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4 **1 Initiation of advance care planning in newly admitted nursing home residents in**
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6 **2 Flanders, Belgium: a prospective cohort study**
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40 **20 Author's contributions:** M. Elseviers and T. Dilles designed the study. K. Paque, I.
41 Ivanova, and M. Elseviers were responsible for the statistical design and analyses. K. Paque
42 wrote the paper. All authors were involved in developing the research questions, discussing
43 and interpreting the results and supervising the draft of the paper.
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49 **25 Running title:** advance care planning in nursing homes
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4 **1 Abstract**

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7 **2 Aim:** to describe (1) the timing of initiation of advance care planning (ACP) after nursing
8 home admission, (2) the association of dementia and physical health with ACP initiation,
9 (3) if and how analgesic use and use of lipid modifying agents is related to ACP, in a cohort
10 of newly admitted residents.
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17 **6 Methods:** Prospective, observational cohort study of nursing home residents. Data were
18 collected three months, 15 months (year1) and 27 months (year2) after admission, using a
19 structured questionnaire and validated measuring tools.
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25 **9 Results:** ACP was never initiated during the two-year stay for 38% of the residents, for
26 22% ACP was initiated at admission, for 21% during year1, and for 19% during year2
27 (n=323). ACP initiation was strongly associated with dementia, but not with physical
28 health. Residents without dementia were more likely to have ACP initiation at admission or
29 not at all, while for residents with dementia ACP initiation was postponed. Between
30 admission and year2, analgesic use increased (34%-42%) and use of lipid modifying agents
31 decreased (28%-21%). Analgesic use increased more in residents with ACP initiation
32 during year1 and year2. The use of lipid modifying agents was not associated with ACP.
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44 **17 Conclusion:** The timing of ACP initiation differed significantly for residents with and
45 without dementia, which highlights the importance of an early onset of ACP before
46 residents lose their decision-making capacity. ACP conversations may create opportunities
47 to discuss adequate pain and other symptom treatment and deprescribing at the end of life.
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53 **21 Key words:** advance care planning, analgesics, cohort study, dementia, nursing home
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1 Introduction

2 As age increases, people are confronted with multimorbidity and increasing
3 physical, cognitive and social decline ⁽¹⁾, and its consequences, such as frailty, decreasing
4 quality of life, increasing hospitalization rates and related costs, and an increasing need for
5 long-term care ^(2, 3). On the one hand, recent progress in medicine enables more and more
6 life-prolonging treatment. On the other hand, the main care goal in nursing homes (NHs) is
7 to support and improve their residents' quality of life. To prevent unnecessary treatments
8 and hospitalizations, and support and preserve quality of life, it is crucial to know people's
9 preferences regarding current and future treatment and care goals ⁽⁴⁾.

10 Advance care planning (ACP) is defined as 'the ability to enable individuals to
11 define goals and preferences for future medical treatment and care, to discuss these goals
12 and preferences with family and healthcare providers, and to record and review these
13 preferences if appropriate' ⁽⁵⁾. ACP has been associated with a decrease in hospitalizations
14 and use of resources, lower levels of unwanted life-sustaining treatments, increasing patient
15 and family satisfaction with care, an increasing number of residents dying in their NH
16 instead of in hospital, and increasing compliance with patients' end-of-life care wishes ⁽⁶⁻⁹⁾.

17 In this study, 'ACP' is used as an umbrella term and includes all forms of forms of
18 ACP, regulated by law or not. Currently, two forms of ACP occur together in Flemish NHs.
19 Firstly, patient driven ACP, which may, but need not to be documented (e.g. in an Advance
20 Directive (AD)), and can include nomination of a proxy decision maker. Both possibilities
21 are provided by the law. Several structured forms in accordance with current legislation are
22 offered by a number of organizations, such as health insurance organizations. Secondly,

1 physician driven ACP by means of written general practitioner (GP) orders, which are
2 medical decisions documented in the medical file in accordance with the institution's
3 protocol. These orders should be discussed with other healthcare professionals, family
4 members or with the resident⁽¹⁰⁻¹²⁾. These orders include do-not-resuscitate and do-not-
5 intubate orders, alleviation of pain and other symptoms, etc.⁽¹²⁾.

6 Earlier studies found a varying prevalence of ACP in NHs: between 45% and 77%
7 for physician driven and between 8% and 14% for patient driven ACP⁽¹⁰⁻¹⁴⁾. Documented
8 care plans were rarely ADs, but mostly written GP orders^(10, 13, 15).

9 The prominent prevalence of GP orders, and particularly the order regarding
10 alleviation of pain and other symptoms, raises the question if having any type of ACP is
11 related to medication use. Generally, medication use should be in accordance with the
12 changing care goals of NH residents⁽¹⁶⁾. Supporting and preserving quality of life should
13 include treating symptoms that are currently undertreated (e.g. pain) and deprescribing of
14 medications which lack short-term benefit. We hypothesize that analgesic use, as an
15 example of adequate treatment according to the definition of palliative care⁽¹⁶⁾, will
16 increase in residents for whom ACP is initiated. Earlier studies have demonstrated an
17 increased use of analgesics in people with pain symptoms caused by advanced disease⁽¹⁷⁾.
18 On the contrary, use of lipid modifying agents, as an evidence based example of preventive
19 medication appropriate for deprescribing in patients with a limited life-expectancy, will
20 decrease in these residents⁽¹⁸⁾. Research has demonstrated that discontinuation of these
21 medications reduces the number of adverse drug events⁽¹⁹⁾. In this context, it is important
22 to include decision-making regarding medication use in ACP discussions.

1 The aim of this longitudinal study is to determine when ACP is initiated during the
2 NH stay in a cohort of newly admitted residents, and whether ACP initiation is related to
3 dementia symptoms and physical health. This information is crucial to determine the need
4 for a systematic approach of ACP. Adding data on possible relationships with medication
5 use, i.e. analgesic use and lipid modifying agents, will feed future discussions on the
6 content and potential outcomes of ACP.

8 **Methods**

9 This study uses baseline data at NH admission and follow-up data of year1 and
10 year2 after admission of the ageing@NH cohort study, examining newly admitted
11 residents' general health. Two other articles reporting on data of this study were published
12 earlier ^(1, 20).

13 ***Study design and study population***

14 A convenience sample of 67 NHs with at least 60 beds in Flanders, the Dutch
15 speaking part of Belgium, were included in the study. In the participating NHs, all newly
16 admitted residents between September 2013 and December 2013 were invited to participate
17 in the study, if aged ≥ 65 , Dutch-speaking and permanently admitted to the NH. All
18 residents were consecutively recruited during the period of four months for the baseline
19 assessment at NH admission. The same residents were invited to participate after one and
20 two years for follow-up assessment, provided that they were still alive and still resided in a
21 participating NH. All residents (or their proxy decision maker in case of dementia) had to
22 provide informed consent before baseline and both follow-up assessments.

23

1 **Procedure**

2 Residents were interviewed one to three months after admission, and one and two
3 years later, using a structured questionnaire and validated measuring tools for activities of
4 daily living (Katz-ADL) ⁽²¹⁾ and cognitive status (MMSE) ⁽²²⁾. (Supplementary file S.I.)
5 These data were completed with administrative data, data from the nursing chart, and a
6 copy of the resident's medication chart. In case of dementia, the proxy decision maker (at
7 admission) or the responsible nurse (year1&2) was interviewed.

8 **Measures**

9 We considered that ACP was initiated if data on ACP initiation were documented in
10 the nursing chart, or mentioned by the responsible nurse where this information was
11 missing. In this study, we refer to all types of documented care plans and all related
12 communication about future medical treatment and care as 'ACP', because our aim was to
13 measure ACP initiation. The available data did not allow to determine if these documented
14 care plans – particularly GP orders – were discussed with the resident himself or not. We
15 determined whether ACP was initiated at 3 months, 15 months and 27 months after
16 admission, for the construction of a new dichotomous variable 'ACP initiation' for every
17 measuring point. We categorized ACP initiation at the different time points into four groups
18 of ACP trajectories throughout the two-year stay or stay until death: *no ACP* (never), *ACP*
19 *from admission on* (initiated within the first 3 months after NH admission), *ACP initiation*
20 *during year1* (> 3 months and <= 15 months after admission), and *ACP initiation during*
21 *year2* (> 15 months and <= 27 months after admission). Only residents for whom data on
22 ACP initiation at three time points were available were included in further analyses. The

1 categories *ACP initiation during year1* and *ACP initiation during year2* were collated to
2 one category *delayed ACP initiation* for further analyses.

3 Physical health was defined using Katz-ADL, survival time in months and total
4 number of medications. Residents with an MMSE score lower than 16 out of 30, and a
5 KATZ score for disorientation greater than or equal to 6 out of 8 – showing a daily
6 disorientation in time and place – and who were unable to respond adequately to the
7 questionnaire, were considered to have dementia symptoms. (S.I).

8 Medications were recorded using the brand or generic name in a data-entry
9 program, based on the official register of medications on the market from the Belgian
10 Centre for Pharmaceutical Information. The medication was translated into the Anatomical
11 Therapeutic Chemical (ATC) classification (WHO ATC/DDD index, the current version of
12 each year of data entering). Focus was on anatomical main groups (first ATC level) and
13 therapeutic subgroups (second ATC level). Due to difficulties in the collection of the
14 medication charts at year1, data on medication of year1 were not suitable for further
15 analyses. Therefore, we compared medication use at two time points: at admission and
16 year2.

17 18 ***Data analysis***

19 We used SPSS 23.0 (IBM Statistics Inc., Chicago, IL) for all statistical analyses.
20 We described residents' characteristics using descriptive statistics, and explored factors
21 influencing ACP initiation at NH admission with independent samples t-tests, crosstabs and
22 χ^2 . We used ACP initiation at NH admission as outcome variable in logistic regression
23 analyses.

1 We explored differences between the prevalence of ACP initiation at admission, year1 and
2 year2, and the prevalence of analgesics and lipid modifying agents at admission and year2,
3 with Cochran's Q and McNemar tests. We examined associations between ACP initiation
4 and dementia with crosstabs and χ^2 , associations with physical health with One Way
5 ANOVA.

6 We explored associations of ACP initiation with the evolution of the prevalence of
7 analgesics and lipid modifying agents between admission and year2 with Cochran-Mantel-
8 Haenszel and McNemar tests. A statistical significance level of $p < 0.05$ was set.

9 *Ethical considerations*

10 The ethics committee of Antwerp University Hospital and Antwerp University
11 approved the study protocol (EC-number 13/43/420).

12 The board of directors and the supervising GP of the NH signed a study agreement.

13 Residents, or their proxy decision maker in case of dementia, signed an informed consent.

14 **Results**

15 *Research population*

16 For 741 residents in 67 NHs informed consent was obtained at NH admission. Mean
17 Katz ADL was 14.69 (range 6-24), and 34% suffered from dementia. (Table 1.) After two
18 years, 342 of the participating residents were still alive, resided in a participating NH, and
19 confirmed informed consent. In this group, mean Katz ADL was 16.12, and 46% suffered
20 from dementia (data not shown).

21 *Advance Care Planning (ACP)*

22 *ACP initiation at NH admission:* At NH admission, ACP was initiated for 22% of
23 the participants (n=741). A higher MMSE score increased the odds of having ACP

1 initiation at NH admission with 3.5% per point on the MMSE. No associations were found
2 with physical health. (Table 2.)

3 *ACP initiation at three time points:* Longitudinal data on ACP initiation at three
4 time points were available for 323 of the 342 residents who were still alive in year2. ACP
5 was never initiated during the two-year stay for 38% of the residents, for 22% ACP was
6 initiated at NH admission, for 21% during year1, and for 19% during year2. (Table 3).

7 ACP initiation was associated with dementia symptoms, and the direction of this
8 relationships depended on the measurement time: at NH admission, ACP was initiated for
9 23% of residents without dementia symptoms and 16% of residents with dementia
10 symptoms, while during year1 and year2, ACP was initiated for respectively 34% and 53%
11 of residents without dementia symptoms, in relation to 38% and 64% of residents with
12 dementia symptoms ($p=0.003$). (Figure 1.) No associations were found with physical health
13 (data not shown).

14 *Associations of ACP initiation with medication use:* At NH admission, 34% of the
15 residents used analgesics and 28% used lipid modifying agents. Between admission and
16 year2, the use of analgesics increased significantly (34%-42%, $p=0.001$) and the use of
17 lipid modifying agents decreased significantly (28%-21%, $p=0.009$). (Table 3.) A
18 significant increase in the use of analgesics between admission and year two was found in
19 residents with delayed ACP initiation ($p=0.002$). (Figure 2.) This relationship remained
20 after controlling for dementia with Cochran Mantel-Haenszel tests. ACP initiation was not
21 related to the decreasing use of lipid modifying agents (data not shown).

22 **Discussion**

1 **Main findings**

2 *ACP initiation:* ACP was initiated at NH admission for 22% of the residents, and
3 postponed for 40% (i.e. for 21% postponed to year1, for 19% to year2). Moreover, for 38%
4 ACP was never initiated during the two-year stay. The timing of ACP initiation differed
5 significantly for residents with and without dementia symptoms. Residents without
6 dementia symptoms were more likely to have ACP initiated at NH admission or not at all,
7 while residents with dementia symptoms were more likely to have ACP initiation later on
8 during their stay in the NH.

9 *Medication use:* This study confirms our a priori hypothesis that analgesic use
10 increases in residents for whom ACP has been initiated, but only for residents with delayed
11 ACP initiation. The hypothesis regarding the association between ACP initiation and a
12 decreasing use of lipid modifying agents was not confirmed.

13 **Strengths and limitations**

14 To the best of our knowledge, this is the first study providing baseline and follow-
15 up data on ACP initiation and its associations with physical health, dementia symptoms and
16 medication use in an observational study with strong design. Moreover, the timing of ACP
17 initiation – or the ‘onset’ – has not been measured before.

18 A few limitations apply to this study. Firstly, only 323 residents were available for
19 the analyses of admission and follow-up data, mainly due to death, which is common in this
20 frail population. Secondly, this study describes a trend and an indication of the timing of
21 ACP initiation in NHs. This is not a study of the prevalence of normative ACP, but an
22

1 empiric approach of the practices in the field of ACP, and also the absence of ACP. Neither
2 content, nor quality of ACP were studied. The concept and outcomes of ACP substantially
3 vary between countries, which complicate comparison with international studies. Finally,
4 data on the use of analgesics describe the prevalence and not the initiation of those
5 medications. Furthermore, pain assessment is crucial to determine if the increasing use of
6 analgesics indicates better pain treatment. Therefore, further research is necessary to clarify
7 these aspects.

8 ***Interpretation of the findings***

9 *ACP initiation:* Concordant with earlier studies of ACP engagement in older adults,
10 we found a low prevalence of ACP initiation at every measuring point ^(7, 23, 24).
11 Furthermore, Bollig et al. found that the majority of residents without dementia had not
12 been engaged in ACP at all ⁽²⁵⁾. In the current study, these residents were more likely to
13 have ACP initiation at NH admission or not at all. Various explanations for not initiating
14 ACP in NH residents are possible: residents were unwilling to discuss their preferences or
15 rejected ACP, existing pre-admission arrangements for end-of-life care (e.g. ADs) may
16 need no further discussion, residents trust their relatives and NH staff to make important
17 decisions for them, in their best interest, residents were unaware of the possibility to
18 discuss their preferences for future care, or ACP was not embedded in routine care ⁽²⁴⁻²⁷⁾.
19 Research has demonstrated that lack of knowledge of ACP is an important barrier to
20 engage in or successfully implement ACP. Informing residents and their family about ACP
21 and the ACP policy within the NH is crucial for residents to be able to share their
22 preferences for future care adequately ⁽²⁴⁾. Probably, the minority for whom ACP was

1 initiated at NH admission, were more aware of the possibilities of ACP. Consistent with the
2 findings of Harrison et al., physical health was not associated with ACP initiation in this
3 study⁽²³⁾. Thus, physical decline or illness cannot explain ACP initiation at admission. This
4 supports the previous assumption of an increased awareness. However, physical decline as
5 self-reported reason for admission was associated with ACP initiation at admission. This
6 finding suggests a possible importance of subjective recognition of physical decline to ACP
7 initiation.

8 For most residents with dementia, ACP was initiated later than three months after
9 admission. Earlier studies confirm that residents are less likely to participate in ACP if they
10 have cognitive impairment⁽²³⁾. This 'delayed' initiation can be explained by difficulties in
11 determining the optimal timing of ACP due to prognostic uncertainty, or unwillingness to
12 participate in ACP because the resident is in denial of his diagnosis or he does not feel the
13 urge to discuss his preferences for future care⁽²⁸⁾. When this resident loses his decision-
14 making capacity, end-of-life decisions will have to be made by a family member or proxy
15 decision maker. In this context, it is vital that preferences are known and residents are
16 engaged in ACP before their health deteriorates and/or the first signs of dementia appear
17 ⁽¹²⁾.

18 *Medication use:* Concordant with earlier studies, we found a significant increase in
19 the use of analgesics, which are considered to be always appropriate at the end-of-life⁽²⁹⁾,
20 ³⁰⁾. This increasing use of analgesics was associated with ACP initiation, which might
21 indicate an increased attention for pain treatment. This finding has not yet been described in
22 literature, and thus creates opportunities for further research. In accordance with Morin et
23 al., we found a decrease in the use of lipid modifying agents, which might indicate a

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4 1 practice of deprescribing⁽²⁹⁾. However, this decrease was not associated with ACP
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6 2 initiation.
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11 4 ***Implication for practice / research***

13 5 This study highlights the necessity of an early onset of ACP in NH residents, and
14 6 particularly in those with dementia. The low prevalence of ACP initiation at every
15 7 measuring point implicates that ACP is not embedded into routine care yet. The recently
16 8 developed consensus definition of ACP and recommendations for its application⁽⁵⁾ may be
17 9 an important impulse to register ACP in the nursing chart and to clarify which aspects of
18 10 ACP were discussed with the resident himself, his family, and/or the healthcare team.

21 11 Our findings regarding medication use may create an opportunity to discuss
22 12 adequate treatment of pain and other symptoms and deprescribing of ‘futile’ medications at
23 13 the end of life. Further research is necessary to confirm the association between ACP and
24 14 an increasing use of analgesics and to explore the influence of other mediating factors, such
25 15 as pain. ACP conversations may create opportunities to discuss adequate pain and other
26 16 symptom treatment and deprescribing at the end of life.

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33 21

1 References

1. Paque K, Goossens K, Elseviers M, Van Bogaert P, Dilles T. Autonomy and social functioning of recently admitted nursing home residents. *Aging Ment Health*. 2017;21(9):910-6.
2. Hogan DB, Maxwell CJ, Afilalo J, Arora RC, Bagshaw SM, Basran J, et al. A Scoping Review of Frailty and Acute Care in Middle-Aged and Older Individuals with Recommendations for Future Research. *Can Geriatr J*. 2017;20(1):22-37.
3. Marcucci M, Franchi C, Nobili A, Mannucci PM, Ardoino I. Defining Aging Phenotypes and Related Outcomes: Clues to Recognize Frailty in Hospitalized Older Patients. *J Gerontol A Biol Sci Med Sci*. 2017;72(3):395-402.
4. Mitchell G, Agnelli J, McGreevy J, Diamond M, Roble H, McShane E, et al. Palliative and end of life care for people living with dementia in care homes: part 1. *Nurs Stand*. 2016;30(43):54-63.
5. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol*. 2017;18(9):e543-e51.
6. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med*. 2014;28(8):1000-25.
7. Martin RS, Hayes B, Gregorevic K, Lim WK. The Effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review. *J Am Med Dir Assoc*. 2016;17(4):284-93.
8. Nakashima T, Young Y, Hsu WH. Are Hospital/ED Transfers Less Likely Among Nursing Home Residents With Do-Not-Hospitalize Orders? *J Am Med Dir Assoc*. 2017;18(5):438-41.
9. Weathers E, O'Caomh R, Cornally N, Fitzgerald C, Kearns T, Coffey A, et al. Advance care planning: A systematic review of randomised controlled trials conducted with older adults. *Maturitas*. 2016;91:101-9.
10. De Gendt C, Bilsen J, Stichele RV, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *J Pain Symptom Manage*. 2013;45(2):223-34.
11. Vandervoort A, Houttekier D, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. 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(2):245-56.
12. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. *PLoS One*. 2014;9(3):e91130.
13. Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *Int Psychogeriatr*. 2012;24(7):1133-43.
14. Johnson VM, Teno JM, Bourbonniere M, Mor V. Palliative care needs of cancer patients in U.S. nursing homes. *Journal of palliative medicine*. 2005;8(2):273-9.
15. Tjia J, Dharmawardene M, Givens JL. Advance Directives among Nursing Home Residents with Mild, Moderate, and Advanced Dementia. *J Palliat Med*. 2018;21(1):16-21.
16. Organization WH. World Health Organization definition of palliative care 2012 [Available from: <http://www.who.int/cancer/palliative/definition/en/>].
17. Paque K, Elseviers M, Vander Stichele R, Pardon K, Hjermsstad MJ, Kaasa S, et al. Changes in medication use in a cohort of patients with advanced cancer: The international multicentre

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2
3
4 1 prospective European Palliative Care Cancer Symptom study. *Palliative medicine*. 2018;32(4):775-
5 2 85.
6 3 18. Kutner JS, Blatchford PJ, Taylor DH, Jr., Ritchie CS, Bull JH, Fairclough DL, et al. Safety and
7 4 benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness: a
8 5 randomized clinical trial. *JAMA internal medicine*. 2015;175(5):691-700.
9 6 19. Todd A, Nazar H, Pearson H, Andrew L, Baker L, Husband A. Inappropriate prescribing in
10 7 patients accessing specialist palliative day care services. *International journal of clinical pharmacy*.
11 8 2014;36(3):535-43.
12 9 20. Ivanova I, Wauters M, Vander Stichele R, Christiaens T, De Wolf J, Dilles T, et al.
13 10 Medication use in a cohort of newly admitted nursing home residents in relation to evolving
14 11 physical and mental health. *Archives of gerontology and geriatrics*. 2018.
15 12 21. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. STUDIES OF ILLNESS IN THE AGED.
16 13 THE INDEX OF ADL: A STANDARDIZED MEASURE OF BIOLOGICAL AND PSYCHOSOCIAL FUNCTION.
17 14 *Jama*. 1963;185:914-9.
18 15 22. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading
19 16 the cognitive state of patients for the clinician. *Journal of psychiatric research*. 1975;12(3):189-98.
20 17 23. Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low Completion and Disparities in
21 18 Advance Care Planning Activities Among Older Medicare Beneficiaries. *JAMA internal medicine*.
22 19 2016;176(12):1872-5.
23 20 24. Gilissen J, Pivodic L, Gastmans C, Vander Stichele R, Deliens L, Breuer E, et al. How to
24 21 achieve the desired outcomes of advance care planning in nursing homes: a theory of change.
25 22 *BMC geriatrics*. 2018;18(1):47.
26 23 25. Bollig G, Gjengedal E, Rosland JH. They know!-Do they? A qualitative study of residents
27 24 and relatives views on advance care planning, end-of-life care, and decision-making in nursing
28 25 homes. *Palliat Med*. 2016;30(5):456-70.
29 26 26. Gilissen J, Pivodic L, Smets T, Gastmans C, Vander Stichele R, Deliens L, et al. Preconditions
30 27 for successful advance care planning in nursing homes: A systematic review. *International journal*
31 28 *of nursing studies*. 2017;66:47-59.
32 29 27. Gjerberg E, Lillemoen L, Forde R, Pedersen R. End-of-life care communications and shared
33 30 decision-making in Norwegian nursing homes--experiences and perspectives of patients and
34 31 relatives. *BMC geriatrics*. 2015;15:103.
35 32 28. Tilburgs B, Vernooij-Dassen M, Koopmans R, van Gennip H, Engels Y, Perry M. Barriers and
36 33 facilitators for GPs in dementia advance care planning: A systematic integrative review. *PloS one*.
37 34 2018;13(6):e0198535.
38 35 29. Morin L, Vetrano DL, Rizzuto D, Calderon-Larranaga A, Fastbom J, Johnell K. Choosing
39 36 Wisely? Measuring the Burden of Medications in Older Adults near the End of Life: Nationwide,
40 37 Longitudinal Cohort Study. *The American journal of medicine*. 2017;130(8):927-36.e9.
41 38 30. Morin L, Laroche ML, Vetrano DL, Fastbom J, Johnell K. Adequate, questionable, and
42 39 inadequate drug prescribing for older adults at the end of life: a European expert consensus. *Eur J*
43 40 *Clin Pharmacol*. 2018.

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4 **1 Figure 1. ACP initiation in residents with and without dementia symptoms**
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6 ACP was initiated at admission for 23% of residents without dementia symptoms compared
7 to 16% in those with dementia symptoms. In year 1 and 2 the proportion of residents with
8 dementia symptoms for whom ACP was initiated was resp. 38% and 64%, compared to
9 resp. 34% and 53% in those without dementia symptoms. These findings indicate that the
10 proportion of residents with dementia symptoms for whom ACP was initiated at admission
11 was lower than for those without dementia. In year 1 and 2 the proportion of residents with
12 dementia symptoms exceeded the proportion of residents without dementia symptoms and
13 increased stronger.
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1 **Figure 2. Evolution of the use of analgesics between admission and year2 in the 3**
2 **groups of ACP initiation**

3 Analgesic use increased significantly in the group of residents for whom ACP initiation
4 was delayed to year 1 or year 2.

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For Peer Review

- 1 **Supplementary File S.I. Validated measuring tools and cut off used in this study**
- 2 More information on the topic, subtopics, cut off and range of the validated measuring tools
- 3 used in this study.
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For Peer Review

Table 1. Socio-demographic characteristics of the baseline population

Characteristics of the baseline population	All
	n=741
Age in years mean (range)	83.94 (65-105)
Gender % (n):	
female	65.7 (486)
male	34.3 (254)
Most important reason for admission[†] % (n):	
physical decline	64.4 (415)
increased care needs	57.4 (372)
cognitive decline	36.2 (234)
increased caregiver burden	16.0 (102)
(risk of) social isolation	10.6 (68)
explicit wish of the resident	10.6 (68)
partner deceased	3.8 (24)
increasing need for palliative care	1.3 (8)
Living situation before admission % (n):	n=641
alone	61.6 (394)
with partner and children	31.2 (231)
other	7.2 (16)
Highest education % (n):	n=637
no education	4.9 (32)
primary school	18.9 (119)

low secondary	44.3 (283)
high secondary	22.7 (143)
higher - university	9.2 (60)
Stay before admission % (n):	
hospital	43.7 (318)
at home	21.9 (159)
other	34.5 (250)
Katz ADL mean (SD) (6-24)	14.69 (4.507)
Dementia symptoms[‡] % (n)	34.0 (251)

[†] according to the resident or his proxy decision maker in case of dementia, more than one answer possible

[‡] based on MMSE-score (cut-off < 16), ability to respond to the questionnaire, and the combination of the KATZ scores for disorientation in time and place (≥ 6 on 8 points)

Table 2. ACP initiated at NH admission and its associated characteristics

ACP initiated at NH admission	No n=573	ACP n=168	p-value*	Univariate OR(95%CI)	Multivariate OR(95%CI)
MMSE (mean)	18.03	19.82	0.017	1.034(1.008-1.060)	1.035(1.007-1.064)
Reason for admission: physical decline (%)	60.8	75.5	0.001	1.986(1.315-2.999)	1.776(1.149-2.744)
Age (mean)	83.79	84.48	0.239	1.016(0.989-1.043)	
Gender: female	67.1	60.7	0.123	0.757(0.530-1.080)	
Living alone before admission (%)	51.3	59.5	0.061	1.396(0.985-1.978)	
Dementia symptoms (%)	35.5	30.1	0.198	0.783(0.539-1.137)	
Education: >= high college (%)	29.3	32.9	0.413	1.182(0.792-1.765)	
KATZ-ADL (mean)	15.67	15.45	0.593	0.990(0.953-1.028)	
Survival time in months (mean)	19.52	18.58	0.265	0.989(0.971-1.008)	
Total number of medications (mean)	8.92	9.11	0.565	1.013(0.969-1.059)	

*Nagelkerke r^2 : 0.046 *Independent samples t-test for means, χ^2 for percentages
Multivariate controlled for age and female gender*

Table 3. ACP initiation, analgesics and lipid modifying agents at NH admission and its evolution to year1 and year2

n=323	at admission	year1	year2	p-value*
Patient driven ACP: resident expressed a wish or preference for future care [†] % (n)	20.3 (68)	36.4 (114)	56.0 (186)	<0.001
Physician driven ACP: written physician's order (GP orders) [‡] % (n)	10.6 (33)	33.7 (105)	53.0 (176)	<0.001
ACP (patient driven or physician driven) % (n)	22.3 (72)	36.2 (114)	56.1 (192)	<0.001
Initiation of ACP % (n):				
ACP initiation at NH admission	22.3 (72)	22.3 (72)	22.3 (72)	
ACP initiation during year1 [§]	/	21.4 (69)	21.4 (69)	
ACP initiation during year2 [§]	/	/	18.6 (60)	
ACP not initiated	77.7 (251)	56.3 (182)	37.8 (122)	
Analgesics (N02^f) % (n)	34.2 (117)	NA	41.8 (143)	0.001
Lipid modifying agents (C10^f) % (n)	27.8 (95)	NA	21.1 (72)	0.009

*McNemar for paired comparison of proportions in two groups, Cochran's Q in three groups

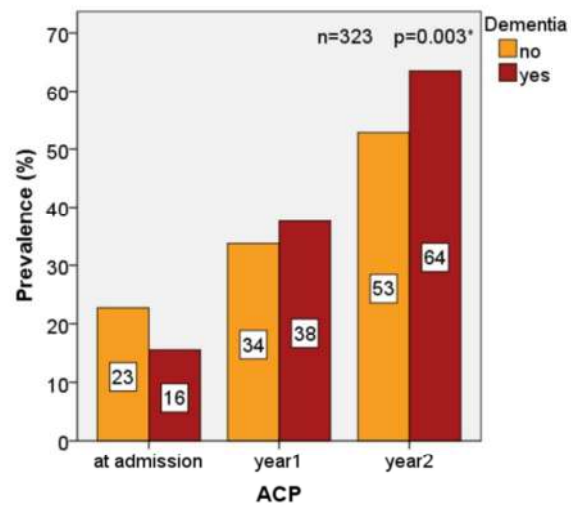
NA = Not available

[†]Based on the following question which was to be answered by the responsible nurse: "Did the resident express an explicit wish or preference for future care?"

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3 ‡ Based on the following question which was to be answered by the responsible nurse: "Did the GP
4 write down orders for future treatment in the medical file?"
5 § collated to one category 'delayed ACP initiation' for further analyses
6 ¶ ATC codes: N02 analgesics, C10 lipid modifying agents
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For Peer Review

Figure 1. **Timing of ACP initiation in residents with and without dementia symptoms**

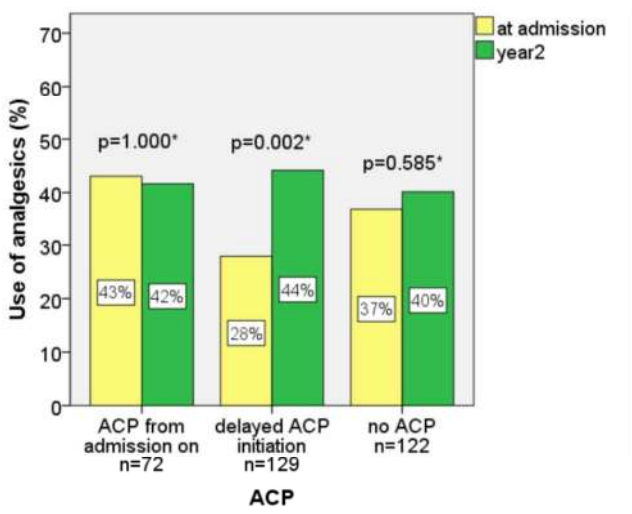


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Figure 2. Evolution of the use of analgesics between admission and year2 in the 3 groups of ACP initiation



*McNemar

Figure 2

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