NOTE

THE LIMITS OF THE AUTONOMY PRINCIPLE:
REFUSAL OF LIFE-SUSTAINING MEDICAL
TREATMENT FOR INCOMPETENT PERSONS

I. INSTITUTIONALIZING AUTONOMY

A moral position is inherent in every act of selection. This is illustrated by the patent untruth of the aphorism that morality cannot be legislated. "Cannot" here really means "should not" and "should not" itself is a moral construct. Legal values reflecting detachment from moral values in order to encourage tolerance of diverse moral values are usurping the role formerly played by moral values themselves. Noninterference with the choices of others has become a favored moral stance which institutionalizes the American deification of the illusion of choice.

Noninterference as a political philosophy has its counterpart in the moral philosophy of cultural relativism which posits that as indi-
viduals, and as a culture, we must not judge others by our values but by their own. Noninterference stems from the liberal tradition\textsuperscript{7} which exalts, "separation, autonomy, individuation and natural rights"\textsuperscript{8} and equates "maturity . . . with personal autonomy."\textsuperscript{9} Liberal notions of autonomy originally focused on the individual's relationship to the state and the need to keep the government from interfering with the beliefs and actions of individuals.\textsuperscript{10} Autonomy values are no longer only part of the way we conceive our relationship to the government: they are a part of the way we conceive of our relationships with each other.\textsuperscript{11} We think in terms of whether someone has a "right" to interfere in our decision-making. If we conclude that a decision is "none of his business" then the other may be excluded from participation in the decision.\textsuperscript{12}

\textsuperscript{7} The only freedom which deserves the name, is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it. Each is the proper guardian of his own health, whether bodily, or mental and spiritual. Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest.


\textsuperscript{8} CAROL GILLIGAN, \textit{IN A DIFFERENT VOICE} 23 (1982); see also Kelley v. Johnson, 425 U.S. 238, 251 (1976) (Marshall, J., dissenting) ("[The] values of privacy, self-identity, autonomy, and personal integrity [are those] I have always assumed the Constitution was designed to protect.").

\textsuperscript{9} GILLIGAN, supra note 8, at 17.

\textsuperscript{10} See \textit{Olmstead v. United States}, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting) ("[T]he right to be let alone—[is] the most comprehensive of rights and the right most valued by civilized men . . . ."); see also William W. Bratton, Jr., \textit{The "Nexus of Contracts" Corporation: A Critical Appraisal}, 74 CORNELL L. REV. 407, 463 (1989) (noting "the liberal goal of noninterference by the sovereign").

\textsuperscript{11} See, e.g., \textit{Union Pac. Ry. Co. v. Botsford}, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others . . . ."); Robert A. Burt, \textit{Constitutional Law and the Teaching of the Parables}, 93 YALE L.J. 455, 489 (1984) (finding that the Supreme Court, in cases involving "the claim for individual autonomy from relations with others in its recent cases involving retardation and racial segregation treats the simple assertion of the wish to avoid association as intrinsically justified without any need to account for, or listen to, competing claims").


Suppose I am at a dinner party, and the host urges me to stop drinking because I will be driving home soon. I can respond by saying "Don't pester me so much; I am solely responsible for my drunk driving. It is really none of your business." I have taken subject-responsibility for my drunk driving. I identify it as an aspect of myself . . . .
A. Autonomy and the Right to Refuse Medical Treatment

This veneration of autonomy as our societal prime directive makes grappling with the existence and scope of an individual’s “right” to refuse medical treatment the source of dissension. A competent patient has a right to refuse medical treatment. This right has been based on an individual’s common law right to refuse consent for treatment and has also been described as a constitutionally protected liberty interest covered by the Fourteenth Amendment Due Process Clause. The right to refuse life-sustaining medical treatment...
is not, despite popular shorthand, the right to die, a phrase which is used to cover euthanasia and assisted suicide as well as refusal of life-sustaining medical treatment. Possession of the right is dependent upon that right being exercised at some time when the individual had sufficient capacity to make a decision.

Societal hesitancy to fully accept this right may spring from an unwillingness to protect suicide, generalized discomfort with death, and uncertainty of how those who are not viewed as autonomous are to be valued and treated in a society where autonomy is the defining and primary value. Decisions in this society are viewed

interest in preserving life. Cruzan v. Harmone, 760 S.W.2d 408, 419-20 (Mo. 1988). The court concluded that a guardian may not decide to terminate treatment without proof of the patient's wishes that would satisfy a clear and convincing evidence standard. Id. at 425. In Nancy Cruzan's case, the Missouri Supreme Court found insufficient evidence of Nancy's wishes to satisfy a clear and convincing evidence standard. Id. at 426.

As evidence of the deep, fundamental disagreements that so mark this area, consider the status of the debate over active and passive euthanasia. If there is a dominant position with respect to these terms, it is that passive euthanasia may be ethically and legally permissible under certain circumstances, while active euthanasia is not ethically permissible and constitutes homicide, at least under some circumstances.


The differences between the choice made by a competent person to refuse medical treatment, and the choice made for an incompetent person by someone else to refuse medical treatment, are so obviously different that the State is warranted in establishing rigorous procedures for the latter class of cases which do not apply to the former class.

See id. at 287 n.12

Id.


Michael R. Flick, Comment, The Due Process of Dying, 79 CAL. L. REV. 1121, 1123 n.9 (1991) ("Because the choice of whether to die still eludes human grasp, people can exert power only by positing how to die.").

See, e.g., Robin West, Jurisprudence and Gender, 55 U. CHI. L. REV. 1, 5 (1988) (West describes "legal liberalism" as asserting that "[b]ecause I am separate, I am 'autono-
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exclusively in terms of competence and autonomy. Personhood is conceived of as bound to the ability to make choices to an extent which denies the personhood of people who are considered as not having the ability to choose.

1. Autonomy and Suicide

If individual liberty is coextensive with autonomy, the right to commit suicide is the logical extension of a right to refuse medical treatment. Recognition of a right to commit suicide, however, requires acknowledgement that our notions of our relationship to God and to each other have changed radically. To acknowledge a right to commit suicide is to say that ultimately each man is an island and that life and death are no longer the province of God or

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nature but of human beings. Much of the commentary discussing the difference between the right to refuse treatment and the right to commit suicide focuses on the notion that the refusal of medical treatment passively allows the natural progression towards death. This reasoning adheres to the idea that death is an area of natural control outside the realm of human order which therefore must be resisted as long as possible in order to extend the reach of humanly assigned meaning.

2. Discomfort with Death
The consideration and acceptance of death implicit in acknowledgment of the right to refuse life-sustaining medical treatment is the source of the ambivalence which characterizes discussion of the scope of the right. The nature of death eludes consensus. Death may

the same God who does not want us to foist on him a responsibility which we ourselves can and should bear.

29. See SHERWIN B. NULAND, HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER at xv (1994) ("We can now deny the power not only of death but of nature itself.").
30. See Fetterly v. Paskett, 15 F.3d 1472, 1483 (9th Cir. 1994) ("Where does the judge get the authority to sentence a person to die if not from a statute?"); The Supreme Court, 1983 Term—Leading Cases, 100 HARV. L. REV. 100, 106 (1986) ("The deep meaning of capital punishment . . . [is] that the state absolutely controls life and death within its borders.").
31. See, e.g., In re Conroy, 486 A.2d 1209, 1224 (N.J. 1985) ("Refusing medical intervention merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease, and not the result of a self-inflicted injury.").
32. Death is unique. It is unlike aught else in its certainty and its incidents. A corpse is in some respects the strangest thing on earth. A man who but yesterday breathed and thought and walked among us has passed away. Something has gone. The body is left still and cold, and is all that is visible to mortal eye of the man we knew. Around it cling love and memory. Beyond it may reach hope.
33. See NULAND, supra note 29, at 10 (describing "the prevailing temperament of our times, when death is regarded as the final and perhaps the ultimate challenge of any person's life—a pitched battle that must be won").
34. Cf. James E. Hannah, The Signs of Death: Historical Review, 28 N.C. MED. J. 457, 457 (1967) ("Every individual devises his own emotional constructs with which he protects himself from involvement with thoughts of death.").
be conceived of as a part of life, an absolute end to all life, the beginning of a new earthly life or relocation to another plane of existence. There is no definitive opinion on how death should be approached and weighed. There may be an underlying societal sense that death has its own inherent value or meaning and that it is, in some important and universal way, not something that human
beings can know how to weigh, even for themselves. The sense that life has an inherent, unknowable value, often spoken of as the sanctity of life,\(^42\) is also part of our sense that determining the scope of the right to refuse life-sustaining medical treatment is uniquely difficult. The right to refuse medical treatment is sometimes conceived of as an extension of the doctrine of informed consent.\(^43\) But there is no such thing as informed consent because both the value of life and the aftermath of death are unknowable.\(^44\)

3. Autonomy and the Incompetent Person

Discomfort with the right to refuse treatment is intensified because exercise of the right is often predicated on loss of autonomy. If someone has lost competence without making a decision as to the kind of medical treatment she would want if she became incompetent or has never been competent to refuse medical treatment, the decision cannot actually be made by the incompetent person. Difficulty arises here because the necessity of making a decision outlasts, or exists separately from, the decision-making ability of the person possessing the right to decide.\(^45\)

II. DISTINGUISHING THE DECISION FROM THE RIGHT

When the capacity for autonomy on which liberty interests and doctrines of consent are premised\(^46\) has vanished, the decision re-

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42. See, e.g., David A. Maraniss, John Paul's Farewell Mass Celebrates Life, WASH. POST, Oct. 8, 1979, at A1 (The Pope stated during Mass on the Mall in Washington D.C., "I do not hesitate to proclaim before you and before the world . . . that all human life—from the moment of conception and through all subsequent stages—is sacred, because human life is created in the image and likeness of God.").

43. See John N. Suhr, Jr., Note, Cruzan v. Director, Missouri Department of Health: A Clear and Convincing Call for Comprehensive Legislation to Protect Incompetent Patients' Rights, 40 AM. U. L. REV. 1477, 1479 n.5 (1991) ("The doctrine of informed consent is designed to respect an individual's right of self-determination in medical treatment matters and requires that physicians or other health care providers treat a patient only after having obtained the patient's consent.").

44. See Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 343 (1990) (Stevens, J., dissenting) ("[N]ot much may be said with confidence about death unless it is said from faith . . . .").

45. See COORDINATING COUNCIL ON LIFE-SUSTAINING MEDICAL TREATMENT DECISION MAKING BY THE COURTS, GUIDELINES FOR STATE COURT DECISION MAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES 74 (2d ed. 1993) ("[E]ven where no surrogate is recognized as having authority to make LSMT (life-sustaining medical treatment) decisions, some LSMT decision has to be made, even if that decision is that the court has no authority but to order the continuation of LSMT.").

46. See Kelley v. Johnson, 425 U.S. 238, 244 (1975) (stating that Fourteenth Amend-
mains. Regardless of whether the incompetent person is capable of exercising his or her right to refuse medical treatment, or whether the person even retains that right in the face of his or her incompetence, the decision of whether to continue treatment remains to be made. Non-action in this case is a decision. Where the required action is decision-making, action and non-action both constitute actions, because both are effectively decisions.

If a person is no longer sufficiently competent, her liberty interest is extinguished and the decision whether to refuse life-sustaining medical treatment must be made either by someone who has a different legal right to make this decision or someone who has no legal right to make the decision. If the state is deciding itself, it should be extremely hesitant to terminate life-sustaining medical treatment. To do so may deprive the incompetent person of her life interest. To allow the state to discontinue treatment is to acknowledge the state's authority to judge when a particular life is not worth continuing. Assessing the validity of a particular life is not the kind of decision we as a society generally want government to make. Only in

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47. See Cruzan, 497 U.S. at 273 (citing In re Conroy, 486 A.2d 1209, 1229-33 (N.J. 1985) as "[r]easoning that the right of self-determination should not be lost merely because an individual is unable to sense a violation of it").

48. See id. at 280 ("An incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a 'right' must be exercised for her, if at all, by some sort of surrogate.").

49. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction. Id. at 283; see also In re Conroy, 486 A.2d at 1233 ("When evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if it all, in favor of preserving life.").

50. See Cruzan, 497 U.S. at 281 ("It cannot be disputed that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment.").

The due process requirements established by Cruzan, where the state is exercising control of an individual's liberty interest, may not be coextensive with the due process requirements implicated by state deprivation of a life interest. See Morrissey v. Brewer, 408 U.S. 471, 481 (1972) ("[D]ue process is flexible and calls for such procedural protections as the particular situation demands.").

51. See, e.g., Callins v. Collins, 114 S. Ct. 1127, 1129 (1994) (Blackmun, J., dissenting
the absence of anyone truly intimate with the incompetent person\(^5\) should the government be the decision-maker.\(^3\) Where no one is intimately connected to the incompetent person and the choice is therefore left to the government, given the possibility that the government is wrong about death,\(^4\) the decision must be life.

III. DETERMINING INTERESTS

The authority to make a decision for someone else can no longer be characterized as the exercise of a liberty interest. Liberty interests are premised on traditional liberal notions of individual autonomy which have at their heart the idea that each person has one’s own domain, guarded by rights which prevent interference from other people or the state.\(^5\) A liberty interest is by definition an interest in doing as one chooses rather than as someone else would choose. Therefore it is not sensible to speak of a liberty interest as being exercised where someone else is choosing in the rightholder’s stead.

Substituted judgment is essentially substituted value. The judgment of someone who is sufficiently valuable in terms of autonomy is substituted for that of a person who is not valuable in those terms.

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\(^5\) See, e.g., Martha Minow, The Role of Families in Medical Decisions, 1991 UTAH L. REV. I, 23 (“I think that families should be entrusted to make treatment decisions on behalf of a comatose or incompetent relative absent a specific showing of their conflicting interests because the alternative of a state decision-maker is not presumptively better.”).

This equation treats those for whom the decision must be made as possessions of the autonomous decision-maker. If someone is viewed as lacking capacity to make a choice (read the "right" or rational choice) about something that person putatively owns, the person who is viewed as not being able to choose will not be allowed absolute control—some sort of guardian or trustee will be appointed. Tangible property owned by an incompetent person still belongs to him in some sense because he is still allowed to use it. In speaking of the right to make a decision, use and possession are indistinguishable. The ability to decide in this case is not merely the control of something but the thing itself. There are no other sticks in the bundle where the "property" is the right to make a decision.

An individual's authority to exercise the right to refuse medical treatment is dependent upon satisfying a competency standard. Competency standards are adopted to identify those abilities considered indicative of ability to exercise a specific right. In the context of the right to refuse medical treatment, the ability to base one's decision on factors that a reasonable person would consider in making such a decision is generally not required.

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56. See Linda S. Mullenix, *Creative Manipulation of Federal Jurisdiction: Is There Diversity After Death?*, 70 CORNELL L. REV. 1011, 1014-15 n.13 (1985) (quoting McSparran v. Weist, 402 F.2d 857, 870 (3d Cir. 1968)) ("[A] guardian of the person of a minor or other incompetent has no interest in his ward's property and a guardian of his estate does not take legal title to the property, which remains in the ward, but merely acts as its custodian or manager.").


To be sure, Karen Quinlan [who had become completely incompetent] was not 'dead' in most of the increasingly multiple senses of that term, but the task of giving content to the notion that she had rights, in the face of the recognition that she could make no decisions about how to exercise any such rights, remains a difficult one.

Id.

58. Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENG. J. MED. 1635 (Dec. 22, 1988) ("Competent patients have the right to decide whether to accept or reject proposed medical care. Patients thought to be incompetent are denied this right, and others make their decisions for them.").

59. See, e.g., Lane v. Candura, 376 N.E.2d 1232 (Mass. App. Ct. 1978); State Dept. of Human Serv. v. Northern, 563 S.W.2d 197, 210 (Tenn. Ct. App. 1978); see also Appelbaum & Grisso, supra note 58, at 1636 (asserting that court holdings, "that as long as patients understand and appreciate the relevant data, they have the right to reach decisions that outside observers consider irrational . . . result[] from a failure to distinguish the outcome . . . from the process.").
IV. DEFINING COMPETENCE

Capacity is the measure of societal authorization to act. If one can direct oneself to accomplish a particular action within the societally agreed-upon parameters for performance of that action, then capacity to perform that action has been established and is rewarded with the right to act autonomously, without societal oversight. Those who perform that action in a non-societally-approved way are considered to act irrationally and thus be incompetent. Such people are no longer allowed to choose to effectively perform the action.

A. The Legal Function of Capacity Determinations

Capacity or competency and the concomitant possession of the right to act autonomously are societal conclusions premised on what characteristics or patterns of behavior are considered prerequisites to the exercise of a particular right. Contracts may not be enforced

60. See THOMAS G. GUTHEIL & PAUL S. APPELBAUM, CLINICAL HANDBOOK OF PSYCHIATRY AND THE LAW 215 (1982) ("The Uniform Probate Code . . . defines incompetency as follows: A mentally incompetent person is one who is so affected mentally as to be deprived of sane and normal action, or who lacks sufficient capacity to understand in a reasonable manner the nature and effect of the act he is performing.").

61. See id. ("Specific competency is defined only in relation to a particular act: whether one is competent to write a will, make a contract, testify in court, or stand trial for murder.").

62. Evaluating competence to contract entails an evaluation that resembles a determination of competency to refuse medical treatment. The evaluation in the case of competency to contract requires weighing an individual right (that individuals should be able to contract freely) against a burden imposed by society (that an individual should only be able to contract if she is aware that she is contracting and appreciates the consequences of doing so). "The standard for determining competency to refuse medical treatment likewise requires a balancing of individual autonomy rights and societal concerns." Benjamin Freedman, Competence, Marginal and Otherwise, 4 Int'l. J. L. & PSYCH. 53, 56-57 (1981).

63. [Let us face squarely the question of whether competency is an empirical or a moral term. Does it describe a fact in the world, or how we evaluate that fact? . . . Competence is not pure description . . . nor pure evaluation; but, perhaps, an evaluation that stems from certain described facts coupled with a moral theory that tells us what those facts mean, how we ought to respond to those facts. A middle step between description and action is always needed, i.e., a moral theory that interprets experience and guides action.

Id. at 55.

64. See Christopher T. Wonnell, The Contractual Disempowerment of Employees, 46 STAN. L. REV. 87, 88 (1993) ("In the Jim Crow South, blacks were often forbidden to enter into contractual relationships allowed to whites. For many years, married women could not enter into legally binding contracts. Notwithstanding the paternalistic justifications for these
against minors because minors are perceived as lacking the capacity to understand the ramifications of a contract. That rationale has societal consensus because it comports with our vision of what is required to make a contract enforceable and our perceptions about minors. In the past, married women were not allowed to act autonomously with regard to their property because maleness was considered a prerequisite for rationality, and rationality as a prerequisite for the exercise of the right to alienate property or make contracts. In both cases understanding the consequences of entering into a contract are important. This requirement is satisfied by constructive capacity. A showing of actual lack of understanding is generally not sufficient to invalidate a contract in the absence of a characteristic which bars the possessor from making a binding contractual commitment as a matter of law.

restrictions, modern observers recognize their tendency to disempower and economically weaken the targeted groups." (citations omitted)).

65. See Robert E. Richardson, Note, Children and the Recorded-Message Industry: The Need for a New Doctrine, 72 Va. L. Rev. 1325, 1332-33 (1986) ("[T]he so-called infancy doctrine allows the minor to avoid or disaffirm contracts that later prove not to be in his best interests, or that simply lose their appeal over time. The common law's view has traditionally been that children are naive and unsophisticated, especially in the marketplace." (citations omitted)).

66. See Duncan Kennedy, Distributive and Paternalistic Motives in Contract and Tort Law, with Special Reference to Compulsory Terms and Unequal Bargaining Power, 41 Md. L. Rev. 563, 645 (1982) ("The paternalist notion that contracts shouldn't be enforced if one party lacks capacity is constitutive of the institution of freedom of contract.").

67. See, e.g., Daniel Goleman, Teen-Age Risk-Taking: Rise in Deaths Prompts New Research Effort, N.Y. Times, Nov. 24, 1987, at C1 ("From acrobatics on skateboards to sex without contraceptives, teen-agers are notoriously reckless. Research suggests a combination of hormonal factors, an inability to perceive risks accurately and the need to impress peers help explain this. All of these influences seem to peak in the years between 10 and the mid-20's.").


The theory that married women lacked capacity to enter into contracts was derived from feudal England. Upon a woman's marriage, her personal property and possessions came under the control of her husband. In exchange for his protection and guardianship, she lost all capacity to enter into contracts unless she was contracting as her husband's agent.

Id.

69. Alexander M. Meiklejohn, Contractual and Donative Capacity, 39 Case W. Res. L. Rev. 307, 308 (1988-89) ("[T]he capacity doctrine requires courts to identify the abilities that are necessary for the exercise of contractual and donative choices.").

70. Arthur L. Corbin, CORBIN ON CONTRACTS, § 104 at 153-54 (1 vol. ed. 1950).
It is important to note that the legal background understanding of competency is generally considered to comprise two elements. The first is a bare knowledge of what you are doing: the fact that you are making a contract; an example is the fact that you have agreed to the doctor’s removal of your appendix. The second element requires that you appreciate the consequences of the act, including its typical attendant pitfalls or dangers: the fact that, after certain services have been provided, you will be legally required to pay a certain sum; the fact that you will have a scar, etc.71

It is a fiction that knowledge and appreciation of consequences are separate elements. Knowledge of an action incorporates appreciation of the qualities of that action, including consequences which flow from that action. Equally, to appreciate the consequences of an action one must understand or know what the action is. An action has little, if any, meaning aside from the consequences of taking that action since all characteristics of an action can be classified as consequences. Therefore, the right to refuse medical treatment must be exercised when the individual is still competent.72

B. The Complicated Role of Capacity Determinations in Cases Involving the Right to Refuse Medical Treatment

Capacity to decide to exercise liberty based upon constitutional rights is an integral part of possessing these rights. However, the right to refuse life-sustaining medical treatment differs because it involves competent people making a decision which may be premised on the possibility that they will lose capacity.73 One of the central reasons

71. Freedman, supra note 62, at 56-57.
73. See NULAND, supra note 29, at 151 (quoting Seneca).

I will not relinquish my old age if it leaves my better part intact. But if it begins to shake my mind, if it destroys the faculties one by one, if it leaves me not life but breath, I will depart from the putrid or tottering edifice. I will not escape by death from disease so long as it may be healed and leaves my mind unimpaired.
for seeking termination of life-sustaining treatment is that the person
who is receiving the treatment has permanently (short of a miracle)
lost the capacity to make decisions. It is often said that one “would
not want to live like that” with “that” meaning diminished from one’s
former state in some significant way. Diminished mental capability
is perceived as being more of a loss than diminished physical capabil-
ity. Self-definition is more closely tied to mental capacity than to
physical capability. It is easier for us to imagine ourselves physically
disabled than mentally disabled. It seems somehow more alienating
and puts the person who has experienced the injury at a more pro-
found distance from the rest of humanity than does a physical injury.
That separation from the whole is viewed as so tragic that the loss is
irreparable and the wish to die is considered reasonable.

A liberty interest which extends only to the competent raises
several problems. Such a conception makes, at least in relation to
liberty interests, competency the test of personhood. It is also not
clear what the measure of competency to decide to refuse medical
treatment should be. Reliance on capacity to make a “rational”

Id.

74. See Yale Kamisar, Are Laws Against Assisted Suicide Unconstitutional?, 36 L.
Quadrangle Notes 29 (1993). Professor Kamisar notes that in the case of Nancy Cruzan,
“[n]o doubt many thought that she ‘might as well be dead’ or that she was ‘better off dead’
but if her feeding tube had not been removed Nancy might well have been kept alive anoth-
er 20 or 30 years.” Id. at 34.

Professor Kamisar fears that a similar response may be common in regard to the dis-
similar case of elderly people. “Ageism . . . may manifest itself in . . . the view that an
elderly person’s desire to commit suicide is more rational than a younger patient’s would be,
or, more generally, the attitude that the elderly has every reason to be depressed or that ‘if I
were in his place I would want to die too.’” Id. at 35-36.

75. Norman L. Cantor, The Permanently Unconscious Patient, Non-Feeding and Euthana-
sia, 15 AM. J. L. & MED. 381, 414 (1989) (“The real reason why most people would prefer
death over permanent unconsciousness . . . is that an indefinite insensate limbo constitutes a
demeaning and degraded existence devoid of human dignity.”).

To be treated as a person, one must not only enjoy states of consciousness as well
as intentional states, but must also have the capacity to link together by memory
experiences which occur at different times . . . . Whether rationality or social
interactive capabilities are the controlling criteria to establish personhood remains
an open philosophical question.

George P. Smith II, All’s Well that Ends Well: Toward a Policy of Assisted Rational Suicide

77. See Lane v. Candura, 376 N.E.2d 1232, 1235 (Mass. App. Ct. 1978) (noting that
expert testimony on which the trial court relied “indicates that . . . [there is no] incompe-
tency in the legal sense, but rather that [the patient’s] ability to make a rational choice (by
which [the doctor] means the medically rational choice) is impaired by . . . [the patient’s]
consideration of irrational and emotional factors”).
choice creates the possibility that refusal of treatment itself will be used as a basis for determinations of whether an individual has the constitutionally required competence.\textsuperscript{78} One way of assessing competence is whether factors rationally related to the decision at hand provide the bases of the decision. This raises the question of what considerations are rational in deciding whether to refuse medical treatment.\textsuperscript{79} The choice of standard is particularly likely to affect meaningful possession of a right by someone who is in general marginally competent. Premising exercise of a right based upon notions of respect for individualistic decision making on mandatory consideration of those factors most people would weigh is not necessarily helpful or logically coherent where the basis for subjecting someone to a competency test in the first place is that she is not like most people.

"In general, to be considered competent an individual must be able to comprehend the nature of the particular conduct in question and to understand its quality and its consequences."\textsuperscript{80} When considered in the context of a decision to refuse medical treatment, this seemingly basic proposition raises several questions. What is the nature of the decision to refuse medical treatment? Does it have a general nature or is the nature dependent upon characteristics of the particular treatment or on the severity or painfulness of the consequences? Is the nature of the decision different from its quality? Are either the nature or the quality separable from the consequences?

V. THIRD PARTY EXERCISE OF THE RIGHTS OF INCOMPETENTS

Third parties have no right to exercise an incompetent individual's liberty interest.\textsuperscript{81} A family member is entitled only to a

\textsuperscript{78} See Kevin R. Wolff, Note, Determining Patient Competency in Treatment Refusal Cases, 24 GA. L. REV. 733, 744 (1990) ("Clinicians have identified five traditional approaches to evaluating capacity in the informed consent context: (1) evidencing a choice; (2) reasonable outcome of choice; (3) rational reasons for choice; (4) ability to understand; and (5) actual understanding." (citations omitted)). All but the first of these approaches invite the evaluator to find incompetence based on the refusal of treatment. Cf. Lane, 376 N.E.2d at 1236 ("The law protects her right to make her own decision to accept or reject treatment, whether that decision is wise or unwise[,] and requires only that the patient, "understand that . . . she is, in effect, choosing death over life.").

\textsuperscript{79} See, e.g., In re Conroy, 486 A.2d 1209, 1229 (N.J. 1985) ("The question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself.").

\textsuperscript{80} Freedman, supra note 62, at 56 (quoting Loren H. Roth et al., Test of Competency to Consent to Treatment, 134 AM. J. PSYCH. 279 (1977)).

\textsuperscript{81} See Ira M. Ellman, Cruzan v. Harmon and the Dangerous Claim that Others Can
rebuttable presumption that she is the preferred substitute decision-maker, both where the incompetent person has always been incompetent and where there is no convincing evidence that a formerly competent person exercised his right to accept or refuse life-sustaining medical treatment. It is not the disconnected state but the intimately-connected family which should make the choice.

There are two ways to reach this result. One, implicit in the decision of a number of courts, continues to focus on autonomy as the important element and substitutes the will of some sufficiently autonomous person or entity for the insufficient/inadequate/unexercisable will of the incompetent person. Where the state allocates the power to make this decision on behalf of the incompetent person to the family, the court is intimating that the incompetent person belongs to the closest autonomous person. Alternately, the court can focus on the need for disinterestedness and allocate the incompetent’s choice to a supposedly neutral party i.e., a guardian ad litem. Neutrality may not be desirable or possible in assessing the value or quality of someone else’s life. The value an individual places on her life is inherently and ultimately personal. Many people whose lives seem enviable in every measurable aspect demonstrably do not place much value on continuing to live those lives.


Since the autonomy principle is foundational to any constitutional claim that individuals may decide for themselves whether to accept or refuse life-sustaining treatment, the constitutional claim fails in [the case where a third party seeks to exercise the incompetent person’s right]. The family’s claim to decide cannot be piggybacked on [the incompetent person’s] autonomy.

Id.

82. See Browning v. Herbert, 568 So. 2d 4, 16 (Fla. 1990).
84. But see id. at 286 (“Close family members may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterestedness, either—that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless, or even degrading.”).
85. See Thornburgh v. American College of Obstetricians and Gynecologists, 476 U.S. 747, 777 n.5 (Stevens, J., concurring) (quoting Charles Fried, Correspondence, 6 PHIL. & PUB. AFF. 288-89 (1977)) (“The concept of privacy embodies the ‘moral fact that a person belongs to himself and not others nor to society as a whole.’”)
86. See Cruzan, 497 U.S. at 327 (Brennan, J., dissenting) (“Is there any reason to suppose that a State is more likely to make the choice that the patient would have made than someone who knew the patient intimately? To ask this question is to answer it.”).
87. See id. at 281 (“The choice between life and death is a deeply personal decision of obvious and overwhelming finality.”).
88. See, e.g., Jason DeParle, A White House Death: Grief Wrapped in Confusion, N.Y.
er lives seem pathetic or tragic from the outside but are clung to nonetheless.89

The other way of placing control with the families of incompetent people, while properly valuing the incompetent people, is to abandon the myopic vision of autonomy as the only valuable trait a person can possess. This exaltation of autonomy has eroded the status of families as units with their own dominion, and has limited recognition of the importance of each individual’s status within the family unit. An exclusive focus on individual autonomy obscures the reasonableness and fundamental rightness of having those people who love an individual most, who are most closely connected to that individual, decide for her when she cannot decide for herself.

A. Current Standards

Courts have primarily used either the “substituted-judgment” standard90 or the “best-interests” standard91 in assessing an incompetent person’s right to refuse life-sustaining treatment. The substituted-judgment standard directs the decision-maker to reach the same decision that the incapacitated person would make if he or she could choose.92 Courts have applied the substituted-judgment standard in two distinct ways. Under a subjective version courts narrow the inquiry to the incompetent person’s intent.93 The easy case under this standard is where the person made a living will or selected a health

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89. See Lawrence Langer, Tainted Legacy: Remembering the Warsaw Ghetto, Tikkun, May 1993, at 37 (Langer quotes a diary kept in the Warsaw Ghetto during World War II in which the author wrote upon his wife’s seizure by Nazis, “eclipse of the sun, universal blackness.” Yet after a week had passed, added, “[i]f only I could die and be free of the whole nightmare. But I am still tied to life and it is still difficult for me to take my own life.”).

90. See United States v. Charters, 829 F.2d 479 (4th Cir. 1987).

91. Id.

92. See id. at 497 (“Courts employing substituted judgment have required that if a patient is medically incompetent, the decision-maker must attempt to determine what the patient would have done if he were competent.”).

93. See, e.g., In re Conroy, 486 A.2d 1209, 1229 (N.J. 1985) (“The standard we are enunciating is a subjective one, consistent with the notion that the right that we are seeking to effectuate is a very personal right to control one’s own life.”).
proxy while fully competent. Where the now-incompetent person did not manifest any such express intent, the court considers all evidence of intent in light of its remoteness, consistency, thoughtfulness, and specificity.

Ideally, the subjective substituted-judgment standard "maximizes principles of self-determination and individuality" by directing decision-makers to concentrate on the values of the incompetent person and disregard their own ideas of what is important. To ensure that the decision-maker is actually focusing on the incompetent's values is difficult, and the less familiar the decision-maker is, or was, with the incompetent person, the less likely it is that the decision-maker will even be able to identify the values of the incompetent person. Courts have held that the objective version of the substituted-judgment standard does not require express intent of an individual's treatment preference. "Clear and convincing evidence of a person's intent can be derived from the context of an individual's entire life. The person's religious beliefs, philosophical views, life goals, and attitudes toward death are appropriate factors to be considered."

Under the best-interests standard the decision-maker uses "objective" criteria like pain, prognosis for recovery, and life expectancy to assess whether "the burdens of a continued existence clearly outweigh the benefits." Consideration of pain and prognosis are inherently quality of life determinations.

B. Proposed Standards for Determining Competency and Allocating Substitute Decision Making

An incompetent person's life interest is qualitatively different from the state's interest in her life, since life interest is defined in the Fourteenth Amendment as being held against the state. A conflict

94. See id. (noting that "an intent not to have life-sustaining medical intervention . . . might be embodied in a written document, or 'living will,' stating the person's desire not to have certain types of life-sustaining medical treatment administered under certain circumstances.").

95. Id.


99. See U.S. Const. amend. XIV, § 1 ("[N]or shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws."); see also Cruzan v. Director, Missouri Dep't of
arises when the state is characterized as the protector of the individual’s rights by setting up a high evidentiary burden like a “clear and convincing” standard. That burden falls on the individual, advancing the state’s goal of preserving life by making it more difficult for the individual to exercise her right.

The decision to refuse medical treatment cannot itself be the basis for a determination of incompetence to make a decision to refuse treatment. "It hardly needs to be said that if a person can be declared incompetent based on disagreement with a medical choice he has made, the right to make personalized and individualized decisions concerning one’s own body would become a nullity." The competency issue in United States v. Charters was whether a mentally ill prisoner had the right to refuse an antipsychotic drug. The Fourth Circuit held that "to determine ... competence, the district court should evaluate whether ... [the individual] has followed a rational process in deciding to refuse [medical treatment] and can give rational reasons for the choice he has made. Latitude must be given in defining a ‘rational reason’ supporting ... [the] decision." The scope of the Fourth Circuit’s “latitude” may be gauged by the court’s recognition that

Health, 497 U.S. 261, 313 (1990) ("[T]he State as no legitimate general interest in someone’s life, completely abstracted from the interest of the person living that life, that could outweigh the person’s choice to avoid medical treatment.").

100. Various courts have long erected clear and convincing evidence standards to place the greater risk of erroneous decisions on those bringing disfavored claims .... Missouri has no such power to disfavor a choice by Nancy Cruzan to avoid medical treatment, because Missouri has no legitimate interest in providing Nancy with treatment until it is established that this represents her choice. Just as a State may not override Nancy’s choice directly, it may not do so indirectly through the imposition of a procedural rule.

Cruzan, 497 U.S. at 316 (Brennan, J., dissenting).

101. Id.

Only [clear and compelling] evidence of specific statements of treatment choice made by the patient when competent is admissible to support a finding that the [now-incompetent] patient ... would wish to avoid further medical treatment .... No proof is required to support a finding that the incompetent person would wish to continue treatment.

Id.


103. United States v. Charters, 829 F.2d 479, 479 (4th Cir. 1987).

104. Id. at 496.
[The very foundation of the doctrine [of informed consent] is every one's right to forego treatment or even cure if it entails what for him are intolerable consequences or risks, however warped or perverted his sense of values may be in the eyes of the medical profession, or even of the community, so long as any distortion falls short of what the law regards as incompetency.]

VI. EXERCISE OF AN AUTONOMY-BASED RIGHT IN THE ABSENCE OF DECISION-MAKING CAPACITY

The autonomy notions which support the right of private choice for competent patients are not effective in those cases where the putative rightholder lacks the capacity to choose. If the right is the right to decide, then actual lack of decision-making capacity extinguishes the liberty interest. The liberty interest can only be revitalized in such a case by transforming the value protected by the liberty interest in a way which de-emphasizes decisional autonomy and instead elevates respect for individuality. Valid personhood is not dependent on decision-making capacity; there are other qualities deserving of consideration and respect. Predicating possession of

105. Id.
106. In re Storar, 420 N.E.2d 64, 72-73 (N.Y. 1981) ("John Storar was never competent at any time in his life. He was always totally incapable of understanding or making a reasoned decision about medical treatment . . . . Mentally John Storar was an infant and that is the only realistic way to assess his rights in this litigation.").

One could argue that an incompetent patient has a right to have a proxy decide for the patient on the basis of her previous values. But that claim cannot be based on the comatose patient's current interests (there are none). Surely there is no constitutional right to be treated 'like one once was' now that one is so radically different.

109. The meaning of respect for [Nancy Cruzan's] personhood, and for that of others who are gravely ill and incapacitated, is, admittedly, not easily defined: Choices about life and death are profound ones, not susceptible of resolution by recourse to medical or legal rules. It may be that the best we can do is to ensure that these choices are made by those who will care enough about the patient to investigate his or her interests with particularity and caution.
Cruzan, 497 U.S. at 354 (Stevens, J., dissenting).
an autonomy interest on capacity may "negate[] the incompetent's personality and violates his or her human dignity."

The dilemma caused by the desire not to degrade the incompetent person is that those who value autonomy so highly are unsure of how to maintain an individual's "human dignity" in a way other than the recognition of that individual's right to act autonomously. Because autonomy values do not provide for meaningful evaluation of the rights of an incompetent person, respect for individuality should replace decision-making autonomy as the value we seek to implement when considering who should be the incompetent person's decision-maker. If respect for individuality, even in the absence of decision-making capacity, is incorporated into liberty interest analysis, decisions can be left to the family of the incompetent person, who are presumptively most likely to know what is of value to this particular incompetent person, and therefore in a better position to make the determination. The family of an incompetent person should not be empowered with a governmentally granted "right" to decide for the incompetent person because they are likely to have the best idea of what the incompetent person would do if he were competent. The general futility of determining what someone else would do is compounded where the incompetent person has never been competent. The attempt in and

111. Id. at 559 ("The question of withholding or withdrawing life sustaining treatment to a seriously disabled incompetent thus draws into issue whether there is any meaningful way of extending to an incompetent some protection respectful of his or her moral personality.").
112. Cf. NULAND, supra note 29, at 3 ("Every life is different from any that has gone before it, and so is every death. The uniqueness of each of us extends even to the way we die."). But cf. Robin West, Foreword: Taking Freedom Seriously, 104 HARV. L. REV. 43, 100 (1990) ("The endless variability of subjective, individual life has its limit in natural death. It is the antithesis of the experience of individuality, idiosyncrasy, and peculiarity that the liberal understands and celebrates as the essence that underlies individual existence.").
113. See In re Jobes, 529 A.2d 434, 457 (N.J. 1987) (Handler, J., concurring) ("The theory of substituted judgment is that if we know someone well enough—her ideals, values, attitudes, philosophy of life—we can figure out how she would have reacted to a new situation.").
114. See Note, Burdens on the Free Exercise of Religion: A Subjective Alternative, 102 HARV. L. REV. 1258, 1271 n.79 (1989) (citing RICHARD J. BERNSTEIN, BEYOND OBJECTIVISM AND RELATIVISM 126-31 (1983)) ("Part of this difficulty is the inherent inability to know the subjective. Courts never really have access to another's mind and must instead rely on fallible extrinsic evidence of subjective beliefs and feelings.").
115. See Cantor, supra note 75, at 422.

[T]he notions of indignity, degradation and humane medical handling are extremely problematic in the context of the never-competent patient. We certainly cannot say that the level of deterioration which would make continued medical intervention
of itself is degrading because it treats the never-competent person as a "normal" person by manipulating the realities of the situation in order to make the decision be about autonomy instead of about the incompetent person.

The family of an incompetent person has a right in the moral sense to decide about the incompetent person because they love the incompetent person—they have cared for this person in every sense. Although the family may not make the choice that the incompetent person would have made in some hypothetical universe where the incompetency vanishes, the decision has to be made and the family are the people who are most likely to understand how to value this person’s life in the making of the decision.

*Id.*


Concealed is the substantive way in which man has become the measure of all things. Under the sameness standard, women are measured according to our correspondence with man, our equality judged by our proximity to his measure. Under the difference standard, we are measured according to our lack of correspondence with him, our womanhood judged by our distance from his measure. Gender-neutrality is thus simply the male standard, and the special protection rule is simply the female standard, but do not be deceived: masculinity or maleness, is the referent for both.


117. If mental composition is the essence of who someone is, the always-incompetent person is himself as much as someone with a more standard mental composition. See Kamisar, *supra* note 74, at 33 (“How can self-determination have any limits? Why are not a person’s desires or motives, whatever they be, sufficient?”) (quoting Callahan, *supra* note 37).

118. [The incompetent person’s] mother over his lifetime had come to know and sense his wants and needs and was acutely sensitive to his best interests; . . . she had provided more love, personal care, and affection for [him] than any other person or institution, and was closer to feeling what [he] was feeling than anyone else; . . . his best interests were of crucial importance to her . . . .


119. See, e.g., Cruzan v. Director, Missouri Dep’t of Health, 497 U.S. 261, 286 (1990) (“[T]here is no automatic assurance that the view of close family members will necessarily be the same as the patient’s would have been had she been confronted with the prospects of her situation while competent.”); In re Storar, 420 N.E.2d at 72 (“[I]t is unrealistic to attempt to determine whether [an always-incompetent person] would want to continue potentially life prolonging treatment if he were competent.”).

120. See Norman L. Cantor, *Legal Frontiers of Death and Dying* 105 (1987) (recognizing that “the surrounding loved ones . . . possess[] maximum knowledge of the moribund patient’s preferences, tastes, hopes, and aspirations, and presumptively possess[] an
edge of the person entitles the family to decide because they are best equipped to make a decision which treats the person with meaningful dignity. The consensus is that the incompetent are entitled to be treated with dignity\(^{121}\) although there is little sense of how to do so. Locating decision-making authority in the state disregards individuality.\(^{122}\) Allowing family members to decide, based upon the fiction of substituted judgment treats the incompetent person's liberty interest, and consequently the person herself, as belonging to autonomous family members.\(^{123}\)

In order to treat the incompetent person with dignity, the authority to make decisions should be given those who are most likely to understand how to value this individual person.\(^{124}\) The very concept of treating people with dignity involves treating each individual as valuable.\(^{125}\) Since the way in which individuals are of value is their

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abiding concern for the patient's welfare\(^{121}\).

\(^{121}\) It does not advance the interest of the State or the ward to treat the ward as a person of lesser status or dignity than others. To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons.


\(^{122}\) Rights language . . . can only express the human ideal of fraternity as mutual respect for rights, and it can only defend the claim to be treated with dignity in terms of our common identity as rights-bearing creatures . . . . The administrative good conscience of our time seems to consist in respecting individuals' rights while demeaning them as persons.


\(^{123}\) In an admirable effort to affirm individual autonomy and to authorize individuals to protect their humanity from the cruelty of fate, the majority have overlooked the limits of our power to accomplish such goals . . . . \(^{[1]}\) It would be an error of great magnitude to confute a substituted judgment with an actual judgment. Such a mistake is a far greater blow against individual autonomy than it might as first seem. It is paternalism masquerading as the mere ratification of autonomous choice.


\(^{124}\) See Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 325 (1990) (Brennan, J., dissenting) (quoting Steven A. Newman, Treatment Refusals for the Critically and Terminally Ill: Proposed Rules for the Family, the Physician, and the State, 3 N.Y.L.S. HUM. RTS. ANN. 35, 46 (1985)) ("Family members have a unique knowledge of the patient which is vital to any decision on his or her behalf.") .

\(^{125}\) Cf. Hannah, supra note 34, at 460.

As Mark Twain wrote: "The dignity of death—the only earthly dignity that is not artificial—the only safe one . . . . Death—the only immortal who treats us all alike, whose pity and whose peace and whose refuge are for all—the soiled and
capability of autonomous decision making, treating them with dignity (i.e., respecting them as individuals) usually depends on allowing them to make choices. Where that measure of dignity is not available, the emphasis on autonomy must be abandoned in favor of a way of treating people as individuals which recognizes their connectedness to others as itself a source of dignity because it is a source of being known.

VII. CONCLUSION

Families are the potential decision-makers most likely to base medical treatment decisions on the individual identity of the incompetent person and least likely to measure a life (always a subjective endeavor) in objective terms. In those situations where the family is demonstrably unlikely to know this incompetent person and thus not know how to value him or her, someone else close to the incompetent person should be able to petition the court to be recognized as the proper decision-maker regarding medical treatment. Only if there is no potential decision-maker with sufficiently intimate knowledge of the incompetent person should the state assume the decision-making role, which is then limited to maintaining medical treatment.

the pure—the rich and the poor—the loved and the unloved.”

Id.

126. See CANTOR, supra note 120 (“[H]uman dignity in the context of death and dying is coming to mean . . . respect for the human prerogative to exercise self-determination.”).

127. See, e.g., Barbara Moretti, Note, Outing: Justifiable or Unwarranted Invasion of Privacy? The Private Facts Tort as a Remedy for Disclosure of Sexual Orientation, 11 CARDOZO ARTS & ENT. L.J. 857, 869 n.55 (1993) (describing the right to privacy as “the right to define one’s circle of intimacy—to choose who shall see beneath the quotidian mask”).

128. See Bender, supra note 35, at 537-38 (“Caring for dying people requires careful attention to their particularized needs. The caregivers must discover what those needs are by listening to the patient; conversing with her and with those who know her best and are responsible for her care . . . .”).

129. [W]e prohibit family members from mercifully ending the suffering of loved ones or create high legal barriers to families making termination of life-support decisions for incompetent loved ones based on our fear of bad families. The social and ethical price of designing our laws and rules for the bad actors is significant suffering and indignity to innocent, humane people because of unnecessary restraints on their freedom to act out of care in a manner responsive to particularized circumstances of need.

Id. at 532.
Status as a member of family is more informative of essential identity than status as a citizen. Therefore, a family decision-maker should be accorded greater discretion than is permitted the state.

Jean Kephart Cipriani


Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. . . . It is . . . they who treat the patient as a person, rather than a symbol of a cause. [citation omitted]

The State, in contrast, is a stranger to the patient.

Id. (quoting In re Jobes, 529 A.2d 434, 445 (N.J. 1987)).

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