

Original Article

Concordance Between Proxy Level of Care Preference and Advance Directives Among Nursing Home Residents With Advanced Dementia: A Cluster Randomized Clinical Trial



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Abstract

Context. Care consistent with goals is the desired outcome of advance care planning (ACP).

Objectives. The objectives of this study were to examine concordance between advance directives and proxy care preferences among nursing home residents with advanced dementia and to determine the impact of an ACP video on concordance.

Methods. Data were from Educational Video to Improve Nursing home Care in End-stage dementia, a cluster randomized clinical trial conducted in 64 Boston-area facilities (32/arm) from 2013 to 2017. Participants included advanced dementia residents and their proxies ($N = 328$ dyads). At the baseline and quarterly (up to 12 months), proxies stated their preferred level of care for the resident (comfort, basic, or intensive) and advance directives for specific treatments (resuscitation, hospitalization, tube-feeding, intravenous hydration, antibiotics) were abstracted from the charts. At the baseline, proxies in intervention facilities viewed an ACP video. Their care preferences after viewing it were shared via a written communication with the primary care team. At each assessment, concordance between directives and proxy preferences was determined.

Results. Among the residents (mean age, 86.6 years; 19.5% male), the most prevalent directive was DNR (89.3%) and foregoing antibiotics was least common (parenteral, 8.2%; any type, 4.0%). Concordance between directives and each level of care preference was as follows: comfort, 7%; basic, 49%; and intensive, 58%. When comfort care was preferred, concordance was higher in intervention versus control facilities (10.8% vs. 2.5%; adjusted odds ratio, 2.48; 95% CI, 1.01–6.09).

Conclusion. Better alignment between preferences for comfort-focused care and advance directives is needed in advanced dementia. An ACP video may help achieve that goal. *J Pain Symptom Manage* 2019;57:37–46. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Dementia, nursing home, preferences, advance care planning, cluster randomized clinical trial, advance directives

Introduction

Patients with advanced dementia often receive burdensome treatments that may be of little clinical benefit and inconsistent with preferences.^{1–5} Advance

care planning (ACP) offers the opportunity to promote goal-directed care for persons with life-limiting disease.^{3,5–10} A recent expert panel ranked “care consistent with goals” as the most important outcome

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of successful patient-centered ACP¹¹; however, little research has been conducted examining this construct as it applies to advanced dementia care.

Despite its importance, “care consistent with goals” is challenging to define and operationalize as an outcome.^{11–16} As a key first step, goals of care must be defined and captured, which in and of itself may be difficult for individual patients to conceptualize and articulate. While there is no set approach, a common rubric categorizes three levels of goals of care: life-prolonging care, basic or intermediate care; and comfort care. A main limitation of this approach is that these goals are not mutually exclusive (e.g., a patient who desires life-prolonging care likely also wants treatment that maximizes their comfort). Moreover, the middle category is relatively more ambiguous and challenging to define. Nonetheless, this three-tiered framework has been widely applied by researchers and clinical instruments, such as the Physician Orders for Life-Sustaining Treatment Paradigm.^{17–26}

With these caveats, once a goal of care is articulated, concordance with that goal must be operationalized in terms of treatment decisions and actual care received, an exercise that is not straightforward and largely subjective.^{11–16} Little evidence is available to clearly state whether specific treatments will achieve a desired goal (e.g., do antibiotics prolong life in advanced illness?). Furthermore, individual patients with varying conditions may differ in terms of how they categorize an uncomfortable intervention. Measuring “care consistent with goals” as a research outcome is particularly difficult. Ascertaining care preferences requires primary data collection, and a large cohort must be followed for an extended period to capture enough treatment events (e.g., hospitalizations) to have adequate power to demonstrate the efficacy of an ACP intervention. Consequently, alignment between goals of care and documented advance directives to either receive or withhold specific treatments may be used as a more feasible surrogate measure.^{27,28} Finally, research studies must incorporate changes in goals of care over time into their design.

To better examine concordance between goals of care and advance directives in nursing home (NH) residents with advanced dementia, this report leveraged unique data from the Educational Video to Improve Nursing home Care in End-stage dementia (EVINCE) trial. EVINCE was a cluster randomized clinical trial in 64 Boston-area NHs (32/arm) that followed residents with this condition and their proxies for up to 12 months. In the intervention facilities, proxies viewed an ACP video at the baseline, whereas those in the control facilities experienced usual ACP practices. Proxy level of care preferences and documented resident advance directives were rigorously

ascertained at the baseline and quarterly up to 12 months. A single, exploratory analysis presented in an earlier report found that when proxies preferred comfort care, residents in intervention facilities were more likely to have documented do-not-hospitalize and no tube-feeding orders.²⁹ In this report, we extend this limited analysis to describe in greater detail the patterns (i.e., combinations) of all documented directives according to proxy level of care preferences in the combined EVINCE cohort, as well as concordance between these patterns and proxy preferences. We also examine whether an ACP video improved concordance between care preferences and the patterns of directives.

Methods

Data were obtained from the EVINCE study, the methodology of which is detailed elsewhere.²⁹ EVINCE was a cluster randomized clinical trial conducted in 64 Boston-area NHs (32/arm) that evaluated an ACP video decision tool for proxies of NH residents with advanced dementia. This report focuses on post hoc analyses examining the concordance between proxy level of care preferences and advance directives documented in residents’ charts. The results of the planned primary and secondary aims of the main EVINCE trial are reported elsewhere.²⁹ The study’s conduct was approved by the Hebrew Senior-Life Institutional Review Board.

Facility Recruitment and Randomization

Study information was mailed to senior administrators of 181 eligible facilities (>60 beds, within 60 miles of Boston). A research assistant telephoned these administrators one week later to solicit their participation. A total of 64 facilities were recruited and randomized in pairs matched on profit status. Using deidentified labels, the statistician used a computer-generated algorithm to randomly assign each NH in a pair to either the control or intervention arm. Matched pairs began the study in a staggered fashion between February 1, 2013 and May 1, 2016.

Participants

Participants included residents with advanced dementia and their health care proxies recruited as dyads. Participant enrollment began on February 15, 2013, and data collection was completed on July 12, 2017. Residents were eligible if they were aged ≥ 65 years, had dementia (any type), scored 7 on the Global Deterioration Scale (range 1–7; higher scores indicate worse dementia),³⁰ had resided in the NH > 90 days, and had an English-speaking proxy who was available for an in-person interview within

two weeks. Residents with a Global Deterioration Scale score of 7 have profound memory deficits (cannot recognize family), speak fewer than five words, are nonambulatory, and are incontinent of urine and stool.³⁰ The proxy was the formally or informally designated medical decision-maker for the resident.

Every three months, a research assistant interviewed nurses to screen for residents meeting the aforementioned eligibility criteria. The research assistant then reviewed the residents' charts to confirm they were over 65 years and had dementia. Subsequently, the proxies of eligible residents were mailed study information and telephoned two weeks later to solicit their participation and obtain informed consent for themselves and that of the residents.

Video Intervention. At an in-person baseline interview, proxies in the intervention arm were shown a 12-minute video on a tablet by a research assistant. The video narration began by explaining the typical features of advanced dementia while showing images of an NH resident with this condition. The video then presented three levels of care options: intensive medical care, basic medical care, and comfort care. It stated that the goal of intensive care was to prolong life using all available medical treatments, such as cardiopulmonary resuscitation (CPR), breathing machines, tube-feeding, hospitalization, and intensive care unit (ICU) level care. Images included a simulated resuscitation, a resident being tube-fed, and an older patient on a ventilator. Basic care was described as including relatively conservative but potentially curative treatments. The video stated this care could include the use of antibiotics, parenteral therapy, and hospitalization but would exclude the use of CPR, breathing machines, tube-feeding, and ICU level care. The video depicted an older patient receiving oxygen and intravenous antibiotics. For comfort care, the video stated that only treatments aimed at relieving uncomfortable symptoms would be provided, such as pain medications and oxygen. Parenteral therapy, tube-feeding, and hospitalization would be avoided unless necessary to provide comfort. The video showed images of an advanced dementia patient getting hand-fed, being assisted with personal care, and receiving oxygen.

Proxy Level of Care Preferences. At the baseline (in-person) and quarterly interviews (telephone), a research assistant read a description of three levels of care options (comfort, basic, intensive) (Appendix A) to the proxies in both trial arms, after which proxies stated their preferred level for the resident. At the baseline interview, proxies in the intervention arm were asked their preferences before and immediately after viewing the video. A form stating their postvideo preferences was placed in the resident's chart and

sent (e-mail, mail, or fax) to their medical providers (physician, nurse practitioner, or physician assistant), nursing units, and social worker. At the baseline interview in the control arm, proxies were only asked their preferences once and their choice was not communicated to the primary care team. Proxies in control arm facilities otherwise experienced usual ACP practices.

Other Variables. Proxy and resident data were collected at the baseline and quarterly thereafter for up to 12 months. One research assistant conducted all the baseline proxy interviews and showed the video to proxies in intervention facilities; thus, she was not masked to the trial arm. The three other research assistants who collected all resident chart review data and follow-up proxy data were masked, as were the investigators, statistician, and data programmers.

Data ascertained at the baseline from the residents' charts included age, gender, race (white vs. other), and dementia type (Alzheimer's disease vs. other). Resident functional status was ascertained at the baseline by nurse interview using the Bedford Alzheimer's Nursing Severity Subscale (range 7–28; higher scores indicate greater disability).³¹ Research assistants administered the Test for Severe Impairment (range 0–24, lower scores indicate greater impairment; dichotomized to 0 vs. >0)³² directly to the residents only at baseline to quantify their cognitive status. At each assessment, advance directives to forego the following treatments were ascertained from the residents' charts, as indicated by either medical orders or other provider documentation (e.g., progress notes): resuscitation (DNR), hospitalization (DNH), tube-feeding, IV hydration, parenteral antibiotics, and all forms of antibiotics (i.e., including oral).

In addition to level of care preferences, proxy data collected at baseline included age, gender, race (white vs. other), education level, and relationship to resident (spouse, child, or other).

Concordance Between Level of Care Preferences and Advance Directives. EVINCE investigators (S. L. M., S. M. C., L. C. H., and A. E. V.) categorized combinations of advance directives as concordant, possibly concordant, or not concordant with the proxies-stated level of care preferences based on the descriptions read to the proxies (Appendix A) and their clinical expertise.

Concordance with a preference for intensive care was defined as the absence of any advance directive to forego treatment. Circumstances when directives to forego resuscitation and/or tube-feeding were present, but all other treatment restrictions were absent, were deemed as possibly concordant with intensive care as ICU admission was still possible and tube-feeding has not been shown to prolong life in advance

dementia.^{9,33,34} Any combination of directives that included foregoing hospitalization, IV hydration, or antibiotics was deemed not concordant with a preference for intensive care.

Concordance for basic care was defined as any combination of advance directives that included, at minimum, foregoing both resuscitation and tube-feeding. (The exception was when there were directives to withhold resuscitation, hospitalization, tube-feeding, IV hydration, parenteral antibiotics, and/or all forms of antibiotics, as this was concordant with comfort care.) Alternatively, if directives to forego either resuscitation or tube-feeding were absent, this situation was deemed not concordant with basic care.

Concordance with comfort care was defined as the presence of advance directives to forego all the aforementioned treatments. If there were directives to forego all treatments except “all forms of antibiotics,” this situation was deemed possibly concordant with comfort care, as it still included the use of oral antibiotics, which may be perceived as reducing discomfort from an infection.

Analysis. Continuous variables were described using means with SDs, and categorical variables were reported using frequencies and percentages. Analyses were performed using SAS Version 9.4 (SAS Institute Inc., Cary, NC) and Stata Version 13.1 (StataCorp, College Station, TX). Baseline resident and proxy characteristics were described at the participant level. All other subsequent analyses were conducted at the quarterly interval assessment level.

Based on resident chart reviews and proxy interviews conducted at the same quarterly assessment interval, the proportion of assessment intervals at which specific directives were present for each level of care preference was calculated. The proportion of assessment intervals at which preferences were deemed concordant, possibly concordant, or not concordant with directives was then determined, first considering all preferences combined and then stratified by three levels of care preferences.

The next analyses used ordinal logistic regression models to examine the association between trial arm (intervention vs. control) and whether the combination of directives was either concordant, or possibly concordant, or not concordant with the level of care preference (outcome). This analysis was conducted considering all preferences combined and then for each of the three levels of care preferences. All models adjusted for proxy race (white vs. other), which was significantly associated with the outcome variable, and clustering at the facility level using generalized estimating equations. Adjusted odds ratios with 95% CIs were generated. All tests were conducted at the $\alpha = 0.05$ level of significance.

Results

Participant Recruitment and Follow-Up

Among 181 NHs identified as eligible, 64 facilities were enrolled and randomized (32/arm). The administrators in 69 facilities declined participation and those in 48 NHs could not be contacted. In the intervention arm, 36% ($N = 212/546$) of eligible dyads were recruited, whereas 38% ($N = 190/528$) were recruited in the control arm. The only reason for nonparticipation was proxy refusal. Enrolled and non-enrolled eligible residents did not differ significantly in age or gender. The analytic sample for this report was further restricted to include only dyads that had at least one follow-up resident chart review and one follow-up proxy interview conducted at the same period (total, $N = 328$ dyads; intervention, $N = 172$ dyads; control, $N = 156$ dyads).

Baseline Characteristics

In the combined cohort, residents' mean age was 86.6 years and 19.5% ($N = 64/328$) were male. Baseline demographic characteristics of residents and proxies were similar between trial arms; except in intervention facilities, there was a lower proportion of white proxies (intervention, $N = 143/172$ [83.1%]; control, $N = 141/156$ [90.0%]; $P = 0.05$).

Baseline advance directives and proxy preferences were similar in both trial arms (Table 1). In the combined cohort, DNR (89.3%) was the most prevalent directive, whereas directives to forego parenteral (8.2%) and all forms (4.0%) of antibiotics were least common. A total of 60.4% of proxies preferred that the resident should receive comfort care, 32.6% opted for basic care, and 7.0% felt the resident should receive intensive care.

Patterns of Advance Directives

Table 2 presents the proportion of follow-up assessments with each documented advance directive stratified by proxy level of care preference at that assessment. Tables 3–5 display the proportion of follow-up assessments with various combinations of directives stratified by each level of care preference.

At assessments, when the proxy preferred intensive care, 36.5% of residents' charts had DNR directives, 13.5% had directives to withhold tube-feeding, and fewer than 4% had directives to withhold any other treatment. The most common pattern of directives when intensive care was preferred was the absence of all directives (57.7%), followed by a DNR alone (26.9%).

When basic care was preferred, 87.7% of residents' charts had DNR orders, 53.4% had directives for no tube-feeding, and 39.0% had DNH orders. The most common distribution of directives with basic care

Table 1
Baseline Resident and Health Care Proxy Characteristics

Resident Characteristic	Full Sample (N = 328)	Intervention (n = 172)	Control (n = 156)
	No. (%) or Mean ± SD		
Age (yrs)	86.6 ± 7.6	86.0 ± 7.7	87.3 ± 7.4
Male	64 (19.5)	35 (20.3)	29 (18.6)
White (vs. other)	284 (86.6)	144 (83.7)	140 (89.7)
Alzheimer's dementia (vs. other dementia)	231 (70.4)	117 (68.0)	114 (73.1)
Bedford Alzheimer's Nursing Severity Subscale ^a	20.1 ± 2.7	19.9 ± 2.8	20.2 ± 2.6
Test for Severe Impairment % = 0 ^b	152 (46.3)	80 (46.5)	72 (46.2)
Advance directives			
No resuscitation	293 (89.3)	151 (87.8)	142 (91.0)
No hospitalization	157 (47.9)	78 (45.3)	79 (50.6)
No tube-feeding	178 (54.3)	95 (55.2)	83 (53.2)
No intravenous hydration	79 (24.1)	44 (25.6)	35 (22.4)
No parenteral antibiotics	27 (8.2)	16 (9.3)	11 (7.1)
No antibiotics (any form)	13 (4.0)	10 (5.8)	3 (1.9)
Proxy characteristic			
Age (yrs)	62.5 ± 11.0	61.8 ± 10.9	63.3 ± 11.0
Male	113 (34.5)	56 (32.6)	57 (36.5)
White (vs. other)	284 (86.9)	143 (83.1)	141 (91.0)
≥High school completion	323 (98.5)	169 (98.3)	154 (98.7)
Relation to resident			
Child	201 (61.3)	111 (64.5)	90 (57.7)
Spouse	42 (12.8)	23 (13.4)	19 (12.2)
Other	85 (25.9)	38 (22.1)	47 (30.1)
Level of care preference ^c			
Intensive medical care	23 (7.0)	15 (8.7)	8 (5.1)
Basic medical care	107 (32.6)	53 (30.8)	54 (34.6)
Comfort care	198 (60.4)	104 (60.5)	94 (60.3)

^aBedford Alzheimer's Nursing Severity Subscale, range 7–28, higher scores indicate more functional disability.

^bTest for Severe Impairment, range 0–24, lower scores indicate greater cognitive impairment.

^cPreference among those in the intervention arm.

was DNR alone (29.6%), followed by a combination of DNR, DNH, and no tube-feeding (20.5%).

Finally, when comfort care was preferred, the majority of residents' charts had directives for DNR (98.4%), DNH (72.5%), and no tube-feeding (71.7%). However, only 40.3% of residents had directives for no IV hydration, and directives to withhold antibiotics were uncommon (parenteral, 15.1%; all types, 7.3%). The most common combination of directives with comfort care included the simultaneous presence of DNR, DNH, no tube-feeding, and no IV hydration (24.3%), followed closely by a combination of DNR, DNH, and no tube-feeding (24.1%).

Concordance Between Advance Directives and Preferences.

When proxies-stated intensive care was preferred, 57.7% of residents' charts were deemed to be concordant with that preference (i.e., no advance directives), and 36.5% were categorized as possibly concordant (i.e., directives for DNR and/or no tube-feeding) (Table 3). When a preference for basic care was indicated, 49.3% of assessments were felt to be concordant with that preference, whereas 50.7% were determined not to be concordant. Finally, when comfort care was

preferred, only 7.0% of charts were deemed to be concordant with that preference, and 6.6% were felt to be possibly concordant. The vast majority were categorized as not concordant with comfort care (86.4%).

Figure 1 displays the proportion of residents' charts that have patterns of directives deemed concordant, possibly concordant, and not concordant with proxy preferences separately for the intervention and control arms. In the adjusted ordinal logistic regression analyses, when comfort care was preferred, residents in the intervention arm were significantly more likely to have directives deemed concordant with that preference compared to those in the control arm (AOR = 2.48, 95% CI = 1.01–6.09) (Fig. 1). Concordance did not differ between trial arms when all preferences were considered together or when restricted to assessments when either intensive or basic care was preferred.

Discussion

In these analyses of EVINCE trial data, NH residents with advanced dementia commonly had documented directives to withhold the most aggressive

Table 2
Documented Advance Directives Stratified by Proxy Level of Care Preference at Each Assessment^a (N = 1011)

Proxy Level of Care Preference	Advance Directives No. (%)					
	No Resuscitation	No Hospitalization	No Tube-Feeding	No IV Hydration	No Parenteral Antibiotics	No Antibiotics
Intensive medical care (n = 52)	19 (36.5%)	2 (3.9%)	7 (13.5%)	2 (3.9%)	2 (3.9%)	0 (0.0%)
Basic medical care (n = 341)	299 (87.7%)	133 (39.0%)	182 (53.4%)	45 (13.2%)	16 (4.7%)	4 (1.2%)
Comfort care (n = 618)	608 (98.4%)	448 (72.5%)	443 (71.7%)	249 (40.3%)	93 (15.1%)	45 (7.3%)

^aThe unit of analyses was the quarterly follow-up assessment interval.

interventions (e.g., DNR), whereas it was much less common to have directives to withhold less invasive, albeit still potentially curative treatments (e.g., antibiotics, IV hydration). Although the majority of proxies preferred comfort care, concordance between directives and preferences was lowest among proxies with that preference (7%) compared to those opting for basic (49%) or intensive medical care (58%). When comfort care was preferred, concordance was higher among proxies who viewed the ACP video decision support tool compared to those who did not view the video.

Our results confirm prior research describing advance directives among NH residents with advanced dementia,^{16,35,36} but further that work by examining the pattern of those directives in the context of care preferences as stated by their proxies. As in earlier research, we found that most residents had DNR orders, whereas directives to withhold hospital transfers, tube-feeding, and IV hydration were less common, and directives to withhold antibiotics were particularly low.^{16,35,36} Advance directive ascertainment requires two conditions; first, clinicians must discuss a particular treatment with proxies, and second, proxies must make a deliberate decision to withhold that treatment. Not surprisingly, DNR was the most prevalent directive, as it is both widely addressed in ACP discussions,²⁵ and a relatively straightforward decision as resuscitation is very aggressive and not beneficial for residents with life-limiting disease.^{37,38} At the other extreme, antibiotic use is not commonly discussed

with proxies of advanced dementia residents,³⁵ and the decision to withhold antibiotics is more nuanced as their administration is less burdensome and may be perceived as potentially beneficial even when the goal of care is comfort.³⁹ Across all advance directives, the proportion of residents with a given directive was highest when proxies preferred comfort care and lowest when proxies preferred intensive care.

In clinical practice, achieving concordance between level of care preferences and advance directives or treatments requires high-quality, potentially time-consuming, shared decision making between proxies and clinicians. Thus, we found it is not surprising that concordance was lowest when proxies preferred comfort care, which required documentation of treatment decisions to avoid multiple burdensome interventions. By contrast, concordance with intensive care aligned with an absence of directives, reflecting the glide path of a “default” condition for ACP documentation. In terms of a research outcome, the prior studies that have reported concordance between care preferences and treatments received have differed considerably in terms of their definitions of preferences and concordance, reflecting the challenges of operationalizing this outcome.^{11–16} EVINCE builds on this past research to provide a framework for understanding and measuring concordance. The most comparable study to EVINCE, the Goals of Care trial, also found approximately two-thirds of proxies of residents with advanced dementia preferred comfort care, but only half felt that their preferred primary

Table 3
Documented Advance Directives When Proxies Indicated a Preference for Intensive Medical Care^a (N = 52)

No Resuscitation	Advance Directives						No. (%)	Concordance
	No Hospitalization	No Tube-Feeding	No IV Hydration	No Parenteral Antibiotics	No Antibiotics			
— ^b	—	—	—	—	—	30 (57.7%)	Yes	
X ^c	—	—	—	—	—	14 (26.9%)	19 (36.5%)	Possibly
X	—	X	—	—	—	3 (5.8%)		
—	—	X	—	—	—	2 (3.8%)		
X	X	—	—	—	—	1 (1.9%)	3 (5.8%)	No
X	X	X	X	X	—	1 (1.9%)		
—	—	X	X	X	—	1 (1.9%)		

^aAnalyses performed at the resident assessment level.

^b— = No advance directive.

^cX = Advance directive.

Table 4
Documented Advance Directives Among Proxies that Indicated a Preference for Basic Medical Care^a (N = 341)

Advance Directives						No. (%)	Concordant
No Resuscitation	No Hospitalization	No Tube-Feeding	No IV Hydration	No Parenteral Antibiotics	No Antibiotics		
X ^b	X	X	— ^c	—	—	70 (20.5%)	168 (49.3%) Yes
X	—	X	—	—	—	62 (18.2%)	
X	X	X	X	—	—	32 (9.4%)	
X	X	X	—	X	—	3 (0.9%)	
X	—	X	X	—	—	1 (0.3%)	
X	—	—	—	—	—	101 (29.6%)	
—	—	—	—	—	—	40 (11.7%)	
X	X	—	—	—	—	17 (5.0%)	
Other ^d						15 (4.4%)	

^aAnalyses performed at the resident assessment level.

^bX = Advance directive.

^c— = No advance directive.

^dCombinations: no resuscitation, no hospitalization, no tube-feeding, no IV hydration, no parenteral antibiotics ($n = 8, 2.3\%$); no resuscitation, no hospitalization, no tube-feeding, no IV hydration, no parenteral antibiotics, no antibiotics ($n = 3, 0.9\%$); no tube-feeding ($n = 2, 0.6\%$); no resuscitation, no parenteral antibiotics ($n = 1, 0.3\%$); no resuscitation, no tube-feeding, no IV hydration, no parenteral antibiotics, no antibiotics ($n = 1, 0.3\%$).

Table 5
Documented Advance Directives Among Proxies That Indicated a Preference for Comfort Care^a (N = 618)

Advance Directives						No. (%)	Concordant
No Resuscitation	No Hospitalization	No Tube-Feeding	No IV Hydration	No Parenteral Antibiotics	No Antibiotics		
X	X	X	X	X	X	43 (7.0%)	534 (86.4%) Yes Possibly No
X	X	X	X	X	—	41 (6.6%)	
X ^b	X	X	X	— ^c	—	150 (24.3%)	
X	X	X	—	—	—	149 (24.1%)	
X	—	—	—	—	—	107 (17.3%)	
X	X	—	—	—	—	55 (8.9%)	
X	—	X	—	—	—	40 (6.5%)	33 (5.5%)
Other ^d							

^aAnalyses performed at the resident assessment level.

^bX = Advance directive.

^c— = No advance directive.

^dCombinations: no resuscitation, no tube-feeding, no IV hydration ($n = 11, 1.8\%$); no advance directives ($n = 9, 1.5\%$); no resuscitation, no hospitalization, no tube-feeding, no parenteral antibiotics ($n = 7, 1.1\%$); no resuscitation, no IV hydration ($n = 2, 0.3\%$); no tube-feeding ($n = 1, 0.2\%$); no resuscitation, no hospitalization, no IV hydration ($n = 1, 0.2\%$); no resuscitation, no hospitalization, no IV hydration, no parenteral antibiotics, no antibiotics ($n = 1, 0.2\%$); no resuscitation, no hospitalization, no tube-feeding, no parenteral antibiotics, no antibiotics ($n = 1, 0.2\%$).

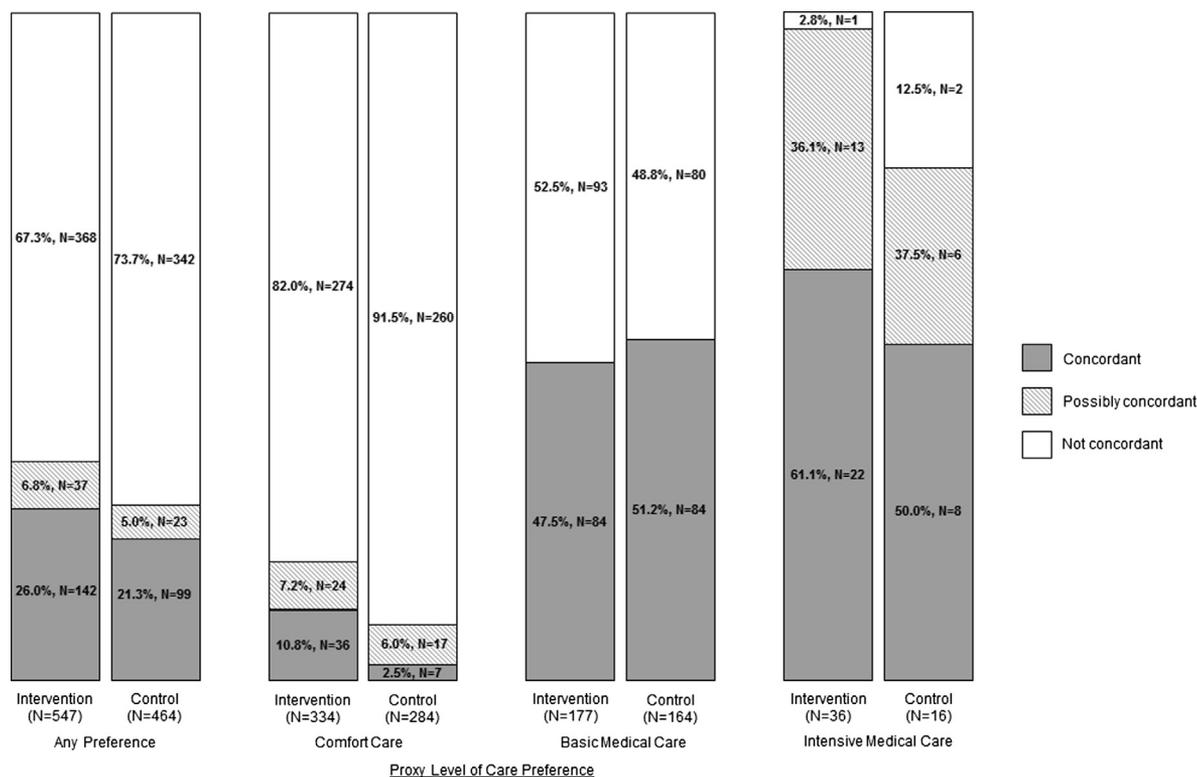


Fig. 1. Comparison of concordance between trial arms by proxy level of care preference. Any preference, AOR = 1.37, 95% CI = 0.82–2.27, $P = 0.230$; comfort care preference, AOR = 2.52, 95% CI = 1.03–6.17, $P = 0.042$; basic medical care preference, AOR = 0.86, 95% CI = 0.42–1.74, $P = 0.671$; intensive medical care preference, AOR = 1.83, 95% CI = 0.43–7.79, $P = 0.414$. AOR = adjusted odds ratio.

goal of care was aligned with that of the residents' NH providers. Residents whose primary goal was comfort experienced significantly fewer hospital transfers and had greater, albeit not significantly different, directive documentation compared to those whose goal was "life prolongation" or "maintaining function."¹⁶ In EVINCE, there were too few events to examine hospital transfers as an outcome.

We found that the ACP video increased concordance between preferences and advance directive documentation when comfort care was preferred. This finding may be driven, in part, by the fact that the EVINCE main trial results showed that the ACP video significantly increased goals-of-care discussions between proxies and providers, as well as documented directives to withhold tube-feeding, albeit not other directives.²⁹ Thus, the video may have particularly helped proxies understand that tube-feeding was not aligned with comfort care, prompting greater communication of a decision to withhold that intervention to NH clinicians among proxies with that preferred level of care. These results suggest that integrating the ACP video into clinical practice could help promote goal-concordant directive documentation among proxies who prefer comfort care.

This study has several limitations that merit discussion. First, defining concordance between level of care preferences and patterns of directives was somewhat subjective. Evidence was not always available to delineate whether a specific treatment aligned with a desired goal of care (e.g., do antibiotics promote comfort?), and individual perceptions of the relative burden of specific interventions vary. Second, generalizability of our study was limited to a primarily white cohort in Boston NHs. The prevalence of most directives was higher among the advanced dementia residents in EVINCE compared to those in the Goals of Care trial, which was conducted in North Carolina,²⁵ and nationwide findings based on Minimum DataSet data.⁶ However, the relative pattern of directives (i.e., DNR being the most common) was similar to these other studies.^{16,35,36} Third, our definition of treatment concordance focused on treatments that may be considered burdensome when comfort is the primary goal, but we did not have additional data on treatments to promote comfort, such as pain medications. Finally, we did not have adequate power to examine concordance between level of care preferences and actual treatments received due to the low number of events (e.g., hospital transfers), which speaks to the

challenge of operationalizing concordance as a research outcome.

“Care consistent with goals” may be considered the ultimate objective of successful ACP,¹¹ but there are clear challenges in defining and measuring this construct.^{11–16} There is a need for standardization of measurement methods and validation of instruments to meaningfully assess this outcome.¹⁵ Our analyses of EVINCE data offer a preliminary framework to try to operationalize concordance between patterns of documented directives and care preferences for NH residents with advanced dementia, which can serve as a reference for future research. Our findings also clearly demonstrate the need and opportunity to better align advance directives with a preference for comfort-focused care in these residents and suggest that an ACP video intervention may be helpful in achieving that goal.

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References

- Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 2003;290:73–80.
- Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004;164:321–326.
- Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212–1221.
- Givens JL, Jones RN, Shaffer ML, Kiely DK, Mitchell SL. Survival and comfort after treatment of pneumonia in advanced dementia. *Arch Intern Med* 2010;170:1102–1107.
- Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538.
- Mitchell SL, Teno JM, Intrator O, Feng ZL, Mor V. Decisions to forgo hospitalization in advanced dementia: a nationwide study. *J Am Geriatr Soc* 2007;55:432–438.
- Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2010;58:2284–2291.
- Goldfeld KS, Stevenson DG, Hamel MB, Mitchell SL. Medicare expenditures among nursing home residents with advanced dementia. *Arch Intern Med* 2011;171:824–830.
- Mitchell SL, Kiely DK, Lipsitz LA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Intern Med* 1997;157:327–332.
- Engel SE, Kiely DK, Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *J Am Geriatr Soc* 2006;54:1567–1572.
- Sudore RL, Heyland DK, Lum HD, et al. Outcomes that define successful advance care planning: a Delphi panel consensus. *J Pain Symptom Manage* 2018;55:245–255.e248.
- Dy SM, Kiley KB, Ast K, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *J Pain Symptom Manage* 2015;49:773–781.
- Unroe KT, Hickman SE, Torke AM, Grp ARCW. Care consistency with documented care preferences: methodologic considerations for implementing the “measuring what matters” quality indicator. *J Pain Symptom Manage* 2016;52:453–458.
- Sepucha K, Ozanne EM. How to define and measure concordance between patients’ preferences and medical treatments: a systematic review of approaches and recommendations for standardization. *Patient Educ Couns* 2010;78:12–23.
- Johnson SB, Butow PN, Kerridge I, Bell ML, Tattersall MHN. How well do current measures assess the impact of advance care planning on concordance between patient preferences for end-of-life care and the care received: a methodological review. *J Pain Symptom Manage* 2018;55:480–495.
- Ernecoff NC, Zimmerman S, Mitchell SL, et al. Concordance between goals of care and treatment decisions for persons with dementia. *J Palliat Med* 2018;21:1442–1447.
- El-Jawahri A, Paasche-Orlow MK, Matlock D, et al. Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. *Circulation* 2016;134:52–60.
- El-Jawahri A, Podgurski LM, Eichler AF, et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. *J Clin Oncol* 2010;28:305–310.
- Volandes AE, Ferguson LA, Davis AD, et al. Assessing end-of-life preferences for advanced dementia in rural patients using an educational video: a randomized controlled trial. *J Palliat Med* 2011;14:169–177.
- Volandes AE, Levin TT, Slovin S, et al. Augmenting advance care planning in poor Prognosis cancer with a video decision Aid: a Pre-post study. *Cancer* 2012;118:4331–4338.

21. Volandes AE, Barry MJ, Chang YC, Paasche-Orlow MK. Improving decision making at the end of life with video images. *Med Decis Mak* 2010;30:29–34.
22. Volandes AE, Lehmann LS, Cook EF, Shaykevich S, Abbo ED, Gillick MR. Using video images of dementia in advance care planning. *Arch Intern Med* 2007;167:828–833.
23. Volandes AE, Mitchell SL, Gillick MR, Chang Y, Paasche-Orlow MK. Using video images to improve the accuracy of surrogate decision-making: a randomized controlled trial. *J Am Med Dir Assoc* 2009;10:575–580.
24. Volandes AE, Paasche-Orlow MK, Barry MJ, et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. *BMJ* 2009;338:b2159.
25. Hanson LC, Zimmerman S, Song MK, et al. Effect of the goals of care intervention for advanced dementia: a randomized clinical trial. *JAMA Intern Med* 2017;177:24–31.
26. Paradigm NP. Elements of a POLST paradigm form 2018. Available at <http://polst.org/wp-content/uploads/2018/01/2018.01.31-POLST-Care-Continuum-Toolkit.pdf>. Accessed October 18, 2018.
27. Heyland DK, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013;173:778–787.
28. You JJ, Dodek P, Lamontagne F, et al. What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *Can Med Assoc J* 2014;186:E679–E687.
29. Mitchell SL, Shaffer ML, Cohen S, Hanson LC, Habtemariam D, Volandes AE. An advance care planning video decision support tool for nursing home residents with advanced dementia: a cluster randomized clinical trial. *JAMA Intern Med* 2018;178:961–969.
30. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982;139:1136–1139.
31. Volicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimer's disease. *J Gerontol* 1994;49:M223–M226.
32. Albert M, Cohen C. The Test for Severe Impairment: an instrument for the assessment of patients with severe cognitive dysfunction. *J Am Geriatr Soc* 1992;40:449–453.
33. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 1999;282:1365–1370.
34. Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000;342:206–210.
35. Mitchell SL, Shaffer ML, Loeb MB, et al. Infection management and multidrug-resistant organisms in nursing home residents with advanced dementia. *JAMA Intern Med* 2014;174:1660–1667.
36. Tjia J, Dharmawardene M, Givens JL. Advance directives among nursing home residents with mild, moderate, and advanced dementia. *J Palliat Med* 2018;21:16–21.
37. Dull SM, Graves JR, Larsen MP, Cummins RO. Expected death and unwanted resuscitation in the prehospital setting. *Ann Emerg Med* 1994;23:997–1002.
38. Finucane TE, Harper GM. Attempting resuscitation in nursing homes: policy considerations. *J Am Geriatr Soc* 1999;47:1261–1264.
39. Gaw CE, Hamilton KW, Gerber JS, Szymczak JE. Physician perceptions regarding antimicrobial use in end-of-life care. *Infect Control Hosp Epidemiol* 2018;39:383–390.

Appendix A. Verbatim Text Read by Research Assistants to Proxies in Both Arms When Asking Proxies to State Their Preferred Level of Care for Residents With Advanced Dementia

“Intensive medical care includes the use of all medical treatments available, such as cardiopulmonary resuscitation or CPR, breathing machines, and feeding tubes. With intensive care, patients are sent to the hospital for serious illnesses and admitted to an intensive care unit or ICU if necessary. Basic medical care includes some, but not all, available medical treatments. Patients choosing basic care may get treated with antibiotics, fluids, or other

medicines through a tube placed in a vein and may be sent to the hospital for sudden illnesses. People choosing basic care want to avoid intensive medical treatments including CPR, breathing machines, tube-feeding, or treatment in an ICU. Comfort care includes only treatments that help relieve uncomfortable symptoms, for example, medications to relieve pain, and oxygen to reduce trouble breathing. People choosing comfort care do not want CPR, breathing machines, tube-feeding, or additional fluids or medications given through a tube placed in a vein. With comfort care, hospitalization is avoided unless the hospital is needed to relieve pain, such as to fix a hip fracture.”