Original Study

Change in Advance Care Plans of Nursing Home Residents With Dementia and Pneumonia: Secondary Analysis of Randomized Controlled Trial Data

Laura Bavelaar MSc, Mandy Visser PhD, Philine Schlicksupp MSc, Bram Tilburgs PhD, Tessa van der Maaden PhD, Wilco P. Achterberg MD, PhD, Jenny T. van der Steen PhD, FGSA

Keywords: Advance care planning, dementia, nursing homes, pneumonia, shared decision making

A B S T R A C T

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 <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.

© 2022 The Authors. Published by Elsevier Inc. on behalf of AMDA – The Society for Post-Acute and Long-Term Care Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).

The authors declare no conflicts of interest.

* Address correspondence to Jenny T. van der Steen, PhD, FGSA, Department of Public Health and Primary Care, Leiden University Medical Center, Hippocratespad 21, Postbox 9600, 2300 RC Leiden, the Netherlands.

E-mail address: jtvandersteen@lumc.nl (J.T. van der Steen).

https://doi.org/10.1016/j.amda.2022.06.024

1525-8610/© 2022 The Authors. Published by Elsevier Inc. on behalf of AMDA – The Society for Post-Acute and Long-Term Care Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).
Advance care planning (ACP) entails the person concerned, family, and health care 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. It can support the future provision of care in line with personal wishes and contribute to high-quality care. A key aspect of ACP is shared decision making. When a person’s condition or wishes change, advance care plans should be revisited. Several moments can trigger (re)engaging with ACP.

Many people with dementia in Western countries are admitted to nursing homes when their needs are no longer met at home. Pneumonia occurs frequently among nursing home residents and is a common cause of death. 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. Dutch nursing homes are required to establish care plans within 6 weeks after a resident’s admission and revisit these biannually. Such plans must contain agreements about care goals, but may lack detail beyond decisions on cardiopulmonary resuscitation and hospitalization. Certified elderly care physicians trained in care for older people including palliative care approaches are responsible for care plans, which, in the case of dementia, often focus on comfort. Elderly care physicians are employed by nursing homes, on average attending to 103 residents per full-time equivalent. They, rather than an external palliative team, provide end-of-life care.

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. Further, antibiotics are also used to relieve symptoms: 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, nonprofit nursing homes conducted between January 2012 and May 2015 (Netherlands Trial Register NTR5071). Nursing homes were selected to cover the provinces of the Netherlands. The homes provided care as usual during a preintervention 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, 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 because of 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 to 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). This scale measures physician’s clinical judgment and was an accurate estimate of illness severity. Further, within 48 hours after diagnosis, the physicians reported pneumonia symptoms, behavioral changes after pneumonia, and treatments received.

One to 3 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)]. The physicians also reported dependency on 7 dementia severity as hospitalization is rare (1%) in this population.

Analyses

We performed descriptive statistics for the residents’ characteristics and the prevalence of advance care plans (ie, 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, and (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, indicators of health status and disease progression (ie, length of stay, dementia severity, illness severity at pneumonia diagnosis, and closeness to the end of life at pneumonia diagnosis), 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 3 main groups. The factor closeness to the end of life was dichotomized into terminal prognosis [≤3 months to live (1) vs >3 months to live or unclear (0)]. In the Netherlands, having <3 months to live is considered the terminal phase, which is when community-dwelling people are granted access to hospice care services. 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, attending physicians therefore served as the 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% to 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. Analysis of variance, 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 Corp, Armonk, NY).

Results

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

Advance Care Plans: Presence, Content, and (Re)engagement

Only 15 residents (3.8%) had a living will (Table 2). For 8 residents (2.0%), this was an euthanasia statement and 5 residents (1.3%) 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 1). 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 hypothermoclysis for

Table 1  Resident Characteristics Assessed at Baseline (T0) or After Diagnosis of the Pneumonia (T1)

| Characteristics                                      | Timing of Assessment | n = 429 |
|------------------------------------------------------|----------------------|---------|
| Demographics                                         |                      |         |
| Age, y, mean (SD)                                    | T0                   | 84.5 (7.4) |
| Sex, female, n (%)                                   | T0                   | 256 (59.7) |
| Illness progression indicators                       |                      |         |
| Length of stay, mo, median (IQR)                     | T0                   | 16.0 (5.0-34.0) |
| Illness severity1 at pneumonia diagnosis, n (%)      | T0                   | 12.8 (2.8) |
| Not ill (1-2)                                        |                      |         |
| 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 wk                                               |                      | 71 (17.1) |
| 1-6 wk                                               |                      | 28 (6.7) |
| 6 wk–3 mo                                            |                      | 18 (4.3) |
| 3-6 mo                                               |                      | 96 (23.1) |
| 6-12 mo                                              |                      | 82 (19.7) |
| >12 mo                                               |                      | 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, BANS-S score, mean (SD)           | T1                   | 16.1 (4.6) |
| Severe dementia, n (%)                               | T1                   | 171 (45.0) |
| Full ADL dependency2 prior to pneumonia diagnosis, n (%) | T1 | 53 (14.2) |
| Pneumonia severity                                   | T0                   |         |
| Number of pneumonia symptoms newly presented or aggravated due to pneumonia, mean (SD) | T0 | 5.2 (2.1) |
| Number of sudden behavioral changes compared with before pneumonia, median (IQR) | T0 | 2 (1-2) |
| Treatments, n (%)                                    | T0                   | 345 (82.5) |
| Antibiotic treatment                                 |                      | 7 (1.6) |
| Artificial nutrition                                 |                      | 1 (0.2) |
| Rehydration                                          |                      | 272 (65.1) |
| Symptom control                                      |                      |         |
| Person most influential in decisions regarding treatment goals and treatment of pneumonia, n (%) | T1 | 39 (10.3) |
| Person with dementia                                 |                      | 180 (47.4) |
| Family/representative of person with dementia         |                      |         |
| 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) |

ADL, activities of daily living; BANS-S, Bedford Alzheimer Nursing Severity-Scale.

*Missing data: Age was missing for 2 persons, length of stay was missing for 61 persons, prognosis was missing for 13 persons, BANS-S score 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.

1BANS-S score range 7-28.

2Severe dementia: BANS-S scores ≥ 17.
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 treatment⁴                         | 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 Pneumonia Diagnosis         | After Pneumonia Diagnosis |
|---------------------------------------------------------------|---------------------------|
| No—no treatment goal established                              | 12 (2.8)                  |
| Yes—treatment goal established                                | 408 (95.1)                |
| Prioritized goal:                                             |                           |
| Prolongation of life                                          | 48 (11.2)                 |
| Maintenance of function                                       | 95 (22.1)                 |
| Maximization of comfort                                       | 265 (61.8)                |
| Other—partial or context-specific goals                       | 9 (2.1)                   |

| Advance Treatment Decisions Before Pneumonia Diagnosis         | 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)                |
| Antibiotics                                                   | 331 (85.4)                |
| Hospitalization                                               | 313 (80.3)                |
| Intubation                                                    | 287 (73.6)                |
| Artificial nutrition                                          | 252 (64.6)                |
| IV therapies (antibiotics, hydration)                         | 256 (56.6)                |
| Hydropemoclysis (hydration)                                   | 205 (52.6)                |
| Any other life-prolonging treatments                          | 298 (76.4)                |

IV, intravenous.

¹ Missing data: Presence of living will was missing for 38 persons; advance treatment decisions was missing for 39 persons.

³ Advance decision to refuse treatment can comprise 1 to several specific treatments that a person does not want to receive in specific situations, eg, cardiopulmonary resuscitation, intubation, etc.

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 1 (Supplementary Table 1); however, antibiotics and any life-prolonging treatment orders were mostly “do” orders.

Changes in Advance Care Plans

For 61 residents (15.9%), 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 preidentified factors were significantly associated with changes in prioritized treatment goals (all P > .05; Table 3).

For 72 residents (20.0%), 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, intravenous therapies and hypodermoclyses were discussed more often; decisions increased by 3.1%, 3.8%, and 5.1%, respectively (Figure 1, Supplementary Table 1). 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.

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 3 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 [χ² (2) = 9.912, P = .007].

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 <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.⁵ Documented ACP with people with dementia themselves is thus not standard practice in primary⁶ and long-term care, and several barriers have been identified.⁶¹ One barrier is capacity; many had severe dementia (45%) and probably limited capacity, or temporally diminished capacity because of 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 cardio-pulmonary resuscitation, antibiotics, and hospitalization were discussed for most residents although content of care plans was not regulated. This may reflect a general consensus among health care 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 treatments such as foregoing antibiotic treatment or other life-prolonging treatments. 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 the attending physician. Further, in contrast to findings from, for example, the United States,

| 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% CI) |

| 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, y* 1.0 (1.0-1.1) 1.0 (1.0-1.0) |
| Illness progression indicators | Length of stay, mo 1.0 (1.0-1.0) 1.0 (1.0-1.0) | Dementia severity, BANS-S score 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 (0.8-3.5) 0.9 (0.4-2.1) | Family 0.8 (0.7-2.2) 1.1 (0.6-1.9) |
| Attending physician | 1 1 |

BANS-S, Bedford Alzheimer Nursing Severity-Scale.

*Odds ratios per 1-point increment.

**Significant association at P level < .05 (Bonferroni corrected).

| 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 | Resident age, y, mean (SD) 84.1 (8.6) 84.7 (7.0) 84.2 (7.8) | 0.83 |
| | Resident sex, female, n (%) 22 (56.4) 110 (61.1) 81 (60.0) | 0.86 |
| Illness progression indicators | Length of stay, mo, median (IQR) 11.0 (3.0-23.0) 20.0 (5.25-36.0) 14.0 (5.0-34.5) | 0.06 |
| | Dementia severity, BANS-S score, mean (SD)* 13.8 (4.3) 16.7 (4.6) 15.9 (4.2) | 0.001 |
| | Severe dementia, n (%) 9 (23.1) 27 (100) 27 (20.0) | 0.004 |
| | Illness severity, n (%) | Not ill (1-2) 3 (7.7) 5 (2.8) 4 (3.0) | 0.45 |
| | Mild illness (3-4) 8 (20.5) 35 (19.4) 26 (19.2) | 0.22 |
| | Moderate illness (5) 13 (33.3) 49 (27.2) 42 (31.1) | 0.27 |
| | Severe illness (6-7) 12 (30.7) 75 (41.7) 58 (43.0) | 0.38 |
| | Moribund (8-9) 3 (7.7) 16 (8.9) 5 (3.7) | 0.72 |
| | Terminal prognosis, n (%) 7 (18.9) 52 (29.2) 33 (24.8) | 0.38 |

BANS-S, Bedford Alzheimer Nursing Severity-Scale.

*Severe dementia: BANS-S scores ≥17 (range 7-28).27

**P = .001 (post hoc comparison).

1P = .028 (post hoc comparison).

1P = .39 (post hoc comparison).

1P = .006 (post hoc comparison).

1P = .06 (post hoc comparison).

1P = .68 (post hoc comparison).
of themselves as responsible for medical decision making. The person that 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, which is representative of nearly all Dutch provinces.24 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, 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. Familial 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.25–27 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. Therefore, 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 health care professionals specifically, can lower barriers to conduct ACP conversations.

Acknowledgments

We thank all who were involved in the original trial.

References

1. Harrison Dening K, Sampson EL, De Vries K. Advance care planning in dementia: recommendations for healthcare professionals. Palliat Care. 2019;12:1178242119852679.

2. Hove-Chishiri van Dael A, Bunn F, Lynch J, et al. Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. Int J Nurs Stud. 2020;107:103576.

3. Van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2014;28:197–209.

4. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. Ann Intern Med. 2010;153:256–261.

5. Jalbert JJ, Daello IA, Lapane KL. Dementia of the Alzheimer type. Epidemiol Rev. 2008;30:15–34.

6. Zomer TP, van der Maaden T, van Gageldonk-Lafeber AB, et al. Incidence of pneumonia in nursing home residents with dementia in the Netherlands: an estimation based on three differently designed studies. Epidemiol Infect. 2017;145:2400–2408.

7. Manabe T, Fujikura Y, Mizukami K, et al. Pneumonia-associated death in patients with dementia: a systematic review and meta-analysis. PLoS One. 2019;14:e0213825.

8. Hendriks SA, Smalbrugge M, Hertogh CPM, van der Steen JT. Changes in care goals and treatment orders around the occurrence of health problems and hospital transfers in dementia: a prospective study. J Am Geriatr Soc. 2017;65:769–776.

9. Anon. Long-Term Care Act 2015. In: Dutch Civil Code. Government of the Netherlands. 2015. Accessed September 29, 2021. https://www.overniethuiszorg.nl/boeken/LN63872159/2015-01-01/2.

10. Koopmans RTCM, Pellegrin M, Van der Geer ER. The Dutch move beyond the concept of nursing home physician specialists. J Am Med Dir Assoc. 2017;18:746–749.

11. Van der Steen JT, Deliens L, Koopmans RTCM, Onwuteaka-Philipsen BD, Deliens LH. Factors related to establishing a comfort care goal in nursing home patients with dementia: a cohort study among family and professional caregivers. J Palliat Med. 2014;17:1317–1327.

12. Bloemendal I, van de Leemkolk B, Noordzij E. Werkcontext en tijdsbesteding van de specialist ouderengeneeskunde vanuit verpleeghuizen [Work context and time use of the elderly care physician from nursing homes]. Capaciteitsorgan PrismaNT. 2019. Accessed March 3, 2022. https://capaciteitsorganprixmaan.org.nl/upload/20191015/prismaNT-2019-Eindrapport-Werkcontext-en-tijdsbesteding-van-de-so-beraalhmeting-2018.pdf.

13. Van der Steen JT, Deliens L, Koopmans RTCM, Onwuteaka-Philipsen BD. Physicians’ perceptions of suffering in people with dementia at the end of life. J Palliat Med. 2015;18:585–599.

14. van der Steen JT, Meuleman-Peperkamp I, Ribbe MW. Trends in treatment of pneumonia among Dutch nursing home patients with dementia. J Palliat Med. 2009;12:789–795.

15. van der Maaden T, de Vet HC, Achterberg WP, et al. Improving comfort in people with dementia and pneumonia: a cluster randomized trial. BMC Med. 2016;14:116.

16. van der Maaden T, van der Steen JT, de Vet HC, et al. Development of a practice guideline for optimal symptom relief for patients with pneumonia and dementia in nursing homes using a Delphi study. Int J Geriatr Psychiatry. 2015;30:487–496.

17. Charlson ME, Sax FL, MacKenzie CR, et al. Assessing illness severity: does clinical judgment work? J Chronic Dis. 1986;39:439–452.

18. Van der Steen JT, Ooms ME, van der Wal G, Ribbe MW. Withholding or starting antibiotic treatment in patients with dementia and pneumonia: prediction of mortality with physicians’ judgment of illness severity and with specific prognostic models. Med Decis Making. 2005;25:210–221.

19. Vollicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimer’s disease. J Gerontol. 1994;49:M223–M226.

20. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. J Gerontol A Biol Sci Med Sci. 1999;54:M546–M553.

21. van Wijnen MPS, Pasman HRW, Twisk JWR, et al. Stability of end-of-life preferences in relation to healthy status and life-events: a cohort study with a 6-year follow-up among holders of an advanced directive. PLoS One. 2018;13:e0209315.

22. Friborg F, van Houwelingen A, van Nus-Stad J. Palliatieve zorg [Palliative care]. 2012. Accessed July 21, 2021. https://www.pallialine.nl/index.php?pagina=praktijk/gedeelte-besl uitvorming-met-ouderen.

23. Helson MR, van der Steen JT, Daaleman TP, et al. A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. Ann Fam Med. 2006;4:221–227.

24. Van der Steen JT, Galway K, Carter G, Brazil K. Initiating advance care planning on end-of-life issues in dementia: ambiguity among UK and Dutch physicians. Arch Gerontol Geriatr. 2016;65:225–230.

25. Van Soest-Poortvliet MC, van der Steen JT, Gutschow G, et al. Advance care planning in nursing home patients with dementia: a qualitative interview study among family and professional caregivers. J Am Med Dir Assoc. 2015;16:979–989.

26. Stiggelbout AM, Gartner FR, Pieterse AH. Gedeelde besluitvorming met ouderen [Shared decision making with older people]. Accessed June 3, 2022. https://www.versen.org/nl/magazine-november-2015/no-3-november-2015/praktijk/gedeelte-besluitvorming-met-ouderen.

27. van der Steen JT, Vollicer L, Gerritsen DL, et al. Defining severe dementia with the Minimum Data Set. Int J Geriatr Psychiatry. 2006;21:1099–1106.

28. Vandervoort A, Houttekier D, Van den Block L, et al. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. J Pain Symptom Manage. 2014;47:245–256.

29. Arora V, Tilburgs B, van Houwelingen A, et al. Occurrence and timing of advance care planning in persons with dementia in general practice: analysis of linked electronic health records and administrative data. Front Public Health. 2022;10:553174.

30. Tilburgs B, Vernooy-Jassen M, Koopmans R, et al. The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: a qualitative study. BMC Geriatr. 2018;18:184.
31. Keijzer-van Laarhoven AJ, Touwen DP, Tilburgs B, et al. Which moral barriers and facilitators do physicians encounter in advance care planning conversations about the end of life of persons with dementia? A meta-review of systematic reviews and primary studies. BMJ Open. 2020;10:e038528.
32. Kollisch DO, Santulli RB, Bernat JL. The limits of advance directives in maintaining autonomy in patients with advanced dementia. Am J Med. 2021;134:963–967.
33. Arcand M. End-of-life issues in advanced dementia: Part 2: management of poor nutritional intake, dehydration, and pneumonia. Can Fam Physician. 2015;61:337–341.
34. Zhu CW, Cosentino S, Ornstein KA, et al. Interactive effects of dementia severity and comorbidities on medicare expenditures. J Alzheimers Dis. 2017;57:305–315.
35. Sternberg SA, Shinan-Alman S, Volcier L, et al. Palliative care in advanced dementia: comparison of strategies in three countries. Geriatrics. 2021;6:44.
36. The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. BMJ. 2002;325:1326.
37. Farina N, King D, Burgon C, et al. Disease severity accounts for minimal variance of quality of life in people with dementia and their carers: analyses of cross-sectional data from the MODEM study. BMC Geriatr. 2020;20:232.
38. Moorhouse P, Mallery LH. Palliative and therapeutic harmonization: a model for appropriate decision-making in frail older adults. J Am Geriatr Soc. 2012;60:2326–2332.
39. van der Steen JT, Lane P, Kowall NW, et al. Antibiotics and mortality in patients with lower respiratory infection and advanced dementia. J Am Geriatr Soc. 2004;52:691–699.
40. van der Steen JT, Kruse RL, Ooms ME, et al. Treatment of nursing home residents with dementia and lower respiratory tract infection in the United States and the Netherlands: an ocean apart. J Am Geriatr Soc. 2002;50:691–699.
41. Harnas S, Toersen W. Rapport meldactie ‘Wilsverklaring’ [Report of registration action ‘Living Will’]. Patiëntenfederatie Nederland. 2018. Accessed July 20, 2021. https://www.patientenfederatie.nl/downloads/rapporten/178-meldactie-wilsverklaring/file
**Supplementary Table 1**
Advance Decisions Regarding Treatments: Residents’ Treatment Orders Before and After a Pneumonia Diagnosis (n = 390)*

| Treatment                                      | Before Pneumonia Diagnosis, n (%) | After Pneumonia Diagnosis, n (%) |
|------------------------------------------------|----------------------------------|---------------------------------|
|                                                | 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) |

*Missing data: 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.

IV, intravenous.