

End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy

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**END OF LIFE AND AUTONOMY: THE CASE FOR
RELATIONAL NUDGES IN END-OF-LIFE DECISION-MAKING
LAW AND POLICY**

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Autonomy is a central principle in many areas of health law. In the case of end-of-life decision-making law and policy, however, the principle of autonomy requires revision. On the whole, law conceptualizes autonomy at the end of life as an individual making private, personal decisions based solely on their interests and values, and independent of others. But ordinary people understand autonomous decisionmaking at the end of life differently, in a way that acknowledges the importance of their interpersonal relationships. Social science research has documented that strengthening relationships with others, sharing responsibility in the decision-making process with healthcare providers, and taking care to not burden loved ones become important when confronting death and making decisions at the end of life.

The divergence in how law and most people conceptualize autonomy becomes particularly consequential when people do not have decision-making capacity when an end-of-life decision must be made, and have not adequately planned in advance for loss of capacity. Failures of rationality explain this all too common situation: a fear and avoidance of death makes people less likely to plan for it, and even when they do plan, they are unable to anticipate every possible end-of-life scenario and their preferences for each scenario. In such cases, the law provides default processes and standards for end-of-life decisionmaking, which constitute a best guess of a surrogate decision-making process that will effectuate the principle of autonomy. However, in this default decision scheme, relational concerns are often accorded a different weight

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or valence than most people would prefer as evidenced in empirical studies. For example, state statutes may direct an incapacitated person's surrogate to make end-of-life decisions in the context of the patient's religious or moral beliefs but not explicitly instruct surrogates to consider the patient's relationality. Thus, decisions made at the end of life may not accord with people's values, preferences, and interests. Paradoxically, therefore, the current defaults in end-of-life law may impede, rather than promote, autonomy.

In order to address this unintended consequence and make consistent the purpose and intended outcome of end-of-life decision-making law and policy, which is respect for autonomy, this Article argues for changes to accommodate the relational nature of autonomy at the end of life. Drawing on the law and behavioral economics literature about choice architecture, I argue that relational "nudges" should be built into end-of-life decision-making law and policy. The proposed nudges are meant to combat failures of rationality, promote a relational autonomy, and reduce negative externalities in end-of-life decisionmaking. These nudges would be designed to affect an individual's end-of-life decisions prior to loss of capacity; a surrogate's healthcare decisions in the absence of advance directives; and healthcare providers' shared decisions with the patient or surrogate. While this necessitates changing some defaults, more consequentially, the nudges at the policy level would also change the way information and choices are presented to decisionmakers, such as patients and physicians, to prime the decisionmaker to decide, in part, based on relationality. These changes may increase the likelihood that end-of-life decisions are made in accordance with most persons' stated preferences—namely that these decisions are shared with and made in consideration of others.

TABLE OF CONTENTS

I. AUTONOMY AND END-OF-LIFE DECISION-MAKING LAW AND POLICY	1068
A. Establishing the Right for Competent Adults to Refuse Life-Sustaining Treatment	1069
B. Surrogate Decisions about Refusing Life-Sustaining Treatment	1072
C. Medical Futility Disputes and Discontinuing Life-Sustaining Treatment	1078
D. Physician Aid in Dying	1079
II. END-OF-LIFE DECISION-MAKING PREFERENCES AND RELATIONAL AUTONOMY	1081
A. Patient and Family End-of-Life Decision-Making Preferences	1082
B. Relational Autonomy and End-of-Life Decisionmaking....	1093
III. ALIGNING END-OF-LIFE DECISION-MAKING LAW AND POLICY WITH RELATIONAL AUTONOMY	1095
A. Explaining Gaps Between Preferences and Behavior in End-of-Life Decisionmaking	1096
B. Choice Architecture (“Nudging”).....	1101
C. Relational Nudges in End-of-Life Decision-Making Law and Policy	1103
D. Responses to Objections and Counterarguments	1120
IV. CONCLUSION	1139

INTRODUCTION

Autonomy is a central principle in many areas of health law.¹ This is because of the connection between healthcare provision and the right to bodily integrity.² As the Supreme Court stated, “[n]o right is held more sacred,

1. There are multiple definitions of autonomy, but throughout this Article, I will use the definition proposed by eminent bioethicists, Professors Beauchamp and Childress. “We analyze autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) *without controlling influences* that determine their action.” TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 104 (7th ed. 2013) (emphasis added).

2. These autonomy and bodily integrity rights are private and regulate conduct between individuals, but can also be public if the state is involved. See Alexander Morgan Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340, 365 n.58 (1974); see also Anne Flamm & Heidi Forster, *Legal Limits: When Does Autonomy in Health Care Prevail?*, in 3 *LAW AND MEDICINE: CURRENT LEGAL ISSUES* 141, 141 (Michael Freeman & Andrew

or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”³ Or, as stated by then-Judge Benjamin Cardozo of the New York Court of Appeals in an opinion that has been cited in several well-known end-of-life cases,⁴ “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body”⁵

The importance of autonomy can be seen in various areas of health law. For example, the legal requirement that physicians and clinical researchers obtain voluntary, informed consent from patients and research participants prior to providing treatment or interventions foregrounds the importance of autonomy.⁶ Also, in public health law, there is a tension between respect for an individual’s autonomy and government action to promote collective welfare, as in the case of mandating vaccinations to ensure population health.⁷ This same tension is present in recent debates about healthcare reform in the United States, which include questions about the proper balance between individual choice to purchase health insurance and the federal government’s assessment of a penalty on persons who choose not to purchase it, highlighting issues of autonomy with respect to health insurance regulation.⁸ And central to this Article, the body of law that has developed to regulate end-of-life decisionmaking in the United States also privileges autonomy, allowing competent adults to refuse life-sustaining treatment.⁹

D. E. Lewis eds., 2000) (describing two doctrinal strands that privilege autonomy in healthcare decisionmaking: bodily integrity and self-determination).

3. *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891) (holding that a trial court cannot order an examination of a plaintiff’s body without their consent); *see also* *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 847 (1992) (“It is a promise of the Constitution that there is a realm of personal liberty which the government may not enter.”).

4. *See, e.g.,* *Washington v. Glucksberg*, 521 U.S. 702, 777 (1997) (Souter, J., concurring).

5. *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

6. *See, e.g.,* *Pratt v. Davis*, 118 Ill. App. 161, 166 (1905), *aff’d*, 79 N.E. 562 (Ill. 1906) (“On the contrary, under a free government at least, the free citizen’s first and greatest right, which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence”); *see also* Capron, *supra* note 2, at 364–65 (discussing *Pratt*).

7. *See, e.g.,* *Jacobson v. Massachusetts*, 197 U.S. 11, 29 (1905) (“There is . . . a sphere within which the individual may . . . rightfully dispute the authority of . . . government . . . to interfere with the exercise of [their] will. But it is equally true that in . . . well-ordered societ[ies] . . . the rights of the individual . . . may . . . be subjected to such restraint . . . as the safety of the . . . public . . . demand[s].”).

8. *See, e.g.,* *Coons v. Lew*, 762 F.3d 891, 899 (9th Cir. 2014) (“Coons contends that the individual mandate unduly burdens his right to medical autonomy by ‘forcing him to apply limited financial resources to obtaining a health care plan he does not desire or forcing him to save his income and pay a penalty’ . . .”).

9. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 279 (1990) (“But for purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.”).

In the case of end-of-life decision-making law, however, the principle of autonomy requires revision.¹⁰ On the whole, law conceptualizes autonomy at the end of life in terms of an individual making private, personal decisions based solely on their interests and values, and independent of others.¹¹ Indeed, adjudicators and legislators attempt to protect persons making end-of-life decisions from the influence of others, fearing that others' interests will compromise individual autonomy.¹²

But ordinary people understand autonomous decisionmaking at the end of life differently, in a way that acknowledges the importance of their interpersonal relationships. Indeed, empirical research demonstrates that while people want to have control over their end-of-life decisions, which accords with the traditional legal conceptualization of autonomy, they also value others' input and consider others' interests.¹³ Because of these preferences, when end-of-life decisions are made voluntarily in the context of their relationships, people are exercising their autonomy in a relational manner.

This mismatch in how autonomy is conceptualized occurred, in part, because the philosophical notion of autonomy that influenced the drafters of the United States Constitution and was relied upon in common law decisions, is highly individualistic.¹⁴ Indeed, alternative conceptualizations of autonomy that more fully admit the significant role of relationships is a much more recent development in philosophical scholarship.¹⁵ Furthermore, end-of-life decision-making law was largely settled prior to the time when researchers began asking people about their values, preferences, and interests at the end of life.¹⁶ Social science research has since documented that strengthening relationships with others, sharing responsibility in the decision-making process with healthcare providers, and taking care to not burden loved ones become important when confronting death and making decisions at the end of life.¹⁷

10. This principle may require revision in other areas of health law, but the focus in this Article is on end of life. See, e.g., Nan D. Hunter, *Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms*, 45 WAKE FOREST L. REV. 1525, 1527–28 (2010) (describing how patient-centered medicine needs an updated account of autonomy).

11. See *infra* Part I.

12. See *infra* Part I.

13. See *infra* Part II.

14. See Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives*, 37 VILL. L. REV. 1705, 1732–35, 1737 (1992) (describing the history of autonomy in U.S. law, with a special emphasis on mental health law).

15. See, e.g., RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF (Catriona Mackenzie & Natalie Stoljar eds., 2000).

16. See *infra* Part II.A.1.

17. See *infra* Part II.A.

The divergence in how law and most people conceptualize autonomy becomes particularly consequential when people do not have decision-making capacity when an end-of-life decision must be made, and have not adequately planned in advance for loss of capacity. Failures of rationality explain this all too common situation: a fear and avoidance of death makes people less likely to plan for it, and even when they do plan, they are unable to anticipate every possible end-of-life scenario and their preferences for each scenario. In such cases, the law provides default processes and standards for end-of-life decisionmaking, which constitute a best guess of a surrogate decision-making process that will effectuate the principle of autonomy. However, in this default decision scheme, relational concerns are accorded a different weight and valence than most people would prefer, based on evidence from empirical studies of end-of-life preferences. For example, state statutes may direct an incapacitated person's surrogate to make end-of-life decisions in the context of the patient's religious or moral beliefs but not explicitly instruct surrogates to consider the patient's relationality.¹⁸ Thus, decisions made at the end of life may not accord with people's values, preferences, and interests. Paradoxically, therefore, the current defaults in end-of-life law may impede, rather than promote, autonomy.

In order to address this inadvertent consequence and make consistent the purpose and intended outcome of end-of-life decision-making law and policy, which is respect for autonomy, this Article argues for changes to accommodate the relational nature of autonomy at the end of life. Such changes would account for the effects that end-of-life decisions have on third parties—namely surviving family members and healthcare providers—and thus may also reduce negative externalities, such as witnessing or causing prolonged physical suffering at the end of another's life, in this decision-making domain.

Drawing on law and behavioral economics literature about choice architecture, I argue that relational “nudges” should be built into end-of-life decision-making law and policy. The proposed nudges are meant to combat failures of rationality in end-of-life decisionmaking, and promote a relational autonomy. These nudges would be designed to affect an individual's end-of-life decisions prior to loss of capacity; a surrogate's healthcare decisions in the absence of advance directives; and healthcare providers' shared decisions with the patient or surrogate. While this necessitates changing some defaults, more consequentially, the nudges at the policy level would change the way information and choices are presented to decisionmakers, such as

18. “Relationality,” in this Article, will be used according to a dictionary definition of “relational,” because relationality is the condition of being relational. “Relational” is defined as “of or relating to kinship” and “characterized or constituted by relations.” *Relational*, MERRIAM-WEBSTER, <https://www.merriam-webster.com/dictionary/relational> (last visited May. 7, 2018).

patients and physicians, to prime the decisionmaker to decide, in part, based on relationality. This may increase the likelihood that end-of-life decisions are made in accordance with most persons' stated preferences—namely that these decisions are shared with and made in consideration of others. The nudges are meant to influence rather than mandate, which also allows for autonomous decisionmaking for people who prefer not to consider or involve others.

Given that autonomy is of central importance in health law, this reconceptualization of autonomy has implications in many other contexts. Indeed, there is a parallel in the disability law context where some advocates have argued that autonomy should be understood in a way that respects the capabilities of persons with disabilities and acknowledges the reality of interdependencies with others.¹⁹ This Article is the first in a series that will explore and reconceptualize the principle of autonomy in health law. While a relational conceptualization of autonomy in the end-of-life context may not be unique, it is especially salient and is therefore a good place to begin this scholarly agenda.

This Article is organized as follows. Part I briefly reviews existing law to demonstrate how autonomy is conceptualized in the end-of-life decision-making context, focusing on withholding and withdrawing life-sustaining treatment in the case of competent and incompetent adults, medical futility, and physician aid in dying.²⁰ Part II surveys what people report wanting and valuing at the end of their lives and describes relational autonomy. Part III explains why people often fail to make end-of-life decisions that accord with their values and preferences. Part III also advances a normative argument that end-of-life decision-making law and policy should change to promote relational autonomy, argues for specific relational nudges to accomplish this goal, and attends to potential objections, demonstrating how concerns can be adequately addressed. The Article concludes by noting some implications of the reconceptualization of autonomy as relational for other areas of health law.

I. AUTONOMY AND END-OF-LIFE DECISION-MAKING LAW AND POLICY

This Part will briefly review the law of end-of-life decisionmaking, including a summary of law on end-of-life decisions for competent adults, de-

19. See, e.g., Nina A. Kohn, Jeremy A. Blumenthal, & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN STATE L. REV. 1111 (2013).

20. End-of-life decisionmaking in the case of children and infants is outside the scope of this paper given that autonomy is not the underlying principle in the decision-making process for minors.

cisions by surrogates for incompetent adults, medical futility cases, and physician aid in dying.²¹ This review will demonstrate how, in each part of the law, autonomy is the primary principle (beneficence is a secondary value), and it is conceptualized and applied in a way that views persons in isolation from their relations to others, that is, these conceptualizations are highly individualistic.

A. *Establishing the Right for Competent Adults to Refuse Life-Sustaining Treatment*

The “right to die” was first established and defined in state courts, and in the context of making end-of-life decisions for persons who were *not* competent. In the widely influential case *In re Quinlan*,²² a New Jersey court grappled with state law about refusing life-sustaining treatment.²³ The court characterized the case as, in part, “involving questions related to the . . . impact of such durationally indeterminate and artificial life prolongation on the rights of the incompetent, her family and society in general.”²⁴ The court found that the “vegetative” Karen Quinlan’s state and federal constitutional rights to privacy encompassed the right to refuse life-sustaining medical treatment.²⁵ Although Karen Quinlan’s father, her legal guardian, asserted both her privacy rights and his privacy rights, the court noted, when it came to discontinuing life-sustaining treatment, there was “no parental constitutional right.”²⁶ In this case, the New Jersey court limited consideration of anyone’s interests other than the individual for whom an end-of-life decision must be made. Indeed, throughout the opinion, the court often discussed the facts and law using phrases such as individual “right of choice” and “individual’s right to privacy,” promoting a highly individualistic conceptualization of choice in this domain.²⁷

A year after *In re Quinlan* was decided, in another influential end-of-life decision-making case, *Superintendent of Belchertown State School v. Saikewicz*,²⁸ the Massachusetts Supreme Court recognized the right of an adult to refuse life-sustaining medical treatment and outlined potential limits

21. For a brief review on end-of-life decision-making law, see Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1693, 1697–1704 (2014). For a comprehensive treatise on end-of-life decision-making law, see generally ALAN MEISEL ET AL., *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* (3d ed. 2017).

22. 355 A.2d 647 (N.J. 1976).

23. *Id.* at 651.

24. *Id.* at 652.

25. *Id.* at 663–64.

26. *Id.* at 664.

27. *Id.*

28. 370 N.E. 2d 417 (Mass. 1977).

on this right.²⁹ The court first identified the source of the right, beginning with the evolution of the informed consent doctrine, which is based on the right to “bodily integrity,” in the common law of Massachusetts and other states.³⁰ The court then turned to the Federal Constitution:

Of even broader import, but arising from the same regard for human dignity and self-determination, is the unwritten constitutional right of privacy found in the penumbra of specific guaranties of the Bill of Rights. As this constitutional guaranty reaches out to protect the freedom of a woman to terminate pregnancy under certain conditions, so it encompasses the right of a patient to preserve his or her right to privacy against unwanted infringements of bodily integrity in appropriate circumstances.³¹

The court referred to the right to refuse life-sustaining treatment in terms like “dignity,” “self-determination,” and “bodily integrity,” all of which refer to a self, independent of its relation to others.³²

However, the court described state interests that must be balanced against a person’s right to refuse life-sustaining medical care including: the interest in preserving life; “protection of the interests of innocent third parties”; preventing suicide; and maintaining the integrity of the medical profession.³³ Two of these interests define the scope of the right to refuse life-sustaining treatment by presenting the decision in the context of relationality. First, the concern about the effect of a person’s decision on third parties recognizes that one person’s decision impacts others in their network of relationships. Second, the concern about the ethical integrity of the medical profession recognizes that patients exist in relation to a system of healthcare provision, and in particular, in relation to their physicians and other treating clinicians. As some scholars note, however, these interests have never been able to trump a competent patient’s choice to hasten their death.³⁴

The Supreme Court of the United States eventually weighed in on the question of whether competent adults have a right to refuse life-sustaining treatment, constitutionalizing this common law right in *Cruzan v. Director*,

29. *Id.* at 425–27.

30. *Id.* at 424.

31. *Id.* (citations omitted) (first citing *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965); and then citing *Roe v. Wade*, 410 U.S. 113, 153 (1973)).

32. *Id.*

33. *Id.* at 425–27.

34. BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 327 (7th ed. 2013).

Missouri Department of Health.³⁵ The Supreme Court stated that the Fourteenth Amendment Due Process Clause is the source of this right.³⁶ Refusing unwanted medical treatment—even if such treatment is necessary to preserve life—is a constitutionally protected liberty interest, as Justice O’Connor wrote in her concurring opinion in this case:

Requiring a competent adult to endure such procedures against her will burdens the patient’s liberty, dignity, and freedom to determine the course of her own treatment. Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual’s deeply personal decision to reject medical treatment, including the artificial delivery of food and water.³⁷

Given that the case also concerned the evidentiary requirements for surrogates to make such a decision on behalf of incapacitated adults, the Court discussed surrogate decisionmaking.³⁸ In this portion of the opinion, the Court noted the need for the state to protect vulnerable patients from their family members:

Not all incompetent patients will have loved ones available to serve as surrogate decisionmakers. And even where family members are present, “[t]here will, of course, be some unfortunate situations in which family members will not act to protect a patient.” A State is entitled to guard against potential abuses in such situations.³⁹

The Court further wrote that there is not a constitutional right to have surrogates refuse life-sustaining treatment on behalf of an incompetent patient.⁴⁰ Much of the reasoning focused on the possibility that family members would assess the quality of an incompetent patient’s life as lower than the patient would if they regained capacity. The state, then, is permitted to have a high evidentiary bar for surrogate decisions to refuse life-sustaining treatment. The Court explained,

Close family members may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterested, either—that they do not wish to witness the continuation of life of a loved one which they regard as hopeless, meaningless, and even degrading.

35. 497 U.S. 261 (1990).

36. *Id.* at 279. The constitutional right only applies to state action, however, and so this right is only relevant when people are receiving treatment in state facilities. Private facilities respect the right to refuse medical treatment based on the common law doctrine of informed consent and because they do not wish to risk liability. See DAVID ORENTLICHER ET AL., *BIOETHICS AND PUBLIC HEALTH LAW* 283 (3d ed. 2013).

37. *Cruzan*, 497 U.S. at 289 (O’Connor, J., concurring).

38. *Id.* at 273–75 (majority opinion).

39. *Id.* at 281 (alteration in original) (citation omitted) (citing and quoting *In re Jobes*, 529 A.2d 434, 447 (N.J. 1987)).

40. *Id.*

But there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent.⁴¹

The *Cruzan* case exemplifies the conceptualization of autonomous decisionmaking at the end of life as isolated decisionmaking, grounded in individual liberty, privacy, self-determination, and dignity.

In sum, both state and federal case law privilege autonomy in end-of-life decisionmaking. Autonomy as conceived by the courts is personal, private decisionmaking, independent from consideration of anyone else's interests.⁴² Indeed, while some courts have noted that relational considerations do have a place in defining the limits of these rights, courts are also suspicious of the motives of third parties and want to protect people from others' potentially conflicting interests.⁴³

B. Surrogate Decisions about Refusing Life-Sustaining Treatment

The law of end-of-life surrogate decisionmaking differs somewhat depending upon whether the incompetent person is an adult, minor, or infant. This Section will review only the law of end-of-life surrogate decisionmaking for adults.⁴⁴ While competent adults can refuse life-sustaining medical treatment, in many cases in which a decision must be made about whether to begin or continue such treatment, the person no longer has decisional capacity. In such cases, surrogates (often family members) make a decision on behalf of the patient.

The law of surrogate decisionmaking originated when courts were confronted with questions about how to make healthcare decisions on behalf of an incapacitated patient, and indeed, the cases described above that established the right to refuse life-sustaining medical treatment involved patients in the vegetative state or with lifelong intellectual disabilities.⁴⁵ Thus, the conceptualization of autonomy described in the previous Section is the same as the conceptualization of autonomy in surrogate decision-making law. The

41. *Id.* at 286.

42. See Bruce Jennings, *Solidarity Near the End of Life: The Promise of Relational Decision-Making in the Care of the Dying*, in *ETHICS AT THE END OF LIFE: NEW ISSUES AND ARGUMENTS* 218, 219, 224–27 (John K. Davis ed., 2017) (describing the individualistic conceptualization of autonomy in end-of-life decision-making law).

43. See *supra* text accompanying note 40.

44. This paper will not delve into surrogate decisionmaking for adults who have never had competence.

45. See *supra* Part I.A.

law of surrogate decisionmaking differs by state, with variations on evidentiary standards and procedural processes.⁴⁶ A review of all state laws is beyond the scope of this Article.⁴⁷ Instead, this Section will focus on model laws and highlight a few state laws when illustrating broader points.

Surrogate decisionmaking can be relatively straightforward when it is the case that people have planned for their eventual incapacity.⁴⁸ This planning may take the form of completing a written advance directive with instructions about what medical treatments a person wants at the end of life.⁴⁹ In theory, these directives are then followed upon incapacity, and thus autonomous decisionmaking survives the patient's loss of capacity. People may also have executed a healthcare power of attorney, in which case they have appointed an agent to make decisions on their behalf; the agent is often a family member or close friend.⁵⁰

Many people do not plan for incapacity,⁵¹ however, and so there is a growing movement in health care for physicians to assist with their patient's end-of-life planning by completing Physician Orders for Life-Sustaining Treatment ("POLST") for their elderly or seriously ill patients.⁵² After having a conversation with their patient (or their patient's legally authorized surrogate) about what kinds of treatment they may or may not want, the physician documents these preferences as a medical order to be relied upon in an emergency situation.⁵³ Given that the POLST is a medical order made in consultation with a capacitated patient or their legally authorized surrogate, it is unlikely that this order will be revised (although it can be), and again, as

46. ORENTLICHER ET AL., *supra* note 36, at 320.

47. For a comprehensive summary of state law regarding surrogate decisionmaking, see generally MEISEL ET AL., *supra* note 21.

48. See INSTITUTE OF MEDICINE, DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 122 (2015) [hereinafter IOM] (describing various types of advance directives).

49. Federal law attempted to promote advance directives by directing healthcare facilities to inform patients upon admission about their right to make medical decisions, inquire whether patients have an advance directive, and then document the patients' responses. Patient Self-Determination Act of 1990 ("PSDA"), 42 U.S.C. § 1395cc(f)(1)(A) (2012). Not only has the PSDA not increased the use of advance directives, but healthcare facilities often do not comply with the law's documentation requirements. ORENTLICHER ET AL., *supra* note 36, at 336 (summarizing scholarly literature on the success of the PSDA).

50. Jiska Cohen-Mansfield et al., *The Decision to Execute a Durable Power of Attorney for Health Care and Preferences Regarding the Utilization of Life-Sustaining Treatments in Nursing Home Residents*, 151 ARCHIVES INTERNAL MED. 289, 290 (1991).

51. BEAUCHAMP & CHILDRESS, *supra* note 1, at 189; IOM, *supra* note 48, at 125.

52. There is variability in whether providers follow advance directives, which is another reason why there is a push to have a patient's end-of-life preferences put in the form of a physician's order, which will be followed. FURROW ET AL., *supra* note 34, at 359–64 (describing the POLST paradigm).

53. IOM, *supra* note 48, at 173 (defining the POLST paradigm as an approach to advance care planning).

in the case of writing an advance directive, individual autonomy survives incapacity.⁵⁴

In the vast majority of cases in which there are no verbal or written instructions and no healthcare agent, surrogate decisionmakers may try to make what courts have termed a “substituted judgment”⁵⁵; that is, to do what the patient would do if the patient had capacity, which is an attempt to preserve patient autonomy. As the Supreme Court of New Jersey wrote in *In re Conroy*,⁵⁶ when discussing the substituted judgment standard: “The question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself.”⁵⁷

A substituted judgment decision-making standard “commends itself simply because of its straightforward respect for the integrity and autonomy of the individual.”⁵⁸ A substituted judgment “can be done through a thoughtful analysis of the patient’s values during life or through review of formal statements made by the patient when the patient had capacity.”⁵⁹

If making a substituted judgment is not possible, then surrogate decisionmakers will make a decision according to what is in the incapacitated patient’s best interest. In order to discontinue medical treatment under the best interests test as described in *In re Conroy*,

the net burdens of the patient’s life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient’s life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane.⁶⁰

The law also recognizes that incapacitated persons will sometimes have no family or friends who can act as surrogate decisionmakers, or that sometimes family members may not be the best surrogates. In these cases, courts

54. *Id.* at 173–76. A POLST may not actually be autonomy-promoting, however, if a particular patient prefers that their family members have flexibility over their end-of-life decisions, and the family has not been present for discussion about, and completion of, the POLST. *See also* Stanley A. Terman, *It Isn’t Easy Being Pink: Potential Problems with POLST Paradigm Forms*, 36 *HAMLIN L. REV.* 177, 178–79 (2013) (detailing potential problems with POLST forms).

55. *See, e.g., Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977).

56. 486 A.2d 1209 (N.J. 1985).

57. *Id.* at 1229.

58. *See, e.g., Saikewicz*, 370 N.E.2d at 431.

59. FURROW ET AL., *supra* note 34, at 343.

60. *In re Conroy*, 486 A.2d at 1232.

can appoint a guardian to make decisions on behalf of the incapacitated person,⁶¹ or as in the case of disputes between family members about whether to withhold or withdraw life-sustaining medical treatment for an incompetent patient, the court can itself act as a decisionmaker or guardian.⁶²

While these standards for surrogate decisionmaking evolved through case law, states have also codified the procedure for surrogate healthcare decisionmaking in statutes. The Uniform Health-Care Decision Act,⁶³ model legislation that has been adopted in some states, directs healthcare agents to follow the principal's instructions, or if instructions are unknown, to make a substituted judgment.⁶⁴ If this is not possible, then the Act directs the agent to make a decision in the principal's best interest.⁶⁵ If the patient has not appointed a healthcare agent, then according to the Uniform Health-Care Decision Act, a surrogate decisionmaker will be chosen from the patient's family or social network.⁶⁶ The order of priority for surrogate decisionmakers is the patient's spouse, followed by their adult children, their parents, and finally, their adult siblings.⁶⁷ Should there not be any eligible surrogate decisionmakers from the patient's family, "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available may act as surrogate."⁶⁸ Surrogate decisionmakers also make healthcare decisions based on the patient's instructions, and in the absence of such instructions, make a substituted judgment on the basis of the patient's values.⁶⁹ If there are no instructions and the patient's values are not known, then a surrogate will make decisions in the patient's best interests.⁷⁰

Questions still arise, however, about the degree to which others' interests should be considered when surrogates make end-of-life decisions on behalf of incompetent patients. In the well-known case of Theresa Schiavo, her husband and parents disagreed about whether she should continue to receive

61. See generally Andrew B. Cohen et al., *Guardianship and End-of-Life Decision Making*, 175 JAMA INTERNAL MED. 1687 (describing end-of-life decision-making law in the context of guardianship).

62. *In re Guardianship of Schiavo*, 780 So. 2d 176, 179 (Fla. Dist. Ct. App. 2001) ("In this context, the trial court essentially serves as the ward's guardian.").

63. UNIF. HEALTH-CARE DECISIONS ACT (UNIF. LAW COMM'N 1993). This legislation applies to all healthcare decisions, not just end-of-life decisions.

64. *Id.* § 2(e).

65. *Id.*

66. *Id.* § 5(b).

67. *Id.*

68. *Id.* § 5(c).

69. *Id.* § 5(f).

70. *Id.*

artificial nutrition and hydration in her permanent vegetative state.⁷¹ One court faced with the issue commented:

But in the end, this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo's right to make her own decision, independent of her parents and independent of her husband. In circumstances such as these, when families cannot agree, the law has opened the doors of the circuit courts to permit trial judges to serve as surrogates or proxies to make decisions about life-prolonging procedures. It is the trial judge's duty not to make the decision that the judge would make for himself or herself or for a loved one. Instead, the trial judge must make a decision that the clear and convincing evidence shows the ward would have made for herself. It is a thankless task, and one to be undertaken with care, objectivity, and a cautious legal standard designed to promote the value of life. But it is also a necessary function if all people are to be entitled to a personalized decision about life-prolonging procedures independent of the subjective and conflicting assessments of their friends and relatives. It may be unfortunate that when families cannot agree, the best forum we can offer for this private, personal decision is a public courtroom and the best decision-maker we can provide is a judge with no prior knowledge of the ward, but the law currently provides no better solution that adequately protects the interests of promoting the value of life.⁷²

The court noted neither parents nor judges have the right to make surrogate decisions based on their own values, but instead, surrogate decisions should be based on what the incompetent person would have chosen.⁷³ Words such as "independent," "personal," and "private" are used in this opinion, which again emphasize an understanding of autonomy that is highly individualistic.⁷⁴ Furthermore, the court cautioned that families may even have preferences that conflict with the incompetent person, and care must therefore be taken to ensure that end-of-life decisions are independent of others' preferences.⁷⁵ This recalls the language and concerns of the *Cruzan* court.⁷⁶

As can be seen from this brief review of surrogate healthcare decision-making law, which covers medical decisions that must be made at the end of

71. *In re Guardianship of Schiavo*, 851 So. 2d 182, 183–85 (Fla. Dist. Ct. App. 2003).

72. *Id.* at 186–87 (citations omitted) (citing *In re Guardianship of Browning*, 560 So. 2d 4 (Fla. 1990); FLA. STAT. § 765.401(3) (2000)).

73. *Id.* at 187.

74. *See id.*

75. *Id.*

76. *See supra* text accompanying notes 35–41.

life, the law always privileges autonomy followed by beneficence. The law prefers that people make decisions themselves or through “an individual instruction,”⁷⁷ which is viewed by lawmakers and judges as fairly straightforward respect for autonomous decisionmaking. However, the law recognizes that such decisionmaking will not always be possible, and so, privileges autonomy through a notion of substituted judgment.⁷⁸ State statutes do not direct substituted judgments to consider the individual’s relations with others as part of the examination of their values, beliefs, and preferences; this silence again reveals how law conceptualizes autonomy as individualistic in nature.⁷⁹ Some courts conceive substituted judgments in a way that excludes consideration of any interests besides the incompetent individual, as in the *Schiavo* case, but if there is evidence that the incompetent individual would have made a particular end-of-life decision based on relational interests or in consultation with others, this may become part of the substituted judgment.⁸⁰ On the whole, however, in end-of-life surrogate decision-making law, there is a presumption that preservation of an individual’s autonomy upon incapacity must mean examining their preferences for a particular choice in isolation from how such preferences may be formed in consideration of their relationships with others.⁸¹

77. UNIF. HEALTH-CARE DECISIONS ACT § 1(1) (UNIF. LAW COMM’N 1993).

78. See *supra* text accompanying notes 55–59.

79. See, e.g., N.Y. PUB. HEALTH LAW § 2994-d(4) (McKinney 2015); 20 PA. STAT. AND CONS. STAT. ANN. § 5461(d)(1)(vi) (Supp. 2017).

80. “The law does not generally promote respect for autonomy as including respect for choices that benefit others’ interests over the patient’s interests, even if a competent patient could freely make such decisions.” Shepherd, *supra* note 21, at 1699. But, if a particular person valued making decisions in consideration of their relationships when they were competent, it follows that a healthcare decision made on their behalf could also consider such relationships. *Id.*

Indeed, the actual process of making a substituted judgment may involve consideration of the individual’s family, the impact the decision will have on them, and how the individual viewed their family relationships and responsibilities. For example, in *Conservatorship of Wendland*, during the California court proceedings about a conservator’s request to have artificial nutrition and hydration withheld from their conservatee, the court heard testimony from family members about Wendland’s desire to not burden his children with a prolonged death. 28 P.3d 151, 157 (Cal. 2001). The family offered evidence Wendland had stated: “I would never want to live like that, and I wouldn’t want my children to see me like that and look at the hurt you’re going through as an adult seeing your father like that.” *Id.* In this instance, Wendland’s interest in his family relationships was intertwined with the analysis of his autonomy interests in end-of-life decisionmaking. *Id.* at 168.

Similarly, in *In re Westchester County Medical Center, ex rel. O’Connor*, the New York court heard testimony from an incompetent patient’s family that the patient “desire[d] to remain independent and avoid burdening her children.” 531 N.E.2d 607, 624 (N.Y. 1988) (Simons, J., dissenting). Again, the court connected the analysis of what a patient wanted in regard to medical treatment at the end of life with what they wanted for their family.

In both *Conservatorship of Wendland* and *O’Connor*, the courts ultimately refused to allow for the termination of life-sustaining medical treatment because the evidence of the patients’ wishes did not meet the “clear and convincing” evidentiary standard. *Conservatorship of Wendland*, 28 P.3d at 175; *O’Connor*, 531 N.E.2d at 615.

81. Shepherd, *supra* note 21, at 1699–1700.

C. *Medical Futility Disputes and Discontinuing Life-Sustaining Treatment*

Sometimes physicians determine that providing or continuing to provide a patient with an intervention meant to prolong or sustain life is “futile.” A physician may think that the requested treatment is scientifically or medically futile, in which case the treatment will not have the effect that the patient or surrogate decisionmaker desires.⁸² Or the physician may think that the requested treatment is ethically futile as it “will not serve the underlying interests of the patient”⁸³ and may harm the patient.⁸⁴ When patients or their surrogate decisionmakers disagree with this assessment and insist on the medical intervention, this is known as a medical futility dispute.⁸⁵ The question becomes who is the ultimate decisionmaker: the physician (and hospital ethics committee) or the patient and their representatives.⁸⁶ This directly raises questions about the extent to which an individual’s autonomy in healthcare decisionmaking is respected.

When the disagreement between the physician and the patient or their surrogate decisionmaker cannot be resolved, state statutes or specific hospital policies may provide a process for reaching a decision.⁸⁷ For example, Texas has a futility statute as part of the state’s Advance Directives Act that outlines a detailed procedure to follow when providers refuse to honor a patient’s advance directive or treatment decision because the provider believes that to do so would be futile.⁸⁸ Court cases arising under the Texas futility statute note that providers are the appropriate decisionmaker about whether a treatment is futile, rather than the patient or their family.⁸⁹ Hospitals also often have

82. FURROW ET AL., *supra* note 34, at 444.

83. *Id.* at 445. Some research has shown that clinicians feel distress when asked to provide futile care, and that this distress likely comes from thinking patients or their families do not trust them or from feeling like they are violating a taboo against abusing a dead or dying body. J. Randall Curtis & Robert A. Burt, *Why Are Critical Care Clinicians so Powerfully Distressed by Family Demands for Futile Care?*, 18 J. CRITICAL CARE 22, 23 (2003).

84. IOM, *supra* note 48, at 288 (describing physician assessments of futile care as follows: “the burden on the patient greatly outweighed the benefits, the treatment could never achieve the patient’s goals, death was imminent, and the patient would never be able to survive outside the critical care unit”); *see also* BEAUCHAMP & CHILDRESS, *supra* note 1, at 169–70 (describing seven definitions of futility and arguing that a futility assessment is both a scientific and a value judgment).

85. James L. Bernat, *Medical Futility: Definition, Determination, and Disputes in Critical Care*, 2 NEUROCRITICAL CARE 198, 201 (2005).

86. If a person has been declared dead, however, families have no legal basis to insist on continued mechanical ventilation unless they can dispute the definition of death used. ORENTLICHER ET AL., *supra* note 36, at 392–93.

87. Only a limited number of futility cases make it to court. *Id.* at 385–87 (summarizing the few futility cases).

88. TEX. HEALTH & SAFETY CODE ANN. §§ 166.046, .052, .053 (West 2017).

89. *See, e.g.,* Nikolouzos v. St. Luke’s Episcopal Hosp., 162 S.W.3d 678, 683 (Tex. App. 2005) (Fowler, J., concurring) (“Section 166.046 permits the withdrawal of life-sustaining care for patients

written policies about how to handle conflict between healthcare providers and their patients in cases in which providers think a requested intervention would be futile.⁹⁰

Law and policy attempt to accommodate all actors' views by encouraging shared decisionmaking, but often weigh a provider's professional judgment more heavily. If consensus cannot be reached, the provider's judgment ultimately trumps the patient's autonomy. Indeed, the principle of medical futility has come to be seen as an exception to the principle of patient autonomy in the realm of healthcare decisionmaking.⁹¹

D. Physician Aid in Dying

Physician aid in dying ("physician AID"),⁹² in which a mentally competent, terminally ill adult voluntarily hastens death by ingesting a lethal drug prescribed by a physician, is, at the time of this writing, legal, with strict eligibility requirements, in seven U.S. jurisdictions: Oregon, Washington, Vermont, Montana, California, Colorado, and the District of Columbia.⁹³

Oregon was the first state to permit physician AID. In 1994, the citizen-initiated Death with Dignity Act⁹⁴ passed and then survived challenges at both the state and federal levels.⁹⁵ Washington legalized physician AID, also via voter initiative, in 2008.⁹⁶ In 2009, the Supreme Court of Montana held

who are not brain dead if the hospital's ethics committee has determined that the care is inappropriate.").

90. BEAUCHAMP & CHILDRESS, *supra* note 1, at 170. Some hospitals emphasize that providers should communicate clearly, honestly, and respectfully with patients and their families. Such policies assert that, whenever possible, conflict should be avoided, but if it cannot, the policies outline procedures to resolve the conflict. *See, e.g.*, FURROW ET AL., *supra* note 34, at 440–44 (providing examples of hospital futility policies); *see also* NANCY BERLINGER ET AL., THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE 57 (2d ed. 2013) (advising clinicians to avoid using the term "futile" and instead emphasizing how the requested intervention will not meet treatment goals).

91. Curtis & Burt, *supra* note 83, at 22; *see also* BEAUCHAMP & CHILDRESS, *supra* note 1, at 170 ("Respect for the autonomy of patients or authorized surrogates is not a trump that allows them alone to determine whether a treatment is futile."). *But see* Nancy S. Jecker, *Medical Futility and Respect for Patient Autonomy*, in ETHICS AT THE END OF LIFE: NEW ISSUES AND ARGUMENTS 138, 149 (John K. Davis ed., 2017) (arguing that respect for autonomy does not mean that patients or surrogates receive care they demand because, "[p]roperly understood, autonomy requires that competent adults be allowed to choose from among medically appropriate options, or reject all options").

92. There are many terms used in the literature to reference this end-of-life decision. Advocates tend to call it "aid in dying" or "death with dignity." Opponents tend to call it "assisted suicide." *See* FURROW ET AL., *supra* note 34, at 449–50 (discussing the controversy over terminology).

93. The Supreme Court of New Mexico recently failed to find a right to physician AID under its state constitution. *Morris v. Brandenburg*, 376 P.3d 836, 857 (N.M. 2016).

94. OR. REV. STAT. §§ 127.800–.897 (2015).

95. *Gonzales v. Oregon*, 546 U.S. 243, 275 (2006) (holding that Oregon's Death with Dignity Act did not violate the federal Controlled Substances Act).

96. WASH. REV. CODE ANN., §§ 70.245.010–.903 (West 2011).

that physician-assisted suicide did not constitute homicide under Montana's criminal law.⁹⁷ Vermont's legislature passed the Patient Choice and Control at End of Life Act in 2013.⁹⁸ The California legislature passed the End of Life Option Act in 2015,⁹⁹ which assured that a significant proportion of the United States population would have access to this end-of-life option. Finally, residents in Colorado and the District of Columbia voted in the fall of 2016 to legalize physician AID.¹⁰⁰

The words used to name the legislation permitting physician AID demonstrate the central importance of autonomy in this body of law: "dignity,"¹⁰¹ "choice," "control," and "options."¹⁰² Further, the rationale for passing such laws also demonstrates the underlying motivation of preserving autonomous choice to end one's life on one's own terms. As California Governor Jerry Brown stated upon signing the law,

In the end, I was left to reflect on what I would want in the face of my own death. I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others.¹⁰³

There is no federal right to physician AID. When advocates for the practice litigated the question of whether, like the right to hasten death by refusing life-sustaining treatment, physician AID is a constitutional right, the Supreme Court held that there is no fundamental constitutional right under the Fourteenth Amendment Due Process Clause to access this method of dying.¹⁰⁴ In *Washington v. Gluckberg*,¹⁰⁵ the Court argued, "That many of the

97. *Baxter v. Montana*, 224 P.3d 1211, 1222 (Mont. 2009).

98. VT. STAT. ANN. tit. 18, §§ 5281–5293 (Supp. 2016).

99. CAL. HEALTH & SAFETY CODE §§ 443–444.12 (West 2016) (some parts of the law have been repealed, but the provisions discussed in this paper at the time of writing remain good law).

100. COLO. REV. STAT. ANN. §§ 25-48-101–123 (West 2017); D.C. CODE §§ 7-661.01–.17 (2001); see also Thaddeus Mason Pope, *DC Death with Dignity Survives Federal Congress Repeal*, MEDICAL FUTILITY BLOG (Mar. 23, 2018), <http://medicalfutility.blogspot.com> (describing the federal congressional efforts to repeal the D.C. Death with Dignity Act).

101. "Dignity" is an oft-used but rarely defined word. It can encompass autonomy and control in decisionmaking, however. Annette F. Street & David W. Kissane, *Constructions of Dignity in End-of-Life Care*, 17 J. PALLIATIVE CARE 93 (2001).

102. See *supra* text accompanying notes 94–99.

103. Letter from Edmund G. Brown Jr., Governor, Cal., to Members of the Cal. State Assembly (Oct. 5, 2015), heartwiredforchange.com/wp-content/uploads/2017/04/ABX2_15_Signing_Message.pdf; see also Patrick McGreevy, *After Struggling, Jerry Brown Makes Assisted Suicide Legal in California*, L.A. TIMES (Oct. 5, 2015, 5:50 PM), <http://www.latimes.com/local/political/la-me-pc-gov-brown-end-of-life-bill-20151005-story.html>.

104. *Washington v. Glucksberg*, 521 U.S. 702, 709 (1997). In another case decided in the same term, the Supreme Court held that a state ban on physician-assisted suicide did not violate the Fourteenth Amendment's Equal Protection Clause. *Vacco v. Quill*, 521 U.S. 793, 797 (1997).

105. 521 U.S. 702 (1997).

rights and liberties protected by the Due Process Clause sound in personal autonomy does not warrant the sweeping conclusion that any and all important, intimate, and personal decisions are so protected”¹⁰⁶ The Court acknowledged, however, that end-of-life laws and policies were changing to ensure “dignity and independence” for a population likely to die in institutions after suffering from chronic conditions given technological and medical advancements that can prolong life.¹⁰⁷ The language in this refusal to find a right to physician AID underscores how the Supreme Court conceptualizes autonomy in this end-of-life option: autonomy is “personal” decisionmaking,¹⁰⁸ which is meant to ensure independence.¹⁰⁹

In sum, proponents of physician AID laws describe them in terms of an individual’s right to choose to die, and the conceptualization of autonomy in the law is mostly abstracted from social relationships.¹¹⁰ It is one’s relation to others, however, that the Supreme Court and opponents of physician AID fear will compromise autonomy for some “vulnerable” persons with respect to this end-of-life option.¹¹¹

II. END-OF-LIFE DECISION-MAKING PREFERENCES AND RELATIONAL AUTONOMY

The previous Part demonstrated how end-of-life decision-making law and policy conceives of autonomy as personal, private, and independent decisionmaking. This Part will demonstrate, however, that in the end-of-life decision-making context, ordinary people conceive of autonomous decisionmaking much differently. While many people want to make decisions

106. *Id.* at 727 (citing *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 33–35 (1973)).

107. *Id.* at 716 (“Because of advances in medicine and technology, Americans today are increasingly likely to die in institutions, from chronic illnesses. Public concern and democratic action are therefore sharply focused on how best to protect dignity and independence at the end of life, with the result that there have been many significant changes in state laws and in the attitudes these laws reflect.” (citation omitted) (citing PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 16–18 (1983))).

108. *Id.* at 727. Indeed, those petitioning the Court for a constitutional right to physician AID argued that the Court’s substantive due process jurisprudence is about “self-sovereignty” and “personal autonomy,” which again abstracts individuals from their social relationships. *Id.* at 723–24 (quoting Brief for Respondents at 10, 12, *Glucksberg*, 521 U.S. 702 (No. 96–110)).

109. *Id.* at 716.

110. An important exception is contained in the form of the requests for physician AID in some states wherein a patient is asked whether they have family members who have been informed about the decision to use physician AID. *See infra* Part III.

111. *See Glucksberg*, 521 U.S. at 731–32 (“The risk of harm is greatest for the many individuals in our society whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatized social group.” (quoting NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, *WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT* 120 (1994))); *infra* text accompanying note 273.

on the basis of their values and preferences, which aligns with the legal understanding of autonomous decisionmaking, their preferred decision-making process is often in consultation or even collaboration with family members and physicians, and they may also decide on the basis of others' interests. That is, people understand autonomy as relational and interdependent, in contrast to the legal conceptualization of autonomy as individual and independent.

This Part will begin with a review of empirical literature on what people in the United States want at the end of life and how they make end-of-life decisions, and will analyze the role and understanding of autonomy in such preferences and actions. Next, this Part will describe physician use of shared decision-making models, which are an attempt to respond to patient preferences. Given that it is reasonable to expect that preferences differ within a society, this Part will also note end-of-life decision-making preferences for different racial and ethnic groups. This Part will conclude with a discussion of the concept of relational autonomy.

A. *Patient and Family End-of-Life Decision-Making Preferences*

1. *Values, Preferences, and Interests at the End of Life*

It has only been in the last twenty years that scholars have devoted their attention to asking people what they want at the end of life. This timeline matters because U.S. end-of-life decision-making law, including the definition of autonomy and beneficence within this body of law, was largely settled prior to knowing people's preferences.¹¹² So what is it that people want and value at the end of life?

The foundational study of American end-of-life values and preferences, published nearly two decades ago, demonstrates that people confronting death primarily value caring relationships with family, friends, and physicians.¹¹³ In this study, Steinhauer and colleagues surveyed Veterans Affairs

112. The law of refusing life-sustaining treatment was decided at the state level beginning in the 1970s and was constitutionalized in 1990. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990); *In Re Quinlan*, 355 A.2d 647 (N.J. 1976). Surrogate decision-making laws date prior to this time period as well. See, e.g., UNIF. HEALTH-CARE DECISIONS ACT (UNIF. LAW COMM'N 1993). Physician aid in dying laws were first passed in 1994. See OR. REV. STAT. §§ 127.800–897 (2015). Perhaps the only area of end-of-life decision-making law that remains unsettled is medical futility law. See *supra* Part I. Even if preferences were known, however, they may not have been incorporated into the common law. See Lois Shepherd & Mark A. Hall, *Patient-Centered Health Law and Ethics*, 45 WAKE FOREST L. REV. 1429, 1432 (2010) (describing how “the patient is often absent as an active participant in the shaping of law”). But at least knowing preferences can influence biomedical ethics policy formation.

113. Karen E. Steinhauer et al., *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, 284 JAMA 2476, 2476 (2000).

patients with advanced disease, people who had recently lost a family member to disease, and physicians and others involved in end-of-life care, such as chaplains, and found broad consensus amongst all survey respondents about what matters at the end of life.¹¹⁴ In particular, the study revealed that all participants wanted to be able to say goodbye to loved ones who were prepared for the impending death, be around friends, not die alone, and be known and well cared for well by healthcare professionals with whom one could discuss their fears.¹¹⁵ These concerns encompass relationships with family,¹¹⁶ friends, and healthcare providers.¹¹⁷ Patient respondents differed from physician respondents in terms of some of the things they thought mattered at the end of life, however.¹¹⁸ Among the factors patients considered important, but physicians did not, were “not being a burden to family or society [and] being able to help others.”¹¹⁹ It thus appears that physicians may underestimate the importance of some relational dimensions of life to dying patients.

114. *Id.* This article has been cited almost 2,000 times since its publication. Search of Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers, GOOGLE, <http://www.google.com>.

115. Steihauser et al., *supra* note 113, at 2478–79. All respondents also thought adequate pain relief, preparation for death (e.g., getting financial affairs in order and deciding on medical treatment preferences in advance), and maintaining dignity to the end were important factors. *Id.* Importantly, however, the authors note that dying is still highly personal and that end-of-life care providers should determine what is important to individuals they care for. *Id.* at 2482.

116. This Article uses a broad definition of family, similar to that used by bioethics and medical associations. A leading bioethics organization wrote the following about “family”:

“Family” . . . may include close friends or an intimate partner whose relationship to the person may or may not be recognized by the law. It may include a relative, friend, or paid caregiver who serves as the patient’s designated care partner by accompanying the patient to treatment and helping the patient to coordinate care. It may include the patient’s appointed health proxy or surrogate decision-maker. The family may include individuals who love the sick person deeply and individuals who detest this person, or individuals immobilized by the circumstances of their emotions. It may include someone who does not want the sick person to die, and someone who wishes this person dead sooner rather than later.

BERLINGER ET AL., *supra* note 90, at 26. Similarly, the IOM writes that family includes “spouses, blood relatives, in-laws, step-relatives, fiancés, significant others, friends, caring neighbors, colleagues, fellow parishioners or congregants, and other people . . . ‘for whom it matters.’” IOM, *supra* note 48, at 45–46.

117. Steihauser et al., *supra* note 113, at 2478–79.

118. *Id.* at 2479.

119. *Id.* Patients’ concerns about being a burden are well-grounded in reality. The empirical literature demonstrates that medical care at the end of life is often financially burdensome, both as a proportion of Medicare or Medicaid spending and on families who pay out of pocket for medical care. See IOM, *supra* note 48, at 289, 300–01 (summarizing statistics on spending on medical care at the end of life). Indeed, the cost of medical care at the end of life is patients’ highest concern, especially as it relates to burdening their families. *Id.* at 350 (surveying research on patient concerns about medical care at the end of life). As one person who submitted testimony to the IOM stated, “the emotional cost is great, the financial cost is astronomical.” *Id.* at 451.

Studies of non-veteran populations had similar findings regarding the importance of relationality. A recent review of empirical literature demonstrates that many psychosocial and relational factors are important to people at the end of life.¹²⁰ Significantly, many dying patients report that relationships matter to them at the end of life; that being with family and friends and strengthening these relationships is important; and that having good relationships with healthcare professionals who treat them with dignity and support them and their families with all of their end-of-life needs (including non-medical needs) is also a key concern.¹²¹ For patients without close family, it is especially crucial to them that their healthcare providers care about them and treat them compassionately.¹²² While some patients prefer privacy at the end of life, others find that being around patients who are similarly situated is helpful and value their interactions with these patients.¹²³ Thus, at the end of life, people care both about mending and maintaining existing relationships and also developing new, supportive relationships, highlighting the significant role of relationality in this context.

2. Preferences Regarding End-of-Life Decisionmaking

While the previous Section demonstrates that relationships matter to people at the end of life, it is still necessary to determine people's perspectives on autonomy—the fundamental principle in end-of-life decision-making law and policy—and whether people want others involved in their healthcare decision-making processes at the end of life. One study, relying on focus groups of bereaved family members across the country, sheds some

Surrogate decisionmaking is also emotionally burdensome to families who feel like they do not have adequate information about what their loved one would decide in a particular situation. The majority of people do not want their family to be burdened or stressed by making medical decisions on their behalf. *See id.* at 350; BERLINGER ET AL., *supra* note 90, at 54.

Finally, actually providing care at the end of life is difficult and exhausting for informal, untrained family caregivers. *See IOM, supra* note 48, at 312–13. Indeed, research has demonstrated that the majority of people, should they be completely dependent on another for care, would choose to refuse life-sustaining treatment. *Id.* at 348. Furthermore, about a third of people report that they believe there should be a right to suicide if they are a burden on others, although this differs by race. *Id.* at 347–48 (describing results from a nationally representative survey about end-of-life preferences).

120. Anecdotes from clinicians support this as well. *See, e.g.,* Lydia S. Dugdale, *Conclusion: Toward a New Ethical Framework for the Art of Dying Well*, in DYING IN THE TWENTY-FIRST CENTURY: TOWARD A NEW ETHICAL FRAMEWORK FOR THE ART OF DYING WELL 173, 183–87 (Lydia S. Dugdale ed., 2015). Other factors important at the end of life included “being mentally aware, having funeral arrangements planned, feeling that one’s life was complete . . . coming to peace with God, and praying.” Steinhauser et al., *supra* note 114, at 2479.

121. Tuva Sandsdalen et al., *Patients’ Preferences in Palliative Care: A Systematic Mixed Studies Review*, 29 PALLIATIVE MED. 399, 411, 413 (2015).

122. *Id.* at 413–15.

123. *Id.* at 414.

light on this. This study revealed that the most significant concerns for those receiving medical care at the end of life include not only physical comfort and pain relief, but also controlling everyday decisions, sharing in the medical decisionmaking with healthcare providers (rather than feeling abandoned to make such decisions alone), and ensuring that family members are supported in their caregiving efforts and when they are grieving.¹²⁴ This study demonstrates that dying patients want to be in charge of their healthcare decisions, and they prefer to decide in collaboration with clinicians and in consideration of their families.

More recent studies make clear that patients value their autonomy when making decisions at the end of life, but that this autonomy is exercised in a relational manner in which families and physicians are invited to participate in decisionmaking. A systematic review of studies examining the values of people receiving palliative care in a final stage of illness provides insight into what matters to patients in their end-of-life decisionmaking.¹²⁵ Patients want their families involved in end-of-life decisionmaking to some degree, which may, in some cases, mean informing families about the illness and healthcare decisions or, in other cases, desiring family input or assistance in making decisions.¹²⁶ To further their autonomy and ensure their values are respected and considered when making decisions, patients also generally desire clear information from healthcare staff about their illness, and to make decisions about their medical care in consultation with the treatment team.¹²⁷

The previously described empirical studies are based on responses to survey or interview questions.¹²⁸ However, social scientists have also studied medical decisionmaking *in action*, and their findings make clear that the *practice* of autonomy in end-of-life decisionmaking accords with *discourse* about autonomy in end-of-life decisionmaking. For example, a qualitative study of in-patient hospice patients illustrates actively dying, capacitated persons making end-of-life decisions in consultation with, and in consideration of, family members.¹²⁹ In this study, the authors found that the primary reason that dying individuals were using in-patient hospice was to reduce the

124. Joan M. Teno et al., *Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members*, 22 J. PAIN & SYMPTOM MGMT. 738, 745, 749 (2001). In this study, the authors argue for a “patient-focused, family-centered [end-of-life] medical care” that is “focused on the patient, but . . . also acknowledges the important role of family members,” and attempts to promote quality of life for both groups. *Id.* at 745 (emphasis omitted).

125. Sandsdalen et al., *supra* note 121.

126. *Id.* at 414.

127. *Id.* There is variation in preferences, however, in that some patients wanted to defer decisionmaking to others. *Id.* Those who do want to participate in medical decisionmaking expressed a desire to have access to healthcare personnel for help and coordinated care. *Id.*

128. *See id.* at 403–10 (listing and describing the nature of the studies used).

129. Alex Broom & Emma Kirby, *The End of Life and The Family: Hospice Patients’ Views on Dying as Relational*, 35 SOC. HEALTH & ILLNESS 499 (2013).

burden and stress on their families from providing care or witnessing the physiological decline of their loved one.¹³⁰ As one study participant stated, “I would prefer to be at home. Um, but then again, by the same token, if hubby doesn’t think he can cope, which, it may come to that point, where he can’t cope, with the whole physical thing, the mental thing of me being at home, then I will willingly come in [again].”¹³¹ Notably, this participant has different preferences from her family members, but *willingly* chooses to prioritize their preferences, exercising autonomy in a relational way. The patients in this study also show how being in hospice provides an opportunity to say goodbye to loved ones and improve relationships at the end-of-life.¹³² Every single patient in the study, regardless of whether they had close relationships with their family members, “expressed considerable concern regarding their family’s capacity to cope and the broader impact of their dying process on families and relationships.”¹³³

It thus appears that persons making decisions in the end-of-life context do not view autonomous decisionmaking as inconsistent with the participation or consideration of others.

3. *Surrogate Decisionmaking*

Given that some people will ultimately be unable to make medical decisions for themselves at the end of life, it is necessary to analyze patient autonomy with respect to the many empirical studies about surrogate decisionmaking. One body of literature demonstrates that there is discordance between what medical decisions an individual would make at the end of life, and what their surrogate would decide for the individual, even when trying to decide based on the individual’s values.¹³⁴ This discrepancy has led many to advocate for people to complete advance directives that specify their wishes at the end of life in order to preserve autonomy upon incapacity,¹³⁵

130. *Id.* at 503–06.

131. *Id.* at 503 (alteration in original).

132. *Id.* at 504.

133. *Id.* at 505.

134. See, e.g., Nina A. Kohn, *Improving Healthcare Decisions Through a Shared Preferences and Values Approach to Surrogate Selection*, in *NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS* 297, 298–300 (I. Glenn Cohen et al. eds., 2016) [hereinafter *NUDGING HEALTH*] (summarizing studies on surrogate decisionmaking); Stephen C. Hines et al., *Improving Advance Care Planning by Accommodating Family Preferences*, 4 *J. PALLIATIVE MED.* 481, 482, 485–87 (2001) (finding discordance between individual preferences and surrogate decisions).

135. Nikki Ayers Hawkins et al., *Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making*, 45 *GERONTOLOGIST* 107, 107, 113–14 (2005). Many have critiqued the emphasis on autonomy in advance directives given that people value more than just autonomy in healthcare decisionmaking, including family relationships. IOM, *supra* note 48, at 125; Theresa S. Drought & Barbara A. Koenig, “Choice” in *End-of-Life Decision Making: Researching Fact or Fiction?*, 42 *GERONTOLOGIST* 114, 118 (2002) (“It is the relationship that

but few people complete such directives.¹³⁶ The reasons for this are numerous, but include a desire to avoid discussing death,¹³⁷ a preference to provide verbal rather than written instructions, and a preference to delegate decision-making responsibility and flexibility.¹³⁸ Surrogates may prefer more precise instructions, however,¹³⁹ because making a decision often causes them immense stress,¹⁴⁰ which can be somewhat alleviated if surrogates think they are making the decision the patient would have made.¹⁴¹

Surrogates' preferences for precise instructions show that they respect the autonomy of the person for whom they are deciding, and they understand respecting this autonomy to be deciding as the patient would decide. In cases in which surrogates are uncertain of the patient's preferences, surrogates may be comforted to know that most patients want others to share in the decision-making process. Assuming the surrogate is a family member, a competent patient would likely make the decision at least in part based on the surrogate's input. Furthermore, even if a surrogate decides differently than a competent patient would decide, patients still believe surrogates respect their autonomy as long as the surrogate has decided conscientiously in light of the patient's values.¹⁴² Therefore, absence of specific information about patient preferences about the particular end-of-life decision as well as discordance between patient and surrogate choices may be less critical to respecting autonomy than surrogates (and the law) presume.

matters, yet the relational values patients hold and want preserved through their advance directive (and symbolically charged appointments of surrogates) cannot be accounted for by the autonomy paradigm.”).

136. BEAUCHAMP & CHILDRESS, *supra* note 1, at 189 (describing multiple problems with advance directives, including that persons do not complete them); IOM, *supra* note 48, at 125.

137. See IOM, *supra* note 48, at 117, 350–51; Linda Briggs, *Shifting the Focus of Advance Care Planning: Using an In-Depth Interview to Build and Strengthen Relationships*, 7 J. PALLIATIVE MED. 341, 347 (2004).

138. Hawkins et al., *supra* note 135, at 113; Hines et al., *supra* note 134, at 487; see also Joseph J. Fins et al., *Contracts, Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy*, 29 J. PAIN & SYMPTOM MGMT. 55, 56, 64–65 (2005) (describing how proxies can deviate from patient instructions without feeling like they are violating the patient's autonomy because discretion in making clinical choices is often necessary, and through their appointment as proxies, they have procedural moral authority to deviate from the substance of decisions).

139. Hines et al., *supra* note 134, at 487. But patients want their families to have more flexibility in decisionmaking. *Id.*

140. IOM, *supra* note 48, at 129, 137–39 (summarizing research that shows many surrogate decisionmakers experience “negative psychological impact”); Briggs, *supra* note 137, at 347.

141. BEAUCHAMP & CHILDRESS, *supra* note 1, at 191 (summarizing research findings on surrogate decisionmaking).

142. Michael Cholbi, *Grief and End-of-Life Surrogate Decision-Making*, in *ETHICS AT THE END OF LIFE: NEW ISSUES AND ARGUMENTS* 201, 214–15 (John K. Davis ed., 2017) (arguing that choosing someone to make decisions bestows an honor on the chosen surrogate).

4. *Physician-Patient Relationships and Shared Decisionmaking*

As discussed previously, patients prefer to make end-of-life decisions with their healthcare providers, although this does not always happen in practice. Indeed, many empirical studies have found that patients desire better communication, the foundation of the physician-patient relationship, with their healthcare providers when it comes to decisionmaking at the end of life.¹⁴³ Physicians are often uncomfortable having such conversations or do not have the time to discuss these matters.¹⁴⁴ The literature also demonstrates that patients have non-medical concerns at the end of life, but physicians rarely address them, instead focusing solely on medical issues such as treatment, even when patients raise issues such as autonomy, maintaining control, and concerns for family members and relationships.¹⁴⁵ However, having conversations about end-of-life decisions is associated with greater patient well-being and family adjustment after patient deaths; such conversations are not associated with patient distress.¹⁴⁶

Given these consistent patient preferences about their relationship with their doctors, it is useful to review a medical decision-making model that attempts to improve physician-patient communication and accommodate patient values and concerns in the decision-making process. This process is known as shared decisionmaking, which is viewed “as a compromise in the longstanding debate about the relative role of patient autonomy and provider beneficence in medical decision-making.”¹⁴⁷ According to the Institute of

143. See IOM, *supra* note 48, at 351 (reviewing literature showing that most people want, but do not receive, good communication with clinicians at the end of life).

144. Rachele E. Bernacki & Susan D. Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174 JAMA INTERNAL MED. 1994, 1996, 1998 (2014) (reviewing scholarly literature about physicians’ role in end-of-life decisionmaking); see also IOM, *supra* note 48, at 117, 159–62 (describing how patients and families are often emotional when discussing poor prognoses, and physicians are uncomfortable performing emotional labor). The perception of time constraints is likely accurate given that these conversations may not always be reimbursed, or reimbursed at a high rate. Even though there have been recent changes to Medicare reimbursement for such conversations, there remains a cultural fear of having the government pressure people to hasten their death in order to save money. Jonel Aleccia, *Doctors Bill Medicare for End-of-Life Advice as “Death Panel” Fears Reemerge*, PBS NEWSHOUR (Feb. 15, 2017), <http://www.pbs.org/newshour/runtdown/doctors-bill-medicare-end-life-advice-death-panel-fears-reemerge/>; see also IOM, *supra* note 48, at 367–69 (arguing that the fear about “death panels” misunderstands the role and importance of discussions about end-of-life decisions).

145. Bernacki & Block, *supra* note 144, at 1998 (reviewing scholarly literature focusing on end-of-life discussions).

146. *Id.* at 1996.

147. IOM, *supra* note 48, at 166 (quoting Meredith Stark & Joseph J. Fins, *What’s Not Being Shared in Shared Decision-Making?*, 43 HASTINGS CTR. REP. 13, 13 (2013)).

Medicine (“IOM”), shared decisionmaking is the “standard for [patient-centered] good care.”¹⁴⁸ The goal of shared decisionmaking is, in part, to ensure that the patient’s medical care conforms to their values and preferences,¹⁴⁹ and to allow for the possibility that some patients will prefer to defer to their physician’s judgment and authority.¹⁵⁰

Shared decisionmaking has been described as follows:

Most simply put, the physician’s role is to use his or her training, knowledge, and experience to provide the patient with facts about the diagnosis and about the prognoses without treatment and with alternative treatments. The patient’s role in this division of labor is to provide the values—his or her own conception of the good—with which to evaluate these alternatives, and to select the one that is best for himself or herself.¹⁵¹

In ideal shared decisionmaking, all parties understand the important factors underlying the decision, and together make the decision about how best to proceed.¹⁵² Clinician-scholars emphasize that shared decisionmaking—which is meant to respect patients’ autonomy—does not mean abandoning patients, but instead, “support[s] autonomy by building good relationships, respecting both individual competence and interdependence on others.”¹⁵³

148. *Id.* This is especially so in the context of chronic illness in which “an ongoing partnership needs to be developed between the clinical team, the patient and the family.” Tim Rapley, *Distributed Decision Making: The Anatomy of Decisions-in-Action*, 30 SOC. HEALTH & ILLNESS 429, 433 (2008).

149. IOM, *supra* note 48, at 166–67.

150. Lisa M. Lines et al., *Patient-Centered, Person-Centered, and Person-Directed Care: They Are Not the Same*, 53 MED. CARE 561, 561 (2015). Notably, leading bioethicists argue that “no fundamental inconsistency exists between autonomy and authority if individuals exercise their autonomy in choosing to accept an institution, tradition, or community that they view as a legitimate source of direction.” BEAUCHAMP & CHILDRESS, *supra* note 1, at 105 (discussing the case of religious and medical authority).

151. Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 KENNEDY INST. ETHICS J. 28, 28 (1991). The Institute of Medicine defines shared decisionmaking as a process that includes physicians:

eliciting and understanding the patient’s perspective; understanding the patient’s psychosocial and emotional context; developing a shared understanding of the clinical problem and its appropriate treatment, given the patient’s goals, preferences, and values; and empowering patients, which is achieved through active involvement of patients in decision making.

IOM, *supra* note 48, at 166–67.

152. Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—The Pinnacle of Patient-Centered Care*, 366 NEW ENG. J. MED. 780, 781 (2012).

153. Glyn Elwyn et al., *Shared Decision Making: A Model for Clinical Practice*, 27 J. GEN. INTERNAL MED. 1361, 1361 (2012). Patients want their physicians to aid in making end-of-life decisions because they may feel abandoned if left alone with the choice. Drought & Koenig, *supra* note 135, at 122 (“A few patients expressed the feeling that offering choice reflected incompetence or indifference on the provider’s part.”).

Clinician-scholars also note that patients “are not entirely free, self-governing agents but that [their] decisions will always relate to interpersonal relationships and mutual dependencies.”¹⁵⁴ The IOM notes, however, that it is difficult to shift from a culture of physician paternalism, and so shared decisionmaking may not occur in practice, despite the vast majority of patients’ and surrogates’ desires to the contrary.¹⁵⁵ The IOM reports that rather than physicians engaging with patients and families in decisionmaking, “[p]eople feel that explanations are rushed, issues are not explained, choices are not understood, and clinicians do not listen” and, that “[g]ood communication, by contrast, is greatly appreciated.”¹⁵⁶

Contemporary guidance about shared decisionmaking also includes a heavy focus on involving family in the medical decision-making process,¹⁵⁷ given that “important health decisions are usually not made in isolation . . . [but] are usually made in the context of social networks with friends, family, other social contacts, and health care professionals.”¹⁵⁸ While family involvement may be important in a variety of healthcare decision-making contexts, it is crucial for end-of-life planning and decisions.¹⁵⁹ There are two reasons for the importance of family involvement at the end of life. First, having family involved in end-of-life decisionmaking reflects patients’ preferences for such involvement, as described above. Second, given that most

154. Elwyn et al., *supra* note 153, at 1361–62.

155. IOM, *supra* note 48, at 351; *see also* Barry & Edgman-Levitan, *supra* note 152, at 781 (describing how physicians are not ceding paternalistic control over decisionmaking, although patients desire to be actively involved in decisionmaking and often do become involved when given the opportunity); Hines et al., *supra* note 134, at 487 (describing how surrogates desire shared decisionmaking with physicians); Laura C. Hanson et al., *What is Wrong with End-of-Life Care? Opinions of Bereaved Family Members*, 45 J. AM. GERIATRICS SOC. 1339, 1343 (1997) (“Because current practices emphasize individual autonomy rights, physicians may overlook family or purposely exclude them from key clinical discussions.”).

“Paternalism” in this context can be defined as “the intentional overriding of one person’s preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefitting or of preventing or mitigating harm to the person whose preferences or actions are overridden.” BEAUCHAMP & CHILDRESS, *supra* note 1, at 215 (emphasis omitted).

156. IOM, *supra* note 48, at 351.

157. Barry & Edgman-Levitan, *supra* note 152, at 780–81 (“[S]hared decision making . . . involves, at minimum, a clinician and the patient, although other members of the health care team or friends and family members may be invited to participate.”). However, this is a relatively recent development, given that bioethicists and clinicians previously ignored the role of the patient’s family. *See* HILDE LINDEMANN NELSON & JAMES LINDEMANN NELSON, *THE PATIENT IN THE FAMILY: AN ETHICS OF MEDICINE AND FAMILIES* 84 (1995).

158. Ronald M. Epstein & Richard L. Street, *Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness*, 9 ANNALS FAM. MED. 454, 456 (2011) (citing Beth A. Lown et al., *Mutual Influence in Shared Decision Making: A Collaborative Study of Patients and Physicians*, 12 HEALTH EXPECTATIONS 160, 160–74 (2009)).

159. IOM, *supra* note 48, at 167; *see also* Jennings, *supra* note 42, at 228 (noting the shift towards prioritizing relational decisionmaking at the end-of-life with “consensus building among providers, surrogates, and family members, and the dying person, if capacity has not been lost”).

people do not have advance directives, the family may ultimately end up being surrogate decisionmakers with no written instructions, and so, the family needs to be involved earlier in the decision-making process. Earlier involvement may assist the family in gathering information necessary to know how to make a decision that best accords with the patient's values based on the options available given the specific illness.¹⁶⁰

A patient's preference for the clinical model of shared decisionmaking demonstrates that everyday decision makers such as patients and their families understand the involvement of multiple parties in a decision to be compatible with autonomous choice in the context of health care and end-of-life decisionmaking.

In sum, when making an end-of-life decision, relationships matter in two ways. First, an individual may take into account others' views and interests. Second, an individual may actually involve others, such as their physician or family members, in the decision-making process.¹⁶¹

5. *Are End-of-Life Decision-Making Preferences and Values Universal?*

In the United States, people subject to end-of-life law and policy are not a homogeneous group. The United States is a racially, ethnically, and culturally diverse nation.¹⁶² Thus, prior to making normative and prescriptive arguments that impact everyone, it is sensible to examine whether there are distinct end-of-life values and preferences by race, ethnicity, and culture.

With respect to end-of-life decisionmaking, bereaved African American family members report a desire for physicians to honestly, openly, compassionately, and respectfully communicate with them about what is happening at the end of their loved one's life, and to inquire about the family's wishes about end-of-life care.¹⁶³ These findings about African American end-of-life

160. Larry W. Foster & Linda J. McLellan, *Translating Psychosocial Insight into Ethical Discussions Supportive of Families in End-of-Life Decision-Making*, 35 SOC. WORK IN HEALTH CARE 37, 38–39 (2002); Lee H. Igel & Barron H. Lerner, *Moving Past Individual and "Pure" Autonomy: The Rise of Family-Centered Patient Care*, 18 AM. MED. ASS'N. J. ETHICS 56, 58 (2016); see also Hines et al., *supra* note 134, at 487 (recommending that physicians obtain prior patient consent before physicians directly talk with surrogates).

161. Indeed, leading guidance for clinicians on end-of-life decisionmaking advises that clinicians respect patient self-determination, but also notes,

[r]espect for persons also recognizes that individuals are social beings who may consider the interests of others when making decisions and who may choose to make decisions in consultation or collaboration with loved ones or with other trusted individuals.

BERLINGER ET AL., *supra* note 90, at 14.

162. See IOM, *supra* note 48, at 38 (advising physicians to expect to care for a diverse population).

163. Carolyn Jenkins et al., *End-of-Life Care and African Americans: Voices from the Community*, 8 J. PALLIATIVE MED. 585, 587–88 (2005).

preferences are similar to the findings of studies that survey the preferences of broader populations.¹⁶⁴ Indeed, scholars have noted a similarity amongst racial groups with respect to desires for better communication with physicians.¹⁶⁵ And again, similar to what matters at the end of life for the general population, African Americans report a desire not to burden their families.¹⁶⁶

A more recent article addressing end-of-life preferences and ethnicity suggests that non-Western, “collectivis[t]” cultures may value beneficence more than autonomy, whereas autonomy is the primary value emphasized in “individualis[t],” Western law and medicine with respect to patient decisionmaking.¹⁶⁷ Many persons in the United States come from collectivist cultures, and thus, cultural differences (as distinct from racial differences) are also necessary to consider in end-of-life decisionmaking. Searight and Gafford note: “These non-Western cultures believe that communities and families, not individuals alone, are affected by life-threatening illnesses and the accompanying medical decisions.”¹⁶⁸ With respect to this point, Searight and Gafford perhaps overplay cultural differences, given the above described empirical research of the United States general population, consisting of both individualistic and collectivist subgroups, that illustrates the importance of relationships at the end of life and documents concern for grieving family members.¹⁶⁹

However, Searight and Gafford do correctly point out that in some cultures, family members are viewed as the appropriate decisionmakers rather than the patient; in other cultures, however, physicians are viewed as the most appropriate decisionmaker, and families and patients defer to the physician.¹⁷⁰ Research has demonstrated that Mexican Americans and Asian

164. See, e.g., IOM, *supra* note 48, at 351 (reviewing literature showing that most people want, but do not receive, good communication with clinicians at the end of life); Steinhauser et al., *supra* note 113, at 2481–82 (describing respondents’ desire for “strong relationships” between patients and physicians).

165. Jenkins et al., *supra* note 163, at 589.

166. *Id.* at 587.

167. H. Russell Searight & Jennifer Gafford, *Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*, 71 AM. FAM. PHYSICIAN 515, 516 (2005).

168. *Id.*

169. See Jung Kwak & William E. Haley, *Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups*, 45 GERONTOLOGIST 634, 639 (2005) (“The importance of involvement of family members in the decision-making process was found across all racial or ethnic groups, although preferences for how family members were involved in the process differed.”). Other studies have shown that there is variability within a particular subgroup as to whether members think patients, patients’ families, or physicians should be making end-of-life decisions. Jenkins et al., *supra* note 163, at 589 (describing the results of focus groups with African Americans).

170. Searight & Gafford, *supra* note 167, at 518–19; see also H. Eugene Hern, Jr. et al., *The Difference that Culture Can Make in End-of-Life Decisionmaking*, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 27, 30–31 (1998) (describing end-of-life decisionmaking in the case of Chinese immigrants); IOM, *supra* note 48, at 150 (“In many cultures, collective family decision making—and

Americans are more likely than other racial and ethnic groups to informally involve family in end-of-life decisionmaking.¹⁷¹

To accommodate variability in patient preferences while still privileging autonomy, many scholars argue that physicians should follow the American model of informed consent in medical decisionmaking, but respect a patient's preference for their family or physician to make or participate in making their end-of-life decisions; respecting such preferences is both respecting autonomy and exercising cultural competence.¹⁷² Other scholars have cautioned, however, that culture should not be used as a proxy for an individual patient's preferences, and physicians should ask each patient how they would like to make decisions.¹⁷³

In conclusion, the findings on the significance of interpersonal connections to persons at the end of life, the desire for good, respectful communication with healthcare providers, and the desire to involve families in decisionmaking to some extent seem to be shared widely across the U.S. population, regardless of cultural background.

B. Relational Autonomy and End-of-Life Decisionmaking

The above cited studies of attitudes, beliefs, and values describe ideal decisionmaking at the end of life. Many people want to maintain autonomy, but they understand the exercise of autonomy to be relational in two distinct dimensions: deciding with others and deciding, in part, based on others' interests. For example, patients want physicians to respect their values and not be overly paternalistic, but they also want physicians to assist with their decisionmaking. People also want to retain control over decisions, but many want their family involved in the decision-making process or at least consider their families when making these decisions.

Conceiving the nature of autonomy as relational makes sense:

As many [scholars] have pointed out, our self is constituted to an important degree by relations with and responsibilities towards our

even sometimes the paternalistic decisions of the family patriarch—is considered as important or more so than patient autonomy.”).

171. Kwak & Haley, *supra* note 169, at 639 (“For most Asian and Hispanic Americans, the family’s role is meant to remove the burden of making treatment decisions from the patient.”). Mexican Americans, Korean Americans, and Native Americans are also more likely to prefer that poor diagnoses and prognoses not be disclosed to patients. *Id.* at 638–39.

172. Searight & Gafford, *supra* note 167, at 521; *see also* Hern et al., *supra* note 170, at 36 (“*Choosing not to participate is still an exercise of autonomy.*”); Kwak & Haley, *supra* note 169, at 640 (“Policy makers need to find ways to allow flexibility to support values and norms of various racial or ethnic groups in order to respect and protect rights of patients and their families.”).

173. Hern et al., *supra* note 170, at 30; *see also* IOM, *supra* note 48, at 348 (“[C]linicians cannot make assumptions about patients’ beliefs and preferences based on race, ethnicity, religion, or culture.”).

intimates, and these relations and the welfare of our loved ones may be more significant than the interests of any individual self in isolation.¹⁷⁴

Coupled with the reality that most “[p]eople never make decisions without the participation of others,”¹⁷⁵ feminist philosophers, bioethicists, and critical disability scholars have thus advanced the concept of “relational autonomy.”¹⁷⁶ Importantly, *relational autonomy is autonomy*, just conceptualized in a way that accords with social reality.¹⁷⁷

Some philosophers have therefore argued that making medical decisions with family in mind is not necessarily counter to exercising autonomy at the end of life, and that such decisions may actually promote agency.¹⁷⁸ Therefore, if physicians, other actors, or the law try to prevent family involvement on the grounds of protecting an individual’s autonomy, they may actually be undermining autonomy.¹⁷⁹

The concept of relational autonomy has extended over time to include relationships not only with family members contributing to the constitution of self, but also relationships with members of one’s larger community. This version of autonomy is “set in a context of community relations.”¹⁸⁰ Some

174. Anita Ho, *Relational Autonomy or Undue Pressure? Family’s Role in Medical Decision-Making*, 22 SCANDINAVIAN J. CARING SCI. 128, 131 (2008).

175. Autumn Alcott Ridenour & Lisa Sowle Cahill, *The Role of Community*, in DYING IN THE TWENTY-FIRST CENTURY: TOWARD A NEW ETHICAL FRAMEWORK FOR THE ART OF DYING WELL 107, 122 (Lydia S. Dugdale ed., 2015); see also Rapley, *supra* note 148, at 434 (“[D]ecisions can and are ‘thought about’ in and through interactions. . . . [I]t is a routine feature of everyday life that we talk to, listen to and ask advice from others. In this way, our decision making is deeply embedded in, shapes and is shaped by, interactions with others.”).

176. See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 1, at 106 (“In our view, relational conceptions of autonomy are defensible as long as they do not neglect or obscure the principal features of autonomy”); JENNIFER NEDELSKY, LAW’S RELATIONS: A RELATIONAL THEORY OF SELF, AUTONOMY, AND LAW 3 (2011) (“Autonomy . . . comes into being (or is harmed) through relationships”); MACKENZIE & STOLJAR, *supra* note 15, at 4; Harold Braswell, *Can There Be a Disability Studies Theory of “End-of-Life Autonomy”?*, 31 DISABILITY STUD. Q. (2011).

177. Some clinicians do not recognize the involvement of family in healthcare decisionmaking as compatible with autonomy, and refer to such involvement as “post-autonomy” clinical practice. Igel & Lerner, *supra* note 160, at 56–57.

178. Ho, *supra* note 174, at 129. Indeed, Ho asserts, “[f]or those whose family is at the centre of their existence, consideration of their advice, needs and mutual interests is part of their autonomous agency.” *Id.* at 132.

179. *Id.* at 133. “[I]n the absence of abuse and neglect, respect for autonomous agency requires clinicians to abide by patients’ expressed wishes.” *Id.* at 129. Acknowledging the reality of relational autonomy, the Hastings Center advises clinicians:

[p]romoting autonomy and respecting relationships are compatible goals. Autonomy means “self-rule,” not “self-isolation.” Respecting a patient as a person means respecting this person’s relationships and supporting a patient’s ability to draw on these relationships in making decisions and approaching the end of life.

BERLINGER ET AL., *supra* note 90, at 14–15.

180. Ridenour & Cahill, *supra* note 175, at 107.

have argued that communities, particularly religious communities, have a significant role to play in providing support when a member is dying, including economic support and provision of care.¹⁸¹ These scholars also note, however, that at the end of life, people may perceive themselves as a burden in their particular community.¹⁸²

The next Part will explain why decisions at the end of life may not be made relationally, and highlight the role of law's individualistic conceptualization of autonomy in undermining autonomy at the end of life. Given that autonomy is the central principle of this body of law, the next Part will argue for the reform of end-of-life decision-making law and policy to accommodate and promote relational autonomy.

III. ALIGNING END-OF-LIFE DECISION-MAKING LAW AND POLICY WITH RELATIONAL AUTONOMY

The law does not always track what people want with respect to end-of-life decisionmaking given differing conceptualizations of autonomy. The gap between end-of-life decision-making preferences and law and policies governing end-of-life decisionmaking may not be significant if a person is making decisions while competent and capacitated. However, such end-of-life decisions are often made when a person lacks capacity. Many people do not plan for loss of capacity, which means that surrogate decisions are made based on law and policy defaults.

In this Part, I address reasons why there may be a mismatch between what people say they want (consideration of familial interests and shared decisionmaking with physicians) and the choices they actually make at the end of life. I then draw on the law and behavioral economics literature to describe the concept of choice architecture, also known as “nudging.” I next outline some changes to the background architecture of end-of-life decision-making law and policy that may aid individuals, families, clinicians, and courts in making end-of-life decisions in line with an individual's values. Specifically, I argue that relational nudges, focusing on the modification of existing defaults and the strategic use of priming, should be built into existing end-of-life decision-making law and policy in an attempt to influence various actors'

181. *Id.* at 117. Also, the community can sustain a person's “relationships, values, and spirituality” when a person's capacity declines at the end of life. *Id.* at 121. Community is not only family and friends, but also the community of the hospital—other patients, their families, and hospital staff. *Id.* at 121; *see also* Dugdale, *supra* note 120, at 186–87 (noting how physicians and patients, especially in the context of long-standing relationships, constitute a community). The IOM has argued that communities also have a responsibility to help their members prepare for death. IOM, *supra* note 48, at 370–71.

182. Ridenour & Cahill, *supra* note 175, at 114–15. The Vatican has concluded that considering the financial burden on others, including family or the larger community, at the end of life is a valid concern. *Id.* at 116.

behavior to accommodate and promote *relational* autonomy. I conclude by addressing objections to my recommendations.

A. *Explaining Gaps Between Preferences and Behavior in End-of-Life Decisionmaking*

This discussion of how people conceive of autonomy differently than does the body of end-of-life decision-making law and policy would not be necessary if end-of-life decisions were routinely made in accord with a person's values and preferences, and in particular, if such decisions were made in collaboration with or in consideration of others. But, there are potentially significant gaps between what people report wanting at end of life with respect to relational decisionmaking, and what happens to them at the end of life.¹⁸³ One reason that people do not make the best decisions (i.e., decisions that align with their values, preferences, and interests) with respect to their health, generally, is because of the somewhat unique nature of healthcare decisionmaking, including “the special importance of health . . . [and] the emotional nature of the questions.”¹⁸⁴

When it comes to end-of-life healthcare decisionmaking, it is reasonable to assume that people are even worse at making decisions.¹⁸⁵ For example, it is well known that while most people think it is smart to have an advance directive, they typically never complete the document.¹⁸⁶ People often fail to

183. See Shepherd, *supra* note 21, at 1704 (arguing that the complexity of end-of-life decision-making law “can result in decisions that do not adequately honor or protect a patient’s preferences and interests, especially when decisions are made about life-sustaining treatment for patients lacking capacity”).

184. I. Glenn Cohen, *Introduction to Part I*, in NUDGING HEALTH, *supra* note 134, at 58 (citation omitted) (citing NORMAN DANIELS, JUST HEALTH: MEETING HEALTH CARE NEEDS FAIRLY (2008)). That people are prone to predictable cognitive biases is well known to health policymakers. As the IOM notes, based on their review of the research on decisionmaking, people do not tend to make “rational choices based on well-established views and preferences.” IOM, *supra* note 48, at 167. Instead, decisions are biased or based on heuristics, which can “unintentionally thwart what patients themselves see as their best interest and goals.” *Id.* at 168.

185. See *id.* at 167 (explaining how various cognitive biases and irrationality in decisionmaking may manifest at the end of life).

186. *Id.* at 125 (summarizing scholarly literature on the completion rates of advanced directives).

complete an advance directive due to fear of talking about death¹⁸⁷ or physicians' failure to initiate discussions about end of life with their patients.¹⁸⁸ Thus, many people put off making any decisions at all, and failure to plan for future incapacity leaves them at the mercy of default laws, policies, and decisions made on their behalf by surrogates who may not be well informed. When people do not plan for incapacity and there is no evidence of what they would want in a particular end-of-life scenario, the default is to try to sustain life.¹⁸⁹

Even when people are able to make their own end-of-life decisions because they are still competent or they have planned for their incapacity, they may not make decisions that actually effectuate their desires due to flawed

187. *Id.* at 128. The IOM notes:

Advance care planning is an example of an action that has fairly steep immediate costs (contemplation of one's mortality and the possibility of being unable to make decisions) and benefits that may appear only theoretical. The younger and healthier the person is, the more theoretical those benefits may seem.

Id. at 168.

188. Even if physicians are willing to have conversations with their patients about end-of-life planning, they may not be adequately reimbursed by healthcare payers for time spent on these conversations, disincentivizing physicians to conduct the conversations. *Id.* at 320 (explaining how the Affordable Care Act has no reimbursement mechanism for end-of-life conversations physicians conduct with patients). *But see* Aleccia, *supra* note 144 (describing recent changes in Medicare rules that reimburse physicians for end-of-life planning conversations); *see also* David Orentlicher, *The Limits of Legislation*, 53 MD. L. REV. 1255, 1275–76 (1994) (arguing that inadequate physician compensation leads to less understanding of patient end-of-life wishes); Shepherd, *supra* note 21, at 1741 (arguing that all conversations between patients and providers about healthcare matters should be reimbursed).

189. IOM, *supra* note 48, at 169, 330 (explaining that one default rule in medicine is “aggressive care unless stated otherwise”); *see also* Sarah Conly, *Better Off Dead: Paternalism and Persistent Unconsciousness*, in NUDGING HEALTH, *supra* note 134, at 292 (explaining that continued care is the default option because of a physician's oath to “do no harm”); NELSON & NELSON, *supra* note 157, at 98 (explaining that continued care is used as a defense to tort claims because of a bias towards using available technology to sustain life); Bernacki & Block, *supra* note 144, at 1997 (explaining that physicians default to aggressive care because of their preferences); Shepherd, *supra* note 21, at 1701 (explaining that continued care is assumed to be in the patient's best interest).

Aggressive care can be considered a penalty default if most people would not prefer it. *See* Ian Ayres, *Regulating Opt-Out: An Economic Theory of Altering Rules*, 121 YALE L.J. 2032, 2097 (2012) (“The default is a penalty . . . if the legal effect of silence is disfavored by the contractors.”).

decisionmaking and routine cognitive biases.¹⁹⁰ People have “bounded rationality” when making decisions,¹⁹¹ and thus, may not understand their preferences in a particular situation or be able to predict their future preferences.¹⁹² This has led some scholars to argue, “[t]hus, unassisted, patients’ decisions might be neither truly informed nor autonomous, and patients may have limited insight into their own cognitive biases and limitations.”¹⁹³ For example, research has demonstrated that when faced with decisions to participate in research, where a requirement of such participation is voluntary informed consent (i.e., an autonomous decision), people report understanding the information upon which their decision is based, when in fact, they do not.¹⁹⁴ This same lack of understanding occurs in healthcare decisionmaking,¹⁹⁵ particularly in the end-of-life context where other barriers to rational decisionmaking may include being ill at the time of the decision.¹⁹⁶

Beyond physical and psychological factors that limit understanding, there are “institutional and situational factors”¹⁹⁷ that may result in decisionmaking that is not truly autonomous and that will not promote a person’s

190. See generally DANIEL KAHNEMAN, THINKING, FAST AND SLOW (2013) (summarizing scholarly literature on cognitive biases); RICHARD H. THALER & CASS R. SUNSTEIN, NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS (2009) (summarizing scholarly literature on cognitive biases, and arguing for how to improve decisionmaking in light of such biases). People are particularly poor at decisionmaking when the decision is complex and good, complete information is unavailable, which is the case with healthcare generally and end-of-life decisionmaking specifically. *Id.* at 9–10.

191. Russell Korobkin, *Three Choice Architecture Paradigms for Healthcare Policy*, in NUDGING HEALTH, *supra* note 134, at 15. Behavioral law and economics scholars note:

Traditional, neoclassical economists . . . assum[e] perfect rationality: that choices made maximize the subjective expected utility of the chooser given constraints. Or, put in a slightly different way, that our “revealed preferences,” as determined by the choices we make, match our experienced utility or hedonic experience But the burgeoning body of social science research in the field . . . has provided a bumper crop of insights into the variety of ways in which our bounded rationality causes people to make decisions using heuristics that frequently lead to suboptimal outcomes.

Id. (citations omitted) (first citing Gul & Pesendorfer 2008); and then citing Gilovich, Griffin and Kahneman 2002).

192. See Epstein & Street, *supra* note 158, at 456 (“[P]atients’ preferences may be vague, unstable, and uninformed.”); Carl E. Schneider, *After Autonomy*, 41 WAKE FOREST L. REV. 411, 421–22 (2006) (describing how people are bad at predicting their future preferences).

193. Epstein & Street, *supra* note 158, at 456 (“Clinicians’ preferences and decision-making processes are similarly affected.”).

194. BEAUCHAMP & CHILDRESS, *supra* note 1, at 131.

195. See Schneider, *supra* note 192, at 418–20 (summarizing research on patients’ failure to understand information received from clinicians about treatments).

196. See Conly, *supra* note 189, at 289–90. Even if patients are not ill, studies show they still do not understand end-of-life options contained in advance directive forms (e.g., patients do not understand that ventilation does not keep the heart beating). Schneider, *supra* note 192, at 419–20. Patients are also poor at planning for loss of capacity because they cannot anticipate how they will react to the experience of disability and illness. *Id.* at 428.

197. BEAUCHAMP & CHILDRESS, *supra* note 1, at 131.

welfare. For example, prior to admission to a hospital to undergo a medical procedure, patients may be presented with an advance directive as part of routine admission paperwork. If they quickly complete the advance directive while waiting to be admitted, they may not be thinking carefully through their treatment preferences. Additionally, they may not be feeling well, which could affect their ability to make decisions that align with their true values and preferences. These contextual factors may result in different decisions than the patient would have made had they completed the advance directive at a time when they were less vulnerable, in a nonmedical setting such as at home or with their estate planning attorney, and where they had more time to consider what is truly important to them, including their social relationships.¹⁹⁸

The default processes and standards built into end-of-life decision-making law and policy matter a great deal when surrogates are called upon to make end-of-life decisions, when people use standardized advance directive forms, and when people opt into physician AID. The discrepancy between how autonomy, the principle value and goal of this body of law, is conceptualized by judges, lawyers, and legislators compared to ordinary people thus may become problematic. Problems arise because standards and processes governing these situations may not actually effectuate autonomy, which is what the law is meant to do.

Based on the empirical studies described previously, end-of-life law and policy fails to promote autonomy because it accords relational concerns a different weight and valence than most people would prefer. The cases described in Part I show the stark disconnect between how people want to make end-of-life decisions and how such decisions may be made in court upon incapacity. With respect to surrogate decisionmaking, for example, in the *Schiavo* case, the court characterized the end-of-life decision as “about Theresa Schiavo’s right to make her own decision, independent of her parents and independent of her husband.”¹⁹⁹ In this instance, the weight the court gave family input in Schiavo’s end-of-life decision was equal to zero because the court assumed that Schiavo would not consider her family’s input while making the decision.²⁰⁰ However, given the above described studies, if competent, Schiavo likely would not make decisions “independent” of her family members, and would either decide with them, or at least weigh their input at some value greater than zero.²⁰¹

198. See Christopher T. Robertson et al., *Introduction*, in *NUDGING HEALTH*, *supra* note 134, at 5 (discussing how factors such as the initial framing of choices may intersect with cognitive biases).

199. *In re Guardianship of Schiavo*, 851 So. 2d 182, 186 (Fla. Dist. Ct. App. 2003).

200. See *id.* at 187 (noting that a judicial determination is “a necessary function if all people are to be entitled to a personalized decision about life-prolonging procedures independent of the subjective and conflicting assessments of their friends and relatives”).

201. See *id.* at 186.

In the case of physician AID, when addressing the state interest in protecting vulnerable groups with compromised autonomy, the *Glucksberg* Court discussed the risk that persons may “resort to [physician AID] to spare their families the substantial financial burden of end-of-life health-care costs.”²⁰² The Court assumed that anyone who makes such decisions in part for economic reasons has compromised autonomy. The Court does not seem to recognize, however, that access to physician AID might actually be autonomy-promoting in this case, an option that persons—even those from disadvantaged social groups—may knowingly, willingly, and happily make out of consideration for their families, just as they have likely made many other decisions in consideration of the wellbeing of their families. Indeed, the review of empirical literature demonstrates that the majority of patients do not want to be a burden on their families and may, therefore, intentionally and autonomously make end-of-life decisions with economic considerations in mind.²⁰³ One participant in a research study stated:

I hope to stop myself from becoming a burden to them [children]. Looking after somebody either takes a lot of money, in which case you may get somebody to baby-sit for you, or you have to do it yourself, and I do not wish my children to be in the position of having to do that. Therefore, I would rather die faster than later.²⁰⁴

Courts may thus accord a different valence to relational considerations than dying persons might.

In brief, decisions made on the basis of existing end-of-life decision-making law and policy may not accord with most people’s values, preferences, and interests, many of which are relational in nature. This means that current law and policy may actually impede rather than promote autonomy.

202. *Washington v. Glucksberg*, 521 U.S. 702, 732 (1997); see also *id.* at 783 (Souter, J., concurring) (“[T]he terminally sick might be pressured into suicide decisions by close friends and family members . . . not only because the costs of care might be more than family members could bear but simply because they might naturally wish to see an end of suffering for someone they love.”).

203. Considering the generosity of the social safety net matters for this discussion, and I do not mean to suggest that the only choices are between hastening death and being a burden on family or society. While the focus of this paper has been mostly on the micro-level of decisionmaking, focusing on dyadic or small group relationships, it is also important to consider the macro-level conditions that influence autonomy. See, e.g., Susan Sherwin, *Relational Autonomy and Global Threats*, in *BEING RELATIONAL: REFLECTIONS ON RELATIONAL THEORY AND HEALTH LAW* 13, 19 (Jocelyn Downie & Jennifer J. Llewellyn eds., 2012) [hereinafter *BEING RELATIONAL*] (“Often, oppressed people fail to act with full autonomy because the options that are meaningfully available to them do not include a choice that is compatible with their deepest values and needs In such cases, increasing autonomy requires making changes to the background conditions . . .”). There could be structural changes to, for example, the provision and financing of long-term care that could decrease the burden on families, which may change how people make decisions at the end of life. The background conditions of social and economic inequality decrease true autonomy.

204. Peter A. Singer et al., *Quality End-of-Life Care: Patients’ Perspectives*, 281 *JAMA* 163, 166 (1999).

To make consistent the purpose of end-of-life decision-making law and policy—respect for, and promotion of, autonomy—and its effect, changes must be made to accommodate and advance people’s relational interests. As leading health law scholars note, “the central purpose of health care law is to improve the lives of patients.”²⁰⁵ The following sections will outline some proposals to achieve this outcome.²⁰⁶

B. Choice Architecture (“Nudging”)

Given that people do not always choose autonomously or in a way that increases their welfare, and given the complexity of healthcare decisionmaking, insights from behavioral psychology have been applied to this decision-making domain through intentional manipulation of the decision-making process.²⁰⁷ The growing influence of behavioral law and economics has, to date, only had limited application to the domain of end-of-life decision-making policy, however.²⁰⁸ This Section will review the basic outlines of choice architecture, and the next Section will apply these insights to end-of-life decision-making law and policy.

Legal academics and economists have been interested in ways in which an individual’s cognitive biases can be countered and overall welfare increased by altering the way decisions are made through intentional “choice architecture” or “nudging.” Professors Cass Sunstein and Richard Thaler are among the most well-known scholars advancing these ideas.²⁰⁹ They emphasize that decisions are not made a-contextually and that the way choices are

205. Mark A. Hall et al., *Rethinking Health Law*, 41 WAKE FOREST L. REV. 341, 342 (2006); see also Shepherd & Hall, *supra* note 112, at 1433 (“[L]aw that affects patients should better take into account what it means to be a patient.”).

206. This normative move is also consistent with other scholars who argue that once we realize that autonomy is relational, given the importance of autonomy to much of law, which conceptualizes autonomy as individualistic, we must change laws. See NEDESKY, *supra* note 176, at 5.

207. See generally NUDGING HEALTH, *supra* note 134.

208. This application seems to be in the realm of experimental studies of the effect of changing default rules about comfort or aggressive care in advance directives. See IOM, *supra* note 48, at 167–170 (exploring the ways that clinicians can use insights from behavioral psychology about how decisions are made “to develop, test, and implement scalable interventions that improve the quality of the health decisions made by patients, family members, and providers” (citation omitted) (quoting Scott D. Halpern, in *Young Leaders: Employing Behavioral Economics and Decision Science in Crucial Choices at End of Life*, 31 HEALTH AFF. 2789 (2012))).

209. While they have authored many articles advancing their ideas, a summary is found in their book. THALER & SUNSTEIN, *supra* note 190, at 3, 6. For a shorter, but comprehensive summary, see Richard H. Thaler et al., *Choice Architecture*, in THE BEHAVIORAL FOUNDATIONS OF PUBLIC POLICY 429 (Eldar Shafir ed., 2013); see also Christine Jolls et al., *A Behavioral Approach to Law and Economics*, 50 STAN. L. REV. 1471 (1998).

presented impacts a person's final choice.²¹⁰ They refer to people and institutions who structure decisions as "choice architects."²¹¹ They define "nudging" as "any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives."²¹² They assert that nudging is particularly appropriate when decisions are "difficult and rare . . . and when [people] have trouble translating aspects of the situation into terms that they can easily understand."²¹³

Much of the literature about choice architecture discusses default rules.²¹⁴ A default is what happens in a particular decision system if a person decides to do nothing.²¹⁵ The selection of a default rule is one of the most powerful tools of choice architecture,²¹⁶ and thus is potentially controversial,²¹⁷ especially because in many situations most people choose to do nothing.²¹⁸

Beyond the use of default rules, Thaler, Sunstein, and colleagues describe other aspects of choice architecture. Because choices can be complex, and because cognitive biases exist, people can be expected to make errors when making decisions.²¹⁹ Good choice architecture attempts to reduce these decision-making errors and aids with selection of a choice that improves an individual's welfare.²²⁰ Good choice architecture "takes into account the ways 'choices are presented and the environment in which decisions are

210. See generally THALER & SUNSTEIN, *supra* note 190. They also stress that choice design is never neutral. *Id.* at 3.

211. *Id.*

212. *Id.* at 6.

213. *Id.* at 72.

214. See *id.*

215. Thaler et al., *supra* note 209, at 430.

216. As Thaler and colleagues observed:

For reasons of laziness, fear, and distraction, many people will take whatever option requires the least effort All these forces imply that if, for a given choice, there is a default option . . . then we can expect a large number of people to end up with that option, whether or not it is good for them.

Id.

217. THALER & SUNSTEIN, *supra* note 190, at 85.

218. Sticking with the selected default is due to status quo bias. *Id.* at 7–8, 34, 83.

219. Thaler et al., *supra* note 209, at 431–33; see also THALER & SUNSTEIN, *supra* note 190, at 87; Korobkin, *supra* note 191, at 21 ("Medical care decisions are often complex . . . most are novel for the patient; and when such decisions require trading off money against health, which most of us are instinctively reluctant to have to do, they can undermine rational cost-benefit analysis.").

220. Thaler et al., *supra* note 209, at 433 (describing the use of checklists in medical practice to reduce medical errors in hectic environments where complex medical decisions must be made).

made,' adjusting them so that better decisions result,"²²¹ and may also try to simplify choices.²²²

Another element of choice architecture is priming. Priming makes "use of the principle that our acts are influenced by subconscious cues. These cues can be strategically used as primers for [desired] behaviors."²²³ Social science on priming "shows that subtle influences can increase the ease with which certain information comes to mind."²²⁴ For example, using visible primes, such as displaying healthier food earlier in a buffet line, has been shown to increase healthy eating behaviors.²²⁵

There are many other tools of choice architecture, such as the use of incentives,²²⁶ although a complete discussion of such tools and their application to this body of law is beyond the scope of this Article. The next Section will discuss how the structure of choices can be altered in end-of-life decision-making law, policy, and practice to promote relational autonomy.

C. Relational Nudges in End-of-Life Decision-Making Law and Policy

Most people want to maintain control over decisionmaking, and also have loved ones and physicians involved in decisionmaking, at the end of life. This is because autonomous decisionmaking at the end of life is understood relationally. Individuals may not always be able to decide based on their relational values and preferences, however, due to failures of rationality in this specific context. Laws and policies can be designed to better accord with most people's decision-making preferences by nudging actors to consider relationality in end-of-life decisionmaking. What I call "relational nudges" are meant to account for failures of rationality and increase the likelihood that end-of-life decisions will be made in the manner most people prefer—in consultation with and in consideration of others. These nudges should increase autonomous decisionmaking in this domain and also promote

221. IOM, *supra* note 48, at 168 (quoting S.D. Halpern, *Young Leaders: Employing Behavioral Economics and Decision Science in Crucial Choices at End of Life*, 31 HEALTH AFF. 2789, 2789 (2012)); *see also* THALER & SUNSTEIN, *supra* note 190, at 36–37 (describing how framing choices matters).

222. Korobkin, *supra* note 191, at 21 ("Policymakers can enhance the ability of individuals to make decisions that maximize their own subjective expected utility by combining and presenting information in ways that simplify the relevant choice.").

223. J.S. Blumenthal-Barby & Hadley Burroughs, *Seeking Better Health Care Outcomes: The Ethics of Using the "Nudge"*, 12 AM. J. BIOETHICS 1, 6 (2012).

224. THALER & SUNSTEIN, *supra* note 190, at 69.

225. *Id.* at 69–71 (describing studies of priming); Amy L. Wilson et al., *Nudging Healthier Food and Beverage Choices Through Salience and Priming, Evidence from a Systematic Review*, 51 FOOD QUALITY & PREFERENCE 47, 51 (2016) (reviewing studies about the effects of priming on behavior); *see also* Blumenthal-Barby & Burroughs, *supra* note 223, at 6.

226. *See, e.g.*, Blumenthal-Barby & Burroughs, *supra* note 223, at 1–2 (reviewing studies about the use of incentives).

overall welfare.²²⁷ In this Section, I will describe an example of an existing relational nudge. I will then illustrate other possible forms of relational nudges, first focusing on defaults and then moving onto priming. It is beyond the scope of this Article to list all possible relational nudges or propose model laws, but I instead want to suggest places where low-cost interventions may have a potentially large impact.

1. *Example of Relational Nudge in End-of-Life Decision-Making Law*

Before moving into a discussion of my proposed relational nudges, it is instructive to examine an existing relational nudge in end-of-life decision-making law. Oregon's Death with Dignity Act²²⁸ contains examples of relational nudges that also preserve patient autonomy. The law requires that a physician recommend that a patient requesting AID inform their family of their decision, but does not make this a condition of receiving physician AID.²²⁹ Additionally, should a physician not make this recommendation, the patient will be nudged in this direction again when they complete the written request for the lethal medication and must initial next to one of the following options: informed family "and taken their opinions into consideration," chosen not to inform family, or have no family to inform.²³⁰ Oregon's law explicitly acknowledges the dying individual's relationships with family members, and requires persons pursuing this end-of-life option to take this relationality into account as well by at least prompting them to think about the fact that their decision to die in this manner likely matters to their family.

The law thus accounts for people, particularly physicians, making mistakes and forgetting to discuss with their patients whether the family has been consulted, and contains nudges in multiple parts of the process to ensure that relationality is considered when making this end-of-life decision. Never does the law require that an individual talk to their family, but it nudges them to do so when making the decision to hasten their death. This law promotes a "relational autonomy," preserving a person's free choice to make their own medical decisions without consulting family members or strongly weighing

227. My arguments are a response to the challenge identified by leading end-of-life ethicist Bruce Jennings. See Jennings, *supra* note 42, at 220 (asserting "that the challenge facing the relational orientation in end-of-life care is twofold: (1) to provide a more practical and feasible template for medical planning and decision-making that more effectively serves the needs and rights of dying persons; and (2) to avoid bluntly rejecting or abandoning ideals of personal autonomy and respect for persons").

228. OR. REV. STAT. § 127.800–.897 (2015).

229. *Id.* § 127.815.

230. *Id.* § 127.897. Interestingly, there is no option to select reflecting that patients may choose to inform their families but not take their opinions into consideration.

their family's interests, but also attempts to put the patient on the path to consider relevant others' "voice[s]" or "stake[s]."²³¹

Oregon's Death with Dignity Act is an outlier in this area of law²³² because it contains relational nudges and explicit references to a patient's family and their interests. The following sections will suggest how relational nudges can be built into other types of end-of-life decision-making law and policy.

2. *Relational Nudges: Modifying Existing Defaults*

This Section will describe how existing end-of-life decision-making law and policy defaults can be modified to promote and accommodate relational autonomy.²³³

a. *Defaults in the Decision-Making Process for Competent Adults*

The current default in end-of-life decision-making law is to respect an individual's decision, given that it is part of a liberty-based privacy interest to make healthcare decisions regardless of the effect the decision has on others.²³⁴ An attempt to override this decision may come through attempts at persuasion or through a medical evaluation that finds someone lacks capacity to make the decision. While I do not argue for a change in *legal* defaults around end-of-life decisionmaking for competent persons, defaults in healthcare organizational *policy* interpreting and facilitating this right can be improved to promote relational autonomy. Changes to policy are both more feasible and perhaps more effective, given that policy may affect physician's clinical practice (and thus end-of-life decisionmaking) more than law.²³⁵

231. Robert A. Burt, *The End of Autonomy*, 35 HASTINGS CTR. SPECIAL REP. S9, S12 (2005) (describing the interest others have in an individual's end-of-life decision).

232. It may be the case that specific healthcare organizational policies contain relational nudges around withholding or withdrawing care for competent patients or assisting surrogates in making decisions on behalf of an incompetent patient. A survey of such policies would have to be conducted in order to know the extent to which they promote relational autonomy.

233. Notably, the rules in end-of-life decision-making law and policy are almost all default rules rather than mandatory rules because people can always opt out of the defaults. Mandatory rules are those that cannot be contracted around (i.e., opt out). See Ayres, *supra* note 189, at 2035–39 (defining terms).

234. See Winick, *supra* note 14, at 1735 ("Unless incompetent, the patient's medical decisions must be respected, no matter how foolish these decisions are thought to be."). Others have argued for changing this default. See, e.g., NELSON & NELSON, *supra* note 157, at 114–15; Burt, *supra* note 231, at S10.

235. See Orentlicher, *supra* note 188, at 1301–05 (describing how end-of-life decision-making legislation does not change physician practice, and arguing that professional and policy changes may result in more patient autonomy).

For example, when a competent adult patient decides to forgo life-sustaining treatment, institutional (e.g., hospital) policy or clinical practice guidelines should explicitly nudge patients to consider making this decision in consultation with others (or at least inform them of their decision). This decision could trigger clinicians to inquire as to whether patients have discussed their decision with their family, friends, religious leaders, or extended social network.²³⁶ If the patients have not, the clinician could recommend they do so, although the patient should never be made to feel as though they are required to discuss their private medical decisions with anyone.²³⁷ I am not arguing for any changes to current default rules of maintaining patient confidentiality contained in the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”),²³⁸ nor am I suggesting weakening the fiduciary relationship between physicians and their patients wherein physicians owe patients a duty of confidentiality.²³⁹ This means that clinicians would not legally or ethically be permitted to inform a patient’s family of their decisions without the patient’s consent.²⁴⁰

The clinician arguably will have also had the opportunity to weigh in on the decision as well.²⁴¹ If clinicians are responsible for this nudge, they will need a reminder to make this inquiry and recommendation, because they too are affected by cognitive biases and distorted rationality.²⁴² Checklists, or tying this to a referral to hospice may be useful clinical practice.²⁴³

236. To ensure that physicians do not forget to follow such a policy, reminders could be built into electronic health record systems, so when a physician makes notes in the patient’s medical record about the decision to withhold or withdraw care, they see the reminder to suggest the patient talk to their family.

237. Truly respecting autonomy may actually require physicians to inform their patients that relationships are important to many people at the end of life. As Beauchamp and Childress note, one of the positive obligations of respecting autonomy is “respectful treatment in disclosing information and actions that foster autonomous decision making.” BEAUCHAMP & CHILDRESS, *supra* note 1, at 107.

238. Pub. L. No. 104–191, 110 Stat. 1936.

239. BEAUCHAMP & CHILDRESS, *supra* note 1, at 319–20 (discussing physicians’ duty of confidentiality and some exceptions to this duty); *see also* BERLINGER ET AL., *supra* note 90, at 45 (discussing the duty of confidentiality in end-of-life context).

240. This is true even in the palliative care and hospice contexts. And, it is true even if families would prefer otherwise. I also recognize that patient confidentiality may hinder communities from fulfilling their obligations to members at the end of life. *See, e.g.*, IOM, *supra* note 48, at 247 (explaining how HIPAA prevents clergy who are not part of hospital staff from knowing if their congregants are hospitalized).

241. Indeed, the withdrawal of many methods of life-sustaining treatment (e.g., artificial nutrition or ventilation) by its nature will involve shared decisionmaking with physicians. Decisions not to pursue care may not, however (e.g., decisions not to treat cancer that has recurred).

242. Alexander M. Capron & Donna Spruijt-Metz, *Behavioral Economics in the Physician-Patient Relationship: A Possible Role for Mobile Devices and Small Data*, in NUDGING HEALTH, *supra* note 134, at 235 (noting that clinicians suffer from the same cognitive biases that patients do).

243. Checklists and reminders are priming nudges. Blumenthal-Barby & Burroughs, *supra* note 223, at 6. For a brief description of the nudges, *see supra* notes 220 and 236 and accompanying

b. Defaults in Surrogate Decision-Making Standards

More significant is the issue of default rules and standards in surrogate decisionmaking. If people do not plan for future incapacity by completing an advance directive, a series of default rules apply when they lose capacity and healthcare decisions must be made. Given that most people do not complete an advance directive,²⁴⁴ these defaults are especially consequential.²⁴⁵

The current defaults in end-of-life surrogate decisionmaking, based on the Uniform Health-Care Decisions Act discussed in Part I, are as follows. When a surrogate has not been chosen in advance, the law provides a familial-based hierarchy to select a surrogate.²⁴⁶ This default is particularly appropriate because patients can always opt out of it prior to incapacity by selecting a healthcare agent who is not a family member, for example. If a patient does nothing to plan for incapacity, however, the default likely matches well enough with whom a patient would have selected to be their surrogate decisionmaker, given that most persons who choose a healthcare agent select an agent who is a family member or close friend.²⁴⁷ If they have

text. It is also important to note that in certain institutional settings, like hospice, the default is that healthcare providers assume the family is actively involved in the end-of-life decision-making process. See, e.g., IOM, *supra* note 48, at 249 (describing the role of family in the palliative care setting).

244. IOM, *supra* note 48, at 125. Federal laws have tried to promote the use of advance directives, but have failed as a nudge because institutions were noncompliant in following the law. ORENTLICHER ET AL., *supra* note 36, at 336.

245. I do not advocate for forcing people to complete an advance directive or mandating that they at least actively elect to choose the default rather than completing an advance directive. Doing so is a form of what Sunstein refers to as “choice-requiring paternalism.” Cass R. Sunstein, *Foreword*, in NUDGING HEALTH, *supra* note 134, at xiii (emphasis omitted). As Sunstein argues, there are many reasons that people may not want to make choices, particularly with respect to the end of life, and that the choice not to choose but instead to rely on the default, should be respected in order to respect autonomy. *Id.* at xi–xiii; see also BERLINGER ET AL., *supra* note 90, at 25–26 (describing the range of decision-making preferences that people have at the end of life); THALER & SUNSTEIN, *supra* note 190, at 87 (arguing against mandated choice, especially when the decision is complex); Schneider, *supra* note 192, at 436–38 (summarizing research that shows that many people do not want to make or participate in healthcare decisions, especially when they are very sick, in which case they defer to others).

Another reason I do not recommend requiring completion of an advance directive is because preferences can shift over time, and if someone completes an advance directive many years before death because doing so has been required as part of obtaining a driver’s license or enrolling in health insurance, for example, a person may be bound by prior preferences they no longer have. See Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1835 (2003). This would thwart patient autonomy. See *id.* at 1833–34.

246. See *supra* Part I.B.

247. Or as one court asserted, “A reasonable person presumably will designate for such purposes only a person in whom the former reposes the highest degree of confidence.” Conservatorship of Wendland, 28 P.3d 151, 168 (Cal. 2001).

not done so, laws that list who is an appropriate surrogate decisionmaker impute this preference,²⁴⁸ acknowledging that generally, the person who knows an individual best and who an individual would most trust to make the decision will be their spouse, followed by other close family members.²⁴⁹ The default instructions for surrogate decisionmaking are to follow written or oral instructions, and if this is not possible, to try to decide as the patient would. Should a substituted judgment not be possible, the law requires decisions to be made in the patient's best interest.²⁵⁰ Currently, the statutory guidelines in the Uniform Health-Care Decisions Act do not instruct surrogate decisionmakers to consider the incapacitated person's relationships or how the person would make decisions in light of their relationships. And when surrogate decisions or disputes go before a hospital ethics committee or to court,²⁵¹ there may be a presumption against considering anything other than the patient and their individual interests,²⁵² supposedly in the service of respecting autonomy.

The default rules and standards for making a surrogate end-of-life decision should change to incorporate relational considerations. Based on empirical evidence of preferences and values at the end of life, and given that a failure of rationality may have led persons not to plan adequately for incapacity, to truly respect autonomy and make decisions in accord with a person's interests, both substituted judgments and best interests analyses should account for relationality.²⁵³ There should not be a presumption against considering relational interests in surrogate decisionmaking. Thus, the Uniform

248. This default does not always match an individual's preferences, however. The default may give decision-making authority to a family member who knows nothing about the patient or has conflict with the patient, and still chooses to make the decision on behalf of the patient. *See* BEAUCHAMP & CHILDRESS, *supra* note 1, at 190 (describing problems with families as surrogate decisionmakers).

249. Those most likely to be able to make an accurate substituted judgment are those who know the person's values and beliefs the best, which will be those closest to the patient. There has been research, however, that demonstrates that people are quite poor at making substituted judgments in the healthcare context. *See, e.g.*, NELSON & NELSON, *supra* note 157, at 87; Kohn, *supra* note 134, at 298–300 (describing studies).

250. *See supra* Part I.B.

251. *See* Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 434 (Mass. 1977) (describing the Massachusetts Supreme Court's view that decision-making issues should go before a court, and contrasting this with New Jersey's judiciary's view that these decisions should stay with physicians and ethics committees at hospitals).

252. *See, e.g.*, *In re* Guardianship of Schiavo, 851 So. 2d 182, 186–87 (Fla. Dist. Ct. App. 2003).

253. My argument is similar to that of the U.S. President's Commission. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 135 (1983) ("The impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates."). Some prominent

Health-Care Decisions Act and state-specific surrogate decision-making laws should be amended so that the autonomy and beneficence principles underlying this body of law appropriately intersect with the two dimensions of relational autonomy: deciding with, and in consideration of, others.²⁵⁴

Surrogate decisionmakers should be explicitly directed to consider whether the incapacitated person would have decided in consultation with or with concern toward any other persons, and if so, include these relational considerations as an element of the surrogate's decisionmaking. For example, when agents or surrogates are directed to decide about treatment based on "the patient's wishes, including the patient's religious and moral beliefs," as New York's Family Health Care Decisions Act requires,²⁵⁵ this could be explicitly revised to include directions to consider how the patient made decisions, especially in the context of their family relationships.²⁵⁶

Modifying statutory defaults will impact parties beyond the surrogate. Presently, adjudicators, whether judges or ethics committees, at times seem fixated on questions of what an incapacitated person would choose with respect to a particular medical intervention for a particular illness (e.g., would the person want artificial nutrition and hydration after a cardiac arrest that left them neurologically devastated?).²⁵⁷ The questions asked in the service of making a substituted judgment or deciding on the basis of someone's best

bioethicists disagree with this position unless a person explicitly wants others' interests considered in a best interests analysis. BEAUCHAMP & CHILDRESS, *supra* note 1, at 173.

254. While the common law in many states may have developed to accommodate relational autonomy on the two dimensions discussed in this Article—deciding with and deciding in consideration of others—this type of law is not easily accessible to non-lawyers, and many persons tasked with adjudicating end-of-life decisions, such as clinical ethicists, may not have access to this information. See Ayres, *supra* note 189, at 2088, 2093, 2094 ("[T]he law can make opt-out mechanisms more opaque by burying the description of altering rules in common-law decisions.").

255. N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2015).

256. This suggested additional language is not solely a relational nudge, but also a grant of explicit permission to surrogates to make decisions in a way that accounts for interests of others besides the patient or by consulting with others who are not legally designated surrogates, *if this is how the incompetent patient would have decided*. While the existing instructions about making the decision on the basis of the "patient's wishes" are broad enough to cover deciding in a relational manner (if that is how the patient would have wished to decide), non-legal actors present for the decisionmaking process, such as healthcare providers, may not understand the guidance to permit for relational decisionmaking. In this way, the additional language promotes any relational decisionmaking that may occur when ordinary people tasked with making a surrogate decision consider the effect of the decision on the patient's loved ones, just as the incompetent patient would likely have considered others if they were competent.

This explicit permission may lead to less suspicion on the part of healthcare providers that the patient's autonomy is not being respected by their surrogates, and thus, prevent *routine* surrogate decisionmaking from being reviewed by an ethics committee or a court, a review that may cause distress for all parties and delay the decision. Such a review is always an option, however, if there is serious concern that a decision is too heavily influenced by others' interests at the expense of the patient's welfare. See *supra* Part III.D.3 (describing existing safeguards).

257. See Shepherd, *supra* note 21, at 1735–36.

interests should instead focus on how the person would decide (e.g., what factors would weigh in their decision, and with whom, if anyone, would they consult?). In the case of the conflict between Terri Schiavo's husband and her family of origin about whether to discontinue Schiavo's life support, to resolve the issue, the court could have asked with whom Schiavo would have consulted about making healthcare decisions and whose interests she may have weighed. If Schiavo typically consulted with her parents, rather than her husband, about her healthcare and weighed their opinions more heavily, then the court should have followed that process.

The suggested modification permits a focus on the process of the decisionmaking as well as the substance of the decision, which is also a benefit from an evidentiary perspective. It is likely that a court faced with resolving an end-of-life dispute could more confidently determine *how* a person would have decided than *what* they would have decided.

c. Defaults in Medical Futility Disputes

Defaults in medical futility disputes are often embedded in organizational policy rather than statute.²⁵⁸ As discussed previously, the default is that healthcare decisions of competent patients are respected.²⁵⁹ This default may be reversed if it is the case that someone is requesting what healthcare providers have assessed is a futile medical intervention.²⁶⁰ In this case, while there is a legal or organizational process of appeal that a patient or their surrogate can pursue, the healthcare provider's decision not to treat is the default. At times, however, neither policies nor statutes are available to offer guidance in futility disputes. In this circumstance, the default is likely the continuance of what healthcare providers think is a futile medical intervention.

If a healthcare organization does not have medical futility policies, and the state in which it is located does not have futility statutes, the organization should adopt such policies to assist healthcare providers and patients or their surrogates when there are questions about, or disputes over, end-of-life decisionmaking. Medical futility policies should be designed to reduce conflict and accommodate various interests and perspectives, but the default policy should not be to provide what the treatment team and any appellate body

258. Texas is a notable exception given that its futility policy is in statute form. TEX. HEALTH & SAFETY CODE ANN. §§ 166.046, 166.052–.053 (West 2017).

259. See *supra* Part III.C.2.a.

260. This is the default in many healthcare organization policies and in the body of case law developing around medical futility, but some organizations may still opt for respecting patient/surrogate choice over provider judgment.

views as futile care.²⁶¹ While most of the earlier discussion about medical futility focused on the relationship between physicians and patients or their surrogates,²⁶² it is also necessary to examine patients in relation to larger society. Healthcare resources are finite, and spending them on futile care may deprive others of necessary care.²⁶³ Indeed, futile care at the end of life is unnecessarily costly.²⁶⁴ Hospital policies can also empower institutional actors, such as ethics committees, to consider the cost of futile care.²⁶⁵

However, built into the medical futility policy should be an option for the healthcare team to opt out of the no-treatment default when clinicians assess it is appropriate to engage in “compassion[ate]” futile procedures for the sake of relational interests.²⁶⁶ Hospital ethics committees with experience mediating futility disputes may be best situated to draft these policies, which should advise clinicians of the following with respect to interactions with surrogates: “Instead of refusing family participation and creating professional-family animosity, it may be more helpful for clinicians to listen to the family’s concerns and reasoning process, and then explore with them various options that can best respect the interests of all parties. Such effort can clarify expectations and misconceptions.”²⁶⁷

The empirical literature demonstrates that people do want shared decisionmaking with their physicians at the end of life,²⁶⁸ and one way of avoiding a futility dispute is for physicians to engage in shared decisionmaking as a matter of routine *practice*. That is, shared decisionmaking should become

261. See Jecker, *supra* note 91, at 147–48 (arguing that there is a social contract that gives physicians professional and moral responsibility to refuse to provide futile care, and that this does not violate respect for patient autonomy). *But see* Shepherd, *supra* note 21, at 1745–46 (critiquing the Texas Advance Directives Act for not permitting access to court review of a hospital futility determination).

262. See *supra* Part I.C.

263. See IOM, *supra* note 48, at 364–65 (discussing tradeoffs between costs of futile care and respecting patient autonomy); see also Jecker, *supra* note 91, at 142 (describing justice considerations with respect to futility disputes in the context of scarce resources); Ridenour & Cahill, *supra* note 175, at 116 (describing the Vatican’s belief that it is permissible to consider the cost of end-of-life care to society when making end-of-life decisions).

264. See IOM, *supra* note 48, at 288 (describing studies about the cost of futile care).

265. *But see* Conly, *supra* note 189, at 294–96 (arguing that physicians should not consider the cost of care because their loyalty should only be to their patient). Considering costs would not violate fiduciary duties, however, because the ethics committees would not be composed of the patient’s treating physician. See Jecker, *supra* note 91, at 148 (describing the conflict resolution role for hospital ethics committees in futility disputes).

266. See BEAUCHAMP & CHILDRESS, *supra* note 1, at 170 (“[U]ndertaking a futile intervention, such as CPR, may be an act of compassion and care toward the grief-stricken family of a seriously ill child, and could be justified, within limits.”); BERLINGER ET AL., *supra* note 90, at 108 (“Delaying the withdrawal of some or all supports for a clearly specified period of time is a reasonable accommodation to help bereaved loved ones begin to adjust to their loss.”).

267. Ho, *supra* note 174, at 133.

268. See *supra* Part II.A.4.

the default model of healthcare provision, rather than something physicians opt into (although patients should still be able to opt out of this model if they prefer to defer to their physician in decisionmaking, which, if done willingly and knowingly, is consistent with respect for their autonomous choice).²⁶⁹ Perhaps if people feel like their physician is truly trying to understand their values and concerns in the decision-making process and is respecting their autonomy, then when a physician advises that a particular treatment is futile in light of the medical circumstances and the patient's goals and values, patients and their surrogates will be more willing and able to respect this assessment.²⁷⁰

d. Defaults in Physician Aid in Dying

Finally, physician AID is not the default in states that allow patients to choose this form of death. Instead, people have to select physician AID at two time points, at least fifteen days apart, using a written form.²⁷¹ Autonomy is preserved with an opt-in system, even if the various steps one must take to avail themselves of this option may be burdensome.²⁷² Given concerns about patient vulnerability at the end of life and the issue of externalities with this end-of-life decision, an opt-in rather than an opt-out system is likely the best

269. Opting for no physician involvement at all is not possible in the case of requesting an intervention that only a medical provider can offer, however.

270. See Jennings, *supra* note 42, at 228–29 (arguing that if physicians properly and respectfully communicate with patients and surrogates, then most of the time, they will not persist in requesting futile care). Access to courts should still be available in cases of disagreement, however. See Shepherd, *supra* note 21, at 1745.

271. Ayres notes that “[a]ltering rule formalities can slow the . . . process and therefore reduce the likelihood of imprudent action.” Ayres, *supra* note 189, at 2063. And the fifteen-day wait is a cooling off period, which can also reduce the risk of error with respect to this end-of-life decision. *Id.* at 2083–84; see also THALER & SUNSTEIN, *supra* note 190, at 250–51 (asserting that cooling off periods are appropriate when “people make the relevant decisions infrequently and therefore lack a great deal of experience, and . . . emotions are likely to be running high”).

272. The fifteen-day wait may prevent some people from using physician AID, however, if they lose competence during that time period, which makes them ineligible for this form of death. See Alicia Ouellette, *Barriers to Physician Aid in Dying for People with Disabilities*, 6 LAWS 23, 28 (2017). But the potential loss of autonomy is negligible given how few people use AID. See *infra* note 273. Reducing the cooling off period to a shorter time period (e.g., one week) may satisfy those who are concerned that not everyone initially eligible for and desiring of AID will also sustain the benefits of cooling off periods.

default.²⁷³ Furthermore, this default process promotes shared decisionmaking, at least with respect to the physician-patient dyad, because selecting this option requires multiple conversations with a healthcare provider.²⁷⁴

3. Relational Nudges: Priming

Priming, another component of choice architecture that influences behavior through subconscious cues, is a potentially powerful way to promote relational autonomy in end-of-life decision-making law, policy, and practice. With respect to planning for incapacity, standardized advance directive forms and POLSTs can be revised to prime decisionmakers to consider an individual's relational interests upon loss of capacity. Similarly, the standard form to request physician AID can be designed to prime individuals to discuss their decision to pursue physician AID with family members. This Section will suggest some revisions to standard legal forms.²⁷⁵

273. Very few people opt for physician AID. For example, 218 people requested a lethal prescription in Oregon in 2015, but only 132 used the prescription. OR. HEALTH AUTH., OREGON DEATH WITH DIGNITY ACT: 2015 DATA SUMMARY 2 (2016), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.

Through the use of formalities and waiting periods, dying in a manner other than through the use of physician AID may fall into the category of “sticky defaults” that manage and restrain negative externalities and internalities while simultaneously permitting opt-[in] for a subset of [persons] who . . . pass a social cost-benefit test.” Ayres, *supra* note 189, at 2045 (footnote omitted). If the default were flipped, and upon receiving a terminal diagnosis, a physician wrote a prescription for a lethal drug unless the patient opted not to have it, this would be a massive departure from current medical practice in the United States. This option would likely inspire significant political and cultural backlash, especially because “[i]n many contexts defaults have some extra nudging power because [people] may feel, rightly or wrongly, that default options come with an implicit endorsement from the default setter” and thus, some might interpret the reverse default as an endorsement of euthanasia. THALER & SUNSTEIN, *supra* note 190, at 35; *see also* IOM, *supra* note 48, at 362–63 (discussing the controversy over AID with respect to vulnerable patients).

What may be an interesting middle ground, however, is that when patients receive a terminal diagnosis, they are also informed of the option of physician AID, and at that point they could choose to have the prescription or not. This is known as mandated choice. This, in theory, is what occurs in Vermont's physician AID regime, wherein physicians are required by law to inform patients of this end-of-life option as part of informed consent conversations. VT. STAT. ANN. tit. 18, § 5282 (2016). However, one could argue that if presented the choice, people will feel like their physician is pressuring them to hasten their death.

274. *See, e.g.*, OR. REV. STAT. §§ 127.815, .820 (2015).

275. With the exception of the AID form, these standard forms are defaults, which can be tailored or replaced with alternative forms. But given that many people will use the default forms, especially since the forms are provided by the state government or healthcare providers and imply they are the “preferred” forms, coupled with the fact that people are not likely, due to status quo bias, to change their forms once completed, it is necessary to make sure the forms are designed to ensure that most people's preferences are accommodated. *See* THALER & SUNSTEIN, *supra* note 190, at 12, 34, 83–85. For a discussion of some default rules contained in standardized advance directive forms, *see* Shepherd & Hall, *supra* note 112, at 1443.

a. Advance Directives

As discussed previously, relatively few people complete advance directives,²⁷⁶ which means that their relational autonomy may not be respected upon loss of capacity. People should thus be nudged to complete an advance directive of some sort.²⁷⁷ But, given that laws meant to increase advance directives have not been particularly successful,²⁷⁸ in this instance it may be better to focus on adapting policy to fit individuals' behavior rather than trying to modify their behavior.²⁷⁹

For the few who do complete an advance directive, standardized advance directive documents (e.g., living wills and durable power of attorneys) used by states, hospitals, medical practices, and lawyers should be revised to prime an individual to make end-of-life healthcare decisions in light of their connectedness to relevant significant others, which research demonstrates is the end-of-life decision-making mode many people prefer.²⁸⁰ Prior research has shown that the primary benefits of completing advance directives come from choosing healthcare agents rather than making specific healthcare choices.²⁸¹ When selecting an agent, the form should advise an individual to

276. See *supra* note 126 and accompanying text.

277. The timing of the nudge to complete the advance directive matters. In my view, it would be best to have these nudges temporally close to expected death or to have a nudge to revise one's advance directive regularly to ensure that documented preferences reflect current preferences. See *supra* note 245 (discussing problems with binding oneself to former preferences).

Another form of choice architecture—the use of incentives—could be particularly powerful here. For example, if health insurance adequately covered the cost of physicians having extensive conversations with their patients about end-of-life planning, this may financially incentivize physicians to have these conversations. Now that Medicare reimburses for end-of-life planning discussions, physicians may be more likely to have them with their patients. Aleccia, *supra* note 144. But see Megan S. Wright, *Change without Change? Assessing Medicare Reimbursement for Advance Care Planning*, 48 HASTINGS CTR. REP. 1 (May–June 2018) (discussing how Medicare reimbursement for advance care planning conversations has had limited impact on provider billing practices to date).

Incentives such as this, in combination with the other changes I argue for in this Article, may do the best job of ensuring a relational autonomy with respect to end-of-life decisionmaking. But see Schneider, *supra* note 192, at 425–29 (arguing that all efforts to increase the rate of living will completion should cease because efforts are costly and have little impact, and because even when patients complete living wills, they do not make decisions that ensure they receive the type of care they desire); Shepherd, *supra* note 21, at 1713 (arguing against efforts to continue revising advance directive forms “to discover the Holy Grail for respecting patient autonomy”).

278. ORENTLICHER ET AL., *supra* note 36, at 336 (discussing the failure of PSDA in this respect).

279. See Michael Hallsworth, *Seven Ways of Applying Behavior Science to Health Policy*, in NUDGING HEALTH, *supra* note 134, at 44. For a discussion of POLST and priming, see *infra* Part III.C.3.b.

280. See *supra* text accompanying note 126.

281. See Drought & Koenig, *supra* note 135, at 118. Indeed, even scholars who are opposed to prioritizing patient autonomy and attempting to increase the completion of living wills support completion of durable power of attorneys. See, e.g., Schneider, *supra* note 192, at 439–40 (arguing that

provide detail about how much freedom their agent has to deviate from their written instructions. Surrogate decisionmakers are often stressed with the responsibility of making a decision on behalf of another and fear they are not deciding correctly, and the form may reduce this burden, which is something patients desire.²⁸² Further, the form should advise people to inform their healthcare agent that they have been selected to fulfill this responsibility, so that agents are not caught unaware when the individual loses capacity,²⁸³ and so that the agent will have had an opportunity to discuss the person's end-of-life wishes with them and their family.²⁸⁴

Some state governments provide online standardized forms that residents can complete to be accepted as a valid legal document governing their end-of-life decisions upon loss of capacity. Many of these forms combine living wills (i.e., written instructions) and durable power of attorney forms.²⁸⁵ For example, the Health Law Section of the Arkansas Bar Association provides a document that is distributed by the Arkansas Department of Human Services.²⁸⁶ The document begins with answers to common questions about living wills and power of attorneys, and then provides a "Declaration of Living Will" form. This living will form begins by asking about preferences for life-sustaining treatments that should be withheld or withdrawn in the case of an "incurable or irreversible condition with no hope of recovery that will cause . . . death within a relatively short [period of] time" or in case of permanent unconsciousness. The form also provides a checklist of medical interventions (e.g., surgery, dialysis, CPR, antibiotics, etc.) that a person can opt out of, as well as a few lines for people to write in additional directions.²⁸⁷ The form then asks about preferences regarding artificial nutrition and hydration. The form concludes with a place for the individual's signature and

this device can "resolve questions of authority to make decisions for incompetent patients, present[] patients a task within their competence, and cost[] little").

282. See Hines et al., *supra* note 134, at 487. Research shows that patients do not want to be a burden at the end of life. See, e.g., Broom & Kirby, *supra* note 129, at 504; Steinhauer et al., *supra* note 113, at 2479.

283. See BERLINGER ET AL., *supra* note 90, at 51 ("Confusion and tension may arise when family members do not know who the surrogate is, make an incorrect assumption about the surrogate's identity, or are unaware of treatment decisions being made by a surrogate who is not present at the patient's bedside.").

284. NELSON & NELSON, *supra* note 157, at 96 ("A real advantage to formally appointing a proxy is that it offers an opportunity to think through one's wishes, aloud, in the presence of the people most concerned to hear them.").

285. Shepherd, *supra* note 21, at 1731. Some argue that states should not provide standardized forms at all. *Id.* at 1740.

286. ARK. INNOVATIVE PERFORMANCE PROGRAM, ADVANCED DIRECTIVES—AGING WITH DIGNITY (2007), <https://wadleyhealthathope.org/sites/default/files/wadley-hope-advanced-directives.pdf>.

287. *Id.*

the signature of two witnesses.²⁸⁸ The next page consists of a form titled “Durable Power of Attorney for Health Care” for the individual to appoint an agent to make decisions on their behalf should they lose capacity.²⁸⁹

While this form is meant to ascertain preferences about medical interventions and ensure that autonomy survives loss of decision-making capacity at the end of life, the document does not do the best job of reaching the relational dimensions of a person’s autonomy.²⁹⁰ When persons have capacity at the end of life, they often make decisions with and in consideration of others. The standardized form Arkansas provides to its residents does not promote this preferred style of decisionmaking. Restructuring the document to prime people to consider relational interests and to discuss their decisions with others by, for example, moving the durable power of attorney form before the living will form, and requiring that the person appointed as agent sign the form, may result in decisions that are more consistent with how the person would actually make their decisions at the end of life. Patients do not make treatment decisions in a vacuum, and being reminded of other people rather than just presented with choices of whether, for example, to have a Do Not Resuscitate order, which may seem rather abstract, may prime people to make decisions differently. These forms should also direct an individual to discuss the documents with family members.²⁹¹ Both of these suggested revisions to the forms are low-cost and potentially high benefit.²⁹²

288. *Id.*

289. *Id.*

290. As Shepherd notes, standard living will forms promote a “de-relationalized” autonomy. Shepherd, *supra* note 21, at 1700. She writes,

it would be unusual to see a living will that explicitly directed that life-sustaining treatment be either discontinued or continued for the benefit of another (as in, “if I am ever in a persistent vegetative state, I would like my husband to choose what to do on the basis of what is best for our children”). Such language is far removed from the typical language of living wills. Even if that statement were written into a personalized living will, a court would likely be flummoxed to know what to do with it.

Id. (footnote omitted) (first citing FLA. STAT. ANN. § 765.303 (West 2010); and then citing OKLA. STAT. ANN. NT.63, § 3101.4 (West Supp. 2013)).

291. These forms should also be readable and easy to follow. See IOM, *supra* note 48, at 178 (discussing problems with advance directives).

292. See THALER & SUNSTEIN, *supra* note 190, at 3, 13 (describing small changes to choice architecture with little or no costs). There is a low cost to revise standardized forms, but there may be increased transactional costs with respect to the time it takes to complete the forms. Slowing down the process, however, may be beneficial in this significant decision in that it would prevent the possibility of unintended consequences. See Ayres, *supra* note 189, at 2063–65 (describing transactional cost and error tradeoffs).

The advance directive form provided by the state of Oregon is more consistent with these suggestions.²⁹³ On the first page of the form, the individual is prompted to appoint a health care representative.²⁹⁴ The next page asks about limits on the agent's power.²⁹⁵ Next comes the "Health Care Instructions" form, which highlights the shared decisionmaking between patient and physician by including options such as "I want to receive tube feeding[;] I want tube feeding only as my physician recommends[;] I DO NOT WANT tube feeding."²⁹⁶ Thus far, this document likely primes a person to consider end-of-life decisionmaking in the context of their social relationships by placing the durable power of attorney form prior to the living will, and by letting an individual opt to have decisions made by their healthcare provider.

Oregon also requires the appointed agent to sign, indicating they accept their appointment.²⁹⁷ The statement they sign reads, in part,

I accept this appointment and agree to serve as health care representative. I understand I must act consistently with the desires of the person I represent, as expressed in this advance directive or otherwise made known to me. If I do not know the desires of the person I represent, I have a duty to act in what I believe in good faith to be that person's best interest.²⁹⁸

However, this is the last page of the document. It is therefore possible, and maybe even likely, that a person would first complete their written instructions and then separately request their intended agent to sign the form. But it may be better for acceptance of the appointment to be prior to the written instructions, to increase the likelihood that the individual completing the form will discuss their preferences with the intended agent prior to completing the form. Should this occur, these end-of-life decisions may be made with and in consideration of others, and relational autonomy will survive incapacity.

b. POLSTs

As stated above, because laws meant to encourage completion of advance directives have had little impact, it may be better to adapt policies to

293. ORE. DEP'T OF CONSUMER & BUS. SERVS., ADVANCE DIRECTIVE FORM, http://healthcare.oregon.gov/shiba/Documents/advance_directive_form.pdf.

294. *Id.*

295. *Id.* This form is an excellent example of choice architecture and altering rules. It spells out what the default is, and asks whether people opt out, requiring initials for each opt-out.

296. The document notes, "'as my physician recommends' means that you want your physician to try life support if your physician believes it could be helpful and then discontinue it if it is not helping your health condition or symptoms." *Id.*

297. *Id.*

298. *Id.*

individual behavior.²⁹⁹ Institutional policies that promote the use of POLSTs, which are initiated by a physician and therefore not dependent upon patient planning, thus may be a more beneficial way to ensure that autonomy survives loss of capacity. Many POLST forms—which are meant to ensure patients’ goals for care at the end of life are respected³⁰⁰—are modeled after the Oregon form.³⁰¹ The front of Oregon’s one-page POLST form consists of medical orders about cardiopulmonary resuscitation, various medical interventions, and artificial nutrition, and the back of the form has instructions about completing the POLST.³⁰² It is not until the last section of Oregon’s form that clinicians are asked to document whether the discussion upon which the POLST is based was with the patient or their surrogate.³⁰³

A better way to structure this document to nudge clinicians to discuss treatment options with their patients in light of patients’ relationships with others is to 1) have the form require clinicians to ask patients if they have appointed a healthcare agent or who their surrogate is, and 2) have this be the first question on the form. That way, all other questions are primed to be answered with respect to relational considerations, which is consistent with most patient’s values and preferences.³⁰⁴ And when physicians plan to discuss the POLST with their patient, they may want to go one step further and advise the patient to bring their surrogate decisionmaker with them to the meeting, so that the patient, physician, and potential surrogate decisionmaker

299. See *supra* notes 278–279.

300. IOM, *supra* note 48, at 173. Because the POLST forms are for seriously ill patients, documenting end-of-life wishes in these forms likely does not have the same precommitment issues discussed previously with respect to advance directives. See *supra* note 245.

301. The form is available at CTR. FOR ETHICS IN HEALTH CARE, PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST) (2014), http://www.jsicm.org/pdf/DNAR20161216_kangae_03.pdf. See also *Order OR POLST Forms, OREGON POLST*, <http://oregonpolst.org/order> (last visited May 3, 2018).

302. The signature of a patient (or their surrogate) is recommended, but not required. *Id.* In the instructions on the form, it recommends that patients have an advance directive and has an optional section for contact information for healthcare agents or surrogates. *Id.* Given that this form is a medical order and only requires a signature from the responsible clinician, it is unclear that patients ever see the form or its advance directive recommendation. See *id.*; see also IOM, *supra* note 48, at 179 (expressing concern that some physicians may not actually have the necessary conversations with patients or their surrogates before completing a POLST); Terman, *supra* note 54, at 207–09 (detailing the potential for abuse in completing POLSTs for incapacitated patients). Thus, I would also recommend, to ensure that patients or their surrogates are truly knowledgeable and assenting, that a signature be required. See Ayres, *supra* note 189, at 207–76 (describing manifestations of assent as an error reduction strategy); Shepherd, *supra* note 21, at 1738 (“We need to develop guidelines and practices to allow physicians and hospitals to slow down and allow reconsideration of these quick judgments, without unduly impairing patient autonomy.”); Terman, *supra* note 54, at 207–09 (arguing that any formalities required by POLST would slow the process down, but that the benefits of preventing premature death may outweigh those time related costs).

303. OR. DEP’T OF CONSUMER & BUS. SERVS., *supra* note 293.

304. See *supra* Part II.A.

are informed and involved in the decisionmaking.³⁰⁵ Hospitals may want to institute the latter recommendation as a matter of policy. If both of these proposals are implemented, then both dimensions of relational autonomy are promoted: deciding in consideration of and in consultation with others.

c. Physician Aid in Dying

As part of the mandatory process to opt into physician AID in Oregon, the written request form provided by law asks patients to initial whether they have informed their family of their decision to hasten death in this manner or whether they have no family to inform.³⁰⁶ This requirement likely primes individuals to think about their decision in the context of their family relationships, which promotes relational autonomy. Given that Washington³⁰⁷ and California³⁰⁸ modeled their physician AID laws after Oregon's,³⁰⁹ they contain this same relational nudge. The physician AID laws in Vermont³¹⁰ and Colorado³¹¹ do not, however. Vermont and Colorado should amend their laws to include relational nudges, and as other jurisdictions legalize this practice, they too should include such nudges.

If states choose not to model their statutes after Oregon's, which contains many relational nudges, then these relational nudges should be built into hospital policies. As a matter of practice, physicians should ask patients who request AID whether they have informed or consulted with their loved ones, but not require that they do so in order to receive AID. Based on the model of shared decisionmaking, physicians also should have an extensive conversation with such patients to help them in determining whether this end-of-life choice is consistent with their values, preferences, and goals, especially in

305. See BERLINGER ET AL., *supra* note 90, at 38 (recommending that clinicians advise patients to bring surrogates with them to advance planning discussions with medical professionals). Again, this slows the process down, but if it minimizes errors, a slower process can be justified. See Ayres, *supra* note 189, at 2063–65.

306. See *supra* note 230.

307. WASH. REV. CODE ANN. § 70.245.220 (West 2011).

308. CAL. HEALTH & SAFETY CODE § 443.11 (West 2016).

309. *Oregon Death with Dignity Act a Model for Other States: Washington Post Editorial*, OREGONIAN (June 22, 2015), http://www.oregonlive.com/opinion/index.ssf/2015/06/oregons_death_with_dignity_act.html.

310. See VT. DEP'T OF HEALTH, REQUEST FOR MEDICATION FOR THE PURPOSE OF HASTENING MY DEATH (2013), http://www.healthvermont.gov/sites/default/files/documents/2016/11/End_of_Life_Choice_patient_medication_request_form.pdf.

311. See COLO. REV. STAT. ANN. § 25-48-112 (West 2017).

the context of relationality. To assist physicians in conducting such conversations, professional organizations to which physicians belong may construct decision aids to distribute to physicians.³¹²

Any of the nudges that promote better communication between physicians and their patients (or patient surrogates) or between patients and their families will likely reduce medical futility disputes. There is no common standardized form related to medical futility disputes, so I cannot make suggestions about priming for relational decisionmaking in this context, although specific healthcare organizations should ensure that their written policies have steps to promote shared decisionmaking.

D. Responses to Objections and Counterarguments

When making any changes to law and policy, especially when the stakes are life and death, objections to the proposed changes should be carefully considered. This Section will address various counterarguments to my proposal to build relational nudges into existing law and policy.

1. Autonomy Should Remain Privileged in End-of-Life Decision-Making Law, but Accounting for Others' Interests Is Also Important

Some may be skeptical that changing end-of-life decision-making law and policy to promote relational autonomy is desirable. One strand of skepticism concerns whether autonomy, in any conceptualization, is always valuable,³¹³ or whether coercion to protect people from poor choices is preferred with respect to some actions.³¹⁴ Similarly, law can legitimately take into account effects on others associated with autonomous decisions, and choose to

312. This would require that professional organizations such as the American Medical Association were at least neutral on this end-of-life option, rather than in opposition to it. AMA CODE OF MEDICAL ETHICS, OPINIONS ON CARING FOR PATIENTS AT THE END OF LIFE, PHYSICIAN-ASSISTED SUICIDE 5.7 (2016), <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-5.pdf> (“Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”).

313. There is a strand of literature that is skeptical or even hostile toward privileging autonomy in health care, noting that attempts to promote patient autonomy often fail or that other values, such as respect for patient dignity and relationships, are more important. See, e.g., Shepherd, *supra* note 21, at 1720. But see NEDELSKY, *supra* note 176, at 41–42, 45 (arguing that even in a legal and political system that centers relationships, autonomy is still valuable); Schneider, *supra* note 192, 413, 439–44 (arguing that it is still important to determine what patients want and base an ethical agenda on patient preferences).

314. Poor decisions can be thought of as “negative externalities.” Ayres, *supra* note 189, at 2093 (emphasis omitted). See SARAH CONLY, AGAINST AUTONOMY: JUSTIFYING COERCIVE PATERNALISM 1 (2013) (arguing that some courses of action, like consuming trans fats or smoking cigarettes, should be illegal because they are harmful, and that arguing that they should be legal because people should be able to make autonomous decisions overvalues autonomy).

impede certain courses of action to reduce negative externalities.³¹⁵ With respect to end-of-life decision-making law and policy, either of these arguments (paternalism and externalities) could be used to justify a mandatory rule that people must consult with others and consider others' interests when making decisions about the end of their lives. This mandatory rule could be seen as giving people what they want and as good for them even if they do not themselves choose according to their preferences, or reducing harm to third parties.

In fact, Robert Burt, who argued that people should have a say in other's end-of-life decisions, even when a patient is fully competent, has suggested this. He wrote, for example,

When the patient is competent and prepared to make a decisive choice, the autonomy principle does properly bestow hierarchically superior authority with the patient. But even in this clear-cut case, there are other, importantly affected participants who should have some voice in the patient's ultimate decision—not a veto but a voice, a chance to talk to the patient and address and amplify the ambivalence that the decision-making patient himself is likely to feel but also likely to deny.³¹⁶

Burt also suggests that consultation with others may be mandatory, or if there is an exception, a patient should have to justify why they refuse to consult with others affected by their decision.³¹⁷ He also suggests that if the patient is incompetent, all possible surrogate decisionmakers must achieve

315. See, e.g., Ayres, *supra* note 189, at 2084 (discussing effects on third parties in the context of sticky defaults).

316. Burt, *supra* note 231, at S12. Others have made more extreme arguments:

Simple fairness, Hardwig believes, dictates that all those with an interest in the decision be taken into account as it is made.

This is an upsetting and radical claim for the profession. It means, first of all, that families should be involved in the decisionmaking process not just as sounding-boards and not just as a source of patient-centered love and support, but in their own right. Rather than being instructed by the health care team to focus on what is best for the patient, family members should be encouraged to get their own interests, fears, and preferences on the table. They should be treated not just as means to the patient's ends, but as ends in themselves.

But that is not all. If we have the courage to follow the argument from fairness to wherever it leads us, we must acknowledge that when a fundamental disagreement arises between the patient and the rest of the family, and no amount of discussion or mediation can resolve it, the health care team might be obliged to try to do what the family wants *even though the patient dissents*.

NELSON & NELSON, *supra* note 157, at 114–15 (footnote omitted) (citing John Hardwig, "What About the Family?", 20 HASTINGS CTR. REP. 5 (1990)).

317. Burt, *supra* note 231, at S12.

consensus on what to do for the patient, although he acknowledges the practical difficulties of such a proposal.³¹⁸

In my view, mandatory consultation with affected parties interferes too much with the patient's autonomy interest (in the face of physician paternalism or family coercion or conflict) and burdens the fundamental value of bodily integrity.³¹⁹ It is, after all, the patient's body that bears physical suffering (or indignity) associated with the decisions.³²⁰ Furthermore, not all persons prefer to consider other's perspectives on their end-of-life decisions, and this variation in preferences is also another reason not to have mandatory rules in this body of law. Finally, when persons are permitted to exercise choice, they experience psychological benefits,³²¹ and this is an important social good that would be weakened by mandatory consultation.

Law and policy can take relational preferences and values into account without imposing too much on the autonomy or bodily integrity principles by incorporating insights from behavioral law and economics and building in relational nudges like those proposed in Part III.C.2. This nudging will steer actors such as patients, families, and healthcare providers, as well as institu-

318. *Id.* at S13. After all, how are "affected parties" defined? How far out from the patient's immediate family and primary clinician should the impact be measured? And the further out one goes, the more difficult it is to achieve consensus, and at some point, a decision about medical treatment must be made.

319. Indeed, Burt's proposal is inconsistent with modern bioethics, as can be seen from Beauchamp and Childress's discussion about physicians disclosing healthcare information to patients' relatives. BEAUCHAMP & CHILDRESS, *supra* note 1, at 305 ("Families provide important care and support for many patients, but an autonomous patient has the right to veto familial involvement altogether."). Jennings also notes that it is important to "[r]econstruct . . . patient-centered rights and values," working with the reality of relationships, rather than "reject" rights. Jennings, *supra* note 42, at 228; *see also* Shepherd & Hall, *supra* note 112, at 1446 (arguing that respecting patient autonomy remains important even as other values matter as well).

320. As Justice Brennan wrote, "Dying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. A quiet, proud death, bodily integrity intact, is a matter of extreme consequence." *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 310–11 (1990) (Brennan, J., dissenting).

321. *See* Winick, *supra* note 14, at 1755–68 (describing various psychological benefits of autonomy).

Our political and legal conceptions of autonomy are aspirational. They are based on a conception of the individual as a rational decisionmaker able to make free choices reflecting internal values and preferences. In reality, however, this atomistic conception of the individual is artificial. The individual is a component of . . . several social groups The individual's decisionmaking is heavily dependent upon the desires of these other groups and the anticipated impact the individual's decisions will have on them. We are by nature communal, more interdependent than independent. . . .

Our idealized model of individual autonomy is thus inconsistent with psychological realities and largely artificial. *Nevertheless, our political conception of the individual as an autonomous decisionmaker . . . is a useful foundation upon which to build a legal system.*

Id. at 1768–69 (emphasis added).

tions such as courts and hospitals, to consider relationality in end-of-life decisionmaking. But the nudges will never require individuals to make their end-of-life decisions in consultation with family members or on the basis of relational interests, thus preserving autonomy.

It is important to consider the interests others may have in what happens to an individual at the end of their life. End-of-life decisions may have profoundly negative effects on third parties that outlast the autonomy interest of the individual in question (that is, their autonomy interest ends upon death while the effects of their decisions may linger for some time). A person's decisions may impact healthcare providers who may feel moral distress in some instances.³²² They also likely have a strong impact on surviving family members.³²³

Laws and policies often take into consideration externalities,³²⁴ and have done so with respect to end-of-life decisionmaking as well. For example, the *Saikewicz* decision described the effect end-of-life decisions have on others, and argued it is a significant state interest to balance against the fundamental right to refuse life-sustaining treatment.³²⁵ The *Saikewicz* court wrote:

A second interest of considerable magnitude, which the State may have some interest in asserting, is that of protecting third parties, particularly minor children, from the emotional and financial damage which may occur as a result of the decision of a competent adult to refuse life-saving or life-prolonging treatment. Thus . . . [when] the State's interest in preserving an individual's life [is] not

322. See, e.g., Curtis & Burt, *supra* note 83, at 22 (describing clinician distress at providing futile care); Betty R. Ferrell, *Understanding the Moral Distress of Nurses Witnessing Medically Futile Care*, 33 ONCOLOGY NURSING F. 922 (2006).

This is also why there are conscience-based opt-outs in physician AID laws, for example. See, e.g., OR. REV. STAT. ANN. § 127.885 (West 2015). This is also why providers are not required to provide "futile" treatment under the Uniform Health-Care Decisions Act (but if there is a refusal, care must be transferred to another facility or provider). UNIF. HEALTH-CARE DECISIONS ACT § 7(e)–(g) (UNIF. LAW COMM'N 1993). States that have not adopted the Uniform Health-Care Decisions Act have created similar processes for surrogate healthcare decisionmaking for adults who lack decisional capacity. See, e.g., N.Y. PUB. HEALTH LAW § 2994-d(4)(b) (McKinney 2011).

323. See, e.g., *Cruzan*, 497 U.S. at 311 ("A long, drawn-out death can have a debilitating effect on family members."); Rachel Aviv, *The Death Treatment*, NEW YORKER (June 22, 2015), <http://www.newyorker.com/magazine/2015/06/22/the-death-treatment> (describing the trauma a woman's decision to be euthanized had on her family).

324. See Ayres, *supra* note 189, at 2084, 2086–87 (discussing externalities); see also *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 852 (1992) ("Abortion is a unique act. It is an act fraught with consequences for others: for the woman who must live with the implications of her decision; for the persons who perform and assist in the procedure; for the spouse, family, and society which must confront the knowledge that these procedures exist, procedures some deem nothing short of an act of violence against innocent human life; and, depending on one's beliefs, for the life or potential life that is aborted.")

325. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 426 (Mass. 1977).

sufficient, by itself, to outweigh the individual's interest in the exercise of free choice, the possible impact on minor children would be a factor which might have a critical effect on the outcome of the balancing process.³²⁶

Here the court explicitly raises the possibility that someone's family relationships, financial responsibilities toward family members, and family members' emotional responses to their death can be raised as a countervailing state interest that may restrict a person's autonomy in end-of-life decisionmaking.³²⁷ This interest is often raised in cases involving Jehovah's Witnesses who need, but refuse, blood transfusions,³²⁸ but as the Supreme Court of Florida wrote, "[w]hile we agree that the nurturing and support by two parents is important in the development of any child, it is not sufficient to override fundamental constitutional rights."³²⁹

Also with respect to physician AID, arguments in favor of this end-of-life option have often been framed in terms of externalities. As Justice Souter summarized, "without a physician to assist in the suicide of the dying, the patient's right will often be confined to crude methods of causing death, most shocking and painful to the decedent's survivors."³³⁰ And the actual Death with Dignity law in Oregon also requires active consideration of a person's family when making the written request, which is another way that legislators have tried to reduce negative effects on third parties from this decision—by trying to increase the chance that people will inform their loved ones of their decision in advance.

My suggestions for relational nudges are not only in the service of promoting autonomy, but are also meant to reduce negative externalities by, for example, reducing surrogate decisionmakers' emotional burdens by attempting to have persons while competent talk to people about their end-of-life preferences and values. Thus, even if one does not agree with my argument that autonomy should continue to be privileged in this body of law, perhaps an argument that nudging decisionmakers to consider the effect end-of-life

326. *Id.* (citation omitted) (citing *Holmes v. Silver Cross Hosp. of Joliet, Ill.*, 340 F. Supp. 125 (D. Ill. 1972)).

327. *Id.*

328. *See, e.g.*, *Pub. Health Trust of Dade Cty. v. Wons*, 541 So. 2d 96, 98 (Fla. 1989) (holding that a Jehovah's Witness could refuse a blood transfusion despite having minor children to care for).

329. *See id.* at 97. Other cases also demonstrate that persons with minor children are legally permitted to refuse life-sustaining medical treatment. *See, e.g.*, *Stamford Hosp. v. Vega*, 674 A.2d 821, 832 (Conn. 1996) (holding for Jehovah's Witnesses who are parents who refuse blood transfusions); *Fosmire v. Nicoleau*, 551 N.E.2d 77, 84 (N.Y. 1990). Importantly, however, often lower courts order blood transfusions, and only on appeal does a court vindicate the parent's right to refuse life-sustaining medical treatment, a vindication that is too late to matter in practice. ORENTLICHER ET AL., *supra* note 36, at 389 n. 3.

330. *Washington v. Glucksberg*, 521 U.S. 702, 778 (1997) (Souter, J., concurring).

decisions—whether to hasten death or attempt to prolong life—have on third parties will be persuasive.

2. *Nudging is Not Inconsistent with Autonomy*

Some scholars object to the concept of nudging on philosophical grounds, arguing that nudging is inconsistent with autonomy. Others may object that in this particular case, the relational nudges I have proposed are inconsistent with autonomy in end-of-life decisionmaking. This Section will address both objections.

a. *Philosophical Objections*

There is currently a lively scholarly debate about whether nudging is consistent with autonomy. Many scholars who think nudging is incompatible with autonomy often oppose nudging.³³¹ It is necessary to address this debate because with respect to medical decisionmaking, the law prioritizes autonomy followed by beneficence, and I have not proposed deviating from this ordering of principles. This Section will first briefly summarize this debate and then argue that nudging is not necessarily inconsistent with autonomy, and in this particular realm of law, as I have proposed nudging, it is actually autonomy-promoting.

331. See Thomas Ploug & Soren Holm, *Doctors, Patients, and Nudging in the Clinical Context—Four Views on Nudging and Informed Consent*, 15 AM. J. BIOETHICS 28, 37 (2015) (arguing that, because nudging may involve manipulation and bypass reason, it is incompatible with autonomous decisionmaking, and thus, incompatible with informed consent requirements, and that nudging is only justifiable when informed consent is not required); see also Blumenthal-Barby & Burroughs, *supra* note 223, at 7 (noting that priming is manipulation, but can be ethically justified if the benefits outweigh harms and reasoning cannot be used). But see J.S. Blumenthal-Barby & Anand D. Naik, *In Defense of Nudge-Autonomy Compatibility*, 15 AM. J. BIOETHICS 45, 45 (2015) (“Nudging may even enhance informed consent by producing levels of understanding more aligned with dual process models of reasoning . . . it is not the case that nudges necessarily (or even often) interfere with patients pursuing their own goals, and nudges may actually aid patients through their values clarification.”) (citation omitted) (citing Paul Slovic et al., *Risk as Analysis and Risk as Feelings: Some Thoughts About Affect, Reason, Risk, and Rationality*, 24 RISK ANALYSIS 311 (2004)).

Nudging is often paternalistic.³³² Some scholars thus pose the issue of nudging as a competition between autonomy and beneficence.³³³ Paternalistic beneficence is “attempting to protect patients against the potentially harmful consequences of their own stated preferences.”³³⁴ If there is true support for autonomy, some argue, then people will be permitted to make whatever choices they want, even if such choices are “bad” or mistakes.³³⁵

Thaler and Sunstein advocate for a type of nudging called “libertarian paternalism.”³³⁶ By this they mean that policies should “maintain or increase freedom of choice,” but should be designed to “influence choices in a way that will make choosers better off, *as judged by themselves*.”³³⁷ They view libertarian paternalism as compatible with autonomy because it can be used to correct for cognitive biases that prevent people from making choices based on their true preferences.³³⁸ Beauchamp and Childress similarly describe the autonomy-promoting benefits of libertarian paternalism: “This paternalism

332. Again, as noted earlier in the Article, Beauchamp and Childress “define ‘paternalism’ as the intentional overriding of one person’s preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden.” BEAUCHAMP & CHILDRESS, *supra* note 1, at 215 (emphasis omitted).

According to this definition, nudging is not always paternalistic. This is because it may be unintentional. THALER & SUNSTEIN, *supra* note 190, at 12. Or because it can be used in ways that are meant to influence another’s actions, but not for the individual’s benefit, but rather for the benefit of society (e.g., presumed consent for cadaveric organ transplantation). See, e.g., David Orentlicher, *Presumed Consent to Organ Donation*, in NUDGING HEALTH, *supra* note 134, at 340. Nudging can also be used in a way that benefits corporations trying to profit from manipulating decisionmaking in a way that may be opposed to a person’s interests and societal interests.

333. See Capron & Spruijt-Metz, *supra* note 242, at 233–34 (describing the tension between physician beneficence and physician respect for patient autonomy).

334. BEAUCHAMP & CHILDRESS, *supra* note 1, at 216.

335. See Sunstein, *supra* note 245, at xviii (“[F]reedom of choice has intrinsic and not merely instrumental value.”); Brock, *supra* note 151, at 32. Attempting to persuade people to make a different choice is consistent with respect for autonomy as long as a person’s final choice is respected even if it is not the recommended option. BEAUCHAMP & CHILDRESS, *supra* note 1, at 216. For the purposes of this Article, respect for relational autonomy cuts both directions. If a person autonomously decides to consider their relationships with others as part of their end-of-life decisionmaking, this should be respected even if others think it is a mistake to do so.

336. THALER & SUNSTEIN, *supra* note 190, at 5. *But see* Ryan Bubb & Richard H. Pildes, *How Behavioral Economics Trims Its Sails and Why*, 127 HARV. L. REV. 1593, 1599 (2014) (arguing that nudges often function as “mandates” and only formally preserve choice).

337. THALER & SUNSTEIN, *supra* note 190, at 5.

338. *Id.* (“[I]ndividuals make pretty bad decisions—decisions they would not have made if they had paid full attention and possessed complete information, unlimited cognitive abilities, and complete self-control.”). Importantly, if law nudges rather than mandates or bans, people are still free to make decisions that the choice architect tries to steer them away from, preserving freedom. *Id.* at 5; see also BEAUCHAMP & CHILDRESS, *supra* note 1, at 218–19 (“Libertarian paternalism is premised on the view that people have limited rationality or limited self-control that reduces their capacity to choose and act autonomously.”).

reflects many values that individuals would recognize or realize themselves if they did not encounter internal limits of rationality and control.”³³⁹

I, too, argue that nudging is not necessarily inconsistent with autonomy. As described earlier, people often lack adequate information or understanding, and have distorted rationality due to cognitive biases when making decisions.³⁴⁰ Therefore, addressing these decision-making limitations through good choice architecture can actually promote autonomy rather than undermine it. I recognize, however, that nudging can be used to counter autonomous decisionmaking.³⁴¹ But my recommendations for changes in end-of-life decision-making law and policy are meant to be autonomy-promoting, especially because rationality may be particularly distorted in healthcare decisionmaking.³⁴² Choice architecture can thus be “justified on autonomy grounds in arranging . . . choice situation in a way that likely will correct . . . cognitive biases and bounded rationality.”³⁴³

Given the empirical research on people’s end-of-life decision-making preferences, I have argued that we should structure end-of-life law and policy to promote relational autonomy. The way law and policy are currently structured may in some respects be biased against what people want.³⁴⁴ The

339. BEAUCHAMP & CHILDRESS, *supra* note 1, at 219; *see also id.* at 104–05 (discussing how autonomy can be compromised by irrationality).

340. *See supra* note 184 and text accompanying *supra* notes 190–193.

341. *Id.* at 218 (“Hard paternalism requires that the benefactor’s conception of best interests prevail, and it may ban, prescribe, or regulate conduct in ways that manipulate individuals’ actions to secure the benefactor’s intended result.”).

342. Some scholars have even argued that there is an ethical, although not legal, duty for physicians to assist their patients in overcoming their cognitive biases to make decisions that are in the patient’s best interest. These scholars assert that healthcare decisions should be made collaboratively, however, and with the patient’s values guiding the decision, which is similar to the shared decision-making models described earlier. Jennifer L. Zamzow, *Affective Forecasting in Medical Decision-Making: What Do Physicians Owe Their Patients?*, in NUDGING HEALTH, *supra* note 134, at 227–28 (“Physicians should intervene proactively in at least two kinds of cases: (1) cases where the stakes are high (for example, where different treatment options will lead to very different outcomes and where the outcomes will significantly affect one’s experiential quality of life); and (2) cases where patients typically have a poor understanding of what it is like to have a certain condition or undergo a certain treatment . . .”).

Other scholars are skeptical of nudging because they are anti-paternalism in the physician-patient relationship. These scholars think it is possible to nudge both beneficently and in a way that respects patient autonomy, however, as long as the procedure of nudging is fully transparent and the range of choices a patient has is not diminished. Capron & Spruijt-Metz, *supra* note 242, at 234.

343. BEAUCHAMP & CHILDRESS, *supra* note 1, at 219; Capron & Spruijt-Metz, *supra* note 242, at 234.

344. For example, living will forms that do not reference family in any way, but instead ask people what they would want should they have particular medical conditions at a future point, contain a bias against relationality. Abstracting the experience of medical conditions from the context of family relationships is absurd, and yet, the form does just that, which may ultimately frustrate the intent of the future incapacitated person who would want end-of-life decisions to be made with such relationships in mind.

choice architecture I have proposed would modify defaults and use priming to draw people's attention to their relational context, rather than withhold information or ignore or obscure the reality of social relationships. These relational nudges still prioritize an individual's preferences and values rather than their family's or physician's preferences and values, and would never override people's choices. Rather, these nudges would help those who do prioritize relationality in end-of-life decisionmaking actualize their desires.

In sum, these proposed nudges aim to promote both autonomy (aiding individuals in deciding rationally) and welfare (aiding individuals in deciding on the basis of their interests) by reminding decisionmakers of relationality, which often matters to individuals, but may be overlooked in end-of-life decisionmaking. Thus, my proposals are consistent with the principles underlying existing end-of-life decision-making law and policy, which prioritize an individual's autonomy followed by their best interests (i.e., welfare).

b. Relational Nudges Fit Most People's End-of-Life Preferences

Another common critique of nudging is that policymakers may not actually know what is in people's best interests³⁴⁵ or what default rule people would democratically choose.³⁴⁶ However, in the case of end-of-life decisionmaking, we do know what *most* people's interests are and what default rule *most* people would choose.³⁴⁷ Empirical evidence has demonstrated, in study after study, what people think is important at the end of life, and what their values and preferences are with respect to decisionmaking.³⁴⁸ They want to retain decision-making autonomy, but they value input and guidance from their physicians,³⁴⁹ and they also consider their relationships with their loved ones while making such decisions.³⁵⁰ The default rules and other elements of choice architecture, such as priming, in end-of-life decision-making

345. Mark D. White, *Bad Medicine: Does the Unique Nature of Healthcare Decisions Justify Nudges?*, in *NUDGING HEALTH*, *supra* note 134, at 73 (“[P]olicymakers use nudges to steer people’s decisions in interests that are not necessarily their own, but rather the policymakers’ idea of those interests.”); Korobkin, *supra* note 191, at 17 (describing how policymakers may not know what is best and how suboptimal nudges may succeed in changing behavior).

346. Jonathan Gingerich, *The Political Morality of Nudges in Healthcare*, in *NUDGING HEALTH*, *supra* note 134, at 103. Libertarian paternalists choose defaults that most people, free of distorted rationality, prefer. THALER & SUNSTEIN, *supra* note 190, at 12.

347. We also know that in the end-of-life context, people do not seem to be troubled by default rules. *See* Sunstein, *supra* note 245, at xx (reporting on scholarly findings that, when informed about choice architecture in this context, people still follow the chosen default).

348. *See, e.g.*, Steinhauser et al., *supra* note 113, at 2478–79; Singer, *supra* note 204, at 165–66.

349. *See* Drought & Koenig, *supra* note 135, at 118 (“There is some evidence that patients are also willing to defer to physician judgment over their own previously expressed preferences in a similar manner. . .”) (citation omitted) (citing Ashwini Seghal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 *JAMA* 59 (1992)).

350. *See supra* note 129 and accompanying text.

law and policy should therefore both preserve patient autonomy and accommodate relational considerations; that is, nudging should promote relational autonomy. Given extensive knowledge of people's preferences, the conditions for justifiable nudging in this area of law are met.³⁵¹

It is true that not all people want to make end-of-life decisions in light of their social relationships. For example, people may be estranged from their families.³⁵² Others may not want their families involved in the decision-making process so as to not burden or overwhelm them. Or perhaps an individual does not care to hear their physician's opinion about what end-of-life choices they should make. My proposals account for variation in preferences, however, by preserving opt-out (i.e., not having mandatory rules). Preserving opt-out protects the minority of people who prefer not to make decisions relationally.³⁵³

In conclusion, with respect to objections about nudging, it is impossible to avoid influencing how decisions are made when creating law and policy, even if such influence is unintentional.³⁵⁴ Given this reality, I have argued for intentional changes to this body of law to accommodate the preferences of most people making an end-of-life decision, and to preserve the freedom to opt out or choose differently. These relational nudges are, in the words of Thaler and Sunstein, meant "to help the least sophisticated people while imposing minimal harm on everyone else."³⁵⁵

3. Existing Safeguards Can Adequately Protect Vulnerable Persons

There are existing models of healthcare decisionmaking where the default is that decisions are made in consultation with families, such as in the pediatric setting where parents are legally entitled to make healthcare deci-

351. See Korobkin, *supra* note 191, at 17–18 (arguing that libertarian paternalism is justified "(1) when policy-makers are highly confident about what choices and decisions will maximize the welfare of most actors; (2) when there is a high degree of homogeneity among the actors, so that nudging most people in the direction that is desirable for them will not have the side effect of nudging a large minority in a direction that is undesirable for them; and (3) when there are few negative externalities created by individual choices, such that behavior that is welfare maximizing for most individual decision-makers is also welfare maximizing for society"); see also Blumenthal-Barby & Burroughs, *supra* note 223, at 1 (analyzing the ethics of nudging).

352. Or families may just not have close relationships, and should thus not be involved in one another's healthcare decisions. NELSON & NELSON, *supra* note 157, at 99.

353. *But see* Bubb & Pildes, *supra* note 336, at 1599 ("[T]he opt-out option exists more in theory than in fact.").

354. THALER & SUNSTEIN, *supra* note 190, at 3, 10, 72, 237.

355. *Id.* at 72, 248–49. If someone has planned for death in an alternative manner, using customized documents provided by an attorney, for example, these nudges should not impact their end-of-life decisionmaking.

sions for their children but are often encouraged to make decisions in consultation with their children, and also in the hospice and palliative care setting.³⁵⁶ Many people may be concerned that considering other's interests or consulting others in end-of-life decisionmaking would allow families or others to assert undue pressure on an individual's end-of-life decision,³⁵⁷ overriding a person's autonomy and resulting in decisions that are not in their best interest.³⁵⁸

While in many instances, families may aid in maintaining or restoring patient autonomy,³⁵⁹ autonomy also can be compromised by family influence.³⁶⁰ Decisions to withhold or withdraw life-sustaining medical treatment, or to make use of physician AID, for example, raise concerns about whether the patient is being pressured to hasten their death, contrary to their desire to prolong their lives, at a time when they are particularly vulnerable and may not be able to withstand such pressure.³⁶¹ Sometimes there are allegations of financial conflicts of interest between individuals and their family members,

356. There does not seem to be an accepted model of deciding on the basis of other's interests, however.

357. Liz Blackler, *Compromised Autonomy: When Families Pressure Patients to Change Their Wishes*, 18 J. HOSPICE & PALLIATIVE NURSING 284, 284 (2016).

358. Ho, *supra* note 174, at 129 (“[F]amily members may have divergent values and priorities from those of the patients, such that their involvement could counter patients’ autonomy and best interests.”); *see also* NELSON & NELSON, *supra* note 157, at 85 (describing bioethicists’ suspicions and distrust of patients’ families). “An overly romantic view of the family might lead to the temptation to compromise the patient’s interests, while an overly cynical view might declare irrelevant anything *but* the patient’s interests.” *Id.* at 99.

359. NELSON & NELSON, *supra* note 125, at 131. This Section of the Article focuses on the concern that families will compromise a patient’s autonomy. I would like to emphasize, however, that physicians may also compromise their patient’s autonomy through the paternalistic provision of care that does not take seriously informed consent or their patient’s values. In this instance, family involvement in healthcare decisionmaking can provide welcome support for a patient to assert their preferences in interactions with the healthcare provider, or if the patient is incapacitated, the family can assert the patient’s preferences on behalf of the patient.

Any conflict between a physician and patient/surrogate will likely be referred to an ethics committee, which can also provide a review of the situation and take steps to ensure the patient’s autonomy is respected. Ethics committees involved in mediating such conflicts will need to recognize, however, that autonomy is relational, and not automatically assume family involvement in healthcare decisionmaking is problematic.

360. Blackler describes compromised autonomy as follows:

[T]he form of compromised autonomy that arises when patients with decisional capacity are unduly pressured or coerced by their families into making medical decisions that are not in line with previously held values, beliefs, or perspectives. Family pressure or coercion is defined as occurring when caregivers employ verbal threats, harassment, berating, intimidation, or other manipulative tactics designed to force vulnerable patients to change well-established beliefs or preferences. Patients with a history of power inequities, shifts in familial roles and relationship status, and progressive disease are at higher risk to experience compromised autonomy.

Blackler, *supra* note 357, at 284.

361. Ho, *supra* note 174, at 129.

who may benefit financially if a patient were to die more quickly.³⁶² This benefit may come in the form of a larger inheritance if the patient's financial resources are not being used for medical treatment, which is expensive at the end of life.³⁶³ Or the financial benefit may come in the form of the patient costing the family member less if the family member is the party covering the patient's medical expenses.³⁶⁴ People may also experience pressure to hasten their death from family members or other caregivers if their illness and treatment constitute an emotional or psychological burden on these other parties.³⁶⁵

Others may be concerned that healthcare providers will be indifferent to patients who are vulnerable and that weighing the clinician's views on end-of-life treatment is thus inappropriate (even with respect to the shared decision-making model). "Vulnerable" could mean that the patient is seriously ill and needs care.³⁶⁶ Or "vulnerable" may refer to a class of persons, such as persons with disabilities, who are marginalized in society and thus may be more susceptible to or harmed by assessments that their lives are less valuable than others.³⁶⁷

362. A financial conflict of interest would also exist if it would be in a person's best interest to die, but in their family's interest for the person's life to be extended if the family relies on the person's Social Security benefits or rent-controlled apartment, for example.

363. See IOM, *supra* note 48, at 289–301 (describing the cost of care at end of life); see also *In re Guardianship of Schiavo*, 780 So. 2d 176, 178 (Fla. Dist. Ct. App. 2001) ("[T]here may be occasions when an inheritance could be a reason to question a surrogate's ability to make an objective decision.").

364. See BEAUCHAMP & CHILDRESS, *supra* note 1, at 171 (describing the difficulty of deciding in someone's best interest when also responsible for their healthcare costs).

365. See *Washington v. Glucksberg*, 521 U.S. 702, 783 (1997) (Souter, J., concurring).

366. The IOM defines "vulnerable groups" in the following way:

This report's use of the term "vulnerable populations" goes beyond the conventional usage, which applies to people from ethnic, cultural, and racial minorities; people with low educational attainment or low health literacy; and those in prisons or having limited access to care for geographic or financial reasons. Here it includes people with serious illnesses, multiple chronic diseases, and disabilities (physical, mental, or cognitive); the frail elderly; and those without access to needed health services. In this latter sense, almost all people nearing the end of life can rightly be considered a "vulnerable population."

IOM, *supra* note 48, at 28; see also *id.* at 38–39 (providing specific examples of vulnerable persons).

It is important to note, however, that not all members of "vulnerable groups" are, in fact, vulnerable. BEAUCHAMP & CHILDRESS, *supra* note 1, at 267–68 ("[F]or many groups a label covering all members of the group serves to overprotect, stereotype, and even disqualify members capable of making their own decisions.").

367. See, e.g., *Glucksberg*, 521 U.S. at 732 (majority opinion) ("An insidious bias against the handicapped—again coupled with a cost-saving mentality—makes them especially in need of Washington's statutory protection." (quoting *Compassion in Dying v. Washington*, 49 F.3d 586, 593 (9th Cir. 1995))); see also Elizabeth Pendo, *What Patients with Disabilities Teach Us About the Everyday Ethics of Health Care*, 50 WAKE FOREST L. REV. 287, 292–96 (2015) (describing physician bias against persons with disabilities, and the negative encounters persons with disabilities report having with healthcare providers, which may lead to poor health care); Searight & Gafford,

Given concerns about compromised patient autonomy when seriously ill due to relational conflicts of interest or disregard for the patient's wellbeing, and given that failing to adequately protect patients from coercion may cost them their life or inflict suffering, end-of-life decision-making law and policy appropriately privilege autonomy and beneficence. Fortunately, my proposed modified defaults and use of priming will likely not increase patient vulnerability or reduce autonomy,³⁶⁸ and there are existing safeguards that can also assuage concerns about relational nudges in end-of-life decision-making law and policy.³⁶⁹

The primary existing safeguard for patient autonomy is the fiduciary duty owed by physicians to their patients. The physician should be acting in the best interests of their patient, and if they are fulfilling this duty, they will not act with disregard to their patients³⁷⁰ and will monitor whether their competent and capacitated patients are being unduly influenced by others to decide in a way contrary to the patient's preferences.³⁷¹ Physicians who are concerned about undue familial influence can try to speak to their patients privately.³⁷² Furthermore, physicians can "safeguard [their incapacitated] patient's interests and preferences, where known, by monitoring the quality of surrogate decision making,"³⁷³ and pay special attention to the incompetent

supra note 167, at 519–21 (reviewing literature about how African Americans fear that physicians do not value their lives).

368. See Blumenthal-Barby & Burroughs, *supra* note 223, at 4 (arguing that nudging should not make vulnerable persons worse off). The nudges I discuss in this Article are just that: nudges. There are no mandates to involve or consider anyone else when making end-of-life decisions. With respect to priming, in particular, if someone does not want their family involved in their decision, the priming is unlikely to change their behavior in this context. The nudge, in theory, should only change the behavior of those inclined to decide with or for their family, but who through failures of rationality neglect to do so unless prompted to.

369. See Shepherd, *supra* note 21, at 1744–45 (asserting that existing safeguards are sufficient to protect persons for whom end-of-life decisions are being made).

370. See NELSON & NELSON, *supra* note 157, at 116. Also, should physicians not act in the best interests of their patients, this is a breach of duty, and if it results in harm, the tort system can aid with supplying a remedy.

371. BERLINGER ET AL., *supra* note 90, at 64–65. Further, "[a]ttention to potential signs of neglect and abuse, such as the family's explicit and adamant refusal to consider the patient's wellbeing or repeated attempts to override the patient's expressed preferences can be helpful." Ho, *supra* note 174, at 132. In the context of physician AID, see *Glucksberg*, 521 U.S. at 783 (Souter, J., concurring) ("But one of the points of restricting any right of assistance to physicians would be to condition the right on an exercise of judgment by someone qualified to assess the patient's responsible capacity and detect the influence of those outside the medical relationship.").

When I speak of "monitoring," I do not mean to suggest non-stop surveillance, which would be administratively burdensome for clinicians (and beyond their expertise), and would also violate the patient's and family's privacy. I mean only that in the course of routine provision of medical care, physicians and nurses should observe the patient's interactions with their family and be aware of anything that suggests undue influence or that the patient is being harmed.

372. BERLINGER ET AL., *supra* note 90, at 64–65; Blackler, *supra* note 357, at 287; Ho, *supra* note 174, at 133.

373. BEAUCHAMP & CHILDRESS, *supra* note 1, at 191.

patient's protests or dissent.³⁷⁴ Prior to their patient's incapacity, however, physicians can aid patients in protecting their autonomy against undue familial influence by suggesting that their patients appoint a trusted healthcare agent or write a living will.³⁷⁵ I would still suggest, however, that in this appointment and written directions, patients are primed to consider relationality, as I described above.³⁷⁶

The next existing safeguard is hospitals and healthcare providers, who typically have institutional actors and policies that can aid in protecting patients and facilitating resolution of disagreements.³⁷⁷ Often, hospital ethics committees or consultants can aid in these roles.³⁷⁸ Should oversight by physicians or consultation with ethics committees not be sufficient to protect patients at the end of life, there is always the judicial system. "When good reasons exist to appoint guardians or to disqualify familial decisionmakers or health care professionals to protect an incompetent patient's interests, the courts may legitimately be involved."³⁷⁹

However, it should be noted that people often make decisions with family interests in mind, including financial interests, and this does not necessarily constitute undue pressure or necessitate oversight by physicians, ethics committees, or courts.³⁸⁰ As leading end-of-life clinical care guidelines remind clinicians, "[t]eam members should be mindful that . . . any patient with decision-making capacity may choose to consult with loved ones or others."³⁸¹ Scholars have likewise observed that "[m]ost families have a history of collaborating around critical personal and family decisions long before entering a medical setting. These intimate relationships shape the family's core

374. Shepherd, *supra* note 21, at 1730, 1742–43. Physicians can also rely on capacity determinations rather than a legal designation of incompetence, and allow capacitated patients to make decisions to the extent they are able. *Id.* at 1742.

375. Blackler, *supra* note 357, at 287–88.

376. See *supra* Part III.C.3.

377. BERLINGER ET AL., *supra* note 90, at 14–15. Some argue, however, that hospitals and physicians may not be vigilant in their role in protecting vulnerable patients because of financial disincentives to preserve life. In the context of physicians not maintaining the line between assisted suicide and euthanasia, see, for example, *Glucksberg*, 521 U.S. at 784–85 (Souter, J., concurring) ("Physicians, and their hospitals, have their own financial incentives, too, in this new age of managed care.").

378. BERLINGER ET AL., *supra* note 90, at 64–65. As others have noted, ethics "committees have a robust role to play in circumstances in which physicians acquiesce too readily to parental, familial, or guardian choices that prove contrary to a patient's best interests." BEAUCHAMP & CHILDRESS, *supra* note 1, at 192.

379. BEAUCHAMP & CHILDRESS, *supra* note 1, at 192.

380. There is evidence that individuals willingly make decisions to hasten their deaths to avoid being a financial burden on their families. See, e.g., Singer et al., *supra* note 204, at 166; see also NELSON & NELSON, *supra* note 157, at 90 ("Someone, now incompetent, . . . might well have wanted to forgo treatment that maximally advances her interests if it is gotten at great emotional or financial cost to the rest of her family.").

381. BERLINGER ET AL., *supra* note 90, at 64–65.

values and beliefs and inform decision making.”³⁸² This is because “familial care relationships are not generally based on temporary contracts but on empathy and beneficence family members have towards one another.”³⁸³ Thus, law and policy should not “over protect” people from their families, and should not necessarily assume that an individual’s end-of-life decision-making process with their family is different from other decisions they make with their families. As Sunstein asserts, “[i]n daily life, people defer to others, including friends and family members, on countless matters, and they are often better off as a result.”³⁸⁴

Furthermore, people may change their minds about their end-of-life decisions after they consider relational interests, and this does not necessarily mean they have been unduly pressured. As one scholar argued,

many patients reconsider previously held values, wishes, and preferences in the setting of broader effects on family. . . . Patients may decide to set aside personal wishes for the good of the family or as a means to maintain peace and harmony with loved ones. Given the interconnectedness present in many families, it is reasonable for patients to altruistically consider others when making serious medical decisions, even decisions in conflict with strongly held beliefs.³⁸⁵

The final existing safeguard is physiological in nature. All of the end-of-life decision-making law and policy discussed in this Article is triggered only when a person is dependent upon life-sustaining medical treatment or is terminally ill. It is thus not obvious why there should be so much concern about relational abuses during this time period.³⁸⁶ There should of course be procedural safeguards in place, but fear should not drive policy to the point

382. Blackler, *supra* note 357, at 285. As some scholars have observed,

Reciprocal concern and sympathy that people feel for their loved ones can help to explain why intimates’ involvement and consideration of their well-being do not necessarily constitute undue pressure. For those whose family is at the centre of their existence, consideration of their advice, needs and mutual interests is part of their autonomous agency.

Ho, *supra* note 174, at 132.

383. Ho, *supra* note 174, at 130; *see also* NELSON & NELSON, *supra* note 157, at 90, 94 (describing how family relations are often based on love and obligation and that if surrogates make decisions conscientiously on behalf of a patient, the moral authority given to the surrogates in this context excuses any error in the decision); Joseph J. Fins, *From Contract to Covenant in Advance Care Planning*, 27 J. L. MED. & ETHICS 46, 48 (1999) (describing a covenantal approach to surrogate decisionmaking that can arise from trusting, reciprocal relationships between patient and proxy and contrasting to the contractual approach embodied in existing law).

384. Sunstein, *supra* note 245, at xix.

385. Blackler, *supra* note 357, at 288; *see also* Broom & Kirby, *supra* note 129, at 503–36.

386. Additionally, “[m]ost families don’t use the health care delivery system as a means of mistreating the helpless.” NELSON & NELSON, *supra* note 157, at 115.

that it deprives persons of what they prefer,³⁸⁷ given that the cost of not having adequate protection is relatively low (e.g., deprivation of a few months of likely poor quality living), and the cost of having too much protection is relatively high (e.g., people do not have the death they prefer).

4. *Implementing Recommended Relational Nudges Is Feasible*

Some may argue that my proposed nudges are not feasible to implement. After all, the process of legal change is sometimes difficult. However, end-of-life decision-making law and policy is rapidly changing as more states legalize physician AID and organizations are searching for better ways to manage care at the end of life due to the rapid aging of the population.³⁸⁸ Given that law and policies are in a state of flux, now is an opportune time to make additional changes that can help promote autonomy and welfare in end-of-life decisionmaking.

Furthermore, many of my proposals are directed at institutional policy and clinical practice, such as changing state-provided standardized advance directive forms or POLST forms to prime for relational decisionmaking, which bypass the need for formal legal change and all of the political battles that accompany formal legal changes. Therefore, implementing many of these nudges should not be difficult, although if done without public notice and comment, the process of implementing these nudges may be subject to criticisms of non-transparency.³⁸⁹ So, for example, if the POLST form is changed, physicians should be told the reason for the change (i.e., to promote shared decisionmaking), given that they are a key stakeholder group. It may be that in consulting with physicians about proposed changes, physicians will have the opportunity to provide other feedback about how to make the POLST form more useful in clinical practice (beyond relational nudging and promotion of relational autonomy), and additional changes can be made to

387. The relational nudges are meant to bring more balance to end-of-life decision-making law and policy, which is almost completely derelationalized. If the proposed nudges are adopted, admittedly this may lead to some instances where other parties exert undue influence on a patient when under the current derelationalized system they would be unable to. It is my hope, however, that these instances will be greatly outweighed by the increased numbers of people who are able to make decisions at the end of life in the way that studies show they prefer: in consultation with and in consideration of others.

388. For example, as this Article is in the publication process, Hawaii has legalized physician AID. Carla Herreria, *Hawaii Becomes the 7th State to Legalize Medically Assisted Suicide*, HUFFPOST (Apr. 5, 2018), https://www.huffingtonpost.com/entry/hawaii-legalizes-assisted-suicide_us_5ac6c6f5e4b0337ad1e621fb.

389. See THALER & SUNSTEIN, *supra* note 190, at 240, 244–45 (arguing for increased transparency in the choice architecture process). See generally Capron & Spruijt-Metz, *supra* note 242.

the form that promote overall welfare.³⁹⁰ For state-provided end-of-life planning documents, the websites on which they are hosted can explain to residents of the state that the forms have been revised to prompt people to discuss their end-of-life wishes with family. Disclosing the reasons behind the policy may help create buy-in.

Some may wonder why the focus is on legal and policy change rather than other types of change,³⁹¹ such as attempts to influence the larger culture that fears death to the point of ignoring its reality until someone is actively dying. I have argued, however, for changes beyond law and policy, such as changing clinical practice, especially with respect to shared decisionmaking models becoming the default mode of healthcare provision. And with regard to changing the culture of avoidance around death and dying, it is likely more feasible to change the structure—laws and policies—than to try to enact widespread cultural and psychological change.³⁹² In fact, it is through changing the structure that cultural changes in this realm may become possible; that is, changing law and policy may normalize conversations about end of life, which may decrease avoidance of discussions of death and dying.

5. *More Research Needs to be Conducted*

Some may question whether end-of-life decisions are not routinely being made in consultation with and in consideration of others, even if the law does not promote relational autonomy. There is not a lot of empirical evidence about what happens when these decisions must be made,³⁹³ and more

390. There may be some physician resistance to altering the POLST form in a way that slows down the process of completing the form. If physicians are informed that the changes are to promote patient autonomy, perhaps this explicit explanation of intention will lessen resistance. (More material changes, such as adequate compensation for the time spent discussing end of life with their patients may be more likely to assuage concerns of physicians rather than appeals to principles.) Physician preference for efficiency should not override patient autonomy, however.

391. Clinicians are also beginning to advocate for taking into account patient and family preferences and values in healthcare decisionmaking at the levels of clinical practice and guidelines. This is occurring not just with the proliferation of shared decision-making models, but also includes considering patient perspectives when drafting clinical practice guidelines. See Murray Krahn & Gary Naglie, *The Next Step in Guideline Development: Incorporating Patient Preferences*, 300 JAMA 436, 436–37 (2008). While clinical practice undoubtedly affects end-of-life decisionmaking and experiences, the overall context for end-of-life decisionmaking derives in large part from law and policy.

392. There has been cultural change around end-of-life planning in some places, but it is unclear whether the changes can be reflected in a bigger, more heterogeneous population. See Chana Joffe-Walt, *The Town Where Everyone Talks About Death*, NPR MORNING EDITION (March 5, 2014), <http://www.npr.org/sections/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis/> (discussing how almost everyone who dies in La Crosse, Wisconsin completes an advance directive because a local hospital clinician helped normalize discussing end of life in the community).

393. An ideal research design would study these decisions as they unfold (i.e., using ethnographic methods), which is difficult to do with respect to resources (these decisions occur over time,

research on end-of-life decisionmaking in action should be conducted. The limited evidence available suggests, however, that some people do not perceive that they are making autonomous choices at all,³⁹⁴ leading some scholars to question whether in institutional settings patients can experience autonomy at the end of life,³⁹⁵ especially given power imbalances between physicians and patients,³⁹⁶ which would make some of my proposals especially important.

Even if decisions are routinely made in a relational manner, however, there is value to having relational autonomy explicitly reflected in the law, in part, because it defines the boundaries of permissible behavior,³⁹⁷ while simultaneously expressing the symbolic value³⁹⁸ of the importance of human connectedness. Moreover, as the *Saikewicz* court asserted about the need for law to respond to established medical practice and ethics,

“[t]he law always lags behind the most advanced thinking in every area. It must wait until the theologians and the moral leaders and events have created some common ground, some consensus.” . . . We therefore think it advisable to consider the framework of medical ethics which influences a doctor’s decision as to how to deal with the terminally ill patient. While these considerations are not

and across multiple interactions, and the study thus would ideally be longitudinal), but also in terms of access (it is difficult for researchers to be present for healthcare encounters). There are also not many court cases in which a record of decisionmaking is provided. See Shepherd, *supra* note 21, at 1704 n.38 (“[T]he vast majority of these decisions are made outside of court review [in hospitals and nursing homes].”).

394. See, e.g., Shepherd & Hall, *supra* note 112, at 1445 (“[P]atients are not actively making choices, that that notion is itself a bit of a fiction.”); Drought & Koenig, *supra* note 135, at 121 (“In fact, few patients, family members, or health care providers believed that many decisions were actually made. . . . [I]n most cases, there was not an experience or a perception of choice on anyone’s part. Some patients denied outright that they had made any medical decisions, even though multiple decisions to pursue or forgo treatment (such as surgery) had, in fact, been made, or at least had occurred.”).

395. Ho, *supra* note 174, at 130 (describing how institutionalized patients at the end of life enter unfamiliar settings with unfamiliar people and are not able to exercise agency).

396. Drought & Koenig, *supra* note 135, at 116.

397. See, e.g., *In re Quinlan*, 355 A.2d 647, 659–60 (N.J. 1976) (“It is both possible and necessary for society to have laws and ethical standards which provide freedom for decisions, in accord with the expressed or implied intentions of the patient, to terminate or withhold extraordinary treatment in cases which are judged to be hopeless by competent medical authorities, without at the same time leaving an opening for euthanasia. Indeed, to accomplish this, it may simply be required that courts and legislative bodies recognize the present standards and practices of many people engaged in medical care who have been doing what the parents of Karen Ann Quinlan are requesting authorization to have done for their beloved daughter.”).

398. See generally Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PENN. L. REV. 2021 (1996).

controlling, they ought to be considered for the insights they give us.³⁹⁹

Others might object that my proposals are premature because there is no evidence that these nudges would work in practice,⁴⁰⁰ or that they would have effects that patients, their families, and physicians would desire.⁴⁰¹ While it is true that we do not know the effect of these proposed nudges or whether any effects would be desirable, it is worth seeing if these proposals would be of help to those involved in end-of-life decisionmaking. It may therefore be best to think of these proposals as hypotheses to be tested. Because much of what governs end-of-life decisionmaking is at the level of state law or institutional policy, it may be advisable to test these nudges on a small scale—a particular state statutory schema or a specific hospital’s policy.

For example, one of my proposed nudges can be assessed in the following way. A healthcare organization can alter their POLST form to put the question about healthcare agents at the top of the form. The organization can then randomly give the former POLST form and the revised POLST form to a set of physicians. The organization can then compare whether answers to questions about life-sustaining treatment differ significantly between the two groups to see if the nudge had any effect. The organization can then follow up with these patients, their families, and their healthcare providers over time to determine whether and how the process of end-of-life decisionmaking is different between the two groups and whether the intervention—the nudge to consider relationality prior to making end-of-life decisions—improved the quality of dying.⁴⁰²

As other scholars have noted, “behavioral policy insists on being empirical and pragmatic about any proposed policy intervention. After all, if we are interested in manipulating behavior, the ultimate question is whether the intervention works to achieve the desired behaviors.”⁴⁰³ We will never know

399. Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 423 (Mass. 1977) (alteration in original) (citation omitted) (citing J. Russell Elkinton, *The Dying Patient, the Doctor, and the Law*, 13 VILL. L. REV. 740 (1968)).

400. A common critique of biomedical ethics scholarship is that it is not easily translatable to or reflective of clinical practice. See Larry R. Churchill et al., *Five Threats to Patient-Centered Care: With Questions for Health Law*, 50 WAKE FOREST L. REV. 251, 256 (2015).

401. See Blumenthal-Barby & Burroughs, *supra* note 223, at 6 (arguing that priming is only ethical if it is evidence-based).

402. Because this is research on human subjects, it would need to be approved by an Institutional Review Board, unless it fell under the category of quality improvement for a particular healthcare organization. See U.S. DEP’T OF HEALTH & HUMAN SERVS., *Quality Improvement Activities FAQ*, <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/quality-improvement-activities/index.html> (last visited May 22, 2018).

403. Robertson et al., *supra* note 198, at 4; see also Hall et al., *supra* note 205, at 344 (arguing for a “patient-centered empiricism” that studies “what actually happens to patients and . . . how public policy initiatives actually affect patients” (emphasis omitted)); Shepherd & Hall, *supra* note 112, at 1451 (arguing for empirical analysis rather than assuming proposals will work in practice).

unless we are willing to experiment, and so I advocate for rigorous testing of my proposals, all of which are in the service of promoting relational autonomy, and subsequently the best interests, of people at the end of life.⁴⁰⁴

IV. CONCLUSION

Autonomy is the central principle in end-of-life decision-making law and policy. Much of this body of law conceives of autonomous decisionmaking as an independent, individualistic endeavor and recognizes a person's relation to others only to a limited extent. However, social science research has demonstrated that while people want to retain control over their healthcare decisions at the end of life, many people prefer to make end-of-life decisions in consultation with and in consideration of others. Patients want to share in end-of-life decisions with their healthcare providers, want to have strong relationships with loved ones when they are dying, and often make decisions based on a preference not to burden others—emotionally or financially. Stated differently, for most people, the exercise of autonomy is relational in practice.

The divergence between these conceptualizations of autonomy matter because most people do not adequately plan for decisions that must be made at the end of life, a time when many persons confronting death no longer have decisional capacity. Legal defaults thus determine how decisions are made: by surrogates chosen under a default scheme, using default standards or instructions documented on default forms. While these defaults are meant to effectuate autonomy, given the divergence in understandings of this concept, current law and policy may not do the best job at promoting autonomy, as defined and experienced by those governed by these laws.⁴⁰⁵

The question then becomes, how can the law be more responsive to people's relational preferences, values, and concerns at the end of life and actually promote autonomy, the primary principle in this body of law? This Article argues for building in relational nudges into end-of-life decision-making law and policy, to account for failures of rationality that may prevent people from making decisions according to their stated preferences (in this case, with respect to the background context of their relationships) and to reduce negative effects end-of-life decisions may have on third parties such as surviving

404. Aaron S. Kesselheim, *Introduction to Part V*, in *NUDGING HEALTH*, *supra* note 134, at 220 (“How do we implement these principles in a way that supports positive outcomes and avoids the potential risks? Not surprisingly, the leading answer is more research.”).

405. As other scholars have noted, “social and family considerations are not well captured in the current approach to end-of-life decision making . . . which focuses on the patient's rights individually and not in his or her social and family context. Traditional approaches . . . may underestimate the importance of social and family ties.” Singer et al., *supra* note 204, at 167.

family members and healthcare providers. This Article offers some preliminary thoughts about the form these relational nudges should take. Some of the suggested nudges modify existing defaults, and many also take advantage of priming effects to prompt people to make decisions in consultation with and in consideration of relevant others. These nudges are directed at patients, surrogates, and physicians.

This Article is in conversation with scholars who have recently begun to apply “relational theory” to health law⁴⁰⁶ and who have argued for the development of a “relationship-centered” health law.⁴⁰⁷ To date, most of the existing scholarship focuses on the physician-patient relationship rather than other types of relationships,⁴⁰⁸ whereas this Article has tried to bring family relationships into the legal analysis. Furthermore, while scholars have applied the concept of relational autonomy to other bodies of law,⁴⁰⁹ and in particular to family law where the connection may be clearer,⁴¹⁰ exploring relational autonomy in health law is just beginning.⁴¹¹

406. Jennifer J. Llewellyn & Jocelyn Downie, *Introduction*, in BEING RELATIONAL *supra* note 203, at 4. This seems to be a move made by Canada-affiliated scholars. *See, e.g., id.* (“Relational theory . . . is focused on relationality—the fact of relationship Through this lens . . . we can see the ways in which being in relationship is integral to self-understanding and to interactions with others at individual, collective, and even institutional levels.”); Maneesha Deckha, *Non-Human Animals and Human Health: A Relational Approach to the Use of Animals in Medical Research*, in BEING RELATIONAL, *supra* note 203, at 287 (describing relational theory as the “quite simple acknowledgment that human beings are relational and interdependent and that law’s stark reliance on individualism and independence fails to capture the centrality of relationships and the importance of our responsibilities to others”); NEDELSKY, *supra* note 176, at 41 (discussing how relational theory can be applied to any value, but focusing on autonomy given its importance in the legal system in the West).

407. This can be seen in the United States in recent health law symposia. *See* Mark A. Hall, *Foreword: Toward Relationship-Centered Health Law*, 50 WAKE FOREST L. REV. 233 (2015). Hall describes where relationships are central to various parts of health law, and notes that such an analysis is just beginning. *Id.*; *see also* Hall et al., *supra* note 205, at 341–43 (describing what a relational perspective in health law might look like); Lois Shepherd, *Different Ways to Understand Patient-Centered Health Law*, 45 WAKE FOREST L. REV. 1469, 1470 (2010) (arguing for “family-centered” health law).

408. Shepherd and Hall argue that “[t]here are just too many players involved in modern medical care . . . to think in terms of a physician-patient dyad anymore.” Shepherd & Hall, *supra* note 112, at 1448. But the only article that discussed a relationship other than a physician-patient relationship in a recent symposium on relationship-centered health law discussed the relationship between researchers and subjects in the context of human subjects research regulation. *See generally* Rebecca Dresser, *What Subjects Teach: The Everyday Ethics of Human Research*, 50 WAKE FOREST L. REV. 301 (2015).

409. *See* NEDELSKY, *supra* note 176, at 3–5 (arguing for changes in Anglo-American law to reflect the relational self).

410. JONATHAN HERRING, RELATIONAL AUTONOMY AND FAMILY LAW 59–60 (2014); NEDELSKY, *supra* note 176, at 67.

411. *See, e.g.,* Sheila Wildeman, *Insight Revisited: Relationality and Psychiatric Treatment Decision-Making Capacity*, in BEING RELATIONAL, *supra* note 203, at 255, 267 (relying on the concept of relational autonomy to describe how institutions and societal conditions enable or disable decisional capacity).

This Article thus hopes to advance scholarship on relational autonomy at the end of life and extend beyond the physician-patient relationship, and also set the stage for applications of this concept to the larger body of health law and disability law scholarship. In particular, this Article will set a foundation to consider how alternative, more realistic conceptualizations of autonomy matter for law and policy around general healthcare decisionmaking for persons with cognitive disabilities, and for end-of-life decisionmaking in the context of dementia. That is, when the law recognizes that autonomy is relational in practice, then persons with cognitive disabilities who need assistance in decisionmaking may be able to retain decision-making authority rather than have such authority transferred to an agent, surrogate, or guardian.

Several prominent health law scholars in the United States seem to think there is no further value in analyzing or promoting autonomy in health law, however. *See, e.g.*, Hall, *supra* note 407; Hall et al., *supra* note 205, at 341 (“The dominant paradigms—patient autonomy and market theory—have largely done their work and run their course.”); Shepherd & Hall, *supra* note 112, at 1431 (describing how patient-centered health law perspectives are too focused on autonomy and not focused enough on relationships); Lois Shepherd & Margaret Mohrmann, *Welcome, Healing, and Ethics*, 50 WAKE FOREST L. REV. 259, 259 (2015) (same). This may be because such scholars contrast autonomy with relationships, whereas I think promoting autonomy is compatible with a focus on relationships because autonomy is relational in practice.