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Deja Vu All Over Again: The False
Dichotomy Between Sanctity of Life and
Quality of Life

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Abstract

A longstanding contention of 'right to life' activists is that a quality of life ethic in end-of-life decisionmaking undermines a sanctity of life ethic. A surrogate decision to reject life-sustaining medical intervention – as in the case of a permanently unconscious patient – supposedly delivers a symbolic message contravening the intrinsic value of all human life. This paper argues that quality of life judgments are the only way to avoid transforming human beings into prisoners of medical technology. Under appropriate standards and review, caregivers must be able to end artificial intervention rather than keep pumping fluids and gases into moribund, floundering patients.

**Deja Vu All Over Again:
The False Dichotomy Between Sanctity of Life and Quality of Life**

Norman L. Cantor

The case of Terri Schiavo aroused the longstanding claim that any judgment that death is preferable to life violates the important concept of sanctity of life.¹ Right-to-life advocates largely chose to ignore a judicial finding that Ms. Schiavo had, by oral expressions, dictated her own medical course. Instead, they portrayed her husband's determination to let Ms. Schiavo die as reflecting *his* judgment that her impoverished quality of life in a permanently unconscious state had "no value." In turn, the Florida courts' acceptance of such a determination supposedly contravened society's respect for the intrinsic value of all human life. This theme – that a quality of life ethic undermines sanctity of life – has long been a contention of right to life advocates. As expressed by one judge, in 1987, objecting to removal of life support from a permanently unconscious person:

By its very nature, every human life, without reference to its condition, has a value that no one rightfully can deny or measure. Recognition of that truth is the cornerstone on which American law is built. * * * [Any] declaration that not every human life has sufficient value to be worthy of the State's protection denies the dignity of all human life and undermines the very principle on which American law is constructed.²

Every person's right to life and society's duty to protect that right supposedly preclude "all 'quality of life' judgments."³

Any determination -- especially when made by a surrogate -- that a person would be better off dead than alive is also regarded by the right to life movement as posing grave danger to vulnerable populations such as the developmentally disabled, the elderly, and the seriously ill. The apprehensions include a concern that a person facing a critical medical condition will be

¹ Linda Reid Chassiakos, *The Value of a Life*, Jan. 26, 2005, <http://www.salon.com/opinion/feature/2005/01/26/feeding>, (last visited,); Steven W. Mosher Population Research Institute, *Statement in Support of the Life of Terri Schiavo*, Oct. 13, 2004, at <http://www.pop.org>.

² *Brophy v. New England Sinai Hosp*, 497 N.E.2d 626, 646 (Mass 1987)(O'Connor, J., concurring in part and dissenting in part).

³ See Kevin P. Quinn, *The Best Interests of Incompetent Patients: The Capacity for Interpersonal Relationships as a Standard for Decisionmaking*, 76 CALIF. L. REV. 897, 926 (1988)(describing the position of the right to life movement).

deemed disposable because of lack of worth to society or to others. Anyone who is a burden to others might be subject to a judgment that their life is “not worth preserving.”⁴ Another concern is that there are no objective criteria for assessing quality of life, so that surrogates will operate according to their own preconceptions, values, and biases in assessing a preservable quality of life.⁵ The argument is that in the absence of ways to quantify and compare the benefits and burdens of existence, subjective surrogate judgments will jeopardize the well being of all vulnerable populations.⁶

Beyond premature disposal of helpless humans, a negative quality of life judgment is seen by some advocates for the disabled as conveying an offensive and alarming message to disabled populations. Even when a decision to reject life-sustaining treatment is made by a competent individual, the autonomous patient’s negative judgment supposedly communicates that disabled lives are not worth living. This message purportedly discourages disabled persons and contradicts the sanctity of life notion that every human life is valuable without regard to its quality.⁷

All this aversion to quality of life judgments is understandable, particularly from the perspective of the 1970's and 1980's when end-of-life medical decisions were relatively novel both from practical and jurisprudential viewpoints. The claims about the insidious consequences of a quality of life ethic prompted appropriate hesitation and reflection. Some courts reacted by eschewing end-of-life decisions unless pursuant to explicit prior instructions from a previously competent patient. Most courts were more intrepid and upheld rejection of life-sustaining medical interventions both by competent patients and by surrogates acting on behalf of

⁴ John Wyatt, What’s Wrong with Quality of Life as a Clinical Tool? AMA Virtual Mentor Policy Forum, Feb. 7 2005, <http://www.ama-assn.org/ama/pub14553>.

⁵ Quinn, *supra* note 3, at 925; Elizabeth J. Sher, *Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. Rev. 157, 185 (1983).

⁶ Wyatt, *supra* note 4; Jennifer L. Sabo, SURVEY OF DEVELOPMENT IN NORTH CAROLINA LAW AND THE FOURTH CIRCUIT, 2000: LIMITING A SURROGATE’S AUTHORITY TO TERMINATE LIFE-SUPPORT FOR AN INCOMPETENT ADULT, 79 No. Car. L. Rev. at 1823-24; Tracy L. Merritt, Equality for the Elderly Incompetent: A Proposal for Dignified Death, 39 Stan. L. Rev. 689, 726-27 (1987).

⁷ Any practice that suggests that a disabled human is dispensable is subject to the same objection, even when the human is not yet born. Thus, right to life advocates object to pre-natal screening of genetic traits such as Down’s syndrome because of the negative message about lack of value of disabled persons. See, e.g., T.M. Reynolds, Down’s Syndrome Screening is Unethical, 56 J. Clin. Pathology 268, 270 (2003).

incompetent patients.⁸ Now, in 2005, Theresa Schiavo's protectors echo the original warnings about the dire consequences of a quality of life ethic for a society assertedly dedicated to sanctity of life. Should those plaintive warnings be heeded, or are they an anachronism today, 30 years after the advent of a death and dying jurisprudence geared to autonomy and the implementation of people's actual or likely preferences?

I. Quality of Life and Competent Medical Patients

Every autonomous medical decision involves a quality of life determination according to the personal values and preferences of the competent patient. This is true for the simplest decision such as whether or not to take an aspirin for a headache. The patient considers what the chances of benefit are, the likely quality of life with and without the medical intervention, the risks of treatment, and the alternatives available. The same goes for a competent patient's decision whether to undergo surgery for lumbar sciatica (or for any other serious medical condition).⁹ How much pain and dysfunction is the sciatica causing? What is the likely quality of life improvement via surgery? What are the risks and discomforts of surgery and what are the alternatives?

A similar calculus guides autonomous patient choice even when the context is an end-of-life medical decision. A central factor then is the nature of hardship and debilitation to be encountered with and without life-extending medical intervention. As described by Philip Peters:

[W]hether a painful treatment is worthwhile inevitably requires consideration of the value of extended life to the patient. A painful treatment is only harmful if the additional life expectancy that it offers [i.e., the ensuing length and quality of life] is not worth the pain or burdens of the treatment.¹⁰

And as a California court explained in 1993:

Since death is the natural conclusion of all life, the precise moment may be less critical than the quality of time preceding it. Especially when the prognosis for full recovery from serious illness or incapacity is dim, the relative balance of

⁸ See generally Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 *J.L. Med. & Ethics* 182 (2001).

⁹ Bernd Will & Matthis Synofzik, *Assessing Quality of Life in Patients with Lumbar Sciatica*, AMA Virtual Mentor Policy Forum, Feb. 7, 2005, <http://www.ama-assn.org/ama/pub14553>.

¹⁰ Philip G. Peters, *The State's Interest in the Preservation of Life: From Quinlan to Cruzan*, 50 *OHIO ST. L.J.* 891, 948 (1989).

benefit and burden must lie within the patient's exclusive estimation: That personal weighing of values is the essence of self-determination.¹¹

Even with an enduring societal respect for the intrinsic value of all human life, the reality is that, from the perspective of a fatally stricken medical patient, extended life is not always preferable to death. Anglo-American jurisprudence accepts that a competent patient facing a fatal affliction is entitled to determine whether (and for how long) the quality of prospective existence after treatment warrants accepting the proposed treatment. Because life-sustaining medical intervention constitutes both a bodily invasion and a choice of personal response to an affliction, the competent patient's rights of bodily integrity and self-determination entitle her to personally assess the benefits and burdens of the contemplated medical intervention. Think burn victim. Think cancer patient. Think patient with kidney failure facing dialysis. Think ALS patient contemplating whether to continue to use a respirator in the face of inexorable deterioration. All of these patients are entitled to decide for themselves, using personal values and preferences, whether the prospective preservable state would be so intolerably painful or degrading as to make treatment unwanted.

American cases have uniformly allowed competent patients to make quality of life judgments in determining whether to accept further life-sustaining medical intervention. This was the case, for example, when gangrene-stricken patients declined surgical amputation which could have preserved their lives for years.¹² Similar quality of life decisions have been made by seriously disabled persons – usually quadriplegics – who determine to discontinue respirator support or artificial nutrition and hydration necessitated by their debilitating medical conditions.¹³ (In each case, their medical condition had stabilized, so that the patient was capable of surviving for many years with continued medical support). In like fashion, some sufferers of ALS reach a point when the physical debilitation is so frustrating and the struggle to survive so fatiguing that they decide to withdraw the respirator preserving their existence.¹⁴ Indeed, competent persons making decisions whether to maintain life support frequently rely on quality of life factors – chronic pain, indignity associated with being helpless and dependent, or a distasteful prospect of

¹¹ *Thor v. Super. Ct. of Solano County*, 855 P.2d 375, 384 (Cal. 1993)

¹² *See Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. Ct. 1978); *In re Quackenbush*, 383 A.2d 785 (Morris County, N.J. 1978).

¹³ *Bouvia v. County of L.A.*, 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (Cal. App. 1987); *Georgia v. McAfee*, 385 S.E.2d 651 (Ga. 1989); *Mackay v. Bergstedt*, 801 P.2d 617 (Nev. 1990)

¹⁴ *Satz v. Perlmutter*, 362 So.2d 160 (Fla. App. 1978); *In re Farrell*, 529 A.2d 404 (N.J. 1987).

being a burden on family or others.¹⁵ William Bartling -- a dying victim of emphysema and cancer who was demanding removal of a life-preserving respirator -- cited “the humiliating indignity “(for himself) of having every bodily need and function tended by others.¹⁶ For this formerly vital person, his gravely debilitated condition was “unbearable, degrading, and dehumanizing.”¹⁷

Objections are frequently voiced about the judicial upholding of competent patients’ decisions to decline continued medical intervention capable of preserving their lives for considerable periods. Some objections rely on a religious precept that humans do not have dominion over their own bodies or lifespans, so that rejection of life-sustaining treatment violates divine will. Other objectors see the competent patient’s choice to remove life support based on dismal prospective life circumstances as a form of suicide – anathema in a civilized society. These objectors insist that neither medical personnel nor courts should cooperate with a patient’s assessment that life with an affliction is not worth preserving.

Courts have always acknowledged that states have a significant interest in promoting the sanctity of life, meaning respect for the intrinsic value of human life. However, in the context of competent patients determining their own course of medical treatment or non-treatment, any abstract state interest in preserving life is deemed outweighed “by the patient’s much stronger interest in directing the course of his own life” and in determining how to respond to a natural affliction.¹⁸

Some advocates for the disabled denounce the willingness of courts to accept a disabled patient’s determination to reject life-sustaining treatment and die. For them, the message flowing both from the patient’s choice to decline treatment and the court’s acceptance of that course is

¹⁵ See N.R. Zweibel, *Measuring Quality of Life Near the End of Life*, 260 JAMA 839, 840 (1988); Norman L. Cantor, On Kamisar, Killing, and the Future of Physician-Assisted Death, 102 MICH. L. REV. 1793, 1833 n.198 (2004). Competent patients seeking physician-assisted dying also tend to invoke these kinds of quality of life factors. Eric A. Johnson, Reply: Assisted Suicide, Liberal Individualism and Visceral Jurisprudence: A Reply to *Professor Chemerinsky*, 20 ALASKA L. REV. 321, 324 (2003); Linda Ganzini, et. al, Oregon Physician’s Perceptions of Patients Who Request Assisted Suicide, 6 J. Palliative Med. 381, 387 (2003).

¹⁶ *Bartling v. Superior Court*, 136 Cal. App. 3d 186, 188, 209 Cal. Rptr 220 (Cal. App. 1984).

¹⁷ *Id.*

¹⁸ *In Re Conroy*, 486 A.2d 1209, 1233 (N.J. 1985); *Brophy v. New England Sinai Hos.*, 497 N.E.2d 626, 635 (Mass. 1987); *Foody v. Manchester Memorial Hospital*, 482 A.2d 713 (Conn. 1984); *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. 1980).

that “life as a disabled person is ‘undignified’ or ‘degraded,’” not worth preserving.¹⁹ That message, in turn, supposedly disparages persons living disabled lives, undermines their morale, and reinforces the negative stereotypes harbored by society. Advocacy groups such as Not Dead Yet protest when courts uphold fatal decisions by competent disabled persons. Other advocates for the disabled lament the judicial focus on the helplessness and dependence of the patient as reinforcing the notion that being fed, cleaned, and toileted is intolerably undignified.²⁰ Advocates blame society’s lack of support services for disabled individuals as responsible for any disabled person’s inclination to reject life-preserving medical intervention.

Courts understandably reject the claim that medical or judicial acceptance of a competent person’s refusal of life support devalues a handicapped existence or erodes respect for human life. When a court upholds a patient’s choice to decline treatment, the court is not endorsing either the soundness of the decision or its morality. The best examples are the lines of cases upholding the prerogatives of Jehovah’s Witnesses to decline life-saving blood transfusions and of gangrene stricken patients to decline amputations capable of extending their lives for years. In all these instances, the court is upholding autonomy in medical decisions -- i.e., is respecting self-determination as an aspect of human dignity -- even though the patient’s decision may be imprudent and distasteful to the judge.²¹

Certainly, judicial or medical acquiescence in a competent patient’s chosen medical course does not reflect a negative social utility assessment. Quality of life from the personal perspective of the patient is not the same as value of life to the state or others. “The phrase “quality of life” can mean either the value of prolonged life for the patient or the value to others

¹⁹ Johnson, *supra* note 15, at 323; Tia Powell & Bruce Lowenstein, *Refusing Life-Sustaining Treatment After Catastrophic Injury: Ethical Implications*, 24 *J.L. Med. & Ethics* 54, 59-60 (1996). Recently, disability advocates blasted the film *Million Dollar Baby* for portraying voluntary euthanasia as the desirable response to the heroine’s crippling accident. See Daniel Costello, *Assisted Suicide at Center Stage Once Again: Award Winning Movies and Upcoming Legislation Give New Urgency to the Contentious Issue*, *L.A. Times*, Mar. 7, 2005 at F1. Their objections would be warranted if directed toward the precipitousness of compliance with the paralyzed heroine’s wishes. No effort is made in the film to offer psychological counseling or physical rehabilitation to the heroine. Moreover, the heroine is ventilator dependent, so that a lethal injection rather than removal of life support seems unnecessary. The protestors’ absolute denunciation of a competent person’s choice to forgo life-extending treatment, though, seems misplaced.

²⁰ Lois Sheperd, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, 77 *St. John’s L. Rev.* 445 (2003).

²¹ *Thor v. Super. Ct. of Solano County*, 855 P.2d 375, 382 (Cal. 1993); President’s Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (1983), 26.

of prolonged life based on the patient's contribution to and consumption of society's resources."²² Doctors as well as courts respect each competent person's treatment preferences grounded in the individual's assessment of her own interests.²³ If quality-of-life considerations come into play, they do so according to the patient's own perspective and values. Nor does the acceptance of a competent patient's fatal choice single out disabled persons. "The autonomy of every patient receives equal protection, regardless of current health, age, or disability."²⁴

²² Developments in the Law -- Medical Technology and the Law, 103 Harv. L. Rev. 1519, 1652 (1990).

²³ AMA Code of Medical Ethics, Opinions 2.17 and 2.20 (on line)

²⁴ Peters, supra note 10, at 919.

II. Surrogates' Assessments of Quality of Life

All the above objections to a “quality of life” ethic are asserted even more vigorously in the context of mentally incompetent medical patients whose course of treatment is being determined by others. Again, a decision to terminate life-sustaining medical intervention is viewed by some objectors as a usurpation of a divine function. And any surrogate determination to end life support supposedly violates an important cultural commitment to sanctity of life and the precept that all human life is intrinsically valuable. From that perspective, illness and decline may undermine quality of life and human dignity, but not to an extent justifying a determination that a debilitated existence is not worth preserving. Any surrogate decision to end life support is also said to undermine the status, morale, and well being of healthy disabled persons.²⁵ Terms like “quality of life” and “a life not worth living” are criticized as so subjective as to endanger helpless patients.²⁶ Any negative quality of life determination by a surrogate is deemed unavoidably distorted by the decisionmaker’s subjective perspective. Distortions may include self-interest, insensitivity to the value of disabled persons’ lives, or even concern for utilitarian factors such as costs of care.

A few jurisdictions have responded to such objections by severely constricting the circumstances in which a surrogate decisionmaker – no matter how loving and dedicated to the incompetent patient’s well being – can withhold or withdraw life support. The first judicial decision in that direction was issued in 1982 by then Chief Judge Wachtler of New York’s highest court. Judge Wachtler rejected a mother’s plea to end discomforting treatment for her cancer-stricken, mentally disabled son, saying: “[N]o person or court should substitute its judgment as to what would be an acceptable quality of life for another.”²⁷ For Wachtler, protection of helpless people’s lives overrode any pain or discomfort of the incapacitated, dying patient. The Missouri Supreme Court in 1988 also ruled that no surrogate could remove life support from an incompetent patient – even a patient mired in a permanently unconscious state – in the absence of clear instructions issued by the patient while still competent.²⁸ Without a prior declaration by the now-incompetent patient, the Missouri court feared that vulnerable people would be subject to abusive or arbitrary terminal decisions.

In 1990, the United States Supreme Court found that Missouri’s policy was constitutional

²⁵ “Critics * * * argue that a quality of life approach * * * is actually an invidious method of denigrating the social worth of individuals whom others perceive to be defective or subnormal.” *Developments in the Law*, supra note 22, at 1602.

²⁶ E.g., Elizabeth J. Sher, *Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. Rev. 157, 185 (1983).

²⁷ *In re Storar*, 420 N.E.2d 64 (N.Y. 1981).

²⁸ *Cruzan v. Harmon*, 760 S.W.2d 408, 426 (Mo. 1988).

(whether or not it represented good public policy).²⁹ Several other state courts subsequently adopted Missouri's policy of precluding withdrawal of life support absent clearcut prior expressions from the now-incompetent patient. Maryland,³⁰ Kentucky,³¹ New York,³² Michigan,³³ Wisconsin,³⁴ and California³⁵ initially followed that course. This policy presents a considerable barrier to any removal of an incompetent patient's life-sustaining treatment. Very few people are prescient enough to provide sufficiently clear advance instructions for the spectrum of scenarios that might ensue. Fortunately for dying patients in those states, some mitigating factors have emerged.³⁶

In the few states that still adhere to the Missouri policy,³⁷ the consequences are dire both for never-competent persons (who could never have given prior instructions or designated a health care agent) and for previously competent persons who never issued advance instructions or designated an agent. The main specter is indefinite medical maintenance in a status that the patient herself would deem intolerably painful or demeaning if miraculously able to express personal wishes.

²⁹ *Cruzan v. Harmon*, 497 U.S. 261, 280 (1990) (finding that a state could, in the interests of preventing unwarranted cessation of life support by a surrogate, insist on clearcut prior expressions from the incompetent patient).

³⁰ *Mack v. Mack*, 618 A.2d 744 (Md. 1993)

³¹ *DeGrella v. Elston*, 858 S.W.2d 698 (Ky. 1993).

³² *In re Westchester County Med. Ctr. on behalf of O'Connor*, 531 N.E.2d 607 (N.Y.1988).

³³ *In re Martin*, 538 N.W.2d 399 (Mich. 1995).

³⁴ *Spahn v. Eisenberg (In re Edna M.F.)*, 543 N.W.2d 485 (Wis. 1997)

³⁵ *Matter of Wendland*, 28 P.3d 151 (Calif. 2001)

³⁶ In a few of these states, legislative adoption of health care decisionmaking acts has loosened the judicially constructed policy so that a conscientious surrogate may act according to the incompetent patient's best interests, even if that means an end to further life support. In some states, a person can expand treatment (or non-treatment) options by appointing someone as an agent with authority to make all health decisions should the declarant become incompetent. And a last resort for health care providers stymied by restrictive laws is to spur the patient's next of kin to somehow "remember" previous conversations in which the now-incompetent patient expressed opposition to treatment in the current circumstances.

³⁷ Actually, Missouri itself has abandoned its former rigid policy except as to artificial nutrition and hydration.

The story of Sheila Pouliot provides an illustration.³⁸ Ms. Pouliot was a 42 year old woman, moderately retarded as a result of childhood mumps. She had lived with her loving family for over 20 years, but in December 1999 she was a resident in a New York State facility for the developmentally disabled. On December 21, 1999, Ms. Pouliot was admitted to University Hospital in Syracuse, suffering from aspiration pneumonia, gastrointestinal bleeding, an acute abdomen manifested by severe abdominal pain, and a non-functioning intestine.

Ms. Pouliot's sister, Alice Blouin, in conjunction with the hospital's medical personnel, determined that Ms. Pouliot was unavoidably dying and that further medical intervention, including artificial nutrition and hydration (ANH), would only prolong Ms. Pouliot's dying process. The hospital ethics committee concurred. Palliative care only would be administered. That medical course was followed for several days until the state Attorney General's office intervened.

The Attorney General insisted that New York law would not permit removal of ANH from a patient in the absence of prior instructions – prior instructions that Ms. Pouliot could never have issued because of her mental incapacity. Under this legal pressure, the treating physicians renewed ANH and the family acquiesced. For the next 7 weeks, Ms. Pouliot lingered, unable to relate to her environment and occasionally moaning and grimacing from pain. Her body swelled up with edema to grotesque proportions and her skin broke down around the I.V providing hydration. On March 3rd, 2000, the family and medical staff secured a court order permitting removal of all life support. Ms. Pouliot died shortly thereafter, her course of dying having violated both medical standards of palliative care and standards of humane treatment dictated by compassion and respect for human dignity. In short, a policy demanding clear prior expressions as a prerequisite to withdrawal of life support is inhumane in disregarding the possible harm and degradation to the now-incompetent patient.

In contrast to the Missouri policy, most states permit a surrogate decision to withhold or withdraw life support according to the surrogate's conscientious determination that the patient herself would have wanted that course or according to the patient's best interests (including an interest in quality of life and dignity).³⁹ Many courts, including the Florida court in Schiavo, have insisted that a person's right to refuse medical treatment is not lost when that person

³⁸ See *Blouin v. Spitzer*, 213 F.Supp.2d 184, 194 (N.D. N.Y. 2002), *aff'd* 356 F.3d 348 (2d Cir. 2004); Alicia R. Ouellette, *When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 *Ind. L.J.* 1, 31 (2004). See also "Sheila Pouliot's Story," a summary prepared by her physician Kathy Faber-Langendoen, available at <http://www.familydecisions.org/pouliot.html>.

³⁹ Cantor, *supra* note 8, at 190-93.

becomes mentally incompetent.⁴⁰ The way to preserve the incompetent patient's "right" is to allow a surrogate to vicariously choose a medical course according to what the patient would have wanted.⁴¹

Some commentators have objected to the notion of an autonomy-based right to reject treatment when the now-incompetent patient can no longer make a considered choice based on personal preferences and values. It is true that in the absence of prior competent expressions, the surrogate's medical decision cannot reflect informed choice by the patient herself.⁴² Without prior choice, the surrogate's decision is not self-determination, but rather a means of implementing a patient's right to have appropriate medical decisions made on the patient's behalf.⁴³ Conscientious surrogate choice is the only way to avert unrelenting pumping of fluids and substances into a moribund patient until the last possible breath.

An appropriate surrogate decision, according to the bulk of end-of-life jurisprudence, is one that implements the patient's likely preferences.⁴⁴ Legislative backing of advance directives, legislative articulation of criteria for surrogate medical decisionmakers, and judicially crafted standards for surrogate decisionmaking all aim at fulfilling the now-incompetent patient's likely wishes. A number of jurisdictions use a substituted judgment approach under which a surrogate

⁴⁰ Schiavo; *Woods v. Kentucky*, 142 S.W.2d 24 (Ky. 2004)(although the Kentucky Supreme Court applies that principle only for patients now permanently unconscious or unavoidably dying within days); *In re Browning*, 568 So.2d 4, 12 (Fla. 1990); *Matter of Tavel*, 661 A.2d 1061, 1068 (Del. 1995); *In re Fiori*, 673 A.2d 905 (Pa. 1996); *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *In re Colyer*, 660 P.2d 738 (Wash. 1983).

⁴¹ *Saikewicz v. Superintendent of Belchertown State School*, 370 N.E.2d 417 (Mass. 1977).

⁴² See generally Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 *Annals Health L.* 37, 39 (2004); Cruzan, *supra* 497 U.S. at 280. A surrogate choice is "clearly not a personal choice and no amount of legal legerdemain can make it so." *Matter of Susan S.*, 1996 WL 75343 (Del. Ch. 1996). It is "naive to pretend that the right of self-determination serves as the basis for substituted decision making." *In re Conroy*, 486 A.2d 1209, 1231 (N.J. 1985).

⁴³ Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Disabled Persons*, 13 *Annals of Health L.* 37, 43-44 (2004); Ghan-Shyan Lohiya et al, *End-of-Life Care for a Man with Developmental Disabilities*, 16: *J. Am. Board Fam. Practice* 58, 61 (2003); Peters, *supra* note 10 at 898.

⁴⁴ Cantor, *The Real Ethic of Death and Dying*, 94 *Mich. L. Rev.* 1718, 1731-35 (1996); Norman L. Cantor, *Twenty-Five Years after Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 *J.L. Med. & Ethics* 182 (2001). The American Medical Ass'n concurs.

decisionmaker's object is to replicate what the patient probably would have wanted. This means first considering the patient's prior expressions and, if they are indeterminate, extrapolating from the patient's own relevant preferences and values, such as strong religious precepts. In instances when the patient's personal values cannot be discerned (as in the case of infants, or never-competent persons, or persons whose values don't speak to end-of-life medical decisions), the patient's likely wishes can be gleaned from "what most persons are likely to do in a similar situation."⁴⁵ I call this approach constructive preference -- a technique for making a substitute judgment on behalf of incompetent persons who have not issued prior instructions. The premise is that the vast majority of people care about indignity or quality of life in the dying process, and that — at least as to certain commonly occurring end-of-life scenarios — common preferences about intolerable levels of indignity can be objectively ascertained and used as default presumptions to guide surrogates.

When insufficient knowledge prevents any conclusion about a patient's prior choice, some jurisdictions shift focus from patient self-determination to the patient's best interests. The underlying assumption is that most people would probably want decisions on their behalf made according to their best interests. A best interests formula – asking whether the burdens of the patient's prospective existence outweigh the benefits of continued existence – draws on the elements that people commonly define as their interests when facing a critical affliction. Severe pain is almost universally deemed a substantial burden while pleasure and satisfaction are obvious benefits. Accordingly, physical and emotional pain and pleasure are the most important elements in surrogate consideration of a patient's best interests.⁴⁶ But quality of life, or indignity, is still part of a best interests calculus. Courts defining best interest factors commonly include not just pain, but humiliation, extreme dependence, and loss of dignity.⁴⁷

The reality is that both under standards of substituted judgment and best interests of the patient, quality of life is an unavoidable element in shaping a humane dying process. Pain and pleasure are clearly quality of life factors. Extreme indignity is another quality of life factor – subjection of a formerly competent, fatally stricken patient to a dying process that most people would regard as unconscionable. At some level of degeneration and debilitation, a dying patient's condition reaches a point that the patient would find intolerably undignified. In some instances, the now-incompetent patient has previously defined this treatment boundary. Usually

⁴⁵ *In re Boyd*, 403 A.2d 744, 751, 750 n.11 (D.C. 1979). Nancy Rhoden argued that "unexpressed but probable desires can be equated with implementing the patient's right of choice." Rhoden, *Litigating Life and Death*, 102 Harv. L. Rev. 375, 384 (1988). See also Richard A. McCormick, *The Quality of Life, The Sanctity of Life*, 8 Hastings Center Rep. 30, 36 (Feb. 1978).

⁴⁶ *Conroy*, 486 A.2d at 1233; *In re Grant*, 747 P.2d 545 (Wash. 1987).

⁴⁷ *Woods v. Kentucky*, (Ky. 2004); *Grant* 747 P.2d 545; *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987); *Conroy*, 486 A.2d 1209 (N.J. 1985).

not. In the absence of a patient's prior expressions or determinative personal values, a conscientious surrogate, in conjunction with surrounding health care providers, can project that level of indignity according to what a strong majority of people would deem intolerably undignified for themselves.⁴⁸ There are certain situations, like permanent unconsciousness or semi-consciousness without ability to recognize loved ones, when notions of indignity shared by most people fill out what the now-incompetent patient would consider to be an intolerably demeaning dying process.⁴⁹

Why do people care about indignity if they are not actually experiencing the kind of frustration and humiliation that William Bartling found intolerable? The answer is that people care mightily about the memories and image to be left behind with their loved ones, as well as about the burdens placed on those loved ones. This fact emerges clearly in a multitude of surveys in which people identify the factors they want considered for themselves by a surrogate making post-competence medical decisions.⁵⁰ People facing a fatal, degenerative affliction care about extreme mental debilitation, helplessness, and dependence in a dying process.

In short, the diminished quality of life of a previously competent person is an essential consideration in shaping medical intervention in a now-incompetent person's dying process.⁵¹ The AMA acknowledges that "quality of life, as determined by the patient's interests and values, is a factor to be considered in determining what is best for the individual."⁵²

The injection of indignity and quality of life into surrogate medical decisionmaking does

⁴⁸ As noted, the patient's own preferences and values are the starting point for surrogate decisionmaking; resort to constructive preference happens only when the patient's own preferences are indeterminable.)

⁴⁹ Norman L. Cantor, Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions, 48 Rutgers L. Rev. 1193, 1256-57 (1996).

⁵⁰ E.g., Ashwini Sehgal et al., How Strictly Do Dialysis Patients Want Their Advance Directives Followed? 26 JAMA 59, 62 (1992); Tomlinson, An Empirical Study of Proxy Consent for Elderly Persons, 30 Gerontologist 54 (1990); R.A. Pearlman et al., Insights Pertaining to Patient Assessment of States Worse than Death, 4 J. Clinical Ethics 35 (1993); P.A. Singer et al., Life Sustaining Treatment Preferences of Hemodialysis Patients, 6 J. Am. Soc'y of Nephrology 1410, 1412-13 (1995).

⁵¹ Peters, *supra* note 10 at 946.

⁵² AMA Code Opinion 2.17.

not mean injection of social worth or utilitarian considerations.⁵³ All sources embracing a best interests formula make “the distinction between patient-centered best interests analysis and decision making based on social worth.”⁵⁴ The courts in question emphasize quality of life as “an objective inquiry into the value that continuation of life has for the patient” rather than an opportunity for surrogates to rely on their subjective views or on a utilitarian calculus of social utility.⁵⁵

A patient-centered focus excludes any prejudice that cognitive deficiency is to be equated with an intolerable quality of life.⁵⁶ For example, people with Alzheimer’s disease retain capacity for emotional response to their environment that is a part of quality of life even without rationality or memory.⁵⁷ At the same time, extreme deterioration may reach a level that can reasonably be deemed intolerably demeaning according to either the previous values and preferences of the now-incompetent patient or a concept of intolerable indignity held by an overwhelming number of people contemplating their own dying processes (and not contradicted by anything in the patient’s own value history). A permanently unconscious state is the principal example of an intolerably undignified status. Over 90% of people consistently say that they would not want to be preserved in this condition devoid of emotion or interaction with a human

⁵³ President’s Commission, *supra* note 21, at 97; Nicholas Smedira et al., *Withholding and Withdrawal of Life Support from the Critically Ill*, 322 N. Eng. J. Med. 309, 314 (1990).

⁵⁴ Peters, *supra* note 10, at 974. “The phrase ‘quality of life’ can mean either the value of prolonged life for the patient or the value to others of prolonged life based on the patient’s contribution to and consumption of society’s resources. Courts generally agree that if quality of life considerations have any influence at all, the appropriate scope should be defined by the value to the patient.” *Developments in the Law*, *supra* note 22, at 1652.

⁵⁵ *Woods v. Kentucky*, 142 S.W.3d 24 (Ky. 2004); *Conroy*, 486 A.2d at 1232-33.

⁵⁶ Patrick Corrigan & Brett Duncan, *The Construct Validity of Subjective Quality of Life for the Severely Mentally Ill*, 183 J. Nervous & Mental Disease (May 1995), 281-85. “Nor does reference to quality of life entail derision of a disabled existence as inferior. The phrase “quality of life” can be used in both the intrapersonal and interpersonal sense. Used in the intrapersonal sense, it refers to a comparison between the patient’s former quality of life and the same patient’s likely quality of life with and without treatment. In the intrapersonal sense, it is irrelevant that the patient is retarded and deformed except insofar as these conditions may be exacerbated by treatment or failure to treat. Also, in the intrapersonal sense, comparisons to other persons and their qualities are inappropriate. By contrast, quality of life in the interpersonal sense implies a comparison with others and includes assessment of deformities and mental retardation.” T.S. Ellis III, *Letting Defective Babies Die: Who Decides?* 7 Am. J.L. & Med. 393, 406 (1982).

⁵⁷ Stephen G. Post, *Dementia in Our Midst: The Moral Community*, 4 Cambridge Q. of Health Care Ethics 142 (1995).

environment.⁵⁸ In other words, an overwhelming majority of people would rather die than live “in such a physically, emotionally, and socially impoverished state.”⁵⁹

None of this suggests that it is easy for a conscientious surrogate to determine when a previously competent person has reached a point of such extreme deterioration that, from the perspective of the patient, death can be deemed preferable to life. There is no easy algorithm to accomplish that task. At least next of kin usually know the patient’s history best, meaning that they are most familiar with the patient’s values and preferences and best able to interpret the now-incompetent patient’s current feelings, emotions, and expressions – all of which are relevant factors in making a quality of life medical decision. Also, in the case of previously competent persons, a surrogate can assess both the patient’s own history and any consensus about an intolerably undignified quality of life (as in the case of permanent unconsciousness) that has emerged over time from sources like advance medical directives and surveys of people’s preferences for their own end-of-life decisions. Naturally, surrogates tend to err in favor of life; premature termination of life is rarely documented.

The difficulty of end-of-life medical decisionmaking is exacerbated in the case of never-competent patients. This means people who never had capacity to formulate their own values and preferences about a dying process, and whose concepts of indignity are not interchangeable with those of competent or previously competent persons.⁶⁰ The situation of newborn infants is illustrative. While the best interests of the vast majority of infants – disabled or abled – dictate life-extending treatment, that is not always the case. Some infants face a battery of painful and burdensome treatments that will dominate their shortened existences before unavoidable death.⁶¹ And some very premature infants face unvalidated, invasive, and painful procedures likely to result in prolonged dying or grievous future harm. A recent case involved a premature infant born at 615 grams whose aggressive treatment resulted in lung disease, brain hemorrhaging causing severe mental retardation, cerebral palsy, seizures, spastic quadriplegia in limbs, incontinence, and need for skilled care 24 hours per day. Parents, in conjunction with medical personnel, may, in those rare instances, determine whether further medical intervention is

⁵⁸ While new imaging techniques may show some brain activity in coma patients (though not PVS patients), many people would not want to be medically sustained in that frustrating and degrading condition. That is, an existence devoid of capacity for interaction with others is also unwanted by the vast majority of people thinking about their own medical fates.

⁵⁹ John Arras, *The Severely Demented, Minimally Functional Patient: An Ethical Analysis*, 36 *J. Am. Geriatric Soc’y* 938, 943 (1988).

⁶⁰ See generally Norman L. Cantor, *Making Medical Decisions for Profoundly Mentally Disabled Persons* (MIT Press, 2005).

⁶¹ See Letters from neonatologists at 35:1 *Hastings Center Rep.* (Jan. 2005), 4-5.

consistent with the infant's best interests.⁶²

A similar calculus applies in end-of-life medical decisions on behalf of life-long profoundly mentally disabled persons.⁶³ A conscientious surrogate must interpret the wants, needs, and feelings of the incapacitated patient from sometimes cryptic sounds and gestures. Of course, in the vast majority of cases the surrogate chooses continued medical intervention in the face of fatal affliction. The fact that a person's functioning is limited or prognosis poor does not mean it is in that person's best interests to die. Sometimes, though, the patient's extreme deterioration warrants an end to life-extending medical intervention.⁶⁴ Sheila Pouliot's case was one such instance.

Conclusion

Some people believe that death with dignity is a false hope. They contend that dying is intrinsically traumatic and that an effort to preserve dignity, in the sense of a tranquil passing, is bound to fail. Dignity for them consists of struggling and contending bravely against a fatal affliction, no matter how precipitous the decline in physical and mental condition. And no matter how divorced the now-incompetent person may be from previous mental acuity and previous capacity to relate to an environment. For them, no surrogate -- no matter how loving and devoted to the interests of the patient -- can be entrusted with determining that a fatally afflicted person's quality of life is so dismal that all life-extending medical support should be withdrawn.

Yet the majority of deaths in the U.S. are managed -- meaning that caregivers end medical intervention even though the patient's life could be artificially prolonged. That is the only humane way. The alternative is to keep pumping fluids and gases into a floundering, moribund patient till the last possible breath. That is demeaning and shameful. "To presume that the incompetent person must always be subjected to what many rational and intelligent persons may

⁶² George J. Annas, *Extremely Premature Birth and Parental Authority to Refuse Treatment*, 351 N.Eng. J. Med. 2118, 2121 (2004); Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Matters*, 58 S. Cal. L. Rev. 1283, 1319-20 (1985); In re Christopher I., 106 Cal. App. 4th 533, 548-50 (2003).

⁶³ Ghan-Shyam Lohiya, et al., *supra* note 43, at 58, 60.

⁶⁴ See Sheila Pouliot's case, described in *supra*; *Matter of Richard H.* N.E.2d Mass. App. 1993. Bruce Nichols, *Hospital Ends Life Support of Baby*, Dallas Morning News, 3/15/05, <http://www.dallasnews.com/s/dws/dn/latestnews/stories/031605dntexbaby.bc467.html> (describing withdrawal of life support from a critically ill 5-month old infant suffering from a fatal genetic disorder called thanatophoric dysplasia.); *Saikewicz v. Superintendent of Belchertown State Sch.*, 370 N.E.2d 417 (Mass. 1977).

decline is to downgrade the status of the incompetent person * * *.”⁶⁵ To ignore quality of life in the context of fatally afflicted persons “transforms human beings into unwilling prisoners of medical technology.”⁶⁶

⁶⁵ In Re Boyd 403 A.2d 744, 750 (D.C. 1979).

⁶⁶ In re L.W., 482 N.W.2d 60 (Wis. 1992).