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JAMA Intern Med. 2017 January 01; 177(1): 24–31. doi:10.1001/jamainternmed.2016.7031.**Effect of the Goals of Care Intervention for Advanced Dementia:****A Randomized Clinical Trial****Laura C. Hanson, MD, MPH, Sheryl Zimmerman, PhD, Mi-Kyung Song, PhD, RN, Feng-Chang Lin, PhD, Cherie Rosemond, PhD, Timothy S. Carey, MD, MPH, and Susan L. Mitchell, MD, MPH**

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Abstract

IMPORTANCE—In advanced dementia, goals of care decisions are challenging and medical care is often more intensive than desired.

OBJECTIVE—To test a goals of care (GOC) decision aid intervention to improve quality of communication and palliative care for nursing home residents with advanced dementia.

DESIGN, SETTING, AND PARTICIPANTS—A single-blind cluster randomized clinical trial, including 302 residents with advanced dementia and their family decision makers in 22 nursing homes.

INTERVENTIONS—A GOC video decision aid plus a structured discussion with nursing home health care providers; attention control with an informational video and usual care planning.

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MAIN OUTCOMES AND MEASURES—Primary outcomes at 3 months were quality of communication (QOC, questionnaire scored 0–10 with higher ratings indicating better quality), family report of concordance with clinicians on the primary goal of care (endorsing same goal as the “best goal to guide care and medical treatment,” and clinicians’ “top priority for care and medical treatment”), and treatment consistent with preferences (Advance Care Planning Problem score). Secondary outcomes at 9 months were family ratings of symptom management and care, palliative care domains in care plans, Medical Orders for Scope of Treatment (MOST) completion, and hospital transfers. Resident-family dyads were the primary unit of analysis, and all analyses used intention-to-treat assignment.

RESULTS—Residents’ mean age was 86.5 years, 39 (12.9%) were African American, and 246 (81.5%) were women. With the GOC intervention, family decision makers reported better quality of communication (QOC, 6.0 vs 5.6; $P = .05$) and better end-of-life communication (QOC end-of-life subscale, 3.7 vs 3.0; $P = .02$). Goal concordance did not differ at 3 months, but family decision makers with the intervention reported greater concordance by 9 months or death (133 [88.4%] vs 108 [71.2%], $P = .001$). Family ratings of treatment consistent with preferences, symptom management, and quality of care did not differ. Residents in the intervention group had more palliative care content in treatment plans (5.6 vs 4.7, $P = .02$), MOST order sets (35% vs 16%, $P = .05$), and half as many hospital transfers (0.078 vs 0.163 per 90 person-days; RR, 0.47; 95% CI, 0.26–0.88). Survival at 9 months was unaffected (adjusted hazard ratio [aHR], 0.76; 95% CI, 0.54–1.08; $P = .13$).

CONCLUSIONS AND RELEVANCE—The GOC decision aid intervention is effective to improve end-of-life communication for nursing home residents with advanced dementia and enhance palliative care plans while reducing hospital transfers.

TRIAL REGISTRATION—clinicaltrials.gov Identifier: NCT01565642

Background

Alzheimer disease and related dementias are a cause of functional dependency and death. Over 5 million Americans have dementia, and 1 million have advanced disease with loss of meaningful communication and total functional dependency.¹ Medical complications include nutritional problems, infections, and falls. Median survival in these patients is 1.3 years.²

Family members make difficult choices on behalf of persons with dementia. Common decisions include resuscitation, tube feeding, treatment of infections, and hospital transfer.³ Decisions are made in nursing homes, where 67% of persons with dementia die.⁴ Families report limited communication and support for these choices.^{5,6} The CASCADE study followed 323 nursing home residents with advanced dementia for 18 months. Only 38% of decision makers recalled involvement in treatment choices. Half spent less than 15 minutes discussing advance directives, and limited understanding was associated with more aggressive treatment.^{2,3}

Treatments should align with medical goals such as survival, function, or comfort.⁷ Shared decision making helps patients and families prioritize goals to guide treatment.⁸ Decision aids improve shared decision making by informing and framing health care choices.⁹

However, few decision aids are designed for dementia.^{10–12} To address this gap we developed the Goals of Care (GOC) intervention, consisting of a video decision aid and structured care plan meeting for family decision makers for persons with advanced dementia. Our primary aim was to learn if the GOC intervention improves quality of communication and decision-making. Our second aim was to test whether the intervention would improve palliative care for advanced dementia.

Methods

Trial Design

The study was a single-blind cluster randomized trial of the GOC intervention compared with an attention control. Nursing homes were randomized to minimize contamination and parallel how decision aids are implemented. Outcomes were assessed at the level of the resident-family dyad. The University of North Carolina institutional review board approved the protocol (Supplement 1) prior to initiation of research, and 2 data safety monitors reviewed procedures and preliminary data every 6 months. Family decision makers provided written informed consent for themselves and the resident with advanced dementia. Family decision makers were compensated for their participation.

Randomization of Nursing Home Sites

Nursing homes were eligible within a 60-minute driving radius of the University of North Carolina-Chapel Hill. Administrators and medical directors agreed to site participation, and treating physicians gave permission to recruit families. The study statistician (F.-C.L.) randomized 22 nursing homes in blocks of 4, except for a final block of 2, matched by profit vs nonprofit status and percent African American residents.

Participants

From April 2012 to September 2014 we enrolled dyads of persons with advanced dementia and family decision makers. Nursing homes sent initial letters and referred those who agreed to contact with researchers. Residents were eligible if they were aged 65 years or older, had severe to advanced dementia, and had an English-speaking family decision maker. Nurses verified dementia stage (5–7 on the Global Deterioration Scale [GDS]).¹³ Persons with GDS 5 dementia cannot live independently and are frequently disoriented, while those with GDS 7 have sparse speech, dependency for all activities, and cannot recognize family. Family decision makers were eligible if they were legally authorized representatives for health care decisions as guardian, possessed health care power of attorney, or the decision maker under North Carolina law was sequenced as spouse, adult children, or sibling.

Intervention and Control

Intervention decision makers had the 2-part intervention, consisting of an 18-minute GOC video decision aid and a structured discussion with the nursing home care team. The decision aid was developed using International Patient Decision Aid Standards, and tested for feasibility and acceptability.^{14,15} It provided information on dementia, goals of prolonging life, supporting function, or improving comfort, treatments consistent with each goal, and how to prioritize goals. Decision makers saw the decision aid with research staff

during their initial study visit, and received a print copy of the decision aid and guide called “Questions to Consider in Care Planning” (available on request from the authors).

To prepare staff for a goals of care discussion, investigators gave a 1-hour training session to nurses, social workers, therapists, and nutritionists who create care plans. They viewed the GOC decision aid, learned the VALUE (value family comments, address emotions, listen, understand the patient as a person, and elicit family questions) principles for family communication, and observed a short role play of a goals of care discussion.¹⁶ Research staff also provided them with a written discussion guide, and reminders to meet with decision makers. Physicians and nurse practitioners were invited to these discussions, but rarely attended. Research staff monitored the intervention, and required retraining if 70% fidelity was not achieved. One facility required retraining, and fidelity was achieved for 90% of participants.¹⁷

Family decision makers in control sites experienced an informational video on interaction with someone with dementia and a usual care plan meeting with staff. Nursing home staff received a 45-minute training on study procedures. All other procedures were identical for both arms.

Data Collection

Research assistants blinded to participant assignment assessed outcomes. They interviewed family decision makers in person at baseline, and by telephone at 3, 6, and 9 months. They also completed structured resident medical chart reviews at baseline, and at 3, 6, and 9 months. On a resident’s death, interviews were modified to address care during dying.

Family provided data about age, sex, race, education, and relationship for themselves and the person with dementia. Medical chart reviews provided data to calculate the Advanced Dementia Prognostic Tool (ADEPT), derived from standardized variables in nursing home records. The ADEPT scores range from 1 to 32.5, with higher scores indicating higher mortality risk.¹⁸ Medical chart reviews were also the source of data on treatment in domains of palliative care, hospice enrollment, and transfers to emergency departments or hospitals.

Outcomes

Primary and secondary outcomes were compared at 3 months, 6 months, and a final end point of 9 months or death. Study outcomes for the primary aim were 3 family-rated measures of quality of communication and decision making at 3 months: (1) Quality of Communication (QOC) scores for nursing home staff, (2) concordance with clinicians on goals of care, and (3) the Advance Care Planning problem score. The valid and reliable QOC questionnaire is a 13-item instrument with an overall score and 2 subscale scores for “general communication skills” and “communication about end-of-life care.”¹⁹ Scores range from 0 (“poor”) to 10 (“absolutely perfect”); responses of “clinician did not do” are recoded 0. To measure concordance with clinicians on the primary goal of care, family decision makers reported whether prolonging life, supporting function, or improving comfort was the “best goal to guide the resident’s care and medical treatment,” and separately reported which goal was the nursing home staff and physician’s “top priority for the resident’s care and medical treatment.” Concordance meant the same response to both items. Finally, the

Advance Care Planning Problem score was used to measure use of resident preferences to guide treatment.^{20,21} Three dichotomous items ask family decision makers if the resident's preferences were discussed, used to guide treatment, and if treatment was consistent with preferences. The score is reported as percent with 1 or more unfavorable responses.

Secondary outcomes measured quality of palliative care at 6 months and at 9 months or death. Families rated quality of symptom management and overall care using the validated Symptom Management at the End of Life in Dementia (SM-EOLD) and Satisfaction with Care at the End of Life in Dementia (SWC-EOLD) instruments. The SM-EOLD ranges from 0 to 45 and the SWC-EOLD ranges from 10 to 40, with higher scores indicating better quality.²² Investigators developed a Palliative Care Treatment Plan Domain score to capture the palliative care content of residents' treatment plans. Scores range from 0 to 10, with 1 point assigned when each of the following domains was addressed in the written care plan: prognosis, goals of care, treatment for physical symptoms, emotional needs, spiritual needs, and decisions to use or avoid use of 5 treatments: resuscitation, artificial feeding, intravenous fluids, antibiotics, and hospitalization. Research assistants completed paired medical chart reviews until they achieved an inter-rater reliability of greater than 0.85 on all items. To describe additional details of the treatment plan, research assistants also recorded do not resuscitate orders, orders not to hospitalize or use tube feeding, and completion of a Medical Orders for Scope of Treatment (MOST), the North Carolina version of the Physician Orders for Life Sustaining Treatment (POLST) order set. Medical chart reviews recorded hospice enrollment, hospital transfers, and resident deaths.

Statistical Analysis

Resident-family dyads were the primary unit of analysis, and all analyses used intention-to-treat assignment. Participants in the intervention and control groups were compared on baseline characteristics to explore possible between-group differences despite cluster randomized. Nursing home characteristics were compared using χ^2 tests for categorical variables and *t* tests for continuous variables.

Intervention and control dyads were compared on primary and secondary outcomes measured at 3 months, 6 months, and at the final time point of 9 months or death. Rates of hospital or emergency department transfer were calculated as events per person-day at risk, to account for differential follow-up owing to death. In the longitudinal analysis, intraclass correlations were considered at 2 levels: residents clustered within nursing homes, and repeated measures for the same individual over time. Investigators fit a generalized mixed effects model with both a random intercept and random slope (in time) to control for the variation between nursing homes and correlation among residents within nursing homes, with treatment, time and interaction between treatment and time as covariates. Time was included as a categorical variable. They fit a simpler random intercept model with adjustment for baseline measures for the final 9-month or death outcomes and a fixed effects model with robust variance estimation when the random intercept model did not converge. Resident survival times were analyzed using Cox proportional hazards models for comparison between intervention and control groups, adjusted for nursing home cluster

effects. All of the analyses used SAS statistical software (version 9.3, SAS institute) and P values less than .05 were considered significant.

With a sample size of 300 dyads, the trial was powered to detect a 0.8 mean difference in the overall QOC score, and a 1.5 mean difference in the QOC end-of-life subscale score between the control and intervention arms. Estimation included adjustment for cluster effects, and a 6-month mortality risk of 28%.

Results

Enrollment

Administrators and all physicians agreed to participate in 22 of 25 nursing homes approached. These 22 sites were paired and randomly assigned to intervention or control groups; sites did not differ in organizational characteristics (eTable A in Supplement 2). Nursing home staff identified 534 potentially eligible dyads; of these 118 (22%) decision makers refused contact, and 27 (5%) could not be reached. Of the 387 eligible family decision makers contacted, 302 (78%) agreed to participate and were enrolled. Accounting for expected deaths, participation was 99% complete at 3 and 6 months, and 100% at 9 months (Figure 1).

Participant Characteristics

Residents with dementia had a mean age of 86.5 years, 246 (81.5%) were women, and they had a 12-month mortality risk of 33% based on ADEPT (Table 1). Family decision makers' mean age was 63 years, and most were daughters or daughters-in-law. Characteristics did not differ between study arms.

Communication and Decision-Making Outcomes

With the GOC intervention, family decision makers reported better overall scores on the 10-point QOC questionnaire at 3 months compared with those in the control group (6.0 vs 5.6, $P = .05$) (Table 2). Improvement corresponded to higher ratings of end-of-life communication (QOC end-of-life subscale, 3.7 vs 3.0; $P = .02$). The intervention group continued to report better quality end-of-life communication compared with controls in the final time period (QOC end-of-life subscale, 3.9 vs 3.1; $P = .03$), despite somewhat less positive ratings of general communication (QOC general subscale, 8.2 vs 8.6; $P = .03$). Compared with controls, family decision makers with the GOC intervention perceived greater concordance with providers regarding the primary goal of care by the final assessment (88.4% vs 71.2%, $P = .001$); concordance showed a trend favoring the intervention at 3 months. Comfort was increasingly the primary goal of care over time for both groups. Intervention and control decision makers did not differ on Advance Care Planning Problem scores. Examining individual items in this score, over 90% of decision makers in both groups reported treatment was consistent with resident preferences, but that discussion of residents' preferences to guide treatment was relatively infrequent (eTable B in Supplement 2). Family often discussed medical treatment choices with nurses or social workers, and a minority reported communication with nursing home physicians or nurse practitioners.

Quality of Palliative Care Outcomes

Family ratings of symptom management (SM-EOLD) and satisfaction with care (SWC-EOLD) did not differ between groups (Table 3). However, following the intervention residents had more palliative care domains addressed in their treatment plans by 6 months, compared with residents in the control group (5.6 vs 4.7, $P = .02$). The most directly related domain—goals of care documentation—increased at 6 months (91% vs 42%, $P < .001$), and at the final assessment (95% vs 52%, $P < .001$).

Nursing home physicians or nurse practitioners completed a MOST order set more often for residents in the intervention group (35% vs 16%, $P = .05$). Do not resuscitate (DNR) orders were common, although somewhat less common in the intervention group (85% vs 91%, $P = .04$). During 9 months follow-up there were 33 hospital or emergency transfers in the intervention group and 67 in the control group. Adjusting for person-days at risk, residents in the intervention group were half as likely to experience hospital transfers (0.078 vs 0.163 transfers per 90 person-days; RR, 0.47; 95% CI, 0.26–0.88). During 9 months follow-up, 33 (22%) control residents and 27 (18%) intervention residents died; survival time did not differ significantly (hazard ratio [HR], 0.76; 95% CI, 0.54–1.08; $P = .13$) (Figure 2).

Discussion

The GOC decision aid intervention was effective to improve quality of communication about end-of-life care for nursing home residents with advanced dementia. Over time, family decision makers in both arms increasingly chose comfort as the primary goal of care, but those with the GOC intervention experienced better communication and enhanced confidence that health care providers were prioritizing the same goal. They typically communicated with nurses or social workers, not physicians, reflecting current roles in nursing home care.

These study outcomes are aligned with widely endorsed measures of quality palliative care.²³ Though improvements in quality of communication were modest, they were followed by greater attention to palliative care in treatment plans. The GOC intervention resulted in increased use of MOST to record goals of care and treatment choices. Though the intervention did not explicitly promote its use, the GOC intervention is consistent with MOST and may make it easier to introduce. This GOC study provides the first evidence that a decision aid can be used to enhance implementation of the POLST paradigm.²⁴

The GOC intervention also resulted in half as many hospital transfers for nursing home residents with advanced dementia, without affecting survival. Residents in both study arms had severe underlying illness, but the GOC decision aid allowed families to consider options of hospitalization or care at the nursing home for acute illness. Hospital transfers were a secondary outcome, but the finding is important because persons with dementia have a high rate of transfers.²⁵ Transitional care interventions have excluded persons with dementia, and the GOC intervention provides initial evidence that this outcome can be improved.²⁶

Results from the GOC intervention are promising, yet they highlight elements of dementia palliative care that are in need of improvement. Family ratings of end-of-life communication

improved, yet remained lower than QOC scores in intensive care units.²⁷ While communication with nursing home staff was common, only 1 in 4 family decision makers talked with physicians. Lack of physician communication may account for continued gaps in the quality of end-of-life communication. Further, ratings of symptom management and care were fairly good, but unchanged. The GOC intervention addresses shared decision-making, but targeted interventions are needed to improve symptoms and comfort in patients with dementia.

The GOC study was an efficacy trial, but the intervention was designed for practical implementation in nursing homes.²⁸ The video decision aid made evidence-based information easily accessible. After brief training, nursing home staff used a print guide to conduct all goals of care discussions. Further, the study was conducted in a diverse group of nursing homes, increasing potential for broad use. Finally, the intervention was designed to support shared decision making in a setting with limited physician presence, and to integrate with the national standardized care planning process for nursing home residents.²⁹ The research was completed prior to Medicare reimbursement for advance care planning communication, but this policy change may enhance physician involvement in the future.

Limitations

Findings should be interpreted in the context of study limitations. Although sites had diverse characteristics, all were within a single state. Characteristics match national data on nursing homes, but the GOC intervention could be more or less effective in other regions. The GOC framework was chosen for its relevance to shared decision making in dementia care.^{30,31} Alternative frameworks may be as or more useful to guide family decision makers. Interview questions about goals of care may have prompted some control families to seek discussions with nursing home clinicians, thus reducing measured effects of the intervention. Study findings apply to a long-stay population of residents who live in the nursing home, but should not be generalized to the short-stay rehabilitation population.

The GOC intervention was designed to rely on existing communication skills and strategies used in nursing homes. This study is the first randomized clinical trial to address dementia palliative care needs in nursing homes, and future research is needed to expand on these results. Less pragmatic, but potentially higher impact interventions could include communication skills training for staff, specialty palliative care consultation, or payment reform to engage physicians and nurse practitioners as active participants in interdisciplinary teams in nursing home care.

Conclusions

The GOC decision aid intervention was effective to improve quality of communication for nursing home residents with advanced dementia, and to improve elements of palliative care. Hospital transfers were reduced for these frail patients, without any adverse effects on survival. The GOC study provides evidence for a promising new approach to enhance shared decision making for nursing home residents with advanced dementia and for their families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Key Points

Question

Can a decision aid intervention about goals of care improve communication, decision-making, and palliative care for patients with advanced dementia?

Findings

In this randomized trial of 302 nursing home residents with advanced dementia, family decision makers reported better end-of-life communication with clinicians. Clinicians were more likely to address palliative care in treatment plans, use Medical Orders for Scope of Treatment, and less likely to send patients to the hospital.

Meaning

The goals of care decision aid intervention is effective in improving quality of communication, palliative care treatment plans, and reducing hospitalization rates for nursing home residents with advanced dementia.

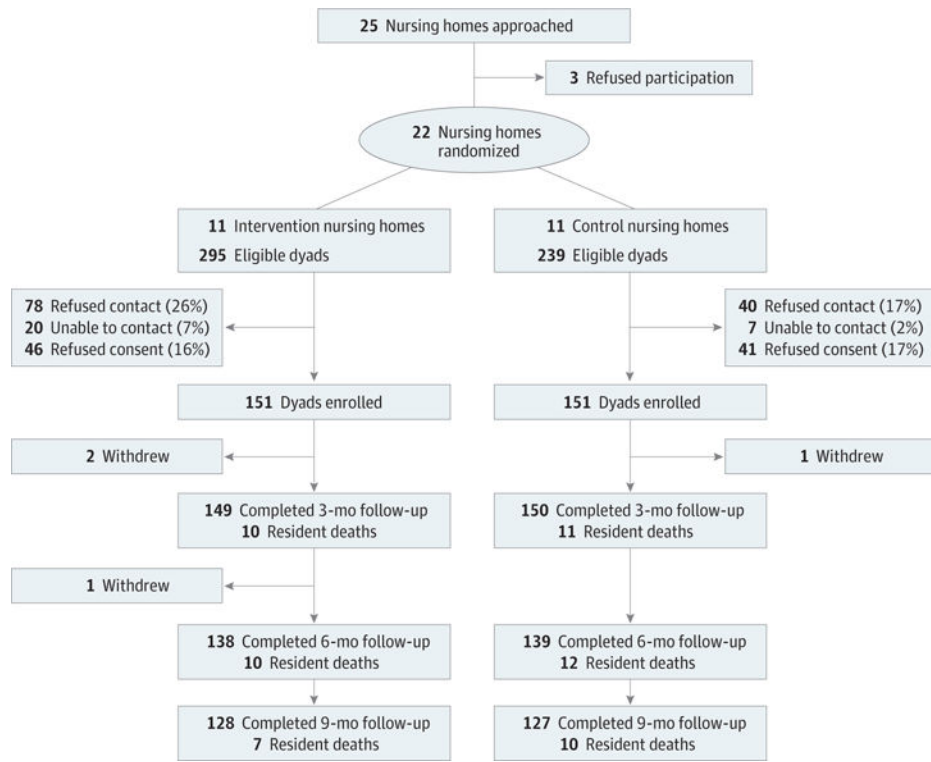


Figure 1.
Enrollment and Participant Flow

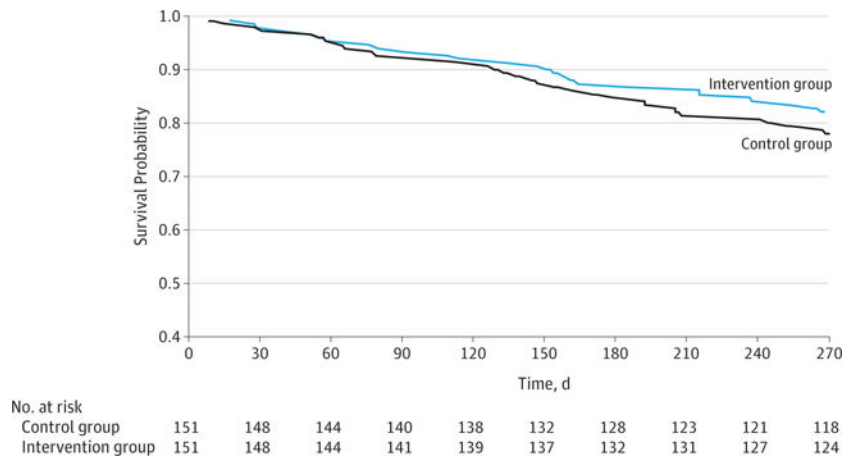


Figure 2.
Survival Comparison Between Control and Intervention Groups

Table 1
Baseline Characteristics of Residents With Dementia and Family Decision Makers

Characteristic	Control Group (n = 151)		Intervention Group (n = 151)		P Value
	No.	% (SD)	No.	% (SD)	
Residents with dementia					
Age, mean, y		87.3 (6.7)		85.7 (7.6)	.23
Female sex	125	82.8	121	80.1	.93
Race					
African American	25	16.7	14	9.3	
White	123	82.0	134	88.7	.98
Other	2	1.3	3	2.0	
Dementia stage: global deterioration scale					
5 (Moderate)	36	23.8	38	25.2	
6 (Moderately severe)	73	48.3	79	52.3	.99
7 (Severe)	42	27.8	34	22.5	
Severity of illness (ADEPT score range, 1–32.5)		8.9 (2.7)		8.9 (2.7)	.87
Nursing home stay, days		706.6 (610.9)		811.1 (1017.2)	.66
Family decision makers					
Age, mean, y		63.4 (10.7)		62.4 (10.6)	.43
Female sex	100	66.2	104	68.9	.98
Race					
African American	25	16.7	13	8.6	
White	125	83.3	136	90.1	.84
Other	0	0.0	2	1.3	
Relationship					
Spouse	21	13.9	19	12.6	
Son and/or son-in-law	39	25.8	38	25.2	
Daughter and/or daughter-in-law	85	56.3	76	50.3	
Other	6	4.0	18	11.9	
Education level					

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Characteristic	Control Group (n = 151)		Intervention Group (n = 151)		P Value
	No.	% (SD)	No.	% (SD)	
Less than high school	1	0.7	2	1.3	
High school graduate	18	12.0	26	17.2	
Some college and/or vocational school	39	26.0	33	21.9	.99
College graduate	55	36.7	47	31.1	
Advanced degree	37	24.7	43	28.5	

Abbreviation: AD/DEPT, Advanced Dementia Prognostic Tool (higher scores indicate higher 6- and 12-month mortality risk).

Table 2
Effect of Goals of Care Intervention on Quality of Communication and Decision-Making for Dementia

Decision-Making Outcomes	Baseline		3 Months		Final (9 Months or Death)				
	Control (n = 151)	Intervention (n = 151)	P Value	Control (n = 150)	Intervention (n = 149)	P Value	Control (n = 150)	Intervention (n = 149)	P Value
Family reported QOC ^a with nursing home staff; mean (SD)									
Overall score (0–10)	5.6 (1.7)	5.5 (1.7)	.59	5.6 (1.8)	6.0 (2.0)	.05	5.6 (1.9)	5.8 (2.4)	.19
QOC subscale, general (0–10)	8.4 (1.7)	8.4 (1.8)	.97	8.7 (1.6)	8.6 (1.7)	.63	8.6 (1.9)	8.2 (2.3)	.03
QOC subscale, end-of-life (0–10)	3.1 (2.3)	2.9 (2.3)	.53	3.0 (2.6)	3.7 (2.7)	.02	3.1 (2.6)	3.9 (3.1)	.03
Family-health care provider concordance on primary goal of care, %	68.2	63.2	.47	70.1	77.2	.12	71.2	88.4	.001
Family’s primary goal is comfort	68.9	63.6	.38	70.3	69.3	.56	78.4	81.0	.55
Advanced care planning problem score 1, ^b %	50.7	53.8	.98	73.9	62.5	.06	66.9	68.3	.82
Family communicated about important medical treatments or goals, ^c %									
With nurse and/or social worker	91.4	89.4	.60	82.6	84.3	.49	81.8	81.0	.93
With physician	55.6	56.3	.78	21.0	25.7	.52	25.0	25.9	.94
With nurse practitioner	36.4	38.4	.55	26.1	30.0	.74	18.9	36.7	.02

Abbreviation: QOC, quality of communication.

^aQuality of Communication scale and subscales range from 0 to 10, with higher scores indicating better quality of communication.

^bPercent of decision makers reporting at least 1 problem with use of resident preferences to guide treatment on 3 items composing the score.

^cRates reflect “ever discussed” at baseline, and reflect the “past 3 months” during each follow-up time period.

Table 3
Effect of Goals of Care Intervention on Quality of Palliative Care for Dementia

Characteristics	Baseline		6 Months		Final (9 Months or Death)		P Value
	Control (n = 151)	Intervention (n = 151)	Control (n = 139)	Intervention (n = 138)	Control (n = 150)	Intervention (n = 149)	
Symptom management (SM-EOLD) (0–45), ^a mean (SD)	33.5 (8.5)	32.7 (8.9)	33.2 (8.8)	32.2 (9.0)	33.7 (8.6)	32.6 (9.7)	.48
Satisfaction with Care (SWC-EOLD) (10–40), ^a mean (SD)	30.1 (5.2)	30.8 (5.4)	31.7 (5.1)	31.4 (5.6)	31.6 (5.3)	31.0 (5.9)	.16
Palliative care treatment plan domain score (0–10), ^b mean (SD)	4.8 (1.9)	5.1 (2.2)	4.7 (1.8)	5.6 (2.0)	5.3 (1.9)	5.9 (2.2)	.17
Goals of care documented, ^c %	30	46	42	91	52	95	<.001
Treatment orders, %							
MOST order set	15	25	15	34	16	35	.05
Do not resuscitate	84	82	90	84	91	85	.04
Do not hospitalize	23	23	30	33	36	36	.91
Do not tube feed	20	33	26	45	31	46	.20
Symptom treatment			68	52	75	67	.39
Hospice enrollment ^c	8	7	13	11	18	17	.97
Hospital transfers per 90 person-days					.16	.08	.02

Abbreviations: MOST, Medical Orders for Scope of Treatment;

SM-EOLD, Symptom Management at the End of Life in Dementia;

SWC-EOLD, Satisfaction With Care at the End of Life in Dementia.

^aSM-EOLD scores range from 0 to 45, with higher scores indicating better symptom management; SWC-EOLD scores range from 10 to 40, with higher scores indicating greater satisfaction with end-of-life care.

^bPalliative care domain score ranges from 0 to 10, with higher scores indicating a greater number of palliative care domains addressed in treatment plans.

^cThese variables are reported as cumulative probability. P values for the final time point are reported based on a robust variance procedure owing to nonconvergence of the random intercept model.