

THE MALADAPTATION OF *MIRANDA* TO ADVANCE DIRECTIVES: A CRITIQUE OF THE IMPLEMENTATION OF THE PATIENT SELF-DETERMINATION ACT

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TABLE OF CONTENTS

INTRODUCTION	140
I. THE PURPOSE OF THE PATIENT SELF DETER- MINATION ACT	146
A. Advance Directives	149
1. The Living Will.....	150
2. The Durable Power of Attorney for Health Care	152
B. The PSDA and the Execution of Advance Directives ..	152
II. THE PROBLEMS WITH THE PSDA	156
A. The Empirical Research.....	157
1. Legal Rights vs. Medical Knowledge.....	157
2. The Medical Knowledge	163
B. The Two Extreme Normative Positions	167
1. <i>Martin</i> and Too Much Deference to Advance Directives.....	168
2. Rebecca Dresser and the Metaphysical Ob- jection to Advance Directives	171
III. INFORMED CONSENT DOCTRINE PROVIDES THE PROPER FRAMEWORK FOR ANALYSIS.....	180
A. Informed Consent is Not Just for Contemporaneous Interventions.....	180

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B. Informed Consent Shares the Same Theoretical Basis as Advance Directives.....	184
IV. A PROPOSAL: INFORMED CONSENT FOR ADVANCE DIRECTIVES	186
A. The Material Information.....	186
B. Understanding the Material Information.....	190
C. New Means to Achieve Adequate Understanding	196
V. CONCLUSION.....	200

INTRODUCTION

WHEN A PATIENT IS ADMITTED into a federally funded hospital, even for the simplest of procedures,¹ she must be given a copy of the hospital's policy and a statement of the relevant state law regarding advance directives.² This is required by the Patient Self-Determination Act (PSDA) of 1990,³ which not only requires that hospitals recognize and honor advance directives when they are made, but also requires that hospitals inform patients of their right to make them in the first place.⁴

¹ See *Compassion in Dying v. Washington*, 79 F.3d 790, 819 n. 80 (9th Cir. 1996), (en banc) (recognizing that Congress favors allowing adult patients to refuse life-sustaining treatment by advance directives and even requires hospitals receiving federal funds to notify adult patients of their right to execute such instruments upon admission to the hospital), *overruled on other grounds sub. nom. Washington v. Glucksberg*, 521 U.S. 702 (1997).

² See 42 U.S.C. § 1395cc(f)(2)(A) (1994) (stating that the "[t]he written information . . . shall be provided to an adult individual, in the case of a hospital, at the time of the individual's admission as an inpatient"). *But cf.* Henry R. Glick et al., *Advanced Medical Directives in U.S. Hospitals and Nursing Homes: The Implementation and Impact of the Patient Self-Determination Act*, 14 POL. & LIFE SCI. 47, 52 (1995) (reporting that over one-third of institutions do not provide advance directive information to psychiatric, incompetent, demented, comatose, or intoxicated individuals, obstetrical patients, emergency room patients, and those held overnight for observation).

³ President George Bush signed the PSDA into law on November 5, 1990 as part of the Omnibus Budget Reconciliation Act of 1990, but the law did not go into effect until December 1, 1991. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508 § 4206, 104 Stat. 1388, 1388-115 to -117, 1388-204 to -206 (setting forth the provisions of the Patient Self-Determination Act, codified as amended in scattered sections of 42 U.S.C. (1990)).

⁴ See 42 U.S.C. § 1395cc(f)(1)(A) (requiring service providers to give individuals written information concerning state laws on advance directives and the right to accept or refuse medical treatment, as well as information on the policies of the service provider regarding implementation of individual rights). The right to refuse lifesaving treatment was constitutionally guaranteed under the Fourteenth Amendment by *Cruzan v. Dir. Mo. Dep't of Health*, 497 U.S. 261, 277-78 (1990) (holding that if Nancy Cruzan had left clear and convincing evidence of her health care prefer-

According to a 1995 General Accounting Office (GAO) report⁵ and a 1995 Robert Wood Johnson Foundation study,⁶ U.S. hospitals have generally complied with the PSDA and do inform patients of their right to complete an advance directive. U.S. hospitals do not, however, do very much to inform these patients how to meaningfully and effectively exercise that right. Although providers comply with the PSDA's formal requirements, they "merely follow the letter of the law"⁷ and fail to meet the PSDA's underlying purpose of protecting patient autonomy and self-determination.⁸ In short, the PSDA's legal requirements have be-

ences before she became incompetent, then Missouri would have had to respect her expressed wishes). The PSDA is regulatorily implemented by the Health Care Financing Administration (HCFA).

⁵ Patient Self-Determination Act – Providers Offer Information on Advance Directives but Effectiveness Uncertain, GAO/HEHS Doc. No.95-135, at 4 (1995) (reporting on the result, to date, of the effectiveness and implementation of advance directives under the Patient Self-Determination Act) [hereinafter GAO REPORT].

⁶ Alfred F. Connors, Jr. et al., *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*, 274 JAMA 1591 (1995) (confirming the existence of barriers to optimal end-of-life patient care and demonstrating increased patient-physician communication is inadequate to address the problem); see also Bernard Lo, *End-of-Life Care After Termination of SUPPORT*, HASTINGS CENTER REP., Nov.-Dec., at S6 (explaining the SUPPORT study findings and exploring what could be done to improve the process of dying).

⁷ Glick et al., *supra* note 2, at 57 (explaining that the PSDA is not as effective as it could be because it merely requires hospitals and nursing homes to make patients aware of advance directives; thus, the PSDA does not provide adequate incentives for the institutions to explain more fully to patients their options; see also John La Puma et al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402, 404 (1991) ("[I]mpos[ing] a minimal standard of behavior . . . may become the maximum standard performed").

⁸ See Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 259, 267 (1997) (examining the legislative history of the PSDA); see also Glick et al., *supra* note 2, at 52 ("Making patients aware . . . of advance directives satisfies the basic requirements of the PSDA, but the effectiveness of the law can be increased if hospitals . . . develop procedures to guarantee that most consumers understand their options . . .").

come a ceiling instead of a floor.⁹ Well-intentioned objectives have been transformed into “paper formalities.”¹⁰

This minimalistic compliance is exemplified in a metaphor often applied to the PSDA. The PSDA has been described as health care’s own “*Miranda* warning,”¹¹ referring to the Fourth Amendment reading of rights at arrest.¹² The metaphor is accurate but unfortunate. Empirical research establishes that most suspects do not understand the *Miranda* warnings.¹³ Although “*Miranda*

⁹ See Susan M. Wolf et al., *Sources of Concern about the Patient Self-Determination Act*, 325 NEW ENG. J. MED. 1666, 1670 (1991) (warning that the legal requirements of advance directives may reduce the discussion of treatment options if they become a ceiling, rather than a floor, for discussion). Indeed, Larson and Eaton explain that “meaningless formality” was a recognized consequence of making the bill modest and politically viable. Larson & Eaton, *supra* note 8, at 265-66.

¹⁰ *Fiscal Year 1991 Reconciliation Issues Relating to Durable Medical Equipment, Clinical Laboratory Services, and Other Issues Under the Medicare Program: Hearing Before the Subcomm. on Health of the House Comm. on Ways and Means*, 101st Cong., 2d Sess. 107 (1990) (statement of Charles P. Sabatino, American Bar Association) (discussing the danger of making the PSDA ineffective by miring it in paperwork).

¹¹ Senator John C. Danforth of Missouri introduced the bill this way. *Senate to Debate Federal Legislation*, SOC’Y FOR RIGHT TO DIE NEWSL. (Society for the Right to Die, New York, N.Y.), Spring 1990, at 1, 7 (referring to the Patient Self-Determination Act of 1989 proposed by Senators Danforth and Moynahan). See also Michael A. Refolo, Comment, *The Patient Self-Determination Act of 1990: Health Care’s Own Miranda*, 8 J. CONTEMP. HEALTH L. & POL’Y 455 (1992) (using the *Miranda* reference to characterize the PSDA); Paul Cotton, *Providers to Advise of Medical Miranda*, 265 JAMA 306 (1991) (presenting requirements of the Patient Self-Determination Act and examples of health care provider responses); Doug Podolsky, *A Right to Die Reminder: A New Law Requires Hospitals to Read You Your Medical Rights*, U.S. NEWS & WORLD REP., Dec. 2, 1991, at 74 (explaining that under the PSDA, hospitals are required to provide patients with a written “medical *Miranda*” outlining their rights as patients); Leonard Sloane, *’91 Law Says Failing Patients Must be Told of Their Options*, N.Y. TIMES., Dec. 8, 1990, at A4 (discussing federal legislation that requires hospitals and nursing homes to tell patients if their state law allows them to refuse treatment).

¹² “[T]he person must be warned that he has a right to remain silent, that any statement he does make may be used as evidence against him, and that he has a right to the presence of an attorney either retained or appointed.” *Miranda v. State of Arizona*, 384 U.S. 436, 444 (1966) (holding that for statements made by a suspect to be admissible in court, the suspect must have been told of his constitutional rights prior to the time the statements were made).

¹³ See Richard A. Leo, *Criminal Law: The Impact of Miranda Revisited*, 86 J. CRIM. L. & CRIMINOLOGY 621 (1996) (discussing the results and procedures of several empirical studies); George C. Thomas III, *Is Miranda a Real-World Failure? A Plea for More (and Better) Empirical Evidence*, 43 U.C.L.A. L. REV. 821 (1996) (arguing that there is no proof of a *Miranda* effect on the confession rate and that *Miranda* warnings may be a real-world torture in providing fairness and equality to the process); Richard J. Medalie et al., *Custodial Police Interrogation in Our Nation’s Capitol: The Attempt to Implement Miranda*, 66 MICH. L. REV. 1347, 1374

provides a convenient *presumption* that [a] confession was voluntary,"¹⁴ "merely reciting the *Miranda* warnings may be insufficient to clearly inform a suspect of the right to counsel [or silence] because recitation of rights does not guarantee that the suspect will understand them."¹⁵ Similarly, advance directives completed pursuant to the PSDA are *presumed* to accurately reflect the health care preferences of the incompetent individuals later bound by them. However, this presumption, like that associated with *Miranda*, is empirically unfounded. In fact, patients do not understand how to exercise their right to control their post-autonomous health care. By erroneously assuming this understanding, the PSDA promotes advance directives which, in fact, do not adequately promote self-determination.

Health care providers regard advance directives in a "narrow, legalistic way."¹⁶ This is exemplified by the fact that the current emphasis in the medical literature is on the *rates* of advance directives completed rather than the *quality* of the advance directives completed.¹⁷ The result, as the GAO report notes but underemphasizes, is that "advance directives may not always be implemented as patients intend,"¹⁸ wholly undermining the purpose of the PSDA, of advance directives in general, and of the common law, and the constitutional right to medical self-determination.

The focus of this Article is "pragmatic" in that it stresses increased attention to the clinical context, to the specific characteristics of the patients such as diagnosis, prognosis, and values.¹⁹ It

(1968) (discussing the practical implementation of the *Miranda* decision in Washington, D.C. by presenting overall ratings of actual studies).

¹⁴ Susan R. Klein, *Miranda Deconstitutionalized: When the Self Incrimination Clause and the Civil Rights Act Collide*, 143 U. PA. L. REV. 417, 472 (1994) (discussing the implications of *Miranda v. Arizona*).

¹⁵ Charles J. Williams, *Connecticut v. Barnett and the Limited Invocation of the Right to Counsel: A New Limitation on Fifth Amendment Miranda Protections*, 73 IOWA L. REV. 743, 769 n.186 (1988) (discussing 1987 Supreme Court analysis of *Miranda v. Arizona*).

¹⁶ NANCY M. P. KING, MAKING SENSE OF ADVANCE DIRECTIVES 113 (rev. ed. 1996) (explaining the tendency of doctors and administrators to disregard advance directives if they do not conform precisely to a specific law).

¹⁷ See *infra* notes 97-100.

¹⁸ GAO REPORT, *supra* note 5, at 12 (contrasting provider groups' general support for advance directives with their lack of implementation).

¹⁹ See Susan M. Wolf, *Shifting Paradigms in Bioethics and Health Law: The Rise of a New Pragmatism*, 20 AM. J. L. & MED. 395, 397 (1994) (discussing the importance of identifying rules concerning the administration of health care and emphasizing the importance of visualizing the clinical settings in which those rules will be enforced); cf. Joseph J. Fins et al., *Clinical Pragmatism: A Method of Moral Problem Solving*, 7 KENNEDY INST. ETHICS J. 129 (1997) (presenting a method for moral problem solving in clinical practice that is inspired by the philosophy of John

is important to identify and legislate rules for the use of advance directives. Yet, it is just as important to pay attention to the empirical effects of following those rules.²⁰ “Merely proclaiming or even legislating rights does not make them real for those who need them.”²¹ It is no success to allow, advise, and even encourage patients to execute advance directives, if those directives fail to reflect the actual health care preferences of those patients.²² As long as patients complete advance directives without a thorough understanding of what they are doing, the formal requirements of the PSDA will fail to protect patient autonomy.²³ Unless the imple-

Dewey); Franklin G. Miller et al., *Clinical Pragmatism: John Dewey and Clinical Ethics*, 13 J. CONTEMP. HEALTH L. & POL’Y 27 (1996) (explaining that bioethics is shifting from principlism to pragmatism, thereby focusing on the needs of individuals in clinical settings). See also John Dewey, in *MY PHILOSOPHY OF LAW: CREDOS OF SIXTEEN AMERICAN SCHOLARS* 71, 76 (Julius Rosenthal Foundation for General Law ed., 1987) (1941) (discussing the theoretical nature of law by stating that “[f]undamentally, a program for action to be tested in action is set forth, not something that can be judged . . . on a purely intellectual basis”).

²⁰ See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 244 (4th ed. 1994) (stating that “[t]he problems are primarily practical”); see also Miguel A. Sanchez-Gonzalez, *Advance Directives Outside the USA: Are They the Best Solution Everywhere?* 18 THEORETICAL MED. 283, 286 (1997) (“It is curious that this amplification of [advance directives] . . . is occurring without sufficient research into the clinical reality”); ARTHUR L. CAPLAN, *IF I WERE A RICH MAN, COULD I BUY A PANCREAS?* xvii (1992) (“The ultimate test of claims in bioethics – as is true in other areas of applied activity, such as agriculture, engineering, or medicine – is not logical consistency with theory but pragmatic application”).

²¹ Wolf, *supra* note 19, at 414 (discussing the importance of helping people understand their rights so that they may learn to take a more active role in the administration of their health care). Indeed, the Supreme Court’s declaration in *Union Pacific Railway v. Botsford*, 141 U.S. 250, 251 (1891), that “[n]o 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 by others,” did little for patients for over seventy years. See *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972) (finding that a physician discharges the duty to disclose when a reasonable effort to convey sufficient information is made, although the patient may not fully grasp the information).

²² See Robert A. Pearlman et al., *Advance Care Planning: Eliciting Patient Preferences for Life-Sustaining Treatment*, 26 PATIENT EDUC. & COUNSELLING 353, 355 (1995) (“[I]nterventions have increased patient completion . . . [h]owever these results may not reflect . . . serious deliberation These ‘quality’ aspects of ACP [advance care planning] were not measured”); see also Chris Hackler, *Introduction to ADVANCE DIRECTIVES IN MEDICINE* 6 (Chris Hackler ed. 1989) (“[S]ome feel that the growing recognition of advance directives has unduly shifted attention away from the substantive adequacy of treatment decisions, focusing it primarily on the procedural adequacy of the decisions”).

²³ Of course, the PSDA is not the only way to protect patient autonomy. Patient autonomy could also be protected by either strengthening state advance directive laws or voluntarily adopting new informed consent standards. This Article focuses on

mentation of these formal requirements is guided by actual clinical experience, by what is actually required for patient understanding, the danger of placing an undue emphasis on procedure over substance looms.²⁴

This Article calls for vastly improved standards of informed consent in the advance directive context. Only with such standards will advance directives reflect, with sufficient accuracy, the preferences of those individuals who are bound by them.²⁵ Section I of this Article is an introduction both to the PSDA and to advance directives. Section II reviews the empirical literature assessing the implementation of the PSDA. This evidence compels the conclusion that although the PSDA's current focus on making patients aware of their legal rights is laudable, without adequate medical understanding, patients cannot effectively exercise those legal rights. After placing this evidence into a normative framework, I argue that patients' lack of understanding is a serious and fundamental problem because the PSDA has *not* successfully helped patients preserve their autonomy through directing their post-autonomous medical care.

I propose that the solution to this problem, identified in Section III, is informed consent.²⁶ Informed consent, although always required for clinical interventions, is not now required in the advance directive context. Nevertheless, it should be and must be implemented in this context. In Section IV, I argue that "safe-

the PSDA not only because it is one viable option, but also because the PSDA already purports to protect patients' "self-determination."

²⁴ See Alexander Morgan Capron & Vicki Michel, *Law and Bioethics*, 27 *LOY. L. REV.* 25, 29 (1993) (explaining that bioethics remains a legal field dominated by concern for substance, but is being encroached upon by procedure); see also 1 ALAN MEISEL, *THE RIGHT TO DIE*, § 3.10, at 91 (2d ed. 1995) (noting that "[a]mong health care professionals, there is a tendency to equate the execution of a consent form with obtaining informed consent").

²⁵ See 1 MEISEL, *supra* note 24, §§ 2.1-2.11 (discussing the state of the law pertaining to the forgoing of life-sustaining treatment); 2 MEISEL, *supra* note 24, § 10.3 at 6-7. I argue that this is intrinsically important. Nevertheless, a concomitant concrete benefit of having more reliable advance directives is that physicians and others would be less willing to ignore them. See Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 *JAMA* 59 (1992) (discussing generally the need for advance directives to be completed and the benefits associated with having the physician and patient discuss the limits of the directive before it is even needed).

²⁶ See generally RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986) (discussing informed consent in the medical field); PAUL S. APPELBAUM ET AL., *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* (1987) (describing the idea of informed consent and its evolution in legal theory); FAY A. ROZOVSKY, *CONSENT TO TREATMENT: A PRACTICAL GUIDE* (2d ed. 1990) (offering practical guidance on informed consent issues).

guards” are necessary to assure that a (future) incompetent self, bound by the choices of an (earlier) competent self, would have made substantially the same choices. Indeed, these safeguards must be so rigorous that they are properly characterized as paternalistic. This paternalism is necessary to assure, as best as possible, that the advance directive embodies preferences genuine to the self bound by it.

I. THE PURPOSE OF THE PATIENT SELF-DETERMINATION ACT

There are “incommensurable and unbridgeable differences between what individuals consider good for themselves or in their best interest.”²⁷ This lack of axiological consensus has led to the preeminence of autonomy as “the dominant value prescribed by bioethicists and legal scholars for mediating provider/patient interactions.”²⁸ Because there is no one true or correct way to die, individuals are free to decide their medical futures for themselves. The right to die is a legally,²⁹ and even a constitutionally,³⁰ protected

²⁷ CAPLAN, *supra* note 20, at 257 (arguing that there is a broad consensus as to what individuals feel is in their best interest). Caplan explains how “autonomy is firmly rooted at the foundation of the contemporary bioethical canon.” *Id.* at 259.

²⁸ *Id.* at 256; *see also* Hackler, *supra* note 22, at 4; PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 445 (1982) (explaining that today’s medical community places more emphasis on health care as a marketable commodity, making both physician and patient autonomy a dominant issue in any interaction); Lawrence O. Gostin et al., *Privacy and Security of Health Information in the Emerging Health Care System*, 5 HEALTH MATRIX 1, 2 (1995) (suggesting that “a complex health care system information infrastructure is emerging in the American health care system” and, consequently, that there will be a need to access high quality information for informed decisions to be made); Hans-Martin Sass, *Advance Directives*, in *ENCYCLOPEDIA OF APPLIED ETHICS* 41, 42 (Ruth Chadwick ed., 1998) (“[A]dvance health care planning by the patient or prospective patient, including the execution of advance directives, must be regarded as indispensable for good clinical practice, as it alone will provide . . . the necessary and vital information to define the *salvus aegroti*, the ‘good of the patient’”).

²⁹ *See* CHOICE IN DYING, *THE RIGHT TO DIE LAW DIGEST* (1998) (collecting state advance directive statutes); *see also* Bretton J. Horttor, *A Survey of Living Will and Advance Health Care Directives*, 74 N.D. L. REV. 233 (1998) (surveying state legislation that establishes advance directives, thereby protecting the legal right to die).

³⁰ *See* *Cruzan v. Dir., Mo. Dep’t. of Health*, 497 U.S. 261 (1990) (holding that “a competent person has a Constitutionally protected liberty interest in refusing unwanted medical treatment”). The Constitutional right to die only encompasses passive euthanasia. *See* *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (holding that there is no due process right to active euthanasia); *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (holding that there is no equal protection right to active euthanasia). Nevertheless, although not constitutionally protected, active euthanasia is not constitutionally prohibited either. Accordingly, the state of Oregon has legally provided for active euthanasia with its Death with Dignity Act. *See* Ann Alpers & Bernard Lo, *Phy-*

right. Nevertheless, even ten years after the first advance directive statutes were enacted in the late 1970s,³¹ few individuals exercised this right, often simply because they were unaware they had it.³² This is where the PSDA came in.

The PSDA, which became effective December 1, 1991, requires health care providers to maintain written policies and procedures that will educate patients and the public as to their right to execute advance directives and to direct their post-autonomous medical care (i.e., direct care provided after the point in time at which they lose the decision-making capacity to do so contemporaneously).³³ As a federal law, jurisdictional constraints require that the PSDA apply only to institutions receiving Medicaid³⁴ and Medicare³⁵ funds. Nevertheless, this includes most providers.³⁶

sician-Assisted Suicide in Oregon: A Bold Experiment, 274 JAMA 483 (1995) (analyzing the provisions of the Oregon Death with Dignity Act, OR. REV. STAT. §§ 127.800-127.897 (1997), permitting active euthanasia).

³¹ See, e.g., CAL. HEALTH & SAFETY CODE §§ 7185-95 (West Supp. 1998) (creating the California Natural Death Act in 1976).

³² See Larson & Eaton, *supra* note 8, at 258 (explaining that few people write advance directives because most people do not know that option is available to them).

³³ See ALAN D. LIEBERSON, ADVANCE MEDICAL DIRECTIVES 539 (1992) (describing the PSDA and the responses to it).

³⁴ See 42 U.S.C. §§ 1396(a)(57) - (58) (1994) (regulating grants to states for medical assistance programs, including requiring the maintenance of written policies and procedures regarding advance directives); 42 U.S.C. §1396(v) (1994). The language in the Medicaid and Medicare provisions is the same. Therefore, for purposes of illustration, I shall refer to only the Medicare provisions at 42 U.S.C. §1395cc (1994) (regulating health insurance for the aged and disabled, in particular, agreements with providers of these services).

³⁵ See 42 U.S.C. § 1395cc(a)(1)(Q) ("Any provider . . . shall be eligible for payments . . . if it files with the Secretary an agreement . . . to comply with the requirement of subsection (f) of this section.") (relating to maintaining written policies and procedures respecting advance directives).

³⁶ See Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination - It Shouldn't Be So Easy*, 58 FORDHAM L. REV. 939, 944 n. 31 (1990) (stating that more than 6,800 hospitals and 13,700 outpatient facilities are recipients of federal financial assistance). The force of this legality lies not just in the threat of suspension of Medicare funds. State law provides remedies for the violation of advance directives. In *Osgood v. Genesys Reg. Med. Ctr.*, No. 94-26731-NH (Genesee Cty. Cir. Ct. Feb. 16, 1996), a Michigan jury recently awarded \$16.6 million to a plaintiff after her husband was provided life support against his will. See *Terminal Patients' Wishes Ignored*, OMAHA WORLD HERALD, May 23, 1996, at 9 (discussing the impact of *Osgood* on hospital liability for ignoring living wills). *But cf.* *Grace Plaza v. Elbaum*, 588 N.Y.S.2d 853, 860 (N.Y. App. Div. 1992), *aff'd*, 623 N.E.2d 513 (N.Y. 1993) (holding husband financially responsible for care provided in contravention of wife's advance directive); Maggie J. Randall Robb, *Living Wills: The Right to Refuse Life Sustaining Treatment - A Right Without a Remedy?*, 23 U. DAYTON L. REV. 169 (1997) (arguing that living wills ought to be enforceable by means of injunctive relief, statutory relief, and damages).

Although this Article discusses only hospitals' implementation of the PSDA, the statute also applies to skilled nursing facilities,³⁷ home health agencies,³⁸ hospice programs,³⁹ and managed care organizations.⁴⁰

The requirements of the PSDA are relatively simple. Providers and eligible organizations must provide written materials to all adult individuals receiving medical care by or through the provider or organization (hereinafter "hospital") regarding an individual's rights under state law to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment, and the right to formulate advance directives.⁴¹ The hospital must also provide written information concerning the written policies of the hospital respecting the implementation of such rights.⁴² The hospital shall document prominently on the individual's medical record whether or not the individual has executed an advance directive.⁴³ The hospital cannot, however, condition the provision of care on whether or not the individual has executed an advance directive.⁴⁴ Hospitals must comply with state laws respecting advance direc-

³⁷ See 42 U.S.C. § 1395cc(f)(2)(B) (1994). Nursing homes generally have better implementation than hospitals for those residents who are included. However, a different problem in the nursing home context is that many residents are presumed incompetent and are excluded from advance directive discussions. See Mathy Mezey et al., *Implementation of the Patient Self-Determination Act in Nursing Homes in New York City*, 45 J. AM. GERIATRICS SOC'Y 43 (1997) (examining implementation of PSDA, verbal directives, procedures for determination of residents' decision-making capacity, and role of ethics committees in nursing homes in New York City); Elizabeth Bradley et al., *Assessing Capacity to Participate in Discussions of Advance Directives in Nursing Homes: Findings from a Study of the Patient Self-Determination Act*, 45 J. AM. GERIATRICS SOC'Y 79 (1997) (proposing that the implementation of the PSDA in long-term care must be better understood).

³⁸ See 42 U.S.C. § 1395cc(f)(2)(C) (1994).

³⁹ See *id.* § 1395cc(f)(2)(D).

⁴⁰ See *id.* § 1395cc(f)(2)(E). *Id.* §§ 1395l(a)(1)(A) (defining "providers"), 1395mm(a) (including HMOs in particular).

⁴¹ See 42 U.S.C. § 1395cc(f)(1)(A)(i). See also *id.* § 1395cc(f)(3) (defining the term "advance directive").

⁴² See 42 U.S.C. § 1395cc(f)(1)(A)(ii) (requiring the provider to provide written information concerning their written policies for the implementation of such rights). Cf. CHOICE IN DYING, ADVANCE DIRECTIVE PROTOCOLS AND THE PATIENT SELF-DETERMINATION ACT: A RESOURCE MANUAL FOR THE DEVELOPMENT OF INSTITUTIONAL PROTOCOLS (1991) (providing guidelines for facilities in the development of their own protocols by summarizing the PSDA, its goals and requirements, and listing components, specific characteristics, and functions of an advanced protocol).

⁴³ 42 U.S.C. § 1395cc(f)(1)(B) (1994) (requiring a provider to document in the individual's medical record whether the individual has an advance directive).

⁴⁴ *Id.* § 1395cc(f)(1)(C) (prohibiting providers from discriminating against an individual based on whether the individual executed an advance directive).

tives.⁴⁵ Nevertheless, a hospital with conscience objections can alert the patient in its policy statements and need not follow advance directives in conflict with its policy.⁴⁶ Finally, hospitals must provide for the education of staff and community on issues concerning advance directives.⁴⁷ The whole thrust of the Act is to alert and educate patients and the public about advance directives. But what exactly is an advance directive?

A. Advance Directives

Advance directives are written instructions such as a living will or a durable power of attorney for health care, recognized under state law,⁴⁸ relating to the provision of health care when an individual's condition makes him or her unable to express his or her wishes.⁴⁹ Essentially, either legal form (living will or durable power of attorney for health care) allows individuals to establish binding "directives" relating to their care on health care providers in "advance" of being in a condition in which they might be unable to make or to communicate such directives.⁵⁰ The basic underlying and motivating idea is that "[e]very human being of adult years and sound mind has a right to determine what shall be done with

⁴⁵ *Id.* § 1395cc(f)(1)(D).

⁴⁶ *Id.* § 1395cc(f)(1).

⁴⁷ *Id.* § 1395cc(f)(1)(E). *Cf.* CHOICE IN DYING, ADVANCE DIRECTIVES AND COMMUNITY EDUCATION: A MANUAL FOR INSTITUTIONAL CAREGIVERS (1991) (providing guidance for creating community education programs about advance directives).

⁴⁸ In 1992, Pennsylvania was the fiftieth state to enact advance directive legislation. 20 PA. CONS. STAT. ANN. §§ 5401-16 (West 1998).

⁴⁹ See GAO REPORT, *supra* note 5, at 1, 3-4 (explaining and defining advance directives). For a comprehensive analysis of the meaning, legal status, and implementation of advance directives, see 2 MEISEL, *supra* note 24, § 10.1-13.38 and LIEBERSON, *supra* note 33.

⁵⁰ "Do Not Resuscitate" Orders (DNRs) are technically, but not legally, a type of advance directive. See COMMITTEE ON CARE AT THE END OF LIFE, INST. OF MED., APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 198-99 (1997) (noting that, although a DNR is technically a physician's order, because the order is placed in the patient's chart only after a doctor-patient consultation and discussion regarding the patient's decision to forego certain forms of life-prolonging treatment, the order takes on the characteristics of a living will in advance-care planning). Typically these are orders that tell health care providers not to perform CPR or not to place the patient on a ventilator if that becomes necessary. See 1 MEISEL, *supra* note 24, §§ 9.4-9.8, at 543-56. See also Vassyl A. Lonchyna, *To Resuscitate or Not . . . In the Operating Room: The Need for Hospital Policies for Surgeons Regarding DNR Orders*, 6 ANNALS HEALTH L. 209 (1997) (describing DNRs and how medical personnel should treat DNRs when caring for a patient).

his body.”⁵¹ Later incompetence or decisional incapacity⁵² shall be no bar to autonomous decision-making, for although advance directives cannot reproduce the contemporaneous decision-making of a competent individual, they do allow individuals to “direct their medical care, even when [they] cannot do so directly.”⁵³

1. The Living Will

The first form of advance directive is the living will. “Living wills are documents that give instructions to health care providers about particular kinds of medical care that an individual would or would not want to have to prolong life.”⁵⁴ Living wills were first proposed in 1969 in response to newly developing technology that prolonged the dying process,⁵⁵ so that individuals would have a means to avoid becoming “passive prisoner[s] of medical technology.”⁵⁶ Seven years later the New Jersey Supreme Court decided the famous *Quinlan* case.⁵⁷

⁵¹ *Schloendorff v. Soc’y of N. Y. Hosp.*, 105 N.E. 92, 95 (N.Y. 1914) (Cardozo, J., dissenting) (holding that the hospital is not liable for surgery performed without consent when the hospital did not have notice of lack of consent).

⁵² “Capacity” typically refers to a factual status regarding one’s ability to make a particular type of decision, while “competence” typically refers to a legal status. See 1 MEISEL, *supra* note 24, § 4.5, at 114. Like Meisel, however, I will use these terms synonymously. See *id.* § 4.2, at 113.

⁵³ Joanne Lynn & Joan M. Teno, *Advance Directives*, in ENCYCLOPEDIA OF BIOETHICS 572, 573 (Warren Thomas Reich ed., 1995) (discussing the history of advance directives in the United States, types of advance directives, consideration in using advance directives, and the policy of advance directive utilization); see also *In re Lawrance*, 579 N.E.2d 32, 39 (Ind. 1991) (“[B]y allowing patients to designate individuals to consent or refuse their own health care . . . [the law] demonstrates respect for patient autonomy”).

⁵⁴ 2 MEISEL, *supra* note 24, § 10.4, at 8.

⁵⁵ See Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L.J. 539 (1969) (presenting the living will as a method by which a competent patient could maintain autonomy by pre-dictating his treatment wishes in the event of incompetency).

⁵⁶ *Cruzan v. Dir., Mo. Dep’t. Health*, 497 U.S. 261, 302 (1990) (Brennan, J., dissenting) (stating that Nancy Cruzan’s fundamental right to choose to die with dignity should outweigh the interests of the state).

⁵⁷ *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976) (holding that the father of a 21-year-old woman who was in a persistent vegetative state could be appointed as her guardian, and upon the conclusion of attending physicians and the hospital ethics committee that there was no possibility of her re-emergence to a cognitive state, could request that her life-support systems be withdrawn). For more background on this landmark case, see JOSEPH & JULIA QUINLAN, *THE QUINLANS TELL THEIR STORY* (1977), which discusses the struggle of Karen Ann Quinlan and the difficulties her family faced in being her surrogate decision-makers. See also B.D. COLEN, *KAREN ANN QUINLAN: DYING IN THE AGE OF ETERNAL LIFE*

Karen Ann Quinlan was a twenty-one-year-old woman condemned to a persistent vegetative state (PVS) after ingesting some combination of narcotic drugs. Although she exhibited motor reflexes, she evinced no indicia of significant cognitive function. Her condition was virtually certainly permanent.⁵⁸ Karen Ann's father sought judicial approval to disconnect his daughter's respirator and let her body die. Unfortunately, Karen Ann had no advance directive. There was no written evidence of her preferences, goals, or values regarding whether she would want substantial technology keeping her alive under conditions where she could not think, feel, or communicate. There was only informal evidence of Karen Ann's wishes, *i.e.* oral communications to friends.

The New Jersey court accepted this informal evidence, holding that Karen Ann's autonomy ought not be discarded merely because she could not contemporaneously exercise it. The court wrote, "[w]e have no doubt . . . that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could [and would] effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death."⁵⁹

Although the *Quinlan* court accepted this informal evidence of Karen Ann's preferences, casual verbal comments are typically far less likely to reflect careful deliberations and are generally less reliable evidence of preferences.⁶⁰ Thus, the need for living wills was recognized and states began to enact legislation authorizing them.⁶¹ Nevertheless, because they anticipate and plan for events

(1976) (describing the meaning and significance of Karen Ann Quinlan's life and death).

⁵⁸ *Quinlan*, 355 A.2d at 655-56 (discussing the etiology and permanence of Karen Ann Quinlan's condition based on medical consensus).

⁵⁹ *Id.* at 663.

⁶⁰ *See, e.g., Cruzan*, 497 U.S. at 285 (affirming the Missouri Supreme Court's holding that testimony consisting of "statements made to a housemate about a year before her accident that she would not want to live should she face life as a 'vegetable'" did not amount to clear and convincing proof of the patient's desire); *In re Martin*, 538 N.W.2d 399, 411 (Mich. 1995) (discussed *infra* at notes 140-60) (stating that evidence of a decision to forego medically necessary treatment must fulfill the clear and convincing evidence standard).

⁶¹ California was the first state to enact such legislation in 1976. CAL. HEALTH & SAFETY CODE §§ 7185-95. Today, advance directive statutes vary significantly in scope and substance. *See, e.g.,* Theodore P. Gustitus, Note, *A Comparative View of Advance Health Care Directives in Florida and North Carolina*, 11 QUINNIPIAC PROB. L.J. 163 (1997) (comparing and contrasting two distinct models of statutory construction of advance directives by discussing specific definitions and interpretations). Still, "there is no reason to believe that an advance directive executed in the absence of a statutory basis is invalid." 2 MEISEL, *supra* note 24, § 10.11.

that might never occur, living wills often require substantial interpretation (*e.g.* what is meant by “extraordinary treatment”). So, upon the recommendation of the 1983 Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,⁶² state legislatures began to enact statutes authorizing durable powers of attorney for health care.⁶³

2. The Durable Power of Attorney for Health Care

The durable power of attorney for health care (DPAHC) is an instrument by which an individual designates another to make health care decisions for her.⁶⁴ The DPAHC “evades problems of [living wills’] interpretation, but it provides no real direction for decisions beyond the naming of a proxy.”⁶⁵ This proxy or surrogate decision-maker has the flexibility to respond to the various clinical situations that might arise, and as long as the patient is incompetent, the proxy has the authority to make health care decisions on behalf of the patient.

In some states this authority is constrained by the directive contained in a living will executed concomitantly with the DPAHC. This makes the directive more useful because it confines the proxy’s role “to implement[ing] the general desires of a person as expressed in the ‘living will’”⁶⁶ and provides assurance that the proxy “is implementing to the greatest extent possible the patient’s wishes.”⁶⁷ Yet, even without a concomitant living will, the DPAHC is an instrument by which patients can exercise their autonomy by making non-contemporaneous decisions regarding their health care.

B. The PSDA and the Execution of Advance Directives

Ideally, advance directives should be completed outside the hospital, within the context of the patient-physician relationship

⁶² *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*, PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, 145 (1983) [hereinafter 1983 PRESIDENT’S COMMISSION REPORT] (describing the absence of proxy and power of attorney provisions in state statutes as “serious shortcomings”).

⁶³ See CHOICE IN DYING, *supra* note 29 (collecting state DPAHC statutes).

⁶⁴ See 2 MEISEL, *supra* note 24, § 12.2 (defining the term “health care power of attorney”).

⁶⁵ Lynn & Teno, *supra* note 53, at 573 (comparing living will and durable power of attorney with regard to interpretation and instructing provisions).

⁶⁶ IDAHO CODE § 39-4505 (1998) (confining proxy’s decisions to guidelines patient set forth in living will).

⁶⁷ 2 MEISEL, *supra* note 24, § 12.1 at 128. See *infra* notes 211-22.

when the patient is healthy and before she “experiences the dislocation that often attends inpatient admission.”⁶⁸ Moreover, the discussion should represent the beginning, not the end, of a dialogue.⁶⁹ This is what patients and physicians want,⁷⁰ and it is what the PSDA aims to accomplish by requiring community education.⁷¹

This community education is supposed to lead patients and physicians to initiate discussions in the doctor’s office, before hospitalization. This outpatient discussion has several advantages to hospital discussion. First, the discussion can be conducted over several visits, leaving the patient time to consider matters and seek further counsel in family and friends. Second, there is time to plan to include family, friends, clergy, or lawyers in the discussion.⁷² The advantages of outpatient completion of advance directives are apparent. The American Hospital Association has observed that “[a]s a practical matter in many cases when the patient arrives at the hospital it is too late really to effectively deal with the situation.”⁷³ One commentator has even proposed state legislation, modeled on the PSDA, which would legally *require* physicians to provide the information to patients whenever they arrive for an office visit.⁷⁴

⁶⁸ Wolf et al., *supra* note 9, at 1667; see Larson & Eaton, *supra* note 8, at 262-64 (discussing the Congressional testimony of medical association representatives).

⁶⁹ See La Puma et al., *supra* note 7, at 405.

⁷⁰ See Sarah Coate Johnston et al., *The Discussion About Advance Directives: Patient and Physician Opinions Regarding When and How It Should Be Conducted*, 155 ARCH. INTERNAL MED. 1025,1025 (1995) (reporting the results of a multi-centered study of 329 patients and 554 physicians and explaining that patients felt that the discussion of advance directives should occur earlier than physicians did).

⁷¹ See 42 U.S.C. § 1395cc(f)(1)(E) (1994) (requiring providers to educate staff and community on issues concerning advance directives); see also GAO REPORT, *supra* note 5, at 10 (listing selected surveys that investigated whether the goals of the PSDA are being met).

⁷² See Maria Torroella Carney & R. Sean Morrisson, *Advance Directives: When, Why, and How to Start Talking*, GERIATRICS, April 1997, at 65, 70 (noting a discussion of advance directives can take place over multiple office visits and can involve input about family and friends); see also FADEN & BEAUCHAMP, *supra* note 26, at 315 (“Empirical evidence suggests that . . . the more [it] is part of a participatory process that extends over time, the greater the degree of patient involvement in communication and decision-making”).

⁷³ *Living Wills: Hearings Before the Subcomm. on Medicare and Long-Term Care of the Senate Comm. on Finance*, 101st Cong., 2d Sess. 38 (1990) (statement of Paul C. Rettig, Director, American Osteopathic Healthcare Association).

⁷⁴ Adrienne E. Quinn, *Who Should Make Medical Decisions for Incompetent Adults? A Critique of RCW 7.70.065*, 20 SEATTLE U. L. REV. 573, 599-600 (1997) (emphasizing the importance of ensuring that patients receive accurate information about their decision-making rights).

The implementation of the community education requirement provides the most visible evidence of the PSDA's beneficial effects. Across the country, hospitals and other health care providers produce videotapes and informational booklets, deliver lectures, and conduct workshops. Local papers and publications for seniors regularly publish notices of these educational opportunities.⁷⁵ In addition, the Health Care Financing Administration (HCFA), which administers Medicare and Medicaid, has done its part⁷⁶ to alert patients of their right to prepare advance directives through its consumer publications.⁷⁷ As a result, individuals are more aware of advance directives than ever before. This is especially true in the wake of the deaths of national figures such as ex-President Richard M. Nixon who had an advance directive which allowed him to die without use of a ventilator.⁷⁸

Yet, despite increased public awareness, only ten to twenty-five percent of the adult population has completed a formal advance directive.⁷⁹ There are many reasons why individuals do not

⁷⁵ See, e.g., *Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 1999: Hearings Before the Subcomm. of the House Comm. on Appropriations*, 105th Cong. 1659 (1998) (statement of Nancy Munro, Critical Care Nurse Specialist, Georgetown University Hospital) (describing efforts of the American Association of Critical Care Nurses in educating people about the PSDA by stressing definition and documentation of patient preferences); *New Guide Available on Making Living Wills*, CHAPEL HILL HERALD, Feb. 21, 1998, at 3 (describing a magazine published by the University of North Carolina regarding advance directives); Tony Cappaso, *Seminar Explains Options for Medical Directives*, STATE J.-REG., Mar. 19, 1998, at 18 (describing medical directives, what options are available, and where additional information can be obtained).

⁷⁶ Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, Title IV, Subtitle B, Part 4, Subpart E, § 4751(d), 104 Stat. 1388-205 (codified as amended in scattered sections of 42 U.S.C. (1990)) (directing the Health and Human Services Secretary to develop and enact a national campaign to educate the public about their right to execute advance directives).

⁷⁷ See HEALTH CARE FIN. ADMIN., U.S. DEP'T OF HEALTH AND HUM. SERVICES, PUB. NO. 02175, ADVANCE DIRECTIVES (1995) (defining the purpose and types of advance directives and listing state phone numbers for further information). See also Medicare and Medicaid Programs; Advance Directives; Final Rule, 60 Fed. Reg. 33,262 (1995) (codified at 42 C.F.R. §§ 417, 430, 431, 434, 483, 484, and 489) (describing public education activities undertaken by HHS, including press kits, telephone hotlines, booklets, and leaflets). Some of these publications can be found at *End of Life Resources* (visited Sept. 21, 1998) <<http://ccme-mac4.bsd.uchicago.edu/CCMEDocs/Death>>.

⁷⁸ Richard A. Knox, *Americans Changing How They Die*, TAMPA TRIB., May 29, 1994, at 18 (describing how Americans are foregoing lifesaving measures with increasing frequency).

⁷⁹ See GAO REPORT, *supra* note 5, at 8 (estimating the number of individuals completing formal advance directives). It has been noted, however, that only "[a]bout 50% of patients have an estate will, so perhaps this represents an upper limit of ex-

execute advance directives.⁸⁰ Many patients complain that it is either just too difficult to talk about, or that they plan to do it later.⁸¹ Many providers, on the other hand, are reluctant to discuss the issue because: (1) they do not know how to formulate advance directives, (2) they do not see advance directives as necessary for young and healthy patients, (3) they are uncomfortable discussing end-of-life issues, or (4) they are not paid for the time it takes to discuss the issue.⁸²

The PSDA addresses this low completion rate. It was enacted specifically because so few individuals complete advance directives and because “the living will, and its close relative, the durable power of attorney [were] counted as abject failures with re-

pectable advance directive use.” Linda Leah Emanuel, *Advance Directives: Do They Work?*, 25 J. AM. C. CARDIOLOGY 35, 36 (1995) (analyzing the use of advance directives with the use of estate wills).

⁸⁰ A related problem mentioned by the GAO report is that hospitals are unable to acquire the advance directives of even those patients who have actually completed them. GAO REPORT, *supra* note 5, at 13. This problem should be ameliorated, however, with services provided by companies like Advance Directives, Inc. in Columbia, SC, and the National Electronic Archive of Advance Directives (NEAAD) in Cleveland, OH, which maintain electronic registries. See *High-Tech Advance Directives*, PEOPLE'S MED. SOC. NEWSLETTER, (People's Med. Soc., Allentown, Pa.) Feb. 1996, at 5 (explaining the function of the NEAAD in maintaining advance directives and quickly producing them when needed).

⁸¹ See Henry J. Silverman et al., *Implementation of the PSDA in a Hospital Setting: An Initial Evaluation*, 155 ARCHIVES INTERNAL MED. 502, 505 (1995) (determining that nurse-dependent PSDA programs in hospitals could be more effective); see also Glick et al., *supra* note 2, at 56 (listing common reasons for not signing advance directives); Larry VanderCreek & Deborah Frankowski, *Barriers That Predict Resistance to Completing a Living Will*, 20 DEATH STUD. 73, 78 (1996) (identifying potential barriers and benefits of completing living wills, through a scientific study of medical outpatients).

⁸² See GAO REPORT, *supra* note 5, at 11 (discussing physicians' role in hindering the development of advance directives). See also Paul R. Dexter et al., *Effectiveness of Computer-Generated Reminders for Increasing Discussion About Advance Directives and Completion of Advance Directive Forms*, 128 ANNALS INTERNAL MED. 102, 102 (1998) (stating that “little is known about how to educate and motivate clinicians to solicit advance directives); Syed Zaman & Timothy Battcock, *Doctors Need to Know More About Advance Directives*, 317 BRITISH MED. J. 146 (1998) (analyzing survey results of doctors indicating little knowledge of advance directives); L.J. Marksonet et al., *Implementing Advance Directives in the Primary Care Setting*, 154 ARCHIVES INTERNAL MED. 2321, 2324-25 (1994) (discussing external factors and individual barriers to physicians' discussion of advance directives); R. Sean Morrison et al., *Physician Reluctance to Discuss Advance Directives: An Empiric Investigation of Potential Barriers*, 154 ARCHIVES INTERNAL MED. 2311, 2314 (1994) (discussing potential barriers to physician-initiated discussions of advance directives).

spect to the protection of autonomy.”⁸³ The PSDA aims to accomplish at hospital admission, what was not being accomplished before admission. Admittedly, hospital admission is not the ideal time to obtain an advance directive. Patients are often “ill, traumatized, or simply overwhelmed.”⁸⁴ Yet, the time of hospital admission is often the last chance to do so before the patient becomes incompetent.⁸⁵

Hospitals, through their agent physicians and staff, are not required to obtain an advance directive from patients, and, in fact, may not demand it as a condition of treatment.⁸⁶ Nevertheless, hospitals should still try to replicate as closely as possible the advance directive discussion that takes place – or should take place – at physicians’ offices. There is little point in obtaining an advance directive from a patient if the preferences memorialized in that patient’s advance directive fail to accurately reflect what, when later incompetent, the patient would have chosen for herself. Yet, unfortunately this is exactly what happens in hospitals across the country.

II. THE PROBLEMS WITH THE PSDA

In the six years since the PSDA has been in effect, more than one hundred articles, books, and reports analyzing the law have been published. After exhaustive analysis of this research, one reaches one inescapable conclusion: the PSDA is a failure by its own terms.⁸⁷ The fundamental flaw upon which I focus is that the

⁸³ CAPLAN, *supra* note 20, at 261 (arguing that living wills and powers of attorney do not promote patient autonomy). Professors Larson and Eaton trace the political history of the PSDA and identify six “clearly distinguishable goals of the Act,” but nevertheless recognize one “overarching objective” of “individual self-determination” and promotion of “autonomy values.” Larson & Eaton, *supra* note 8, at 249, 256, 267.

⁸⁴ GAO REPORT, *supra* note 5, at 12 (explaining how the discussion about end-of-life treatment preferences at the time of admission is a possible barrier to the development of advance directives).

⁸⁵ “Over 80% of Americans die in hospitals. Among those who die in hospitals, many, indeed perhaps most, are incompetent . . . for some period of time before their deaths.” ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION-MAKING I-2* (1989) (citation omitted).

⁸⁶ See 42 U.S.C. § 1395cc(f)(1)(C) (1994) (stating providers may not “condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive”).

⁸⁷ See Larson & Eaton, *supra* note 8, at 284 (concluding the PSDA is only a “modest success” at achieving the goals identified in its legislative history). See also COMMITTEE ON CARE AT THE END OF LIFE, *supra* note 50, at 202-03 (listing various problems which have been discovered with the implementation of the Patient Self-Determination Act).

PSDA, in spite of its title, not only fails to assure self-determination but actually promotes uninformed and under-informed advance directives.

The problem, as one commentator explained, is that the “[m]edical preferences expressed in an advance [directive] are . . . not usually adequately based upon reasoning and understanding”⁸⁸ This, of course, is an empirical point. To determine that this is a problem and that better understanding ought to be required, I turn in the second half of this section to present two popular normative positions toward advance directives: the orthodox position which grants too much deference to advance directives and the reductionist position which grants them no deference. I reject both of these positions and, taking the middle ground, argue that we ought to respect advance directives, but only if they reflect with sufficient accuracy, the preferences of those individuals upon whom they are binding.

A. The Empirical Research

There is a real danger that implementation of the PSDA by U.S. hospitals is merely a formal attempt to comply with the law rather than a real and substantial attempt to comply with the principles of patient self-determination. My argument is that hospitals should not apply the law in a vacuum, ignoring the quality and integrity of the advance directives they solicit. Nevertheless, empirical studies of the PSDA indicate that this is exactly what is being done when hospital-executed advance directives fail to reflect patient preferences.

1. Legal Rights vs. Medical Knowledge

The PSDA focuses on making patients aware of their legal rights. This is important, because not every patient has heard the ordeals of Ann Quinlan or Nancy Cruzan. Not all patients have read their state law authorizing advance directives. The PSDA is aimed at remedying this ignorance, requiring hospitals to “simply suggest [the] subject,”⁸⁹ informing their patients that there exist laws in their state that give them control over their post-competent destinies.

This narrow focus on legal rights is inappropriate. Awareness of one’s legal right to control post-autonomous medical care is only the beginning. The right to execute advance directives, like any legal right, is illusory without the requisite understanding to

⁸⁸ Sanchez-Gonzalez, *supra* note 20, at 288 (evaluating the role and effect of advance directives outside of their original North American context).

⁸⁹ La Puma et al., *supra* note 7, at 403-04.

effectively exercise it. Awareness of a right to prospective self-determination takes the patient from a stage of pre-contemplation (not aware of a need for an advance directive) to a stage of contemplation (consideration of completing an advance directive).⁹⁰ Yet, to take patients only to this stage presumes too much of them.⁹¹ They also need substantive information.

Awareness of a legal right does not necessarily imply the ability to exercise it. For example, under federal law, subjects for biomedical research are made aware of their "legal right" to discontinue the research at any time.⁹² They are even asked for written consent to participate. Yet, it is well-established that with regard to a subject's *awareness* of self-determination, "legal" rights is merely a threshold matter. The right of a research subject to withdraw at any time is meaningless if the material risks are not disclosed. The subject would not have the relevant information with which to make her own personal risk-benefit analysis. If the subject has not been told that there is a risk of sterilization, for example, then she would be unable to take this into account in deciding whether to exercise her legal right not to participate in the research. Without adequate disclosure of risks, a subject's legal rights are effectively eliminated, because the subject would not know either *when* or *how* to exercise them. Similarly, patients completing advance directives also need disclosure in order to adequately exercise their legal rights. Unfortunately, they do *not* get it.⁹³

Patients completing advance directives need to understand two categories of issues: legal issues and medical issues.⁹⁴ Current implementation of the PSDA focuses only on a patient's understanding of the legal issues only. Patients are given a copy of their state's laws on advance directives and an informational booklet explaining in simple language just what these laws mean.⁹⁵ This

⁹⁰ See Pearlman et al., *supra* note 22, at 355 (discussing the five basic stages of change that a patient goes through during advance-care planning).

⁹¹ It is not clear whether most hospitals go even this far and convey information on legal rights in more than a perfunctory manner. See Larson & Eaton, *supra* note 8, at 269-70 (reviewing empirical studies).

⁹² See 45 C.F.R. §§ 46.101 to 46.409 (1997) (stating federal laws protecting human research projects).

⁹³ See La Puma et al., *supra* note 7, at 403 (stating that consent forms generally do not give patients a clear understanding of the procedure, for reasons such as readability problems).

⁹⁴ They should also reflect upon social, familial, and religious issues, however, I leave those outside the scope of this Article.

⁹⁵ See, e.g., Medicare and Medicaid Programs: Advance Directives: Final Rule, 60 Fed. Reg. at 33, 263-65 (giving notice to patients of their rights regarding PSDAs). The blueprint for many of these booklets is the Senate Special Comm. on

awareness and legal knowledge does encourage and permit individuals to execute advance directives. Nevertheless, the objective of the PSDA is not only to encourage the execution of advance directives, but also to assure that those directives are reliable (*i.e.* reflect the preferences of the patients bound by them).⁹⁶

The emphasis in the medical,⁹⁷ legal,⁹⁸ and even the bioethical literature⁹⁹ has been on the rates at which advance directives are

Aging, 102d Cong., CONSUMER'S GUIDE FOR PLANNING AHEAD: THE HEALTH CARE POWER OF ATTORNEY AND THE LIVING WILL, S. PRT. 102-106 (Comm. Print 1992) (outlining guide to assist seniors and their advocates in planning ahead for a disabling accident or illness). Unfortunately this guide, like many of those prepared for health care professionals, focuses only on legal rights. *See, e.g.*, Cynthia A. Parkman & Barbara E. Calfee, *Advance Directives: Honoring Your Patient's End-of-Life Wishes*, NURSING 97, April 1997, at 49, 50-51 (discussing PSDA requirements to be followed by health care facilities and how to implement advance directives).

⁹⁶ *See* Larson & Eaton, *supra* note 8, at 256-62, 267.

⁹⁷ *See, e.g.*, Frank J. Landry et al., *Increasing the Use of Advance Directives in Medical Outpatients*, 12 J. GEN. INTERNAL MED. 412 (1997) (studying whether educational intervention would increase patient completion of advance directives); John E. Heffner et al., *Outcomes of Advance Directive Education of Pulmonary Rehabilitation Patients*, 155 AM. J. RESPIRATORY CRITICAL CARE MED. 1055 (1997) (discussing survey results of patients who have completed an education program and their tendency to complete timely advance directives); Anna Maria Cugliari et al., *Factors Promoting Completion of Advance Directives in the Hospital*, 275 JAMA 578d (1996) (investigating whether the requirement to distribute information to hospital patients increased completion of the health care proxy); K.K. Ishihara, *Advance Directives in the Emergency Department: Too Few Too Late*, 3 ACADEMIC EMERGENCY MED. 50 (1996); Henry S. Perkins, *Are Advance Directives Becoming an Endangered Species?* 109 CHEST 299, 299 (1996) (explaining the obstacles that patients, physicians, and hospitals have regarding advance directives); Herman Small, *Increasing Completion of Advance Directives*, 271 JAMA 1907 (1994) (stating in a letter to the editor of JAMA that a simple educational intervention does not necessarily increase the completion of advance directives); Denise C. Park et al., *Implementation and Impact of the Patient Self Determination Act*, 87 S. MED. J. 971 (1994) (analyzing the PSDA and its impact on the number of patients using advance directives); Linda L. Emanuel et al., *Advance Directives for Medical Care - A Case for Greater Use*, 324 NEW ENG. J. MED. 889 (1991) (concluding from a survey of the general population that many people can complete an advance directive in 15 minutes or less).

⁹⁸ *See, e.g.*, David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1260 (1994) (focusing on the percentages of adults who have completed advance directives); Refolo, *supra* note 11, at 455,457 (pointing to an expected increase in the use of advance directives as a result of the PSDA's enactment).

⁹⁹ *See, e.g.*, Greg A. Sachs, *Increasing the Prevalence of Advance Care Planning*, HASTINGS CENTER REP., Nov.-Dec. 1994, at S13 (discussing the need to increase the use of advance-care planning after analysis of the variables and procedures of other studies). *See also, e.g.*, Glick et al., *supra* note 2, at 55 ("The most direct indicator of the value of the PSDA is the percentage of patients . . . who have signed advance directives . . ."). *But see* Joan Teno, et al., *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and*

completed, and not on the quality of the advance directives themselves. Through employing the narrow measure of completion rate, the PSDA seems to have “reinforce[d] misconceptions about what counts as a valid advance directive.”¹⁰⁰ Arguably, the PSDA has not even done a good job of making patients aware of their legal rights.¹⁰¹ However, even if it had, awareness of legal rights or rates of completion are not proper measures of success. The PSDA has failed to make patients aware of *how* they are to meaningfully exercise those rights. It has failed to assure patients’ substantial understanding of the medical issues to which their legal rights relate.

Just as a research subject cannot meaningfully exercise her legal rights without adequate disclosure, a patient completing an advance directive cannot exercise his legal rights without adequate disclosure. “For a subject’s consent to have meaning...she must know that the consent is for research rather than for therapy . . . [and] [t]he nature of the research[,] and its potential risks must be known.”¹⁰² Certainly, both research subjects and patients completing advance directives can sign a consent form or a durable power of attorney for health care. But, as described earlier, these are merely *formal* exercises that fail to affirm the patients’ autonomy and protect them in the way the laws were intended. Signing a consent to medical treatment or a contract is a merely formal exercise of legal rights. That consent and that contract will be invalid if material information was withheld because under such circumstances a patient would not have known what she was doing.¹⁰³ Patients cannot properly exercise their legal rights under advance

the SUPPORT Intervention, 45 J. AM. GERIATRICS SOC’Y 500, 500 (1997) (observing that increasing rates of advance directive completion may not, by itself, substantially improve their effectiveness).

¹⁰⁰ KING, *supra* note 16, at 111.

¹⁰¹ See Larson & Eaton, *supra* note 8, at 285 (stating that “[m]ost studies suggest that the distribution of PSDA materials has done little to increase the public’s level of understanding of advance directives”).

¹⁰² KING, *supra* note 16, at 46.

¹⁰³ See, e.g., *Ahern v. Veterans Admin.*, 537 F.2d 1098, 1101 (10th Cir. 1976) (holding plaintiff’s consent invalid because defendant physicians did not disclose the experimental nature of treatment); *Bang v. Charles T. Miller Hosp.*, 88 N.W.2d 186 (Minn.1958) (holding consent not valid when plaintiff was not told that sterilization was an inevitable outcome). See also, e.g., MICHAEL J. TREBILCOCK, *THE LIMITS OF FREEDOM OF CONTRACT* 102-26 (1993) (discussing the validity of contracts with respect to the informed status of the contracting parties); Melvin Aron Eisenberg, *The Limits of Cognition and the Limits of Contract*, 47 STAN. L. REV. 211 (1995) (arguing that an understanding of the psychological constraints on decision-making is essential for the development of contract doctrine).

directive statutes without adequate disclosure of material information.¹⁰⁴

Faden and Beauchamp draw a clear distinction between *formal* and *real* exercises of consent. "Sense₂" or "formal" consent refers only to legally or institutionally effective authorization.¹⁰⁵ It is sufficient for Sense₂ consent that the subject or patient execute the directive in the appropriate manner, for example, having the directive signed, dated, witnessed, notarized, and attested to.¹⁰⁶ "Sense₁" or "real" consent, on the other hand, requires the subject or patient to do more than "express agreement with, acquiesce in, yield to, or comply with an arrangement or a proposal."¹⁰⁷ To give sense₁ consent, the subject or patient must substantially understand that to which she consents. Using Faden and Beauchamp's terminology, the problem with the PSDA is that it ensures only sense₂ or formal consent. Patients must know not only *that* they are completing an advance directive, but also *what* they authorize when they execute that advance directive.¹⁰⁸ The PSDA ought to, but does not now, require sense₁ informed consent.

A few years ago, Alan Meisel, a leading expert on death and the law, wrote an article for practicing physicians dispelling legal myths about terminating life support.¹⁰⁹ These myths included the belief that anything that is not specifically permitted by law is prohibited, and the belief that the patient must be terminally ill for life-sustaining treatment to be stopped. Meisel wanted to dispel these myths, because "[p]hysicians who are not knowledgeable about legal consideration in the care of dying patients and are aware of the limits of their knowledge are in a better position to seek advice, and therefore less likely to do harm, than those physicians who are unaware of the limits of their own knowledge."¹¹⁰

¹⁰⁴ In the next section, I will argue that mere disclosure of information is insufficient. Patients need more than just the data; they also need an understanding, a real appreciation of what that information means.

¹⁰⁵ FADEN & BEAUCHAMP, *supra* note 26, at 280 (explaining that consent obtained through a legally valid procedure may not necessarily reflect a patient's truly informed consent).

¹⁰⁶ *See* 2 MEISEL, *supra* note 24, §§ 13.12-20 (discussing the formalities of executing an advance directive).

¹⁰⁷ FADEN & BEAUCHAMP, *supra* note 26, at 278 (explaining that in actual informed consent situations, the patient is authorizing treatment rather than merely assenting to the physician's authority).

¹⁰⁸ *Cf. id.* at 300 (explaining that although patients may be informed of medical treatment and may go through consent procedures, they may not know that they are giving authorization for treatment).

¹⁰⁹ Alan Meisel, *Legal Myths about Terminating Life Support*, 151 ARCHIVES INTERNAL MED. 1497 (1991).

¹¹⁰ *Id.* at 1497.

Those who practice medicine have learned the law. It is time that the law learned the medicine.¹¹¹ At present, the PSDA's "only teeth is to require that patients be fully informed of what they can *legally* do in their state."¹¹² Without also ensuring adequate medical understanding, the PSDA can, at best, only encourage patients to execute more numerous but less reliable advance directives that neither reflect their medical preferences nor provide sufficient guidance to health care professionals.¹¹³

It might be argued that patients can simply ask advice if they need assistance in completing an advance directive. The Georgetown University Hospital policy statement, for example, does inform patients that they may seek counsel from the Departments of Pastoral Care or Social Work.¹¹⁴ I will discuss this counseling below, but here it will suffice to recall the words of Socrates: "[I]t is likely that neither of us knows anything worthwhile, but he thinks he knows something when he does not, whereas when I do not know, neither do I think I know; so I am likely to be wiser than he to this small extent, that I do not think I know what I do not know."¹¹⁵ Patients might seek counsel if they know that they do not understand, but they will probably not seek counsel if, like the uninformed research subject, they think that they already understand, unaware of the limits of their own knowledge. Tellingly, in a recent study only two percent of patients requested to receive additional information on advance directives.¹¹⁶

¹¹¹ Unfortunately, because medical information must be tailored to individual patients, this cannot be done in a medical journal article.

¹¹² Scott Obernberger, *When Love and Abuse Are Not Mutually Exclusive: The Need for Government Intervention*, 12 ISSUES L. & MED. 355, 362 (1997) (emphasis added) (arguing that more government intervention in parents' health care decisions for their children is a necessity).

¹¹³ See KING, *supra* note 16, at 235 (arguing that the PSDA discourages patients from expressing their true wishes by discouraging them from providing more information than a standard form would require).

¹¹⁴ See Georgetown University Medical Center Policy Statement No. 501, Patient Self-Determination Act (Aug. 9, 1993) (on file with the hospital); see also *University of Chicago Hospital's Policy: Patient Self-Determination Act Implementation*, (visited Sept. 21, 1998) <<http://ccme-mac4.bsd.uchicago.edu/ccmepolicies/uch/psda.html>>(stating that the hospital will assign a social worker to a patient who has questions regarding advance directives); see also Bryan Memorial Hospital, *Advance Directive* (visited Sept. 25, 1998) <<http://www.bryan.org/advdirective.htm>> (stating that hospital staff are available to assist patients in completing advance directives).

¹¹⁵ PLATO, *Apology*, in FIVE DIALOGUES § 27d (G.M.A. Grube trans., Hackett Pub. Co., 1981) (referring to a realization by Socrates that the "public m[a]n" with whom he was speaking was no wiser than he).

¹¹⁶ Silverman et al., *supra* note 81, at 505 (explaining the results of a survey of patients who participated in a hospital PSDA program).

2. The Medical Knowledge

The research subject is very well-protected by federal law.¹¹⁷ The subject must be made aware of what the research entails by an explanation of those procedures that would not be performed but for the research. Risks, benefits, and alternatives to participation must be described. Moreover, institutional review boards (IRBs) endeavor to ensure that the language used in consent forms is neither jargonistic nor unduly influential on a potential subject's decision to participate.¹¹⁸ All material information must be disclosed to the subject. Moreover, it is not sufficient that all the information is simply "presented" to the research subject. It must be presented in a way that is meaningful. Otherwise, it might as well have not been presented at all.¹¹⁹

Information about potential medical circumstances is just as material to the patient completing an advance directive as to the research subject. The advance directive form which the Georgetown University Hospital gives to its patients includes a section "Words You Need to Know," which defines eleven terms used in other sections of the form.¹²⁰ These terms are defined outside both their medical and social context. For example, a patient can learn that organ donation is "[w]hen a person permits his/her organs . . . to be removed after death to be transplanted for use by another person."¹²¹ Yet, the patient does not learn (1) that these organs include everything from corneas to saphenous vein in the leg; (2) that these organs are urgently needed for transplant, therapy, research, and education; and (3) that her body might still be properly prepared for funeral rituals. Any or all of these might be important

¹¹⁷ See 45 C.F.R. §§ 46.101 to 46.409 (1997) (detailing the protections available to a variety of human research subjects, including children, pregnant women, and prisoners).

¹¹⁸ See Dale E. Moore, *An IRB Member's Perspective on Access to Innovative Therapy*, 57 ALB. L. REV. 559, 573 (1994) (discussing how IRB members endeavor to protect vulnerable research subjects). See also Robert A. Greenwald, *Informed Consent*, in HUMAN SUBJECTS RESEARCH: A HANDBOOK FOR INSTITUTIONAL REVIEW BOARDS 79, 79-90 (Robert A. Greenwald et al. eds., 1982) (explaining proper methods of preparing informative, clear, comprehensive, and non-deceptive consent forms).

¹¹⁹ See *infra* notes 252-83 and accompanying text.

¹²⁰ Georgetown University Medical Center, *Advance Directive: Your Durable Power of Attorney for Health Care, Living Will and Other Wishes* (May, 1992) (on file with Geo. U. Med. Center) (unpublished advance directive form for use in the District of Columbia, Maryland, and Virginia); see also Walter Reed Army Medical Center, *Patient Information: Advance Directive for Patients* (last modified Dec. 15, 1997) <<http://www.wramc.army.mil/patientinfo/definitions/htm>> (providing a definition section for key terms used in advance directives).

¹²¹ Georgetown University Medical Center, *supra* note 120, at 1.

considerations to a patient completing section three of Georgetown's advance directive form.

It might be objected here that it is not the role of the hospital to encourage patients to complete their advance directives in any particular way, for example, by encouraging organ donation. Instead, information should be presented in an objective manner. This is a compelling point, but it is well-recognized in today's post-Enlightenment world that any context in which information is presented can be only yet another narrative.¹²² While there can be no truly objective presentation, there may be a discernable difference between informing patients of the *context* of their decisions and *biasing* their decisions.

Information that is presented may be framed in certain ways that will influence or encourage patients to reach particular decisions about their medical care.¹²³ Yet, this cannot mean that the information must simply be left out. The organ donation question is included on the form in the first place for a particular reason: there is a tremendous and urgent need for organs.¹²⁴ That reason should be passed along to the patient. Similarly, describing what is involved in artificial nutrition may affect the patient's decision to request it. Nevertheless, to ask the patient to decide whether she would want artificial nutrition without providing her with a good understanding – perhaps even a false understanding – of what it entails makes the patient's advance directive a less reliable indication of her health care preferences. This undermines its central purpose to protect and promote patient autonomy.

The GAO report notes that vague terms like “heroic measures” and “terminal” employed in advance directives limit the effectiveness of the advance directive.¹²⁵ This is absolutely correct. Without an adequate understanding of these concepts, a patient might be able to make a decision – albeit an uninformed decision – regarding artificial nutrition and hydration depending upon whether or not it was, for example, “the main treatment keeping

¹²² See RICHARD RORTY, *CONTINGENCY, IRONY, AND SOLIDARITY* 9 (1989) (theorizing that fundamental changes in language yield new non-linguistic forms of behavior).

¹²³ See Timothy R. Malloy et al., *The Influence of Treatment Descriptions on Advance Medical Directive Decisions*, 40 J. AM. GERIATRICS SOC'Y 1255, 1258-59 (1992) (indicating that the wording of treatment descriptions can have major effects on patient decisions to accept or reject particular medical interventions).

¹²⁴ See A.H. Barnett & David L. Kaserman, *The Shortage of Organs for Transplantation: Exploring the Alternatives*, 9 ISSUES L. & MED. 117 (1993) (describing the transplantable organ shortage and alternatives for meeting the need).

¹²⁵ GAO REPORT, *supra* note 5, at 14 (discussing how terms that can be interpreted differently limit the effectiveness of advance directives).

me alive,” as the Georgetown advance directive states.¹²⁶ Yet, this decision would not be very useful to health care professionals if the patient later becomes incompetent. It would be unclear, for example, whether the patient would want the treatment with only: (1) a small chance of recovery, (2) a limited recovery, (3) a recovery which would not allow her to leave the hospital, (4) a recovery that would leave her permanently unconscious, (5) a recovery that would leave her with mental capacity but permanently unconscious, (6) a recovery with permanent pain, or (7) a recovery requiring ongoing and expensive treatment.

Meisel warns that “it is critical when specifying treatments to be forgone that the conditions under which they are to be forgone are also made clear.”¹²⁷ For example, if through her advance directive, a patient intended to avoid CPR in the context of an incurable illness, it would be unfortunate if CPR were forgone in response to a cardiac arrest in unrelated routine elective surgery from which the patient could have been fully restored to her preoperative condition. Such a result would probably not be what the patient intended. Yet, such unintended results are probable. The poor readability of advance directives prevents thorough understanding and adversely influences choices in ways that thwart the true desires of patients.

The very fact that an advance directive is unclear indicates that the patient did not have an adequate understanding of the issues when she completed the directive in the first place. Karen Orloff Kaplan, executive director of Choice in Dying, the leading organization promoting the use of advance directives, in an interview stated that “[a]dvance directives are a two-part challenge. . . . The first is to get the documents properly executed, but people often stop there. If they don’t take steps to ensure the documents are honored, the first step is of no value.”¹²⁸ What Kaplan overlooks is a third step in which the patient gains sufficient understanding in order to *meaningfully* execute the advance directive in the first place. Without this third step, neither of the other steps is of any value.

Patients’ understanding of advance directives is influenced by “syntactic complexity, concept density, abstractness, organization, coherence, sequence of ideas, page format, length of line of print,

¹²⁶ Georgetown University Medical Center, *supra* note 120, at 2.

¹²⁷ 2 MEISEL, *supra* note 24, § 13.23, at 236.

¹²⁸ *Clear Language Key in Making Sure Client’s Advance Directive is Honored*, SERVING ELDERLY CLIENTS, Mar. 1996, at 1 (finding the factors most likely to interfere with the implementation of a client’s advance directive are the attitudes of health care providers, the wishes of family members, and the availability or specificity of the actual document).

length of paragraph, punctuation, illustrations, color, and reader interest.”¹²⁹ Unfortunately, most advance directive forms currently in use often have neither a reasonable scope nor depth.¹³⁰ They do not ask all the right questions and they do not ask those questions in a manner that elicits clear responses.

Fortunately, with the advance directive forms themselves, hospitals provide pamphlets that explain both the PSDA and advance directives. Thus, it seems there need not be, as some argue, an irreconcilable tension between designing “advance directive documents that are simple enough for patients to complete but [comprehensive enough to] give future decision makers enough information to make decisions that accurately reflect patient wishes.”¹³¹

One new consumer booklet asks patients to ask themselves why they have the goals for medical treatment that they do.¹³² “If you would not want to be kept alive by a ventilator, what is it about being on a ventilator that troubles you? Is it the loss of mobility, the lack of independence, or some other factor? Would it matter if you needed a ventilator for only a few days rather than many months? The answers to these kinds of questions will reflect important values that you hold and that will help you shape your goals of treatment.”¹³³ The careful deliberation that this booklet

¹²⁹ Barbara B. Ott & Thomas L. Hardie, *Readability of Advance Directive Documents*, 29 *IMAGE: J. NURSING SCHOLARSHIP* 54 (1997) (advocating revision of advance directive documents); see also Karl Koenke, *Readability Formulas: Use and Misuse*, 40 *THE READING TCHR.* 672, 674 (1987) (describing a Bell Labs computer program that gives students readability feedback in several categories).

¹³⁰ See KING, *supra* note 16, at 101 (identifying this as a problem with the “communication” goal of advance directives). Indeed, there is a demonstrated problem that physicians routinely ignore advance directives. See Phillip G. Peters, Jr., *The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy*, 45 *U.C.L.A. L. REV.* 673 (1998) (discussing doctors’ failures to follow advance directives and analyzing the legal consequences). Nevertheless, I am concerned that poor validity and reliability of advance directive forms causes them, even if followed to the letter, to be inconsistent with treatment.

¹³¹ Gary S. Fischer et al., *Can Goals of Care Be Used to Predict Intervention Preferences in an Advance Directive?* 157 *ARCHIVES INTERNAL MED.* 801, 801 (1997) (analyzing study of physicians where medical interventions are considered with general goals of care).

¹³² AM. ASSOC. RETIRED PERSONS ET AL., *SHAPE YOUR HEALTH CARE FUTURE WITH ADVANCE MEDICAL DIRECTIVES* (visited Oct. 7, 1998) <<http://www.ama-assn.org/public/booklets/livgwill.htm>> (providing patients with a qualitative method of completing advance directives).

¹³³ *Id.* See also DAVID J. DOUKAS & WILLIAM REICHEL, *PLANNING FOR UNCERTAINTY: A GUIDE TO LIVING WILLS AND OTHER ADVANCE DIRECTIVES FOR HEALTH CARE* (1993) (defining and describing what values are, and discussing their impact on health care decision-making).

prompts individuals to make should lead to clearer and more reliable advance directives. Unfortunately, such efforts at patient education are rare.

The patient must be made aware of her potential future medical circumstances. Otherwise, her advance directive is useless at best, and at worst, it is just wrong. As the *Encyclopedia of Bioethics* puts it, “[a]dvance directives can...be hazardous if written without understanding.”¹³⁴ Nevertheless, some experts estimate that only seven to forty-two percent of medical choices benefit from accurate instructional decision-making.¹³⁵ That means fifty-eight to ninety-three percent of choices are not implemented as intended, making the PSDA “counterproductive.”¹³⁶ So, the PSDA, rather than promoting autonomy has “done a disservice to most real patients and their families and caregivers.”¹³⁷ It has promoted the execution of uninformed and under-informed advance directives, and has undermined, not protected, self-determination. The PSDA looks like a utter failure. But before we draw any final conclusions, we must identify the normative problems with more specificity.¹³⁸

B. The Two Extreme Normative Positions on Advance Directives

There are two popular normative views of advance directives. The first view, exemplified in *In re Martin*, takes the advance directive as almost conclusive evidence of the patient’s health care preferences, because it presumes that the decision-making that went into the drafting of the directive was sound. The problem with this position is that this presumed condition rarely obtains, especially when the advance directive was completed pursuant to the PSDA.¹³⁹ The second position, most famously espoused by Re-

¹³⁴ Lynn & Teno, *supra* note 53, at 575 (discussing the possibility of an advance directive being applicable in particular situations).

¹³⁵ Emanuel, *supra* note 79, at 36 (citing low impact of accurate instructional directives on medical decisions).

¹³⁶ See La Puma et al., *supra* note 7, at 404 (stating that patients could be misinformed about their rights).

¹³⁷ Rebecca Dresser, *Confronting the “Near Irrelevance” of Advance Directives*, 5 J. CLINICAL ETHICS 55, 56 (1994) (discussing the need to develop formal standards to govern the care of patients to assist them in making informed decisions about their care).

¹³⁸ Professors Larson and Eaton evaluated the PSDA on both process- and outcome-oriented goals for the PSDA expressed by its political proponents. Larson & Eaton, *supra* note 8, at 267. I am evaluating the PSDA against its central and implicit promise to promote patient “self-determination.”

¹³⁹ Of course, not all advance directives are completed pursuant to the PSDA. Indeed, some advance directives completed pursuant to the PSDA might be compre-

becca Dresser, is more responsive to new empirical evidence. Yet, it pessimistically holds that advance directives can *never* be morally valid no matter how careful the decision-making that went into them because the drafter of the advance directive and the patient later bound by it are different “selves.” Dresser’s position, which accords no respect to advance directives, represents the opposite extreme of the dominant approach exemplified by *Martin*, which accords too much respect. I turn now to examine each of these positions in more detail.

1. *Martin* and Too Much Deference to Advance Directives

In 1995, the Michigan Supreme Court handed down its opinion in *In re Martin*,¹⁴⁰ in which it decided that seemingly probative evidence not recorded in an advance directive does not satisfy Michigan’s evidentiary standard for determining the health care preferences of incompetent patients. Remarkably, however, the court suggested that even less probative evidence would satisfy the evidentiary standard if it simply were formally recorded in an advance directive.

Michael Martin was injured in an automobile accident “impair[ing] his physical and cognitive abilities, leav[ing] him unable to walk or talk, and render[ing] him dependent on a colostomy for defecation and a gastronomical tube for nutrition.”¹⁴¹ Michael’s wife petitioned the probate court for authorization to withdraw Michael’s nutritive support.¹⁴² Eventually, upon being remanded, the probate court granted the petition, holding that there was clear and convincing evidence that termination is what Michael himself would have wanted.¹⁴³ The Michigan Supreme Court reversed, concluding that there was no such clear and convincing evidence, as required by the Michigan statute.¹⁴⁴

The court, noting that Michael’s right to refuse life-sustaining treatment survived his incompetency, applied a subjective analysis¹⁴⁵ to determine what Michael himself would choose if he were

hensive and accurate. Nevertheless, the empirical evidence suggests that *most* advance directives completed pursuant to the PSDA are completed under conditions not conducive to good decision-making.

¹⁴⁰ *In re Martin*, 538 N.W.2d 399 (Mich. 1995) (holding that the clear and convincing evidentiary standard must be met to forego life-sustaining treatment).

¹⁴¹ *Id.* at 402.

¹⁴² *Id.*

¹⁴³ *Id.* at 404.

¹⁴⁴ *Id.* at 413.

¹⁴⁵ There is a continuum of decision-making standards for incompetent patients that can be collectively identified as employing a “subjective” analysis. *See* 1

able to choose for himself.¹⁴⁶ The court held that self-determination requires that the patient “make” the choice if possible.¹⁴⁷ One way in which Michael might have done this (albeit prospectively) is through an advance directive. Unfortunately, he did not have one. The court, however, rightly still tried to give effect to Michael’s wishes, rather than to use an objective best-interest analysis to determine whether to continue his nutritive support. The court turned to what evidence it did have, which included testimony regarding Michael’s expressed preferences before his accident, that “he would rather die than be dependent on people and machines.”¹⁴⁸

The evidentiary standard in Michigan, as in most jurisdictions, requires that evidence of what an incompetent patient would have wanted must be “clear and convincing.”¹⁴⁹ This standard is more demanding than the usual civil standard of preponderance of the evidence.¹⁵⁰ The court noted that in evaluating oral statements, it looks to their remoteness, consistency, specificity, and solemnity.¹⁵¹ The court stated it would accord oral statements authority only when they “illustrate a serious, *well thought out* consistent decision to refuse treatment under these exact circumstances, or circumstances highly similar to the current situation.”¹⁵² The court held that this standard was not met because there was no clear evidence that Michael Martin’s statements were directed precisely at the situation in question. Michael, when he made the statements that were entered as evidence, “was not presently experiencing and likely had never experienced the form of ‘helplessness’ he supposedly disliked.”¹⁵³ He was only commenting on the condition of others rather than making a serious statement of purpose after careful reflection.

MEISEL, *supra* note 24, § 7.3. The basic goal of this analysis is to identify – at some level of specificity – the patient’s “wants” as opposed to her “needs.”

¹⁴⁶ *In re Martin*, 538 N.W.2d 399, at 406-08 (Mich. 1995).

¹⁴⁷ *Id.* at 408.

¹⁴⁸ *Id.* at 402, 411-12.

¹⁴⁹ *Id.* at 410.

¹⁵⁰ See 2 MEISEL, *supra* note 24, § 10.34 (discussing that courts generally require that an advance directive be proved by clear and convincing evidence).

¹⁵¹ *In re Martin*, 538 N.W.2d 399, at 411 (Mich. 1995).

¹⁵² *Id.* (emphasis added).

¹⁵³ *Id.* See also *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613-14 (N.Y. 1988) (holding that there must be more than speech to “persuade the fact finder that her expressions were more than just immediate reactions” and that “the inquiry must always be narrowed to the patient’s expressed intent”); *Eichner v. Dillon*, 420 N.E.2d 64, 72 (N.Y. 1981) (holding that oral evidence is followed only when it is specific and a “solemn pronouncement”).

The Michigan Supreme Court required a subjective standard to be established by clear and convincing evidence.¹⁵⁴ It held the standard was not met because there was no such evidence. Remarkably, though, the court indicated that the clear and convincing standard would have been met, had Michael simply executed an advance directive -- even if he had done so with no more (and probably even less) understanding than that found in his oral statements.¹⁵⁵ This is merely *obiter dicta*, but it is troubling.

The Michigan Supreme Court was correct to set high evidentiary standards to assure that patients are bound only by their "serious, well thought out, consistent decisions to refuse treatment under highly similar circumstances."¹⁵⁶ After all, self-determination requires that the individual be bound by only her "self" (*i.e.* her authentic preferences) and not by just *any* stated or expressed preference. The preferences by which a patient is bound must "be the same as [the patient's] would have been had she been confronted with the prospect of her situation while competent."¹⁵⁷ This requirement of understanding should apply not only to patients without advance directives, but also to patients executing advance directives.

The *Martin* court, like other courts and other decision makers, employed different evidentiary standards depending upon whether the evidence at issue was in the form of an advance directive. In *Martin*, the Michigan Supreme Court demanded that Michael Martin's oral statements constitute sense₁ informed consent. But at the same time the court would have accepted a sense₁-deficient advance directive as evidence of Michael Martin's preferences. In

¹⁵⁴ I use the term "subjective" in its broadest sense to encompass any decision-making standard that is more concerned with the patient's evaluative interests than her experiential interests. See generally Ronald Dworkin, *Autonomy and the Demented Self*, 64 MILBANK Q. 4 (Supp. 2 1986) (discussing pre- and post-dementia rights of patients with regard to the autonomy interests).

¹⁵⁵ *In re Martin*, 538 N.W.2d 399, at 410 (Mich. 1995). Compare *id.* at 416 (Levin, J. dissenting) (criticizing the majority for demanding a formal advance directive as the only adequate clear and convincing evidence), with *Eichner v. Dillon*, 420 N.E.2d at 72 (noting that written statements do have more indicia of solemnity).

¹⁵⁶ *In re Martin*, 538 N.W.2d 399, at 410-11; see also *In re Edna M.F. v. Eisenberg*, 563 N.W.2d 485, 487 (Wis. 1997) (denying petition to withdraw petition because "the only evidence presented . . . regarding [the incompetent's] views on the use of life-sustaining medical treatment involves a statement made in 1966 or 1967 . . . in which [she remarked] she would rather die of cancer than lose [her] mind"). But see *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626 (Mass. 1986) (finding non-contemporaneous statements sufficient evidence of incompetent's preferences).

¹⁵⁷ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286 (1990) (stating that the state may choose to defer only to the wishes of the patient considering the fact that the views of close family members cannot be assumed to coincide with the views of the decision the patient would make if she were competent).

other words, the court suggested that *either* sense₁ or sense₂ informed consent would be sufficient if in the form of an advance directive.

The *Martin* court assumed that sense₂ informed consent in the form of an advance directive necessarily implied sense₁ informed consent. This is somewhat reasonable. After all, the formalities of execution do impress one “with the seriousness of purpose with which the maker of the instrument acts.”¹⁵⁸ Still, this assumption is erroneous. “The mere existence of an advance directive does not mean that it should be blindly followed.”¹⁵⁹ The court’s inconsistent treatment of oral and written statements of preferences highlights the deference wrongly granted to advance directives just because of their formal sense₂ characteristics. An advance directive is, as Fenella Rouse describes it, “considerably better than nothing.” Nevertheless, “they may not always demonstrate a specific and informed refusal of the treatment at issue in the patient’s current circumstances.”¹⁶⁰

2. Rebecca Dresser and the Metaphysical Objection to Advance Directives

Unquestionably, it is important that patients completing advance directives understand the medical circumstances to which they might later be subject. Professor Rebecca Dresser, among others, has applied this principle very strictly, arguing that such understanding is important not to ensure the autonomy of the decision-maker, but to ensure the autonomy of the incapacitated person.¹⁶¹ Legally these two persons are the same (*e.g.* both Michael Martin), but they are very different “selves” (*e.g.* Michael Martin before and Michael Martin after the accident). On the reductionist theory of personal identity, which Dresser espouses, the radical differences in values, attitudes, and similar attributes which individuals often undergo when they become incompetent make the

¹⁵⁸ 2 MEISEL, *supra* note 24, § 13.11, at 227 (observing that formalities enhance the enforceability of advance directives) *see also* KING, *supra* note 16, at 104 (observing that just completing an advance directive “encourag[es] more thoughtful choices”); Fenella Rouse, *Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?* 5 ISSUES L. & MED. 321, 328 (1989) (observing that courts prefer written statements “on the theory that they demonstrate that the person formally and deliberately set out her wishes after giving thought to her precise instructions in the circumstances delineated in the writing”).

¹⁵⁹ 2 MEISEL, *supra* note 24, § 10.28, at 66.

¹⁶⁰ Rouse, *supra* note 158, at 329 (commenting that a patient’s writings often do not demonstrate the patient’s intent).

¹⁶¹ *See infra* notes 164, 173-77.

person at the later point in time a different person.¹⁶² In other words, the person who wrote the advance directive is a different "person" from the incompetent person bound by it.

Rebecca Dresser argues that personal identity problems challenge the very idea of advance directives. Dresser argues that an individual's preferences, as expressed in her advance directive, may be ignored because she is not in the best position to make decisions for her own (future) self. Indeed, if Dresser's personal identity premise is valid, this argument is quite convincing. Once earlier and later selves are distinguished, the assumption of autonomy implicit in advance directives is undermined: one person, a "stranger,"¹⁶³ simply cannot make medical decisions for another person.¹⁶⁴

In an important sense, Dresser's premise is valid. The person actually facing death is *not* the same person as before. "[A] new set of perceptions and feelings that were previously unknown are now part of his or her consciousness."¹⁶⁵ Arguably, one need not even engage in philosophical or metaphysical discussion to characterize the individual at a future point in time as a different "self."¹⁶⁶ Empirically, the person is radically psychologically dif-

¹⁶² See DEREK PARFIT, *REASONS AND PERSONS* 204-05, 223-26 (1984) (discussing the reductionist theory of personal identity).

¹⁶³ See KING, *supra* note 16, at 82-83 (explaining that one justification for ignoring advance directives is that the person who writes the advance directive is a stranger to the same person in an unconscious or demented state).

¹⁶⁴ Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373 (1986) (discussing the possibility that a person's interests may change over time to the point that a different person exists when the advance directive takes effect). See also Thomas May, *Reassessing the Reliability of Advance Directives*, 6 CAMBRIDGE Q. HEALTH CARE ETHICS 325, 334 (1997) ("If advance directives do not reflect patient autonomy, why should they be given any weight at all?"); see also Anne Moorhouse & David N. Weisstub, *Advance Directives for Research: Ethical Problems and Responses*, 19 INT'L. J. L. & PSYCHIATRY 107, 120 (1996) ("Projecting the wishes of a previously competent person onto the presently incompetent person is to impose the wishes of one person onto a different person").

¹⁶⁵ Donald L. Beschle, *Autonomous Decision-making and Social Choice: Examining the "Right to Die,"* 77 KY. L. J. 319, 344 (1988-89).

¹⁶⁶ There is a debate between reductionist and nonreductionist theorists of personal identity over the moral and legal authority of advance directives. See generally Ben A. Rich, *Prospective Autonomy and Critical Interest: A Narrative Defense of the Moral Authority of Advance Directives*, 6 CAMBRIDGE Q. HEALTH CARE ETHICS 138 (1997) (describing different views regarding advance directives, specifically those of Rebecca Dresser, Nancy Rhoden, and Ronald Dworkin). A more immediate and practical debate focuses on the degree of psychological continuity between the drafter and the incompetent. See BUCHANAN & BROCK, *supra* note 85, at 179. See also Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, in *IN HARM'S WAY: ESSAYS IN HONOR OF JOEL FEINBERG* 290, 302 (Jules L. Coleman & Allan Bu-

ferent, and this alone is sufficient to raise questions as to the authority of earlier decisions embodied in an advance directive over a later, very differently situated and incompetent individual.¹⁶⁷ As Nancy King explains, this psychological difference “challenges the validity of the patient’s decision directly, by challenging the patient’s ability to make it.”¹⁶⁸ Except in special rare circumstances, one individual cannot make medical decisions for another “person.”¹⁶⁹

Whatever one thinks of the reductionist theory of personal identity, it certainly does not fit neatly with the way Western law treats individuals. In particular, even if the patient *qua* competent and the patient *qua* incompetent were different “selves,” they would still be considered as the same legal person because they would share the same physical body. This numerical identity suggests that Dresser’s argument for overriding and ignoring stated (and even adequately informed)¹⁷⁰ preferences is properly charac-

chanan eds., 1994) (“Without going so far as to regard [Patient] Now as a different person from [Patient] Then, I believe it is plain that there has occurred a great transformation in her capacities and perspectives . . . [Her] precedent autonomy that is so far separated and distant from her present circumstances that its entitlement to govern is severely compromised”).

¹⁶⁷ See JOEL FEINBERG, HARM TO SELF: THE MORAL LIMITS OF THE CRIMINAL LAW 370 (1986) (critiquing living will legislation asking, “[c]an we be sufficiently confident that the earlier self acting on the basis of only a partial anticipation of the eventual situation, would not himself have chosen to revoke had he been able to foresee precisely these circumstances in every relevant detail?”); see also John A. Robertson, *Second Thoughts on Living Wills*, HASTINGS CENTER REP., Nov.-Dec. 1991, at 6, 7 (indicating that patient interests change radically once they are incompetent and, thus, their original advance directive may no longer be valid or applicable). In fact Parfit, upon whose philosophical work Dresser bases much of her argument, thinks that whether or not we are the “same person” is not an important or meaningful concept. What matters, Parfit argues, is the degree of psychological connectedness, or what he calls R-relations. He concedes, however, that with a sharp psychological discontinuity a new self may emerge. PARFIT, *supra* note 162, at 304-05. Some have speculated that Donald Cowart changed his name to “Dax” to mark the sharp break in his identification of himself after his accident. See James F. Childress & Courtney C. Campbell, *Who is a Doctor to Decide Whether a Person Lives or Dies? Reflections on Dax’s Case*, in DAX’S CASE: ESSAYS IN MEDICAL ETHICS AND HUMAN MEANING 23, 36 (Lonnie D. Kliever, ed. 1989) (noting that the name change may serve as a separation of the present and future from the painful past). For an exceptionally lucid statement of the personal identity objection to advance directives, see BUCHANAN & BROCK, *supra* note 85, at 155-58.

¹⁶⁸ KING, *supra* note 16, at 68.

¹⁶⁹ One notable exception is the DPAHC, whereby a proxy is chosen by the patient to make health care decisions on her behalf should the patient become incompetent to do so herself. See *supra* notes 64-67.

¹⁷⁰ The problem is not that competent patients are irrational. In fact, their decisions may be perfectly rational for themselves at the time they are made. The prob-

terized as “hard paternalism.”¹⁷¹ Unlike traditional hard paternalism, which is justified on the basis of the (same) patient’s subsequent consent,¹⁷² this paternalism is justified on the basis of the hypothetical ratification of the patient very differently situated at a future time.

Dresser asks, “the later self’s best interests are defined by that individual at an earlier point in time, rather than by another party. Ought this difference be sufficient to remove the ethical and legal concerns paternalism typically elicits?”¹⁷³ She answers, “the fact that the decision-maker and the subject of paternalism share the same body fails to insulate self-binding arrangements from the scrutiny paternalistic interventions generally receive.”¹⁷⁴ Dresser argues that the decision-maker and the individual bound by the decision are sufficiently different that those decisions made at an earlier time and place should *not* control the individual at a future time and place. She argues, therefore, that advance directives lack the moral force of a contemporaneous treatment choice,¹⁷⁵ and are

lem is that they might not be rational for themselves at a future time. See Dan W. Brock & Steven A. Wartman, *When Competent Patients Make Irrational Choices*, in *LIFE AND DEATH: PHILOSOPHICAL ESSAYS IN BIOMEDICAL ETHICS* 80 (Dan W. Brock ed., 1993) (discussing the standards of rational decision-making and how those standards apply to patients’ present and future choices).

¹⁷¹ JOEL FEINBERG, *HARM TO SELF* 12 (1986) (defining and comparing “hard paternalism” and “soft paternalism”).

¹⁷² See Childress & Campbell, *supra* note 167, at 34-35 (noting that a physician must appeal to a patient’s values over time in order to justify treatment).

¹⁷³ Rebecca S. Dresser, *Advance Directives, Self Determination, and Personal Identity*, in *ADVANCE DIRECTIVES IN MEDICINE*, 155, 160 (Chris Hackler et al. eds., 1989) (questioning the best-interest issue within an advance directive, where a person makes a future best-interest decision without the particular facts about the event upon which they will decide).

¹⁷⁴ *Id.* This is also known as the issue of the “double reference point.” It is unclear whether obligations run to the wishes of author of the advance directive or to the interests of the incompetent patient. See Moorhouse & Weisstub, *supra* note 164, at 114.

¹⁷⁵ See Dresser, *supra* note 173, at 157 (citing Allen Buchanan, *The Treatment of Incompetents*, in *HEALTH CARE ETHICS: AN INTRODUCTION* 215, 215-38 (T. Regan ed., 1987)). See also Robertson, *supra* note 167.

just “irrelevant”¹⁷⁶ and “meaningless”¹⁷⁷ when deciding medical care for the incompetent patient.¹⁷⁸

The basic rationale of Dresser’s argument has achieved some resonance in bioethical literature and policy. The problems associated with decision-making for differently situated future selves has been recognized in the context of surrogate motherhood contracts.¹⁷⁹ Martha Field explains that there is a degree of coercion and information failure on the part of the birth mother because she underestimates the strength of gestational bonding and the psychological costs of disrupting those bonds.¹⁸⁰ The birth mother, like the drafter of an advance directive, has difficulty anticipating future hypothetical circumstances. Accordingly, Field argues that birth mothers should have a short time to opt out of the contract.¹⁸¹

Another context in which personal identity concerns were cogently raised was in the debate over the Oregon Medicaid Demonstration Project.¹⁸² In 1993, Oregon radically modified the scheme by which the state distributed Medicaid benefits. The state wanted to achieve the greatest health benefit with each dollar it spent. In

¹⁷⁶ Rebecca Dresser, *Advance Directives: Implications for Policy*, HASTINGS CENTER REP., Nov.-Dec. 1994, at S2, S3 (citing RONALD DWORIN, *LIFE’S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 226 (1993)).

¹⁷⁷ Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 238 (1989).

¹⁷⁸ Sanford Kadish takes a less-extreme position, holding that advance directives still have some force to be balanced against experiential interests of the incompetent patient. See Kadish, *supra* note 166, at 302-03, 312.

¹⁷⁹ *Id.* at 320, n.179.

¹⁸⁰ MARTHA FIELD, *SURROGATE MOTHERHOOD* 151-52 (1988) (arguing that surrogacy contracts should not be encouraged because of society’s interests in preventing the exploitation of women). Cf. *In re Baby M.*, 537 A.2d 1227 (N.J. 1988) (explaining that a mother should fully understand the consequences of her decision to give up her rights to her child and should fully appreciate the importance of that decision).

¹⁸¹ FIELD, *supra* note 180, at 93 (arguing that once a surrogate mother has consented to adoption, she must show proof of coercion or fraud in order to revoke her consent to the adoption). Many states have incorporated Field’s advice. See, e.g., FLA. STAT. ch. 63.212(1)(i)(2)(a) (1997) (giving the volunteer mother a “right of rescission” during “any time within 7 days after the birth of the child”).

¹⁸² See OFFICE OF TECHNOLOGY ASSESSMENT, CONGRESS OF THE UNITED STATES, *EVALUATION OF THE OREGON MEDICAID PROPOSAL* (1992) (describing the proposed Medicaid program, and discussing the likely implications on the Federal Government, the state of Oregon, and Medicaid beneficiaries). See also Catherine Grace Vanchiere, *Stalled on the Road to Health Care Reform: An Analysis of the Initial Impediments to the Oregon Demonstration Project*, 10 J. CONTEMP. HEALTH L. & POL’Y 405, 419-30 (1994) (analyzing the constraints placed upon the Oregon Demonstration Project under the Americans With Disabilities Act and other legal legislation).

order to do this, Oregon had to measure medical benefit in a wide variety of medical interventions. The state obtained the information to rank over 700 treatments and conditions from severe head injury to sprained wrist, by having citizens complete questionnaires by telephone or mail.

The problem, as soon became evident, was that the perceived benefit of some interventions was undervalued. Particularly undervalued interventions were those for individuals with disabilities. Respondents did not think expensive wheelchairs and portable ventilators were important, because they felt that the disabled quality of life was very low and could not be significantly raised.¹⁸³ Nevertheless, not surprisingly, once patients became ill, they were far more likely to prefer a longer life with a disability than a short one without it.¹⁸⁴ The healthy Oregonians failed to vividly imagine what life with a disability would really be like. Similarly, in the advance directive context, competent individuals fail to vividly imagine what life as an incompetent patient would really be like. Yet, like the healthy Oregonian, they still must make decisions for their later selves as very differently situated individuals.

Most persons completing advance directives underestimate the quality of life with disability¹⁸⁵ because individuals with disabilities adapt to their disabilities. In one study "no differences were found with respect to [quality-of-life] indicators: satisfaction with family, friends, work, income, values, activities, community,

¹⁸³ See David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy*, HASTINGS CENTER REP., May-June 1991, at 11, 12 (reviewing the Oregon Basic Health Services Act and its treatments that were ranked low in the "poor-outcome" category based on quality of life).

¹⁸⁴ See Dan W. Brock, *Justice and the ADA: Does Prioritizing and Rationing Health Care Discriminate Against the Disabled?*, 12 SOC. PHIL. & POL'Y 159 (1995) (discussing the perspective problem between disabled and nondisabled persons in prioritizing medical treatments available in regards to quality of life). See also David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1455(1992) (discussing the problems with attempting to put a value or disvalue on certain disabilities for purposes of distribution of health care resources); Paul T. Menzel, *Oregon's Denial: Disability and Quality of Life*, HASTINGS CENTER REP., Nov.-Dec. 1991, at 21(discussing the issues surrounding medical decisions that are made based on quality of life judgements). See generally Michael O'Donnell, *One Man's Burden*, 291 BRITISH MED. J. 1513, 1513 (1985) (acknowledging the need for medical research, but expressing concern that the "race for the cure" leaves doctors devoid of caring for their patients).

¹⁸⁵ See generally Stuart Hornett, *Advance Directives: A Legal and Ethical Analysis*, in EUTHANASIA EXAMINED: ETHICAL, CLINICAL, AND LEGAL PERSPECTIVES 297, 308 & n.64 (John Keown ed., 1995) (noting that in the realm of terminal health care, patients are likely to have an unduly pessimistic view of the quality of life attainable during the process of death).

local government, health, quality of life, psychological functioning, anxiety, depression, positive well-being, general mental well-being, daily activities, and work satisfaction.”¹⁸⁶ Clearly, some paternalism is needed to counteract natural psychological tendencies to exaggerate unknown risks.¹⁸⁷ Nevertheless, Dresser argues that the problem with advance directives goes much deeper than this. The real problem is that individuals are making decisions for their future selves that those future selves would not want made.

Dresser argues that when individuals make decisions for their future selves they are making decisions for different persons altogether. Therefore, according to Dresser, an advance directive, which allows this future-oriented decision-making, cannot promote autonomy. An advance directive cannot help one be in control of one’s life. Instead, according to Dresser, advance directives promote “heteronomy.”¹⁸⁸ The directive (nomos) for the future self is made by another (hetero) person.

Dresser takes a radical approach to dealing with the identity/heteronomy problem with advance directives.¹⁸⁹ She writes, “instead of giving presumptive authority to [advance directives], the courts should adopt an *objective* standard to guide decision-making for incompetent patients. Under such a standard medical decisions regarding incompetent patients are made by weighing the

¹⁸⁶ Johanna C.J.M. de Haes & Ferdinand C.E. van Knippenberg, *Quality of Life of Cancer Patients: Review of the Literature*, in *THE QUALITY OF LIFE OF CANCER PATIENTS* 167, 170 (Neil K. Aaronson & John Beckmann eds., 1987) (examining quality of life factors of cancer patients, in comparison to those of other patients or nonpatients).

¹⁸⁷ See Julian Savulescu, *Rational Desires and the Limitation of Life-Sustaining Treatment*, 8 *BIOETHICS* 191, 206-07 (1994) (advocating that treatment limitation be in accordance with a patient’s rational desires, not merely her expressed desires).

¹⁸⁸ Compare the definition of “heteronomy,” in *THE NEW SHORTER OXFORD ENGLISH DICTIONARY ON HISTORICAL PRINCIPLES* 1227 (1993) (“[s]ubjection to an external law or power”) with the definition of “autonomy,” in *id.* at 153 (“[i]ndependence, freedom from external control or influence; personal liberty”). See generally HENRY E. ALLISON, *KANT’S THEORY OF FREEDOM* (1990) (discussing heteronomy and Kant’s views on freedom and rational agency, his conception of moral agency, and his attempts to justify moral law). Oliver Johnson, *Heteronomy and Autonomy: Rawls and Kant*, in *MIDWEST STUDIES IN PHILOSOPHY* 277 (Peter A. French et al. eds., 1977) (describing Kant’s theory that if an individual promotes self-interest by monitoring other’s interest, then that person is acting heteronomously and not autonomously).

¹⁸⁹ See Rebecca Dresser, *Relitigating Life and Death*, 51 *OHIO ST. L.J.* 425, 434 (1990) (arguing that the moral obligation to protect incompetent patients should overrule living wills); Dresser, *supra* note 164, at 385 (arguing that the court’s application of the best interests standard to incompetent patients is improper because these patients are incapable of possessing the interests which are integral to reasonable, competent persons).

benefits and burdens of treatment. The considerations that typically factor into this analysis include the patient's pain, indignity, quality of life, and social utility.¹⁹⁰ An objective standard holds that "[d]ecisions should rest on observers' systematic evaluations of the patient's present capacities and experiences, because these are the only things that *now* matter to this individual."¹⁹¹ While a subjective standard focuses on the patient's wishes and implements them either as embodied in actual decisions or as inferred from statements and conduct, a best interest standard is unconcerned with the patient's "wants" and instead focuses on her "needs."¹⁹² Dresser moves too quickly to an objective standard, and she takes the individual completely out of the picture in deciding her own future. The objective standard is generally considered to be a last resort.¹⁹³ The 1983 President's Commission, for example, recommended that "when possible, decision-making for incapacitated patients should be guided by the principle of substituted judgment, which [best] promotes the underlying values of self-determination"¹⁹⁴ Nevertheless, Dresser argues that the objective standard is appropriate because any preferences expressed prior to incompetence either orally or in an advance directive are now irrelevant. Therefore, although the subjective standard is preferred, there just cannot be any *subjective* evidence of what an incompetent patient wants.¹⁹⁵

Buchanan and Brock agree with Dresser that less confidence should be accorded to advance directives than to the contextual

¹⁹⁰ See 1 MEISEL, *supra* note 24, §§ 7.11-.25 (proposing the use of the best-interests standard in right-to-die cases).

¹⁹¹ Dresser, *supra* note 189, at 437 (emphasis added). See also Dresser & Robertson, *supra* note 177, at 238 (arguing that orthodox advance directives overlook the interests patients may have in continued life in their diminished state).

¹⁹² See *In re Conroy*, 486 A.2d 1209, 1232-33 (N.J. 1985) (limiting considerations to experiential interests like pain and enjoyment).

¹⁹³ 1 MEISEL, *supra* note 24, § 7.2 (explaining in detail the hierarchy of standards for surrogate decision-making); see also Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 404 (1988) (explaining that under the pure-objective test, only a few patients meet the standard to justify non-treatment). Cf. AMERICAN MEDICAL ASS'N COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS § 2.20, at 36-37 (1994) (suggesting that a competent, adult patient's wishes or the decision of a surrogate decision-maker should be honored absent evidence the directive is not in the patient's best interests).

¹⁹⁴ 1983 PRESIDENT'S COMMISSION REPORT, *supra* note 62, at 136 (comparing substituted judgement with the best interests standard).

¹⁹⁵ Dresser would hold there is no difference between *Martin* and cases like Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); or *In re Storar*, 420 N.E.2d 64 (N.Y. 1981), in which the patients in question were severely retarded from birth and, thus, were never able to express their desires. For both sets of patients all that matters is their present experiential interests.

circumstances of the incompetent.¹⁹⁶ They too recognize that there are, as they describe it, “morally significant asymmetries between the contemporaneous choice of a competent individual and the issuance of an advance directive to govern future decisions.”¹⁹⁷ Buchanan and Brock concede that “the assumption that a person is the best judge of his or her own interests is weaker in the case of a choice about future contingencies under conditions in which those interests might have changed in radical and unforeseen ways.”¹⁹⁸ However, in contrast to Dresser, Buchanan and Brock conclude that, in spite of these “asymmetries,” we still ought to recognize advance directives as having force.¹⁹⁹

Buchanan and Brock recognize that, in order to protect autonomy, our objective ought to be to provide the care that the now incompetent patient would have chosen had she considered the issue while competent. Buchanan and Brock are reluctant to give up altogether on the idea of advance directives as Dresser would have us do. Instead, they are optimistic that advance directives can serve to promote prospective autonomy.²⁰⁰ I am similarly optimistic that we can ensure that advance directives are accurate for those who are bound by them -- even when they are completed at the less-than-ideal time of hospital admission.

There is a presumption in favor of prospective autonomy. Dresser is right to question the conceptual underpinnings of this presumption. Nevertheless, it ought not be rebutted as easily and

¹⁹⁶ BUCHANAN & BROCK, *supra* note 85, at 107.

¹⁹⁷ *Id.* at 103, 152.

¹⁹⁸ *Id.* at 153. See also Kadish, *supra* note 166, at 300 (“[T]he fact that advance directives are executed as future hypotheticals deprives them of the full moral force of contemporaneous choices. Unforeseen changes, such as new medical treatments, may substantially alter the person’s interests. Moreover, the effect of severe, life-imperiling illness may well effect a marked revision in the attitudes and values of the person,” citing Dresser, *supra* note 164, at 381); see also May, *supra* note 164, at 333 (“We must be cautious, then, in ascribing to advance directives the moral weight of a competent patient’s decision”). *Id.* at 325 (“[W]e should not recognize advance directives as equivalent to the decisions made by a competent patient”); Moorhouse & Weisstub, *supra* note 164, at 117 (arguing that, for this reason, advance directives for research are too weak to justify nontherapeutic research).

¹⁹⁹ BUCHANAN & BROCK, *supra* note 85, at 154 (implying that relying on these asymmetries alone might not be enough justification for limiting the authority of advance directives).

²⁰⁰ See May, *supra* note 164, at 335 (“[A]dvance directives do not reflect autonomy per se, but rather act as predictors of what autonomous decisions would be taken”) (citing L. Emanuel et al., *Advance Directives for Medical Care – A Case for Greater Use*, 324 NEW ENG. J. MED. 889-95 (1991)). May, *supra* note 164, at 337 (“[Advance directives] do seem to provide a mechanism for incorporating the values of the patient into health care treatment decisions when these values cannot be incorporated directly”).

quickly as Dresser does.²⁰¹ I agree with Nancy King that we can still shore up the “conceptual foundation . . . of advance directives . . . autonomy.”²⁰² Although the “uncertainty can be improved, [it] . . . can never be eliminated.”²⁰³ This can be done by strengthening the psychological connections between the earlier and later selves and overcoming psychological discontinuity and heteronomy through informed consent.

III. INFORMED CONSENT DOCTRINE PROVIDES THE PROPER FRAMEWORK FOR ANALYSIS OF THE PSDA'S SELF-DETERMINATION

Before proceeding with an informed consent analysis of advance directives and the PSDA, I will establish that this is the appropriate form of analysis. It might be objected that the use of informed consent is improper, because at the time an advance directive is completed, there is no imminent intervention to which consent is required and that there are simply too many potential and unforeseeable interventions for which to obtain informed consent. In this section, I respond to this objection and then develop an independent positive reason why informed consent analysis is appropriate for advance directives.

A. Informed Consent Is Not Just for Contemporaneous Interventions

Informed consent is typically obtained in the contexts of a patient or research subject facing an immediate real-time diagnostic procedure, treatment, or medical intervention.²⁰⁴ Only in such

²⁰¹ I cannot here systematically present an ethical foundation for prospective autonomy. Rather, I take it as a starting point. See Norman L. Cantor, *The Real Ethic of Death and Dying*, 94 MICH. L. REV. 1718, 1730 (1996) (stating “[t]he overwhelming weight of judicial and legislative sentiment endorses prospective autonomy”); see also NORMAN L. CANTOR, *ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY* 23-72, 122-34 (1993) (exploring the effectiveness of advance directives for achieving prospective autonomy, including the issues of drafting and enforcing advance directives). I do assume an evidentiary view of autonomy, that persons are the best judges of their own best interests. *Contra* Ronald Dworkin, *Autonomy and the Demented Self*, 64 MILBANK Q. 4, 13 (Supp. II 1986) (taking an “integrity view” that persons ought to govern their lives according to a coherent scheme of value, and arguing, therefore, that “past decisions . . . be respected even if they do not represent, and even if they contradict, the desires [the decision-maker] has when we respect them”).

²⁰² KING, *supra* note 16, at 103.

²⁰³ *Id.* at 80.

²⁰⁴ Compare *State v. McAfee*, 385 S.E.2d 651 (Ga. 1989) (patient made contemporaneous decision to discontinue ventilator), with *In re Martin*, 538 N.W.2d 399

circumstances is there a concrete, identifiable intervention to which consent can be given.

In the advance directive context, on the other hand, because any "consent" is contingent on unknowable future events, informed consent is not as zealously pursued. As long as the patient is "competent," it is presumed that she is able to direct her own health care for the period for which she might be incompetent. The patient need only have the "*capacity* to understand the material information, to make a judgment about the information in light of [one's] values, to intend a certain outcome, and to freely communicate [one's] wish to caregivers." (emphasis added)²⁰⁵

A competence standard is insufficient to protect patient autonomy.²⁰⁶ Not just the capacity for understanding, but actual, substantial understanding must be required. The material information must be given. It is not sufficient that the patient be an autonomous *person* who formally certified (sense₂) an advance directive. "The autonomous person may fail to act autonomously [sense₁] in a specific situation" ²⁰⁷ The certification itself must be an autonomous *act*. Therefore, not just competence but informed consent must be required of patients completing advance directives. As the *Encyclopedia of Bioethics* puts it, "[a]dvance directives are limited by being no better than the counseling that preceded them."²⁰⁸

It might be objected that informed consent is too burdensome in the advance directive context, that it is impossible to write a directive that leaves no room for interpretation.²⁰⁹ It is impossible to anticipate all the medical conditions which one might confront. "Human foresight being what it is, it is impossible for individuals

(Mich. 1995) (ruling on a case in which patient's surrogates tried to implement patient's previously expressed wishes).

²⁰⁵ BEAUCHAMP & CHILDRESS, *supra* note 20, at 135; *see also* BUCHANAN & BROCK, *supra* note 85, at 23-25 (citing the capacity for understanding and communication, along with the capacity for reasoning and deliberation as two necessary components of establishing competence).

²⁰⁶ *See* BUCHANAN & BROCK, *supra* note 85, at 136 (arguing that defense should be given to family members of incompetent individuals as the primary decision-makers).

²⁰⁷ FADEN & BEAUCHAMP, *supra* note 26, at 237 (explaining that sometimes autonomous people fail to act autonomously in giving consent, thereby causing their consent to fail even though it was formally certified as informed consent).

²⁰⁸ Lynn & Teno, *supra* note 53, at 575 (arguing that caregivers have an obligation to counsel patients appropriately regarding the use of advance directives).

²⁰⁹ *See* Linda Emanuel, *What Makes a Directive Valid*, HASTINGS CENTER REP., Nov.-Dec. 1994, at S27, S28. ("[P]re-drafted documents must provide preference options that bear established relationships to the most common decisions that need to be made Work remains to be done for most pre-drafted instruments to establish such relationships").

to specify with precision all the events that might arise and what sorts of treatment they would or would not want if those conditions were to materialize.”²¹⁰

This foreseeability objection is inapposite because advance directive informed consent would be too burdensome only if it required the *same degree* of particularity as contemporaneous informed consent.²¹¹ In fact, it does not. Advance directive informed consent need not demand this degree of particularity. Indeed, because such a demand is impossible to meet, it would render advance directives useless. Informed consent can be lower because the availability of durable powers of attorney for health care enables the preferences embodied in a living will to be extrapolated by the proxy.

Typically, DPAHCs take effect when the patient is unable to make or to communicate a health care decision.²¹² The patient, via a proxy, can retain not only the right to control health care decisions, but also the ability to do so with the flexibility that is so often necessary in the clinical context.²¹³ Drawing up a living will is like laying down legislation for one’s future incompetent life. Having a DPAHC is like having someone very familiar with the legislative history and intent to be the judge making the statutory interpretation in light of actual circumstances.²¹⁴

The availability of DPAHC allows informed consent for living wills to be lower than that required for contemporaneous inter-

²¹⁰ 2 MEISEL, *supra* note 24, § 10.7, at 20. See also *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 614 (N.Y. 1987) (“[H]uman beings are not capable of foreseeing either their own medical condition or advances in medical technology”); *Cruzan v. Harmon*, 760 S.W.2d 408, 417 (Mo. 1988) (“ [I]t is definitionally impossible for a person to make an informed decision – either to consent or to refuse – under hypothetical circumstances”), *aff’d*, 497 U.S. 261 (1990).

²¹¹ Surprisingly, some judicial opinions actually seem to demand this level of particularity. See, e.g., *Estate of Leach v. Shapiro*, 469 N.E.2d 1047, 1053 (Ohio Ct. App. 1984) (“must satisfy the same standards of knowledge and understanding required for informed consent”); see also 2 MEISEL, *supra* note 24, § 10.7, at 17 n.57 (citing cases from Florida, Maine, Michigan, New Jersey, New York, Ohio, and Pennsylvania).

²¹² See GAO REPORT, *supra* note 5, at 4 (discussing how a health care power of attorney works and when it usually takes effect).

²¹³ Marion Davis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882, 887 (1991) (suggesting the use of advance directives, but questioning their effectiveness).

²¹⁴ Cf. WILLIAM N. ESKRIDGE, JR., DYNAMIC STATUTORY INTERPRETATION (1994) (discussing generally the implications of statutory interpretation), WILLIAM N. ESKRIDGE & PHILIP P. FRICKEY, CASES AND MATERIALS ON LEGISLATION: STATUTES AND THE CREATION OF PUBLIC POLICY 733-806 (1988) (explaining means by which courts may interpret statutes, including the history of the statute, comments made during its drafting, and relevant public policy considerations).

ventions. However, it does not mean it can be eliminated. There are two reasons why DPAHCs should be complemented by living wills and the living wills, in turn, should be completed with informed consent. First, surrogate decision makers often desire some guidance. They do not want to feel the full burden of responsibility for “pulling the plug” of a family member or friend.²¹⁵ The “well-documented if surprising inability of most spouses . . . to accurately predict [patients’] actual prior wishes”²¹⁶ further explains the reluctance of surrogates to act without direction. As long as there is a significant discrepancy between the wishes of previously competent patients and the beliefs of their proxies as to what the patients would want – and the evidence suggests that this is the case – the autonomy of those patients is not preserved.²¹⁷ A living will provides a framework within which the DPAHC can be applied. To be a workable framework, the information in the living will must be reliable.²¹⁸

The second reason living wills are needed to supplement DPAHCs is that if the patient herself had no real understanding of what she might have wanted, the surrogate will be in a formally legal, but substantively empty position to exercise the patient’s desires.²¹⁹ As Justice Handler of the New Jersey Supreme Court explained, “it is not the mere signing over of authority that makes the resulting decision an expression of the patient’s right of self-determination.”²²⁰ The proxy might be able to learn about the medical prognoses and “apply” the patient’s values. Yet, if the patient never understood her circumstances, the proxy cannot know

²¹⁵ See Steven R. Stieber, *Right to Die: Public Balks at Deciding for Others*, HOSPITALS, Mar. 5, 1982, at 72 (stating that only 46% of Americans would be willing to disconnect life support).

²¹⁶ Emanuel, *supra* note 79, at 36 (citing evidence that proxies are often unaware of patient preferences).

²¹⁷ See Cantor, *supra* note 201, at 1732 n.61 (noting that the problem with the substituted judgment standard lies within its administration because reliance on value and character-related information about the patient may create uncertainty about what the patient would have desired). See also Joel Tsevat et al., *Health Values of Hospitalized Patients 80 Years or Older*, 279 JAMA 371, 373 (1998) (discussing the results of a study assessing the health values of older hospitalized patients as compared with those of their surrogate decision-makers).

²¹⁸ See, e.g., KING, *supra* note 16, at 55-56 (noting the impact of *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990), on states’ legislative activities with respect to statutory advances in healthcare decision-making rights through living wills).

²¹⁹ See Rhoden, *supra* note 193, at 377 (arguing that without a living will, proxy decisions “do not, properly speaking, implement the patient’s right to choose, because the patient has made no actual choice”).

²²⁰ *Matter of Jobes*, 529 A.2d 434, 457 n.10 (N.J. 1987) (Handler, J., concurring) (holding that the right of a patient to refuse life-sustaining medical treatment may be exercised by a family member or close friend).

how the patient's values or desires might have been shaped in light of knowledge of varying medical and life conditions.²²¹

To further illustrate that proxies need the guidance of a living will executed with informed consent, take the Georgetown advance directive. It offers the patient a choice between wanting or not wanting artificial nutrition and hydration based on whether or not it would be the "main treatment keeping me alive." This is a vague expression of treatment preferences. A patient's desire for artificial nutrition and hydration may vary according to prognosis and condition. Artificial nutrition and hydration may be desired if the patient is conscious and has a reversible condition, but unwanted if the patient is in a persistent vegetative state. Unless the patient was aware of these potentially different circumstances at the time she executed her advance directive, it will be difficult for her proxy to extrapolate the expressed desires to unanticipated situations, because those desires just would not have ever been explored with sufficient thoroughness. Thus, as Alan Meisel observes, only a combination directive (a living will in addition to a DPAHC) avoids the pitfalls of either, and "permits the spirit of the declarant's instructions to govern, with [*only*] the interstices filled in by the proxy."²²²

B. Informed Consent Shares the Same Theoretical Basis as Advance Directives

A final reason that the informed consent paradigm is appropriate for the analysis of the problems with the PSDA is that advance directives grew out of the "right not to consent, that is, to refuse [medical] treatment," which is itself a "logical corollary of the doctrine of informed consent."²²³ The President's Commission

²²¹ See Fischer et al., *supra* note 131, at 806 (explaining that some research has been done on eliciting goals of care from patients and stating that some commentators conclude that general information about patient's values and goals can complement, though not replace, specific intervention preferences).

²²² 2 MEISEL, *supra* note 24, § 10.4, at 10.

²²³ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 270 (1990) (noting that the advance of medical technology has led to an increase in cases involving the right to refuse treatments). See also *In re Quinlan*, 348 A.2d 801, 819 (N.J. 1975) (discussing the refusal to apply patient's prior informal consent to present medical situation), *rev'd*, 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976). See generally 1 MEISEL, *supra* note 24, § 3.5, at 86 n. 20 (discussing the development of the law of informed consent); BUCHANAN & BROCK, *supra* note 85, at 101 ("[c]oncerns about [the] validity . . . [of] advance directives . . . has an analog in the conditions for informed consent"); Holly Coldwell Gieszl & Peggy Addington Velasco, *The Cruzan Legacy: Legislative and Judicial Responses and Insights for the Future*, 24 ARIZ. ST. L.J. 719, 728 (1992) (explaining that competent patients may refuse medical treat-

for the Study of Ethical Problems with Medicine and Biomedical and Behavioral Research wrote that the principle of self-determination is the basis of both informed consent and the right to forgo life-sustaining treatment.²²⁴ Since the time of the President's Commission in 1983, "[advance directives] have come to be looked upon as a mere extension of the doctrine of Informed Consent."²²⁵

Notably, the Supreme Court in *Cruzan* found a liberty interest in refusing unwanted treatment protected by the Due Process Clause of the Fourteenth Amendment. Specifically, the Court, following a long line of state informed consent cases, held that the "doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment," even if the refusal is not contemporaneous.²²⁶ In later decisions, the Court clarified that this right was "not simply deduced from abstract concepts of personal autonomy," but from the "long legal tradition protecting the decision to refuse unwanted medical treatment"²²⁷ and from "well established, traditional rights to bodily integrity and freedom from unwanted touching."²²⁸ In both theory and practice, the "[l]egal doctrine governing end-of-life medical care [and advance directives relies on] . . . the doctrine of informed consent, a doctrine based on notions of bodily integrity and self-determination."²²⁹

Nancy King is right, we must "plac[e] the issue of the patient's treatment decisions within a larger context of discussion: the principles that properly underlie morally and legally justifiable decision-making in health care [viz.] . . . informed consent."²³⁰ The concept of informed consent, in turn, must be placed in the context of autonomy, the notion that the individual is "master of his own body."²³¹ Norman Cantor observes that "[the] primacy of autonomy extends to "prospective autonomy" – a competent person's right to shape her post-competence medical treatment by advance

ment and with valid advance directives they may control their medical care after becoming incapacitated).

²²⁴ See 1983 PRESIDENT'S COMMISSION REPORT, *supra* note 62, at 43-45 (discussing the elements of good decision-making and its effect on self-determination).

²²⁵ Sanchez-Gonzalez, *supra* note 20, at 286.

²²⁶ *Cruzan*, 497 U.S. at 277.

²²⁷ *Washington v. Glucksberg*, 521 U.S. 702, 117 S. Ct. 2258, 2270 (1997).

²²⁸ *Vacco v. Quill*, 521 U.S. 793, 117 S. Ct. 2293, 2301 (1997).

²²⁹ Cantor, *supra* note 201, at 1729.

²³⁰ KING, *supra* note 16, at 43.

²³¹ *Natanson v. Kline*, 350 P.2d 1093, 1104 (Kan. 1960); *see also* *Schoendorff v. Soc'y of N.Y. Hosp.*, 105 N.E.2d 93 (N.Y. 1914) (holding that a patient has a right not to consent to an operation and stating that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body").

instructions.”²³² However, prospective autonomy manifested through advance directives is illusory without adequate informed consent. So, we turn now to examine what informed consent ought to require of advance directives.

IV. A PROPOSAL: INFORMED CONSENT FOR ADVANCE DIRECTIVES

It is to “hyper-rationalize”²³³ to presume that patients completing advance directives are able to properly and fully take advantage of the law. Hospital patients are not abstracted, objectively defined, prudent patients. They are patients in need of assistance.²³⁴ Choices regarding future medical treatment cannot be autonomous unless they are both informed and understood.

Patients often do not have sufficient material information to form preferences to express in an advance directive. Moreover, to the extent the necessary information is conveyed to patients, it is not communicated in a way that fosters understanding. Autonomy requires positive duties to promote the conditions for rational informed decision-making. These include not only disclosure of material information but also conveyance of this information in a manner that enhances its understandability. In this section, I will discuss what information ought to be disclosed and how that information ought to be disclosed to ensure adequate understanding.

A. The Material Information

“Patients increasingly expect to know not only their diagnoses, but also details of pathophysiology, treatment options, and prognosis.”²³⁵ “To enable the patient to chart his course understandably, some familiarity [on the part of the patient] with the therapeutic alternatives and their hazards becomes essential.”²³⁶ The court in the classic informed consent case *Canterbury v.*

²³² Cantor, *supra* note 201, at 1729.

²³³ See Carl E. Schneider, *Bioethics With a Human Face*, 69 IND. L.J. 1075, 1076 (1994) (defining hyper-rationalism as “the tendency to believe, first, that people behave in ways that can so far be predicted a priori that empirical evidence about their behavior is superfluous and, second, that people think and act rationally, seeking always to maximize and exercise autonomy”).

²³⁴ See Lachlan Forrow, *The Green Eggs and Ham Phenomena*, HASTINGS CTR. REP., Nov.-Dec. 1994, at S29 (analogizing advance directive decision-making to the Dr. Seuss story to illustrate patients’ need for assistance in areas where they are informed).

²³⁵ Christine Laine & Frank Davidoff, *Patient-Centered Medicine: A Professional Evolution*, 275 JAMA 152 (1996).

²³⁶ Ezekiel J. Emanuel & Linda L. Emanuel, *Four Models of the Physician-Patient Relationship*, 267 JAMA 2221, 2223 (1992).

Spence explained, “[t]he average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment” with which to “evaluate knowledgeably the options available and the risks attendant upon each . . . [and] reach an intelligent decision.”²³⁷ The emphasis has been on a patient-oriented standard by which the physician has a duty to disclose those facts which a reasonable patient would consider material to his decision. The physician must provide appropriate facts to empower the patient to use her values to determine what interventions should be implemented.²³⁸

In the advance directive context, the scope of disclosure should ideally include: (1) a “description of [various potential] life-sustaining treatments,” (2) “the patient’s health at the time of discussion,” (3) “the chance of surviving,” (4) “the probability of full recovery,” and (5) “the effects of life-sustaining treatment on the patient’s family.”²³⁹ Of course, because informed consent in the advance directive context is prospective, the disclosure must *anticipate* what is material. However, this is not as difficult as it sounds. Some conditions and interventions are more likely to be encountered than others.

Specifically, patients can learn that some procedures, like cardiopulmonary resuscitation (CPR) which is an intervention widely recognized in the general population to be a successful first-aid response to acute reversible cardiac or respiratory arrests, might not be best for them. It would seem anathema to patients to decline CPR when they recognize it to be a simple successful intervention. Nevertheless, in fact, CPR is not desirable under all circumstances.

²³⁷ *Cantebury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972) (holding that a physician has an obligation to supply those facts that a reasonable patient would need in order to make an informed treatment decision).

²³⁸ Laine & Davidoff, *supra* note 235 (commenting on the shift toward patient-centered care and the growing number of patients who want more information disclosed). See also Jay Katz, *Informed Consent: Must it Remain a Fairy Tale?* 10 J. CONTEMP. HEALTH L. & POL’Y 69, 70-77 (1993) (discussing informed consent and what is needed in a proper doctor-patient relationship).

²³⁹ Johnson et al., *supra* note 70, at 1028 (discussing patient’s beliefs on what they thought should be included in discussions regarding advance directives). Cf. *Cobbs v. Grant*, 502 P.2d 1, 10-11 (Cal. 1972) (discussing the scope of informed consent). Two new books do a good job of describing the technology of intensive care and guiding the individual through the choices that are embodied in an advance directive. See generally EVAN R. COLLINS, JR. & DORAN WEBER, *THE COMPLETE GUIDE TO LIVING WILLS: HOW TO SAFEGUARD YOUR TREATMENT CHOICES* (1991) (a general guide to creating a living will); see generally B.D. COLEN, *THE ESSENTIAL GUIDE TO A LIVING WILL: HOW TO PROTECT YOUR RIGHT TO REFUSE MEDICAL TREATMENT* (1991) (describing the technology of intensive care and guiding the lay individual through the choices that are embodied in an advance directive).

Recent studies indicate that only 0% to 25% of hospitalized patients who undergo CPR survive to discharge from the hospital, and those who survive after discharge from the hospital that is often marked by a poor quality of life. When patients learn of these outcomes, they usually curb their overestimation of the value of CPR and request limitations of life-support based on their health at the time CPR may be required, the likelihood of survival after CPR, and their probable health after recovery from resuscitation.²⁴⁰

A recent physician-oriented article suggests that “[a]lthough it is difficult to cover *all* potential treatments and scenarios . . . [physicians ought to] at least suggest the issues of cardiopulmonary resuscitation (CPR) and the use of artificial nutrition and hydration.”²⁴¹

Another issue which patients should understand, given the likelihood of its materiality, concerns the benefits and risks of administering analgesic or painkilling medications. For example, if the patient wants adequate relief, she should be aware of the risk of death and, in light of the debate on assisted suicide, of physician reluctance to administer such relief in the absence of a clear directive.²⁴²

It might be objected that advance directives ought to be respected and implemented even in the absence of this disclosure, and that it is ironic that patient autonomy can be best protected by *ignoring* patients’ stated uninformed preferences. In fact, there is no such irony. As Jackson and Younger explained twenty years ago, “superficial and automatic acquiescence” does not protect patient autonomy.²⁴³

Informed consent scholars Faden and Beauchamp recognize, “[p]aternalism is at the core of many discussions of informed con-

²⁴⁰ John E. Heffner et al., *Procedure-Specific Do-Not-Resuscitate Orders: Effect on Communication of Treatment Limitations*, 156 ARCHIVES INTERNAL MED. 793, 794 (1996) (citations omitted).

²⁴¹ Carney & Morrisson, *supra* note 72, at 70 (emphasis added) (noting that patients should make informed decisions about common potential treatments).

²⁴² See 2 MEISEL, *supra* note 24, § 13.9 (discussing the use of general and specific terms in advance directives). On the other hand, many physicians do prescribe pain-killing medication that happens to hasten death.

²⁴³ David L. Jackson & Stuart Younger, *Patient Autonomy and “Death with Dignity,”* 301 NEW ENG. J. MED. 404, 408 (1979) (analyzing six cases where superficial preoccupation with patient autonomy and death with dignity could have led to inappropriate clinical and ethical decisions).

sent.”²⁴⁴ “Paternalism is the intentional limitation of the autonomy of one person by another, where the person who limits autonomy justifies the action by the goal of helping the person whose autonomy is limited.”²⁴⁵ In the advance directive context in particular, paternalism is represented during the preparation (not the implementation) of the advance directive by the intentional overriding of one’s expressed preferences for future medical treatment in order to ensure that preferences recorded in the advance directive are either authentic or rational. Overriding for the sole purpose of ensuring that choices are authentic, *i.e.* informed and voluntary, is only “soft” paternalism.²⁴⁶ Soft paternalism involves only a temporary restriction of liberty in order to ensure the individual is acting with adequate knowledge of consequences. It requires that we temporarily ignore stated preferences in order to ascertain that they are authentic, because not just any expressed preferences should be recorded, but only informed and deliberate ones.

Soft paternalism holds that it is proper to intervene in order to benefit a person *only* if her contrary choices are substantially not already autonomous (informed and voluntary). Soft paternalism holds that intervention is proper specifically only to ensure that those choices really are autonomous. After all, “[p]eople do not always mean what they say; they do not always say what they want; and they do not always want what they say they want.”²⁴⁷ Soft paternalistic intervention, therefore, despite the standard nomenclature, is not really paternalistic at all. Instead, it is anti-paternalistic, because there is no baseline of autonomy with which it interferes.

When patients lack sufficient information, the choices they make are not autonomous.²⁴⁸ To hold otherwise is to narrow the possibility of paternalism by presuming hyperrational patients

²⁴⁴ FADEN & BEAUCHAMP, *supra* note 26, at 13 (explaining that paternalism and antipaternalism are generally found in conjunction with moral issues dealing with when consent should be obtained and when refusal of treatment cannot be honored).

²⁴⁵ Tom L. Beauchamp, *Paternalism*, in *ENCYCLOPEDIA OF BIOETHICS*, *supra* note 53, at 1914.

²⁴⁶ *Id.* at 1915 (citing Joel Feinberg, *Legal Paternalism*, 1 *CAN. J. PHIL.* 105, 113 (1971)) (describing the differences between strong paternalism and weak paternalism). *See also* FEINBERG, *supra* note 171, at 12-16 (detailing the concept of soft paternalism).

²⁴⁷ Carl Elliott, *Meaning What You Say*, 4 *J. CLINICAL ETHICS* 61, 61 (1993) (looking at patients’ statements and past behavior to determine motivation behind refusal of treatment).

²⁴⁸ *See* Allen Buchanan, *Medical Paternalism*, 7 *PHIL. & PUB. AFF.* 370, 371-72 (1978) (describing the withholding of information as a form of medical paternalism which acts to interfere with a person’s attempt to make an autonomous, informed decision).

whose autonomy can be restricted by nothing short of deception, coercion, or force. If patients' choices are not autonomous, then interference with those choices (soft paternalism) is not paternalistic. There is no usurpation of autonomous decision-making because there was none to usurp. On the other hand, soft paternalism is needed to *ensure* autonomous decision-making.

A recent analysis of the PSDA asks what constitutes its successful implementation: "[a]re medical institutions merely to hand written information to patients and residents, or should they be certain that consumers fully understand their options and are making conscious decisions about executing forms?"²⁴⁹ Clearly, the latter is what must be required. Patients must be "informed" and not just "Mirandized" of their right to prospective self-determination.²⁵⁰ "Even the most appropriate and abundant information . . . may not sufficiently inform . . . [patients] . . . if they are unable to interpret or understand the content of the information."²⁵¹

B. Understanding the Material Information

Once the formalistic focus of the PSDA is characterized as a failure of informed consent, it becomes clear that autonomy cannot be characterized as a negative relation or as non-interference. It is not enough that physicians leave patients (hand off) to make their own (uninformed and under-informed) decisions with regard to advance directives. To do that would push the autonomy model of medical decision-making too far.²⁵² Mere acquiescence to patients' stated preferences would respect their autonomy only if those

²⁴⁹ Glick et al., *supra* note 2, at 48 (arguing that the PSDA does not give sufficient guidance to hospitals regarding its implementation, thus, leaving them to create their own plans, procedures, and objectives).

²⁵⁰ "The idea of informed consent . . . does not contemplate that informed consent be akin to a medical Miranda warning." See 1 MEISEL, *supra* note 24, § 3.7, at 88. See also *Cobbs v. Grant*, 502 P.2d 1, 11 (Cal. 1972) (discussing the scope of a physician's duty to inform patients of risk thoroughly, but not excessively).

²⁵¹ PRESIDENT'S ADVISORY COMMISSION ON CONSUMER PROTECTION AND QUALITY IN THE HEALTH CARE INDUSTRY, *QUALITY FIRST: HEALTH CARE FOR ALL AMERICANS*, ch.7 (1998) (entitled *Strengthening the Hand of Consumers*) [hereinafter PRESIDENT'S COMMISSION REPORT]. See also Judith H. Hibbard et al., *Informing Consumer Decisions in Health Care: Implications from Decision-making Research*, 75 MILBANK Q. 395, 396-98 (1997) (explaining that more information is not only not better, but perhaps worse as far as improving decisions).

²⁵² See Ron Hamel, *The Reign of Autonomy: Is the End in Sight?*, SECOND OPINION, Jan. 1995, at 75, 78 (discussing how the role of autonomy in medical decision-making often allows a patient's uninformed decisions to trump a physician's professional judgement). See also Schneider, *supra* note 233 (arguing that patients do not always act in a completely rational manner).

stated preferences were well-formed. Unfortunately, as we have seen, they are not.

Mere disclosure of material information, though necessary, is insufficient to enable patients to understand. "The intent of the PSDA is to empower patients to take part in health care decisions that affect the duration and condition of their lives."²⁵³ Such empowerment cannot come from an "informative model" of physician-patient interaction. "[D]isclosure standards . . . , requiring a specified quantity of information are . . . insufficient . . . [instead], [t]he key to effective communication [and understanding] is to invite active participation by patients"²⁵⁴ What is needed is a deliberative model of physician-patient interaction for the execution of advance directives, in which patients and physicians engage in pedagogical dialogue.

On this model, "individuals [can] critically assess their own values and preferences; determin[ing] whether they are desirable; affirm upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the[se] values."²⁵⁵ This is what autonomy requires, and it is what the PSDA should ensure. "What will *not* do is to *presume* that a competent person's decision is autonomous."²⁵⁶

[T]he law has not taken a position of entirely uncritical acceptance of an individual's stated preferences, even in matters ultimately viewed as private. In assessing a patient's decision to accept, rather than reject, preferred medical treatment, for example, courts have insisted that an autonomous decision worthy of respect by the courts must be that of an informed individual. Likewise, it would seem that the decision to refuse treatment should be subject to the same test of informed consent.²⁵⁷

Advance directives cannot have moral authority unless the decisions they embody are preceded by informed consent.

On the other hand, requiring informed consent as a matter of federal law may be too demanding. The Missouri Supreme Court observed that "it is definitionally impossible for a person to make

²⁵³ Laine & Davidoff, *supra* note 235, at 154 (discussing the effects of enacting the PSDA on medical law and patient-centered decision-making).

²⁵⁴ FADEN & BEAUCHAMP, *supra* note 26, at 307 (explaining why emphasis on patient-physician communication is better than emphasis on physician disclosure when obtaining informed consent).

²⁵⁵ Emanuel & Emanuel, *supra* note 236, at 2225.

²⁵⁶ Savulescu, *supra* note 187, at 210 (emphasis added).

²⁵⁷ Beschle, *supra* note 165, at 339.

an informed decision . . . under hypothetical circumstances; under such circumstances, neither the benefits nor the risks of treatment can be properly weighed or fully appreciated.”²⁵⁸ Because self-determination via advance directive lacks “active, contemporaneous personal choice,” there is a greater likelihood that the “patient [does] not adequately envision and consider . . . particular situation[s] within which the actual medical decision[s] must be made.”²⁵⁹ To require that patients anticipate what preferences they might have, but be unable to express in a future medical situation, is so demanding so as to challenge the very idea of making advance directives.²⁶⁰

Nancy King explains that “[b]ecause prospective health care decision-making seems to labor under special handicaps of anticipation and imagination, it might be thought that making good advance directives requires a super capacity.”²⁶¹ King recognizes, however, that “full understanding” is not necessary. Instead, it is sufficient that the patient have “substantial understanding,” of all the materially important descriptions of situations.²⁶²

Like King, Buchanan and Brock are confident that the institutional safeguards that are needed to ensure informed consent for competent patients can be adapted for advance directives. Of course, since the directive must be drafted “so as to cover an indeterminate range of contingencies, [the patient] will not be able to be informed fully.”²⁶³ Nancy King is right that informed consent ought not be as strictly required as it is with contemporaneous interventions.²⁶⁴ Yet, although full understanding is too much to hope for, substantial understanding can still be a legitimate objective. It is not too much to ask for “thoughtful and circumspect con-

²⁵⁸ *Cruzan v. Harmon*, 760 S.W. 2d 408, 417 (Mo. 1988), (holding that the guardians of a state hospital patient in a persistent vegetative condition did not have the authority to order the withdrawal of nutrition and hydration), *aff'd*, 497 U.S. 261 (1990).

²⁵⁹ 1983 PRESIDENT’S COMMISSION REPORT, *supra* note 62, at 137 (cautioning against complete reliance on advance directives).

²⁶⁰ See Wolf et al., *supra* note 9, at 1668 (discussing pre-treatment directives and their future use).

²⁶¹ KING, *supra* note 16, at 74.

²⁶² FADEN & BEAUCHAMP, *supra* note 26, at 302 (King was a collaborating author of this book).

²⁶³ BUCHANAN & BROCK, *supra* note 85, at 101.

²⁶⁴ KING, *supra* note 16, at 78 (advocating against requiring anticipation as a prerequisite for creating an advance directive since it cannot be assessed fairly). See Hornett, *supra* note 185, at 309 (“[T]here are good reasons why the courts should be particularly vigilant to safeguard against ill thought out, misconceived and medically inappropriate refusals . . . and, where appropriate, deny them validity”). See *supra* notes 211-18.

sideration of relevant medical and non-medical circumstances.”²⁶⁵ As King explains, “[w]e should . . . be demanding of persons writing directives. We should assume that writers of [advance] directives have used foresight and carefully considered the implementations of their choices . . . [and] we must endeavor to make that assumption a reality.”²⁶⁶

“[I]n order to be of genuine use to clinicians in making the choices patients want, advance directives should demonstrate, [to the extent psychologically feasible], a higher degree of reflection and foresight than patients’ contemporaneous medical decisions must display.”²⁶⁷ It is already recommended that people periodically review, update, and reaffirm their advance directives every five years or when they experience major life changes.²⁶⁸ There is an increased probability that medical preferences will change dramatically as life conditions do.²⁶⁹ Moreover, patients should “keep up with increases in their knowledge of their own conditions and with advances in medical treatment.”²⁷⁰ This practice highlights the need to “encourage . . . sophistication and foresight in writing of directives.”²⁷¹

My fundamental argument is that to the extent better information can help individuals identify with their later selves, the heteronomy which Dresser argues invalidates advance directives,

²⁶⁵ KING, *supra* note 16, at 105.

²⁶⁶ *Id.*

²⁶⁷ *Id.* at 210. See also Hibbard et al., *supra* note 251, at 401 (“[I]ndividuals often do not know how they will react to an event, or understand what their needs will be during that event until they experience it”).

²⁶⁸ See generally 2 MEISEL, *supra* note 24, §§ 10.32, 13.17 (discussing the need to update advance directives). See also Wolf et al., *supra* note 9, at 1669 (discussing periodic physician reexamination of directives with patients); Steven H. Miles et al., *Advance End of Life Treatment Planning: A Research Review*, 156 ARCHIVES INTERNAL MED. 1062 (1996) (discussing inherent problems with the current systems utilized for advanced planning); BUCHANAN & BROCK, *supra* note 85, at 104, 153 (discussing the importance of frequently updating advance directives so that they parallel the individual’s wishes in light of new life experiences).

²⁶⁹ Nirsa Kohut et al., *Stability of Treatment Preferences: Although Most Preferences Do Not Change, Most People Change Some of Their Preferences*, 8 J. CLINICAL ETHICS 124 (1997) (describing study where 80% of HIV-positive test group changed at least one of their treatment preferences six months after their original treatment preferences were expressed).

²⁷⁰ KING, *supra* note 16, at 81.

²⁷¹ *Id.* at 106; see also *id.* at 73 (“[W]e would like to be able to ensure that medical care decisions and all decisions are mature, well-reasoned, adequately justified, sufficiently informed, and sufficiently appreciative of all relevant issues. Yet agreement is lacking about what constitutes sufficient maturity, appreciation, and reasoning and how they should be measured”).

can be eliminated.²⁷² Moreover, even to the extent it cannot be eliminated, we ought to require very good “reasons to believe that . . . a directive was not an expression of [a patient’s autonomy], [before deciding that] it is appropriate to disregard such a directive.”²⁷³ The question that must be answered with regard to incompetent patients in order to protect their autonomy is what *would* the patient want now?²⁷⁴ We need not, as Dresser argues, determine this hypothetical desire by reference to objective criteria. Instead, we can determine this hypothetical desire and better respect autonomy by ensuring that there is good subjective evidence of prior expressed preferences.

With sufficient informed consent the living will can still serve as a valid expression of autonomy.²⁷⁵ Through sufficient informed consent the earlier self can learn to *think like* the later self would,²⁷⁶ and thus reduce the heteronomy inherent in future-oriented decision-making. The requisite level of informed consent should require and, in fact compel,²⁷⁷ patients to vividly imagine the circumstances in which they might find themselves, so that the earlier self is placed in the best position to make decisions for the

²⁷² See May, *supra* note 164, at 335 (“For advance directives . . . additional criteria must be imposed . . . in order to ensure that the [advance directive] is a reasonable predictor of what decision the patient in question would take . . . [because the] decision [is] taken prior to, and independent from, the actual conditions that obtain”). For the same reasons, some have argued that informed consent is needed so that consumers can better choose health plans. See Hibbard et al., *supra* note 251, at 400-01, 412.

²⁷³ Savulescu, *supra* note 187, at 211. Admittedly, the empirical evidence reviewed in section two of this Article suggests that an advance directive completed pursuant to the PSDA might not deserve to be presumed an expression of a patient’s autonomy. Nevertheless, this is a contingent circumstance which ought not reverse the general presumption.

²⁷⁴ See *In re Quinlan*, 355 A.2d 547, 653, 663-64 (N.J. 1976) (discussing Karen Ann Quinlan’s oral informal advance directive).

²⁷⁵ An alternative, compromise solution weighs the authority of the advance directives proportionate to the degree of psychological connectedness. See BUCHANAN & BROCK, *supra* note 85, at 182-83; see also Mark G. Kuczewski, *Whose Will Is It, Anyway? A Discussion of Advance Directives, Personal Identity, and Consensus in Medical Ethics*, 8 *BIOETHICS* 27, 32-46 (1994) (analyzing Buchanan and Brock’s argument).

²⁷⁶ See Pearlman, *supra* note 22, at 356 (establishing three factors to help patient consider the life-sustaining decisions being made); see also May, *supra* note 164, at 334-35 (“Advance directives provide a mechanism . . . to as closely approximate the autonomous choice the person in question *would take*”).

²⁷⁷ See Savulescu, *supra* note 187, at 194-95 (arguing that people should be forced to make complex evaluations about how they would want their lives to go over time when they consider advance directives).

later self.²⁷⁸ As Nancy King explains, “an advance directive . . . work[s] best when its potential problems are anticipated.”²⁷⁹

Some scholars have argued that “no response can be said to be a genuinely informed one until the *full reality* of the choice is present to the individual.”²⁸⁰

The more important a decision is to one’s life, the less reliable abstract speculation about how that decision would be made in the indefinite future becomes. Despite neoclassical microeconomic theory, important life decisions will not turn entirely on the calculus of rational considerations. These decisions will also include assessment of emotions, desires, fears, and other feelings that cannot possibly be made, except in the actual presence of those sentiments. To be “informed” in such circumstances means not merely to have access to data . . . but to be aware of one’s own reaction to the situation in the concrete – information that cannot be obtained apart from actual confrontation with the situation.²⁸¹

This standard is too high. Still, we must require at least substantial understanding of those completing advance directives. Patients must be able to substantially understand the nature of the circumstances to which they might be subject, before making decisions about whether or not to agree to be placed in those circumstances.²⁸² This is the goal, the standard. In the final section, I suggest how this might be achieved.

²⁷⁸ See Childress & Campbell, *supra* note 167, at 33 (writing that doctors ignored Dax Cowart’s requests to die, because they were of the judgment that the “physical and emotional shock of the accident and burns had rendered him incompetent to engage in effective deliberation”); see also *Confronting Death: Who Chooses, Who Controls? A Dialogue between Dax Cowart and Robert Burt*, HASTINGS CENTER REP., Jan.-Feb. 1998, at 14, 16 (“[U]ntil we are the ones who are on the sick bed, we cannot fully appreciate what the other person is going through”); Videotape: Please Let Me Die (Univ. Tex. Med. Branch, Galveston, 1974) (containing compelling footage of an interview with Dax Cowart soon after his accident).

²⁷⁹ KING, *supra* note 16, at 36 (urging patients to take the initiative when talking with their doctors to identify any problems or questions, thus ensuring the advance directive is effective).

²⁸⁰ Beschle, *supra* note 165, at 345 (emphasis added).

²⁸¹ *Id.* at 341-42.

²⁸² Unfortunately, little has been written about the cognitive capacity needed to execute an advance directive. See Seena Fazel et al., *Ways of Assessing Capacity to Complete an Advance Directive Should be Developed*, 316 BRIT. MED. J. 1321 (1998) (questioning how doctors should assess the capacity of a patient to complete an advance directive); see also Mezey et al., *supra* note 37, at 44 (explaining that some

Clearly, there are limits to informed consent to interventions on behalf of a future self. New and unanticipated therapeutic options might become available, creating options that were not and could not have been anticipated. Nevertheless, proxies may be able to extrapolate other expressed preferences. As Alan Meisel explains, “[a] requirement that an advance directive meet the standards of information and understanding required of contemporaneous informed consent would render advance directives useless.”²⁸³ It’s just impossible for individuals to appreciate and specify all the events that might arise. “Human beings are not capable of foreseeing either their own medical condition or advances in medical technology.”²⁸⁴ Still, advance directives need not meet some abstract standard of absolute genuineness, but need only be as genuine as humanly possible.

C. The Means to Achieve Adequate Understanding

It is important to vividly imagine the future circumstances in which one might be.²⁸⁵ Lachlan Forrow provides a Dr. Seuss example that colorfully illustrates this point. In Forrow’s story a patient responds to “physician” Sam-I-Am after Sam-I-Am’s repeated and detailed questioning, “I could not, would not, on a boat. I will not, will not, with a goat. I will not eat them in the rain. I will not eat them on a train . . . I do not like them anywhere. I do not like green eggs and ham!”²⁸⁶ In fact, as Forrow observes, the patient has no idea what green eggs and ham tastes like. After the

evidence indicates that social workers do not speak in-person with nursing home residents thought to lack decision-making capacity); George J. Agrich, *Can The Patient Make Treatment Decisions? Evaluating Decisional Capacity*, 64 CLEV. CLINIC. J. MED. 461 (1997) (discussing and evaluating treatment decision-making capacity of patients); D. William Malloy et al., *Measuring Capacity to Complete an Advance Directive*, 44 J. AM. GERIATRICS SOC’Y 660 (1996) (studying the validity of current reference standards for the assessment of capacity to complete an advance directive); Susan Busby-Mott, *The Trend Towards Enlightenment Health Care Decision-making in Lawrence and Doe*, 25 CONN. L. REV. 1159, 1179 (1993) (discussing patient decision-making models and the role of courts in these models).

²⁸³ 2 MEISEL, *supra* note 24, § 10.7.

²⁸⁴ *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 614 (N.Y. 1988).

²⁸⁵ See Pearlman, *supra* note 22, at 355 (listing why educational interventions have not generally led to an increase in advance-care planning completion, such as failing to provide the following: “vivid descriptions of common circumstances of mental incapacity,” “vivid descriptions of life-sustaining treatments,” and “vivid descriptions of possible future health states”). However, can “consent in advance . . . be deemed an informed one . . . ? Need one marshal authority for the proposition that many an ‘iffy’ inclination is disregarded when the actual facts are at hand.” Yale Kamisar, *Some Non-Religious Views Against Proposed ‘Mercy-Killing’ Legislation*, 42 MINN. L. REV. 969, 989 (1958).

²⁸⁶ Forrow, *supra* note 234, at S30.

patient tries green eggs and ham, she exclaims in colorful extended verse how much she truly does like them. Similarly, in the advance directive context patients must get as good a sense as possible of the medical green eggs and ham so that they can most accurately predict whether their later selves would like them.²⁸⁷

The most obvious means by which to prompt more deliberation is through direct patient-physician interaction. Unfortunately, there has been a demonstrated unwillingness or inability on the behalf of physicians to do this.²⁸⁸ Of course, this lack of physician input is not so surprising considering advance directive consults are not a reimbursable expense under Medicare and Medicaid.²⁸⁹ The structure of incentives for today's physician in the managed care context does not permit lengthy discussion about advance directives with each patient.²⁹⁰ Still, there are various alternative means to facilitate patients' vivid imagination. Georgia's informed consent statute, for example, endorses "the use of video tapes, audio tapes, pamphlets, booklets, or other means of communication."²⁹¹ Such approaches have been determined to enable patient comprehension.

One alternative means of patient education is through the advance directive form itself and its accompanying literature. There are many different advance directive forms currently in use in hospitals across the United States with many different levels of detail.²⁹² However, "it is unlikely in many settings that a written

²⁸⁷ See Hibbard et al., *supra* note 251, at 400 (stressing the importance that patients "anticipate preferences in those changed circumstances" so they can choose an appropriate health plan for their future).

²⁸⁸ See GAO REPORT, *supra* note 5, at 11 (discussing the reasons physicians are reluctant to discuss end-of-life care with patients). See also *supra* notes 79-82.

²⁸⁹ See JAMES M. HOEFLER, *MANAGING DEATH* 160 (1997) (suggesting Medicare/Medicaid should reimburse for the costs involved with the creation of advance directives).

²⁹⁰ See Susan M. Wolf, *Health Care Reform and the Future of Physician Ethics*, HASTINGS CENTER REP., Mar.-Apr. 1994, at 28 (discussing how managed care has deemphasized the bedside role of physicians). See also Mark. A. Rodwin, *Managed Care and Consumer Protection: What Are The Issues?* 26 SETON HALL L. REV. 1007 (1996) (discussing the potential consumer problems, approaches to consumer protection, trade-offs in consumer protection policy, and reform proposals in managed care).

²⁹¹ GA. CODE ANN. § 31-9-6.1(c) (1996) (referring to disclosure to persons undergoing certain surgical and diagnostic procedures).

²⁹² See, e.g., Peter A. Singer, UNIVERSITY OF TORONTO JOINT CENTRE OF BIOETHICS, *LIVING WILL*, (last modified Aug. 7, 1998) <<http://www.utoronto.ca/jcb/jcblw.htm>> (discussing different directives and commenting that, "[t]o make an instruction for health care decisions, you need to imagine yourself becoming very ill or nearing death. This is not easy to do. To help you do this, we describe in detail some health situations in which a living will might be needed, and the life-sustaining treat-

communication alone, even if well written and augmented with an opportunity to ask questions, will allow for the effective communication of information generally required for substantial understanding."²⁹³ Rather, patient education "may be successful only if illustrations [and] examples...are supplied."²⁹⁴ "Visual materials can also be useful."²⁹⁵

Videotape education has been shown to improve comprehension of living will and CPR concepts.²⁹⁶ This is especially true for those with advanced age and lower educational levels who even more urgently need specially designed educational programs²⁹⁷ and for whom "[w]e need to pursue more effective methods of conveying information about life-sustaining treatments."²⁹⁸ Indeed, Senator Danforth, the PSDA's proponent in the Senate, testified at a hearing on the bill that people should be "shown video tapes ten years before of how they are going to spend the last month of their lives."²⁹⁹ Nevertheless, although videotapes do help patients ex-

ments that might be used"); Ben A Rich, *Advance Directives: The Next Generation*, 19 J. LEG. MED. 63, 87-96 (Mar. 1998) (describing and evaluating the medical directive developed by Linda E. Emanuel & Ezekiel J. Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 261 JAMA 3288 (1989)); FADEN & BEAUCHAMP, *supra* note 26, at 315-16 (arguing that the physician's behavior, mixed with the patient's involvement and communication, is valuable in providing the requisite understanding for informed consent).

²⁹³ FADEN & BEAUCHAMP, *supra* note 26, at 315-16 (explaining that the physician's role in obtaining informed consent is to teach the patient rather than merely disclosing medical information).

²⁹⁴ *Id.* at 315 (describing tools that aid physicians in communicating with patients).

²⁹⁵ *Id.* at 319.

²⁹⁶ See Elisabeth A. Siegert et al., *Impact of Advance Directive Videotape on Patient Comprehension and Treatment Preferences*, 5 ARCHIVES FAM. MED. 207, 210 (1996) (examining a pilot study of the effects of videotape on patient comprehension of advance directive concepts and preferences for resuscitation).

²⁹⁷ See *id.* at 211.

²⁹⁸ *Id.* at 212.

²⁹⁹ *Hearings, supra* note 73, at 4 (statement of Sen. John C. Danforth) (discussing the need to communicate effectively the importance and consequence of not having an informed living will).

plore their values,³⁰⁰ they probably fail to have the interactivity necessary for more careful deliberation.³⁰¹

Customized interactive CD-ROM technology may be one answer to advance directive education. The use of this technology has already been explored in both the classroom³⁰² and the courtroom.³⁰³ Patient education through CD-ROM may, as a recent Presidential Commission advised: (1) permit information to be tailored to individual patients, (2) allow individuals to choose the level of detail they need, and (3) permit patients to view the information in different formats.³⁰⁴

CD-ROM accommodates individual's different learning levels and learning styles.³⁰⁵ "[I]ndividuals rely on mental structures, called mental models, schemas, or situation models, when they learn and use information."³⁰⁶ Any attempt to learn begins with what one already believes. Rather than physicians guessing as to

³⁰⁰ See generally Videotape: Choices (Southwest Prod. 1994) (focusing on the value issues that guide decision-making with respect to advance directives); Videotape: Dax's Case: Who Should Decide? (Unicorn Media 1985); Videotape: A Time to Choose (Choice in Dying 1997) (featuring discussions between non-acutely ill patients, their personal physicians, a lawyer, and an ethicist regarding advance directive choices); Videotape: An Act of Self Determination (Choice in Dying 1997).

³⁰¹ See Emanuel & Emanuel, *supra* note 236, at 2225 (stating that the deliberative model is the ideal physician-patient relationship for appropriate interaction regarding advanced health care decision-making).

³⁰² See W.Craig Shellhart & Larry J. Oesterle, *Assessment of CD-ROM Technology in Classroom Teaching*, 61 J. DENTAL EDUC. 817 (1997) (discussing the potential benefits to students using CD-ROM in the classroom); *Textbooks on CD-ROM: Multimedia in Education is Better for College Students Than for School Tots*, ECONOMIST Apr. 20, 1996, at 11 (explaining that CD-ROMs are a cost-effective and practical method of producing educational materials); Maggie Hill & Joan Novelli, *Multimedia in the Classroom*, INSTRUCTOR, May-June 1994, at 57 (Supp.) (noting the value of CD-ROMs for teachers in classroom use).

³⁰³ See Martin B. Adams, *Malpractice Exhibits Can Persuade*, NAT. L.J., June 15, 1998, at B7 (explaining the process of authentication of demonstrative evidence in malpractice trials); see, e.g., Cindy Collins, *Educate the Jury and the Verdict will Follow . . . Difficult and Diverse Cases Drive Robert Ruyak's Civil Litigation Practice*, INSIDE LITIG., June 1997, at 6 (discussing a lawyer's use of media, such as films and CD-ROMs, to educate jury members about the case they are hearing).

³⁰⁴ See generally 1983 PRESIDENT'S COMMISSION REPORT, *supra* note 62, at 231 (discussing the importance of policies regarding resuscitation decisions and their legal status).

³⁰⁵ See generally Pearlman, *supra* note 22, at 356 (discussing the use of educational materials in helping a patient identify all relevant factors for making an informed decision); see also BEAUCHAMP & CHILDRESS, *supra* note 20, at 157-60 (explaining problems of information processing).

³⁰⁶ Jon F. Merz & Baruch Fischhoff, *Informed Consent Does Not Mean Rational Consent: Cognitive Limitations on Decision-making*, 11 J. LEG. MED. 321, 347 (1990).

what and how to explain to each patient, the patient herself can proceed in ways that she finds useful. Not only can patients learn the relevant factors but also how they relate to each other and to their own medical condition. Patients can go at their own pace, writing down questions, and they can learn more about any aspect by "clicking."³⁰⁷

Patients can get information about risks, side-effects, interventions, and see in graphic animation the physiology, diagnosis, and technology. People need analogies to understand possibilities, for example, risks presented in terms of percentages.³⁰⁸ With interactive CD-ROM (and perhaps even virtual reality), they can see them expressed in pie-charts, bar graphs, in terms of examples, or in any other way they want the information expressed.³⁰⁹

The introduction of CD-ROM technology should not supplant the physician-patient relationship even regarding advance directives. Yet, this technology clearly has something to offer.³¹⁰ It can enable patients to vividly imagine what it will be like to live with various medical conditions and prognoses, and to make advance directives that will be more genuine for their future selves.

V. CONCLUSION

Advance directives are legally considered the most reliable guides to what treatment incompetent patients would want. The implementation of the PSDA, this country's primary force instigating the completion of these declarations, must assure not only

³⁰⁷ Karen I. Adsit, *Multimedia in Nursing and Patient Education*, 15 ORTHOPAEDIC NURSING, July-Aug. 1996 at 59, 60 (discussing how multimedia in the medical field helps patients and health care providers). See also *A Right to Die: The Dax Cowart Case*, Routledge, June, 1997 (allowing the user to participate in the right-to-die decisions through interactive CD-ROM technology).

³⁰⁸ See Cathy J. Jones, *Autonomy and Informed Consent in Medical Decision-making: Toward a New Self-Fulfilling Prophecy*, 47 WASH. & LEE L. REV. 379 (1990) (explaining that patients do not understand or remember what physicians are telling them, in large part, because the information is too technical); Daniel J. Murphy et al., *The Influence of the Probability of Survival on Patients' Preferences Regarding Cardiopulmonary Resuscitation*, 330 NEW ENG. J. MED. 545 (1994) (explaining patient preferences for receiving CPR after understanding the probability of survival after the procedure).

³⁰⁹ See G. Freeman, *CD-ROM Informed Consent May Eliminate Malpractice Risks*, in 2 OBSTETRICAL GYNECOLOGICAL MALPRACTICE PREVENTION 1 (1995); see also Arlene Klepatsky & Laura Mahlmeister, *Consent and Informed Consent in Perinatal and Neonatal Settings*, 11 J. PERINATAL & NEONATAL NURSING, June 1997, at 34, 43 & n.18 (emphasizing the importance of obtaining informed consent for invasive medical procedures).

³¹⁰ Thomas May is right that there is a significant lack of empirical research concerning how advance directives can be designed to reflect patient preferences. May, *supra* note 164, at 336-37.

that advance directives are preceded by informed consent will advance directives deserve to be respected as an expression written, but also that they are written with sufficient understanding. This will require a "more sophisticated consultation" and will be more costly.³¹¹ But only when of what incompetent patients would have wanted. Only with informed consent can we overcome the heteronomy that undermines the moral authority of future oriented medical decision-making.

Legislation introduced in November 1997, the Advance Planning and Compassionate Care Act of 1997,³¹² "aims to expand and clarify the requirements regulating advance directives." The bill "builds on the Patient Self Determination Act," "improves the type and amount of information available to consumers," and "seeks to ensure that the medical care of patients at the end of their lives reflects their [own] desire[s] [for autonomy]."³¹³ One provision requires hospitals "to provide each individual with the opportunity to discuss issues relating to the information provided to that individual pursuant to [the PSDA]."³¹⁴

If these or similar amendments are enacted,³¹⁵ the PSDA will be beneficially strengthened.³¹⁶ Senator Jay Rockefeller, who introduced the bill with Senator Susan Collins, explained that the "law will direct that patients be counseled with and that they have a very clear idea of what choices are available to them. It injects the personal element much, much more than right now, which is kind of a paper element and it's not working."³¹⁷ This legislation is sorely needed so that individuals can meaningfully exercise con-

³¹¹ Kenneth R. Thomas, *The Right to Die: Where Do We Go From Here?* FED. LAW., Oct. 1997, at 22, 29 (discussing the disadvantage of advance directives, including administrative burdens and increased costs).

³¹² S. 1345, 105th Cong. (1997) (sponsored by Rockefeller & Collins); H.R. 2999, 105th Cong. (1997) (sponsored by Levin).

³¹³ 143 CONG. REC. E2318-19 (1997) (statement of Rep. Sander M. Levin).

³¹⁴ S. 1345 § II(a) (clarifying the requirements regarding advance directives in order to "ensure that an individual's health care decisions are complied with").

³¹⁵ Rockefeller's bill died with the 105th Congress. Similar legislation, however, has already been introduced in the 106th Congress. *See, e.g.*, S. 24, 106th Cong. § 501 (a2B) (1999) (sponsored by Specter) (directing HHS to develop a "national advance directive form").

³¹⁶ The operation of the PSDA in some states already requires this because of state law. *See, e.g.*, N.J. STAT. ANN. § 26:2H-65(2) (West 1996) ("A health care institution shall . . . assist patients interested in discussing and executing an advance directive").

³¹⁷ *All Things Considered* (NPR Broadcast, Oct. 30, 1997) (transcript available in 1997 WL 12834163).

trol over their post-autonomous medical care.³¹⁸ Right now, “informed consent is well entrenched in theory, but in practice patient autonomy continues to be elusive.”³¹⁹ Improving patients’ understanding of both legal and medical information regarding their advance directives will help preserve their autonomy and self-determination.

³¹⁸ It is important to note that improving the reliability of advance directives will only help the small percentage of people who use them. Other will need other vehicles to preserve their autonomy interests. See Larson & Eaton, *supra* note 8, at 292.

³¹⁹ George J. Annas & Frances H. Miller, *The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan*, 20 AM. J. L. & MED. 357, 369 (1994) (comparing informed consent laws of the United States with those of the United Kingdom and Japan and exploring the impact of culture on medical practices).