Comparing the effectiveness of palliative care for elderly people in long term care facilities in Europe and in Switzerland

Sophie Pautex, Catherine Bassal, Emilie Morgan, François Herrmann, Claudia Gamondi, Pierre-Alain Charmillot, Tania Fusi-Schmidhauser
Thank you

To program «Research in Palliative Care» with the support of the Gottfried and Julia Bangerter Rhyner and Stanley Thomas Johnson Foundations

To all nursing homes: staff; physician, relatives; administrative...

And to all collaborators.....
1. Mapping palliative care structures in care homes in Europe (EAPC Taskforce)
2. Describing and comparing quality of end-of-life care and quality of dying in 6 EU countries (cross-sectional study)
3. Randomised controlled cluster trial to integrate palliative care “PACE Steps to success” intervention
Figure 6: LTCFs as Place of Death
• Cross-sectional study of deceased residents

Every care home reports all deceased residents (in and outside the facility) over a past three month period. Structured after-death questionnaires on quality of care and quality of dying.

• Cross-sectional study of staff

Knowledge and attitudes.
Primary Outcome

• **EOLD-CAD**: End-of-Life in Dementia Scale Comfort Assessment while dying completed by staff

• **QOD-LTC**: Quality of Dying in Long Term Care completed by staff

• **Knowledge Construct of the Palliative Care Survey** completed by staff
Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study

Lara Pivodic¹, Tinne Smets¹, Nele Van den Noortgate², Bregje D Onwuteaka-Philipsen³, Yvonne Engels⁴, Katarzyna Szczerska⁵, Harriet Finne-Soveri⁶, Katherine Froggatt⁷, Giovanni Gambassi⁸, Luc Deliens¹ and Lieve Van den Block¹; on behalf of PACE
## Characteristics of patients

<table>
<thead>
<tr>
<th></th>
<th>BE (N = 291)</th>
<th>FI (N = 269)</th>
<th>IT (N = 200)</th>
<th>NL (N = 222)</th>
<th>PL (N = 311)</th>
<th>ENG (N = 91)</th>
<th>CH (N = 90)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at time of death, median (IQR)</td>
<td>88 (83–92)</td>
<td>86 (82–91)</td>
<td>87 (81–91)</td>
<td>87 (83–92)</td>
<td>83 (74–89)</td>
<td>89 (85–94)</td>
<td>88.7 (71-101)</td>
<td>&lt;0.00 1</td>
</tr>
<tr>
<td>Gender, female, n (%)</td>
<td>174 (64)</td>
<td>169 (64)</td>
<td>136 (68)</td>
<td>138 (67)</td>
<td>195 (64)</td>
<td>66 (78)</td>
<td>52 (59)</td>
<td>0.38</td>
</tr>
<tr>
<td>Underlying cause of death, n (%)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Cancer</td>
<td>30 (11)</td>
<td>5 (3)</td>
<td>51 (3)</td>
<td>8 (27)</td>
<td>15 (1)</td>
<td>9 (11)</td>
<td>17 (32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Cardiovascular disease (excl. CVA)</td>
<td>71 (25)</td>
<td>51 (3)</td>
<td>7 (4)</td>
<td>15 (27)</td>
<td>15 (1)</td>
<td>9 (11)</td>
<td>17 (32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Stroke/CVA</td>
<td>30 (11)</td>
<td>15 (11)</td>
<td>4 (12)</td>
<td>8 (10)</td>
<td>8 (1)</td>
<td>10 (12)</td>
<td>4 (8)</td>
<td>10</td>
</tr>
<tr>
<td>Dementia</td>
<td>61 (22)</td>
<td>8 (22)</td>
<td>4 (12)</td>
<td>4 (15)</td>
<td>23 (8)</td>
<td>31 (29)</td>
<td>25 (37)</td>
<td>36</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>38 (13)</td>
<td>4 (12)</td>
<td>17 (29)</td>
<td>17 (32)</td>
<td>4 (8)</td>
<td>10 (12)</td>
<td>4 (8)</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>53 (19)</td>
<td>68 (53)</td>
<td>60 (54)</td>
<td>61 (54)</td>
<td>32 (54)</td>
<td>30 (40)</td>
<td>37 (54)</td>
<td>32</td>
</tr>
<tr>
<td>Resident had dementia, n (%)</td>
<td>183 (63)</td>
<td>5 (13)</td>
<td>66 (54)</td>
<td>54 (61)</td>
<td>61 (54)</td>
<td>54 (50)</td>
<td>54 (50)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Functional status 1 month before death (BANS-5), median (IQR)b</td>
<td>19 (15–22)</td>
<td>(20–25)</td>
<td>(14–21)</td>
<td>(14–21)</td>
<td>(14–21)</td>
<td>(14–21)</td>
<td>(14–21)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Place of death, n (%)</td>
<td>Nursing home</td>
<td>227 (83)</td>
<td>80 (71)</td>
<td>71 (82)</td>
<td>79 (88)</td>
<td>80 (71)</td>
<td>71 (82)</td>
<td>79 (88)</td>
</tr>
<tr>
<td></td>
<td>Up to 6 months</td>
<td>55 (19)</td>
<td>80 (30)</td>
<td>68 (34)</td>
<td>49 (22)</td>
<td>163 (53)</td>
<td>53 (26)</td>
<td>30 (24)</td>
</tr>
<tr>
<td></td>
<td>6–12 months</td>
<td>33 (12)</td>
<td>20 (8)</td>
<td>8 (21)</td>
<td>11 (18)</td>
<td>8 (23)</td>
<td>8 (8)</td>
<td>9 (9)</td>
</tr>
<tr>
<td></td>
<td>1 year or more</td>
<td>200 (69)</td>
<td>166 (63)</td>
<td>63 (111)</td>
<td>56 (153)</td>
<td>70 (122)</td>
<td>40 (54)</td>
<td>61 (57)</td>
</tr>
<tr>
<td>Respondent for resident, n (%)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Nurse most involved in care</td>
<td>245 (85)</td>
<td>251 (94)</td>
<td>197 (100)</td>
<td>97 (44)</td>
<td>212 (70)</td>
<td>70 (36)</td>
<td>40 (88)</td>
<td>98</td>
</tr>
<tr>
<td>Other staff most involved in care</td>
<td>45 (16)</td>
<td>15 (6)</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>123 (56)</td>
<td>92 (30)</td>
<td>53 (60)</td>
<td>2 (2)</td>
</tr>
</tbody>
</table>

90 patients
88.7 years old
61% had dementia
36% dies from CVD
88% died in NH

67 % stayed more than 1 year

LTCF
PACE 1
Descriptive
Pace 2
Intervention

10EMS VD_FR et 6 TI
Dementia Scale Comfort Assessment while dying (EOLD-CAD)

Better score 42
Quality of Dying in Long Term Care completed by staff

Better score 55
The palliative care knowledge of nursing home staff: The EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries
Characteristics of the nurses

<table>
<thead>
<tr>
<th></th>
<th>Belgium (n = 559)</th>
<th>Netherlands (n = 440)</th>
<th>England (n = 152)</th>
<th>Finland (n = 559)</th>
<th>Poland (n = 399)</th>
<th>Italy (n = 166)</th>
<th>CH (n=669)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.00</td>
</tr>
<tr>
<td>17–35</td>
<td>224 (40.4%)</td>
<td>128 (29.5%)</td>
<td>61 (41.2%)</td>
<td>141 (25.9%)</td>
<td>67 (17.1%)</td>
<td>86 (55.5%)</td>
<td>177 (27.2%)</td>
<td>1</td>
</tr>
<tr>
<td>36–50</td>
<td>201 (36.3%)</td>
<td>165 (38%)</td>
<td>46 (31.1%)</td>
<td>207 (38.1%)</td>
<td>207 (52.9%)</td>
<td>59 (38.1%)</td>
<td>272 (41.8%)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>129 (23.3%)</td>
<td>141 (32.5%)</td>
<td>41 (27.7%)</td>
<td>196 (36%)</td>
<td>36 (29.9%)</td>
<td>10 (6.5%)</td>
<td>202 (31)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender (female)</strong></td>
<td></td>
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<td>&lt;0.00</td>
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<tr>
<td></td>
<td>495 (88.6%)</td>
<td>412 (94.3%)</td>
<td>139 (92.7%)</td>
<td>527 (95.8%)</td>
<td>371 (94.2%)</td>
<td>107 (67.3%)</td>
<td>561 (84)</td>
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<tr>
<td><strong>Registred nurse</strong></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td>&lt;0.00</td>
</tr>
<tr>
<td></td>
<td>262</td>
<td>146 (26.4%)</td>
<td>164 (41.1%)</td>
<td>156 (99.4%)</td>
<td>139 (21)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Formal training in</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.00</td>
</tr>
<tr>
<td><strong>palliative care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>390 (74.3%)</td>
<td>263 (60.3%)</td>
<td>80 (54.4%)</td>
<td>324 (59)</td>
<td>235 (60.9%)</td>
<td>90 (56.3%)</td>
<td>274 (41)</td>
<td></td>
</tr>
<tr>
<td><strong>Number of years working in direct</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>&lt;0.00</td>
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<tr>
<td><strong>resident care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Less than 10 years</td>
<td>223 (42.3%)</td>
<td>148 (34.7%)</td>
<td>92 (63.4%)</td>
<td>236 (43.9%)</td>
<td>167 (45.3%)</td>
<td>108 (63.7%)</td>
<td>252 (38.9%)</td>
<td></td>
</tr>
<tr>
<td>More than ten years</td>
<td>304 (57.1%)</td>
<td>278 (65.3%)</td>
<td>53 (36.6%)</td>
<td>301 (56.1%)</td>
<td>202 (54.7%)</td>
<td>40 (27)</td>
<td>396 (61.1)</td>
<td></td>
</tr>
</tbody>
</table>

41% formal training in PC
21% are nurse

AS 340 (50.9%)
ASSC 106 (15.9%)
IDE 139 (20.8%)
Knowledge Construct of the Palliative Care Survey

Subscale end-of life factors

Belgium, Netherlands, England, Finland, Poland, Italy, Switzerland
Knowledge Construct of the Palliative Care Survey

Subscale psychological factors

Belgium
Netherlands
England
Finland
Poland
Italy
Switzerland
Knowledge Construct of the Palliative Care Survey

Subscale physical factors

- Belgium
- Netherlands
- England
- Finland
- Poland
- Italy
- Switzerland
Original Study

Physician Visits and Recognition of Residents’ Terminal Phase in Long-Term Care Facilities: Findings From the PACE Cross-Sectional Study in 6 EU Countries

M.G. Oosterveld-Vlug PhD, H.R.W. Pasman PhD, M. ten Koppel MSc, H.P.J. van Hout PhD, J.T. van der Steen PhD, D. Collingridge Moore MSc, L. Deliens PhD, G. Gambassi PhD, M. Kylänen PhD, T. Smets PhD, K. Szczerbińska PhD, L. Van den Block PhD, B.D. Onwuteaka-Philipsen PhD, on behalf of PACE
In Switzerland

• The number of physician visits to residents (median):
  • in the last 3 months of life: 6
  • in the last week of life: 2

• Recognition that the resident was in the terminal phase: 59.0%

• Residents in these countries had palliation as main treatment goal the least: 71%

• Very experimented physician but few have a formal training in PC
PACE Steps to Success intervention

• Based on a UK intervention

• Specifically developed for care home context
  • Nurses and care workers delivering care (with limited PC training)
  • Complex prolonged trajectories, multi-morbidities, dementia, pending death not always recognised
  • “weak context”: high staff turnover, low educated personnel, lack of multidisciplinary input

• Implemented in 7 countries BE, CH, FI, IT, NL, PL, UK
Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries
The PACE Cluster-Randomized Clinical Trial

Lieve Van den Block, PhD; Elisabeth Honinx, MSc; Lara Perodic, PhD; Rosa Miranda, MSc;
Bregje D. Onwutaala-Phillips, PhD; Heins van Hout, PhD; H. Roseline W. Pusman, PhD;
Mariska Oosterveld-Vlug, PhD; Maud Ten Koppel, MSc; Ruth Piers, PhD; Nele Van Den Noortgate, PhD;
Yvonne Engels, PhD; Myrna Vennooij-Doxsen, PhD; Jo Hockley, PhD; Katherine Froggatt, PhD; Sheila Payne, PhD;
Katarzyna Szczepaniak, PhD; Marika Kyllinen, MSc; Giovanni Gambassi, MD; Sophie Pautay, PhD;
Catherine Bassal, PhD; Stefanie De Buysse, PhD; Luc Defans, PhD; Tinne Smets, PhD; for the PACE trial group

404 Nursing homes approached
   → 148 Refused or did not respond
   → 160 Nursing homes assessed for eligibility
      → 82 Excluded
         → 43 Required number reached in country
         → 39 Did not meet criteria

Data on deceased residents
551 of 610 Questionnaires from staff
259 of 497 Questionnaires from relatives

78 Nursing homes randomized

39 Controls
   → 1 Italian nursing home dropped out
   → 38 Included in 12-mo usual care
   → 2 Excluded
      → 1 United Kingdom nursing home provided no questionnaires
      → 1 Dutch nursing home had no deaths

39 Interventions
   → 1 Italian nursing home dropped out
   → 1 United Kingdom nursing home dropped out
   → 37 Included in 12-mo intervention

36 Nursing homes provided data on deceased residents
518 of 647 Questionnaires from staff
282 of 515 Questionnaires from relatives

37 Nursing homes provided data on deceased residents
426 of 531 Questionnaires from staff
261 of 426 Questionnaires from relatives
Residents’ comfort in the last week of life did not differ between intervention and control 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.
Why these results?

The program might be too complex with too many components to be implemented within a 1-year time frame.
The implementation of the intervention might have been suboptimal in some nursing homes.
The different intervention components and the primary outcome measure—comfort in the last week of life—did not match perfectly.
In conclusion

- There is some place for improvement
- How can education improve the care of the patient?
- It’s possible to participate to some EU studies
- Importance to have the money for the data management....
- Possible to do some research in nursing home, even multicentric