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Permalink

https://escholarship.org/uc/item/8qx8q58j

Journal

Neurology. Clinical practice, 12(1)

ISSN

2163-0402

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Publication Date

2022-02-01

DOI

10.1212/cpj.000000000001123

Peer reviewed

Advance Directive and POLST Documentation in Decedents With Dementia at a Memory Care Center

The Importance of Early Advance Care Planning

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Neurology: Clinical Practice February 2022 vol. 12 no. 1 14-21 doi:10.1212/CPJ.00000000001123

Abstract

Background and Objectives

To determine the frequency of and challenges to documentation of advance care planning (ACP) in people with dementia, we conducted a chart review of 746 deceased patients seen at a tertiary memory care center between 2012 and 2017.

Methods

The rates of documented advance directives (ADs), Physician Order

for Life-Sustaining Treatment (POLST), and Do Not Resuscitate

(DNR) status were calculated from review of institutional electronic health records. Regression analysis was used to determine associations between ACP documentation and patient characteristics.

Results

At the time of death, approximately half of the patients had a documented AD and/or DNR status and 37% had a documented POLST; 30% of patients did not have any ACP documentation. Whereas most of the ADs were documented more than 5 years before time of death, POLST and DNR status were documented more frequently within 2 years of time of death. People who presented to clinic at a younger age and who primarily spoke English were more likely to have documented ADs. People living in zip codes with lower household incomes were 2–4.5 times less likely to have a POLST or DNR documentation.

Discussion

ACP is underutilized in people with dementia, even among those seen in a specialty memory care center. ACP should be introduced early on for people with dementia to ensure patients have a voice in their care.

Dementia refers to a progressive loss of memory or other cognitive domains, which is severe enough to interfere with daily function.¹ The lack of a cure for the many neurodegenerative

GBHI dementia geriatric palliative care writing group coinvestigators are listed in Appendix 2 at the end of the article.



Global Brain Health Institute (GN, KLH, TDAR, BP-C, SM, BLM, CSR), University of California, San Francisco; Department of Neurology (GN, BLM), Mount Sinai Hospitals, Ichan School of Medicine, New York, NY; Division of Geriatrics (NDB, KLH, SBG), Department of Medicine, University of California, San Francisco; Philip R. Lee Institute for Health Policy Studies (SBG), University of California, San Francisco; CA; Department of Neurology (TDAR), University of Louisville, Kentucky; Hospital Civil de Guadalajara (Hospital Civil Fray Antonio Alcade) (BP-C), Guadalajara, Jalisco, Mexico; and The Mongan Institute and the Division of Palliative Care and Geriatric Medicine (CSR), Department of Medicine, Massachusetts General Hospital, Boston, MA.

Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

diseases that constitute dementia, including Alzheimer disease, makes dementia a progressive and ultimately terminal illness. People with dementia (PWD) and their families face many challenges throughout the course of their illness, including decision-making about a multitude of treatment choices as disease progresses for PWD.² Common decisions include tube feeding, treatment of infections, hospitalizations for an acute event, and life-sustaining treatment. Advance care planning (ACP) fosters discussion of personal values, life goals, and preferences regarding future medical care.^{3,4} ACP early after a dementia diagnosis allows PWD to participate in or express preferences for decision-making regarding their immediate care, treatment preferences, and future end-of-life care. These discussions ideally occur before progression to cognitive impairment or inability to express any preferences⁵. ACP also has the potential to prepare proxies for medical decision-making when the person they are representing can no longer speak for themselves and reduce caregiver burden at the end of life.⁶

ACP can be documented in various ways, including through an advance directive (AD), a Physician Order for Life-Sustaining Treatment (POLST), and a Do Not Resuscitate (DNR) order. An AD is a legal document that identifies a health care proxy and/or articulates personal wishes for various health care decisions. The POLST is a medical order recognized in 48 states, which contains specific decisions regarding DNR status, level of medical care intensity, and artificial feeding.⁷ Different states may have different names for it, including Medical Order for Life-Sustaining Treatment. The primary purpose of the POLST is to guide first responders and emergency departments in the respective topics contained on the form. Independently, a DNR status can be documented in the chart in the absence of a POLST and usually is only recognized during a hospitalization.

The importance of ACP is widely recognized among practitioners caring for people with dementia. However, it is insufficiently discussed in community-dwelling people living with dementia,⁸ rarely discussed and documented in nursing home residents,^{9,10} and often not attended to in primary care or specialty visits.

We therefore conducted this study to better understand the documentation of ACP in the context of an outpatient tertiary dementia care center. We also aimed to understand the various patient characteristics and socioeconomic factors associated with ACP documentation.

Methods

Sample

We identified all patients who were seen at the Memory and Aging Center (MAC), at the University of California, San Francisco (UCSF) between 2012 and 2017, who carried a diagnosis of dementia of any type, and who were deceased as of December 31, 2018. The MAC is a tertiary specialty care center that provides evaluation and management of patients living with dementia across the Bay Area, California, and other states. We queried the center's Electronic Health Record (EHR) to identify the aforementioned sample. We queried the center's EHR system to identify the aforementioned sample. Death was verified by cross-referencing state public death records. Dementia diagnosis was manually verified during chart review. A behavioral neurologist (G.N.) reviewed all cases in which records did not include a straightforward dementia diagnosis. Figure 1 includes a flowchart of the sample inclusion process.

Standard Protocol Approvals, Registrations, and Patient Consents

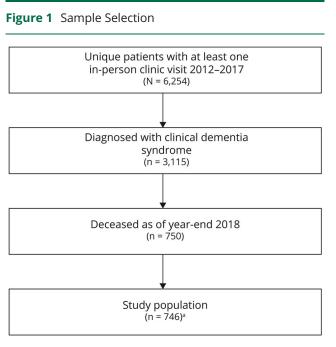
This study was reviewed and approved by UCSF institution's internal review board. A waiver was granted for informed consent (Approval # 18-25610).

Data Abstraction

We conducted a retrospective chart review, combining manual data abstraction and automated report generation. We double-coded 5% of the manually abstracted EHR data (T.R. and B.P.) and achieved an inter-rater reliability, measured as the percentage agreement of unique data fields with matching values between raters, more than 90%. Any discrepancies were verified or corrected based on rereview and group consensus (T.R., B.P., N.B., G.N., and C.R.). For every participant, we abstracted and coded demographic data, including sex, race, primary spoken language, marital status, and level of education. We also coded age at presentation to the clinic, primary dementia diagnosis, and medical insurance type. Our primary measure was a categorical variable noting the presence or absence of each of the following: a documented AD, a POLST, or an in-hospital DNR order. We also collected participants' primary address' zip code and extracted the median income bracket and population density by zip code from the California income statistics website.¹¹

Data Analysis

We determined the frequency of documented AD, POLST, DNR status, or any ACP element and the time between documented ACP element and time of death. We performed a generalized linear regression model with a log link and the Poisson distribution with robust variance estimator to evaluate the effect of 11 demographic factors on ACP documentation, including age, sex, marital status, primary language, race, education, type of dementia diagnosis, hospice at time of death, neighborhood population density, and median neighborhood income. Four regression models were designed for each of the dependent variables: AD, POLST, DNR, and any ACP element. This was performed to capture whether some variables affected some ACP elements more than others because each of the AD, POLST, and DNR status elements contain different information and serve different roles. The independent variables were coded as categorical variables, either binary, in the case of sex, marital status, or primary language (English speakers and English as a



^aFour patients were excluded from final study sample because of special electronic medical record privacy restrictions.

secondary language), or multiple categories such as in patients of age (younger than 65, 65–74, and 75–84 years, and older than 85 years), diagnosis (Alzheimer disease, dementia with Lewy body disease, and other dementia), and median neighborhood income. Results are presented as risk ratios with corresponding 95% confidence intervals. Significance was set at p < 0.05. Missing data were excluded from the analysis. Analyses were performed using Microsoft Excel and Stata 15.1 (64 bit).

Data Availability

The deidentified data that support the findings of this study are available on request from the corresponding author (N.D.B.). The data are not publicly available because they contain information that could compromise the privacy of research participants.

Results

A total of 746 patients were included in the analysis. The mean age at presentation was 75 years; most of the participants were English-speaking, were of White descent, and had Medicare insurance. There was sex balance in the sample. Demographics results are given in the Table.

At the time of death, 53% of participants had an AD documented in their chart at any point in time, 37% had a POLST, and 48% had a DNR status documented in their medical record (either noted during hospitalization or from a completed POLST form). Overall, almost a third of participants had no documentation of ACP. Of those with ACP, 10% had only a DNR status at the time of death. A small number of participants had meaningful changes to their ACP that occurred in the final days of a terminal hospitalization (n = 29, 6%). These included new initiation of a DNR (n = 21, 72%), completion of a first-time POLST (n = 4, 14%), and 1 firsttime advanced directive. Seven of these individuals had no previous ACP.

The timing of the documented ACP varied by element, with most of the ADs documented more than 5 years from time of death and most of the POLST and DNR status were documented within 5 years of death (Figure 2). The timing of documented ACP relative to the time participants was under the care of the MAC was also examined. Most of the ADs were documented before the first MAC visit (64%) while most of the DNR status (81%) and approximately half of POLST (43%) were documented after the last MAC visit (Figure 3). In 2012, the MAC added a query in their intake form that asked about the presence of advance directives. Before this addition, ACP rates were steady from year to year; subsequently, ACP completion rates increased 3.1% on average, from year to year (15.6% over 5 years).

Among those who had a designated power of attorney (DPOA, n = 280, 38%), slightly less than half (n = 123, 44%) named their spouse as DPOA and an equal number (n = 122, 44%) named a child or a child-in-law. In patients who had a documented POLST (n = 138), only 16% of them signed their POLST themselves. The spouse or child signed the POLST 54% of the time. The POLST selections were for DNR status in 90% of the cases, comfort measures in 35% of the cases, and no artificial nutrition in 57% of the cases. Among the completed POLSTs, 7.6% indicated a desire for full treatment and 9% chose long-term artificially administered nutrition.

Nearly half of patients (n = 348, 47%) were on hospice at their time of death. Of whom, 295 (85%) had documented ACP in their medical chart at the time of death. For patients who were not on hospice, just 230 (58%) had some form of ACP documentation.

Generalized linear regression multivariate analyses, controlling for age, sex, education, hospice, and clinical dementia diagnosis, revealed several factors associated with ACP documentation: higher rates of hospice election, older age at presentation, English as preferred language, and zip code associated with lower average income.

The strongest predictor of ACP status was hospice: patients on hospice at the end of life were 1.4 times as likely to have ACP documentation, 1.3 times as likely to have an AD, 2.3 times as likely to have a DNR, and 2.7 times more likely to have a POLST (p < 0.01). People at age 75+ years were 1.3 times more likely to have any ACP or an AD (p < 0.05) compared with people younger than 65 years. People aged 85+ years were 1.3 times more likely to have any ACP or an AD (p < 0.05), 1.6 times as likely to have a DNR, and 1.7

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Table Demographics

Characteristic	No. of participants (%
Sex	
Male	365 (49)
Female	381 (51)
Age ^a , yrs	
Younger than 65	113 (15)
65-74	223 (30)
75-84	264 (35)
85+	146 (20)
Age (y)	
Race	
White	513 (69)
Asian	78 (10)
Black/African American	28 (4)
Hispanic or Latino	39 (5)
Other	44 (6)
Unknown/declined	44 (6)
Primary language	
English	650 (87)
Other	93 (12)
Unknown/declined	3 (0)
Marital status	
Married	459 (62)
Widowed	126 (17)
Divorced	57 (8)
Single	59 (8)
Other	4 (1)
Unknown/declined	41 (5)
Insurance	
Medicare	628 (84)
Private	97 (13)
Medi-Cal	14 (2)
Self-pay	7 (1)
Education	
High school diploma or less	167 (22)
College degree or some college	294 (39)
Graduate or professional degree	200 (27)
Unknown/not documented	85 (11)
Education (y)	

Table Demographics (continued)

Characteristic	No. of participants (%)
Primary dementia diagnosis ^b	
Alzheimer disease	387 (52)
Dementia with Lewy bodies	126 (17)
Other motor-based dementia	76 (10)
Frontotemporal dementia	42 (6)
Language-based dementia	36 (5)
Other	79 (11)
Median income bracket in zip code ^c	
25–50 k	64 (9)
50–75 k	141 (19)
75–100 k	184 (25)
100–125 k	156 (21)
125–150 k	104 (14)
150 k+	69 (9)
Unknown/declined	28 (4)
Enrolled in hospice at death	
Yes	348 (47)
No	399 (53)

^a Age at presentation to memory care clinic.

^b Alzheimer dementias: Alzheimer disease (AD), posterior cortical atrophy; Lewy body dementias (LBDs): LBD, LBD-AD, Parkinson disease dementia; motor-based dementias: corticobasal syndrome, progressive supranuclear palsy; language-based dementias: semantic dementia and logopenic and nonfluent primary progressive aphasia.

^c Determined from US Census demographic data based on participant's zip code.

times as likely to have a POLST (p < 0.01). English speakers were 1.5 times more likely to have an AD than non-English speakers (p < 0.01). Finally, people living in neighborhoods with household incomes 25–50 K were 2.2–2.9 times less likely to have a POLST or DNR compared with households with higher income (p < 0.01). Sex, education level, clinical dementia diagnosis, marital status, and insurance coverage were not significant.

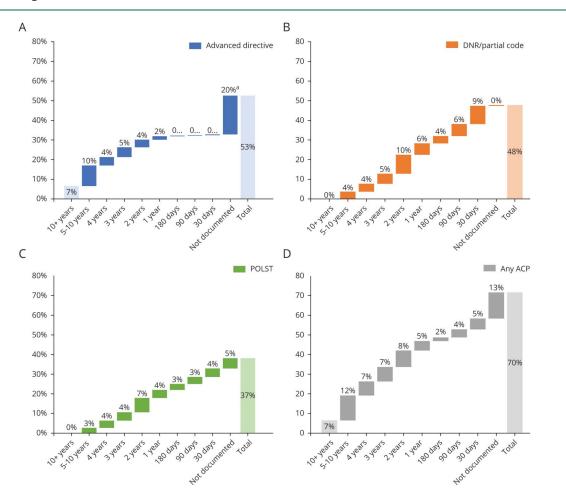
Discussion

Our findings reveal that at least a third of patients living with dementia who had received care from a tertiary memory care center had no documented ACP by the time of death. Presenting at an older age, speaking English, and living in wealthier neighborhoods were associated with a higher likelihood of a documented ACP. Our finding relating older age to a higher likelihood of ACP documentation mirrors a previous study of PWD, which showed for each additional year of age, a 3% increase in the likelihood of having a discussion about ACP.¹² However, a

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Figure 2 Timing of ACP Documentation From Time of Death



A = advanced directive; B = DNR/partial code status; C = POLST; D = Any ACP. \Box Participants with the relevant ACP for whom the effective date of said document was unknown. Notes: Most of the ADs with unknown dates (105 of 147, 71%) are from a self-reported questionnaire administered at the first visit to the University of California, San Francisco Memory and Aging Center, which asked patients and families whether they had a Power of Attorney for Health care or Advanced Directive on file. If a participant had multiple instances of ACP documentation, they are counted under the earliest instance in all graphs presented above. ACP = advance care planning; DNR = Do Not Resuscitate; POLST = Physician Order for Life-Sustaining Treatment.

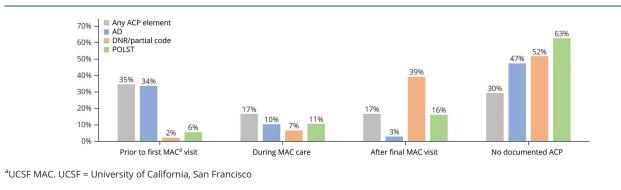
prospective cross-sectional study conducted in another specialized memory care center found that patients aged younger than 65 years were significantly more likely than older patients to complete ACP after learning they had AD.¹³ Although increase in ACP documentation with increased age follows trends seen in people without dementia (albeit at lower rates), the finding of higher ACP completion in those with young-onset dementia may reflect a recognition in younger populations of the relative rarity of earlyonset disease and the need for patients (especially if they have dependents) to plan proactively for the future.

Our findings showing higher ACP completion rates in wealthier neighborhoods align with other studies demonstrating lower ACP completion rates among people living in lower socioeconomic conditions.¹⁴ Reasons for these differentials in ACP documentation may reflect communication barriers between clinicians, patients, and their families; reduced health literacy in completing ACP forms; and

mistrust in health care¹⁵ and argue for thoughtful and proactive efforts to reduce these disparities. What strategies are most effective for reducing disparities in PWD warrants additional research. A recent study using a video decision aid showed promising findings.⁴

The lack of proxy designation or delineation of preferences (as indicated by documented ACP) makes it difficult to care for patients in ways that are consistent with their personal wishes and goals of care. Previous studies show that caregivers of PWD find early ACP helpful to know the patient's wishes in case they had to make a decision on their behalf.¹⁶ Among nursing home residents with dementia, those with a documented ACP were judged by their relatives to have had better ratings of emotional well-being while dying when compared with those who had no documented ACP.¹⁷ In our study, we also found that even in patients with documented ACP, the documented information often may not reflect the patient's self-formulated wishes because the timing of the documented POLSTs and DNR

Figure 3 Timing of Advance Care Planning Relative to UCSF Memory and Aging Center (MAC) Visits



statuses occurred close to the time of death, when patients are likely to be advanced in their cognitive illness. In addition, 84% of POLST forms was signed by a surrogate. Therefore, it is unclear whether the documented choices reflect the patient's or the surrogate's decisions.

Our results are consistent with previous literature that suggests that people living with dementia are less likely to have completed AD than those without dementia and persons with dementia living at home are less likely to have ACP documentation compared with patients who are in facility settings.⁵ Data analyzed from the Health and Retirement Study in 2016 revealed that 65.3% of people with probable dementia had a durable power of attorney, which is only slightly higher than our findings for the frequency of documented AD and consistent with our finding that at least a third of people with dementia have no documented ACP.¹⁸ Our study is among the first to demonstrate that low ACP rates among those with dementia are not necessarily increased by virtue of being seen in a specialty memory care center. Although the goal of specialty dementia memory care centers often revolves around diagnosis, ACP would also be a valuable goal. Features of an effective and sustainable intervention for early ACP completion would include structured feedback, audits, support for the decisions of patients and families, and an ACP champion to foster energy and momentum around ACP documentation.¹⁹ It is worth noting that adding a simple query regarding ACP in an intake form was associated with subsequent modest increases in ACP documentation. Although not causal, this finding points to the potential value of adding an ACP query into the initial assessment in a specialty memory care center.

There are several studies that suggest barriers and facilitators to ACP in PWD. Some barriers included the lack of clarity and consensus among the medical community as to which discipline should initiate ACP discussions in people living with dementia and suggest that providers specialized in dementia are well placed to initiate such discussions.¹⁶ Another barrier was the readiness of patients to discuss ACP. The best time to discuss ACP may be soon after diagnosis when patients have had time

to think about the diagnosis and the future but still have the capacity to make decisions about future care. A cross-sectional observational study at a geriatric and memory clinic found it likely that not only acceptance of illness drove ACP discussion but also ACP discussion helped to increase acceptance of diagnosis.²⁰ Some previously studied facilitators to ACP discussion included early diagnostic disclosure, favorable relationship between patients and their health care providers, and discussions of patients' values and quality of life goals.²¹ We recommend that ACP discussions begin at the time of diagnostic disclosure. Neurologists can normalize these discussions by talking about the value of ACP for everyone and the particular value of ACP in ensuring one has a say in future treatment decisions.

Our study had some important limitations to consider, including its retrospective design. We used data from electronic medical records, which may not capture all ACP documentation. However, the results are still relevant because nondocumented AD, POLST, and DNR statuses are not visible to the medical teams who conduct medical decisions that may go against a person's wishes. Another limitation was our lack of access to comprehensive measures of wealth and socioeconomic status. Although approximate household income by zip code may provide some useful information, it is unable to capture the full breadth of our sample's socioeconomic status. We note that throughout the 5 years of the study span, there were no changes in clinic procedures to affect ACP documentation.

In summary, we found that at least 30% of people living with dementia have no ACP documentation at the time of death. Some factors that may affect ACP documentation include age at presentation, language, and socioeconomic status. Some immediate opportunities for clinical practice may include systematic integration of ACP into diagnostic disclosure discussions and reviewing POLST forms earlier in the disease course. Furthermore, our findings indicate that the window to discuss ACP may be shorter than providers think because these patients are often lost to follow-up because they develop more functional limitations. ACP conversations should be integrated into routine specialty memory care and efforts made to reduce disparities in ACP documentation by language and SES.

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Acknowledgment

Research reported in this publication was conducted with support from the Global Brain Health Institute. All analyses, interpretations, and conclusions reached through this project are the sole responsibility of the authors. The authors thank Kanan Patel for her assistance in data acquisition.

Study Funding

The study was supported by the Global Brain Health Institute. Dr. Harrison was supported by funding from NIH (KL2TY001870 and K01AG059831).

Disclosure

G. Naasan, N.D. Boyd, K.L. Harrison, S.B. Garrett, T. D'Aguiar Rosa, B. Pérez-Cerpa, S. McFarlane, B.L. Miller, and C.S. Ritchie report no disclosures relevant to the manuscript. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

Publication History

Received by *Neurology: Clinical Practice* February 3, 2021. Accepted in final form July 6, 2021.

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Georges Naasan, MD	Mount Sinai, New York City	Drafting/revision of the article for content, including medical writing for content; study concept or design; and analysis or interpretation of data	
Nicole D. Boyd, BA	University of California, San Francisco	rnia, Drafting/revision of the article for content, including medical writing for content; major role in the acquisition of data; I1Study concept or design; and analysis or interpretation of data	
Krista L. Harrison, PhD	University of California, San Francisco	Drafting/revision of the article for content, including medical writing for content; study concept or design; and analysis or interpretation of data	
Sarah B. Garrett, PhD	University of California, San Francisco	Drafting/revision of the article for content, including medical writing for content; study concept or design; and analysis or interpretation of data	
Talita D'Aguiar Rosa, MD, MS	University of Louisville, Louisville	Major role in the acquisition of data; study concept or design	
Brenda Pérez- Cerpa, MD	Hospital Civil de Guadalajara, Guadalajara	Major role in the acquisition of data; study concept or design	

Name	Location	Contribution	
Shamiel McFarlane, MBBS, MSc	University of California, San Francisco	Major role in the acquisition of data and analysis or interpretation of data	
Bruce L. Miller, MD	University of California, San Francisco	Drafting/revision of the article for content, including medical writing for content	
Christine S. Ritchie, MD, MSPH			

Appendix 2 Coinvestigators

Name	Location	Role	Contribution
Alissa Bernstein, PhD, MPH, MA	University of California, San Francisco	Coinvestigator	Participated in study group discussions & logistics management
Maritza Pintado-Caipa, MD	University of California, San Francisco	Coinvestigator	Participated in study group discussions & logistics management

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