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## Do older adults with Alzheimer's disease engage in estate planning and advance care planning preparation?

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### Abstract

**Objectives:** This study investigated the estate planning and advance care planning (ACP) of older adults diagnosed with Alzheimer's disease (AD) for the presence of (1) a valid will, (2) a durable power of attorney for health care, and (3) a living will.

**Method:** We analyzed 10,273 adults aged 65 and older from the 2012 Health and Retirement Study (HRS) using multilevel logistic regression.

**Results:** We found that a diagnosis of AD was significantly associated with the ACP variables. Older adults with AD were more likely to assign a durable power of attorney for health care and have a written living will than older adults without an AD diagnosis. However, we found no significant association between a diagnosis of AD and having a valid will. These findings were robust when adjusting for demographic and socioeconomic variables. Other factors decreased engagement in estate planning and ACP, including lower socioeconomic status, being male, and being a minority.

**Conclusion:** Our findings suggest that a diagnosis of AD is associated with more engagement in ACP for individuals and their families, but important barriers exist for people with fewer resources.

### Keywords

Alzheimer's disease; estate planning; advance care planning (ACP)

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Disclosure of interest

The authors report no conflicts of interest.

## Introduction

Alzheimer's disease (AD) presents many challenges for the affected person, family members, and caregivers. AD is the fifth-leading cause of death in the United States for people aged 65 and older and currently affects more than five million people (Alzheimer's Association, 2016a; Kirova, Bays, & Lagalwar, 2015). Because of the inevitable outcome of people with AD, estate planning and advance care planning (hereafter referred to as "ACP") are critical and necessary steps to face for patients and their families. Estate planning and ACP include legal decisions, health care decisions, and financial arrangements to help people diagnosed with AD and their families confront tough questions and prepare for the legal and financial consequences of AD (National Institutes of Health, 2008; Timmermann, 2016). However, after a diagnosis of AD, estate planning and ACP frequently are pushed aside because of the stress and dread associated with the end outcome of the disease (Alzheimer's Association, 2016b).

The present study investigated the extent that older adults diagnosed with AD engage in adequate estate planning and ACP and the factors associated with future planning. Essential parts of any future planning include estate planning (i.e., valid will) and ACP (i.e., durable power of attorney for health care and living will). A will serves as the voice of the testator (will-maker) and eliminates many problems that can arise from dying intestate. An individual with AD should have a signed will in place as soon as possible, while he or she is still of sound mind to make decisions. A will is a legal document that identifies whom a person with AD has chosen as executor, the person who will manage the estate, and beneficiaries, the people who will receive the assets in the estate, and is valid when it is written and witnessed.

A durable power of attorney for health care and a written living will are also critical legal documents (Silveira, Kim, & Langa, 2010). These documents serve to state one's intent regarding who can make health care decisions for the person and to state one's views on the care or medical treatment if the person were to become incapacitated and unable to make those decisions. Managing the issues ahead of time can make a substantial difference in how people are cared for and makes it easier for families of those with AD when carrying out estate planning and ACP (Timmermann, 2015). Towards these goals, in 1990, the federal government passed the Patient Self-Determination Act (PSDA) that guarantees individuals the right to make health care decisions and to indicate preferences regarding life-sustaining treatments. The PSDA requires any health care facility receiving federal funding to inform patients about advance directives—a living will and a durable power of attorney. A living will is not a will at all, but rather a legal document expressing an individual's last wishes regarding sustainment of life under specific circumstances. A living will can be used to explain as much or as little as a person wishes about the kind of health care that the person wants to receive (Dalton & Langdon, 2016). Unlike the living will, a durable power of attorney for health care puts health care decision making in the hands of a third person on his or her behalf when he or she is incapable of doing so (Brohoff, 2009; Calio, 2017; Dalton & Langdon, 2016; Dukoff & Sunderland, 1997; Hirschman, Kapo, & Karlawish, 2008). A durable power of attorney for health care may be revoked at any time and in any

manner by which the principal is able to communicate the intent to revoke, without regard to mental or physical condition.

Although people in early stages of AD can sometimes manage estate planning, research suggests that the ability to manage finances can be one of the earliest signs of cognitive impairment. Impairments in dealing with complex financial tasks such as managing one's bank statement and paying bills occurs in the prodromal stage of AD known as Mild Cognitive Impairment (Widera, Steenpass, Marson, & Sudore, 2011). After an official AD diagnosis, dealing with even basic finances like counting currency can become difficult (Marson et al., 2000; Martin et al., 2008). Because of these early and severe deficits in financial capacity, making an estate plan is encouraged at the earliest onset of the disease, or even before any known manifestation of the disease (e.g., Brodoff, 2009; Carr, 2012). Despite these recommendations, only about one half of older adults in the United States make adequate financial preparations (Goetting & Martin, 2001).

One barrier in engaging in the necessary estate planning and ACP preparations includes disagreements between the caregiver and the AD patient. One study found that only 18% of caregivers and AD patients agreed that they needed additional information and services regarding legal and financial planning (Edelman, Kuhn, Fulton, & Kyrouac, 2006). In contrast, 63% of caregivers expressed interest in these types of services, but this sentiment was in disagreement with the patient. These disagreements could stem from the patient being in denial of the disease, an increase in aggression or hostility because of the disease, or a sense that plans can always be made later (e.g., Hirschman et al., 2008; Okonkwo et al., 2008). Each of these factors leads to an avoidance in dealing with estate planning and ACP.

In addition to the above barriers, families sometimes passively avoid financial or health planning discussions. For instance, across 30 families that included a person with AD, over half simply did not think of having a discussion of financial planning with the AD patient (Hirschman et al., 2008). At other times, families avoided the discussions because they felt it was too late. Over 60% of families indicated that their family member with AD had cognitively declined to a point where they could no longer competently reason about their finances.

Considering the low level of estate planning overall and the additional barriers faced with families of AD, how well-prepared are older adults with AD to face these financial difficulties? Few studies have investigated this question. In Hirschman et al. (2008), 22 of 30 families reported that the AD family member had a valid will and 25 of the 30 families also reported that they had a power of attorney for financial affairs. While these numbers suggest a promising amount of financial preparedness, this sample was small and consisted of relatively well-educated and White families, which is not representative of the United States. Furthermore, there are certain factors that may increase the risk of developing AD, such as an older age, being female, having lower education, and previous health issues (e.g., Demakis, 2007; Lipnicki et al., 2013). Might some of these factors also impact estate planning when diagnosed with AD?

The current study used data from the Health and Retirement Study (HRS)—a representative and national sample of individuals—to investigate whether people diagnosed with AD engage in adequate estate planning and ACP including having a valid will, assigning a durable power of attorney for health care, and having a living will. Specifically, our first research question addressed the following question:

Research question 1: Is a diagnosis of AD associated with engaging in estate planning and ACP?

On the one hand, receiving a diagnosis of AD might encourage a reactionary response by starting conversations regarding estate planning and ACP needs. Given the generally low rate of estate planning and ACP, this perspective would predict a diagnosis of AD to be associated with greater estate planning and ACP preparation. On the other hand, some have suggested that the stress and dread associated with the end outcome of the disease lead to an avoidance of the topic altogether. This perspective would predict that an AD diagnosis would be associated with poorer estate planning and ACP preparation.

We also predicted that different types of estate planning and ACP would have different barriers associated with them. A major barrier to the completion of a living will is that a living will connotes personal death (Vandecreek & Frankowski, 1996). Those with anxiety and fear about death are less likely to have completed living wills (Golden, Corvea, Dang, Llorente, & Silverman, 2009). Furthermore, a durable power of attorney for health care requires more elaborate discussions with family members, and thus might be less likely to be obtained than a living will. In addition to ACP (i.e., durable power of attorney for health care and living will), estate planning (i.e., valid will) might be associated with a diagnosis of AD. In reality, both people with AD and their family tend to think that they are not able to create a will or amend an existing will because of legal capacity, and thus they might be less likely to have a valid will. However, it is important to note that if a diagnosis of AD is made in the early stages of the disease, someone with AD often is still capable of making a will or amending an existing will with help (Pfeiffer, 2011).

Furthermore, we investigated the extent to which demographic and socioeconomic factors might explain any relationships found between those diagnosed with AD and estate planning and ACP by comparing unadjusted models and models adjusted for factors previously identified to impact estate planning and ACP. Thus, our second research question addressed the following question:

Research question 2: What demographic and socioeconomic factors might explain the association between a diagnosis of AD and estate planning and ACP?

The results of this investigation might provide useful insights on estate planning and ACP for older adults, caregivers, policymakers, and communities.

## Methods

### Data and sample

The current study used data drawn from the 2012 HRS, consisting of residents within the United States. The HRS is sponsored by the National Institute of Aging and is conducted by

the Institute for Social Research at the University of Michigan. The survey was established to provide a national resource for data on the changing health and economic circumstances associated with aging at both individual and population levels, thus making it a valuable resource for investigating estate planning and ACP in older adults (Sonnega, Faul, Ofstedal, Langa, Phillips, & Weir, 2014). We focused on older adults aged 65 years and older because late onset AD is most likely to be diagnosed after this age (Alzheimer's Association, 2016a).

*Inclusion and exclusion criteria.* To investigate the estate planning and ACP among older adults, of a total of 20,554 respondents, we excluded 9,803 participants under 65 years old, so the potential sample for the present study was reduced to 10,751 (i.e., 65 years and older). An additional 478 respondents did not have complete data for one or more key variables (0.1% of the sample had missing data for a diagnosis of AD; valid will, 1.1%; durable power of attorney for health care, 1.5%; living will, 1.6%). The final analytic sample with complete data consisted of 10,273 respondents.

## Measures

**Dependent variables.**—We used one dependent variable of estate planning and two dependent variables of ACP. Each dependent variable was dichotomously-coded (1 for yes; 0 for no). The single estate planning behavior included: (1) Do you currently have a *will* that is written and witnessed? (1 = yes, 0 = no). The ACP behaviors included: (1) Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you cannot make those decisions yourself? This is sometimes called a *durable power of attorney for health care* (1 = yes, 0 = no), and (2) Have you provided written instructions about the care or medical treatment that you want to receive if you cannot make those decisions yourself? This is sometimes called a *living will* (1 = yes, 0 = no).

**Independent variables.**—The primary independent variable was *whether respondents were ever diagnosed with AD*. This item was obtained from the self-reported response to the question: “Has a doctor ever told you that you have Alzheimer’s disease?” Medical doctors include specialists such as Neurologists, Dermatologists, Psychiatrists, Ophthalmologists, Osteopaths, Cardiologists, as well as family doctors, internists and physicians’ assistants. Also included were diagnoses made by nurses and nurse practitioners. While we had no way of directly assessing the reliability and validity of this measure, the HRS questions are designed to minimize misreporting bias in cognitive impairment or dementia measures using self- or proxy-cognition test performance (Delavade, Hurd, Martorell, & Langa, 2013). Furthermore, self-report measures are often used in research across a wide range of health statuses (Stone, Turkan, Bachrach, Jobe, Kurtzman, & Cain, 2000), including Parkinson’s disease (Grosset, Bone, Reid, & Grosset, 2006), subjective memory problems (Amariglio, Townsend, Grodstein, Sperling, & Rentz, 2011), cognitive impairment (Amariglio et al., 2011), cognitive impairment without dementia (Andrews et al., 2017), dementia (Rist, Liu, & Glymour, 2016), and AD (Reisberg & Gauthier, 2008).

Covariates included *demographic and socioeconomic characteristics*. Given that estate planning and ACP are often influenced by a host of demographic and socioeconomic

characteristics (Carr, 2012; Demakis, 2007; Kirova et al., 2015), we also assessed these variables. Demographic information included age, sex, and race/ethnicity. Socioeconomic status included total household income, total household wealth, homeownership, educational attainment, marital status, parental status (i.e., father alive and mother alive), census region, and employment status. Total household income is the sum of all income from the respondent and spouse in each household.

## Analysis

Descriptive statistics were analyzed for all variables including the three binary outcomes and covariates. We reported chi-square tests for categorical variables and *t*-tests for continuous variables to indicate the association between the AD diagnosis and all other variables including the estate planning and ACP variables and covariates. To examine our first research question, we used logistic regression models by having the binary estate planning and ACP variables as outcomes and the AD diagnosis as a primary predictor (the unadjusted model). To examine our second research question, we also included demographic and socioeconomic characteristics simultaneously in the model (the adjusted model).

While the majority of households only included 1 respondent (66.9%), some households included 2 (32.6%) or more respondents (up to 5). Since respondents were nested within the household, we specifically adopted a multilevel logistic regression model to account for the dependency within the nesting structure. The intra-class correlation coefficient (ICC), which is an index showing the degree of correlations among the members in the same household, was first calculated to determine whether the multilevel logistic regression model was required for the current study (Snijders & Bosker, 1999). To preview, calculation of the ICC indicated that a significant amount of variance was shared among household members (see Table 2). To account for this dependency, we used multilevel logistic regression models to conduct our analysis (i.e., household members were nested within the household). All multilevel logistic regression models were analyzed using GENLIN MIXED procedure in IBM SPSS 23 (IBM Corp., Armonk, NY). Given that multiple hypothesis testing was conducted, we employed the Benjamini-Hochberg correction method to control for the increased Type I error rate (Benjamini & Hochberg, 1995).

To proceed with the multilevel logistic regression analysis, we combined very small categories into an “other” category in the adjusted models. For employment status, we combined unemployed, disabled, and “not in labor force” into an “other” category. For marital status, separated, we combined divorced, widowed, and never married into an “other” category. For census region, we excluded the very small “other (0.2%,  $n = 24$ )” category in the adjusted models. Racial and ethnic groups were analyzed by having separate factors for Non-Hispanic White, Non-Hispanic Black/African American, and Hispanic (any race) in the adjusted models. We excluded Non-Hispanic other race (2.1%,  $n = 217$ , i.e., other race included American Indian, Alaskan Native, Asian, Native Hawaiian, and Pacific Islander) in the adjusted models due to the small number of cases.

## Results

### Descriptive statistics

Table 1 presents descriptive statistics for the sample characteristics. The mean age for all respondents in the current study (i.e., those who were 65 years old or above) was 75.99 ( $SD = 7.34$ ) years old and the average years of education was 12.39 ( $SD = 3.22$ ) years. The mean total household income for the sample was \$53,265 with a median of \$33,971. The mean total household wealth for the sample was \$458,947 with a median of \$178,000. The sample included more females (58.1%) than males (41.9%) and most were Non-Hispanic White (75.4%). Regarding marital status, 55.3% were married and 28.6% were widowed. Among the respondents, the location of current residence was South (42.1%), Midwest (24.6%), West (17.9%), and Northeast (15.1%). In terms of employment status, 77.4% were retired, whereas 6.5% reported that they were currently working full time.

Among a total of 10,273 respondents, about 3% of them ( $n = 310$ ) had been diagnosed with AD. Results from independent samples  $t$ -test and chi-square test statistics indicated that individuals diagnosed with AD were older ( $t = 17.729, p < .001$ ), more likely to be female ( $\chi^2 = 8.557, df = 1, p = .003$ ), Non-Hispanic Black/African American or Hispanic any race ( $\chi^2 = 23.196, df = 3, p < .001$ ), widowed ( $\chi^2 = 93.245, df = 4, p < .001$ ), and retired ( $\chi^2 = 60.345, df = 3, p < .001$ ) than those not diagnosed with AD. In terms of parental status, no mother of those with AD was still alive ( $\chi^2 = 16.731, df = 1, p < .001$ ). Individuals with AD also had lower socioeconomic status, as indicated by lower average years of education ( $t = -7.346, p < .001$ ), household income ( $t = -4.472, p < .001$ ), household wealth ( $t = -3.955, p < .001$ ), and the lower incident of having homeownership ( $\chi^2 = 39.146, df = 1, p < .001$ ).

While more than half of the respondents indicated that they had a valid will (62.2%), a little less than half of them said they assigned a durable power of attorney for health care (48.5%) and had a written living will (47.2%).

### Alzheimer's disease, estate planning, and ACP

Table 1 presents the results of the chi-square tests to determine the association between an AD diagnosis and estate planning/ACP variables. We found a statistically significant relationship between an AD diagnosis and: (1) assigning a durable power of attorney for health care ( $\chi^2 = 70.428, df = 1, p < .001$ ) and (2) having a living will ( $\chi^2 = 5.705, df = 1, p = .017$ ). People who had been diagnosed with AD were more likely to have assigned durable power of attorney for health care and documented living will than those who had not. Those diagnosed with AD were numerically less likely to have a valid will than their counterparts, although the relationship between a diagnosis of AD and having a valid will was not statistically significant ( $\chi^2 = 3.097, df = 1, p = .078$ ).

### Alzheimer's disease, estate planning, and ACP after accounting for demographic and socioeconomic characteristics

Table 2 presents the results of the multilevel logistic regression models having each estate planning and ACP variables as outcomes in separate models. First, the *unconditional model* with no predictors and covariates was analyzed to assess the ICC, which represents the

correlation among the members in the same household. As shown in Table 2, all three estate planning and ACP variables had ICC values that were above the conventional criteria ( $>.10$ ; Snijders & Bosker, 1994), which required us to consider the multilevel data structure. The resulting ICC values were reasonable given that family members generally share and discuss their estate planning and ACP needs such as strategies and legal documents (National Institutes of Health, 2008).

Next, the *conditional models*, which included the primary predictor and covariates, were analyzed to examine the relationship of AD with estate planning and ACP variables. We examined the unadjusted effects of AD on estate planning and ACP first, followed by the adjusted effects accounting for demographic and socioeconomic characteristics that could contribute shared variance in the models. To the extent that the effects do not change between the two analyses, it would suggest that these relationships are quite robust and hold across the additional factors included in the model (Delavade et al., 2013).

As shown in Table 2, unadjusted estimates from the results of the multilevel logistic models showed that those who had received a diagnosis of AD were more likely to assign a durable power of attorney for health care ( $OR = 2.811, p < .001$ ) and have a written living will ( $OR = 1.313, p < .05$ ) than those without an AD diagnosis. Although the difference was not statistically significant, those diagnosed with AD were numerically less likely to have a valid will than those without an AD diagnosis ( $OR = 0.818, p = .133$ ).

After including the covariates (e.g., demographic and socioeconomic characteristics), the results remained similar. Specifically, the adjusted estimates showed that respondents who had been diagnosed with AD were 176% ( $OR = 2.755, p < .001$ ) more likely to assign a durable power of attorney for health care than those without an AD diagnosis. Similarly, respondents who had been diagnosed with AD were 39% ( $OR = 1.386, p = .065$ ) more likely to have a written living will than those without an AD diagnosis, although the association was now marginally significant. We continued to find no significant association between AD diagnosis and having a valid will ( $OR = 1.049, p = .812$ ). The robustness of these associations in the adjusted models suggest that having a diagnosis of AD is associated with ACP across many levels of demographics and socioeconomic conditions.

### **Factors associated with the likelihood of preparing for estate planning and ACP regardless of Alzheimer's disease diagnosis**

Replicating previous work, we found that many demographic and socioeconomic factors were associated with greater estate planning and ACP across the majority of our outcome variables regardless of an AD diagnosis (See Table 2). In brief, these include being older, female, Non-Hispanic White, having more income and wealth, having more education, and being retired.

As shown in the bottom of Table 2, 6.6% of variance of valid will is explained by accounting for the diagnosis of AD, demographic, and socioeconomic characteristics. Similarly, 5.7% and 5.8% of variance of having a durable power of attorney for health care and a living will, respectively, are explained by the models.



## Discussion

This research investigated the estate planning and ACP of older adults with AD and their families for the presence of (1) a valid will, (2) a durable power of attorney for health care, and (3) a living will using a large, nationally representative sample of older adults in the United States. Prior research has suggested that the majority of older adults do not have adequate estate planning and ACP. However, it was unclear whether a diagnosis of AD would serve as a barrier or a promoter of these future financial and health care planning behaviors. The findings in the present study show that an AD diagnosis is a significant predictor of older adults' ACP preparation. These results support testimonial evidence that an AD diagnosis is associated with assigning a durable power of attorney for health care and having a written living will. While this correlational evidence limits us from understanding the exact origin of this relationship, the findings are consistent with studies showing that people rely on reactive (i.e., the onset of a diagnosis) rather than proactive (i.e., general future preparation) reasons to engage in ACP (Hirschman et al., 2008). Despite these positive signs, our results indicate that nearly half of older adults diagnosed with AD in the United States do not have a valid will nor a written living will. In addition, about a quarter of older adults have not assigned a durable power of attorney for health care. These statistics suggest that older adults with a diagnosis of AD do not adequately engage in estate planning and ACP to the extent that is recommended (e.g., Brodoff, 2009; Carr, 2012).

Replicating prior work, we also found some factors that served as barriers to adequate estate planning and ACP across many of our outcome measures regardless of an AD diagnosis. Those who were less likely to engage in estate planning and ACP were men, Non-Hispanic Blacks/African Americans, Hispanics, had low incomes, and had low educational attainment. These latter findings suggest that the lack of existing financial resources and lower education are barriers to appropriate estate planning and ACP behaviors. In light of the racial and ethnic differences in estate planning and ACP, educational programs might need to be more culturally sensitive to differences between racial and ethnic groups. Interestingly, full-time workers were nearly 40% less likely to have a valid will, durable power of attorney for health care, and a written living will compared to retirees. We reasoned that full-time working status might hinder estate planning and ACP due to time-constraints. In contrast, retirees might be more likely to have better estate planning and ACP because they have more flexible time management and can devote more time to prepare for future planning.

### Implications and limitations

Overall, this research suggests that older adults in the United States do not adequately engage in estate planning and ACP. While older adults with a diagnosis of AD appear to engage in more planning, this increase is surprisingly low. We hope that these findings might stimulate public discussions regarding estate planning and ACP, especially for families who have someone diagnosed with AD. Furthermore, policymakers can legislatively apply the findings to help raise awareness of the need for sound estate planning and ACP in advance of an AD diagnosis. This information can then be used as the basis for providing guidelines and developing recommended strategies to improve financial and health care services. Such

services might include the implementation of programs and policies to provide the best possible preparation for the person with AD. For example, starting January 1, 2016, Medicare began covering ACP as a separate service provided by physicians and other health professionals. This new legislation on Medicare reimbursement for ACP encourages physicians to facilitate patient choices and to improve the quality of care for older adults (Zeitoun, 2015). However, these policies only apply to ACP. Thus, more policies or programs designed to encourage people with AD to engage in estate planning are still needed. Program evaluators also might apply these findings to assess the impact of interventions aimed at improving estate planning and ACP to help family caregivers of people with AD. Public health practitioners, geriatric social workers, geriatric psychiatrists, geriatric care managers, mental health therapists, church-based health promoters (Medvene et al., 2003; Sloan, Peters, Johnson, Bowie, Yang, & Aslakson, 2016), or elder law attorneys (Brohoff, 2009) might also use the findings to help clients with an AD diagnosis and their families complete estate planning and ACP to give them more control over their health and resources.

Through intense training and planning, estate planners and advisors might use the findings from this study to explain the importance of personalized planning and preparation to specific clients with AD. Advance estate planning can offer a solution to families with an AD diagnosis. Estate planners might apply the findings to help clients decide what is the best strategy in their situation by assigning a durable power of attorney for health care, having a written living will, and preparing for traditional estate planning documents (i.e., a valid will). Having appropriate estate planning and ACP enables one to prepare for changing physical, psychological, emotional, financial, and legal circumstances and are critical for the well-being of people with AD in late life.

Although our study provides interesting insights to the estate planning and ACP of those with and without AD, the findings must be considered within the context of its limitations. The HRS dataset had included information on “memory-related disease” from wave 4 (i.e., in 1998) to wave 9 (i.e., in 2008) and started collecting data on “Alzheimer’s disease” from wave 10 (i.e., in 2010). Future research is needed to determine whether an AD diagnosis is a causal factor leading to an increase in ACP or whether other factors such as a family history of AD could lead to greater ACP even before a diagnosis occurs.

In addition, the analyses of respondent characteristics and outcomes of interest were derived from self-reported data. Self-reported information is often used across a wide range of health statuses (Stone et al., 2000), health care services (Bhandari & Wagner, 2006), and prescription medications (West, Savitz, Koch, Strom, Guess, & Hartzema, 1995). Importantly, these self-reports often correspond well with information from claims data in an elderly population (West et al., 1995; Delavade et al., 2013). However, caution is still warranted in taking these self-reports at face value because some studies have found that the validity of self-reported data on health information can be variable (Stone et al., 2000; Delavade et al., 2013). Future research implementing a comprehensive neuropsychological battery along with estate planning and ACP outcomes might support the present findings.

Future research might build on our model and expand it to provide a more comprehensive explanation of the association between spousal health condition and one's own estate planning and ACP. Further studies might better exploit the couple level (i.e., married or partnered) data. In particular, more research on whether spousal cognitive functioning affects one's own estate planning and ACP might be an influential factor not considered in this study. Lastly, we did not examine whether an AD diagnosis was associated with a power of attorney for financial affairs due to limited data availability. Future research may explore power of attorney for financial affairs as well for further comprehensive investigation on estate planning.

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## References

- Alzheimer's Association. (2016a). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 12(4), 459–509.
- Alzheimer's Association. (2016b). Financial advisors and Alzheimer's disease: What you need to know Retrieved from Alzheimer's Association: <http://www.alz.org/advisors/alz-fy16-pg.pdf>
- Amariglio RE, Townsend MK, Grodstein F, Sperling RA, & Rentz DM (2011). Specific subjective memory complaints in older persons may indicate poor cognitive function. *Journal of the American Geriatrics Society*, 59(9), 1612–1617. [PubMed: 21919893]
- Andrews JS, Desai U, Kirson NY, Enloe CJ, Ristovska L, King S, . . . & Kahle-Wroblewski K (2017). Functional limitations and health care resource utilization for individuals with cognitive impairment without dementia: Findings from a United States population-based survey. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 6, 65–74.
- Benjamini Y, & Hochberg Y (1995). Controlling the false discovery rate: A practical and powerful approach to multiple testing. *Journal of the Royal Statistical Society. Series B (Methodological)*, 57(1), 289–300.
- Bhandari A, & Wagner T (2006). Self-reported utilization of health care services: Improving measurement and accuracy. *Medical Care Research and Review*, 63, 217–235. [PubMed: 16595412]
- Brodoff LE (2009). Planning for Alzheimer's disease with mental health advance directives. *The Elder Law Journal*, 17(2), 239–308.
- Calio CD (2017). Help clients avoid 10 common estate planning mistakes. *Journal of Financial Planning*, 30(3), 26–28.
- Carr D (2012). Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles. *Journal of Aging and Health*, 24(6), 923–947. [PubMed: 22740168]
- Dalton MA, & Langdon TP (2016). *Estate planning* 9<sup>th</sup> ed. St. Rose, LA: Money Education.<sup>th</sup>
- Delavade A, Hurd MD, Martorell P, & Langa KM (2013). Dementia and out-of-pocket spending on health care services. *Alzheimer's & Dementia*, 9, 19–29.
- Demakis GJ (2007). Disability in Alzheimer's disease: Causes, consequences, and economic considerations. *Journal of Health and Human Services Administration*, 30(3), 292–305. [PubMed: 18236705]

- Dukoff R, & Sunderland T (1997). Durable power of attorney and informed consent with Alzheimer's disease patients: A clinical study. *American Journal of Psychiatry*, 154(8), 1070–1075. [PubMed: 9247391]
- Edelman P, Kuhn D, Fulton BR, & Kyrouac GA (2006). Information and service needs of persons with Alzheimer's disease and their family caregivers living in rural communities. *American Journal of Alzheimer's Disease and Other Dementias*, 21(4), 226–233.
- Goetting MA, & Martin P (2001). Characteristics of older adults with written wills. *Journal of Family and Economic Issues*, 22(3), 243–264.
- Golden AG, Corvea MH, Dang S, Llorente M, & Silverman MA (2009). Assessing advance directives in the homebound elderly. *The American Journal of Hospice Palliative Care*, 26(1), 13–17. [PubMed: 18843136]
- Grosset KA, Bone I, Reid JL, & Grosset D (2006). Measuring therapy adherence in Parkinson's disease: A comparison of methods. *Journal of Neurology, Neurosurgery, and Psychiatry*, 77(2), 249–251.
- Hirschman KB, Kapo JM, & Karlawish J (2008). Identifying the factors that facilitate or hinder advance planning by persons with dementia. *Alzheimer Disease and Associated Disorders*, 22(3), 293–298. [PubMed: 18580595]
- Kirova A, Bays RB, & Lagalwar S (2015). Working memory and executive function decline across normal aging, mild cognitive impairment, and Alzheimer's disease. *BioMed Research International*, 2015, 1–9.
- Lipnicki DM, Sachdev PS, Crawford J, Reppermund S, Kochan NA, Trollor JN, . . . Brodaty H (2013). Risk factors for late-life cognitive decline and variation with age and sex in the Sydney Memory and Ageing Study. *PLoS ONE*, 8(6), e65841. [PubMed: 23799051]
- Marson DC, Sawrie SM, Snyder S, McInturff B, Stalvey T, Boothe A, . . . Harrell LE (2000). Assessing financial capacity in patients with Alzheimer disease: A conceptual model and prototype instrument. *Archives of Neurology*, 57(6), 877–884. [PubMed: 10867786]
- Martin R, Griffith HR, Belue K, Harrell LE, Zamrini EY, Anderson B, . . . Marson DC (2008). Declining financial capacity in patients with mild Alzheimer disease: A one-year longitudinal study. *The American Journal of Geriatric Psychiatry*, 16(3), 209–219. [PubMed: 18263665]
- Medvene LJ, Wescott JV, Huckstadt A, Ludlum J, Langel S, Mick K, . . . Base M (2003). Promoting signing of advance directives in faith communities. *Journal of General Internal Medicine*, 18(11), 914–920. [PubMed: 14687277]
- National Institutes of Health. (2008). Legal and financial planning for people with Alzheimer's disease NIH Publication No. 08–6422. Retrieved from National Institutes of Health: [https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/legal\\_and\\_financial\\_planning-final\\_10-14-13.pdf](https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/legal_and_financial_planning-final_10-14-13.pdf)
- Okonkwo OC, Wadley VG, Griffith HR, Belue K, Lanza S, Zamrini EY, . . . Marson DC (2008). Awareness of deficits in financial abilities in patients with mild cognitive impairment: Going beyond self-informant discrepancy. *The American Journal of Geriatric Psychiatry*, 16(8), 650–659. [PubMed: 18669943]
- Pfeiffer E (2011). *The art of caregiving in Alzheimer's disease* Tampa, FL: Lulu Press.
- Reisberg B, & Gauthier S (2008). Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. *International Psychogeriatrics*, 20(1), 1–16. [PubMed: 18072981]
- Rist PM, Liu SY, & Glymour MM (2016). Families and disability onset: Are spousal resources less important for individuals at high risk of dementia? *The American Journal of Geriatric Psychiatry*, 24(7), 585–594. [PubMed: 27066733]
- Silveira MJ, Kim S, & Langa KM (2010). Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine*, 362(16), 1211–1218. [PubMed: 20357283]
- Sloan DH, Peters T, Johnson KS, Bowie JV, Yang T, & Aslakson R (2016). Church-based health promotion focused on advance care planning and end-of-life care at Black Baptist churches: A cross-sectional survey. *Journal of Palliative Medicine*, 19(2), 190–194. [PubMed: 26840855]
- Snijders T, & Bosker RJ (1994). Modeled variance in two-level models. *Sociological Methods & Research*, 22(3), 342–363.

- Snijders T, & Bosker RJ (1999). *Multilevel analysis: An introduction to basic and advanced multilevel modeling*. London, UK: SAGE Publications.
- Sonnega A, Faul JD, Ofstedal MB, Langa KM, Phillips J, & Weir DR (2014). Cohort profile: The Health and Retirement Study (HRS). *International Journal of Epidemiology*, 43(2), 576–585. [PubMed: 24671021]
- Stone AA, Turkkan JS, Bachrach CA, Jobe JB, Kurtzman HS, & Cain VS (2000). *The Science of Self-report: Implications for Research and Practice* Mahwah, NJ: Lawrence Erlbaum.
- Timmermann S (2015). What (besides money) is on our minds when we do estate planning? A gerontological perspective. *Journal of Financial Service Professionals*, 69(1), 33–36.
- Timmermann S (2016). Preparing clients for the possibility of cognitive impairment: The difficult retirement planning discussion. *Journal of Financial Service Professionals*, 70(3), 37–40.
- Vandecreek L, & Frankowski D (1996). Barriers that predict resistance to completing a living will. *Death Studies*, 20(1), 73–82. [PubMed: 10160533]
- West SL, Savitz DA, Koch G, Strom BL, Guess HA, & Hartzema A (1995). Recall accuracy for prescription medications: Self-report compared with database information. *American Journal of Epidemiology*, 142, 1103–1112. [PubMed: 7485055]
- Widera E, Steenpass V, Marson DC, & Sudore R (2011). Finances in the older patient with cognitive impairment: “He didn’t want me to take over.” *JAMA*, 305(7), 698–706. [PubMed: 21325186]
- Zeitoun NK (2015). New Medicare rule will reimburse physicians for advance care planning. *The Hospitalist*, November 2015. Retrieved from The Society of Hospital Medicine: <http://www.the-hospitalist.org/hospitalist/article/122030/health-policy/new-medicare-rule-will-reimburse-physicians-advance-care>

**Table 1.**

Descriptive statistics by AD status: Chi-square and *t*-test results (*N* = 10,273).

Categories	All respondents <i>N</i> = 10,273	Respondents who ever had AD <i>n</i> = 310	Respondents who never had AD <i>n</i> = 9,963	<i>t</i> or $\chi^2(df)$
	M (SD) or %	M (SD) or %	M (SD) or %	
<i>Demographic and socioeconomic characteristics</i>				
Age (years)	75.99 (7.34)	82.86 (6.91)	75.78 (7.25)	<i>t</i> = 17.729 ***
Educational attainment (years)	12.39 (3.22)	11.07 (3.76)	12.43 (3.19)	<i>t</i> = -7.346 ***
Total household income (\$)	53,264.72 (89,166.78) Median=33,971.05	30,980.58 (39,814.73) Median=19,448	53,958.10 (90,183.28) Median=34,428	<i>t</i> = -4.472 ***
Total household wealth (\$)	458,947.01 (1,079,410.97) Median=178,000	220,335.92 (439,946.37) Median=45,200	466,371.42 (1,092,499.13) Median=183,000	<i>t</i> = -3.955 ***
Homeownership	68.7	61.6	79.4	$\chi^2(df) = 39.146(1)$ ***
Sex				$\chi^2(df) = 8.557(1)$ **
Male	41.9	33.9	42.2	
Female	58.1	66.1	57.8	
Race/Ethnicity				$\chi^2(df) = 23.196(3)$ ***
Non-Hispanic White	75.4	66.1	75.6	
Non-Hispanic Black/African American	13.5	20.3	13.3	
Non-Hispanic Other	2.1	0.6	2.2	
Hispanic any race	9.1	12.9	8.9	
Marital status				$\chi^2(df) = 93.245(4)$ ***
Married	55.3	35.5	55.9	
Partnered	3.3	1.6	3.3	
Separated/Divorced	10.2	8.1	10.2	
Widowed	28.6	52.9	27.9	
Never married	2.6	1.9	2.7	
Parental status				
Father alive	1.0	0.3	1.0	$\chi^2(df) = 1.344(1)$
Mother alive	5.1	.	5.2	$\chi^2(df) = 16.731(1)$ ***

Categories	All respondents N = 10,273		Respondents who ever had AD n = 310		Respondents who never had AD n = 9,963		t or $\chi^2(df)$
	M (SD) or %	M (SD) or %	M (SD) or %	M (SD) or %			
Census region							$\chi^2(df) = 1,300(4)$
Northeast	15.1	13.9	15.1	15.1			
Midwest	24.6	25.2	24.6	24.6			
South	42.1	43.5	42.1	42.1			
West	17.9	17.4	17.9	17.9			
Other	0.2	.	0.2	0.2			
Employment status							$\chi^2(df) = 60,345(3)$ ***
Works full-time	6.5	0.3	6.5	6.7			
Works part-time/Partly retired	10.9	0.6	10.9	11.2			
Retired	77.4	92.9	77.4	76.9			
Unemployed, disabled, not in labor force	5.1	6.1	5.1	5.1			
<i>Estate planning and ACP</i>							
Had a valid will	62.2	57.4	62.2	62.3			$\chi^2(df) = 3,097(1)$
Assigned durable power of attorney for health care	48.5	71.9	48.5	47.7			$\chi^2(df) = 70,428(1)$ ***
Had a written living will	47.2	53.9	47.2	47.0			$\chi^2(df) = 5,705(1)$ *

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$ .

† Non-Hispanic Other category included American Indian, Alaskan Native, Asian, Native Hawaiian, and Pacific Islander.

**Table 2.**Multilevel logistic regressions for likelihood of estate planning and ACP ( $N = 10,273$ ).

Model/Variable	Estate planning	ACP	
	Valid will	Durable power of attorney for health care	Living will
<i>Unconditional model</i>			
Intraclass correlation (ICC)	0.24	0.17	0.20
Random effects	1.047	0.685	0.817
<i>Unadjusted effects model</i>			
	Odds ratio	Odds ratio	Odds ratio
Intercept	1.669 ***	0.914 ***	0.879 ***
Ever had Alzheimer's disease	0.818	2.811 ***	1.313 *
<i>Adjusted effects model</i>			
Ever had Alzheimer's disease	1.049	2.755 ***	1.386
Demographic characteristics			
Age	1.079 ***	1.053 ***	1.047 ***
Sex (ref.=Male)			
Female	1.242 ***	1.161 **	1.311 ***
Race/ethnicity <sup>1</sup> (ref.=Non-Hispanic White)			
Non-Hispanic Black/African American	0.222 ***	0.524 ***	0.345 ***
Hispanic any race	0.279 ***	0.468 ***	0.370 ***
Socioeconomic characteristics			
Log of total household income	1.730 ***	1.299 ***	1.379 ***
Log of total household wealth	1.163 ***	1.094 ***	1.112 ***
Homeownership (ref.=non-homeowner)			
Homeowner	2.115 ***	0.916	0.911
Educational attainment (years)	1.143 ***	1.120 ***	1.141 ***
Employment status (ref.=Retired)			
Works full-time	0.640 ***	0.581 ***	0.636 ***
Works part-time/partly retired	0.874	0.918	0.919
Other <sup>2</sup>	0.956	0.881	0.747 *
Marital status (ref.=Other <sup>3</sup> )			
Married/Partnered	0.950	0.725 ***	0.815 **
Parental status (ref.=Father not alive)			
Father alive	1.660	1.139	1.348
(ref.=Mother not alive)			
Mother alive	1.142	0.851	0.859
Census region <sup>4</sup> (ref.=South)			
Northeast	1.174	1.087	0.874



Model/Variable		<u>Estate planning</u>	<u>ACP</u>	
		Valid will	Durable power of attorney for health care	Living will
	Midwest	1.099	1.263***	1.104
	West	0.825*	1.306***	1.043
Random effects		0.978	0.646	0.770
$R^2$		0.066	0.057	0.058

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$ .

*Note.* Given that multiple hypothesis testing was conducted, the Benjamini-Hochberg correction method was employed to control for the increased Type I error rate.

ref. = reference category.

<sup>1</sup> Non-Hispanic Other race (i.e., American Indian, Alaskan Native, Asian, Native Hawaiian, and Pacific Islander) excluded in the adjusted models due to the small number of cases (2.1%,  $n = 217$ ).

<sup>2</sup> Other category included unemployed, disabled, and not in labor force.

<sup>3</sup> Other category included separated, divorced, widowed, and never married.

<sup>4</sup> Other category of census region excluded in the adjusted models due to the very small number of cases (0.2%,  $n = 24$ ).