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Healthcare Utilization and Advance Care Planning Among Older Adults Across Cognitive Levels

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Abstract

This study examined the impact of advance care planning (ACP) on healthcare utilization among older adults with normal cognition and impaired cognition/dementia. Using datasets from the Health and Retirement Study, we conducted a cross-sectional study on 17,698 participants aged 51 years and older. Our analyses included survey descriptive and logistic regression procedures. ACP measures included a living will and durable power of attorney for healthcare. Healthcare utilization was measured using the days spent in hospitals, hospice care, nursing homes, and home care. Of the participants, 77.8% had normal cognition, and 22% had impaired cognition/ dementia. The proportion of impaired cognition/dementia was higher among racially minoritized

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Conflicts of Interest declaration

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participants, single/widowed participants, and those who lived alone and were less educated. The results showed that having an ACP measure was associated with longer stays in hospitals, nursing homes, and home healthcare in all participants.

Alzheimer's disease and related dementias (ADRD) comprise a leading cause of death in the United States (US) (Centers for Disease Control and Prevention, 2021). The prevalence of ADRD in the US is estimated to reach nearly 14 million by 2050 (Alzheimer's Association, 2022; Pereira et al., 2022). In addition to significant risk factors for ADRD (e.g., advanced age, genetic predisposition, and low education level), chronic conditions, such as cardiovascular problems, have been associated with increased rates of cognitive impairment and dementia diagnosis (Alzheimer's Association, 2022). Thus, particular risk groups for chronic conditions have an increased risk of dementia. Older adults in certain racial/ethnic groups, such as Black older adults, are specifically vulnerable to ADRD, in part, because of their higher prevalence of chronic health conditions (Alzheimer's Association, 2022).

ADRD is characterized by a progressive cognitive and functional decline that can advance into impaired activities of daily living and disability (Cunningham et al., 2015). Families, caregivers, and healthcare systems face challenges when making decisions regarding care and treatment options due to progressive decline in patients' cognitive and functional abilities (Cunningham et al., 2015). These challenges urge healthcare providers and policymakers to design methods for improving goal-concordant care, particularly at end of life. Advance care planning (ACP) allows people to convey their desires and values about future healthcare and helps provide care that aligns with patients' goals (goal-concordant care). ACP encompasses different approaches, such as verbal discussions of wishes and/or the completion of advance directives in medical records, which can be modified over time and across disease progression stages (Sudore et al., 2017). Advance directives often include a durable power of attorney for healthcare (DPOAH), a designation of a proxy with decision-making power, and a living will, a document expressing the person's medical treatment preferences. These methods can help individuals plan for future healthcare in conditions with severe health issues or decision-making incapacities like ADRD (Dalton & Langdon, 2022).

With the growing population of older adults and people living longer with chronic health conditions, individuals and healthcare settings have been challenged to balance the provision and expenditures of healthcare services and improve individuals' quality of life and wellbeing. Regarding this challenge, there is an increasing interest in home and community as the optimal place of care— known as aging in place (National Council for Aging Care, 2019). People with ADRD prefer to age in place and receive the care and treatments they need at home or in the location of their choice with comfort as long as possible (Wagner, 2021). However, evidence indicates that the emergency department admission and hospitalization rate increases as individuals' cognitive impairment progresses (Chen et al., 2021).

Sociodemographic characteristics (e.g., education, race, and ethnicity) and health factors (e.g., cognitive impairment, limitations in activities of daily living, and the number of

chronic conditions, collectively known as frailty) are associated with disparities in ACP and healthcare utilization and the type of healthcare settings used, such as home or hospital (Mah et al., 2021; Pereira et al., 2022; Rahemi, 2019; Rahemi et al., 2019; Rahemi & Williams, 2016, 2020; Suntai et al., 2022). For example, certain racial groups, including Black individuals with dementia, may have inadequate access to information to make informed end-of-life decisions (Bonner et al., 2021) and may underutilize ACP because of racism, discrimination, and/or inequitable treatment within the health system (Bonner et al., 2021; McDonnell & Idler, 2020). Optimal care for persons with dementia includes goal-concordant care, reducing unnecessary treatments and improving quality of life for patients, families, and caregivers (Sampson et al., 2018).

Some researchers argue that ACP has failed to reduce extensive care and expenditures at the end of life (Morrison et al., 2021). Alternative viewpoints put by other researchers suggest that the goal of ACP is to improve care that aligns with patients' goals and enhance patients' and care partners' satisfaction with care and quality of life (Dixon et al., 2018; McMahan et al., 2021; Pereira et al., 2022). ACP can improve patients' future autonomy and reduce surrogate stress and grief (Bélanger et al., 2022; Jacobsen et al., 2022; McMahan et al., 2021; Rahemi & Williams, 2016). In this regard, the ADRD disease trajectory is unique, and persons vary in the pace of dementia symptoms advancement. Some patients experience a precipitous cognitive decline, while others experience gradually increasing disability, dependence, and difficulty making decisions over a decade or longer (Alzheimer's Association, 2022). In either case, healthcare decision making is challenging for ADRD care partners. Thus, early preparation for medical decision making before persons with dementia exhibit severe cognitive decline is highly recommended (de Jong et al., 2023) as uncertain prognoses and long-term progressive functional and cognitive decline may result in inevitable reliance on surrogate decision-makers in the future (Bélanger et al., 2022; Dalton & Langdon, 2022).

To the authors' knowledge, there are no studies about the factors associated with healthcare utilization based on ACP across cognitive levels. In this study, we used data from the Health and Retirement Study (HRS) to investigate the impact of ACP on healthcare utilization among older adults with different cognitive functioning levels. Our research question was: How does ACP relate to healthcare utilization among older adults with normal cognition and impaired cognition/dementia? We define ACP as having a living will and DPOAH, measures available in HRS 2014 survey. We measured healthcare utilization based on the number of days the participants stayed at a hospital, hospice care, nursing home, and home healthcare.

Materials and Methods

We conducted an observational, cross-sectional study using data from the HRS, a nationally representative dataset of more than 43,000 respondents aged 51 years and older (Sonnega et al., 2014). The Institute for Social Research at the University of Michigan conducted this population-based survey. The HRS collects data every two years and includes four major components of data: health and well-being, work and retirement, social connections, and economic status. A probability sample methodology with oversampling of African American, Hispanic, and Floridian participants is incorporated into the survey

administration. We used a sample of 17,698 respondents from the HRS 2014 survey (wave 12), a comprehensive wave in selected harmonized datasets, specifically in the end-of-life sections. We used data from two HRS datasets, the harmonized HRS version B and the 2016 Rand HRS Longitudinal version 2. As this study involved a secondary data analysis, it was determined to be exempt from review by the university Institutional Review Board (IRB)

Data Analysis

The primary independent variables of interest were having a living will (yes/no) and having a DPOAH (yes/no). To assess the joint effects of these factors, we also created a combination variable with the levels: no ACP measure, at least one ACP measure, and both ACP measures. Based on the Langa-Weir approach, respondents' cognitive levels are classified as normal cognition (> 11 points), impaired cognition (7–11 points), and dementia (< 7 points) using the 27-point HRS cognition scale (Langa et al., 2017). Next, we re-grouped the respondents' cognition levels into normal and impaired cognition/dementia groups. Similar to our previous work (Rahemi et al., 2022), the analyses were stratified by cognition level, a priori, to allow for comparisons between cognition groups. Due to small cell sizes, we combined the impaired cognition and dementia groups into a single group (i.e., the impaired cognition/dementia group).

The dependent variables for analysis were the number of days of hospital care, hospice care, nursing home care, and home care utilization (yes/no). These variables were derived from self-reported information queried in the HRS. For each type of healthcare, participants reported the number of days of utilization. The distribution was highly right skewed for hospital and hospice care days, with a large proportion of 0 days. After evaluating the fit of different models using the Pearson Chi-square statistic from the model goodness of fit output, it was determined that the negative binomial model best fits these dependent variables. For nursing home care, the negative binomial model was only appropriate for the impaired cognition/dementia group. The normal cognition group had too much dispersion for any linear model fit. To have consistency between the normal and impaired cognition/ dementia group, we categorized the length of the nursing home stay into none, moderate (365 days or less), and long (more than 365 days).

Weighted descriptive statistics (Proc surveyfreq and Proc survey mean) were initially calculated to account for the complex sampling frame and allow for the generalization of findings to the national level. However, we did not incorporate sample weights into our modeling approaches as previous work has demonstrated that this introduces significant bias in measures of association (Winship & Radbill, 1994). We modeled the outcomes of hospital and hospice days using a negative binomial distribution (Proc Genmod/dist=negbin), the outcome of nursing home days using polytomous logistic regression (Proc logistic/ link=glogit), and the outcome of home care using logistic regression (Proc logistic). To assess disparities in the relationship between ACP and healthcare utilization, we created initial models with each ACP variable (living will, DPOAH, or joint effect) and race, ethnicity, or rurality in separate models. To minimize Type I statistical errors, we limited our interaction testing to only those variables that were needed to address our a priori research question. We used the Wald statistic from the interaction term (ACP*race, ACP*rurality,

or ACP*ethnicity) to assess for statistically significant effect moderation. None of the interaction terms had a significance level less than 0.05; therefore, we lacked evidence that race, ethnicity, and rurality were effect modifiers in the relationship between any ACP and any healthcare utilization variable. In the HRS data, race (white/black/other) and ethnicity (Hispanic/non-Hispanic) have significant collinearity. Therefore, we removed ethnicity from our analysis to avoid introducing bias into our models.

Having failed to find evidence of effect modification, we adjusted all subsequent models for race (white vs. Black/other races), rurality (urban vs. rural), marital status (married vs. single), impairment in activities of daily living (yes vs. no), presence of chronic conditions (0 vs. 1–3 vs. 4+), education level (high school diploma vs. 13+ years), gender (male vs. female), and age. Results for hospital and hospice days were presented as adjusted means. We presented the results for hospice and home care utilization using odd ratios (OR) and 95% confidence intervals (CI). We conducted all analyses via SAS version 9.4 and used an alpha level of 0.05 to determine statistical significance.

Results

Of the 17,698 participants, 77.8% had normal cognition, and 22% had impaired cognition/ dementia (Table 1). The mean age for the impaired cognition/dementia group was higher (71 years old \pm 0.7) than the normal cognition group (63.5 years old \pm 0.3). About 55% of the participants in both groups were females. The proportion of impaired cognition/ dementia decreased with education. About 16.8% of participants with impaired cognition/ dementia had graduated from college, compared to 38.8% in the normal cognition group. Most participants were white (86% in normal cognition and 66% in the impaired cognition/ dementia group). The proportions of Black participants and participants of other races in the impaired cognition/dementia group were higher than in the normal cognition: 7.9% and 5.8% in the normal cognition and 22.4% and 10.7% in the impaired cognition/dementia group, respectively. Most participants who were married or living with a partner had normal cognition (76%). Conversely, more participants who lived alone had impaired cognition/ dementia (29.6%) compared to normal cognition (24%).

Having a living will was more common among people with normal cognition, but participants with impaired cognition/dementia were more likely to have a DPOAH. More than 63% of the participants in both cognition groups had one to three chronic conditions; however, having four or more chronic diseases was more common in the impaired cognition/ dementia group (29.2%) compared to the normal cognition group (15.5%). Additionally, having at least one difficulty in daily living activities was more common in the impaired cognition/dementia group.

Hospital and Hospice Stays

Table 2 shows the adjusted mean days in the hospital or hospice care among participants with and without an ACP by cognition status. Participants with impaired cognition/dementia spent more days in the hospital (average days of 3.4 to 3.8) than cognitively normal participants (average days of 2.3 to 2.4) when they had an ACP. Adjusted means for hospice care stay ranged from 12.7 to 14.8 days for participants with ACP in the normal cognition

compared to the impaired cognition/dementia group, with average days ranging from 9.8 to 10.5.

In the impaired cognition/dementia group, the mean hospital days for participants with a DPOAH were higher than those without DPOAH (3.8 vs. 2.9 days, p<0.01). Similarly, in examining the joint effects of ACP in the impaired cognition/dementia group, those with one or both ACP measures had significantly longer hospital stays than those with neither ACP measure (3.5 and 3.7 vs. 2.7 days, p=0.04). In addition, participants with a living will, DPOAH, or both in the normal cognition group had more extended hospital stays than those without a living will or DPOAH (2.4, 2.3, and 2.4 days vs. 1.7, 1.7, and 1.6 days, respectively, p<0.01). Conversely, ACP did not appear to be associated with hospice care utilization in the normal or impaired cognition/dementia groups.

Nursing Home Stays

Table 3 shows the odds of moderate or long nursing home stays by ACP and cognition status. We observed higher odds of nursing home stay for the impaired cognition/dementia compared to the normal cognition group. Among those with normal cognition, individuals with either a living will (OR=2.33, 95% CI: 1.71-3.17) or DPOAH (OR=1.70, 95% CI: 1.28–2.28) were significantly more likely to have a moderate stay compared to those without the ACP. Additionally, the joint effects of having one or both ACP measures showed similar, statistically significant odds of moderate stays (ORs=1.65, 95% CI: 1.06-2.57 and 2.34, 95% CI: 1.66–3.30). These odds were decreased for long nursing home stays for any ACP measures or joint effects. Interestingly, the p-value comparing the trend of ORs between moderate and extended stays was statistically significant for all three ACP variables (p<0.01). The impaired cognition/dementia group had similar findings for moderate nursing home stays (2.61 95% CI: 1.80–3.77 and 2.56 95% CI: 1.75–3.73). Additionally, this group had significantly higher odds of an extended nursing home stay for those with an ACP (3.28, 95% CI: 1.66–6.48 and 4.22, 95% CI: 1.94–9.19). The joint effects of ACP measures also demonstrated significantly elevated ORs for both moderate and long nursing home stays with increasing odds as the number of ACP measures increased (1.82 vs. 3.33 and 1.50 vs. 4.62). Tests for trends between the moderate and extended stay ORs were statistically significant for the three ACP measures.

Home Care Stays

Table 4 shows the odds of utilizing home care by living will, DPOAH, or joint effects. Cognitively normal participants with a living will were 38% more likely, and participants with impaired cognition/dementia were 31% more likely to use home care than participants without a living will. Similarly, among those with a DPOAH, the odds of using home care were 29% higher in the normal cognition participants and 61% higher in the impaired cognition/dementia participants compared to their counterparts without DPOAH. For the joint effects variable, the odds of utilizing home care were significantly increased for having one (cognitively normal 43%; impaired cognition/dementia 39%) or both (cognitively normal 46%; impaired cognition/dementia 63%) ACP measures among either cognition group.

Discussion

We used the HRS dataset from the 2014 interviews to investigate the impact of ACP on healthcare utilization in participants with normal cognition and impaired cognition/ dementia. We considered two critical legal documents that were available in this dataset as ACP measures: a living will and DPOAH. We found that the proportion of impaired cognition/dementia was higher among Black participants and those of other races, single/ widowed participants, and those who lived alone and were less educated compared to their counterparts. Our participants predominantly had one to three chronic diseases. Having four or more chronic diseases and at least one difficulty in daily living activities was more common in the impaired cognition/dementia group. Impaired cognition/dementia group participants were older than the normal cognition group participants, which could explain the observed health status of participants, as cognitive impairment and age are two common factors contributing to multiple morbidities among older adults (Alzheimer's Association, 2022).

Participants with normal cognition tended to plan for their future care through a living will, and participants with impaired cognition/dementia tended to assign a proxy for their healthcare planning through a DPOAH. In line with our study findings, Gaster and colleagues indicated that, typically, healthcare proxies make medical decisions for patients with dementia. They explained that although cognitive impairment progresses slowly, older adults may lose their decision-making capacity quickly at some point, which urges these older adults to assign a proxy for their decision making (Gaster et al., 2017).

We found that hospital length of stay was similar between the impaired cognition/dementia and normal cognition groups. We detected a slightly higher range of nursing home days of stay among the impaired cognition/dementia group compared to the normal cognition group. Similarly, Chen and colleagues (2021) found that with the progression of dementia to severe stages, the frequency of outpatient visits decreased, and hospital and nursing home admissions increased. Older patients had higher rates of emergency department visits and hospitalizations and a longer length of stay in the hospital than younger patients, who, in turn, had higher outpatient department visits (Chen et al., 2021). Our participants with impaired cognition/dementia were older and had higher nursing home stays than participants with normal cognition. Progressive cognitive and functional decline, including swallowing difficulties, infectious diseases, and fall injuries, may explain the higher utilization of healthcare in older adults with ADRD (Murray et al., 2018; Pereira et al., 2022; Sampson et al., 2018).

Our findings demonstrating the association between ACP and more extended stays in hospitals, nursing homes, and home care were inconsistent with a recent review on people with dementia, which found decreased hospitalization in patients with ACP. This review found that ACP improved concordance between the care received and prior wishes (Wendrich-van Dael et al., 2020). Overall, there are debates regarding the effectiveness of ACP in reducing hospitalization and extensive care (Morrison et al., 2021). Some believe ACP transcends issues of healthcare use and hospitalization (Jacobsen et al., 2022). From this stance, the belief is that ACP mainly focuses on goal concordance in care, thereby

improving resilience, feelings of peace, and satisfaction with end-of-life care while reducing grief and anxiety about surrogate decision making (Curtis, 2021; Gaster et al., 2017; Jacobsen et al., 2022; McMahan et al., 2021). Regarding persons with dementia, de Jong and colleagues (2023) indicated that a continuous process of ACP will help healthcare at end of life to align with the values and needs of older adults and their caregivers.

ACP can be different for those with cognitive disorders than for those with other diseases (Gaster et al., 2017). Cognitive disorders often progress slowly over many years and can leave patients with impairment to decisional capacity for a decade or longer. Across the care spectrum, from outpatient clinics to long-term facilities, family members and providers are frequently uncertain about a patient's healthcare preference and choices, contributing to their anxiety and stress trying to guess those preferences. Thus, older adults and their care partners may seek opportunities to set care plans before severe cognitive impairment occurs (Gaster et al., 2017). ACP is essential in the early stages of ADRD (Dalton & Langdon, 2022; Wendrich-van Dael et al., 2020) as it can provide knowledge and realistic expectations for people with cognitive impairment and their care partners, regarding what they may confront and how to manage healthcare as cognitive impairment becomes more severe (Chen et al., 2021). With early ACP, ADRD caregivers may experience decreased physical and emotional tensions and improved quality of life and satisfaction (Dixon et al., 2018; Pereira et al., 2022).

We also found that hospice care utilization was not associated with ACP, and hospice length of stay was lower in the impaired cognition/dementia group. These findings may be explained by this group's higher nursing home and hospital stays. Additionally, hospice care can be provided in alternate setting, such as nursing homes and hospitals, which we did not explicitly examine in this study as hospice data within different settings were not available in the HRS datasets.

The present study builds upon our previous study demonstrating that race, ethnicity, education, age, marital status, loneliness, number of chronic diseases, and limitations in activities of daily life were associated with ACP among older adults with different cognition levels (Rahemi et al., 2022). The previous study showed that African American and Hispanic participants and people with cognitive impairment were less likely to engage in ACP than their counterparts (Rahemi et al., 2022). At the same time, intensive care use and expenditures have been reported to be higher in minoritized populations and people with dementia (Alzheimer's Association, 2022; Bélanger et al., 2022). Our findings support prior research reporting that older Black and other racially minoritized individuals are more likely to be diagnosed with ADRD (Alzheimer's Association, 2023). Older Black and other racially minoritized individuals with cognitive impairment represent underserved groups who may not have access to ACP resources but experience higher healthcare expenditures. Additional research is needed to uncover the relationships among ACP, healthcare utilization, and other contributing factors in racial/ethnic minority populations. It is critical that healthcare providers understand and honor end-of-life values, authority, and sense of dignity of older adults from marginalized populations (Rahemi & Williams, 2015).

Our study showed that ACP was associated with more extended nursing home stays in both cohorts. Our participants with impaired cognition/dementia stayed longer in nursing homes than cognitively normal people. This finding is consistent with previous research that among the Medicare beneficiaries with mild cognitive impairment, 22% had a long-term nursing home stay over 14 years. The odds of long-term stay among people with dementia were considerably higher than people with other chronic conditions (Willink et al., 2016). The increase in nursing home use is associated with cognitive impairment and dementia progression due to challenges for families and caregivers, such as patients' escalating dependence on others, limitations of activities of daily living, and behavioral and psychiatric symptoms (Chen et al., 2021).

We found that in both groups, participants with ACP were more likely to use home care than participants without ACP. Home healthcare is a preferred healthcare service among older adults (Sefcik et al., 2017). Even with progressive disorders and limitations in activities of daily living, health, and autonomy, older adults often prefer to age in place and live at home and in natural, familiar environments and use home care services (de Jong et al., 2023; Mah et al., 2021). Care in natural living environments can improve person-centered care and quality of life for older adults. Studies also reported that home healthcare was associated with decreased hospitalization rates and delayed institutionalization in persons with dementia (Dixon et al., 2018; National Council for Aging Care, 2019). However, our findings indicated that with ACP, both hospitalization and home care use increased. Notably, our participants who did not have ACP also used healthcare services in hospitals, nursing homes, and home care less than those with ACP. This result may represent lower access to healthcare services and ACP among this group of participants. To explain the relationship between ACP and higher healthcare use, more research is needed to examine the underlying factors, such as healthcare access and use and care-seeking behaviors.

Another critical element that might contribute to these results is the fragmented nature of US healthcare. For example, if patients with cognitive impairment convey their healthcare wishes to their primary care providers, those wishes may not be recognized by other healthcare providers. As de Jong and colleagues indicated, a close interaction between dementia care partners is critical to provide care compatible with the wishes of patients. Jong and colleagues (2023) emphasized that good communication between persons with dementia and care partners is pivotal, even when ACP is established.

Given the growing usage of ACP globally, our study has international relevance and implications at the individual (i.e., people with dementia and their caregivers), community (e.g., global health professionals/social workers and geriatricians), and policy levels (e.g., managers, administrators, and decisionmakers within the health system). To extrapolate these findings to populations outside of the US, researchers are encouraged to utilize Gateway to Global Action (g2aging.org) and replicate these analyses with data from harmonized sister studies to the HRS across the world. Such efforts may be useful to guide ACP strategies and associated research tailored to a particular country's cultural context to improve person-centered care. Further research is needed to replicate our study findings in other longitudinal aging studies.

Strengths and Limitations

One strength of the present study was using a large national sample of US older adults for assessing ACP and healthcare utilization. However, it is accompanied by limitations that are worth noting for their implications for interpretation of the findings. First, we did not determine participants' care preferences to assess whether the healthcare service they used was goal concordant. Second, our study did not examine social networks, healthcare access, and healthcare-seeking behaviors that may moderate healthcare utilization patterns (Gaugler et al., 2014; Mah et al., 2021; Sefcik et al., 2017). Third, a considerable proportion of our sample included participants younger than 65 who may seek hospitalization more often than older patients. Fifth, it may be unachievable to capture the value of ACP and its benefits using traditional mechanisms, such as a living will and DPOAH, and conventional outcome measures, such as hospitalization. ACP encompasses various formal and informal mechanisms for medical decision making and focuses more on improving joy, gratitude, dignity and reducing grief and fear than on the type of utilized healthcare (Curtis, 2021). Sixth, secondary data analysis is limited to available data and measurement tools. Thus, we could not assess hospice care within different settings.

Conclusion and Recommendations

To our knowledge, this study is the first to address healthcare utilization based on ACP and cognition status using a US nationwide population-based dataset of older adults. Our results can inform future studies to better understand the impact of cognition and ACP on healthcare utilization. We found that cognitively impaired older adults had longer stays in hospitals and nursing homes, and those with ACP used more home care services. The effects of ACP on improving home care represent expected and desired ACP outcomes for the palliative and hospice care community. However, the effect of ACP on increasing hospital stays and institutionalization needs additional research. Individuals may seek hospice care through hospitals and other settings to reduce the burden of end-of-life care for their loved ones that needs further research.

Future research is needed to examine different values, beliefs, and perspectives on endof-life care and ACP among people with dementia from diverse cultural, ethnic, and geographical contexts. This research is critical to providing culturally safe care for underserved groups (such as rural older adults) that have often experienced issues of inequitable access and disparate treatment in the healthcare system. Due to the increased usage of ACP globally, this research will have international implications and relevance for healthcare professionals to enhance culturally safe end-of-life care for diverse populations. We encourage future research on older participant using post-mortem data, such as HRS exit data, to better uncover the influence of ACP on healthcare utilization at the end of life. We also recommend incorporating questions on individuals' healthcare preferences, healthcare access, and healthcare-seeking behaviors in future ACP research. ACP is specifically important for persons with dementia as it can inform healthcare providers about patients' and family members' desires and goals of care, whether comfort or intensive care.

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References

- Alzheimer's Association. (2022). 2022 Alzheimer's disease facts and figures. In Alzheimer's & Dementia (Vol. 15). https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf
- Bélanger E, Couch E, Carroll MS, DePasquale N, Gadbois EA, Shepherd-Banigan M, Jutkowitz E, Van Houtven CH, Plassman BL, & Wetle TT (2022). Advance directives among cognitively impaired persons who had an amyloid PET scan and their care partners: a mixed-methods study. BMC Palliative Care, 21(1). 10.1186/s12904-022-01082-4
- Bonner GJ, Freels S, Ferrans C, Steffen A, Suarez ML, Dancy BL, Watkins YJ, Collinge W, Hart AS, Aggarwal NT, & Wilkie DJ (2021). Advance Care Planning for African American Caregivers of Relatives With Dementias: Cluster Randomized Controlled Trial. American Journal of Hospice and Palliative Medicine, 38(6), 547–556. 10.1177/1049909120916127 [PubMed: 32308012]
- Centers for Disease Control and Prevention, N. C. for H. S. (2021). Underlying Cause of Death 1999–2020 on CDC WONDER Online Database, released in 2021. http://wonder.cdc.gov/ucd-icd10.html on Dec 22, 2021 9:52:42 PM
- Chen YH, Lai YC, Wu YC, Sasaki J, Tsai KT, & Ho CH (2021). Healthcare utilization in different stages among patients with dementia: A nationwide population-based study. International Journal of Environmental Research and Public Health, 18(11). 10.3390/ijerph18115705
- Crimmins EM, Kim JK, Langa KM, & Weir DR (2011). Assessment of cognition using surveys and neuropsychological assessment: the Health and Retirement Study and the Aging, Demographics, and Memory Study. The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 66 Suppl 1, 162–171. 10.1093/geronb/gbr048
- Cunningham E, McGuinness B, Herron B, & Passmore A (2015). Dementia. The Ulster Medical Journal, 84(2), 79–87. [PubMed: 26170481]
- Curtis JR (2021). Three Stories about the Value of Advance Care Planning. Jama, 326(21), 2133–2134. 10.1001/jama.2021.21075 [PubMed: 34874415]
- Dalton MA, & Langdon TP (2022). Estate planning (13th ed.). Money Education.
- de Jong LM, Francke AL, Donker G, van den Buuse S, & van der Heide I (2023). What Facilitates or Hampers Living at Home With Advanced Dementia Until the End of Life? A Qualitative Study Using Retrospective Interviews Among Family Caregivers, General Practitioners, and Case Managers. Journal of Applied Gerontology, 0(0), 1–10. 10.1177/07334648231153722
- Dixon J, Karagiannidou M, & Knapp M (2018). The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers : A Systematic Review and Critical Discussion. Journal of Pain and Symptom Management, 55(1), 132–150.e1. 10.1016/j.jpainsymman.2017.04.009 [PubMed: 28827062]
- Gaster B, Larson EB, & Curtis JR (2017). Advance directives for dementia meeting a unique challenge. JAMA - Journal of the American Medical Association, 318(22), 2175–2176. 10.1001/ jama.2017.16473 [PubMed: 29114779]
- Gaugler J, Yu F, Davila H, & Shippee T (2014). Alzheimer's disease and nursing homes. Health Aff (Millwood), 33(4), 650–657. 10.1377/hlthaff.2013.1268 [PubMed: 24711327]
- Jacobsen J, Bernacki R, & Paladino J (2022). Shifting to serious illness communication. JAMA - Journal of the American Medical Association, 327(4), 321–322. 10.1001/jama.2021.23695 [PubMed: 34994773]

- Kent T, Lesser A, Israni J, Hwang U, Carpenter C, & Ko KJ (2019). 30-Day Emergency Department Revisit Rates among Older Adults with Documented Dementia. Journal of the American Geriatrics Society, 67(11), 2254–2259. 10.1111/jgs.16114 [PubMed: 31403717]
- Langa KM, Larson EB, Crimmins EM, Faul JD, Levine DA, Kabeto MU, & Weir DR (2017). A comparison of the prevalence of dementia in the United States in 2000 and 2012. JAMA Internal Medicine, 177(1), 51–58. 10.1001/jamainternmed.2016.6807 [PubMed: 27893041]
- Mah JC, Stevens SJ, Keefe JM, Rockwood K, & Andrew MK (2021). Social factors influencing utilization of home care in community-dwelling older adults: a scoping review. BMC Geriatrics, 21(1), 1–21. 10.1186/s12877-021-02069-1 [PubMed: 33388045]
- McDonnell J, & Idler E (2020). Promoting advance care planning in African American faith communities: literature review and assessment of church-based programs. Palliative Care and Social Practice, 14, 1–15. 10.1177/2632352420975780
- McMahan RD, Tellez I, & Sudore RL (2021). Deconstructing the complexities of advance care planning outcomes: What do we know and where do we go? A Scoping Review. Journal of the American Geriatrics Society, 69(1), 234–244. 10.1111/jgs.16801 [PubMed: 32894787]
- Morrison S, Meier DE, & Arnold RM (2021). What's wrong with advance care planning? JAMA - Journal of the American Medical Association, 326(15), 1575–1576. 10.1001/jama.2021.16430 [PubMed: 34623373]
- Murray CJL, Mokdad AH, Ballestros K, Echko M, Glenn S, Olsen HE, Mullany E, Lee A, Khan AR, Ahmadi A, Ferrari AJ, Kasaeian A, Werdecker A, Carter A, Zipkin B, Sartorius B, Serdar B, Sykes BL, Troeger C, ... Murray CJL (2018). The state of US health, 1990–2016: Burden of diseases, injuries, and risk factors among US states. JAMA - Journal of the American Medical Association, 319(14), 1444–1472. 10.1001/jama.2018.0158 [PubMed: 29634829]

National Council for Aging Care. (2019). Aging in Place. https://doi.org/https://www.aginginplace.org/

- Pereira C, LaRoche A, Arredondo B, Pugh E, Disbrow E, Reekes TH, Brickell E, Boettcher A, & Sawyer RJ (2022). Evaluating racial disparities in healthcare system utilization and caregiver burden among older adults with dementia. Clinical Neuropsychologist, 36(2), 353–366. 10.1080/13854046.2021.1951844 [PubMed: 34338590]
- Rahemi Z (2019). Planning Ahead for End-of-Life Healthcare among Iranian-American Older Adults: Attitudes and Communication of Healthcare Wishes. Journal of Cross-Cultural Gerontology, 34(2). 10.1007/s10823-019-09371-x
- Rahemi Z, Dunphy LM, & Newman D (2019). Preferences regarding and communication about endof-life care among older Iranian-American adults. Western Journal of Nursing Research, 41(10), 1499–1516. 10.1177/0193945919832304 [PubMed: 30793665]
- Rahemi Z, Malatyali A, Adams SA, Jarrín OF, Demiris G, Parker V, Anaraky RG, & Dye CJ (2022). Advance Care Planning Among Older Adults with Cognitive Impairment. American Journal of Hospice & Palliative Medicine, 0(0), 1–8. 10.1177/10499091221146255
- Rahemi Z, & Williams C (2016). Older adults of underrepresented populations and their endoflife preferences: An integrative review. Advances in Nursing Science, 39(4), E1–E29. 10.1097/ ANS.000000000000148
- Rahemi Z, & Williams CL (2015). Development of a dignity-enhancing model of caring for older adults. International Journal for Human Caring, 19(3), 36–42.
- Rahemi Z, & Williams CL (2020). Does ethnicity matter—Cultural factors underlying older adults' end-of-life care preferences: A systematic review. Geriatric Nursing, 41(2), 89–97. 10.1016/ j.gerinurse.2019.07.001 [PubMed: 31320127]
- Sampson EL, Candy B, Davis S, Gola AB, Harrington J, King M, Kupeli N, Leavey G, Moore K, Nazareth I, Omar RZ, Vickerstaff V, & Jones L (2018). Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. Palliative Medicine, 32(3), 668–681. 10.1177/0269216317726443 [PubMed: 28922625]
- Sefcik JS, Ritter AZ, Flores EJ, Nock RH, Chase JAD, Bradway C, Potashnik S, & Bowles KH (2017). Why older adults may decline offers of post-acute care services: A qualitative descriptive study. Geriatric Nursing, 38(3), 238–243. 10.1016/j.gerinurse.2016.11.003 [PubMed: 27964972]

- Sonnega A, Faul J, Ofstedal M, Langa K, Phillips J, & Weir D (2014). Cohort Profile: The Health and Retirement Study (HRS). Int J Epidemiol, 43(2), 576–585. 10.1093/ije/dyu067 [PubMed: 24671021]
- Sudore R, Lum H, You J, & Al E (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage, 53(5), 821–832.e21. [PubMed: 28062339]
- Suntai Z, Noh H, & Won CR (2022). Examining Racial Differences in the Informal Discussion of Advance Care Planning Among Older Adults: Application of the Andersen Model of Health Care Utilization. Journal of Applied Gerontology, 41(2), 371–379. 10.1177/0733464821993610 [PubMed: 33605185]
- Wagner A (2021). Aging in place with age-related cognitive changes: The impact of caregiving support and finances. Societies, 11(2). 10.3390/soc11020031
- Wendrich-van Dael A, Bunn F, Lynch J, Pivodic L, Van den Block L, & Goodman C (2020). Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. International Journal of Nursing Studies, 107, 103576. 10.1016/ j.ijnurstu.2020.103576 [PubMed: 32380259]
- Willink A, Davis K, & Schoen C (2016). Risks for Nursing Home Placement and Medicaid Entry Among Older Medicare Beneficiaries with Physical or Cognitive Impairment. The Commonwealth Fund, 37(October).
- Winship C, & Radbill L (1994). Sampling Weights and Regression Analysis. Sociological Methods & Research, 23(2), 230–257. 10.1177/0049124194023002004

What this paper adds

- Sociodemographic and social characteristics, such as race, education, marital status, and loneliness, contributed to higher rates of cognitive impairment and dementia.
- Patients with advance care planning used healthcare services more frequently, including hospitals, nursing homes, and home healthcare.

Applications of study findings

- There is a need to replicate this study considering the potential effects of healthcare access and healthcare-seeking behaviors on the relationships between advance care planning and healthcare utilization.
- Future research needs to recruit participants with older ages or in end-of-life circumstances to better understand the healthcare demands of older adults across cognition levels and the influence of advance care planning.
- Advance care planning and healthcare use research can improve evidenceinformed knowledge to facilitate modifications and reforms related to advance care planning and healthcare service design and allocation as the population ages.

Table 1.

Descriptive statistics for the 2014 Health and Retirement Survey cohort by cognition groups

Cognition group	Normal Cognition	Impaired/Dementia	
Cognition Score	(12+)	(0–11)	
	(%) N=13,774	(%) N= 3924	р
Age (Median [SE])	63.5 (0.3)	71.0 (0.7)	
Education			
12 years	61.2 (7062)	27.2 (890)	< 0.01
13+ years	38.8 (5572)	16.8 (2733)	
Gender			
Male	45.1 (5304)	45.4 (1517)	0.82
Female	54.9 (7394)	54.6 (2124)	
Race			
White	86.3 (9666)	66.2 (2084)	< 0.01
Black	7.9 (2055)	22.4 (1155)	
Other	5.8 (944)	10.7 (391)	
Marital Status			
Married/ Partnered	76.0 (9643)	70.4 (2708)	< 0.01
Single/Widowed	24.0 (2952)	29.6 (931)	
Living Will			
Yes	54.1 (3743)	46.2 (1071)	< 0.01
No	45.8 (3051)	53.8 (1396)	
Durable Power of Attorney			
Yes	45.8 (3024)	49.4 (1252)	0.03
No	54.2 (3787)	50.6 (1215)	
Joint Living Will or DPOA			
Both	47.5 (3259)	38.7 (892)	< 0.01
At least 1	13.3 (956)	19.1 (470)	
None	39.2 (2547)	42.2 (1078)	
Chronic Conditions			
0	15.6 (1689)	7.2 (251)	< 0.01
1–3	68.9 (8739)	63.6 (2314)	
4+	15.5 (2269)	29.2 (1076)	
Limitations in Activities of Daily Living			
None	88.3 (10,937)	70.6 (2564)	< 0.01
1+	11.7 (1757)	29.4 (1069)	
Rurality			
Rural	26.4 (3163)	28.3 (937)	0.27
Urban	73.6 (9480)	71.7 (2678)	
	Range	Range	
Hospitalization Days	0–95	0–97	
Hospice Care Days	0–90	0–90	

Cognition group	Normal Cognition	Impaired/Dementia	
Cognition Score	(12+)	(0–11)	
	(%) N=13,774	(%) N =3924	р
Nursing Home Days	0–792	0–914	

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Table 2.

Adjusted mean hospital and hospice days by advance care planning among adults with normal or dementia/impaired cognition, Health Retirement Survey, 2014.

Rahemi et al.

		Hospital Days	l Days			Hospie	Hospice Days	
ACP Variable	Normal Cognition Mean [95% CI]	d	Impaired/Dementia Mean [95% CI]	d	Normal Cognition Mean [95% CI]	d	Impaired/Dementia <i>Mean</i> [95% CI]	d
Living Will								
Yes	2.4 [1.8, 3.2]	< 0.01	3.4 [2.2, 5.0]	0.23	12.7 [3.9, 41.1]	0.83	9.8 [3.4, 28.2]	0.80
No	1.7 [1.3, 2.2]		2.9 [2.0, 4.3]		13.3 [4.2, 43.4]		10.5 [4.0, 27.5]	
DPOA								
Yes	$2.3 \ [1.8, 3.0]$	< 0.01	3.8 [2.5, 5.7]	0.01	14.8 [4.3, 51.1]	0.61	10.2 [3.7, 28.1]	0.97
No	1.7 [1.3, 2.2]		2.9 [2.0 [4.2]		12.7 [4.1, 39.8]		10.3 [4.0, 26.6]	
Joint Effects								
Both	2.4 [1.8, 3.2]	< 0.01	3.5 [2.3, 5.4]	0.04	13.4 [4.0, 45.8]	0.97	10.5 [3.6, 31.0]	0.78
At Least One	2.2 [1.6, 2.9]		3.7 [2.4, 5.7]		13.8 [3.7, 51.3]		8.8 [3.0, 26.4]	
None	1.6 [1.2, 2.1]		$2.7 \ [1.9, 4.0]$		12.6 [3.9, 40.5]		11.3 [4.2, 30.5]	

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Odds ratios for a moderate or long nursing home stay by ACP measures across cognition levels

	Normal Cognition	Cognition		Impaired/Dementia	-	
ACP Variable	Moderate Stay OR [95% CI]	Long Stay OR [95% CI]	p-value for trend	Moderate Stay OR [95% CI]	Long Stay OR [95% CI]	p-value for trend
Living Will						
Yes	2.33 [1.71, 3.17] 1.07 [0.43, 2.63]	1.07 [0.43, 2.63]	< 0.01	2.61 [1.80, 3.77]	2.61 [1.80, 3.77] 3.28 (1.66, 6.48)	< 0.01
No	1.00	1.00		1.00	1.00	
DPOA						
Yes	1.70 [1.28, 2.28]	1.70 [1.28, 2.28] 1.52 [0.49, 3.89]	< 0.01	2.56 [1.75, 3.73]	4.22 (1.94, 9.19)	< 0.01
No	1.00	1.00		1.00	1.00	
Joint Effects						
Both	2.34 [1.66, 3.30]	1.22 [0.45, 3.29]	< 0.01	3.33 [2.16, 6.14]	3.33 [2.16, 6.14] 4.62 (1.98, 10.78)	< 0.01
At Least One	1.65 [1.06, 2.57]	$0.54 \ [0.11, 2.70]$		1.82 [1.06, 3.10]	1.82 [1.06, 3.10] 1.50 (0.49, 4.59)	
None	1.00	1.00		1.00	1.00	

Table 4.

Odds of Utilizing home care for participants with/without advance care planning across cognition levels

	Cognitio	on Group
ACP Variable	Normal Cognition	Impaired/Dementia
	OR [95% CI]	OR [95% CI]
Living Will		
Yes	1.38 (1.14, 1.67)	1.31 (1.04, 1.67)
No	1.00	1.00
DPOA		
Yes	1.29 (1.07, 1.56)	1.61 (1.27, 2.05)
No	1.00	1.00
Joint Effects	p-value for trend $^{**} < 0.01$	p-value for trend ** < 0.01
Both	1.46 (1.18, 1.80)	1.63 (1.24, 2.13)
At Least One	1.43 (1.09, 1.88)	1.39 (1.01, 1.91)
None	1.00	1.00

* All models adjusted for race, rurality, marital status, functional limitations, chronic diseases, gender, education, and age.

** The trend between normal cognition and cognitively impaired/dementia groups.