



Published in final edited form as:

*J Am Geriatr Soc.* 2019 March ; 67(3): 443–448. doi:10.1111/jgs.15769.

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

Lee A. Jennings, MD, MSHS<sup>1</sup>, Maurice Turner, BS<sup>2</sup>, Chandra Keebler, MD<sup>3</sup>, Carl H. Burton, MD<sup>2</sup>, Tahmineh Romero, MS, MQM<sup>4</sup>, Neil S. Wenger, MD, MPH<sup>5</sup>, David B. Reuben, MD<sup>2</sup>

<sup>1</sup>Reynolds Department of Geriatric Medicine, University of Oklahoma Health Sciences Center

<sup>2</sup>Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School Medicine, University of California, Los Angeles

<sup>3</sup>Division of Geriatrics and Supportive Care, Kaiser Permanente, Vallejo, California

<sup>4</sup>Statistics Core, David Geffen School of Medicine, University of California, Los Angeles

<sup>5</sup>Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine, University of California, Los Angeles

### Abstract

**Background/Objectives:** Although Alzheimer’s 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:** 322 persons enrolled in dementia care management after July 1, 2012 who died before July 1, 2016

---

Corresponding author: Lee A. Jennings, MD, MSHS, Reynolds Department of Geriatric Medicine, University of Oklahoma Health Science Center, 1122 N.E. 13<sup>th</sup> Street, ORB 1200, Oklahoma City, OK 73117, (405) 271-8558 x31387, (405) 271-3887 (fax), lee-jennings@ouhsc.edu, Alternate corresponding author: David B. Reuben, MD, David Geffen School of Medicine at UCLA, Division of Geriatrics, 10945 Le Conte Ave., Suite 2339, Los Angeles, CA 90095-1687, phone 310-825-8253, fax 310-794-2199, dreuben@mednet.ucla.edu.

Author Contributions:

1. Lee A. Jennings, M.D., M.S.H.S.: conception and design, acquisition of data, analysis and interpretation of data; drafting the article; revising the article critically for important intellectual content; final approval.
2. Maurice Turner, B.S.: acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.
3. Chandra Keebler, M.D.: acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.
4. Cal Burton, M.D.: acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.
5. Tahmineh Romero, M.S., M.Q.M.: analysis and interpretation of data; revising the article critically for important intellectual content; final approval.
6. Neil S. Wenger, M.D., M.P.H.: conception and design; analysis and interpretation of data; revising the article critically for important intellectual content; final approval
7. David B. Reuben, M.D.: conception and design; acquisition of data; analysis and interpretation of data; revising the article critically for important intellectual content; final approval.

Conflicts of Interest: The authors have no conflicts of interest to report.

**Intervention:** Dementia care co-management 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 six 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, IQR [2, 4]), 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 six 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=0.03) and die at home (70% vs. 59%, p=0.04).

**Conclusions:** Enrollees in a comprehensive dementia care co-management 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.

### Keywords

dementia; end-of-life; care management

---

## INTRODUCTION

Advance care planning is a critical component of high quality care for persons with Alzheimer's 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.<sup>1-4</sup> Studies have shown that persons with dementia or their designated family decision-makers may desire less aggressive care as the disease progresses,<sup>5,6</sup> 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 CPR and intubation, are the default in U.S. acute care settings if care preferences are unknown. Moreover, lack of an advance directive,<sup>7</sup> multiple care transitions from hospital to nursing home,<sup>8,9</sup> and placement of feeding tubes<sup>10,11</sup> 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.<sup>12,13</sup> 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,<sup>14,15</sup> including the Physician Orders for Life Sustaining Treatment (POLST) ([www.polst.org](http://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.<sup>1,16</sup> The UCLA Alzheimer's and Dementia Care (ADC) program,<sup>17</sup> a longitudinal, comprehensive nurse-practitioner dementia co-management 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.<sup>18</sup>

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 Physician Orders for Life Sustaining Treatment (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, and hospice use in the last six months of life for 322 decedents enrolled in a comprehensive dementia care management program over a four-year period from July 1, 2012 to June 30, 2016. The UCLA Institutional Review Board reviewed the study protocol and determined that the study did not constitute human subjects research as all participants were decedents. (IRB #13-001480).

### Description of the clinical program and study population

The UCLA Alzheimer's and Dementia Care (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's 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, which is a co-management program with nurse practitioner dementia care managers and partnering physicians,<sup>19</sup> 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 twenty-four hours, seven 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, 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 six 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 cardiopulmonary resuscitation, medical interventions, and artificial nutrition, including use of feeding tubes; use of the Physician Orders for Life Sustaining Treatment (POLST); hospice discussions, consults and enrollment; and place of death. Utilization outcomes including hospitalizations, hospital length of stay, intensive care unit (ICU) stays, and emergency department 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 (i.e., 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 who also serve west Los Angeles and use EPIC-based EHRs. Three physicians (CK, CB, and DR) and one medical student (MT) performed medical record abstractions using a detailed chart abstraction instrument and written abstraction guidelines. Abstractors were trained by two study investigators (DR and NW) who also provided consultation for abstractors as needed. A 5% random sample of all records was re-abstracted 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 six months of life, use of POLST, place of death, and health care utilization in the last six months of life. Hospital, emergency department, hospice use, and place of death were stratified by whether or not the decedent completed a POLST and compared using chi-square test or Fisher's Exact test for categorical variables and Wilcoxon-Mann-Whitney rank sum 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, IQR (2, 4)), and 64% had a documented advance care preference regarding cardiopulmonary resuscitation, 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 cardiopulmonary resuscitation 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 do not resuscitate (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 six months of life. The median number of days spent in the hospital or in the ED in the last six months of life among those with any acute care utilization was 2.8 days (IQR 0.3, 6.0; range 0.01–51). Among those with any hospital stay (N=122), the median length of stay was 5.1 days (IQR 3.3, 8.7). Very few (5%) had an ICU stay in the last six months of life, and 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 six months of life, and 69% of decedents died in hospice care. (Table 3)

Although decedents with a completed a POLST were more likely to be hospitalized (43% vs. 31%,  $p=0.04$ ), hospital length of stay, ICU stays, and emergency department 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%,  $p=0.01$ ), die in hospice care (74% vs. 62%,  $p=0.03$ ), and die at home (70% vs. 59%,  $p=0.04$ ). (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 six months of life. Consistent with prior research,<sup>20</sup> the majority of decedents with recorded care preferences chose less aggressive care, including no cardiopulmonary resuscitation (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's disease and other dementias. Barriers to the use of hospice and other palliative care services for persons with Alzheimer's disease and other dementias continue to exist in community-practice settings,<sup>12,20,21</sup> engagement in advance care planning is uncommon,<sup>13</sup> and hospitalizations,<sup>22</sup> burdensome interventions (i.e., parenteral therapy or tube feeding)<sup>23</sup> and care transitions<sup>8</sup> near the end of life are common. An estimated 20–40% of persons with advanced dementia in nursing home settings experience a burdensome intervention<sup>23</sup> or burdensome care transition, including multiple hospitalizations,<sup>8</sup> in the last 90 days of life. About half of persons with Alzheimer's disease are hospitalized in the last six months of life,<sup>22</sup> and most die in the hospital (16%) or nursing home (67%) while only 13% die at home.<sup>24</sup>

There have been several tools developed to improve shared decision-making about end-of-life care,<sup>14,15</sup> including some focused specifically on persons with dementia and their family caregivers.<sup>5,25</sup> 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.<sup>13</sup> 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 U.S. has been generally low<sup>26–28</sup> 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 2008–2011 national random sample of hospices;<sup>27</sup> whereas, 18% of hospice enrollees had a primary diagnosis of dementia in 2016.<sup>29</sup> Barriers to hospice use among persons with dementia have included a lack of understanding of dementia prognosis and expected clinical complications by health care proxies,<sup>23</sup> provider difficulty in predicting survival,<sup>28</sup> and difficulty viewing dementia as an illness from which one dies.<sup>21</sup>

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 six 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, 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 visits<sup>30</sup> 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.<sup>31</sup> 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.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## ACKNOWLEDGMENTS

We thank Holly Wilhalme, MS, Statistics Core, David Geffen School of Medicine, University of California, Los Angeles and Tuff Witarana, MPH, Cedars Sinai Medical Center, Los Angeles, California for their assistance with data management.

Sponsor's Role: The funders of this work had no role in the design, methods, subject recruitment, data collection, data analysis, or preparation of this manuscript.

### Support:

This work was supported in part by the Centers for Medicare & Medicaid Services under contract number HHSM 500-2011-000021 Task Order HHSM-500-T0009. Disclaimer: The views expressed in this article are the authors' and do not necessarily represent the views of the Centers of Medicare & Medicaid Services or the U.S Department of Health and Human Services. Maurice Turner was supported by the Medical Student Training in Aging Research (MSTAR) program (NIA T35AG026736). Dr. Jennings was also supported by the National Institute on Aging Claude D. Pepper Older Americans Independence Center at UCLA (P30AG028748), the NIH/National Center for Advancing Translational Science (NCATS) UCLA CTSI Grant Number UL1TR000124, and an Alzheimer's Association New Investigator Research Grant (15-364406).

## References

1. Callahan CM, Sachs GA, Lamantia MA, Unroe KT, Arling G, Boustani MA. Redesigning systems of care for older adults with Alzheimer's disease. *Health affairs (Project Hope)*. 2014;33(4):626–632. [PubMed: 24711324]

2. Reuben DB, Roth CP, Frank JC, et al. Assessing care of vulnerable elders--Alzheimer's disease: a pilot study of a practice redesign intervention to improve the quality of dementia care. *Journal of the American Geriatrics Society*. 2010;58(2):324–329. [PubMed: 20374405]
3. Wenger NS, Solomon DH, Amin A, et al. Application of assessing care of vulnerable elders-3 quality indicators to patients with advanced dementia and poor prognosis. *Journal of the American Geriatrics Society*. 2007;55 Suppl 2:S457–463. [PubMed: 17910571]
4. American Medical Association. Physician Consortium for Performance Improvement (PCPI): Dementia Performance Measurement Set. October 2011.
5. Volandes AE, Paasche-Orlow MK, Barry MJ, et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. *BMJ (Clinical research ed)*. 2009;338:b2159.
6. Givens JL, Sudore RL, Marshall GA, Dufour AB, Kopits I, Mitchell SL. Advance Care Planning in Community-Dwelling Patients With Dementia. *Journal of pain and symptom management*. 2018;55(4):1105–1112. [PubMed: 29247754]
7. Nicholas LH, Bynum JP, Iwashyna TJ, Weir DR, Langa KM. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health affairs (Project Hope)*. 2014;33(4):667–674. [PubMed: 24711329]
8. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *The New England journal of medicine*. 2011;365(13):1212–1221. [PubMed: 21991894]
9. Teno JM, Gozalo P, Mitchell SL, Tyler D, Mor V. Survival after multiple hospitalizations for infections and dehydration in nursing home residents with advanced cognitive impairment. *JAMA : the journal of the American Medical Association*. 2013;310(3):319–320. [PubMed: 23860991]
10. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane database of systematic reviews (Online)*. 2009(2):Cd007209.
11. Teno JM, Mitchell SL, Kuo SK, et al. Decision-making and outcomes of feeding tube insertion: a five-state study. *Journal of the American Geriatrics Society*. 2011;59(5):881–886. [PubMed: 21539524]
12. Torke AM, Holtz LR, Hui S, et al. Palliative care for patients with dementia: a national survey. *Journal of the American Geriatrics Society*. 2010;58(11):2114–2121. [PubMed: 21054292]
13. Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low Completion and Disparities in Advance Care Planning Activities Among Older Medicare Beneficiaries. *JAMA internal medicine*. 2016;176(12):1872–1875. [PubMed: 27802496]
14. Austin CA, Mohottige D, Sudore RL, Smith AK, Hanson LC. Tools to Promote Shared Decision Making in Serious Illness: A Systematic Review. *JAMA internal medicine*. 2015;175(7):1213–1221. [PubMed: 25985438]
15. Oczkowski SJ, Chung HO, Hanvey L, Mbuagbaw L, You JJ. Communication Tools for End-of-Life Decision-Making in Ambulatory Care Settings: A Systematic Review and Meta-Analysis. *PloS one*. 2016;11(4):e0150671.
16. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Annals of internal medicine*. 2006;145(10):713–726. [PubMed: 17116916]
17. Tan ZS, Jennings L, Reuben D. Coordinated care management for dementia in a large academic health system. *Health affairs (Project Hope)*. 2014;33(4):619–625. [PubMed: 24711323]
18. Jennings LA, Tan Z, Wenger NS, et al. Quality of Care Provided by a Comprehensive Dementia Care Comanagement Program. *Journal of the American Geriatrics Society*. 2016;64(8):1724–1730. [PubMed: 27355394]
19. Reuben DB, Evertson LC, Wenger NS, et al. The university of california at los angeles Alzheimer's and dementia care program for comprehensive, coordinated, patient-centered care: preliminary data. *Journal of the American Geriatrics Society*. 2013;61(12):2214–2218. [PubMed: 24329821]
20. Mitchell SL, Black BS, Ersek M, et al. Advanced dementia: state of the art and priorities for the next decade. *Annals of internal medicine*. 2012;156(1 Pt 1):45–51. [PubMed: 22213494]
21. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of general internal medicine*. 2004;19(10):1057–1063. [PubMed: 15482560]



22. Faes K, Cohen J, Annemans L. Resource Use During the Last 6 Months of Life of Individuals Dying with and of Alzheimer's Disease. *Journal of the American Geriatrics Society*. 2018;66(5):879–885. [PubMed: 29446066]
23. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *The New England journal of medicine*. 2009;361(16):1529–1538. [PubMed: 19828530]
24. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society*. 2005;53(2):299–305. [PubMed: 15673356]
25. Hanson LC, Carey TS, Caprio AJ, et al. Improving decision-making for feeding options in advanced dementia: a randomized, controlled trial. *Journal of the American Geriatrics Society*. 2011;59(11):2009–2016. [PubMed: 22091750]
26. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*. 2010;58(12):2284–2291. [PubMed: 21143437]
27. De Vleminck A, Morrison RS, Meier DE, Aldridge MD. Hospice Care for Patients With Dementia in the United States: A Longitudinal Cohort Study. *Journal of the American Medical Directors Association*. 2018;19(7):633–638. [PubMed: 29153752]
28. Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: a national survey of hospice programs. *Journal of the American Geriatrics Society*. 1995;43(1):56–59. [PubMed: 7806741]
29. National Hospice and Palliative Care organization Facts and Figures Hospice Care in America. April 2018; [https://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2017\\_Facts\\_Figures.pdf](https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf). Accessed August 24, 2017.
30. Centers for Medicare and Medicaid Services Advance Care Planning Medical Learning Network Fact Sheet. June 2018; <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>. Accessed August 24, 2018.
31. Hayhurst C. Why providers are slow to adopt new Medicare codes. November 9, 2017; <https://www.athenahealth.com/insight/why-providers-are-slow-adopt-new-medicare-codes>. Accessed August 24, 2108.

**Impact Statement:**

We certify that this work is novel. This work adds to the literature by describing the effect of a comprehensive dementia care management program on end-of-life care, including engagement in advance care planning, hospice use, and acute care utilization in the last six months of life.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 1:**

Description of ADC Program Decedents and Documentation of Goals of Care Conversations and Care Preferences (N=322)

	Mean (SD) or N (%)
Age at death, range 56 to 102 years	86.7 (7.9)
Female	174 (54%)
White, non-Hispanic, N=242	175 (72%)
Alzheimer's disease or dementia type not specified	256 (80%)
Medicare and Medicaid dually insured	41 (13%)
Mini Mental State Exam score, range 0–30	13.3 (7.1)
Number of ADL dependencies, range 0–6	3.7 (2.2)
Number 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%)
Number of goals-of-care conversations in the last 6 months of life, median (IQR), range 1–14	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 six months of life	184 (57%)
Documented proxy decision-maker	322 (100%)

Scores are the last value recorded in ADC clinical program data within 18 months prior to death.

**Table 2:**

## Care Preferences of ADC Program Decedents

<b>Resuscitation and Medical Interventions Preferences</b>		
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 <sup>*</sup>	11 (5%)
CPR		24 (12%)
<b>Artificially Administered Nutrition Preferences</b>		
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%)

N=117 decedents (36%) did not have care preferences regarding cardiopulmonary resuscitation, medical interventions, or artificial nutrition recorded in the electronic health record.

Data reflect the last POLST completed or last goals-of-care conversation recorded in the electronic health record if no POLST was completed before death for each patient.

<sup>\*</sup> No selection was made regarding medical Interventions for 5 decedents (1.5%).

All recorded combinations of cardiopulmonary resuscitation, medical interventions, and artificial nutrition care preferences are provided in Appendix 1.

**Table 3:**

Hospital, Emergency Department, and Hospice Use in Last Six Months of Life and Place of Death by POLST Completion

	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), N (%)	148 (46%)	94 (51%)	54 (39%)	<b>0.03</b>
>1 acute care event, N (%)	81 (25%)	56 (30%)	25 (18%)	<b>0.01</b>
Total acute care days among those with any event, median (IQR), range 0.01–51	2.8 (0.3, 6.0)	3.1 (0.6, 6.6)	2.1 (0.2, 4.6)	<b>0.01</b>
Any ED visit or observational stay, N (%)	85 (26%)	53 (29%)	32 (23%)	0.27
Any hospitalization, N (%)	122 (38%)	79 (43%)	43 (31%)	<b>0.04</b>
>1 hospitalization, N (%)	57 (18%)	41 (22%)	16 (12%)	<b>0.02</b>
Hospital length of stay (days), median (IQR), range 2–51 days	5.1 (3.3, 8.7)	5.8 (3.7, 8.3)	4.1 (3.1, 8.9)	0.22
Any ICU stay, N (%)	17 (5%)	11 (6%)	6 (4%)	0.62
ICU length of stay (days), median (IQR), range 0.3–27.3	2.5 (1.0, 5.6)	2.0 (1.0, 3.4)	5.8 (0.4, 11.7)	0.41
Place of death, N (%) <sup>*</sup>				
Hospital ward or ED	49 (15%)	27 (15%)	22 (16%)	0.75
ICU	7 (2%)	3 (2%)	4 (3%)	0.45
Skilled nursing facility	39 (12%)	22 (12%)	17 (12%)	0.96
Home	211 (66%)	129 (70%)	82 (59%)	<b>0.04</b>
Hospice discussion or consult, N (%)	232 (72%)	144 (78%)	88 (64%)	<b>0.01</b>
Died in hospice care, N (%)	222 (69%)	136 (74%)	86 (62%)	<b>0.03</b>

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

Wilcoxon Rank-Sum test used to compare continuous variables and chi-square test or Fisher's exact test used to compare categorical variables. Comparisons with  $p < 0.05$  are bolded.

ED=emergency department; ICU=intensive care unit

\* Place of death was unknown for 16 decedents (5%).