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HOW TO END OUR STORIES: A STUDY OF THE PERSPECTIVES OF SENIORS ON DEMENTIA AND DECISION-MAKING

James Toomey

Dementia can cause individuals to make decisions that they otherwise would not and the law needs a mechanism to determine which decisions are entitled to the respect of the legal system and which may be overridden. In the philosophical literature, three primary theories for how to make this determination have been offered. First, "Cognitivism" posits that whether a decision should be recognized is a function of the mechanical functioning of the individual's brain at the time the decision is made. Second, "Essentialism" holds that decisions should be recognized so long as they are consistent with the cluster of values and attributes that define the individual. Third, "Narrativism" argues that decisions should be respected where they follow from the life story of the individual making them.

In the growing tradition of experimental philosophy, this Article empirically analyzes support for these three alternative theories in a mixed-methods study involving a population of American seniors, including an online survey (n=235) and interviews (n=25). Close analysis of the results revealed a near-consensus that Narrativism is the theoretical framework through which participants understood the question of when the legal system should intervene in private decisionmaking. In short, participants wanted

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the legal capacity to make decisions taken from them only when dementia became so advanced that they would no longer be the same person they previously had been, which they understood as a question of narrative continuity.

Introduction

The law plays an important role in recognizing and enforcing many of the most important and intimate decisions that people make—getting married, buying a home, or allocating possessions after death. Dementia—the gradual loss of cognitive functions—can cause people to make decisions that they otherwise would not have, sometimes decisions that are patently wrong or patently absurd. In our aging population, it is no surprise that the relationship between dementia and decision-making is a growing legal problem, playing an increasing role in widespread elder abuse,¹ in the intergenerational transmission of wealth,² and in questions of end-of-life care.³ More generally, dementia plays a role in questions about the rights and responsibilities of older people as they decide where to live, what to do with their time, and how to spend their money.⁴

The law currently addresses the problem of dementia in decision-making through the construct of legal capacity.⁵ Although this construct varies to some extent across contexts and jurisdictions, the essential idea is that a court will, when called upon, inquire into whether an individual has the mental abilities required to make a particular decision.⁶ If they do, they can make the decision unimpeded.⁷ Otherwise, the individual's legal ability to make that decision will be restricted or reversed.⁸ Moreover, if an individual is deemed to have met a certain

1. See generally Peter A. Lichtenberg, *Financial Exploitation, Financial Capacity, and Alzheimer's Disease*, 71 AM. PSYCH. 312–20 (2016).

2. See Jennifer Moye et al., *Assessment of Capacity in an Aging Society*, 68 AM. PSYCH. 158, 162 (2013) (discussing the implications of dementia for questions of testamentary capacity).

3. See Kirsten Moore & Elizabeth Sampson, *Advanced dementia and care at the end of life*, in DEMENTIA 349 (David Ames et al., 5th ed. 2017).

4. See Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L.J. 495, 501–02 (2016).

5. See generally Kelly Purser, *CAPACITY ASSESSMENT AND THE LAW: PROBLEMS AND SOLUTIONS* (Springer, 2017).

6. See, e.g., Moye et al., *supra* note 2, at 161.

7. See Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity*, 39 AM. J. L. & MED. 134, 146–47 (2013).

8. *Id.*

threshold of mental incapacity, the court will appoint a guardian or conservator to make some or all legal decisions on their behalf.⁹

The standards for making capacity rulings are notoriously vague and largely unempirical.¹⁰ This has, predictably, resulted in uneven application,¹¹ excessive curtailments of rights,¹² periodic stories of outright abuse,¹³ and a great deal of scholarly criticism.¹⁴ In response, there has been a movement in recent years to reform and improve the legal doctrine, in particular by integrating modern neuroscience into the legal capacity analysis.¹⁵ This promises to bring a much needed rigor and consistency to judicial capacity rulings.

But there is a deeper problem. Setting aside the scientific challenges of measuring cognitive deterioration, we need a normative theory of *which types* of cognitive abilities matter and how *much* ability is required for a particular decision.¹⁶ In other words, before science can measure whether what we care about is still there in the brain, we need to know what it is we care about. We need a foundational normative theory of the necessary and sufficient conditions of a legally recognizable decision. There is no neurological answer to this question. There can't be.¹⁷

9. *Id.*

10. See Moye et al., *supra* note 2, at 167 (discussing the ABA and APA's joint nine-factor test for legal capacity).

11. See, e.g., *id.* at 171 ("[C]linicians arrive at significantly discrepant judgments of capacity in dementia, focusing on different cognitive and decisional abilities in patients, or holding values different from those of patients. . . .").

12. See Diller, *supra* note 4, at 511 ("A growing chorus of critics argues that even under the best guardianship, the mere fact that the guardianship has adjudged an individual as incapacitated or incompetent, and stripped her of the right to act on her own behalf, causes significant harm.").

13. See Interview with Person 2, in Brookline, Mass. (Nov. 24, 2018) (on file with author) (discussing an anecdote where a judge would appoint his wife as guardian, and who was suspected to be stealing from those under her guardianship).

14. See, e.g., Diller, *supra* note 4, at 496 ("For the last several decades, guardianship has been the subject of continual calls for reform, often spurred by revelations of guardian malfeasance and other abuses in the system.").

15. See generally, e.g., Betsy J. Grey, *Aging in the 21st Century: Using Neuroscience to Assess Competency in Guardianships*, 4 WIS. L. REV. 735 (2018); Ryan Darby & Bradford C. Dickerson, *Dementia, Decision Making, and Capacity*, 25 HARV. REV. PSYCHIATRY 270 (2017).

16. See Grey, *supra* note 15, at 738 ("A legal finding of incompetency involves a value-driven judgment as to whether an individual has the minimal ability to care for oneself or one's property. . . . Where we strike this balance reflects our social values, moral judgments, and legal principles.").

17. See Lois A. Weithorn, *Psychological Distress, Mental Disorder, and Assessment of Decisionmaking Capacity Under U.S. Medical Aid in Dying Statutes*, 71 HASTINGS L.J.

There has been a tremendous amount of work done on dementia and legal capacity in recent years across a variety of academic fields and in practice.¹⁸ But so far, the search for a foundational normative theory of what matters for capacity has been largely limited to professional academic philosophy. Debate in that field has centered around three theories of what matters for legal capacity. The first, and most prevalent, is Cognitivism, the theory that what matters is the mechanical functioning of the brain—up to a certain threshold of functionality, people with dementia should be permitted to make any decision they would like to, and past that threshold their decision-making may be controlled. This is the theory that serves as the normative basis for the current legal understanding of decision-making capacity. The second, which has become very influential in dementia care, is Essentialism, the theory that what matters is personal identity as defined by a cluster of values and characteristics (for example, an individual's moral, religious, or political commitments). So long as a person with dementia makes decisions consistent with those characteristics, they should be permitted to make them, but deviation from these characteristics may serve as a basis for intervention consistent with those essential values

637, 687 (2020) (“How high must the levels of understanding, appreciation, and reasoning be to lead to a conclusion that the patient meets the legal criterion of capacity under the statute? In developing the [prominent capacity test, its creators] expressly declined to set such thresholds, recognizing that such decisions are *policy* matters that reflect a number of considerations relevant to each treatment context or decision.”).

18. See, e.g., Lauren Padama, *Informed Consent and Decision-Making After Loss of Competency in Dementia Patients: A New Model*, 28 S. CAL. INTERDISC. L.J. 173–74 (2018) (explaining “the challenges facing both the medical and legal community as the aging population of the United States leads to an inevitable increase in the number of dementia patients”); Sam Boyle, *Determining Capacity: How Beneficence Can Operate in an Autonomy-Focused Legal Regime*, 26 ELDER L.J. 35, 35 (2018) (“Capacity is a central issue for people with disabilities and some older adults, and its place in the legal system is the subject of debate.”); EILIONÓIR FLYNN ET AL., EDs., *GLOBAL PERSPECTIVES ON LEGAL CAPACITY REFORM: OUR VOICES, OUR STORIES* (2019) (offering perspectives on global reform efforts to the concept of legal capacity); Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decisionmaking*, 79 MD. L. REV. 257, 262 (2020) (arguing for the adoption of a “supported decisionmaking” model in the healthcare context); Zachary Sager et al., *Making End-of-Life Care Decisions for Older Adults Subject to Guardianship*, 27 ELDER L.J. 1 (2019) (discussing the challenging problem of healthcare decisionmaking by professional guardians); see also Rebecca C. Morgan et al., *A View from the Bridge: A Brief Look at the Progression of Cases of Elder Financial Exploitation Prosecutions*, 25 ELDER L.J. 271 (2018) (describing challenges and strategies in elder justice prosecutions); cf. also, e.g., Francis X. Shen, *Ageing Judges*, OHIO STATE L.J. (forthcoming 2020) (analyzing the challenge of dementia in the aging judiciary).

and characteristics. Finally, Narrativism posits that what matters is personal identity defined by narrative coherence—people with dementia may make decisions so long as they are narratively consistent with their life story, and intervention in their decision-making is justified when the disease disrupts that narrative.

This Article empirically analyzes support for the alternative theories proposed in the philosophical literature among the population most affected by dementia and its legal challenges—seniors. Seniors face the possibility of dementia most closely and most often and are directly affected by legal interventions in decision-making based upon it. In the growing tradition of experimental philosophy, this Article presents the results of a small, mixed-methods empirical study into the perspectives of seniors on when and how they would want the law to intervene in their lives as they began to develop dementia. The study includes a quantitative analysis of an online survey of 235 seniors from around the United States, as well as a qualitative analysis of twenty-five in-person interviews with seniors in retirement communities in Brookline, Massachusetts.

The results suggest that there is a consensus, or a near consensus, among the diverse but limited pool of participants that Narrativism is the theoretical framework through which they understand the question of when and how the legal system should intervene in their decision-making. Notwithstanding a certain superficial diversity in the specific triggers at which participants would want the law to intervene, they almost without exception agreed on the analytical *process* by which they arrived at their specific triggers. That common inquiry is an analysis of the continuity of their narrative identity. Participants wanted their legal capacity to make decisions taken away from them only when their dementia was so advanced that they would no longer be the same person that they are and have been; which they conceptualized as occurring when their future self with dementia was no longer narratively continuous with the story of their lives.

This Article has four parts. In Part I, I offer a background on dementia and the prevailing philosophical efforts to understand when others ought to intervene in the decision-making of persons with dementia and summarize the contemporary American legal approach to the problem. Part II discusses my study and its methods, Part III presents and analyzes its results, and Part IV offers a preliminary discussion of these findings.

I. Background

Both the science of dementia and the legal concepts it implicates are complex, vary extensively, and have evolved so rapidly over the last several decades that any attempt to be brief must also be somewhat cursory. This Part, however, offers an account of the relevant background of our understanding of dementia, in particular its most common cause, Alzheimer's disease; introduces the prevailing normative theories of when intervention is appropriate in the course of dementia; and then turns to discuss the contemporary legal framework and the prevailing theories of what the concept of legal capacity should attempt to capture. Finally, it situates this study in a growing experimental turn in normative philosophy.

This Part is by no means a comprehensive literature review. The empirical, legal, medical, and disabilities studies on dementia and decision-making is too large for comprehensive discussion here. Only a comparatively narrow slice of this scholarship, however, directly bears on the question addressed by this study—*when* during the dementia's progress should the law begin to intervene. In contrast, much more has been written on *how* we ought to treat people without capacity—a question outside the scope of this Article—which generally assumes some answer to the underlying normative questions.¹⁹ For example, there is a robust empirical literature in the healthcare context showing that surrogate decisionmakers regularly make different decisions than the patients for whom they are deciding would have, and legal scholars have proposed solutions to this incongruity.²⁰ This work assumes, however, that we want surrogate decisionmakers to make the decision the patient would have made. Although not pertinent to this particular Article, my study contested that assumption—a majority of participants endorsed the principle, but a determinate minority would want surrogate deci-

19. See Sager et al., *supra* note 18, 20–26 (offering guidance to professional guardians serving as surrogate decisionmakers in the healthcare context on the assumption that those decisions should incorporate the values of the person without capacity to the extent possible).

20. See, e.g., Nina A. Kohn, *Matched Preferences and Values: A New Approach to Selecting Legal Surrogates*, 52 SAN DIEGO L. REV. 399 (2015) (summarizing empirical literature and proposing that people select decisionmakers with an eye toward their values).

sionmakers to make an independent judgment of the person with dementia's best interests.²¹ Therefore, to condense the literature on dementia and decisionmaking to its most manageable and pertinent form, this Part draws primarily on three sources: background medical literature on dementia, academic philosophy's direct engagement with the normative question of when others may decide for a person with dementia, and a high-level summary of the contemporary law of incapacity.

A. Dementia

Dementia is a broad term that refers to symptoms of gradual degradation of cognition over a relatively long period of time caused by any of a number of pathologies.²² Historically, a diagnosis of dementia required cognitive decline in more than one domain, one of which must be the loss of memory.²³ More recently, leading standards have dropped the requirement of memory loss and refer generically to cognitive decline.²⁴ For purposes of this Article, "dementia" will be used broadly to refer to the long-term, gradual decline of cognitive abilities in ways that implicate decision-making and everyday living, with any cause.²⁵

Alzheimer's disease is the most common cause of dementia.²⁶ It is characterized by the build-up, typically in plaques,²⁷ of neurotoxic²⁸

21. Specifically, 63 percent of survey respondents would want surrogate decisionmakers to make the decision they would have made, 33 percent wanted such decisionmakers to make an independent judgment of their best interest, and 4 percent would permit surrogate decision-makers to consider their own interests in making a decision.

22. See Greg Savage, *Neuropsychological Assessment of Dementia*, in *DEMENTIA* 52 (David Ames et al., 5th ed. 2017) ("Dementia is usually defined in terms of deterioration in two areas: cognition and instrumental activities of daily living.").

23. *Id.*

24. *Id.* ("[N]either NIA-AA nor DSM-5 require the presence of amnesia as part of their evidence of cognitive decline. This represents a common shift away from the use of AD as the blueprint for conceptualization of dementia, a criticism which has long been levelled at dementia diagnostic criteria.").

25. *Id.*

26. Andy Coghlan, *The Alzheimer's Problem*, 233 *NEW SCIENTIST* 22, 22 (Jan. 28, 2017).

27. See Victor L. Villemagne & Christopher C. Rowe, *Molecular Brain Imaging in Dementia*, in *DEMENTIA* 125 (David Ames et al., 5th ed. 2017) (discussing the neuroimaging of A β plaques).

28. See Colin L. Masters, *The Neuropathology of Alzheimer's Disease*, in *DEMENTIA* 478 (David Ames et al., 5th ed. 2017) (stating "A β has both toxic and trophic effects on neurons in culture . . .").

amyloid- β protein (A β) (the benign function of which, if it has one, in non-toxic isoforms is not well understood)²⁹ and neurofibrillary tangles of hyperphosphorylated tau proteins (which in their benign form play a role in neuron stability).³⁰ The exact pathological mechanism remains controversial, but the prevailing hypothesis is that the disease pathway is driven by amyloid- β ,³¹ although the mixed results of high-profile drugs targeting the build-up of the protein cast doubt on this hypothesis.³²

These chemical changes cause brain matter to atrophy and result in cognitive decline, most notably the decline of memory.³³ Indeed, “[t]he pattern of memory impairment in [Alzheimer’s] is quite distinctive.”³⁴ Short-term memory and learning, such as remembering new people, the details of the conversation one is having, or where one put the car keys, are the first to go.³⁵ Longer term memories and procedural

29. See Mikko Hiltunen et al., *Functional Roles of Amyloid-beta Protein Precursor and Amyloid Beta Peptides: Evidence from Experimental Studies*, 18(2) J. ALZHEIMER’S DISEASE 401, 401 (Aug. 2009) (“[T]he function of the amyloid beta protein precursor . . . and its processing products in the central nervous system is controversial.”).

30. See generally Tong Guo et al., *Roles of Tau Protein in Health and Disease*, 133 ACTA NEUROPATHOLOGICA 665 (2017).

31. See Craig W. Ritchie & Colin L. Masters, *The Central Role of A β Amyloid and Tau in the Pathogenesis of Alzheimer’s Disease*, in DEMENTIA 492, 500 (David Ames et al., 5th ed. 2017) (“The theory that A- β amyloid underlies the neurodegenerative changes in [Alzheimer’s] remains pre-eminent . . . despite emergence in recent years of alternative disease pathways . . . The two most well-defined pathological processes in [Alzheimer’s] are the aggregation of tau protein and subsequent destabilization of the cytoskeletal protein tubulin, and the aggregation of A- β to form amyloid plaques.”); Masters, *supra* note 28, at 478 (“While the cause of [Alzheimer’s] is now clearly defined as the cerebral deposition of A- β amyloid, the pathogenesis of [Alzheimer’s] is not fully understood.”). Specifically, there is increasing evidence that it is the 42 amino acid form of the amyloid- β protein (A β -42) that is particularly pathogenic. See Ritchie & Masters, *supra* note 31, at 493 (“In concert with traditional explanations of the disconnect between plaque number and disease severity, there is now a gathering consensus that the soluble/diffusible A β -42 load may be more closely related to clinical severity, whether or not the A β -42 exists as an oligomer or complexed to other proteins.”).

32. See Sharon Begley, *Alzheimer’s and amyloid: ‘It’s time to do something else’*, STAT NEWS (Mar. 21, 2019), <https://www.statnews.com/2019/03/21/alzheimers-amyloid-time-to-do-something-else/> (discussing the implications of Biogen’s suspension of its prospective [Alzheimer’s] drug aducanumab after its failure in Phase III trials).

33. See Jody Corey-Bloom & Michael S. Rafii, *The Natural History of Alzheimer’s Disease*, in DEMENTIA, at 453 (David Ames et al., 5th ed. 2017) (“Memory loss is the cardinal and commonest presenting complaint in [Alzheimer’s].”).

34. *Id.*

35. *Id.*; see also Klaus P. Ebmeier et al., *Functional Brain Imaging and Connectivity in Dementia*, in DEMENTIA 112 (David Ames et al., 5th ed. 2017) (“The first cognitive deficit in [Alzheimer’s] is often associated with episodic memory loss” This is

memories (i.e., memories associated with particular routines, habits or skills), which are stored in different parts of the brain, can remain for many years, but “[w]ith progression, the memory loss worsens to include remote memory.”³⁶

This gradual decomposition of a unique human brain occurs differently in each individual and, “[t]he course of [Alzheimer’s] and the combination of symptoms that manifest in each patient are markedly heterogeneous.”³⁷ Yet, certain patterns have been observed. For example, judgment and abstraction are often impaired early in the disease, while social comportment and interpersonal skills can remain for many years.³⁸ This may help explain the anecdotal phenomenon of people with Alzheimer’s “tricking” those with whom they interact into thinking they have retained more cognitive skills and awareness than they actually have.³⁹ Moreover, people with Alzheimer’s often have increasing difficulty with mathematics,⁴⁰ experience a variety of personality changes,⁴¹ including increased aggression,⁴² and often exhibit any of a

apparently caused by the faster atrophy in the hippocampus and entorhinal cortex areas of the brain, which are involved in processing memory for recent events.); see Robert Barber & John T. O’Brien, *Structural Brain Imaging*, in *DEMENTIA* 95 (David Ames et al., 5th ed. 2017) (“[I]n [Alzheimer’s], the rate of hippocampal atrophy is greater than the global atrophy rate—approximately 3%-8% compared with 1%-3% depending on the study.”).

36. *Id.*; see also Leon Flicker, *Screening and Assessment Instruments for the Detection and Measurement of Cognitive Impairment*, in *DEMENTIA* 45 (David Ames et al., 5th ed. 2017) (“In a longitudinal study of cognitive function in people with Alzheimer’s disease, it was demonstrated that dementing processes particularly affect remote memory, intermediate memory and language function.”).

37. Flicker, *supra* note 36 at 45.

38. *Id.* at 44.

39. See, e.g., Interview with Person 1, in Brookline, Mass. (Nov. 24, 2018) (on file with author) (“[M]y mother in law, had major issues, *major* issues and at one point she was hospitalized and we asked the physician, I’m not sure how well the physician knew her, to go in, because she was wildly out there, and he came back and said there’s nothing wrong. . . . [S]he was a very socially accomplished person and often she could do a five-minute conversation with someone.”); Interview with Person 4, in Brookline, Mass. (Dec. 1, 2018) (on file with author) (“I don’t think they realized how far gone [my mother] was. . . . [S]he covered up a lot.”).

40. See Corey-Bloom & Rafii, *supra* note 33, at 454.

41. See Ajit Shah, *Measurement of Behaviour Disturbance, Non-Cognitive Symptoms and Quality of Life*, in *DEMENTIA* 69 (David Ames et al., 5th ed. 2017) (“Changes in personality features include: coarsening of affect, disinhibition, increase in passivity, apathy, spontaneity, irritability, belligerence, demanding attention, indifference, egocentricity, less conscientiousness, lower extraversion, higher neuroticism, and higher openness.”).

42. See Ian James & Louisa Jackson, *Treating Problem Behaviours in Dementia by Understanding Their Biological, Social and Psychological Causes*, in *DEMENTIA* 248 (David Ames et al., 5th ed. 2017) (“[B]ecause the person with dementia does not always

suite of neuropsychiatric symptoms including apathy, anxiety, depression, and psychosis.⁴³ Throughout, basic cognitive functions decline over time.⁴⁴

There is currently no cure for Alzheimer's⁴⁵ and no lifestyle choices can definitively prevent it.⁴⁶ Genetics play an important role, and certain alleles have been linked to increased chances of developing the disease.⁴⁷ Fortunately, there are a number of promising disease-altering treatments in development, but a long period of failure has tempered hopes for a simple cure.⁴⁸ Other causes of dementia vary in their pathologies and characteristic attributes, but all include cognitive decline and changes in both everyday functioning and behavior.⁴⁹

share the same reality as his/her caregiver, they can often perceive such management strategies as restrictive practices, which evokes anger and aggression.”).

43. See Nilika Perera et al., *Neuropsychiatric Aspects of Dementia*, in *DEMENTIA* 61 (David Ames et al., 5th ed. 2017) (“[A]pathy is the most common symptom, appearing in 55% of clinic patients, followed by anxiety and depression in about 37%. Delusions and hallucinations have a similar prevalence to the population-based findings from the United States.”).

44. See Corey-Bloom & Rafii, *supra* note 33, at 453 (“Symptoms begin insidiously, making it difficult to date the onset of cognitive and functional decline precisely. Progression is generally gradual, yet can be interleaved with occasional plateaus; however, reliable measurement of clinical disease progression in [Alzheimer’s] is difficult because of variability between and within subjects.”).

45. See Paul Yates & Michael Woodward, *Drug Treatments in Development for Alzheimer’s Disease*, in *DEMENTIA* 554 (David Ames et al., 5th ed. 2017) (“[W]e still only have symptomatic therapies for [Alzheimer’s] and no therapies for the other dementias.”); but see Alexander Kurz & Nicola T. Lautenschlager, *Established Treatments for Alzheimer’s Disease*, in *DEMENTIA* 539–46 (David Ames et al., 5th ed. 2017) (discussing the symptomatic relief provided by cholinesterase inhibitors, such as donepezil, and memantine, which can delay cognitive decline by as much as a year. Cholinesterase inhibitors are also effective at mitigating the course of other dementias.); see Gustavo C. Román, *Therapeutic Strategies for Vascular Cognitive Disorder*, in *DEMENTIA* 660, 670–72 (David Ames et al., 5th ed. 2017) (discussing the use of cholinesterase inhibitors in the treatment of vascular dementia).

46. See generally Tom C. Russ, et al., *Prevention of Alzheimer’s Disease and Alzheimer’s Dementia*, in *DEMENTIA* 599 (David Ames et al., 5th ed. 2017) (discussing correlative evidence related to certain modifiable mid-life characteristics, such as body mass index, blood pressure, and vitamin D, and development of Alzheimer’s).

47. See Patricia A. Boyle & Robert S. Wilson, *Risk Factors for Alzheimer’s Disease*, in *DEMENTIA* 447 (David Ames et al., 5th ed. 2017) (“[S]everal polymorphisms are associated with an increased risk of [Alzheimer’s], but the apolipoprotein E gene is the only consistently replicated risk factor for the most common expression of [Alzheimer’s].”).

48. See generally Yates & Woodward, *supra* note 45.

49. See generally Timo Erkinjuntti et al., *What is Vascular Cognitive Impairment?*, in *DEMENTIA* 630 (David Ames et al., 5th ed. 2017) (discussing vascular dementia, caused by a failure of adequate blood flow to all parts of the brain, which “do[es]

Alzheimer's (and dementia) notwithstanding, it is worth noting that people's decision-making processes often change as they age.⁵⁰ Moreover, many older adults experience some measurable cognitive decline, generically referred to as mild cognitive impairment ("MCI").⁵¹ There is a broad consensus that this decline is usually a preclinical form of dementia,⁵² but many people with MCI "do not experience a further cognitive decline and may even revert to normal status."⁵³

There are three important points about Alzheimer's and dementia most relevant to this Article. The first is that these diseases are all, for the foreseeable future, incurable.⁵⁴ The second is that the diseases progress gradually.⁵⁵ A diagnosis of dementia does not make someone incompetent; people can remain broadly competent for years after a clinical diagnosis, which may occur at different points in the development of the disease in different patients. But the third point is that these diseases do, over time, cause real changes in people; changes that are perhaps uniquely challenging from a legal and ethical perspective. There is certainly a point at which people with dementia cannot be permitted

not have the same regional predilection" in the brain as Alzheimer's, and thus presents in a variety of ways that does not necessarily include the characteristic memory loss of Alzheimer's); Ian G. McKeith, *Dementia with Lewy Bodies: A Clinical Overview*, in *DEMENTIA*, 703 (David Ames et al., 5th ed. 2017) (discussing dementia with Lewy bodies, a kind of abnormal aggregation of protein, which is characterized by fluctuating cognition and a greater level of psychosis or delirium than Alzheimer's).

50. See generally, e.g., Rui Mata et al., *Age Differences in Risky Choice: A Meta-Analysis*, 1235 *ANNALS N.Y. ACAD. SCI.* 18 (2011) (describing the impact of age on risk taking behavior and finding that because of decreased learning performance older adults took more risky choices where learning led to risk avoidance and fewer risky choices where learning led to risk seeking). But see Karen Ritchie & Sylvaine Artero, *Mild Cognitive Impairment (MCI): A Historical Perspective*, in *DEMENTIA* 419, 420 (David Ames et al., 5th ed. 2017) [hereinafter MCI] ("[R]esearchers such as Schaie and Willis (1991) . . . have demonstrated that much of the difference in cognitive performance observed between young and elderly cohorts [is caused by] generation differences (notably in education and healthcare) rather than ageing related changes in the brain.").

51. See generally, e.g., Perminder S. Sachdev et al., *The Prevalence of Mild Cognitive Impairment in Diverse Geographical and Ethnocultural Regions: The COSMIC Collaboration*, 10 *PLOS ONE* 1, 2 (2015) ("Applying uniform criteria to harmonized data greatly reduced the variation in MCI prevalence internationally.").

52. MCI, *supra* note 50, at 421 ("[M]any clinical observations of the long-term outcome of cognitive complaints . . . led to the general conclusion by many neurologists that subclinical cognitive disorder in the elderly is in fact principally, if not exclusively, early-stage dementia.").

53. *Id.* at 433.

54. See Yates & Woodward, *supra* note 45.

55. See Ebmeier et al., *supra* note 35.

to live independently, no matter how generously we hope to draw the legal doctrine. We know this because there is a point at which they are effectively catatonic.⁵⁶

B. Theories of Incapacity

Over the past several decades, a number of philosophers and other theorists have considered when caretakers or the law ought to intervene in the decision-making of individuals with dementia. These theorists have primarily settled into three schools, which, as alluded to in the introduction, I term Cognitivism, Essentialism and Narrativism. This Section briefly discusses each theory in turn.

1. COGNITIVISM

The dominant set of theories about what matters for legal capacity are the “Cognitivist” theories, which posit that the sole necessary and sufficient condition for a purported decision to be respected by others is that it be made with a certain level of cognitive, intellectual functioning.⁵⁷ In other words, the theory—which also draws on classically liberal understandings of the role of law as well as ethical philosophy⁵⁸—is that the problem of dementia in decision-making is that at a certain point dementia strips a person of those characteristics that entitle a person’s decisions to the community’s respect.⁵⁹ And those characteristics

56. 18 AM. JUR. PROOF OF FACTS 3D § 185 (2020) (“The courts universally hold that mere impairment of memory, even when accompanied by extreme physical infirmity, does not deprive the individual of legal capacity. Likewise, the courts have no difficulty in concluding that a person in the final stages of dementia, deprived of all powers of reason and conscious action, and living a vegetative existence, lacks legal capacity for all purposes.”); cf. David Conn, John Snowdon & Nitin Purandare, *Residential Care for People with Dementia*, in *DEMENTIA*, at 266, 271 (David Ames et al. eds., 5th ed. 2017) (“[E]uthanasia in cases of dementia is almost an unthinkable option due to impaired cognitive skills and inability of such patients to provide informed consent.”).

57. See, e.g., ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION-MAKING* (1990).

58. *Id.* at 69–70 (“If the irrationality of the choice is accepted as ground justifying paternalistic interference with it, it is virtually certain that choices accurately reflecting a patient’s own aims and values would frequently and wrongly be interfered with by others who have different values and preferences and a different view of what is best for the patient.”).

59. *Id.* at 115 (“The very notions of self-determination, and hence of a right of self-determination, only apply to beings who have, or at least have the potential for developing, certain rather complex cognitive functions: the ability to conceive of the future, to discern alternative courses of action, and to make judgments about their own good [I]t only makes sense to ascribe a right of self-determination only to

are “usually cognitive;”⁶⁰ the mechanical, process-related functions of situational awareness, ability to process new information at a certain speed, and to reason among competing alternatives.⁶¹ What does not matter is the *content* of the decision.⁶²

For example, Allen Buchanan and Dan Brock outlined a prominent Cognitivist theory of dementia and decision-making (though specifically in the healthcare context) in their book *Deciding for Others*.⁶³ They argue that what matters for legal (and ethical) capacity are the abilities to (1) understand and communicate⁶⁴ and (2) reason and deliberate⁶⁵ based on (3) a conception of the good.⁶⁶ Under Cognitivist theories, the assessment of whether a person has the capacity to make a particular decision is conceptualized as occurring at a single instant.⁶⁷ As a practical matter, Buchanan and Brock do care about *some consistency* over time, such that the person in question has the ability to rationally pursue goals rather than be erratically unable to decide.⁶⁸ But the consistency Buchanan and Brock have in mind is merely the consistency

beings who are capable of conceiving of themselves as agents—beings distinct from, and capable of changing, their environment.”).

60. Tom L. Beuchamp, *The Failure of Theories of Personhood*, in PERSONHOOD AND HEALTHCARE 59, 59–60 (David C. Thomasma et al. eds., 2001).

61. See BUCHANAN & BROCK, *supra* note 57, at 115; see also RAYMOND J. DEVETTERE, PRACTICAL DECISION MAKING IN HEALTH CARE ETHICS: CASES AND CONCEPTS 127 (2d ed. 2000) (arguing that decision-making capacity consists of “(1) the ability to understand and communicate relevant information, (2) the possession of a framework of values providing a context for particular value judgments, and (3) the ability to reason about different outcomes, risks and chances of success.”).

62. BUCHANAN & BROCK, *supra* note 57, at 50 (“An adequate standard of competence will focus primarily not on the content of the patient’s decision but on the *process* of the reasoning that leads up to that decision.”).

63. See generally *id.*

64. *Id.* at 24 (“Understanding is not merely a formal or abstract process, but also requires the ability to appreciate the nature and meaning of potential alternatives—what it would be like and ‘feel’ like to be in possible future states and to undergo various experiences.”).

65. *Id.* at 23 (“Two [capacities] may be distinguished: the capacity for understanding and communication, and the capacity for reasoning and deliberation.”).

66. *Id.* (“A third important element of competence is that the individual must have a set of values or conception of the good.”).

67. *Id.* at 20 (“A person may be competent to make a decision about whether to have an elective surgical procedure if the choice is presented in the familiar surroundings of home by someone known and trusted, but may be incompetent to make the same choice in what is found to be the intimidating, confusing, and unfamiliar environment of the hospital.”).

68. *Id.* at 25 (“[S]ufficient internal consistency and stability over time in the values relative to a particular decision are needed to yield and enable pursuit of a decision outcome; for example, a depressed patient subject to frequent mood changes

required to be able to *factually make* a rational decision (i.e., there is no decision at all if it cannot be maintained long enough to be put into practice). "Sufficient short-term memory"⁶⁹ is a prerequisite to the ability to make decisions that the law ought to respect, such that broadly rational decisions can be made and maintained, but long-term memory and the substantive consistency of a decision with abstractions such as personality or life-story are not morally significant in themselves. As such, under Cognitivist theories, personal identity is not what matters for decision-making. The question of decision-making capacity is much closer to the question of whether the person with dementia remains a person at all.⁷⁰

2. ESSENTIALISM

Essentialism posits itself as a holistic and humane alternative to Cognitivism's narrow procedural focus and its theoretical flirtation with the possibility that individuals with advanced dementia may not be persons.⁷¹ Essentialism is the theory that what matters to decision-making is the consistency of a purported decision with the identity of the person making it, where that identity is conceptualized by an extrinsic cluster of socially-constructed, essential characteristics—"values," "beliefs," "preferences" and "choices."⁷² An Essentialist theory of dementia and decision-making holds that intervention is appropriate—

may repeatedly consent to electroconvulsive treatment, but then change his or her mind before treatment can be carried out.”).

69. *Id.* (emphasis added).

70. See *id.* at 115; see also BECKY COX WHITE, COMPETENCE TO CONSENT 121–25 (1994) (discussing the relationships between theories of decision-making capacity that turn on cognitive capacity with theory of personhood that base personhood on those same capacities).

71. See generally TOM KITWOOD, DEMENTIA RECONSIDERED: THE PERSON COMES FIRST (1997).

72. See, e.g., Lichtenberg, *supra* note 1, at 315 (“[The person-centered approach] aims to build on the individual’s strengths and honor a person’s values and his or her choices and preferences.”); Marylou Harrigan & Grant Gillet, *Hunting Good Will in the Wilderness*, in DECISION MAKING, PERSONHOOD AND DEMENTIA: EXPLORING THE INTERFACE 47, 55 (Deborah O’Connor & Barbara Purves eds., 2009) (“Decision-making reflecting one’s own character, values, commitments, convictions and (both critical and experiential) interests is not the same as being in charge of one’s life presently or precedently but is rather the experience of living according to the dictates of a good will”); Cherly Tilse et al., *Personhood, Financial Decision-Making and Dementia: An Australian Perspective*, in DECISION MAKING, PERSONHOOD AND DEMENTIA, 133, 141 (Deborah O’Connor & Barbara Purves eds., 2009) (“A response respecting personhood will view decision-making as a collaborative process and consider what the person values.”).

indeed, morally compelled—where the dementia causes decisions that, if permitted, would be inconsistent with that cluster of characteristics.

Under Essentialist conceptions of the person with dementia, which owe their origin to Tom Kitwood's influential book *Dementia Reconsidered*,⁷³ characteristics such as short-term memory, the ability to think at a certain speed, and other general cognitive abilities are not in themselves of ethical significance.⁷⁴ Rather, to the extent they matter at all, they matter because they are the media of things of moral significance, namely the values, commitments, and community identifications that Kitwood and others see as constituting personal identity.⁷⁵ Deviations from longstanding values, commitments, and community identifications, then, would serve as the trigger for intervention under Essentialist theories of dementia and decision-making, rather than loss of clinically testable cognitive measures. In contrast to Cognitivism, Essentialism is concerned with the philosophical construct of *personal identity*, not *personhood*.

Moreover, unlike Cognitivism, Essentialist theories of dementia and decision-making are not agnostic to the content of a purported decision—indeed, the permissibility of a particular decision is based *entirely* on its content.⁷⁶ But the permissibility of the content of a purported decision is judged in reference to an assessment of the character of the individual making it, as understood by what constitutes the char-

73. See generally KITWOOD, *supra* note 71.

74. See *id.*

75. *Id.* at 8 ("One problem here, however, is that in declarations of rights the person is framed primarily as a separate individual; there is a failure to see human life as interdependent and interconnected."); *id.* at 10 ("There is another approach to the question of what it means to be a person, which gives priority to experience, and relegates analytic discussion to a very minor place. One of its principal exponents was Martin Buber, whose small book *Ich und Du* was first published in 1922, and later appeared in an English translation, with the title *I and Thou* in 1937."); *id.* at 12 ("To see personhood in relational terms is, I suggest, essential if we are to understand dementia.").

76. See, e.g., Lichtenberg, *supra* note 1, at 315 ("[The person-centered approach] aims to build on the individual's strengths and honor a person's values and his or her choices and preferences."); Harrigan & Gillet, *supra* note 72, at 55 ("Decision-making reflecting one's own character, values, commitments, convictions and (both critical and experiential) interests is not the same as being in charge of one's life presently or precedently, but is rather the experience of living according to the dictates of a good will . . ."); *id.* at 141 ("A response respecting personhood will view decision-making as a collaborative process and consider what the person values.").

acter of the individual under Essentialist theory, not whether a particular family member or government official approves of the decision.⁷⁷ Therefore, the *state* could, at least in principle, embrace an Essentialist test for legal capacity without itself opining on the normative desirability of the decisions it sanctions or overrides, except to the extent that (as with any one of these theories), it endorses a particular normative criterion.

3. NARRATIVISM

A third theoretical framework, or perhaps more a persistent suggestion in the literature than a fully articulated theory, agrees with Essentialism that the question of whether an individual with dementia should be permitted to make a legally binding decision is whether that individual is the same person as they were previously, but disagrees that *that* inquiry is one of deviation from an exogenously defined cluster of values. Rather, these identity-based theories, which I term Narrativist, see the question of personal identity as one of narrative continuity or coherence.⁷⁸ Therefore, a Narrativist legal doctrine would permit individuals with dementia to make binding decisions so long as those decisions are narratively coherent with the story of the person's life, while precluding decisions that are not narratively coherent or continuous with that story.

While undertheorized in comparison to Cognitivism and Essentialism, the premises of Narrativist theory can be found in the works of several thinkers, perhaps most notably those of Ronald Dworkin and Marya Schechtman. Neither directly addressed the question of how we should go about inquiring whether an individual with dementia has

77. See Susan A. Gelman, *Essentialism in everyday thought*, AM. PSYCH. ASS'N (May 2005), <https://www.apa.org/science/about/psa/2005/05/gelman>.

78. See, e.g., Harrigan & Gillet, *supra* note 72, at 26 ("I want to suggest that personhood is more a process—and a narrative process at that—to which we all contribute."); see also RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA AND INDIVIDUAL FREEDOM* 229–30 (Vintage 2011) ("Even a seriously demented person . . . has experiential interests. . . . But . . . they are ignorant of self—not as an amnesiac is, not simply because they cannot identify their pasts—but, more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole.").

the legal capacity to make a decision.⁷⁹ In *Life's Dominion*, Dworkin addressed the related question of whether the law should enforce prior written wishes regarding healthcare decisions over the present desires of someone without capacity due to dementia.⁸⁰ For purposes of his analysis, Dworkin assumed a clear written instrument (which, of course, will not always be present) and apparently assumed a largely Cognitivist determination that the individual in question has lost capacity.⁸¹ But he ultimately argued that prior written instruments should be enforceable over the present objections of an individual with dementia on the ground that the narrative of one's life is of tremendous normative significance—that at a fundamental level the ability to write the story of one's life in the choices one makes, and that story itself, are what gives the lives of persons value.⁸² From this premise, it follows that we should not permit a meaningful story written over the course of a lifetime (and, Dworkin sees, codified in a document such as a healthcare proxy or durable power of attorney) to be undermined by decisions caused by dementia that are inconsistent with that narrative or do not follow in a narrative way from the proceeding of the person's life.⁸³

Schechtman's theory is a generally applicable theory of narrative as the basis of personal identity that is not limited to legal questions or dementia, but it could be applicable in this context.⁸⁴ Schechtman agrees with Dworkin that the narrative form of our lives gives them meaning,

79. See DWORKIN, *supra* note 78; see also MARYA SCHECHTMAN, *THE CONSTITUTION OF SELVES 2* (Cornell University Press 2007); see generally Craig Edwards, *Respect for Other Selves* 21 KENNEDY INST. ETHICS J. 349 (2011) (summarizing Dworkin and Schechtman's ideas about legal capacity and dementia).

80. See DWORKIN, *supra* note 78.

81. See *id.* at 228 ("What makes the difference, when we are deciding whether to honor someone's plea even though it contradicts his past deep convictions, is whether he is now competent to make a decision of that character, not whether he will regret making it later.").

82. See *id.* at 230 ("Value cannot be poured into a life from the outside; it must be generated by the person whose life it is, and this is no longer possible for [someone with dementia]. But when we consider the patient's whole life, not just its sad final stages, and we consider his future in terms of how it affects the character of the whole.").

83. See *id.* at 229 ("Someone anxious to ensure that his life is not then prolonged by medical treatment is worried precisely because he thinks that the character of his whole life would be compromised if it were.").

84. See SCHECHTMAN, *supra* note 79.

and that decisions inconsistent with that narrative (and, she adds, decisions consistent with a narrative that does not conform to reality)⁸⁵ are not necessarily worth legally respecting, because they are not, in a meaningful sense, made by that person.⁸⁶ But, she has a somewhat different view about the nature of these narratives: where Dworkin gives a broad view to the role of particular acts of agency, such as writing a healthcare proxy, in authoring our lives,⁸⁷ Schechtman argues that persons are narratively *self-constituting*.⁸⁸ That is, our narratives are written not in conscious acts of authorship, but in the countless decisions we make and the way in which we remember these things.⁸⁹ Thus, Schechtman's view (which is more consistent with the empirical psychology of the ways in which we craft self-narratives)⁹⁰ offers a practical way to extend the importance of narrative to individuals who never bothered to write theirs down.

For the question of whether a person with dementia can make a legally binding decision, Narrativist theories find most relevant the features most indicative of coherent narrative identity—the long-term

85. See *id.* at 120 (“A narrative that reveals the narrator to be deeply out of touch with reality is thus undermining of personhood and cannot—at least with respect to those elements of the narrative which seem grossly inaccurate—be identity-constituting.”).

86. See *id.* at 150–51 (“Certainly there is a real sense in which it is right to say that to never develop out of the psychological organization of infancy is never to exist as a person at all; and to contemplate a descent into a second infancy such as that present in late-stage Alzheimer's is, as has been observed repeatedly, to contemplate the loss of oneself—a personal death. In short, the formation of a narrative self-conception of the proper form creates a persisting subject with the phenomenological life and set of capacities peculiar to persons, and these last only as long as the narrative does.”).

87. See DWORKIN, *supra* note 78, at 228 (“A competent person's right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected even if they contradict the desires he has at that later point.”).

88. See SCHECHTMAN, *supra* note 79, at 93 (“I call my response to the characterization question the narrative self-constitution view. . . . I develop a view according to which a person creates his identity by forming an autobiographical narrative—a story of his life.”).

89. See *id.* at 94 (“On this view a person's *identity* . . . is constituted by the content of her self-narrative, and the traits, actions, and experiences including in it are, by virtue of that inclusion, hers.”).

90. See JONATHAN GOTTSCHALL, *THE STORYTELLING ANIMAL: HOW STORIES MAKE US HUMAN* 18 (Mariner Books, 1st ed. 2012) (“We ask our friend ‘What's up?’ or ‘What's new?’ and we begin to narrate our lives to one another, trading tales back and forth over cups of coffee or bottles of beer, unconsciously shaping and embellishing to make the tales hum. And every night, we reconvene with our loved ones at the dinner table to share the small comedies and tragedies of our day.”).

memories that hold stories and recognition of the relationships with other characters that make them up.⁹¹ Like Essentialism, Narrativist theories are not agnostic to the content of the decision, though in their focus on narrative continuity they are more concerned with the *cause* or *explanation* of the decision than its particular substance.⁹² Moreover, an important theoretical point about Narrativist theories is that they coherently explain and endorse the subsidiary importance of the features in which Cognitivism and Essentialism vest importance as well. As both Dworkin⁹³ and Schechtman⁹⁴ acknowledge, cognitive functions are a prerequisite to narrative formation. Cognitive features such as the ability to connect different ideas do matter under a Narrativist theory, but they matter *because* they make narrative formation possible, not, as Cognitivism would hold, on their own terms.⁹⁵ Similarly, both Schechtman and Dworkin recognize that the Essentialist features of values and beliefs may be indispensably important features of some people's narrative identity—but they argue that these features matter *because* they are a part of the narrative, not because they are independently significant.⁹⁶ Under a Narrativist understanding of personal identity, moreo-

91. See SCHECHTMAN, *supra* note 79, at 147 (“Those who suffer from [late-stage Alzheimer’s] begin to lose the glue that holds their lives together. They no longer recognize persons important to them, lose touch with their pasts, are at a loss to understand how they came to be where they are, no longer know how to anticipate the implications of the present for the future, and so on. . . . There are a number of well-known instances of individuals who, because of damage to the brain through disease, illness, or drug and alcohol abuse, have lost the ability to form long-term memories, and hence construct a narrative of their lives.”).

92. See *id.* at 98 (describing the requirement of the narrative theory that a life story be “intelligible”).

93. See DWORKIN, *supra* note 78, at 222 (discussing the assumption of a predicate Cognitivist test of incapacity before his philosophical inquiry about whether to enforce a prior written document is triggered. Specifically, “[m]any prominent issues about the rights of the demented, then, depend on how their interests now relate to those of their past, competent selves.”).

94. See SCHECHTMAN, *supra* note 79, at 148 (“A person in late-stage Alzheimer’s may be unable to retain short-term memory, yet have vivid recollections of childhood friends. The important element in these cases, however, is the loss of narrative capacity, and even though such an individual may have memories of long ago, he cannot integrate these with anything else, or have any kind of coherent sense of himself as an extended subject.”).

95. Cf. *id.*

96. See E-mail from Marya Schechtman to James Toomey, (Jan. 14, 2019) (on file with author) (“I would want to say that beliefs, values and desires are in relevant respects, narrative in form, and moreover, since I have a holistic approach to the

ver, values and beliefs are not identity-constituting but subject to evolution across the story of a life, and that evolution can itself be a valuable part of a narrative.⁹⁷

Therefore, while philosophically distinct, Narrativist theories can be reconciled with the normative importance of the features in which Cognitivist and Essentialist theories are grounded.

Table 1 - Summary of Theories of Dementia and Decisionmaking

	Cognitivism	Essentialism	Narrativism
Philosophical construct of importance	Personhood	Personal identity	Personal identity
Content of philosophical construct	Mechanical cognitive features (processing speed and quality, situational awareness, reasoning abilities, etc.)	Static features (personality, values, commitments, etc.)	Narrative continuity (consistency with a story developed over a long period of time by a series of previous decisions)
Agnostic to the content of the decision?	Yes	No	No

C. The Law of Incapacity

The concept of legal capacity is the primary way in which the law addresses the problem dementia poses for decision-making. As the regime that governs legal capacity varies from jurisdiction to jurisdiction,

mental, are not well-defined outside the overall narrative context in which they occur.”) [hereinafter Email]; DWORKIN, *supra* note 78, at 224 (“The most plausible alternative emphasizes the integrity rather than the welfare of the choosing agent; the value of autonomy, on this view, derives from the capacity it protects: the capacity to express one’s own character—values, commitments, convictions, and critical as well as experiential interests—in the life one leads.”).

97. See Email, *supra* note 96 (“[T]he important things . . . that . . . makes me an individual person is that I have a psychological organization in which I experience the world against the backdrop of an ongoing self-narrative so that, e.g., a desire always comes to me as familiar or unfamiliar, consistent with my life plans and directions or potentially undermining, one that my parents would approve of or one that they would not, etc. Similarly, a belie[f] will be one that troubles me or one that does not; one that has implications for what I must do or on that does not, etc. This is the general idea of what it means to have a narrative conception of self, and for those values, desires, and beliefs to be part of an ongoing narrative . . .”).

this Section necessarily offers something of a high-level abstraction.⁹⁸ The critical point for purposes of this study is that the American concept of legal capacity is grounded in Cognitivist ethical theories of intervention in decision-making.

As a general rule, otherwise legally effective decisions can be set aside if the individual who made them is deemed to have lacked the necessary mental capacity at the time the decision was made.⁹⁹ People (typically family members) who disagree with a given decision can contest the mental capacity of the individual who made it in court, and upon a finding that the person was, in fact, incapacitated, the decision will be annulled. These contests can occur with respect to any decision or action recognized at law, such as marriage,¹⁰⁰ real estate transactions,¹⁰¹ ordinary business contracts,¹⁰² and gifts.¹⁰³ But, the question is litigated most in the context of testamentary capacity—the mental capacity required to execute an enforceable will—where the concept has an extensive and well-developed case law.¹⁰⁴

Where an individual's incapacity is comprehensive enough that they are considered unable to make decisions as a general matter, the court may appoint a guardian or conservator (the difference between which, if any, is regulated by state statute; the traditional distinction is that conservators handle the person's finances while guardians take care of other day-to-day decisions, though many states have modified

98. See Boyle, *supra* note 18, at 37–38 (“Although the specifics vary between jurisdictions, in general, the common law on capacity presents itself as protecting and promoting, as can be seen in a number of features of this law.”); 18 AM. JUR. 3D PROOF OF FACTS § 5 (2020) (regarding the concept of capacity in the civil law, not the criminal law, where it plays a fundamentally different role. Specifically, “[a]lthough there are differences between jurisdictions, most [guardianship] statutes deprive the ward of the right to buy or sell property, to contract, to sue and be sued, to make gifts, to write checks, and generally to engage in financial transactions of any kind.”).

99. See, e.g., Estate of Matthews III, 510 S.W.3d 106, 109 (Tex. App. 2016) (holding that decedent had lacked mental capacity to consent to marriage to his in-house health aide).

100. See *id.*

101. See, e.g., *McGlaughlin v. Pickerel*, 46 N.E.2d 368, 370 (1943) (reversing execution of a deed on grounds of mental incapacity).

102. See ARTHUR C. WALSH ET AL., MENTAL CAPACITY: LEGAL AND MEDICAL ASPECTS OF ASSESSMENT AND TREATMENT 2–22 (2d ed. 1994) (discussing contractual capacity).

103. See MIKE E. JORGENSEN, ELDER LAW 50 (1st ed., 2008) (“The standard for donative capacity is similar to contractual capacity.”).

104. See Moye et al., *supra* note 2.

or abolished this distinction in various ways).¹⁰⁵ The court has discretion to appoint a guardian in the best interests of the individual, and although courts typically show a preference for members of the individual's family,¹⁰⁶ they may appoint a professional guardian, often trained as a lawyer or social worker.¹⁰⁷ In a guardianship, the guardian is empowered to make decisions for the incapacitated individual, regardless of that person's views at the time.¹⁰⁸ Although in principle, under many state statutes, guardianships can be tailored to the individual's particular need,¹⁰⁹ "[s]tudies demonstrate that judges rarely appoint limited guardianships in place of plenary guardianships."¹¹⁰ And although the presumption of capacity is intended to require substantial proof of general incapacity before a guardianship is granted, the paternalistic view that guardianship principally benefits the ward, "has made a judicial determination of incapacity relatively easy to obtain, particularly where the proposed ward has been an old person."¹¹¹

It is important to note that, while informed by medical expert testimony, legal capacity is a *legal* concept and not a medical one.¹¹² Med-

105. *See id.*; *see also* 18 AM. JUR. 3D *Proof of Facts* 185 § 1 (2020) ("Many jurisdictions make a distinction between guardianship of the person and estate.").

106. *See* Peter J. Guthrie, Annotation, *Priority and Preference in Appointment of Conservator or Guardian for an Incompetent*, 65 A.L.R. 3d 991 § 2 (1975) ("As a general rule, courts follow the practice of selecting the next of kin or those with familial ties, or the nominees of such persons, as guardians of incompetents, on the theory that they ordinarily will be the ones most solicitous of the incompetents' welfare and the ones most likely to rehabilitate them mentally. However, it is not mandatory to appoint the next of kin or those with familial ties, and the court will disregard the application of the next of kin or those with familial ties, or reject their nominees, if they do not have the requisite ability or if their interests and those of the incompetent would conflict in the administration of the latter's property, and the court will appoint a stranger as guardian.").

107. *See* Sager et al., *supra* note 18, at 17 (noting that a very small sample of guardians comprised individuals "trained as attorneys (60%), social workers (25%), healthcare workers (10%), and other (5%).").

108. *See id.* at 224 ("When the courts appoint a guardian, the following rights of the ward may be removed[:] [1] Determine residence [2] Make end-of-life decisions [3] Manage, buy, or sell property [4] Contract or file lawsuits [5] Own or possess a firearm or weapon [6] Consent to medical treatment [7] Possess a driver's license [8] Marry [9] Vote.").

109. *See* Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity*, 39 AM. J. L. & MED. 134, 148 (2013) (explaining that this was a legal development of the late-twentieth century).

110. *See id.*

111. *See* 18 AM. JUR. 3D *Proof of Facts* 185 § 5 (2020).

112. *See id.* ("Determination of incapacity is a legal and not a medical decision."); Boyle, *supra* note 18, at 36 ("[C]apacity can be conceived of as two different things.

ical professionals will often opine on an individual's capacity for *medical* purposes, such as determining whether they are capable of giving informed consent to a procedure or simply to inform the individual of their medical opinion.¹¹³ In order for this opinion to have general legal effect, it must be ratified by a court—that is, a court must rule that the person is *legally* incapacitated under the applicable standard.¹¹⁴

The legal standard for capacity varies with respect to the decision being contested, and “[t]he tendency in the courts is to find that the more the client is willing to give up or the more complex the act, the more capacity the client must have.”¹¹⁵ For reasons of public policy and evidence, the standard for testamentary capacity is somewhat more relaxed.¹¹⁶ The traditional articulation of that standard, which has generally informed the legal concept of capacity, is:

[T]hat a testator [person composing a will] shall understand the nature of the act and its effects; shall understand the extent of the property of which he is disposing; shall be able to comprehend and appreciate the claims to which he ought to give effect; and, with a view to the latter object, that no disorder of the mind shall poison his affections, pervert his sense of right, or prevent the exercise of his natural faculties.¹¹⁷

These basic concerns of the individual's understanding of the nature of the act, what is being given up, and what is being gained, are

First, ‘capacity’ can refer to a medical appraisal of the decision-making capabilities of a person, and the extent to which they are impaired; sometimes described as ‘mental capacity.’ Second, capacity is used to describe the ability to make a legally effective decision. This second measure is often described as ‘competence,’ or ‘legal capacity’”). *But see* AM. BAR ASS'N, GIVING SOMEONE A POWER OF ATTORNEY FOR YOUR HEALTH CARE: A GUIDE WITH AN EASY-TO-USE, LEGAL FORM FOR ALL ADULTS 4 (2011) (explaining that, in some instances, private parties may delegate the capacity determination to medical practitioners by contract. Includes the draft provision that “This Power of Attorney for My Health Care will become effective during any time in which, in the opinion of my agent and attending physician, I am unable to make or communicate a choice about a particular health care decision,” but noting that “some states have a required procedure for certifying someone's incapacity.”).

113. *See* Arias, *supra* note 7, at 136 (“In contrast [to legal capacity], clinicians—physicians, psychiatrists, or other experts—determine whether an individual has decision-making capacity.”).

114. *See* Moye et al., *supra* note 2, at 161 (“A clinical finding of incapacity does not alter an individual's legal status, whereas a finding of legal incapacity does.”).

115. JORGENSEN, *supra* note 103, at 4. *But see* Weithorn, *supra* note 17, at 690 (noting that many state statutes “do not characterize the inquiry as assessing capacity to make decisions regarding physician aid in dying. They focus more generically on the capacity to make health care decisions.”).

116. *See* Weithorn, *supra* note 17, at 691–92.

117. *Banks v. Goodfellow* [1870] 5 QB 549 (Eng.).

broadly consistent throughout the concept of legal capacity regardless of the specific decision at issue.¹¹⁸ Indeed, a similar definition of “incapacitated person” can be found in the Uniform Probate Code:

any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person.¹¹⁹

In short, the concept of legal capacity embraces a Cognitivist theory of when the law should intervene in the decision-making of those with dementia—it assesses the cognitive capacity of the individual at a specific point in time and is agnostic to the content of the decision. The test is primarily one of understanding, *comprehending*, and *appreciating*. It is a test of how well the brain is working as a computational machine at the moment of decision. It is not a test of whether the choice is consistent with who the individual has been as a person.

As a result of the inconsistent application of this test,¹²⁰ stories of excessive curtailments of rights¹²¹ and outright abuse,¹²² and scholarly criticism,¹²³ there has been a widespread push to reform capacity and guardianship law over the past several decades. Legislative reforms in many states have shifted the emphasis of guardianship to require courts to balance the community’s interest in the guardianship against

118. Cf. JORGENSEN, *supra* note 103, at 50 (“Contractual capacity generally requires that the client possess the ability to comprehend in a reasonable manner, the nature and effect of the act in which he or she is engaged.”) (citations omitted).

119. See UNIF. PROB. CODE § 5-102 (amended 2019) (defining “incapacitated person” as: “an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance.”).

120. See, e.g., Moye et al., *supra* note 2, at 171 (“[C]linicians arrive at significantly discrepant judgments of capacity in dementia, focusing on different cognitive and decisional abilities in patients, or holding values different from those of patients. . .”).

121. See Diller, *supra* note 4, at 511 (“A growing chorus of critics argues that even under the best guardianship, the mere fact that the guardianship has adjudged an individual as incapacitated or incompetent, and stripped her of the right to act on her own behalf, causes significant harm.”).

122. See Interview with Person 2, in Brookline, Mass. (Nov. 24, 2018) (on file with author) (discussing an anecdote where a judge would appoint his wife as guardian, and who was suspected to be stealing from those under her guardianship).

123. See, e.g., Diller, *supra* note 4, at 496 (“For the last several decades, guardianship has been the subject of continual calls for reform, often spurred by revelations of guardian malfeasance and other abuses in the system.”).

the individual's interest in autonomy.¹²⁴ Moreover, reforms have raised the standards of proof for a finding of incapacity required for a guardianship.¹²⁵ Other common law countries have taken more radical approaches. The United Kingdom comprehensively amended the legal regime governing issues of capacity in older people with the 2005 Mental Capacity Act ("MCA"), which adopted a familial mechanism for determining the best interests of the person with dementia and making decisions for them.¹²⁶ The MCA, however, did little to alter the underlying common law of capacity, and a legal finding of incapacity is still necessary to begin the best interests-based decision-making process.¹²⁷ In short, there is a great deal of debate and legislative action concerning how we should treat those mentally incapacitated by dementia. There has been less legal action—and, indeed, less productive discussion—on the question that animates this paper: when is someone incapacitated?

Indeed, although there has been some effort in state statutory reforms to sharpen and clarify the definition of capacity, at least as concerns guardianships, and there is a trend towards more "functional" definitions that focus more on impairments of the ability to live independently than on diagnoses on their own, these reforms have not significantly deviated from the Cognitivist understanding of capacity. For example, one "reformist" statute defines an "incapacitated individual" as:

an adult whose ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that he or she lacks the capacity to manage all or some of his or her financial resources or to meet all or some essential requirements for his or her physical health, safety, habilitation, or therapeutic needs without court-ordered assistance or the appointment of a guardian or conservator.¹²⁸

Thus, while statutory reforms have attempted to more clearly delineate functional thresholds of cognitive loss past which guardianship is required, they have not wrestled with the premise that the concept of

124. See 18 AM. JUR. 3D *Proof of Facts* 185 § 6 (2020).

125. See *id.*

126. See Hugh Series, *Best Interests Determination: A Medical Perspective*, in *LAW AND ETHICS OF DEMENTIA* 85, 85 (Charles Foster et al. eds., 2014).

127. See *id.* at 89–90 ("A best interests meeting should be convened only for a person who lacks capacity to make a particular decision. An assessment of capacity therefore needs to have taken place before the meeting. If the person concerned has capacity, then that person should make the decision, and no meeting will be necessary."). But see *id.* at 91 ("The majority of best interests decisions did, as required, follow an assessment that the person lacked capacity, but one in ten did not.").

128. D.C. CODE § 21-2011(11) (emphasis added).

capacity is a basically cognitive one—a function of the individual’s “ability to receive and evaluate information.”¹²⁹

Finally, it is worth remembering that regardless of the specifics of the jurisdiction, and even under reformed regimes that aspire to better reflect the wishes of the person with dementia, legal capacity determinations inherently involve a serious abrogation of rights—an abrogation of rights that would never be contemplated with respect to a healthy adult, even if their family members hate the decisions they are making and would love to be permitted to intervene.¹³⁰ However we conceptualize a legal capacity regime, it requires us to treat people who are incapacitated by dementia differently, in important ways, than we do other adults. It is important, then, to ensure that we draw the line of incapacity in the right place.

D. The Role of Empirical Research in the Normative and Legal Question of Capacity

As discussed, the debate about how we ought to think about the underlying normative necessary and sufficient conditions of legal capacity has been largely confined to academic philosophy, with each of the three schools of thought, Cognitivism, Essentialism and Narrativism, offered by their academic proponents as the philosophically, normatively *correct* answer to the question of how we should think about this problem. In a departure from, or tangential intervention into, this tradition, this study seeks to understand how a small sample of American seniors understand these philosophical issues. To some readers, particularly the more philosophically inclined, this may seem a strange, unsolicited offering. It is a well-worn dictum of philosophy, if not one universally endorsed, that empirical research, which can answer questions about what is, cannot answer normative questions

129. *Id.*

130. 18 AM. JUR. PROOF OF FACTS 3D 185 §1 (2020) (“Guardianship deprives the individual of personal rights and civil liberties and such deprivation can be devastating.”); See Boyle, *supra* note 18, at 37 (“For most of us, having the legal right to make any of [the decisions potentially restricted through legal capacity] removed would be a fundamental intrusion on our civil liberties.”). Cf. Interview with Person 16, Brookline, MA (Nov. 25, 2018) (on file with author) (discussing how her sister would “like to be able to stop” her from collecting Snoopy dolls, but “can’t find a reason to do so.”).

about the way things ought to be.¹³¹ And the question about when society ought to intervene in the decision-making of those with dementia is a normative question about the way things ought to be.

My study, however, fits comfortably within the parameters of a growing movement in academic philosophy, called experimental philosophy, “to use empirical methods and techniques typically associated with the sciences to help investigate philosophical questions.”¹³² This movement has empirically investigated the moral intuitions of ordinary people in a variety of contexts, arguing such research can shed light on traditional philosophical problems in a variety of ways.¹³³ Proponents of the field hope that empirical research can supplement, rather than replace, traditional conceptual philosophical reasoning, while conceding that a philosophical perspective being widely held does not make it correct.¹³⁴ Thus, the results of this study are not dispositive of any philosophical questions, nor are they intended to be. Rather, they inform the philosophical conversation and the legal debates that build upon those questions with the perhaps surprising finding of consensus among the participants of this study on the normative framework with which we should approach this problem. Moreover, the consensus found in this study is different from the theory on which the legal concept of capacity is currently built.

Experimental philosophy has been controversial, and some readers may remain unconvinced.¹³⁵ Regardless of one’s views on the experimental turn in philosophy, however, the findings of this study are both

131. See, e.g., STEVEN PINKER, *THE BLANK SLATE: THE MODERN DENIAL OF HUMAN NATURE* 150 (2002).

132. JUSTIN SYTSMAN & WESLEY BUCKWALTER, *Introduction to A COMPANION TO EXPERIMENTAL PHILOSOPHY* 1, 1 (Justin Sytsma & Wesley Buckwalter eds., 2016).

133. See, e.g., Joshua D. Greene, *Solving the Trolley Problem*, in *A COMPANION TO EXPERIMENTAL PHILOSOPHY* 175 (Justin Sytsma & Wesley Buckwalter eds., 2016).

134. See, e.g., JOSHUA KNOBE & SHAUN NICHOLS, *An Experimental Philosophy Manifesto*, in *EXPERIMENTAL PHILOSOPHY* 3, 6 (Joshua Knobe & Shaun Nichols eds., 2008) (“Philosophical inquiry has never been a popularity contest, and experimental philosophy is not about to turn it into one. If the experimental results are to have any meaningful impact here, it must be in some more indirect way. The mere fact that a certain percentage of subjects hold a particular view cannot on its own have a significant impact on our philosophical work. Instead, it must be that the statistical impact is somehow helping us to gain access to some other fact and that this other fact—whatever it turns out to be—is what is really playing a role in philosophical inquiry.”).

135. See *id.* at 3 (“Reactions to this movement have been largely polarized. Many find it an exciting new way to approach the basic philosophical concerns that attracted them to philosophy in the first place. But many others regard this movement as insidious—a specter haunting contemporary philosophy.”).

theoretically and practically interesting. They are theoretically interesting at a minimum because consensus is rare, and a finding of consensus on a philosophically contestable issue—even in a limited population—is necessarily worth reckoning with. Moreover, this consensus is found not among the population in general, but among a population of seniors—the group of people that face implications of the legal concept of capacity most closely and most often. It is conceivable that this population may simply have greater insight on these questions than philosophers for whom these questions are more abstract.¹³⁶ Further, it is defensible in a democratic society to endorse the principle that the law ought to reflect the views of the people affected by that doctrine (if indeed the consensus found here extends to seniors more broadly), regardless of whether their answer is the philosophically correct one, if such a thing exists. Finally, it is almost inevitable that in considering our own relationship to the consensus found in this study population—whether we agree, or disagree, or have our own nuances to add—that we will come to novel and, we hope, more informed, philosophical conclusions than we otherwise would have.

Therefore, even if we were to conclude that the perspectives of this study population are most theoretically interesting because they are wrong, the results would be of practical significance. If a consensus of the study population is normatively wrong in their thinking about what matters for the ability to make legally binding decisions, further research would be needed into where this error comes from and how far it extends—it could be a cultural relic or artifact of a limited sample, a more general quirk of the human brain, a fact about the relationship of seniors and the rest of society—and what to do about it—maybe we think it critically important to educate people on the better way to think about these issues, or maybe we are comfortable with a legal doctrine that encodes popular but normatively wrong ways of thinking.

In short, then, my study does not, and cannot, purport to resolve ongoing philosophical debates regarding how the legal system ought to think about problems that arise when people start to make bad, inconsistent, or narratively inexplicable decisions. Rather, in the growing

136. Cf. JOSHUA ALEXANDER, *EXPERIMENTAL PHILOSOPHY: AN INTRODUCTION* 90–98 (discussing the objection to experimental philosophy that the philosophical intuitions of professional philosophers matter more than those of ordinary people because of professional philosopher's greater expertise).

tradition of experimental philosophy, it simply gives us more tools to think about, understand, and tackle these issues.

II. Study Design and Methods

This study on the perspectives of seniors involved an online survey and a series of interviews. This Part discusses the survey and interview methods and the limitations of the data. Both studies were deemed exempt by the Harvard University Area Committee on the Use of Human Subjects because they involved survey and interview research with no more than minimal risk to participants.¹³⁷

A. Online Survey Methods

The survey was developed and run in Qualtrics, an online survey platform routinely used in academic research.¹³⁸ Participants were recruited with Amazon Mechanical Turk,¹³⁹ through which they were compensated \$1 each. Using the Mechanical Turk interface, the participants were limited to those within the United States and over fifty-five years of age. Participation was further limited by a screening question in the Qualtrics survey to individuals over sixty-two years old. This particular age qualification was made to match the survey population

137. HARV. COMM. USE OF HUMAN SUBJECTS Protocol No. IRB18-1373.

138. See Francis X. Shen et al., *The limited effect of electroencephalography memory recognition evidence on assessments of defendant credibility*, 4 J.L. & BIOSCIENCES 330, 345 n. 114 (2017).

139. Michael D. Buhrmester et al., *Amazon's Mechanical Turk: A New Source of Inexpensive, yet High-Quality Data?* 6 PERSP. ON PSYCH. SCI. 3 (2011); Joseph K. Goodman et al., *Data Collection in a Flat World: The Strengths and Weaknesses of Mechanical Turk Samples*, 26 J. BEHAV. DECISION MAKING 213 (2012) (However, researchers have recognized limitations with Mechanical Turk populations); Winter Mason & Siddharth Suri, *Conducting behavioral research on Amazon's Mechanical Turk*, 44 BEHAV. RES. METH. 1 (2012); see, e.g., Tara S. Behrend et al. *The Viability of Crowdsourcing for Survey Research*, 43 BEHAV. METHODS 800 (2011); see, e.g., Adam J. Berinsky, Gregory A. Huber & Gabriel S. Lenz, *Evaluating online labor markets for experimental research: Amazon.com's Mechanical Turk*, 20 POL. ANALYSIS 351 (2012); Gabriele Paolacci & Jesse Chandler, *Inside the Turk: Understanding Mechanical Turk as a participant pool*, 23 CURRENT DIRECTIONS PSYCH. SCI. 184 (2014); see, e.g., Francis X. Shen et al., *The limited effect of electroencephalography memory recognition evidence on assessments of defendant credibility*, 4 J.L. & BIOSCIENCES 330, 345 n. 114 (2017) (collecting recent legal studies employing both Mechanical Turk and Qualtrics; research combining Amazon Mechanical Turk and Qualtrics has become common in empirical legal research and the social sciences; a variety of studies have validated Mechanical Turk's data against convenience samples).

to the interview population, as interviews were conducted at retirement communities which housed people aged sixty-two and older. Individuals previously diagnosed with dementia or neurodegenerative diseases were also excluded with a screening question on Qualtrics.

The survey text is presented in Appendix A. The survey included nine substantive closed- and open-ended questions, an attention filter,¹⁴⁰ and demographic questions. The closed-ended questions asked participants to consider whether and how they would want family or the government to intervene in their decision-making. Of particular significance to this Article, Question 6 listed a series of cognitive skills and personal attributes and asked respondents to select those without which they would not want a decision to change their will to be legally binding. These attributes and cognitive skills were short-term memory; long-term memory; certain specific long-term memories; mathematical abilities; ability to recognize people in general; ability to make connections between different ideas; ability to think at a certain speed; current personality; moral values; religious values; political views; interests or hobbies; other; and none of the above. Participants were asked to select *all* of the characteristics without which they would not want a decision they purported to make to be legally binding.

Each of these answers was later categorized by the theoretical perspective, described at greater length above, that would best support its status as a trigger for the intervention of law. Short-term memory, mathematical abilities, the ability to recognize people in general, the ability to make connections between different ideas and the ability to think at a certain speed were categorized as Cognitivist. Each of these responses is concerned with the basic mechanical, cognitive functions of the brain, in terms of situational awareness and computational ability.¹⁴¹ Current personality, moral values, religious values, political views, and interests and hobbies were categorized as Essentialist. Deviations from each of these characteristics are suggested by proponents

140. See *infra* Appendix A. This was a screening question built into the middle of the survey designed to make sure that participants were reading the questions. See Appendix A for its text. Otherwise-complete responses that failed the attention filter were excluded from the population.

141. See BUCHANAN & BROCK, DECIDING FOR OTHERS, *supra* note 57, at 23–24 (discussing the core cognitive “competencies” relevant to their Cognitivist theory of decision-making).

of person-centered theories of dementia care as triggers for intervention, and that use implies an Essentialist view of a person's values and personality as arbitrary, fixed, and identity-constituting.¹⁴²

Long-term memory, certain specific long-term memories and the ability to recognize family and friends in particular were categorized as Narrativist. Long-term memory is distinguished from short-term memory, which is more of a form of situational awareness, by its being organized in the form of a life story.¹⁴³ Long-term memory is, indeed, the medium in which life stories are written.¹⁴⁴ Specific long-term memories important enough to serve as a trigger for intervention are those of narrative significance—indeed, it is probably fair to say that what distinguishes the specific long-term memories we do have from the mass of unremembered experiences are their narrative significance in our lives.¹⁴⁵ Finally, what distinguishes the ability to recognize family and friends from the ability to recognize people in general is a recognition of the narrative role those particular people have played as characters in our life stories.¹⁴⁶

142. See, e.g., Lichtenberg, *supra* note 1, at 315; Harrigan & Gillet, *supra* note 72, at 55.

143. See, e.g., SCHECHTMAN, *supra* note 79, at 147 (“There are a number of well-known instances of individuals who, because of damage to the brain through disease, illness, or drug and alcohol abuse, have lost the ability to form long-term memories, and hence to construct a narrative of their lives.”); JONATHAN GOTTSCHALL, *THE STORYTELLING ANIMAL: HOW STORIES MAKE US HUMAN* 176, 176 (2012) (“Until the day we die, we are living the story of our lives. And like a novel in process, our life stories are always changing and evolving, being edited, rewritten, and embellished by an unreliable narrator.”) [hereinafter *STORYTELLING*].

144. It is possible some respondents selected this response out of concern for its symptomatic role as an indicator of cognitive decline, rather than for its independent significance.

145. See *STORYTELLING*, *supra* note 143, at 161 (“We spend our lives crafting stories that make us the noble—if flawed—protagonists of first-person dramas. A life story is a ‘personal myth’ about who we are deep down—where we come from, how we got this way, what it all means. Our life stories are who we are. They are our identity. A life story is not, however, an objective account. A life story is a carefully shaped narrative that is replete with strategic forgetting and skillfully spun meanings.”).

146. See, e.g., SCHECHTMAN, *supra* note 79, at 147 (“Those who suffer from [late-stage Alzheimer’s] begin to lose the glue that holds their lives together. They no longer recognize persons important to them . . .”).

Theoretical Framework	Question 6 Answers
Cognitivist	<ul style="list-style-type: none"> - <i>Short term memory</i> - <i>Mathematical ability</i> - <i>The ability to recognize people in general</i> - <i>The ability to make connections between different ideas</i> - <i>The ability to think at a certain speed</i>
Essentialist	<ul style="list-style-type: none"> - Personality - Moral values - Religious values - Political views - Interests and hobbies
Narrativist	<ul style="list-style-type: none"> - <i>Long term memory</i> - <i>Specific long term memories</i> - <i>Ability to recognize family and friends in particular</i>

The open-ended survey questions asked participants to reflect on why they chose the answers to the closed-ended questions that they did. These responses were coded and analyzed in NVivo, a software designed for qualitative analysis. Of particular significance for this Article, Question 7 asked participants to explain why they selected their answers to Question 6. The goal of this question was to understand the extent to which participants could articulate the analytical process by which they reached their conclusions in Question 6, and to compare their processes. My methodology for analyzing these qualitative responses was similar to the inductive, grounded theory method of the social sciences, and took place contemporaneously with conducting and analyzing the interviews.¹⁴⁷ In other words, I developed hypotheses, themes, and codes in the course of data collection and review, rather than imposing them *a priori*.

147. See, e.g., Robert Thornberg & Kathy Charmaz, *Grounded Theory and Theoretical Coding*, in THE SAGE HANDBOOK OF QUALITATIVE DATA ANALYSIS 153 (Uwe Flick ed., 2014) (“Grounded Theory (GT) is a research approach in which data collection and analysis take place simultaneously. Each part informs the other, in order to construct theories of the phenomenon under study. GT provides rigorous yet flexible guidelines that begin with openly exploring and analyzing inductive data and leads to developing a theory grounded in data.”).

Between December 3 and December 22, 2018, 235 participants fully completed the survey and passed the attention filter. The responses of fifty-three participants were then excluded. In four cases, the participants selected “None of the Above” or “Other” in response to Question 6, and their response to Question 7 belied analysis or categorization as cryptic or unhelpful.¹⁴⁸

The remaining forty-nine excluded participants misunderstood the question in a uniform way. The goal of Question 6 was for participants to consider when *either* the government should intervene in decision-making directly *or* when family members should be permitted to intervene *backed by the state*, as when acting under a guardianship or power of attorney. The forty-nine excluded participants selected “None of the Above” or “Other” on Question 6 and on Question 7 explained this choice with reference to an aversion to government intervention in private decision-making. That is, they misunderstood Question 6 as referencing only direct government intervention, rather than familial intervention. In interviews, I was able to correct this (not unreasonable) misunderstanding,¹⁴⁹ but I was not able to do so in the online survey. Because there are good reasons to believe that the answers of these participants would have been different had they understood what the question was looking for,¹⁵⁰ their responses were excluded from further analysis. The results of the next Part, then, include the remaining 182 responses, a small sample of American seniors.

Descriptive demographic data of the survey population are reproduced in the Appendix. In general, survey participants, while representing a broad demographic profile of American seniors, differed from the general population in several notable ways. In particular, survey

148. See, e.g., Survey Response 185 (on file with author) (“external help is available”).

149. See Interview with Person 13, Brookline, Mass. (Nov. 28, 2018) (on file with author) (Person 13: “I think in general I’d like to keep the state out of all of that. I really think those are really...” Interviewer: “But your family, your family, in connection with the state, to the extent that they would need power of attorney, to, to make these kinds of decisions?” Person 13: “Yeah, I mean, I’ve got health proxies, and, they’ve got powers of attorney. So in what way would the state be involved in that?” Interviewer: “I mean the state, the state backs up powers of attorney. If there were a dispute between you and them, it would... They’re a state device, is the point. They’re a legal contraption.” Person 13: “Right, and we believe in legal contraptions to set up the framework for our care.”).

150. See Survey Response 196 (on file with author) (“I would not want the law or government to intervene of any decisions to be made. Only personal family to decide.”); see also Survey Response 14 (on file with author) (“I would have 2 people that I have already assigned to be my Power of Attorney.”).

respondents were less racially diverse and more white than the American population of seniors, more female, better educated, and appear to have been somewhat more politically liberal. These differences are important limitations on the generalizability of the survey results because substantial research indicates that culture influences attitudes towards aging.¹⁵¹ Perhaps most significantly, survey respondents were substantially less religious than the general population of seniors. Because religious commitment and affiliation may play an important role in people's thinking about aging, identity, dementia, and death, this deviation in particular could implicate the generalizability of the data.¹⁵²

Of similar importance, the fact that the study was conducted online necessarily limits the extent to which its results can be generalized. There is a well-documented digital divide among seniors, with internet usage correlated with a variety of individual and social-level variables such as age within the category "seniors," gender, cultural context, socioeconomic status, familial pressure, and education.¹⁵³ This "offline" population could not be reached by an online survey, and it is

151. See, e.g., Helene H. Fung, *Aging in Culture*, 53 GERONTOLOGIST 369, 371 (2013) (reviewing empirical research in attitudes towards aging in different cultures and finding that "people increasingly internalize cultural values with age"); Randi S. Jones et al., *Asian Americans and Alzheimer's Disease: Assimilation, Culture and Beliefs*, 20 J. AGING STUD. 11, 11 (2006) ("The results suggest that, while these communities share a keen awareness of AD, beliefs regarding the disorder may be influenced at least as strongly by folk wisdom and culturally acceptable partial truths as by scientific information.").

152. See, e.g., Kyle E. Karches et al., *Religiosity, Spirituality, and End-of-Life Planning: A Single-Site Survey of Medical Inpatients*, 44 J. PAIN & SYMPTOM MNGT. 843, 849 (2012) (presenting survey results showing that more religious and/or spiritual patients are more likely to have designated healthcare proxies); Hyejin Kim et al., *Ethical Frameworks for Surrogates' End-of-Life Planning Experiences: A Qualitative Systematic Review*, 24 NURSING ETHICS 46, 54 (2017) (noting the influence of religion on surrogate decision-making in a qualitative review of healthcare proxy-decision-making studies). But see M. Herrera et al., *Predictors of End-of-Life Planning: Health and Retirement Study*, 1 INNOVATION AGING 1209, 1209 (2017) (observing no statistically significant influence of religion on probability of having a living will).

153. See Thomas N. Friemel, *The Digital Divide Has Grown Old: Determinants of a Digital Divide Among Seniors*, 18 NEW MEDIA & SOC'Y. 313, 319 (2014) (demonstrating results of an empirical study on the digital divide among seniors in Switzerland); Helen Levy et al., *Health Literacy and the Digital Divide Among Older Americans*, 30 J. INT. MED. 284, 285 (2015) ("Low health literacy is associated with significantly less use of the Internet for health information among Americans aged 65 and older. Web-based health interventions targeting older adults must address barriers to substantive use by individuals with low health literacy, or risk exacerbating the digital divide.").

conceivable that their views on dementia and decision-making differ in consistent ways from those of the “online” population.¹⁵⁴

Finally, while the survey itself asked a series of questions regarding a variety of different legal situations, including deciding where to live, making donations, and getting married, the results presented in this Article exclusively concern the capacity required to make or change a will. To minimize the duration and repetitiveness of the survey, only one question asked about the itemized cognitive and personal features without which people would not want to be permitted to make a legally binding decision, and testamentary capacity was chosen as the most written about and litigated question of capacity.

The focus on testamentary capacity may limit the generalizability of the data to other legal questions. Indeed, my data provisionally suggest that many seniors endorse a view of capacity as decision-specific—that is, that more capacity is required for certain decisions than for other decisions—which would suggest that what may hold true for testamentary capacity may not hold true for other issues of legal capacity.¹⁵⁵ Some of the explanations of respondents are particularly attuned to testamentary issues. But many are not, and it does appear from the explanations respondents offered that many of them were thinking about this question in a more general way. It is certainly possible, then, that the Narrativist consensus found in this study is limited to questions of testamentary capacity. They may, however, be much broader. Further

154. *But see* sources cited *supra* note 139 (discussing the multitude of studies that have validated Mechanical Turk samples against convenience samples notwithstanding the existence of a (smaller) digital divide among the general population).

155. *See, e.g.*, Interview with Person 3, in Brookline, Mass. (Dec. 1, 2018) (on file with author) (“So, back to the question [about whether there should be one standard for legal capacity or it should be decision-specific]. It would be lovely if there were a scale, maybe a five-step scale, that said, you know, the self-care issues here, the automobile, you know, driving safely, living safely, that’s a huge one. That, that’s sort of like harm to self and others, you know, that that’s a huge one, that one has to be taken away.”); Interview with Person 4, in Brookline, Mass. (Dec. 1, 2018) (on file with author) (“Well, [it would depend] partly on their mental ability at the time but I think it would depend on what the decision’s about . . . I mean, if it’s something that’s not going to affect anyone adversely, then they should have the right.”); Interview with Person 5, in Brookline, Mass. (Nov. 30, 2018) (on file with author) (“Medical care certainly, but certainly with financial decisions that, that’s important because that’s the wherewithal I would need to, either I, or both of us [including his wife], would need to continue living . . . You lose your money, you’re, you know, you’re up a creek. So basically those are probably the two. I’m not going to ask anybody to make a political decision for me.”).

research will be required to determine the scope of the Narrativist consensus.

B. Interview Methods

I interviewed twenty-five individuals aged sixty-two and over at the Center Communities of Brookline retirement community/assisted living facilities in Brookline, Massachusetts, in November and December 2018. The Center Communities of Brookline facilities, part of the Hebrew SeniorLife network of elder living in the greater Boston area, were chosen because of their affiliation with Harvard Medical School, and interviews were arranged through contacts at the Petrie Flom Center at Harvard Law School. These interviews were roughly contemporaneous with the time in which the Mechanical Turk survey was active but were conducted before the survey results were collected and analyzed. The purpose of these interviews was to supplement the broader survey data to better understand on a qualitative level the way seniors thought about the issues related to capacity and decision-making, to ask follow-up questions, and to get a sense of how strongly people felt about their responses. An interview script that I used as a skeleton is reproduced in the Appendix. To preserve the privacy of participants, they are referred to in this paper by numbers, but the interviews were not anonymous to the extent that I am aware of the identity of the participants. Each interview lasted between 30–90 minutes, and participants were given a ten-dollar gift card to Trader Joe's at the conclusion of the interview.

These interviews were recorded, transcribed and coded, and analyzed in NVivo, alongside the qualitative survey answers, and were ultimately coded with a similar scheme. Themes and selected portions of the interview data are presented in the next Part to illustrate more deeply the interview participants' thinking about the survey findings, and to challenge some of the generalizations found in that data. Moreover, my thinking about patterns, themes, and codes that would arise in the survey data was shaped by my discussions with interview participants, consistent with the grounded theory methodology of qualitative analysis.

Demographically, the interview population was different in many ways from the survey population, and certainly different than the population of American seniors, raising questions about the generalizability of the data. Interview participants were predominately (about 68

percent), but not exclusively, Jewish¹⁵⁶ and politically liberal (about 60 percent). They were a very highly educated group, with at least 56 percent having a post-college degree, and they were likely substantially wealthier than average (one participant described her building as a “gilded ghetto”¹⁵⁷). But several interview participants were living in Section 8 apartments and subsisting primarily on social security and public assistance.¹⁵⁸

Based on these descriptive statistics, it is clear that the interview population was substantially less diverse and less representative of the American population than the survey population. For the reasons discussed above, themes from the interviews are therefore likely to be less generalizable than the survey data. The purpose of the interviews, however, was not to generate independent generalizable patterns. Rather, it was to supplement the survey findings with additional qualitative data and offer further possible explanation for the patterns found in that data. Indeed, in this Article, the bulk of the data is drawn from the online survey, supplemented where relevant by the interview data. In any event, interview data analysis together with the survey data revealed few areas of consistently divergent opinions between the two study populations.

III. Results

This Part presents the results of the study, in particular the results to survey Question 6, which asked participants to consider those things about themselves without which they would not want to be legally permitted to change their will, and Question 7, which asked participants to explain why they answered Question 6 the way they did. Results and themes from the interviews are included where relevant.

The central finding of this study is something approaching a consensus among participants regarding the question to be asked in considering whether to intervene in the decision-making of an individual with dementia—whether that person is the same person that they had

156. See *Our Mission and Heritage*, HEBREWSENIORLIFE, <https://www.hebrewseniorlife.org/mission-heritage> (last visited Jan. 25, 2021).

157. Interview with Person 2, *supra* note 13.

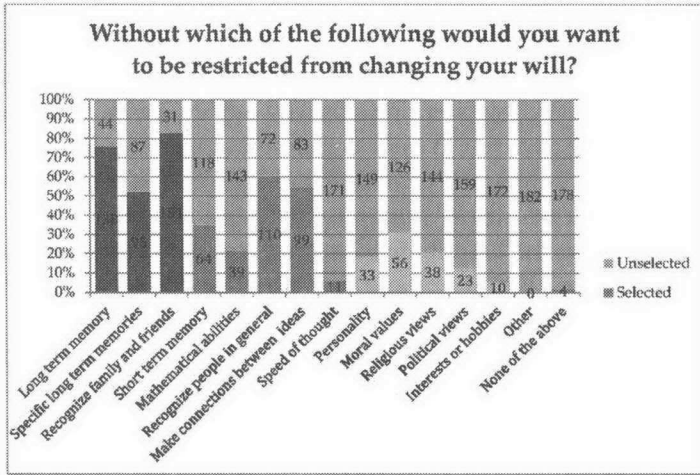
158. Interview with Person 9, in Brookline, Mass. (Nov. 24, 2018) (on file with author) (“[Y]ou gotta remember this is a Section 8 building, so people here are more in contact with social workers . . .”); Interview with Person 11, in Brookline, Mass. (Dec. 1, 2018) (on file with author) (“I’d love to go back to Needham but I can’t afford it, I’m on Section 8 housing.”).

been when healthy, as defined by narrative continuity of their identity. This consensus subsumes the Cognitivist and Essentialist theoretical outlooks also found in many responses. Since, as mentioned above, cognitive features are a prerequisite of a narrative theory of personal identity, it is consistent with a narrative consensus that most participants pointed to cognitive capacity in some form or another as important to their ability to make legally binding decisions. Similarly, since a self-conception of identity based on values and personality is in many ways a subset of narrative conceptions of identity, it is to be expected that a narrative consensus would include a substantial minority of participants pointing to the importance of the Essentialist views of their selves in considering when the law should intervene in their decision-making.

This Part first discusses the extent to which this consensus is quantitatively evidenced in the survey responses to Question 6. Second, I will give a fuller discussion of this consensus with discussion from the qualitative responses to Question 7 and the interview data. Finally, I analyze potentially contrary cases, in which participants either selected none of the Narrativist responses to Question 6, purported to explicitly reject narrative analysis in qualitative responses, or articulated potentially contrary theories. In each case, these potentially contrary cases can be seen to nuance rather than undermine the broader narrative consensus in the study population.

A. Responses to Question 6

As discussed above, Question 6 asked respondents to select from a list of mental and personal attributes that without which they would want the law to prevent them from making legally binding changes to their will. Each response was categorized as theoretically based on Narrativism, Cognitivism, or Essentialism. The following chart depicts the responses, clustered by their corresponding theoretical category.

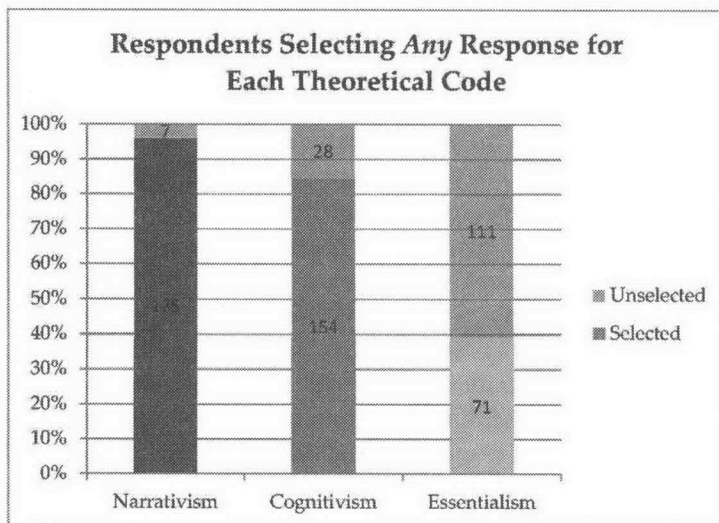


The ability to recognize family and friends and long-term memories, two archetypical features of a narrative conception of self, were the two most selected responses, chosen by approximately 83 percent and 76 percent of respondents, respectively. The remaining Narrativist feature, specific long-term memories, was chosen by a smaller majority of respondents, approximately 52 percent. In contrast, features associated with the other two theoretical frameworks were chosen by fewer respondents: of the non-Narrativist responses, only the Cognitivist features of the ability to recognize people in general (60 percent) and the ability to make connections between different ideas (54 percent) were selected by a majority of respondents. None of the Essentialist features were selected by a majority of respondents, and moral values, the most commonly selected Essentialist feature, was chosen by only approximately by 31 percent of respondents. While the significance of these averages should not be overstated, given the different numbers of responses each theory is associated with, Narrativist responses were chosen by an average of 70 percent of respondents, Cognitivist an average of 35 percent of respondents, and Essentialist responses an average of 18 percent.

Although viewing each answer in isolation does not tell the full story of the responses to a question that asked respondents to select as many as they felt appropriate, these data may offer some insight into

which particular features within each category were selected most often, and which were selected least. It may be significant, for example, that among the Cognitivist features the ability to recognize people in general and the ability to make connections between ideas were quite popular, while very few respondents saw a decrease in their speed of thought as being a barrier to their decision-making. Similarly, for those working within the person-centered care literature it may be interesting, if supported by further research, to design care that takes into account that among the Essentialist features, moral values were the most widely considered important and few were concerned about changes in their interests or hobbies.

Moreover, the individual selections and averages cited above are broadly consistent in the relative importance they assign to each theoretical framework to the study population, with the following data, which reflects the numbers of respondents that selected *any* response associated with each theoretical category.



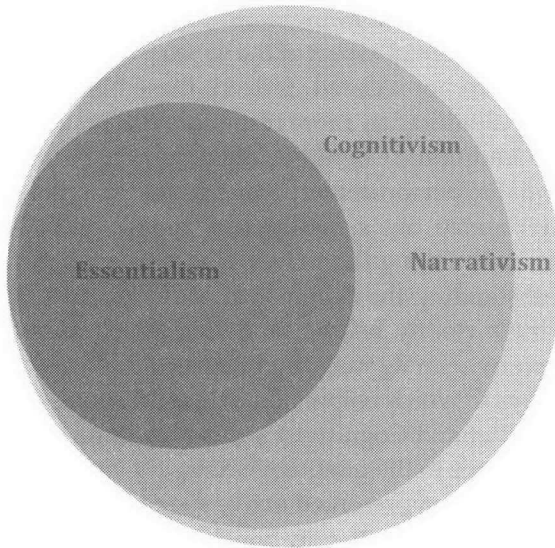
Viewed at this higher level of abstraction, the extent to which features from the Narrativist theoretical framework were selected by a near consensus of respondents is clarified. Indeed, 96 percent of respondents selected at least one of the three Narrativist responses. Most respondents, approximately 84 percent, chose at least one of the Cognitivist responses, while less than half, approximately 39 percent, of respondents selected any of the five Essentialist responses.

The data therefore suggest that features associated with a Narrativist theory, in particular the ability to recognize family and friends and an individual's long-term memories, are more generally considered by seniors an essential aspect of the inquiry into legal capacity than has previously been appreciated. Indeed, these Narrativist responses were selected by significantly more respondents than the features associated with the traditional Cognitivist theory or the more academically popular Essentialist/person-centered theory, and the importance of being able to recognize one's family and friends independently approaches consensus among the survey respondents. A second finding is that, notwithstanding the dominance of the Narrativist responses, Cognitivism trails closely behind, and Cognitivist answers were selected by an overwhelming majority of survey participants. This finding, and the ways in which respondents thought about the distinctions between Narrativist and Cognitivist answers, will be further analyzed below, with reference to the qualitative data.

Finally, as the data presented above suggest, few respondents selected answers associated with only one theoretical framework. That is, many respondents selected some Narrative responses, some Cognitivist responses, and some Essentialist responses. The distribution of respondents selecting each possible combination of responses is contained in the following table.

Narrativist Only	Narrativist & Cognitivist	Cognitivist Only	Cognitivist & Essentialist	Essentialist Only	Essentialist & Narrativist	Essentialist & Narrativist & Cognitivist
19	87	1	2	0	7	62
						Total = 178

These overlapping sets are roughly graphically depicted below:



Consistent with the data in its other forms, these data show the widespread theoretical dominance—indeed, the near consensus—of the Narrativist mode of thinking about testamentary capacity in the survey population. Moreover, divided in this way, they appear to suggest that Cognitivist and Essentialist theories are subsets of a Narrativist conception. That is, while 10 percent of respondents chose *only* Narrativist responses, only one person chose exclusively Cognitivist or Essentialist responses, and the two largest groups chose either only Narrativist and Cognitivist responses (48 percent), or responses from all three theoretical categories (34 percent). This finding supports the theoretical proposition that Cognitive features are a prerequisite to what matters in the Narrativist theory but are independently significant, while Essentialist features are narrative in form but not necessary features of a narrative.

B. Responses to Question 7 and Interview Responses

Analysis of the responses to Question 6 suggest a broad consensus among seniors that what matters most in considering whether they should be permitted to continue making legally binding decisions on their own is whether they continue to be narratively connected to the person they have been their entire lives. Alone, these data are merely suggestive. Answers to Question 7, which asked respondents to explain

why they chose the answers they did to Question 6, and my interview data, provide an opportunity to understand how respondents thought about choosing the features they did. These responses further support the conclusion that there was a consensus among the study population that Narrativism, as opposed to Cognitivism or Essentialism, is what matters to the participant seniors in whether they should be permitted to make a legally binding decision, at least to change their will.

A number of themes appeared in participants' explanations for why they chose the answers that they did, and to explain their thought process as they considered these issues. Each theme reflected different ways of conceptualizing the importance of narrative in overlapping but distinct ways. These themes were not mutually exclusive, and many responses reflected more than one.

1. NARRATIVIST EXPLANATIONS

First, a substantial minority of responses (roughly 33 percent) explicitly pointed to a sense of narrative continuity as their explanation for why they selected the answers that they did. For example, Survey Respondent 144 wrote "[M]y present is the culmination of all events from my past. Certain long-term memories are more important than others, as some may be fun to recall from time to time but are not critical to my life functions. . . ." ¹⁵⁹ Survey Respondent 155 wrote "Where I forget where I've been, physically and emotionally, I feel I will no longer be who I have been. . ." ¹⁶⁰ and Survey Respondent 199 wrote "[L]ong-term memory because you want to remember what and who is important to you. Specific long-term memories because these are the events that shaped the person you ended up becoming." ¹⁶¹ In perhaps the most explicit rejection of the alternative theories, Survey Response 112 wrote:

I wrote my will many years ago with specific things in mind that related to my life. If I lost my long-term memory, I would not have a reliable guide to decide those things that were important to me. Also, my will has specific connections between my memories and my efforts over a lifetime. I would not want a will without

159. Survey with Respondent 144, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

160. Survey with Respondent 155, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

161. Survey with Respondent 199, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

those connections. All other things—including short-term memories, are not important. Skills I have or do not have are not important. My past life is important.¹⁶²

This theme emerged in several interviews, as well. For example, Person 4 explained the importance of long-term memories on the grounds that “they’re who we are. Life is made of all those little decisions and things that we’ve done our whole life long.”¹⁶³ Person 12 pithily did the same with “long-term memory, [they’re] your friendships.”¹⁶⁴ Person 18 spoke about the difference between the long-term memories that matter for the narrative of her life and those that do not:

Person 18: I look at the knick knacks [that I chose to keep, rather than books] and I can remember where I bought them, who I was with, and so on. And so my history is much less involved with the books and I had to make this decision, which one is more involved with my long-range memories.

Interviewer: And which is more important to you? That’s where you get at your values.

Person 18: Now, there’s some long-range memories that, you know, we all have that we’d rather be without, I don’t, I can think of some things, yeah, that if I could no longer remember these, I probably would not particularly want to stay around.¹⁶⁵

Each of these responses, and others that articulate similar concerns, bolster the hypothesis that narrative continuity of identity is the dispositive criterion for many senior participants. Each of these respondents chose the Narrativist responses to Question 6 and did so for precisely, and with self-awareness, for the reasons that the Narrativist theory would hypothesize—they cared about these things because they cared about their selves as stories. This group not only cares about their narrative self-conception, they know they do.

2. ESSENTIALIST EXPLANATIONS

Second, a number of responses (approximately 17 percent of responses to Question 7) were phrased in the language of person-centered care, and reflected an Essentialist conception of the respondent’s person, a deviation from which would serve as the rationale for legal

162. Survey with Respondent 112, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

163. Interview with Person 4, in Brookline, Mass. (Dec. 1, 2018) (on file with author).

164. Interview with Person 12, in Brookline, Mass. (Nov. 25, 2018) (on file with author).

165. Interview with Person 18, in Brookline, Mass. (Nov. 30, 2018) (on file with author).

intervention in their decision-making. On closer analysis, however, several of these respondents clearly embraced a sense of identity rooted in narrative continuity. For example, Survey Respondent 1 stated "These are the four main things that make you who you are and what you want. With out [sic] these you are nothing."¹⁶⁶ In contrast to the predictions of person-centered care, however, Survey Respondent 1 selected none of the Essentialist responses to Question 6. The "four main things" this respondent believed "make you who you are" were short-term memory, long-term memory, your ability to recognize people in general, and your ability to recognize family and friends in particular (that is, two Narrativist and two Cognitivist responses). Similarly, Survey Respondent 2 wrote "Because I would be becoming someone who is not me anymore,"¹⁶⁷ in explaining why she selected long-term memory, ability to recognize family and friends in particular, the ability to make connections between different ideas, and moral values. Thus, while these responses share a concern for the continuity of their personhood with the person-centered theory, they appear to define that continuity in almost exclusively narrative ways.

Several other responses more explicitly embraced an Essentialist conception of their selves, but did so in addition to, rather than in exclusion of, a concern about the continuity of their narrative. For example, Person 218 wrote "If I can't recognize family and friends, I most likely would not be able to make wise decisions. I am a conservative. If my political views were to change or become more liberal, I would want someone to make the decisions for me."¹⁶⁸ While this respondent clearly has an Essentialist conception of himself with respect to his political views (that is, he would consider himself not to be himself anymore if they were to change substantially), he also acknowledges the importance of narrative, in the continuity of the relationships he has with the other characters in his life. Another respondent, Survey Respondent 187, selected all three of Narrativist, Cognitivist, and Essentialist responses to Question 6 (indeed, she selected nearly all of the responses to Question 6). She wrote in the explanation that "My hobbies and even my political and religious views can change with time

166. Survey with Respondent 1, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

167. Survey with Respondent 2, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

168. Interview with Person 218, in Brookline, Mass. (Nov. 30, 2018) (on file with author).

through development and ongoing enriching experiences. New information or new interests can affect these things. My thinking skills and basic personality and morality are more integral to my core self. I consider short term and long term memory important to my analytical ability."¹⁶⁹ While this respondent has a strong sense of her "core self," she also acknowledges the narrative process by which some but not all of those aspects might evolve, namely "development and ongoing enriching experiences."

A similar dynamic appeared in interviews as well:

Person 1: Well, say I bought a Mercedes and I don't have a license to drive anymore, that might be a sign.

Interviewer: Yeah. Yeah, but what if you just wanted a Mercedes?

Person 1: To do what with?

Interviewer: Good question.

Person 1: Well, then I can hire a chauffeur.

Interviewer: You could hire a chauffeur, you could be...

Person 1: And that sounds so like me. I absolutely think that if that were to happen that would certainly be cause for concern.

Interviewer: So when you say it's, it's, it's not like you to do something like that, do you mean it, it would be sort of inconsistent with your values and your personality for a long time?

Person 1: Yeah.

Interviewer: So, you think if you started...

Person 1: Also, that's a good phrase. That could be in your research. That's a very good...what you just said.

Interviewer: Personality and...

Person 1: Yeah...you said inconsistent something...well, you'll have it.

Interviewer: Yeah, yeah, yeah, yeah.

Person 1: But quote yourself, because that's really good, that phrase.

Interviewer: Yeah, so that is, that's sort of what you think this is more about?

Person 1: That's really, that's really strong. Yeah. Okay.¹⁷⁰

While this interview subject thus had a strong sense of her determinate, values-based identity, elsewhere in the interview she drew a distinction between the kinds of narrative changes she would be comfortable making decisions after, and the kinds of non-narrative changes

169. Survey with Respondent 187, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

170. Interview with Person 1, in Brookline, Mass. (Nov. 24, 2018) (on file with author).

after which she would expect her daughters with whom she has a narrative relationship to intervene: “[My daughters] are pretty sophisticated. They are. . . . Also, they know me, so anything that would be *aberrant* would certainly strike them as what’s going on here, but, to have a new *enthusiasm* [would not be a problem]. . . .” (emphasis added).¹⁷¹ Perhaps the distinction between enthusiastic and aberrant behavior is the extent to which it can be conceptualized as narratively continuous.

3. COGNITIVIST EXPLANATIONS

Another group of respondents offered apparent Cognitivist explanations. For the most part these respondents—because of the answers they had selected to Question 6, the full context of their explanations, or closer analysis, do not challenge the hypothesis that they, too, care fundamentally about the narrative continuity of their identity. Indeed, many of their explanations offer support to the hypothesis that cognitive functions are important as a *prerequisite* to narrative continuity but are not independently significant. A small group of respondents, however, whose explanations arguably support the opposite hypothesis, will be discussed at greater length in the following Section. In total, explanations reflecting primarily Cognitivist themes made up approximately 30 percent of the survey responses.

Examples of Cognitivist explanations not inconsistent with the Narrativist consensus include that of Survey Respondent 123, “To me, the choices I made demonstrate a disconnection with the ability to make a rational choice.”¹⁷² While, on its face, this explanation appears only concerned with the rational cognitive abilities of the brain, Survey Respondent 123 chose long-term memory, certain specific long-term memories, ability to recognize people in general, ability to recognize family and friends in particular, and the ability to make connections between different ideas. In context, then, what this survey respondent means by “rational” must not simply be rational in some abstract and objective sense, as Cognitivism contemplates, but rational from the perspective of *his particular* life story (because he chose both Narrativist and Cognitivist triggers for intervention). Similarly, Survey Respondent 37 saw narrative continuity as a kind of prerequisite to identity as a person: “When long term memory is gone, one becomes almost a non-

171. *Id.*

172. Survey with Respondent 123, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

person, who has no or faulty reasoning ability, and has no idea how the world works, or why. At that point, an individual would have no capacity to make informed decisions of any kind."¹⁷³ Other respondents used the word "cognitive" to describe concerns that were really about narrative continuity (and, periodically, Essentialist self-conceptions). For example, Survey Respondent 43 wrote vaguely "Losing all of these cognitive abilities are the most important in making important decisions. By the time these abilities are gone, much of the person's self or personality are no longer intact,"¹⁷⁴ after selecting, among other things, specific long-term memories and religious and political views in response to Question 6, and Survey Respondent 52 wrote "If you've lost any of these cognitive abilities, your decisions will likely be suspect," after selecting only long-term memory, specific long-term memories, and ability to make connections between different ideas.¹⁷⁵

Further, by describing a connection between narrative continuity and a healthy mind, some respondents explicitly endorsed the notion that cognitive abilities are an important prerequisite, but not an ethical alternative, to narrative continuity. For example, Survey Respondent 58 wrote "I would want to be 'of sound mind.' I can't imagine a sound mind without short and long term memory. If I had made a will before these losses I probably would not be able to understand the decisions I made. I wouldn't be able to analyze it properly on my own and I might damage *that which, prior to my loss, I wanted to preserve*"¹⁷⁶ (emphasis added). Similarly, Survey Respondent 94 wrote "If I were suffering from dementia and could not reason properly I should [not] be allowed to make life changing decisions. *I must know who I am, who are my associates, and have a firm grasp on reality if I were to make important decisions*"¹⁷⁷ (emphasis added).

A similar dynamic was found in several of my interviews. Person 7, for example, drew a distinction between "reasonable" changes and changes that were the legally unrecognizable result of dementia by

173. Survey with Respondent 37, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

174. Survey with Respondent 43, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

175. Survey with Respondent 52, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

176. Survey with Respondent 58, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

177. Survey with Respondent 94, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

pointing to the consistency of those changes with narrative coherence over a long period of time:

Person 7: I don't even know how to evaluate that question. Because I don't know what would be, I don't know how to identify what would be a reasonable change, just because I change my mind about something, and what would be the dementia, so I don't know how to get there. I think, I think...

Interviewer: Do you think that that's an impossible...

Person 7: I think if it was really incongruous with the way I've treated people over the years, I would want somebody to tell me and to take that option away.¹⁷⁸

Person 8, throughout the interview, pointed to cognitive abilities as of fundamental importance to her:

Person 8: The fact that [someone starts] contributing to way left-wing or way right-wing organizations . . . that they never would have, I mean, to my mind, and this is just a feeling, I don't think that's a reason for them to be told...no.

Interviewer: OK, yeah. So, people can be sort of allowed to evolve in their values and their personality, as they develop dementia?

Person 8: As long as, as long as they have cognition going on.¹⁷⁹

Yet, immediately following this exchange, Person 8 softened her stance on the sole importance of cognition and reflected that it is an important part of the continuity of narrative:

Interviewer: So, the line for you is really one of cognition, and mental capabilities, it's not really about sort of the continuity of the life story?

Person 8: No, it's cognition, but it is about also the continuity of autonomy.¹⁸⁰

Moreover, elsewhere in the interview Person 8 described determinate, Essentialist values that she would not want to be permitted to undermine as she developed dementia, "Most primarily, I want to be comfortable. I want to be comfortable physically, and I want to be comfortable psychically,"¹⁸¹ indicating that while she has a clear view of the underlying importance of cognition, she also cares about her life story, and particular value-based features of that story, in determining whether changes associated with dementia should preclude her legal right to continue making decisions.

178. Interview with Person 7, in Brookline, Mass. (Dec. 5 2018) (on file with author).

179. Interview with Person 8, in Brookline, Mass. (Dec. 5, 2018) (on file with author) (emphasis added).

180. *Id.*

181. *Id.*

3. FEAR OF ABUSE

A fourth theme that emerged from the survey explanations and interview data was a concern about abuse and exploitation. A notable minority, around 8 percent of survey respondents, pointed to the fear of abuse as the primary reason they selected the answers that they did. Many of these respondents explicitly explained this concern by describing the way such abuse would manifest as a deviation from their sense of narrative self-identity. For example, Survey Respondent 91 wrote "The most important are recognizing, people, family and friends. This is so important, if you can't distinguish people you may trust anyone. Long term [sic] memories are important, but it's not like knowing who to trust. *Not recognizing family and friends is one of the cruelest things your brain could do to you*"¹⁸² (emphasis added). In other words, this respondent found the ability to rely on trusted characters in one's story essential to avoiding what she conceptualized as abuse or exploitation.

In general, a concern about being taken advantage of *logically requires* a concern about personal identity: the distinguishing feature between abuse and a bad judgment is a claim about what the person making the decision *really wanted* at some underlying level. In other words, abuse and exploitation are words for relative deviations of behavior from some baseline, a baseline that requires a conception of the identity of the person being abused. The question, then, is not whether the respondents concerned with abuse are also concerned with personal identity, they are. It is whether they define that identity as narrative, which theoretically they need not. The results, however, demonstrate that narrative continuity was the way in which these respondents conceptualized their identity: *every respondent* whose explanation manifested a bare concern for their safety, such as Survey Respondent 25, who wrote "Because I would be afraid that I was being influenced by people who might have ulterior motives and were using my disability to their advantage," selected at least some of the Narrativist responses of long-term memory, specific long-term memories, and the ability to recognize family and friends in particular. Some selected only these things.¹⁸³

182. Survey with Respondent 91, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

183. Survey with Respondent 25, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

4. DESIRE TO MAKE "GOOD" DECISIONS

A final theme that emerges from the explanations, and which was the primary concern in approximately 12 percent of the responses, was a concern with making *good* decisions, as judged by their content or outcome, in contrast to the Cognitivist concern with the process of decision-making. As with the other themes, some of these responses explicitly tied their concerns to a concern about the continuity of the respondent's narrative identity, such as Survey Respondent 162, who wrote "If I can't recognize those around me then I should not be allowed to change any will. I would want to make sure the I [sic] was making the right decisions. Also remember [sic] some old memoire [sic] might mean I have some rights left . . ." tying old memories to both a conception of the right to make legal decisions and the ability to make "the right decisions."¹⁸⁴ Survey Respondent 154 considered, among other things, the importance of one's life story on making "good and sensible decisions."

Loss of short-term memory can impact your decisionmaking process. Loss of long-term memory, especially certain specific memories of how you feel about your family, can have a big impact on decision making. If you can't recognize family and friends, how could anyone expect you to make good and sensible decisions?¹⁸⁵

Moreover, as with those concerned about safety or abuse, a concern with the outcome of decisions almost presupposes a concern with personal identity (although this conclusion is less logically compelled than it is with abuse). The participants concerned with the outcomes of their decisions wanted to make good choices *from their own perspective* and *according to their own standards*, not as measured by some objective standard. For example, Survey Respondent 127 wrote "If I could not recognize these people, I feel that I could not make a rational decision. I could be taken advantage of and be coerced into doing something that was not what I intended."¹⁸⁶ The contradiction this participant drew between a "rational decision" and one that "was not what I intended" requires a continuity of intent. And, as with those concerned primarily with abuse, those concerned with outcome, nearly without exception, selected at least some of the Narrativist responses to Question 6.

184. Survey with Respondent 162, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

185. Survey with Respondent 154, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

186. Survey with Respondent 127, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

In sum, while different themes present in the explanations and interviews offered different reasons for and understandings of the importance of narrative, the overwhelming majority of responses and interviews bolster the quantitative finding of the previous Section that the continuity of narrative identity is a consensus, or near consensus, analytical frame for answering the question of when the law should intervene in decision-making by people with dementia among the study population.

C. Challenge Cases

Although the foregoing quantitative and qualitative data make a *prima facie* case that something approaching a consensus of study participants conceptualized the inquiry of when the law should intervene in decision-making in Narrativist ways, this analysis may not explain every data point. There are three groups in the data that potentially challenge the Narrativist consensus. The first, and potentially the most serious, was a group of survey respondents who selected Narrativist responses to Question 6 but explained this choice in Question 7 as based on their view that such features are probative symptoms of the serious cognitive decline that they are fundamentally worried about. The second group are the 4 percent of survey respondents who did not select any Narrativist answers to Question 6. The third is the single interview participant who, when asked directly, explicitly rejected Narrativism.

In each of these cases, there is insufficient data to definitively foreclose the possibility that these groups do, in fact, deviate from or undermine the Narrativist consensus. As the analysis in this section indicates, however, it is similarly not clear whether these participants are actually *not* within the Narrativist consensus. That is, notwithstanding their apparent rejection of Narrativism, there are good reasons to believe on further analysis that these participants may in fact be thinking about these questions in the same ways as those who more explicitly offered Narrativist reasoning. While the case that these respondents, too, fall within the Narrativist consensus can be made with the data available, further research would be required to assess whether these groups do represent iconoclastic thought, in fact better capture the intuitions of seniors more generally, or simply nuance rather than undermine the Narrativist consensus.

1. THE "CANARY IN THE COAL MINE"—NARRATIVE ANSWERS AS COGNITIVE INDICATORS

As discussed in the previous section, a near consensus (96 percent) of survey respondents selected at least one of the three responses categorized as Narrativist on Question 6. For the most part, as discussed above, the fact that these respondents were, in fact, thinking in narrative terms in choosing these responses is corroborated by their answers to Question 7. But there is a category of responses that undermines this conclusion and undermines the view that cognitive features may be important as a prerequisite to narrative features. In fact, it reverses that view. This group of respondents explained that they chose Narrativist responses as the best indicators of egregious cognitive decline and it is that decline that is what matters to the ability to make the decision to change their will, not the Narrativist features in their own right.

For example, Survey Respondent 119, who selected long-term memory, wrote that he "selected the 2 memory choices b/c I see these as representative of larger mental health issues/symptoms. They could be the canaries in the coal mine indicating very significant problems."¹⁸⁷ Survey Respondent 79, who selected long-term memory and the ability to recognize family and friends, wrote "If I no longer even have the ability to recognize family or friends and cannot make connections between different ideas, my cognitive function has deteriorated to the point that I cannot make decisions for myself that would be in my best interests. I prefer that such decisions would be made for me (by my family) based on what they would consider best for me or what they would consider to be decisions closes [sic] in line with my desires were I still functioning cognitively at a high level."¹⁸⁸ Survey Respondent 116, who selected all three Narrativist responses, wrote "These are all abilities that would affect critical thinking skills and other logic and reason-based thinking skills. Furthermore, if I can't recognize my family and friends or any people in general, I would be so far along that I shouldn't be making any decisions whatsoever or live in an unsupervised situation."¹⁸⁹

187. Survey with Respondent 119, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

188. Survey with Respondent 79, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

189. Survey with Respondent 116, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

These responses, although not common, are significant because they suggest that reading too much into the widespread selection of Narrativist answers as a Narrativist theoretical consensus may be misguided. If the rejection of Narrativist theory offered in answers like these means what it says, it could be the case that Cognitivism is a better (or at least more popular) theory of what matters, and the Narrative accoutrements of a high functioning brain are merely indicators of the fact that it is high functioning. Alternatively, and perhaps more plausibly, these responses could indicate that there is no theoretical consensus among seniors at all, and that, while Narrativism may command a majority, a determinate minority theoretically dissents.

There are, however, several reasons to be skeptical that these responses have far-reaching implications for the finding of a Narrativist consensus elsewhere in the data. First, responses making this argument were not common. On a generous count, they make up approximately 7 percent of responses, significantly fewer than responses that explicitly expressed concerns about the continuity of narrative or personal identity. Moreover, it is important to acknowledge that the theory that the problem with the loss of Narrativist features is that they are indicative of other functional cognitive decline may be a red herring entirely. It is implausible that the respondents offering these kinds of explanations want to be limited in their decision-making as they develop dementia simply *because it is a disease*. People care about diseases not because they are diseases but because they *do things*. Symptoms, not etiologies, are what give people pause.

The symptoms of dementia are uniquely two-fold: it decreases cognitive abilities, situational awareness, etc., *and* disrupts, through these biological mechanisms, normative or metaphysical abstractions such as identity in the potential of the disease to change personality, values, and narrative continuity.¹⁹⁰ In the ordinary course of Alzheimer's, the latter changes occur later in time than the former.¹⁹¹ The respondents in this category are factually right that the loss of long-term memory, certain long-term memories and the ability to recognize friends and family are indicative of late-stage Alzheimer's.¹⁹²

190. See Linda Garand et al., *The Biological Basis of Behavioral Symptoms in Dementia*, 21 ISSUES MENTAL HEALTH NURSING 91–107 (2000).

191. See *id.*

192. *Stages of Alzheimer's*, ALZHEIMER'S ASS'N, <https://www.alz.org/alzheimers-dementia/stages> (last visited Jan. 25, 2021) [Stages of Alzheimer's].

But the key to understanding them is to consider why late-stage Alzheimer's, as opposed to earlier stage Alzheimer's, is the line of legal intervention for these respondents. That is, why do these respondents care that the canary in the coal mine is dead? It is conceptually possible, and the phrasing of some of the explanations would seem to suggest, that these respondents simply see the degree of cognitive decline associated with late-stage Alzheimer's as ensuring insufficient cognitive function to make significant decisions. If this is what they were thinking, however, the lines of the loss of long-term memory, specific long-term memories, and the ability to recognize friends and family are arbitrary and incidental. The loss of these features are not *directly* or *necessarily* connected with any amount of cognitive decline *per se*,¹⁹³ and, as a matter of fact, they can, and do, occur at different points of mechanical decline in different people with Alzheimer's.¹⁹⁴ Thus, if it were only as indicators of cognitive decline that these respondents found Narrativist features significant, it would make more sense for them to select only the Cognitivist features (the features the decline of which they *actually* care about) and offer in explanation some standard for determining *how much* loss of the selected features they would find problematic. For example, perhaps they could have selected short-term memory, the ability to make connections between different ideas, the ability to recognize people in general, etc., and explained themselves with something like, "I would want to keep the ability to make decisions as long as possible, until the late stages of the disease, when I don't know where I am."

But these respondents did not do this. Rather, they selected the Narrativist features and explained that at the loss of *those* things, they would *deem* the disease advanced enough that the law ought to intervene in their decision-making. Perhaps the best explanation of this choice is that it is precisely this turn from the cognitive-decline role of Alzheimer's to its identity-disrupting role, indicated by the disruption of narrative continuity the loss of the Narrativist features entails, that this group of respondents finds legally and ethically significant. If this is, in fact, the better interpretation of these respondents' choices, they care as profoundly about narrative as the other respondents. Late-stage Alzheimer's would not be significant for them merely because it is late-

193. See David S. Knopman & Ronald C. Petersen, *Mild Cognitive Impairment and Mild Dementia: A Clinical Perspective*, 89 MAYO CLINIC PROC. 1452-19 (2015).

194. Stages of Alzheimer's, *supra* note 192.

stage and the brain has been deteriorating for an arbitrarily long enough period of time, but *because* it is at that stage that they have lost the narrative features *that they really care about*. If this is right, these respondents, too, are a part of the Narrativist consensus found elsewhere in the data.

This interpretation finds some support in the interview data. For example, Person 5, much like these survey respondents, stated that “being profligate” would for him “be a *harbinger* of things, something’s wrong,”¹⁹⁵ suggesting that underlying cognitive abilities are what matters. Yet, he immediately followed this statement by saying he would want the law to intervene if he was “not really being the person who I am” and:

you know there’s, weighing If I mean, because if you behave in a certain way for X number of years and then go, suddenly change, your friends and your people who know what’s going on ask you something’s wrong, they know. I’m acting, you know, not myself. Or, you know, like for instance when I had this surgery done on this hand, I was really curt, and making sure that I did not hurt the incisions, and so on. So I’m sure [my wife] experienced that, recognized that, but, so that’s the only time. . . .¹⁹⁶

Here, Person 5 demonstrates an endorsement of the critical features of the Narrativist theory: conceptualizing whether the law should be involved in decision-making as a question of personal identity (“Not really being the person who I am”), and understanding personal identity with a distinction between narrative changes that do not break identity (being abnormally curt as the result of the narratively explicable cause of a surgery) and non-narrative changes that do (“if you behave in a certain way for X number of years and then go, suddenly change . . . I’m acting, you know, not myself”).¹⁹⁷

A similar phenomenon could be observed with Person 15. She stated that “If I’m lucid I guess I should be able to make decisions. But once I cross that line, I can’t see myself making any decisions.”¹⁹⁸ Later in the interview, Person 15 defined “that line” as behaving “out of her character” as determined by her children, who “know me all their life.”¹⁹⁹

195. Interview with Person 5, in Brookline, Mass. (Nov. 30, 2018) (on file with author) (emphasis added).

196. *Id.*

197. *Id.*

198. Interview with Person 15, Brookline, Mass. (Dec. 1, 2018) (on file with author).

199. *Id.*

Thus, the existence of explanations in this vein does not definitively disprove the existence of the Narrativist near-consensus otherwise suggested by the data.

2. SURVEY RESPONDENTS WHO SELECTED NO NARRATIVIST RESPONSES TO QUESTION 6

As indicated in the survey results presented above, 96 percent of respondents selected at least one of the Narrativist responses to Question 6. While an overwhelming majority, 96 percent is not literally a consensus, of course. Obviously, 4 percent of survey respondents selected no Narrativist responses. This group of respondents potentially challenges the consensus on thinking about Question 6 in Narrativist ways.

On closer analysis, however, this small group in fact offers at best a tepid challenge to that understanding. First, a majority (four of seven) respondents that selected no Narrativist responses to Question 6 selected no responses to Question 6 whatsoever, and left it blank or chose none of the above. These responses, therefore, do not support the prevailing alternative theories of Cognitivism and Essentialism. Moreover, for the most part, the explanations they offered in Question 7 are not inconsistent with the hypothesis that their authors care about Narrativism. For example, Survey Respondent 8 wrote:

Hopefully I would not be so bad off that I could not make reasonably sensible decisions about these things. Maybe my family would help me, while I still had most of my faculties, to get these things down on paper and legally so. I don't think I could trust anyone else later, to have my and my family's best interests at heart. They are likely to take unfair advantage of the situation.²⁰⁰

Similar to many of the other responses concerned with safety or abuse discussed above, this response presupposes a concern with personal identity. More directly, though, the respondent's desire to "get things down on paper and legally so" is consistent with (and, indeed, suggests an agreement with) Dworkin's Narrativism. One response, that of Survey Respondent 16, "MAY BE I MAY NOT BE THINKING RIGHT , SO I DON [sic] WANT TO TAKE THAT CHANCE,"²⁰¹ arguably embraces a Cognitivist, rather than a Narrativist, theory. This re-

200. Survey with Respondent 8, survey conducted online (Dec. 3–Dec. 22, 2018).

201. Survey with Respondent 16, survey conducted online (Dec. 3–Dec. 22, 2018).

sponse, however, is not exactly a paragon of theoretical clarity, and especially in light of the fact that the respondent did not select any answers to Question 6, it is simply too vague to speculate with any confidence where its author was coming from.

This leaves three respondents who did not select any Narrativist responses and did select other responses. Survey Respondent 9 selected the ability to recognize people in general, a Cognitivist response, and moral values, an Essentialist one, and explained herself by writing "If I couldn't recognize people I don't believe I would have the ability to trust anyone to make decisions for me therefore would need guidance in that area. As for losing any moral values I would want someone to protect me from being harmed or taken advantage of."²⁰² This explanation, as with the others concerned with safety or abuse, logically presupposes a concern with personal identity. Moreover, given the respondent's emphasis on the ability to recognize people in general as a vehicle for ensuring that he trusts the right people, he may be thinking of this feature more in its potential Narrativist role as the mechanism by which we understand the *roles* of other characters in our stories, rather than the mechanical, Cognitivist function of recognizing people, as Facebook does when I upload a photo. In short, it is not clear that Survey Respondent 9 does not, in fact, care about Narrativist features of his identity.

Survey Respondent 152 selected mathematical abilities, the ability to recognize people in general, the ability to make connections between different ideas, and personality. Survey Respondent 152 is in fact a double challenge case: she was quoted above as an example of a respondent who appeared to believe Narrativist features are indicative of serious cognitive change for her, writing "If one's current personality has changed that indicates brain damage affecting personality."²⁰³ And, as discussed above, Survey Respondent 152 offered additional explanation that is Narrativist: "Not recognizing people indicates the loss of remembering and memory which means one is no longer the person they were."²⁰⁴ In context, it may well have been an oversight that she did not select Narrativist features, or perhaps she felt that they were subsumed by her selection of ability to recognize people in general.

202. Survey with Respondent 9, survey conducted online (Dec. 3–Dec. 22, 2018).

203. Survey with Respondent 152, survey conducted online (Dec. 3–Dec. 22, 2018).

204. *Id.*

Finally, Survey Respondent 188 selected only the ability to make connections between different ideas and wrote “If I cannot make connections for different ideas, then I would want help from family that I trust. I obviously cannot make an informed decision. It would not be a wise decision.”²⁰⁵ This response is not clearly based on Narrativism. But, like the other outcome-oriented responses discussed generally above, it may presuppose a conception of personal identity from the perspective of which the “wisdom” of a decision can be assessed. Moreover, the respondent’s desire for “help from family that [she] trust[s]” suggests a present concern with the important characters in her life and the people that best understand her story.

In short, none of the 4 percent of respondents who did not select any of the Narrativist responses clearly embraced an alternative theory. Rather, it appears that for the most part the failure of these respondents to select Narrativist responses was an oversight, a misinterpretation, or cannot be read as a rejection of that theory because they failed to select an alternative or describe any theory at all. Carefully analyzed, the already very small minority of respondents not selecting Narrativist responses do not challenge the Narrativist consensus.

3. INTERVIEW SUBJECTS REJECTING THE IMPORTANCE OF NARRATIVE

A final challenge for the conclusion of a Narrativist consensus among the study population, is that, when asked directly, one interview subject rejected the importance of narrative as opposed to the alternative theories:

Interviewer: Now, do you also think it matters whether or not [“marry[ing] some floozy”²⁰⁶] would be consistent with [your father’s] personality for a long time, with his values, with who he had been before he developed dementia? Or is it about just being able to understand?

Person 13: You mean if it were completely out of character, would that, there be less of an obligation to honor it? When he didn’t have the understanding to see that it was not in the, his life’s trajectory. . . .

Interviewer: Right, but the question is does it matter more that it was not in his life’s trajectory or that he didn’t understand its ramifications?

205. Survey with Respondent 188, survey conducted online (Dec. 3–Dec. 22, 2018); Online Interview with Survey Respondent 188 (on file with author).

206. Interview with Person 13, in Brookline, Mass. (Nov. 28, 2018) (on file with author).

Person 13: More that he didn't understand its ramifications. I mean, people can do all kinds of things.

Interviewer: People can do, and that should be respected even if they have dementia, so long as they, they have the cognitive abilities to make that decision?

Person 13: Yeah, yeah. I used to tell my students that if there was something they really wanted to do, they owed it to themselves to do it, even if it turned out to be wrong. And I, I think you probably have to apply the same thing to, to everybody else. . . . These questions are hard.²⁰⁷

Person 13 was the only interview subject who so explicitly expressed a preference for an inquiry of cognitive understanding over a consistency of a prospective decision with one's "life trajectory." It is not clear, however, that Person 13 actually believed narrative is immaterial, nor clear that she is not, in fact, part of the Narrativist consensus. For example, immediately preceding the exchange quoted above, Person 13 set the hypothetical by saying "if my father had decided to marry some floozy, *which was not outside the realm of possibility*, I don't know what we would have done about that."²⁰⁸ The way she said the italicized phrase suggested that she did not necessarily think such a possibility *would have been* inconsistent with her father's life story (a conclusion supported by her saying "you mean *if it were* completely out of character" in the subjunctive in the above-quoted passage). It therefore might have been the case that the hypothetical was not effectively teasing out the distinction between narrative consistency and cognitive understanding because, while Person 13 would have found such a marriage *objectionable* on its own terms, she would not necessarily have found it *inconsistent* with her father's life story.

Second, and perhaps most importantly, the language of Person 13's preference for an inquiry of cognitive abilities is entirely consistent with and in fact provides support for the hypothesis that she cares about cognitive abilities *because* they are a prerequisite to a coherent narrative identity. Indeed, closely reading her statements suggests that she was in fact objecting only to what would be an Essentialist conception of legal capacity and not a Narrativist one. Her logic was that "if there [is] something [her students/people with dementia] really wanted to do, they owe it to themselves to do it, even if it turned out to be wrong."²⁰⁹ To owe something to oneself presupposes personal identity.

207. *Id.*

208. *Id.* (emphasis added).

209. *Id.*

A purely Cognitivist test does not care about personal identity. The identity Person 13 cares about, then, could be Essentialist, could be Narrativist, or could be something else. She clearly does not have an Essentialist conception of the self, and in the exchange quoted above she rejects such a view (“people can do all kinds of things”). Therefore, she must either have a Narrativist conception of personal identity, or something else. Support for the idea that she has a Narrativist conception of personal identity comes from considering *why* she thinks it is valuable for people to actively do things that might be wrong if they want to: because it is a vector of *growth*, which is, of course, a kind of story.²¹⁰

IV. Discussion

The results of this study reveal a consensus among participants that Narrativism, rather than Cognitivism or Essentialism, is the appropriate theoretical framework through which to consider whether an individual with dementia has the capacity required to change their will. For the reasons discussed above, the limitations of this study mean these results are necessarily limited. They are certainly insufficient to confidently speak generally about all kinds of decisions that may implicate the concept of legal capacity, or about the population of American seniors in all its diversity.

But the results are importantly suggestive. The online survey found in a fairly diverse, if small and limited, group of seniors a consistency in the analytical framework applied to the challenging, deeply personal questions the survey asked. Moreover, this analytical framework was *different* from the one currently embodied in the law and different from the most academically popular alternative. Because the consensus found in the online survey group is different from the prevailing alternatives in the broader culture, the results seem to suggest that the way in which respondents thought about this issue was not hugely dependent on their cultural backgrounds. Similarly, invocation of the Narrativist frame did not appear to vary in correlation with demographic variables, even though the survey population included participants from every state in the Union and roughly tracked the American population along some important variables such as income and having

210. Such behavior is the *sine qua non* of a Bildungsroman. *What Is a Bildungsroman? Definition and Examples of Bildungsroman in Literature*, MASTERCLASS (last updated Nov. 8, 2020), <https://www.masterclass.com/articles/what-is-a-bildungsroman-definition-and-examples-of-bildungsroman-in-literature>.

children. And the survey results were corroborated by the interview data, which drew from a population that, while less diverse in its own ways, was demographically distinct from the survey population.

Similarly, although the survey only collected granular data with respect to characteristics without which participants would not want to be permitted to change their will, the study offers good reasons to believe that the consensus regarding the Narrativist approach extends beyond estate planning questions. It is true that some of the explanations of respondents are particularly attuned to testamentary issues—for example, Survey Respondent 15 wrote that her response was “specifically in relation to a will,”²¹¹ and Survey Respondent 82 reiterated that “the question was about changing my will.”²¹²

But most responses were far more general in their reasoning. Some respondents, such as Survey Respondents 4, 116, and 171, specifically stated that their reasoning applied to “any decision.” Others phrased their explanations in terms of their identities and personhood without indication that the way they were thinking about the question was limited to estate planning, such as Survey Respondent 1, who simply stated that “these are the four main things that make you who you are and what you want. Without [sic] these you are nothing,”²¹³ or Survey Respondent 21, who noted that the characteristics he chose “go to the fabric of who a person is. If these things change then the basic person is changed.”²¹⁴ Still others referred to the issues in a general-enough way to suggest that their reasoning was not limited to testamentary decisions, such as Survey Respondent 6, who wrote “If I could not function with my previous cognitive ability, I would want my previous decisions to stand”²¹⁵ and Survey Respondent 123, who wrote “to me, the choices I made demonstrate a disconnection with the ability to make a rational choice.”²¹⁶ Similarly, in the interviews, many kinds of

211. Survey with Respondent 15, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

212. Survey with Respondent 82, survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

213. Survey with Respondent 1 survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

214. Survey with Respondent 21 survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

215. Survey with Respondent 6 survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

216. Survey with Respondent 123 survey conducted online (Dec. 3–Dec. 22, 2018) (on file with author).

decisions were discussed together with estate planning decisions, and there were no suggestions that the fundamental analytical process (as opposed to the *extent of deviation* required within that process) would differ between estate planning decisions and other kinds of decisions.

In short, it is possible that the Narrativist consensus found in this study population is limited to that population and limited to the question of changing a will—or is not as powerful a “consensus” more generally. But analysis of the strength of the consensus in light of the demographic diversity of the study population, coupled with the broad reasoning articulated by most survey respondents and the interview subjects, suggests that this Narrativist consensus might extend more broadly. Further research will certainly be required. But this study offers the first glimpses of the real possibility that there is a broader consensus among seniors that the way in which we ought to think about decision-making capacity is with reference to the narrative continuity of personal identity, not the momentary mechanical functioning of the brain, as the legal regime presently would have it. It is therefore worth discussing briefly what a legal regime based on a Narrativist consensus might look like.

Part of the enduring legal appeal of a Cognitivist test for legal capacity may be that it is perceived as basically administrable. Where life stories may seem complex, nebulous, ephemeral, unprovable, or even non-existent,²¹⁷ cognitive tests might appear scientific, empirical, and cheap. Even if they do not *perfectly* reflect the way in which people might want the doctrine to behave, predictable, efficient brain scans may just be, on balance, a better way for society to take away people's decision-making rights than expensive, squishy probes into the metaphysics of narrative. This is a powerful consideration. Every legal doctrine, of course, trades off some number of false positives and false negatives for administrative efficiency. But it is not obvious that the

217. While it is certainly possible that narrative is all of these things, a growing body of research in evolutionary psychology suggests that narrative may be a determinate, describable form that is the result of universal ways in which the evolved human mind processes information. See, e.g., GOTTSCHALL, *supra* note 90, at 105 (“[S]tudies show that if you give people random, unpatterned information, they have a very limited ability *not* to weave it into a story.”); see also DAN P. MCADAMS, *THE STORIES WE LIVE BY: PERSONAL MYTHS AND THE MAKING OF THE SELF* (1993); see also Fritz Heider & Marianne Simmel, *An Experimental Study of Apparent Behavior*, 57 AM. J. PSYCH. 243 (1944) (demonstrating the immediate and natural inclination of the human mind to organize information into narrative form); see also DONALD E. BROWN, *HUMAN UNIVERSALS* (1991).

premises of this argument are applicable in this context. At the very least, it is worth considering that Narrativist elements could realistically be incorporated into a legal doctrine that better reflects the ways in which seniors think about the issue.

First, the current Cognitivist test is not particularly efficient in absolute terms at all. The amount of American money lost annually to senior financial exploitation under the current system is denominated in the billions.²¹⁸ While recent developments in neuroscience have made the prospect of brain scans or biomarker tests to test for a certain stage of Alzheimer's more plausible,²¹⁹ many scientists maintain that these developments are unlikely to actually make capacity tests cheaper or more accurate.²²⁰ There is no doubt that at present, capacity tests are erratic, inconsistent, and do not always even accurately measure the core cognitive functions they are designed to.²²¹ Hanging over these challenges is the normative problem that a theory of *how much* cognitive loss cognitive tests should be looking for is required—a theory which we do not currently have, and as to which my study offers little to no insight, despite the search for such a theory being its original *raison d'être*. It remains unclear, then, how a cognitive test of capacity *can* efficiently search for what it does not even know it is searching for.

Second, there are many ways in which Narrativist theories can be integrated into the doctrine of capacity and with current capacity testing. The following two possibilities are not exclusive and could both be

218. See METLIFE ET AL., THE METLIFE STUDY OF ELDER FINANCIAL ABUSE: CRIMES OF OCCASION, DESPERATION, AND PREDATION AGAINST AMERICA'S ELDERS 2, 2 (2011) (calculating annual losses to senior financial exploitation at \$2.9 billion); see also TRUE LINK FINANCIAL, THE TRUE LINK REPORT ON ELDER FINANCIAL ABUSE 2015 1, 1 (2015) (calculating the same figure at \$36.48 billion).

219. See Press Release, Alzheimer's Ass'n, A Blood Test for Alzheimer's? Markers for Tau Take us a Step Closer (July 28, 2020), https://www.alz.org/aaic/releases_2020/blood-biomarkers-tau.asp.

220. Darby & Dickerson, *supra* note 15, at 274 ("Stephen Morse, among others, has argued that in most cases, neuroimaging is unlikely to add value beyond behavioral data. Showing functional neuroimaging abnormalities in a given patient is irrelevant if this abnormality is not associated with behavioral differences in the patient; and if such behavioral differences exist, it is unclear that the neuroimaging evidence helps in determining capacity or competency.").

221. Moye et al., *supra* note 2, at 171 ("[C]linicians arrive at significantly discrepant judgments of capacity in dementia, focusing on different cognitive and decisional abilities in patients, or holding values different from those of patients. . . . Clinical interviews for capacity vary in quality, ranging from broad mental status interviews providing little information from which to infer capacity to sophisticated capacity interviews directed to core abilities and values.").

operationalized in a number of different ways. But the fact that different degrees of integration of Narrativist theory are possible suggests that a method that strikes the right balance between efficiency and reflection of the intuitions of the legally affected population is possible.

The first possibility, which might be called a Cognitivist-Narrativist conception of legal capacity, would be a limited intervention of Narrativist theory into capacity testing. In this possibility, as now, courts would order clinical capacity tests (or parties would voluntarily submit to capacity tests where they may be relevant) and the law would remain agnostic to the content of a proposed decision. Rather than focusing on core cognitive abilities in opining on an individual's legal capacity, however, the tests would look for the Narrativist features popularly selected in this study, including long-term memory, certain specific long-term memories,²²² and the ability to recognize family and friends. That is, while the most commonly used capacity tests today focus exclusively on short-term memory, the ability to connect ideas, and other core cognitive features,²²³ there is no reason these tests could not focus more closely on the features that my study respondents found more probative of their entitlement to make decisions, namely, the Narrativist features. Moreover, there is no reason in principle that the loss of Narrativist features, long-term memories, and the ability to recognize family and friends, could not be empirically correlated with measurable mental states and biomarkers, potentially ensuring that the benefits of consistency and efficiency associated with prospective neuroscience are not lost in a Narrativist legal turn.

The second possibility, which we might call a Pure Narrativist test, would be more radical. Judges would be far more involved in understanding the life stories of people with dementia and would no longer be agnostic to the content of their decisions. A Pure Narrativist test, however, could more accurately capture the way seniors think about when they would want to lose the ability to make a particular

222. This would take some thinking about how to know which memories were of such significance in cases where they no longer exist, and the person cannot tell us. It does not seem insurmountable, however, as practitioners could collect lists of such memories after the individual is diagnosed with Mild Cognitive Impairment, or family members could be called in to discuss possible such memories (though depending on the circumstances family members may be unlikely to be aware of many constitutive memories).

223. See Mini-Mental Status Examination, DEMENTIA CARE CENTRAL, <https://www.dementiacarecentral.com/mini-mental-state-exam.pdf> (last visited Jan. 25, 2021).

decision and such a test would not be obviously impossible. In a nutshell, this legal doctrine would permit people with dementia, regardless of their stage of dementia, to make decisions that are narratively continuous with the person's preceding life, and not permit them to make decisions that are not narratively continuous. This doctrine would require, or imply, a theory of narrative continuity that would permit judges to distinguish between changes that are narrative in form and those that are not. We do not currently have such a theory.

But we could develop one. Indeed, researchers working on the evolutionary psychology of literature have offered suggestions of the universal features of the narrative form that could provide the empirical backbone for such a theory.²²⁴ Similarly, research in empirical psychology could seek to understand what people are thinking about when they think about their life stories²²⁵ or culture scholars could look at the stories particular national or cultural groups tell themselves.

Alternatively, rather than theorizing *a priori*, it may be sufficient to begin with a fairly minimalist theory of narrative continuity based on general, uncontroversial principles about how stories work, and hope the law develops from there. For example, we might say that narrative changes, at the very least, must be caused by something external

224. See GOTTSCHALL, *supra* note 90, at 52–56 (“Stories the world over all almost always about people . . . with problems. The people want something badly—to survive, to win the girl or the boy, to find a lost child. But big obstacles loom between the protagonists and what they want. . . . Stories universally focus on the great predicaments of the human condition. Stories are about sex and love. They are about the fear of death and the challenges of life. And they are about power: the desire to wield influence and to escape subjugation. Stories are not about going to the bathroom, driving to work, eating lunch, having the flu, or making coffee—*unless those activities can be tied back to the great predicaments.*”).

225. See Dan P. McAdams, *Narrative Identity: What Is It? What Does it Do? How Do You Measure It?*, 37 *IMAGINATION, COGNITION & PERSONALITY: CONSCIOUSNESS THEORY, RESEARCH, & CLINICAL PRACTICE* 359, 365–68 (2018) (discussing the empirical measurement of narrative identity); see also Kenneth J. Gergen & Mary M. Gergen, *Narratives of the self*, in *MEMORY, IDENTITY, COMMUNITY: THE IDEA OF NARRATIVE IN THE HUMAN SCIENCES* (Lewis P. Hinchman & Sandra K. Hinchman, eds., 1997) (“One’s present identity is thus not a sudden and mysterious event, but a sensible result of a life story. As Bettelheim has argued, such creations of narrative order may be essential in giving one’s life a sense of meaning and direction.”); see also Emily Postan, *Defining Ourselves: Personal Bioinformation as a Tool of Narrative Self-Conception*, 13 *J. BIOETHICAL INQUIRY* 133, 133 (2016) (“The proposal is that the identity-value of personal bioinformation may be understood in terms of its instrumental role in the construction of our narrative identities, specifically that its value lies in helping us to develop self-narratives that support us in navigating our embodied existences.”).

from the perspective of the person (a character) making the change.²²⁶ In other words, if a character can experience a change as *caused*, subjectively, we might hold that to be sufficient to establish its narrative continuity under a minimalist theory. Application of this minimalist test would at least permit changes the person with dementia experienced as being caused, perhaps by reading a book or talking to a friend, and preclude ones uncaused from the perspective of the person, such as 'waking up with a structurally different brain. Such a minimalist definition would put a lot of faith in the intuitions of individual judges. But over time, the case law might develop clearer and more determinate rules. This is, after all, how we got the common law.

The Cognitivist-Narrativist and Pure Narrativist tests can be seen as occupying a spectrum from less to more integration of Narrativist theory into the doctrine of legal capacity, between which countless permutations are possible. For example, the long-term memory assessment proposed by the Cognitivist-Narrativist test could be to the exclusion of or in conjunction with testing for core cognitive functions such as short-term memory. The range of potential ways to integrate, in whole or in part, Narrativist assumptions into the doctrine of legal capacity, and the low administrative burden of at least some of these formulations suggest that it is worthwhile to discuss the normative merits of this move. We must consider, in short, whether we ought to match the legal test of the capacity more closely to the concerns of the affected population.

The answer to that question is not obvious. On the one hand, a democratic system of laws may aspire to reflect the normative conceptions of the populations most affected by particular principles.²²⁷ On the other, majorities—even where they approach consensus—cannot conclusively answer normative questions.²²⁸ Perhaps more importantly, the normative question of when the law may intervene in the decision-making of a person “as they develop dementia” is not the only norma-

226. GOTTSCHALL, *supra* note 90, at 52 (“Story = Character + Predicament + Attempted Extrication.”).

227. Cf. Joshua Kleinfeld, *Manifesto of Democratic Criminal Justice*, 111 NW. U. L. REV. 1367 (2017) (defending a “democratic” critique on the criminal justice system).

228. See Knobe & Nichols, *supra* note 134, at 6 (“Philosophical inquiry has never been a popularity contest, and experimental philosophy is not about to turn it into one. If the experimental results are to have any meaningful impact here, it must be in some more indirect way.”).

tively significant way of looking at the problem. Indeed, there is an important debate in philosophy and disability studies—which this study elides—over whether it is *ever* normatively appropriate to override the wishes of a person with dementia with reference to who they were before the onset of the disease.²²⁹ Indeed, some argue that the concept of legal capacity should not be used to override the contemporaneous desires of those with dementia, even if those desires make little sense to us.²³⁰ This debate is necessarily outside the scope of my study, as participants were all seniors without dementia and it was designed to judge support for three normative theories—all of which assume that under some circumstances it is ethically permissible and may be ethically required to override the decision-making of those with dementia. But as these philosophers argue, that may not be the case.

V. Conclusion

This Article presented the results of a small-scale mixed-methods study on the attitudes of seniors regarding issues of dementia and decision-making. In particular, the study sought to determine which features about themselves, potentially inhibited or altered by dementia, seniors thought were indispensable to their ability to make legally binding decisions, and sought to understand the logic for why they thought those things in particular were more important than others.

The results of the study—in both its quantitative and qualitative components—suggest that a consensus of the study population supports Narrativist theories of legal capacity, those that see the inquiry into whether a decision ought to be legally binding as an inquiry into

229. See, e.g., DWORKIN, *supra* note 78; Alexander A. Boni-Saenz, *Sexual Advance Directives*, 68 ALA. L. REV. 1, 19–26 (2016) (summarizing work in philosophy and disability studies on whether advance directives can be ethically enforced over the present wishes of someone with dementia).

230. See, e.g., Kristin Booth Glen, *Introducing a “New” Human Right: Learning From Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 5 (2018) (“Legal capacity is a ‘new’ right for U.S. jurisprudence because, as a *human right*, it is inalienable—that is, it cannot be taken away. . . . [B]ecause legal capacity is inextricably tied to *mental capacity*, it can be—and routinely is—curtailed by courts on a finding of incapacity. To the contrary, the *human right* of legal capacity is understood to be separate and distinct from mental capacity, and therefore independent of it.”); see also Nandini Devi, *Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities*, 41 J. L. MED & ETHICS 792, 799 (2013); see also Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT’L L. 124, 127–30 (2014).

the narrative coherence of the decision with the story of the individual's life. This theory is in contrast to the prevailing academic and legal theories, which would either have the legal efficacy of a decision turn on the cognitive capacities of the person at the time it is made or the consistency of the decision with an essential cluster of values and beliefs that define the person.

As with other studies in experimental philosophy, this finding does not necessarily mean that Narrativism is the morally correct way to think about these ethical questions, much less that it must be codified into legal doctrine. That is, even if further research were to confirm that the Narrativist consensus found in this study extends more broadly, it would not tell us what to do with that finding. Yet, there are many reasons we may want to consider integrating Narrativist assumptions into the legal concept of capacity, to the extent feasible. We may find the reasons my study participants offered for why they thought about these questions in a Narrativist way compelling and find ourselves convinced that they are right. Or we may simply want to design a legal doctrine that protects that which those most affected by the doctrine want it to protect.

Certainly, the fact that there could be a consensus among seniors in favor of one theory of dementia and decision-making, rather than apparently plausible alternatives, is striking. It would be valuable for all of us to learn that what seniors care about in whether they should continue to be permitted to make legally binding decisions as they develop dementia is not the mechanical function of their brains, nor clusters of exogenous values, but the basic coherence of the stories of their lives.

Appendix A—Online Survey Protocol

Consent Information

Thank you for your interest in participating in this study. This page outlines the purposes of the study and provides a description of your involvement and rights as a participant.

The purpose of this study is to better understand the perspectives of seniors on the legal ability to make certain important decisions.

In order to be eligible to participate in this study, you must be 62 years older or older, and you must never have been diagnosed with a neurodegenerative disease, such as Alzheimer's. If you do not meet the study criteria, please click here to exit.

There are less than minimal risks associated with completing this survey. There are no direct benefits to participating in this study.

We estimate that the survey will take you no more than 20 minutes to complete, and you will be compensated with \$1 for your participation.

Your participation in this research is voluntary. You have the right to withdraw at any point during the study if you no longer wish to participate. Your decision whether or not to participate will not affect your current or future relations with the Harvard University.

Your Amazon Mechanical Turk unique ID will be stored by the research team to ensure that no one completes the survey twice. However, your name will not be required. Your Amazon Mechanical Turk ID will be stored securely, and only the research team will have access to it.

If you would like to contact the Principal Investigator in the study to discuss this research, please e-mail:

Principal investigator: James Toomey
Contact: jtoomey@jd19.law.harvard.edu
Research Organization: Harvard University

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, you are encouraged to contact the Harvard University Area Institutional Review Board at (617) 496-2847 or cuhs@harvard.edu.

By continuing, you are agreeing to participate in this research study.

Screening

How old are you? _____

Are you currently being treated for a neurodegenerative disease, such as Alzheimer's which affects your ability to remember or think?

- Yes
- No

[If participant enters an age under 62 or selects "Yes", they were redirected out of the study and the following text was displayed:

Thank you for your interest in taking part in this study. Unfortunately, you do not meet the criteria for participation.]

Question 1

If you were to develop dementia, such as Alzheimer's, how would you like to make the decision to **change your will**?

- I would still want to make the decision on my own
- I would want to make the decision with the help and guidance of family and friends
- I would want someone I trust to make the decision for me, even if I disagree
- I would not want to be allowed to change my will
- Other (please explain below):

Question 2

If you were to develop dementia, such as Alzheimer's, how would you like to make the decision to **get married or divorced**?

- I would still want to make the decision on my own
 - I would want to make the decision with the help and guidance of family and friends
 - I would want someone I trust to make the decision for me, even if I disagree
 - I would not want to be allowed to get married or divorced
 - Other (please explain below):
-
-

Question 3

If you were to develop dementia, such as Alzheimer's, how would you like to make the decision to **make a major purchase**?

- I would still want to make the decision on my own
 - I would want to make the decision with the help and guidance of family and friends
 - I would want someone I trust to make the decision for me, even if I disagree
 - I would not want to be allowed to make a major purchase
 - Other (please explain below):
-
-

Question 4

If you were to develop dementia, such as Alzheimer's, how would you like to make the decision to **donate a large amount of money**?

- I would still want to make the decision on my own
- I would want to make the decision with the help and guidance of family and friends
- I would want someone I trust to make the decision for me, even if I disagree
- I would not want to be allowed to donate a large amount of money
- Other (please explain below):

Question 5

If you were to develop dementia, such as Alzheimer's how would you like to make the decision to **choose end-of-life care**?

- I would still want to make the decision on my own
 - I would want to make the decision with the help and guidance of family and friends
 - I would want someone I trust to make the decision for me, even if I disagree
 - Other (please explain below):
-
-

Question 6

If you lost any of the following personal characteristics or mental capabilities as a result of dementia, would you want the law to intervene before permitting you to **change your will** on your own? Please select all that apply:

- Short-term memory (ability to remember a conversation you are having)
- Long-term memory (ability to remember who you are and who other people are, your background and old stories)
- Certain specific long-term memories (particular memories or stories that you would not want to make major decisions without, i.e., your memory of the birth of your child)
- Your mathematical abilities
- Your ability to recognize people in general
- Your ability to make connections between different ideas
- Your ability to think at a certain speed
- Your current personality (i.e., if you have always been extroverted, but become introverted, or if you have never enjoyed trying new foods, but start to do so)
- Your moral values
- Your religious views
- Your political views
- Your interests or hobbies
- Other (please explain on the next page)

- None of the above

Question 7

When thinking about the things about yourself that you would not want to be allowed to make decisions without, you chose:

[Previously selected choices displayed here]

Please explain your choices below. Why did you choose these things and not others? Why are these things the most important to you?

Question 8

When thinking about the things about yourself that you would not want to be allowed to make decisions without, you chose:

[Previously selected choices displayed here]

If these were impaired by dementia and your family and the government had to make a decision about changing your will, would you want them to:

- make the decision based on what they think you would have wanted when you were healthy
- make the decision based on what they think is best for you in terms of your health or finances
- be allowed to consider their own interests or well-being in making the decision

Question 9

Please elaborate or explain why you chose your answer to the previous question here:

Attention Filter

In this experiment, you have been asked to make decisions after evaluating information. Most modern theories of decision making recognize the fact that decisions do not take place in a vacuum. Individual preferences and knowledge, along with situational variables can greatly impact the decision process. In order to facilitate our research on decision making we are interested in knowing certain factors about you, the decision maker. Specifically, we are interested in whether you actually take the time to read the directions; if not, then some of our questions will be ineffective. So, in order to demonstrate that you have read the instructions, please ignore the question below. Instead, please click only the "Magazines" button and then type 654 into the Other field at the bottom of the screen and then click on the next button below to proceed to the next screen.

From which of these sources have you received information in the past month?

(Click all that apply and answer according to the directions above)

- Local newspaper
 - National newspaper
 - Local TV news
 - Nightly network news
 - Cable TV news
 - Magazines
 - Speaking with family/friends
 - Radio newscast
 - Internet web sites
 - Other
-

Demographic Questions

Has anyone close to you suffered from dementia?

- Yes, and I was involved in caring for them, including helping them make decisions
- Yes, and I was involved in caring for them, but I did not help them make decisions
- Yes, but I was not involved in caring for them
- No

Do you consider yourself religious?

- Religious
- Somewhat religious
- Not religious

What religion do you associate yourself with? [select all that apply]

- Agnostic
- Assemblies of God
- Atheist
- Baptist
- Buddhist
- Catholic
- Christian Scientist
- Church of Christ
- Eastern Orthodox
- Episcopalian
- Evangelical
- Hindu
- Islamic
- Jewish
- Latter Day Saints
- Lutheran
- Methodist
- Non-denominational Christian
- Pentecostal/Apostolic
- Presbyterian
- Seventh Day Adventist
- Sikh
- Southern Baptist

- Unitarian Universalist
- United Church of Christ
- Other Christian religion
- Other or don't have a religious affiliation

What is the highest level of education you have completed?

- Some high school
- High school degree
- Some college
- College degree
- Graduate or advanced degree

Generally speaking, do you usually think of yourself as a Republican, a Democrat, an Independent, or what?

- Strong Democrat
- Weak Democrat
- Independent Democrat
- Independent Independent
- Independent Republican
- Weak Republican
- Strong Republican
- Apolitical

What is your current ZIP code?

Please select all states you've lived in as an adult: [select all that apply]

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Georgia
- Hawaii
- Idaho

- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming

What is your marital status?

- Married (first marriage)
- Married (not first marriage)
- Divorced
- Widowed
- Never married

Do you have children?

- Yes—if so, how many? _____
- No

What is your gender?

- Male
- Female
- Other
- Prefer not to say

What is your household income (or, if you are retired, what was your household income at retirement)?

- Less than \$20,000
- \$20,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- Over \$100,000

Are you of Hispanic, Latino, or of Spanish origin?

- Yes
- No

How would you describe yourself?

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other
- Prefer not to say

[Participants who completed the survey were shown the text:

Your validation code for mTurk is [code generator]. Please write this number down, and enter it into MTurk.

Appendix B—Demographics of Survey Population; n=235²³¹

Question	Answer	Number of responses	Percent responses	Approximate percent American 65+ population ²³²
What is your household income (or, if you are retired, what was your income at retirement)?	Less than \$20,000	29	12.3%	18.01% ²³³
	\$20,000 to \$34,999	47	20%	15.62%
	\$35,000 to \$49,999	50	21.2%	13.12%
	\$50,000 to \$74,999	51	21.6%	17.04%
	\$75,000 to \$99,999	32	13.6%	11.55%
	Over \$100,000	26	11.1%	24.66%

231. One participant who completed the substantive questions and passed the attention filter did not complete the demographic questions. This respondent was nevertheless included in the analysis.

232. Because studies asking precisely these demographic questions are not available, this column presents approximations based on available data and is for illustrative purposes only. Where senior-specific data is not available data for the general American population is used. This is noted in footnotes.

233. These data are personal, not household income statistics for the general American population, because the question asked for either current income or income at retirement. See U.S. CENSUS BUREAU, PINC-01. PERSON INCOME IN 2017, BOTH SEXES, ALL RACES, https://www2.census.gov/programs-surveys/cps/tables/pinc-01/2018/pinc01_1_1_1.xls.

What is your gender?	Male	75	31.9%	44.4% ²³⁴
	Female	160	68.1%	55.6%
What is your marital status?	Married (first marriage)	76	32.3%	71.6% ²³⁵
	Married (not first marriage)	41	17.4%	
	Divorced	67	28.5%	14%
	Widowed	24	10.2%	6.4%
	Never married	27	11.5%	5.6%

234. These figures are for the 65+ American population, which is more female than the general population. See STATISTA, RESIDENT POPULATION OF THE UNITED STATES BY SEX AND AGE AS OF JULY 2017 (in millions), <https://www.statista.com/statistics/241488/population-of-the-us-by-sex-and-age/>.

235. These figures are for the American 65+ population, but a breakdown of this population by whether individuals are on their first or a later marriage do not appear to be available. See U.S. CENSUS BUREAU, THE POPULATION 65 YEARS AND OLDER IN THE UNITED STATES: 2016, <https://www.census.gov/content/dam/Census/library/publications/2018/acs/ACS-38.pdf>.

Do you have children?	Yes	174	74%	80% ²³⁶
	No	61	26%	20%
Do you consider yourself religious?	Religious	85	36.2%	65% ²³⁷
	Somewhat religious	72	30.6%	20%
	Not religious	78	33.2%	16%
What religion do you associate yourself with?	Agnostic	18	7.7%	2% ²³⁸
	Assemblies of God	1	0.4%	2%
	Atheist	18	7.7%	2%
	Baptist	23	9.8%	14%
	Buddhist	4	1.7%	1%
	Catholic	28	11.9%	24%

236. See Kate de Medeiros, et al., *Childless Elders in Assisted Living: Findings from the Maryland Assisted Living Study*, 27 *J. Housing Elderly* 206, 206 (2013) (“The percentage of childless [assisted living] residents (26%) in our study was slightly higher than US population estimates of childless persons age 65 and over (20%)”).

237. These figures from the 65+ population are in response to the question “How important is religion to your life?” I combined “Not too important,” “Not at all important,” and “Don’t know” into “Not religious” here. See Pew Research Center, *Importance of religion in one’s life among adults ages 65 and older*, ADULTS AGES 65 AND OLDER, <http://www.pewforum.org/religious-landscape-study/age-distribution/65/>.

238. See Pew Research Center, *Religious composition of adults ages 65 and older*, ADULTS AGES 65 AND OLDER, <http://www.pewforum.org/religious-landscape-study/age-distribution/65/>.

Christian Scientist	2	0.9%	<1%
Church of Christ	2	0.9%	1%
Eastern Orthodox	0	0%	<1%
Episcopalian	7	3.0%	2%
Evangelical	0	0%	3%
Hindu	0	0%	<1%
Jewish	9	3.8%	3%
Latter Day Saints	0	0%	1%
Lutheran	9	3.8%	5%
Methodist	7	3.0%	8%
Non-denominational Christian	29	12.3%	3%
Pentecostal/Apostolic	4	1.7%	5%
Presbyterian	7	3.0%	4%
Seventh Day Adventist	0	0%	1%
Sikh	0	0%	<1%
Southern Baptist	2	0.9%	8%
Unitarian Universalist	3	1.3%	1%
United Church of Christ	1	0.4%	1%
Islamic	0	0%	<1%
Other Christian Religion	13	5.5%	<1%
Other or don't have a religious affiliation	42	17.9%	13%

Generally speaking, do you usually think of yourself as a Republican, a Democrat, an Independent, or what?

Strong Democrat	58	24.7%	30% ²³⁹
Weak Democrat	19	8.1%	
Independent Democrat	35	14.9%	
Independent Independent	30	12.8%	37%
Independent Republican	25	10.6%	31%
Weak Republican	30	12.8%	
Strong Republican	31	13.2%	
Apolitical	7	3.0%	

239. These figures are for the general American population, not only seniors. *See Party Affiliation*, GALLUP (last visited Mar. 11, 2019), <https://news.gallup.com/poll/15370/party-affiliation.aspx>.

Please select all states you've lived in as an adult.	Alabama	11	4.7%	1.48% ²⁴⁰
	Alaska	3	1.3%	0.22%
	Arizona	15	6.4%	2.17%
	Arkansas	9	3.8%	0.91%
	California	51	21.7%	11.96%
	Colorado	13	5.5%	1.72%
	Connecticut	12	5.1%	1.08%
	Delaware	2	0.9%	0.29%
	Florida	54	23.9%	6.44%
	Georgia	25	10.6%	3.18%
	Hawaii	6	2.6%	0.43%
	Idaho	5	2.1%	0.53%
	Illinois	30	12.8%	3.85%
	Indiana	7	3.0%	2.02%
	Iowa	9	3.8%	0.95%
	Kansas	5	2.1%	0.88%
	Kentucky	10	4.3%	1.35%
	Louisiana	9	3.8%	1.41%
	Maine	8	3.4%	0.40%
	Maryland	9	3.8%	1.83%

240. These figures simply represent the percentage of the American population living in each state. See U.S. CENSUS BUREAU, POPULATION ESTIMATE STATE TOTALS 2017, <https://www2.census.gov/programs-surveys/popest/tables/2010-2017/state/totals/nst-est2017-01.xlsx>.

Massachusetts	25	10.6%	2.09%
Michigan	25	10.6%	3.02%
Minnesota	13	5.5%	1.7%
Mississippi	15	6.4%	0.9%
Missouri	16	6.8%	1.85%
Montana	2	0.9%	0.32%
Nebraska	3	1.3%	0.58%
Nevada	5	2.1%	0.92%
New Hampshire	3	1.3%	0.41%
New Jersey	17	7.2%	2.69%
New Mexico	3	1.3%	0.63%
New York	37	15.7%	5.91%
North Carolina	22	9.4%	3.14%
North Dakota	3	1.3%	0.23%
Ohio	22	9.4%	3.53%
Oklahoma	3	1.3%	1.19%
Oregon	14	6.0%	1.27%
Pennsylvania	33	14.0%	3.87%
Rhode Island	6	2.6%	0.32%
South Carolina	17	7.2%	1.54%
South Dakota	4	1.7%	0.27%
Tennessee	10	4.3%	2.05%
Texas	34	14.5%	8.68%
Utah	3	1.3%	0.96%
Vermont	1	0.4%	0.19%
Virginia	17	7.2%	2.58%

What is the highest level of education you have completed?

Washington	11	4.7%	2.28%
West Virginia	5	2.1%	0.55%
Wisconsin	9	3.8%	1.76%
Wyoming	4	1.7%	0.17%
Some high school	2	0.9%	7.3% ²⁴¹
High school degree	26	11.1%	32.5%
Some college	67	28.5%	16.2%
College degree	81	34.5%	24.9%
Graduate or advanced degree	59	25.1%	12.8%

241. Associates degrees were counted as college degrees in translating the census data into this table. See U.S. CENSUS BUREAU, EDUCATIONAL ATTAINMENT DETAILED TABLES 2018, <https://www2.census.gov/programs-surveys/demo/tables/educational-attainment/2018/cps-detailed-tables/table-1-1.xlsx>.

How would you describe yourself?	American Indian or Alaska Native	4	1.7%	0.5% ²⁴²
	Asian	0	0.0%	4.2%
	Black or African American	14	6.0%	8.9%
	Native Hawaiian or Other Pacific Islander	0	0.0%	0.1%
	White	217	92.3%	77.3%
Are you of Hispanic, Latino, or of Spanish origin?	Yes	3	1.3%	8% ²⁴³
	No	232	98.7%	92%

242. See U.S. CENSUS BUREAU, THE POPULATION 65 YEARS AND OLDER IN THE UNITED STATES: 2016, <https://www.census.gov/content/dam/Census/library/publications/2018/acs/ACS-38.pdf>.

243. See U.S. CENSUS BUREAU, THE POPULATION 65 YEARS AND OLDER IN THE UNITED STATES: 2016, <https://www.census.gov/content/dam/Census/library/publications/2018/acs/ACS-38.pdf>.

Has anyone close to you suffered from dementia?	Yes, and I was involved in caring for them, including helping them make decisions	64	27.2%	NA
	Yes, and I was involved in caring for them, but I did not help them make decisions	15	6.4%	NA
	Yes, but I was not involved in caring for them	75	31.9%	NA
	No	81	34.5%	NA

Appendix C—Interview Script

My name is James Toomey and I'm a law student at Harvard. I'm doing research on the perspectives of seniors on when and how families and the government should step in and make decisions for people who have lost some of the abilities they used to have, or help them to make their own decisions. Because I will be asking you to think about the possibility that in the future you might lose some of the abilities that you have now, some of these questions might make you uncomfortable. You also may not have an answer. Please feel free not to answer any questions for any reason. You should also feel free to end the interview early if you want.

I am recording our discussion for my records, but I will not share it with anyone else without your permission. I will be using what you tell me, along with what other people tell me, to think about the concept of capacity, what it means, what it should mean, and how the legal system should approach it. After I am done talking to people, I will be writing a paper based on what you and other people tell me. I may quote you in that paper, or recount some experiences you tell me about, but if I do, I will use a made-up name.

I am most interested in your stories and your perspectives on these issues, not necessarily with specific answers to questions I have. So, while I do have some questions to get us started, I want this to feel like a conversation, and I want you to feel free to interrupt me tell me anything you think might be relevant or interesting, even if I don't ask about it specifically.

Do you understand that? Do you have any questions for me?

Alright, let's get started with a bit of background.

Demographic Questions

- 1) Tell me a bit about where you grew up. [Begin a conversation that establishes the following information]:
 - a. Religious background
 - b. Political views

- c. General view on government intervention
- d. Where the individual lived
- e. What the individual did for work
- f. Marital status and family structure
- g. Do they have a will

Questions:

- 1) If you were to develop Alzheimer's or dementia, as you understand those diseases, would you want to be allowed to change your will in a way you don't currently want to? If not, would you want the government or your family to help or make the decision for you?
 - a. Why or why not? [Get at: what is it about these diseases that makes them such that you would want to make legally binding decisions]
 - b. Does your answer vary for different kinds of decisions? Is it the same for other decisions such as buying a house, spending your savings on leisure or getting married? Why?
 - c. As you may know, Alzheimer's can affect different people differently, and can start slowly. I'd like you to think a bit about *when* you would want your family or the government to step in and help you make decisions. If the disease started slowly, do you think there is any way for your family or friends to know when to start helping you make decisions, or making decisions for you?
 - d. If you lost the following would you still want to be able to make important legal and financial decisions?
 - i. Short-term memory
 - ii. Long-term memory
 - iii. Specific memories
 - iv. Mathematical ability
 - v. Recognizing people

- vi. Associating ideas
- vii. Thinking with the speed you currently think at
- viii. Aspects of your personality
- ix. Moral values
- e. If your family or the government starts making decisions for you, would you want them to
 - i. make those decisions based on what they think you would have wanted, or
 - ii. Make those decisions based on what they think is best for you in terms of your health or finances?
- f. Should your family be allowed to consider their own interests or well-being in making those decisions? Why?
- g. Based on your experience, do you have any thoughts about whether doctors and lawyers are doing a good job of identifying people that need help making decisions and properly helping them make decisions?

