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ARTICLE

Reconsidering Capacity Assessments

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Abstract

Despite the routine assessment of decisional capacity in the clinical context, the concept of capacity is contested, and its measurement is flawed. For example, scholars and clinicians disagree about the criteria for demonstrating capacity. There is further lack of consensus about whether some types of medical decisions should require more evidence of capacity. Moreover, there is robust literature demonstrating that formal capacity assessment instruments are not always valid and reliable.

This Article focuses on these and other issues, namely the fact that (in)capacity as currently understood is often not viewed relationally and contextually. (In)capacity is viewed as a cognitive property of an individual — an individual has capacity or does not. However, properly conceived, (in)capacity is constituted in interaction with others (e.g., health care providers, family, friends) and one's environment, and mediated through one's body and experience of health, illness, or disability. When this reality is not acknowledged, clinicians, caregivers, family members, and others miss opportunities to strengthen patients' decisional capacity by modifying how they communicate with patients and by changing patients' environment to improve decision-making. In fact, not acknowledging the relational and contextual nature of (in)capacity likely leads to weakening of patients' decision-making abilities and the unnecessary disqualification of patients from contemporaneous decision-making, which subsequently negatively affects patient interests in maintaining autonomy and bodily integrity and experiencing wellbeing.

This Article will foreground the relational and contextual nature of (in)capacity and address problems with capacity assessments for adult patients in the medical decision-making context, propose reforms to the capacity assessment process, and conclude by discussing the implications of these arguments in other decision-making contexts.

Introduction

Because respect for patient autonomy is a central goal of medical decision-making law and ethics, health care providers must obtain their patient's informed consent prior to administering treatment.[1] Obtaining informed consent requires that physicians disclose information about the patient's diagnosis,

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[1] Jessica W. Berg et al., Informed Consent: Legal Theory and Clinical Practice 15–16 (2d ed. 2001).

prognosis, and risks and benefits of various treatments.[2] During the informed consent process, health care providers may assess their patient's decision-making abilities to determine if the patient is able to understand relevant medical information and communicate a treatment decision. If the patient fails to demonstrate one or more decision-making abilities — understanding, appreciation, reasoning, or communication[3] — providers may deem the patient incapacitated.[4] This is because the patient's decision-making impairments may make it impossible for the patient to understand information, act intentionally, or withstand undue influence, hallmarks of autonomous decision-making that the informed consent requirement is designed to promote.[5]

If a patient is determined to lack capacity, providers may disqualify the patient from making contemporaneous medical decisions.[6] In such instances, providers instead rely on the patient's advance directive or substitute decision-makers to provide consent to medical treatment.[7] The disqualification of patients with impaired decision-making capacity from making contemporaneous decisions is facilitated by health care decision-making law.[8]

Despite the routine assessment of decisional capacity and common use of substitute decision-makers in the clinical context, the concept of capacity is contested[9] and its measurement is flawed.[10] For example, scholars and clinicians disagree about whether there should be more or fewer criteria for demonstrating capacity.[11] There is further lack of consensus about whether some types of medical decisions should have different evidentiary burdens for demonstration of capacity.[12] Moreover, there is robust literature demonstrating that formal capacity assessment instruments are not always valid and reliable.[13] This Article focuses on these and other issues with capacity assessments.

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[2] *Id.* at 46.

[3] *See* Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEJM 1834, 1835 (2007) (describing commonly accepted elements of decisional capacity that the author developed and demonstrating how to apply them); *see also* Unif. Health-Care Decisions Act § 1(3) (Unif. L. Comm'n 1994) ("'Capacity' means an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision."); Unif. Health-Care Decisions Act § 3(a)(1)–(2) (Unif. L. Comm'n 2023) ("An individual has capacity . . . if the individual [] is willing and able to communicate a decision independently or with appropriate services, technological assistance, supported decision-making, or other reasonable accommodation; and [] in making or revoking [] a health-care decision, understands the nature and consequences of the decision, including the primary risks and benefits of the decision.").

[4] Appelbaum, *supra* note 3, at 1836. This Article will use the word "capacity" instead of "competence." Some scholars distinguish between the two words, using "capacity" to refer to a physician's judgment of a patient's decision-making abilities and "competence" to refer to a court's judgment of a person's decision-making abilities. *See, e.g.*, Linda Ganzini et al., *Ten Myths About Decision-Making Capacity*, 6 J. Am. Med. Dirs. Ass'n 263, 264 (2004) (distinguishing between "capacity" and "competence"). However, many use the words interchangeably or use only "capacity" to refer to all judgements about decision-making abilities. *See* Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics 114 (7th ed. 2013) (arguing that the distinction "breaks down in practice"). It is also important to note that in the medical decision-making context, a capacity determination is functionally a competence determination as patients likely will not be going to court to challenge their physician's judgment about the patient's incapacity. *See* Ganzini et al., *supra*, at 264.

[5] Beauchamp & Childress, *supra* note 4, at 104.

[6] Appelbaum, *supra* note 3, at 1834.

[7] *See, e.g.*, Unif. Health-Care Decisions Act §§ 8, 11, 12 (Unif. L. Comm'n 2023) (outlining how clinicians may instead rely on advance directives or substitute decision-makers to provide consent).

[8] *Id.* § 21.

[9] *See* Megan S. Wright, *More, Fewer, Reconceptualized, or Relational Criteria? Recent Trends in Bioethics Scholarship on Decision-Making Capacity*, 24 Am. J. Bioethics 121, 121 (2024) [hereinafter Wright, *Recent Trends*] (describing scholarly debates about the concept of decisional capacity).

[10] *See, e.g.*, Jennifer Moye & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62B J. Gerontology P3, P5 (2007) (discussing problems with the validity and reliability of instruments used to assess capacity); Canadian Ass'n of MAiD Assessors & Providers, Assessment for Capacity to Give Informed Consent for Medical Assistance in Dying (MAiD): Review and Recommendations 15 (2020), https://camapcanada.ca/wp-content/uploads/2022/02/Capacity-assessment.pdf [https://perma.cc/8RK2-K8SH] (noting that formal tools to assess capacity do not include a role for patient values).

[11] Wright, *Recent Trends*, *supra* note 9, at 121.

[12] *Id.*

[13] *See infra* Part II.A.

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This Article also argues that capacity as currently understood is often de-relationalized. (In)capacity is viewed as a cognitive property of an individual — an individual has capacity or does not.[14] However, when properly conceived, (in)capacity is constituted in interaction with others (e.g., health care providers, family, friends) and one's environment, and mediated through one's body and experience of health, illness, or disability. When this reality is not acknowledged or appreciated, there are missed opportunities for strengthening patients' decisional capacity by, for example, modifying how providers communicate with patients or changing the environment to improve decision-making. Furthermore, not acknowledging the relational and contextual nature of (in)capacity likely leads to weakening of patients' decision-making abilities and the unnecessary disqualification of patients from contemporaneous decision-making, which subsequently negatively affects patient interests in maintaining autonomy and bodily integrity and experiencing wellbeing.

Understanding (in)capacity as relational and contextual is also consistent with the legal trend toward supported decision-making. Supported decision-making is one tool to promote autonomy for individuals with cognitive disabilities, and many state legislatures have passed supported decision-making legislation.[15] And supported decision-making can be used informally in states without supported decision-making laws.[16] Conceptualizing capacity as relational and further institutionalizing supported decision-making can help individuals with disabilities achieve equal legal capacity.

This Article will foreground the relational and contextual nature of (in)capacity and address problems with capacity assessments for adult patients in the medical decision-making context.[17] Part I discusses the centrality of decisional capacity to informed consent law along with arguments about how capacity should be understood. This Part will also argue that (in)capacity should be understood relationally and contextually. Part II discusses problems with formal capacity assessments, including validity and reliability problems with assessment instruments along with other issues related to the assessment process. This Part also discusses how concerns about health care provider power over patients and patients' subjective wellbeing and privacy interests have received inadequate attention from scholars writing about capacity. Finally, this Part highlights how assessing capacity and deeming a patient incapacitated can, in some instances, conflict with disability law. Part III proposes reforms to the capacity assessment process, including altering the clinical environment to make it conducive to autonomous decision-making, improving health care provider communication, preventing abuse of the incapacity exception to informed consent, and modifying formal tools to include the practice of supported decision-making. Part IV discusses objections to these proposals. This Article concludes by discussing the implications of these arguments about the nature and assessment of (in)capacity in other decision-making contexts with different legal interests and stakeholders, raising questions about implementation of supported decision-making and how to achieve "legal capacity on an equal basis to others in all aspects of life"[18] for persons with cognitive impairments.

I. Capacity and Law of Medical Decision-Making

Adults are generally entitled to make decisions about their medical treatment. This entitlement is enshrined in both informed consent law and medical ethics and is based on the principles of respect for

[14]*See, e.g.*, Ganzini et al., *supra* note 4, at 264 (acknowledging that capacity is decision-specific but still emphasizing that capacity is a cognitive property). This Article will use "(in)capacity" as short-hand to mean both "capacity" and "lack of capacity."

[15]*See* Nina A. Kohn, *Legislating Supported Decision-Making*, 58 Harv. J. on Legis. 313, 314–15 (2021) (explaining that states are rapidly adopting statutes enabling supported decision-making for individuals with cognitive disabilities).

[16]*See* Nina A. Kohn, *Realizing Supported Decision-Making: What It Does—And Does Not—Require*, 21 Am. J. Bioethics 37, 37–40 (2021) (arguing that laws authorizing supported decision-making agreements are not necessary for the practice of supported decision-making).

[17]This Article will not focus on the mental health treatment decision-making context, but patients with mental health diagnoses who are making medical decisions are within the scope of this Article. This Article is relevant for medical decision-making in hospitals given that this is likely the context where capacity can be formally assessed (including by specialists) and where serious medical decisions are made.

[18]G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 12 (Dec. 13, 2006).

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patient autonomy, maintenance of patient bodily integrity, and promotion of patient wellbeing.[19] This Part will first discuss the law of informed consent and then discuss the concept of capacity, which is an important limitation on medical decision-making rights. This Part will then discuss evolving scholarly understandings of capacity.

A. Informed Consent and Decisional Capacity

Physicians have a legal duty to obtain informed consent from their patients for medical interventions. Although the specifics of this duty differ by state, physicians typically must disclose information about the patient's diagnosis, prognosis, recommended interventions and their risks and benefits, and alternatives to the recommended intervention along with their risks and benefits.[20] Patients can then decide to accept or refuse treatment, even if the result of their decision may be death or disability.[21] The doctrine and practice of informed consent is meant to ensure patients make autonomous medical decisions (i.e., make decisions intentionally, voluntarily, and with understanding).[22]

Given the importance of respect for patient autonomy, one important limitation of the right to make medical decisions is the requirement that an individual be competent to decide (i.e., demonstrate capacity for autonomous decision-making).[23] The commonly accepted elements of decisional capacity include the ability to communicate decisions, understand information, appreciate how the information applies to individual circumstances, and reason about or through the decision.[24] Some refer to this

[19] *See* 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, 1132 (2018) [hereinafter Wright, *End of Life*] (discussing how respect for autonomy and patient wellbeing underlie ethical and legal standards in end-of-life care); Megan S. Wright, *Resuscitating Consent*, 63 B.C. L. Rev. 889, 890, 895–96 (2022) [hereinafter Wright, *Resuscitating Consent*] (discussing informed consent law, medical ethics, and patient autonomy). *See also* 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.").

[20] *See generally* Berg et al., *supra* note 1 (explaining that physicians must disclose diagnoses, prognoses, treatment options, and related risks and benefits); 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."). The relational and contextual nature of capacity can be seen at this stage in medical decision-making. Understanding and appreciation of one's medical situation will depend greatly on how medical information is disclosed, which is why many scholars have argued for patient decision-making aids and shared decision-making. *See, e.g.*, Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 Am. J.L. & Med. 429, 463–68 (2006) (describing the evolution of informed consent law leading to shared decision-making and use of decision aids); Thaddeus Mason Pope, *Certified Patient Decision Aids: Solving Persistent Problems with Informed Consent Law*, 45 J.L. Med. & Ethics 12, 29 (2017) (summarizing evolution of informed consent law leading to shared decision-making and arguing for certification of decision aids); Nadia N. Sawicki, *Patient Protection and Decision-Aid Quality: Regulatory and Tort Law Approaches*, 54 Ariz. L. Rev. 621, 628–33 (2012) (describing the evolution of informed consent law leading to shared decision-making and use of decision aids); *see also* Ganzini et al., *supra* note 4, at 266 (arguing for oral and written communication to aid in patient understanding).

[21] *See, e.g.*, Cruzan v. Mo. Dep't of Health, 497 U.S. 261, 278–79 (1990) (describing a person's liberty interest to refuse medical treatment).

[22] Beauchamp & Childress, *supra* note 4, at 104.

[23] For a discussion on the close connection between autonomy and capacity, see *id.* at 116–17.

[24] Paul S. Appelbaum & Thomas Grisso, *The MacArthur Treatment Competence Study: Mental Illness and Competence to Consent to Treatment I*, 19 L. & Hum. Behav. 105, 109–11 (1995) (defining legal competence as "ability to communicate a choice"; "ability to understand relevant information"; "ability to appreciate the nature of the situation and its likely consequences"; and "ability to manipulate information rationally"); Jennifer Hawkins, *Affect, Values and Problems Assessing Decision-Making Capacity*, 24 Am. J. Bioethics 71, 71 (2024) (describing the Appelbaum and Grisso "four abilities" capacity criteria as the "dominant approach"); *see also* Beauchamp & Childress, *supra* note 4, at 114–22 (defining competence and expanding on competence standards); Lois A. Weithorn, *Psychological Distress, Mental Disorder, and Assessment of Decisionmaking Capacity Under U.S. Medical Aid in Dying Statutes*, 71 Hastings L.J. 637, 654–57 (2020) (providing historical overview of how researchers have understood and measured decisional capacity). Sometimes the criterion of the ability to communicate is placed after the reasoning criterion; where this criterion falls in the list of abilities may have

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conceptualization of capacity as the "four abilities model."[25] Additional elements of capacity may include the ability to value or to have preferences.[26] Medical decision-making laws direct that capacity is to be presumed for adults.[27]

Capacity may change over time.[28] An obvious example is when children mature into adults and gain decision-making abilities, skills, and responsibilities. Individuals may also lose capacity, however, if they acquire a neurodegenerative illness such as Alzheimer's disease or acquire a severe brain injury.[29] Additionally, individuals may experience periods of incapacity due to conditions such as psychiatric illness but regain capacity when their illness is appropriately treated.[30]

It is generally accepted that an individual need not demonstrate capacity for all decisions (e.g., financial) or even for all medical decisions, but instead just for the medical decision that needs to be made.[31] Capacity is "task" or "decision" specific.[32] With respect to the decision, some argue for a "sliding scale" approach to capacity: the more serious or risky the medical decision, the greater capacity (or evidence thereof) needed.[33]

If an individual has impaired capacity and is unable to make contemporaneous decisions autonomously (i.e., they are deemed incapacitated), medical decision-making law still facilitates respect for patient autonomy. The law directs that health care providers rely on their incapacitated patient's advance directive, which is a legal document that contains the patient's written wishes about medical treatment or appoints a proxy decision-maker.[34] Relying on advance directives respects the patient's precedent autonomy (i.e., autonomous decisions made in the past).[35] Given that many individuals do not complete an advance directive,[36] the law permits family members to decide on behalf of the incapacitated patient, trying to decide as the patient would decide if they were able, based on the patient's values, beliefs, preferences, and interests,[37] which also respects the patient's precedent autonomy. In the absence of family members who can function as substitute decision-makers or information about how the patient would decide (or if the patient was never competent), the law requires that substitute decision-makers decide based on the patient's best interests, which is intended to promote patient wellbeing.[38]

normative significance or may instead be understood as logically following solely cognitive aspects of decision-making, although this may not be how decisions are made in practice. Theresa S. Drought & Barbara A. Koenig, *"Choice" in End-of-Life Decision Making: Researching Fact or Fiction?*, 42 Gerontologist 114, 116 (2002) (describing how patients may not perceive that decisions have been made).

[25]Hawkins, *supra* note 24.

[26]*See* Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value*, 28 Phil. & Pub. Affs. 105, 109 (1999); *see also* Mark C. Navin et al., *Three Kinds of Decision-Making Capacity for Refusing Medical Interventions*, 22 Am. J. Bioethics, 73, 73 (2022); Hawkins, *supra* note 24, at 71–77, 80–81 (arguing for adding affective and not solely cognitive criteria for capacity assessment).

[27]*See, e.g.*, Unif. Health-Care Decisions Act § 4 (Unif. L. Comm'n 2023) (defining "capacity" for health-care decision-making purposes).

[28]Beauchamp & Childress, *supra* note 4, at 115.

[29]*Id.* at 116.

[30]*Id.* Fluctuating capacity would also be experienced in the case of intoxication. *Id.* at 116.

[31]*Id.* at 115.

[32]*Id.*; Appelbaum & Grisso, *supra* note 24, at 119; Ganzini et al., *supra* note 4, at 264.

[33]*See* Beauchamp & Childress, *supra* note 4, at 119–20; James F. Drane, *Competency to Give an Informed Consent: A Model for Making Clinical Assessments*, 252 [J]AMA 925, 925 (1984).

[34]*See, e.g.*, Unif. Health-Care Decisions Act §§ 2, 8, 11 (Unif. L. Comm'n 2023).

[35]*See* John K. Davis, *Precedent Autonomy, Advance Directives, and End-of-Life Care*, *in* The Oxford Handbook of Bioethics 358–59 (Bonnie Steinbock ed., 2009).

[36]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, 1244 (2017).

[37]*See, e.g.*, Unif. Health-Care Decisions Act § 17 (Unif. L. Comm'n 2023).

[38]*Id.*

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B. Evolving Understandings of Capacity

After decades of seeming consensus on the concept of decisional capacity, scholars in law, medicine, and philosophy have recently begun arguing that capacity for medical decision-making should be understood differently.[39]

Some scholars argue that the "four [cognitive] abilities" of decision-making capacity should be retained, but that more criteria are also necessary to demonstrate capacity.[40] For example, some scholars argue that the decision itself should factor into consideration of a patient's capacity.[41] On this view, if a patient's decision causes medical harm, then the patient does not have capacity (even if they can pass a "four abilities" capacity assessment) and should be disqualified from the decision-making process.[42] Other scholars suggest that in addition to the traditional elements of capacity, the affective dimensions of patient's decisions should also be assessed.[43] Others also argue that individuals who have opioid use disorder and refuse medical observation post-resuscitation from opioid overdose should be considered incapacitated even if they evidence the "four abilities" model of capacity, which suggests that some scholars view the absence of a substance use disorder as another criterion necessary to demonstrate capacity, at least for substance use treatment decisions.[44] If clinical practice adopts any of these views, fewer patients would be permitted to make their own medical decisions as the burden for demonstrating capacity would be greater.

Some scholars advocate reducing the criteria (or relaxing the standard) to demonstrate capacity in specific medical contexts.[45] For example, I argued that in instances of treatment refusal, the ability to communicate a refusal should suffice for a demonstration of capacity.[46] If my arguments are adopted, then more patients would be able to refuse treatment even if they had decisional impairments.

Others argue that the "four abilities" model of decisional capacity should be retained while being reconceptualized for the context of treatment refusals.[47] These scholars assert that the abilities to understand, appreciate, and reason not be analyzed with respect to the facts of a specific medical intervention but instead be considered with respect to a patient's goals for treatment or views of the burdens of treatment.[48] If these arguments are adopted, more patients would be permitted to refuse treatment despite their decisional impairments.

Finally, scholars are increasingly interested in how supported decision-making can be used in a medical setting for various populations of patients with impaired cognition (e.g., patients with dementia, intellectual disabilities, etc.).[49] With this relational form of decision-making, a patient's capacity can potentially be strengthened when others provide decision-making assistance, such as through gathering

[39] *See* Wright, *Recent Trends*, *supra* note 9, at 121–23 (summarizing the state of this scholarship). There are also ongoing debates about how to understand capacity in other legal contexts. For example, some scholars have advanced understandings of capacity in private law as decisions "linked by a coherent narrative structure to the story of the person making them" (i.e., "narrative capacity"). James Toomey, *Narrative Capacity*, 100 N.C. L. Rev. 1073, 1080 (2022).

[40] *See* Wright, *Recent Trends*, *supra* note 9, at 121.

[41] *See* Neil Pickering et al., *Harmful Choices, the Case of C, and Decision-Making Competence*, 22 Am. J. Bioethics 38, 38 (2022). *But see* Megan S. Wright, *Against Externalism: Maintaining Patient Autonomy and the Right to Refuse Medical Treatment*, 22 Am. J. Bioethics 58, 58–59 (2022) (critiquing Pickering et al.'s arguments).

[42] *See* Pickering et al., *supra* note 41, at 39, 48.

[43] *See* Hawkins, *supra* note 24. *But see* Wright, *Recent Trends*, supra note 9 (critiquing Hawkins' arguments).

[44] *See* Kenneth D. Marshall et al., *Revive and Refuse: Capacity, Autonomy, and the Refusal of Care after Opioid Overdose*, 24 Am. J. Bioethics 11, 12, 20–21 (2024). *But see* Megan S. Wright, *Hospitals Are Not Prisons: Decision-Making Capacity, Autonomy, and the Legal Right to Refuse Medical Care, Including Observation*, 24 Am. J. Bioethics 37, 37 (2024) (critiquing Marshall et al.'s arguments).

[45] *See* Wright, *Recent Trends*, *supra* note 9, at 121.

[46] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 921.

[47] *See* Wright, *Recent Trends*, *supra* note 9, at 121–22.

[48] *See* Navin et al., *supra* note 26, at 73 (referring to proposed types of decisional capacity as "goals"- or "burdens"-based capacity); *see also* Megan S. Wright, *Supported Decision Making, Treatment Refusal, and Decisional Capacity*, 22 Am. J. Bioethics, 89, 89–90 (2022) (commenting on Navin et al.'s article).

[49] *See* Wright, *Recent Trends*, *supra* note 9, at 122.

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additional information, helping the patient deliberate, or helping the patient communicate their values and preferences.[50] If proposals to implement supported medical decision-making are adopted, more patients may be able to demonstrate capacity with support and thus more patients would be able to make contemporaneous medical decisions.[51]

It is this final set of ideas about capacity with which this Article is most interested in engaging. Although not explicit in this body of scholarship, those asserting that supported medical decision-making can be appropriate for patients with decisional impairments view capacity as relational and contextual in nature.

This Article asserts that (in)capacity should be understood as relational and contextual for all patients making medical decisions. The cognitive abilities traditionally understood to constitute capacity ("four abilities") can be strengthened or weakened through interactions with not only supporters, but also health care providers and the environment. Understanding (in)capacity as relational and contextual provides insight into how and why to ensure that more patients can make contemporaneous medical decisions even when they have decisional impairments. More specifically, this conceptualization of capacity accords with decision-making realities for all individuals facing serious medical conditions.[52] And if this conceptualization of capacity was explicitly adopted in law and medical practice, then there should be more opportunities for patients to demonstrate capacity and for more patients to make contemporaneous medical decisions, which would lead to true respect for patient autonomy and an increase in patient wellbeing, as will be discussed in Parts III and IV.

The next Part will focus on problems with capacity assessments and highlight where a relational and contextual understanding of (in)capacity could be beneficial.

II. Problems with Capacity Assessments

Because capacity is an essential component of and restriction on the right to make contemporaneous medical decisions, there must be ways to determine whether a patient has or lacks capacity. Sometimes determining incapacity is easy, as is the case when the patient is unconscious and thus clearly lacks the ability to make contemporaneous decisions.[53] Other times, however, the question of whether a patient

[50] *See, e.g.*, Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability Law*, 47 J.L. Med. & Ethics, 25, 29-30 (2019) [hereinafter Wright, *Dementia and Disability Law*] (applying supported decision-making to patients with dementia); Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decisionmaking*, 79 Md. L. Rev. 257, 284–86 (2020) [hereinafter Wright, *Dementia and Supported Decisionmaking*] (applying supported decision-making to patients with dementia); Megan S. Wright, *Equality of Autonomy? Physician Aid in Dying and Supported Decision-Making*, 63 Ariz. L. Rev. 157, 196–97 (2021) [hereinafter Wright, *Equality of Autonomy*] (applying supported decision-making to terminally ill patients with cognitive impairments); Andrew Peterson et al., *Supported Decision Making with People at the Margins of Autonomy*, 21 Am. J. Bioethics 4, 4 (2020); Megan S. Wright, *Implementing Ethical and Legal Supported Decision Making: Some Unresolved Issues*, 21 Am. J. Bioethics, 40, 40–41 (2021) (commenting on Peterson et al.'s arguments); Allison M. McCarthy & Dana Howard, *Supported Decision-Making: Non-Domination Rather than Mental Prosthesis*, 14 Am. J. Bioethics Neuroscience 227, 227 (2023); Megan S. Wright, *Supported Decision Making in the United States: Supporters Provide Decision-Making Assistance but Are Not Decision Makers*, 14 Am. J. Bioethics Neuroscience 252, 252–54 (2023) [hereinafter Wright, *Supported Decision Making in the U.S.*] (critiquing McCarthy and Howard's arguments). *See generally infra* Part II.D.4 (describing supported decision-making); see also the special issue "*Supported Decision Making and Clinical Research"* of the J.L. Med. & Ethics (forthcoming Mar. 2026) (discussing other types of decisional support such as motivation, encouragement, and advocacy and discussing supported decision-making and capacity in the context of clinical research).

[51] It may also be the case formal supported decision-making agreements governed by state supported decision-making laws entitle a person to make their own decisions even if the individual does not receive support or have their capacity strengthened through support. *See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 287, 298.

[52] *See generally* Wright, *End of Life*, *supra* note 19 (discussing practice of medical decision-making at the end of life); Wright, *Dementia and Supported Decisionmaking*, *supra* note 50.

[53] Ganzini et al., *supra* note 4, at 263 (describing how someone in a coma clearly lacks capacity). *But see* Megan S. Wright et al., *Disorders of Consciousness, Agency, and Health Care Decision Making: Lessons from a Developmental Model*, 9 Am. J. Bioethics Neuroscience 56, 60 (2018) (describing how the determination of consciousness itself may be a problem).

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has decisional capacity is more difficult to answer. Although many health care providers use their clinical judgment about whether their patient has capacity (i.e., informally assess capacity),[54] others may use an instrument such as the Macarthur Competence Assessment Tool-Treatment ("MacCAT-T")[55] or Aid to Capacity Evaluation ("ACE")[56] (i.e., formally assess capacity).[57]

Researchers have devoted considerable attention to developing ways to measure capacity. There are many instruments to assess capacity available (too many to cover in this Article), but these tools include questions designed to assess patient abilities to understand, appreciate, reason, and communicate.[58] To illustrate with the MacCAT-T instrument, clinicians assess a patient's ability to understand by asking patients to paraphrase information from their informed consent conversation, such as asking patients to tell clinicians what their medical condition is and what the recommended intervention is along with risks and benefits and to discuss the alternatives and their risks and benefits through "paraphrased recall" or by identifying facts they were told during the informed consent discussion.[59] This instrument assesses a patient's ability to appreciate by determining whether the patient recognizes what their illness is, and that treatment may have value.[60] This instrument assesses rationality by testing "problem-solving abilities" and "logical and adequate reasoning process" by asking the patient to make a treatment decision and explain why they made that decision.[61] Communicating a choice is assessed by whether the patient makes a treatment choice in response to the vignette or whether they are ambivalent or make no choice.[62]

Despite the widespread clinical practice of assessing patient capacity, there are numerous and well-documented problems with both formal and informal capacity assessments. This Part will discuss various problems with the instruments used to assess capacity, the process of assessing capacity, and the ethical and legal issues with capacity assessment and, where relevant, note how a relational and

[54]*See* Moye & Marson, *supra* note 10, at P3; Ganzini et al., *supra* note 4, at 266.

[55]*See* Thomas Grisso & Paul S. Appelbaum, Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals 173 (1998).

[56]*See* Edward Etchells, Aid to Capacity Evaluation (ACE) 2, https://www.cmpa-acpm.ca/static-assets/pdf/education-and-events/resident-symposium/aid_to_capacity_evaluation-e.pdf [https://perma.cc/NPP6-YLUZ] (last visited Oct. 26, 2025). This evaluation focuses on the understanding and appreciation elements of capacity.

[57]*See* Craig Barstow et al., *Evaluating Medical Decision-Making Capacity in Practice*, 98 Am. Fam. Physician 40, 42–45 (2018). Some instruments created to screen for certain medical conditions such as dementia, such as the Mini-Cog may be used to screen patients for decisional impairments. *See Quick Screening for Early Dementia*, Mini-Cog, https://mini-cog.com [https://perma.cc/4U27-BKC6] (last visited Oct. 26, 2025). This instrument asks people to repeat a list of words and to draw a clock with a time of 11:10 to quickly screen for memory and thinking problems. Mini-Cog, Instructions for Administration & Scoring (2016), https://mini-cog.com/wp-content/uploads/2022/04/Standardized-English-Mini-Cog-1-19-16-EN_v1-low-1-2.pdf [https://perma.cc/ZCY5-9CKK]. There are FAQs for clinicians using the Mini-Cog about how to proceed when someone "fails" the Mini-Cog. *Mini-Cog FAQ's*, Mini-Cog, https://mini-cog.com/faqs/ [https://perma.cc/8CNK-WVFH] (last visited Jan. 4, 2026). The FAQs focus on adverse effects on clinicians for having to inform patients they have "failed" rather than the adverse effects on patients from receiving this feedback. *Id.* ("What do you say to a person who unexpectedly fails the Mini-Cog? You are surprised—and the patient has no complaints. This can be an awkward moment for a health care provider. It is important to be prepared."). Although these disease-specific screenings are not meant to function as formal capacity assessments, results likely will predict findings of capacity as measured by other tests. *See, e.g.*, Daniel I. Kaufer et al., *Cognitive Screening for Dementia and Mild Cognitive Impairment in Assisted Living: Comparison of 3 Tests*, 9 J. Am. Med. Dirs. Ass'n 586, 590–93 (2008) (comparing results of the Mini-Cog to other instruments).

[58]*See* Grisso & Appelbaum, *supra* note 55, at 173. As an example, the Aid to Capacity Evaluation (ACE) contains questions such as "Why are you in the hospital?", "What could happen to you if you have [proposed treatment]?", and "Do you have any hope for the future?" to assist clinicians with assessing various domains of capacity. Etchells, *supra* note 56, at 2, 3.

[59]Thomas Grisso et al., *The MacArthur Treatment Competence Study II: Measures of Abilities Related to Competence to Consent to Treatment*, 19 L. Hum. Behav. 127, 128, 131 (1995); *see also* Grisso & Appelbaum, *supra* note 55, at 177.

[60]*See* Grisso et al., *supra* note 59, at 128–29, 132–34. The researchers note that denial of illness or treatment benefits may not be related to impaired decisional abilities but may instead be due to cultural or religious beliefs or other rational reasons, and so they designed their instrument to focus on "delusional" denial. *See id.* at 131–32; Grisso & Appelbaum, *supra* note 55, at 178–79, 180; *see also* Beauchamp & Childress, *supra* note 4, at 117 (describing how seemingly irrational decisions may stem from religious beliefs and that such actions can be rational when considering such beliefs).

[61]*See* Grisso et al., *supra* note 59, at 129, 134–36; Grisso & Appelbaum, *supra* note 55, at 187–90.

[62]*See* Grisso et al., *supra* note 59, at 136; Grisso & Appelbaum, *supra* note 55, at 190.

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contextual understanding of capacity could improve the assessment. This Part first will note problems with the validity and reliability of tools used to assess capacity. It will also highlight issues with poor provider communication and the lack of accommodations for patients with disabilities in the assessment of their decision-making abilities. This Part will also discuss how capacity assessments can be abused and patients harmed when they are disqualified from making their own medical decisions. This Part will conclude by describing legal issues raised by disqualifying adult patients with decisional impairments from making contemporaneous medical decisions.

A. Questions about the Validity and Reliability of Capacity Assessment Instruments

There may be problems with the instruments used to formally assess capacity. Indeed, there is a body of empirical literature that reviews the capacity assessment process and instruments for reliability and validity.[63] Reliability can be understood as either "consistency"[64] or the reduction of measurement error.[65] In the process of constructing measures, in this case of decisional capacity, researchers will attempt to ensure the measure is stable (i.e., measurement over time is the same or test-retest reliability), that there are multiple measures that are internally consistent, and that when different evaluators use the measure, they come to the same result (i.e., interrater reliability).[66] Validity is "the extent to which a concept is accurately measured"[67] or "the extent to which an instrument measures what it purports to measure."[68] Reliability is necessary for validity.[69]

Sometimes there are issues with the validity of a particular instrument or means used to assess capacity. Although the researchers who developed the instrument likely intended it to measure the abilities to understand, appreciate, and reason (i.e., elements of decisional capacity),[70] the instrument may instead be assessing literacy, educational attainment, English proficiency, fear, cultural differences, communication disorders, or sensory disabilities.[71] Indeed, individuals with typical cognitive

[63]*See* Moye & Marson, *supra* note 10, at P8. These instruments often undergo testing prior to their publication and subsequent use. Other researchers can then assess the instruments as they are used in clinical practice.

[64]*See* Roberta Heale & Alison Twycross, *Validity and Reliability in Quantitative Studies*, 18 Evid. Based Nurs. 66, 66–67 (2015).

[65]*See* Carole L. Kimberlin & Almut G. Winterstein, *Validity and Reliability of Measurement Instruments Used in Research*, 65 Am. J. Health-Sys. Pharmacy 2276, 2277 (2008) (explaining that reliability involves "minimizing measurement error").

[66]*Id.*

[67]Heale & Twycross, *supra* note 64, at 66.

[68]Kimberlin & Winterstein, *supra* note 65, at 2278.

[69]*See id.* ("Validity requires that an instrument is reliable, but an instrument can be reliable without being valid.").

[70]Not every instrument assesses all domains of capacity. *See* Etchells, *supra* note 56, at 1–2, 4, 6–7, 10–11 (detailing how the Aid to Capacity Evaluation (ACE) focuses on understanding and appreciation).

[71]*See* Rebecca Dresser, *Autonomy and Its Limits in End-of-Life Law*, *in* The Oxford Handbook of U.S. Health Law 339, 402 (I. Glenn Cohen et al. eds., 2017) (emphasizing that a "patient's communication difficulties, fear, ambivalence, or hostility to medical professionals can lead evaluators to mistakenly label the patient incompetent"). Indeed, although researchers know that culture matters for medical decision-making, at present, research is limited on how culture may matter for assessing and demonstrating decisional capacity. *See* Moye & Marson, *supra* note 10, at P7. *See also* Grisso & Appelbaum, *supra* note 55, at 73–74 (describing "situational factors" that influence capacity assessments and ability to make health care decisions such as anxiety and culture). Capacity assessments may also be measuring "cultural health capital," a concept social scientists have developed and defined as "a specialized set of cultural skills, behaviors and interactional styles that are valued and leveraged as assets by both patients and providers in clinical encounters." Leslie A. Dubbin et al., *Cultural Health Capital and the Interactional Dynamics of Patient-Centered Care*, 93 Soc. Sci. & Med. 113, 114 (2013). Examples of cultural health capital can include "knowledge of medications and health conditions, the ability to communicate that knowledge efficiently, the ability to adjust one's interactional style, organizational skills, and cues of favorable social and economic status." *Id.* It is possible that some of these capacity instruments are measuring cultural health capital rather than the elements of decisional capacity. It is further possible that someone with high cultural health capital will avoid questions of their decisional capacity even if they have decisional impairments, and someone with low cultural health capital will have their decision-making abilities questioned despite having typical cognitive abilities. Finally, it is also important to note that instruments developed to assess capacity may not contain other relevant decision-making considerations and their relationship to capacity. Importantly, if formal assessments do not include a discussion of a patient's values, the findings may miss how a patient's decision can be "rational"

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functioning may perform poorly on a formal capacity assessment.[72] Clinical judgment of patient capacity in the absence of a formal instrument (i.e., informal assessment) may suffer from similar problems.

There are also questions about the reliability of instruments to assess decisional capacity. Indeed, different providers using the same instrument to assess the same patient may come to different conclusions about a patient's capacity, which could indicate poor reliability, and thus decreased confidence about the usefulness of the instrument. Significant problems with reliability in assessing capacity will prompt questions about the validity of the assessment.[73] If reliability is poor, perhaps the means of assessing capacity is not valid. However, even if there is excellent reliability for a particular instrument, it may not be valid.[74]

Researchers have conducted studies comparing different instruments (used to assess the same patient) or comparing results from instruments to clinicians' judgment.[75] A review of empirical literature found that there are significant validity and reliability issues in assessing capacity because different conclusions are reached about a patient's decisional capacity depending on the instrument or clinical judgment relied upon.[76] Specifically, this review found that "[a]greement between physicians [about capacity] is near chance for patients with dementia,"[77] which means there is poor reliability (and thus poor validity) of physicians' judgments of patient capacity. The review also concluded that physician

considering these values. Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 15–16 (noting that values are not part of many capacity assessment tools and arguing that "in situations where a capacity determination is more challenging, being able to ascertain, from the patient and/or collateral sources, whether the [decision] is in line with the patient's longstanding values can add strength to the determination of capacity," although values can change and a decision at odd with previous values does not necessarily indicate incapacity). Including questions designed to elicit patient values to assess their capacity may result in more accurate determinations but will come at the cost of patient privacy. *See infra* Part II.C.1.

[72]Many studies have found that individuals with typical cognitive abilities do not understand their diagnoses, prognoses, or the risks and benefits of various medical interventions even after they have been given this information. *See, e.g.*, Wright, *Resuscitating Consent*, *supra* note 19, at 900–05, 901 n.70 (summarizing empirical research demonstrating that patients without decisional impairments do not understand their medical conditions and treatment options due to failure of providers to meet all informed consent legal obligations); *see generally* Carl E. Schneider, The Practice of Autonomy: Patients, Doctors, and Medical Decisions (1998) (explaining how medical decisions are rarely autonomous, even for patients without decisional impairments). This is, in part, because the information is often unfamiliar and complex, and the individuals are deciding in moments of sickness or stress. Schneider, *supra*, at 55, 62 ("Much information is readily and fully comprehensible only to someone with medical training" and "Patients may be mentally enfeebled by decay, disease, and distress; their minds will frequently be clouded by drugs and other treatments."). Other studies have demonstrated that individuals with typical cognitive abilities often do not act rationally given various cognitive biases. *See* Wright, *End of Life*, *supra* note 19, at 1067, 1097–98 (discussing failures of rationality in end-of-life decision-making, even for patients who are capable of making medical decisions); Hawkins, *supra* note 24, at 75 (arguing that capacity should not "rely on idealized notions of decision-making" and that the bar for demonstrating capacity should not be so high it excludes adults with ordinary decision-making abilities); Navin et al., *supra* note 26, at 77–78 (arguing that many individuals may struggle to explain or justify their values); Sean M. Scott, *Contractual Incapacity and the Americans with Disabilities Act*, 124 Dickinson L. Rev. 253, 297–302 (2020) (arguing that insights from behavioral economics demonstrate that people with typical cognitive abilities make irrational economic decisions and that people with disabilities should not be held to a higher standard of rationality).

[73]*See, e.g.*, Cornelia M. Ruland et al., *Reliability and Validity Issues Related to Interactive Tailored Patient Assessments: A Case Study*, J. Med. Internet Rsch., Aug. 1, 2007, at 1, 8 ("[A] basic core of evidence of reliability and validity is needed for any instrument. Reliability is a prerequisite for validity, and an unreliable instrument cannot be valid.").

[74]*See* Heale & Twycross, *supra* note 64, at 66 (illustrating that even if a research instrument consistently produces the same results and is thus reliable, if it does not measure what it purports to measure, it cannot be valid). *See also* Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 5 (noting limitations of capacity assessment instruments and that although they are reliable, there are limitations to their validity because "they may grant too great an importance to a person's measurable cognitive skills and not enough to their ability to make others aware of their wishes through verbal and non-verbal communication" (internal citations omitted)).

[75]*See* Moye & Mason, *supra* note 10, at P6 ("Agreement between instrument-based assessments of capacity and physician-based assessments is poor in some studies and good in others . . . . Agreement between different capacity measures is good for understanding, fair for reasoning and expressing a choice, and poor for appreciation." (internal citations omitted)).

[76]*See id.* at P7.

[77]*Id.* at P6.

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judgment of patient capacity often differed from the outcome from a formal capacity assessment, and that various capacity instruments had little agreement on the four criteria for capacity.[78] In sum, research has found that "[r]ates of [decisional] impairment varied, depending on the instrument used."[79]

B. Problems in Process of Assessing Capacity

Even if a capacity instrument is valid and reliable, there may also be problems with when and how capacity is assessed in clinical encounters.

First, questioning a patient's decision-making abilities may occur too early in the clinical encounter and focus too much on the patient rather than the communication between the patient and health care provider. If a patient seems confused and does not appear to understand their diagnosis, prognosis, or treatment options, a health care provider may think their patient has impaired decision-making abilities, which may prompt a capacity assessment. It could be that the patient has typical decision-making abilities, however, and that the reason for comprehension difficulties is that the provider has communicated poorly[80] or because the patient has received conflicting information from different providers.[81] Thus, the patient may fail to demonstrate capacity because there have been provider communication failures. In this instance, the patient's capacity has been weakened through suboptimal interactions with providers and could be strengthened if appropriate changes are made.

If providers can improve the informed consent discussion to increase patient understanding, they should.[82] Instead of assuming problems with comprehension are due to patient's cognitive impairments, providers should assess whether they can increase comprehension by altering their communication style and how they disclose information. It may be the case that with further discussion and with changes in how information is presented to patients (e.g., more slowly, with less jargon, with opportunity for the patient to ask clarifying questions, with complementary visual or written information, in a language in which the patient is fluent), the patient may obtain and be able to demonstrate better understanding.[83] Again, (in)capacity is relational in this context. Patient understanding depends, in large part, on their interactions with their health care providers.[84]

[78] *See id.* at P7 ("[T]hose studies focusing on reliability between capacity assessment methods tend to find limited agreement between evaluations by multiple clinicians, multiple measures, or between a clinician and a measure, especially for the standards of appreciation and reasoning. This suggests that more work may be needed to further flesh out these constructs and to improve the reliability and validity of their measurement.").

[79] *Id.* at P5 (describing studies on cognitive impairment and capacity to consent to medical treatment for individuals with dementia).

[80] Wright, *Resuscitating Consent*, *supra* note 19, at 900–02, 905 (summarizing research that providers are not meeting their informed consent obligations and that providers often do not provide sufficient information necessary for patients to make medical decisions, which has led to arguments for patient decision-making aids). *See also* Ganzini et al., *supra* note 4, at 265 ("Lack of adequate information should not be mistaken for lack of decision-making capacity.").

[81] *See* Ganzini et al., *supra* note 4, at 265 (discussing how patients who receive inconsistent or incomplete information cannot be expected to make an informed decision and that receiving inconsistent information happens frequently in medical settings, because information comes from many different sources, including an inpatient treatment team, primary care providers, etc.).

[82] *Compare* Valerie Gutmann Koch, *Reimagining Informed Consent: From Disclosure to Comprehension*, 14 U.C. Irvine L. Rev. 894, 896 (2024) (arguing for patient understanding as a legal requirement in informed consent law and practice), *with* Wright, *Resuscitating Consent*, *supra* note 19, at 953–55, (arguing against legal requirement of patient understanding in context of treatment refusals). My prior work should not be read to suggest that physicians should not try to increase patient understanding but rather that the existence or evidence of patient understanding in this specific context — treatment refusal — should not be required for patients to exercise their legal rights to refuse treatment.

[83] *See* Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10 at 5, 7–8, 11–12, 17 (discussing variety of techniques to better facilitate comprehension and thus increase autonomy and decision-making opportunities for individuals with intellectual disabilities, Alzheimer's disease, dementia, and psychiatric disorders).

[84] *See* Ganzini et al., *supra* note 4, at 265–66 (noting that providers can also ensure patient understanding by making "special efforts," including exercising "patience and repetition, or allowing extra time for patients to digest information or to consult with family and friends").

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Second, if a patient's decisional capacity is only assessed once, the results may not be indicative of the patient's typical decision-making abilities. Patient's decision-making abilities may change based on the environment (e.g., noisy, crowded hospital area), time of day, prescription drug use (e.g., overly sedated, insufficient dose or incorrect medication for psychiatric illness, etc.), other substance use (e.g., impaired from alcohol), and many other factors.[85] Indeed, incapacity may be only temporary,[86] and so if a patient is found to be incapacitated and it is not an emergency, it may be advised to see if the patient regains capacity or whether capacity can be restored prior to making a decision.[87] Ideally, capacity should be assessed multiple times.[88]

Third, because patients with disabilities that affect their ability to receive information or communicate their decisions may wrongly be thought to lack decision-making capacity, accommodating these patients so they can make their own medical decisions should be a priority (e.g., providing disability-specific accommodations such as word boards, interpreter, captioning technologies, etc.).[89]

C. Insufficient Consideration for Privacy, Wellbeing, and Power

Assessing capacity and disqualifying patients who are determined to lack capacity raises serious ethical considerations. As discussed previously, adults are entitled to make their own medical decisions because of their interests in maintaining bodily integrity, exercising autonomy and self-determination, and experiencing wellbeing.[90] There are other interests that are important to consider, however, such as medical providers' professional autonomy,[91] the patient's family's preferences about the patient's medical treatment and its effects on the family unit,[92] and state interests in promoting life and health

[85] *See* Wright, *Equality of Autonomy*, *supra* note 50, at 174 n.102.

[86] *See* Ganzini et al., *supra* note 4, at 265. An example of an instance of temporary incapacity is when an older person has a urinary tract infection (UTI), which can cause delirium (i.e., "a syndrome of severe neuropsychiatric disturbance resulting in a change in awareness, cognition, and fluctuation in attention in a short span due to medical conditions that cannot be described by already existing neurocognitive disorders"). Chandrani Dutta et al., *Urinary Tract Infection Induced Delirium in Elderly Patients: A Systematic Review*, Cureus, Dec. 2022, at 1, 6, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9827929/ [https://perma.cc/39KL-MTLE]. When the UTI is treated with antibiotics, the delirium may cease, although antibiotic treatment should be delayed in asymptomatic patients with delirium until the UTI diagnosis is confirmed. *Id.* at 10. If delaying all other medical decisions until the UTI-caused delirium is reversed will not harm the patient, this may be the best way to respect the patient's autonomy. *See also* Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 12–13 (discussing fluctuating capacity and more specifically, delirium).

[87] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 935–36 (arguing that one reform to ensure that more adult patients can make their own medical decisions is that "in the instance of temporary incapacity, providers can wait until capacity is regained").

[88] *See* Ganzini et al., *supra* note 4, at 265 (explaining in circumstances where patients are "intermittently incapacitated," "decision-making capacity must be regularly reassessed").

[89] *See* Wright et al., *supra* note 53, at 61–62 (illustrating ways that patients with disabilities can communicate medical decisions, including through detailed yes/no question frameworks and use of fMRI imaging tools); Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 6–7, 11–12. For an example of suggestions for how to accommodate memory impairments for patients with mild cognitive impairments or dementia in the process of discussing end-of-life options, see Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 5. The authors note that although memory impairments can hinder understanding without interventions (e.g., providing written information), "deficits in short-term memory do not necessarily preclude capacity." *Id.*

[90] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 895–96, 896 n.44.

[91] *Id.* at 944–45 (discussing patient and provider autonomy interests in the case of treatment refusals but pointing out that "informed consent law should weigh patients' interests more heavily than provider autonomy in order to promote patient well-being").

[92] *See* Wright, *End of Life*, *supra* note 19, at 1071–72, 1081–86 (discussing concerns that the interests of family members may not be consistent with those of the patient's but noting that patients often take into account their family members' opinions, the burden of their decision on the family unit, and the family unit's abilities to cope with a patient's decision regarding end-of-life care).

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and controlling costs.[93] However, the patient's interests will often outweigh these (possibly) competing interests because the corporeal effects of the medical decision are primarily experienced by the patient.[94] It may thus be the case that even if a patient has decisional impairments, they should remain the rightful decision-maker even if in other social or legal contexts they may be prohibited from deciding.[95]

This part will focus on the implications of assessing capacity for patient privacy, patient wellbeing, and health care provider power.

1. Capacity Assessments May Infringe Patient Privacy

Assessing capacity can constitute an infringement on patient privacy.[96] The infringement may only be minimal if a clinician asks patients to discuss the risks and benefits of potential medical interventions to assess understanding. However, to judge the quality of the patient's decision-making, the assessment may delve into the patient's values, beliefs, preferences, goals, plans, relationships, or other matters that ordinary individuals may not wish to discuss with strangers.[97] This raises an important question. Specifically, should patients have to divulge information in order to retain their legal rights to make their own medical decisions?[98] For example, if a patient believes that prayer will result in healing, should patients be required to disclose their religious beliefs to health care providers, and should these beliefs be subject to investigation by health care providers?[99]

This Article does not argue that patients should not divulge information about their values and beliefs. Indeed, discussing treatment options with their health care providers in light of such information is the hallmark of shared decision-making, which many patients prefer, and which will likely result in an autonomous medical decision.[100] This Article instead asserts that patients should not be required to disclose such information if they prefer not to and that the privacy implications of treatment decision-making capacity assessments are underappreciated in the bioethical and clinical literature.[101]

[93] *See id.* at 1070, 1123–24 (discussing how countervailing state interests such as preserving life and protecting innocent third parties from emotional and financial harm must be weighed against a patient's autonomy and ability to refuse life-saving medical treatment).

[94] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 943. Other material effects of the medical decision include costs, which are often spread among the population through insurance design or taxation policies, and potential spread of contagious disease, considerations of which are outside the scope of this Article. *See* Wright, *End of Life*, *supra* note 19, at 1065, 1111, 1114 n.277.

[95] Others may disagree, noting that the serious stakes of medical decisions (e.g., loss of life or health) may mean that the more serious the decision, the more important it is for patients to demonstrate decisional capacity. *See* Drane, *supra* note 33, at 925–27.

[96] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 917–18, 921 (explaining that recent understandings of autonomy within informed consent law are rooted in right to privacy and arguing that "[t]he use of capacity assessments to investigate patients' decisions is an affront to patient privacy").

[97] Asking about patient values would likely occur in the context of an informal capacity assessment (i.e., a conversation between a patient and their health care provider) given that many formal capacity assessments do not include discussion of patients' values. Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 15–16. Recent scholarship has argued for much more intrusive questioning of patients by health care professionals. *See* Hawkins, *supra* note 24, at 7 (suggesting questions such as "Would the life be dominated by suffering? Would it have as many opportunities for pursuit of her values? Is she likely to be able to find happiness in that life? Good answers will require knowledge of the particular individual, her values, her likes and dislikes, as well as her psychological dispositions."). Similarly, scholars have argued that more individuals should be involved in the assessment process, which increases the burden on patient privacy, although it may function as a safeguard against finding a patient incapacitated. *Id.* at 7–8.

[98] I have argued in prior work that they should not have to do so in the case of treatment refusals and that "informed refusals" are not legally required. *See* Wright, *Equality of Autonomy*, *supra* note 50, at 166 n.49; Wright, *Resuscitating Consent*, *supra* note 19, at 920–22. *See also infra* Part II.D.3 (explaining why capacity assessments should not be required for treatment refusals).

[99] If patients do disclose such religious beliefs, leading experts in capacity assessment caution that these beliefs are not necessarily indicative of impaired decision-making abilities and that any subsequent inquiry should be limited to determining whether the religious beliefs are genuine rather than valid. Grisso & Appelbaum, *supra* note 55, at 47–48.

[100] *See generally* Wright, *End of Life*, *supra* note 19 (discussing relational autonomy and shared decision-making).

[101] *See* Wright, *Recent Trends*, *supra* note 9, at 122. Indeed, clinicians argue for probing the genuineness of religious beliefs, for example. *See* Grisso & Appelbaum, *supra* note 55, at 47–48. It is unclear how this is considered appropriate given that such a

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2. Accounting for the Negative Effects of Capacity Assessment, Determination of Incapacity, and Decision-Making Disqualification on Patient Wellbeing

If a patient has been expressing stable preferences (despite their decisional impairments), this is something that others should take seriously in order to promote patient wellbeing.[102] Even if an individual lacks capacity, they retain the interest in maintaining bodily integrity,[103] and if they are conscious, they can experience a decline in wellbeing if they are treated in a manner that conflicts with their wishes.[104]

Indeed, it is important to consider the effect of the capacity assessment process and determination of incapacity on the patient's wellbeing.[105] When a patient is subjected to a formal assessment of their decisional capacity and is deemed "incapacitated," this can be damaging to their sense of self and to their subjective wellbeing.[106] Additionally, if the effect of such a determination means that providers forcibly override their patient's contemporaneous treatment refusals, this will have a profoundly detrimental effect on patient wellbeing, including medical wellbeing.[107] Even if the patient assents to treatment, if they are marginalized in the medical decision-making process, this can decrease wellbeing because many patients report a desire to participate in decision-making that affects them even if someone else ultimately makes the decision.[108]

Additionally, formally assessing capacity may be too physically burdensome for some patients, including those who are very sick or actively dying.[109] Insisting on assessments under such circumstances may have the effect of not allowing patients to make the decision,[110] to the patient's detriment.

These potential adverse effects on patient wellbeing should be considered prior to formally assessing capacity. Indeed, these negative effects on patient subjective wellbeing may be so great and the expected benefits to patient objective medical wellbeing from substitute decision-making so marginal that patients should be permitted to make contemporaneous medical decisions despite suspected cognitive impairments without having to endure the capacity assessment process.

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probe would not be acceptable in other contexts, how such a probe should be conducted, or why clinicians would assume they have any expertise in this domain and are qualified to investigate patient beliefs. Perhaps the privacy implications of capacity assessments are underappreciated in clinical scholarship because there is a significant lack of patient privacy in hospital settings. *Id.* at 74.

[102]*See* Jason Adam Wasserman & Mark Christopher Navin, *Capacity for Preferences: Respecting Patients with Compromised Decision-Making*, 48 Hastings Ctr. Rep. 31, 34–35 (2018).

[103]Jonathan Herring & Jesse Wall, *The Nature and Significance of the Right to Bodily Integrity*, 76 Cambridge L.J. 566, 583 (2017).

[104]Wright, *Resuscitating Consent*, *supra* note 19, at 926.

[105]*See generally* Wright, *Recent Trends, supra* note 9 (commenting on scholarship on decision-making capacity). I have argued that wellbeing is not given sufficient consideration when discussing capacity and determination thereof. *See id.* at 122.

[106]*See* Jeffrey P. Spike, *Informed Consent is the Essence of Capacity Assessment*, 45 J.L. Med. & Ethics 95, 99 (2017). Even starting the capacity assessment process negatively affects patients. *See id.*

[107]Wright, *Resuscitating Consent*, *supra* note 19, at 913–14, 927–29. This provides an additional reason to be cautious about using capacity assessments in the treatment refusal context. Finding a patient to lack capacity when they are seeking a particular medical treatment may also be detrimental to their wellbeing. *See, e.g.*, stef m. shuster, *Performing Informed Consent in Transgender Medicine*, 226 Soc. Sci. & Med. 190, 196 (2019). This may be more ethically justified than in the treatment refusal context, however, given that providers' professional autonomy interests may outweigh patient autonomy interests in this context. *See* Wright, *Resuscitating Consent*, *supra* note 19, at 922.

[108]*See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 282–84 (explaining that persons with dementia prefer to be involved in decisions about their lives and are unhappy when marginalized in the process); Wright, *Resuscitating Consent*, *supra* note 19, at 900–05 (describing research on decision-making preferences, which largely supports patients' desire to engage in shared decision-making).

[109]*See, e.g.*, Linda Ganzini et al., *Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists*, 157 Am. J. Psychiatry 595, 599 (2000) ("The extensive procedure for determining competence recommended by respondents might be physically difficult for debilitated dying persons to tolerate.").

[110]Providers may justify this requirement as a "safeguard" or protection. *Id.*

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3. Using Capacity Assessments to Exert Power over Patients

Experts in the science of capacity assessment note that "[c]apacity assessments are ultimately human judgments occurring in a social context. It is therefore crucial that we understand how clinical judgments of decisional capacity relate to the social dynamics of decision making."[111]

One important consideration about the context of capacity assessments concerns power dynamics in the patient-provider relationship. In the medical setting, physicians and other clinicians have more power than patients.[112] There are many reasons for this power imbalance, including physicians' greater medical knowledge, their exclusive right to provide medical services and their subsequent ability to function as gatekeepers to desired treatment, their high status in society, and patients' medical vulnerability.[113]

Although physicians most likely have noble motives (e.g., helping patients), they can use their power over patients along with assessments of capacity to direct the ultimate medical decision and determine who makes it (i.e., paternalism persists).[114] For example, patients' capacity may only be formally assessed (and their decisional authority subsequently removed) when they disagree with their physician or when there is conflict in the patient-provider relationship.[115] And if patients with decisional impairments are compliant or agreeable, they may never have their decision-making abilities assessed and thus may be permitted to "decide" (i.e., agree with their physician) even if they are incapacitated.[116] Moreover, when providers in hospitals request a formal capacity assessment from colleagues in the hospital's psychiatric department, consulting psychiatrists may be pressured to find the patient incapacitated because that is what the treating physician wants.[117]

Additionally, empirical studies have demonstrated that for medical decisions that are "controversial," in their role as gatekeepers to treatment, physicians may impose stricter capacity requirements on their patients.[118] This has been documented in the context of patients seeking

[111]Moye & Marson, *supra* note 10, at P8.

[112]*See generally* Laura Nimmon & Terese Stenfors-Hayes, *The "Handling" of Power in the Physician-Patient Encounter: Perceptions from Experienced Physicians*, BMC Med. Ed., Apr. 18, 2016, at 1 (reporting physicians' perceptions of the power dynamic between patients and physicians).

[113]*See generally id.* (explaining the circumstances in which physicians have greater power in the physician-patient relationship).

[114]*See id.* at 4. It is also possible that third parties may use the capacity assessment process to exert power over patients, but analysis of this possibility not within the scope of this Article.

[115]Wright, *Resuscitating* Consent, *supra* note 19, at 893 n.53, 919. *See* Berg et al., *supra* note 1, at 103–06; Beauchamp & Childress, *supra* note 4, at 117; Linda Ganzini et al., *Pitfalls in Assessment of Decision-Making Capacity*, 44 Psychosomatics 237, 238, 241 (2003); Andrew H. Mebane & Harry B. Rauch, *When Do Physicians Request Competency Evaluations?*, 31 Psychosomatics 40, 41–42, 44–45 (1990); C. Umapathy et al., *Competency Evaluations on the Consultation-Liaison Service: Some Overt and Covert Aspects*, 40 Psychosomatics 28, 32 (1999); Katrina Hauschildt & Raymond De Vries, *Reinforcing Medical Authority: Clinical Ethics Consultation and the Resolution of Conflicts in Treatment Decisions*, 42 Socio. of Health & Illness 307, 311 (2020); Grisso & Appelbaum, *supra* note 55, at 81. Indeed, treatment refusal has been identified as a major reason why physicians seek to have their patient's capacity assessed. *See id.* at 63–66.

[116]*See* Wright, *Resuscitating Consent*, *supra* note 19, at 918–19. It is also important to question whether even individuals who appear, to their physicians and family members, to have decisional capacity could evidence this capacity if subjected to an assessment. *See* Wright, *End of Life*, *supra* note 19, at 1098. Given that capacitated patients could "fail" a capacity assessment, it is worth questioning the utility of assessing capacity. *See also* Wright, *Resuscitating Consent*, *supra* note 19, at 922 ("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.").

[117]Mark Katz et al., *Psychiatric Consultation for Competency to Refuse Medical Treatment*: *A Retrospective Study of Patient Characteristics and Outcome*, 36 Psychosomatics 33, 39 (1995); Umapathy et al., *supra* note 115, at 28–29. Further, a consulting psychiatrist will have very limited contact with the patient and may thus be unable to adequately "assess whether the patient's decision is consistent with his or her goals and values." *See* Ganzini et al., *supra* note 4, at 266. *But see* Grisso & Appelbaum, *supra* note 55, at 79 (discussing benefits of capacity consultations).

[118]*See* shuster, *supra* note 107, at 196.

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gender-affirming care[119] and in surveys of psychiatrists' views of the capacity needed to access medical aid in dying.[120]

Further, physicians can use their power over patients in combination with the capacity assessment process to ensure that medical logic is privileged in decision-making. Patients may make medical decisions based on non-medical factors (e.g., religious beliefs, family relationships, etc.), and when forced to justify their decisions to health care providers, their decisions may seem irrational even when they are not.[121] Questioning patient capacity in such circumstances is unwarranted.[122] It is also important to note that physicians are not experts in their patients' values or beliefs, and so assessment of their patients' capacity considering values and beliefs may be more appropriate for other types of clinicians (e.g., medical social workers).[123]

In brief, capacity assessments implicate issues of power and control. Indeed, using a capacity assessment grants decision-making power to doctors instead of patients,[124] and as I have noted in prior work, this process can be abused by physicians who want to control the patient's medical decisions despite the legal and ethical requirement to obtain their patient's consent.[125] This is another way in which (in)capacity is constructed relationally and contextually. Patient (in)capacity in this context is a property of the patient-physician relationship and relationships between health care providers.

D. Potential Legal Problems with Capacity Assessments

This section will discuss the legal implications of preventing adult patients from making their own medical decisions based on the incapacity exception to the informed consent requirement. The first section discusses how sometimes providers unlawfully presume incapacity and disqualify patients from making contemporaneous decisions. The second section discusses how providers may not know or follow the requirements for capacity in their jurisdiction. The third section describes the special instance of capacity for treatment refusals. The final section discusses capacity assessments and supported decision-making.

1. Presuming Incapacity Conflicts with Legal Mandate to Presume Capacity

Despite the criticisms present in this Article about assessing capacity, such an exercise is preferable to making assumptions about a patient's decisional abilities based on diagnosis alone. Indeed, researchers have described how there may be a presumption that some individuals are incapacitated due to their medical conditions, such as schizophrenia or Alzheimer's disease,[126] despite the fact that

[119]*See id.* at 192–93; *see also* Wright, *Resuscitating Consent*, *supra* note 19, at 904 ("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 the requested medical interventions even if otherwise medically indicated.").

[120]*See generally* Ganzini et al., *supra* note 109 (surveying forensic psychiatrists about their views on medical aid in dying and capacity assessments and finding that the vast majority thought that two clinicians needed to assess patient capacity, that a high evidentiary standard for incapacity such as "preponderance of evidence" or "beyond a reasonable doubt" should be required despite the risk that competent people would be excluded from this end-of-life option, and that a diagnosis of depression should automatically disqualify patients on incapacity grounds).

[121]Wright, *Resuscitating Consent*, *supra* note 19, at 919 n.155.

[122]*See* Grisso & Appelbaum, *supra* note 55, at 48. Scholars assert that patients making decisions on the basis of values or beliefs should not necessarily result in a finding of incapacity. *See id.* This Article argues that making decisions on such bases should not lead to a capacity assessment in the first place.

[123]*See* Wright, *Resuscitating Consent*, *supra* note 19, at 945 (asserting that health care providers are not experts in their patients' preferences or values, and thus should not automatically be deferred to in relation to such). As discussed previously, however, mandating that patients disclose such information is a privacy infringement. *See supra* Part II.C.1.

[124]Wright, *Resuscitating Consent*, *supra* note 19, at 918–22.

[125]*See id.* at 920 n.159, 922.

[126]Renée L. Beard, Living with Alzheimer's: Managing Memory Loss, Identity, and Illness 109 (2016) (describing how at the moment of informing patients about their diagnosis of mild cognitive impairment or dementia, providers begin

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many such individuals are able to make decisions and despite legal, ethical, and clinical guidance to the contrary.[127] It is thus a legal problem if medical decision-making authority is removed from an adult solely on the basis of their diagnosis; therefore, in some instances, it can be problematic not to assess capacity.

2. Legal Standards for Capacity Differ by Jurisdiction and Type of Health Care Decision

Additional legal issues arise when capacity is assessed. For example, the standard for legal competence may differ by jurisdiction, and health care providers may not be aware of what standard governs their assessment.[128] Providers who work in hospitals may instead rely on the hospital organizational policy without understanding that their legal obligations may differ from this policy. This misunderstanding may result in a patient being unlawfully deprived of a fundamental right to maintain bodily integrity. Similarly, the jurisdiction's legal standard for capacity may differ by type of health care decision,[129] and if providers use a single capacity standard, some patients may be disqualified from decisions they are, in fact, able (cognitively and legally) to make.

3. Capacity Assessments Should Not Be Required for Treatment Refusals

Another legal implication concerns the special context of treatment refusal (compared to treatment consent). Although physicians are legally required to disclose information to their patients as part of the informed consent process, patients generally have no *legal* duty to disclose any information to their health care providers.[130] This lack of legal duty includes a lack of duty to participate in a capacity assessment in the case of treatment refusals.[131] When patients are seeking particular treatments, physicians can condition access to the treatment on patient disclosure of some types of information because (absent special circumstances) providers are entitled to use their professional judgment to decide whether providing a specific treatment is medically appropriate based on information available to

treating their patient as lacking capacity despite their actual decision-making abilities); *see* Thomas Grisso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 L. & Hum. Behav. 149, 171 (1995) (demonstrating that individuals with severe mental illness may perform "adequately" on capacity assessments and sometimes even better than individuals without mental illness and arguing that incapacity should not be presumed for the mentally ill); *see also* Weithorn, *supra* note 24 (discussing problems with presuming incapacity based on psychiatric conditions or other mental disorders).

[127] *See* Grisso & Appelbaum, *supra* note 55, at 68–71 (describing the relationship between diagnosis, decision-making abilities, and need for capacity assessments); *see also* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 273–77, 281 (summarizing empirical literature on the decision-making abilities, preferences, and experiences of persons with dementia and finding that many individuals with mild to moderate dementia remain able to make contemporaneous medical decisions); Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 3–4 (summarizing empirical literature on the decision-making abilities of persons with dementia and noting that many individuals with mild cognitive impairment and mild to moderate dementia retain medical decisional capacity); Ganzini et al., *supra* note 4, at 266 (arguing that neuropsychiatric diagnoses do not automatically cause incapacity). The ACE instrument reminds evaluators: "Remember that people are presumed capable. Therefore, for your overall impression, if you are uncertain, then err on the side of calling a person capable." Etchells, *supra* note 56, at 4.

[128] Grisso & Appelbaum, *supra* note 126, at 170; Grisso & Appelbaum, *supra* note 55, at 78–79 (asserting that providers need to know the legal standard for capacity in their jurisdiction). Scholars summarizing the literature on assessing capacity point to seven general legal standards of capacity and note that any of them can be used or multiple can be used in a particular jurisdiction. Beauchamp & Childress, *supra* note 4, at 118. The most basic standard is the ability to communicate a decision. *Id.* Other standards focus on whether information is understood and appreciated, and still others require the person to reach a decision judged to be reasonable. *Id.*

[129] This may be the case for life-ending decisions such as medical aid in dying or for other serious, irreversible decisions such as sterilization, for example. Wright, *Resuscitating Consent*, *supra* note 19, at 897 n.53.

[130] *Id.* at 920–21. *But see* David Orentlicher et al., Bioethics and Public Health Law 211–12 (3d ed. 2013) (noting how some courts have imposed contributory liability when patients have not fully or truthfully disclosed information to their physicians). Further, patients may be advised to disclose relevant information to their physicians to receive medical care that matches their values and treatment goals. Wright, *End of Life*, *supra* note 19, at 1088–91 (describing shared decision-making).

[131] Wright, *Resuscitating Consent*, *supra* note 19, at 920–21.

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them.[132] However, when the patient is refusing medical intervention, given the law's respect for maintenance of bodily integrity, physicians' judgment of the soundness of their patient's decision to refuse medical intervention should have limited legal relevance.[133] In instances of treatment refusal, the only capacity that must be assessed or demonstrated is the ability to communicate "no."[134]

4. Capacity Assessments May Conflict with Supported Decision-Making and Other Disability Laws

There are also legal questions about the appropriateness of assessing decisional capacity and removing decision-making authority from patients with disabilities. The Americans with Disabilities Act requires that health care providers, as places of public accommodations,[135] reasonably accommodate patients with disabilities and ensure effective communication.[136] This means that health care providers must explore alternatives to disqualifying their patients with cognitive and other impairments from making their own decisions, including providing access to assistive technology[137] or allowing decisional support to increase capacity or assist with communication,[138] both of which can be considered "reasonable accommodations."[139] The latter option is known as supported decision-making, which many states now provide as an option to persons with cognitive impairments as an alternative to guardianship and substitute decision-making.[140]

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[132] *Id.*; *see also supra* note 91 (discussing health care provider interests in patient medical decision-making); *supra* note 107 (discussing health care provider interests in patient medical decision-making).

[133] Wright, *Resuscitating Consent*, *supra* note 19, at 926.

[134] *Id.* at 921; *see also supra* note 98. This argument is more fully developed in Wright, *Resuscitating Consent*, *supra* note 19. Of note, my view conflicts with clinical guidance to assess capacity when treatment is refused. *See* Grisso & Appelbaum, *supra* note 55, at 63–66. It also conflicts with the development of the concept of "informed refusals" in the bioethical literature. Wright, *Resuscitating Consent*, *supra* note 19, at 920–21. It is a view that is broadly consistent with law, however, especially given that it is about *not requiring* patients to participate in capacity assessments for treatment refusal rather than the advisability and voluntariness of such participation. *See generally* Wright, *Resuscitating Consent*, *supra* note 19. This view also privileges the corporeal aspects of patient autonomy as well as patient privacy.

[135] Health care providers who work in private settings are covered in the ADA Title III definition of "places of public accommodation," which includes "professional office of a healthcare provider" and "hospital." 28 C.F.R. § 36.104 (2025) (ADA Title III Regulations Definitions). Health care providers who work in public settings are covered by ADA Title II. 42 U.S.C. ch. 126(II).

[136] ADA regulations direct that:

> A public accommodation shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, *i.e.*, significant difficulty or expense.

28 C.F.R. § 36.303(a). ADA regulations further direct that "A public accommodation shall furnish appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities." 28 C.F.R. § 36.303(c)(1).

[137] Illustrations of required auxiliary aids and services can be found at 28 C.F.R. § 36.303(b).

[138] Decisional supports are also addressed in ADA Title III regulation when places of public accommodation are prohibited from relying on "companions" of disabled individuals to "interpret or facilitate communication, except . . . where the individual with a disability specifically requests that the accompanying adult interpret or facilitate communication, the accompanying adult agrees to provide such assistance, and reliance on that adult for such assistance is appropriate under the circumstances." 28 C.F.R. § 36.303(c)(3)(ii). Supported decision-making is also consistent with the ADA because it can be considered an accommodation appropriate for some types of disabilities. Wright, *Dementia and Disability Law*, *supra* note 50, at 30; Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 305.

[139] Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 305.

[140] *Id.* State legislatures continue to adopt this decision-making model into law, and nearly half of states have adopted supported decision-making legislation. To see a map of states that currently recognize supported decision-making agreements, see *U.S. Supported Decision-Making Laws*, Ctr. for Pub. Representation, https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/ [https://perma.cc/ZBY2-ENHM] (last visited Sep. 16, 2024). This decision-making model can be used informally as an accommodation for disability in states that have not adopted supported decision-making legislation. *See supra* note 138.

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Supported decision-making is premised on principles of self-determination and equality under the law.[141] The development of supported decision-making models and their adoption into law is responsive to the United Nations Convention on the Rights of Persons with Disabilities Article 12 "Equal Recognition before the Law" that directs that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and that parties to the Convention must "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."[142]

With supported decision-making, an adult with a cognitive disability enters into an agreement with someone they trust to assist them with making decisions.[143] The ultimate decision-making authority (under state law) lies with the person with the disability,[144] but they may ask their supporter(s) to assist with gathering information, thinking through their options, and communicating the decision to third parties, as well as other decision-making tasks.[145] The goal of supported decision-making is for a person with cognitive impairments to be self-determining, and supported decision-making is consistent with the concept of relational autonomy.[146]

Importantly, current supported decision-making laws in the United States direct that third parties rely on formal agreements, which means that a patient with such an agreement who may otherwise be deemed incapacitated by their providers may be entitled as a matter of law to make their own decisions.[147] Separate but related, if providers disqualify their patients from making their own medical

[141]Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 284–85.

[142]*Id.* Article 12 directs:

> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law . . . . The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 12 (Dec. 13, 2006).

[143]Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 285.

[144]*Id.* at 285, 290–92.

[145]*Id.* at 289–90. Other examples of decision-making assistance can be seen in articles in the symposium on "Supported Decision Making and Clinical Research". *See supra* note 50.

[146]Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 323.

[147]*Id.* at 262–63. *See also* Wright, *Resuscitating Consent*, *supra* note 19, at 923 ("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."). However, as I have noted elsewhere:

> This raises the question of what in the model of formal supported decision-making provides legal capacity: the existence of the agreement with its declaration that the person with a disability can act independently of the agreement or the provision of support to assist in decision-making that leads to choices that further the interests of the person with a disability (as defined by the person with a disability).
>
> In the former case, no capacity assessment should ever be conducted because the results are irrelevant; they have legal capacity regardless of what an assessment would reveal. In the latter case, however, the important question is whether the provision of support would increase decisional capacity to the point of passing a clinician-administered assessment. That is, does the provision of decision-making assistance lead to an increase in the understanding, appreciation, and reasoning abilities of the principal? If not, the principal would be ineligible to make the particular decision."

Wright, *Equality of Autonomy*, *supra* note 50, at 186 n.145.

There are questions about whether someone who lacks capacity can enter into a supported decision-making agreement and then subsequently use decisional supports to demonstrate capacity. *See* Reid Kress Weisbord & David Horton, *The Future of Testamentary Capacity*, 79 Wash. & Lee L. Rev. 609, 665 (2022) (discussing how some states allow support to demonstrate capacity, how others require capacity prior to entering a supported decision-making agreement, and others do not address the issue).

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decisions when these patients may be able to demonstrate capacity with support from others, this also may violate state informed consent law.[148] Such circumstances also ignore the relational components of capacity, autonomy, and decision-making.

Although supported decision-making is not the law in all states,[149] it is becoming a more common legal option and can be used informally or as a "reasonable accommodation" even in states without such laws.[150] Scholars and health care providers thus need to grapple with how supported decision-making matters for the understanding and demonstration of capacity. As I have written previously, supported decision-making "troubles the reliance on capacity assessments and surrogate decision makers in healthcare settings" and "is inconsistent with . . . use [of] capacity assessments to disregard the contemporaneous preferences of patients with decisional impairments."[151] And this Article argues that because (in)capacity is, in part, a property of relationships, scholars should study whether and how capacity can be strengthened through supported decision-making.

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In conclusion, there are debates about how capacity is conceptualized, and there are many problems with how capacity is measured and assessed.[152] There are also ethical and legal implications related to assessing capacity.[153] The legal implications of scholarly arguments are often ignored by scholars of medicine or philosophy and by clinicians.[154] However, as I have argued in prior work, ignoring the law of medical decision-making leads to the erosion of the rule of private law.[155]

To address some of these issues, the next Part will discuss proposals for future use of capacity assessments for medical decision-making, based on a conceptualization of (in)capacity as relational and contextual, and in consideration of the increase in supported decision-making agreements and relationships recognized and facilitated by law.

III. Using Capacity Assessments for Medical Decision-Making: Proposed Reforms

Given differences in how capacity is understood and the many problems with how capacity is measured, some may argue that capacity assessments should not be used in clinical practice.[156] However, this prospect will likely prove too difficult to obtain widespread agreement among stakeholders such as lawmakers, judges, and clinicians or even patients and their families.

An alternative proposal, based on the principles of equal treatment and beneficence, is to assess the decisional capacity of every patient, especially if the patient is facing a serious medical decision.[157] Of course, formally assessing the capacity of every patient would increase significantly the length of the clinical encounter, result in substantial financial costs, seriously interfere with patient autonomy, and

[148]Wright, *Resuscitating Consent*, *supra* note 19, at 933–34. And aside being legally entitled to make one's own medical decisions if an individual has capacity, as a practical matter, it may be the case that this collaborative model of decision-making increases capacity for all patients.

[149]*U.S. Supported Decision-Making Laws*, *supra* note 140.

[150]*See* Jonathan Martinis et al., *State Guardianship Laws and Supported Decision-Making in the United States After Ross and Ross v. Hatch: Analysis and Implications for Research, Policy, Education, and Advocacy*, 34 J. Disabil. Pol'y Stud. 8, 14 (2023) ("The avalanche of SDM . . . shows little sign of slowing in the United States and other countries.").

[151]Wright, *Resuscitating Consent*, *supra* note 19, at 923.

[152]*See generally id.*

[153]*Id.* at 895–900, 917–30.

[154]Wright, *supra* note 9, at 122; Wright, *Supported Decision Making in the U.S.*, *supra* note 50, at 253.

[155]Wright, *Resuscitating Consent*, *supra* note 19, at 930–32.

[156]Daniel Fogal & Ben Schwan, *Ditching Decision-Making Capacity*, 51 J. Med. Ethics 832, 838–40 (2025).

[157]*See, e.g.*, Weithorn, *supra* note 24, at 660 (describing how *everyone* requesting aid in dying in Hawaii must have their decisional capacity assessed). A more common view is that capacity should be assessed for interventions that have high risks relative to expected benefits. *See* Ganzini et al., *supra* note 4, at 264.

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inappropriately increase providers' power and authority over patient decisions.[158] Further, any benefits would likely be primarily dignitary in nature (i.e., symbolic) and thus insignificant relative to the many material costs. For these reasons, a proposal to formally assess every patient's capacity would also likely fail to be adopted.

So, on the assumption that the status quo continues wherein only some patients will have their decisional capacity assessed, the following sections offer some feasible reforms to capacity assessments that could be adopted to ensure that patients can exercise contemporaneously their legal medical decision-making rights and to promote patient agency, wellbeing, and bodily integrity. All the proposed reforms are based on the conceptualization of (in)capacity as relational and contextual in nature and would require that others change how they communicate with patients and require modifications to the decision-making environment to strengthen patients' decisional capacity.

The first section recommends changes prior to the assessment, focusing mainly on changes to clinical practice and institutional policy that would have the effect of increasing patients' decision-making abilities and reduce the need for capacity assessments and substitute decision-making. The second section recommends changes to the assessment process, focusing on changes to the capacity assessment instrument and changes in law, again with the aims of increasing patients' capacity and decreasing the number of patients disqualified from making contemporaneous medical decisions. The third section recommends changes after the assessment to preserve patients' wellbeing.

A. Before the Assessment

(In)capacity is not primarily a property inherent in a patient but instead is a property of the patient's cognitive abilities and affective state in interaction with their providers, environment, relationships, medications, and illness or medical condition. (In)capacity is influenced by many factors, some of which the provider can change to strengthen the patient's decision-making abilities. This section discusses how changes to clinical practice and hospital policy (rather than legal change) can support patients' decisional capacity.

As a first matter, providers should exercise patience in clinical encounters. If providers have reason to suspect that their conscious and communicative adult patient may have impaired decision-making abilities, the provider should try to determine if there is a possibility that their patient's abilities may improve with time or in a different environment; and if circumstances warrant, providers should wait until the patient regains capacity before a medical decision is made.[159] It may be the case, for example, that their patient is under the influence of psychoactive substances that are impairing the patient's cognition and that if the patient discontinues use of those substances, their decision-making abilities will improve.

Providers can also try to address medical issues that may be affecting their patient's decision-making abilities before focusing on other medical decisions.[160] It may be the case, for example, that the patient is in acute pain and can barely communicate, but if their pain was adequately managed, they would be able to discuss other medical circumstances. Instead of trying to formally or informally assess the patient's capacity, deeming the patient incapacitated, and turning to others to decide on the patient's behalf,

[158]Wright, *Equality of Autonomy*, *supra* note 50, at 194 n.180.

[159]Wright, *Resuscitating Consent*, *supra* note 19, at 935–36 (stating that providers can help the patient regain capacity by bringing in the patient's family, providing assistive technology, or by providing or discontinuing the use of certain medications); *see also* Grisso & Appelbaum, *supra* note 55, at 92–93 (calling for delays in making decisions and for repeated capacity assessments); Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 12–13 (discussing delirium and how to treat it).

[160]*See* Grisso & Appelbaum, *supra* note 55, at 96–97 (describing "pharmacologic interventions" to restore capacity).

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providers should instead focus on the patient's medical condition or environment and try to intervene to restore decisional capacity.[161]

If health care providers work in hospital settings that provide a capacity assessment consultation service, hospital policy should direct that providers be asked whether the motivation for the requested assessment is that their patient has disagreed with their recommendations or is using a non-medical logic to make medical decisions (e.g., deciding based on religious beliefs or family relationships). In such cases, the consulting service can remind the physician requesting the consultation that these are insufficient bases for questioning decisional capacity and redirect the physician to have further conversations with their patient before turning to a capacity assessment. Hospital policy can also prompt providers to ask their patients whether they would like to include family or supporters in health care discussions,[162] which may help the decision-making process by strengthening patient capacity.[163]

Finally, physicians should change how they communicate with their patients to try to ensure that patients, with or without cognitive impairments, can achieve understanding of their medical situation. Researchers have found that *all* patients evidence better understanding when information is given piece by piece instead of all at once, and so physicians may be able to avoid questions about patient capacity if they alter their communication style, especially if they are willing to repeat information and allow patients opportunities to ask questions.[164] Further, physicians can use patient decision-making aids to supplement their oral disclosures so that patients have additional sources of information to which they can refer at different points in time.[165] Finally, providers can adapt their interaction style to improve communication by facing their patients when speaking to them, limiting noise and distractions (e.g., from televisions), and avoiding jargon.[166]

If the relational and contextual aspects of patient (in)capacity are recognized by health care providers — both physicians and hospitals — and efforts are made to strengthen patient capacity and allow

[161] *See id.* at 92–93 (calling for delays in making decisions and intervening to restore or support capacity). This recommendation assumes that the patient agrees to interventions to restore capacity. Wright, *Resuscitating Consent*, *supra* note 19, at 935–36 ("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; including family members, friends, or formal supporters in decision making; or providing assistive technology to aid in communication . . . . Alternatively, in the instance of temporary incapacity, providers can wait until capacity is regained.").

[162] Such a policy would promote relational decision-making, which is consistent with the preferences of many patients. *See* Wright, *End of Life*, *supra* note 19, at 1082–91.

[163] Early writing on decisional capacity observed that there are roles for patients' family and relevant others to assist with decision-making. *See, e.g.*, Ganzini et al., *supra* note 4, at 265–66 ("Some patients could be capable of making healthcare decisions only if their clinicians make special efforts to help them. In some cases, all that is required is . . . allowing extra time for patients . . . to consult with family and friends. Other strategies [include] . . . enlisting the patient's own support system to convey information."); Grisso & Appelbaum, *supra* note 55, at 97–98 ("[F]amily members, friends, . . . can help patients process the information they have been given, often by reinterpreting it for them in language with which they are familiar and by clarifying distortions."). If the patient and their family/supporters agree on the decision, this may also make providers more comfortable with the decision made by the patient with decisional impairments given providers' concern about liability for bad medical outcomes. Wright, *Resuscitating Consent*, *supra* note 19, at 937. It is important to note, however, that not all family relationships may be conducive to the patient's exercise of autonomy and that the patient may actually need to be protected from their family. *See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 307–10 (noting that there is a risk that supported decision-making agreements could be used to harm patients with dementia). It is possible, too, that it is the patient's family making the request for a capacity assessment in order to control the patient. This issue is beyond the scope of this Article, however.

[164] *See* Grisso & Appelbaum, *supra* note 126, at 173 (explaining that patients usually better understood medical treatment information when it was presented twice, the second time being a part-by-part description of the treatment). *See also* Ganzini et al., *supra* note 4, at 264–66 (suggesting that patients with impaired decisional capacity still be permitted to participate in their medical decisions and recommending that clinicians be patient).

[165] King & Moulton, *supra* note 20, at 463–68; Pope, *supra* note 20, at 21–22; Sawicki, *supra* note 20, at 631–33. *See also* Ganzini et al., *supra* note 4, at 265–66 (arguing for oral and written communication to aid in patient understanding); Koch, *supra* note 82, at 933–34 (suggesting ways to ensure patient understanding); Grisso & Appelbaum, *supra* note 55, at 94–95 (explaining better ways of providing information to patients).

[166] Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 17–18 (providing communication tips for providers assessing decisional capacity); Grisso & Appelbaum, *supra* note 55, at 98.

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patients to make medical decisions to the extent they desire, then patients can exercise autonomy contemporaneously, experience increased subjective wellbeing, and maintain their bodily integrity.

B. The Assessment

It may be the case that a patient's decision-making abilities cannot be improved by changing the decision-making environment, the physical, mental, or emotional state of the patient, or physician communication style and that health care providers may still wish to know if their patient is able to make their own decisions. Therefore, capacity assessments will remain a reality in clinical practice. This section thus proposes some changes to the process of the assessment — in clinical practice, institutional policy, and the law — to acknowledge the relational and contextual nature of capacity and promote patient agency, wellbeing, and bodily integrity.

1. Change Who Assesses Capacity

The initial set of proposed changes targets clinical practice and institutional policy rather than legal change. First, given that capacity may only be formally assessed in cases of patient-provider disagreement[167] and that sometimes psychiatrists who are asked to formally assess capacity may feel pressure to find the patient incapacitated,[168] it is important that patients be given the choice of an objective, independent, non-conflicted clinician to perform the formal capacity assessment.[169] This proposal recognizes the complex web of relations in the health care setting that can influence whether patients are able to exercise autonomy contemporaneously by participating in medical decision-making, and the proposal can function as a safeguard against abuses of the incapacity exception to the requirement of obtaining patient consent to treatment. This proposal also reduces treating physicians' power relative to their patients' exercise of rights meant to protect patients' bodily integrity.

2. Facilitate Communication during the Capacity Assessment

Second, "optimal assessment conditions should be prioritized to increase rates of autonomous decision making."[170] As a first matter, this means that the assessment should be in a language in which the patient is comfortable, and failing this, a medical interpreter should be available to ensure the patient understands the questions asked and the provider understands the patient's answers.[171]

Relatedly, if there are comorbidities that may inhibit communication, these should be addressed or accommodated. This would include, for example, if the patient has difficulty speaking, but is able to write, type, or point at words/images/symbols or indicate their preferences through blinking. These

[167] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 898 n.53 (citing research that shows that patient-provider disagreement may lead to a capacity assessment).

[168] *Id.* at 916.

[169] Some may suggest that the best person to assess capacity will be the patient's doctor who presumably knows the patient, including how the patient communicates and what their values are. However, in hospitals, patients are often treated by several different physicians, many of whom the patient has limited prior familiarity. *See generally* David G. Hewett et al., *Intergroup Communication between Hospital Doctors: Implications for Quality of Patient Care*, 69 Soc. Sci. & Med. 1732 (2009) (reporting results of a study on how patients are treated by different medical providers in an academic hospital and how conflict between these providers can harm patient care). And even if the patient's physician is involved in a capacity assessment, their prior knowledge of their patient may limit their ability to be objective.

[170] Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 5.

[171] *See* Grisso & Appelbaum, *supra* note 55, at 95 (discussing possible role for translators for patients whose first language is not English during the informed consent process); Ganzini et al., *supra* note 4, at 265–66 (arguing for "use of personnel specially trained to bridge language or cultural barriers" to aid in patient understanding). This language accommodation is required by law under the Civil Rights Act, the Affordable Care Act, and Executive Order. *See* Sara Heath, *Understanding Patient Rights to Medical Interpreters, Language Access*, PatientEngagement (Aug. 3, 2022), https://www.techtarget.com/patientengagement/feature/Understanding-Patient-Rights-to-Medical-Interpreters-Language-Access [https://perma.cc/C429-Y5TT].

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alternative responses should be accommodated.[172] And if the patient has difficulty hearing, sign language interpreters should be provided (if this would be of use to the patient), patients should be provided other technology to assist with hearing, or they should receive information and be asked questions in alternative formats (e.g., writing). Indeed, these "comorbidities" used as illustrations are disabilities, and reasonable accommodations must be made under the Americans with Disabilities Act.[173] Further, this understanding of how physical disabilities may make it difficult for some patients to demonstrate decisional capacity is reflected in the most current version of the Uniform Health-Care Decisions Act, which notes that the communication criterion of capacity can be demonstrated with "appropriate services, technological assistance, . . . or other reasonable accommodation."[174]

Finally, the assessment should account for the patient's level of educational attainment and literacy and be adapted accordingly.[175] Indeed, all communication, including in the instrument used for capacity assessment, should be free of medical jargon, and the pace of conversation should be slow with frequent pauses.[176]

If these changes are made, then it is possible that more patients will pass the capacity assessment (i.e., demonstrate capacity). Regardless of the results of the assessment, however, there can be more confidence of the findings related to the patient's cognitive abilities if the proposed changes occur.

3. Incorporate Supported Decision-Making in Capacity Assessments

Most importantly, given the relational nature of (in)capacity and the rapid spread of supported decision-making as an option recognized and facilitated by state law, capacity assessments should be modified to account for the presence of and decision-making assistance provided by supporters.

Because of the relative novelty of supported decision-making in the United States,[177] existing formal capacity instruments need to be adapted to assess whether a patient with decisional impairments can evidence capacity with support from others. The instrument should include a role for supporters (and this may require re-validation of the instrument).[178] The role of supporters in the process of assessing a patient's capacity can take many forms,[179] of which full exploration is beyond the scope of this Article. In brief, supporters may provide information to the patient during the assessment, rephrase questions from or information provided by the assessors, assist the patient in reflecting on their values and preferences, or help communicate the patient's responses to the assessor.[180] Research also then should be conducted about how decisional supports affect patients' decision-making abilities as measured by formal capacity

[172]Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 6–7 (describing communication-related disabilities such as hearing loss, motor speech disorder, and aphasia and augmentative and alternative communication systems that can be used to communicate with individuals who have such disabilities).

[173]28 C.F.R. § 36.105(a)(1)(i) (2025) ("Disability means . . . [a] physical or mental impairment that substantially limits one or more of the major life activities of such individual."). *See also id.* § 36.105(b) (defining physical and mental impairment); *id.* § 36.105(c) (defining major life activities); *id.* § 36.105(d)(1) (defining substantially limits).

[174]Unif. Health-Care Decisions Act § 3(a)(1) (Unif. L. Comm'n 2023).

[175]And initial written information about diagnosis, prognosis, and the risks and benefits of treatment options should also account for varying levels of patient literacy. Ganzini et al., *supra* note 4, at 265–66 (arguing that clinicians should present "information at the appropriate reading level").

[176]Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 17–18 (providing general communication tips).

[177]*See* David M. English, *Supported Decision-Making in the US: History and Legal Background*, Special Needs All. (Aug. 2022), https://www.specialneedsalliance.org/the-voice/supported-decision-making-in-the-us-history-and-legal-background/ [https://perma.cc/VU9C-W6GP] (noting that other countries adopted elements of supported decision-making in the 1980s and 1990s, but it was not until 2015 that Texas became the first state to pass a supported decision-making statute).

[178]There are so many capacity assessment instruments that it is not within the scope of this Article to discuss how, exactly, they should be modified, but building in opportunities for patients to be provided decisional support to demonstrate capacity is something for researchers to study.

[179]*See generally* "*Supported Decision Making and Clinical Research*", *supra* note 50.

[180]Some of these types of supports are reflected in the current version of the Uniform Health-Care Decisions Act, which in defining "capacity" mentions that an individual can demonstrate the communication criterion of capacity through support. *See* Unif. Health-Care Decisions Act § 3(a)(1) (Unif. L. Comm'n 2023). Although the Act does not mention support increase

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assessments and whether and how the type of decision-making support provided matters, the relationship between supported person and supporters matters, and type of cognitive impairments matters to the demonstration of capacity.

Given the well-documented reality that physicians do not understand their legal obligations to patients with disabilities,[181] incorporating supported decision-making in the capacity assessment process requires other changes, especially for informal capacity assessments. For example, medical education must include information on how federal disability law applies to the practice of medicine and the concept of supported decision-making.[182] Health care providers also need to know whether their state has supported decision-making legislation.[183] This may be a role for hospital policy, which can provide such information to physicians.

Importantly, providers should understand the difference between supporters, health care power of attorneys, substitute decision-makers, and guardians. This knowledge would (in theory) affect the provider's informal capacity assessments of their patients. Instead of disqualifying their patients from making their own decisions, they may instead ask whether their patient has anyone who could assist with treatment decision-making or ask whether the state has a supported decision-making agreement. Formal capacity assessment instruments can also be modified to explicitly prompt the clinician administering the assessment and the patient being assessed to recommend that patients include their supporters in the assessment process and that if they do not have supporters, that they seek them out prior to the assessment.

4. Highlight Supported Decision-Making in Multiple Areas of State Law

As discussed in the previous section, health care providers need more clarity about supported decision-making and the rights of their patients with cognitive and communication disabilities.[184] States thus should cross-reference all laws that reference capacity, including medical decision-making laws, with the state's supported decision-making statutes (if the state has adopted formal supported decision-making). State laws referencing capacity should also include a brief discussion of supported decision-making, so that it is clear to policymakers, judges, lawyers, clinicians, and the public that they should consider the implications of supported decision-making for the demonstration of decisional capacity.

Indeed, although some states have adopted supported decision-making legislation that contemplates that individuals could demonstrate capacity with support,[185] this information may remain effectively hidden without additional legislative efforts to highlight it by amending other parts of the statutory code. For example, California's supported decision-making statute directs that "[t]he capacity of an adult should be assessed with any supports, including supported decisionmaking, that the person is using or

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and convey understanding when defining 'capacity' in discussing capacity, it does when defining "supported decision-making" in the definitions section. *See id.* §§ 2(27), 3(a)(2).

[181] *See generally* Nicole D. Agaronnik et al., *Knowledge of Practicing Physicians About Their Legal Obligations when Caring for Patients with Disabilities*, 38 Health Affs. 545 (2019) (reporting that physicians had little training regarding their legal obligations to accommodate patients with disabilities); Lisa I. Iezzoni et al., *US Physicians' Knowledge About the Americans with Disabilities Act and Accommodation of Patients with Disability*, 41 Health Affs. 96 (2022) (reporting that many physicians know little about their legal obligations in relation to the Americans with Disabilities Act); Lisa I. Iezzoni et al., *Have Almost Fifty Years of Disability Civil Rights Laws Achieved Equitable Health Care?*, 41 Health Affs. 1371 (2022) (explaining that even though the Americans with Disabilities Act and Affordable Care Act provide protections for individuals with disabilities, many still suffer from inadequate services in health care).

[182] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 915, 949–50 (stating that providers do not know about informed consent laws or supported decision-making laws).

[183] Providers often are unaware of laws that apply to how they practice medicine and care for patients. *See, e.g.*, *id.* at 915 n.134 (describing provider ignorance of laws about leaving hospitals against medical advice and disability laws).

[184] *See* Agaronnik et al., *supra* note 181, at 550 (discussing how physicians often had an incorrect understanding of their legal obligations towards patients with disabilities and that they also received little training to learn about those obligations).

[185] For example, N.Y. Mental Hyg. Law § 82.03(b) (McKinney 2022) ("Capacity shall include capacity with decision-making support and/or accommodations."); Cal. Welf. & Inst. Code § 21000(c) (2023) (noting that supported decision-making is "a valid way for people with disabilities to strengthen their capacity and maintain their autonomy").

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could use"[186] and that "[s]upported decisionmaking can be a way to strengthen the capacity of an adult with a disability."[187] It is not clear, however, that individuals reading California's body of informed consent case and statutory law or other medical decision-making laws would know about supported decision-making, because it is not referenced in these other areas of law.[188]

Some specific medical decision-making laws also recognize that other people may help individuals demonstrate capacity (i.e., these laws recognize the relational nature of capacity),[189] but because this information may not be in the state's informed consent statute, this recognition may not be extended to general medical decision-making even when it would be appropriate. For example, the Oregon Death with Dignity Act, which legalizes medical aid in dying for some terminally ill adults, states that capacity is defined as "the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available."[190] Providers who are not involved in medical aid in dying, and thus not necessarily familiar with this law that references communication assistance from others to increase patient capacity, may not realize that this type of decisional support can also be applied to other types of medical decisions.

In brief, supported decision-making can potentially increase decisional capacity and facilitate the exercise of contemporaneous relational agency for persons with cognitive impairments.[191] Supported decision-making can also increase the subjective wellbeing of and promote equal treatment for persons

[186]Cal. Welf. & Inst. Code § 21000(d) (2023).

[187]*Id.* § 21000(f). However, there is no information about how capacity assessments should incorporate supported decision-making.

[188]*See, e.g.*, Cal. Health & Safety Code § 1599.15 (2024) (defining informed consent in the context of psychotherapeutic drugs but not referencing supported decision-making). Indeed, the California End of Life Option Act directs that capacity is required to access medical aid in dying, but the law does not refer to supported decision-making. Megan S. Wright, *Medical Aid in Dying, Decisional Capacity, and Supported Decision Making*, *in* Research Handbook on Voluntary Assisted Dying Law, Regulation & Practice (Ben P. White ed., 2025); Cal. Health & Safety Code § 443.

[189]*See, e.g.*, Or. Rev. Stat. Ann. § 127.800(3) (2023) (defining "capable" to include communication through other people).

[190]*Id.* Interestingly, the California End of Life Option Act does not permit individuals seeking medically-assisted dying to receive decisional support to demonstrate capacity and to communicate their request to physicians. Cal. Health & Safety Code § 443.2(c) (West 2022). The law requires that "[a] request for a prescription for an aid-in-dying drug under this part shall be made solely and directly by the individual diagnosed with the terminal disease." *Id.* The law further directs that physicians discuss "with the qualified individual, outside of the presence of any other persons . . . whether or not the qualified individual is feeling coerced or unduly influenced by another person." *Id.* § 443.5(a)(4). As I note elsewhere, "[t]his requirement impedes supported decision making and may hinder access [to aid in dying] for individuals with communication disorders." Megan S. Wright, *Current Medical Aid-in-Dying Laws Discriminate against Individuals with Disabilities*, 23 Am. J. Bioethics 33, 34 (2023); Wright, *supra* note 188, at 260 n.73. It also seems inconsistent with California's supported decision-making statute. *See supra* notes 185–187. Medically-assisted dying is also legal in Canada, and a Canadian professional association wrote a document about assessing capacity for patients who request MAiD. *See generally* Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10 (providing information from the Canadian Association of MAiD Assessors and Providers about assessing capacity to access MAiD). Canada uses the commonly accepted capacity criteria of understanding, appreciation, reasoning, and communication, and notes that communication is the "ability to communicate a choice; (even with appropriate help)." *Id.* at 3. It thus appears that Canada takes a similar approach to Oregon, but it is not clear why "appropriate help" is limited only to communication and not permitted for a patient trying to demonstrate understanding, appreciation, or reasoning abilities. *Compare* Canadian Ass'n of MAiD Assessors & Providers, *supra* note 10, at 3 (stating that capacity can be demonstrated if a patient can communicate a choice even if help is required), *with* Or. Rev. Stat. Ann. § 127.800(3) (2023) (defining "Capable" to include using others to communicate one's wishes). This is also a strange oversight given that Canada also has supported decision-making. *See generally* Cmty. Living Ont., Intellectual Disability and the Right to Decide, https://communitylivingontario.ca/wp-content/uploads/2024/04/TheRightToDecide_3_SDMAcrossCanada.pdf [https://perma.cc/WP9H-VV3P] (last visited Oct. 26, 2025) (discussing various Canadian laws pertaining to supported decision-making).

[191]*See generally* Wright, *Dementia and Disability Law*, *supra* note 50, at 26, 29–30 (explaining how the supported decision-making model enables a person with a disability to retain legal authority to make contemporaneous decisions); Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 323 (defining relational agency in health care decision-making); Wright, *Equality of Autonomy*, *supra* note 50, at 173, 182, 196 (defining relational agency in end-of-life and other health care decision-making).

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with cognitive impairments.[192] Capacity assessments should adapt to include a role for supported decision-making, and state laws should publicize how decisional support can increase capacity.

C. After the Assessment

Even if the above changes are adopted, some patients will still be unable to demonstrate decisional capacity. However, if a finding of incapacity results in someone else having legal authority to make decisions on the patient's behalf, this does not mean the patient ceases to retain interests in experiencing wellbeing, exercising agency to the extent possible, and maintaining bodily integrity.[193]

Indeed, care must be taken to preserve a patient's sense of dignity and wellbeing after the capacity assessment.[194] Providers should not use words such as "fail" or "lack capacity" and should instead consider framing the situation as an opportunity for the patient to receive assistance in making medical decisions according to the patient's goals, values, and preferences.

There should also be efforts to support the patient's agency, which is closely connected to the patient's sense of subjective wellbeing.[195] As other scholars of capacity have also asserted, patients who lack capacity can, in some instances, still be afforded the opportunity to make their own medical decisions.[196] There should be discussion of what kinds of medical decisions such patients may be permitted to make. Perhaps they can make decisions that are less serious or risky. Or maybe they can make decisions to refuse but not choose a treatment.[197] Further, when looking to advance directives and substitute decision-making based on precedent autonomy or best interest standards, providers should try to incorporate the patient's current interests and expressed preferences to the extent possible to maintain patient wellbeing.[198]

It is also imperative that health care providers take care to respect the personhood of their conscious patient with decisional impairments, particularly when touching the patient's body to provide treatment or care, given the patient's interests in maintaining bodily integrity.[199] Providers should seek patient assent to touching (or at a minimum, non-dissent)[200] and avoid, when possible, interfering with the

[192]*See generally* Wright, *Dementia and Disability Law*, *supra* note 50, at 29–30 (describing equality principles embodied in international, federal, and state disability law, including supported decision-making law); Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 282–84, 321–23 (explaining how supported decision-making may lead to better emotional, psychological, and physical wellbeing); Wright, *Equality of Autonomy*, *supra* note 50, at 182–84 (arguing that supported decision-making can promote equality for patients with impaired cognition facing end-of-life decisions).

[193]*See* Wright, *Resuscitating Consent*, *supra* note 19, at 926 (explaining that these interests persist even in the presence of decisional impairments).

[194]Claire Vain, *Upholding Dignity in Care: Why It's Central to Patient Well-Being*, CPD Online Coll. (Jan. 15, 2025), https://cpdonline.co.uk/knowledge-base/care/upholding-dignity-care-central-patient-well-being/#patients-with-cognitive-impairments. Dignity and wellbeing are also relational properties. For example, a person may lose dignity in interaction with others who do not treat them with respect or regard them as a person. *See id.*

[195]Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 322 ("[F]eeling autonomous can lead to increased wellbeing.").

[196]Grisso & Appelbaum, *supra* note 126, at 172 ("They might receive extra educational efforts to improve their performance, or additional protection, including independent clinical review, . . . to ensure appropriateness of care.").

[197]*See* Wright, *Resuscitating Consent*, *supra* note 19, at 920–22 (explaining that patient autonomy should be privileged for treatment refusals but that physician autonomy has greater weight for treatment consent); Drane, *supra* note 33, at 925–27 (explaining that more evidence of capacity should be required for riskier decisions).

[198]This is a recommendation included in the Uniform Health-Care Decisions Act as well as many guardianship statutes. *See* Unif. Health-Care Decisions Act § 17(d) (Unif. L. Comm'n 2023); *see, e.g.*, Mass. Gen. Laws ch. 190B, § 5-306 editor's note on Desire of Ward (2009) ("Even if ward lacks capacity to make medical treatment decisions, her expressed preference must be treated as a critical factor in the determination of her "best interests," since it is the patient's true desire that the court must ascertain; procedural intricacies and technical niceties must yield to the need to know the actual values and preferences of the ward.").

[199]Wright, *Resuscitating Consent*, *supra* note 19, at 926.

[200]*See* Marc Tunzi et al., *The Consent Continuum: A New Model of Consent, Assent, and Nondissent for Primary Care*, 51 Hastings Ctr. Rep. 33, 35 (2021) (proposing that consent be understood on a continuum that includes consent, assent, and non-dissent).

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patient's body in a manner upsetting to the patient. Although the providers' goal is to ensure good medical outcomes, such outcomes are more likely if patients are not mistreated during the clinical encounter.[201]

Finally, individuals must always be able to challenge the finding of incapacity. Should the assessment occur in a hospital, the hospital should provide another opportunity for patients to demonstrate capacity. And judicial review should also be available to patients given that legal rights and interests are at stake,[202] including maintenance of bodily integrity, respect for patient autonomy, promotion of wellbeing, and preservation of life and health. Many argue against judicial review as a matter of course for questions about capacity,[203] but judges have a role to affirm the legal rights of patients and to ensure that the capacity assessment process and incapacity exception to the informed consent requirement are not being abused.[204]

IV. Other Considerations

Clinicians, scholars, judges, and others who hold traditional views about decisional capacity may object to some of the proposals offered in this Article. The primary objections likely relate to concerns about autonomy and wellbeing. More specifically, some may think that permitting patients with decisional impairments to make contemporaneous medical decisions is inconsistent with respect for patient autonomy and that it may lead to a decrease in the patient's objective wellbeing.[205] This Part will first address concerns about autonomy before addressing concerns about wellbeing.

A. Relational Capacity, Relational Autonomy

The reason that capacity is assessed is because respect for patient autonomy is a primary goal of the law and ethics of informed consent, and the concept of capacity is defined by elements thought necessary to exercise contemporaneous autonomy.[206] Thus, proposals to reconsider how capacity is understood and assessed have implications for how patient autonomy is or is not respected. This Article argues that just as the exercise of autonomy in medical decision-making is often relational,[207] decisional capacity is also relational.

There is a temporal dimension to the exercise of and respect for autonomy. Typically, respect for patient autonomy means respecting the patient's current decisions that are made with intention and understanding and absent coercion and undue influence (i.e., contemporaneous autonomy).[208] Respect for contemporaneous autonomy is the standard for conscious adult patients with typical cognitive abilities.[209] However, respect for patient autonomy may also mean respecting decisions made intentionally, voluntarily, and with understanding at some point in the past (i.e., precedent autonomy) and that are perhaps memorialized in an advance directive. Respect for precedent autonomy is often the

[201]Wright, *Resuscitating Consent*, *supra* note 19, at 928–29.

[202]*See, e.g.*, N.Y. Pub. Health Law § 2994-c(6) (McKinney 2021) ("Notwithstanding a determination pursuant to this section that an adult patient lacks decision-making capacity, if the patient objects to the determination of incapacity . . . the patient's objection . . . 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 persons."); Unif. Health-Care Decisions Act § 5 (Unif. L. Comm'n 2023) (describing the right to object a finding of incapacity).

[203]Grisso & Appelbaum, *supra* note 126, at 172. *But see* Wright, *Resuscitating Consent*, *supra* note 19, at 951–53.

[204]Wright, *Resuscitating Consent*, *supra* note 19, at 952–53.

[205]There may be other objections, such as costs, feasibility concerns related to accommodating patients with disabilities or modifying capacity assessments, or abuse of discretion when there is no standard definition or measurement of capacity, but this Article will focus only on the major ethical challenges to my arguments.

[206]Beauchamp & Childress, *supra* note 4, at 104.

[207]*See generally* Wright, *End of Life*, *supra* note 19; Wright, *Dementia and Disability Law*, *supra* note 50; Wright, *Dementia and Supported Decisionmaking*, *supra* note 50.

[208]*See* Wright, *Equality of Autonomy*, *supra* note 50, at 174–79 (explaining the elements of autonomy).

[209]Wright, *End of Life*, *supra* note 19, at 1072.

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standard used for patients who are not expected to regain capacity (e.g., patients with advanced dementia).[210] Finally, respect for patient autonomy could mean enabling the patient to make autonomous decisions at a future point (i.e., prospective autonomy). If a patient that lacks capacity, but is expected to regain capacity (e.g., patient with untreated psychiatric illness), they may be prevented from making contemporaneous decisions that could decrease the likelihood that they could exercise autonomy in the future.

Critics may argue that failure to demonstrate capacity to the satisfaction of a health care provider means that a patient is incapable of contemporaneous autonomy, and that in such instances respecting patient autonomy necessitates respecting precedent or prospective autonomy. In past work, I have argued that many patients with decisional impairments who may be considered incapacitated, can with decisional support, exercise contemporaneous autonomy if autonomy is understood as relational agency.[211] I offer the same arguments in support of the proposals to facilitate contemporaneous decision-making for patients with cognitive or communication impairments in this Article and assert that understanding capacity as relational and contextual in nature — something that can be strengthened or weakened through interaction with others and by changes to the decision-making environment — can facilitate respect for the contemporaneous autonomy of individuals with decisional impairments.

Admittedly, the proposals in this Article, if adopted, may in some circumstances be inconsistent with respect for a particular patient's past and future exercises of autonomy. Sometimes a patient's current wishes accord with their past wishes and probable future wishes, in which case permitting patients to decide — even if they are deemed to lack capacity — can be consistent with respect for autonomy however it is defined. However, if the patient's current wishes differ from their past wishes or predicted future wishes, allowing them to decide based on their current wishes will conflict with respect for their precedent and prospective autonomy.[212] Given the extensive problems with capacity assessments listed in this Article and the important interests in ensuring the patient's subjective wellbeing and maintenance of bodily integrity, current preferences should be privileged even if they are inconsistent with respect for autonomy — precedent, contemporaneous, or prospective.[213]

Further, if someone uses supported decision-making to plan for cognitive decline,[214] this is strong evidence that they want to maintain autonomy for as long as possible, even when experiencing decisional impairments, which means they have contemplated a future where they may make decisions differently than they do in the present.[215] This would also weigh in favor of respecting a patient's current choices despite their decisional impairments.

B. Adopting Proposals Can Promote Patient Wellbeing

Another major objection to the proposals in this Article concerns the potential negative implications for patient wellbeing. Typically, health care providers are concerned about patients' medical wellbeing —

[210] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 898–99 n.57 (describing advance directives and precedent autonomy).

[211] *See generally* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50. This understanding of autonomy not only has the benefit of facilitating contemporaneous decision-making for people with cognitive impairments but also accords with how many people — including individuals with typical cognitive abilities — make decisions that others consider to be autonomous. *See generally* Wright, *End of Life*, *supra* note 19; Wright, *Dementia and Disability Law*, *supra* note 50; Wright, *Dementia and Supported Decisionmaking*, *supra* note 50. This understanding of autonomy has implications for equal treatment of people with disabilities. *See* Wright, *Equality of Autonomy*, *supra* note 50.

[212] *See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 314–17 (describing debates about respecting the current or former wishes of people with dementia).

[213] *See also* Unif. Health-Care Decisions Act § 17(d)(1) (Unif. L. Comm'n 2023) (arguing that determining a patient's best interests should include giving "primary consideration to the individual's contemporaneous communications, including verbal and nonverbal expressions").

[214] *See generally* Megan S. Wright, *Planning for Cognitive Decline: Combining Formal Supported Decision-Making Agreements and Healthcare Advance Directives*, 35 Health Matrix 225 (2025) (describing how individuals planning for cognitive decline can use supported decision-making agreements).

[215] *See generally id.* Otherwise, the individual planning for cognitive decline would use only power of attorney, which would be evidence they want someone else to make decisions for them when they acquire decisional impairments.

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ensuring their patients live, do not acquire disabilities, and do not experience a decline in health status.[216] Providers may be concerned that patients with decisional impairments do not adequately understand medical information, apply information to their circumstances, or reason appropriately and thus will make a bad decision that costs the patient their life or health. As a result, providers may want to, on grounds of beneficence and non-maleficence, protect patients from the consequences of poor decision-making and use capacity assessments to remove legal decision-making authority from patients with decisional impairments.[217]

What providers (and others holding paternalistic views) may fail to adequately appreciate, however, is their patient's global wellbeing, of which medical wellbeing is only one component. Many scholars and commentators advocating for the use of stringent capacity assessments and the disqualification of patients with decisional impairments from medical decision-making conclude their ethical analysis without considering the patient's perspective when the patient is prevented from choosing a treatment they desire or from refusing a treatment they do not want.[218] Given that many patients want to participate in medical decisions, many will feel a range of negative emotions if they are excluded from or marginalized in the decision-making process, which is detrimental to their sense of wellbeing.[219]

If a conscious patient is trying to refuse an intervention, but their contemporaneous refusals are overridden, physical force or sedation may be required to treat the patient over their objection. Use of force against patients to provide a treatment is inconsistent with promoting patient subjective wellbeing,[220] even if the patient has decisional impairments.[221] This fact is underappreciated in scholarly proposals to increase the requirements for demonstrating capacity (proposals that will result in fewer people being able to make contemporaneous medical decisions).[222] Aside from these considerations about subjective wellbeing, there are medical reasons to involve the patient in decision-making, such as enhanced treatment compliance.[223]

Still other critics may view individuals with disabilities as needing special protection from outcomes such as death or decline in health status given the history of medical mistreatment and neglect of this patient population.[224] They may argue that it is cruel to not intervene in decision-making for individuals with cognitive impairments to prevent negative consequences. For this reason, some view individuals with disabilities as a vulnerable group and argue that they should be treated differently based on this vulnerability.[225] It is not clear, however, that making decisions on behalf of individuals with disabilities reduces their vulnerability compared to ensuring that they are able to make their own decisions. Indeed, the proposals in this Article are designed with patients with disabilities in mind and rely on insights from disability rights law and the disability justice movement to promote the agency, wellbeing, and equality

[216]Wright, *Resuscitating Consent*, *supra* note 19, at 928.

[217]*Id.* at 914–16.

[218]*See, e.g.*, Hawkins, *supra* note 24, at 80–81 (discussing patient welfare in the context of the patient's initial medical decision but not when the patient is judged to lack capacity); *see also* Wright, *Recent Trends*, *supra* note 9, at 122 (arguing that the welfare effects of adding criteria to the concept of capacity have been ignored in contemporary scholarly debates).

[219]*See generally* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50 (asserting that when persons with dementia are included in decisions about their health care, they have enhanced wellbeing).

[220]Wright, *Resuscitating Consent*, *supra* note 19, at 928–29. There are also questions about racial-ethnic (and other) disparities in finding patients to lack capacity and restraining patients. *Id.* at 929.

[221]*See id.* at 928–29.

[222]*See, e.g.*, Hawkins, *supra* note 24, at 80–81 (proposing two additional requirements for decision-making capacity).

[223]*See* Wright, *Resuscitating Consent*, *supra* note 19, at 928–29 (arguing forced care can have significant negative effects on patient wellbeing).

[224]*See* Emily Johnson, Letter from the Editor, *Disability, Medicine, and Ethics*, 18 AMA J. Ethics 355, 355 (2016) (describing long history of mistreatment and abuse of patients with disabilities).

[225]*See generally* Monika Mayrhofer, *The Concept of Vulnerability and its Relation to the Concepts of Inequality and Discrimination — a Review Article*, 29 Int'l J. Hum. Rts. 1589 (2025) (discussing the concept of vulnerability, including vulnerability on the basis of disability); *see also Research Involving Individuals with Questionable Capacity to Consent*, Nat'l Inst. of Health (Nov. 2009), https://grants.nih.gov/policy-and-compliance/policy-topics/human-subjects/policies-and-regulations/vulnerable-populations/questionable-capacity [https://perma.cc/8EXQ-NK75] (describing individuals with impaired decision-making capacity as a "vulnerable population").

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interests of this population instead of resorting to stereotypes that individuals with disabilities as a class are vulnerable.

In brief, the proposals in this Article weigh patient subjective wellbeing more heavily than patient medical wellbeing (as perceived by providers or disability activists).[226]

Conclusion: Moving Toward "Legal Capacity on an Equal Basis"

This Article builds on my prior work on the law and practice of medical decision-making. I have written extensively about how supported health care decision-making for individuals with cognitive impairments can enable self-determination for this patient population.[227] And, in the context of treatment refusals, I have argued for relaxing capacity standards to the minimum requirement of assessing a patient's ability to communicate to maintain respect for bodily integrity and embodied autonomy.[228] Also, I have argued against incorporating an understanding requirement into the informed consent process given that this requirement is often not satisfied by individuals with typical cognitive abilities and can be weaponized against individuals with cognitive impairments, holding them to a higher standard to have their autonomy respected.[229]

In the present Article, I have described how currently there is profound disagreement about how capacity should be understood (i.e., operationalized), and I have argued that there are problems with how capacity is assessed.[230] Specifically, I have argued that the traditional view of (in)capacity accounts for the cognitive abilities of the individual patient, but that (in)capacity instead should be understood as a property of relationships with others and one's decision-making environment, mediated through one's body and cognitive abilities.[231]

Combining these insights about the relational and contextual nature of (in)capacity, the existing legal mandate to accommodate patients with disabilities so they can participate in contemporaneous medical decision-making, and the development of new models of decision-making (i.e., supported decision-making), this Article argues for extensive modifications to the capacity assessment process. The hope is that by adopting the proposals, more patients with decisional impairments will be able to make their own medical decisions at the time the decision needs to be made and that the decisions will be consistent with their preferences, goals, values, and interests (i.e., autonomous decision-making occurs).

These arguments are grounded in concerns for decisionally-impaired patients' autonomy, bodily integrity, subjective wellbeing, and equality interests in the *medical* context. This decision-making context provides ample opportunities for patients to receive information and discuss their decisions, and for other parties to intervene if they suspect the patient has mistaken understanding of their medical circumstances or if they suspect the patient is being abused, neglected, or exploited.[232] All these factors may increase the likelihood that the patient will make contemporaneous autonomous decisions even if the patient has cognitive impairments.[233]

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[226] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 941 (arguing it is always possible that providers are incorrect in their assessment of their patient's prognosis).

[227] *See generally* Wright, *Dementia and Disability Law*, *supra* note 50; Wright, *Dementia and Supported Decisionmaking*, *supra* note 50; Wright, *Equality of Autonomy*, *supra* note 50; Megan S. Wright, *Dementia, Cognitive Transformation, and Supported Decision Making*, 20 Am. J. Bioethics 88 (2020).

[228] *See* Wright, *Resuscitating Consent*, *supra* note 19, at 921 (noting that health care providers should respect a patient's contemporaneous treatment refusals).

[229] *See id.* at 921, 953–56 (arguing against requiring that patients evidence understanding in medical decision-making); *cf.* Koch, *supra* note 82, at 896 (arguing that informed consent should ensure subjective patient understanding rather than focus solely on physician disclosure).

[230] *See supra* Part II.

[231] *See* discussion *supra* Part II.D.4 & Part III.A.

[232] *See* Wright, *End of Life and Autonomy*, *supra* note 19, at 1129–35 (discussing safeguards); Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 307–10 (discussing safeguards).

[233] *See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 297–300, 321–24 (describing how patients with cognitive impairments may still be able to exercise autonomy); Wright, *supra* note 214, at 242 (describing how the context of medical decision-making can prevent poor medical decisions).

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However, given that my arguments rely on laws that are broader than informed consent law (i.e., state and federal disability laws),[234] analyze interests that matter beyond the clinical encounter (e.g., autonomy and wellbeing),[235] and refer to the construct of capacity, which is central to many areas of law,[236] questions arise about whether and how my arguments about autonomy, capacity, and decision-making should be extended beyond the context of medical decision-making.

Although this Article focuses on decisional capacity and assessments thereof for medical decision-making, formal capacity assessment instruments may be administered in other contexts to determine whether an individual has the requisite legal capacity to make decisions to which the law will defer. Findings of incapacity can include a range of legal consequences such as whether someone will be permitted to participate in clinical research or will be placed under guardianship.[237]

If the proposals in this Article are adopted — and result in fewer capacity assessments for medical decision-making, the incorporation of supported decision-making in capacity assessments, and a relaxed standard for demonstrating capacity — should these proposals be accepted in other legal contexts?[238]

Legal scholars are grappling with how to understand (in)capacity in various areas of law. Some have explored novel understandings of capacity for private law (e.g., "narrative capacity").[239] And with respect to individuals with disabilities, other scholars have explored how federal disability law and state-supported decision-making statutes can expand the number of people who are deemed to have capacity.[240] There are many articles about changing guardianship and conservatorship law to reduce the number of individuals who have had their decision-making rights revoked.[241] Further, scholars have considered how supported decision-making may strengthen (or "boost") testamentary capacity[242] and how the mental incapacity doctrine in contract law, which can be raised to prevent enforcement of a contract for individuals who did not understand the contract or its consequences, is inconsistent with the Americans with Disabilities Act.[243]

[234] *See supra* Parts II & III.

[235] *See supra* Part II.

[236] *See* Moye & Marson, *supra* note 10, at P3–P4 (describing seven areas in the civil context where capacity matters legally: independent living, financial management, treatment consent, testamentary capacity, research consent, sexual consent, voting, and driving). Legal scholars have recently been examining capacity in other civil contexts as well. *See, e.g.*, Andrew Gilden & Eva E. Subotnik, *Copyright's Capacity Gap*, 57 U.C. Davis L. Rev. 899, 969–76 (2023) (arguing that copyright law does not adequately protect creators with cognitive impairments).

[237] *See* Benjamin C. Silverman et al., *Supported Decision-Making Can Advance Clinical Research Participation for People with Disabilities*, 28 Nat. Med. 2250 (2022) (arguing that supported decision-making could facilitate equitable participation in clinical research for people with disabilities); *see also* Paul S. Appelbaum, *Preventing Abuses in Guardianship Cases*, 74 Psychiatric Servs. 1108, 1108–09 (2023) (explaining relationship of incapacity and guardianship).

[238] *See* Beauchamp & Childress, *supra* note 4, at 117 ("In criminal law, civil law, and clinical medicine, standards for competence cluster around various abilities to comprehend and process information and to reason about the consequences of one's actions.").

[239] *See generally* Toomey, *supra* note 39.

[240] *See generally* Martinis et al., *supra* note 150 (reviewing supported decision-making laws in the United States).

[241] *See, e.g.*, Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn. St. L. Rev. 1111, 1126, 1154 (2013) (discussing potential of supported decision-making to reduce guardianship); Kohn, *supra* note 15, at 345–55 (proposing legal and other changes to advance the rights of persons with disabilities).

[242] *See* Weisbord & Horton, *supra* note 147, at 613, 628–35 (discussing testamentary capacity and its intersection with supported decision-making).

[243] *See* Scott, *supra* note 72, at 280 (arguing that tests measuring mental incapacity could violate the Americans with Disabilities Act). There are also discussions about sexual (in)capacity and supported decision-making in intimate relationships. *See generally* Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 Ohio St. L.J. 1201, 1205 (2015) ("[S]exual incapacity doctrine should grant legal capacity to adults with cognitive impairments if they are embedded in an adequate decision-making support network. In other words, the right to sexual expression should not be withheld due to cognitive impairment alone."); Leslie Francis, *Intimate Relationships and Supported Decision Making*, 77 Okla. L. Rev. 31, 51-52 (2024); Sarah Lorr, *Capacity to Marry*, Colum. L. Rev. (forthcoming 2026).

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Much of this work is responsive to the Convention on the Rights of Persons with Disabilities recognition that individuals with disabilities should "enjoy legal capacity on an equal basis,"[244] but this scholarship on capacity, disability, and supported decision-making is still in its early stages, and there is much more for legal scholars to explore.

For example, how should supported decision-making work for routine decision-making, including decisions that may have legal consequence? At present, supported decision-making agreements are structured according to a particular mode of decision-making. The agreement forms seem to contemplate decisional support for a discrete decision that is of some importance (e.g., deciding on a medical intervention or where to live or go to school) and which is made with extensive information and contemplation.[245] Yet, this is not how people make decisions most of the time.

Instead, individuals — including individuals with cognitive impairments — make many decisions each day, often with no information, understanding, or deliberation and maybe without perceiving intention,[246] and some of these decisions matter legally. For example, someone may be presented with an opportunity for a sexual encounter, decide to do something that may be a criminal or civil offense, or be asked to click "yes" on a terms and conditions agreement and have no time (or desire) to talk to others (including their supporters, if they have them) about their choices. If the individual has decisional impairments and would be considered to lack capacity, should their routine decisions made in the absence of support be a defense to liability? How can supported decision-making agreements and models be modified to account for routine, everyday decision-making? And what does "equal capacity" mean in the context of routine decision-making that could have legal consequences?[247]

As another example of unanswered questions about supported decision-making and capacity, should capacity requirements be connected to specific legal interests, decision-making contexts, and potential stakeholders? I have argued that individuals who have entered supported decision-making agreements should be able to make medical decisions independent of their supporters even if the consequences are disability, illness, or death given the importance of bodily integrity and subjective wellbeing, because the benefits and burdens of the decision are borne primarily by the individual making the decision, and because the context reduces the possibility of mistake or abuse.[248] However, would it be ethical to impose criminal liability on individuals who under current understandings and measurements of capacity would be considered incapacitated, especially given the different interests (e.g., punishment, freedom, public safety, etc.) and stakeholders (e.g., the public)?[249] Or to hold such an individual to the terms of a contract they entered that may deplete their financial assets and given important associated interests (e.g., protecting vulnerable individuals, deterring exploitation or wrongdoing[250]) and different actors and stakeholders (e.g., financial institutions, businesses,

[244]G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 12 (Dec. 13, 2006).

[245]*See* Wright, *Dementia and Supported Decisionmaking*, *supra* note 50, at 290-92 (describing the form of supported decision-making agreement and listing examples of decision-making domains for which support can be sought). This type of decision would also include making a will. For a discussion of supported decision-making and estate planning, see Weisbord & Horton, *supra* note 147, at 663–64.

[246]*See* Drought & Koenig, *supra* note 24, at 121 (discussing results of their study in which many patients did not perceive themselves as making medical decisions even though many medical decisions had been made).

[247]Additionally, if someone is using supported decision-making in anticipation of future cognitive decline, how will they or others know at what point in the trajectory of decline the individual no longer has capacity? And how can such persons be ensured protection? *See generally* Wright, *supra* note 214, at 240–43 (discussing unanswered questions about how to combine supported and substitute decision-making to respect autonomy and ensure wellbeing).

[248]*See id.* at 241–43 (summarizing these arguments).

[249]*See, e.g.*, Christie Thompson, *The Never-Ending Murder Case: How Mental Competency Laws Can Trap People with Dementia*, The Marshall Project (June 28, 2023, at 05:00 ET), https://www.themarshallproject.org/2023/06/28/massachusetts-murder-courts-dementia? [https://perma.cc/J5UM-XGSG] (describing man with dementia who killed his roommate in a long-term care facility, was charged with murder despite not understanding his actions or the legal proceedings, and was treated as though his capacity could be restored with confinement to a psychiatric institution and multiple competency hearings).

[250]*See* Scott, *supra* note 72, at 255 (describing purposes of mental incapacity doctrine in contract law).

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unscrupulous actors, etc.)? What is the role of supported decision-making, and how should legal capacity on an equal basis be understood in these non-medical contexts?[251]

Should a determination of incapacity continue to be an option in other legal contexts, and should formal assessments that could be used as evidence in legal proceedings be retained? Assuming the answer is yes, how capacity is assessed still needs to be modified given principles of equal participation in legal institutions and the importance of the dignity of risk.[252] However, if capacity assessments become more valid and reliable in medical contexts, then perhaps they will be better tools in other contexts as well.

This Article offers criticism of current understandings and assessments of (in)capacity for medical decisions. However, the flawed process of capacity assessment along with new interventions to increase capacity such as supported decision-making have implications for other decision-making contexts that have legal consequences. This Article hopes to move the scholarly conversation about (in)capacity forward with the goal that individuals with impaired cognition will eventually attain "equal legal capacity."

[251]In both the criminal and contract contexts, (in)capacity is also relational and contextual — there are victims and perpetrators, parties to a contract, and public and private interests at stake.

[252]*See* Scott, *supra* note 72, at 302–05 (describing how when courts try to "protect" individuals with disabilities, this protection may be inconsistent with respect for autonomy if it conflicts with the individual's financial wishes).

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