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Home Residents on Hospital Use in the Last Month of Life and on Place of
Death: A Secondary Analysis of a Multicountry Cluster Randomized
Control Trial

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Lack of effect of a multicomponent palliative care program for nursing home residents on hospital use in the last month of life and on place of death: a secondary analysis of a multicountry cluster randomised control trial.

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Running title: Effect of PACE steps to Success on hospital use in last week of life.

Keywords: Palliative care, nursing homes, hospital use, RCT, end-of-life care

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Summary: Palliative care training programmes that aim to implement a general non-specialist palliative care approach, should be more specifically tailored to meet the goals of reducing hospitalizations at the end of life.

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Lack of effect of a multicomponent palliative care program for nursing home residents on hospital use in the last month of life and on place of death: a secondary analysis of a multicountry cluster randomised control trial.

ABSTRACT

Objectives

'PACE Steps to Success' is a one-year train-the-trainer programme aiming to integrate non-specialist palliative care into nursing homes via staff education and organizational support. In this study aimed to explore whether this programme resulted in changes in residents' hospital use and place of death.

Design

Secondary analysis of the PACE cluster randomized controlled trial (ISRCTN14741671). Data were collected on deaths over the previous four months via questionnaires at baseline and post-intervention.

Setting and Participants

Questionnaires were completed by nurse/care-assistant most involved from 78 nursing homes in seven EU countries.

Measures

We measured number of emergency room visits, hospital admissions, length of hospital stay and place of death. Baseline and post-intervention scores between intervention and control groups were compared and we conducted exploratory mixed-model analyses. We collected 551/610 questionnaires at baseline and 984/1,178 post-intervention in 37 intervention and 36 control homes.

Results

We found no statistical significant effects of the programme on emergency room visits (OR=1.38, p=0.32), hospital admissions (OR=0.98, p=0.93), length of hospital stay (geometric mean difference=.85, p=0.44) or place of death (OR=1.08, p=0.80).

Conclusions and Implications

We found no effect of the PACE programme on either hospital use in the last month of life or place of death. Although this may be related to implementation problems in some homes, the programme might also require a more specific focus on managing acute end-of-life situations

and a closer involvement of general practitioners or specialist palliative care services to influence hospital use or place of death.

Keywords: Palliative care, nursing homes, hospital use, RCT, end-of-life care

Introduction

The PACE Steps to Success programme is a one-year train-the-trainer palliative care programme for nursing homes¹⁻² which aims to implement a general non-specialist palliative care approach in six steps over a 12-month period using a train-the-trainer approach. It aims to train staff to deliver high-quality end-of-life care in the nursing home, starting from advance care planning until the delivery of high-quality care in the last days of life and after death.

To evaluate its effectiveness we conducted a cluster randomized controlled trial in seven EU countries³. While we did not find an effect on the primary outcome, resident comfort in last week of life measured by staff, the programme was promising regarding the secondary outcome, the resident quality of care in the last month of life using the QoD-LTC scale (baseline-adjusted mean difference on a scale of 11 to 55, 3.40; 95%Cl, 2.01-4.80; P < .001) ^{3,4}. The change was most apparent in the subscale 'preparatory tasks' (baseline-adjusted mean difference, 6.77; 95% Cl, 4.19-9.36;P < .001), containing items such as 'resident appeared to be at peace', 'resident indicated being prepared to die'³. From the process evaluation of the trial⁵ we learned that implementation was highly variable across nursing homes and countries, but the training for 'advance care planning' (first step of the programme), appeared to have reached most staff.

Based on this knowledge, we aimed to explore further whether the PACE programme had an effect on place of death and hospital use at the end of life in a secondary analysis. While avoiding hospitalizations in not a delineated step in the PACE training programme, the topic is addressed as part of the intervention, and particularly in the first step where advance care planning is discussed including preferences for place of care and death, and in the fifth step focusing on organizing care in the last days of life in the nursing home. Place of death is also an important quality indicator of end-of-life care and although sometimes needed, hospitalization of older patients with complex care needs comes with a number of drawbacks and should thus be avoided as much as possible 6-7-8-9. We hypothesized that the improvement in quality of care in the last month of life and staff training regarding advance care planning and care in the last days of life could have impacted hospital use and place of death.

The research questions of this secondary analysis are:

(1) does the 'PACE Steps to Success' programme have an effect on hospital use in the last month of life of nursing home residents in terms of numbers of emergency room visits, hospital admissions and length of stay following admission

(2) does the programme have an effect on the place of death of nursing home residents?

Methods

Study design

To compare the PACE Steps to Success Programme with usual care, a clustered randomized controlled trial (2015-2017) was conducted in 78 nursing homes in Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland ². We randomized at the level of the nursing home instead of at the individual level because the programme involved the training of nurses and care assistants in each nursing home. The trial was registered on July 30th, 2015 at www.isrctn.com — ISRCTN14741671 (FP7-HEALTH-2013-INNOVATION-1 603111). Central randomization was blinded and stratified by country and median number of beds in a 1:1 ratio; in each country, all participating nursing homes were categorized into two groups based on the median number of beds. Then, half were assigned to the control group (usual care) and half to the intervention group (PACE programme). Blinding of treatment allocation was not possible for participants or researchers collecting data because of the nature of the study.

More details about the study design and protocol have been published^{3,2}.

PACE Steps to Success Programme

The six steps of the PACE programme (Table 1) include (1) advance care planning with residents and family via discussions about current and future care, (2) care planning, assessment, and review of needs and problems via change-mapping charts, (3) coordination of care via monthly multidisciplinary review meetings, (4) high-quality care delivery focusing on pain and depression via assessment and management charts, (5) care in the last days of life using a checklist, and (6) after-death care via reflective debriefing sessions for staff¹⁰.

Participating nursing homes

Nursing homes in a predetermined region in each country were asked for participation via phone or e-mail. We assessed whether they were eligible based on specific inclusion and exclusion criteria. Nursing homes were included if they (1) provided nursing care and personal assistance with activities of daily living by staff on-site, and medical care by a general practitioner (GP) off-site; (2) had a minimum of 30 beds and 15 deaths in the past year; and (3)

the manager/director signed a written consent to participate (before randomization) and allowed up to six staff members to spend half a day per week as PACE coordinators. They were excluded if they (1) already contributed to the programme's pilot study; or (2) were already using palliative care guidelines or instruments or were certified users of the Gold Standards Framework¹¹ or InterRAI-PC¹². If a nursing home was excluded, did not reply or declined to participate, another was randomly chosen from the list until there were enough in each country.

Data collection

Each nursing home assigned one administrative contact person who identified all residents dying over the previous four months, and one staff member most involved in their care (nurse or care assistant). Baseline data (T0 at month 0) on the deceased residents were collected through after-death structured questionnaires. Post-intervention, at month 13 (T1) and month 17 (T2), analogous after-dead questionnaires were collected on residents dying during the previous four months. In those questionnaires, the nurse most involved in care and the home administrator provided data on the resident characteristics (age, gender, functional and cognitive status during last month of life, and presence of dementia at the time of death) and on hospital use outcomes. Resident records were used by staff if needed.

Outcomes and measurements

Questionnaires were forward-backward translated according to EORTC guidelines where official translations did not exist¹³. In the current paper, we focus on the variables related to hospital use in the last month of life and place of death, i.e. visits to the emergency room (ER), hospital admissions, the length of hospital stay if admitted, admission to the intensive care unit (ICU), total nights spent in the ICU, place of death and, if death occurred in hospital, the reason for the last admission. The presence of dementia was based on the estimation of either the nursing staff or the general practitioner. Functional and cognitive status during last month of life was calculated usinf the Bedford Alzheimer Nursing Severity Scale (BANS-S). Scores on BANS-S range from 7 to 28 and higher scores indicate greater severity.

Statistical analysis

These secondary analyses in the current study were post hoc, i.e. not planned prior to the start of the trial. A non-response analysis regarding the main demographic characteristics of the residents (age, gender, length of stay) was performed to examine missingness in the data. Exploratory descriptive analyses of the hospital use data and place of death were conducted by comparing baseline scores between control and intervention groups in SPSS24 without adjusting for clustering. In R (RStudio Version 1.2.1335)¹⁴, generalized linear mixed models with three random intercepts were fitted to account for clustering within staff member, nursing home, and country. Because of concerns for overfitting, we only considered those outcomes (ER visits, hospital admissions, length of hospital stay, death in hospital) with at least 30 respondents for the mixed model analysis. For the binary outcomes, a binomial distribution with logit link was specified. For length of hospital stay, a linear distribution with identity link was specified and the natural logarithm of length of hospital stay was used as outcome. Then, the adjusted estimated geometric mean difference in length of stay was calculated. Geometric mean multiplies values, whereas arithmetic mean uses their sum, and then splits them up by taking the root. Results were transformed back to the original scale by taking the exponential. Geometric mean is better in managing outliers than median or arithmetic mean. The fixed part of all models contained group (intervention versus control), time (T1+T2 versus T0) and their two-way interaction. All hypothesis testing was two-sided with significance level of 0.05.

Ethical aspects

Consent to participate was obtained from the nursing home management before the randomization was performed. Written informed consent was obtained from all participating staff except for Poland and the Netherlands, where a separate informed consent is not needed for anonymous questionnaires. Ethics approval for the study was obtained from the relevant committees in all countries².

Results

We collected 551/610 (response rate: 90%) questionnaires from staff at baseline and 984/1,178 (response rate: 84%) post-intervention in 37 intervention and 36 control homes (Figure 1A in Appendix). Response rates per country are given in Table 2. For the demographic

characteristics, 604/613 (response rate: 99%) questionnaires were collected from nursing home administrators at baseline and 1,146/1,179 (response rate: 97%) at post-intervention.

Non-response analysis

A non-response analysis found no statistically significant differences regarding demographic characteristics of the residents (age, gender, length of stay; Table 1A in Appendix).

Resident characteristics at baseline

None of the resident characteristics differed significantly at baseline between the control group and the intervention group (Table 3). The mean age of residents at the time of death was comparable (85 in control group - 86 in intervention group). In both groups, most of the deceased residents were female (71% control - 61% intervention) and more than 70% had dementia at time of death (72% control - 70% intervention). The mean cognitive and functional status during last month of life was similar in both groups (20 in control group - 19 in intervention group).

Hospital use in the last month of life

ER visits in the last month of life decreased in the control group (17% baseline – 13% post intervention) and increased in the intervention group (16% baseline – 19% post-intervention), but with an increase in one-time visits (74% baseline – 83% post-intervention) and a drop in multiple visits (26% baseline – 18% post-intervention) in the intervention group. The number of hospital admissions for more than 24 hours in the last month did not change in the control group (25% baseline and post-intervention), with a majority being admitted once (78% baseline – 84% post-intervention). The number of admissions increased with 3% in the intervention group (24% baseline – 27% post-intervention) mostly for just a one-time admission (86% baseline – 80% post-intervention). The mean length of stay in the hospital remained seven days on average in the control group and shortened from ten days (baseline) to seven days (post-intervention) in the intervention group. Of those who were hospitalized, the number of residents admitted to the ICU in the last month of life increased with 5% (8% baseline – 13% post-intervention). The number of admitted residents in the intervention group however

dropped strongly (21% baseline - 11% post-intervention). Because of low numbers of cases the significance of this difference could not be tested. In both groups, the mean length of stay in the ICU remained nearly stable (four days baseline - five days post-intervention).

The mixed models showed no statistically significant effects of the PACE programme on one of the three hospital use variables (Table 4): ER visits (p=0.32), hospital admissions (p=0.93), length of hospital stay (p=0.44). In our sample, the geometric mean difference in length of stay before versus after implementation of the programme was 15% lower in the control group than in the intervention group. This means that the decline in length of stay post-intervention was 15% larger in the intervention group. However, this estimated difference varies extensively and was not statistically significant in the multilevel analyses (95% confidence interval ranges from 47% lower to 31% higher difference in control group; p=0.44).

Place of death

The number of residents that died in hospital decreased in the control group (18% baseline – 14% post-intervention) and almost remained the same in the intervention group (17% baseline – 18% intervention). For residents who died in hospital, the reason for the last hospital admission was most often 'sudden onset or exacerbation of symptoms' or 'due to a life-threatening situation' (control group: 82% baseline – 71% post-intervention; intervention group: 71% baseline – 69% post-intervention). Other reasons were for a specific treatment (control group: 13% baseline – 21% post-intervention; intervention group: 12% baseline – 10% post-intervention) or a specific diagnostic evaluation to make further decisions (control group: 5% baseline – 12% post-intervention; intervention group: 12% baseline – 14% post-intervention). In the mixed model analyses, no statistically significant effects of the PACE programme on place of death were found (Table 4; p=0.80).

Discussion

We found no statistically significant effect of the PACE Steps to Success programme on emergency room visits, hospital admissions, length of hospital stay in the last month of life, or place of death. We did observe a shorter mean length of stay post-intervention; however, this was not statistically significant.

To the authors' knowledge, this is the first study to explore the effectiveness of a nursing home-based multicomponent palliative care programme on hospital use in the last month of life on such a large scale. The strengths of this study include the high-quality research design, the high response rates at all times of measurement, and the fact that non-response analysis shows minimal indication of bias.

Contrary to our hypothesis, this secondary analysis did not find a statistically significant effect of the PACE programme on nursing home residents' hospital use in the last month of life or on their place of death. Several reasons might explain this. Overall, programmes aiming to implement a general non-specialist palliative care approach such as this one might not be sufficient to improve specific outcomes like hospitalizations at the end of life or place of death. An earlier review investigating the effectiveness of staff interventions to improve resident outcomes in nursing homes highlighted that studies targeting specific care tasks were more likely to produce positive outcomes than those requiring global practice changes¹⁵. While the PACE training programme did include several components² such as 'care in the last days of life' (step 5) or 'advance care planning' aiming to prepare for future care (step 1) that were found to be related to end-of-life hospitalizations in earlier research, these might not have been focused or targeted enough on preventing unnecessary hospitalizations themselves^{16,17,18}. Additionally, several other important elements might have been missed as there were no specific steps explicitly targeting hospitalizations at the end of life.

More specifically, the PACE training programme did not include specific clinical or pharmacological guidelines on treatment of dying symptoms (for staff or GPs), nor did it focus on when to involve GPs and specialist palliative care services. Yet, we did find that for residents who ultimately died in hospital, staff indicated a sudden onset or exacerbation of symptoms or a life-threatening situation as the main reason for the hospital admission. As nursing home staff and GPs play an important role in end-of-life decision-making in nursing homes (we only included nursing homes with an offsite GP), they might not have been sufficiently qualified to address such end-of-life situations or even available. For complex cases, the involvement of specialist palliative care services might also be essential, and the PACE programme was not focused on including these. A previous trial in US nursing homes 19 also suggested that reducing end-of-life hospitalizations is more achievable when there are permanent palliative care teams,

well-integrated advanced practice nurses who offer clinical support to other staff, and good teamwork, communication and organizational readiness.

Although family was highlighted as an important stakeholder in the PACE programme (particularly in step 1 and 5), they might be not targeted well or systematically enough in the PACE programme to reach effect on end-of-life hospitalizations. A recent qualitative study conducted in US nursing homes compared those with high and low hospitalization rates²⁰. Staff at high-hospitalizing facilities were more likely to leave complex choices about hospitalization to families while those at low-hospitalizing facilities were more convinced that certain residents should not be hospitalized and felt responsible for helping residents and families come to the same conclusion (following an 'enhanced autonomy model'). Other research also showed that as acute medical problems emerge in nursing homes, the family often requests hospitalization, whether or not in consultation with nursing home staff^{21,22}. This decision is mainly made out of fear of imminent death, in case of an acute medical condition the acute hospital setting is seen as a safe place by the family^{13,21,22}. Hence, involving family early on, as part of the advance care planning process, and educating staff as well as family on the benefits and burdens of hospitalizations at the end of life will be important elements to consider in future interventions.

As well as reasons related to the PACE intervention itself, implementation problems might also partly explain the lack of effects found in this secondary analysis. The process evaluation showed that the implementation of the programme was feasible in all types of nursing homes, but also very challenging, and highly variable between countries and nursing homes⁵. The implementation rating consisted of two components: fidelity (score between 0 and 8 for the number, order and timing of delivered steps) and the staff's appreciation of the programme and the trainers' competences (score between 0 and 8). The fidelity scores for all homes were computed via country trainers' diary notes and were high in most countries, ranging between 5 and 8. The appreciation score, which was measured with staff evaluation questionnaires, ranged between 3.2 and 7.8. Combining both scores resulted in 64.9% of the homes with a medium implementation rating, 29.7% of homes with a high implementation rating and 5.4% with a low implementation rating. Finally, the nursing home is a very complex context and sustainably changing practice can therefore be very difficult. Characteristics of the intervention itself, as well as of the individuals involved and the contextual factors shaping the nursing home

are all important categories influencing the implementation, regardless of its specific target or focus. More details on the implementation of the programme are published in the process evaluation⁵.

Limitations

Our research also has limitations. Firstly, due to the retrospective nature of the study, recall bias is possible, even though staff could always use the resident's file when filling in the questionnaire. Secondly, mixed model analyses were not possible for the admission to and total nights in the ICU because the minimum level of respondents (n=30) was not reached for these variables. Thirdly, we did not ask for clinical details of all hospitalizations but only the main reason for the last hospitalization of those who died in hospital, nor did we question relatives on hospitalization in the last month. Finally, the exploratory analyses in this study were secondary post hoc analyses so caution is required when interpreting the findings. The study was originally not powered to detect differences in hospitalization rates.

Conclusions and Implications

This secondary analysis found that the PACE Steps to Success Programme did not affect hospital use in the last month of life or place of death. Reasons for this might be the complexity of the implementation of palliative care in nursing homes as well as the specific components of the intervention itself. Future research could investigate whether a targeted multicomponent intervention specifically aimed at reducing unnecessary end-of-life hospitalisations, which takes into account the whole nursing home context, focuses on residents and family, and includes staff education as well as involvement of GPs and specialist palliative care services to improve end-of-life symptom management, could lead to more success.

Conflicts of interest

The authors declare that they have no competing interests.

References

- 1. Payne S, Froggatt K, Hockley J, Sowerby E, Collingridge-Moore D, Kylänen M. PACE Steps to Success Programme: Information Pack. 2018. https://www.eapcnet.eu/research/european-union-funded-projects/pace.
- 2. Smets T, Onwuteaka-Philipsen BBD, Miranda R, et al. Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the "PACE Steps to Success" intervention in seven countries. *BMC Palliat Care*. 2018;17(1):47. doi:10.1186/s12904-018-0297-1
- 3. Van den Block L, Honinx E, Pivodic L, et al. Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries: The PACE Cluster-Randomized Clinical Trial. *JAMA Intern Med*. November 2019:1-10. doi:10.1001/jamainternmed.2019.5349
- 4. Munn JC, Zimmerman S, Hanson LC, et al. Measuring the quality of dying in long-term care. *J Am Geriatr Soc.* 2007;55(9):1371-1379. doi:10.1111/j.1532-5415.2007.01293.x
- 5. Oosterveld-Vlug M, Onwuteaka-Philipsen B, ten Koppel M, et al. Evaluating the implementation of the PACE Steps to Success Programme in long-term care facilities in seven countries according to the RE-AIM framework. *Implement Sci IS*. 2019;14. doi:10.1186/s13012-019-0953-8
- 6. Pivodic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*. 2016;70(1):17-24. doi:10.1136/jech-2014-205365
- 7. Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, Deliens L. Implementing the care programme for the last days of life in an acute geriatric hospital ward: a phase 2 mixed method study. *BMC Palliat Care*. 2016;15(1):27. doi:10.1186/s12904-016-0102-y
- 8. Pivodic L, Pardon K, Miccinesi G, et al. Hospitalisations at the end of life in four European countries: a population-based study via epidemiological surveillance networks. *J Epidemiol Community Health*. 2016;70(5):430-436. doi:10.1136/jech-2015-206073
- 9. Van den Block L, Ko W, Miccinesi G, et al. Final transitions to place of death: patients and families wishes. *J Public Health*. 2017;39(4):e302-e311. doi:10.1093/pubmed/fdw097
- 10. Hockley J, Froggatt K, Van den Block L, et al. A framework for cross-cultural development and implementation of complex interventions to improve palliative care in nursing homes: the PACE steps to success programme. *BMC Health Serv Res.* 2019;19(1):745. doi:10.1186/s12913-019-4587-y
- 11. Badger F, Plumridge G, Hewison A, Shaw KL, Thomas K, Clifford C. An evaluation of the impact of the Gold Standards Framework on collaboration in end-of-life care in nursing homes. A qualitative and quantitative evaluation. *Int J Nurs Stud.* 2012;49(5):586-595. doi:10.1016/j.ijnurstu.2011.10.021
- 12. Steel K, Ljunggren G, Topinková E, et al. The RAI-PC: an assessment instrument for palliative care in all settings. *Am J Hosp Palliat Care*. 2003;20(3):211-219. doi:10.1177/104990910302000311
- 13. Dewolf L, Koller M, Velikova G, et al. EORTC Quality of Life Group translation procedure. March 2009. https://abdn.pure.elsevier.com/en/publications/eortc-quality-of-life-group-translation-procedure. Accessed February 4, 2019.
- 14. RStudio Team. *RStudio: Integrated Development for R.* Boston, MA: RStudio Inc.; 2015. http://www.rstudio.com/.

- 15. Low L-F, Fletcher J, Goodenough B, et al. A Systematic Review of Interventions to Change Staff Care Practices in Order to Improve Resident Outcomes in Nursing Homes. *PLOS ONE*. 2015;10(11):e0140711. doi:10.1371/journal.pone.0140711
- 16. Graverholt B, Forsetlund L, Jamtvedt G. Reducing hospital admissions from nursing homes: a systematic review. *BMC Health Serv Res.* 2014;14:36. doi:10.1186/1472-6963-14-36
- 17. Wolters A. Emergency admissions to hospital from care homes: how often and what for? The Health Foundation. https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes. Published July 2019. Accessed October 1, 2019.
- 18. Tejwani V, Wu Y, Serrano S, Segura L, Bannon M, Qian Q. Issues surrounding end-of-life decision-making. *Patient Prefer Adherence*. 2013;7:771-775. doi:10.2147/PPA.S48135
- 19. Temkin-Greener H, Mukamel D, Ladd H, et al. Impact of Nursing Home Palliative Care Teams on End-of-Life Outcomes: A Randomized Controlled Trial. *Med Care*. 2018;56:1. doi:10.1097/MLR.000000000000035
- 20. Cohen AB, Knobf MT, Fried T. Avoiding Hospitalizations from Nursing Homes for Potentially Burdensome Care: What Helps Facilities Succeed? *JAMA Intern Med*. 2017;177(1):137-139. doi:10.1001/jamainternmed.2016.7128
- 21. Reyniers T, Houttekier D, Cohen J, Pasman HR, Deliens L. What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. *Palliat Med.* 2014;28. doi:10.1177/0269216314522317
- 22. Keeley MP. Family Communication at the End of Life. *Behav Sci.* 2017;7(3). doi:10.3390/bs7030045

Table 1: The six steps of the PACE Steps to Success Programme

| Step | Tool/material used | Description |
|---|--|---|
| Advance care planning (discussions) | 'Looking and Thinking Ahead' document | Advance care planning (ACP) discussions with residents and families are organized to acquire wishes and preferences around end-of-life care. |
| Care planning, assessment and review | 'Mapping Changes in Condition' chart | A 'Mapping Changes in Condition chart' is used monthly by nurses and care assistants to plot changes (deterioration and improvement) in a resident's physical condition. |
| 3. Coordination of care | Palliative Care Register with monthly multidisciplinary palliative care review meetings | Using a Palliative Care Register, residents who are expected to live less than six months are discussed in detail during monthly multidisciplinary review meetings. A summary sheet is sent to physicians who were not able to attend the meeting. |
| 4. High-quality care delivery | Pain Assessment and Management Tool including numerical pain scale or PAINAD in case of advanced dementia ² 'Geriatric Depression Scale' (short version) ³ or 'Cornell Depression Scale for people with dementia' ⁴ | Staff learn about symptom control and complex communication skills, with a focus on pain and depression. |
| 5. Care in the last days of life | Integrated care plan for the last days of life using the Last Days of Life checklist | The checklist stimulates and guides the care in the last days of life, with a focus on recognizing dying, communication with family, regular assessment of symptoms, anticipatory medication prescription, hydration, and psychosocial and spiritual support. |
| 6. After-death care | Monthly reflective de-briefings groups OCE Steps to Success Programme. It is describe | Reflective meetings following a death are held to support staff and encourage experiential learning. |

This table summarizes the PACE Steps to Success Programme. It is described in full elsewhere¹

Table 2. Response Rates per country

| | Staff* concerning deceased resident questionnaire | | | | | | |
|-----------------|---|-------------------|-----------------|-------------------|--|--|--|
| | | Control | Intervention | | | | |
| | T0 | T1 + T2 | T0 | T1+T2 | | | |
| Belgium | 95.6% (N=43/45) | 77.5% (N=86/111) | 97.4% (N=37/38) | 93.5% (N=100/107) | | | |
| England | 70.4% (N=57/81) | 84.7% (N=72/85) | 100% (N=51/51) | 66.2% (N=43/65) | | | |
| Finland | 94% (N=47/50) | 97% (N=102/105) | 89.2% (N=48/65) | 73.9% (N=99/134) | | | |
| Italy | 96.7% (N=59/61) | 88.4% (N=130/147) | 92.9% (N=52/56) | 88.8% (N=71/80) | | | |
| The Netherlands | 87.5% (N=28/32) | 70.4% (N=50/71) | 78.9% (N=15/19) | 51.5% (N=17/33) | | | |
| Poland | 87.9% (N=29/33) | 72.5% (N=37/51) | 100% (N=31/31) | 98.4% (N=62/63) | | | |
| Switzerland | 100% (N=26/26) | 87% (N=67/77) | 100% (N= 22/22) | 98% (N=48/49) | | | |

T0=baseline measurement at month 0; T1=month 13; T2= month 17; *staff= nurse or care assistant most involved in the resident's care.

Table 3. Resident and hospital use characteristics of deceased residents for whom an assessment by staff was made

| | Baseline | | Post-intervention (T1 + T2) | | |
|---|------------------------|------------------------|-----------------------------|------------------------|--|
| | Control | Intervention | Control | Intervention | |
| | (N = 272) | (N = 279) | (N = 558) | (N = 425) | |
| Resident characteristics | | | | | |
| Age at death, cluster-unadjusted mean (SD)* | 85.22 (9.13) | 85.68 (9.00) | 85.58 (8.81) | 85.91 (8.57) | |
| Gender (female), cluster-unadjusted frequency (count/n (%)) | 190/269 (70.6%) | 160/264 (60.6%) | 354/547 (64.7%) | 265/414 (64%) | |
| Functional status during last month of life (BANS-S), cluster-unadjusted mean (SD) † | 19.93 (4.31) ‡§ | 19.03 (4.90) ‡ | 18.95 (4.93) § | 18.75 (5.14) | |
| Dementia at time of death, cluster-unadjusted frequency (count/n (%)) | 188/262 (71.8%) | 194/276 (70.3%) | 399/556 (71.8%) | 278/416 (66.8%) | |
| Hospital use in the last month of life | Count (% or <i>M</i>) | Count (% or <i>M</i>) | Count (% or <i>M</i>) | Count (% or <i>M</i>) | |
| Did the resident visit the emergency room in the last month of life (for less than 24 hours)? (yes) | 43/259 (16,6%) | 42/264 (15,9%) | 71/533 (13.3%) | 72/385 (18.7%) | |
| How often did the resident visit the emergency room in the last month of life (for less than 24 hours)? | | | | | |
| Once | 36/43 (83.7%) | 31/42 (73.8%) | 51/71 (71.8%) | 60/72 (83.3%) | |
| Twice or more | 7/43 (16.3%) | 11/42 (26.2%) | 20/71 (28.2%) | 12/72 (16.7%) | |
| Was the resident admitted to the hospital in the last month of life for more than 24 hours? (yes) | 63/253 (24,9%) | 63/264 (23,9%) | 127/517 (24.6%) | 100/371 (27%) | |
| How often was the resident admitted to the hospital in the last month of life for more than 24 hours? | | | | | |
| Once | 49/63 (77.8%) | 54/63 (85.7%) | 106/127 (83.5%) | 80/100 (80%) | |
| Twice or more | 14/63 (22.2%) | 9/63 (14.3%) | 21/127 (16.5%) | 20/100 (20%) | |
| If admitted to hospital in last month of life, average length of stay in hospital in days, cluster-unadjusted mean^ | 7.29 (4.88) N = 48 | 9.56 (8.56) N = 52 | 7.31 (7.36) N = 95 | 7.08 (5.75) N = 71 | |
| Was the resident admitted to an ICU in the last month of life? (yes) | 4/49 (8,2%) | 11/52 (21.2%) | 12/96 (12.5%) | 8/72 (11.1%) | |
| If admitted to an ICU in the last month of life, average length of stay in the ICU in days? cluster-unadjusted mean`` | 4.25 (3.86) N = 4 | 4.91 (5.49) N = 11 | 4.08 (2.97) N = 12 | 4.63 (4.84) N = 8 | |
| Resident died in hospital | 46/263 (17.5%) | 45/269 (16.7%) | 75/551 (13.6%) | 72/405 (17.8%) | |
| If the resident died in hospital, what were the medical reasons for the last admission to the hospital? | | | | | |
| A specific diagnosis was required to take further decisions | 2/44 (4.5%) | 5/41 (12.2%) | 9/73 (12.3%) | 9/64 (14.1%) | |
| For specific treatment | 6/44 (13.3%) | 5/41 (12.2%) | 15/73 (20.5%) | 6/64 (9.4%) | |
| Sudden onset or exacerbation of symptoms or a life-threatening situation | 36/44 (81.8%) | 29/41 (70.7%) | 52/73 (71.2%) | 44/64 (68.8%) | |

Data are mean (SD) or n/N (%)

Abbreviations: SD (Standard Deviation), BANS-S (Bedford Alzheimer Nursing Severity Scale), ICU (Intensive Care Unit)

Table 4. Cluster-adjusted estimates of hospital use in the last month of life and place of death of residents of long-term care facilities, assessed by nurses.

| · · · · · · · · · · · · · · · · · · · | · | | G | | • | |
|--|-------------------------------|-------------------------------|------------------------------------|-------------------------------|-----------------------|---------------|
| | Baseline score (T0) | | Post-intervention score (T1+T2) | | OR (95% CI) | P interaction |
| | Control (n=272) | Intervention (n = 279) | Control (n = 558) | Intervention (n = 425) | _ | |
| | Probability (95% CI) | Probability (95% CI) | Probability (95% CI) | Probability (95% CI) | | |
| | Number of cases | Number of cases | Number of cases | Number of cases | | |
| Did the resident visit the emergency room in the last month of life? (yes) | 0.14 (0.10 – 0.21) N=43 | 0.13 (0.09 -0.20) N=42 | 0.11 (0.08 – 0.16) N=71 | 0.14 (0.10 – 0.20) N=72 | 1.38 (0.73 – 2.62) | .32 |
| Was the resident admitted to a hospital in the last month of life? (yes) | 0.24 (0.16 – 0.34) N=63 | 0.24 (0.16 – 0.34) N=62 | 0.25 (0.18 – 0.34) N=127 | 0.24 (0.17 – 0.34) N=99 | 0.98 (0.57 – 1.66) | .93 |

^{*}Missing data at baseline for 11 cases in intervention and 4 cases in control group. Data missing at post-intervention for 11 cases in intervention and 18 cases in control group.

[†]Missing data at baseline for 14 cases in intervention and 9 cases in control group. Data missing at post-intervention for 19 cases in intervention and 10 cases in control group.

[^]Missing data at baseline for 26 cases in intervention and 34 cases in control group. Data missing at post-intervention for 82 cases in intervention and 73 cases in control group.

[&]quot;Missing data at baseline for 26 cases in intervention and 33 cases in control group. Data missing at post-intervention for 72 cases in intervention and 96 cases in control group.

[‡] P value (adjusted) for the difference in functional status between control and intervention group at baseline: p=0.008; Functional status, mean (adjusted): 19.77 in control and 18.45 in intervention group.

[§] P value (adjusted) for the difference in functional status between control groups at baseline and post-intervention: p=0.008; Functional status, mean (adjusted): 19.77 in control at baseline and 18.87 in control group post-intervention.

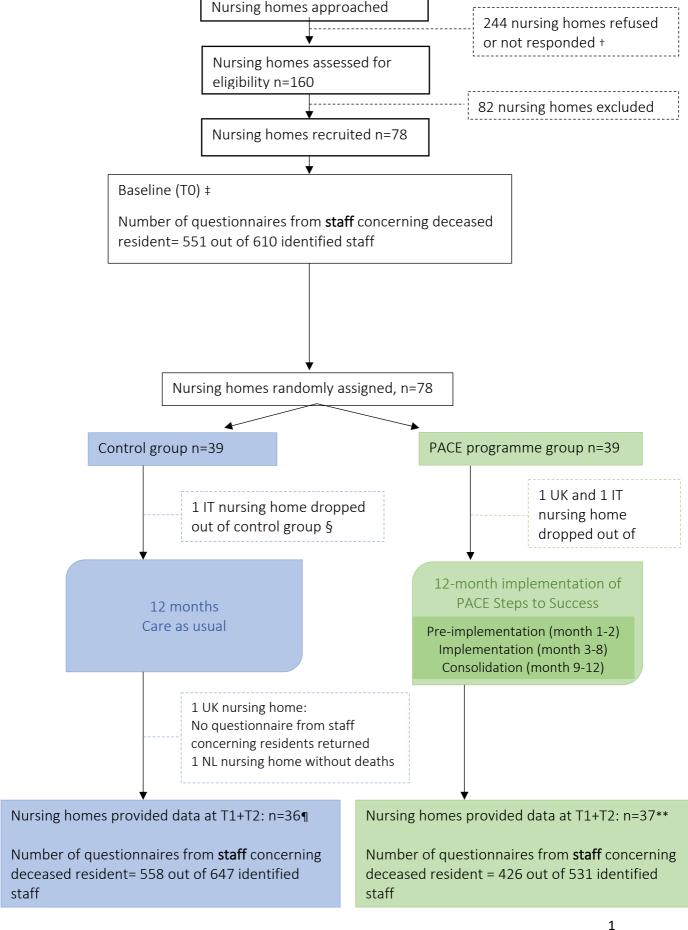
[°]Other includes: LTCF/hospice/Pall care unit/other

| Resident died in the hospital | 0.14 (0.08 – 0.23) N=46 | 0.16 (0.10 – 0.25) N=45 | 0.12 (0.07 – 0.18) N=75 | 0.14 (0.09 – 0.22) N=72 | 1.08 (0.58 – 2.02) | .80 |
|---|---|---|---|---|--|---------------|
| | Expected count (95% CI) Number of cases | Expected count (95% CI) Number of cases | Expected count (95% CI) Number of cases | Expected count (95% CI) Number of cases | Adjusted estimated geometric mean* difference (95% CI) | P interaction |
| If admitted to hospital in last month of life, average length of stay in hospital | 6 (4 – 8) N=49 | 7 (5 – 9) N=48 | 5 (4– 6) N=91 | 5 (4 – 7) N=73 | 0.85 (0.53 – 1.31) | .44 |

CI = Confidence interval; OR = Odds Ratio

Appendix

Figure 1A: Flowchart of recruitment, randomization and data collection at resident level*



- * The flowchart includes the number of clusters or nursing homes participating throughout the trial, in intervention and control group, and the number of deceased residents identified at baseline and post-intervention in both groups. T0=baseline measurement at month 0; T1=month 13; T2=month 17; Staff = nurse or care assistant most involved in care for that resident
- † Reasons for refusing included insufficient time, no interest, understaffing, already involved in other studies, change in management.
- ‡ We identified 617 deceased residents across nursing homes. For 7 residents, no staff member could be identified; for 120 residents.

Reasons for dropouts: § Reorganizing of the nursing home; || intervention was taking too much time.

- ¶ We identified 649 deceased residents in the control group. For 2 residents, no staff member could be identified; for 136.
- ** We identified 542 deceased residents in the intervention group. For 11 residents, no staff member could be identified; for 116.

IT = Italy, UK = United Kingdom, NL = the Netherlands

Table 1A. P-values for differences between response and non-response for nurses' assessments*.

| Table 17 to 1 values for t | | line (T0) | Post-intervention (T1+T2) | | |
|----------------------------|-----------------------------------|--------------|---------------------------|-------------------------|--|
| | Response (n=272) Response (n=279) | | Response (n=558) | Response (n=425) | |
| | Non-response | Non-response | Non-response | Non-response (n=114) | |
| | (n=35) | (n=31) | (n=91) | | |
| | Control | Intervention | Control | Intervention | |
| Mean age at time of death† | P= 0.906 | P= 0.963 | P=0.320 | P=0.957 | |
| Gender† | P=0.638 | P=0.811 | P=0.927 | P=0.539 | |
| Mean length of stay in | P=0.368 | P=0.585 | P= 0.528 | P=0.607 | |
| nursing home† | | | | | |

^{*}Difference between cases where questionnaires were and were not returned

Results of Pearson's Chi2 test

[†] reported by the nursing home administrator