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The Nursing Home as Part of the POLST Paradigm

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THE NURSING HOME AS PART OF THE POLST PARADIGM

Marshall B. Kapp *

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I. INTRODUCTION

Improving the quality of care and quality of life for individuals with advanced, irreversible illness is a paramount goal from the perspectives of both ethics and public health. One aspect of achieving such improvement entails assuring that the care those individuals receive is consistent with their important, authentic, personal values and wishes.¹ The physician and other professional members of the health care team are the experts on medical

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¹ This proposition is based on the fundamental ethical principle of autonomy. See Kathy L. Cerminara, *The Law and Its Interaction With Medical Ethics in End-of-Life Decision Making*, 140 CHEST 775 (2011); Deborah L. Volker & Hung-Lan Wu, *Cancer Patients' Preferences for Control at the End of Life*, 21 QUALITY HEALTH RESOL. 1618 (2011) (examining the widely-shared value of patient autonomy in American culture). *But see* Gentian Vyshka & Jera Kruja, *Inapplicability of Advance Directives in a Paternalistic Setting: The Case of a Post-Communist Health System*, 12 BMC MED. ETHICS 12 (2011) (observing that patient autonomy is treated as a pernicious value in totalitarian regimes).

means to achieve specific outcomes, but the individual patient is the best expert about his or her own values, goals, and preferences.² The quality of care and quality of life challenge is exacerbated by the fact that, as the medical and social ramifications of advanced illness unfold over time, many people receive care within several different settings, often moving back and forth among settings as their immediate needs and resources change. Consequently, it is imperative that the mechanisms we develop for the purpose of enforcing persons' personal care values and preferences follow individuals across and throughout the care continuum.

Many people with advanced, irreversible illness reach a point at which they need to receive most of their care in a nursing home,³ and a large proportion of those individuals ultimately die in that venue⁴ after receiving various forms of medical care there.⁵ The care actually provided to nursing home residents during the period prior to their deaths too frequently deviates from that which they, on the basis of their own values, really want.⁶ This article discusses one initiative—the Physician Orders for Life-Sustaining Treatment (POLST) paradigm—that holds the promise of improving the quality of care and quality of life for nursing home residents with advanced, irreversible illness by more closely reconciling the details of the actual care they receive at the most crucial juncture of their lives with their desired care in that context.

The next section of this article provides background on the intersection of nursing homes and the care of people with advanced,

² J. Andrew Billings & Eric L. Krakauer, *On Patient Autonomy and Physician Responsibility in End-of-Life Care*, 171 ARCH. INTERNAL MED. 849 (2011).

³ See, e.g., Mary E. Dellefield & Rebecca Ferrini, *Promoting Excellence in End-of-Life Care: Lessons Learned From a Cohort of Nursing Home Residents With Advanced Huntington Disease*, 43 J. NEUROSCI. NURSING 186 (2011) (explaining that many people with advanced Huntington Disease need to be cared for in a nursing home setting).

⁴ E.g., Steven C. Zweig et al., *The Physician's Role in Patients' Nursing Home Care*, 306 JAMA 1468, 1475 (2011) (indicating that 30% of Americans will die in nursing homes); Susan L. Mitchell et al., *A National Study of the Location of Death for Older Persons With Dementia*, 53 J. AM. GERIATRICS SOC'Y 299 (2005).

⁵ Anita Bercovitz et al., *End-of-Life Care in Nursing Homes: 2004 National Nursing Home Survey*, NAT'L. No. 9 HEALTH STATISTICS REP. (Oct. 8, 2008).

⁶ See, e.g., Lauren W. Cohen et al., *Family Perceptions of End-of-Life Care for Long-Term Care Residents with Dementia: Differences Between the United States and the Netherlands*, 60 J. AM. GERIATRICS SOC'Y 316 (2012) (noting inappropriate treatment of nursing home residents with dementia). The present article focuses solely on the nursing home context. The problem of medical interventions deviating from patients' wishes in other health care settings has been discussed extensively elsewhere and is beyond the present scope of concern. See, e.g., John J. Mitchell, Jr., *The Findings of the Dartmouth Atlas Project: A Challenge to Clinical and Ethical Excellence in End-of-Life Care*, 22 J. CLINICAL ETHICS 267 (2011) (finding huge variations in the quantity and quality of medical care provided to critically ill Medicare beneficiaries across the United States, with the main determinant being the supply of services available in a particular geographic area); Jacqueline K. Yuen et al., *Hospital Do-Not-Resuscitate Orders: Why They Have Failed and How to Fix Them*, 26 J. GEN. INTERNAL MED. 791 (2011) (documenting that many cardiopulmonary resuscitation attempts in hospitals would not have been desired by the patients involved).

irreversible illness. First, it outlines the importance of nursing homes within the contemporary American health care enterprise and then describes the ways in which medical care decisions are made today in this context and identifies some of the major shortcomings of the status quo.⁷ The ensuing section proposes the POLST paradigm as a viable alternative to the status quo, laying a foundation by setting forth information on the nomenclature, definition, and legal status of the POLST concept and then specifically exploring the adaptability of the POLST paradigm to the nursing home setting. The advantages of this mechanism as compared with conventional Advance Directives (ADs) are highlighted. The article concludes that POLST can and should be an integral facet of ideal nursing home care for all willing and appropriate residents.

II. NURSING HOMES AND THE CARE OF RESIDENTS WITH ADVANCED, IRREVERSIBLE ILLNESS

A. Nursing Homes in the Contemporary American Health Care Enterprise

Although tremendous strides have been made in recent years in shifting much of the care of older disabled people away from institutions and toward home and community-based environments,⁸ and that rebalancing was modestly further incentivized by the 2010 Affordable Care Act (ACA),⁹ nursing homes nonetheless remain an important and inevitable component of the present and future American health care enterprise.¹⁰ Several factors

⁷ The present article concentrates exclusively on nursing homes in the United States, but it is noteworthy that many of the same issues also arise in nursing homes in other countries. See, e.g., Elisabeth Gjerberg et al., *Ethical Challenges in the Provision of End-of-Life Care in Norwegian Nursing Homes*, 71 SOC. SCI. MED. 677 (2010).

⁸ See H. Stephen Kaye, *Gradual Rebalancing of Medicaid Long-Term Care Services and Supports Saves Money and Serves More People, Statistical Model Shows*, 31 HEALTH AFF. 1195, 1198 (2012); Donald L. Redfoot & Ari Houser, *More Older People With Disabilities Living in the Community: Trends From the National Long-Term Care Survey, 1984–2004*, AARP PUB. POL'Y INST. (Sept. 2010); David C. Grabowski et al., *Supporting Home- and Community-Based Care: Views of Long-Term Care Specialists*, 67 MED. CARE RES. & REV. 82S (2010).

⁹ Charlene Harrington et al., *Medicaid Home- and Community-Based Services: Impact of the Affordable Care Act*, 24 J. AGING & SOC. POL'Y 169 (2012). The Affordable Care Act (ACA), 124 Stat. 119 (2010), was upheld in *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566 (2012).

¹⁰ Mitchell H. Katz, *There's No Place Like Home*, 171 ARCH. INTERNAL MED. 804, 804 (2011); NOELLE DENNY-BROWN ET AL., MONEY FOLLOWS THE PERSON DEMONSTRATION: OVERVIEW OF STATE GRANTEE PROGRESS, JANUARY TO JUNE, 2011 xii (Mathematica Policy Research 2011), available at www.mathematica-mpr.com/publications/pdfs/health/mfp_jan-jun2011_progress.pdf (last visited Mar. 4, 2013) (reporting a significant rate of temporary or permanent reinstitutionalization of previous nursing home residents back from community settings); Nancy A. Miller et al., *A Profile of Middle-Aged and Older Adults Admitted to Nursing Homes: 2000-2008*, 24 J. AGING & SOC.

place individuals at increased risk for nursing home admission, such as problems with independently carrying out multiple activities of daily living (ADLs), cognitive impairment, and prior nursing home use.¹¹ Currently, there are approximately 15,600 federally certified nursing homes (skilled nursing facilities (SNFs) or nursing facilities (NFs)) operating in the United States,¹² with slightly more than 1.6 million certified beds and approximately 1.4 million residents on any given night.¹³

An older person's likelihood of living in a nursing home increases sharply with age. The share institutionalized remained [during 2006–2008] extremely low from ages 65–69 (1.0%) and ages 75–79 (3.0%), then began to rise markedly, reaching 11.2% at ages 85–89, 19.8% at ages 90–94, 31.0% at ages 95–99, and 38.2% at 100 years of age and older.¹⁴

Beyond the demographics, the financial impact of nursing homes on the American economy is significant.¹⁵ Nursing home care commands major state and federal expenditures by Medicaid programs and out-of-pocket expenditures by residents and their families, with private long-term care insurance, Medicare, and private philanthropy playing important but much smaller financial roles.¹⁶ Of particular interest to the states: “[n]ursing home coverage is the fastest growing area of Medicaid coverage, and is likely to

POL’Y 271, 272 (2012) (noting that middle-aged adults with chronic medical and psychiatric problems are becoming an increasing share of the nursing home population).

¹¹ Joseph E. Gaugler et al., *Predicting Nursing Home Admission in the U.S.: A Meta-Analysis*, 7 BMC GERIATRICS 13 (2007).

¹² American Health Care Association, Reimbursement and Research Department, *Trends in Nursing Facility Characteristics* 3 (2011), available at www.ahcancal.org/research_data/trends_statistics/documents/trend_PVNF_Finalrpt_december.pdf. (last visited Mar. 6, 2013). These data are derived from the CMS Online Survey and Certification Reporting (OSCAR) data network. *Id.*

¹³ Zweig et al., *supra* note 4, at 1475 (indicating that 30% of Americans will die in nursing homes).

¹⁴ Wan He & Mark N. Muenchrath, *90+ in the United States: 2006 -2008*, 17 AM. CMTY. SURVEY RPT. 15 (U.S. Census Bureau 2011).

¹⁵ See, e.g., Keith S. Goldfeld et al., *Medicare Expenditures Among Nursing Home Residents With Advanced Dementia*, 171 ARCH. INTERN. MED. 824, 827 (2011).

¹⁶ Kate A. Stewart et al., *Annual Expenditures for Nursing Home Care: Private and Public Payer Price Growth, 1977 to 2004*, 47 MED. CARE 295, 295–301 (2009); Centers for Medicare and Medicaid Services, NATIONAL HEALTH EXPENDITURE DATA, available at <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/index.html?redirect=/NationalHealthExpendData/> (last visited Mar. 6, 2013).

increase at a faster rate than ‘all health care expenditures, Medicare, Medicaid, and the national Gross Domestic Product.’”¹⁷

B. Medical Decision Making and Care for Nursing Home Residents

The legal environment surrounding medical decision making in the United States for individuals with advanced, irreversible illness has been evolving—not always in linear fashion¹⁸—since the 1976 Karen Anne Quinlan case¹⁹ brought the matter clearly into the public consciousness.²⁰ The present complex legal environment is largely a product of statutes enacted by Congress and individual state legislatures, particularly regarding ADs. However, statutes must be consistent with principles contained in the federal and various state constitutions.²¹ These foundational documents (as their provisions may be interpreted and applied by the courts to concrete fact situations) are Americans’ primary source of individual rights, as well as the primary constraint on governmental power regarding medical decision making.²²

The 1990 case involving Nancy Cruzan²³ is the United States Supreme Court decision that decided the issue of discontinuing life-prolonging medical treatment for a particular person.²⁴ Ms. Cruzan was an automobile accident victim who was kept alive in a permanent vegetative state within a government (state of Missouri) long-term care facility, through the use of feeding and hydration tubes. Her parents asked that this intervention be discontinued, a request they believed was consistent with the

¹⁷ Alexander N. Daskalakis, *Public Options: The Need for Long-Term Care, Its Costs, and Government’s Attempts to Address Them*, 5 ST. LOUIS U. J. HEALTH L. & POL’Y 181, 186 (2011).

¹⁸ See LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 35–36 (2009) (describing the disruptive impact of the controversy surrounding the dying of Terri Schiavo).

¹⁹ In re Quinlan, 355 A.2d 647 (N.J. 1976).

²⁰ See, e.g., Phillip Kim, *Navigating the Maze of End-of-Life Decisions Regarding the Rejection of Life-Sustaining Treatment, Medical Futility, Physician-Assisted Death, and Abortion*, 14 SMU SCI. & TECH. L. REV. 127 (2010).

²¹ Despite recent insinuations by President Obama to the contrary, the courts still possess the authority to invalidate legislation that conflicts with the federal and state constitutions. See Carrie B. Brown & Jennifer Epstein, *Obama, the Left Take on the Supreme Court*, POLITICO (Apr. 3, 2012), available at www.politico.com/news/stories/0412/74759.html; *Marbury v. Madison*, 5 U.S. 137 (1803).

²² See, e.g., Michael P. Allen, *Justice O’Connor and the “Right to Die”*: *Constitutional Promises Unfulfilled*, 14 WM. & MARY BILL RTS. J. 821 (2006); Jack Tuholske, *Going With the Flow: The Montana Court’s Conservative Approach to Constitutional Interpretation*, 72 MONT. L. REV. 237 (2011) (discussing state constitutions as a source of individual rights to make medical decisions).

²³ *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261 (1990).

²⁴ Cf. *Washington v. Glucksburg*, 521 U.S. 702, 734–36 (1997); *Vacco v. Quill*, 521 U.S. 793, 807–09 (1997) (rejecting a right under the U.S. Constitution to physician-assisted death). This was a different question than was presented to the Court in *Cruzan*.

patient's previously expressed (although not formally documented) wishes. The attending physicians refused to honor this request, and the Missouri Supreme Court denied the parents' request to discontinue treatment.

The U.S. Supreme Court granted certiorari and held that a mentally capable adult has a fundamental federal constitutional right, under the liberty guaranty of the Fourteenth Amendment's Due Process clause,²⁵ to make personal medical decisions (even regarding refusal of artificial feeding and hydration) when death is expected to ensue shortly after the refusal. For patients with insufficient cognitive and emotional ability, however, the court ruled that the state's legitimate interest in preserving life is strong enough to permit the state, if it so chooses, to require "clear and convincing" evidence—prior to following a surrogate's discontinuation instructions—that the patient would want that treatment withdrawn if the patient were currently able to make and express an autonomous choice.²⁶ Ordinarily, a written declaration made by the patient while the patient was still cognitively and emotionally capable would provide sufficient evidence of the patient's treatment preference in the event of subsequent incapacity. Under the *Cruzan* decision, states also are free to set lower standards of proof than "clear and convincing" evidence for incapacitated patients, namely proof by a preponderance of the evidence (i.e., greater than a 50% likelihood), but not many states have chosen to avail themselves of this opportunity.²⁷

One form of treatment limitation around which there is by now substantial agreement is the Do-Not-Resuscitate order (DNR), also known as a Do-Not-Attempt-Resuscitation order (DNAR) or No Code order, which instructs caregivers not to initiate cardiopulmonary resuscitation (CPR) for a patient who suffers a foreseeable cardiac arrest. There have been very few reported legal decisions directly regarding this topic.²⁸ Nonetheless, the prevailing rule is that a patient capable of making decisions has the right to

²⁵ U.S. CONST. amend. XIV, § 1.

²⁶ *Cruzan*, 497 U.S. at 280.

²⁷ See, e.g., Bernadette Tuthill, *Want to Terminate Life Support? Not in New York—Time to Give New Yorkers a Choice*, 26 *TOURO L. REV.* 675 (2010) (explaining that the state of New York requires clear and convincing evidence before authorizing surrogates to withdraw medical treatment from a decisionally-incapacitated patient).

²⁸ Nicole M. Saitta & Samuel D. Hodge, Jr., *Wrongful Prolongation of Life—A Cause of Action That Has Not Gained Traction Even Though a Physician Has Disregarded a "Do Not Resuscitate" Order*, 30 *TEMP. J. SCI., TECH. & ENVTL. L.* 221 (2011); *Guardado v. Valley Medical Ctr.*, 2012 WL 1501271 (Wash. Ct. App. 2012) (denying summary judgment in a lawsuit seeking to impose liability for failure to resuscitate); *Jones v. Ruston La. Hosp.*, 46,356–CW, 46,202–CW (La. App. 2 Cir. Aug. 10, 2011), 71 So. 3d 1154 (2011) (suit to impose liability for hospital's failure to honor patient's DNR order); *Betancourt v. Trinitas Hosp.*, 1 A.3d 823 (N.J. Super. Ct. App. Div. 2010) (action to enjoin hospital from implementing a DNR order rendered moot by the patient's death); *Messenger v. Heos*, 2008 WL 5158901 (Mich. Ct. App. 2008) (claim for legal malpractice brought against attorneys who failed to pursue plaintiff's claim against hospital for disobeying a DNR order for the plaintiff's infant).

refuse CPR,²⁹ and that surrogates may choose to forego CPR for a patient if the likely burdens of this intervention to the patient would seriously outweigh any expected benefits (such as mere continued existence until the next arrest).³⁰ As with all medical decisions, a DNR order should be written by the physician only after a thorough consultation with the patient or surrogate and should be clearly documented in the medical record.³¹ A DNR order may be folded easily into a more comprehensive POLST document.³²

The most vigorously disputed issue in the treatment limitation arena is still the status of artificial feeding and hydration.³³ The courts have been unanimous in holding that artificial feeding tubes (of all kinds) are merely another form of medical intervention that may be withheld or withdrawn under the same circumstances that would justify withholding or withdrawal of any other type of medical intervention such as a respirator, dialysis, or antibiotic use.³⁴ Major medical professional groups endorse this position.³⁵ The contrary position is that feeding and hydration, even when they can be achieved only through tubes surgically or forcibly inserted into the patient's body, are fundamentally different and more morally elemental than medical treatment, and therefore they should be maintained as long as they might keep the patient alive (that is, as long as they are not physiologically futile gestures).³⁶ A number of state legislatures reflect this position in their living will or durable power of attorney statutes (discussed below), which are intended to severely constrain the rights of patients and surrogate decision

²⁹ Jeffrey P. Burns et al., *Do Not Resuscitate Orders After 25 Years*, 31 CRITICAL CARE MED. 1543 (2003).

³⁰ Uniform Health-Care Decisions Act § 5 (1993).

³¹ Dan M. Westphal & Stefanie A. McKee, *End-of-Life Decision Making in the Intensive Care Unit: Physician and Nurse Perspectives*, 24 AM. J. MED. QUALITY 222 (2009). *But see* Wendy G. Anderson et al., *Code Status Discussions Between Attending Hospitalist Physicians and Medical Patients at Hospital Admission*, 26 J. GEN. INTERNAL MED. 359 (2011) (documenting that code status is not discussed by physicians with many seriously ill patients); J.A. DePalma et al., *"Slow" Code: Perspectives of a Physician and Critical Care Nurse*, 22 CRITICAL CARE NURS. Q. 89 (1999) (discussing the previous common practice of "slow" codes or "show" codes).

³² *See infra* Part III (discussing the POLST paradigm).

³³ Jeannette Y. Wick & Guido R. Zanny, *Removing the Feeding Tube: A Procedure With a Contentious Past*, 24 CONSULTANT PHARMACIST 874, 874–76 (2009) (describing the national debate surrounding the removal of artificial nutrition/hydration in the cases of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo).

³⁴ *Cruzan*, 497 U.S. at 288–89 (O'Connor, J., concurring).

³⁵ Robert D. Truog et al., *Recommendations for End-of-Life Care in the Intensive Care Unit: A Consensus Statement by the American Academy of Critical Care Medicine*, 36 CRITICAL CARE MED. 953 (2008).

³⁶ *See, e.g.*, Melanie Evans, *Moral Obligations: Catholic Officials Differ Over Vatican Feeding-Tube Rules*, 37 MODERN HEALTHCARE 17, 17 (2007) (explaining the Vatican's position on artificial nutrition and hydration, which states "[t]he administration of food and water even by artificial means is, in principle and ordinary and proportionate means of preserving life.").

makers to authorize the removal of feeding tubes.³⁷ Both the wisdom and the constitutionality of these purported restrictions are extremely questionable.³⁸

The federal Patient Self-Determination Act (PSDA) went into effect in 1991.³⁹ The PSDA mandates that all nursing homes—as well as all hospitals, home health agencies, hospices, health maintenance organizations, and preferred provider organizations—participating in the Medicare and Medicaid programs engage in the following actions at the time a person is initially admitted or enrolled: (a) provide written information to individuals about their right to make their own medical decisions to the extent guaranteed by applicable state law, and make available to them the facility or organizational policy for effectuating that right for the facility's or organization's patients; (b) ask patients whether they have completed an AD already and, if the response is in the affirmative, have a system for recording the patient's AD; (c) offer currently capable individuals a chance to execute an AD if they have not previously done so; (d) not discriminate in the provision of care based on the presence or absence of an AD; (e) create a system to assure compliance with relevant state laws on medical decision making; and (f) educate institutional or organizational staff and the community about patients' rights pertaining to medical decision making.⁴⁰

When the patient or surrogate refuses aggressive, technologically intensive medical interventions, the physician nonetheless has the legal obligation to offer basic palliative (comfort, pain control, and emotional support) and hygiene measures.⁴¹ Failure to do so could constitute negligence or form the basis for professional discipline.⁴² Good palliative care may sometimes include the practice of palliative sedation to unconsciousness (also called total, terminal, or controlled sedation) for distress or suffering during the dying process that cannot otherwise be treated satisfactorily.⁴³

³⁷ Tuthill, *supra* note 27, at 694.

³⁸ Kathryn L. Tucker, *The Campaign to Deny Terminally Ill Patients Information and Choices at the End of Life*, 30 J. LEGAL MED. 495 (2009).

³⁹ Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, tit. IV, §§ 4206, 4751 (1990); *see, e.g.*, LAWRENCE P. ULRICH, *THE PATIENT SELF-DETERMINATION ACT: MEETING THE CHALLENGES IN PATIENT CARE* (H. Tristram Engelhardt, Jr. & Kevin Wildes eds., Georgetown University Press 1999).

⁴⁰ Critiques of the effectiveness of the PSDA in practice are numerous. *See, e.g.*, Catherine J. Jones, *Say What? How the Patient Self-Determination Act Leaves the Elderly With Limited English Proficiency Out in the Cold*, 13 ELDER L.J. 489 (2005); United States General Accounting Office, *Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness Uncertain* (Aug. 1995).

⁴¹ *See* Sara L. Imhof & Brian Kaskie, *Promoting a "Good Death": Determinants of Pain-Management Policies in the United States*, 33 J. HEALTH POL. POL'Y & L. 907 (2008).

⁴² *See* Timothy McIntire, *Ouch! That Really Hurts. Pain Management in the Elderly and Terminally Ill: Is This a Legal or a Medical Problem?* 6 N.Y. CITY L. REV. 151 (2003).

⁴³ Thaddeus M. Pope & Lindsey E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363, 378–80 (2011); George P. Smith, II, *Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being*, 20 CORNELL J.L. & PUB. POL'Y 469, 510–12

In every state, it is a criminal offense (as a form of homicide) for a physician to engage in positive or affirmative actions that are intended to speed up a patient's death (such as administering a lethal injection), even if a competent patient voluntarily requests such action.⁴⁴ Similarly, in every state except Oregon,⁴⁵ Washington,⁴⁶ Vermont,⁴⁷ (and possibly Montana),⁴⁸ it is criminal for a physician to go along with a patient's request that the physician supply the patient with the means to hurry up his or her own death (such as writing a prescription for a lethal dose of a medication, knowing very well that the patient intends to commit suicide by taking that lethal dose).⁴⁹ The Supreme Court has unanimously rejected the assertion that individuals have a federal constitutional right to obtain physician-assisted death (PAD).⁵⁰

Conversely, a patient, or more usually the patient's family, may insist on initiating or continuing medical treatment ("doing everything possible") that the clinician believes is futile in terms of patient benefit. Neither a patient nor a family (nor any other surrogate) possesses a legal right to demand, nor does a physician owe an enforceable duty to provide, nonbeneficial medical treatment.⁵¹ On the rare occasions when courts have become involved prospectively with the futility issue, the judicial opinions generally have been confusing, inconsistent, and poorly reasoned. However, most courts do not hold a provider liable after the fact for failure to begin or perpetuate futile interventions for a critically ill patient, even when the family was insisting on doing everything technologically possible.⁵² In

(2011) (citing the position statement of the American Academy of Hospice and Palliative Medicine); Richard A. Mularski et al., *Pain Management Within the Palliative and End-of-Life Care Experience in the ICU*, 135 CHEST 1360 (2009); Norman L. Cantor, *On Hastening Death Without Violating Legal and Moral Prohibitions*, 37 LOY. U. CHI. L.J. 407, 418–22 (2006).

⁴⁴ Ruth C. Stern & J. Herbie Difonzo, *Stopping for Death: Re-framing Our Perspective on the End of Life*, 20 U. FLA. J. L. & PUB. POL'Y 387 (2009).

⁴⁵ Oregon Death with Dignity Act, OR. REV. STAT. ANN. §§ 127.800 TO .-127 (West).

⁴⁶ Washington Death with Dignity Act, WASH. REV. CODE ANN. §§ 70.245.901 to .-70.245 (West 2012).

⁴⁷ VT. STAT. § 5283 (West 2012).

⁴⁸ *Baxter v. State*, 354 Mont. 234, 224 P.3d 1211 (Mont. 2009).

⁴⁹ Cyndi Bollman, *A Dignified Death? Don't Forget About the Physically Disabled and Those Not Terminally Ill: An Analysis of Physician-Assisted Suicide Laws*, 34 S. ILL. U. L.J. 395, 399–400 (2010).

⁵⁰ *Washington*, 521 U.S. at 702; *Vacco*, 521 U.S. at 793.

⁵¹ Norman L. Cantor, *No Ethical or Legal Imperative to Provide Life Support to a Permanently Unaware Patient*, 10 AM. J. BIOETHICS 58 (2010); Robert D. Truog, *Medical Futility*, 25 GA. ST. U. L. REV. 985 (2008–09); Mary Whitmer et al., *Medical Futility: A Paradigm as Old as Hippocrates*, 28 DIMENSIONS CRIT. CARE NURS. 67 (2009).

⁵² Thaddeus M. Pope, *Involuntary Passive Euthanasia in U.S. Courts: Reassessing the Judicial Treatment of Medical Futility Cases*, 9 MARQ. ELDER'S ADVISOR 229, 230 (2008) (arguing that "courts have generally neither prohibited nor punished the unilateral refusal of LSMT. Providers have regularly obtained both ex ante permission and ex post forgiveness for stopping LSMT without consent.").

practice, clinicians usually seem to take the path of least resistance in such circumstances and “treat the family,” often out of misapprehension about potential liability exposure.⁵³ In the vast majority of cases, better physician-family communication (often assisted by the involvement of an institutional ethics committee), in which the realistic (that is, the negative) implications of “doing everything possible” are clearly delineated, can avoid or resolve serious disagreement over how best to proceed.⁵⁴

Over the past four decades, a lot of attention has been concentrated on advance or prospective health care planning as a mechanism for individuals to maintain a degree of control over their future medical treatment even if, at some point, they become physically or mentally incapable of making and expressing important decisions about their own care.⁵⁵ Advocates of advance care planning also suggest that it may help people and their families avoid unwanted court involvement in medical treatment decisions,⁵⁶ diminish the emotional or psychological stress on family and friends that occurs in difficult crisis circumstances,⁵⁷ and conserve limited health care resources in a manner consistent with patient autonomy or self-determination.⁵⁸

Two chief types of advance directive legal mechanisms (ADs) are available for use in prospective health care planning. Statutes explicitly authorizing individuals to execute ADs have been enacted in every state; many of these state statutes (sometimes called “natural death acts”) are modeled on the Uniform Health Care Decisions Act adopted by the National Conference of Commissioners on Uniform State Laws.⁵⁹ In some other Western countries, such as England, the medical and legal establishments

⁵³ Thaddeus M. Pope, *Surrogate Selection: An Increasingly Viable, But Limited, Solution to Intractable Futility Disputes*, 3 ST. LOUIS U. J. HEALTH L. & POL’Y 183, 186–87 (2010) (“Physicians are overwhelmingly reluctant to withhold or withdraw treatment without the consent of the authorized decision maker. Accordingly, without explicit permission to do otherwise, physicians generally comply with surrogate requests for treatment even when they think it is cruel and wrong.”).

⁵⁴ *Id.*, at 205; Thaddeus M. Pope, *Physicians and Safe Harbor Legal Immunity*, 21 ANNALS OF HEALTH LAW 121, 132 (“Fortunately, most futility disputes are resolved consensually and informally. Only rarely do they become intractable.”) Cf. Nancy N. Dubler, *A “Principled Resolution”: The Fulcrum for Bioethics Mediation*, 74 L. & CONTEMP. PROBS. 177 (2011) (describing the mediation of difficult bioethical disputes among family members and between them and health care providers).

⁵⁵ See, e.g., Rebecca C. Morgan, *The New Importance of Advance Directives*, 2 EST. PLAN. & CMTY. PROP. L.J. 1 (2009).

⁵⁶ See David M. Shelton, *Keeping End-of-Life Decisions Away from Courts After Thirty Years of Failure: Bioethical Mediation as an Alternative for Resolving End-of-Life Disputes*, 31 HAMLIN L. REV. 103 (2008).

⁵⁷ *Id.* at 2, 224 P.3d 1211 (“It is unlikely that a patient wants family members fighting over decisions regarding end of life treatment or wants special interests and government officials interceding in the determination and exercise of the patient’s wishes.”).

⁵⁸ Lauren H. Nicholas et al., *Regional Variation in the Association Between Advance Directives and End-of-Life Medicare Expenditures*, 306 JAMA 1447 (2011).

⁵⁹ Uniform Health-Care Decisions Act (1993).

have broadly accepted ADs,⁶⁰ although acceptance of the AD model has not been universally endorsed.⁶¹

One legal advance planning mechanism is the proxy directive, usually a durable power of attorney (DPOA) for health care. The proxy directive is an AD that enables an individual to voluntarily designate another person—called a health care agent, surrogate, proxy, or attorney-in-fact—to make health care decisions in the event that the principal (the individual who has delegated away decision-making authority) subsequently loses decision-making capacity. Many states have enacted statutes that designate a legal hierarchy of family members and other persons who may make decisions on behalf of patients incapacitated to make decisions when no guardian has been appointed or instruction directive (discussed below) has been written;⁶² in those jurisdictions, a DPOA may clarify which person has the authority to decide when two persons otherwise would have equal status (for example, the patient’s multiple adult siblings) within the hierarchy. Additionally, a DPOA is valuable when a person prefers to name a non-relative as the future decision maker. For instance, it is fairly common in the gay community for individuals to appoint domestic partners or friends, rather than family members, to act as their health care agents.⁶³

Unlike the situation created with an ordinary power of attorney, the authority of an agent under a DPOA is not automatically ended when the principal subsequently becomes incapacitated to make a decision. The agent’s decision making authority may become effective immediately (an immediate DPOA) upon execution of the document or it may “spring” into action when a specifically-delineated event (such as “when my physician certifies that I am unable to make my own medical decisions”) has taken place. The DPOA would then endure beyond that triggering event. The principal may terminate or revoke the arrangement at any time, so long as the principal remains mentally competent to do so.

One limitation of the DPOA device is the legal and practical requirement that the principal, or person who would like to delegate certain decision making authority to an agent, actually have available a suitable,

⁶⁰ See, e.g., Samantha Halliday, *Advance Decisions and the Mental Capacity Act*, 18 BRIT. J. NURS. 697 (2009); Catherine J. Bond & Karen Lowton, *Geriatricians’ Views of Advance Decisions and Their Use in Clinical Care in England: Qualitative Study*, 40 AGE & AGEING 450 (2011); Tom Goffin, *Advance Directives as an Instrument in an Ageing Europe*, 19 EUR. J. HEALTH L. 121 (2012).

⁶¹ See, e.g., Werner Gruber, *Life and Death on Your Terms: The Advance Directives Dilemma and What Should Be Done in the Wake of the Schiavo Care*, 15 ELDER L.J. 503, 525–27 (2007) (describing the rejection of the living will model in Japan).

⁶² See, e.g., 755 ILL. COMP. STAT. ANN. 40/25(a)(1) (West 2013) (providing, in order of priority, a list of family members and “close friend[s]” who may make decisions on behalf of an incapacitated patient who has not designated a “health care agent”).

⁶³ Annick Persinger, *Still Pioneers: Special Social and Economic Hardships for Elderly Gays and Lesbians*, 21 HASTINGS WOMEN’S L.J. 137, 151–52 (2010); Matthew T. Moore, *Long-Term Plans for LGBT Floridians: Special Concerns and Suggestions to Avoid Legal and Family Interference*, 34 NOVA L. REV. 255, 272 (2009).

willing, and able person to whom to delegate that authority. The DPOA does not help people (the “unbefriended” population) who do not have someone else whom they can trust to make future personal decisions for them.⁶⁴

By contrast, an instruction (living will)-type AD documents an individual’s desires about wanted, limited, or unwanted life-sustaining medical treatments (LSMTs) in case the person at some point becomes cognitively or emotionally incapacitated or is unable to communicate treatment wishes at all. These instructions may be detailed (in the sense of relating to specific medical treatments in particular clinical situations), general (such as “no extraordinary or heroic measures”), or phrased in terms of a patient’s personal values (like “[k]eep me alive forever regardless of pain or expense” or “[j]ust don’t let me suffer”).⁶⁵

Proxy directives and instruction directives are not mutually exclusive. Some AD documents combine the instruction and proxy elements. Only a presently capable person may execute a valid AD. The AD becomes effective only when the person creating the AD subsequently lacks decisional capacity concerning a particular medical treatment question to be decided; if the patient currently possesses sufficient decisional capacity,⁶⁶ there is neither a need nor a right for health care providers to defer instead to an AD for advice.

Courts and state legislatures have consistently made it clear that AD statutes are not intended to be the exclusive means by which patients may exercise the right to make future decisions about medical treatment.⁶⁷ For example, a patient might convey concerns regarding future medical treatment orally to the physician during an office visit, with the physician documenting the patient’s words in the medical chart.⁶⁸ When that person subsequently

⁶⁴ Naomi Karp & Erica Wood, *Incapacitated and Alone: Health Care Decision Making for Unbefriended Older People*, HUMAN RTS. MAG. (2004), available at www.abanet.org/irr/hr/spring04/incapacitated.html (describing the challenges associated with medical decision-making in the context of incapacitated, “unbefriended” patients).

⁶⁵ See, e.g., NORMAN L. CANTOR, *ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY* 54–71 (1993); Aging With Dignity, *Five Wishes*, available at <http://www.agingwithdignity.org/five-wishes.php/> (last visited Mar. 13, 2013).

⁶⁶ See Karin T. Kirchhoff et al., *Effect of a Disease-Specific Advance Care Planning Intervention on End-of-Life Care*, 60 J. AM. GERIATRICS SOC’Y 946 (2012) (reporting on a study finding that a majority of patients with congestive heart failure or end-stage renal disease continued to make their own decisions about care until the end of their lives).

⁶⁷ See, e.g., FLA. STAT. § 765.106 (West 2012):

The provisions of this chapter [Fla. Stat. § 765, authorizing individuals to execute ADs] are cumulative to the existing law regarding an individual’s right to consent, or refuse to consent, to medical treatment and do not impair any existing rights or responsibilities which a health care provider, a patient, including a minor, competent or incompetent person, or a patient’s family may have under the common law, Federal Constitution, State Constitution, or statutes of this state.

See also, e.g., *Stouffer v. Reid*, 993 A.2d 104 (Md. 2010) (finding that competent adults have a constitutional right to refuse unwanted medical intervention).

⁶⁸ E.g., TENN. CODE ANNOT. § 68-11-1806(a).

becomes unable to make personal medical decisions, his or her oral instructions are just as legally valid as would be a written document executed in compliance with all of the formalities contained in the state's AD statute. Nonetheless, even though a legally valid AD may be oral, the patient's treatment wishes are much more likely to be followed by the health care system if they are enshrined in a written document.⁶⁹

C. Problems With Advance Directives

There are a myriad of serious problems with the legal status quo and the prevalent clinical practice that the legal climate helps to engender regarding the medical care of individuals with advanced, irreversible illness in the United States. There is a significant body of evidence that has been accumulated showing, too often, patients' previously stated wishes concerning LSMT are not respected and implemented by health care providers, and very often also are not respected and implemented by families who are supposed to be acting as the patient's surrogate. Individuals with advanced, irreversible illness frequently receive more aggressive medical treatment than they had earlier said they would want.⁷⁰ These problems frequently specifically impact nursing home residents, their families, and their professional caregivers in negative ways, creating or exacerbating an unfortunate chasm between the values and wishes of the resident on one hand, and the actual care provided to that resident on the other.

The primary problems discussed in this section are: nursing home residents without ADs; disagreements concerning the interpretation and application of AD instructions; nursing home residents whose ADs do not follow them when they are transferred to a hospital, another nursing home, or a home- or community-based setting; and inadequate mechanisms to assure health care provider compliance with nursing home residents' ADs.

1. Residents Without Directives

Despite substantial public attention, deep-seated psychological resistance to the contemplation of illness and death, coupled with inertia and legal complexities⁷¹ complicating the execution of an AD, keeps the rate of

⁶⁹ See, e.g., Erin Webley, *Law, Insouciance, and Death in the Emergency Room*, 19 ELDER L.J. 257, 260 (2011) (describing personnel in the hospital emergency department ignoring the patient's oral directive to withhold life-prolonging medical intervention).

⁷⁰ Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CENT. REP. 30, 36–37 (2004).

⁷¹ See generally Lesley S. Castillo et al., *Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care*, 154 ANN. INTERNAL MED. 121 (2011).

AD completion discouragingly low among members of the general public.⁷² Personal characteristics may influence AD completion rates among members of different population groups.⁷³ Most critically ill patients have failed to formally designate a surrogate decision maker or express (let alone document) their preferences regarding life-sustaining medical treatments.⁷⁴

Nursing home residents are considerably more likely to complete an AD than community-dwelling older persons,⁷⁵ no doubt in large part because the time of admission to a nursing home is a very teachable moment when the entering resident's mind is keenly focused on the medical future. Nevertheless, the AD completion rate in nursing homes is still far less than perfect.⁷⁶ The PSDA, while mandating at least some semblance of an advance planning inquiry, expressly forbids any health care provider from requiring a patient/resident to execute an AD as a condition of admission or receiving services⁷⁷ and some residents choose not to take advantage of the AD opportunity. Additionally, a significant proportion of people who enter nursing homes are already seriously mentally compromised at the time of admission,⁷⁸ and therefore probably are precluded from executing a valid legal document such as a medical AD.

⁷² Gina Bravo et al., *Assessing the Effectiveness of Interventions to Promote Advance Directives Among Older Adults: A Systematic Review and Multi-Level Analysis*, 67 SOC. SCI. & MED. 1122 (2008).

⁷³ Manjula K. Tamura et al., *Preferences for Dialysis Withdrawal and Engagement in Advance Care Planning Within a Diverse Sample of Dialysis Patients*, 25 NEPHROLOGY DIALYSIS TRANSPLANTATION 237, 237 (2010). See also Amy S. Kelley et al., *Determinants of Death in the Hospital Among Older Adults*, 59 J. AM. GERIATRICS SOC'Y 2321, 2323–24 (2011) (finding that the black race and Hispanic ethnicity are correlates of in-hospital death). But see James F. Lawrence, *The Advance Directive Prevalence in Long-Term Care: A Comparison of Relationships Between a Nurse Practitioner Healthcare Model and a Traditional Healthcare Model*, 21 J. AM. ACAD. NURSE PRAC. 179, 182–83 (2009) (finding that black people and white people in the Evercare healthcare model, which relies heavily on the involvement of nurse practitioners, had similar rates of AD completion).

⁷⁴ Sharon L. Camhi et al., *Deciding in the Dark: Advance Directives and Continuation of Treatment in Chronic Critical Illness*, 37 CRITICAL CARE MED. 919 (2009).

⁷⁵ Zweig et al., *supra* note 4, at 1475 (“The majority (65%) of nursing home residents have some form of advance directive and 56% have ‘do not resuscitate’ (DNR) orders.”).

⁷⁶ Helaine E. Resnick et al., *Advance Directives in Nursing Home Residents Aged > or = 65 Years: United States 2004*, 25 AM. J. HOSPICE & PALLIATIVE CARE 476, 476 (2008); Adrienne L. Jones et al., *Use of Advance Directives in Long-Term Care Populations*, NCHS Data Brief No. 54 1, 3 (2011), available at <http://www.cdc.gov/nchs/data/databriefs/db54.pdf> (last visited Mar. 13, 2013).

⁷⁷ 42 U.S.C. § 1395cc(f)(1)(C) (2006).

⁷⁸ See Kelly L. Moore et al., *Age and Sex Variation in Prevalence of Chronic Medical Conditions in Older Residents of U.S. Nursing Homes*, 60 J. AM. GERIATRICS SOC'Y 756, 758 (2012) (documenting nursing home prevalence rates for dementia of 45% for men and 52% for women and for depression of 31% for men and 37% for women).

2. Interpretation and Application Disagreements

Moreover, even when a jurisdiction's advance directives law is clear and the patient has timely executed an instruction directive, health care providers and surrogates often are unclear about when the living will applies and are uncomfortable about deciding when a patient is on a dying trajectory that warrants triggering the declaration's instructions. Also, health care providers sometimes find a living will's instructions either too broad or too narrow to provide much useful guidance in a specific situation.

Living wills have come under widespread criticism for either being badly written or not being sufficiently specific. Considering that many living wills are usually drafted far in advance of a person actually being ill, one wonders if there can ever be a sufficient degree of precision regarding the circumstances meant to be addressed. Complications arise when a living will is written in a manner that allows for multiple interpretations. . . . [S]uch unclear language may require interpretation from medical professionals and family members who may disagree. This becomes problematic when families or other surrogates ask for treatment that would not have been desired by the patient and/or is medically futile.⁷⁹

The ideal function of an instruction directive is to facilitate a meeting of the minds between the ill person and the health care team. However, misunderstandings about a directive's true intent may be exacerbated by the reluctance of many physicians to engage patients in meaningful discussions about medical care goals and preferences in a timely manner.⁸⁰

3. Document Portability Problems

Frequently, individuals with advanced, irreversible illness move over time from one health care or residential setting to another as their health and other circumstances constantly change. Hospitalized or community-dwelling

⁷⁹ Carolyn Standley & Bryan A. Liang, *Addressing Inappropriate Care Provision at the End-of-Life: A Policy Proposal for Hospitals*, 15 MICH. ST. U. J. MED. & L. 137, 147 (2010). See also Donna A. Casey & David M. Walker, *The Clinical Realities of Advance Directives*, 17 WIDENER L. REV. 429, 439–40 (2011) (using a clinical vignette to illustrate the problems of interpreting and applying an AD to a specific set of facts).

⁸⁰ Jennifer W. Mack et al., *End-of-Life Care Discussions Among Patients With Advanced Cancer*, 156 ANN. INTERNAL MED. 204, 207–09 (2012); Dorothy D. Nachman, *Living Wills: Is It Time to Pull the Plug?*, 18 ELDER L.J. 289, 292 (2011) (“The goal in end-of-life planning should be to encourage an open and honest conversation among the individual, his or her health care providers, and health care agent about the patient’s desires at end of life.”).

people may be admitted to nursing homes,⁸¹ and nursing home residents may be transferred—temporarily or until death occurs—to acute care hospitals⁸² (generally through the emergency department)⁸³ or other facilities as an individual’s provider-perceived⁸⁴ needs appear to dictate. Financial incentives also play a role in encouraging hospital to nursing home transfers.⁸⁵ Nursing home residents and their surrogates relatively rarely refuse such transfers when they are requested by attending physicians.⁸⁶ The “patterns of transitions between nursing facilities, hospitals, and homes” have been described as “dynamic . . . , complex, interdependent, [and] longitudinal.”⁸⁷

Decisions about the initiation, continuation, withholding, or withdrawal of specific medical interventions may need to be made by physicians and other caregivers working within the facilities or home environments to which nursing home residents may be transferred. These decisions are not aided by ADs—even if the ADs are beautifully drafted—when the documents do not physically (or electronically) follow the individual among different settings, and that therefore are not known and available to personnel in the transferee facilities or home settings in a timely manner. In theory, ADs are intended to be patient-specific rather than place-specific, but in practice they often become lost or forgotten when the individual is transferred to a different setting from the nursing home or back to the nursing home from an alternative setting.

⁸¹ See Emily R. Smith & Alan B. Stevens, *Predictors of Discharges to a Nursing Home in a Hospital-Based Cohort*, 10 J. AM. MED. DIR. ASS’N 623 (2009).

⁸² Masayo Sato et al., *Residential and Health Care Transition Patterns Among Older Medicare Beneficiaries Over Time*, 51 GERONTOLOGIST 170 (2011) (finding the most frequent transition pattern was transfer to the hospital and back to the nursing home); David C. Grabowski et al., *Predictors of Nursing Home Hospitalization: A Review of the Literature*, 65 MED. CARE RES. REV. 3 (2008).

⁸³ Caroline E. Stephens et al., *Emergency Department Use by Nursing Home Residents: Effect of Severity of Cognitive Impairment*, 52 GERONTOLOGIST 383 (2012).

⁸⁴ Many of these transfers are criticized as unnecessary or inappropriate. See, e.g., Jane L. Givens et al., *Hospital Transfers of Nursing Home Residents With Advanced Dementia*, 60 J. AM. GERIATRICS SOC’Y 905 (2012) (finding that the majority of hospitalizations of nursing home residents with dementia are due to infections that could have been treated competently in the nursing home and that tube feeding complications account for almost half of all emergency department visits by nursing home residents when the tube feedings were questionable in the first place).

⁸⁵ Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMED. L. 27, 52 (2012).

⁸⁶ Susan L. Mitchell et al., *Decisions to Forgo Hospitalization in Advanced Dementia: A Nationwide Study*, 55 J. AM. GERIATRICS SOC’Y 432 (2007).

⁸⁷ Christopher M. Callahan et al., *Transitions in Care for Older Adults With and Without Dementia*, 60 J. AM. GERIATRICS SOC’Y 813, 817 (2012).

4. Enforcement Shortcomings

State AD statutes specifically excuse a health care provider who decides, for reasons of personal conscience, not to carry out the explicitly stated treatment preferences of a patient or surrogate, so long as that provider does not impede efforts to have the patient transferred to the care of a different provider who is willing to respect the patient's AD.⁸⁸ These statutes embody a strong public policy interest in protecting the physician's right of personal conscience,⁸⁹ and are consistent with Section 7(E) of the Uniform Health Care Decisions Act,⁹⁰ although they have inspired complaints that "advance directive statutes meant to protect patients' right of self-determination may instead better protect physicians from punitive action."⁹¹ In the same vein, courts have declined to hold health care providers liable for failure to follow a patient's or surrogate's instructions to withdraw or withhold particular forms of treatment,⁹² often on the grounds that providing life-prolonging intervention can never cause the sort of cognizable injury or harm for which the tort system is designed to provide monetary compensation.⁹³ These conscience-based statutes and judicial decisions would apply with full force in the nursing home context.

Physician noncompliance with patient wishes to limit medical interventions that have been expressed in ADs sometimes happens,⁹⁴ especially when physician anxiety (ordinarily ungrounded but sincere) about potential negative legal repercussions takes over the situation.⁹⁵ Those

⁸⁸ E.g., MINN. STAT. ANN. § 145B.06 (West 2012).

⁸⁹ See generally Don R. Castleman, *Conflict of Conscience: Refusal of a Health Care Provider to Withdraw Life Support*, 3 EST. PLAN. & CMTY. PROP. L.J. 175, 191 (2011); Peter D. Jacobson & Soniya K. Mathur, *Health Law 2010: It's Not All About the Money*, 36 AM. J. L. & MED. 389, 398 (2010); Stephen Wear & Susan Lagaipa, *Toleration of Moral Diversity and the Conscientious Refusal of Physicians to Withdraw Life-Sustaining Treatment*, 19 J. MED. & PHIL. 147, 153 (1994).

⁹⁰ See 22 ISSUES L. & MED. 83 (2006).

⁹¹ Castillo et al., *supra* note 71, at 125.

⁹² E.g., *Bartling v. Glendale Adventist Med. Ctr. (Bartling II)*, 229 Cal. Rptr. 360 (Ct. App. 1986); *Scheible v. Joseph L. Morse Geriatric Ctr., Inc.*, 988 So. 2d 1130 (Fla. Dist. Ct. App. 2008). But see Thaddeus M. Pope, *Nonconsensual Provision of Life-Sustaining Treatment: Civil, Criminal, and Disciplinary Sanctions*, 9 J. HEALTH & BIOMEDICAL L. (In Press 2013).

⁹³ *Cronin v. Jamaica Hosp. Med. Ctr.*, 875 N.Y.S.2d 222 (N.Y. App. Div. 2009); Saitta, *supra* note 28.

⁹⁴ See Nachman, *supra* note 80, at 303 ("While physicians generally view the use of advance directives positively, their professional actions indicate some reluctance to fully respect the decisions of patients regarding their end-of-life care decision making. Frequently patients' or surrogates' wishes are merely one factor considered by physicians in making treatment decisions at the end of life."). The other side of the coin—individuals and families who demand medical treatments that the physician believes to be clinically and ethically futile—has spawned an enormous quantity of literature, a discussion of which is beyond the scope of the present article.

⁹⁵ See Casey, *supra* note 79, at 441 (describing a clinical scenario in which, contrary to their father's AD, a patient's daughters continued to demand dialysis, invasive

anxieties reinforce the general philosophical biases in favor of aggressive action and against acceptance of the limits of medicine that still animate much of the modern medical enterprise.⁹⁶ Entreaties by patient advocates for judicial recognition of a cause of action for “wrongful living” when an individual’s treatment wishes as expressed in an AD are not respected by the care providers have thus far gone unheeded.⁹⁷

III. THE POLST ALTERNATIVE

A. Background

“The evolution of advance directives has mirrored that of many new medical technologies: initial unbridled enthusiasm evolved into skepticism as empirical evidence raised questions about the current practice, followed by a wiser, more constrained application.”⁹⁸ Growing frustration with the inherent limitations of existing instruments for promoting the prospective autonomy of patients with advanced, irreversible illness who may become incapacitated to make a decision⁹⁹ has led many attorneys, health care providers, and commentators to advocate as the next step in the evolution of health care advance planning law and policy the use of POLST (Physician Orders for Life-Sustaining Treatment) forms.¹⁰⁰ From a variety of perspectives, the POLST paradigm offers a number of opportunities for going beyond the status quo, including our present strong reliance on ADs, to

catheters, and other aggressive treatments). The authors comment, “The unfortunate result of this type of conflict is that healthcare professionals give more authority for decision making to families than to advance directives, mostly out of fear of potential litigation from surviving family members.” *Id.*; Nachman, *supra* note 80, at 292 (ascribing the failure of ADs primarily to the incompatibility of their two distinct goals of “protecting an individual’s right to determine the nature and scope of their (sic) end-of-life care and protecting health care professionals from liability”).

⁹⁶ See Daniel Callahan, *End-of-Life Care: A Philosophical or Management Problem?*, 39 J. L. MED. & ETHICS 114, 115 (2011).

⁹⁷ Holly F. Lynch et al., *Compliance With Advance Directives*, 29 J. LEGAL MED. 133, 139 (2008).

⁹⁸ Douglas B. White & Robert M. Arnold, *The Evolution of Advance Directives*, 306 JAMA 1485, 1485 (2011); see also Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211 (2010).

⁹⁹ But see Benjamin H. Levi & Michael J. Green, *Too Soon to Give Up: Re-examining the Value of Advance Directives*, 10 AM. J. BIOETHICS 3 (2010) (arguing against the abandonment of ADs just yet).

¹⁰⁰ The exact nomenclature varies among different jurisdictions; some states, for instance, use the language of MOLST, or Medical Orders for Life Sustaining Treatment. Patricia Bomba, *Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning Including MOLST: A Model of Shared, Informed Medical Decision-Making and Honoring Patient Preferences for Care at the End of Life*, 17 WIDENER L. REV. 475 (2011).

potentially improve the care of individuals with advanced, irreversible illness.¹⁰¹

Unlike a traditional AD executed by a patient while still capable of making decisions, POLST entails a medical order written by a physician¹⁰² (with the concurrence of the patient or surrogate)¹⁰³ instructing other health care providers such as emergency medical squads¹⁰⁴ about the treatment of a patient with advanced, irreversible illness under specific factual circumstances. “The POLST form is a more uniform, comprehensive, and portable method of documentation of patients’ end-of-life treatment desires. Although the POLST form is not intended to replace ADs executed by patients, it corrects many of the inadequacies of current forms and intends to lessen the discrepancy between a patient’s end-of-life care preferences and the treatment(s) eventually provided by the patients’ health care providers.”¹⁰⁵

At least sixteen states have formally implemented the POLST Paradigm, with national coordination efforts being administered through the Center for Ethics in Health Care at the Oregon Health & Science University.¹⁰⁶ Many more states are in the process of developing and implementing their own versions of POLST.¹⁰⁷

B. Adapting POLST for Nursing Home Residents

Some nursing homes already participate in POLST programs.¹⁰⁸ Experience thus far with the use of the POLST approach for nursing home residents with advanced, irreversible illness indicates that residents for whom

¹⁰¹ See Thaddeus M. Pope & Melinda Hexum, *Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment*, 23 J. CLINICAL ETHICS 353 (2012); Keith E. Sonderling, *POLST: A Cure for the Common Advance Directive—It’s Just What the Doctor Ordered*, 33 NOVA L. REV. 451 (2009).

¹⁰² Although this article discusses POLST exclusively as a physician’s order, some states also permit advanced nurse practitioners and physicians’ assistants to write the order. See CHARLES P. SABATINO & NAOMI KARP, *IMPROVING ADVANCED ILLNESS CARE: THE EVOLUTION OF STATE POLST PROGRAMS* 29–35 (2011).

¹⁰³ There is variation among jurisdictions regarding whether the patient or surrogate, in addition to the physician, must sign the POLST form for it to be legally effective. *Jamaica Hosp. Med. Ctr.*, 875 N.Y.S.2d at 10–11.

¹⁰⁴ See Stanley Sam et al., *Survey of Emergency Medical Services Professionals’ Experience With Advance Directives and Medical Orders for Life-Sustaining Treatment*, 59 J. AM. GERIATRICS SOC’Y 2383 (2011).

¹⁰⁵ Sara Catherine Spillers & Brittany Lamb, *Is the POLST Model Desirable for Florida?*, 8 FLA. PUB. HEALTH REV. 80, 82–84 (2011).

¹⁰⁶ See generally POLST, www.polst.org (last visited June 27, 2013).

¹⁰⁷ See, e.g., FLORIDA POLST, <http://med.fsu.edu/medlaw/POLST> (last visited June 27, 2013) (providing materials describing the Florida POLST effort).

¹⁰⁸ Helaine E. Resnick et al., *Nursing Home Participation in End-of-Life Programs: United States, 2004*, 26 AM. J. HOSPICE & PALLIATIVE CARE 354, 354 (2009) (finding that, in 2004, 13.3% of surveyed nursing homes were participating in a POLST program).

POLSTs have been written are significantly more likely to have care provided to them that is consistent with their authentic personal values and wishes.¹⁰⁹ This contrasts with the disjuncture between actual and desired medical interventions often witnessed in the absence of a POLST, even when the individual has executed an AD. Health care professionals ordinarily are used to, and reasonably comfortable with, respecting physicians' orders. Thus, a POLST is more likely than an AD to be honored by health care professionals within nursing homes,¹¹⁰ as well as more likely to be honored across care settings as the individual is transferred from setting to setting within the continuum of care.¹¹¹

Because a POLST becomes part of a patient's medical record, the form is meant to travel with the patient between health care facilities. This documentation is helpful in situations such as emergency care [when a nursing home transfers a resident to the hospital] when the health care provider may be unfamiliar with the patient. The POLST then allows a receiving physician to follow medical orders regarding the patient's end-of-life wishes without the need for repeated questioning regarding life-sustaining treatment.¹¹²

Moreover, nursing home residents for whom POLSTs have been written are less likely to be transferred out the nursing home to another health care setting.¹¹³ Those residents, therefore, are more likely to ultimately die in their own familiar, supportive nursing home surrounding, rather than in a hospital.¹¹⁴ As explained by a commentator:

¹⁰⁹ Susan E. Hickman et al., *A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program*, 58 J. AM. GERIATRICS SOC'Y 1241, 1247 (2010).

¹¹⁰ Susan E. Hickman et al., *The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment Form*, 59 J. AM. GERIATRICS SOC'Y 2091, 2094–97 (2011); Judy L. Meyers et al., *Physician Orders for Life-Sustaining Treatment Form*, 30 J. GERONT. NURS. 37, 43 (2004). *But see* Karin T. Kirchhoff et al., *Effect of a Disease-Specific Advance Care Planning Intervention on End-of-Life Care*, 60 J. AM. GERIATRICS SOC'Y 946 (2012) (claiming that most patients in this study either received the care they desired at the end of life or altered their preferences to be in accord with the care they could receive).

¹¹¹ *See* Janet L. Abraham, *Advances in Palliative Medicine and End-of-Life Care*, 62 ANN. REV. MED. 187, 196–97 (2011) (promoting POLST as a major advance because of the document's portability across different care settings).

¹¹² Kathryn L. Tucker, *When Dying Takes Too Long: Activism for Social Change to Protect and Expand Choice at the End of Life*, 33 WHITTIER L. REV. 109, 134–35 (2011).

¹¹³ *See, e.g.*, Aram Dobalian, *Nursing Facility Compliance With Do-Not-Hospitalize Orders*, 44 GERONTOLOGIST 159, 163 (2004) (finding that nursing home residents with DNH orders were half as likely to be hospitalized as those without such orders).

¹¹⁴ An Vandervoort et al., *Advance Directives and Physicians' Orders in Nursing Home Residents With Dementia in Flanders, Belgium: Prevalence and Associated Outcomes*,

The hospital is the worst place to put dying people. These patients are unable to recognize relatives, confined to bed, and can't swallow. In the hospital, tubes and machines may keep them alive for weeks or months. Is this the care and dignity you want to give your loved one?¹¹⁵

Additionally, POLSTs enable greater precision (and hence, less ambiguity) in the specification of prospective treatment orders. For example, according to one commentator:

CPR and the order to forgo it, the DNR order, have taken on a constellation of important symbolic meanings that are often different to patients, their families, and the healthcare team. These disparate meanings can then serve to hijack discourse about prognosis and the possibility of actual therapies...and instead encourage an all-or-nothing approach informed by the hypothetical of future resuscitation.¹¹⁶

Nonetheless, many individuals with DNR orders do, in fact, request that certain other forms of life-sustaining medical intervention be attempted, while people who want CPR to be attempted in the event of a cardiopulmonary arrest usually want less than “everything” to be attempted for them.¹¹⁷ The POLST provides a mechanism to effectuate those specific preferences. In a related illustration of the precision possible in a POLST:

The POLST form offers an advantage over traditional do-not-hospitalize orders, because it includes orders for hospitalization when comfort needs cannot be met in the current care setting and also allows for hospitalization while opting out of more-aggressive ICU [intensive care unit] care. Residents with POLST forms [in this study] who desired full

24 INT'L PSYCHOGERIATRIC 1133, 1141 (2012) (finding that the chances of dying in a hospital were lower if there was a General Practitioner's (GP) order (the European counterpart to the POLST)); Bernard J. Hammes et al., *The POLST Program: A Retrospective Review of the Demographics of Use and Outcomes in One Community Where Advance Directives Are Prevalent*, 15 J. PALLIATIVE MED. 77, 83 (2012).

¹¹⁵ Carl Hammerschlag, *Die With Dignity*, 31 CARING 54 (2012).

¹¹⁶ Daniel J. Braunner, *Later Than Sooner: A Proposal for Ending the Stigma of Premature Do-Not-Resuscitate Orders*, 59 J. AM. GERIATRICS SOC'Y 2366, 2366 (2011).

¹¹⁷ Susan E. Hickman et al., *Use of the Physician Orders for Life-Sustaining Treatment Program in Oregon Nursing Facilities: Beyond Resuscitation Status*, 52 J. AM. GERIATRICS SOC'Y 1424, 1429 (2004); Erik K. Fromme et al., *Research Letter: POLST Registry Do-Not-Resuscitate Orders and Other Patient Treatment Preferences*, 307 JAMA 34, 34 (2012) (“Thus, half of patients with DNR orders would want to be transported to the hospital if indicated, and half would not unless comfort needs could not be met in their current location.”).

treatment received the same level of treatment as residents without POLST forms.¹¹⁸

This opportunity for greater specificity on the POLST form makes it more probable that the patient's authentic values and preferences will be carried out in practice, either in the nursing home or within the hospital or other setting to which the erstwhile nursing home resident has been transferred.

Another potentially beneficial facet of the POLST paradigm is reduction in the emotional stress placed upon the nursing home resident's family members and friends in their capacity as proxy or surrogate for the currently incapacitated individual.¹¹⁹ The presence of a clear POLST reduces the likelihood that aggressive medical intervention will be initiated or continued by default because a surrogate feels psychologically bound to ask for "everything" when the patient's preferences are not precisely known.¹²⁰ In the absence of a clear expression of the presently incapacitated individual's treatment preferences about future care, made while that person was still capable of decision-making, there is evidence that surrogates are rather unreliable predictors or reflectors of what the patient would have selected for himself or herself.¹²¹ By providing a high degree of clarity, based upon the patient's timely prior input, a POLST can reduce the discordance between surrogate and patient decisions and the emotional strain for the surrogate engendered by the need to make treatment choices largely in the dark.¹²²

Attempts to implement a successful POLST paradigm program for nursing home residents face several particular challenges. One challenge concerns medical care continuity; when an individual is admitted to a nursing home, frequently that person's primary care is taken over by a new physician (who may be under contract as the facility's Medical Director) because the physician who had been providing primary care in the community does not continue his or her caregiving relationship with the resident after nursing

¹¹⁸ Hickman et al., *supra* note 9, at 1747.

¹¹⁹ See, e.g., David Wendler & Annette Rid, *Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others*, 154 ANNALS INTERNAL MED. 336, 343-34 (2011).

¹²⁰ Ursula K. Braun & Laurence B. McCullough, *Preventing Life-Sustaining Treatment by Default*, 9 ANNALS FAM. MED. 250, 254 (2011).

¹²¹ See, e.g., Liat Ayalon et al., *Preferences for End-of-Life Treatment: Concordance Between Older Adults With Dementia or Mild Cognitive Impairment and Their Spouses*, 24 INT'L PSYCHOGERIATRICS 1798 (2012).

¹²² See Brenna Kelly et al., *Systematic Review: Individuals' Goals for Surrogate Decision-Making*, 60 J. AM. GERIATRICS SOC'Y 884 (2012) (documenting that two of the primary goals of individuals regarding surrogate decision making during times of decisional incapacity are being treated consistently with one's own treatment preferences and reducing the burden on their families).

home admission has taken place.¹²³ Another set of challenges concerns physician availability.¹²⁴ There generally is much less active physician presence in nursing homes than in acute care hospitals, and time pressure is the most commonly cited barrier to the conduct of the type of extensive, thoughtful physician or nursing and resident/family (or other surrogate) conversations that the POLST paradigm ideally envisions.¹²⁵

In the circumstance of nursing home residents with advanced, irreversible illness who are transferred to a hospital or other health care setting despite the presence of a POLST, the portability of the document—the POLST physically or electronically accompanying the person in real time—is a challenge that has been discussed already. Apprehensions about potential adverse legal repercussions permeating the minds of physicians and other health care providers is another challenge to enthusiastic POLST support that was mentioned earlier. These challenges are exacerbated in the nursing home arena, which is surrounded by an especially complex and adversarial regulatory and litigation climate.¹²⁶

One of the most substantial challenges is lack of knowledge about POLST, its conceptual underpinnings, and the practical details of implementation, on the part of nursing home personnel.¹²⁷ Because the POLST paradigm can and should be integrated significantly into the nursing home setting, and indeed many POLSTs are initiated in the nursing home, information and exercises on this subject matter for staff at all levels (since staff at all levels interact with residents and their families) should regularly be provided as part of each facility's in-service continuing education endeavors.¹²⁸ For instance, it is important that physicians and other staff understand how to present the POLST concept to residents and their families straightforwardly as a voluntary option rather than as a mandatory requirement.¹²⁹ At the same time, nursing homes should utilize their resident

¹²³ See Zweig et al., *supra* note 4, at 1474 (“Most nursing home residents are cared for by family physicians, general internists, and geriatricians who work part-time in the nursing home.”); Paul R. Katz et al., *Nursing Home Physician Specialists: A Response to the Workforce Crisis in Long-Term Care*, 150 ANNALS INTERNAL MED. 411 (2009).

¹²⁴ Zweig et al., *supra* note 4, at 1474 (“Physicians are rarely present in the nursing facility when residents become acutely ill.”); Meyers et al., *supra* note 110, at 43 (indicating “concerns about physicians’ accessibility for end-of-life discussions”).

¹²⁵ Anthony J. Caprio et al., *Health Care Professionals’ Perceptions and Use of the Medical Orders for Scope of Treatment (MOST) Form in North Carolina Nursing Homes*, 13 J. AM. MED. DIRECTORS ASS’N. 162, 165 (2012).

¹²⁶ See Marshall B. Kapp, *The Liability Environment for Physicians Providing Nursing Home Medical Care: Does It Make a Difference for Residents?*, 16 ELDER L.J. 249, 251–52 (2009).

¹²⁷ See Caprio, *supra* note 125, at 162–63.

¹²⁸ Meyers et al., *supra* note 110, at 44; Neil S. Wenger et al., *Implementation of Physician Orders for Life Sustaining Treatment in Nursing Homes in California: Evaluation of a Novel Statewide Dissemination Mechanism*, 28 J. GEN. INTERNAL MED. 51 (2012).

¹²⁹ See Fromm et al., *supra* note 117, at 34.

councils and family councils¹³⁰ as structural vehicles to educate their residents and families about the POLST paradigm option.

Despite a jurisdiction-specific statutory or regulatory overlay, each institutional nursing home will likely retain substantial discretion about how POLSTs written by physicians for residents they serve are to be reconciled and integrated with existing institutional bylaws and protocols regarding the treatment of persons with advanced, irreversible illness. For example, will the institutional provider presently caring for a particular resident recognize and act upon a POLST signed by a physician who earlier cared for that individual in the community or in another institutional provider, but who does not have active admitting and treating privileges within the current provider? Conversely, will the nursing home limit its recognition of POLSTs to those that are written by physicians who are members of that nursing home's medical staff? In a connected vein, even if state law permits non-physicians to write POLSTs in consultation with patients or their surrogates, would any particular nursing home elect to recognize and implement a POLST written by a non-physician?

VI. CONCLUSION

As stated eloquently by one commentator:

[I]f our society fervently believes that self-determination at the end of life is a hallmark of an evolved society, health care professionals, attorneys, and legislatures have a duty to work together to develop a clear and consistent process that allows clients and patients to choose their end-of-life care options with the confidence that their choices will satisfy underlying statutory law and hospital policies while supporting patient autonomy. By working together, professionals can understand the complex concerns of the other and work in tandem to create a reliable process that lawyers, doctors, and hospitals can accept to support the dying patient.¹³¹

As we engage in innovative, inter-professional collaboration in pursuing the goal of assuring that individuals with advanced, irreversible illness receive until the end of their lives the health care most consistent with their basic values and preferences, promoting and implementing the POLST paradigm should be prominently on the agenda. Further, those POLST-related efforts ought to go beyond the hospital and home-based settings, to

¹³⁰ See generally Donna R. Lenhoff, *LTC Regulation and Enforcement*, 26 J. LEGAL MED. 9, 30 (2005) (explaining the value of resident and family councils).

¹³¹ Nachman, *supra* note 80, at 293.

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include attention to the important nursing home venue, where many people who can benefit from POLST will—and should—spend their final days.