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The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care

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See related Editorial by Soo Borson in this issue.

BACKGROUND/OBJECTIVES: Although Alzheimer disease and other dementias are life limiting, only a minority of these patients or their proxy decision makers participate in advance care planning. We describe end-of-life care preferences and acute care and hospice use in the last 6 months of life for persons enrolled in a comprehensive dementia care management program.

DESIGN: Observational, retrospective cohort.

SETTING: Urban, academic medical center.

PARTICIPANTS: A total of 322 persons enrolled in dementia care management after July 1, 2012, who died before July 1, 2016.

INTERVENTION: Dementia care comanagement model using nurse practitioners partnered with primary care providers and community organizations to provide comprehensive dementia care, including advance care planning.

MEASUREMENTS: Advance care preferences, use of Physician Orders for Life Sustaining Treatment (POLST), hospice enrollment, and hospitalizations and emergency department (ED) visits in the last 6 months of life obtained from electronic health record data.

RESULTS: Nearly all decedents (99.7%, N = 321) had a goals-of-care conversation documented (median = 3

conversations; interquartile range = 2-4 conversations), and 64% had advance care preferences recorded. Among those with recorded preferences, 88% indicated do not resuscitate, 48% limited medical interventions, and 35% chose comfort-focused care. Most patients (89%) specified limited artificial nutrition, including withholding feeding tubes. Over half (54%) had no hospitalizations or ED visits in the last 6 months of life, and intensive care unit stays were rare (5% of decedents). Overall, 69% died on hospice. Decedents who had completed a POLST were more likely to die in hospice care (74% vs 62%; $P = .03$) and die at home (70% vs 59%; $P = .04$).

CONCLUSIONS: Enrollees in a comprehensive dementia care comanagement program had high engagement in advance care planning, high rates of hospice use, and low acute care utilization near the end of life. Wider implementation of such programs may improve end-of-life care for persons with dementia. *J Am Geriatr Soc* 67:443-448, 2019.

Key words: dementia; end of life; care management

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Advance care planning is a critical component of high-quality care for persons with Alzheimer disease and other dementias, which are progressive, incurable diseases with an expected decline in cognition and function until death. Engaging persons with dementia and their family caregivers in goals-of-care conversations, eliciting and documenting care preferences, and identifying a designated proxy decision maker are widely accepted care processes identified as necessary for the delivery of high-quality dementia care.¹⁻⁴ Studies have shown that persons with dementia or their designated family decision makers may desire less aggressive care as the disease progresses,^{5,6} including choosing not to be resuscitated or hospitalized

and enrolling in hospice services. However, persons with dementia may receive unwanted care at the end of life because aggressive interventions, including cardiopulmonary resuscitation (CPR) and intubation, are the default in US acute care settings if care preferences are unknown. Moreover, lack of an advance directive,⁷ multiple care transitions from hospital to nursing home,^{8,9} and placement of feeding tubes^{10,11} have been associated with poor outcomes among persons with dementia, including decubitus ulcers, late enrollment in hospice, receipt of care in the intensive care unit (ICU) in the last month of life, and in-hospital death.

Despite the known benefits of engaging persons with dementia and their caregivers in these discussions, only a minority of patients with dementia or their proxy decision makers participate in end-of-life advance care planning or receive palliative care services in community settings.^{12,13} Busy primary care providers often lack the time, and sometimes the skills, needed to engage in end-of-life care planning conversations, which can be challenging, emotional, and lengthy. Tools have been developed to help providers elicit and document care preferences and promote shared end-of-life decision making among seriously ill patients,^{14,15} including the Physician Orders for Life Sustaining Treatment (POLST) (www.polst.org), but these have not been widely integrated into clinical practice.

Comprehensive dementia disease management programs have also been developed to address poor quality of care in dementia, including low rates of advance care planning and low use of palliative care and hospice services.^{1,16} The University of California, Los Angeles (UCLA), Alzheimer's and Dementia Care (ADC) program,¹⁷ a longitudinal, comprehensive nurse practitioner dementia comanagement program, was launched in November 2011 and has resulted in high quality of care, with pass rates exceeding 90% on advance care planning process-of-care measures.¹⁸

The purpose of this study was to examine end-of-life care in a dementia care program that specifically addressed advance care planning with all participants. We examined end-of-life care preferences, use of the POLST, place of death, and acute care and hospice use in the last 6 months of life for UCLA ADC program decedents.

METHODS

We examined advance care preferences, POLST completion, and hospital, emergency department (ED), and hospice use in the last 6 months of life for 322 decedents enrolled in a comprehensive dementia care management program over a 4-year period from July 1, 2012, to June 30, 2016. The UCLA Institutional Review Board (IRB) reviewed the study protocol and determined that the study did not constitute human subjects research as all participants were decedents (IRB number 13-001480).

Description of the Clinical Program and Study Population

The UCLA ADC program is based at an urban, academic healthcare system and partners with community-based organizations to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer disease and other

dementias. The goals of the ADC program include maximizing patient function, independence, and dignity while minimizing caregiver strain and reducing unnecessary costs. The ADC program, which is a comanagement program with nurse practitioner dementia care managers and partnering physicians,¹⁹ consists of five key components: structured needs assessments of patients and their caregivers; creation and implementation of individualized dementia care plans; monitoring and revising care plans; referral to community organizations for dementia-related services and support; and access to a clinician 24 hours a day, 7 days a week for assistance and advice. Program enrollees must have a diagnosis of dementia, be community dwelling at the time of enrollment, and be referred by a UCLA provider. Decedents were enrolled in the ADC program for 14.8 months on average (SD = 10.1 months; range = 1-44 months).

Measures and Data Collection

Data were abstracted from the UCLA electronic health record (EHR), which is Epic based, for the last 6 months of life for each decedent. We abstracted the following information from each decedent's chart: documentation of goals-of-care conversations; documentation of an identified proxy decision maker; advance care preferences regarding CPR, medical interventions, and artificial nutrition, including use of feeding tubes; use of the POLST; hospice discussions, consults, and enrollment; and place of death. Utilization outcomes, including hospitalizations, hospital length of stay, ICU stays, and ED visits, were extracted from the EHR by UCLA information support services and provided to the study investigators.

All documentation and notes in the UCLA EHR (ie, inpatient and outpatient encounters, telephone and electronic mail encounters, goal-of-care notes, documents scanned into the EHR, and any documented correspondence among providers) were included in the abstraction. Chart abstractors also used the "Care Everywhere" feature in the EHR to abstract utilization outside of UCLA that occurred in two hospital systems that also serve west Los Angeles and use Epic-based EHRs. Three physicians (C.K., C.B., and D.R.) and one medical student (M.T.) performed medical record abstractions using a detailed chart abstraction instrument and written abstraction guidelines. Abstractors were trained by two study investigators (D.R. and N.W.) who also provided consultation for abstractors as needed. A 5% random sample of all records was reabstracted to evaluate the reliability of the abstraction process and resolve any differences among abstractors.

Statistical Analysis

Descriptive statistics were used to report demographic information, selected clinical variables abstracted from the medical record or obtained from UCLA ADC program records, goals-of-care conversations, advance care preferences, change in advance care preferences in the last 6 months of life, use of POLST, place of death, and healthcare utilization in the last 6 months of life. Hospital, ED, hospice use, and place of death were stratified by whether or not the decedent completed a POLST and compared using χ^2 test or Fisher's exact test for categorical variables and Wilcoxon-Mann-Whitney rank sum

Table 1. Description of ADC Program Decedents and Documentation of Goals-of-Care Conversations and Care Preferences (N = 322)^a

Variable	Value
Age at death (range, 56-102), y	86.7 (7.9)
Female sex	174 (54)
White, non-Hispanic (N = 242)	175 (72)
Alzheimer disease or dementia type not specified	256 (80)
Medicare and Medicaid dually insured	41 (13)
Mini-Mental State Examination score (range, 0-30)	13.3 (7.1)
No. of ADL dependencies (range, 0-6)	3.7 (2.2)
No. of IADL dependencies (range, 0-7)	6.6 (1.0)
Neuropsychiatric Inventory Questionnaire symptom severity score (range, 0-36)	11.9 (7.1)
Caregiver relationship	
Spouse/partner	110 (34)
Child	157 (49)
Other	55 (17)
Modified Caregiver Strain Index score (range, 0-26)	11.4 (6.8)
Any documented goals-of-care conversation in last 6 months of life	321 (99.7)
No. of goals-of-care conversations in the last 6 months of life (range, 1-14), median (IQR)	3 (2-4)
Advance care preference regarding cardiopulmonary resuscitation recorded in the electronic health record in the last 6 months of life	205 (64)
Completed POLST in last 6 months of life	184 (57)
Documented proxy decision maker	322 (100)

Abbreviations: ADC, Alzheimer and Dementia Care; ADL, activity of daily living; IADL, instrumental ADL; IQR, interquartile range; POLST, Physician Orders for Life Sustaining Treatment.

^aData are given as mean (SD) or number (percentage) unless otherwise indicated. Scores are the last value recorded in ADC clinical program data within 18 months prior to death.

test for continuous variables. Analyses were performed using STATA 15 (StataCorp 2017. *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC).

RESULTS

Demographic characteristics of decedents are provided in Table 1. Nearly all decedents (99.7%, N = 321) had at least one goals-of-care conversation documented in the last 6 months of life (median = 3 conversations; interquartile range [IQR] = 2-4 conversations), and 64% had a documented advance care preference regarding CPR, medical interventions, or artificial nutrition recorded in the EHR. Over half (57%) of decedents (or their proxy decision maker) had completed a POLST. All decedents had a proxy decision maker identified in the medical record (Table 1).

Among those with recorded advance care preferences, 88% of decedents or their proxies indicated a preference for do not resuscitate (DNR), 48% limited medical interventions, and 35% chose comfort-focused care. Most patients or their proxies (89%) limited artificial nutrition, with 74% choosing no artificial nutrition, including no feeding tubes (Table 2).

Fifty-one program decedents (16%) had a change in CPR preference in the last 6 months of life recorded in the medical record; nearly all (N = 47, 92%) changed from a preference of attempt CPR to DNR. Similarly, among the 43 decedents who had a recorded change in medical intervention preference, 91% (N = 39) chose less aggressive care (change from full treatment to selective treatment or change from selective treatment to comfort-focused treatment). Ninety percent of those who changed their artificial nutrition preference (19 of 21 decedents or their proxies) chose less aggressive care (change from long-term artificial nutrition to trial period or change from trial period to no artificial nutrition).

Over half of program decedents (54%) had no hospitalizations or ED visits in the last 6 months of life. A minority of decedents had recurrent hospitalizations or recurrent ED visits, with 25% having more than one hospital stay, observational stay, or ED visit in the last 6 months of life. The median number of days spent in the hospital or in the ED in the last 6 months of life among those with any acute care utilization was 2.8 days (IQR = 0.3-6.0 days; range = 0.01-51 days). Among those with any hospital stay (N = 122), the median length of stay was 5.1 days (IQR = 3.3-8.7 days). Few (5%) had an ICU stay in the last 6 months of life, and

Table 2. Care Preferences of ADC Program Decedents^a

Resuscitation and Medical Interventions Preferences		
Cardiopulmonary resuscitation	Medical interventions	Decedents with recorded care preferences (N = 205)
DNR	Comfort-focused treatment	72 (35)
	Selective treatment	98 (48)
	Full treatment or no selection made ^b	11 (5)
CPR		24 (12)
Artificially Administered Nutrition Preferences		
Long-term artificial nutrition, including feeding tubes		6 (3)
Trial period of artificial nutrition, including feeding tubes		31 (15)
No artificial means of nutrition, including feeding tubes		151 (74)
No preference recorded		17 (8)

Abbreviations: ADC, Alzheimer and Dementia Care; CPR, cardiopulmonary resuscitation; DNR, do not resuscitate.

Data reflect the last Physician Orders for Life Sustaining Treatment (POLST) completed or last goals-of-care conversation recorded in the electronic health record if no POLST was completed before death for each patient.

All recorded combinations of CPR, medical interventions, and artificial nutrition care preferences are provided in Supplementary Appendix S1.

^aData are given as number (percentage). N = 117 decedents (36%) did not have care preferences regarding CPR, medical interventions, or artificial nutrition recorded in the electronic health record.

^bNo selection was made regarding medical interventions for five decedents (1.5%).

Table 3. Hospital, ED, and Hospice Use in Last 6 Months of Life and Place of Death by POLST Completion^a

Variable	All Decedents (N = 322)	POLST Completed (N = 184)	No POLST Completed (N = 138)	P Value
Any acute care event (hospitalization, ED visit, or observational stay), No. (%)	148 (46)	94 (51)	54 (39)	.03
>1 Acute care event, No. (%)	81 (25)	56 (30)	25 (18)	.01
Total acute care days among those with any event (range, 0.01-51), median (IQR)	2.8 (0.3-6.0)	3.1 (0.6-6.6)	2.1 (0.2-4.6)	.01
Any ED visit or observational stay, No. (%)	85 (26)	53 (29)	32 (23)	.27
Any hospitalization, No. (%)	122 (38)	79 (43)	43 (31)	.04
>1 Hospitalization, No. (%)	57 (18)	41 (22)	16 (12)	.02
Hospital length of stay (range, 2-51 d), median (IQR), d	5.1 (3.3-8.7)	5.8 (3.7-8.3)	4.1 (3.1-8.9)	.22
Any ICU stay, No. (%)	17 (5)	11 (6)	6 (4)	.62
ICU length of stay (range, 0.3-27.3 d), median (IQR), d	2.5 (1.0-5.6)	2.0 (1.0-3.4)	5.8 (0.4-11.7)	.41
Place of death, No. (%) ^b				
Hospital ward or ED	49 (15)	27 (15)	22 (16)	.75
ICU	7 (2)	3 (2)	4 (3)	.45
Skilled nursing facility	39 (12)	22 (12)	17 (12)	.96
Home	211 (66)	129 (70)	82 (59)	.04
Hospice discussion or consult, No. (%)	232 (72)	144 (78)	88 (64)	.01
Died in hospice care, No. (%)	222 (69)	136 (74)	86 (62)	.03

Abbreviations: ED, emergency department; ICU, intensive care unit; IQR, interquartile range; POLST, Physician Orders for Life Sustaining Treatment.

Wilcoxon rank-sum test used to compare continuous variables, and χ^2 test or Fisher's exact test used to compare categorical variables. Comparisons with $P < .05$ are bolded.

^aHospital observational stays with length of stay less than 48 hours were grouped with ED visits. ED visits directly preceding a hospitalization were not counted as separate events. Partial days were included in calculations and rounded to the hundredth place.

^bPlace of death was unknown for 16 decedents (5%).

17% died in the hospital. Most patients died at home (66%). The majority of decedents or their proxies (72%) had a hospice discussion or consultation in the last 6 months of life, and 69% of decedents died in hospice care (Table 3).

Although decedents with a completed POLST were more likely to be hospitalized (43% vs 31%; $P = .04$), hospital length of stay, ICU stays, and ED use in the last 6 months of life did not differ by POLST completion. Decedents with a completed POLST were also more likely to have had a discussion about hospice (78% vs 64%; $P = .01$), die in hospice care (74% vs 62%; $P = .03$), and die at home (70% vs 59%; $P = .04$) (Table 3).

DISCUSSION

Enrollees in this comprehensive dementia care management program had high engagement in advance care planning, high rates of hospice use, and low acute care utilization in the last 6 months of life. Consistent with prior research,²⁰ the majority of decedents with recorded care preferences chose less aggressive care, including no CPR (88%), limited medical interventions or comfort care (83%), and limited or no artificial nutrition (89%). Receipt of care in the last 6 months of life was largely consistent with less aggressive preferences, including few persons with ICU stays (5%) or recurrent hospitalizations (18%), high rates of hospice use (69%), and the majority (66%) of patients dying at home.

These findings have important implications for improving end-of-life care for persons with Alzheimer disease and other dementias. Barriers to the use of hospice and other palliative care services for persons with Alzheimer disease and other

dementias continue to exist in community-practice settings;^{12,20,21} engagement in advance care planning is uncommon;¹³ and hospitalizations,²² burdensome interventions (ie, parenteral therapy or tube feeding),²³ and care transitions⁸ near the end of life are common. An estimated 20% to 40% of persons with advanced dementia in nursing home settings experience a burdensome intervention²³ or burdensome care transition, including multiple hospitalizations,⁸ in the last 90 days of life. About half of persons with Alzheimer disease are hospitalized in the last 6 months of life,²² and most die in the hospital (16%) or nursing home (67%) while only 13% die at home.²⁴

There have been several tools developed to improve shared decision making about end-of-life care,^{14,15} including some focused specifically on persons with dementia and their family caregivers.^{5,25} However, implementing such interventions is difficult in the context of primary care, where visit lengths are short and other acute issues and chronic conditions must be addressed. An alternative approach, integrating these conversations into disease-specific care, such as the UCLA ADC program or comprehensive cancer programs, allows assessment of preferences to be conducted in a systematic manner with time dedicated to this process. As a result, in this program, 99% of participants or their proxies had advance care planning discussions. In contrast, in a 2012 nationally representative sample of community-dwelling Medicare beneficiaries, only half (54%) of those with possible or probable dementia reported ever having had a discussion about medical treatment desired if seriously ill in the future.¹³ The comprehensive nature of the program, including visiting patients in the hospital and nursing home, home visits, frequent follow-up, and after-hours telephone

access, may help to decrease length of stay and prevent readmission or recurrent ED visits.

Despite being widely available, use of hospice among persons with dementia in the United States has been generally low,^{26–28} with some increase in hospice enrollment in recent years. Five percent of hospice enrollees were reported to have a primary diagnosis of dementia in a 2008 to 2011 national random sample of hospices,²⁷ whereas 18% of hospice enrollees had a primary diagnosis of dementia in 2016.²⁹ Barriers to hospice use among persons with dementia have included a lack of understanding of dementia prognosis and expected clinical complications by healthcare proxies,²³ provider difficulty in predicting survival,²⁸ and difficulty viewing dementia as an illness from which one dies.²¹

In this cohort, completing a POLST form was associated with greater hospice use in the last 6 months of life and dying at home. POLST completion was also associated with a higher likelihood of being hospitalized in the last 6 months of life. While POLST is an important tool for documenting care preferences as actionable orders and for making these orders portable across care settings, it is not necessarily an indication that patients want less care. In this program, in the majority (65%) of participants who had completed POLST forms, the choice was for selective or full treatment. Another possibility is that POLST completion may be a marker of more severe illness or that hospitalization may prompt completion of a POLST.

Recent implementation of new Medicare billing codes for advance care planning visits³⁰ also have the potential to improve to the quality of end-of-life care for Medicare beneficiaries, including those with dementia. However, the uptake of these codes has been slow to date.³¹ While providing reimbursement for time spent in advance care planning is an important first step, it does not help providers address the specific challenges persons with dementia and their families face near the end of life nor does it help providers gain the skills to navigate difficult end-of-life conversations.

These findings should be interpreted in the context of the study's limitations. First, this is a descriptive study of the end-of-life care provided by a single dementia care management program using nurse practitioners in a community-dwelling population in an academic health system. Thus, these findings may not generalize to some other dementia care settings and cannot be interpreted as causal. In addition, while our abstraction included the complete UCLA EHR as well as utilization captured through the Care Everywhere feature in the Epic-based EHR, we were not able to capture all other utilization outside UCLA.

In summary, a comprehensive dementia care program with dedicated nurse practitioner care managers achieved high-quality end-of-life care, including high engagement in advance care planning, high rates of hospice use, and low acute care use. Although the UCLA ADC model offers promise for improving end-of-life care for persons with dementia, the majority of program services are not currently supported by Medicare fee for service, creating a barrier to wider implementation.

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Author Contributions:

Lee A. Jennings: conception and design, acquisition of data, analysis and interpretation of data; drafting the article; revising the article critically for important intellectual content; final approval.

Maurice Turner acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

Chandra Keebler: acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

Carl H. Burton acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

Tahmineh Romero analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

Neil S. Wenger: conception and design; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

David B. Reuben: conception and design; acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Appendix S1. All Combinations of Recorded Care Preferences (N = 205)