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An Advance Care Planning Video Decision Support Tool for Nursing Home Residents With Advanced Dementia
A Cluster Randomized Clinical Trial

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IMPORTANCE Better advance care planning (ACP) can help promote goal-directed care in patients with advanced dementia.

OBJECTIVES To test whether an ACP video (vs usual care) has an effect on documented advance directives, level of care preferences, goals-of-care discussions, and burdensome treatments among nursing home residents with advanced dementia.

DESIGN, SETTING, AND PARTICIPANTS The Educational Video to Improve Nursing home Care in End-stage dementia (EVINCE) trial was a cluster randomized clinical trial conducted between February 2013 and July 2017, at 64 Boston-area nursing homes (32 facilities per arm). A total of 402 residents with advanced dementia and their proxies (intervention arm, n = 212; control arm, n = 190) were assessed quarterly for 12 months.

INTERVENTIONS A 12-minute ACP video for proxies with written communication of their preferred level of care (comfort, basic, or intensive) to the primary care team.

MAIN OUTCOMES AND MEASURES The primary outcome was the proportion of residents with do-not-hospitalize (DNH) directives by 6 months. Secondary outcomes included preference for comfort care, documented directives to withhold tube-feeding and intravenous hydration, documented goals-of-care discussions, and burdensome treatments (hospital transfers, tube-feeding, or parenteral therapy) per 1000 resident-days. Exploratory analyses examined associations between trial arm and documented advance directives when comfort care was preferred.

RESULTS The mean age of the 402 study residents was 86.7 years [range, 67-102 years]; 350 were white (87.1%) and 323 were female (80.3%), with DNH directives that by 6 months did not differ between arms (63% in both arms; adjusted odds ratio [AOR], 1.08; 95% CI, 0.69-1.69). Preferences for comfort care, directives to withhold intravenous hydration, and burdensome treatments did not differ between arms. Residents in intervention vs control facilities were more likely to have directives for no tube-feeding at 6 months (70.10% vs 61.90%; AOR, 1.79; 95% CI, 1.13-2.82) and all other time periods, and documented goals-of-care discussions at 3 months (16.10% vs 7.90%; AOR, 2.58; 95% CI, 1.20-5.54). When comfort care was preferred, residents in the intervention arm were more likely to have both DNH and no tube-feeding directives (72.20% vs 52.80%; AOR, 2.68; 95% CI, 2.68-5.85).

CONCLUSIONS AND RELEVANCE An ACP video did not have an effect on preferences, DNH status, or burdensome treatments among residents with advanced dementia, but did increase directives to withhold tube-feeding. When proxies preferred comfort care, advance directives of residents in the intervention arm were more likely to align with that preference.

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Supplemental content

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Patients with advanced dementia commonly receive burdensome treatments that may be of little clinical benefit and inconsistent with care preferences.[1-5] Advance care planning (ACP) offers an opportunity to promote goal-directed care.[2,3,6-10] However, current ACP is often inadequate; proxy counseling is inconsistent, preferences are not routinely ascertained, and advance directives may not reflect the goals of care.[1,2,6,8,11-16]

Traditional ACP discussions are limited because of challenges of envisioning complex scenarios, inconsistent physician counseling, and literacy and language barriers. Video decision support tools aim to address these shortcomings.[17-25] Prior randomized clinical trials (RCTs) by our group found that healthy adults randomized to watch videos about ACP in advanced dementia, compared with those who read verbal descriptions, were more likely to want comfort-focused care when they imagined having this condition.[18,21,22] However, these trials did not investigate the effect of ACP videos on preferences or clinical outcomes among actual patients with advanced dementia.

We conducted a cluster RCT, Educational Video to Improve Nursing home Care in End-stage dementia (EVINCE), in 64 Boston-area nursing homes (NHs). At baseline, proxies of residents with advanced dementia in intervention facilities viewed an updated version of an ACP video.[18,19,21,22] Proxies in control facilities experienced usual ACP practices. Residents were followed for 12 months. The primary outcome was documented advance directives to forgo hospitalization by 6 months. Secondary outcomes included preferences for comfort care, directives to withhold other treatments, goals-of-care discussions, and burdensome treatments. Exploratory analyses examined associations between trial arm and advance directives, stratified by level of care preference.

Key Points

Question Can an advance care planning (ACP) video have an effect on advance directives, preferences, and burdensome treatments among nursing home residents with advanced dementia?

Findings In this cluster randomized clinical trial of 402 patients with advanced dementia, do-not-hospitalize directives, care preferences, and burdensome treatments did not significantly differ between trial arms. In intervention facilities, residents were more likely to have directives to withhold tube-feeding, and, when comfort care was preferred, to have do-not-hospitalize and no tube-feeding directives.

Meaning In advanced dementia, an ACP video did not have an effect on do-not-hospitalize directives, care preferences, or burdensome treatments, but may promote alignment of preferences with advance directives.

Methods

Design

EVINCE was a cluster RCT conducted in 64 Boston-area NHs (32 facilities per arm). Participant enrollment began February 15, 2013. Data collection was completed July 12, 2017. The Hebrew SeniorLife institutional review board approved this study's conduct. Patients and proxies provided written informed consent and were not compensated. See the study protocol in Supplement 1.

Facilities and Randomization

Eligible facilities had more than 45 beds and were within 60 miles of Boston. A research assistant (RA) mailed information to senior administrators at 181 eligible facilities and telephoned them 1 week later to solicit their facilities' participation.

Facilities were enrolled and randomized as pairs matched on profit status; a factor associated with ACP.[4,6,16] Once a pair was recruited, facilities were assigned deidentified labels that the statistician used to randomly assign 1 NH to each arm using a computer-generated algorithm. Approximately 1 matched pair was randomized and began the trial every 2 months from February 1, 2013, to May 1, 2016.

Participants

Resident eligibility criteria included age of at least 65 years; dementia (any type); Global Deterioration Scale (GDS) score of 7 (range, 1-7; higher scores indicate worse dementia)[26]; length of stay greater than 90 days; and having an English-speaking proxy available for an in-person interview within 2 weeks. With a GDS of 7, patients with dementia have profound memory deficits (eg, cannot recognize family members), speak fewer than 5 words, are incontinent of urine and stool, and are nonambulatory.[26] The proxy was the resident's formally or informally designated medical decision maker.

At the time of NH recruitment and quarterly thereafter, RAs asked nurses to identify residents with dementia, with GDS of 7, and available proxies. Age and dementia diagnosis were confirmed by medical record review. Proxies of eligible residents were mailed information and telephoned 2 weeks later to solicit their participation. Proxies provided consent for themselves and the residents, and were informed only about conditions of participation in the arm to which their facility was randomized.

Intervention

The intervention included an ACP video for proxies and provision of a form to the residents' primary care team indicating the proxy's preferred level of care after viewing the video. The 12-minute video was developed by geriatricians and palliative care specialists, with earlier versions refined for EVINCE.[18,19,21,22] Proxies were shown the video on tablets by an RA during a baseline in-person interview.

The video first described the typical features of advanced dementia accompanied by images of an individual with this condition. Next, 3 levels of care options were presented: intensive, basic, and comfort care. Intensive medical care was described as potentially including "all medical treatments available, such as cardiopulmonary resuscitation (CPR), breathing machines, tube-feeding, and hospitalization including the intensive care unit (ICU)." Images included a simulated resuscitation on a mannequin, a ventilated patient, and a tube-fed NH resident.

Basic medical care was described as "somewhere between wanting to live as long as possible and maximizing comfort," with possible treatments including antibiotics, parenteral therapy, and hospitalization, but not CPR, intubation, tube-feeding, or ICU care. Visual images included a hospitalized older patient receiving intravenous antibiotics and oxygen via nasal cannula.

Comfort care was described as including only treatments to promote comfort. Hospitalization would be avoided except when needed for comfort. Patients would receive assistance eating but not tube-feeding or intravenous fluids. The video depicted a patient with advanced dementia being handfed, assistance with personal care, and oxygen.

The proxy's preferred level of care after viewing the video was documented on a form that was emailed or mailed to the residents' clinicians, nursing units, and social worker, and placed in their medical records. At baseline, proxies in control facilities were read descriptions of the levels of care (eMethods in Supplement 2) and asked their preferences. Their choice was not communicated to clinicians, and they otherwise experienced usual ACP practices.

Data Collection and Elements

Resident data were collected at baseline and quarterly up to 12 months from their medical records, except for baseline measures of functional and cognitive status. Proxy data were collected at baseline in-person interviews and quarterly telephone interviews for up to 12 months. Medical record reviews were performed within 14 days of a resident's death.

Four RAs collected data. One RA conducted all baseline in-person interviews when the video was also shown and therefore was not masked. Three other RAs who conducted medical record abstractions and follow-up proxy interviews, which included all outcome data, were masked. The investigators, statistician, and data programmers were masked.

Baseline resident data from the medical record included demographics (age, sex, and race [white vs other]), and dementia type (Alzheimer disease vs other). Nurses quantified functional status using the Bedford Alzheimer Nursing Severity-Subscale (range, 7-28; higher scores indicate greater disability).[27] The RAs administered the Test for Severe Impairment to residents (range, 0-24; lower scores indicate greater impairment; dichotomized to ≤0).[28]

Variables abstracted from medical records at each assessment included advance directives to forgo hospital transfers (DNH), tube-feeding, and intravenous hydration, as indicated by either medical orders or other clinician documentation (eg, progress notes). Documented goals-of-care discussions between clinicians and proxies in the prior 3 months was ascertained. Finally, feeding tube insertions, parenteral therapy (hydration or medications), and hospital transfers (admission or emergency department) were abstracted.

During in-person baseline and quarterly telephone interviews, proxies were read descriptions of intensive, basic, and comfort care (eMethods in Supplement 2) and asked which level they felt the resident should receive. At baseline, proxies in intervention facilities were asked their preferences before and immediately after viewing the video; proxies in control facilities were asked their preferences only once. After viewing the video, proxies were asked whether the video was helpful (very, somewhat, a little, or not), and whether they would recommend it to others (definitely, probably, probably not, or definitely not).

Additional proxy data ascertained at baseline included age, sex, race (white vs other), education level, relationship to resident (spouse, child, or other), and whether NH clinicians had asked their opinion regarding goals of care.

Outcomes

The primary outcome was the cumulative proportion of residents with documented DNH directives by 6 months. Secondary outcomes included the cumulative proportion of residents who had DNH directives by 3, 9, and 12 months, and directives to forgo other treatments (tube-feeding, intravenous hydration) and documented goals-of-care discussions by 3, 6, 9, and 12 months. Acquisition of new directives to withhold specific treatments and goals-of-care discussions over follow-up among residents who lacked them at baseline was also examined.

Additional secondary outcomes included proportions of proxies preferring comfort care (vs basic or intensive care) at baseline (postvideo in the intervention arm) and cumulatively at each follow-up interview. Finally, burdensome treatments per 1000 resident-days included any hospital transfers, feeding tube insertions, or parenteral therapy.

Two exploratory analyses were conducted. The first examined the association between trial arm and directives for DNH and no tube-feeding (the 2 most aggressive interventions) stratified by level of care preference. The second examined the association between level of care preferences among proxies in the intervention arm before watching the video and whether they found the video helpful.

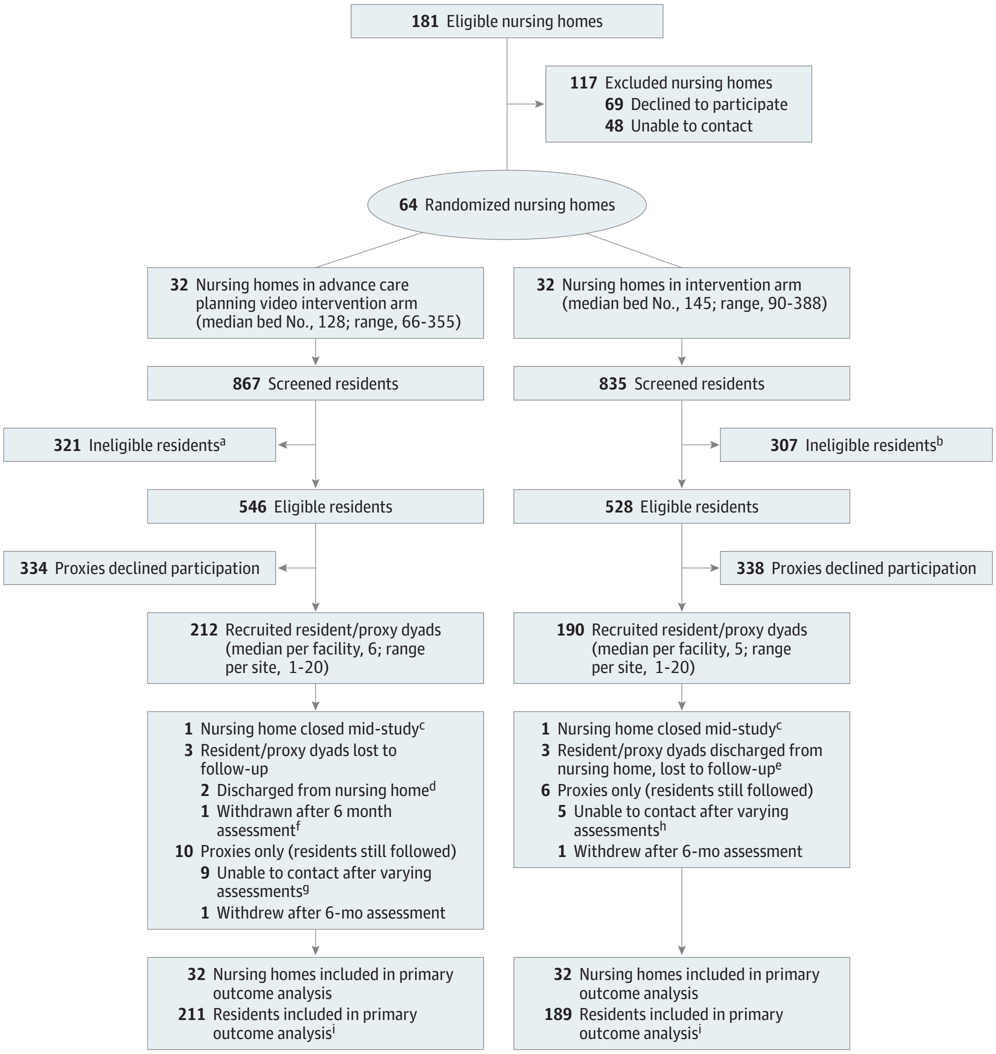
Statistical Analysis

Analyses were performed at the resident or proxy level (unless otherwise noted) and followed intention-to-treat principles. Variables were described using means (SDs) and frequencies for continuous and categorical variables, respectively. All models comparing outcomes between arms were adjusted for resident age and race (white vs other) and clustering at the facility level using generalized estimating equations (GEEs) for logistic regression models and robust variance estimates for Cox proportional hazards and Poisson hurdle models. Adjusted odds ratios (AORs) or adjusted hazard ratios (AHRs) with 95% CIs were generated. Analyses were performed using SAS (version 9.4; SAS Institute Inc) and Stata (version 13.1; StataCorp) statistical software.

Logistic regression compared the proportion of proxies in each arm opting for comfort care at baseline (postvideo in intervention group) and cumulatively at 3, 6, 9, and 12 months. For example, proxies were considered to prefer comfort care by 6 months if they stated that preference at either baseline, 3 months, or 6 months.

Logistic regression compared cumulative proportions of residents in the intervention vs control arms with each advance directive at 3, 6, 9, and 12 months. The proportion of residents with each directive were considered cumulatively up until each time point, including those who died (eg, residents were considered to have DNH directives by 6 months if it was documented at the 3-month, 6-month, or death assessment [if they

Figure. CONSORT Diagram



CONSORT diagram of nursing homes and participants.

[a] Unable to contact proxy (n = 163); resident did not have dementia (n = 56), resident died before consent was obtained (n = 47), proxy could not meet (n = 24), resident Global Deterioration Scale (GDS) score was <7 (n = 17), proxy did not speak English (n = 9), resident in was in a coma (n = 4), and no proxy (n = 1).

[b] Unable to contact proxy (n = 158); resident died before consent was obtained (n = 53), resident did not have dementia (n = 49), proxy could not meet (n = 20), resident was in a coma (n = 13), resident GDS score was <7 (n = 8), proxy did not speak English (n = 5), and no proxy (n = 1).

[c] All participants at nursing home completed follow-up either before the facility closed or at another study facility and were included in the primary outcome analysis.

[d] Discharged from nursing home after baseline assessment (n = 1) and 3-month assessment (n = 1).

[e] Discharged from nursing home after baseline assessment (n = 1) and 9-month assessment (n = 2).

[f] Proxy was unstable and could not continue to provide consent for resident.

[g] Unable to contact after baseline assessment (n = 4), 3-month assessment (n = 2), and 6-month assessment (n = 3).

[h] Unable to contact after baseline assessment (n = 3) and 3-month assessment (n = 2).

[i] Excluded 1 resident with only baseline data, included all residents with at least 1 follow-up assessment.

died before the 6-month assessment]). Baseline advance directives were excluded. The cumulative incidences of acquiring an advance directive over follow-up, among those who lacked the directive at baseline, were compared between the 2 arms using Cox proportional hazards regression. Time to acquisition was calculated from baseline assessment dates to follow-up assessment dates when the directive was first noted. Residents who never acquired the directive were censored.

Burdensome treatments per 1000 resident-days were compared between trial arms using Poisson hurdle models that compared the odds of having at least 1 burdensome treatment, and then conditionally on having at least 1 intervention and the number of interventions received. A joint test of effect on both model components was conducted, generating a *P* value.

Exploratory analyses examining associations between trial arm and documented directives stratified by level of care pref-

Table 1. Baseline Resident and Health Care Proxy Characteristics

Characteristics	No. (%) Intervention (n = 212)	Control (n = 190)
Resident		
Age, mean (SD), y	86.0 (7.4)	87.4 (7.3)
Male	45 (21.2)	34 (17.9)
White vs other	178 (84.0)	172 (90.5)
Alzheimer dementia vs other dementia	146 (68.9)	137 (72.1)
Bedford Alzheimer nursing severity subscale, mean (SD)[a]	19.9 (2.8)	20.4 (2.6)
Test for severe impairment = 0[b]	101 (47.6)	89 (46.8)
Percutaneous endoscopic gastrostomy tube	3 (1.4)	4 (2.1)
Documented advance directives[c]		
No hospitalization	103 (48.6)	97 (51.1)
No tube-feeding	122 (57.5)	101 (53.2)
No intravenous hydration	61 (28.8)	44 (23.2)
Goals-of-care discussion in prior 3 mo	27 (12.7)	29 (15.3)
Proxy		
Age, mean (SD), y	61.8 (10.9)	62.8 (10.6)
Male	66 (31.1)	70 (36.8)
White vs other	177 (83.5)	173 (91.0)
≥High school completion	208 (98.1)	188 (98.9)
Relationship to resident		
Child	137 (64.6)	119 (62.6)
Spouse	30 (14.2)	21 (11.0)
Other	45 (21.2)	50 (26.3)
Clinician asked about goals-of-care for resident	148 (69.8)	127 (68.4)
Baseline level of care preference[c]		
Comfort	132 (62.3)	118 (62.1)
Basic	63 (29.7)	63 (33.1)
Intensive	17 (8.0)	9 (4.7)

[a] Bedford Alzheimer Nursing Severity–Subscale: range, 7-28; higher scores indicate more functional disability.

[b] Test for Severe Impairment: range, 0-24; lower scores indicate greater cognitive impairment.

[c] Data reflect status prior to the proxies' exposure to the video in intervention arm.

erences were conducted at the assessment level (ie, care preference and directive status were derived from the same assessment period) using logistic regression with GEEs to adjust for clustering at the proxy and/or dyad and facility levels. The baseline period was excluded. Logistic regression was used to examine the association between level of care preferences among proxies in the intervention arm before watching the video and whether they found the video unhelpful.

The sample size was calculated as 360 dyads from 20 matched facilities (180 dyads from 10 facilities and/or arm) to provide at least 95% power to detect an absolute difference of 25% between arms for the primary outcome and 80% power to detect a 20% difference. The sample size calculation assumed 2-sided testing, 5% type I error rate, intraclass correlation coefficient within facilities of 0.05, and 18 dyads per facility. Because resident and proxy recruitment yielded fewer dyads per facility than anticipated, 64 facilities (32 facilities per arm) were ultimately enrolled to achieve the target sample size.

Results

Recruitment and Follow-up

Among the 181 eligible NHs, 48 administrators could not be contacted and 69 declined to participate (**Figure**). The remaining 64 facilities were enrolled and randomized (32 facilities per arm). A total of 36% (212 of 546) and 38% (190 of 528) of eligible dyads were recruited in the intervention and control arms, respectively. Mean age and sex distribution of nonparticipating and participating eligible residents did not significantly differ. The mean age of the residents was 86.7 years (range, 67-102 years); 350 were white (87.1%) and 323 were female 80.3%), with DNH directives that by 6 months did not differ between arms (63% in both arms; AOR, 1.08; 95% CI, 0.69-1.69). Proxy refusal was the sole reason for nonparticipation.

Six residents (3 in the intervention arm and 3 in the control arm) were lost during follow-up, 14 proxies (9 in the intervention arm and 5 in the control arm) stopped responding to phone calls, and 2 proxies (1 in the intervention arm and 1 in the control arm) withdrew. The final sample size for the primary outcome analysis, which required at least 1 follow-up resident assessment, included 211 and 189 residents in the intervention and control arms, respectively.

Baseline Characteristics

Baseline resident characteristics were similar between arms (**Table 1**), except residents in intervention facilities were younger (intervention arm, mean [SD], 86.0 [7.4] years; control, 87.4 [SD] years; P = .07) and a lower proportion were white (intervention arm, 178 of 212 [84.0%]; control arm, 172 of 190

Table 2. Cumulative Prevalence of Preferences for Comfort Care Among Residents in Intervention vs Control Arm

Care Preference	Baseline		3 mo		6 mo		9 mo		12 mo	
	Intervention[a] (n = 212)	Control (n = 190)	Intervention (n = 209)[b]	Control (n = 186)[b]	Intervention (n = 209)[b]	Control (n = 182)[b]	Intervention (n = 206)[b]	Control (n = 184)[b]	Intervention (n = 209)[b]	Control (n = 184)[b]
Comfort care, No. (%)[c]	138 (65.1)	118 (62.1)	151 (72.2)	133 (75.1)	153 (73.2)	140 (76.9)	155 (75.2)	149 (81.0)	159 (76.1)	151 (82.1)
AOR[d] (95% CI)	1.28 (0.85-1.94)		1.21 (0.76-1.94)		0.96 (0.58-1.58)		0.68 (0.38-1.23)		0.72 (0.38-1.38)	

Abbreviation: AOR, adjusted odds ratio.

[a] Baseline in intervention arm is postvideo preference.

[b] Missing data are due to missing proxy interviews at specific time points.

[c] Cumulative number (percentage) of proxies stating comfort care as preference at any time prior to or at assessment period.

[d] Compares intervention with control arm, adjusted for resident race (white), resident age, and clustering at the facility level.

[90.5%]; *P* = .05). Baseline characteristics of proxies were similar in both arms.

Care Preferences

Proxies' baseline preferences were similarly distributed in the control arm (intensive, 9 of 190 proxies [4.7%]; basic, 63 of 190 [33.1%]; comfort, 118 of 190 [62.1%]) and intervention arms (before watching the video) (intensive, 17 of 212 [8.0%]; basic, 63 of 212 [29.7%]; comfort, 132 of 212 [62.3%]). Proxies' preferences in intervention facilities immediately after watching the video were as follows: intensive, 9 of 212 [4.2%]; basic, 64 of 212 [30.2%]; comfort, 138 of 212 [65.1%]; refused to answer, 1 of 212 [0.5%]). The proportion of proxies preferring comfort care did not differ between arms at baseline (postvideo in intervention arm), or cumulatively at any follow-up interview (**Table 2**).

Advance Directives and Goals-of-Care Discussions

The proportion of residents with DNH directives by 6 months (primary outcome) did not differ between arms (AOR, 1.08; 95% CI, 0.69-1.69) or any other time (**Table 3**). Directives to forgo tube-feeding were significantly more likely in the intervention vs control arm at all assessments (3 months: AOR, 1.78; 95% CI, 1.14-2.76; 6 months: AOR, 1.79; 95% CI, 1.13-2.82; 9 months: AOR, 1.97; 95% CI, 1.22-3.17; 12 months: AOR, 2.32; 95% CI, 1.38-3.91). Documented goals-of-care discussions at 3 months were significantly more likely in the intervention arm vs the control arm (AOR, 2.58; 95% CI, 1.20-5.54), but not at other periods. Directives to forgo intravenous hydration did not differ between arms. The cumulative incidence of acquiring a decision for no tube-feeding over the follow-up period was significantly higher in the intervention arm (AHR, 1.99; 95% CI, 1.08-3.66) (**Table 4**) but did not differ for other directives.

In exploratory analyses, when comfort care was preferred, residents in the intervention vs control arm were significantly more likely to have directives for no tube-feeding (AOR, 3.39; 95% CI, 1.62-7.11), both DNH and no tube-feeding together (AOR, 2.68; 95% CI, 2.68-5.85) but not DNH alone (eTable 1A in Supplement 2). Associations between trial arm and advance directives when basic or intensive care was preferred were not significant, albeit some associations involved too few events to analyze.

Burdensome Treatments

Residents experiencing burdensome treatments over follow-up were hospital transfers, intervention arm, 20 of 211 residents (9.5%), control arm, 21 of 189 residents (11.1%); feeding-tube insertions, intervention arm, 4 of 211 (1.9%), control arm, 4 of 189 (2.1%); parenteral therapy, intervention arm, 17 of 211 (8.1%), control arm, 10 of 189 (5.3%); and any, intervention arm, 33 of 211 (15.6%), control arm, 25 of 189 (13.2%). The rate of burdensome treatments per 1000 resident-days did not differ significantly between arms (intervention arm, mean [SD], 1.23 [2.31]; control arm, 1.42 [5.03]; *P* = .32).

Proxy's Opinion of the Video

Sixty-eight percent of proxies rated the videos as very or somewhat helpful; 8.5%, a little helpful; and 23.6%, unhelpful. A total of 97.1% of proxies stated they would definitely or probably recommend the video to others. Proxies who preferred comfort care (n = 131) (vs basic or intensive [n = 80]) before watching the video were significantly more likely to find the video unhelpful (40 of 131 [30.5%] vs 9 of 80 [11.3%]; OR, 3.47; 95% CI, 1.58-7.62).

Discussion

In this cluster RCT, the proportion of proxies preferring comfort care for NH residents with advanced dementia did not differ between those who did and did not view an ACP video. The primary outcome, DNH directives by 6 months, also did not differ between arms. Secondary outcomes revealed that residents in intervention facilities were more likely to have documented directives for no tube-feeding throughout follow-up and goals-of-care discussions at 3 months. Burdensome treatments did not differ between arms. In exploratory analyses, when proxies preferred comfort care, residents in the intervention arm were more likely to have advance directives reflecting that preference.

This study corroborates and furthers what is known about proxies' preferences in patients with advanced dementia and the effect of video decision aids on those preferences. The Goals-of-Care trial, the only other cluster RCT of a video decision aid for proxies of NH residents with advanced dementia,[29] also found that approximately 60% of proxies preferred comfort care at baseline, and that this proportion increased over time but never differed between intervention vs control arms. In contrast, prior studies conducted among patients with other diseases[17,20,24,25] and healthy adults asked to imagine they had advanced dementia[18,21,22] found that ACP videos increased preferences for comfort care. Through visual images, these videos are intended to promote a better understanding of future health

Table 3. Cumulative Prevalence of Documented Advance Care Planning Among 211 Residents in the Intervention Arm vs 189 in the Control Arm

Documented Advance Care Planning	3 mo			6 mo			9 mo			12 mo		
	Intervention[a]	Control[a]	AOR (95% CI)[b]	Intervention[a]	Control[a]	AOR (95% CI)[b]	Intervention[a]	Control No.(%)[a]	AOR (95% CI)[b]	Intervention[a]	Control[a]	AOR (95% CI)[b]
No hospitalization	127 (60.2)	110 (58.2)	1.15 (0.74-1.77)	133 (63.0)	119 (63.0)	1.08[c] (0.69-1.69)	140 (66.4)	125 (66.1)	1.06 (0.66-1.69)	144 (68.2)	126 (66.7)	1.07 (0.66-1.72)
No tube-feeding	142 (67.3)	109 (57.7)	1.78 (1.14-2.76)	148 (70.1)	117 (61.9)	1.79 (1.13-2.82)	152 (72.0)	119 (63.0)	1.97 (1.22-3.17)	161 (76.3)	121 (64.0)	2.32 (1.38-3.91)
No intravenous hydration	77 (36.5)	53 (28.0)	1.46 (0.91-2.34)	79 (37.4)	60 (31.7)	1.32 (0.83-2.12)	84 (39.8)	66 (34.9)	1.34 (0.83-2.16)	91 (43.1)	68 (36.0)	1.51 (0.93-2.44)
Goals-of-care discussion	34 (16.1)	15 (7.9)	2.58 (1.20-5.54)	49 (23.2)	29 (15.3)	1.70 (0.94-3.07)	63 (29.9)	42 (22.2)	1.49 (0.87-2.54)	72 (34.1)	48 (25.4)	1.46 (0.86-2.70)

Abbreviation: AOR, adjusted odds ratio.

[a] Cumulative number (percentage) of residents with advance care planning variable documented in their medical record as ascertained from any assessment prior to or at the time point including from death assessments of residents who died prior to the time point. Data from baseline residents' assessments were excluded because they reflected advance care planning prior to exposure to the intervention.

[b] Compares intervention with control arm, adjusted for resident age and race (white), and clustering at the facility level.

[c] Primary trial outcome.

states that are difficult to imagine. The residents in EVINCE already had advanced dementia, which presumably developed over some time. It is conceivable that the video did not have an effect on preferences because proxies were already well aware of the illness experience and had had ample opportunity to establish preferences. This possibility is supported by the observation that proxies in the intervention arm who already had comfort as their preference before viewing the video were more likely to rate the video as unhelpful. Taken together, ACP videos may have a greater effect on preferences if shown to proxies earlier in the course of dementia before they have a clear understanding of what to expect in late-stage disease.

In contrast with many earlier trials,[17,18,20-22,24,25] EVINCE examined not only the ACP video's effect on preferences but also clinical outcomes. Findings were mixed. DNH directives were unaffected, but rates of documented directives to withhold tube-feeding were consistently higher in intervention facilities. The video's explicit images and explanations regarding tube-feeding may have been particularly informative for proxies, whereas depictions of hospitalizations were more nuanced. The few prior RCTs reporting the impact of ACP videos on clinical outcomes also had mixed findings.[24,29,30] The Goals-of-Care trial intervention, which combined a goals-of-care video with a semi-structured care planning meeting,[29] improved family ratings of communication and reduced hospitalizations but had no effect on documented advance directives. There are several possible reasons why the EVINCE intervention did not have an effect on DNH status and burdensome treatments. First, as discussed, the video did not change proxy preferences. Second, DNH directives were well established in approximately half the residents prior to the study, and burdensome treatments were rare. DNH orders, hospital transfer rates, and feeding tube insertions are less common in Boston-area NHs compared with other US regions.[4,8,29,31,32] The intervention may have greater effect on clinical outcomes in settings that, at baseline, have a more aggressive approach to advanced dementia care. Finally, the efficacy of the EVINCE intervention may have been hindered by the fact that, unlike the Goals-of-Care trial, there was no integration of the video into actual NH care processes and no direct engagement with the resident's clinicians.

A recent expert consensus panel ranked "care consistent with goals" as the top-rated outcome to evaluate the success of an ACP initiative.[33] Exploratory analyses suggest that the ACP video promoted better alignment of goals with care; when proxies preferred comfort care, residents in the intervention arm were more likely to have documented directives (ie, DNH and no tube-feeding) consistent with that preference. Insufficient power precluded similar analyses of the effect of the intervention on the concordance between preferences and burdensome treatments.

Limitations

Several limitations warrant discussion. The participation rate was similar in both arms and in comparable studies.[2,29,34] However, our findings cannot be generalized to eligible nonparticipants because proxies' decisions not to participate may be related to their care preferences. Generalizability is further limited to a mostly white cohort in Boston. The effect of the intervention may differ in other populations and regions, par-

Table 4. Cumulative Incidence of Documented Advance Care Planning Among Residents in Intervention Arm vs Control Arm[a]

Documented Advance Care Planning	Arm, No. (%) Intervention	Control	Adjusted HR (95% CI)[b]
No hospitalization	41/108 (38.0)	30/92 (32.6)	1.20 (0.66-2.20)
No tube-feeding	39/89 (43.8)	22/89 (24.7)	1.99 (1.08-3.66)
No intravenous hydration	31/150 (20.7)	25/145 (17.2)	1.13 (0.67-1.90)
Goals-of-care discussion	61/184 (33.2)	38/160 (23.8)	1.40 (0.92-2.13)

Abbreviation: HR, hazard ratio.

[a] Analyses examine the cumulative incidence of residents who acquired the advance care planning variable at any time during follow-up among those who did not have the variable at baseline.

[b] Compares intervention with control arm, adjusted for resident age, resident race, and clustering within facility.

ticularly those with a more aggressive approach to advanced dementia care.[4,8,29,31,32] Power may have been insufficient to detect significant differences for some secondary outcomes, particularly burdensome treatments.

Conclusions

EVINCE has several important implications for future RCTs of ACP video interventions in patients with advanced dementia. In accordance with the recent consensus report,[33] trials should be designed such that the primary outcome reflects concordance between preferences and care delivered. A logical next step would also include testing the effect of the video on clinical outcomes among proxies of patients with less advanced dementia and in settings where comfort-focused care is less prevalent. Finally, future interventions should include the integration of these videos into a broader ACP program within the clinical setting, as they would be used in practice.

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Invited Commentary

The Complexities of Advance Care Planning in Individuals With Advanced Dementia

Nathan E. Goldstein, MD; Harriet Mather, MD, MSc

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In this issue of *JAMA Internal Medicine*, Mitchell and colleagues[1] present their findings from a randomized clinical trial of a video-assisted decision support tool to improve advance care planning in nursing home residents with advanced dementia. They performed a cluster randomized trial of 402 residents with advanced dementia in the setting of 64 Boston-area nursing homes. Proxies of dyads in the intervention arm watched a brief video depicting scenarios for treatment options within 3 care levels—comfort, basic, and intensive. Preferences for care were then elicited and communicated to the patient's health care team. The investigators examined the relationship of the video intervention to the primary outcome of do-not-hospitalize (DNH) orders, with secondary outcomes including preference for comfort care, documented directives to withhold tube-feeding and intravenous hydration, documented goals-of-care discussions, and burdensome treatments (hospital transfers, tube-feeding, or parenteral therapy). The intervention did not increase DNH directive completion, change care preferences, increase directives to withhold parenteral hydration, or reduce use of burdensome treatments. Residents in the intervention arm were more likely to have directives to withhold tube-feeding.

This was a well-designed trial from a team of highly experienced investigators with expertise in the care of patients with dementia and the use of videos as decision support tools for advance care planning. Dr Mitchell has run successful randomized clinical trials to improve the care of patients with advanced dementia,[2] and Dr Volandes has shown that his videos of advance care planning improve outcomes for patients across a wide range of illnesses.[3,4] It is logical to assume that combining their expertise would have created a synergistic effect to improve the care of these patients. The question that remains is, why didn't their intervention achieve all of its desired effects?

The authors assert that DNH directives (the primary outcome) were already well established in this population with advanced dementia, with correspondingly less scope for the intervention to have an effect on outcomes; at baseline, approximately 50% of patients had a DNH order, and almost 70% of surrogates reported having been asked by a clinician about goals of care. This finding is encouraging and suggests that efforts to increase advance care planning in the early stages of dementia have taken effect in this region. The authors rightly suggest that the intervention may have been more effective in other regions where care, even in advanced stages of dementia, continues to be characterized by aggressive interventions. In these regions, the focus should primarily be on improving advance care planning much earlier and not waiting until dementia is advanced. The natural course of dementia evolves over a period of years and provides multiple opportunities to engage in basic education about the trajectory of the illness and begin advance care planning conversations—yet these conversations rarely happen.[5] In the earlier stages of dementia, patients retain the capacity to make their own decisions regarding their current and future treatment. It is important to note that this allows surrogates to ensure that the patients' autonomy and right to self-determination will be respected once the patients can no longer speak for themselves, removing the need for surrogates to use substituted judgment. In recent years, a number of advance care planning initiatives