

# Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries

## The PACE Cluster-Randomized Clinical Trial

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**IMPORTANCE** High-quality evidence on how to improve palliative care in nursing homes is lacking.

**OBJECTIVE** To investigate the effect of the Palliative Care for Older People (PACE) Steps to Success Program on resident and staff outcomes.

**DESIGN, SETTING, AND PARTICIPANTS** A cluster-randomized clinical trial (2015-2017) in 78 nursing homes in 7 countries comparing PACE Steps to Success Program (intervention) with usual care (control). Randomization was stratified by country and median number of beds in each country in a 1:1 ratio.

**INTERVENTIONS** The PACE Steps to Success Program is a multicomponent intervention to integrate basic nonspecialist palliative care in nursing homes. Using a train-the-trainer approach, an external trainer supports staff in nursing homes to introduce a palliative care approach over the course of 1 year following a 6-steps program. The steps are (1) advance care planning with residents and family, (2) assessment, care planning, and review of needs and problems, (3) coordination of care via monthly multidisciplinary review meetings, (4) delivery of high-quality care focusing on pain and depression, (5) care in the last days of life, and (6) care after death.

**MAIN OUTCOMES AND MEASURES** The primary resident outcome was comfort in the last week of life measured after death by staff using the End-of-Life in Dementia Scale Comfort Assessment While Dying (EOLD-CAD; range, 14-42). The primary staff outcome was knowledge of palliative care reported by staff using the Palliative Care Survey (PCS; range, 0-1).

**RESULTS** Concerning deceased residents, we collected 551 of 610 questionnaires from staff at baseline and 984 of 1178 postintervention in 37 intervention and 36 control homes. Mean (SD) age at time of death ranged between 85.22 (9.13) and 85.91 (8.57) years, and between 60.6% (160/264) and 70.6% (190/269) of residents were women across the different groups. Residents' comfort in the last week of life did not differ between intervention and control groups (baseline-adjusted mean difference, -0.55; 95% CI, -1.71 to 0.61;  $P = .35$ ). Concerning staff, we collected 2680 of 3638 questionnaires at baseline and 2437 of 3510 postintervention in 37 intervention and 38 control homes. Mean (SD) age of staff ranged between 42.3 (12.1) and 44.1 (11.7) years, and between 87.2% (1092/1253) and 89% (1224/1375) of staff were women across the different groups. Staff in the intervention group had statistically significantly better knowledge of palliative care than staff in the control group, but the clinical difference was minimal (baseline-adjusted mean difference, 0.04; 95% CI, 0.02-0.05;  $P < .001$ ). Data analyses began on April 20, 2018.

**CONCLUSIONS AND RELEVANCE** Residents' comfort in the last week of life did not improve after introducing the PACE Steps to Success Program. Improvements in staff knowledge of palliative care were clinically not important.

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In many countries more than 1 in 4 people die in a nursing home,<sup>1,2</sup> and this is expected to increase substantially in the future.<sup>3,4</sup> Research has consistently shown that the quality of end-of-life care and dying is suboptimal in many nursing homes. A considerable proportion of residents die with unrecognized, undertreated symptoms, and after multiple hospitalizations and/or burdensome life-prolonging treatments in the final months,<sup>3-9</sup> yet access to palliative care services is usually low,<sup>10,11</sup> as is staff palliative care knowledge.<sup>12</sup>

Although palliative care has been advocated as the preferred approach in nursing homes in many countries,<sup>3</sup> very few initiatives aimed at implementing it exist, and available evidence is weak. Previous studies have used existing data,<sup>13,14</sup> but, to our knowledge, no large scale clinical trials have been conducted. A 2011 Cochrane review<sup>7</sup> on outcomes of multicomponent palliative care interventions for nursing homes found only 2 randomized clinical trials (RCTs) and 1 before-after study, and highlighted the critical need for high-quality studies. A few trials focusing on evaluating single-component interventions<sup>15,16</sup> have been performed since, and 2 trials evaluating the impact of a multicomponent palliative care program found no effects.<sup>1,17</sup>

Current research<sup>18-21</sup> suggests that education alone is insufficient to change practice in nursing homes. Achieving effective change seems to require a whole-setting approach.<sup>18-21</sup> Based on these premises, the UK Six Steps to Success for Care Homes was developed<sup>22,23</sup> and adapted to the Palliative Care for Older People (PACE) Steps to Success Program for multi-country evaluation. It consists of a 1-year palliative care program for nursing homes, aimed at implementing a basic, non-specialist palliative care approach.

The research questions for this cluster-randomized clinical trial across nursing homes in 7 European countries were:

- Does the PACE Steps to Success Program have an effect on resident outcomes as reported by staff, including comfort in the last week of life (primary resident outcome), and quality of care in the last month of life (secondary resident outcome)?
- Does the program have an effect on staff outcomes, including knowledge of palliative care (primary staff outcome), self-efficacy, educational needs, and opinions on palliative care (secondary staff outcomes)?

## Methods

### Trial Design

We conducted the multifacility cluster-randomized clinical PACE trial (2015-2017) in Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland, to compare the PACE Steps to Success Program (intervention) with usual care (control). We randomized at the nursing home level (cluster) because the intervention involved the training of all staff in each nursing home.

There were no deviations from the methods in the protocol after trial commencement. We followed CONSORT guidelines for cluster trials to design and report the study registered at <http://www.isrctn.com> on July 30, 2015. The full

## Key Points

**Question** Is the Palliative Care for Older People (PACE) Steps to Success Program, a multicomponent intervention to integrate basic nonspecialist palliative care in nursing homes, effective in improving resident and staff outcomes?

**Findings** In a cluster-randomized clinical trial in 78 nursing homes in 7 countries evaluating data concerning 551 deceased residents at baseline and 984 postintervention, and data concerning 2680 staff at baseline and 2437 postintervention, comparing PACE Steps to Success with usual care, residents' comfort in the last week of life did not improve. Staff knowledge of palliative care improved, but the difference was very small.

**Meaning** The PACE Steps to Success Program was not effective in improving residents' comfort in the last week of life, nor in improving staff knowledge of palliative care to a clinically relevant degree.

protocol of this trial has previously been published and is available in [Supplement 1](#).<sup>24</sup> All persons filling in questionnaires gave their prior informed consent in writing. In Poland and the Netherlands, informed consent was not required because questionnaires were filled in anonymously. We obtained ethics approval from the relevant ethics committees in all countries<sup>24</sup> ([Supplement 1](#)).

### Participating Nursing Homes

Nursing homes were approached randomly from a list of all nursing homes in a predefined geographical location in each country by telephone or e-mail to inquire about interest in participating in the study, and to evaluate inclusion and exclusion criteria using a standardized checklist. If a nursing home did not respond, was excluded, or declined to participate, another from the list was randomly approached until a sufficient number agreed to participate in each country.

Inclusion criteria were as follows:

- On-site provision of nursing care and personal assistance with activities of daily living and off-site general physicians responsible for medical care.
- At least 30 beds and 15 or more residents dying in or outside the nursing home over the past year (to obtain sufficient power<sup>24</sup>).
- Consent of management for participation in writing before randomization and agreement to allocate time for staff to act as PACE coordinators for approximately 0.5 days per week.

Nursing homes were excluded if they:

- Already used detailed palliative care guidelines or planning tools, or were accredited users of the Gold Standards Framework<sup>23</sup> or InterRAI-PC.<sup>25</sup>
- Were involved in the pilot testing of the intervention materials preceding the trial.

### Randomization and Blinding

Randomization was done for each country separately. Randomization was stratified by country and median number of beds in a 1:1 ratio using a computer-generated random sequence; in each country all participating nursing homes were divided into 2 groups based on the median number of beds in

the country; half were randomized to the intervention group, half to the control group delivering care as usual. The randomization procedure was repeated per country if the number of beds was unbalanced, ie, if the difference in number of beds between the control and intervention groups was more than 15%. Randomization was blinded and performed by independent statisticians. Owing to the nature of the study, blinding of treatment was not possible for participants or researchers.

### Intervention

The PACE Steps to Success Program is a multicomponent intervention program to integrate basic nonspecialist palliative care in nursing homes. Using a train-the-trainer approach, an external trainer supports staff in the nursing homes to introduce a palliative care approach over the course of 1 year following a 6-steps program. The program has 3 phases, implemented over a 12-month period (2 months preparation, 6 months implementation of 6 steps, and 4 months consolidation with ongoing support where needed). The 6 steps are (1) advance care planning with residents and families; (2) assessment, care planning, and review of resident needs and problems; (3) coordination of care via monthly multidisciplinary palliative care review meetings; (4) high-quality care with a focus on pain and depression; (5) care in last days of life; and (6) care after death (eTable 1 in Supplement 2).<sup>24</sup>

Each country had PACE country trainers trained by experienced international trainers (J.H. and K.F.) during a 1-week international workshop and supported via monthly 1-hour online group-coaching sessions during the intervention period (J.H.). In each nursing home, between 1 and 6 staff members were identified as PACE coordinators and trained and supported to develop the knowledge and skills to train all nursing home staff via workshops, support and education alongside the country trainers who visited or made contact every 7 to 10 days. The materials were based on the Six Steps to Success for care homes developed in the UK from the Gold Standards Framework for Care Homes program.<sup>22,23</sup> They were translated from English into the relevant languages and cross-culturally adapted based on review meetings in several nursing homes per country.<sup>24</sup>

### Outcomes

#### Resident Outcomes

The primary resident outcome was comfort in the last week of life reported by staff using the End-of-Life in Dementia Scale Comfort Assessment while dying (EOLD-CAD).<sup>26</sup> The scale has 4 subscales: physical distress, dying symptoms, emotional distress, well-being. The minimal clinically important difference on the scale is 3 points.<sup>27</sup> Although the EOLD-CAD was originally developed and validated for people with dementia, it was recommended for use in mixed populations in nursing homes.<sup>28</sup> It has also been shown to be responsive to change in a recent cluster RCT in acute geriatric hospital wards.<sup>29</sup>

The secondary resident outcome was quality of care in the last month of life reported by staff using the Quality of Dying in Long Term Care (QOD-LTC). This scale comprises 3 subscales: personhood, preparatory tasks, and closure.<sup>30</sup>

We considered the use of staff to report primary and secondary resident outcome data as the best possible strategy in

this population and setting; self-report of residents would not be feasible for all, and would possibly introduce selection bias, staff would have had most contact with residents compared with relatives, and response rate (RR) from staff would be higher than from relatives.

Other resident measures were:

- Comfort in the last week of life reported by relatives using the EOLD-CAD.<sup>26</sup>
- Relatives' perception of the quality of end-of-life care, measured using End-of-Life in Dementia-Satisfaction with Care (EOLD-SWC).<sup>26</sup>
- Family Perception of Physician-Family Communication reported by relatives (FPPFC).<sup>31</sup>

#### Staff Outcomes

The primary staff outcome was knowledge of palliative care, measured using the Knowledge Construct of the Palliative Care Survey. The scale comprises 3 subscales: end-of-life factors (knowledge of common end-of-life issues); knowledge of physical factors that can contribute to physical pain; knowledge of psychological factors that can contribute to physical pain.<sup>12,32</sup> There is strong empirical and psychometric support for the instrument and evidence of adequate validity and reliability for use in nursing homes<sup>32</sup>; however, the minimal clinically important difference is unknown.

Secondary staff outcomes were (1) self-efficacy in communicating with residents and their families at the end of life (Self-Efficacy in End-of-Life Care Survey S-EOLC<sup>33</sup>), (2) self-perceived educational needs regarding communication and cultural and ethical values (End-of-Life Professional Caregiver Survey EPCS<sup>34</sup>), and (3) opinions on palliative care (Rotterdam Move2PC<sup>35</sup>).

Before trial commencement, we had listed several primary resident and staff outcomes (trial registered as ISRCTN14741671 at <http://www.isrctn.com>). From this list, the PACE consortium selected the herein mentioned outcomes as primary and secondary, thus after trial commencement but before the start of the analyses.

### Data Collection Procedure and Respondents

Each nursing home assigned 1 administrative contact person to the study who listed:

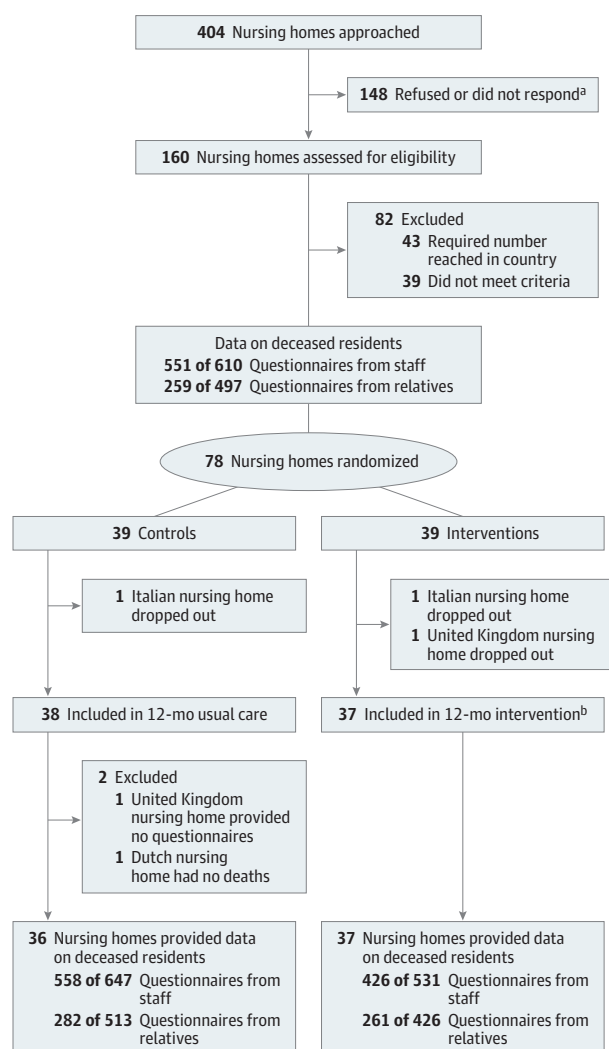
- All residents who had died over the previous 4 months, and 2 key respondents: (1) 1 staff member most involved in their care (preferably a nurse or care assistant), and (2) 1 closely involved relative (family or friend).
- All nurses and care assistants employed in the facility.

For deceased residents, baseline data were collected in all participating nursing homes (at month 0) through after-death structured questionnaires to the key respondents (staff member and relative) and to the administrator/manager. These questionnaires surveyed:

- Resident characteristics: age, sex, functional status using BANS-S<sup>36</sup> and presence of dementia.
- Primary, secondary, and other resident outcomes.

Postintervention (at month 13 and at month 17), the same data were collected on residents who had died during the previous 4 months.

**Figure. 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 the intervention and control groups, and the number of deceased residents identified at baseline and postintervention in both groups. Measurements taken at month 0 (baseline); month 13; and month 17. Staff included the nurse or care assistant most involved in care for that resident.

<sup>a</sup> Reasons for refusing included insufficient time, no interest, understaffing, already involved in other studies, change in management.

<sup>b</sup> Preimplementation (months 1-2), implementation (months 3-8), and consolidation (months 9-12).

For nurses and care assistants employed in the facility, baseline data were collected in all participating nursing homes (at month 0) through structured questionnaires surveying:

- Staff characteristics: age, sex, professional role (nurse or care assistant), whether formal palliative care training had been undertaken, and years of experience working in direct care.
- Primary and secondary staff outcomes.

Postintervention (at month 13), the same data were collected on nurses and care assistants employed in the facility at that time.

Staff and relatives who were asked to complete questionnaires were not informed about the outcome measures or study hypotheses.

### Statistical Analyses

We estimated that a sample of 144 patients for each group (corresponding to 36 nursing homes with 4 deceased residents per nursing home) would achieve 90.6% power to detect a difference in mean EOLD-CAD score of 3 points,<sup>27</sup> assuming a standard deviation of 5.61 points for each group, an intracluster correlation coefficient (ICC) of 0.3 and a significance level of 5%. This was increased to 288 patients per group (total sample size of 576) to allow for a 20% nonresponse of staff and a 50% nonresponse on relative questionnaires.<sup>24</sup>

For resident outcomes, the unit of analysis was a resident death; for staff outcomes, the unit of analysis was the staff member.

We used linear mixed models (LMMs) to analyze continuous outcomes. These models accounted for the clustered study design (residents or measurement points nested within staff, staff nested within nursing home, nursing homes nested within country). For continuous measurements where the respondents were staff, LMMs were fitted with staff, nursing home, and country as random factors (only random intercepts), and with group (intervention vs usual care), time (postintervention combining data collected between month 9 and month 17 vs baseline), and their interaction group  $\times$  time as fixed factors. For continuous measurements where the respondents were relatives, similar LMMs were fitted, but without a random intercept for staff.

Results are expressed as estimated means with corresponding 95% CIs. Comparisons are reported in terms of expected baseline-adjusted mean differences between groups postintervention (group  $\times$  time interaction) with 95% CIs. The presented ICC corresponds to the proportion of variance in the outcome at baseline that can be explained at the level of the nursing home and was calculated by fitting a null model with random intercepts for staff, nursing home, and country on the baseline data.

All LMM analyses were performed using SAS statistical software (version 9.4; SAS Institute, Inc). All hypothesis testing was 2-sided. *P* values and 95% CIs were not adjusted for multiple testing. However, to address the problem of multiplicity with Bonferroni correction, *P* values should be compared against a significance level of 1% for the primary resident-level analyses and 1.25% for the primary staff-level analyses. All analyses were on an intention-to-treat and complete-case basis, assuming data were missing at random.

### Results

Trial recruitment started in each country after obtaining ethics approval (after May 2015) with the last data collection completed in the UK December 2017. Data analyses were began on April 20, 2018.

Of 160 clusters assessed for eligibility, 82 were excluded, and 78 were recruited and randomized to intervention or con-



Table 1. Characteristics of Deceased Residents<sup>a</sup>

| Characteristic   | Baseline          |                        | Postintervention  |                        |
|--|-------------------|------------------------|-------------------|------------------------|
|  | Control (n = 272) | Intervention (n = 279) | Control (n = 558) | Intervention (n = 425) |
| Age at time of death, unadjusted mean (SD), y <sup>b</sup>                         | 85.22 (9.13)      | 85.68 (9.00)           | 85.58 (8.81)      | 85.91 (8.57)           |
| Female sex, unadjusted frequency, No./No. (%)                                      | 190/269 (70.6)    | 160/264 (60.6)         | 354/547 (64.7)    | 265/414 (64.0)         |
| Functional status 1 month before death (BANS-S), unadjusted mean (SD) <sup>c</sup> | 19.93 (4.31)      | 19.03 (4.90)           | 18.95 (4.93)      | 18.75 (5.14)           |
| Resident had dementia, unadjusted frequency, No./No. (%)                           | 188/262 (71.8)    | 194/276 (70.3)         | 399/556 (71.8)    | 278/416 (66.8)         |

<sup>a</sup> The table presents characteristics of deceased residents for whom an assessment by nurses was made.

<sup>b</sup> Data missing at baseline for 11 cases in the intervention and 4 cases in the control group. Data missing at postintervention for 11 cases in the intervention

and 18 cases in the control group.

<sup>c</sup> Data missing at baseline for 14 cases in the intervention and 9 cases in the control group. Data missing at postintervention for 19 cases in the intervention and 10 cases in the control group.

trol after baseline data collection (Figure). Characteristics of participating nursing homes are described in eTable 3 in Supplement 2.

### Resident Outcomes

Concerning deceased residents, we collected 551 of 610 questionnaires from staff at baseline (RR, 90.3%) and 984 of 1178 postintervention (RR, 83.5%) in 37 intervention and 36 control homes. We collected 259 of 467 questionnaires from relatives at baseline (RR, 55.5%) and 498 of 939 at postintervention (RR, 53.0%). Response rates per country are included in eTable 4 in Supplement 2.

Characteristics of deceased residents are presented in Table 1. Nonresponse analyses showed no differences in deceased residents' characteristics between cases where the staff member returned a questionnaire and cases where the staff member did not return a questionnaire (eTable 5 in Supplement 2).

The primary resident outcome, comfort in the last week of life (EOLD-CAD total score) reported by staff did not differ between intervention and control groups (baseline-adjusted mean difference, −0.55; 95% CI, −1.71 to 0.61;  $P = .35$ ) (Table 2).

The secondary resident outcome quality of care in the last month of life (Quality of Dying in Long-Term Care total score) reported by staff differed significantly between intervention and control groups (baseline-adjusted mean difference, 3.40; 95% CI, 2.01-4.80;  $P < .001$ ) (Table 2). We found a significant difference between intervention and control responses on the subscale preparatory tasks (baseline-adjusted mean difference, 6.77; 95% CI, 4.19-9.36;  $P < .001$ ) (Table 2), but not on the other 2 subscales.

We found no significant differences between control and intervention groups for the measures reported by relatives: resident's comfort in the last week of life (EOLD-CAD total score), relatives' perception of the quality of end-of-life care (End-of-Life in Dementia-Satisfaction with Care total score), and relatives' perception of physician-family communication (Family Perception of Physician-Family Communication; eTable 8 in Supplement 2).

### Staff Outcomes

We collected 2680 of 3638 questionnaires on staff at baseline (RR, 73.7%) and 2437 of 3510 postintervention (RR, 69.4%) in

37 intervention and 38 control homes (eFigure 1 in Supplement 2). Characteristics of participating staff are presented in Table 3.

The primary staff outcome knowledge of palliative care (Palliative Care Survey) differed significantly between intervention and control groups for the subscale end-of-life factors (baseline-adjusted mean difference, 0.04; 95% CI, 0.02-0.05;  $P < .001$ ) (Table 4) but not for the other subscales or the total scale score (baseline-adjusted mean difference, 0.02; 95% CI, 0.001-0.03;  $P = .03$ ) (eTable 9 in Supplement 2).

Regarding secondary staff outcomes, we found that staff in the intervention group indicated fewer educational needs regarding cultural and ethical values (End-of-Life Professional Caregiver Survey, subscale cultural and ethical values) than in the control group (baseline-adjusted mean difference, 0.11; 95% CI, 0.05-0.17;  $P < .001$ ) (Table 4), but not regarding resident/family communication (End-of-Life Professional Caregiver Survey, subscale communication; baseline-adjusted mean difference, 0.05; 95% CI, −0.003 to 0.11;  $P = .07$ ). There was no significant difference in staff self-efficacy in communicating with residents and their families at the end of life (Self-Efficacy in End-of-Life Care Survey baseline-adjusted mean difference, 0.09; 95% CI, −0.04 to 0.21;  $P = .16$ ). Opinions on palliative care (Rotterdam Move2PC) differed (eTable 10 in Supplement 2) on 2 items with staff in the intervention group being more likely to say "palliative care includes care for the family" and "residents should be clearly informed about imminent death."

## Discussion

This multifacility cluster-RCT in 7 European countries found that the PACE Steps to Success Program did not improve the comfort in the last week of life of residents as reported by staff. We found a significant difference between intervention and control groups for staff knowledge of end-of-life care issues, but this difference was very small and hence not clinically important. We did not find any negative effects.

To our knowledge, our study is the first cluster RCT testing the outcomes of a 1-year multicomponent palliative care program on a very large scale in 78 nursing homes in 7 different countries. A major strength of our trial is its pragmatic

Table 2. Resident Outcomes: Cluster-Adjusted Mean Scores and Differences for the Primary and Secondary Outcomes<sup>a</sup>

| Variable   | Baseline Score |                        | Postintervention Score <sup>b</sup> |                        | Baseline-Adjusted Mean Difference Between Groups Postintervention (95% CI) |                        | P Value for Interaction <sup>c</sup> | ICC                    |       |                       |
|--|----------------|------------------------|-------------------------------------|------------------------|--|------------------------|--------------------------------------|------------------------|-------|-----------------------|
|  | Control        |                        | Intervention                        |                        | Intervention   |                        |                                      |                        |       |                       |
|  | Cases, No.     | Mean (95% CI)          | Cases, No.                          | Mean (95% CI)          | Cases, No.   | Mean (95% CI)          |                                      |                        |       |                       |
| Primary resident outcome <sup>d</sup>  |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| Comfort in the last week of life (CAD-EOLD, range 14-42)   | 251            | 30.22 (28.92 to 31.53) | 258                                 | 30.64 (29.33 to 31.95) | 526  | 31.00 (29.77 to 32.23) | 387                                  | 30.86 (29.61 to 32.12) | .35   | -0.55 (-1.71 to 0.61) |
| Physical distress  | 252            | 29.32 (28.05 to 30.58) | 260                                 | 29.38 (28.12 to 30.64) | 529  | 29.59 (28.46 to 30.71) | 387                                  | 29.52 (28.35 to 30.70) | .87   | -0.13 (-1.62 to 1.37) |
| Dying symptoms   | 255            | 31.21 (29.80 to 32.62) | 258                                 | 32.02 (30.60 to 33.44) | 527  | 32.24 (30.96 to 33.53) | 391                                  | 32.50 (31.17 to 33.83) | .49   | -0.55 (-2.11 to 1.01) |
| Emotional distress   | 252            | 32.98 (31.72 to 34.24) | 259                                 | 33.48 (32.22 to 34.74) | 528  | 33.72 (32.61 to 34.83) | 386                                  | 33.65 (32.49 to 34.81) | .47   | -0.57 (-2.13 to 0.99) |
| Well-being   | 252            | 29.71 (26.87 to 32.55) | 258                                 | 29.16 (26.32 to 32.01) | 524  | 28.37 (25.61 to 31.13) | 387                                  | 29.27 (26.48 to 32.06) | .11   | 1.45 (-0.34 to 3.23)  |
| Secondary resident outcome   |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| Quality of care in the last month of life (QOD-LTC, range 11-15) <sup>d</sup>  | 264            | 39.09 (36.71 to 41.48) | 266                                 | 37.89 (35.50 to 40.29) | 541  | 39.28 (36.96 to 41.61) | 399                                  | 41.49 (39.13 to 43.85) | <.001 | 3.40 (2.01 to 4.80)   |
| Personhood   | 268            | 47.20 (46.06 to 48.34) | 271                                 | 45.97 (44.83 to 47.12) | 548  | 47.51 (46.47 to 48.55) | 411                                  | 47.60 (46.52 to 48.68) | .04   | 1.33 (0.07 to 2.58)   |
| Closure  | 264            | 33.90 (31.19 to 36.62) | 268                                 | 33.82 (31.10 to 36.55) | 543  | 34.32 (31.73 to 36.92) | 402                                  | 36.64 (33.99 to 39.28) | .03   | 2.40 (0.26 to 4.54)   |
| Preparatory tasks  | 258            | 29.57 (23.67 to 35.46) | 259                                 | 29.27 (23.36 to 35.18) | 538  | 29.92 (24.10 to 35.74) | 382                                  | 36.40 (30.54 to 42.26) | <.001 | 6.77 (4.19 to 9.36)   |
| Abbreviations: EOLD-CAD, End-of-Life in Dementia Scale Comfort Assessment While Dying; ICC, unconditional intraclass correlation coefficient from baseline assessments; QOD-LTC, Quality of Dying in Long Term Care.   |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| All estimated means, and 95% CIs, are cluster adjusted; differences are cluster and baseline adjusted.   |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| Postintervention measurements collected for residents at T1 (month 13) and T2 (month 17).  |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| Interaction effect of group (control and intervention) and time point (baseline and postintervention) calculated with a mixed linear regression model. We calculated differences in change (postintervention minus baseline) between the intervention and control groups (interaction group × time). |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |
| <sup>d</sup> Total scale scores are averages per subscale multiplied by total number of items. Cases with missing data on more than 50% of items per subscale were excluded from the calculation of the total scale scores.  |                |                        |                                     |                        |  |                        |                                      |                        |       |                       |

Abbreviations: EOLD-CAD, End-of-Life in Dementia Scale Comfort Assessment While Dying; ICC, unconditional intraclass correlation coefficient from baseline assessments; QOD-LTC, Quality of Dying in Long Term Care.

<sup>a</sup> All estimated means, and 95% CIs, are cluster adjusted; differences are cluster and baseline adjusted.

<sup>b</sup> Postintervention measurements collected for residents at T1 (month 13) and T2 (month 17).

<sup>c</sup> Interaction effect of group (control and intervention) and time point (baseline and postintervention) calculated with a mixed linear regression model. We calculated differences in change (postintervention minus baseline) between the intervention and control groups (interaction group × time).

<sup>d</sup> Total scale scores are averages per subscale multiplied by total number of items. Cases with missing data on more than 50% of items per subscale were excluded from the calculation of the total scale scores.

Table 3. Characteristics of Staff (Staff Outcomes)

| Characteristic  | Baseline           |                         | Postintervention   |                         |
|---|--------------------|-------------------------|--------------------|-------------------------|
|   | Control (n = 1409) | Intervention (n = 1270) | Control (n = 1278) | Intervention (n = 1159) |
| Age, unadjusted mean (SD), y <sup>a</sup>   | 42.3 (12.1)        | 43.7 (11.6)             | 42.3 (12.1)        | 44.1 (11.7)             |
| Female sex, unadjusted frequency, No./No. (%)   | 1224/1375 (89.0)   | 1092/1253 (87.2)        | 1094/1229 (89.0)   | 990/1131 (87.5)         |
| Professional role, unadjusted frequency   |                    |                         |                    |                         |
| Care assistant, No./No. (%)   | 565/1205 (46.9)    | 509/1091 (46.7)         | 546/1087 (50.2)    | 470/977 (48.1)          |
| Nurse, No./No. (%)  | 640/1205 (53.1)    | 582/1091 (53.3)         | 541/1087 (49.8)    | 507/977 (51.9)          |
| Undertaken formal training in palliative care (yes), unadjusted frequency, No./No. (%) <sup>b</sup> | 797/1337 (59.6)    | 643/1218 (52.8)         | 732/1196 (61.2)    | 718/1086 (66.1)         |
| Years of experience working in direct resident care, unadjusted mean (SD) <sup>c</sup>              | 14.7 (10.8)        | 15.1 (10.8)             | 14.9 (11.0)        | 14.9 (10.7)             |

<sup>a</sup> Data missing at baseline for 48 cases in intervention and 63 cases in control group. Data missing at postintervention for 63 cases in the intervention and 95 cases in the control group.

<sup>b</sup> Yes, as part of education to become nurse or care assistant, or additional

education after obtaining the degree.

<sup>c</sup> Data missing at baseline for 68 cases in intervention and 91 cases in control group. Data missing at postintervention for 101 cases in intervention and 151 cases in control group.

nature, focusing on implementation in actual practice in countries with different health care systems,<sup>10</sup> varying nursing home populations,<sup>8</sup> and end-of-life care cultures,<sup>2</sup> which increases external validity and generalizability of our findings. Additional strengths are the high-quality research design and the measurement of multiple resident and staff outcomes with good-to-high response rates for this type of research.

Several reasons might explain why the PACE program did not reach its intended outcomes. First, the program might be too complex with too many components to be implemented within a 1-year time frame. A systematic review of nursing home interventions concluded that studies targeting specific care tasks were more likely to produce positive outcomes than those requiring broader practice changes<sup>37</sup> such as the PACE program. Hence, it might be better to focus on 1 component at a time.

Second, the implementation of the intervention might have been suboptimal in some nursing homes. This was also the case in another palliative care trial<sup>1</sup> in US nursing homes, where only 6 of the 14 intervention facilities had implemented the intervention as foreseen. The nursing home is a complex context, and previous research has outlined the many contextual barriers, such as high staff turnover and workload,<sup>37</sup> influencing the ability to adopt new practices. Also, although we did adapt the intervention materials to make them feasible and culturally appropriate for use in the 7 countries,<sup>24</sup> our PACE intervention might have been too standardized to ensure optimal implementation in all settings, not allowing tailoring of intervention components to the local nursing home context. A thorough process evaluation is needed to test this hypothesis.

Third, the different intervention components and the primary outcome measure—comfort in the last week of life—did not match perfectly. The intervention included 6 different steps targeting the whole trajectory of residents, from admission to death; however, care in the last days of life was only 1 of these steps, implemented at the end (step 5 at month 7). Moreover, the intervention program focused more on symptom assessment than on treatment of complex symptoms in the terminal phase, hence, closer involvement of GPs or specialist palliative care services might be necessary to achieve better

comfort at the end of life. Finally, the focus on symptom assessment rather than treatment could also have increased staff's ability to recognize symptoms, leading to improved reporting and masking of the potential effect.

The finding that the quality of care in the last month of life did significantly improve after the PACE intervention needs further study. The change was most apparent in the preparatory tasks subscale. Hence it could be hypothesized that the advance care planning step in the PACE program brought about a conversational shift in nursing homes around the end of life. It was also the first step introduced as part of the PACE program, thus implemented for the longest time in the nursing homes. Although this might explain the effect found, we need to be careful with this interpretation because this was a secondary outcome of the study.

The results of the PACE trial affirm the difficulty of improving the end of life of nursing home residents. However, nursing homes in the future must be able to provide excellent palliative care to all residents as an integral part of their work. Moving forward, it might be necessary to (1) focus on a single, more delineated or targeted component at a time (eg, 1 step in the program), (2) allow more flexibility and tailoring to the local context during implementation, and (3) ensure a close fit between the intervention and outcome measures used in the evaluation.

### Limitations

Our trial also has limitations. First, staff filling in the questionnaires were not blinded. This might have influenced their responses, in particular for items such as evaluations of the quality of care because staff may have wanted to report better quality after the intervention. However, the fact that the study did not find an improvement in staff-reported comfort in the last week of life in the intervention group, suggests that bias on the outcome measures owing to an overly optimistic assessment is limited. Second, evaluations of quality of care in the last month of life and comfort were performed after death, which might have introduced recall bias. Nevertheless, in this population, after-death evaluations by staff have been judged appropriate for several reasons including that complete data are difficult to achieve in prospective studies with

Table 4. Staff Outcomes: Cluster-Adjusted Mean Scores and Differences for the Primary and Secondary Outcomes<sup>a</sup>

| Variable   | Baseline score |                     |              | Postintervention score <sup>b</sup> |            |                     | Baseline-adjusted Mean Difference Between Groups Postintervention (95% CI) | P Value for Interaction <sup>c</sup> | ICC    |
|--|----------------|---------------------|--------------|-------------------------------------|------------|---------------------|--|--------------------------------------|--------|
|  | Control        |                     | Intervention | Control                             |            | Intervention        |  |                                      |        |
|  | Cases, No.     | Mean (95% CI)       | Cases, No.   | Mean (95% CI)                       | Cases, No. | Mean (95% CI)       |  |                                      |        |
| Primary staff outcome  |                |                     |              |                                     |            |                     |  |                                      |        |
| Knowledge of palliative care (PCS, range 0-1) <sup>d</sup>   | 1399           | 0.58 (0.52 to 0.63) | 1261         | 0.58 (0.52 to 0.63)                 | 1273       | 0.59 (0.54 to 0.65) | 0.02 (0.001 to 0.03)   | .03                                  | 0.02   |
| End-of-life factors  | 1398           | 0.39 (0.31 to 0.47) | 1261         | 0.39 (0.31 to 0.47)                 | 1272       | 0.41 (0.33 to 0.49) | 0.04 (0.02 to 0.05)  | <.001                                | 0.02   |
| Physical   | 1387           | 0.83 (0.79 to 0.87) | 1244         | 0.83 (0.79 to 0.87)                 | 1247       | 0.84 (0.80 to 0.88) | -0.01 (-0.03 to 0.01)  | .31                                  | 0.02   |
| Psychological  | 1378           | 0.69 (0.63 to 0.76) | 1241         | 0.70 (0.63 to 0.76)                 | 1244       | 0.71 (0.64 to 0.77) | 0.01 (-0.02 to 0.04)   | .51                                  | 0.01   |
| Secondary staff outcomes <sup>e</sup>  |                |                     |              |                                     |            |                     |  |                                      |        |
| Staff self-efficacy in communicating with residents at the end of life and their families with the subscale "Communication" (S-EOLC, range 0-7)  | 1270           | 4.83 (4.44 to 5.23) | 1155         | 4.72 (4.32 to 5.11)                 | 1156       | 4.81 (4.42 to 5.21) | 0.09 (-0.04 to 0.21)   | .16                                  | 0.0009 |
| Staff educational needs (EPCS, range 1-5)  |                |                     |              |                                     |            |                     |  |                                      |        |
| Regarding patient and family communication with the subscale "Patient and family communication"  | 1310           | 3.81 (3.63 to 3.99) | 1161         | 3.77 (3.59 to 3.96)                 | 1167       | 3.82 (3.63 to 4.00) | 0.05 (-0.003 to 0.11)  | .07                                  | 0.01   |
| Regarding cultural and ethical values with the subscale "cultural and ethical values"  | 1376           | 3.74 (3.52 to 3.96) | 1235         | 3.69 (3.47 to 3.91)                 | 1244       | 3.73 (3.51 to 3.96) | 0.11 (0.05 to 0.17)  | <.001                                | 0.009  |
| <sup>a</sup> Abbreviations: EPCS, End-of-Life Professional Caregiver Survey; ICC, unconditional intraclass correlation coefficient from baseline assessments; PCS, Palliative Care Survey; S-EOLC, Self-Efficacy in End-of-Life Care Survey.<br><sup>b</sup> All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted. All staff members who filled in a questionnaire at baseline (T0) and/or at postintervention (T1) are included in the analyses.<br><sup>c</sup> Interaction effect of group (control and intervention) and time point (baseline and postintervention) calculated with a mixed linear regression model. We calculated differences in change (postintervention minus baseline) between the intervention and control groups (interaction group × time).<br><sup>d</sup> Aggregated score of all items of the Knowledge construct of the Palliative Care Survey.<br><sup>e</sup> Total scores are averages per subscale/whole scale multiplied by total number of items. Cases with missing data on more than 25% of items per scale/subscale were excluded from the calculation of the total scores. |                |                     |              |                                     |            |                     |  |                                      |        |

<sup>c</sup> Interaction effect of group (control and intervention) and time point (baseline and postintervention) calculated with a mixed linear regression model. We calculated differences in change (postintervention minus baseline) between the intervention and control groups (interaction group × time).

<sup>d</sup> Aggregated score of all items of the Knowledge construct of the Palliative Care Survey.

<sup>e</sup> Total scores are averages per subscale/whole scale multiplied by total number of items. Cases with missing data on more than 25% of items per scale/subscale were excluded from the calculation of the total scores.

Abbreviations: EPCS, End-of-Life Professional Caregiver Survey; ICC, unconditional intraclass correlation coefficient from baseline assessments; PCS, Palliative Care Survey; S-EOLC, Self-Efficacy in End-of-Life Care Survey.

<sup>a</sup> All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted. All staff members who filled in a questionnaire at baseline (T0) and/or at postintervention (T1) are included in the analyses.

<sup>b</sup> Postintervention measurements collected for staff only at T1 (month 13).



living patients owing to high attrition rates and incorrect prognostication.<sup>5,38,39</sup> However, the fact that we identified deaths in the previous 4 months means that some staff may have reported on a death that occurred 4 months prior, whereas other staff reported on a more recent death. Prospective data collection (asking staff to complete an assessment within 2 weeks of a resident death) would have been a stronger approach, although this would have substantially inflated the workload for staff.

## Conclusions

We did not observe an improvement in comfort of residents in the last week of life after introducing the PACE Steps to Success Program, and improvements in staff knowledge of palliative care were minimal. The observed differences in quality of care in the last month of life are promising but need further investigation.

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