Original Article

Triggered Palliative Care for Late-Stage Dementia: A Pilot Randomized Trial

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Abstract

Context. Persons with late-stage dementia have limited access to palliative care.

Objective. The objective of this study was to test dementia-specific specialty palliative care triggered by hospitalization.

Methods. This pilot randomized controlled trial enrolled 62 dyads of persons with late-stage dementia and family decision-makers on admission to hospital. Intervention dyads received dementia-specific specialty palliative care consultation plus postacute transitional care. Control dyads received usual care and educational information. The primary outcome was 60-day hospital or emergency department visits. Secondary patient- and family-centered outcomes were patient comfort, family distress, palliative care domains addressed in the treatment plan, and access to hospice or community-based palliative care. Secondary decision-making outcomes were discussion of prognosis, goals of care, completion of Medical Orders for Scope of Treatment (MOST), and treatment decisions.

Results. Of 137 eligible dyads, 62 (45%) were enrolled. The intervention proved feasible, with protocol completion ranging from 77% (family two-week call) to 93% (initial consultation). Hospital and emergency department visits did not differ (intervention vs. control, 0.68 vs. 0.53 transfers per 60 days, $P = 0.415$). Intervention patients had more palliative care domains addressed and were more likely to receive hospice (25% vs. 3%, $P < 0.019$). Intervention families were more likely to discuss prognosis (90% vs. 3%, $P < 0.001$) and goals of care (90% vs. 25%, $P < 0.001$) and to have a MOST at 60-day follow-up (79% vs. 30%, $P < 0.001$). More intervention families made decisions to avoid rehospitalization (13% vs. 0%, $P = 0.033$).

Conclusion. Specialty palliative care consultation for hospitalized patients with late-stage dementia is feasible and promising to improve decision-making and some treatment outcomes. J Pain Symptom Manage 2019;57:10–19. *© 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Dementia, randomized trial, palliative care

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Introduction

Alzheimer's disease and related dementias are leading causes of functional dependency and death. Over 5 million Americans live with dementia; more than 1 million have late-stage dementia with profound cognitive deficits and dependence for activities of daily living.[1,2] Family caregivers provide extraordinary practical and emotional support and face average out-of-pocket expenses of $66,000 in the last year of life.[3,4] Societal costs for dementia care exceeded $250 billion in 2018, and the affected population is projected to double by 2030.[5,6]

Dementia is the only leading cause of death in the U.S. without meaningful treatment to prevent, cure, or slow down disease progression. Palliation should be an important focus of dementia care, yet the evidence shows unmet need. Among nursing home residents with dementia, half experience frequent and unrelieved pain.[7–9] Distressing symptoms—shortness of breath, neuropsychiatric symptoms, feeding problems, and problems with personal cleanliness—are common.[10–14] Decisions about life-sustaining treatment are delayed, and access to hospice is limited by lack of a discrete terminal phase of illness.[15–18]

Hospitalization is common in late-stage dementia, creating an opportunity to improve access to palliative care.[19] While only 27% of U.S. nursing homes report any type of specialized palliative or end-of-life care, 85% of large hospitals have specialty palliative care.[20,21] Infections, hip fracture, and nutritional decline are common reasons for hospital transfer, and signal worsened prognosis with six-month mortality risk of 20%–50%.[17,22–25]

Specialty palliative care improves treatment decision-making and other patient-centered outcomes for persons with cancer and other serious illnesses, but has rarely been studied for persons with dementia.[26–30] Palliative care clinicians rarely have training for dementia-specific symptom management, decision-making, and caregiver support, yet their fundamental skills and interdisciplinary team approach are well matched to needs in late-stage dementia. We therefore developed a model of specialty palliative care consultation specific to the needs of persons with late-stage dementia and their families. Specific aims were 1) to develop a best-practice model of specialty palliative care for late-stage dementia and 2) to conduct a pilot randomized trial of specialty palliative care for late-stage dementia triggered by hospitalization for acute illness. We hypothesized this model would be feasible and show potential to improve outcomes of subsequent hospital or emergency department visits, hospice and community-based palliative care use, enhanced palliative care content of care plans, increased completion of Medical Orders for Scope of Treatment (MOST) forms, and decisions to avoid future hospitalization and potentially burdensome treatments.

Methods

Trial Design

Investigators reviewed evidence on palliative care needs and interventions in late-stage dementia. They held three meetings with key stakeholders—three family caregivers for persons with late-stage dementia and four clinicians with extensive experience in dementia care. Using these sources, investigators designed a dementia-specific protocol for specialty palliative care consultation with postacute telephone support.

Research staff enrolled dyads of hospitalized persons with late-stage dementia with their primary family decision-makers and randomized them to receive specialty palliative care consultation during hospitalization with postdischarge telephone support by a palliative care nurse practitioner (intervention) versus usual hospital care with educational material on dementia caregiving (control). The University of North Carolina institutional review board approved the protocol, and a Data Safety Monitor reviewed study procedures and preliminary data every six months; the study is a registered clinical trial (NCT02719938).

Participant Enrollment and Randomization

From March 31, 2016, to August 31, 2017, research staff enrolled dyads of hospitalized patients with late-stage dementia and family decision-makers. Investigators developed and refined a dementia phenotype within the hospital electronic health record based on patient age, hospital admission date, and ever use of ICD-9 or ICD-10 codes for dementia diagnoses.[31] Potentially eligible patients were thus identified within 24 hours of admission, and reviewed by research staff for eligibility. A palliative care physician then confirmed dementia diagnosis and stage with the patient's attending physician and sought permission to approach the family decision-maker about participation.

Patients were eligible if they were aged 65 years or older, were hospitalized with an acute illness, had a diagnosis of dementia Stage 5–7 on the Global Deterioration Scale (GDS) verified by their attending physician, and had an eligible family decision-maker.[1] Persons with GDS 5 dementia and later cannot live independently and are frequently disoriented, whereas those who progress to GDS 7 have sparse speech, have dependency for all activities, and cannot recognize family. Family decision-makers were eligible if they were legally authorized representatives for health care decisions and could complete interviews in English. They provided written consent for themselves and the person with late-stage dementia. After informed consent, the study biostatistician randomized each dyad in a 1:1 ratio to intervention vs. control arms before the baseline interview. Allocation was revealed to the baseline interviewer, family decision-maker, and the attending physician but concealed from the investigators and research staff collecting interview outcome data. Family decision-makers were compensated for time to complete interviews.

Intervention and Control Conditions

Patient-family dyads randomized to the intervention received protocolized specialty palliative care consultation while hospitalized, plus two-week postdischarge transitional telephone support by a palliative care nurse practitioner. Clinicians delivering the intervention were board-certified physicians and nurse practitioners in palliative care. The consult protocol addressed 1) stage, prognosis, and trajectory of dementia; 2) assessment and treatment of pain and other physical symptoms; 3) assessment and management of neuropsychiatric symptoms; 4) social support for caregiver stress; 5) spiritual needs assessment; 6) cultural concerns framing care; 7) goals of care decision-making; and 8) key clinical decisions such as feeding options, antibiotic use, and rehospitalization. Consultants provided families with a copy of the informational booklet "*Advanced Dementia: A Guide for Families.*"[32] Based on their assessments, consultants provided individualized recommendations for palliative care domains, offered to assist with completion of a MOST order set, the North Carolina version of Physician Orders for Life Sustaining Treatment (POLST), and recommended referrals to postdischarge services.[33,34] Transitional care included 1) provision of consult recommendations and MOST form to the postacute primary provider and 2) follow-up supportive calls by a palliative care nurse practitioner to the family decision-maker at 72 hours and two weeks after discharge. Investigators provided a one-hour training session to palliative care physicians and nurse practitioners to teach them the dementia protocol and to provide access to an electronic health record—templated consult note.

Family decision-makers randomized to control received information on caregiving for late-stage dementia from the Alzheimer's Association, and patients received usual hospital care.[35] Specialty palliative care consultation was allowed, if requested by attending physicians. All other procedures were identical for intervention and control participants.

Data Collection

Research staff masked to study arm collected data using 30- and 60-day postdischarge telephone interviews with family decision-makers. When an enrolled patient died, staff conducted family interviews with modifications for care during dying. A separate research staff member conducted chart reviews at 60 days after discharge but could not be masked due to the differential documentation between study arms.

Feasibility

Investigators evaluated feasibility based on dyad enrollment and follow-up and on fidelity to components of the intervention. Research staff monitored six components (initial consult, call to postacute provider, palliative care consult records to postacute provider, MOST discussion, 72-hour call to family, and two-week call to family), with a goal of 80% completion.

Outcomes

The prespecified primary outcome was hospital or emergency department visits in the 60 days after discharge, defined as hospital readmissions or emergency room visits reported in family interviews. Secondary patient- and family-centered outcomes were patient comfort, family distress, palliative care domains addressed in the treatment plan, and access to hospice or community-based palliative care services. Secondary decision-making outcomes were discussion of prognosis, discussion of goals of care, completion of MOST order set, and documented decisions against rehospitalization or other potentially burdensome treatments.

Patient comfort was measured in follow-up interviews using the reliable and valid Comfort at the End of Life in Dementia (CAD-EOLD). Fourteen items are rated 1—3 and summed, for a range of 14—42 with higher scores indicating better symptom control over the past week. It has good internal consistency (Cronbach's alpha 0.83—0.90) and convergent validity ($r = 0.81$ with the Decision Satisfaction Inventory).[36,37] Family distress was measured using the Family Distress in Advanced Dementia Scale, with 21 items rated and averaged on a 1—5 scale to create a potential range of 1—5, with higher scores indicating greater distress. The Family Distress in Advanced Dementia has good internal consistency in three domain scores for emotional distress (alpha = 0.82), dementia preparedness (0.75) and clinician relations (0.83).[38] Palliative care domains (range 0—10) were measured in chart review as count of the presence or absence of 10 domains of palliative care addressed in the medical treatment plan—prognosis, overall goals of care, physical symptoms, psychiatric symptoms, spiritual needs, and five treatment preferences: resuscitation, artificial feeding, intravenous fluids, antibiotics, and hospitalization. This measure has been used in a large clinical trial and has good interrater reliability (kappa = 0.90).[39] Access to hospice or community-based palliative care, MOST completion and decision-making about specific treatments were measured using family report at 60 days, with verification in medical record review. Finally, research assistants reviewed charts for evidence of adherence to process measures for dementia quality of care using the Physician Quality Reporting System 2015 measures for dementia staging (#280), cognitive assessment (#281), functional assessment (#282), neuropsychiatric symptom assessment (#283), safety counseling (#286), and caregiver education and support (#288).[40]

Additional Variables

Research staff recorded data on patient and family decision-maker demographics, prior hospital transfers, and advance directives from baseline family interviews. Patient functional status was measured in baseline family interviews using the valid and reliable Bedford Alzheimer Nursing Severity Scale, framed to represent function in the weeks just before acute illness.[41] The BAN-S ranges 7–28, with higher scores indicating greater functional impairment. During baseline and follow-up interviews, research staff asked family respondents about their perception of prognosis for the person with dementia, and perception of their involvement in decision making. During chart review, staff recorded data on major comorbid diagnoses and the acute illness causing hospital admission, postacute site of care, and patient's vital status at 60-day follow-up.

Analysis

Patient-family dyads were the primary unit of analysis. Baseline characteristics of the dyads were reported in either means and SDs or medians and ranges if the variables are continuous, and in percentages if the variables are categorical. Intervention and control dyads were then compared on the baseline characteristics to explore possible differences between arms after randomization. All the comparisons were tested using either chi-square tests or two-sample t-tests except hospital length of stay, which was compared using Mann-Whitney test because of nonnormality. The primary outcome of hospital and emergency department visits was reported as the number of events per 60 days of follow-up, with censoring of eligible follow-up days if the patient died or the dyad withdrew from the study. In a priori power calculation, the sample size of 60 patients with 30 patients per group was estimated to give 81% power to detect a relative risk of 2.7. Poisson regression, which accounts for the length of follow-up, was used to compare the rate of hospital and emergency department visits between the two arms. Comparisons of the secondary outcomes were implemented using either chi-square tests or two-sample t-tests, when appropriate. Comparisons were not further adjusted because there was no apparent imbalance between arms. All analyses used intention-to-treat assignment, with a P-value of <0.05 threshold for statistical significance. Software SAS 9.4 (Cary, NC) was used to implement statistical tests.

Results

Study Enrollment and Feasibility

Automated screening generated 3296 admissions with a dementia diagnosis code during the 18-month enrollment period, of whom 426 had late-stage dementia (Fig. 1). One-third of patients were discharged before contact due to very short lengths of stay ($n = 161$), and others were admitted during periods when study personnel were not available ($n = 50$). Some were not eligible due to active dying or current hospice enrollment ($n = 32$), attending physician refusal ($n = 29$), or lack of eligible decision-maker ($n = 17$). Of 137 eligible dyads contacted, 62 (45%) enrolled and randomized (32 control, 30 intervention). One-third of family caregivers who refused participation stated this was due to feeling overwhelmed by caregiving and other roles. After enrollment, one family decision-maker withdrew and four were lost to follow-up. Fidelity to the intervention was high, with completion of each of six intervention protocol components ranging from 77% (family two-week call) to 93% (palliative care consultation).

Characteristics of Enrolled Patients and Families

Hospitalized patients with late-stage dementia had an average age of 83.9 years, 56% were female, 71% white, and 24% African American (Table 1). Thirty-seven percent had GDS Stage 5, 42% Stage 6, and 21% Stage 7 dementia. The most common admitting diagnoses were infections and neuropsychiatric symptoms. Two-thirds of patients had advance directives. Baseline characteristics did not differ significantly between study arms.

Family decision-makers had an average age of 59.7 years, 79% were female, and more than half were daughters. At enrollment, 92% of caregivers felt they were very involved in treatment decisions for the person with dementia, and 60% expected that person to get worse or possibly die in the next six months.

Patient- and Family-Centered Outcomes

One of three enrolled patients with late-stage dementia visited an emergency department or was

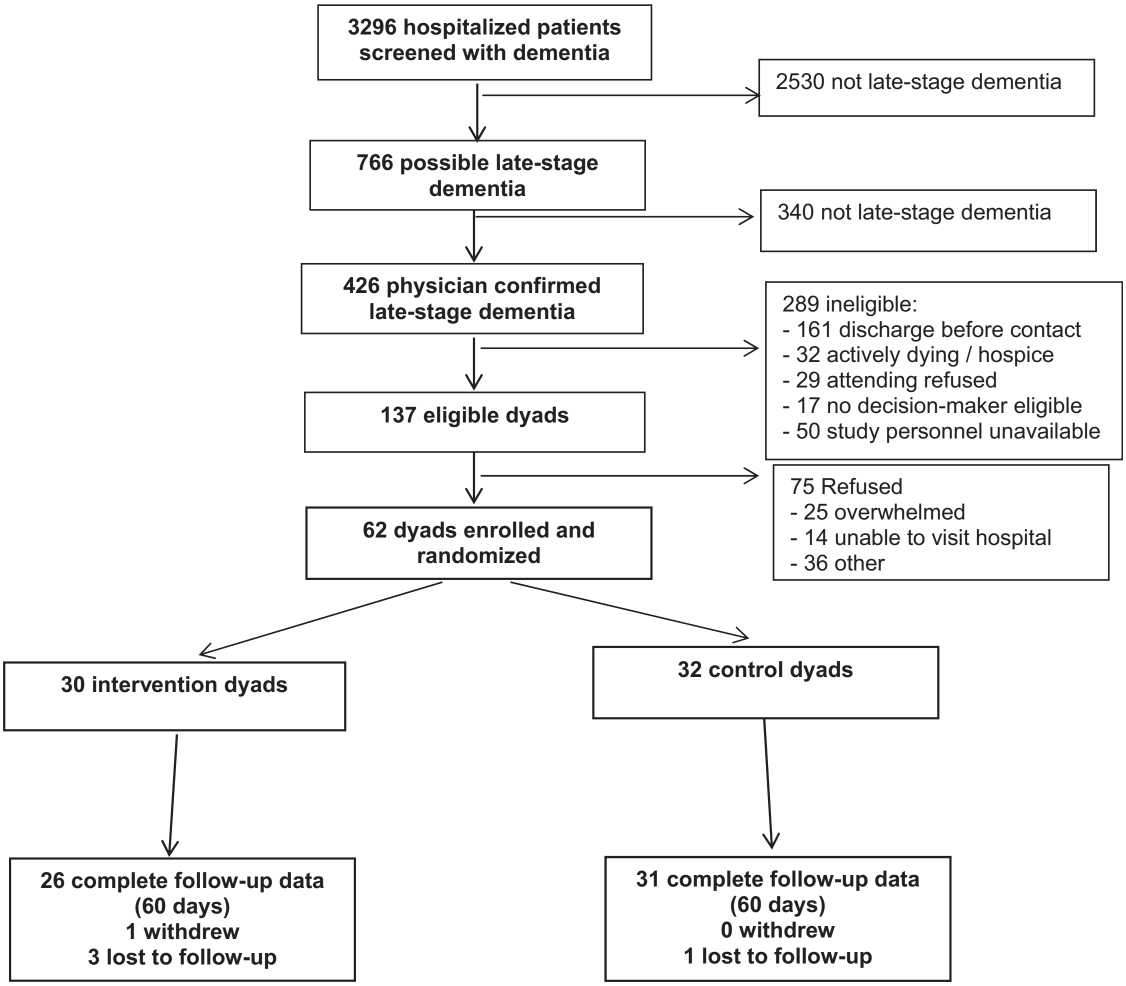

Fig. 1. Enrollment and participant flow.

hospitalized in the 60 days after discharge. The primary outcome of 60-day hospital or emergency department visits did not differ significantly between intervention and control arms (0.68 vs. 0.53 visits, $P = 0.415$) (Table 2). Family caregivers' ratings of comfort for the person with dementia and of distress for themselves did not differ between arms at 60 days. However, dementia patients in the intervention arm had more elements of clinical palliative care addressed in their hospital treatment plan, as measured on the 10-point Palliative Care Domain score (7.6 vs. 2.7, $P < 0.001$). Intervention patients were more likely to have assessment and treatment for physical symptoms of dyspnea, constipation, and nausea and for neuropsychiatric symptoms. Spiritual needs were addressed for 47% of patient-family dyads in the intervention arm, and for 0% of those in the control arm. In the 60 days after discharge, family reported that patients in the intervention arm were more likely to receive hospice (25% vs. 3%, $P < 0.019$), with a trend toward greater access to community-based palliative care. In the intervention arm, more patients with dementia discharged to home or assisted living settings, while patients in the control arm were more likely to enter nursing homes ($P = 0.046$). As anticipated, few patients died during follow-up, and mortality did not differ between arms.

Decision-Making Outcomes

Specialty palliative care during hospitalization also resulted in increased communication and decision-making about treatments relevant to late-stage dementia. Family decision-makers in the intervention arm were more likely to participate in discussions of prognosis (90% vs. 3%, $P < 0.001$) and goals of care (90% vs. 25%, $P < 0.001$). These families were more likely to complete a MOST in hospital (70% vs. 13%, $P < 0.001$) and have an active MOST in use at 60-day follow-up (79% vs. 30%, $P < 0.001$). While do-not-resuscitate orders were common for persons with dementia in both arms, more intervention families made decisions to avoid future burdensome treatments such as tube feeding,

Table 1

Characteristics of Patients With Late-Stage Dementia and Family Decision-Makers

Patient Characteristics	Total $N = 62$	Intervention $n = 30$	Control $n = 32$	P-value
Patient age, mean (SD)	83.9 (8.7)	83.0 (8.8)	84.7 (8.7)	0.434
Patient female, %	56%	67%	47%	0.116
Patient race, %				
White	71%	70%	72%	
African American	24%	27%	22%	
Other	5%	3%	6%	0.808
Patient Hispanic or Latino, %	5%	3%	6%	0.593
GDS[a] stage, %				
5	37%	43%	31%	
6	42%	40%	44%	
7	21%	17%	25%	0.556
BANS-S[b], mean (SD)	15.9 (3.6)	15.4 (3.5)	16.3 (3.6)	0.271
Admitting diagnosis in chart review				
Urinary tract infection	28%	37%	19%	0.114
Sepsis	16%	13%	19%	0.562
Neuropsychiatric symptoms	15%	17%	13%	0.642
Hip fracture	11%	3%	19%	0.055
Pneumonia	8%	3%	13%	0.185
Dehydration/malnutrition	8%	7%	9%	0.700
Delirium	6%	7%	6%	0.947
Other	8%	13%	2%	0.298
Hospitalized in past 30 days	10%	10%	9%	0.934
ER in past 30 days	35%	40%	31%	0.472
Prior advance directive	63%	63%	63%	1.000
Preadmission residence				
Home	51%	43%	60%	
Assisted living	18%	30%	6%	
Nursing home	26%	23%	28%	
Other	5%	4%	6%	0.107
Hospital length of stay, median (range)	6 (2–36)	6 (2–36)	6 (2–32)	0.437
Family decision-maker characteristics				
Family decision-maker, age, mean (SD)	59.7 (10.5)	60.0 (9.9)	59.5 (11.1)	0.844
Family decision-maker, female, %	79%	73%	84%	0.286
Family decision-maker, race, %				
White	71%	70%	72%	
African American	24%	27%	22%	
Other	5%	3%	6%	0.808
Hispanic or Latino, %	2%	0%	3%	0.329
Relationship to person with dementia, %				
Daughter	52%	47%	56%	
Son	18%	27%	9%	
Spouse	19%	20%	19%	
Other	11%	6%	16%	0.262
Family decision involvement, %				
Not at all involved	0%	0%	0%	
Somewhat involved	10%	14%	6%	
Very involved	90%	86%	97%	0.323
Family perceived six-month prognosis, %				
Get better	17%	17%	17%	
Stay same	23%	23%	23%	
Get worse	37%	40%	33%	
Likely to die	23%	20%	27%	0.926

[a] GDS = Global Deterioration Scale, range 1–7, higher stage indicates more advanced dementia.

[b] BANS-S = Bedford Alzheimer's Nursing Severity-Subscale, range 7–28, higher scores indicate more functional disability.

antibiotics, and IV fluids. Decisions to avoid rehospitalization were also increased (13% vs. 0%, $P = 0.033$).

Dementia Quality of Care

Compared to controls, persons with dementia in the intervention arm were more likely to receive formal dementia staging (93% vs. 9%, $P < 0.001$) and structured assessment of cognition (73% vs. 9%, $P < 0.001$) and function (97% vs. 25%, $P < 0.001$). Neuropsychiatric symptoms were more commonly addressed, as were caregivers' safety concerns. Finally, this intervention resulted in more education of family caregivers about late-stage dementia (80% vs. 25%, $P < 0.001$).

Table 2
Outcomes of Triggered Palliative Care for Persons With Late-Stage Dementia

Outcomes	Intervention $n = 30$	Control $n = 32$	*P*-value
Primary outcome	60 days	60 days	
Hospital/emergency visits per 60 days (no. of events/follow-up days)	0.68 (21/1843)	0.53 (20/2264)	0.415
Patient- and family-centered secondary outcomes			
Patient comfort (CAD-EOLD[a]), mean (SD) (range 14–42)	34.8 (4.2)	34.0 (4.1)	0.521
Family caregiver distress (FDAD[b]), mean (SD) (range 1–5)	2.3 (0.5)	2.4 (0.5)	0.409
Palliative Care Domain Index (0–10) in hospital care plan	7.6 (2.5)	2.7 (1.7)	<0.001
Physical symptom addressed			
Pain	87%	72%	0.153
Dyspnea	77%	34%	<0.001
Constipation	93%	25%	<0.001
Poor appetite	37%	38%	0.946
Nausea	90%	25%	<0.001
Falls	33%	16%	0.104
Neuropsychiatric symptom addressed			
Depression	83%	25%	<0.001
Anxiety	83%	16%	<0.001
Decreased level of consciousness	67%	22%	<0.001
Hyperactive delirium	80%	19%	<0.001
Spiritual needs addressed	47%	0%	<0.001
Hospice at 60 days	25%	3%	0.019
Community palliative care at 60 days	21%	7%	0.124
Hospital discharge location			
Home	33%	25%	
Assisted living	24%	3%	
Nursing home	33%	63%	
Death	0%	0%	
Other	10%	9%	0.046
Patient vital status alive at 60 days, %	87%	94%	0.346
Decision-making secondary outcomes			
Documented discussion of prognosis, % yes	90%	3%	<0.001
Documented discussion of goals of care, % yes	90%	25%	<0.001
MOST[c] completion at 60 days	79%	30%	<0.001
Code status in hospital			
Full code	27%	22%	
Do-not-resuscitate, present at admission	53%	66%	
Do-not-resuscitate, new	20%	12%	0.583
Decision not to rehospitalize	13%	0%	0.033
Decision made NOT to tube feed	53%	6%	<0.001
Decision made NOT to use antibiotics	7%	3%	<0.001
Decision made to LIMIT use of antibiotics	43%	0%	
Decision made NOT to use IV fluids	13%	6%	<0.001
Decision made to LIMIT use of IV fluids	43%	3%	
Dementia care quality metrics (chart review)			
Dementia staged	93%	9%	<0.001
Cognitive assessment	73%	9%	<0.001
Functional assessment	97%	25%	<0.001
Neuropsychiatric symptoms addressed	83%	25%	<0.001
Safety concerns addressed	83%	44%	0.001
Caregiver education	80%	25%	<0.001

[a] CAD-EOLD = Comfort Assessment in Dying, End of Life in Dementia, range overall 14–42, higher scores indicate more comfort.
[b] FDAD = Family Distress in Advanced Dementia, range overall and subscales 1–5, higher scores indicate more distress.
[c] MOST = Medical Orders for Scope of Treatment, the North Carolina version of POLST (Physician Orders for Life Sustaining Treatment) order set.

Discussion

Specialty palliative care consultation specific to late-stage dementia, initiated during hospitalization for acute illness, is feasible and promising to improve decision-making and clinical outcomes for persons with dementia and their families. In this pilot randomized trial, investigators used an innovative, efficient method to identify hospitalized patients with late-stage dementia. Compared to usual hospital care, triggered palliative care consultation was effective to improve decision-making, dementia neuropsychiatric symptom management, and use of hospice. While the intervention did not change the primary outcome of 60-day hospital or emergency department visits, it did increase decisions to forego further hospitalization and thus may affect this outcome over longer follow-up. Family decision-makers were more likely to discuss prognosis and goals of care and make decisions to avoid burdensome treatments for the person with dementia. Furthermore, they were much more likely to record these decisions in a MOST order set, and these orders remained in use 60 days after hospital discharge.

Persons with dementia and their families need intervention research to reduce or moderate the effects of frequent health care transitions—including hospitalizations and admissions to nursing facilities. We found that one in three persons with dementia returned to a hospital or emergency room in the 60 days after discharge. Stakeholders interviewed in preparation for this trial likened the experience of late-stage dementia health care to "being nomads" and "becoming homeless." They referenced frequent hospitalizations and transitions to nursing facility care, resulting in the loss of a trustworthy primary clinician to guide treatment. While facility placement was not a prespecified outcome, an unexpected finding in this study was that fewer persons with dementia in the intervention arm entered nursing home care. It is possible that skilled discussions of prognosis and goals of care supported families to opt for home or home-like assisted living facilities with dementia care units.

This pilot trial is an important addition to very limited research on specialty palliative care for dementia, and its promising intermediate outcomes warrant testing in a larger trial. A small randomized trial of specialty palliative care consultations for hospitalized patients with dementia found increased use of palliative care plans (23% vs. 4%, $P = 0.008$) and reduction in intravenous therapies (66% vs. 81%, $P = 0.025$), but no effect on life-sustaining treatment decisions.[42] In a small pre-post study ($n = 52$), proactive case finding of intensive care unit patients with advanced dementia for palliative care was associated with fewer hospital days (7.4 vs. 12.1, $P < 0.007$) and ICU days (3.5 vs. 6.8, $P < 0.004$), with no difference in overall treatment intensity.[43] Mitchell conducted a single site pre-post pilot study of an Advanced Dementia Consult Service, which provided postacute recommendations to the primary physician, and a follow-up call to the family caregiver. Investigators enrolled 24 controls followed by five intervention participants and found promising trends in increased hospice use (40% vs. 25%), reduced 30-day readmissions (0% vs. 29%), and improved family understanding of advanced dementia (50% vs. 0%).[44]

Investigators have also tested interventions in which nonspecialty clinicians deliver elements of palliative care, termed "primary palliative care." Our research team has extensive experience in primary palliative care interventions for dementia, delivered by interdisciplinary nursing home staff and geriatric care teams in nursing homes, assisted living, and in the community. In the nursing home setting, we have shown that dementia-specific decision aids can improve communication and decision-making for family caregivers, enhance palliative care treatment plans, improve goal-concordant care, and reduce hospitalizations.[39,45–48] Ongoing clinical trials include primary palliative care interventions to improve decision-making about treatment for infection in advanced dementia (TRAIN-AD AG032982) in nursing homes and dementia palliative care delivered community-dwelling patients and their families (IN PEACE AG057733). Given the large population of persons with Alzheimer's and related dementias, and the prolonged suffering associated with this condition, improvements in both specialty and primary palliative care are necessary to improve outcomes.

Meaningful interpretation of our results requires consideration of limitations. This pilot clinical trial provides promising evidence for feasibility and efficacy, yet a statistically powered efficacy trial is necessary to prove this intervention can reduce hospital transfers and improve other outcomes important to persons with dementia and caregivers such as comfort and caregiver distress. As expected in a pilot trial, this study had limited statistical power. In addition, the duration of specialty palliative care may need to be extended beyond discharge to affect these important outcomes. The study site has robust clinical resources in palliative care and geriatric care, and multisite testing is needed to ensure this model can be exported and replicated. Study participation was good, but many persons with dementia could not be enrolled due to short hospital stays and caregiver stresses. Enrollment and outcomes may be improved if the intervention includes extended postdischarge specialty palliative care services, or access to services by telemedicine. As persons with dementia experience transitions between hospital, emergency room, nursing home, home, or assisted living settings, it may be important to offer enhanced elements of transitional care.[19,49]

Specialty palliative care tailored to late-stage dementia, triggered by hospitalization for acute illness, is feasible and demonstrates potential to improve decision-making and clinical outcomes for persons with dementia and their families. This promising new model for dementia palliative care was designed using stakeholder input and evidence-based standards for dementia care. Results from this research will be used to develop a multisite randomized controlled trial of specialty palliative care for hospitalized patients with late-stage dementia.

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