Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning

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Change in advance care plans of nursing home residents with dementia and pneumonia: secondary analysis of RCT data

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Abstract

Objectives To explore changes in advance care plans of nursing home residents with dementia following pneumonia, and factors associated with changes. Second, to explore factors associated with the person perceived by elderly care physicians as most influential in advance treatment decision making.

Design Secondary analysis of physician-reported PneuMonitor trial data.

Setting and Participants The PneuMonitor trial took place between January 2012 and May 2015 in 32 nursing homes across the Netherlands; it involved 429 residents with dementia who developed pneumonia.

Methods We compared advance care plans before and after the first pneumonia episode. Generalized logistic linear mixed models were used to explore associations of advance care plan changes with the person most influential in decision making, with demographics and indicators of disease progression. Exploratory analyses assessed associations with the person most influential in decision making.

Results For >90% of the residents, advance care plans had been established before the pneumonia. After pneumonia, treatment goals were revised in 15.9% of residents, 72% of all changes entailed refinements of goals. Significant associations with treatment goal changes were not found. Treatment plans changed in 20.0% of residents. Changes in treatment decisions were more likely for residents who were more severely ill (odds ratio 1.5, 95% CI 1.2-1.9) and those estimated to live less than 3 months (odds ratio 3.3, 95% CI 1.9-5.8). Physicians reported that a family member was often (47.4%) most influential in decision making. Who is most influential was associated with the resident’s dementia severity.

Conclusions and Implications Overall, changes in advance care plans after pneumonia diagnosis were small, suggesting stability of most preferences or limited dynamics in the advance care planning process. Advance care planning involving family is common for nursing home residents with dementia, but advance care planning with persons with dementia themselves is rare and requires more attention.

Introduction

Advance care planning (ACP) entails the person concerned, family and healthcare professionals discussing wishes, preferences and values, and documenting plans to guide future care and treatment. ACP anticipates situations in which a person is unable to contribute to decision making, for example in case of cognitive impairment due to severe dementia.[1] It can support the future provision of care in line with personal wishes and contribute to high-quality care.[2] A key aspect of ACP is shared decision making.[3] When a person's condition or wishes change, advance care plans should be revisited.[4] Several moments can trigger (re)engaging with ACP.[1]

Many people with dementia in western countries are admitted to nursing homes when their needs are no longer met at home.[5] Pneumonia occurs frequently among nursing home residents[6] and is a common cause of death.[7] ACP may guide treatment of pneumonia, and pneumonia and possible burdensome treatment may trigger discussion and updating of care plans. In the Netherlands, ACP is usually initiated shortly after nursing home admission.[8] Dutch nursing homes are required to establish care plans within six weeks after a resident's admission and revisit these biannually.[9] Such plans must contain agreements about care goals,[9] but may lack detail beyond decisions on cardiopulmonary resuscitation and hospitalization.[8] Certified elderly care physicians, trained in care for older people including a palliative approach,[10] are responsible for care plans, which, in the case of dementia, often focus on comfort.[11] Elderly care physicians are employed by nursing homes, on average attending to 103 residents per FTE.[12] They, rather than an external palliative team, provide end-of-life care.[13]

In this study, we examine ACP practice in Dutch nursing home residents with dementia who develop pneumonia. As good ACP practice is responsive to health changes and implements shared decision making, we explore any advance care plan changes following pneumonia and the influence of the people involved in shared decision making. We focus on change regardless of the direction because there is no assumption that changes only occur in the direction of less aggressive treatment and changes may be more nuanced. For example, there is no expectation of increased forgoing hospitalization as hospitalization is rare (1%) in this population.[14] Further, antibiotics are also used to relieve symptoms:[14] a wish for treatments may thus not always express a wish for life prolongation. We describe the prevalence and content of advance care plans before and after pneumonia diagnosis, and explore factors associated with changes in treatment goals and advance decisions following pneumonia. Our secondary objective was to explore what factors are associated with the person who is perceived by elderly care physicians as most influential in the decision making.

Methods

Design and setting

We performed secondary data analysis of the PneuMonitor study, a longitudinal single-blind, multicenter, cluster-randomized controlled trial to improve symptom relief in 32 Dutch public, non-profit nursing homes conducted between January 2012 and May 2015 (Netherlands Trial Register NTR5071).[15, 16] Nursing homes were selected to cover the provinces of the Netherlands. The homes provided care as usual during a pre-intervention phase. Data collection continued after randomization to the intervention arm (introducing a practice guideline) or the control arm (continued usual care). As no intervention effect of the guideline was found regarding treatments or outcomes such as discomfort,[15] we used data collected in control homes and intervention homes, before and after the intervention, to examine changes in advance care plans following pneumonia. Physicians were aware of the PneuMonitor study aim. As the current study focuses on ACP around a pneumonia episode, which is not directly related to the PneuMonitor study aim, negligible bias in physician-reported data is expected.

During the study period, elderly care physicians included residents with dementia diagnosed with pneumonia. Some residents experienced multiple pneumonia episodes during the study period. For the current study, we selected the first episode. The Medical Ethics Review Committee of the VU University Medical Center Amsterdam approved performing the PneuMonitor study (2011/155 and 2012/318). The common procedure for obtaining consent was considered disproportionate and infeasible due to the acute nature of pneumonia and other aspects of the trial and therefore an opt-out approach to consent was used; residents' families were informed about the study by letter and they could refuse transfer of the resident's data for this research.

Measures

All data were reported by the resident's attending physician; 131 reported on 1-22 (median, 2) residents. We distinguished a prioritized treatment goal, living will, and advance treatment decision. A prioritized treatment goal is a general care goal deemed most important in guiding treatment decisions and is established by the attending physician and the resident or family. A living will is a written, legal document drawn up (prior to admission) by the resident when still competent that indicates wishes regarding care, treatment or representation in medical decision making. An advance treatment decision stipulates specific agreements that the attending physician and resident or family make regarding treatments in the nursing home. Advance treatment decisions are often informed by the prioritized treatment goal or living will.

At pneumonia diagnosis (T0), the attending physicians completed a 'pneumonia notification form' with 8 questions. We analyzed prioritized treatment goals before pneumonia: prolongation of life, maintenance of function, or maximization of comfort. We also analyzed sex and age, and the physicians’ estimate (free text) of how close the resident was to the end of life at the time of pneumonia diagnosis. We further included illness severity at the time of pneumonia diagnosis rated on a scale of 1 (‘not ill’) to 9 (‘moribund’).[17] This scale measures physicians’ clinical judgement and was an accurate estimate of illness severity.[17, 18] Further, within 48 hours after diagnosis, the physicians reported pneumonia symptoms, behavioral changes after pneumonia and treatments received.

One to three weeks after pneumonia diagnosis (T1), the attending physicians completed another questionnaire, comprising 60 questions. We analyzed the presence and type of living wills, the prioritized treatment goal and advance treatment decisions before and after the pneumonia diagnosis. The physicians also reported changes, including in open-ended items. Changes reflected aggressiveness of treatment and refinements of orders such as stipulating conditions. Further, we identified the person whom the attending physician had listed first in a top-3 of persons that they perceived as most influential in their decision making regarding prioritized treatment goals and treatment (person with dementia, family, attending physician, nurse, other). Additionally, we included length of stay, type of dementia and severity of dementia assessed with the 7-item Bedford Alzheimer Nursing Severity-Scale (BANS-S, range 7 (no impairment)–28 (complete impairment)).[19] The physicians also reported dependency on seven activities of daily living (ADL) items in the two weeks prior to pneumonia diagnosis.[20]

Analyses

We performed descriptive statistics for the residents’ characteristics and the prevalence of advance care plans (that is: living wills, prioritized treatment goals, advance treatment decisions) before and after pneumonia diagnosis. We categorized free text answers about how close the resident was to the end of life at the time of pneumonia diagnosis in: (1) ‘less than 1 week’, (2) ‘1 to 6 weeks’, (3) ‘6 weeks to 3 months’, (4) ‘3 months to 6 months’, (5) ‘6 months to 1 year’, (6) ‘more than 1 year’, (7) ‘unclear.’

We explored which factors were associated with changes in the prioritized treatment goal (model 1) or in advance decisions (model 2), using logistic generalized linear mixed models. We added a random intercept for ‘nursing home’ to adjust for possible effects of nursing home culture on ACP practice. The outcome variables were dichotomized (yes (1) or no (0)) into change in prioritized treatment goal and change in any treatment decision. We investigated sex and age,[21] indicators of health status and disease progression (namely: length of stay, dementia severity, illness severity at pneumonia diagnosis and closeness to the end of life at pneumonia diagnosis),[1, 8, 21] and variables related to shared decision making: who (resident, family or physician) was most influential in decision making as perceived by the physician. We focused on these three main groups. The factor closeness to the end of life was dichotomized into terminal prognosis ((1), ≤ 3 months to live) versus (0), > 3 months to live or unclear. In the Netherlands, having less than 3 months to live is considered the terminal phase, which is when community-dwelling people are granted access to hospice care services.[22] Two binary dummy variables (yes (1) or no (0)) were created for the person most influential in decision making: 'resident most influential,' and 'family most influential.' Although shared decision making is considered good practice, final responsibility for decisions rests with physicians and Dutch physicians are influential in ACP and treatment decisions for pneumonia;[23-26] attending physicians therefore served as reference category. We first conducted univariable analyses for each factor to explore its associations with advance care plan changes, with Bonferroni correction for the number of tests (16 in total). We then performed stepwise regression with backward elimination of factors to construct a multivariable model of changes that only included strongly contributing factors. All factors were included at the first iteration, after which factors were removed from the multivariable model with *p*-values > .10 until only factors with a *p*-value < .10 remained. Overall, 6% of data was missing, ranging 0-14% per variable. Because mixed models were used, imputing missing data was not needed.

We additionally performed exploratory analyses to assess factors associated with whether the resident, the family or the attending physician was most influential in decision making. We examined the factors sex, age, length of stay, dementia severity, illness severity, and terminal prognosis. ANOVA, Chi-square, Kruskal-Wallis and post-hoc t-tests were used according to type and distribution of the data. All statistical analyses were performed with SPSS version 25.0 (IBM Corporation, New York, 2017).

Results

We included all 429 residents with dementia from the PneuMonitor trial in our analyses. The mean age was 84.5 years (SD 7.4) and the majority (59.7%) was female. A minority (14.2%) was fully dependent in ADL. Most residents were severely ill at pneumonia diagnosis (41.6%) and prognosis varied (Table 1).

Advance care plans: presence, content and (re)engagement

Only 3.8% (15 residents) had a living will (Table 2). For 2.0% (8 residents) this was a euthanasia statement and 1.3% (5 residents) had documented in advance refusing treatment in specified situations.

A prioritized treatment goal was common (95.1%, *n* = 408). For most residents (61.8%, *n* = 265) maximization of comfort was prioritized.

Physician-reported advance treatment decisions were also common (94.6%, *n* = 369). Figure 1 shows treatment orders before and after pneumonia diagnosis (also supplementary Table S1). Orders regarding cardiopulmonary resuscitation were present in most cases (92.3%, *n* = 360), followed by antibiotics (85.4%, 333) and hospitalization (80.3%, *n* = 313). Orders regarding hypodermoclysis for hydration were present least often (52.6%, *n* = 205); this pertains to subcutaneous hydration when oral or intravenous (IV) hydration is insufficient or impractical. Most orders requested to withhold treatments, almost all residents had at least one (supplementary Table S1); however, antibiotics and any life-prolonging treatment orders were mostly 'do' orders.

Table 1 Resident characteristics assessed at (T0) or after diagnosis of the pneumonia (T1)

Characteristics	*Timing of Assessment*	*n = 429**
Demographics		
Mean age, years (SD)	T0	84.5 (7.4)
Sex, female n (%)	T0	256 (59.7)
Illness progression indicators		
Median length of stay, months (IQR)	T0	16.0 (5.0–34.0)
Illness severity[17] at pneumonia diagnosis n (%)	T0	
Not ill (1-2)		12 (2.8)
Mild illness (3-4)		81 (18.9)
Moderate illness (5)		122 (28.4)
Severe illness (6-7)		178 (41.6)
Moribund (8-9)		36 (8.4)
Prognosis: closeness to the end of life n (%)	T0	
≤ 1 week		71 (17.1)
1 - 6 weeks		28 (6.7)
6 weeks - 3 months		18 (4.3)
3 months - 6 months		96 (23.1)
6 months - 12 months		82 (19.7)
> 12 months		69 (16.6)
Unclear prognosis		52 (12.5)
Dementia type n (%)	T1	
Alzheimer's dementia		161 (37.5)
Vascular dementia		88 (20.5)
Mixed Alzheimer's-Vascular		64 (14.9)
Other		29 (6.8)
Unknown		87 (20.3)
Dementia severity, mean BANS-S[†] score (SD)	T1	16.1 (4.6)
Severe dementia[‡] n (%)	T1	171 (45.0)
Full ADL[§] dependency[18] prior to pneumonia diagnosis n (%)	T1	53 (14.2)
Pneumonia severity	T0	
Mean number of pneumonia symptoms newly presented or aggravated due to pneumonia (SD)		5.2 (2.1)
Median number of sudden behavioral changes compared with before pneumonia (IQR)		2 (1-2)
Treatments n (%)	T0	
Antibiotic treatment		345 (82.5)
Artificial nutrition		7 (1.6)
Rehydration		1 (0.2)
Symptom control		272 (65.1)

Table 1 (Continued) Resident characteristics assessed at (T0) or after diagnosis of the pneumonia (T1)

Characteristics	*Timing of Assessment*	*n = 429**
Person most influential in decisions regarding treatment goals and treatment of pneumonia n (%)	T1	
Person with dementia		39 (10.3)
Family/representative of person with dementia		180 (47.4)
Attending physician		135 (35.5)
Other physician		18 (4.7)
Nurse		1 (0.3)
Other		3 (0.8)
Unknown		1 (0.3)
Not discussed		3 (0.8)

*Age was missing for 2 persons, Length of stay was missing for 61 persons, Prognosis was missing for 13 persons, BANS-S was missing for 49 persons, Full ADL dependency was missing for 55 persons, Behavioral changes was missing for 24 persons, Antibiotic treatment was missing for 11 persons, Artificial nutrition was missing for 46 persons, Rehydration was missing for 46 persons, Symptom control was missing for 12 persons, Person most influential in decisions was missing for 49 persons †BANS-S: Bedford Alzheimer Nursing Severity-Scale (range 7-28) ‡Severe dementia: BANS-S scores ≥ 17[27] §ADL: activities of daily living

Changes in advance care plans

For 15.9% (61 residents), prioritized treatment goals changed following pneumonia (Table 2). The prioritization of “maintenance of function” as a treatment goal decreased from 22.1% before diagnosis to 18.4% after pneumonia diagnosis (-3.7%). For 44 cases (72% of all changes), the change entailed further refinements of goals. None of the pre-identified factors were significantly associated with changes in prioritized treatment goals (all *p* > .05; Table 3).

For 20.0% (72 residents), advance treatment decisions changed following pneumonia (Figure 1). In 51 cases ‘do’ orders changed to ‘do-not’ orders, for 31 a ‘do-not’ order was established, for 7 a ‘do-not’ order changed to a ‘do’ order and for 5 a ‘do’ order was established. Orders regarding artificial nutrition, IV therapies and hypodermoclyses were discussed more often; decisions increased by 3.1%, 3.8% and 5.1% respectively (Figure 1, supplementary Table S1). Table 3 shows that illness severity and terminal prognosis were significantly associated with changes in advance treatment decisions and these associations remained in the multivariable model. More severe illness (OR 1.3, 95% CI 1.1-1.7, *p* = .010) and a terminal prognosis (OR 2.2, 95% CI 1.1-4.3, *p* = .019) both increased the odds of changes in treatment decisions. In the adjusted multivariable model, length of stay showed a small association with changes in advance treatment decisions. The odds of changes decreased for a longer length of stay (0.99/month, 95% CI 0.97-1.0, *p* = .048). There was no significant random effect of the nursing home level in any of the models.

Table 2 ACP and decision making before and after diagnosis of the pneumonia

Care Plans and Decisions n (%)*		
Presence of living will		
No	376 (96.2)	
Yes	15 (3.8)	
Type:		
Euthanasia statement	8 (2.0)	
Advance Decision to Refuse Treatment†	5 (1.3)	
Do Not Resuscitate Order	4 (1.0)	
Self-drafted statement	3 (0.8)	
Power of Attorney	2 (0.5)	
Other	1 (0.3)	
Prioritized treatment goal	**Before**	**After**
	Pneumonia Diagnosis	
No - no treatment goal established	12 (2.8)	9 (2.1)
Yes - treatment goal established	408 (95.1)	398 (92.8)
Prioritized goal:		
Prolongation of life	48 (11.2)	43 (10.0)
Maintenance of function	95 (22.1)	79 (18.4)
Maximization of comfort	265 (61.8)	276 (64.3)
Other – partial or context-specific goals	9 (2.1)	22 (5.1)
Advance treatment decisions	**Before**	**After**
	Pneumonia Diagnosis	
No decisions or discussions	21 (5.4)	
Decisions	369 (94.6)	
Treatments with a decision (do or do-not):		
Cardiopulmonary resuscitation	360 (92.3)	358 (91.8)
Antibiotics	333 (85.4)	339 (86.9)
Hospitalization	313 (80.3)	322 (82.6)
Intubation	287 (73.6)	290 (74.4)
Artificial nutrition	252 (64.6)	264 (67.7)
IV therapies (antibiotics, hydration)	256 (56.6)	271 (69.5)
Hypodermoclysis (hydration)	205 (52.6)	225 (57.7)
Any other life-prolonging treatments	298 (76.4)	306 (78.5)

*Presence of living will was missing for 38 persons, Advance treatment decisions was missing for 39 persons.

†Advance Decision to Refuse Treatment can comprise one to several specific treatments that a person does not want to receive in specified situations, for example cardiopulmonary resuscitation, intubation, etc.

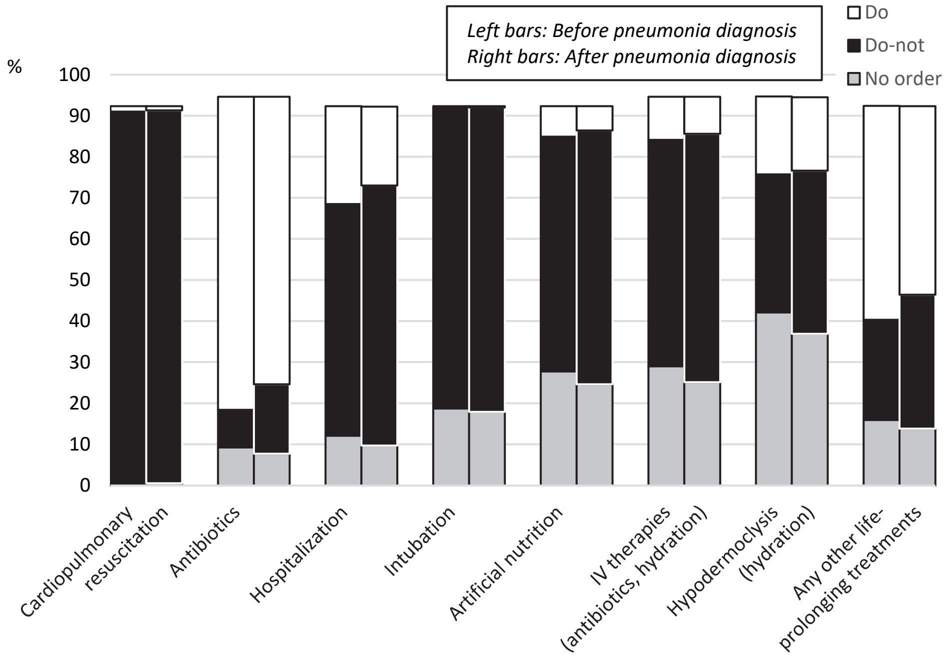

Figure 1 Advance decisions regarding treatments: residents' treatment orders before and after the first pneumonia diagnosis during the trial period (N = 390)

Table 3 Factors associated with changes in prioritized treatment goals or any advance treatment decisions after pneumonia diagnosis compared with before pneumonia diagnosis (odds ratio, 95% confidence interval)

Factor	**Change in Prioritized Treatment Goal** *Univariable*	**Change in any Advance Treatment Decision** *Univariable*
Demographics		
Sex (male)	0.9 (0.5–1.7)	0.9 (0.6–1.6)
Age (years)†	1.0 (1.0–1.1)	1.0 (1.0–1.0)
Illness progression indicators†		
Length of stay (months)	1.0 (1.0–1.0)	1.0 (1.0–1.0)
Dementia severity (BANS-S)§	1.0 (0.9–1.1)	1.0 (1.0–1.1)
Illness severity	1.1 (0.9–1.4)	1.5 (1.2–1.9)*
Terminal prognosis	1.3 (0.7–2.4)	3.3 (1.9–5.8)*
Person most influential in decision making‡		
Resident	1.7 (0.8–3.9)	0.9 (0.4–2.1)
Family	0.8 (0.7–2.2)	1.1 (0.6–1.9)
Attending physician (reference)	1	1

*Significant association at *p*-level < .05 (Bonferroni corrected) †Odds ratios per 1 point increment, ‡odds ratios for specified person as most influential in decision making compared with the attending physician as most influential §BANS-S: Bedford Alzheimer Nursing Severity-Scale

Person most influential in decision making

The attending physicians reported that the person most influential in their decisions regarding prioritized treatment goals and treatment was a family member or representative of the person with dementia in most cases (47.4%, *n* = 180), followed by themselves (35.5%, *n* = 135), and the person with dementia (10.3%, *n* = 39) (Table 1). There were no significant differences in the residents' age, sex, length of stay, illness severity or terminal prognosis between these three groups (Table 4) but dementia severity differed ($F(2, 351) = 6.864$, $p = .001$). Dementia was less severe when the resident was most influential in decision making compared with the family or physician. Also, the prevalence of severe dementia differed between groups, with higher prevalence when the family was most influential compared to the resident ($X^2(2) = 9.912$, $p = .007$).

Table 4 Resident characteristics in the case the resident, the family or the attending physician was most influential in the physician's decision making

	Person Most Influential in the Physician's Decision Making			
	Resident *(n = 39)*	*Family* *(n = 180)*	*Attending Physician* *(n = 135)*	*p-value (overall differences)*
Demographics				
Mean resident age, years (SD)	84.1 (8.6)	84.7 (7.0)	84.2 (7.8)	.83
Resident sex, female n (%)	22 (56.4)	110 (61.1)	81 (60.0)	.86
Illness progression indicators				
Median length of stay, months (IQR)	11.0 (3.0-23.0)	20.0 (5.25-36.0)	14.0 (5.0-34.5)	.06
Dementia severity, mean BANS-S (SD)[*]	13.8 (4.3)[†,‡]	16.7 (4.6)[†,§]	15.9 (4.2)[‡,§]	.001
Severe dementia n (%)[*]	9 (23.1)[‖,**]	91 (50.6)[‖,††]	59 (43.7)[**,††]	.007
Illness severity n (%)				.45
Not ill (1-2)	3 (7.7)	5 (2.8)	4 (3.0)	
Mild illness (3-4)	8 (20.5)	35 (19.4)	26 (19.2)	
Moderate illness (5)	13 (33.3)	49 (27.2)	42 (31.1)	
Severe illness (6-7)	12 (30.7)	75 (41.7)	58 (43.0)	
Moribund (8-9)	3 (7.7)	16 (8.9)	5 (3.7)	
Terminal prognosis n (%)	7 (18.9)	52 (29.2)	33 (24.8)	.38

[*] BANS-S: Bedford Alzheimer Nursing Severity-Scale, Severe dementia: BANS-S scores ≥ 17 (range 7–28)[27] [†] *p* = .001 (post-hoc comparison) [‡] *p* = .028 (post-hoc comparison) [§] *p* = .39 (post-hoc comparison) [‖] *p* = .006 (post-hoc comparison) [**] *p* = .06 (pos-hoc comparison) [††] *p* = .68 (post-hoc comparison)

Discussion

This study found that physician-reported advance care plans were usually developed after nursing home admission, and only changed for a minority of residents with dementia after pneumonia diagnosis. Illness severity and having less than 3 months to live were associated with any changes in advance treatment decisions. There were no such associations with changes in prioritized treatment goals. Often, the physicians perceived family as most influential, in particular when residents had severe dementia.

Few residents had living wills or were most influential in the decision making. This mirrors Belgian findings, where living wills were rare and physicians did not discuss end-of-life care regularly with residents.[28] Documented ACP with people with dementia themselves is thus not standard practice in primary[29] and long-term care, and several barriers have been identified.[30, 31] One barrier is capacity; many had severe dementia (45%) and probably limited capacity, or temporally diminished capacity due to the acute illness. The majority of residents did not have a power of attorney despite family being most influential in decision making, highlighting the need to identify who people with dementia would want to involve in future decision making.

Absence of living wills did not imply absence of care guidance. Treatment goals were prioritized, and advance treatment decisions were recorded for nearly all residents. It is remarkable that cardiopulmonary resuscitation, antibiotics and hospitalization were discussed for most residents although content of care plans was not regulated. This may reflect a general consensus among healthcare professionals to address these topics, and the fact that this is routine may decrease hesitance to initiate discussions. Artificial nutrition and hydration were discussed least often, but that increased after the pneumonia. Pneumonia might serve as a trigger to discuss relevant treatment orders,[1] indicating declining health. Especially in case of artificial nutrition and hydration, sensitive topics for which decisions are challenging,[32, 33] discussions may have been postponed until after an acute event.

For 16% of the residents, prioritized treatment goals changed, but no factors significantly associated with a change were found. Multiple treatment goals can apply simultaneously, with the priority of treatment goals shifting over time.[3] This process may be influenced by interacting factors which may not have been included in our analyses. For 20% of the residents, treatment decisions changed. The odds of changing treatment decisions was largest for residents who were close to the end of life or more severely ill. Despite an indicator of the residents' health,[34] there was no association with dementia severity. Dutch physicians base their decision to treat pneumonia with antibiotics mainly on prognosis;[35] more so than on dementia severity.[14] They often focus on quality of life and avoiding futile treatment in medical decision making,[36] the majority already upon admission.[11] The relationship between dementia severity and quality of life is complex[37] and survival (and hence medical futility) can be difficult to predict.[5] Using a model that orients decision makers to consider frailty in a holistic way resulted in lower preference of aggressive treatment[38] that may prolong suffering for people with advanced dementia.[39] This suggests that a diagnosis of dementia alone offers insufficient basis to forego treatment, but other illness and frailty should be considered. This holistic approach may also apply to other changes in advance care plans that we found, such as specifying conditions for specific treatments.

In the current study, physicians were asked to report changes in advance care plans made 1-3 weeks after pneumonia diagnosis. Longer time frames might have given more opportunity for change. Further, in contrast to findings from, for example, the United States,[40] goals already favored symptom management rather than life prolongation before the pneumonia in the majority of cases. However, there was still room for changes in the direction of more conservative specific treatments such as foregoing antibiotic treatment or other life-prolonging treatment. Moreover, we found that most changes entailed detailing of plans rather than a change of direction.

We did not find that changes in prioritized treatment goals or treatment decisions were more likely when physicians perceived the family or resident as most influential in their decision making instead of themselves as responsible for medical decision making. The person that the attending physician had listed as “most influential in decision making” is thus not the person taking decisions in the Netherlands.[23] The physicians may have been thinking about the person who provided relevant information that guided their decisions. Future research may examine physician variability regarding shared decision making and ACP.

Strengths and limitations

The strengths of this study include the sample that is representative of nearly all Dutch provinces.[15] We reported on ACP around a pneumonia episode using data that were partly collected prospectively. We used the physicians’ estimation of terminal prognosis, assessed prospectively. Thus we have described ACP practice in a realistic, frequently occurring[6, 7] and therefore relevant situation in nursing home residents with dementia.

A limitation relates to power with infrequent outcomes. The models with outcome change of prioritized treatment goal and of treatment decisions showed considerable uncertainty around the coefficients. Further, all data are physician-reported. Family representatives or residents may have a different perspective on their influence in shared decision making and the prioritized treatment goals. Next, the time between data collection (2012-2015) and reporting may limit the relevance of the findings for current practice. However, the incidence of pneumonia in people with dementia is stable.[6, 14] The prevalence of living wills has increased between 2012 and 2018 in the general population from 13% to 21%, but it remains rare for people with dementia.[29, 41] As ACP practice varies across jurisdictions according to local culture, care practice and legislation, cross-national research is needed to examine generalizability of findings in the Dutch context.

Conclusions and Implications

There is a strong ACP practice in Dutch nursing homes involving family, but ACP with persons with dementia themselves is rare and requires more attention. Overall, changes in advance care plans after pneumonia diagnosis were small, suggesting stability of most preferences or limited dynamics in the process of ACP. Changes in specific treatment decisions following pneumonia diagnosis were associated with severe illness and a terminal prognosis. The pneumonia triggered discussions about artificial nutrition and hydration in particular and led to refinement of plans. Future research could investigate if educating the general public, or family caregivers and healthcare professionals specifically, can lower barriers to conduct ACP conversations.

Competing interests

The authors declare that they have no competing interests.

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Appendix

Supplementary Materials. Table S1. Advance decisions regarding treatments: residents’ treatment orders before and after a pneumonia diagnosis

Table S1 Advance decisions regarding treatments: residents’ treatment orders before and after a pneumonia diagnosis (n=390)*

	Before pneumonia diagnosis n (%)			**After pneumonia diagnosis n (%)**		
Treatment	*No order*	*Do-not*	*Do*	*No order*	*Do-not*	*Do*
Cardiopulmonary resuscitation	0 (0)	355 (91.0)	5 (1.3)	2 (0.5)	354 (90.8)	4 (1.0)
Antibiotics	36 (9.2)	36 (9.2)	297 (76.2)	30 (7.7)	66 (16.9)	273 (70.0)
Hospitalization	47 (12.1)	220 (56.4)	93 (23.8)	38 (9.7)	247 (63.3)	75 (19.2)
Intubation	73 (18.7)	286 (73.3)	1 (0.3)	70 (17.9)	289 (74.1)	1 (0.3)
Artificial nutrition	108 (27.7)	223 (57.2)	29 (7.4)	96 (24.6)	241 (61.8)	23 (5.9)
IV therapies (antibiotics, hydration)	113 (29.0)	215 (55.1)	41 (10.5)	98 (25.1)	236 (60.5)	35 (9.0)
Hypodermoclysis (hydration)	164 (42.1)	131 (33.6)	74 (19.0)	144 (36.9)	155 (39.7)	70 (17.9)
Any other life-prolonging treatments	62 (15.9)	95 (24.4)	203 (52.1)	54 (13.8)	127 (32.6)	179 (45.9)
Any of these treatments	**208 (53.3)**	**365 (93.6)**	**308 (79.0)**	**190 (48.7)**	**366 (93.8)**	**284 (72.8)**

*Cardiopulmonary resuscitation was missing for 30 persons, Antibiotics was missing for 21 persons, Hospitalization was missing for 30 persons, Intubation was missing for 30 persons, Artificial nutrition was missing for 30 persons, IV therapies was missing for 21 persons, Hypodermoclysis was missing for 21 persons, Any other life-prolonging treatments was missing for 30 persons