

Understanding the Perspectives of Seniors on Dementia and Decisionmaking

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Background: The legal doctrine of capacity, which governs legally-authorized intervention in the decisionmaking of persons with dementia, has been subject to recent scholarly criticism and reform efforts. Such efforts require a coherent normative theory of when and how intervention in the decisionmaking of those with dementia is appropriate. This mixed-methods study sought to understand the perspectives of seniors on this normative question.

Methods: A survey, including closed- and open-ended questions and conversational interviews were conducted.

Results: Quantitative results of 236 seniors were heterogeneous but showed important patterns. Qualitative results from survey data and interviews of 25 seniors presented 6 key themes: (1) a difficulty of giving concrete answers; (2) reliance on professional opinions; (3) concern for personal identity; (4) fear of abuse; (5) trust of family; and (6) fear of dementia.

Conclusions: The study suggests support among seniors for: (1) a model of “supported decisionmaking” rather than “surrogate decisionmaking;” (2) a presumption that in order to preclude a person with dementia from making more “personal” decisions a more heightened showing of incapacity is required; and (3) a shift to a model of capacity as based more on features such as long term memory and relationships rather than cognitive functions or values. In reforming our understandings of capacity, ethicists and practitioners will have to navigate tensions found in the qualitative data, including: (1) between participants’ fear of abuse and their expressions of trust in family members to decide when intervention is appropriate; and (2) between expressions of confidence in medical professionals’ ability to tell participants when they are no longer able to make decisions and participants’ own understanding of the question in terms of the philosophical construct of personal identity.

Introduction

When people develop dementia, their ability to make important decisions recognized by law—such as to change an estate plan, make a large purchase, or get married or divorced—is increasingly compromised (Lichtenberg 2016).

Because age is the single most important risk factor for dementia—with the incidence of Alzheimer’s Disease, a common cause of dementia, rising from 1%-3% in persons aged 60-64 to 25%-35% among those older than 85 (Chen et al. 2009)—the relationship between dementia and capacity is an important issue in elder law and ethics (Kohn 2020).

The law does not recognize decisions made without “capacity,” that is, the requisite mental functioning to sufficiently understand the nature of a decision and its implications, as defined in case law (Jorgensen 2008). The legal standards applied to determine capacity vary from jurisdiction to jurisdiction and from decision to decision, but, in general, adults are presumed to have capacity unless a court finds that they do not understand the nature and consequences of the decision they intend to make, as a measure of cognitive functioning (Kohn 2020) (Boyle 2018). Traditionally, this determination has been understood to be binary—either a person has capacity or they do not (Jorgensen 2008). Moreover, where an individual’s dementia has progressed far enough that they are unable to make decisions in general, a judge may appoint a guardian or conservator who is legally empowered to make some or all decisions for them (Arias 2013).

The legal standards applicable to finding that a person with dementia lacks capacity are notoriously vague and difficult to apply (Moye et al. 2013). There is ample evidence that these standards are applied inconsistently (Moye et al. 2013), often excessively curtail the rights of those with dementia (Diller 2016), and can

serve as a vector for elder abuse, particularly financially (Lichtenberg 2016). Indeed, in recent years, the legal doctrine of capacity has been the subject of a great deal of scholarly criticism and active reform (Diller 2016) (Series 2014). One area of reform is a move from a model of “surrogate decisionmaking” to one of “supported decisionmaking” (Wright 2020). The former, the traditional approach, would appoint an individual to make decisions on behalf of the person with dementia after a finding of incapacity (Wright 2020). The latter would appoint one or more people to attempt to help the person with dementia make their own decisions and to interpret their wishes (Wright 2020).

Reform efforts have been hindered, however, by the lack of a coherent normative theory establishing when in the course of dementia third-party intervention in decisionmaking is ethically defensible (Grey 2018). Thus far, the search for such a theory has been largely limited to academic philosophy (Devettere 2016) (Kitwood 1997) (White 1994) (Dworkin 1993) (Buchanan & Brock 1990). Moreover, while there is a substantial literature analyzing the capacity required for informed consent and other healthcare decisions (Kim et al. 2011) (Lai & Karlawish 2007) (Dresser 2001), much less has been written about people’s understanding of the capacity required to make other kinds of important decisions, such as to get married or divorced, make a major purchase, or change an estate plan.

This mixed-methods study sought to understand the perspectives of seniors—the population most affected by dementia and the legal and ethical debates pertaining thereto—on when and how the law should intervene in the decisionmaking of people with dementia. An online survey that asked both closed- and open-ended questions of 236 seniors from around the United States was

conducted, along with interviews of 25 seniors at three retirement communities in Brookline, Massachusetts. The results advance the conversation on reform to the legal doctrine of capacity in several ways. First, the results show an apparent heterogeneity of perspective as to when intervention is appropriate. Therefore, reforms to the law of capacity should continue to be guided by the principle of private ordering embodied in the current doctrine, which generally enforces personal preferences.

However, some clear patterns pertinent to reform efforts emerged from the data. Specifically, the results show support among seniors for: (1) continuing the push towards a “supported decisionmaking” model rather than the traditional “surrogate decisionmaking” model; (2) a declining scale of capacity that retains discretion as to more “personal” decisions longer; and (3) a capacity testing regime more focused on long term memories and relationships than core cognitive functions or values. The first pattern is widely discussed in the literature and has achieved growing legislative support (Wright 2020). The latter two patterns have not yet been discussed as clearly in normative work, but this study suggests that they may be fruitful sources of reform. Moreover, analysis of the qualitative data revealed (1) tensions between seniors’ fear of abuse and expressions of absolute faith in family members; and (2) tensions between seniors’ apparent deference to healthcare professionals on the question of when intervention is appropriate and their resort to metaphysical constructs such as personal identity in their own analysis of the question. Ethicists, legal and healthcare practitioners, and reformers will have to navigate these tensions as they work to bring the legal doctrine of capacity closer in line with the understandings of the most affected population.

Methods

This mixed-methods study included both an online survey and a series of interviews, each of which asked seniors to consider when and how they would want others, including the government, to intervene in their decisionmaking if they were to develop dementia. Both components of the study were deemed exempt by the IRB at . The survey and interview components each involved a distinct participant cohort that was recruited differently. To the author's knowledge, no participant was involved in both components of the study.

The survey was developed and run in Qualtrics, an online survey platform routinely used in academic research. Participants were recruited with Amazon Mechanical Turk, through which they were compensated \$1 each. Research combining Amazon Mechanical Turk and Qualtrics has become common in empirical legal research and the social sciences (Shen et al. 2017). A variety of studies have validated Mechanical Turk's data against convenience samples (Behrend et al. 2011) (Buhrmester et al. 2011) (Goodman et al. 2012). However, researchers have recognized limitations with Mechanical Turk populations (Berensky et al. 2012) (Paolacci & Chandler 2014) (Mason & Suri 2012).

Using the Mechanical Turk interface, participants were limited to those within the United States and those over 55 years of age. Participation was further limited by a screening question in the Qualtrics survey to individuals over 62 years old. This qualification was made to match the survey population to the interview population because interviews were conducted at retirement communities which housed people aged 62 and older, as discussed below. Individuals previously diagnosed with dementia or neurodegenerative diseases were also excluded with a screening question on Qualtrics. This exclusion was designed to avoid the

challenging question—very similar to the question the survey was designed to address in the first place—of whether there is a point (or a sliding scale) in the progress of dementia at which assertions of continued entitlement to make independent decisions may be ethically discounted. The survey was available on Mechanical Turk from December 3 to December 22, 2018, and sufficient funds were added to the account to compensate 500 participants, based on the funding available for the project.

Interview subjects were recruited and interviewed at the Center Communities of Brookline retirement community/assisted living facilities in Brookline, Massachusetts, from November through 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 [institution], and interviews were arranged through contacts at [institution]. Subjects were solicited through presentations at community meetings. Interviews were conducted at three specific facilities, with roughly a third of the participants drawn from each.

The survey text and an interview script were developed together. Neither the survey questions nor the interview script specifically defined dementia, but used the phrase “dementia, such as Alzheimer’s” to indicate the kind of cognitive decline at issue. The survey text is reproduced in Appendix A. It included nine substantive closed- and open-ended questions, an attention filter¹ and demographic questions.

¹ This was a screening question built into the middle of the survey designed to make sure that participants were reading the questions, modelled on the attention filter used by Francis Shen and colleagues (Shen et al. 2017). The question instructed participants who carefully read the paragraph-long prompt

The closed-ended questions asked participants to consider whether and how they would want family or the government to intervene in their decision-making. The open-ended questions asked participants to reflect on why they chose the answers to the closed-ended questions that they did. The survey was anonymous, and responses are identified only by random identification numbers assigned by the survey software.

The interviews were conducted roughly contemporaneously with the time in which the Mechanical Turk survey was active, but before the survey results were collected and analyzed. The purpose of these interviews was 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 is reproduced in Appendix C. However, as indicated by the script, the interviews were conducted in a primarily conversational mode and many deviated substantially from the skeleton. Each interview lasted between 30 and 90 minutes, depending on the engagement of the participant, and participants were given a \$10 gift card to Trader Joe's at the conclusion of the interview. The interviews were recorded and transcribed. To preserve the privacy of participants, they are not identified in this Article, but the interviews were not anonymous to the extent that the author is aware of the identity

to disregard the bold-faced question above and below the paragraph. See Appendix A for the complete text of the attention filter. Attention filters are widely used in online survey research to compensate for the fact that participants cannot be monitored while completing tasks (Shen et al. 2017) (Oppenheimer et al. 2009). Otherwise complete responses that failed the attention filter were excluded from the population.

of the interview subjects. The interviews were conducted between November and December 2018.

Quantitative data from the closed-ended survey questions were analyzed in Microsoft Excel to produce descriptive statistics and are presented below. Data from each of the interviews was analyzed by the author, together with the qualitative data from the open-ended survey questions, in NVivo, a software designed for qualitative analysis. Analysis was conducted according to the grounded theory methodology of qualitative analysis (Tie et al. 2019). This methodology involved the comprehensive analysis of the qualitative data for patterns and themes contemporaneously with the development of codes designed to narrow and organize the analysis. The codes were then used to develop and test hypotheses and theoretical explanations for the data.

Results

236 participants completed the survey fully and passed the attention-filter and 25 seniors were interviewed. Descriptive demographic data of the survey population are reproduced in Appendix B.

In general, survey participants differed from the general population in several notable ways. In particular, survey 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. Survey respondents were substantially less religious than the general population of seniors.

The interview population was demographically different from the survey population. Interview participants were predominately (~68%) Jewish and politically liberal (~60%). They were a very highly educated group, with at least 56% having a post-college degree, and they likely had greater assets than average. However,

several interview subjects were living in Section 8 apartments and subsisting primarily on social security and public assistance.

Quantitative Results

The online survey involved seven closed-ended questions. The first five of these were variations on a theme. Each asked how respondents would want to go about making a particular decision (specifically, to change their will, to get married or divorced, to make a major purchase, to donate a large amount of money, or to choose end-of-life care, respectively) if they were to develop dementia.

Respondents were prompted to consider whether they would want to (1) make the decision on their own; (2) make the decision with the help of family and friends; (3) want the decision to be made by a trusted surrogate decisionmaker; or (4) if they should not be permitted to make the decision at all. The results of these five questions are presented in Table 1.

The results varied for each decision asked about. For example, 22% of respondents would want to make end-of-life care decisions on their own after they developed dementia, while only 8% would want to make the decision to donate a large amount of money on their own. Similarly, 37% of respondents would want to be prevented from making the decision to donate a large amount of money entirely, while only 11% would want the power to make a large purchase categorically taken away. With respect to each decision, a plurality of respondents—and in some cases a majority—indicated that they would want to make the decision with the help of family and friends.

Next, Question 6 of the survey listed a series of personal characteristics and cognitive abilities: short term memory, long term memory, certain specific long term memories, mathematical abilities, ability to recognize people in general, ability to

recognize family and friends, ability to make connections between different ideas, ability to think at a certain speed, personality, moral values, religious views, political views, interests or hobbies, other, and none of the above. The question asked respondents to select from the list all of those things without which they would not want to be permitted to make a binding change to their will. The results are presented in Table 2. These results also indicated heterogeneity of preferences—no response was selected by all respondents, and no response (except “Other”) was selected by none. However, long term memory and the ability to recognize family and friends were selected by clear majorities.

Finally, Question 7 of the survey asked about the method by which surrogate decisionmakers should think about making decisions. Respondents were reminded of the answers they selected to Question 6. The survey then asked them to consider, if they lost those characteristics because of dementia and a surrogate decisionmaker had to make decisions on their behalf, whether that decisionmaker should (1) make the decision the respondent would have wanted, if healthy; (2) make their own evaluation of the best decision based on the respondent’s health or finances; or (3) be allowed to consider their own interests or well-being in making the decision. The results are presented in Table 3. 63% of respondents indicated that they would want another person deciding for them to make the decision they would have made when healthy, 33% that they would want the decisionmaker to make an independent judgment of best interests, and 4% that the decisionmaker should be allowed to consider their own interests.

Qualitative Results

The survey involved two open-ended questions, one which asked participants to

explain why they selected the answers they did in response to Question 6, and another that asked them to explain their choice on Question 7. Further qualitative data was gathered in the interviews, which involved subjects discussing a series of open-ended questions, similar in purpose to the survey questions, in a conversational way.

Analysis of the qualitative data—both from survey responses and interview data—revealed several consistent themes that help interpret the quantitative results in understanding the perspectives of seniors on when the law should intervene in decisionmaking as dementia develops.

Difficulty of Concrete Answers to Questions

The first general theme was an expression of frustration with the difficulty of the questions. One interview subject described the question of when the law should intervene in his decisionmaking as he developed dementia as “the crux,” and “the really hard question,” another acknowledged that “it’s hard to define how in legal terms this would work,” and another that it was “a very hard question to answer.” This theme emerged in the survey responses as well, where respondents often wrote about how hard they found the questions. One wrote “[e]ven though I have worked in geriatric nursing, and had relationships and empathy for the elderly most of my life, I find this hard to discern.” Another survey respondent simply wrote that it was “difficult deciding” how to answer the question.

For some participants, it was clear that some of the difficulty in answering the questions came from challenges associated with the way the dementia manifests, such as “it’s kind of hard to say, because as you go through this process, I imagine you’re not really aware that this is what’s happening,” or “I don’t

think there's a way to know ahead of time, and I don't know how I could judge [it] subjectively." Others regarded the questions as hard in part because of their own lack of knowledge about the disease; "it's hard to forecast something you don't know too much about."

Reliance on Professionals

Many qualitative responses relied on the opinions of professionals regarding when intervention in their decisionmaking would be appropriate. For example, one interview subject said that she hoped her family would help "if they can" but that "[i]t may take more professional help than that," because "training is probably pretty important." For this particular interview subject, bringing in a professional was also important because professionals had "less emotional involvement" and could be more objective. Another interview subject stated that she thought she should "follow someone's directions to get a professional opinion of whether I'm sane enough" and that she would defer to that decision.

The theme of reliance on professional guidance was found in the survey responses as well. One respondent, for example, stated that she "would want a trusted professional (lawyer, financial advisor, etc.) to guide my decision." Another survey respondent similarly wanted his caretakers to "consult with health professionals . . . as well as those dealing with finances"

On the other hand, some participants were deeply distrusting of professional assistance. For example, one interview subject expressed that she was "going to give my money away while I'm alive" out of fear that a "crooked" doctor would misdiagnose her and the "government" would end up taking the money. Another described "professional . . . elderly guardian[s]" as "terrible."

Personal Identity

Many respondents described the point at which they would no longer want to be permitted to make their own decisions as the point at which they were no longer “themselves” or “the same person.” For example, one survey respondent explained her selection of change in personality in response to Question 6 by saying that “if [my personality] changed drastically then I would no longer be the person I had always been and would want someone else to make decisions for me based on how the person I was [would have],” and another reflected this idea by stating that “[i]f my personality or moral values changed suddenly, it could mean that I am not myself and should not be trusted with a will.”

There was a range of clarity with which this idea was expressed in the survey responses. Some responses directly and parsimoniously pinpointed personal identity as the dispositive variable for them, such as “[i]n essence, I would be dead and reborn,” “[w]ithout these abilities I would not be me,” or “I would be becoming someone who is not me anymore.” Other respondents, however, seemed to express this same idea in more oblique language, such as the concern of one that he “want[s] to be as much like myself as I possibly can,” another’s sense that the choices she had selected “go[] to the fabric of who a person is,” such that when they are lost “the basic person is changed” or a fear that “the person I was becoming . . . [might] make decisions which would undo the good choices I made as a rational person.”

Many interview subjects also honed in on their sense of personal identity when thinking about when intervention would be appropriate. One interview subject, for example, stated that he would want others to intervene when “I’m not being who I am,” and another said that “if [a proposed decision] 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." As with survey respondents, some interview subjects alluded to this concern in a somewhat more oblique way, such as by expressing a sense that "as much as possible I would want to be treated as the authentic person . . . that I was," or that "I am who I am" such that changes would be "scary." Similarly, an interview subject expressed the view that changes to the things that constitute a person's identity "matter[] not in . . . concrete kinds of [ways]," but that "it matters in terms of who you are, who I am . . . is the person still there."

Abuse

A concern that surfaced consistently in survey responses and interviews was a fear of abuse and the need for a legal regime equipped to prevent it. For example, respondents were worried about "becoming a victim that would be abused by unscrupulous entities," with "people creating their own piggy bank for themselves," or the respondent's "be[ing] manipulated by someone who . . . didn't have good intentions." Many saw this risk as tied to decline in cognitive function, seeing intervention as appropriate where, for example, "I can no longer make a judgment on the character of the people attempting to assist me," and observing that "[i]f I can no longer remember my family and the important events of my life, I may also be persuaded to do something I really would not want to do." Indeed, many respondents related personal anecdotes in which friends or family members had been taken advantage of. For one survey respondent, it was a father-in-law who was "persuaded to change [his] will from what he and his deceased wife had always wanted to something else entirely," an interview subject who "worried at one

point about having to have my aunt declared incompetent,” and another whose father-in-law “had a . . . friend [who] had the will put in his name and everything that my daughter and her cousin should have gotten went to his grandson.”

Some participants spoke of abuse particularly strongly. One interview participant, for example, related an anecdote she was aware of where a judge appointed his wife as a professional guardian, and the participant “didn’t know how many millions of dollars she took from people.” The participant tied this story to her broader concerns with the elder law system:

[T]hey did a terrible job on these people. They took all their money away from them and they ended up in some kind of a recluse, secluded nursing home that nobody gave a damn about them. . . . I mean, people work their asses off to make, to get this money, so they could be, have it when they needed it. Or they could give it to their children or do something with it. And there’s nothing left after people get through with them. . . . Lawyers are terrible.

Indeed, many participants expressed skepticism that the legal system was currently sufficient to protect them against abuse. For example, one interview subject saw the estate system as “[c]rooked.” She related a story in which her sister “made a plan” with a “financial planner,” but failed to properly execute the estate plan, “[a]nd so the government made \$420,000 on her excess taxes.” Similarly, some respondents felt that “[i]f the government was involved” in their decisionmaking, “it probably wouldn’t be interested in anything I may have wanted but only what would be in the government’s best interests.”

Trust of Family Members

Although many respondents expressed a fear of abuse and a distrust of the legal system’s ability to prevent it, few saw that threat as arising from their family members. Indeed, a common theme among participants was a sense of trust in

family members. One way this manifested itself, particularly in the interviews, was that while many participants struggled to define the line past which they would want decisionmaking discretion taken away from them, they expressed faith in the ability of their family members to do so intuitively. For example, one interview subject related that “[w]hen my mother-in-law . . . began to have cognitive issues, and then marked cognitive issues, I would say to my daughters who were then teenagers ‘please tell me if, if I have stains on my clothes, if my rouge is in circles,’ . . . and one of the daughters said ‘but mother, we already do.’ So that’s how it is.” Another interview subject reported that he spoke to his younger brothers every night on the phone, and expressed that “if I was starting to go south . . . I’m sure other people would, around me, but especially my younger brothers would know, [things that] I wouldn’t want to do, get married and spend money I would depend on my brothers to bring that to my attention.” Similar themes arose in the survey responses, such as “I trust my family to do what is right;” “[m]y family would know what I would have wanted, even if it sounds odd to most people;” and “[m]y family is in[]tune with me.”

Another way in which trust in family members manifested was a confidence that family members, unlike others, would not be tempted to enrich themselves at the expense of the interests of the participant. For example, one interview respondent said that “[k]nowing my children, I know they wouldn’t be wanting to be sure that I left all the money to them . . . [I]f it were my children I would trust them,” and another had every confidence that her sister “would make [decisions] based on what she thinks my best interests are.”

Indeed, many respondents explicitly distinguished between family members intervening in their decisionmaking, which they considered acceptable, and the

government intervening, which they did not. For example, one survey respondent wrote “I would not want the law or government to intervene of any decisions to be made,” but that he wanted “[o]nly personal family to decide,” and another wrote that “[o]nly family should make those decision[s] based on what the[y] think I would want, the government’s only role should be to protect against greed exhibited by individuals.” Interview participants also distinguished between direct intervention by the government, which they tended not to trust, and their family’s use of state-backed devices such as powers of attorney:

Participant: I think in general I’d like to keep the state out of all of that. I really think those are really

Interviewer: I mean . . . the state backs up powers of attorney. . . . They’re a . . . legal contraption.

Participant: Right, and we believe in legal contraptions to set up the framework for our care.

Finally, several participants expressed concern for those who, unlike themselves, might not have family to rely on. One participant acknowledged that “within my own experiences it’s just been a matter of watching families,” and recalled a “guy with no family” bringing “a perspective to me that I had never considered,” specifically, that “an attorney . . . would step in and make those kinds of decisions for him.”

Fear of Dementia

A final theme that arose, particularly in the interviews, was a widely felt fear of dementia. One interview subject described “not knowing my grandchildren or my children” as “probably [her] biggest fear.” In a similar vein, a survey respondent stated that “[n]ot recognizing friends and family is one of the cruelest things your

brain could do to you” and that when her mother “didn’t recognize her children” anymore “[s]he lived in constant fear,” while another respondent “fear[ed] [she] would be worthless” if she lost memory of her family. An interview subject said that changes to her personal identity, understood as the way she generally behaved, “would be scary.” One interview subject described the potential loss of some specific long term memories in stark terms:

I think if I, I helped care for my mother and my father, and I think if I forgot that whole six-year stint, where I was very much involved, that would be really a huge red light. I mean, and scary. And I think that would be a very important thing to lose. And I think that would be, that kind of thing, would be more frightening than the short term [memory loss], because, OK, maybe I would forget to take a pill one day or something, but to lose my knowledge of Alzheimer’s, my knowledge of care, my knowledge of that kind of interaction, would be really devastating.

Many study participants emphatically hoped dementia would never happen to them. One interview subject “hope[d] [dementia] would never happen” but admitted that she “do[es] worry about it.” Another was “worr[ied] . . . about what the questions you’re asking me” because if he developed dementia he “hope[d] [he] can still see that” something was wrong.

Finally, some interview subjects spoke of dementia with a kind of reverence. One described feeling “such a sense of sadness” at seeing a family member with stains on his sweater because of dementia, and another reflected on “how many famous dramas, including Greek tragedies, deal with some of these issues, of what they called madness vs. reputation.”

Discussion

The results of this study demonstrate several things pertinent to ongoing debates on reforming the law’s understanding of capacity. Three conclusions are worth

discussing. First, although the quantitative results are heterogeneous and support a general regime of private ordering, they suggest widespread agreement on: (1) continuing current efforts to shift from a “surrogate decisionmaking” model to one of “supported decisionmaking;” (2) a shift to a regime that offers people with dementia more freedom to make more “personal” decisions on their own for longer as compared to less personal decisions; and (3) a shift to an understanding of capacity as based on features such as long term memory and relationships rather than cognitive abilities or values. Second, the qualitative results reveal tension between participants’ fear of abuse and their trust of family members to decide when intervention is appropriate. Third, the results show tension between reliance on medical assessments of capacity and participants’ own understanding of the problem through the philosophical construct of personal identity.

Quantitative Results

On their face, the quantitative results do not show clear consensus answers to any of the questions. The answer selected by the most participants to any question was a comfortable majority of respondents indicating that they would want the right to change their will removed after they could no longer recognize their family and friends (64.4%). It is difficult to interpret the meaning of the 35.6% of respondents who did not select this response, because it was one of several in a question that asked respondents to select as many as they felt appropriate. The only other answer to Question 6 selected by a majority of respondents was long term memory (59.7%). Another clear majority of respondents (63%) wanted surrogate decisionmakers to make the decision they would have made under the circumstances, but 33% of respondents expressed a preference for surrogate

decisionmakers making their own determination of best interests. Answers to the questions about how respondents would want to make different decisions as they developed dementia were even more heterogeneous. Support for continuing to make the decision on one's own varied from 8%-22% depending on the decision, making the decision with the help of friends and family from 38%-60%, delegating the decision to a surrogate decisionmaker from 8%-15%, and not being permitted to make the decision any more at all from 11%-37%.

Therefore, this study reveals no easy and uncontroversial bright-line reforms that could be made to the legal doctrine to better tie it to the widespread perspectives of seniors. In the diversity of opinions the survey reveals, it suggests that legal reforms in this area based on the preferences of a majority would have to be made over substantial and determinate dissent—at least where such reforms would seek to impose legal rules on the kinds of narrow issues investigated by the quantitative questions in this survey. Rather, the results of this study support the focus of the current elder law regime on private ordering and legal flexibility to enforce individual preferences and suggest that efforts to reform the doctrine should retain room for individual choice (Sitkoff & Dukeminier 2017). While the data suggest adopting legal presumptions based on the general views of seniors may be appropriate in some instances, individuals should be permitted to opt out of them on the front end.

Analysis of the range of answers to the first five questions, asking how respondents would want to make particular decisions as they developed dementia, yields interesting conclusions. One is that there is a lack of support for the model of surrogate decisionmaking, under which an individual is appointed to make decisions on behalf of the person with dementia. This model guides the doctrine of

capacity in most of the United States (Jorgensen 2008), but only 8%-15% of respondents selected this answer depending on the decision at issue. Indeed, for each of the decisions, more respondents wanted not to be able to make the decision at all than would be comfortable delegating it. In contrast, deciding together with friends and family commanded a plurality of respondents for every decision, and majorities for making a major purchase (60%) and choosing end-of-life care (53%). Thus, the survey suggests that at least a plurality of seniors favor the “supported decisionmaking” model, under which family members and the person with dementia work together to make decisions (Diller 2016). This model has recently been adopted by some jurisdictions, including at least five U.S. states and the District of Columbia, and has been influential in legal reforms in the United Kingdom (Wright 2020) (Diller 2016) (Series 2014).

Respondents apparently valued personal discretion most with respect to choosing end-of-life care (22%) and getting married or divorced (16%), while they were least wedded to making decisions on their own in making major purchases (10%) and making large donations (8%). On the other hand, 37% of respondents wanted to be legally prevented from making a large donation at all if they developed dementia and 33% would want to be prevented from getting married or divorced, but only 11% wanted the right to make a major purchase categorically stripped from them. These variations would appear to be best explained by considering the extent to which the decision at issue is “personal,” i.e., choosing end-of-life care and getting married or divorced are more “personal” than deciding to make a large donation. In this sense, more personal decisions are those more intimately related to values and family relationships, rather than the commercial sphere. Thus, the data suggest that doctrine’s current requirement of greater

cognitive capacity for more *complex* decisions (Jorgensen 2008), rather than more *personal* decisions, is out of step with the way seniors understand the issue.

Finally, the responses to Question 6 suggest that the features most widely considered important in order for decision to be entitled to respect are the ability to recognize family and friends (64.4%) and long term memory (59.7%). In contrast, fewer respondents selected responses concerned with narrow cognitive functioning such as short term memory (27.5%), mathematical abilities (17.4%) and the ability to think at a certain speed (5.1%). This suggests that the law's current focus on cognitive abilities (Jorgensen 2008) may be misplaced. Similarly unpopular were responses associated with values, such as personality (14.0%), moral values (23.7%), or religious views (9.7%). Thus, this study may also suggest that the focus on values in the person-centered dementia care movement (Kitwood 1997) may also not correspond to the general understandings of seniors. Rather, a normative theory based in long term memories, friendships and family relationships would be more likely to garner support among seniors.

In sum, the quantitative results of the survey would support adopting three new presumptions in the applicable legal framework: (1) a background principle of "supported decisionmaking" rather than "surrogate decisionmaking;" (2) a presumption requiring a greater showing of incapacity to prevent a person from making a more "personal" decision such as choosing end-of-life care or getting married or divorced; and (3) a re-conceptualization of the concept of incapacity around features such as long term memory and personal relationships rather than cognitive functions or values.

Misunderstanding of Abuse

Of particular note for legal and medical professionals working with seniors and those in the early stages of dementia, the results revealed that while participants were aware of and concerned about the possibility of elder abuse, they misunderstood its most common sources and methods to prevent it. It is generally acknowledged that most elder abuse, at least outside the institutional setting, is committed by family members (Kohn 2020), but a persistent theme of the qualitative data was the trust participants had in their family members. Indeed, it is possible that the prevalence of elder abuse committed by family members is *enabled* by the trust seniors often have in them.

This finding is not surprising: it makes sense that while seniors are generally aware of horror stories of abuse and exploitation, most people love and trust their family members. Of course, this love and trust is valuable and should not be discouraged, among other reasons because lonelier seniors are more at risk for abuse (Hafemeister 2003). But practitioners in this field should take steps to ensure that the seniors they work with are aware of the possibility of abuse by their family members and, to the extent possible, ensure that less partial non-relative professionals such as lawyers, healthcare workers, and financial advisors remain in contact with all parties, subject to oversight by the senior and family members.

Similarly, many respondents expressed confidence in their family members, not only to make decisions for them, but to know when intervention in their decisionmaking would be appropriate. Given the heterogeneity of the specific points at which survey respondents would find intervention appropriate, trusted family members should certainly have a role in ensuring the process of surrogate decisionmaking is appropriately tailored to the individual with dementia. However,

the legal system must offer determinate guidance for family members making intervention decisions and ensure appropriate safeguards to prevent abuse because the widespread faith seniors have in their family members leaves them vulnerable to exploitation from that quarter.

Professional Determinations and Normative Theories

Finally, and perhaps most challenging from the perspective of designing a determinate legal or ethical regime, the results reveal a tension between the confidence participants hoped to have in medical, familial or legal resolution of the question of when intervention is appropriate and their own resort to philosophical constructs such as personal identity in explaining what mattered most to them. Many respondents expressed the hope that it would be their doctors, based on objective medical knowledge, their lawyers, based on knowledge of the applicable legal doctrine, or their family members, based on longstanding personal relationships, who would decide—and tell them—when their dementia had progressed far enough that they would not be permitted to make a particular decision. But each of these alternatives is plainly inadequate on its own as a normative guide.

Medical professionals cannot determine when decisionmaking is no longer possible based solely on objective scientific evidence. Rather, they can only use objective medical evidence to determine whether what normatively matters for decisionmaking is still present in a particular person with dementia, which requires an underlying normative theory about what matters to decisionmaking (Grey 2018). Similarly, while lawyers can advise clients whether their current mental state is likely to be found sufficient to make a particular decision under the legal doctrine,

doing so does not bear on whether the legal doctrine is normatively right. Finally, without a normative theory guiding when intervention is appropriate, reliance on family members is likely to result in abuse and family tensions.

Thus, participants' purported reliance on medical advice or family members in deciding when intervention would be appropriate is likely a result of the first theme in the qualitative results discussed above—participants found the underlying normative questions hard and reliance on others for answers a relatively straightforward solution. This resort will not do, however, for the purposes of this study, which sought to understand the perspectives of seniors on the challenging normative question itself. And elsewhere, the results of this study offer insight on seniors' thoughts on that normative question. Specifically, the qualitative responses suggest that the philosophical construct of personal identity was the way in which participants were thinking about the question: that is, participants wanted to be permitted to make decisions so long as they felt that those decisions were made by "themselves," and found intervention to be appropriate when dementia caused them to no longer be "themselves."

Personal identity is not something that can be directly measured by medicine. It is a philosophical construct that, while having physical manifestations and correlatives, is not the sort of thing we have the objective capability to measure. This, then, is a profound tension in the qualitative data of this study: participants wanted medicine to find something—the disruption of their personal identity—that it simply is not qualified to do. Reliance on family members to determine when intervention is appropriate fares better in this regard, but faces challenges of its own. Specifically, there are different theories of personal identity, and it is not obvious how family members should go about picking one. Moreover,

even assuming that family members' intuitions are likely to be broadly reliable when it comes to determining whether a person with dementia is the same person that they used to be, family members' personal interest may lead them to make self-interested determinations without realizing it when relying on their un-articulable intuitions.

Rather, an understanding of capacity that reflects the ways in which seniors think about intervention in their decisionmaking requires an exogenous normative theory of personal identity consistent with their understanding of the construct. Such a theory will need to be intelligible and explicable in order to guide family members in determining when intervention is appropriate and give medical professionals a sense of the degree of dementia required for a disruption of identity. Similarly, the legal doctrine would have to clarify that it is a disruption of personal identity, not a deterioration of the person's mental computational power (although these things are likely to happen together in practice) that triggers a finding of incapacity and a legally-enforceable intervention in decisionmaking.

Limitations

Because of the small sample-size of both the survey and interview data, the extent to which these results can be generalized to the American population is unclear.

Moreover, although a wide-range of perspectives was represented in the data, the participant population differed in important ways from the general population.

Perhaps most significantly, it appears that both the survey and interview populations were substantially less religious than the senior population of the United States as a whole. Because religious commitment and affiliation may play an important role in people's thinking about aging, identity, dementia and death

(Hulko & Stern 2009) this deviation in particular could implicate the generalizability of the data.

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[not included in draft to avoid identifying institution]

Declaration of Interest Statement

The authors report no conflict of interest.

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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=235²

Question	Answer	Number responses	of Percent responses	Approximate percent American 65+ population ³
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% ⁴
	\$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%
What is your gender?	Male	75	31.9%	44.4% ⁵
	Female	160	68.1%	55.6%
What is your marital status?	Married (first marriage)	76	32.3%	71.6% ⁶
	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%
Do you have children?	Yes	174	74%	80% ⁷

² 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.

³ 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.

⁴ 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_1.xls.

⁵ 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/>.

⁶ 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>.

⁷ 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%)”).

Do you consider yourself religious?	No	61	26%	20%
	Religious	85	36.2%	65% ⁸
	Somewhat religious	72	30.6%	20%
	Not religious	78	33.2%	16%
What religion do you associate yourself with?	Agnostic	18	7.7%	2% ⁹
	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%
	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%
Weak Democrat		19	8.1%	
Independent Democrat		35	14.9%	
Independent Independent		30	12.8%	37%
Independent Republican		25	10.6%	31%

⁸ 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/>.

⁹ 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/>.

¹⁰ 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.	Weak Republican	30	12.8%	
	Strong Republican	31	13.2%	
	Apolitical	7	3.0%	
	Alabama	11	4.7%	1.48% ¹¹
	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	23.0%	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%
	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%
	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%
What is the highest level of education you have				

¹¹ 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>.

completed?	Some high school	2	0.9%	7.3% ¹²
	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%
How would you describe yourself?	American Indian or Alaska Native	4	1.7%	0.5% ¹³
	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% ¹⁴
	No	232	98.7%	92%
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

¹² 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>.

¹³ 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>.

¹⁴ 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>.

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?

- Preprint not peer reviewed
- 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?

Table 1. n=236. Percentages rounded to the nearest whole number (number of respondents).

If you were to develop dementia, how would you want to make the decision to:	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 that decision.	Other
Change your will?	14% (32)	44% (103)	14% (33)	22% (53)	6% (15)
Get married or divorced?	16% (38)	39% (92)	8% (18)	33% (78)	4% (10)
Make a major purchase?	10% (23)	60% (142)	16% (37)	11% (27)	3% (7)
Donate a large amount of money?	8% (18)	38% (90)	11% (26)	37% (88)	6% (14)
Choose end-of-life care?	22% (53)	53% (125)	15% (35)	NA	10% (23)

Table 2. n=236. Percentages rounded to the nearest tenth (number of respondents).

If you lost any of the following personal characteristics or mental abilities, would you want the law to intervene before permitting you to change your will on your own?	Selected by:
Short term memory	27.5% (65)
Long term memory	59.7% (141)
Certain specific long term memories	41.9% (99)
Mathematical abilities	17.4% (41)
Ability to recognize people in general	47.0% (111)
Ability to recognize family and friends	64.4% (152)
Ability to make connections between different ideas	42.8% (101)
Ability to think at a certain speed	5.1% (12)
Personality	14.0% (33)
Moral values	23.7% (56)
Religious views	16.1% (38)
Political views	9.7% (23)
Interest or hobbies	4.2% (10)
Other	0% (0)
None of the above	22.9% (55)

Table 3. n=236. Percentages rounded to the nearest whole number (number of respondents).

If others had to make decisions for you, should they:	
Make the decision you would have wanted when you were healthy	63% (148)
Make the decision based on what they think is best for you in terms of your health or finances	33% (79)
Be allowed to consider their own interest or well-being in making the decision	4% (9)