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Advance care planning and outpatient visits among older adults across cognitive levels

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Abstract

Advance care planning (ACP) can help reduce end-of-life care challenges for persons with Alzheimer's disease and related dementia and their care partners. Building on our previous work, we examined the impact of ACP on outpatient/doctor visits in older adults with dementia/impaired cognition and normal cognition. Using datasets from the 2014 Health and Retirement Study (HRS), we conducted a cross-sectional study of 17,698 participants aged 51 years and older. Our analyses included survey descriptive and logistic regression procedures. Our findings indicated that having at least one ACP measure was significantly associated with a higher mean number of outpatient visits in both cognition groups. Based on our findings, we recommend considering healthcare access and use as an intervening variable in future ACP research.

Keywords

Cognitive impairment; Advance care planning; Outpatient visits; Healthcare use; Health and retirement Study

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

1. Introduction

Alzheimer's disease and related dementia (ADRD) are major causes of disability, dependency, and death among older adults [1]. As cognitive and functional decline and disability progress, persons with ADRD have higher healthcare utilization than other groups, including greater use of intensive care near the end of life (EOL). They also experience higher healthcare costs and are less satisfied with their care than others [2,3]. Moreover, persons with ADRD and their care partners face challenges such as frequent hospitalizations and disagreements about healthcare and living arrangements. Optimal ADRD care aims to ease these challenges and improve the quality of life for patients and their care partners [4]. Advance care planning (ACP) is one approach that has been reported effective in improving the quality of care, increasing satisfaction with care, and reducing the burden of aggressive EOL treatments among persons with ADRD and their care partners [5,6].

ACP enables persons with ADRD to communicate their preferences for future care proactively in anticipation of a time when they may be unable to make decisions [7–9]. The ACP process includes mechanisms for patients to communicate their wishes both verbally and in writing [8]. One such mechanism is a durable power of attorney for healthcare (DPOAH), which transfers decision-making powers to a person designated by the patient. Having a DPOAH in place is particularly important for people with a prognosis of future incapacity in cognitive functioning, such as persons with ADRD [10]. A living will is another ACP mechanism; this documents a patient's medical treatment preferences in case of severe health issues or decision-making incapacities. Engaging in early ACP enables persons with ADRD and their care partners to acquire relevant health-related information and plan for the future, which may reduce their stress and enhance their quality of life [10–12].

Some work has already been done to examine healthcare utilization among patients with dementia. Chen and colleagues reported that as dementia progressed to severe stages, the frequency of outpatient visits decreased, and hospital and nursing home admissions increased [3]. The authors noted that older dementia patients had higher rates of emergency department visits and hospitalization, as well as extended lengths of stay, while younger patients had higher rates of outpatient visits. However, studies on ACP and healthcare utilization in persons with ADRD are rare and mainly focus on long-term care, hospitalization, emergency department use, and home care. Our previous work indicated that ACP was linked to extended stays in hospitals, nursing homes, and home healthcare in participants across cognition levels, which highlights the importance of healthcare access considerations in ACP research [13]. To comprehensively evaluate the influence of ACP on healthcare utilization, it is essential to encompass all healthcare services in our research. It is imperative to incorporate outpatient healthcare in ACP research, given its significance in the context of dementia and other chronic diseases, particularly for patients residing in communities and their care continuum. To the authors' knowledge, no existing studies have looked at the association between ACP and outpatient visits in older adults with different cognition levels. Therefore, our goal for the present study was to identify the role of ACP in the rate of doctor visits among older adults with cognitive impairment and dementia. To accomplish this, we built upon our previous study, which looked at the impact of ACP on

stays in nursing homes, hospices, hospitals, and home care services in older adults with normal cognition and dementia/cognitive impairment [13]. We believe improved knowledge of ACP and healthcare utilization will help ADRD care partners understand what to expect when providing care for older adults across cognition levels [3,12,14].

2. Methods

2.1. Datasets

The University of Michigan Health and Retirement Study (HRS) surveys a nationally representative sample of approximately 20,000 adults over the age of 51 who reside in the US [15]. For this analysis, we used the 2014 (Wave 12) participants (N=17,698) with a final harmonized dataset consisting of the end-of-life sections (the Harmonized HRS Version B and 2016 RAND HRS Longitudinal Version 2). Our study was exempt from IRB review, as it was based on de-identified, public-use data.

2.2. Variable operationalization

The primary independent variables were the ACP measures, including a living will and DPOAH. To examine the combined effects of having a living will and DPOAH, we created a summary variable with the following groupings: none, at least 1 (either living will or DPOAH), and both. Doctor visits were reported as the number of times the participant had seen or talked to a medical doctor about their health, including emergency department visits, clinic visits, or house calls in the last two years, excluding hospital stays and outpatient surgery. Other demographic and health status variables utilized were age, race (white/black/other), education (< 12 years/13+ years), rurality (urban/rural), gender (male/female), marital status (married/partnered vs. single/widowed), and limitations in activities of daily living (none/1+). The number of chronic conditions was categorized based on the underlying distribution of the variable into 0, 1–3, and 4+ [16]. Participants were grouped into cognition categories using a Langa-Weir approach (normal cognition > 11 points vs. dementia/impaired cognition ≤ 11 points) [15].

2.3. Data analysis

SAS (<https://www.sas.com/>) Version 9.4 was used for data analyses. To account for the complex sampling design, weighted descriptive statistics were calculated using the ‘proc surveyfreq’ and ‘proc surveymeans’ procedures [17]. Regarding inferential statistics, we used standard general linear models (weighted models were not used due to bias [17]) to compute the adjusted mean number of doctor visits by cognition group. A natural log transformation of the variable was computed for modeling purposes due to skewness of the distribution. All adjusted means presented have been back-transformed. All models were adjusted for education, gender, race, marital status, chronic conditions, and limitations in activities of daily living.

3. Results

The participants’ mean age was 67 years. Most participants had 13 or more years of education, one to three chronic conditions, and no limitations in activities of daily living.

The mean number of doctor visits was 5.2 (ranged 0 to 96) (Table 1). For both cognition groups, having some type of ACP resulted in a significantly higher mean number of visits after adjusting for demographic and health factors (Table 2). For participants in the normal cognition group with no living will or DPOAH, the number of doctor visits was 4.7. In this group, having a living will or DPOAH was associated with 5.9 and 5.8 doctor visits, respectively. We noted similar results for the group with dementia/impaired cognition (4.4 and 4.4, respectively). In this group, participants with no living will or DPOAH had 3.1 doctor visits. Across both cognition groups, having at least one ACP measure was associated with a significantly higher number of visits. There was no significant difference in mean doctor visits between participants with one ACP measure and participants with both measures in either cognition group.

4. Discussion

The present study demonstrated that ACP was associated with more outpatient/doctor visits in a cohort of older adults with normal cognition and dementia/impaired cognition. This is the first known study to incorporate outpatient visits into the research on ACP and healthcare utilization among older adults with dementia/impaired cognition. These findings align with our previous work that found ACP was associated with extended stays in hospitals, nursing homes, and home health care in a retrospective cohort study of 17,698 HRS participants with dementia/impaired cognition and normal cognition [13].

The results of the present and the previous study may indicate that those research participants who had easy access to healthcare or who were more likely to seek healthcare services had more opportunities to access ACP, or vice versa, than other participants. An alternative explanation for increased healthcare utilization among those with ACP could be related to fragmented care and a resulting deficit in communication between care providers. More research is needed to explain the link between increased healthcare utilization and ACP, as well as to explore healthcare-seeking behaviors and the underlying causes of outpatient visits.

The present study also showed that participants with normal cognition had more outpatient visits on average compared to participants with dementia/cognitive impairment. Our previous study on the same cohort can explain this result, as it indicated that persons with dementia/cognitive impairment had extended stays in hospitals and nursing homes, and as such, may have been less likely to utilize outpatient care [13]. These results are also consistent with Chen and colleagues' results that patients with severe dementia had lower outpatient visits and, in turn, greater hospital and nursing home admissions compared to patients with less advanced dementia [3].

Our study is not without limitations. For example, our secondary data analysis is constrained by the availability of data and measurement tools. More specifically, studying ACP using traditional mechanisms like a living will and DPOAH may not fully capture the breadth of ACP, which involves a range of formal and informal methods for medical decision-making, such as discussions with healthcare providers and family members [18]. In addition, a significant portion of our sample comprises participants under the age of 65. Expanding our

research to include older participants and those in the final months of life (e.g., utilizing the HRS Exit File for data on deceased participants) would be valuable in examining healthcare utilization more comprehensively within the context of ACP. Further research is needed to focus on older adults with dementia/cognitive impairment to better understand healthcare utilization and ACP, especially in relation to addressing the unique needs of dementia-specific ACP [19].

5. Conclusion

In conclusion, this study has reinforced our prior findings by demonstrating a significant association between ACP and healthcare utilization among older adults with normal cognition and dementia/impaired cognition [13]. Specifically, it has shown increased outpatient/doctor visits in participants who engaged in ACP. The consistency of results indicating increased healthcare utilization observed with ACP engagement emphasizes the critical need to integrate healthcare access into ACP research. Furthermore, the findings highlight the potential for targeted intervention studies in the realm of dementia-specific ACP to address the unique needs of individuals with cognitive impairment.

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References

- [1]. Alzheimer's Association, "2022 Alzheimer's disease facts and figures," 2022. [Online]. Available: <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>.
- [2]. Cunningham E, McGuinness B, Herron B, Passmore A. Dementia. *Ulster Med. J* 2015;84(2):79–87. [PubMed: 26170481]
- [3]. Chen YH, Lai YC, Wu YC, Sasaki J, Tsai KT, Ho CH. Healthcare utilization in different stages among patients with dementia: a nationwide population-based study. *Int. J. Environ. Res. Public Health* 2021;18(11). 10.3390/ijerph18115705.
- [4]. Sampson EL, et al. Living and dying with advanced dementia: a prospective cohort study of symptoms, service use and care at the end of life. *Palliat. Med* 2018;32(3): 668–81. 10.1177/0269216317726443. [PubMed: 28922625]
- [5]. McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? *A Scoping Review. J. Am. Geriatr. Soc* 2021;69(1):234–44. 10.1111/jgs.16801. [PubMed: 32894787]
- [6]. Bazargan M and Bazargan-hejazi S, "Disparities in palliative and hospice care and completion of advance care planning and directives among non-hispanic blacks : a scoping review of recent literature," vol. 38, no. 6, pp. 688–718, 2021, doi:10.1177/1049909120966585.
- [7]. Rahemi Z, et al. Advance care planning among older adults with cognitive impairment. *Am. J. Hosp. Palliat. Med* 2022;0(0):1–8. 10.1177/10499091221146255.
- [8]. Sudore RL, et al. Defining advance care planning for adults: definition from a multidisciplinary delphi panel. *J. Pain Symptom Manag* 2017;53(5):821–32. 10.1016/j.jpainsymman.2016.12.331.Defining.

- [9]. Rahemi Z Planning ahead for end-of-life healthcare among iranian-american older adults: attitudes and communication of healthcare wishes. *J. Cross. Cult. Gerontol* 2019;34(2). 10.1007/s10823-019-09371-x.
- [10]. Choi S, Kim M, McDonough IM. Do older adults with Alzheimer’s disease engage in estate planning and advance care planning preparation? *Aging Ment. Heal* 2019; 23(7):872–9. 10.1080/13607863.2018.1461192.
- [11]. Gaster B, Larson EB, Curtis JR. Advance directives for dementia meeting a unique challenge. *JAMA - J. Am. Med. Assoc* 2017;318(22):2175–6. 10.1001/jama.2017.16473.
- [12]. Dixon J, Karagiannidou M, Knapp M. 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. *J. Pain Symptom Manage* 2018;55(1): 132–50. 10.1016/j.jpainsymman.2017.04.009. e1. [PubMed: 28827062]
- [13]. Rahemi Z, et al. Healthcare utilization and advance care planning among older adults across cognitive levels. *J. Appl. Gerontol* 2023;7334648231. 10.1177/07334648231191667.
- [14]. Rahemi Z, Williams CL, Tappen RM, Engstrom GA. Health-related decisions for serious illness among ethnically diverse older adults. *Adv. Nurs. Sci Jan.* 2018;41 (1):84–97. 10.1097/ANS.000000000000192.
- [15]. Langa K, Weir D, Kabeto MM, and Sonnega A, “Langa-Weir classification of cognitive function (1995 onward). Survey Research Center, Institute for Social Research, University of Michigan.” [Online]. Available: https://hrsdata.isr.umich.edu/sites/default/files/documentation/data-descriptions/Data_Description_Langa_Weir_Classifications2016.pdf.
- [16]. Bailar JC, Mosteller F. *Medical Uses of Statistic*. Waltham, MA: Massachusetts Medical Society; 2003.
- [17]. Winship C, Radbill L. Sampling weights and regression analysis. *Sociol. Methods Res* 1994;23(2):230–57. 10.1177/0049124194023002004.
- [18]. Rahemi Z, Parker V. Does culture matter? Young and middle-aged Iranian-American adults’ perspectives regarding end-of-life care planning. *Am. J. Hosp. Palliat. Med* 2021;39(5):555–61. 10.1177/104990912111036894.
- [19]. Van den Block L Advancing research on advance care planning in dementia. *Palliat. Med* 2019;33(3):259–61. 10.1177/0269216319826411. [PubMed: 30758274]

Table 1

Descriptive statistics for the 2014 Health and Retirement Study cohort.

Characteristics	Weighted n (%) or mean [SE]
Age (years)	67 [0.2]
Education	
12 years	8813 (45.1)
13+ years	8196 (54.9)
Gender	
Male	7248 (45.9)
Female	9843 (54.1)
Race	
White	12,287 (83.0)
Black	3338 (10.2)
Other	1420 (6.8)
Marital status	
Married/partnered	13,143 (75.8)
Single/widowed	3943 (24.2)
Living Will	
Yes	5063 (52.2)
No	4729 (47.8)
Durable power of attorney for healthcare	
Yes	5311 (53.6)
No	4514 (46.4)
Joint living will or DPOAH	
Both	4378 (45.5)
At least 1	1515 (14.6)
None	3840 (39.9)
Chronic conditions	
0	2013 (14.1)
1–3	11,477 (67.6)
4+	3600 (18.3)
Limitations in activities of daily living	
None	13,953 (84.6)
1+	3126 (15.4)
Rurality	
Rural	12,714 (73.3)
Urban	4285 (26.7)
Doctor visits (number)	5.2 [0.27]

Table 2

The adjusted mean number of doctor visits by advanced directive measure, Health and Retirement Study, 2014.

ACP Variable	Doctors' Visits			
	Normal Cognition		Dementia and Impaired Cognition	
	Adjusted Mean Visits	<i>p</i> -value	Adjusted Mean Visits	<i>p</i> -value
Living Will				
Yes	5.9	<0.01	4.4	<0.01
No	4.8		3.3	
DPOAH				
Yes	5.8	<0.01	4.4	<0.01
No	4.8		3.3	
Joint				
Effects	5.9	<0.01 [*]	4.5	<0.01 [*]
Both		0.04 [†]		0.54 [†]
At Least One	5.4	<0.01 [*]	4.2	<0.01 [*]
None	4.7		3.1	

* Compared to 'none';

[†] Compared to 'at least one'