.*

¹²⁶ See Smith, *Utility and The Principle of Medical Futility*, *supra* note 40.

¹²⁷ See George P. Smith, II, *Gently into The Good Night: Toward a Compassionate Response to End-Stage Illness*, 22 TEMPLE POLITICAL & CIV. RIGHTS L. REV. 101 (2013).

See also Cass Sunstein, *The Right to Die*, 106 YALE L. J. 1123 (1997); Magnusson, *supra* note 64; *The right to die: Why assisted suicide should be legal*, THE ECONOMIST, June 27-July 3, 2015, at 16.