
Dementia, Healthcare Decision Making, and Disability Law

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The right to make one's own healthcare decisions, premised on the importance of autonomy and bodily integrity, is well-established in law and medical ethics, and legal tools such as advance directives are meant to ensure that this right survives even when a person is incapacitated. While early court cases and subsequent state legislative action to create living wills focused on incapacity in the context of the permanent vegetative state, the law of healthcare decision making in the event of incapacity has application to other more common instances, including when a person is conscious but has impaired decision-making abilities, as is the case for persons with dementia.

Dementia is an acquired syndrome characterized by cognitive impairments and functional limitations. While predominantly a disease of older persons, dementia is not a normal part of aging.¹ Dementia covers a variety of disorders that negatively impact "multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement."² These cognitive effects are associated with behavioral changes, and sometimes with personality changes.³ The most common dementia is Alzheimer's Disease followed by vascular dementia.⁴ Because dementia is most often progressive, a person may have early-

stage (e.g., some forgetfulness, some difficulty finding the right words to use in conversation), middle-stage (e.g., significant forgetfulness, frequently using vague words such as "something"), or late-stage dementia (e.g., not oriented to time or place, unable to speak at all or to speak intelligibly to others).⁵ Over time, persons with dementia will need assistance with the activities of daily living, such as bathing and feeding. As the disease progresses, persons with dementia will also need assistance with healthcare decision making.

For decades, law and philosophy scholars have been debating about the preferred standard for how others should make healthcare decisions on behalf of patients with dementia.⁶ Because dementia is a special case of incapacity due to changes in personal identity that may result in perceived loss of personhood and in tensions between former and current preferences and interests, there are questions about which interests should be prioritized in healthcare decision making. Many argue that honoring precedent (or prospective) autonomy is the preferred decision-making standard, and advocate for use of advance directives or other evidence of the persons' wishes prior to the onset of dementia.⁷ Others, however, argue that the current best interests of the person with dementia should instead be prioritized.⁸

While healthcare decision-making law accommodates both perspectives, precedent autonomy is privileged in surrogate decision making. As the number of persons with dementia increases⁹ and understandings of the lived experience of dementia evolve,¹⁰ it becomes especially important to revisit whether reliance on advance directives and surrogate healthcare decision making best promote autonomy and welfare for this population, however.

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This article enters the existing debates from a disability rights perspective, which emphasizes the importance of autonomy for persons with disabilities, including dementia. By centering the preferences and experiences of persons with dementia, and looking to existing disability law for insight, alternatives to advance directives and surrogate decision making can be identified. More specifically, this article argues that federal disability law mandates that healthcare providers accommodate their patients with dementia so these patients can participate in decision making. This article also argues that new forms of contracts, known as supported decision making agreements, can also prolong patient autonomy through the earlier stages of dementia.

dementia should be honored. He argued that while a person with dementia has current interests that could be accounted for in a healthcare decision, these interests are merely experiential (e.g., experiencing pleasure while eating).¹¹ In contrast, prior to the onset of dementia, a person's values or understanding of what makes a good life (e.g., valuing self-determination and independence) constitute critical interests.¹² Should there be a conflict between critical and experiential interests, according to Dworkin, the critical interests of a person with dementia should be privileged.

In contrast, in her voluminous scholarship on the subject, Rebecca Dresser has outlined many problems with privileging precedent autonomy when deciding for persons with dementia. Indeed, she has explained

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In brief, this article argues that despite their cognitive impairments, many persons with dementia, with appropriate accommodations and support, can make their own healthcare decisions at the time a decision needs to be made, exercising their autonomy in the present. This reduces the need for advance directives and surrogate decision makers until the later, more severe stages of dementia.

Dementia and the Law of Healthcare Decision Making

Given that dementia often causes memory loss and may result in changes to personality, there is significant potential for conflict between the current interests of persons with dementia and their interests prior to the onset of dementia; indeed, they may not remember or care about their former preferences. This reality has led to a decades-long debate in the legal and philosophical scholarship on dementia and healthcare decision making about the best surrogate decision-making standards for persons with dementia.

Ronald Dworkin was especially influential in arguing that the precedent autonomy of a person with

that it is impossible for individuals to accurately predict how they will experience dementia and what their preferences will be, and that relying on prior preferences does not allow persons with dementia to change their mind after they have been declared incompetent.¹³ Because advance directives typically do not account or allow for adaptation to illness or disability, she instead argues that the current best interests of persons with dementia should be prioritized.¹⁴

Healthcare decision-making law largely reflects Dworkin's view with its emphasis on following advance directives and directions to surrogates to make decisions based on a patient's prior wishes, but does acknowledge a role for using a best interests determination as a last resort. As previously noted, because of the importance of autonomy and bodily integrity, it is settled in United States law and medical ethics that patients with decision-making capacity are entitled to make their own healthcare decisions.¹⁵ But when a patient's decision-making abilities are impaired, perhaps because of mental illness, brain injury, or the onset of dementia, state healthcare decision-making laws provide a process for others to

make decisions on behalf of the incapacitated patient. Because autonomy remains a primary value even when a patient is incapacitated, typically surrogate decision makers will be instructed to follow the written or oral wishes of the patient prior to incapacity,¹⁶ when the patient would have been considered autonomous. If the incapacitated patient never had specific wishes or these wishes were not communicated to relevant third parties, then a surrogate will be instructed to make a substituted judgment, deciding on the basis of the patient's prior values, beliefs, and preferences, to respect the patient's precedent autonomy.¹⁷ If surrogates have no information to make a substituted judgment and it is not possible to respect the patient's precedent autonomy, then surrogates will be asked to decide in accordance with what they consider to be the best interests of the patient.¹⁸

Recent legal scholarship on dementia and healthcare decision making maintains an emphasis on precedent autonomy. This scholarship often describes how to use existing legal tools to ensure that should a person develop dementia, they would be able to control the circumstances of their decline and death. Some recommend using extremely tailored advance directives to decline food and water upon loss of decision-making capacity due to dementia,¹⁹ while others argue for extending access to physician aid in dying to persons who may not have decisional capacity at the time they would otherwise be eligible for this end-of-life option.²⁰ An underlying theme of this scholarship is dread at the prospect of acquiring dementia and subsequently losing autonomy; many legal scholars view dementia as incompatible with a dignified existence.²¹

Living with Dementia

For many persons with dementia, however, their life is not as intolerable or undignified as many persons without dementia may imagine. Indeed, several studies demonstrate that suffering and low quality of life are not necessary consequences of dementia. One quality of life (QOL) assessment of persons with Alzheimer's Disease (AD) who lived at home found that most study participants "rated their overall QOL as good or excellent, despite losses that many of us would consider devastating."²² What explains the disconnect between the relatively good quality of life many persons with dementia experience compared to how their lives are perceived by others? Studies have shown that persons without disabilities rate the quality of life of persons with disabilities lower than the persons with disabilities rate their own quality of life.²³ Research has also shown that people adapt to acquired disabilities,²⁴ as is also true for dementia,²⁵ which may result in changed healthcare preferences

and assessments of what is important.²⁶ Current healthcare decision-making law may not accommodate these changed preferences if surrogates follow advance directives or attempt to honor precedent autonomy rather than present agency of persons with dementia.

In another study with focus groups of persons with AD and their informal caregivers, participants reported feeling depressed, anxious, and angry once diagnosed.²⁷ Importantly, however, the majority of study participants with AD adjusted over time and began to cope with their illness, and only about a fifth were still depressed, with the vast majority reporting being "ok," and a fifth reporting that they were happy. One participant remarked, "You adjust to things you never thought you could—not driving, losing your independence."²⁸

Indeed, while some may say that persons with dementia "suffer" from their illness,²⁹ embedded in this terminology are the assumptions that suffering is occurring and that dementia is the cause of it.³⁰ But as others argue,

"... it is often not so much the impairment itself, but the response of society around the person that creates much of the misery and suffering of dementia. True, neurological impairment creates great difficulties for both sufferer and carers, but it is possible to respond in a much more positive way to minimize the damage and in doing so to enhance the experience, quality of life and level of function of the person affected."³¹

This alternative understanding of dementia emphasizes the personhood of the individual with an acquired cognitive impairment, and their remaining abilities to feel, relate, and communicate,³² rather than focusing on what abilities have been lost. This accords with what is referred to as the social model of disability, which focuses on the relationship of a person with an impairment to others and their environment. The social model of disability contrasts to the medical model, which seeks to "fix" an individual's impairment.³³

The original social model of disability arose from the efforts of persons with physical impairments to "participate fully in society, to live independently, to undertake productive work, and to have full control over their lives."³⁴ According to revised understandings of the social model, individuals may have impairments that they experience as unpleasant or problematic and for which they seek medical treatment, but what is disabling (or oppressing) is society's failures to accommodate them through structural changes

(e.g., elevators, closed captioning, etc.).³⁵ Applying the social model of disability to the case of dementia, persons likely find the onset of typical symptoms such as forgetfulness or aphasia unwelcome, and hope for an efficacious medical treatment to slow or reverse these symptoms, but also maintain a sense of self³⁶ and desire that others acknowledge their personhood and remaining abilities.

A Dementia Patient-Centered Approach

In addition to the empirical findings on the quality of life of persons with dementia, there are studies on the decision-making abilities and preferences of this population. Many persons with dementia, particularly in the early stages, remain capable of making their own healthcare decisions, which they are entitled to do under existing healthcare decision-making law. Research has shown, however, that *there is a presumption of incapacity beginning upon the diagnosis of dementia*.³⁷ Many studies of the experience of persons with dementia in healthcare decision making demonstrate that they are often excluded from or marginalized in the process as healthcare providers turn to surrogate decision makers.³⁸ This is despite their remaining abilities and their desires to be recognized as agentic, self-determining persons and to be actively involved in making or participating in decisions that affect their lives.³⁹ Many persons with dementia recognize their cognitive impairments, but also assert that they have significant remaining capabilities.⁴⁰ When treated as incapable and marginalized in the decision-making process, there is a decrease in their psychological wellbeing.⁴¹

Given their capabilities and preferences, questions arise about how best to create healthcare decision-making law that affects persons with dementia. Scholars have drawn attention to the relative lack of research on the experiences of persons with dementia in healthcare encounters,⁴² and there has similarly been a neglect of the perspectives of persons with dementia in legal scholarship on healthcare decision making. Instead of looking to arguments advanced by persons without dementia, law and policymakers should instead consider centering the perspectives and experiences of persons with dementia, as they are governed by these laws. Doing so should increase the welfare of patients with dementia.⁴³

Insights from Disability Law

Healthcare decision-making law is triggered by concerns about a loss of decision-making capacity (i.e., a presumed loss of the ability to exercise contemporaneous autonomy). These laws permit surrogates to disregard the remaining agency of persons with cog-

nitive impairments should a surrogate perceive there to be conflicts with the patient's prior preferences or current welfare. As discussed previously, this occurs once someone is diagnosed with dementia regardless of their decision-making abilities. There are, however, other bodies of law that are relevant to healthcare decision making that are more consistent with the interests of persons with disabilities to be self-determining and align with the social model of disability's emphasis on accommodating impairments, including decisional impairments.

Indeed, healthcare decision making is also governed by disability law, given that important medical decisions, especially occurring in late or end of life, are made when the patient meets the definition of disabled. Looking to disability law in the context of dementia and healthcare decision making produces different answers to long-standing ethical questions and different guidance to patients, prospective surrogates, and physicians. While there are multiple relevant federal and state disability laws,⁴⁴ this article will focus on two particularly important examples, namely the Americans with Disabilities Act (ADA) and supported decision-making legislation.

AMERICANS WITH DISABILITIES ACT

The most important disability law is the ADA, enacted in 1990 and later amended in 2008. The ADA is a federal civil rights law for persons with disabilities, and it prohibits discrimination against persons with disabilities by employers (Title I), state and local governments (Title II), private entities deemed public accommodations (Title III), and telecommunications (Title IV).⁴⁵ For the purposes of this article, it is worth emphasizing that the ADA requires public and private healthcare facilities and providers to make reasonable accommodations for patients with disabilities so that healthcare services are received in the most integrated setting unless doing so would constitute an undue burden or fundamentally alter the good or service provided.⁴⁶

Dementia constitutes a disability as defined in the ADA because a person with dementia "has a physical or mental impairment that substantially limits one or more major life activities, ... has a history or record of such an impairment, or ... is perceived by others as having such an impairment."⁴⁷ Thus, under the ADA, there is a duty to provide accommodations that enable the full participation of patients with dementia in healthcare decision making unless doing so would be unreasonable or unduly burdensome.⁴⁸

When physicians rely on surrogates to make decisions for their patients with dementia in accord with healthcare decision-making law,⁴⁹ they may not be

meeting their obligations under the ADA. In fact, recent research has shown that physicians are largely ignorant of their duties to accommodate their patients with disabilities,⁵⁰ including their responsibility to provide “alternative and effective types of communication.”⁵¹ Under the ADA, physicians are prohibited from discriminating against and have an affirmative duty to accommodate their patients with dementia just as they have duties to accommodate their patients with other types of disabilities (e.g., providing an interpreter for their patients with a hearing-related disability).⁵²

If a patient with dementia can, with or without accommodations, participate in healthcare decision making, they are legally entitled to do so under the ADA. Typical accommodations or modifications for patients with dementia may include healthcare providers altering their communication style by speaking more slowly, simply, and without jargon; pausing during speaking; asking yes/no questions; and paying attention to nonverbal communication.⁵³ Accommodations may also involve targeting comorbid disabilities, such as hearing loss, with assistive technology; changing the environment to reduce noise and distraction so it is easier for the patient with dementia to concentrate and communicate; and changing medications that negatively impact the patient’s ability to communicate.⁵⁴

If accommodations are necessary for a patient with dementia to participate in healthcare decision making, they will likely not be so unreasonable as to qualify for an exception to the ADA’s mandate.⁵⁵ Healthcare facilities and providers already have access to some of the technology necessary to accommodate dementia-related disabilities, such as assistive devices or medications, and the costs of the extra time needed to communicate with patients with dementia is not unreasonably burdensome from a cost-perspective.⁵⁶ In fact, taking the necessary time to help patients make decisions is also consistent with the best clinical practice of shared decision making wherein healthcare providers and patients together make decisions on the basis of the physician’s expertise and the patient’s values.⁵⁷

In brief, many persons with dementia are legally entitled to make their own healthcare decisions at the time the decision must be made. This is the case under existing healthcare decision-making law if a person with early-stage dementia retains decisional capacity, or under the ADA if the person with dementia can make decisions with any necessary accommodations. The documented experience of many patients with dementia being sidelined when decisions are made regarding their healthcare⁵⁸ suggests providers’ ignorance of disability law. Healthcare providers thus need

to be educated about their legal obligations to their patients with dementia.

STATE DISABILITY LAWS: SUPPORTED DECISION MAKING

The ADA sets a floor for protecting persons with disabilities from discrimination, and states may have additional laws that provide greater protections,⁵⁹ including for disabilities that impair decision making. Most significantly for the purposes of this article, some states have adopted supported decision-making legislation. Supported decision making is an alternative to surrogate decision making and guardianship for persons with cognitive disabilities⁶⁰ and can be applied to persons with dementia.

Under this model, a person with a disability that impairs cognition enters into agreements with people they trust, known as supporters, to assist them in their decision-making process. Supporters can assist in obtaining information necessary to decide; thinking through the decision; and communicating the decision to others.⁶¹ Importantly, with supported decision making, the person with the disability retains legal authority to make their own decisions; supporters are not surrogates who can make the decision for the person with a disability.⁶²

Supported decision making is inspired in part by Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD), which states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”⁶³ While the United States signed the CRPD, the Senate never ratified it. The principles contained within the CRPD have been influential in some domestic court cases, however,⁶⁴ and advocates for persons with developmental and intellectual disabilities recently have been successful in spreading the model of supported decision making.

Supported decision making is currently law on the books of six jurisdictions in the United States.⁶⁵ Texas was the first state to adopt supported decision making,⁶⁶ followed by Delaware,⁶⁷ Wisconsin,⁶⁸ the District of Columbia,⁶⁹ Alaska,⁷⁰ and Indiana.⁷¹ Other states reference supported decision making in their guardianship statutes, directing that before someone be appointed a guardian, other less restrictive alternatives such as supported decision making are explored.⁷² Still other states reference supported decision making for some types of decisions, such as organ donation.⁷³

There has been relatively little sustained engagement with this model specifically for persons with dementia,⁷⁴ although some have argued that supported decision making should be explored for older persons at risk of guardianship, including those with dementia.⁷⁵ A recent report on dementia from the World

Health Organization (WHO) argues that “a legitimate expectation of the law is that it should establish a structure within which appropriate autonomy and self-determination are recognized and protected.”⁷⁶ While the WHO acknowledges that supported decision making can be an appropriate means for respecting the autonomy of persons with dementia,⁷⁷ it also argues that surrogate decision making and advance directives are other means of respecting the autonomy of patients with dementia.⁷⁸

More recent scholarship has argued instead that supported decision making should be the default for persons with dementia, particularly those in the early to moderate stages, as this is the best way to respect their *present* autonomy.⁷⁹ In states where supported decision-making agreements are formally recognized, persons with dementia may elect this option, in addition to or in lieu of an advance directive. Doing so would ensure that patients with dementia remain involved in their healthcare decision making, which matches their documented preferences.⁸⁰

Discussion

For too long, the discussion about dementia and decision making found in the law and philosophy literature has ignored the perspectives and lived experiences of persons with dementia, and has been dominated by the view that persons with dementia are not capable of exercising autonomy and that living with dementia is undignified.⁸³ This has led to a body of scholarship that debates the best standards of surrogate decision making, which assumes that surrogates are necessary, and more recently includes proposals for detailed advance directives to ensure that persons who develop dementia can hasten their death, should this be their preference prior to the onset of dementia.⁸⁴

If persons with dementia are centered, however, future scholarly conversation about dementia and healthcare decision making will be different. Instead of focusing on deficits caused by dementia, legal scholars should acknowledge the desire and capability of many persons with dementia to participate in decision making when a healthcare decision needs to be made.

Instead of focusing on deficits caused by dementia, legal scholars should acknowledge the desire and capability of many persons with dementia to participate in decision making when a healthcare decision needs to be made. Such recognition will likely translate into law and policy that respects the current autonomy of persons with mild to moderate dementia, and thus increase their wellbeing.

While healthcare providers would need to be educated about supported decision making, this model should be familiar to physicians who strive to engage in shared decision making with patients given the similarities between these decision-making models,⁸¹ which could remove a barrier to its routine use. Furthermore, supported decision making can be viewed as a reasonable accommodation under the ADA because having support in decision making can offset some of the impairments that dementia brings. If a patient with dementia has aphasia, for example, a supporter may be able to help interpret what the patient is trying to communicate to a healthcare provider. Or if a patient with dementia is having difficulty remembering information important to a decision, a supporter can remind them of this information. Further, even if states have not adopted supported decision making into law, this does not mean it cannot be used informally by physicians and surrogate decision makers.⁸²

Such recognition will likely translate into law and policy that respects the current autonomy of persons with mild to moderate dementia, and thus increase their wellbeing.

Disability law, which emphasizes autonomy, but also contains a broader range of values, such as self-determination, equality, relationality, recognition of personhood, and inclusion, provides alternatives to surrogate decision making for persons with dementia. Incorporating insights from this body of law should shift scholarly focus on dementia and healthcare decision making to how best to accommodate the impairments caused by dementia so that patients with dementia can participate in healthcare decision making on an equal basis to patients without dementia.

Some may be pessimistic about the realistic prospects of patients with dementia being able to make their own healthcare decisions at the time they need to be made, regardless of what kinds of accommodations or support they receive, given the significant

impairments that some persons with dementia experience, especially as dementia progresses. Admittedly, if someone has late-stage dementia, they are more likely to be unable to participate in healthcare decision making, and surrogates or advance directives will remain necessary. However, research has demonstrated that even patients with advanced dementia can, if properly supported in a conversation, communicate meaningfully with their healthcare providers.⁸⁵ More importantly, most persons have early or moderate dementia, and accommodations and support increase the likelihood that persons with dementia can remain autonomous for longer in the progression of dementia, especially if autonomy is understood as relational in nature.⁸⁶ Relatedly, not all persons with dementia will have persons they trust with whom to enter into a supported decision-making agreement; even in these instances, however, patients with dementia can still benefit from accommodations in their conversations with their healthcare providers.

Others may be concerned that any decisions made by a patient with dementia will not be autonomous. This concern is grounded in the reality of the power differential between them and their physicians and family members, and the fear that the patient with dementia will be coerced into deciding on the basis of others' preferences or interests.⁸⁷ There are, however, safeguards built into existing law, such as physicians' fiduciary duty to their patients and directions to third parties to contact adult protective services should they suspect problematic influence of supporters,⁸⁸ that decrease the likelihood of coercion. Additionally, preventing persons with dementia from participating in their healthcare decision making because of fears of coercion is overly paternalistic.⁸⁹ Finally, many persons make late-life healthcare decisions on the basis of others' interests and view doing so as compatible with autonomous decision making;⁹⁰ it is not clear why persons with dementia would decide differently.

Some may dislike this proposal and prefer to continue to privilege precedent autonomy because they do not want to be able to change their minds about hastening their own deaths in the event that they acquire dementia. Because I have not argued for eliminating advance directives or surrogate decision making entirely, for persons who hold this view, they can opt not to enter into a formal supported decision-making agreement should they acquire dementia and decline decision-making accommodations provided by their healthcare providers, in which case their prior wishes would be honored in healthcare decision making. But their views should not be a roadblock to making additional decision-making models available to the

majority of patients with dementia who do want to be actively involved in their healthcare decision making, despite their acquired cognitive impairments.

Conclusion

A medical ethicist recently asserted, "... it is an ethical priority in the care of people with dementia to maximize the likelihood that they will have opportunities to live lives reflective of their values and maintain active, central roles in decision making."⁹¹ It is time for healthcare decision-making law and medical practice to catch up to this point of view.

Existing federal and state disability law, which offer welcome alternatives to advance directives and surrogate decision making found in healthcare decision-making law, should be applied to persons with dementia. If provided appropriate accommodations and support, respect for the autonomy of patients with dementia can be respect for present, rather than precedent, autonomy.⁹²

Note

The author has nothing to declare.

References

- Centers for Disease Control and Prevention, *The Truth about Aging and Dementia*, available at <<https://www.cdc.gov/aging/publications/features/dementia-not-normal-aging.html>> (last visited December 6, 2019).
- World Health Organization (WHO), *Dementia: A Public Health Priority* (2012): at 7.
- Id.*
- Id.*
- Id.*
- Because people generally do not wish to lose their independence and possibly become a burden on others, many fear the prospect of acquiring dementia. While some plan for the possibility that they may lose decision-making capacity because of dementia and create advance directives to instruct others how they should make decisions on their behalf (typically not to prolong their life), many persons never engage in advance care planning and must rely on others to make decisions on their behalf. K.N. Yadav et al., "Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care," *Health Affairs* 36, no. 7 (2017): 1244-1251.
- N.L. Cantor, "On Avoiding Deep Dementia," *Hastings Center Report* 48, no. 4 (2018): 15-24.
- R. Dresser, "Missing Persons: Legal Perceptions of Incompetent Patients," *Rutgers Law Review* 46, no. 2 (1994): 609-719; R. Dresser, "Precommitment: A Misguided Strategy for Securing Death with Dignity," *Texas Law Review* 81, no. 7 (2003): 1823-1847.
- The prevalence of dementia has significantly declined in the United States between 2000 and 2012. K.M. Langa et al., "A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012," *JAMA Internal Medicine* 177, no. 1 (2017): 51-58. Although this is true, the numbers of persons with dementia in the U.S. are projected to double over the next forty years given the increase in the aging population. Centers for Disease Control and Prevention, *U.S. Burden of Alzheimer's Disease, Related Dementias to Double by 2060*, available at <<https://www.cdc.gov/media/releases/2018/>>

- p0920-alzheimers-burden-double-2060.html> (last visited December 6, 2019).
10. See, e.g. T. Powell, *Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End* (New York: Avery, 2019).
 11. R. Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York: Vintage Books, 1994).
 12. *Id.*
 13. Dresser (2003), *supra* note 8.
 14. *Id.*
 15. See e.g., *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 (N.Y. 1914); Uniform Health Care Decisions Act (UHCDA) (1994); T.L. Beauchamp and J.F. Childress, *Principles of Bio-medical Ethics* (New York: Oxford University Press, 7th ed. 2013).
 16. See UHCDA § 5(f) (1994).
 17. See *id.*
 18. See *id.*
 19. See, e.g., P.T. Menzel and C. Chandler-Cramer, "Advance Directives, Dementia, and Withholding Food and Water by Mouth," *Hastings Center Report* 44, no. 3 (2014): 3-37.
 20. See, e.g., P.T. Menzel and B. Steinbock, "Advance Directives, Dementia, and Physician-Assisted Death," *Journal of Law, Medicine & Ethics* 41, no. 2 (2013): 484-500. Interestingly, a recent study of persons who have a biomarker for cognitive impairment due to Alzheimer's Disease found that becoming aware of the presence of the biomarker did not increase their desire for physician aid in dying compared to their baseline support for this end-of-life option. E.A. Largent et al., "Attitudes toward Physician-Assisted Death from Individuals Who Learn They Have an Alzheimer Disease Biomarker," *JAMA Internal Medicine* 76, no. 7 (2019): 864-866.
 21. Cantor, *supra* note 7.
 22. R.G. Logsdon, "Making the Most of Every Day: Quality of Life," in P.B. Harris, ed., *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (Baltimore: The Johns Hopkins University Press, 2002): 75-87, at 82. In a larger study, the investigators found that the majority of persons with dementia residing in their homes (i.e., those with mild to moderate dementia) reported positive feelings (e.g., happiness, contentment, and hope) and a high QOL. H. Series, "Best Interests Determination: A Medical Perspective," in C. Foster, J. Herring, and I. Doron, eds., *The Law and Ethics of Dementia* (Oxford: Hart Publishing, 2014): at 107. A study of persons with dementia living in nursing homes found no difference in reports of QOL compared to those living at home, and so the level of dementia may not clearly correspond to perceptions of quality of life. *Id.* It may be the case that moving into a long-term care facility provides more opportunities to socialize with others than when one lived at their own home, which may offset any negative aspects of living in a facility such as loss of privacy or being required to abide by policies that may not accord with one's preferences. J. Killick, "I Can't Place This Place at All: The Nursing Home Experience," in P.B. Harris, ed., *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (Baltimore: The Johns Hopkins University Press, 2002): 270-282.
 23. D. Orentlicher, "Deconstructing Disability: Rationing of Health Care and Unfair Discrimination against the Sick," *Harvard Civil Rights-Civil Liberties Law Review* 31, no. 1 (1996): 49-87.
 24. N.F. Boyd et al., "Whose Utilities for Decision Analysis?" *Medical Decision Making* 10, no. 1 (1990): 58-67.
 25. R.F. Young, "Medical Experiences and Concerns of People with Alzheimer's Disease," in P.B. Harris, ed., *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (Baltimore: The Johns Hopkins University Press, 2002): 29-48. Additionally, in the case of dementia, persons probably do not have poor quality of life in the later stages, not just due to adaptation, but also because they are not experiencing their life as poor. D. Callahan, "Terminating Life-Sustaining Treatment of the Demented," *Hastings Center Report* 25, no. 6 (1995): 25-31.
 26. R.S. Dresser and J.A. Robertson, "Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach," *Law, Medicine & Health Care* 17, no. 3 (1989): 234-244.
 27. See Young, *supra* note 25.
 28. *Id.*, at 36. Not all adjusted well. One study participant commented, "It's been three years since I found out, but in the meantime they took away my car, my business, and everything that was important to me. I knew it was coming and I know I should move on to some positive action, but I'm so down." *Id.* Other studies of the experience of living with dementia have likewise found a range of emotional responses and QOL assessments. For example, one small study found that about half of the respondents with dementia reported negative feelings (e.g., sadness, anger, frustration), but that there was variation in responses, with some respondents reporting feelings of happiness or pleasure. Series, *supra* note 22, at 107. Another qualitative study of persons with AD found that while some people with AD reported experiencing confusion, fear, frustration, and anger, as well as embarrassment about how others may perceive them, these feelings were not universal. A. Phinney, "Living with the Symptoms of Alzheimer's Disease," in P.B. Harris, ed., *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (Baltimore: The Johns Hopkins University Press, 2002): 49-74. Indeed, some people with AD framed memory loss and other functional limitations as a normal experience of aging and did not report being bothered. *Id.*
 29. This terminology is used even by persons who specialize in elder law. See, e.g., K. Peck and R.L. Law, *Alzheimer's and the Law: Counseling Clients with Dementia and Their Families* (ABA Book Publishing, 2014): at 57.
 30. J. Perry et al., "Nurse-Patient Communication in Dementia: Improving the Odds," *Journal of Gerontological Nursing* 31, no. 4 (2005): 43-52.
 31. Series, *supra* note 22, at 106. See also Perry, *supra* note 30.
 32. *Id.*
 33. T. Shakespeare, "The Social Model of Disability," in L.J. Davis, ed., *The Disability Studies Reader* (New York: Routledge, 2013): 195-203.
 34. *Id.* at 196.
 35. *Id.*
 36. S.R. Sabat, "Surviving Manifestations of Selfhood in Alzheimer's Disease," *Dementia* 1, no. 1 (2005): 25-36.
 37. R. Beard, *Living with Alzheimer's: Managing Memory Loss, Identity, and Illness* (New York, NYU Press, 2016). Indeed, decision-making capacity is often not formally assessed. L.M. Miller et al., "Shared Decision-Making in Dementia: A Review of Patient and Family Carer Involvement," *Dementia* 15, no. 5 (2016): 1141-1157.
 38. Miller et al., *supra* note 37.
 39. *Id.*; D. Fetherstonehaugh et al., "Being Central to Decision Making Means I am Still Here!": The Essence of Decision Making for People with Dementia," *Journal of Aging Studies* 27, no. 2 (2013): 143-150; M.S. Wright, "Dementia, Autonomy, and Supported Healthcare Decision Making," *Maryland Law Review* 79, no. 2 (forthcoming 2020).
 40. *Id.*
 41. Miller et al., *supra* note 37.
 42. R.H. Fortinsky, "Health Care Triads and Dementia Care: An Integrated Framework and Future Directions," *Aging & Mental Health* 5, Supplement 1 (2001): S35-S48, at S43.
 43. See, e.g., M.A. Hall et al., "Rethinking Health Law," *Wake Forest Law Review* 41, no. 2 (2006): 341-345; L. Shepherd and M.A. Hall, "Patient-Centered Health Law and Ethics," *Wake Forest Law Review* 45 (2010): 1429-1452; M.S. Wright, "End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy," *Maryland Law Review* 77, no. 4 (2018): 1062-1141; Miller et al., *supra* note 37; A. Hall, "Making Good Choices: Toward a Theory of

- Well-being in Medicine,” *Theoretical Medicine and Bioethics* 37 (2016): 383-400; Wright, *supra* note 39.
44. This includes state guardianship law, which may apply when a person or an organization petitions a court for guardianship on behalf of a person with impaired decision making. If a court finds the person incompetent to manage their affairs, then a guardian will be appointed and will be responsible for making decisions on behalf of the person. L. Salzman, “Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act,” *University of Colorado Law Review* 81, no. 1 (2010): 157-245. Because dementia impairs decision making, persons with dementia may have guardians appointed for them.
 45. 42 U.S.C.A. §§ 12101 to 12213.
 46. § 12182(b)(2)(A)(iii); *Olmstead v. L.C.*, 527 U.S. 581 (1999). See also Salzman, *supra* note 44; N.D. Agaronnik et al., “Knowledge of Practicing Physicians about Their Legal Obligations When Caring for Patients with Disability,” *Health Affairs* 38, no. 4 (2019): 545-553.
 47. 42 U.S.C.A. § 12102 (West).
 48. Section 1557 of the Affordable Care Act contains a similar nondiscrimination and accommodation mandate. 45 C.F.R. § 92.202.
 49. Physicians are not following healthcare decision-making law if they rely on a surrogate when their patient with dementia still has decision-making capacity, however.
 50. Agaronnik et al., *supra* note 46.
 51. ADA National Network, *Research Brief: Health Care Access and the ADA*, available at <<https://adata.org/publication/health-care-access-and-ada>> (last visited December 6, 2019).
 52. ADA National Network, *Accessible Health Care*, available at <<https://adata.org/factsheet/accessible-health-care>> (last visited December 6, 2019).
 53. *Id.*; Perry, *supra* note 30; J.B. Orange and E.B. Ryan, “Alzheimer’s Disease and Other Dementias: Implications for Physician Communication,” *Clinics in Geriatric Medicine* 16, no. 1 (2000): 153-173.
 54. *Id.*
 55. This is also the case in other healthcare contexts for other types of disabilities. Agaronnik et al., *supra* note 46; Salzman *supra* note 44.
 56. See, e.g., Salzman, *supra* note 44, at 223.
 57. See Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (2015): at 166-67. Often the patient’s family is also involved in important decisions in what is known as the physician-patient-companion triad. Fortinsky, *supra* note 42; R.D. Adelman et al., “The Physician-Elderly Patient-Companion Triad in the Medical Encounter: The Development of a Conceptual Framework and Research Agenda,” *The Gerontologist* 27, no. 6 (1987): 729-734.
 58. Miller et al., *supra* note 37; Featherstonehaugh et al., *supra* note 39.
 59. See, e.g., M.S. Wright et al., “Severe Brain Injury, Disability, and the Law: Achieving Justice for a Marginalized Population,” *Florida State University Law Review* 45, no. 2 (2018): 313-382, at 355. Some scholars have argued that guardianship is incompatible with the ADA because it is a form of disability discrimination. Salzman, *supra* note 44. Others have argued that guardianship is incompatible with the Convention on the Rights of Persons with Disabilities. R.D. Dinerstein, “Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making,” *Human Rights Brief* 19 (2011-12): 8-12. Some states have thus started to reform their guardianship laws to attempt to find “least restrictive alternatives.” See, e.g., Me. Rev. Stat. tit. 18-C, § 5-401.
 60. Salzman, *supra* note 44; N.A. Kohn et al., Supported Decision Making: A Viable Alternative to Guardianship, *Penn State Law Review* 1117 (2013): 1111-1157; R. Diller, “Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision Making,” *Fordham Urban Law Journal* 43, no. 3 (2016): 495-538.
 61. Kohn et al., *supra* note 60.
 62. This is in contrast to some models found in other countries. *Id.*
 63. Convention on the Rights of Persons with Disabilities (CRPD) art. 12, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006).
 64. See, e.g., *In re Guardianship of Dameris L.*, 56 N.Y.S.2d 848, 853 (Surr. 2012).
 65. For a detailed discussion of these supported decision-making laws, see Wright, *supra* note 39.
 66. Tex. Est. Code Ann. §§ 1357.001 to 1357.102 (West).
 67. Del. Code Ann. tit. 16, §§ 9401(a) to 9410(a) (West).
 68. Wis. Stat. Ann. §§ 52.01 to 52.32 (West).
 69. D.C. Code Ann. §§ 7-2131 to 7-2134 (West).
 70. Alaska Stat. Ann. §§ 13.56.010 to 13.56.195 (West).
 71. Ind. Code Ann. §§ 29-3-14-1 to 29-3-14-13 (West).
 72. See, e.g., Me. Rev. Stat. tit. 18-C, § 5-401.
 73. See, e.g., Kan. Stat. Ann. § 65-3276 (West).
 74. Many scholars are, in fact, dismissive of supported decision making for this population. M.I. Hall, “Dementia, Autonomy and Guardianship for the Old,” in C. Foster, J. Herring, and I. Doron, eds., *The Law and Ethics of Dementia* (Oxford: Hart Publishing, 2014): 339-350.
 75. Diller, *supra* note 60.
 76. WHO, *supra* note 2, at 45.
 77. *Id.*
 78. *Id.*, at 3.
 79. Wright, *supra* note 39.
 80. Miller et al., *supra* note 37.
 81. Kohn et al., *supra* note 60.
 82. See, e.g., Powell, *supra* note 10 (describing an instance in which her mother, who had dementia, was arguably being supported in her healthcare decision making by her adult children).
 83. Cantor, *supra* note 7.
 84. Disabilities that affect cognitive abilities are already highly stigmatized, and writing about dementia in overwhelmingly negative terms may further stigmatize this disorder. As some disability rights advocates have argued, when society accepts choosing death over living with a disability, it demonstrates bias against persons with disabilities. S.R. Bagenstos, “Disability, Life, Death, and Choice,” *Harvard Journal of Law & Gender* 29 (2006): 425-463. Although this article does not address the substance of healthcare decisions persons with dementia make, deferring to individuals with dementia to decide what is in their own current interests (be that prolonging life or hastening death), this article does argue for different decision-making processes that do not prevent persons with dementia from making their own healthcare decisions.
 85. Perry, *supra* note 30.
 86. Wright, *supra* note 43. This would be consistent with recent trends in health law scholarship that place greater emphasis on relationality. See e.g., M.A. Hall, “Foreword: Toward a Relationship-Centered Health Law,” *Wake Forest Law Review* 50 (2015): 233-249; B. Jennings, “Solidarity Near the End of Life: The Promise of Relational Decision Making in the Care of the Dying,” in J.K. Davis, ed., *Ethics at the End of Life: New Issues and Arguments* (New York: Routledge, 2017): 218-234.
 87. Bagenstos, *supra* note 84.
 88. This is described in Wright, *supra* note 39.
 89. Bagenstos, *supra* note 84.
 90. Wright, *supra* note 43.
 91. J.M. Wilkins, “Dementia, Decision Making, and Quality of Life,” *AMA Journal of Ethics* 19, no. 7 (2017): 637-639, at 637.
 92. Wright, *supra* note 39.