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# Resuscitating Consent

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**Abstract:** The scholarly focus on autonomy in healthcare decision making largely has been on information about, rather than consent to, medical treatment. There is an assumption that if a patient has complete information and understanding about a proposed medical intervention, then they will choose the treatment their physician thinks is best. True respect for patient autonomy means that treatment refusal, whether informed or not, should always be an option. But there is evidence that healthcare providers sometimes ignore treatment refusals and resort to force to treat patients over their contemporaneous objection, which may be facilitated by the incapacity exception to informed consent requirements. This Article uses the case of treatment over objection to resuscitate analysis of consent. This Article asserts that the nature of autonomy in medical decision making is misunderstood, which can lead to wrongful use of the incapacity exception and subsequent harm. Autonomy has become erroneously conflated with an individual's capacity for rational decision making, obscuring the reality that the exercise of autonomy is mediated by the body. That is, autonomy is not solely cognitive, but also corporeal. Indeed, bodily integrity is a necessary component of autonomy, and so violating bodily integrity by treating patients over their objection is inconsistent with respect for autonomy. Further, when healthcare providers violate patients' bodily integrity, there can be significant harms to wellbeing. Moreover, if providers misuse the incapacity exception in order to treat patients over their objection, this nullifies informed consent law. This Article argues that patients should not be treated over their objection even when providers do not perceive refusals to be rational because such treatment is inconsistent with respect



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for patient autonomy and bodily integrity, promotion of wellbeing, and maintenance of the rule of law. In order to prevent or remedy treatment over objection, this Article argues that states should adopt laws that provide adults with absolute legal capacity to refuse medical treatment unless a court overrides their decision. The proposed law thus would prevent healthcare providers from disqualifying their patients from refusing treatment even when there are questions about the patient's decisional capacity.

## INTRODUCTION

Because adult patients are entitled to make their own healthcare decisions,[1] healthcare providers must obtain their patient's informed consent prior to providing treatment,[2] which is a means to respect patient autonomy.[3] Securing informed consent from patients is both an ethical and legal requirement, and healthcare providers may incur liability for treating patients without their informed consent.[4]

Promoting patient autonomy by seeking informed consent, however, has largely failed.[5] Most of the studies assessing informed consent find that patients are largely ignorant about the treatments that they choose, along with the attendant risks and benefits, if they perceive themselves to be choosing at all.[6] Patients' lack of understanding about medical treatment is due to inherent cognitive biases; what information healthcare providers offer patients; how providers frame the information; and the difficulty lay persons, especially when they are sick, have in understanding complex medical interventions.[7]

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[1] *See, e.g.*, Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . .").

[2] *See, e.g.*, Canterbury v. Spence, 464 F.2d 772, 781 (D.C. Cir. 1972).

[3] JESSICA W. BERG, PAUL S. APPELBAUM, CHARLES W. LIDZ & LISA S. PARKER, INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE 15–16 (2d ed. 2001).

[4] *Id.* at 12–13.

[5] *See, e.g.*, George J. Annas, *Informed Consent: Charade or Choice?*, 45 J.L. MED. & ETHICS 10, 11 (2017) ("Informed consent . . . [is] a superficial charade rather than an autonomous choice."). To be autonomous, healthcare decisions must be voluntary, intentional, and understood. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 104 (7th ed. 2013).

[6] *See* Theresa S. Drought & Barbara A. Koenig, *"Choice" in End-of-Life Decision Making: Researching Fact or Fiction?*, 42 THE GERONTOLOGIST (SPECIAL ISSUE III) 114, 116 (2002). *See generally* CARL E. SCHNEIDER, THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS (1998) (summarizing empirical research on how patients make medical decisions).

[7] *See generally* NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS (I. Glenn Cohen, Holly Fernandez Lynch & Christopher T. Robertson eds., 2016) (discussing how to improve healthcare decision making); DANIEL KAHNEMAN, THINKING, FAST AND SLOW (2011) (discussing rational and irrational modes of thinking); RICHARD H. THALER & CASS R. SUNSTEIN, NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS (2008) (advocating for changes in policy to improve decision making and promote wellbeing); Carl E. Schneider & Michael H. Farrell, *Information, Decisions, and the Limits of Informed Consent*, in 3 LAW AND MEDICINE: CURRENT

Because of the primacy of autonomy in American law[8] and medical decision-making ethics,[9] as well as the importance of autonomy to patients,[10] there has been a significant scholarly undertaking to change how providers disclose medical information so that patients can truly understand their healthcare options. For example, legal scholars have advocated for using certified patient decision-making aids such as videos or decision grids in the informed consent process.[11]

As such, the scholarly focus on autonomy and healthcare decision making largely has been on *information about* medical treatment, and much less about the issue of *consent to* medical treatment. Indeed, there is an assumption in the law, bioethics, and clinical literature that if a patient has complete information and understanding about a proposed medical intervention, then the patient will choose the treatment their physician thinks is in their best interests.[12] However, despite how well-informed patients are, autonomous healthcare decision making is impossible if patients do not consent to treatment they receive, and in particular, if providers override their treatment refusals.

True respect for patient autonomy in healthcare decision making means that treatment refusal should always be an option.[13] Though empirical research and court cases demonstrate that patients sometimes refuse both routine and life-sustaining medical treatment, there is also evidence that patient treatment refusals,[14] whether contemporaneous or conveyed through advance directives,

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LEGAL ISSUES 107 (Michael Freeman & Andrew D.E. Lewis eds., 2000) (arguing that there are limits to rationality when people are sick). Patients may also have limited English proficiency or be unable to hear their healthcare providers, factors that contribute to poor understanding if patients are not accommodated.

[8] *See generally* Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives*, 37 VILL. L. REV. 1705 (1992) (canvassing areas of law where autonomy is protected).

[9] BEAUCHAMP & CHILDRESS, *supra* note 5, at 101–49.

[10] Many patients report a desire to participate in decisions about their healthcare. *See, e.g.*, Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decisionmaking*, 79 MD. L. REV. 257, 273–74 (2020) (summarizing "decision-making preferences of persons with . . . dementia").

[11] *See generally* Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429 (2006) (proposing that informed consent law incorporate shared decision making); Thaddeus Mason Pope, *Certified Patient Decision Aids: Solving Persistent Problems with Informed Consent Law*, 45 J.L. MED. & ETHICS 12 (2017) (discussing the modern change from traditional informed consent practices in healthcare to patient decision-making aids models); Nadia N. Sawicki, *Patient Protection and Decision-Aid Quality: Regulatory and Tort Law Approaches*, 54 ARIZ. L. REV. 621 (2012) (discussing how best to regulate the quality of patient decision aids).

[12] BERG ET AL., *supra* note 3, at 227 ("[T]he term informed consent itself suggests that patients are expected to agree to be treated rather than to decline treatment.").

[13] *Id.*

[14] *See, e.g.*, T. van Kleffens & E. van Leeuwen, *Physicians' Evaluations of Patients' Decisions to Refuse Oncological Treatment*, 31 J. MED. ETHICS 131, 134 tbl.2 (2005) (reporting patients' reasons for refusing recommended cancer treatment).

are sometimes ignored by healthcare providers who may resort to force or deception when treating patients over their objection in hospitals or seek a surrogate to authorize the undesired treatment.[15]

Scholars have examined treatment over objection[16] in some specific medical and legal contexts; for example, psychiatric,[17] public health, obstetric,[18] and advance directives declining life-sustaining medical care.[19] But the law and ethics of medical treatment over contemporaneous objection for the general patient population have received scant scholarly attention.[20] This Article aims to fill this gap by focusing on medical treatment—not necessarily life-sustaining—over contemporaneous patient objection in acute care hospitals.[21] This Article uses

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[15] *See generally* Elizabeth Kukura, *Obstetric Violence*, 106 GEO. L.J. 721 (2018) (documenting nonconsensual treatment that some women experience during childbirth); Holly Fernandez Lynch, Michele Mathes & Nadia N. Sawicki, *Compliance with Advance Directives: Wrongful Living and Tort Law Incentives*, 29 J. LEGAL MED. 133 (2008) (describing cases in which advance directives were not followed and possible tort remedies); Thaddeus Mason Pope, *Legal Briefing: Unwanted Cesareans and Obstetric Violence*, 28 J. CLINICAL ETHICS 163 (2017) [hereinafter Pope, *Unwanted Cesareans*] (describing instances of nonconsensual obstetric treatment); Thaddeus Mason Pope, *Legal Briefing: New Penalties for Disregarding Advance Directives and Do-Not-Resuscitate Orders*, 28 J. CLINICAL ETHICS 74 (2017) [hereinafter Pope, *New Penalties*] (discussing common types of undesired healthcare treatment at the end of life and possible legal sanctions for disregarding patients' advance directives); Nadia N. Sawicki, *A New Life for Wrongful Living*, 58 N.Y.L. SCH. L. REV. 279 (2014) (reviewing legal recourse for patients when healthcare providers do not respect their advance directives declining life-sustaining medical care).

[16] I distinguish between nonconsensual treatment and treatment over objection in this Article. Nonconsensual treatment means that the patient has not given permission for the treatment or the patient has agreed to treatment under undue influence. In contrast, in the case of treatment over objection, there is evidence of refusal, and force or deception may be required to treat over objection.

[17] *See generally* ELYN R. SAKS, REFUSING CARE: FORCED TREATMENT AND THE RIGHTS OF THE MENTALLY ILL (2002) (discussing coercive treatment in context of mental illness); GEORGE SZMUKLER, MEN IN WHITE COATS: TREATMENT UNDER COERCION (2018) (discussing mental health laws in psychiatric treatment).

[18] *See generally* Kukura, *supra* note 15 (describing nonconsensual obstetric treatment); Pope, *Unwanted Cesareans*, *supra* note 15 (describing instances of unwanted cesareans and associated legal implications).

[19] *See generally* Fernandez Lynch et al., *supra* note 15 (proposing legal remedies for patients who receive treatment refused in their advance directive); Pope, *New Penalties*, *supra* note 15 (documenting cases of life-sustaining treatment over patient objection); Sawicki, *supra* note 15 (exploring legal remedies for patients who receive life-sustaining treatment over their refusal).

[20] *But see, e.g.*, Mark Christopher Navin, Jason Adam Wasserman & Mark H. Haimann, *Treatment Over Objection—Moral Reasons for Reluctance*, 94 MAYO CLINIC PROC. 1936, 1938 (2019).

[21] Acute care hospitals are the focus of this Article because they are sites with the equipment and staff necessary to treat patients over their objection unlike many outpatient settings. This Article will not focus on medical interventions over objection in psychiatric, jails/prison, human subjects research, or public health contexts. These contexts are outside of the scope of this Article because they draw on different bodies of law and different assumptions and principles. In the case of mental health treatment, for example, there may be a presumption of patient incompetence, whereas in medical treatment, there is a presumption of patient competence. For similar reasons, this Article only focuses on adult patients rather than including pediatric patients.

the case of treatment over patient objection to make two novel theoretical contributions: (1) autonomy in healthcare decision making is not solely cognitive, but also corporeal, and should be understood to include bodily integrity; and (2) healthcare providers contribute to the erosion of the rule of law when they provide medical treatment over their patients' objection.

First, despite various definitions of autonomy in the philosophical literature, in healthcare settings, autonomy in medical decision making has become conflated with an individual's capacity for rational decision making.[22] But conflating autonomy and rationality in clinical practice obscures other important aspects of autonomous healthcare decision making, identified in the foundational legal case that directs that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body."[23] Though there is a minimum rationality requirement embedded in this principle of autonomy (sound mind), autonomy in this context is less about rational decision making and more about maintaining bodily integrity, which can be defined as "a person's exclusive use and control over his or her body."[24] This Article argues for a return to the understanding that bodily integrity is a necessary component of autonomy, and so violating bodily integrity by treating patients over their objection is inconsistent with respect for patient autonomy.[25] In short, autonomy is impossible if others can do what they want to another person's body. Thus, the provision of medical treatment should not occur without patient authorization, even if providers do not perceive the refusal as "informed" or "understood," that is, rational.

Second, when healthcare providers treat patients over their objection in the absence of legal exceptions to informed consent requirements or state-

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[22] *See generally* John Christman, *Autonomy in Moral and Political Philosophy*, STAN. ENCYC. OF PHIL., https://plato.stanford.edu/entries/autonomy-moral/ [https://perma.cc/U4SF-PF5R] (June 29, 2020) (discussing "the concept of autonomy" and its context in moral, social, and political philosophy). This conflation is evident when providers use formal capacity assessments to remove decision-making authority from their patients. *See, e.g.*, BEAUCHAMP & CHILDRESS, *supra* note 5, at 114–15.

[23] Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914), *abrogated by* Bing v. Thunig, 143 N.E.2d 3 (N.Y. 1957), *and superseded by statute*, N.Y. PUB. HEALTH LAW § 2805-d (McKinney 2021), *as stated by* Retkwa v. Orentreich, 584 N.Y.S.2d 710 (Sup. Ct. 1992).

[24] Jonathan Herring & Jesse Wall, *The Nature and Significance of the Right to Bodily Integrity*, 76 CAMBRIDGE L.J. 566, 576 (2017).

[25] Healthcare providers may disregard their decisionally impaired patients' contemporaneous refusal and instead look to their advance directive or surrogate decision makers to authorize the medical treatment and understand their treatment over patient objection to be consistent with respect for patient autonomy. But current understandings of autonomy show that even patients with decisional impairments may be capable of autonomy if they have proper support and accommodations, which makes such treatment disrespectful of contemporaneous autonomy. Wright, *supra* note 10, at 321–24; Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability Law*, 47 J.L. MED. & ETHICS 25, 30–31 (2019). Providers who ignore advance directives are disrespectful of precedent autonomy.

mandated legal process to override treatment refusals, those healthcare providers are violating their professional duties to follow the law.[26] This nullifies informed consent laws and contributes to an erosion of the rule of private law. That is, treating patients over their objection is not solely paternalistic, but also has wider implications for the stability and legitimacy of the legal system. To the extent that the rule of law is valuable, then providers should not treat patients over their objection in the absence of legal process, and courts should hold providers accountable when providers engage in medical battery. This Article will thus argue that the law should ensure that patients always have legal capacity to refuse medical treatment unless a court decides otherwise.

This Article hopes to resuscitate analysis of consent in healthcare decision making and proceeds as follows. Part I describes the law and ethics of informed consent; empirical research on patients' and healthcare providers' attitudes about and practice of informed consent; and patients' experiences receiving treatment over their objection and healthcare providers' reasons for doing so.[27] Part II advances the normative argument that treatment over patient objection is inconsistent with respect for patient autonomy, of which bodily integrity is a necessary component, has a negative effect on both patient and provider wellbeing, and is inconsistent with the rule of law, and thus should rarely, if ever, occur.[28] Part III proposes legal changes to ensure that treatments over patient objection do not occur in the absence of legal process that is protective of patients' bodily integrity.[29] Specifically, Part III argues that states should pass laws that provide adults with absolute legal capacity to refuse medical treatment unless a court overrides their decision; that is, the law would prevent healthcare providers from disqualifying their patients from making the decision to refuse treatment even when there are questions about the patient's decisional capacity. Finally, the Article concludes by addressing counterarguments and offering a conceptualization of informed consent as "informed enough assent."[30]

## I. Informed Consent Law, Ethics, and Practice

Section A of this Part first summarizes informed consent law and ethics.[31] Section B of this Part then surveys empirical literature on healthcare decision

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[26] *See, e.g.*, *AMA Code of Medical Ethics: AMA Principles of Medical Ethics*, Am. Med. Ass'n, https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/principles-of-medical-ethics.pdf [https://perma.cc/X964-8W86 ] (June 2001) ("A physician shall respect the law . . . .").

[27] *See infra* notes 31–142 and accompanying text.

[28] *See infra* notes 143–223 and accompanying text.

[29] *See infra* notes 224–250 and accompanying text.

[30] *See infra* notes 251–309 and accompanying text. For specific explanation of what is meant by "informed enough assent," see *infra* notes 310–318 and accompanying text.

[31] *See infra* notes 34–62 and accompanying text.

making, describing how the legal doctrine of informed consent is often not achieved in practice and summarizing legal scholars' proposals to address problems with physician disclosure and patient understanding.[32] Section C of this Part then concludes by discussing failures of consent, specifically treatment over patient objection.[33]

### *A. Law and Ethics of Informed Consent*

Adults have a long-established legal right to make their own healthcare decisions.[34] This Section will provide a brief overview of the law and ethics of informed consent, including exceptions to the requirement for informed consent and understanding informed consent as shared decision making.

#### 1. Overview of Informed Consent Law

Healthcare decision-making law requires that healthcare providers obtain patient consent (authorization or permission) prior to medical treatment; if the patient has not consented, then the healthcare provider has committed medical battery regardless of whether a good medical outcome has been achieved.[35] Consent is required even for life-sustaining treatment, which patients have a legal right to decline.[36]

The requirement that healthcare providers obtain patient consent to medical treatment has changed over time. Now, healthcare providers may be liable not only for not obtaining a patient's authorization for treatment, but also if they have not obtained *informed* consent from their patients.[37] Providers have an affirmative duty to disclose information about their patient's medical condition; the proposed medical intervention; the reason for the intervention and its risks and benefits; and other options besides the recommended intervention including no treatment.[38] If a patient consents to medical treatment in the ab-

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[32] *See infra* notes 63–96 and accompanying text.

[33] *See infra* notes 97–142 and accompanying text.

[34] *See, e.g.*, Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914), *abrogated by* Bing v. Thunig, 143 N.E.2d 3 (N.Y. 1957), *and superseded by statute*, N.Y. PUB. HEALTH LAW § 2805-d (McKinney 2021), *as stated by* Retkwa v. Orentreich, 584 N.Y.S.2d 710 (Sup. Ct. 1992).

[35] RESTATEMENT (THIRD) OF TORTS: INTENTIONAL TORTS TO PERSONS § 19 (AM. L. INST., Tentative Draft No. 4, 2019).

[36] *See* BERG ET AL., *supra* note 3, at 228, 230; Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1068–77 (2018).

[37] When patients bring legal claims after there have been problems in the informed consent process, these claims tend to be in negligence rather than battery. BERG ET AL., *supra* note 3, at 135.

[38] *Id.* at 12, 53–65 (describing elements of required disclosure, which differ by jurisdiction, as does the standard for assessing whether physicians have met their disclosure duty).

sence of complete and correct information when they otherwise would not,[39] and subsequently suffers harm, the provider may be liable.[40]

The maintenance and protection of bodily integrity justifies the patient consent to treatment requirement,[41] but the development of the doctrine of *informed* consent is meant to promote patient self-determination.[42] That is, it is no longer sufficient to obtain patient permission for a medical intervention, but patients also must have information necessary to make choices.[43] The legal requirements for informed consent are meant to increase patient autonomy and decrease provider paternalism by offsetting the power clinicians have in the healthcare setting.[44]

### 2. Informed Consent Exceptions and Scope Conditions

There are several exceptions to informed consent requirements recognized in law and medical ethics.[45] For example, it may not be possible to obtain informed consent during a medical emergency, in which case treatment

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[39] *See, e.g.*, Canterbury v. Spence, 464 F.2d 772, 783 (D.C. Cir. 1972) ("[I]t is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient's edification.").

[40] This liability will mostly be in tort. *See, e.g.*, Pope, *supra* note 11, at 15–16. Patients could in rare circumstances bring constitutional claims; the constitutional right "to refus[e] unwanted medical treatment" under the Fourteenth Amendment is not applicable in most cases of nonconsensual treatment, however, given that "state actors are [likely not] involved." Fernandez Lynch et al., *supra* note 15, at 139–40; Sawicki, *supra* note 15, at 295–96. If the nonconsensual treatment occurs in a public hospital or is ordered by a court, then it may constitute a violation of the individual's constitutional right to refuse medical treatment. Kukura, *supra* note 15, at 793 n.462. There are also cases where paramedics treat or transport competent patients over their objections, and some courts have held that this could lead to claims for both Fourth and Fourteenth Amendment violations. *See, e.g.*, Green v. City of New York, 359 F. App'x 197, 198–201 (2d Cir. 2009). There are also possible Eighth Amendment claims if a patient is treated over their objection while in prison. Sawicki, *supra* note 15, at 296 & n.107 (first citing Klavan v. Crozer-Chester Med. Ctr., 60 F. Supp. 2d 436 (E.D. Pa. 1999); and then citing Ross v. Hilltop Rehab. Hosp., 676 F. Supp. 1528 (D. Colo. 1987)).

[41] BERG ET AL., *supra* note 3, at 41–42, 49, 132; King & Moulton, *supra* note 11, at 438; *see also* Mohr v. Williams, 104 N.W. 12, 16 (Minn. 1905) ("[E]very person has a right to complete immunity of his person from physical interference of others . . . ."), *overruled in part by* Genzel v. Halvorson, 80 N.W.2d 854 (Minn. 1957). Psychic integrity is also protected and can be addressed through emotional distress torts. BERG ET AL., *supra* note 3, at 42.

[42] King & Moulton, *supra* note 11, at 438. Indeed, scholars have argued that medical battery claims are "narrow and limited" and that negligent informed consent, although imperfect, is more protective of patients' rights and autonomy interests. Pope, *supra* note 11, at 13–17.

[43] BERG ET AL., *supra* note 3, at 49 ("The purpose of the simple consent requirement—protecting patients from unwanted interferences with their bodily integrity—was important, but limited in comparison with the other purpose of informed consent, which is to permit patients to make informed choices about their health care.").

[44] The primary justifications for and goals of informed consent are "promotion of [patient] autonomy and well-being." *Id.* at 11, 16, 18–20; *see also id.* at 20–21, 75–76, 140, 146 (describing other values and principles).

[45] *See id.* at 75–93 (describing informed consent exceptions).

can be provided without patient authorization.[46] This is because "consent is [understood] to be implied," based on a reasonable person standard, and because of the likelihood of irreparable harm if medical intervention does not occur.[47] Another example of the exception to the requirement to obtain patient permission is when a court orders a particular treatment, which may occur when a person has a contagious but treatable disease and their treatment refusal poses risks to third parties.[48]

It is also necessary to note the scope conditions of the right to make medical decisions. First, only adults are legally entitled to make their own healthcare decisions.[49] All other decisions are made by parents or guardians on behalf of minor children, although it is considered good clinical practice to involve and obtain the assent of the pediatric patient.[50]

Second, generally only patients with decisional capacity—competent patients[51]—are legally entitled to make contemporaneous medical decisions.[52] Even if a patient is deemed to lack decisional capacity,[53] healthcare providers

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[46] *Id.* at 76; *see Informed Consent: Code of Medical Ethics Opinion 2.1.1*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/informed-consent [https://perma.cc/WB5A-UK5Z].

[47] BERG ET AL., *supra* note 3, at 76, 78 ("The emergency exception assumes that the patient would have consented if he had been fully informed. When there is strong evidence to the contrary, the physician may not override the patient's wishes.").

[48] *See generally* Thaddeus Mason Pope & Heather Michelle Bughman, *Legal Briefing: Coerced Treatment and Involuntary Confinement for Contagious Disease*, 26 J. CLINICAL ETHICS 73 (2015) (describing legal standards and rules regarding involuntary treatment in the public health context).

[49] There are limited exceptions via statute or common law for mature minors to make certain types of medical decisions, such as reproductive decisions. BERG ET AL., *supra* note 3, at 97, 233.

[50] *See, e.g.*, *id.* at 97–98; *Pediatric Decision Making: Code of Medical Ethics Opinion 2.2.1*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/pediatric-decision-making [https://perma.cc/W3NU-YVXY] Courts may require treatment when parents decide to reject life-saving treatment for their children. BERG ET AL., *supra* note 3, at 233.

[51] Decisional capacity is typically defined as "communicating a choice, understanding relevant information, appreciating the current situation and its consequences, and manipulating information rationally." Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENG. J. MEDICINE 1635, 1635 (1988). There are evolving understandings of capacity in the treatment refusal context, however, although they still rely on these four criteria. Mark Christopher Navin, Abram L. Brummett & Jason Adam Wasserman, *Three Kinds of Decision-Making Capacity for Refusing Medical Interventions*, AM. J. BIOETHICS, Aug. 3, 2021, at 1, 3–5, https://www.tandfonline.com/doi/full/10.1080/15265161.2021.1941423 [https://perma.cc/5R43-P9BM] (describing the capacity to refuse treatment based on its incompatibility with a patient's goals or willingness to endure certain burdens). Incapacity can either be "global" or "specific"; that is, a patient may be able to make no decisions at all, or may be able to make some but not all decisions. BERG ET AL., *supra* note 3, at 96; Linda Ganzini, Ladislav Volicer, William Nelson & Arthur Derse, *Pitfalls in Assessment of Decision-Making Capacity*, 44 PSYCHOSOMATICS 237, 241 (2003).

[52] BERG ET AL., *supra* note 3, at 106.

[53] Patients can be deemed incompetent by a court during guardianship proceedings or, more commonly, deemed incapacitated by their physician after a capacity assessment. *Id.* at 95–96, 106–09, 117–19, 232. Judicial review of decisional capacity is more common for end-of-life decisions, involuntary psychiatric treatment decisions, or particular medical interventions such as sterilization. *Id.* at

must still obtain authorization prior to a medical intervention.[54] State laws anticipate circumstances where a patient is unable to make their own decisions. These state laws provide the option to consent to or refuse treatment through an advance directive—prior directions or selection of a healthcare power of attorney made when the patient was competent—or in the absence of advance directives, permit family members or court-appointed guardians—surrogate or substitute decision makers—to authorize or refuse treatment on the incapacitated patient's behalf.[55] In a growing number of states, however, persons who otherwise would be considered incapacitated may be able to make their own healthcare decisions at the time the decision needs to be made by making use of formal supported decision making, wherein they receive decision-making assistance from trusted supporters.[56] Though advance directives and surrogate healthcare decision-making laws are designed to respect patient autonomy from a prior point in time,[57] supported decision making can enable the respect

118, 232. Capacity assessments are controversial and have been critiqued for bias and lack of reliability and validity. *Id.* at 101; Ganzini et al., *supra* note 51, at 241; Jennifer Moye & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62B J. GERONTOLOGY SERIES B P3, P7 (2007). Further, capacity assessments may be used to control patients by only being conducted when a patient disagrees with their physician's recommendation and not when patients agree with their physician's recommendation, even if the patient has decisional impairments. BERG ET AL., *supra* note 3, at 101, 103–06; Ganzini et al., *supra* note 51, at 238, 241; C. Umapathy et al., *Competency Evaluations on the Consultation-Liaison Service: Some Overt and Covert Aspects*, 40 PSYCHOSOMATICS 28, 32 (1999).

[54] BERG ET AL., *supra* note 3, at 94, 112, 119–20.

[55] *See, e.g.*, UNIF. HEALTH-CARE DECISIONS ACT §§ 2(c), 5(a), 11(b) (UNIF. L. COMM'N 1994) (noting the presumption of capacity and that advance directives and surrogates should only be relied upon when a patient is incapacitated); *see also* BERG ET AL., *supra* note 3, at 95, 109–13, 232 (describing how physicians should engage in the informed consent process with the incapacitated patient's surrogate).

[56] Recent developments in some states' disability and guardianship laws try to ensure that patients with cognitive disabilities retain contemporaneous decision-making authority despite their decisional impairments by facilitating the use of formal supported decision making. Supported decision-making laws comply with the Convention on the Rights of Persons with Disabilities directive that everyone is entitled to equal legal capacity. G.A. Res. 61/106, art. 12, § 2, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006) [hereinafter CRPD] ("[P]ersons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."). With formal supported decision making, persons with cognitive impairments enter into agreements with supporters who assist with obtaining information, understanding and thinking through options, and communicating decisions to third parties. *See generally* Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111 (2013) (describing supported decision making and how this model compares to guardianship and shared decision making in medical contexts); Wright, *supra* note 10 (describing supported decision-making laws and applying this model to patients with dementia); Wright, *supra* note 25 (describing how supported decision making may be a required accommodation for patients with dementia under federal disability law). Persons who otherwise would be disqualified by physicians or courts from making their own healthcare decisions may be able to do so with these decision-making accommodations.

[57] Surrogates are directed to follow a patient's advance directive or to make healthcare decisions on the basis of the patient's "values, goals, [and] preferences," a standard that respects the patient's

of a patient's contemporaneous autonomous decision to consent to or refuse medical treatment.[58]

3. Informed Consent, Medical Ethics, and Shared Decision Making

Medical ethics affirm the importance of informed consent to medical treatment. The American Medical Association (AMA) Code of Medical Ethics endorses the principle of respect for patient autonomy and the value of informed consent and directs that patients have the right "[t]o make decisions about the care the physician recommends," "to have those decisions respected," and to "accept or refuse any recommended medical intervention."[59]

Though the Code states that "[a]utonomous, competent patients control the decisions that direct their health care,"[60] shared decision making is also an ethical commitment and considered good patient-centered care.[61] In the model of shared decision making, physicians disclose information about the patient's diagnosis, prognosis, and treatment options, and the patient conveys their "values, goals, [and] preferences"; together the patient and their healthcare provid-

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autonomy. UNIF. HEALTH-CARE DECISIONS ACT, §§ 2(e), 5(f); BERG ET AL., *supra* note 3, at 115. For temporarily incapacitated patients, their right to future autonomy is protected. For permanently incapacitated patients, their right to precedent autonomy is protected. *See, e.g.*, UNIF. HEALTH-CARE DECISIONS ACT, §§ 2(e), 5(f); BERG ET AL., *supra* note 3, at 114–15, 232.

[58] Wright, *supra* note 10, at 321–23; Wright, *supra* note 25, at 30–31; Megan S. Wright, *Dementia, Cognitive Transformation, and Supported Decision Making*, AM. J. BIOETHICS, Aug. 2020, at 88, 89–90.

[59] *Patient Rights: Code of Medical Ethics Opinion 1.1.3*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/patient-rights [https://perma.cc/8G6P-G7UJ]; *see also* Comm. on Ethics, Am. Coll. of Obstetricians & Gynecologists, *ACOG Committee Opinion No. 819: Informed Consent and Shared Decision Making in Obstetrics and Gynecology*, 137 OBSTETRICS & GYNECOLOGY, at e34, e35 (Feb. 2021) [hereinafter *ACOG Opinion No. 819*], https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2021/02/informed-consent-and-shared-decision-making-in-obstetrics-and-gynecology.pdf [https://perma.cc/R2KC-QRKT] ("Informed consent is a practical application of the bioethics principle of respect for patient autonomy and self-determination as well as the legal right of a patient to bodily integrity."). The AMA Code can be considered a source of "soft law" in the form of policy statements that governs members of the Association. Indeed, many physicians give great consideration to "standards and recommendations from professional medical bodies" when "making . . . ethically complex medical decision[s]," indicating the influence of AMA guidance. R.E. Lawrence & F.A. Curlin, *Autonomy, Religion, and Clinical Decisions: Findings from a National Physician Survey*, 35 J. MED. ETHICS 214, 215 (2009).

[60] *Patient Responsibilities: Code of Medical Ethics Opinion 1.1.4*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/patient-responsibilities [https://perma.cc/P2YV-PN7A].

[61] *See generally* Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—The Pinnacle of Patient-Centered Care*, 366 NEW ENG. J. MEDICINE 780 (2012) (advocating for use of shared decision making to increase patient wellbeing); JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (Johns Hopkins Univ. Press 2002) (1984) (discussing the relationship of the physician and patient and advocating for shared decision making).

ers, and possibly family members, decide which medical interventions to pursue in light of the patient's subjective wellbeing.[62]

### *B. Empirical Research on Informed Consent*

Both law and medical ethics require physicians to obtain informed consent from patients prior to providing medical treatment; however, a significant body of research has demonstrated that the ideal of informed consent rarely matches the reality of healthcare decision making. This Section first will describe healthcare provider and patient perspectives on and experiences with healthcare decision making, then will discuss scholarly responses to failures of informed consent.

#### 1. Healthcare Decision-Making Practices and Perspectives

Empirical research has overwhelmingly demonstrated that healthcare providers are not consistently engaging in the legally-mandated informed consent process with their patients, nor are they achieving shared decision-making ideals.

Indeed, with respect to physician disclosure requirements, studies have shown that providers spend "less than 5 percent of a typical medical encounter . . . providing information to patients."[63] Another study found that physicians disclose less than a third of the required disclosures.[64]

Healthcare providers' disclosure practices do not match most patients' preferences. Patients report wanting much more information than they receive

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[62] *See* Barry & Edgman-Levitan, *supra* note 61, at 780–81 (describing family involvement); *see also* King & Moulton, *supra* note 11, at 431 (describing shared decision making). *See generally* Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 KENNEDY INST. ETHICS J. 28 (1991) (discussing the challenges of implementing shared decision making); Jennifer Blumenthal-Barby et al., *Potential Unintended Consequences of Recent Shared Decision Making Policy Initiatives*, 38 HEALTH AFFS. 1876 (2019) (describing problems with implementing shared decision making); Benjamin Moulton & Jaime S. King, *Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice*, 38 J.L. MED. & ETHICS 85 (2010) (describing shared decision making).

[63] BERG ET AL., *supra* note 3, at 184 (citing Howard Waitzkin, *Doctor-Patient Communication: Clinical Implications of Social Scientific Research*, 252 JAMA 2441 (1984)). Patients may receive more information when a surgical intervention is to be performed. *Id.* at 148. There are likely reimbursement and time constraints that influence this lack of disclosure. Elizabeth C. Thomas, Sarah Bauerle Bass & Laura A. Siminoff, *Beyond Rationality: Expanding the Practice of Shared Decision Making in Modern Medicine*, SOC. SCI. & MED., May 2021, art. 113900, at 1, 3–4 (2021).

[64] King & Moulton, *supra* note 11, at 461–62 (citing Clarence H. Braddock III et al., *How Doctors and Patients Discuss Routine Clinical Decisions: Informed Decision Making in the Outpatient Setting*, 12 J. GEN. INTERNAL MED. 339, 339–42 (1997)); *see also* KATZ, *supra* note 61, at 58 (arguing that lack of disclosure is intentional).

from their healthcare providers.[65] For example, in one study, many patients were not even informed about the surgery that would be performed on them, nor about alternative procedures.[66] Other studies have revealed that when patients do receive the legally-required information, many feel this information is insufficient, which leads them to "doubt whether the [doctor's decisions are in] their best interests" or just a matter of healthcare provider preference or convenience.[67] Patients emphasize the importance of understanding what will happen and having the opportunity to ask questions.[68] Indeed, patients desire to engage in shared decision making with their providers, but report that this is not occurring in practice.[69]

Even when physicians meet the disclosure requirements, studies and case reports have demonstrated that patients do not understand the medical treatment to which they agree.[70] This lack of understanding is in large part because much of the information patients receive is complicated, and they need more time to understand their diagnosis, prognosis, and treatment options.[71]

There are several reasons why healthcare providers may not engage in shared decision making with their patients or even meet their minimal disclo-

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[65] BERG ET AL., *supra* note 3, at 148.

[66] *See, e.g.*, Vikki Entwistle et al., *Which Surgical Decisions Should Patients Participate in and How? Reflections on Women's Recollections of Discussions About Variants of Hysterectomy*, 62 SOC. SCI. & MED. 499, 501–02 (2006) (reporting that a significant number of study patients undergoing a hysterectomy were not informed about surgical options, the "advantages and disadvantages of [the] different types" of procedures available, or even about what procedure they would be undergoing).

[67] *Id.* at 502–04; *see* BERG ET AL., *supra* note 3, at 156, 178 (summarizing studies demonstrating that regardless of whether patients want to make their own medical decisions, they desire more information); Carole Doherty, Charitini Stavropoulou, Mark NK Saunders & Tracey Brown, *The Consent Process: Enabling or Disabling Patients' Active Participation?*, 21 HEALTH 205, 213–14, 218 (2017) (reporting that although patients may not desire to make their own decisions, they want more information about the effects of the intervention); Sawicki, *supra* note 11, at 629–30 (summarizing studies demonstrating that providers are not disclosing required information to patients); Christina Sinding et al., *"I Like to Be an Informed Person but . . ." Negotiating Responsibility for Treatment Decisions in Cancer Care*, 71 SOC. SCI. & MED. 1094, 1099 (2010) (noting that patients desire more information and stronger treatment recommendations from their physicians).

[68] Doherty et al., *supra* note 67, at 214–16; *see* BERG ET AL., *supra* note 3, at 85.

[69] INST. OF MED. OF THE NAT'L ACADS., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 351 (2015) ("People feel that explanations are rushed, issues are not explained, choices are not understood, and clinicians do not listen."). This feeling is due to lack of time and poor provider communication. Sawicki, *supra* note 11, at 630–31; *see also* Pope, *supra* note 11, at 12.

[70] For summaries of studies, see BERG ET AL., *supra* note 3, at 4–8, 65, 154–55; SCHNEIDER, *supra* note 6, at 35–47; Pope, *supra* note 11, at 12; Sawicki, *supra* note 11, at 629–30.

[71] BERG ET AL., *supra* note 3, at 28; Sinding et al., *supra* note 67, at 1096; Cindy Brach, *Making Informed Consent an Informed Choice*, HEALTH AFFS. BLOG (Apr. 4, 2019), https://www.healthaffairs.org/do/10.1377/forefront.20190403.965852/full/ [https://perma.cc/GG43-D42P]. Patients may also not understand English or be hard-of-hearing, and if they are not accommodated through interpreters or other means, this also contributes to lack of understanding.

sure obligations. Sometimes healthcare providers may not obtain informed consent to all interventions because doing so is simply not practicable. For example, patients may provide informed consent to a specific intervention but never know about all the various procedures required to conduct that intervention or alternatives to these other procedures.[72] Providers may also perceive a lack of time to engage in disclosure, or that disclosure is not necessary because the intervention is commonplace.[73]

Additionally, some providers may not understand the extent to which they are not meeting their informed consent requirements. This misunderstanding may stem from a lack of knowledge about their specific legal obligations.[74] Alternatively, providers who say they are committed to respecting patient autonomy may not be aware of how their interactions with their patients do not accord with this commitment.[75] Scholars refer to the phenomenon of "providers us[ing] the language of informed consent" while acting paternalistic as "performing informed consent."[76]

For some healthcare providers, failure to engage in meaningful informed consent with their patients may be because providers view the requirement as a mere formality required by law. Indeed, "some physicians have claimed that they can almost always get their patients to consent to any procedure they de-

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[72] Entwistle et al., *supra* note 66, at 505 (describing necessity of "bundled" consent, or implied consent to procedures necessary to conduct the procedure to which a patient has explicitly consented (citing MARK A. HALL, MAKING MEDICAL SPENDING DECISIONS (1997))).

[73] King & Moulton, *supra* note 11, at 462, 473 (describing time and resource constraints (citing Braddock et al., *supra* note 64, at 344)); Arwen H. Pieterse, Anne M. Stiggelbout & Victor M. Montori, *Shared Decision Making and the Importance of Time*, 322 JAMA 25, 25–26 (2019) (describing time constraints in implementing shared decision making).

[74] *See* Marc Tunzi, David J. Satin & Philip G. Day, *The Consent Continuum: A New Model of Consent, Assent, and Nondissent for Primary Care*, HASTINGS CTR. REP., Mar.-Apr. 2021, at 33, 34 (noting that physicians are unaware of when they need to obtain informed consent and tend only to do so for invasive procedures like surgery rather than for more common interventions such as medication or screening).

[75] Providers either engage with their patients unilaterally or bilaterally; in the former instance, "the practitioner talks in formats less conducive to patient's participation," consistent with physician paternalism. Sarah Collins, Paul Drew, Ian Watt & Vikki Entwistle, *"Unilateral" and "Bilateral" Practitioner Approaches in Decision-Making about Treatment*, 61 SOC. SCI. & MED. 2611, 2625 (2005). In the latter instance, "the practitioner talks in a way which actively pursues patient's contributions," which is more consistent with shared decision making. *Id.*; *see also* stef m. shuster, *Performing Informed Consent in Transgender Medicine*, SOC. SCI. & MED., Apr. 2019, at 190, 195 (demonstrating that some providers begin the informed consent discussion using the word "we," reflecting joint decision making, but by the end used the word "I," reflecting provider decision making.); Emily S. Mann, *The Power of Persuasion: Normative Accountability and Clinicians' Practices of Contraceptive Counseling*, SSM—QUALITATIVE RSCH. IN HEALTH, Dec. 2022, art. 100049, at 1, 4–6 (reporting that clinicians talk about the importance of patient autonomy, but in practice pressure patients to accept the recommended intervention).

[76] shuster, *supra* note 75, at 190–91, 195.

sire to perform," making patient choice an illusion the law creates.[77] Further, some providers appear to view informed consent conversations and any associated documents primarily as a means to diminish potential liability.[78] Patients also perceive signing a consent form as a standard bureaucratic procedure meant to protect doctors' interests against any subsequent legal action, though they may not feel like they have any choice but to sign it.[79]

Finally, providers may not engage in legally-required informed consent conversations with their patients because of their patients' decision-making preferences. That is, studies have shown that patient decision-making preferences may vary from the ideal informed consent process.[80] Namely, some patients "may not want to make [their own healthcare] decisions" and instead wish to defer to their healthcare provider, and providers may adapt their communication accordingly.[81] This decision-making preference may depend on the

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[77] BERG ET AL., *supra* note 3, at 155 (citing Henry K. Beecher, *Consent in Clinical Experimentation: Myth and Reality*, 195 JAMA 34, 34–35 (1966)). For information about how clinicians obtain patient agreement even after an initial refusal, see Paul S. Appelbaum & Loren H. Roth, *Patients Who Refuse Treatment in Medical Hospitals*, 250 JAMA 1296, 1300 (1983); Jeffrey P. Spike, *Informed Consent is the Essence of Capacity Assessment*, 45 J.L. MED. & ETHICS 95, 98 (2017); Tanya Stivers & Rose McCabe, *Dueling in the Clinic: When Patients and Providers Disagree About Healthcare Recommendations*, SOC. SCI. & MED., Dec. 2021, art. 114140, at 1, 2; Tanya Stivers & Stefan Timmermans, *Medical Authority Under Siege: How Clinicians Transform Patient Resistance into Acceptance*, 61 J. HEALTH & SOC. BEHAV. 60, 74 (2020); Merran Toerien, *When Do Patients Exercise Their Right to Refuse Treatment? A Conversation Analytic Study of Decision-Making Trajectories in UK Neurology Outpatient Consultations*, SOC. SCI. & MED., Dec. 2021, art. 114278, at 1, 2. Some physicians may disclose information not to support patient choice but rather to enable treatment compliance. BERG ET AL., *supra* note 3, at 148; KATZ, *supra* note 61, at 26.

[78] shuster, *supra* note 75, at 194; Sinding et al., *supra* note 67, at 1097.

[79] Doherty et al., *supra* note 67, at 216–17.

[80] *See* BERG ET AL., *supra* note 3, at 26–30, 84 ("[P]hysicians routinely underestimate the degree to which patients would like to be informed . . . [and] overestimate patients' eagerness to make decisions." (first citing Lori B. Andrews, *Informed Consent Statutes and the Decisionmaking Process*, 5 J. LEGAL MED. 163 (1984); then citing Louis Harris et. al., *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, *in* 2 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAV. RSCH., MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP, APPENDICES: EMPIRICAL STUDIES OF INFORMED CONSENT 17 (1982); and then citing *Patients Opt for Medical Information but Prefer Physician Decision Making*, MEDICAL WORLD NEWS (Mar. 26, 1984))); Moulton & King, *supra* note 62, at 89.

[81] BERG ET AL., *supra* note 3, at 27; *see* Brach, *supra* note 71 (noting that patients would participate more in decision making if information was clearer); Doherty et al., *supra* note 67, at 213; Moulton & King, *supra* note 62, at 89; Sinding et al., *supra* note 67, at 1097 (reporting that some patients prefer to be fully informed and participate in decision making but want their physicians to make the ultimate treatment decision given their medical expertise); A. Robinson & R. Thomson, *Variability in Patient Preferences for Participating in Medical Decision Making: Implication for the Use of Decision Support Tools*, 10 QUALITY HEALTH CARE (SUPP. I) i34, i37 (2001) (noting patients' preference for treatment information even if they do not wish to decide). *See generally* Wendy Levinson, Audiey Kao, Alma Kuby & Ronald A. Thisted, *Not All Patients Want to Participate in Decision Making: A National Study of Public Preferences*, 20 J. GEN. INTERNAL MED. 531 (2005) (noting vari-

patient's goal of treatment. If being cured is possible, patients may defer to their providers whereas if patients are at the end of their lives, they may feel that they should make their own decisions.[82] Patients also may not wish to decide because they are sick and do not have the "emotional, intellectual, and physical resources . . . to make decisions."[83] Some scholars thus describe patients' decisions as "not about treatment [but] rather . . . about [whether the patient] trust[s]" their healthcare providers' advice.[84]

Nevertheless, it is important not to overstate the degree of agency patients have in the healthcare encounter. Research has demonstrated that some healthcare providers are paternalistic and make medical decisions on behalf of their patients despite their patients' decision-making preferences, which subverts patient self-determination in the clinical encounter.[85] Providers may do this by framing or manipulating information in a manner meant to ensure patient authorization.[86] Providers may also add an informal capacity assessment to the informed consent discussion, and if they view their patients as lacking sufficient understanding or appreciation about an intervention—despite evidence of their patients' normal cognitive functioning—the provider may deny requested medical interventions even if otherwise medically indicated.[87] Or providers may request a formal capacity assessment and after a finding of incapacity, override a treatment refusal.[88] In this manner, healthcare providers act

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ation in decision-making preferences). Some providers may have problematic assumptions about their patients' ability or willingness to participate in healthcare decision making. *See, e.g.*, Allen I. Goldberg, *Life-Sustaining Technology and the Elderly: Prolonged Mechanical Ventilation Factors Influencing the Treatment Decision*, 94 CHEST 1277, 1278–82 (1988) (reporting physicians' views that older patients cannot participate in medical decision making).

[82] Sinding et al., *supra* note 67, at 1098.

[83] BERG ET AL., *supra* note 3, at 28; *see also* Entwistle et al., *supra* note 66, at 506 ("There may come a point at which the advantages of encouraging patients to engage in an explicit deliberative decision-making process are outweighed by the cognitive and emotional burden on patients."); Schneider & Farrell, *supra* note 7, at 109.

[84] Sinding et al., *supra* note 67, at 1096.

[85] Collins et al., *supra* note 75, at 2625 ("Patients tended to say very little . . ., and what they did say did not always appear to influence the selection of a particular course of action."). Providers may decide for their patients because they do not trust their patients to make good decisions. BERG ET AL., *supra* note 3, at 19; shuster, *supra* note 75, at 194. *But see* Stivers & McCabe, *supra* note 77, at 2 (describing patient power in clinical interactions); Stivers & Timmermans, *supra* note 77, at 74 (describing patient pressure on physicians during clinical interactions); Toerien, *supra* note 77, at 2 (noting that in the adult neurology treatment context, patient treatment refusals are sometimes honored).

[86] *See, e.g.*, Kukura, *supra* note 15, at 751 (describing such actions in the obstetric context). *See generally* Mann, *supra* note 75 (describing same in the contraception context).

[87] shuster, *supra* note 75, at 192–93. Providers may also provide nonconsensual treatment after an informal capacity assessment. Marshall B. Kapp & Bernard Lo, *Legal Perceptions and Medical Decision Making*, 64 MILBANK Q. (SUPP. II) 163, 191–92 (1986).

[88] *See infra* note 137 and accompanying text.

as gatekeepers, and respect for patient autonomy becomes conditional on providers' assessment of capacity for agency.

### 2. Proposed Reforms to Informed Consent Process

Scholars in many disciplines and professions have identified how the ideal of informed consent is not achieved in practice.[89] It is fair to say that "[d]espite its name, 'informed consent' fails to assure that the patient's consent is actually informed" and "that relevant patient questions and concerns are adequately answered."[90] Given that informed consent is illusory in practice, scholars have advocated for reforms to promote physician disclosure and increase patient knowledge and understanding to ensure that patients receive medical care that matches their preferences.

Namely, legal scholars and clinicians have promoted shared decision making that is often paired with patient decision aids to supplement physician oral disclosure.[91] Decision aids "include decision grids, videos, and interactive websites"[92] and "brochures . . . computer programs, or third-party consultations," and are often meant for use "outside [of] the clinical context" to assist patients in choosing between different treatment options.[93] Evidence shows several benefits of using decision aids, such as assisting patients in understanding their values and preferences, and recent legal scholarship has focused on how to increase the use and ensure the quality of decision aids.[94]

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[89] *See, e.g.*, Pope, *supra* note 11, at 12 ("A giant chasm lies between the theory and the practice of informed consent. . . . [I]t has failed to meaningfully empower patients to make . . . decisions that match their preferences.").

[90] *Id.* at 17.

[91] *Id.* at 29; Glyn Elwyn et al., *Shared Decision Making: A Model for Clinical Practice*, 27 J. GEN. INTERNAL MED. 1361, 1365–66 (2012); King & Moulton, *supra* note 11, at 432, 464–68, 480 (arguing that informed consent law should build in shared decision-making requirements). *But see* Blumenthal-Barby et al., *supra* note 62 *passim* (critiquing implementation of shared decision making and patient decision aids).

[92] Pope, *supra* note 11, at 13.

[93] Sawicki, *supra* note 11, at 628–30. Decision aids "help patients understand the various treatment options available to them, including the risks and benefits of each choice"; "help patients communicate their beliefs and preferences related to their treatment options"; and "help patients decide with their clinicians what treatments are best for them." Pope, *supra* note 11, at 21; *see* Sawicki, *supra* note 11, at 631–32.

[94] King & Moulton, *supra* note 11, at 465. For description of additional benefits, see *id.* at 480–86; Pope, *supra* note 11, at 21–22; Sawicki, *supra* note 11, at 629–33. Notwithstanding their benefits, physicians do not widely use decision aids in clinical practice in part because "they reduce and constrain physician discretion and judgment." Pope, *supra* note 11, at 21, 23. For a description of bias and misinformation in existing decision aids, reasons for poor quality, and the necessity for certification to "ensur[e] accurate and [complete] information," see *id.* at 13, 25–29, Brach, *supra* note 71; King & Moulton, *supra* note 11, at 466–67, 488–90; Sawicki, *supra* note 11, at 633–44, 658, 660, 661. For a description of problems with the implementation of supported decision making and use of patient decision aids, see generally Blumenthal-Barby et al., *supra* note 62.

But ensuring patients understand their treatment options is not the only remaining barrier to meeting the ideals of informed consent.[95] The failure of informed consent is not solely a failure related to information and understanding. The scholarly focus on the "informed" element of informed consent may elide failures with the legal requirement to obtain patient consent to medical treatment.[96]

### *C. Treatment Over Objection*

Although there is an extensive body of empirical scholarship on physician disclosures and patient understanding of medical interventions, there is relatively little research about nonconsensual medical treatment, specifically treatment provided over patients' express objection.[97] This is despite "a large amount of anecdotal evidence . . . that significant medical interventions sometimes are imposed on patients in the absence of . . . informed consent. . . . [This occurs] even when no valid exception to the requirement exists."[98] The lack of research is likely due to the reality that studying such unlawful behavior is incredibly difficult.[99]

Though there are many accounts of treatment over objection in the mental health context, legal scholarship about treatment over objection in the *medical* context focuses on two primary circumstances: end-of-life decision making

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[95] And indeed, the focus on patient decision aids may not match patient decision-making preferences that might include having their healthcare providers decide on their behalf. *See supra* Section I.B. Additionally, an excess of information can be harmful to the decision-making process. *See generally* CASS R. SUNSTEIN, TOO MUCH INFORMATION: UNDERSTANDING WHAT YOU DON'T WANT TO KNOW (2020) (arguing that too much and irrelevant information is often provided and that policymakers should instead provide more limited and useful information that will increase patient wellbeing).

[96] Indeed, some clinicians have recently advocated for changing informed consent requirements to fit clinical practice rather than changing clinical practice to fit legal doctrine, and in particular have argued that in many instances patient assent or nondissent in the absence of currently-required physician disclosures is ethically sufficient. Tunzi et al., *supra* note 74, at 38–39.

[97] BERG ET AL., *supra* note 3, at 235, 241; *see also* Kukura, *supra* note 15, at 778 (describing lack of research on nonconsensual treatment during childbirth). There is some evidence of treatment over patient objection found in court cases, but better data about nonconsensual treatment are in the psychiatric context. BERG ET AL., *supra* note 3, at 235 (noting that conclusions derived from such data "are not completely transferable to the general medical context").

[98] Marshall B. Kapp, *Enforcing Patient Preferences: Linking Payment for Medical Care to Informed Consent*, 261 JAMA 1935, 1935 (1989) (footnotes omitted) (first citing P.S. Appelbaum & L.H. Roth, *Involuntary Treatment in Medicine and Psychiatry*, 141 AM. J. PSYCHIATRY 202 (1984); and then citing Appelbaum & Roth, *supra* note 77).

[99] Healthcare providers may be more open to participating in studies when they have at least attempted to engage in informed consent. They may be less likely to allow researchers access to healthcare settings where researchers could observe clear violations of patient rights.

and obstetrics. This section will first describe these contexts before discussing treatment over contemporaneous objection in general acute care settings.

### 1. Noncompliance with Advance Directives Refusing Treatment

There is ample evidence that physicians often do not follow their incapacitated patients' advance directives to refuse life-sustaining treatment.[100] Indeed, studies have shown that advance directives have no bearing on physicians' decisions to resuscitate patients.[101] Disregarding such directives is an example of treatment over objection, although the objection may not be contemporaneous.[102]

There are several reasons that healthcare providers do not comply with their patients' advance directives and treat incapacitated patients over their objection. Some noncompliance may be unintentional; for example, providers may not have access to or understand the advance directive.[103] Or there could be "a lack of communication between providers and patients [or] inadequate institutional documentation of patient wishes."[104]

Noncompliance with patient advance directives may also be intentional; for example, providers may object to following the advance directive for reasons of conscience.[105] Providers may also think they are more likely to be sued for wrongful death than medical battery—or have to pay larger damages in the

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[100] *See, e.g.*, BERG ET AL., *supra* note 3, at 117; Paula Span, *The Patients Were Saved. That's Why the Families Are Suing*, N.Y. TIMES (Apr. 10, 2017), https://www.nytimes.com/2017/04/10/health/wrongful-life-lawsuit-dnr.html [https://perma.cc/D3T4-WHWT] (describing instances where healthcare providers ignored advance directives refusing life-sustaining treatment).

[101] Fernandez Lynch et al., *supra* note 15, at 137 (citing Joan M. Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, 5 J. CLINICAL ETHICS 23, 27 (1994)); *see also* David A. Asch, John Hansen-Flaschen & Paul N. Lanken, *Decisions to Limit or Continue Life-Sustaining Treatment by Critical Care Physicians in the United States: Conflicts Between Physicians' Practices and Patients' Wishes*, 151 AM. J. RESPIRATORY & CRITICAL CARE MED. 288, 290–92 (1995) (reporting that many physicians would provide life-sustaining care over patient or surrogate objections, and almost all would make unilateral decisions about "withholding or withdrawing life-sustaining treatment" without consent or over the objection of the lawful decision maker).

[102] Providing life-sustaining treatment may not be unlawful if the circumstances that trigger the operation of the advance directive have not occurred. Some states have stringent conditions for when an advance directive is considered operative, and sometimes states restrict what types of medical care can be refused via advance directive. Sawicki, *supra* note 15, at 287–88.

[103] *Id.* at 283, 284 n.29 (citing studies and showing noncompliance); Fernandez Lynch et al., *supra* note 15, at 137, 148 (noting that providers may not know their patient has an advance directive or know how to interpret the directive).

[104] Sawicki, *supra* note 15, at 302.

[105] *Id.* at 284 n.29, 301–02. Physicians may also override DNR orders if the need for resuscitation is due to an iatrogenic error because of guilt and also because of uncertainty about whether the DNR order contemplated this type of situation. John Banja & Michele Sumler, *Overriding Advance Directives: A 20-Year Legal and Ethical Overview*, 39 J. HEALTHCARE RISK MGMT., no. 2, 2019, at 11, 13.

event of liability in the former instance—and thus choose to provide life-sustaining treatment despite the directive to forgo such treatment.[106] Finally, providers may not comply with their patients' advance directives because the advance directives may appear to conflict with the patient's current interests and "many physicians not only consider it their responsibility to make treatment decisions in the best interest of the patient, but also believe that patient preferences should be ignored when they are inconsistent with the physician's assessment."[107]

Given that such noncompliance defeats the purpose of advance directives and also may be unlawful, many legal scholars have explored and advocated for remedies in tort, administrative sanctions, and not billing patients for nonconsensual medical treatment.[108] Unfortunately, many courts have not vindicated patients' right to refuse medical treatment via advance directive when providers have overridden the directive, thus making this right illusory.[109]

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[106] Banja & Sumler, *supra* note 105, at 15 ("[Physicians] would rather represent themselves in a wrongful life suit than a wrongful death suit, and there have been no legal precedents to persuade them otherwise."); Fernandez Lynch et al., *supra* note 15, at 149 (quoting a hospital administrator who "stated starkly that she would 'rather have a wrongful li[ving] claim than a wrongful death claim'" (alteration in original)); Pope, *New Penalties*, *supra* note 15, at 74 (noting that providers do not fear lawsuits for overriding patient advance directives (quoting INST. OF MED. OF THE NAT'L ACADS., *supra* note 69, at 133)); Sawicki, *supra* note 15, at 284–86, 288–90, 301–02; *see also* ROBERT A. BURT, TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS 145 (1979) (describing how physicians have "practical" rather than "formal" immunity when not held to account for legal wrongs).

[107] Fernandez Lynch et al., *supra* note 15, at 156–57 (first citing Tricia Jonas Hackleman, Note, *Violation of an Individual's Right to Die: The Need for a Wrongful Living Cause of Action*, 64 U. CIN. L. REV. 1355, 1357–58 (1996); and then citing David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1283 (1994)); *see also* Pope, *supra* note 11, at 34 n.78 ("Substantial evidence shows that the treatment patients get depends more on the physician than on the patient's preferences." (citing DARTMOUTH ATLAS PROJECT, https://www.dartmouthatlas.org/ [https://perma.cc/YLF4-C7LB]); Orentlicher, *supra*, at 1283 ("[L]iving wills . . . have little effect on medical decisionmaking. They will be respected only when they are consistent with the physician's views of the patient's best interests."); John J. Paris, J. Cameron Muir & Frank E. Reardon, *Ethical and Legal Issues in Intensive Care*, 12 J. INTENSIVE CARE MED. 298, 299 (1997) (reporting that a majority of physicians believe that preserving life is more important than respecting patient autonomy and that "physicians . . . continue to function independently of the preferences of critically ill patients"). Providers may also acquiesce to "objections by family members to the patient's preferred course of treatment." Sawicki, *supra* note 15, at 302.

[108] Scholars have argued that providers who are noncompliant with patient advance directives should be liable for intentional infliction of emotional distress and punitive damages, not receive reimbursement for nonconsensual medical services, be subject to professional sanctions, be fined by CMS, and possibly be subject to criminal prosecution. *See, e.g.*, Fernandez Lynch et al., *supra* note 15, at 148, 170, 172–77; Pope, *New Penalties*, *supra* note 15, at 75, 80; Sawicki, *supra* note 15, at 292–93; Mark Strasser, *A Jurisprudence in Disarray: On Battery, Wrongful Living, and the Right to Bodily Integrity*, 36 SAN DIEGO L. REV. 997, 1034, 1036–38, 1039–40 (1999).

[109] *See* Banja & Sumler, *supra* note 105, at 15 ("[N]o court to date has awarded damages to plaintiffs for the defendant's specific autonomy violation of providing life-prolonging interventions despite the patient's refusal . . . ." (citing Nicole Marie Saitta & Samuel D. Hodge, Jr., *What Are the Conse-*

Noncompliance with patient advance directives is undoubtedly an important issue, but scholarship and law reform proposals on this topic do not address the situation where a capacitated patient is contemporaneously refusing medical treatment and the provider is treating over their objection.[110]

2. Nonconsensual Obstetric Interventions

Nonconsensual gynecological and obstetric interventions are not uncommon. First, there is the issue of nonconsensual sterilization, a practice that has been embedded in past institutional policies targeting marginalized women and that is currently alleged to be occurring in migrant detention camps.[111] Second, there is an emerging literature about nonconsensual gynecological exams to train medical students, residents, and fellows; such examinations usually occur when a woman patient is under general anesthesia for a (perhaps) unrelated medical procedure, is not informed about the examination, and thus does not consent to it.[112]

Legal scholars have also written about obstetric violence, which includes nonconsensual medical treatment.[113] There are many documented instances in

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*quences of Disregarding a "Do Not Resuscitate Directive" in the United States?*, 32 MED. & L. 441 (2013))); S. Elizabeth Wilborn Malloy, *Beyond Misguided Paternalism: Resuscitating the Right to Refuse Medical Treatment*, 33 WAKE FOREST L. REV. 1035, 1039–40 (1998). Some of the difficulty for plaintiffs is in proving causation. Strasser, *supra* note 108, at 1035–38. Additionally, courts may not consider continued life to be a harm. *Id.* at 1032–36; *see* Fernandez Lynch et al., *supra* note 15, at 142–48; Sawicki, *supra* note 15, at 284–86, 288–90. Courts may also have difficulty calculating damages, although the damages are relatively straightforward and include costs of nonconsensual medical treatment, physical harm from the treatment, pain and suffering, and perhaps punitive damages. Strasser, *supra* note 108, at 1021–38.

[110] Noncompliance with advance directives is also only an issue for patients who have advance directives; such patients constitute a minority of all patients. Kuldeep N. Yadav et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 HEALTH AFFS. 1244, 1247–48 (2017).

[111] *See generally* Buck v. Bell, 274 U.S. 200 (1927) (holding that forced sterilization of persons with mental disabilities did not violate the Due Process Clause); HARRY BRUINIUS, BETTER FOR ALL THE WORLD: THE SECRET HISTORY OF FORCED STERILIZATION AND AMERICA'S QUEST FOR RACIAL PURITY (2006) (recounting the history of forced eugenics); HARRIET A. WASHINGTON, MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT (2006) (describing how Black women who were enslaved were the objects of medical experimentation); *ICE, A Whistleblower and Forced Sterilization*, NPR (Sept. 22, 2020), https://www.npr.org/2020/09/18/914465793/ice-a-whistleblower-and-forced-sterilization [https://perma.cc/3AZM-R6AA] (discussing allegations of forced sterilization of detained women immigrants).

[112] *See, e.g.*, Emma Goldberg, *She Didn't Want a Pelvic Exam. She Received One Anyway.*, N.Y. TIMES, https://www.nytimes.com/2020/02/17/health/pelvic-medical-exam-unconscious.html [https://perma.cc/SB2S-YG2V] (Feb. 19, 2020).

[113] *See* Kukura, *supra* 15, at 736, 778 (defining obstetric violence as abuse, coercion, disrespect, use of physical restraints, sexual violations, and punitive denial of pain relief); *see also* Pope, *Unwanted Cesareans*, *supra* note 15, at 164 (adding confidentiality breaches to definition of obstetric violence). For a description of birth trauma as a concept distinct from obstetric violence, see Theresa

which pregnant women receive medical interventions to which they have not consented and sometimes to which they have actively objected, despite the fact that these women are competent to make their own healthcare decisions and are legally entitled to do so.[114] Healthcare providers may coerce their patients into agreeing to procedures in a number of ways: threatening to involve the state by seeking a court order or reporting the woman to child welfare, questioning their patient's capacity to make medical decisions, manipulating information they provide to their patient (for example, by emphasizing risks of no treatment and overestimating benefits of intervention), and denying pain relief or other medical treatment when patients resist their recommendations.[115]

The culture and structure of medicine together with gender norms produce the conditions for obstetric violence.[116] Some women are more vulnerable to obstetric violence, such as young women, low-income women, and women

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Morris, Joan H. Robinson, Keridwyn Spiller & Amanda Gomez, "*Screaming, 'No! No!' It Was Literally Like Being Raped": Connecting Sexual Assault Trauma and Coerced Obstetric Procedures*, SOC. PROBS. (SUPP.), July 20, 2021, at 1, 2, https://academic.oup.com/socpro/advance-article/doi/10.1093/socpro/spab024/6324470 [https://perma.cc/HEB9-3X2U].

[114] *See, e.g.*, Kukura, *supra* note 15, at 759 (citing studies demonstrating that the majority of episiotomies are nonconsensual and describing a study where birth workers directly observed physicians "conduct a procedure over a woman's explicit objections" (citing LOUISE MARIE ROTH ET AL., MATERNITY SUPPORT SURVEY: A REPORT ON THE CROSS-NATIONAL SURVEY OF DOULAS, CHILDBIRTH EDUCATORS AND LABOR AND DELIVERY NURSES IN THE UNITED STATES AND CANADA 37 (2014), https://maternitysurvey.files.wordpress.com/2014/07/mss-report-5-1-14-final.pdf [https://perma.cc/ULT3-GPZY])); Morris et al., *supra* note 113, at 7–9 (describing use of force against women during childbirth); Hindi Stohl, *Childbirth Is Not a Medical Emergency: Maternal Right to Informed Consent Throughout Labor and Delivery*, 38 J. LEGAL MED. 329, 343–47 (2018) (arguing that outside of exceptional circumstances, the emergency exception to the informed consent requirements cannot be relied upon during childbirth). For interventions such as cesareans, women may authorize the procedure, but experience significant pressure to do so, making the "consent" not voluntary. Kukura, *supra* note 15, at 759. Scholars have asserted that instances of obstetric violence alleged in court cases "are only the tip of a deep iceberg of other cases that exist 'below the surface,' never filed." Pope, *Unwanted Cesareans*, *supra* note 15, at 170; *see also* Morris et al., *supra* note 113, at 11 (noting cases of obstetric violence where victims did not take legal action). Other types of treatment over a pregnant patient's objection include life-sustaining treatment, refused contemporaneously or via advance directive or surrogate. Kukura, *supra* note 15, at 739 & n.100 (citing *In re* A.C., 573 A.2d 1235, 1237 (D.C. 1990)). Courts, however, have not always affirmed pregnant patients' medical decision-making rights. *See* BERG ET AL., *supra* note 3, at 228 (citing Lawrence J. Nelson & Nancy Milliken, *Compelled Medical Treatment of Pregnant Women: Life, Liberty, and Law in Conflict*, 259 JAMA 1060, 1066 (1988)); Kukura, *supra* note 15, at 738–43; Pope, *Unwanted Cesareans*, *supra* note 15, at 164.

[115] *See* Kukura, *supra* note 15, at 738–54; *see also* Pope, *Unwanted Cesareans*, *supra* note 15, at 166 (noting that physicians may also demean the woman).

[116] Scholars highlight reimbursement models, malpractice concerns, the culture of physician paternalism, the "medicalization of childbirth," the routinization of medical interventions, and gender norms as explanations for obstetric violence. Kukura, *supra* note 15, at 765–78; Morris et al., *supra* note 113, at 2.

of color.[117] Women may experience adverse emotional, psychological, and physical outcomes when treated without consent.[118]

Treating pregnant women over their objection occurs in a somewhat unique medical context in which there may be concerns about the fetus and many of the legal considerations—such as reproductive rights jurisprudence—and ethical considerations in providing such treatment do not apply to other type of patients or medical situations.[119]

### 3. Other Contexts

There are no systematic studies of patient treatment refusal and subsequent treatment over contemporaneous objection for patients with or without decisional capacity, although such treatment is not uncommon.[120] This section

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[117] *See* Kukura, *supra* note 15, at 750. *See generally* Mann, *supra* note 75 (describing how clinicians pressure low-income women to use long-acting contraception).

[118] Some women even experience post-traumatic stress after enduring coercion in the obstetric context. Kukura, *supra* note 15, at 760 (describing studies); Morris et al., *supra* note 113, at 8–9.

[119] Kukura, *supra* note 15, at 777 (describing how in cases of patient-provider disagreement, physicians may assert that there is a "maternal-fetal conflict" that necessitates privileging what the physician perceives to be in the interest of the fetus, which "directly coincide with his own personal treatment preferences" (quoting Michelle Oberman, *Mothers and Doctors' Orders: Unmasking the Doctor's Fiduciary Role in Maternal-Fetal Conflicts*, 94 NW. U. L. REV.451, 454 (2000))); Pamela Laufer-Ukeles, *Reproductive Choices and Informed Consent: Fetal Interests, Women's Identity, and Relational Autonomy*, 37 AM. J.L. & MED. 567, 590–603 (2011) (discussing how women's autonomy is limited by others' concern for "fetal interests"); Morris et al., *supra* note 113, at 2 (describing focus on "healthy baby" and fetal safety); Terri-Ann Samuels et al., *Obstetricians, Health Attorneys, and Court-Ordered Cesarean Sections*, 17 WOMEN'S HEALTH ISSUES 107, 109–11 (2007) (reporting results of a survey of obstetricians and health lawyers, over half of whom support court-ordered cesareans for pregnant women who refuse the procedure).

[120] Appelbaum & Roth, *supra* note 77, at 1299 ("Forced treatment, which was not uncommon, was usually limited to patients who were incompetent to make decisions about medical treatment . . . ."); Appelbaum & Roth, *supra* note 98, at 202 ("[N]onconsensual treatment in general medicine is, in fact, quite common . . . ."); *see, e.g.*, Frank W. Lavoie, *Consent, Involuntary Treatment, and the Use of Force in an Urban Emergency Department*, ANNALS EMERGENCY MED., Jan. 1992, at 25, 27 ("Epidemiologic investigations of involuntary treatment in a general hospital ED have never been performed . . . ."). Small studies reported in the literature indicate that treatment over contemporaneous objection, even when patients have decisional capacity, is "not uncommon." *See, e.g.*, Appelbaum & Roth, *supra* note 77, at 1299 & tbl.4; Appelbaum & Roth, *supra* note 98, at 202; Lavoie, *supra*, at 25–26, 26 tbl.1 (reporting that hospital security personnel used force, including seclusion and restraints, on almost 9% of emergency department patients, even if no one had evaluated the patient's capacity to make their own medical decisions). Further, given the documented problems with capacity assessments, it can be inferred that in some instances where a patient has been deemed incompetent to make their own decisions, they are in fact competent and thus being unlawfully treated over their objections. *See* discussion *supra* Section I.A.2. Additionally, leading clinical ethics textbooks argue for treating competent patients over their objection in some instances, and if this guidance is followed, this would lead to treatment over objection in practice. *See* ALBERT R. JONSEN, MARK SIEGLER & WILLIAM J. WINSLADE, CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE §§ 1.0.8, 2.2.4 (8th ed. 2015). Court cases also shed light on how competent

draws on smaller studies to survey reasons patients refuse treatment and patient experiences of being treated over their objection before examining why providers treat patients over their contemporaneous objection in acute care settings.

### *a. Patient Reasons for Refusing Treatment and Experiences Being Treated Over Objection*

There are manifold reasons why patients may refuse medical treatment. Some treatment refusals may not be rational. Indeed, some scholars assert that patients who refuse treatment may not be well-informed.[121] Patients may not be informed because physicians have not engaged in adequate disclosure, ensured patient understanding, or elicited what is important to their patient.[122] It may also be that the treatment refusal does not reflect the patient's values and is instead a result of psychopathology.[123]

But patients may refuse treatment, including life-sustaining treatment, for what could be considered rational reasons. For example, in one study of older cancer patients' decisions to refuse treatment, researchers found that many were concerned about side effects, did not believe the recommended treatment would be beneficial, thought the treatment would be too risky given their preexisting medical conditions, were considering quality of life, had financial concerns, or did not want to burden others, among other reasons.[124]

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patients may be treated over their contemporaneous objection. *See, e.g.*, Shine v. Vega, 709 N.E.2d 58, 60–61 (Mass. 1999) (alleging forcible intubation over competent adult patient's contemporaneous objection, requiring use of security guards and four-point restraints, which subsequently caused emotional trauma and reluctance to seek future medical treatment, eventually leading to preventable death from asthma); Hinkle v. Kindred Hosp., No. M2010-02499-COA-R3-CV, 2012 WL 3799215, at *1–3 (Tenn. Ct. App. Aug. 31, 2012) (alleging that a nurse forcefully inserted a rectal tube over competent adult patient's contemporaneous objection, which caused physical injury, pain, subsequent surgeries to repair injury, and permanent incontinence).

[121] BERG ET AL., *supra* note 3, at 242.

[122] *See id.* at 235 (summarizing studies about uninformed refusals); Appelbaum & Roth, *supra* note 77, at 1298 & tbl.3 (noting that refusals may be due to [p]roblems in communication"). The structure of healthcare may also contribute to lack of informed refusals as patients often interact with multiple healthcare providers, each spending a limited time with patients. BERG ET AL., *supra* note 3, at 235–36.

[123] *See, e.g.*, Appelbaum & Roth, *supra* note 77, at 1298 (noting that refusals may be due to psychological factors); Rebecca O'Brien et al., *When People Living with Dementia Say "No": Negotiating Refusal in the Acute Hospital Setting*, SOC. SCI. & MED., Oct. 2020, art. 113188, at 1, 3–7 (2020) (reporting that refusals of care, including medical treatment, in the hospital are common for dementia patients). *But see* BERG ET AL., *supra* note 3, at 236–43 ("[R]efusal is only rarely a manifestation of psychiatric illness, and . . . psychiatric illness in itself is not sufficient to render patients incompetent.").

[124] Martine T.E. Puts et al., *A Systematic Review of Factors Influencing Older Adults' Decision to Accept or Decline Cancer Treatment*, 41 CANCER TREATMENT REVS. 197, 199–204, 205 tbl.4, 210 tbl.5, 213 tbl.6 (2015). Some patients reported having communication and trust issues with their healthcare providers as well as poor experiences in prior treatment. *Id.* Many patients, however, did

Whatever the reason for treatment refusal, when providers override a patient's objection, the patient may need to be physically restrained in order to provide the medical treatment. Patients' experience of being physically restrained is overwhelmingly negative. In a review of studies of such experiences, patients report feeling "anger, fear, humiliation, demoralization, dehumanization, degradation, powerlessness, distress, embarrassment, and feeling that their integrity as a person had been violated."[125] Patients report feeling "helpless, hopeless, and as if their spirits had been broken at some point during their restraint experience."[126] The negative effects on psychological and emotional wellbeing are more intense if the medical intervention "permanently alters bodily appearance and function."[127] Aside from psychological and emotional trauma from being restrained, patients may also be physically harmed when treated over their objection.[128] Patients also may lose trust in their healthcare providers and thus not seek medical treatment in the future, which can lead to

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agree to treatment. *Id.* at 212; *see also* Appelbaum & Roth, *supra* note 77, at 1298 tbl.3 (noting that refusals also may be due to insufficient trust in providers or concerns about dying with dignity); Toerien, *supra* note 77, at 17 (describing symptom management reasons for treatment refusals).

[125] Tania D. Strout, *Perspectives on the Experience of Being Physically Restrained: An Integrative Review of the Qualitative Literature*, 19 INT'L J. MENTAL HEALTH NURSING 416, 423 (2010) (first citing G. Bonner, T. Lowe, D. Rawcliffe & N Wellman, *Trauma for All: A Pilot Study of the Subjective Experience of Physical Restraint for Mental Health Inpatients and Staff in the UK*, 9 J. PSYCHIATRIC & MENTAL HEALTH NURSING 465 (2002); then citing Wai-Tong Chien, Carmen W.H. Chan, Lai-Wah Lam & C.-W. Kam, *Psychiatric Inpatients' Perceptions of Positive and Negative Aspects of Physical Restraint*, 59 PATIENT EDUC. & COUNSELING 80 (2005); then citing Ruth Gallop, Elizabeth McCay, Maya Guha & Pamela Khan, *The Experience of Hospitalization and Restraint of Women Who Have a History of Childhood Sexual Abuse*, 20 HEALTH CARE FOR WOMEN INT'L 401 (2010); then citing Mary E. Johnson, *Being Restrained: A Study of Power and Powerlessness*, 19 ISSUES MENTAL HEALTH NURSING 191 (1998); then citing Peter Jones & Biza Stenfert Kroese, *Service Users' Views of Physical Restraint Procedures in Secure Settings for People with Learning Disabilities*, 35 BRIT. J. LEARNING DISABILITIES 50 (2006); then citing Heather Sequeira & Simon Halstead, *"Is It Meant to Hurt, Is It?": Management of Violence in Women with Developmental Disabilities*, 7 VIOLENCE AGAINST WOMEN 462 (2001); then citing N.E. Strumpf & L.K. Evans, *Physical Restraint of the Hospitalized Elderly: Perceptions of Patients and Nurses*, 37 NURSING RSCH. 132 (1988); then citing Ivy SL Wong & Wai-Tong Chien, *Young Medical Patients' Experience of Physical Restraint: An Exploratory Study*, 14 J. CLINICAL NURSING 120 (2005); and then citing Rolf Wynn, *Psychiatric Inpatients' Experiences with Restraint*, 15 J. FORENSIC PSYCHIATRY & PSYCH. 124 (2004)). Physical restraints also caused some patients to become more agitated. *Id.*

[126] *Id.* at 424.

[127] Jonah Rubin & Kenneth M. Prager, Commentary, *Guide to Considering Nonpsychiatric Medical Intervention Over Objection for the Patient Without Decisional Capacity*, 93 MAYO CLINIC PROC. 826, 827 (2018).

[128] *See, e.g.*, Hinkle v. Kindred Hosp., No. M2010-02499-COA-R3-CV, 2012 WL 3799215, at *1–3 (Tenn. Ct. App. Aug. 31, 2012) (alleging ruptured bowel and permanent incontinence from forcible insertion of rectal tube); Debbie Tolson & John E. Morley, *Physical Restraints: Abusive and Harmful*, 13 JAMDA 311, 311–12 (2012) (describing harms from restraints).

further physical harm.[129] Given that patients may have good reasons to refuse treatment, and given the profoundly negative experience of forcible, involuntary treatment, it is important to determine why providers treat patients over their objection.

*b. Provider Reasons for Treating Patients Over Objection*

There are many reasons why healthcare providers may treat patients over their objection in the face of an express, contemporaneous treatment refusal. For example, patient rejection of treatment conflicts with a physician's professional identity and training to heal, especially if the treatment would prolong life or prevent disability, thereby possibly causing the physician to feel upset when treatment is refused.[130] Healthcare providers may also provide nonconsensual treatment because it will be reimbursed by health insurers if determined to be medically necessary or because so doing is convenient for them.[131]

The relative difficulty of treating patients over their contemporaneous objection may be a dispositive factor in some cases. Indeed, treatment over patient objection may require force or incapacitation through use of physical restraints, sedation, or security guards or nurses holding down an actively-resisting patient.[132] Treatments that need to be administered over a lengthy period of time require patient compliance.[133]

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[129] Rubin & Prager, *supra* note 127, at 827; *see, e.g.*, Shine v. Vega, 709 N.E.2d 58, 60–61 (Mass. 1999) (alleging patient did not seek treatment for an asthma attack because she had been forcibly treated over her objection in the past, leading to her preventable death).

[130] *See* BERG ET AL., *supra* note 3, at 227, 233, 234; Barry R. Furrow, *Bouvia v. Superior Court*, *in* FEMINIST JUDGMENTS: HEALTH LAW OPINIONS REWRITTEN (Seema Mohapatra & Lindsay Wiley eds., forthcoming) (manuscript at 10) (on file with author) (noting that patients who do "not conform to the norms of usual patient behavior" by refusing treatment may anger physicians who find them "difficult"); Kukura, *supra* note 15, at 771–72 (linking nonconsensual treatment in the obstretric context to "defensive medicine"); Navin et al., *supra* note 20, at 1938.

[131] *See* Kapp, *supra* note 98, at 1936; *see also* Kukura, *supra* note 15, at 743 (suggesting that cesarean sections may be forced on women because this procedure generates more revenue for providers compared to vaginal deliveries); David Evans & Mary FitzGerald, *Reasons for Physically Restraining Patients and Residents: A Systematic Review and Content Analysis*, 39 INT'L J. NURSING STUD. 735, 741 (2002) (describing how most uses of restraints are to benefit providers and facilities rather than patients).

[132] Lavoie, *supra* note 120, at 26–27 (describing how a hospital employs "security personnel to assist" healthcare providers in treating patients over their objection); Appelbaum & Roth, *supra* note 77, at 1299–1300 (describing use of restraints and conscription of family members to treat patients over their objection); Appelbaum & Roth, *supra* note 98, at 203 (describing use of physical restraints in hospital and surgical wards).

[133] *See, e.g.*, Goldberg, *supra* note 81, at 1280; Rubin & Prager, *supra* note 127, at 827 ("Even with strong ethical justification for treating over objection, it is often impossible due to logistical obstacles. Examples include forcing a patient with kidney failure to undergo dialysis repeatedly or compelling a patient with AIDS to take medication regularly.").

Providers may also be ignorant about the law and purpose of informed consent.[134] They may believe, for example, that they are less at risk for medical malpractice for treating patients over objection than they are for not providing a potentially life-sustaining treatment.[135] Physicians may also provide treatment over their patient's objection if they feel the patient is not competent to make their own medical decisions or if the treatment is in their patient's best medical interests.[136]

Healthcare providers may justify treatment over contemporaneous objection by relying on the exceptions to informed consent, namely the intersection of emergency and incapacity exceptions. In order to justify this action, providers may request capacity assessments from psychiatrists to dis-

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[134] Healthcare providers are often ignorant of the law that governs patient-provider relationships. For example, many healthcare providers do not understand that patients can choose to leave the hospital against medical advice without forfeiting future rights to care. *See generally* Cordelia R. Stearns, Allison Bakamjian, Subrina Sattar & Miranda Ritterman Weintraub, *Discharges Against Medical Advice at a County Hospital: Provider Perceptions and Practice*, 12 J. HOSP. MED. 11 (2017) (describing characteristics of patients who leave hospitals against medical advice and noting provider misconceptions about patients' rights to care); David Alfandre, Editorial, *Improving Quality in Against Medical Advice Discharges—More Empirical Evidence, Enhanced Professional Education, and Directed Systems Changes*, 12 J. HOSP. MED. 59 (2017) (highlighting characteristics of patients who are discharged against medical advice and provider lack of understanding about patients' rights to leave and still access care in the future). Healthcare providers are also often ignorant of their legal obligations to their patients with disabilities. Nicole D. Agaronnik et al., *Knowledge of Practicing Physicians About Their Legal Obligations When Caring for Patients with Disability*, 38 HEALTH AFFS. 545, 546, 548–49 (2019).

[135] *See* BERG ET AL., *supra* note 3, at 52, 124; Kapp, *supra* note 98, at 1935; Kapp & Lo, *supra* note 87, at 191; Kukura, *supra* note 15, at 738, 771–72, 774.

[136] *See, e.g.*, Lawrence & Curlin, *supra* note 59, at 216 & tbl.2 (reporting that only 40% of physicians believe patient autonomy was the most important consideration in ethically complex situations and that other factors included patients' best medical interests, medical society guidance, and the providers' religious beliefs); BERG ET AL., *supra* note 3, at 52 (suggesting that nonconsensual treatment may occur because of "physicians' reluctance to allow even competent patients to refuse medically indicated treatment" (citing Lawrence J. Markson, Donald C. Kern, George J. Annas & Leonard H. Glantz, *Physician Assessment of Patient Competence*, 42 J. AM. GERIATRICS SOC'Y 1074 (1994))); van Kleffens & van Leeuwen, *supra* note 14, at 133–35 (describing how providers view rationality in terms of medical reasoning and assess rationality with respect to treatment goals rather than values). Though physicians may see conflict between their duties to support patient autonomy and promote patient wellbeing, this view may be mistaken. van Kleffens & van Leeuwen, *supra* note 14, at 135. In some cases, there may not be a "best" treatment, and so a patient's choice to refuse the recommended treatment is not "wrong," just based on their personal preference; additionally, the patient may have more insight into the effects of the recommended treatment than the physician if the patient has previous experience with the particular treatment. BERG ET AL., *supra* note 3, at 233–34; *see also* Walter Veit, Brian D. Earp, Heather Browning & Julian Savulescu, *Evaluating Tradeoffs Between Autonomy and Wellbeing in Supported Decision Making*, AM. J. BIOETHICS, Oct. 2021, at 21, 22 (arguing that providers should not assume that persons with cognitive impairments will have a decline in wellbeing if permitted to make their own decisions).

qualify their patient from making their own treatment decisions.[137] Providers may also try to pressure the psychiatrist to determine a patient to be incapacitated despite evidence to the contrary.[138] A finding of incapacity permits healthcare providers to seek consent from a surrogate decision maker.[139] Providers may also consult with hospital attorneys or ethics committees to sign off on the treatment over objection.[140]

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Scholars tend to discuss the history of informed consent doctrine and medical practice as evolving to become more protective of patient autonomy.[141] By contrast, this last Section has shown that even the basic requirement to obtain patient authorization to treatment is not met in some circumstances. There needs to be more research on the "consent" part of informed consent in the context of treatment over contemporaneous patient objection, especially when the law does not permit such treatment.

The scholarly focus on information disclosures and patient understanding may obscure the reality that healthcare providers may resist informed consent not so much because they are required to inform patients, but more so because they may not believe patients should be able to make their own medical decisions, especially decisions refusing treatment.[142]

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[137] *See, e.g.*, Andrew H. Mebane & Harry B. Rauch, *When Do Physicians Request Competency Evaluations?*, 31 PSYCHOSOMATICS 40, 41–42, 44–45 (1990) (reporting that urgent psychiatric consults were requested when patients refused medical interventions and asserting that the consults are motivated by provider frustration rather than concern for patients); Spike, *supra* note 77, at 100 (arguing that capacity assessments are overused and that better communication is the solution); Umapathy et al., *supra* note 53, at 29–32 (reporting that over 20% of hospital psychiatric consultation requests over a one-month period involved treatment refusal cases); *see also* Kukura, *supra* note 15, at 748 (describing psychiatric consultations in obstetric context).

[138] *See, e.g.*, Mark Katz, Susan Abbey, Anne Rydall & Frederick Lowy, *Psychiatric Consultation for Competency to Refuse Medical Treatment: A Retrospective Study of Patient Characteristics and Outcome*, 36 PSYCHOSOMATICS 33, 39 (1995) ("Urgent consultations and those where a more serious treatment is refused put increased pressure on the consulting psychiatrist to quickly decide and support the medical team's wish for intervention by declaring the patient incompetent."); Umapathy et al., *supra* note 53, at 28–29 (describing an "'unspoken but clear expectation' on the part of the treatment team . . . that the patient will be found incompetent so that treatment can proceed" (quoting Katz et al., *supra*, at 34)).

[139] *See, e.g.*, UNIF. HEALTH-CARE DECISIONS ACT § 5(a) (UNIF. L. COMM'N 1994).

[140] For advice to seek legal or ethics counsel in cases of treatment over objection and descriptions of subsequent problematic advice, see Goldberg, *supra* note 81, at 1280; Kukura, *supra* note 15, at 730; Lavoie, *supra* note 120, at 38. *But see* Navin et al., *supra* note 20, at 1938 (suggesting that "it seems likely that . . . institutional ethics permission . . . can contribute to complacency about the ethics of treatment over objection").

[141] *See, e.g.*, BERG ET AL., *supra* note 3, at 20 n.2 ("Another important conceptual shift focuses on the understanding of autonomy, from *mere* freedom from uninvited interference with one's body, to an opportunity to express one's values and preferences.") (emphasis added).

[142] *Id.* at 240.

## II. PATIENTS SHOULD NOT BE TREATED OVER THEIR OBJECTION

The scholarly neglect of consent is problematic for many reasons. First, focusing on information and understanding promotes a conceptualization of autonomy as essentially cognitive in nature; that is, understanding autonomy to be equivalent to rationality, eliding the embodied nature of autonomy and patients' interests in maintaining bodily integrity. Indeed, when healthcare providers treat conscious patients without consent, particularly over their explicit and contemporaneous refusal, patients may suffer physical, emotional, or psychological trauma.

Additionally, conceptualizing autonomy as rationality results in the transfer of power from patients to clinicians who can "disqualify" patients from medical decision making and treat patients over their objection. The use of capacity assessments to investigate patients' decisions is an affront to patient privacy. This practice also conflicts with developments in disability law that aim to help individuals retain decision-making authority in their lives regardless of whether they have decisional impairments.

Finally, there are rule of law implications when providers treat patients over their objection. When providers ignore the law of informed consent, they contribute to the erosion of the rule of private law.

Section A of this Part will focus first on how treating patients over their objection is inconsistent with respect for autonomy and bodily integrity.[143] Section B will then focus on how treating patients over their objection contributes to a decline in overall welfare.[144] Finally, Section C will conclude by discussing how treating patients over their objection is inconsistent with the rule of law.[145]

### *A. Treating Patients Over Their Objection Is Inconsistent with Respect for Patient Autonomy and Bodily Integrity*

Scholars have identified two different conceptualizations of autonomy that healthcare decision-making law recognizes. The first conceptualization of autonomy is as "bodily integrity . . . rooted in the historic, common law right to be free from non-consensual bodily touching or invasion," which is the conceptualization upon which the doctrine of informed consent is historically anchored.[146] Consent to touching the body maintains the integrity of the physical body and allows the medical intervention to be lawful.[147] Refusal of the touch-

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[143] *See infra* notes 146–192 and accompanying text.

[144] *See infra* notes 193–207 and accompanying text.

[145] *See infra* notes 208–223 and accompanying text.

[146] Anne Flamme & Heidi Forster, *Legal Limits: When Does Autonomy in Health Care Prevail?*, *in* 3 LAW AND MEDICINE: CURRENT LEGAL ISSUES, *supra* note 7, at 141, 142.

[147] *Id.*

ing makes any medical treatment provided an invasion of the body and potentially unlawful.[148] The more recent conceptualization of autonomy in informed consent law is as self-determination, based on rights to privacy or liberty interests, and moves from protecting the body to making decisions about the body.[149]

Choosing a particular legal conceptualization of autonomy to emphasize in the doctrine and practice of informed consent has implications for the significance of patient capacity for rational decision making. Maintenance of bodily integrity, the first doctrinal understanding of autonomy in healthcare decision-making law, does not contain a patient rationality requirement.[150] Self-determination, the second conceptualization of autonomy, hints at a minimum rationality requirement. This Section will argue for deemphasizing rationality and emphasizing bodily integrity in the context of treatment refusals, but also that regardless of how autonomy is conceptualized in informed consent law, it is not respectful of autonomy to treat patients over their objection.[151]

### 1. Deemphasizing Decisional Capacity and Rationality

For many healthcare providers, clinical ethicists, and lawyers, patient autonomy has become conflated with a patient's capacity for and subsequent commitment to rational choice as judged by healthcare providers.[152] Conflating

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[148] *Id.* Even if the nonconsensual touching falls under an exception to the requirement to obtain informed consent, thus making the nonconsensual touching lawful, it is still an invasion and violation of bodily integrity. *See id.*; William Lucy, *The Rule of Law and Private Law*, *in* PRIVATE LAW AND THE RULE OF LAW 41, 62–64 (Lisa M. Austin & Dennis Klimchuk eds., 2014).

> The scheme of rights and entitlements embodied in private law constitutes a prima facie hurdle, which must be surmounted through legal means or brazenly discarded, to the exercise of such force. And even when that hurdle is overcome, the overcoming remains either regrettable (as when such rights and entitlements are legally overridden) or plain wrong (when there is no such legal licence).

Lucy, *supra*, at 62.

[149] Flamme & Forster, *supra* note 146, at 142–43. Both conceptualizations of autonomy—maintenance of bodily integrity and self-determination—are found in ACOG's opinion about informed consent. *See ACOG Opinion No. 819*, *supra* note 59, at e35. But this seems to be medical specialty-specific, and the bodily integrity component of informed consent is not present in the AMA opinions.

[150] Herring & Wall, *supra* note 24, at 583 (asserting that bodily integrity interests remain despite the loss of decisional capacity).

[151] This Article does not argue that there is no cognitive component of autonomy and also does not argue that physicians should not be required to disclose information to their patients about risks and benefits of various treatment options. *See infra* notes 152–174 and accompanying text.

[152] There is direct evidence of this conflation in many scholarly writings. *See, e.g.*, Annas, *supra* note 5, at 11 (arguing "to reform our practice to make sure that informed choice actually . . . promotes rational decision-making, and protects self-determination"); BERG ET AL., *supra* note 3, at 146 (describing an aim of informed consent as "promoting rational decisionmaking" (quoting Protection of

autonomy with rationality allows physicians to retain power over medical decision making. If the patient's reaction to the physician's judgment is one of compliance, then the patient's decisional capacity is not in question.[153] If the patient disagrees with the physician, however, the physician can always try to discredit the patient through use of a capacity assessment. A finding of incapacity removes decision-making power from their patient and then allows the physician to turn to a surrogate decision maker or a healthcare power of attorney to authorize a particular treatment.[154] Equating autonomy with rationality based on medical reasoning permits healthcare providers to substitute their own judgment for that of their patients.[155]

Healthcare decision-making law has facilitated the removal of decision-making authority from patients as legislators and judges have largely ceded authority to determine patient decisional capacity to healthcare providers, supporting the notion of autonomy as capacity to make rational medical decisions. Healthcare providers' determination of a patient's incapacity to make medical decisions results in a stripping of legal capacity to decide. Therefore, although

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Human Subjects; Informed Consent, 61 Fed. Reg. 51,498, 51,500 (Oct. 2, 1996) (to be codified at 21 C.F.R. pts. 50, 56, 312, 314, 601, 812, 814))); Thomas et al., *supra* note 63, at 2 (noting that shared decision-making models emphasize rationality). The clinical practice of using capacity assessments to remove decision-making authority from patients also demonstrates an understanding of autonomy as capacity for rationality.

[153] *See, e.g.*, BERG ET AL., *supra* note 3, at 103–04; KATZ, *supra* note 61, at 113; Ganzini et al., *supra* note 51, at 239 tbl.1, 241; Mebane & Rauch, *supra* note 137, at 45 (describing how capacity assessments are requested in cases of treatment refusal but not acceptance).

[154] *See* BERG ET AL., *supra* note 3, at 103–04; Jason Adam Wasserman & Mark Christopher Navin, *Capacity for Preferences: Respecting Patients with Compromised Decision-Making*, HASTINGS CTR. REP., May–June 2018, at 31, 37 ("[N]oncompliant patients are disproportionately determined to lack decision-making capacity . . . ." (citing Ganzini et al., *supra* note 51)).

[155] If patients do not share the same background understanding of their condition as physicians, then when physicians engage in a standardized informed consent process, physicians may deem their patient's decision to be irrational and thus unworthy of legal or moral respect. *See* BERG ET AL., *supra* note 3, at 313–14; van Kleffens & van Leeuwen, *supra* note 14, at 133–35 (noting that physicians understand rationality in terms of goals of medical treatment). But it is important to note that patients who are making rational treatment decisions may not be using a medical logic; they may be making decisions in light of finances, relationships, emotions, religion, or other nonmedical concerns important to their wellbeing. *See, e.g.*, KATZ, *supra* note 61, at 76, 96, 117 (noting that longevity is not the only valid consideration in medical decision making and arguing that physicians' value judgments are incorporated into a determination of medical best interests); Brach, *supra* note 71 (arguing for price transparency as part of the informed consent process); *see also* Puts et al., *supra* note 124, at 205–13; Sinding et al., *supra* note 67, at 1095; Stearns et al., *supra* note 134, at 15; van Kleffens & van Leeuwen, *supra* note 14, at 133–35 (noting that patients may be making rational decisions on the basis of their values).

respect for patient autonomy is the premise of both healthcare decision-making law and medical ethics, physician paternalism remains prevalent.[156]

Why have physicians been granted so much (quasi-legal) power? Arguably, efficiency concerns support this grant of power: patients may need urgent or emergency medical care, physicians have the tools to assess decisional capacity, and courts may be unable to handle significant numbers of requests to determine capacity.

There is also another explanation: some scholars have advanced the concept of "informed refusals," thought to be the corollary of informed consent—that treatment refusals must also be informed.[157] This opens the patient's reasons for refusal up to scrutiny, which is an investigation of whether the refusal is "informed," along with the possibility that a treatment refusal will not be respected due to the incapacity exception to informed consent.[158]

True respect for patient autonomy when refusing treatment, however, would not require patients to evidence their decision-making abilities or justify their decisions. Though providers may inquire about the patient's reasons for refusal in order to clear up any misunderstandings, the patient would not be required to disclose or need a "good reason" in order to have their treatment refusal respected.[159] As others have noted, though physicians are legally re-

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[156] BERG ET AL., *supra* note 3, at 147 (describing "a consistent pattern of subordinating patient autonomy to the interests of the medical profession" (first citing Jay Katz, *Informed Consent—A Fairy Tale?*, 39 U. PITT. L. REV. 137 (1977); and then citing KATZ, *supra* note 61)).

[157] *Id.* at 234, 237 ("If patients are well informed about the treatment options and have made choices that appear largely consistent with their underlying values, they clearly have the right to refuse treatment.").

[158] BERG ET AL., *supra* note 3, at 234–38 (advising physicians to investigate reasons for refusals); Kukura, *supra* note 15, at 749–50 (describing how refusals in obstetric context "may invite mental health examinations [and] scrutiny of [personal] life"). The definition of "informed refusal" incorporates an understanding requirement rather than just a disclosure requirement. *See generally* Joseph Millum & Danielle Bromwich, *Informed Consent: What Must Be Disclosed and What Must Be Understood?*, AM. J. BIOETHICS, Jan. 2021, at 46 (arguing that clinician disclosure and patient understanding should not be conflated). This Article does not argue that physicians should not inform their patients (indeed, they should) or that assumption of risk should not be a defense to negligent informed consent. *See* Nadia N. Sawicki, *Choosing Medical Malpractice*, 93 WASH. L. REV. 891, 915–18 (2018) (describing the assumption-of-risk defense). Rather this Article argues for changes in what constitutes "understanding."

[159] *See generally* KATZ, *supra* note 61 (advocating for extensive discussion between doctors and patients); Rebecca Dresser, *Autonomy and Persuasion*, *in* MALIGNANT: MEDICAL ETHICISTS CONFRONT CANCER 57 (Rebecca Dresser ed., 2012) (arguing that clinicians should seek to clear up mistaken beliefs and should persuade patients to accept beneficial treatment); Samia A. Hurst, *When Patients Refuse Assessment of Decision-Making Capacity: How Should Clinicians Respond?*, 164 ARCHIVES INTERNAL MED. 1757, 1758 (2004) (arguing that clinicians should engage with their patients when a capacity assessment is refused). This is current law, but this Article contends that it is not followed in practice and that exceptions to the requirement to obtain informed consent, such as incapacity, have been abused. There have been debates about whether formal capacity assessments are respectful of autonomy. *See, e.g.*, BERG ET AL., *supra* note 3, at 100–07 (describing how capacity

quired to disclose information to patients, absent a waiver from patients, patients are under no such obligation to disclose information.[160] Patients can decide how they want to exercise their rights under informed consent law. They can choose to be informed and decide, to be informed but not decide, not to be informed nor decide, or not to be informed and decide.[161] Requiring a patient to demonstrate capacity for rational decision making and then to provide what healthcare providers consider to be a rational reason for a particular decision under the guise of needing an "informed refusal" misunderstands patient autonomy rights and interests, which incorporate a right to privacy in decision making. Additionally, such requirements misunderstand the physician's role in patients' medical decisions.[162] Indeed, if a patient can communicate a refusal, providers should respect it.[163]

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assessments interfere with patients' rights to make their own decisions, but also can ensure that patients do not make decisions counter to their medical wellbeing). Rather than a complete formal capacity assessment, assessing whether patients can communicate a choice is comparatively respectful of patients' privacy and legal rights. *Id.* at 100, 152. Scholars and clinicians may be uncomfortable with not assessing capacity further, however, because patients may not make good medical decisions due to inadequate understanding, which by some definitions, is incompatible with autonomy. *Id.* at 100–01. *But see* Millum & Bromwich, *supra* note 158, at 46–48 (arguing that consent is possible despite incomplete understanding). Even ethicists who argue that patients with impaired capacity should still be able to contemporaneously refuse treatment in some instances argue that the patient's reasoning should be explored, neglecting the privacy interests of patients with decisional impairments. Navin et al., *supra* note 51, at 4–6; *see also* Nina Labovich, Note, *Consent, Informed: Rethinking Informed Consent & Competency for Patients with Schizophrenia & Anosognosia*, 62 B.C. L. Rev. 615, 634–37 (2021). It is important to note, however, that requesting a capacity assessment often negatively impacts patients who perceive assessments "as an act of hostility" and lose trust in providers. Spike, *supra* note 77, at 99.

[160] Donald T. Ridley, *Informed Consent, Informed Refusal, Informed Choice—What Is It That Makes a Patient's Medical Treatment Decisions Informed?*, 20 MED. & L. 205, 209 (2001). *But see* KATZ, *supra* note 61, at 157–58 (noting circumstances under which patients' refusals should be overridden); Hurst, *supra* note 159, at 1758–59 (noting that although providers, and not patients, have disclosure obligations, sometimes competent patients should be treated over their objection if the risks of nontreatment are significant). This Article should not be read as advocating that physicians not disclose information to their patients as is currently required under the doctrine of informed consent. *See* Schneider & Farrell, *supra* note 7, at 125–26 (arguing for physician disclosure despite limits to patient comprehension). Rather, this Article emphasizes patients' rights of privacy and bodily integrity in cases of treatment refusal.

[161] Ridley, *supra* note 160, at 209; *see* BERG ET AL., *supra* note 3, at 88.

[162] Indeed, an emphasis on decisional capacity permits a substantial "degree of discretion . . . in the medical profession" and may be used to "look[] not at the . . . decisionmaking process, but at the decision itself." BERG ET AL., *supra* note 3, at 103; *see also* KATZ, *supra* note 61, at 127–28 ("[T]he requirement for conversation creates inevitable conflicts with the right to privacy—the right to keep one's thoughts and feelings to oneself."); Navin et al., *supra* note 51, at 5–6 (noting that even competent patients may not be able to explain why they value what they value).

[163] *See* Wasserman & Navin, *supra* note 154, at 34–35 (describing how persons with cognitive impairments can express unwavering, nonarbitrary preferences worthy of respect); Furrow, *supra* note 130, manuscript at 7.

It is more justifiable to assess decision-making abilities and reasons when a patient is seeking treatment. Physicians have a legitimate stake in deciding whether to provide a particular treatment and may want to decide on the basis of information from the patient. That is, providers also have autonomy and professional rights.[164] Refusing a treatment, however, does not require action or a decision from the physician, and thus there is no entitlement to receive information from the patient. Physicians can ask their patients questions out of care and concern but cannot demand information from their patients when they refuse treatment.

Moreover, aside from privacy considerations and the abuse of capacity assessments to wield power over patients, there are other reasons to decrease reliance on capacity assessments, especially when patients refuse treatment.[165] Although there has long been a sound mind requirement to be legally entitled to make one's own medical decisions, this rationality requirement is not as stringent as some may believe if understandings of autonomy and rationality accord with real world circumstances and typical cognitive capabilities.

In prior work, I have argued that autonomy in late-life healthcare decision making is best understood as "relational in nature" and that many patients make decisions "in collaboration with or in consideration of others."[166] I have also argued that "'autonomy' in healthcare decision-making is [more properly understood] as agency,"[167] given inherent cognitive limitations on rational decision making,[168] structural constraints on available options,[169] power dynam-

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> Once [a patient] expresses her wishes, her motivation is irrelevant so long as she remains "competent." If a right exists, it does not matter what "motivates" its exercise. Nothing in the law suggests that the right to refuse medical treatment may be exercised only if the patient's *motives* meet someone else's approval.

Furrow, *supra* note 130, manuscript at 7.

[164] *See, e.g.*, Herring & Wall, *supra* note 24, at 568.

[165] *See, e.g.*, KATZ, *supra* note 61, at 112–13, 118; Navin et al., *supra* note 51, at 5–6 (noting how patients may not want to have to explain their values and goals).

[166] Wright, *supra* note 36, at 1081–95; *see also* BERG ET AL., *supra* note 3, at 32–35 (describing conceptualizing autonomy as relational to better fit decision-making practices and preferences).

[167] Wright, *supra* note 10, at 264, 280, 323.

[168] *Id.* It is commonly accepted that rationality is "bounded." *See generally* KAHNEMAN, *supra* note 7 (discussing rational and irrational modes of thinking); THALER & SUNSTEIN, *supra* note 7 (discussing irrationality and advocating for changes in policy to improve decision making and promote wellbeing); Wasserman & Navin, *supra* note 154, at 36 (asserting that all patients have limits to rationality along with the right to make bad decisions).

[169] *See generally* BERG ET AL., *supra* note 3, at 308, 311 (describing lack of choice when patients cannot afford available medical treatments or when patients live in institutional settings); Wasserman & Navin, *supra* note 154, at 33 (noting that all patients have limited options); Susan Sherwin, *Relational Autonomy and Global Threats*, *in* BEING RELATIONAL: REFLECTIONS ON RELATIONAL THEORY AND HEALTH LAW 13 (Jocelyn Downie & Jennifer L. Llewellyn eds., 2012) (describing contextual

ics between providers and patients, and the complex nature of medical information disclosed when the patient is medically vulnerable.[170] Combining these insights, when patients make healthcare decisions they are exercising relational agency and research demonstrates that even patients with cognitive impairments are capable of making "decisions that align with their preferences" if they are supported or otherwise accommodated when doing so.[171]

Indeed, there is an evolving understanding of autonomy and capacity for persons with cognitive impairments embedded in international and state disability law in which equal legal capacity is the goal.[172] This is inconsistent with the emphasis on rationality in healthcare decision making and the subsequent empowerment of healthcare providers to use capacity assessments to disregard the contemporaneous preferences of patients with decisional impairments. Supported decision-making legislation, for example, facilitates the contemporaneous exercise of relational agency for persons with cognitive disabilities.[173] Its adoption into the laws of several states troubles the reliance on capacity assessments and surrogate decision makers in healthcare settings when a patient with decisional impairments refuses a recommended medical treatment. A patient with a formal supported decision-making agreement may be able to retain legal capacity despite healthcare providers' determination that they are not entitled to make their own medical decisions.

Given that complete rationality is impossible for anyone, including physicians, it is necessary to question why this thin and unrealistic conceptualization of autonomy has been relied upon in the clinical setting and given credence by courts and scholars.[174] And it is important to determine whether there are better

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constraints on autonomy); Sinding et al., *supra* note 67, at 1095 ("Models of treatment decision making tend to minimize or obscure the social contexts and limits on patients' choices . . . .").

[170] *See generally* BERG ET AL., *supra* note 3, at 25, 101–02 (stating most patients cannot understand medical information, especially when sick, and arguing for a reasonable person standard in determining understanding); NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS, *supra* note 7 (discussing why medical decision making is difficult and applying behavioral science to health law and public policy); Dresser, *supra* note 159, at 62 (describing how competent patients may be susceptible to three types of irrationality: fear, denial, and misunderstanding the burdens of various options); Schneider & Farrell, *supra* note 7 (describing limits to rational decision making when patients are sick).

[171] Wright, *supra* note 10, at 264, 323. *See generally* Wasserman & Navin, *supra* note 154 (arguing that capacity for preferences should be respected).

[172] CRPD, *supra* note 56, art. 12.

[173] Wright, *supra* note 10, at 323.

[174] *See, e.g.*, KATZ, *supra* note 61, at 87, 102, 121–22, 151 (describing physician irrationality); Thomas et al., *supra* note 63, at 3. Feminist philosophers argue that this conceptualization of autonomy serves the interests of the powerful while marginalizing the vulnerable. *See, e.g.*, Letitia Meynell, *Introduction: Minding Bodies*, *in* EMBODIMENT AND AGENCY 1, 3–4 (Sue Campbell, Letitia Meynell & Susan Sherwin eds., 2009); Martha Albertson Fineman, *Reasoning from the Body: Universal Vulnerability and Social Justice*, *in* A JURISPRUDENCE OF THE BODY 17, 19, 25–26 (Chris Dietz, Mitchell Travis & Michael Thomson eds., 2020).

conceptualizations of patient autonomy and consent in healthcare decision making.

### 2. Emphasizing Bodily Integrity

The corporeal interests in law have been relatively neglected.[175] This neglect is problematic because of the body's importance. The body matters to patients because "life is . . . mediated by the body and we cannot make use of our freedom except through the body."[176] The body matters because of its "vulnerability [and periods of] dependence."[177] Indeed, illness and disability are experienced by the body, as well as feelings of powerlessness and degradation. And the common law recognizes the importance of the body and the ability to protect it legally from invasion and confinement.[178]

The body also matters in the law and ethics of informed consent.[179] Indeed, maintenance of bodily integrity is a fundamental interest in tort law generally and the law of informed consent specifically.[180] The requirement to ob-

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[175] In contrast, rationality is emphasized. Chris Dietz, Mitchell Travis & Michael Thomson, *Nobody, Anybody, Somebody, Everybody: A Jurisprudence of the Body*, *in* A JURISPRUDENCE OF THE BODY, *supra* note 174, at 1, 3 ("This separation of law and bodies fails to account for the ways in which bodies are shaped, constituted and constructed by the institutions that they are imbricated within. As a result, this disembodied conception of law has been critic[ized] . . . as 'a socially decontextualized, hyper-rational, wilful individual . . . .'" (quoting Anna Grear, *'Sexing the Matrix': Embodiment, Disembodiment and the Law—Towards the Re-gendering of Legal Rationality*, *in* GENDER, SEXUALITIES AND LAW (Jackie Jones, Anna Grear, Rachel Anne Fenton & Kim Stevenson eds., 2011))). Scholars in other fields have also argued that the body's centrality tends to be inappropriately minimized. *See generally* ELIZABETH BARNES, THE MINORITY BODY, A THEORY OF DISABILITY (2016) (describing disability studies); EMBODIMENT AND AGENCY, *supra* note 174 (describing philosophy); ARTHUR W. FRANK, THE WOUNDED STORYTELLER: BODY, ILLNESS, AND ETHICS (2d ed. 2013) (describing medical ethics); ALLISON JAMES & JENNY HOCKEY, EMBODYING HEALTH IDENTITIES (2007) (describing sociology of health); CHRIS SHILLING, THE BODY AND SOCIAL THEORY (2d ed. 2003) (describing sociology).

[176] Herring & Wall, *supra* note 24, at 579 n.63 (quoting IMMANUEL KANT, LECTURES ON ETHICS 147–48 (Louis Infield trans., Harper & Row 1963) (1920)).

[177] O. CARTER SNEAD, WHAT IT MEANS TO BE HUMAN: THE CASE FOR THE BODY IN PUBLIC BIOETHICS 3 (2020); Fineman, *supra* note 174, at 21.

[178] ANITA BERNSTEIN, THE COMMON LAW INSIDE THE FEMALE BODY 36, 42 (2019) ("[T]he common law believes that unwanted physical contact is at a minimum distasteful to the person touched, and often abhorrent. . . . [P]ersons do not want constraint on their prerogative to move . . . .").

[179] For example, Jay Katz explored what a surgeon might say while interacting with a patient in a hypothetical conversation highlighting the importance of the body in the context of informed consent: "After all it is *your* body that I intend to treat and I can do so in a variety of ways. Since you will have to live with your body for a long time to come, you must have some opinions about which consequences would be easier or more difficult for you to tolerate." KATZ, *supra* note 61, at 126.

[180] *See, e.g.*, Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.").

tain patient consent, informed or not, to medical treatment protects the right to bodily integrity.[181]

Bodily integrity is distinct from, but also a component of, autonomy.[182] Autonomy in healthcare decision making can be thought of as deliberately making choices, perhaps with others, with bounded understanding, and voluntarily.[183] Bodily autonomy is a subset of autonomy; namely, "any exercise of autonomy (any choice or decision) that . . . is to do with the body."[184] In contrast, bodily integrity is "the right not to have [one's] body touched or [one's] body interfered with without [one's] consent."[185] That is, the right to bodily integrity "provides for a person's exclusive use and control over his or her body"; this right "entails power to exclude all others from the body."[186] This right is primarily negative, but also imposes "some positive duties on the state to protect people against interference by others."[187]

Bodily integrity and autonomy are connected because "bodily integrity [is central] to persons' capacity to shape their own lives."[188] That is, autonomy is embodied.[189] Indeed, maintenance of bodily integrity can be considered a core, necessary component of autonomy, as one cannot be autonomous if one cannot prevent others from interfering with their body.[190] When providers treat pa-

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[181] Herring & Wall, *supra* note 24, at 571 ("[T]he proper place for the right to bodily integrity in medical law is in cases where a patient is refusing or withdrawing consent to treatment, but it does not apply to exercises of autonomy that do not directly involve interference with the body.").

[182] *See id.* at 576–77, 580. Although the discourse of autonomy is privileged in healthcare decision-making law, it is actually only negative freedom that is respected legally. That is, a patient has no right to a particular treatment—a positive freedom—but instead only the right of refusal. *Id.* at 567–68; *see also* BERNSTEIN, *supra* note 178, at 7, 57 (describing the common-law negative freedom to "reject invasion" with consent being one exception to this freedom). When healthcare providers decline to administer a treatment a patient requests, this is an autonomy interference and likely legally permissible.

[183] BEAUCHAMP & CHILDRESS, *supra* note 5, at 104; *see* Wright, *supra* note 10, at 279–82; Wright, *supra* note 36, at 1064–68.

[184] Herring & Wall, *supra* note 24, at 568, 575–76.

[185] *Id.* at 568.

[186] *Id.* at 576, 580.

[187] *Id.* at 568 (quoting DAVID FELDMAN, CIVIL LIBERTIES AND HUMAN RIGHTS IN ENGLAND AND WALES 241 (2d ed., Oxford Univ. Press 2002) (1993)); *see* Lucy, *supra* note 148, at 59.

[188] Gregory C. Keating, *Reasonableness and Rationality in Negligence Theory*, 48 STAN. L. REV. 311, 344 (1996); *see also* Lucy, *supra* note 148, at 61 ("[F]reedom as non-domination and autonomy are closely connected—'it is bound to be easier for people to achieve autonomy once they are assured of not being dominated by others' . . . ." (quoting PHILIP PETTIT, REPUBLICANISM: A THEORY OF FREEDOM AND GOVERNMENT 82 (1997))).

[189] SHILLING, *supra* note 175, at 9 ("[I]t is impossible to have an adequate theory of human agency without taking into account the body.").

[190] Herring & Wall, *supra* note 24, at 568 ("The right to bodily integrity is seen as enhancing and giving a special strength to an autonomy claim, making it particularly hard to justify an interference."). This means that even persons with disabilities that prevent movement of the body, such as

tients over their refusal, it is a violation of a patient's autonomy and bodily integrity. Importantly, patients continue to have bodily integrity interests that providers should respect even if the patients acquire decisional impairments and are deemed incapable of autonomy, understood as capacity for rationality.[191]

Consider a physician providing a medical intervention to an unconscious, dying patient over a prior refusal expressed via advance directive. Though this violates both the patient's autonomy and bodily integrity, the patient may never experience the dignitary injury to precedent autonomy interests, especially if they never regain consciousness.[192] When providers treat over an express, contemporaneous refusal of a conscious patient, however, the experience is immediate, profound, and grave—leading to a decrease in wellbeing.

Treating patients over their explicit objection is inconsistent with respect for a patient's bodily integrity and therefore inconsistent with patient autonomy, whether defined as precedent or contemporaneous autonomy. Individuals should not be touched without permission, including in the healthcare setting, except in exceptional circumstances and only when interfering with the right to bodily integrity can be justified by some other compelling value, such as preventing physical harm to third parties, and when the appropriate legal process is followed.

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locked-in syndrome, can still maintain bodily integrity and be autonomous if others respect their refusals of touch.

[191] *Id.* at 583 ("[T]he right to bodily integrity is not lost when autonomy is lost . . . ."); *see also id.* at 577 ("[A] person's basis of moral duties towards them . . . is a basis that is broader than their capacity for rational decision-making."); Wasserman & Navin, *supra* note 154, at 36 ("A person's freedom from bodily coercion is normatively basic, such that deviations from liberty rights require justification. The fact that a coercive act promotes a person's interests is not sufficient to justify coercion, even when a person would otherwise make a less-than-fully-autonomous decision."). *But see* BERNSTEIN, *supra* note 178, at 7, 75–76 (noting that the common law denies some freedom on the basis of mental disability). This Article argues that there should be no understanding requirement to maintain bodily integrity in a treatment refusal, and that in cases of assent to treatment, bodily integrity can be maintained without understanding the treatment as long as the patient understands and agrees to having their body intervened upon. *See* Elizabeth Bromley et al., *From "Informed" to "Engaged" Consent: Risks and Obligations in Consent for Participation in a Health Data Repository*, 48 J.L. MED. & ETHICS 172, 179 (2020) (arguing that consent without understanding is possible in the research context); Millum & Bromwich, *supra* note 158, 46–48 (arguing that consent is possible even without understanding); Schneider & Farrell, *supra* note 7, at 125–26 (arguing that full understanding is an impossible goal of informed consent). *But see* Herring & Wall, *supra* note 24, at 582 ("The exclusive use and control of your own body . . . presumes an understanding . . . of the nature and quality of the actions that are to be undertaken to the body."); Navin et al., *supra* note 51 (arguing for assessing understanding under novel standards of capacity).

[192] There should still be a legal remedy for this dignitary harm, however. This Article should not be read as suggesting that overriding advance directives in such instances is permissible.

### *B. Treating Patients Over Objection Decreases Welfare*

Another important reason not to treat patients over their objection is that doing so decreases wellbeing for patients and healthcare providers. The primary purpose of medicine is to heal, so practices that cause demonstrable harm with questionable benefits, such as treating patients over objection, should be discontinued. This Section will first focus on patient wellbeing before considering provider wellbeing.

#### 1. Treatment Over Objection Decreases Patient Wellbeing

Beyond promoting patient autonomy, the requirement to obtain informed consent is also meant to improve patient wellbeing.[193] In part, this is because patient autonomy and wellbeing are directly connected; that is, when persons exercise autonomy, they tend to do so in a manner that promotes their own subjective conceptualization of the good.[194] Further, research has demonstrated that "informing patients and soliciting their agreement to a treatment plan . . . promote[s] patient health. . . . [This] can [also] reduce anxiety and depression about health states, increase adherence, enhance patient satisfaction, and facilitate monitoring of symptoms."[195] This Article contends that although infor-

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[193] BERG ET AL., *supra* note 3, at 153, 307. This is especially true if wellbeing is defined to include more than medical outcomes. *Id.* at 153–54.

[194] *Id.* at 24 ("In most cases . . . respect for an individual's autonomy coincides with promotion of her well-being. . . . [S]he will act to promote her *subjective* well-being . . . . Her definition, however, may not coincide with her *objectively determined* well-being . . . ."); Herring & Wall, *supra* note 24, at 578 ("[T]o act without consent is to act against the person's own assessment of their well-being . . . ."); Veit et al., *supra* note 136, at 22.

[195] BERG ET AL., *supra* note 3, at 18 (footnotes omitted) (first citing B. Gerle, G. Lunden & P. Sandblom, *The Patient with Inoperable Cancer from the Psychiatric and Social Standpoints. A Study of 101 Cases*, 13 CANCER 1206 (1960); then citing Gerald P. Koocher, *Psychosocial Issues During the Acute Treatment of Pediatric Cancer*, 58 CANCER (SUPP. II) 468 (1986); then citing L.A. Slavin, J.E. O'Malley, G.P. Koocher & D.J. Foster, *Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-Term Adjustment*, 139 AM. J. PSYCHIATRY 179 (1982); then citing Milton S. Davis, *Variation in Patients' Compliance with Doctors' Advice: An Empirical Analysis of Patterns of Communication*, 58 AM. J. PUB. HEALTH 274 (1968); then citing Milton S. Davis, *Variation in Patients' Compliance with Doctors' Orders: Medical Practice and Doctor-Patient Interaction*, 2 PSYCHIATRY MED. 31 (1971); then citing Renée C. Fox, EXPERIMENT PERILOUS: PHYSICIANS AND PATIENTS FACING THE UNKNOWN (Univ. of Pa. Press 1974) (1959); then citing V. Francis, B.M. Korsch & M.J. Morris, *Gaps in Doctor-Patient Communication: Patients' Response to Medical Advice*, 280 NEW ENG. J. MEDICINE 535 (1969); then citing Joseph W. Schneider & Peter Conrad, HAVING EPILEPSY: THE EXPERIENCE AND CONTROL OF ILLNESS (1983); then citing George C. Stone, *Patient Compliance and the Role of the Expert*, 35 J. SOC. ISSUES 34 (1979); then citing D.L. Roter & J.A. Hall, *Studies of Doctor-Patient Interaction*, 10 ANN. REV. PUB. HEALTH 163 (1989); then citing S. Greenfield, S. Kaplan & J.E. Ware, Jr., *Expanding Patient Involvement in Care: Effects on Patient Outcomes*, 102 ANNALS INTERNAL MED. 520 (1985); and then citing Robert M. Kaplan, *Health-Related Quality of Life in Patient Decision Making*, 47 J. SOC. ISSUES 69 (1991)); *see also id*. at 159, 323–24 (describing how patient participation in decision making leads to compliance with care and

mation is important to many patients' wellbeing, agreement to the provided treatment, or lack thereof, has a much greater effect on wellbeing.

As discussed previously, treating patients over their express contemporaneous objection leads to a significant decrease in wellbeing: the exact opposite outcome patients likely hope for when they seek medical care, and counter to the goals of informed consent. Healthcare providers may not recognize this irony if providers understand wellbeing solely in medical terms. If treatment over patient refusal has a positive health outcome—the patient's life is saved, disability is prevented, or the patient recovers from their illness—the provider may feel as though the provider's actions were benevolent and therefore ethically justifiable.

If the patient's experience of the provision or effects of treatment is negative or harmful, however, then their wellbeing may suffer even if understood solely in medical dimensions.[196] There may be adverse physical effects,[197] especially if patients do not comply with or adhere to follow-up treatment, thus defeating the provider's goal in treating the patient over their objection. Patients may also avoid medical care in the future because they do not trust healthcare providers and feel betrayed by the institution of medicine.[198]

More importantly, treating patients over their contemporaneous objection, especially when using force, likely leads to emotional and psychological distress that can become lasting trauma for the patient.[199] This decrease in psychic wellbeing stems from a violation of the patient's bodily integrity.[200] There are gradations of the seriousness of interfering with bodily integrity.[201] When treatment is provided without consent but in the absence of refusal or objection, there has not been respect for bodily integrity, but the experience of the

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information sharing). *See generally* King & Moulton, *supra* note 11 (describing benefits of involving patients in medical decision making).

[196] *See, e.g.*, BURT, *supra* note 106, at 25 (describing such harms in the civil commitment context); Tolson & Morley, *supra* note 128, at 311–12 (describing the harms resulting from physical restraints).

[197] *See, e.g.*, Kukura, *supra* note 15, at 754–57 (discussing the obstetric context).

[198] *See, e.g.*, *id.* at 727; Morris et al., *supra* note 113, at 10 (describing how women who experience birth trauma later avoid hospitals); *see also* Spike, *supra* note 77, at 99 (describing the loss of trust when physicians request capacity assessments). *See generally* Carly Parnitzke Smith & Jennifer J. Freyd, *Institutional Betrayal*, 69 AM. PSYCH. 575 (2014) (exploring the traumatic effect experienced when institutions harm individuals whose wellbeing the institutions are designed to promote).

[199] *See, e.g.*, Morris et al., *supra* note 113, at 10–11 (describing traumatic effects of forced intervention in childbirth context).

[200] Strasser, *supra* note 108, at 1007 ("The harm is not merely the untoward consequences of such an invasion, but the invasion itself." (first citing Wall v. Brim, 138 F.2d 478, 481 (5th Cir. 1943); then citing Shetter v. Rochelle, 409 P.2d 74, 82–83 (Ariz. Ct. App. 1965); and then citing Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir 1941))).

[201] *See* Herring & Wall, *supra* note 24, at 571–75 (describing degrees of interference with the right to bodily integrity).

violation may not be as intense.[202] When patients are treated over express contemporaneous objection, especially when use of restraints is required, this is a much more serious violation of their bodily integrity and security—violations that are incompatible with wellbeing.[203]

Finally, there are also concerns that some types of patients may be more vulnerable to being treated over their objection, which may lead to wellbeing disparities on the basis of race, ethnicity, gender, social class, and disability, among other status characteristics. Indeed, some scholars have documented instances in which patients of color, low-income patients, and younger patients are more likely to experience treatment over objection.[204]

### 2. Treatment Over Objection Decreases Provider Wellbeing

The harms to patient wellbeing should be a sufficient reason not to treat patients over their objection. But self-interested healthcare providers should also know that treating patients over their objection can be detrimental to provider wellbeing. Having to restrain a patient and touch their body over the patient's express objection may cause providers moral distress.[205] Indeed, by treating against express objection, providers may experience burnout and depersonalization when they "treat[] patients as objects rather than as human be-

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[202] Likewise, there has not been respect for their autonomy. It is possible, however, that there is no effect on the patient's wellbeing because the patient would have consented to the intervention had they been given the opportunity to do so.

[203] Indeed, capabilities philosophers argue that in order to flourish, one must have bodily integrity. Martha Nussbaum, *Human Rights and Human Capabilities*, 20 HARV. HUM. RTS. J. 21, 23 (2007). Treatment over objection may also be a violation of patients' human rights. *See* Kukura, *supra* note 15, at 762 (describing relevant human rights in the obstetric context). There may be some limited instances in which patients and providers anticipate a treatment refusal in the course of consensual treatment, however. *See infra* Section IV.B.2.

[204] *See, e.g.*, Kukura, *supra* note 15, 750 (describing such disparities in nonconsensual obstetric treatment). *See generally* Mann, *supra* note 75 (describing how low-income women are subject to coercion in contraceptive context); Stearns et al., *supra* note 134 (describing disparities in the types of patients who want to be discharged against medical advice); Michael Sun, Tomasz Oliwa, Monica E. Peek & Elizabeth L. Tung, *Negative Patient Descriptors: Documenting Racial Bias in the Electronic Health Record*, 41 HEALTH AFFS. 203, 203–05 (2022) (reporting that Black patients and publicly-insured patients have more negative descriptions in their medical records, which includes mentions of treatment resistance and refusal).

[205] *See* FRANK, *supra* note 175, at 173–74 (describing how some physicians feel like they are inflicting torture on their patients); Wasserman & Navin, *supra* note 154, at 39 (describing how providers are reluctant to treat patients over their objection); Linda M. Janelli, Suzanne S. Dickerson & Marlene R. Ventura, *Focus Groups: Nursing Staff's Experiences Using Restraints*, 4 CLINICAL NURSING RSCH. 425, 433, 437–38 (1995) (reporting that nurses experience moral distress when restraining patients because they are "violating patient dignity"); Dawn Perez, Kath Peters, Lesley Wilkes & Gillian Murphy, *Physical Restraints in Intensive Care—An Integrative Review*, 32 AUSTRALIAN CRITICAL CARE 165, 173 (2019) (summarizing studies that show that clinicians feel moral distress when restraining patients because so doing is "a violation of human rights").

ings."[206] Additionally, if providers do not meet their legal obligations because they do not obtain patient consent to treatment, then they expose themselves to potential liability.[207]

### *C. Treating Patients Over Their Objection Erodes the Rule of Law*

Another compelling reason to refrain from treating patients with or without decisional impairments over their objection is that doing so is often inconsistent with and in defiance of existing law.[208] To the extent that legal compliance is valuable, then healthcare providers should not treat patients over their objection.

Physicians are not exempt from an obligation to follow the law.[209] Indeed, the AMA acknowledges this general duty and directs that "[a] physician shall respect the law"[210] and that "[a] physician shall respect the rights of patients."[211] If the physician does not believe the law is consistent with patients' best interests, the AMA advises physicians "to seek changes" to the law.[212]

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[206] *See generally* Colin P. West, Liselotte N. Dyrbye & Tait D. Shanafelt, *Physician Burnout: Contributors, Consequences and Solutions*, 283 J. INTERNAL MED. 516 (2018) (discussing the state of burnout among doctors and its implications).

[207] *See generally* Thaddeus Mason Pope, *Clinicians May Not Administer Life-Sustaining Treatment Without Consent: Civil, Criminal, and Disciplinary Sanctions*, 9 J. HEALTH & BIOMEDICAL L. 213 (2013) (describing legal consequences when clinicians provide "unwanted life-sustaining treatment").

[208] As described previously, to treat competent patients in the absence of consent can give rise to multiple tort claims. Additionally, noncompliance with decisionally-impaired patients' advance directives refusing treatment violates the Patient Self-Determination Act. 42 U.S.C. § 1395cc. Furthermore, using a determination of decisional incapacity to disregard the patient's objection can conflict with the Americans with Disabilities Act as well as state supported decision-making laws. *See generally* Wright, *supra* note 10 (surveying supported decision-making laws in the United States); Wright, *supra* note 25 (arguing that federal disability law may require accommodating supported decision making). Finally, treating patients over their objection without a court order is also inconsistent with some state's healthcare decision-making laws. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2994-c(6) (McKinney 2021).

[209] *But see* Peter Koch, *How Should Ethics Consultants Weigh the Law (and Other Authoritative Directives)?*, 48 J.L. MED. & ETHICS 768, 771 (2020) (arguing that clinicians may not have a duty to follow the law).

[210] *AMA Code of Medical Ethics: AMA Principles of Medical Ethics*, *supra* note 26. Though physicians are not permitted to disregard the law, they are permitted to exercise their conscience to maintain a sense of moral and professional integrity. *Physician Exercise of Conscience: Code of Medical Ethics Opinion 1.1.7*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/physician-exercise-conscience [https://perma.cc/LYM2-7PVB]. Although medical ethics permit providers to act or refuse to act "in accordance with the dictates of conscience," there are limits to conscientious objections. *Id.* One important limit is that physicians still must "[u]phold standards of informed consent and inform the patient about all relevant options for treatment, including options to which the physician morally objects." *Id.*

[211] *AMA Code of Medical Ethics: AMA Principles of Medical Ethics*, *supra* note 26.

[212] *Id.*

When physicians disregard informed consent law and do not respect the rights of their patients to refuse medical treatment, the rule of law is eroded. These laws created through the democratic process are nullified, and physicians' power relative to their patients is inappropriately increased.[213]

There has been a significant body of scholarship devoted to theorizing the rule of law, most of which focuses on public law.[214] Recent scholarship has challenged the presumption that the rule of law is solely relevant to public law given that private law serves many of the same values associated with the rule of law, namely "dignity, autonomy, and liberty (understood as freedom from interference [and as non-domination])."[215] Indeed, "private law protects against arbitrariness [and domination] in much the same way as does the [public] rule of law"[216] and "can be viewed as a constraint upon 'horizontal' arbitrariness, by which is meant that it impedes the power . . . deployed by all addressees of the law,"[217] including healthcare providers.[218] In contrast to an understanding of the rule of law as solely applicable to public law, this Article takes the view that the rule of law "means that people should obey the law and be ruled by it."[219]

Healthcare providers may violate private law duties and the values that private law serves when they treat patients over patients' explicit objection, whether contemporaneous or conveyed by an advance directive. Treating patients over their objection can erode contract law when providers are noncompliant with their incapacitated patients' advance directives or if providers do not respect their patients' supported decision-making agreement. As private law theorists have argued: "If any or all of the contracts and other arrange-

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[213] *See* Wright, *supra* note 58, at 88 (describing physician "nullification of [medical decision-making] law"); Megan S. Wright, Commentary, *Implementing Ethical and Legal Supported Decision Making: Some Unresolved Issues*, AM. J. BIOETHICS, Nov. 2021, at 40, 41 (discussing physician "erosion of the rule of law" (citing Wright, *supra* note 58)). Prior to the development of informed consent doctrine, "[t]he rule of law in hospitals [could be considered] guided by principles of custody, not liberty." KATZ, *supra* note 61, at 52, 59 (describing constraints on physician "professional authority in a democratic society" but also how physicians have needed to be reminded of such constraints). *But see* Koch, *supra* note 209, at 771 (questioning whether law must be followed solely because it is the law).

[214] For a discussion of the components of the rule of law, see Lucy, *supra* note 148, at 42–43, 50.

[215] *Id.* at 54, 61, 62–65 (asserting that the state is not necessary for an account of arbitrariness or the rule of law).

[216] *Id.* at 43.

[217] *Id.* at 64.

[218] The arbitrariness against which rule of law values protect include "when power (or control or force) is deployed without warrant and legitimacy"; when "power is exercised without warrant by those who usually or sometimes have warrant to exercise power"; when "a decision-maker exercises power inconsistently"; or when "a decision, deed, or course of conduct is marked by a defect of reason." *Id.* at 46, 48 (footnote omitted).

[219] *Id.* at 54 (quoting Joseph Raz, *The Rule of Law and Its Virtue*, 93 LAW Q. REV. 195, 196 (1977)).

ments one enters into can be ended at the whim of another not privy to those transactions, then those transactions and, in a sense, one's self are in the thrall of that other. That is domination, not freedom."[220] Such domination in the medical encounter is especially harmful to patients.

When capacitated patients are treated over their contemporaneous objection, this is even more arbitrary. This is because providers do not have legal warrant to touch their patient without consent and the patient will not know in advance of forming a treatment relationship whether their right to bodily integrity will be respected.[221] In this case, providers are not obeying the law and their actions are inconsistent with respect for the rule of law.

Further, when courts rubberstamp healthcare provider requests for treatment orders or do not permit patients to recover for unlawful treatment over objection, courts fail in their duty to uphold the rule of law by failing to provide "security against interference . . . on an arbitrary basis" and allowing "domination by others."[222] Courts need to vindicate patient rights when they have been violated, including when patients have been unlawfully treated over their objection, so that patients and their families feel confident that the legal system can provide justice when they are harmed.[223]

Treatment over objection does not further dignity, autonomy, or liberty interests—all of which are rule of law values. If promoting the rule of law is valuable, then this is an independent reason that physicians should not treat patients over their objection.

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Treating patients over their objection is inconsistent with respect for patient autonomy and bodily integrity and is also detrimental to patient and provider wellbeing. Further, treating patients over their objection may be an instance where healthcare providers nullify the law, leading to an erosion of the rule of private law. Because autonomy, bodily integrity, wellbeing, and the rule of law are valued social goods, patients should rarely be treated over their objection, and such treatment should be in accord with the law and protective of patient rights.

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[220] *Id.* at 63–64 (citing PETTIT, *supra* note 188, at 63 n.50).

[221] Indeed, this is not a case of "order without law" because many physicians do not treat patients over their objection, and given the unpredictability of when such treatment will be imposed, this is the very definition of arbitrariness.

[222] Lucy, *supra* note 148, at 59 (quoting PETTIT, *supra* note 188, at 51).

[223] *See* Strasser, *supra* note 108, at 1020 ("The societal interest in the integrity of the legal system also must be promoted when individuals are subjected to nonconsensual invasions."); *see also* KATZ, *supra* note 61, at 59 (describing how the law's veneration for doctors' expertise has "made it impossible for the law of informed consent to advance patients' right to self-decision making in significant ways").

Because both healthcare providers and courts have not upheld patient rights to refuse medical treatment, the next Part will describe necessary changes to healthcare decision-making laws to promote patient autonomy, wellbeing, and the rule of law.

## III. Informed Consent Law and Practice Should Change to Ensure That Patients Are Not Treated Over Their Objection

As previous Parts have demonstrated, treating patients over their objection is harmful in many respects—to patients, providers, and the rule of law. Ideally, treatments over patient objection should not occur and patients' right to refuse treatment should be respected. This requires that informed consent law and practices change.

Informed consent law should affirm and protect patients' rights to refuse medical treatment, and when patients are treated over their objections, conveyed contemporaneously or through an advance directive, there should be a legal remedy for this wrong. Scholars have documented the difficulty patients have in recovering for this rights violation because of difficulty with obtaining legal representation, proving causation in negligent informed consent cases, or convincing courts that life or improved health are remediable harms.[224] There are also problems with an overly broad incapacity exception given issues with and abuses of capacity assessments, along with the retention of bodily integrity interests of persons with cognitive impairments.

These barriers to plaintiff success require additional changes to the law to vindicate patients' rights to refuse medical treatment and maintain bodily integrity. This Part will propose general changes to existing informed consent law to try to prevent treatment over *contemporaneous* objection, and failing this, to provide for a process that is protective of patient rights and that offers a remedy when providers do not follow the legal process prior to treating patients over their objection. Section A of this Part highlights one state's law that can serve as a model,[225] and Section B of this Part offers additions to the model.[226]

### *A. Model Law*

Informed consent law needs to emphasize the importance of consent and respecting patient refusals, which safeguards patients' interests in maintaining bodily integrity. Ideally, informed consent law would grant patients, even those with decisional impairments, the absolute right to refuse medical treatment

[224] Kukura, *supra* note 15, at 781–90.
[225] *See infra* notes 227–231 and accompanying text.
[226] *See infra* notes 232–250 and accompanying text.

unless a court orders the treatment, as this accords with the principle of "legal capacity on an equal basis" as outlined in the United Nations Convention on the Rights of Persons with Disabilities.[227] Further, informed consent law would shift determination of whether patients' legal rights would be infringed upon from healthcare providers to courts, the appropriate institution to adjudicate issues with legal rights.[228]

New York's Family Health Care Decisions Act provides a model law upon which to build. This law accounts for patient treatment refusals in the presence of questionable decisional capacity by providing absolute legal capacity to refuse medical treatment absent a court order.[229] In New York, a patient's objection to medical treatment trumps a finding of decisional incapacity unless a court deems the patient to be incompetent.[230]

Other states should have similar laws, but should also address important unanswered questions from New York's law: (1) what legal process providers should follow; (2) how patients assert their rights; (3) what sanctions there are for providers who do not follow the legal process; and (4) what relief is available to patients who are treated over their objections in the absence of the mandated legal process.[231] What follows are general guidelines and suggestions that answer these questions.

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[227] CRPD, *supra* note 56, art. 12, § 2.

[228] Law "offer[s] the best protection for individual liberty and . . . [should] be the ultimate forum for adjudicating the legitimacy of coercive social power, for rationalizing the principles of social order." BURT, *supra* note 106, at 133 (citing Fay v. Noia, 372 U.S. 391 (1963), *overruled in part by* Wainwright v. Sykes, 433 U.S. 72 (1977)).

[229] The New York law states:

> Notwithstanding a determination pursuant to this section that an adult patient lacks decision-making capacity, if the patient objects to the determination of incapacity, or to the choice of a surrogate or to a health care decision made by a surrogate . . . the patient's objection or decision shall prevail unless: (a) a court of competent jurisdiction has determined that the patient lacks decision-making capacity or the patient is or has been adjudged incompetent for all purposes and, in the case of a patient's objection to treatment, makes any other finding required by law to authorize the treatment, or (b) another legal basis exists for overriding the patient's decision.

N.Y. PUB. HEALTH LAW § 2994-c(6) (McKinney 2021). Other states have laws that grant long-term care facility residents the right to refuse treatment, but generally most states allow for others to authorize a treatment over incapacitated patients' objections.

[230] This Article does not, however, claim that the law is followed in clinical practice.

[231] New York's mental hygiene regulations contain much more detail on the right of mental health patients to refuse treatment as well as procedures for providers to follow for refusals or when a patient assents after an initial refusal. N.Y. COMP. CODES R. & REGS. tit. 14, § 527.8 (2022).

### *B. Additional Reforms*

Although adult patients are legally entitled to make their own medical decisions, healthcare providers may lawfully treat them over their objection if patients are deemed incapacitated and providers obtain consent from a surrogate or healthcare power of attorney. This exception to informed consent should be tightened given previously-discussed problems with capacity assessments, as well as the expansion of legal capacity and the recognition of bodily integrity interests for persons with cognitive disabilities.

State healthcare decision-making laws should therefore unequivocally state that patients have an absolute right, barring a court order, to refuse medical treatment, regardless of their decision-making abilities. A declarative statement would have more than symbolic significance, although this is important for affirming rights to bodily integrity for persons with cognitive disabilities.[232] It would function as baseline direction to providers and would unambiguously reduce their authority to override patients' decisions absent court involvement.[233]

In instances where healthcare providers do not believe their patients have decisional capacity, the law should direct providers to try to restore capacity if the patient is amenable. Interventions to restore capacity could include administration of pharmacologic agents that treat psychiatric issues, such as antidepressants, or discontinuing pharmacologic agents that impair capacity, such as sedatives;[234] including family members, friends, or formal supporters in decision making;[235] or providing assistive technology to aid in communication, all of which would need patient permission.[236] Alternatively, in the instance of

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[232] *See* KATZ, *supra* note 61, at 60 ("[S]ymbols can nag and prod and disturb and ultimately bring about some change."). *See generally* Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PA. L. REV. 2021 (1996) (discussing how law expresses values and can change norms).

[233] Additionally, there should be mechanisms for patients to know, assert, and defend their rights. *See* Annas, *supra* note 5, at 11. A hospital ethics committee that includes community representatives, including persons with disabilities, as well as trained patient advocates can play a role in patient education and mediating patient-provider conflicts.

[234] BERG ET AL., *supra* note 3, at 239; Umapathy et al., *supra* note 53, at 31.

[235] BERG ET AL., *supra* note 3, at 239; Umapathy et al., *supra* note 53, at 31. Third parties may be able to assist the patient in decision making but can also act as advocates for the patient in their encounters with healthcare providers. Care should be taken to ensure that third parties are not asked to aid in treating patients over their objection, however. *See, e.g.*, Appelbaum & Roth, *supra* note 77, at 1300 (describing how clinicians try to involve patients' families in overriding a treatment refusal); Morris et al., *supra* note 113, at 8 (reporting that clinicians may have women's partners physically restrain them during forced childbirth interventions).

[236] Patients may not be amenable to treatment but may be amenable to these other interventions, possibly affecting subsequent treatment decisions.

temporary incapacity, providers can wait until capacity is regained.[237] Even if decisional capacity cannot be restored, healthcare providers may be able to provide care to patients with decisional impairments without treating them over their objection if they change how they communicate.[238] Importantly, however, the law should state that whether or not capacity is restored, the patient retains the right to refuse treatment. Providers should not be under the impression that if they make attempts to restore their patient's capacity that they then have permission to provide treatment over their patient's objection.

The law should note that providers can continue to discuss with patients their treatment recommendations; that is, persuasion should continue to be legally permissible.[239] Indeed, if physicians begin to engage in shared decision making, considered a best clinical practice to promote both patient and physician autonomy, then physicians may be less likely to want to treat patients over their express objection because they will have decided together not to pursue a particular treatment. In shared decision making, patients may convey information relevant to their past experiences with a treatment or how their values conflict with their providers' medical recommendations, and through this disclosure persuade their provider to change their recommendation.[240] Additionally, it may be the case that patients do accept the first recommended treatment after being persuaded to do so following a series of conversations.[241]

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[237] For example, patients may be in a short-term delirium or be intoxicated, and they can be asked to decide later. It is also important to note that although providers may have a sense of urgency, it may not be a true emergency, and it may be possible to delay a decision until capacity is restored.

[238] Providers can respect the autonomy of patients with impaired decisional capacity, despite frequent refusals of care, by modifying their interactional style to make patient assent more likely. *See* O'Brien et al., *supra* note 123, at 1, 3–7; *see also* BERG ET AL., *supra* note 3, at 239 (providing recommendations for how providers can respond when patients refuse treatment); Katz et al., *supra* note 138, at 39–40 (describing how incompetent patients may eventually accept treatment); Stivers & McCabe, *supra* note 77, at 4 (describing how providers can alter their communication style to obtain patient assent).

[239] For an example of language in the mental health context that could be imported into medical informed consent laws, see, for example, N.Y. COMP. CODES R. & REGS. tit. 14, § 527.8(6) (2021) ("Nothing in this subdivision shall prevent a treating physician, treatment team, or others involved in the patient's . . . care from continuing to explain the proposed treatment to the patient . . . and to seek his or her voluntary agreement thereto."). Some researchers have found that refusals are accepted without further conversation with the patient. Appelbaum & Roth, *supra* note 77, at 1299 & tbl.4, 1300 & tbl.5. Many scholars argue that providers should not immediately accept a treatment refusal but instead that this should trigger conversations with patients to ensure that patients are not mistakenly rejecting treatment that is actually consistent with their goals and values. *See, e.g.*, KATZ, *supra* note 61, at 125; Dresser, *supra* note 159, at 63. When physicians question their patients in a manner respectful of the patient's privacy and bodily integrity interests, this can be consistent with relational autonomy. *See generally* Wright, *supra* note 36 (describing relational autonomy in end-of-life decision making).

[240] *See, e.g.*, BERG ET AL., *supra* note 3, at 238.

[241] *See* Dresser, *supra* note 159, at 62 (noting that decision making occurs over time, and after an initial refusal, a patient may decide to accept treatment); Katz et al., *supra* note 138, at 39–40 (de-

And if the patient continues to object despite attempts to persuade, this is a sign of a consistent and serious preference that providers should respect. Providers may feel more comfortable honoring this genuine preference after attempts to restore capacity or persuade, even if the result of the patient's refusal is death or significant disability. Of course, providers should document their conversations with their patients in the medical record to note consents and refusals, which will be especially important for liability protection.

The above recommendations involve slowing the healthcare decision-making process. If a patient who is refusing treatment has questionable decisional capacity and there is no time to restore it before a medical intervention would become moot, there is still a role for law, prior either to treating the patient over their objection or not intervening when faced with an adverse health outcome. The law should allow for emergency applications to judges to determine whether the treatment should be provided.[242] Judges will be the ultimate decision maker about whether the provider must respect a patient's refusal.[243] Further, judges are responsible for weighing a patient's liberty, bodily integrity, and medical wellbeing interests, with input from medical experts, against any other compelling interests, and ensuring the law is followed.[244] Judicial involvement would hopefully be rare if medical culture changes and laws such as those proposed are adopted. By the time a judge becomes involved, howev-

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scribing how 50% of competent patients who initially opposed treatment ultimately consented to it, and an additional nearly 20% accepted a treatment alternative); Stivers & Timmermans, *supra* note 77, at 74 (describing how providers transform treatment refusals into assents in the pediatric context); Thomas et al., *supra* note 63, at 3 (describing how patient preferences are not necessarily stable over time and are also context-dependent). Scholars and medical associations correctly assert that the informed consent doctrine does not require physicians to be neutral with respect to their recommendations and allows them to try to persuade patients, but what is left undetermined is how much pressure they can put on their patients to obtain consent. *See* BERG ET AL., *supra* note 3, at 67–70; Comm. on Ethics, Am. Coll. of Obstetricians & Gynecologists, *ACOG Committee Opinion No. 439: Informed Consent*, 114 OBSTETRICS & GYNECOLOGY 401, 405 (2009) [hereinafter *ACOG Opinion No. 439*]. Indeed, there may be concerns about when persuasion becomes undue influence. BERG ET AL., *supra* note 3, at 234, 237–40; *see also* Mann, *supra* note 75, at 4–6 (describing how providers pressure patients into accepting treatment). It is important that persuasion does not turn into coercion, especially given that patients are in a medically vulnerable state that further decreases their power to resist pressure. Safeguards could include having another clinician, instead of the original physician, talk to the patient or issuing a verbal reminder that patients can refuse treatment and that such a refusal will be respected.

[242] *But see* BURT, *supra* note 106, at 132–33 (arguing that judges should not intervene before physicians decide whether to treat their patients over their patients' objection).

[243] There are procedural due process considerations when healthcare providers are asking courts to order medical treatment over patient objection. *See, e.g.*, Kukura, *supra* note 15, at 742–43 (highlighting quick hearings in the absence of counsel). In cases of applications for involuntary treatment orders, counsel should be available for the patient. This should help prevent sham court proceedings.

[244] One such compelling interest may be preventing harm to third parties, such as in the case of court-ordered tuberculosis treatment to prevent its spread when individuals refuse treatment or to isolate.

er, there should already be an indication that the patient is serious about refusal, which should carry significant weight in the judge's determination.[245]

Finally, given the importance of the right to bodily integrity and the necessity of maintaining the rule of law, there should be significant negative sanctions for healthcare providers who have treated patients over their objection without following the required legal process. The law should provide for statutory damages, setting a minimum amount that patients will be awarded so that patients can be guaranteed a recovery for dignitary harms, and so that judicial discretion, which to date has tended to disfavor plaintiffs, will be constrained.[246] The law should also grant additional damages in especially egregious cases of treatment over objection and, to incentivize lawyers to represent plaintiffs, allow for attorney's fees.[247]

There should be additional sanctions when providers unlawfully treat patients over their objection. For example, the law should direct that if a patient has refused treatment, a healthcare provider cannot treat the patient over their objection and then bill the patient or their insurer for the costs of the treatment.[248] The law should also require hospitals and other healthcare organizations to develop policies that comply with the principle that patients always have the capacity to refuse medical treatment absent a court order. This way, if a practitioner treats patients over their objection without going to court, they may lose their employment or medical staff privileges for violating hospital policy.[249] There should also be protection for whistleblowers affiliated with hospitals, many of whom will likely be employees who are lower in the hospital hierarchy, such as nurses who are asked to physically restrain patients. Such

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[245] Furthermore, if the patient has engaged in advance care planning, judges should dismiss the emergency petition so that these legal tools continue to have a purpose. Given that most patients do not engage in advance care planning, when a patient does, this is strong evidence that the patient values their autonomy and bodily integrity, which should be dispositive in cases of conflict with their healthcare providers.

[246] *But see* BURT, *supra* note 106, at 139–40 (arguing against certainty in this context because it may be inconsistent with establishing "motivation . . . for conversation, for negotiation").

[247] An example would be a case in which a patient is restrained—physically or chemically—for the sole purpose of treating them over their objection. If restraints are not medically indicated or used in the course of *consensual* medical treatment, use of restraints should be per se a violation of informed consent law. *See infra* Section IV.B.2. The law should also be clear that treating patients over their objection may be a criminal act in some instances. Pope, *supra* note 11, at 32 n.46 ("While rare, breaches of informed consent have sometimes resulted in criminal liability." (citing Thaddeus Mason Pope & Melinda Hexum, *Legal Briefing: Informed Consent in the Clinical Context*, 25 J. CLINICAL ETHICS 152 (2014))).

[248] *See, e.g.*, Kapp, *supra* note 98, at 1936, 1938 (proposing connecting reimbursement for medical care to documentation that attests that providers obtained informed consent, which cannot "guarantee the quality of the [informed] consent process" but can ensure assent).

[249] Others have proposed revocation of licensure as a possible sanction. BERG ET AL., *supra* note 3, at 150 (quoting Note, *Restructuring Informed Consent: Legal Therapy for the Doctor-Patient Relationship*, 79 YALE L.J. 1533, 1564 (1970)); Pope, *supra* note 11, at 32 n.46).

employees need assurance their jobs will be protected should they speak out against providers who violate patient rights. Additionally, lawyers for hospitals should be on notice that they may be at risk of professional sanctions if they knowingly advise healthcare providers to disregard informed consent law and patients' rights.

Finally, given the proposed liability, informed consent and medical malpractice law should also provide for limits to liability for providers who follow the mandated legal process regardless of whether treatment is provided and regardless of any subsequent non-negligent medical outcomes.[250]

These proposed reforms to informed consent law do not envision that providers will *never* override a patient's treatment refusal—contemporaneous or precedent. Instead, the reforms envision such treatment occurring only rarely and that when it does, a court is the actor deciding the legality of treatment over objection. To date, courts have permitted physicians to erode the rule of law and become more powerful relative to both patients and the institution of law than is warranted. The proposed reforms are meant to shift power over their bodies back to patients and shift questions of legal rights to the courts.

## IV. OTHER CONSIDERATIONS

To minimize the chance that adoption of the proposed law will be detrimental to patients, it is important to consider counterarguments seriously. This Part will explore possible objections to the arguments presented thus far in this Article. Part A addresses the possibility that the proposed law will cause medical harm.[251] Part B argues that the exceptions to the informed consent need to be stricter.[252] Part C asserts that patient autonomy is more important than provider autonomy in the case of treatment refusals.[253] Part D explains that extra time may be necessary to spend on the informed consent process.[254] Part E ar-

[250] Some of these state laws will interact with Medicare requirements and AMA ethical duties that require safe discharges of patients from inpatient settings. If a patient desires to leave the hospital against medical advice, and this is documented in the record, providers should first try to convince the patient to stay until the patient can leave safely, or to stay and receive some other treatment even if it is not the provider's recommended treatment. If the patient still wants to leave, they should be permitted to leave. The hospital is not a prison, and if the patient leaves on good terms with providers, providers can continue the conversation about treatment after discharge. *But see generally* Erick H. Cheung, Jonathan Heldt, Thomas Strouse & Paul Schneider, *The Medical Incapacity Hold: A Policy on the Involuntary Medical Hospitalization of Patients Who Lack Decisional Capacity*, 59 PSYCHOSOMATICS 169 (2018) (arguing that hospitals should develop policies to facilitate holding patients with decisional impairments against their will). Further, Medicare does not permit reimbursement for injuries caused from restraints.

[251] *See infra* notes 257–262 and accompanying text.

[252] *See infra* notes 263–268 and accompanying text.

[253] *See infra* notes 269–275 and accompanying text.

[254] *See infra* notes 276–278 and accompanying text.

gues that legal change is necessary to change provider behavior.[255] Finally, Part F argues that courts are a necessary component of informed consent law.[256]

### *A. Loss of Life or Health Is an Acceptable Cost of Respecting Patient Autonomy*

The primary normative objection to respecting patients' treatment refusals is that preventing death or disability should be the most important consideration in healthcare. Some may prioritize promoting objective medical wellbeing more than respecting patient autonomy and bodily integrity.[257] Those with this view may favor hard paternalism in which patients are not entitled to make decisions that conflict with their providers' recommendations.[258] Or they may favor soft paternalism and oppose laws that specifically grant patients legal capacity, despite having decisional impairments, to refuse medical treatment on the grounds that these laws will lead to preventable death or disability.

Changing the law to require respecting patients' treatment refusal absent resorting to court, regardless of whether patients have decisional impairments, will indeed result in some deaths that may have been averted through forcible medical treatment. But it is important not to overstate the extent to which this will occur. As empirical evidence demonstrates, most patients are willing to defer to their healthcare providers' medical judgment, and so only a small minority of patients will: (1) prefer to make their own medical decisions; (2) disagree with their providers' treatment recommendations; (3) actually refuse treatment even after attempts at persuasion; and (4) die or suffer irreparable harm because of a treatment refusal. For this small group of patients, given the seriousness and stability of their preferences, it is more important to respect their autonomy and bodily integrity by respecting their treatment refusal than to treat them over their objection, especially given that their subjective, and possibly medical, wellbeing will likely decline after forcible treatment.[259] That is, autonomy should prevail when there is a (likely rare) conflict between autonomy and life.

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[255] *See infra* notes 279–301 and accompanying text.

[256] *See infra* notes 302–309 and accompanying text.

[257] *See generally* SARAH CONLY, AGAINST AUTONOMY: JUSTIFYING COERCIVE PATERNALISM (2013) (arguing for "coercive paternalism" in the healthcare context).

[258] *See* BERG ET AL., *supra* note 3, at 152, 156 (observing that physicians who focus on medical wellbeing often do not seem to think patients have legitimate decision-making interests).

[259] The third factor is also relevant in this analysis. It may be that the patient does not affirmatively consent to treatment but no longer objects, in which case if the treatment is provided, it is not consensual, but is also perhaps not as significant a harm to bodily integrity interests. *See generally* Tunzi et al., *supra* note 74 (describing differences between informed consent, assent, and nondissent).

Further, it is important to consider the role of uncertainty in medicine. It may be the case that a provider's diagnosis, prognosis, or treatment recommendations are incorrect, and thus a patient who refuses medical treatment may not have the poor outcome healthcare providers predict.[260] Additionally, it may be the case that if the patient were to receive the recommended intervention, they would die or have a decline in their health status. In these circumstances, the treatment refusal is not medically harmful to the patient and may actually prevent harm. There is no such uncertainty about the guaranteed dignitary harm that occurs when patients are treated over their objection. Even if death or disability could have been prevented, maintaining subjective wellbeing and bodily integrity is more important than providing treatment.

Proponents of paternalism may also argue that patients will later regret their treatment refusal when it is too late to intervene to save their life or prevent disability.[261] Regretting one's decisions is not uncommon in any context, and indeed is one price of freedom to make decisions. But if policymakers are concerned that patients will later regret their choice to refuse treatment, the solution is neither to keep them from making their own decisions, nor to override their refusal. Rather, the solutions are to provide, among other things, information about different medical options, or to tweak the choice architecture to allow for cooling-off periods, or to grant opportunities either for healthcare providers to try to persuade and for patients to think through decisions with trusted others or for patients to regain capacity. The law reforms proposed in this Article would accomplish this.[262]

### *B. Exceptions Should Not Be Permitted to Overtake the Rule*

As discussed previously, there are exceptions to the requirement that physicians must obtain informed consent prior to a medical intervention. This Article does not argue for getting rid of the exceptions, but rather making the exceptions stricter to respect patient autonomy and to promote patient wellbeing by reducing treatment over objection.

#### 1. Emergency and Capacity Exceptions Should Be Stricter

The emergency exception to the requirement to obtain informed consent is meant for cases in which there is a medical emergency, an absence of patient

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[260] *See, e.g.*, KATZ, *supra* note 61, at 86; Annas, *supra* note 5, at 10; Kukura, *supra* note 15, at 740–41; Pieterse et al., *supra* note 73, at 25.

[261] This may be especially troubling in the case of patients with illnesses that impact their decision-making abilities in a cyclical manner—such as mental illness that waxes and wanes over time—who refuse treatment during a period of impaired cognition.

[262] *See also* KATZ, *supra* note 61, at 124–25; Dresser, *supra* note 159, at 62.

consent, and no time to obtain consent. This exception is important to retain because in emergencies, the default assumption that a patient desires treatment is likely correct and time is of the essence to prevent loss of life or health. This is an example of implied consent. On the other hand, in the case of treatment over objection, it would be perverse to allow providers to rely lawfully on the emergency exception to override their patient's prior treatment refusal. This is because if permitted to do so, providers could just delay intervention until their patient's health status becomes a medical emergency, allowing this exception to diminish patient rights.[263]

Additionally, the incapacity exception is also important to retain. Patients who are unconscious, for example, should be able to have a surrogate decision maker authorize or refuse treatment on their behalf even in the absence of an advance directive. As discussed earlier, however, the capacity exception should be tightened because many people who are currently disqualified on the basis of decisional incapacity can make their own decisions, especially if provided decisional support, and are legally entitled to do so. Further, although the predominant scholarly view is that treatment refusals should be informed, true respect for patient autonomy and bodily integrity does not require patients justifying their decisions to others or proving their rationality. Though informed refusals may be ideal, they are unnecessary and cannot be justified on the basis of the incapacity exception.

### 2. Treating Patients Over Contemporaneous Objection May Sometimes Be Necessary to Administer Consensual Medical Care

There may be instances in which providing a medical intervention over an explicit contemporaneous patient objection or using physical restraints to control a patient may be required to treat a particular illness *consensually*. For example, a patient may consent to a course of treatment, such as a surgical operation under anesthesia, and experience post-operative confusion wherein they fight against nursing staff or attempt to remove life-sustaining devices.[264] In

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[263] For a discussion of this occurring in the context of noncompliance with advance directives, see Fernandez Lynch et al., *supra* note 15, at 162–64; Strasser, *supra* note 108, at 1008.

[264] *See, e.g.*, Thomas N. Robinson & Ben Eiseman, *Postoperative Delirium in the Elderly: Diagnosis and Management*, 3 CLINICAL INTERVENTIONS AGING 351, 352–55 (2008); *see also Use of Restraints: Code of Medical Ethics Opinion 1.2.7*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/use-restraints [https://perma.cc/9W94-9ER3] ("All individuals have a fundamental right to be free from unreasonable bodily restraint. At times, however, health conditions may result in behavior that puts patients at risk of harming themselves. In such situations, it may be ethically justifiable for physicians to order the use of chemical or physical restraint to protect the patient."); *id.* (advising that physicians "[o]btain the patient's informed consent to the use of restraint[s]"). *But see* Tolson & Morley, *supra* note 128, at 311–12 (describing a lack of evidence on the benefit of re-

such a situation, the post-operative confusion is predictable, and a patient can make use of a short-term written or oral advance directive to permit the use of restraints to ensure the medical treatment is successful. Providers can also attempt to prevent delirium from occurring or take other steps to mitigate the need to use force when providing medical care.[265] However, it is important that healthcare providers are not permitted to broaden this exception beyond very specific medical circumstances. Otherwise, the right for patients to change their mind and refuse treatment after a course of treatment has begun will be nonexistent.

### 3. Preventing Harm to Third Parties Is Generally Insufficient to Justify Treatment Over Objection

Sometimes providing medical treatment over someone's objection is justified by reason of preventing harm to third parties. Though this is ethically justifiable in the instance of someone with a communicable disease who refuses treatment and isolation because their treatment decision is adversely affecting others' physical health, the same rationale does not apply to the case of medical treatment where the patient solely bears the corporeal costs of refusal.[266] Concerns about emotional harm to third parties through a patient's decision to refuse treatment, such as family member sadness when the patient's death is hastened, should not outweigh respect for the patient's decision. Preserving bodily integrity is more important than speculative non-physical effects of the treatment decisions on others whose psychic interests are not legally protected.[267]

There may be more immediate safety considerations with respect to provision of consensual medical treatment that need to be accounted for. As discussed above, a patient may consent to an intervention, but then have an adverse reaction that causes agitation that in turn poses a risk of physical danger to nursing and medical staff and the patient. In this case, ensuring healthcare provider safety and preventing a medical emergency weigh against the need to

straints and overwhelming evidence of harm). *See generally* Evans & FitzGerald, *supra* note 131 (describing patient safety reasons for using restraints).

[265] *See, e.g.*, Robinson & Eiseman, *supra* note 264, at 353 (describing prevention as a first step).

[266] Public health law, rather than informed consent law, provides legal justification for treatment over objection in this case.

[267] This is not to suggest that family member interests are not important to patient decision making. Indeed, many patients will gladly incorporate others' interests when making serious medical decisions because "the exercise of autonomy is [often] relational in practice." Wright, *supra* note 36, at 1139. When there is a conflict between patient and family decisions, however, the patient's interests should ultimately prevail. *But see* Robert A. Burt, *The End of Autonomy*, HASTINGS CTR. REP. (SUPP.), Nov.–Dec. 2005, at S9, S13.

obtain patient consent to the use of restraints or another medical intervention to address the agitation.[268]

### *C. Patient Autonomy Trumps Healthcare Provider Autonomy in the Case of Treatment Refusals*

Some may argue that laws that deem patients to have the legal capacity to refuse medical treatment, excepting a court order, interfere too much with healthcare professionals' autonomy. In other words, medicine is a profession, and physicians are due a certain amount of deference as they practice their profession. Indeed, several "medical associations have advocated against legislative interference with patient care and the patient-physician relationship."[269] And some scholars have suggested that "[physicians] . . . not permit lawyers or administrators to set the rules,"[270] whereas others have cautioned against language and interventions that may intensify discord between patients and their providers.[271]

But given decline in patient wellbeing when providers treat patients over their objection, there should be additional regulation of the medical profession to prevent this harm. Indeed, informed consent law should weigh patients' interests more heavily than provider autonomy in order to promote patient wellbeing.[272]

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[268] *See, e.g.*, *Use of Restraints: Code of Medical Ethics Opinion 1.2.7*, *supra* note 264 ("[W]hen a patient poses a significant danger to self or others, it may be appropriate to restrain the patient involuntarily.").

[269] Pope, *supra* note 11, at 20 (first citing *Statement of Principles on the Role of Governments in Regulating the Patient-Physician Relationship*, AM. COLL. OF PHYSICIANS (July 2012), https://www.acponline.org/system/files/documents/advocacy/current_policy_papers/assets/sop_issue_brief.pdf [https://perma.cc/W5CA-XWUS]; then citing *Statement of Policy: Legislative Interference with Patient Care, Medical Decisions, and the Patient-Physician Relationship*, AM. COLL. OF OBSTETRICIANS & GYNECOLOGISTS, https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2019/legislative-interference-with-patient-care-medical-decisions-and-the-patient-physician-relationship [https://perma.cc/2ZQ4-4PFB] (Aug. 2021); and then citing Jane E. Brody, *Law on End-of-Life Care Rankles Doctors*, N.Y. TIMES (June 6, 2011), https://www.nytimes.com/2011/06/07/health/07brody.html [https://perma.cc/PX8Q-WPYX]); *see ACOG Opinion No. 819*, *supra* note 59, at e38.

[270] BERG ET AL., *supra* note 3, at 156 (quoting Ronald L. Katz, *Informed Consent—Is It Bad Medicine?*, 126 W.J. MED. 426, 428 (1977)).

[271] *See, e.g.*, Kukura, *supra* note 15, at 764–65. Other scholars think that the law should privilege neither physicians nor patients as the ultimate decision maker. BURT, *supra* note 106, at 43–44, 164–69.

[272] "[H]ealth care law [should] improve the lives of patients." *See* Mark A. Hall, Carl E. Schneider & Lois Shepherd, Introduction, *Rethinking Health Law*, 41 WAKE FOREST L. REV. 341, 342 (2006). Laws that facilitate harm to patients, such as laws that allow physicians to override their patients' treatment refusals should the provider decide their patient lacks capacity, should be changed.

Further, healthcare providers are not experts in legal rights or their patients' preferences and values, and therefore are not due any professional deference in these matters. Law should cabin healthcare provider expertise and subsequent professional deference to medical practice. This does not mean that healthcare providers cannot direct patient care, but rather that their power over patient decision making stops when a patient refuses medical treatment. This is because of the importance of maintaining a patient's bodily integrity, a negative right to prevent others, including physicians, from unwanted physical invasions. Privileging physician autonomy over patient autonomy is more appropriate when patients *seek* particular medical interventions rather than when patients refuse treatments. That is to say, physicians can act as gatekeepers to treatment they provide but cannot impose treatment on patients.

This is closely related to the exercise of physician conscience. Physicians are ethically and legally entitled to practice medicine on the basis of their conscience.[273] The exercise of conscience does not permit physicians to treat patients unlawfully over their objection, however. Conscience is more properly exercised in the refusal to participate in care, such as in the case of refusing to contribute physician aid in dying on the basis of personal moral beliefs.[274] Lawful exercise of conscience cannot be twisted to permit violations of a patient's bodily integrity.[275]

### *D. Extra Time Is Worth It*

It is also necessary to consider the cost of slowing the medical decision-making process. Delaying some care may be life-threatening or result in permanent disability, so there may be concerns about loss of life or health when providers attempt to negotiate with patients. The proposed reforms, however, do include a path for emergency court petitions that may allay some concerns. And it is important to note that providers' sense of urgency may not actually

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[273] *See, e.g.*, Dana Howard, *Civil Disobedience, Not Merely Conscientious Objection, in Medicine*, 33 HEC F. 215, 216 (2021) ("[P]hysicians should have considerable latitude to practice in accord with well-considered, deeply held beliefs." (quoting Ronit Y. Stahl & Ezekiel J. Emanuel, *Physicians, Not Conscripts—Conscientious Objection in Health Care*, 376 NEW ENG. J. MEDICINE 1380, 1381 (2017))). *See generally id.* at 215–31 (discussing differences between conscientious objection and civil disobedience); Nadia N. Sawicki, *The Conscience Defense to Malpractice*, 108 CALIF. L. REV. 1255 (2020) (surveying state healthcare provider conscience laws in the reproductive healthcare context).

[274] *See, e.g.*, Sawicki, *supra* note 273, at 1304.

[275] New York's law granting legal capacity to refuse medical treatment also contains conscience provisions. N.Y. PUB. HEALTH LAW § 2994-n(2)(a) (McKinney 2021). Because of a lack of case law on the issue, it is unclear whether a provider in New York could treat a patient over their objection on the basis of their conscience and claim that this is good-faith compliance with the law, limiting their liability for violating other parts of the law.

indicate the presence of a medical emergency, meaning that slowing the decision-making process will not harm the patient. Regardless of whether there is harm to the patient's medical wellbeing, it is still the patient's decision to refuse medical treatment even if the cost of respecting patient autonomy is otherwise preventable death or disability.

Another concern is that it can be time-consuming for physicians to try to follow the proposed legal process when they respond to a patient's treatment refusal in a manner intended to result in the patient receiving the recommended treatment and that this time may not be compensated. Providers can, however, bill for time spent talking with their patients.[276] For other parts of the recommended process, such as seeking an emergency court order, physician involvement is not necessary. Instead, other allied professionals such as hospital lawyers can initiate legal proceedings, and nurses and medical social workers can spend time negotiating with the patient and coordinating care.[277] Further, additional billing codes could be created to allow providers to request reimbursement for lengthy informed consent conversations. Finally, others have argued that "[t]he advantages gained in increased trust, decreased likelihood of lawsuits, and patient compliance far outweigh the costs in time and effort expended by physicians."[278]

### *E. Legal Change Is Necessary*

Some may question why new statutes are necessary given that tort law should prevent or allow for recovery in many instances of nonconsensual treatment, including treatment over objection. But physicians' legal duties to patients have not prevented treatment over objection—contemporaneous or conveyed via advance directive—and patients have been generally unsuccessful in bringing lawsuits after unlawful treatment over objection. Because healthcare providers have not respected patient rights to autonomy and bodily integrity and courts have not vindicated violations of these rights, legislative change is necessary. This Section will first describe how the current law disad-

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[276] For example, providers are able to bill for advance care planning conversations with Medicare patients. Megan S. Wright, *Change Without Change? Assessing Medicare Reimbursement for Advance Care Planning*, HASTINGS CTR. REP., May–June 2018, at 8, 8–9.

[277] Some scholarship has addressed a novel way to provide collaborative services for complex patients. *See* Kenneth Lam et al., *How an Interdisciplinary Care Team Reduces Prolonged Admissions Among Older Patients with Complex Needs*, NEJM CATALYST INNOVATIONS IN CARE DELIVERY, Sept. 2021, at 1, 3–10, https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0204 [https://perma.cc/2APP-J6K6]; *see also* Pieterse et al., *supra* note 73, at 26 (describing how some parts of the decision-making process can be outsourced to non-physicians).

[278] BERG ET AL., *supra* note 3, at 65.

vantages plaintiffs, before moving to discuss how new laws can change medical practice and why significant liability for dignitary harms is necessary.

1. Current Laws Fail Patients

Medical battery claims are appealing to patients for many reasons, but battery law may not be helpful in remedying treatment over objection.[279] Physicians may defend against a medical battery claim in the context of treatment over objection by arguing that an exception applies to the requirement to obtain informed consent.[280] Providers may assert that the patient did not have decisional capacity and thus patient consent to the medical intervention was not required, or that an emergency existed and there was no time to obtain patient consent. Without making the exceptions to informed consent requirements stricter, as discussed previously, patients will not be as successful bringing battery claims.

Plaintiffs may also bring a negligent informed consent claim if they are treated over their objection, but again, it is difficult for plaintiffs to prevail. One barrier for plaintiffs is that tort requires the standard of care be breached. But if the standard of care is nonconsensual treatment, and physicians provide such treatment, they have followed the standard of care.[281] Scholars have also noted the general difficulty in demonstrating causation[282] and harm.[283]

Additionally, legal scholars have observed that given how financing medical malpractice claims work, only those with wealth or with a "bad enough"

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[279] For example, patients do not have to prove physical harm, just lack of consent. *Id.* at 134–35. Patients also prefer battery because no expert witnesses are required, and the full range of damages is available, including punitive. *See id.*; *see also* Pope, *supra* note 11, at 14.

[280] BERG ET AL., *supra* note 3, at 75–129. Another problem in bringing battery claims is that the standard is "reasonable person" when considering whether physical contact is offensive, which does not account for subjective reasons for not wanting to be touched.

[281] Kukura, *supra* note 15, at 779, 783. Similarly, the two different disclosure standards for informed consent may also be problematic for plaintiffs. *Id.* at 780; *see* BERG ET AL., *supra* note 3, at 134–35.

[282] There are more elements to prove in negligent informed consent than in medical battery, and it is thus more difficult for patients to prevail. BERG ET AL., *supra* note 3, at 136. There are multiple elements of the causation analysis. First, did the disclosure process cause the patient to make a particular decision? And second, did the medical intervention or lack thereof cause the patient harm? *Id.* at 136–40.

[283] *See, e.g.*, *id.* at 141 ("In general, recovery may not be obtained if the patient suffers no physical injury. Inadequate disclosure alone . . . is not a legally protected interest under a negligence theory."); Kapp, *supra* note 98, at 1935 (observing that it is challenging to establish that "the patient is demonstrably worse off . . . by virtue of receiving the intervention compared with not receiving it"); Kukura, *supra* note 15, at 784–85, 787–88 (describing how nonconsensual obstetric procedures may not be performed negligently and arguing that juries thus may not understand the harm to the woman, especially if there is no harm to her child or the harms from the intervention seem typical for childbirth).

outcome that an attorney will take their case on contingency are going to be able to find counsel to represent them, a very tiny subset of those who are treated over objection.[284] Indeed, in medical battery cases where the harm is dignitary in nature, damages tend to be negligible, disincentivizing lawyers from taking these cases.[285] Patients who are very ill or who have decisional impairments may find it even more difficult to obtain representation and initiate a lawsuit.[286] Even when there are other damages, courts may not be willing to impose liability on physicians which creates another barrier to finding legal representation.[287]

All of these issues result in no effective legal deterrent to disrespecting patients' rights when they wish to refuse treatment.

### 2. New Laws Can Successfully Change Medical Practice

There have been numerous proposals to reform the law to change the practice of informed consent, raising the question of whether the proposals in this Article will actually have an effect. Indeed, as others have observed, "[T]he law has had surprisingly little impact on most doctor-patient interactions."[288]

Some may argue that medical culture, regardless of informed consent laws, will always be opposed to respecting patient autonomy and bodily integrity when patient preferences conflict with providers' medical judgments.[289]

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[284] *See, e.g.*, Kukura, *supra* note 15, at 781–82 (noting how women who endure nonconsensual treatment during childbirth may not be able to obtain representation unless their child has been harmed); Pope, *Unwanted Cesareans*, *supra* note 15, at 170 (arguing that attorneys need "adequate reimbursement" in order to bring cases in tort (quoting Brief of Human Rights in Childbirth et al. as Amicus Curiae in Support of Plaintiff Rinat Dray at 16, Dray v. Staten Island Univ. Hosp., No. 500510/14, 2019 N.Y. Misc. LEXIS 250 (Sup. Ct. Jan. 7, 2019))).

[285] BERG ET AL., *supra* note 3, at 149.

[286] Kapp, *supra* note 98, at 1935 ("[P]atients who are most at risk for having interventions imposed on them . . . may lack the physical or mental capacity [to initiate a claim].").

[287] For a discussion of how courts do not allow victims of treatment over objection to recover, see BERG ET AL., *supra* note 3, at 132; Kukura, *supra* note 15, at 778; Strasser, *supra* note 108, at 1038.

[288] BERG ET AL., *supra* note 3, at 160–61; *see also id.* at 161, 310, 320 (asserting that law will not affect practice because providers manage interactions with patients and are resistant to regulation); Annas, *supra* note 5, at 10 (arguing that physicians resist being told how to interact with their patients by lawyers and judges); KATZ, *supra* note 61, at 228 ("The radically different climate of physician-patient decision making . . . cannot be implemented by judicial, legislative, or administrative orders."); Kapp, *supra* note 98, at 1937 ("The abstract, distant threat of a possible civil action is unlikely to substantially deter many . . . physicians and institutional administrators . . . .").

[289] *See, e.g.*, BERG ET AL., *supra* note 3, at 320 ("Physicians . . . and their attorneys are sufficiently imaginative . . . to devise means of defeating the intent of most legal regulation, perhaps even masking their response as mechanical compliance with its mandates."); Cheung et al., *supra* note 250, at 171–73 (proposing a policy designed to defend against a false imprisonment claim deriving from medically detaining a patient against the patient's will). *But see* KATZ, *supra* note 61, at 60 ("Doctors . . . will have to learn to live at least with the [informed consent] doctrine's symbolic significance. While it has always been the fate of symbols to be honored more in words than in deeds . . . symbols

But sufficient legal incentives to ensure patient permission to a medical intervention may be more successful in changing medical practices than proposed reforms that focus solely on mandated physician disclosures or promoting patient understanding.

Moreover, other recent laws may also assist with changing medical practice with respect to informed consent. More specifically, supported decision-making laws that allow for retention of legal capacity may require physicians to obtain informed consent from their patients with decisional impairments. Further, the presence of supporters in healthcare settings can help patients assert their legal rights against healthcare providers should this become necessary.[290]

But even if the proposed law is adopted, the barrier to legal representation remains, which can diminish the effectiveness of changing medical practice or remedying rights violations. Experiential legal education can provide a solution to this problem. Law school clinics provide an opportunity for law students to obtain legal experience under close supervision of a licensed attorney, and legal services typically are provided pro bono for community benefit. Law schools with health law curricula may choose to build clinical programs that represent patients in legal proceedings against healthcare providers, which would help solve the problem of lack of access to representation and civil justice.[291]

Should law schools create opportunities for students to represent patients whose healthcare decision-making rights have been violated, there is a possibility for profound changes to medical culture. This is because many law schools are located in cities with academic medical centers. If legal clinics brought lawsuits against healthcare providers at medical schools, regardless of whether the outcome was a settlement or a trial, then perhaps hospital practice and internal policy would change to prevent treatments over objection, and subsequent lawsuits.[292] The physicians at the academic medical institution are also scholars, and

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can nag and prod and disturb and ultimately bring about some change."). It remains to be seen, however, whether a new generation of physicians—who have grown up having conversations about consent in other contexts, such as affirmative consent in sexual relationships—will shift informed consent practices even in the absence of legal change.

[290] *See* Crystal Adams & Mica Curtin-Bowen, *Countervailing Powers in the Labor Room: The Doula-Doctor Relationship in the United States*, SOC. SCI. & MED., art 114296, at 1, 5–6 (2021) (arguing that doulas can assist pregnant women in resisting coercion).

[291] There are questions about how prospective clients would know to reach out to the clinic for legal assistance that would need to be addressed when designing the clinic.

[292] *See* Kukura, *supra* note 15, at 798 ("Physicians are more likely to adapt their practices . . . when . . . guidelines provide clear rules with a 'credible threat of enforcement' from outside of the profession." (quoting David Orentlicher, *The Influence of a Professional Organization on Physician Behavior*, 57 ALB. L. REV. 583, 596 (1994))). Any cases that did make it to court could help build a body of case law that may help future patients assert their legal rights and prevail against healthcare providers who disregard them. In fact, court cases could showcase the diversity of reasons patients

so they may communicate a changed standard of care to their peers through publication in medical journals, highlighting that treatments over objection are unlawful and unethical and thus influencing wider medical culture.

3. Significant Liability Is Necessary

There may be concerns that the possibility of significant negative sanctions for providers who treat patients over their objection may have unintended consequences that would harm patients.[293] Healthcare providers may be concerned about potential liability and thus be less likely to treat patients if they fear their patients will later say that they refused care. This could switch the current default from saving lives in cases of emergency or patient incapacity, but the proposed law retains exceptions to the requirement to obtain consent and also contains limits to liability if physicians follow the legal process.[294]

Relatedly, some may be concerned that the proposed law could incentivize physicians not to treat "difficult" patients. But it is not clear how providers would know in advance which patients would be considered difficult by refusing recommended treatment. If providers are using categories such as gender, age, race, social class, etc. to predict patient "difficulty," this raises the possibility that there will be health disparities on these bases.[295] Some patients with these status characteristics, however, will be protected by nondiscrimination laws.

Another concern is that some patients who are initially inclined to refuse a recommended medical treatment will not know enough to ask further questions about their treatment options, along with each options' risks and benefits. Medical knowledge correlates with the status characteristics described in the above paragraph, and so again, there may be health disparities. But the answer to this concern is not to override a treatment refusal, but instead for physicians to disclose information about treatment options and then to engage in conver-

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refuse treatment and contribute to the development of a "reasonable patient refusing treatment" standard. It is important to note, however, that there is a conflict of interest if the law school clinic clients are patients suing providers affiliated with a different unit—a medical center—in the same university.

[293] *See, e.g.*, BERG ET AL., *supra* note 3, at 159–60 (arguing that punishing physicians will not benefit patients).

[294] Punishment should be reserved for when physicians "knowing[ly] disregard [their] patient's legal right[s]." *See* Strasser, *supra* note 108, at 1039 & n.301 (quoting Willard H. Pedrick, *Arizona Tort Law and Dignified Death*, 22 ARIZ. ST. L.J. 63, 82 (1990)).

[295] *See* Appelbaum & Roth, *supra* note 77, at 1299–1300 (finding that some providers allowed "undesirable patient" refusals). *See generally* Sun et al., *supra* note 204 (describing how healthcare providers may be biased against Black patients and publicly-insured patients).

sation about their patient's refusal. Indeed, the proposed law is meant to prompt conversation and allows for persuasion.[296]

There may also be the danger that providers will use this law to refuse to provide life-sustaining care for vulnerable and marginalized populations, risking use of the law as a cover for rationing care or devaluing some patients' lives.[297] Concerns about unlawful and unethical rationing of care are somewhat ameliorated by the statutory duty to treat patients upon admission to hospitals for emergency medical conditions,[298] the ethical duty not to abandon patients,[299] and nondiscrimination laws such as the Americans with Disabilities Act.[300]

In sum, patients are entitled to recover when their rights have been violated, and healthcare providers need incentives not to treat patients over their objection.[301] It is anticipated, however, that providers will be receptive to changes in the law and take consent seriously and thus that most severe sanctions will be rare.

### *F. Judicial Review Is Warranted to Affirm Patient Rights and Prevent Erosion of Rule of Law*

Some may be opposed to involving judges in the healthcare decision-making process as provided for in many current laws and in the proposals outlined in this Article. Reasons for opposition are manifold but include: (1) con-

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[296] Existing scholarship addresses the need for conversation between patients and physicians. *See* KATZ, *supra* note 61, at 130–206; Dresser, *supra* note 159, at 62. *See generally* Appelbaum & Roth, *supra* note 77 (describing problematic acceptance of treatment refusals without further discussion with patient).

[297] Kapp, *supra* note 98, at 1937 (describing a need to safeguard against undertreatment for vulnerable groups). Many disability advocates worry about the effect of healthcare decision-making laws on persons with disabilities, particularly laws that allow patients to die rather than live with a disability. *See, e.g.*, Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. ST. U. L. REV. 893, 909–11 (2017). *But see* Fernandez Lynch et al., *supra* note 15, at 175 ("Enforcement . . . would 'send a message that patient rights must be respected, not a message that other patients with a similar prognosis must decline care.'" (quoting Philip G. Peters, Jr., *The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy*, 45 UCLA L. REV. 673, 695 (1998))); Alicia Ouellette, *Disability and the End of Life*, 85 OR. L. REV. 123, 126 (2006); Strasser, *supra* note 108, at 1040–41 (arguing that legal compliance is about respecting people's rights to make their own decisions and is not a statement about the quality of the lives of persons with disabilities).

[298] Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd.

[299] *Terminating a Patient-Physician Relationship: Code of Medical Ethics Opinion 1.1.5*, AM. MED. ASS'N, https://www.ama-assn.org/delivering-care/ethics/terminating-patient-physician-relationship [https://perma.cc/EYB7-GRWF].

[300] *See, e.g.*, Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2(b), 104 Stat. 327, 329 (codified at 42 U.S.C. § 12101).

[301] *See* Fernandez Lynch et al., *supra* note 15, at 168 n.148 ("History establishes that the fear of liability works, and works quickly." (quoting Kellen F. Rodriguez, *Suing Health Care Providers for Saving Lives: Liability for Providing Unwanted Life-Sustaining Treatment*, 20 J. LEGAL MED. 1, 63 (1999)).

cerns that physicians and patients will become opponents in a legal process, eroding trust; (2) physicians' desire to retain autonomy, deference, and control; and (3) the privileging of medical wellbeing in healthcare decision making.[302] There are also more practical issues with judicial involvement, such as creating a time delay that could negatively affect patient health, forfeiture of patient privacy, monetary burdens, and clogging the courts.[303]

Yet there are benefits to judicial review of healthcare decision making, especially when there is a disagreement between patients and providers. For example, the process can help ascertain the truth of patient treatment preferences if there is uncertainty.[304] More importantly, judges have a role in affirming patients' legal rights to control what happens to their bodies, preventing abuse of capacity assessments to disempower patients, encouraging discussion between patients and their healthcare providers, ensuring that healthcare providers follow the law and obtain patient consent to treatment, and providing a legal remedy when providers do not.[305] Indeed, judicial oversight in cases of treatment over patient objection can help shore up the rule of private law.[306]

If legal process is to have any true significance for patients' rights, however, judges must not cede questions of patients' rights to physicians' judgments.[307] Judges must independently weigh rights to bodily integrity against any harms that may occur should patients not receive the recommended treatment and uphold healthcare decision-making law. There is evidence from other types of cas-

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[302] Kukura, *supra* note 15, at 742–43 (describing the obstetric context); *see* BERG ET AL., *supra* note 3, at 119–20, 239; BURT, *supra* note 106, at 120; *ACOG Opinion No. 439*, *supra* note 241, at 403.

[303] BERG ET AL., *supra* note 3, at 120, 239; Paris et al., *supra* note 107, at 301, 307 (describing problems with judicial review and arguing that the appropriate adjudicator is a hospital ethics committee); *see also In re* Quinlan, 355 A.2d 647, 669 (N.J. 1976) ("We consider that a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome."), *receded from by In re* Conroy, 486 A.2d 1209 (N.J. 1985). But judicial involvement is the last step in the proposed law, aligning with others' suggestions that court is the "last resort to be reserved for otherwise intractable cases with potentially serious outcomes" such as "when efforts to restore patient competence have failed and the patient's refusal risks serious disability." BERG ET AL., *supra* note 3, at 239.

[304] BERG ET AL., *supra* note 3, at 121.

[305] BURT, *supra* note 106, at 124, 129.

[306] *See* Strasser, *supra* note 108, at 1039–40 ("Recognizing that imposing life-extending treatment against the will of the patient can cause a harm only reinforces the established jurisprudence in torts."). This Article does not anticipate that judges would override a patient's treatment refusal except in very rare cases, and most such cases would likely not be in the medical context, but rather in the public health context where considerations of the public may legitimately outweigh the individual's interests.

[307] *See* BURT, *supra* note 106, at 133–34 (describing a view of law's supremacy); KATZ, *supra* note 61, at xliii, 58–59 (describing how judges have let doctors remain paternalistic despite a rhetorical "commitment to [patient] self-determination").

es that judges sometimes seem to approve pro forma physicians' requests to treat patients over their objection, even when the law directs otherwise, thus providing no meaningful protection of vulnerable patients' rights or respect for the rule of law.[308] It is important to cabin deference to healthcare professionals to the medical domain and leave questions of legal rights to legal experts.[309]

## CONCLUSION: THEORIZING CONSENT

A significant body of scholarship on informed consent has developed around "information" to the neglect of "consent." The proposals outlined in this Article aim to revitalize the importance of consent and strengthen the rule of private law governing relationships between patients and healthcare providers by preventing treatment over objection and allowing patients to recover when their rights have been violated.

Many commentators have generally assumed that consent to or refusal of medical treatment requires patients to be informed and *understand* the intervention, along with its risks and benefits.[310] This conceptualization of consent conflates autonomy with rationality, ignoring the bodily integrity interests at the core of autonomy, and facilitates treatment over contemporaneous patient

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[308] BERG ET AL., *supra* note 3, at 120 ("The result is substantial deference to professional medical judgment."); Kukura, *supra* note 15, at 742–43 (observing that judges' lack of knowledge of the medical risks of childbirth results in deference to medical professionals); *see also* Strasser, *supra* note 108, at 1039 n.301 ("Such knowing disregard of the patient's legal right, whether for good motives or ill, cannot be tolerated." (quoting Pedrick, *supra* note 294, at 82)).

[309] *See, e.g.*, Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 434 (Mass. 1977) ("We take a dim view of any attempt to shift the ultimate decision-making responsibility away from . . . courts . . . to any committee, panel or group, ad hoc or permanent."). *But see* Susy Lam, *MD vs. JD: Doctors and Judges in Medical Decisions—Who Should Have the Last Say?*, IMS MAG., Fall 2014, at 24, 25 (arguing that physicians and not judges should make final medical decisions). Judicial training is also important. Judges should receive special training on how to respond to requests for a court order to treat patients over their objection. There is also the question of where hearings will be held. If a judge is permanently embedded in a hospital to handle disputes such as this, there is the potential for them to be captured or coopted by medical professionals' interests. One solution to this is to have judges be on call, and to have on call responsibilities rotate so one particular judge does not hear all of these cases. Another possibility would be to have a room set aside in the hospital that could function like a courtroom so hearings are not at the patient's bedside and judges are reminded that they, and not healthcare professionals, were in charge of this legal process and that the outcome is not guaranteed to be in physicians' favor. *But see* Robert A. Burt, *Uncertainty and Medical Authority in the World of Jay Katz*, 16 LAW MED. & HEALTH CARE 190, 192–96 (1988) (critiquing a judge who used a makeshift courtroom in a hospital for not talking to the patient at her bedside before ruling). *See generally* MARA BUCHBINDER, SCRIPTING DEATH: STORIES OF ASSISTED DYING IN AMERICA (2021) (describing how physicians sometimes have to decide questions of law but are not equipped to do so).

[310] *See, e.g.*, BERG ET AL., *supra* note 3, at 65 ("But it is uncertain whether an apparently competent patient who fails to understand . . . may render a legally valid consent.").

objection.[311] It also allows healthcare providers to nullify healthcare decision-making law.

This Article has argued against importing a requirement to demonstrate understanding in the case of treatment refusals. Although it may be difficult to obtain agreement on a robust definition of consent, there should be agreement on what consent is not.[312] Defined in the negative, consent is incompatible with the use of force or threats, both of which may be required to provide medical treatment in the instance of contemporaneous refusals.[313] Indeed, consent at its core is permission or authorization. According to dictionary definitions, consent is assent, and does not include a requirement of rationality or understanding.[314]

There are significant harms to patient autonomy, wellbeing, and the rule of law in the cases of treatment over objection, which is often justified by importing understanding requirements into the act of refusing treatment. Given these harms, an alternative conceptualization of consent is required. This conceptualization must be one that goes back to the original interests that medical decision-making law protects—the right to bodily integrity—as well as a recognition of the embodied nature of the exercise of autonomy.

Perhaps what the law and practice of informed consent should strive for is obtaining "informed enough assent" from patients prior to medical interventions.[315] The informed component should be defined by what patients want.

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[311] As discussed earlier, when patients are treated over their objection, the treatment is unlawful unless an exception to the requirement of obtaining consent applies. In the case of contemporaneous objection to treatment, providers may try to deem their patients to lack decisional capacity, seek consent from another party or from the patient at a prior time by looking to the patient's advance directive, and understand themselves to be acting ethically and lawfully and respecting their patients' precedent autonomy.

[312] For example, if a patient agrees to treatment, how can others be sure that the agreement was "voluntary," and thus consensual, and that undue pressure was not exerted?

[313] BERG ET AL., *supra* note 3, at 67–70 ("[A] decision obtained by the use of physical force or the threatened or attempted use of force is highly suspect in its legal and ethical validity."); *ACOG Opinion No. 439*, *supra* note 241, at 405 ("Informed consent includes freedom from external coercion, manipulation, or infringement of bodily integrity. It is freedom from being acted on by others when they have not taken account of and respected the individual's own preference and choice."). Ordinary people also understand consent to be incompatible with threats or force. *See generally* Roseanna Sommers, *Commonsense Consent*, 129 YALE L.J. 2232 (2020) (detailing the disconnect between philosophical and legal theories of consent and ordinary people's understanding of consent). Other words are also easier to define in the negative, such as "dignity." BERNSTEIN, *supra* note 178, at 45–46.

[314] *Consent*, MERRIAM-WEBSTER, https://www.merriam-webster.com/dictionary/consent [https://perma.cc/7T9W-7NJG] (defining consent as "to give assent or approval" or "agree"); *see also* BERNSTEIN, *supra* note 178, at 57 (describing "near synonyms" of consent).

[315] Others argue for a minimum of ensuring nondissent to medical treatment, at least in the context of patients with decisional capacity. Tunzi et al., *supra* note 74 *passim*; *see also* Bromley et al., *supra* note 191, at 176–77 (arguing for "informed enough" consent from human subjects in biobanking research); J. Randall Curtis, Commentary, *The Use of Informed Assent in Withholding Cardiopulmonary Resuscitation in the ICU*, 14 AMA J. ETHICS 545, 546 (2012) (arguing for "informed assent" when surrogates prefer that physicians make life-ending decisions); Alexander A. Kon & Denise M.

Many want more information than they currently receive from healthcare providers, whereas some may want no information at all. Further, the informed component should not contain an understanding requirement.[316] And the consent component should be defined as assent to having one's body touched in the manner the patient was told it would be touched.[317] If there is an understanding requirement for consent, it is about understanding that one's body will be intervened upon rather than understanding the risks and benefits of the intervention. There should not be an understanding requirement incorporated into patients' rights to refuse treatment.[318] Defining informed consent to a patient-centered informed enough assent and respecting patient dissent will further patient autonomy and bodily integrity interests, as well as subjective well-being.

Understanding autonomy as an embodied experience incorporating the right to bodily integrity, rather than a solely cognitive exercise equating autonomy with rationality, justifies what this Article has argued should be an absolute legal right to refuse medical treatment and empowers patients relative to their physicians. Using force to touch patients' bodies cannot be understood as consistent with respect for autonomy, precedent or otherwise. That is, autonomy is impossible if others can do what they want to a person's body with no recourse.

The cost of respecting patients' treatment refusals may be loss of life or health, but such costs are only rarely going to be incurred, given that many patients defer to their healthcare providers. Furthermore, the costs of respect for patient autonomy and maintenance of bodily integrity are worth incurring, especially because refusals of medical treatment are unusual and a sign of a

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Dudzinski, *Navigating End-of-Life Decisions Using Informed Nondissent*, AM. J. BIOETHICS, Mar. 2019, at 42, 42–43 (arguing for "informed nondissent" when surrogates prefer that physicians make life-ending decisions).

[316] For those who believe that consent requires understanding of the medical intervention, recent empirical research has demonstrated that many ordinary people may disagree because they view consent as compatible with deception. Sommers, *supra* note 313, at 2277–83. Scholars who understand the consent requirement to protect bodily integrity also downplay the information component of informed consent. *See* Herring & Wall, *supra* note 24, at 569 ("While on any reasonable definition of the right to bodily integrity, treating a patient without consent will breach that right, it is not clear that a failure to disclose a risk is sufficient to vitiate consent."). Other scholars assert that consent is possible without complete comprehension. *See* Bromley et al., *supra* note 191, at 179; Millum & Bromwich, *supra* note 158, at 46–50; Schneider & Farrell, *supra* note 7, at 125–26.

[317] *See* Navin et al., *supra* note 20, at 1938 (applying the concept of "pediatric assent to adult patients who lack decision-making capacity"). *See generally* Megan S. Wright, Claudia Kraft, Michael R. Ulrich & Joseph J. Fins, *Disorders of Consciousness, Agency, and Health Care Decision Making: Lessons from a Developmental Model*, 9 AJOB NEUROSCIENCE 56 (2018) (applying the concept of assent to patients with disorders of consciousness).

[318] *But see* Navin et al., *supra* note 51, at 7 (describing how understanding should be assessed in light of different conceptualizations of decisional capacity).

serious preference worthy of respect. If there are exceptions to the requirement to obtain patient consent to medical treatment, they should not be determined by healthcare providers but instead by courts, in order to respect patients' rights and maintain the rule of private law.