

1 Abstract

2 *Background:* An important part of palliative care is discussing preferences at end of life,  
3 however such conversations may not often occur. Care staff with greater self-efficacy towards  
4 end-of-life communication are probably more likely to have such discussions, however, there  
5 is a lack of research on self-efficacy towards end-of-life discussions among long-term care  
6 staff in Europe and related factors .

7 *Objectives:* Firstly, to describe and compare the self-efficacy level of long-term care staff  
8 regarding end-of-life communication across six countries; secondly, to analyse characteristics  
9 of staff and facilities which are associated to self-efficacy towards end-of-life communication.

10 *Design:* Cross-sectional survey.

11 *Settings:* Long-term care facilities in Belgium, England, Finland, Italy, the Netherlands and  
12 Poland (n=290).

13 *Participants:* Nurses and care assistants (n=1680) completed a self-efficacy scale and were  
14 included in the analyses.

15 *Methods:* Care staff rated their self-efficacy (confidence in their own ability) on a scale of 0  
16 (cannot do at all) to 7 -(certain can do) of the 8-item communication subscale of the Self-  
17 efficacy in End-of-Life Care survey. Staff characteristics included age, gender, professional  
18 role, education level, training in palliative care and years working in direct care. Facility  
19 characteristics included facility type and availability of palliative care guidelines, palliative  
20 care team and palliative care advice. Analyses were conducted using Generalized Estimating  
21 Equations, to account for clustering of data at facility level.

22 *Results:* The proportion of staff with a mean self-efficacy score >5 was highest in the  
23 Netherlands (76.4%), ranged between 55.9% and 60.0% in Belgium, Poland, England and  
24 Finland and was lowest in Italy (29.6%). Higher levels of self-efficacy (>5) were associated  
25 with: staff over 50 years of age (OR 1.86 95% CI[1.30-2.65]); nurses (compared to care  
26 assistants) (1.75 [1.20-2.54]); completion of higher secondary or tertiary education  
27 (respectively 2.22 [1.53-3.21] and 3.11 [2.05-4.71]); formal palliative care training (1.71 [1.32-  
28 2.21]); working in direct care for over 10 years (1.53 [1.14-2.05]); working in a facility with  
29 care provided by onsite nurses and care assistants and offsite physicians (1.86 [1.30-2.65]);  
30 and working in a facility where guidelines for palliative care were available (1.39 [1.03-  
31 1.88]).

32 *Conclusion:* Self-efficacy towards end-of-life communication was most often low in Italy and  
33 most often high in the Netherlands. In all countries, low self-efficacy was found relatively

34 often for discussion of prognosis. Palliative care education and guidelines for palliative care  
35 could improve the self-efficacy of care staff.

36 Keywords: Health Communication; Licensed Practical Nurses; Nurses; Nurses' Aides;  
37 Nursing Homes; Nursing Staff; Palliative Care; Residential Facilities; Self Efficacy.

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40 What is already known about the topic:

- 41 • Although discussing end-of-life topics is associated with positive outcomes for  
42 patients, research indicates that end-of-life issues are often not discussed with  
43 residents of long-term care facilities.
- 44 • When care staff has greater self-efficacy towards discussing end-of-life topics with  
45 residents, they may be more likely to have such discussions.
- 46 • Self-efficacy towards end-of-life communication among long-term care staff in  
47 Europe and associated factors have not been explored.

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49 What this paper adds:

- 50 • Self-efficacy towards end-of-life communication varied between countries: it was  
51 relatively high among care staff in the Netherlands and low among staff in Italy.
- 52 • In all countries low self-efficacy levels were found most often for the discussion of  
53 disease course or prognosis.
- 54 • Staff had higher levels of self-efficacy when they: were older, were nurses (opposed to  
55 care assistants), had been working longer in direct care, had completed a higher level  
56 of education, worked in facilities with onsite nurses and offsite physicians or where  
57 palliative care guidelines were available.

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## 61 **Introduction**

62 An increasing number of older people in Europe are expected to be admitted to long-term  
63 care facilities, due to the ageing population ((2015, OECD, 2016). They will present with  
64 extensive care needs at the end of life (Davies and I.J., 2004, Hall et al., 2011, Van den Block,  
65 2015), for which palliative care is recognized as a suitable approach (Hall et al., 2011, Van  
66 den Block, 2015). An important aspect of providing palliative care is good communication  
67 between the patient, their relatives and care providers, which includes discussion of issues  
68 related to death and dying (Barazzetti et al., 2010). Discussing end-of-life issues is associated  
69 with higher quality of life (Leung et al., 2012), with receiving less aggressive treatments  
70 (Wright et al., 2008) and increasing patients' satisfaction with provided care (You et al.,  
71 2014).

72 The literature shows that physicians do not always discuss the end of life. For instance, in  
73 Belgium, physicians were less likely to discuss end-of-life topics with patients who died in  
74 residential homes, compared to patients who died in hospital (Evans et al., 2014). Similarly,  
75 nursing home physicians in France did not discuss any end-of-life topics with residents or  
76 their families in about one-third of residents (Morin et al., 2016). In a qualitative study in  
77 Norwegian nursing homes, only few residents and relatives reported to have participated in  
78 conversations about the end of life with nursing home staff (Gjerberg et al., 2015), which  
79 indicates that care staff in long-term care facilities probably do not discuss end-of-life topics  
80 with residents that often.

81 The occurrence of end-of-life discussions in European long-term care facilities could be  
82 influenced by care staff's level of self-efficacy for having such discussions. Self-efficacy  
83 refers to the belief in one's personal capabilities to perform a specific task. Theoretical work  
84 testifies that, the greater the individuals' perceived self-efficacy is, the more likely they are to  
85 successfully perform that behaviour (Bandura, 1997). Individuals with a stronger sense of  
86 self-efficacy will set higher goals for themselves and are more motivated to make an effort to  
87 achieve these goals, persevere when faced with difficulties and are more resilient to failed  
88 attempts. Those who have stronger perceived self-efficacy, experience less stress and  
89 depression in difficult situations, which in turn positively affects their functioning (Bandura,  
90 1994). One's sense of self-efficacy can be influenced by four sources 1) mastery experiences,  
91 where successful behaviour strengthens self-efficacy 2) vicarious experiences, when self-  
92 efficacy raises by seeing people similar to oneself succeed 3) social persuasion, when others

93 create optimal situations to succeed and convince one of possessing certain capabilities 4)  
94 physical and emotional states interpreted as signs of one's capabilities (Bandura, 1997).

95 A low perceived self-efficacy among healthcare providers has been identified as a factor  
96 contributing to a lack of discussing difficult issues with patients (Mirand et al., 2002, Yoast et  
97 al., 2008) while an improved sense of self-efficacy is accompanied by improved  
98 communication practices (Banerjee et al., 2017, Gulbrandsen et al., 2013, Liu et al., 2007).

99 Regarding end-of-life discussions, a small-scale study among long-term care staff in  
100 Canada showed relatively high levels of perceived self-efficacy (Brazil et al., 2012). However,  
101 self-efficacy towards end-of-life discussions has not been researched among long-term care  
102 staff in Europe. Using data from the PACE study which included long-term care facilities in  
103 six EU countries, the aims of the present this study are:

104 1) to describe and compare long-term care staff's perceived self-efficacy level regarding end-  
105 of-life communication across countries

106 2) to analyze which facility and staff characteristics are associated with long-term care staff's  
107 perceived level of self-efficacy regarding end-of-life communication in long-term care  
108 facilities.

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## 110 **METHODS**

### 111 **Study setting and design**

112 This study used data from the "Palliative Care for Older People" (PACE) project (Van den  
113 Block et al., 2016), obtained between January and December 2015. The PACE project  
114 includes a cross-sectional study of care staff in long-term care facilities in Belgium, England,  
115 Finland, Italy, the Netherlands and Poland. Long-term care facilities included collective  
116 institutional settings where onsite care is provided to older people 24/7 (Froggatt, 2017) and  
117 three types of facilities were identified: type 1 with 24/7 onsite care from physicians, nurses  
118 and care assistants; type 2 with 24/7 onsite care from nurses and care assistants and care from  
119 offsite-based physicians; and type 3 with 24/7 onsite care from care assistants and care from  
120 offsite-based nurses and physicians.

121 Representative samples of facilities were obtained through proportional stratified random  
122 sampling, based on region, facility type and bed capacity. As a public list of facilities was  
123 unavailable in Italy, a previously constructed convenience sample was used, covering the  
124 three macro regional areas and taking into account bed capacity and facility types in Italy  
125 (Onder et al., 2012).

126 In each participating facility, a questionnaire containing items on self-efficacy towards  
127 end-of-life communication was distributed to all nurses and care assistants who were on duty  
128 at the time of the research visit. Another questionnaire on facility characteristics was  
129 completed by the administrator or manager in each facility.

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### 131 **Ethics**

132 In each country, ethical approval was obtained from the relevant ethics committees.  
133 Participants provided informed consent in writing, except in the Netherlands and Poland  
134 where an informed consent form was not required when questionnaires are filled in  
135 anonymously.

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### 137 **Measurements**

138 Self-efficacy towards end-of-life communication was measured with the communication  
139 subscale from the Self-Efficacy in Palliative Care scale (SEPC), consisting of 8 statements  
140 (see table 2) (Mason and Ellershaw, 2004). For each of the eight statements, care staff rated  
141 their confidence in their own ability (perceived self-efficacy) on a scale of 0 (I cannot do at  
142 all) to 7 (certain I can do), with higher scores indicating higher levels of self-efficacy. An  
143 optional response to indicate ‘not my responsibility’ for any of these items was available. A  
144 forward-backward translation according to the EORTC guidelines was conducted in each  
145 country, except England (Dewolf et al., 2009). In the development of the SEPC scale content  
146 validity was assessed to be adequate. The communication subscale showed uni-dimensionality  
147 (factor loadings 0.70 – 0.89) and high internal consistency (Cronbach’s alpha 0.93) in a  
148 sample of English medical students (Mason and Ellershaw, 2004).

149 The staff characteristics included in the analysis were age, gender, professional role,  
150 education level, formal training in palliative care and number of years of employment in  
151 direct care. Characteristics of facilities where staff were employed included: type of facility,  
152 availability of guidelines regarding palliative care, availability of a palliative care team and  
153 availability of palliative care advice.

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### 155 **Sample**

156 In the PACE project a total of 3392 care staff members in 322 facilities received a  
157 questionnaire, of whom 2275 staff members returned a questionnaire. This study included  
158 1680 care staff (in 290 facilities) who indicated their level of self-efficacy on all SEPC  
159 communication items. Staff who did not indicate their self-efficacy level (leaving the item

160 open or only indicating ‘not my responsibility’) on one or more items were excluded from the  
161 analyses. Compared to participants who filled in all SEPC items, participants with missing  
162 items more often: were care assistants, had lower educational levels, had no palliative care  
163 training, worked less years in direct care and worked in a facility without palliative care  
164 guidelines or with onsite physicians (see table 1).

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167 **Table 1. Comparison of characteristics between complete cases and cases with missing**  
 168 **values on the Self-Efficacy in Palliative Care communication subscale.**

|   | <b>Cases without missing values</b> | <b>Cases with missing values</b> | <b>p-value</b>  |
|---|-------------------------------------|----------------------------------|-----------------|
|   | % within group                      | % within group                   |                 |
| <b>Age</b>  |                                     |                                  | .302            |
| 17-35 years (ref)   | 32.2                                | 30.3                             |                 |
| 36-50 years   | 40.1                                | 38.6                             |                 |
| >50 years   | 27.7                                | 31.0                             |                 |
| <b>Gender (Female)</b>  | 90.7                                | 92.5                             | .151            |
| <b>Professional role</b>  |                                     |                                  | <b>&lt;.001</b> |
| Care assistant (ref)  | 37.6                                | 71.8                             |                 |
| Nurse   | 62.4                                | 28.2                             |                 |
| <b>Education level</b>  |                                     |                                  | <b>&lt;.001</b> |
| Primary or lower secondary (ref)  | 16.1                                | 23.4                             |                 |
| Higher secondary  | 49.4                                | 55.6                             | *               |
| Tertiary  | 34.5                                | 21.0                             | *               |
| <b>Formal training in palliative care (Yes, as part of degree or additional education after degree)</b> | 55.4                                | 47.5                             | <b>.001</b>     |
| <b>Number of years working in direct resident care</b>  | 57.4                                | 47.1                             | <b>&lt;.001</b> |
| More than 10 years (ref. 10 years or less)  |                                     |                                  |                 |
| <b>Working in which type of facility</b>  |                                     |                                  | <b>&lt;.001</b> |
| Onsite physicians, nurses and care assistants (ref)   | 14.0                                | 22.9                             |                 |
| Onsite nurses and care assistants, offsite physicians   | 83.8                                | 75.3                             | *               |
| Onsite care assistants, offsite nurses and physicians   | 2.2                                 | 1.8                              |                 |
| <b>Working in facility with specific guidelines regarding palliative care</b>                           | 64.9                                | 48.5                             | <b>&lt;.001</b> |
| <b>Working in facility where palliative care team is available</b>                                      | 19.7                                | 20.9                             | .657            |
| <b>Working in facility where specialist palliative care advice is available</b>                         | 62.0                                | 68.0                             | .496            |

169 \*significantly different from reference category

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174 **Data preparation**

175 Data was assembled using paper questionnaires, which participants sent back to the  
176 research institutes in each country. Subsequently, in each country data was entered in  
177 Limesurvey (Limesurvey GmbH.) and stored on a secured server. All data entry was  
178 conducted according to a protocol that was established beforehand by the study coordinator.  
179 Next, databases from all countries were merged and cleaned systematically. All decisions  
180 regarding data cleaning were documented.

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182 **Analyses**

183 Frequencies were used to describe the participant and facility characteristics and staff's  
184 level of self-efficacy. A self-efficacy scale score was calculated as the mean self-efficacy  
185 level of the SEPC communication subscale. As the level of self-efficacy was not normally  
186 distributed, including after log-transformation, it was dichotomised in lower ( $\leq 5$ ) and higher  
187 ( $> 5$ ) scores, based on the median score of all countries.

188 To take into account the nested data structure (care staff within facilities), Generalized  
189 Estimating Equations (GEE) were used to assess whether participant and facility  
190 characteristics and level of self-efficacy differed between countries and to assess which  
191 factors were associated with care staff's level of self-efficacy. Model specifications included  
192 an exchangeable correlation matrix.

193 With respect to factors associated with the level of self-efficacy, first the relation between  
194 the mean level of self-efficacy and each staff and facility characteristic and country was  
195 analysed. Next all staff and facility factors and country were included in the GEE models and  
196 with manual stepwise backward selection factors were removed until p-values in the model  
197 were  $< 0.05$ , to identify the factors most strongly associated with the mean level of self-  
198 efficacy. Odds ratios (OR) and 95% confidence intervals (CI) were calculated. Participant and  
199 facility characteristics were checked for collinearity.

200 In all analyses an alpha level  $< 0.05$  was considered statistically significant. All analyses  
201 were performed with SPSS version 22 (IBM Corp. Released 2013. IBM SPSS Statistics for  
202 Windows, Version 22.0. Armonk, NY: IBM Corp).

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204 **RESULTS**

205 Most staff members were female and the majority were above 35 years of age, with the  
206 exception of Italy (see table 2). In England and the Netherlands, a minority of staff members  
207 were nurses, opposed to the other countries. Less than 10% of staff had a primary or lower  
208 secondary education, except in the Netherlands and Poland. In Italy most staff had a tertiary  
209 level of education. Over half of staff had formal palliative care training, except in England.  
210 Contrary to the other countries, less than half of staff in England and Italy had more than 10  
211 years of experience in direct care. In Belgium and Finland all care staff worked in facilities  
212 with onsite nurses and offsite physicians and in England part of the staff worked in facilities  
213 with offsite nurses and physicians. Most staff worked in facilities where guidelines for  
214 palliative care were available, except in Italy and Poland. Less than half of the care staff  
215 worked in a facility where a palliative care team was employed and with Finland excepted  
216 most staff worked in a facility where palliative care advice was available.

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219 **Table 2. Characteristics of the participating care staff and differences between countries**  
 220 **(n=1680)**

|   | NL<br>(n=309) | BE<br>(n=422)      | FI<br>(n=515)      | IT<br>(n=115)        | NL<br>(n=309) | PL<br>(n=199)      | EN<br>(n=120)    | p-<br>value |
|---|---------------|--------------------|--------------------|----------------------|---------------|--------------------|------------------|-------------|
| <b>Age<sup>a</sup></b>  |               |                    |                    |                      |               |                    |                  | <.001       |
| 17-35 years (ref)   | 94 (31.0 )    | 167 (39.8)         | 133 (26.4 )        | 59 (54.6 )           | 94 (31.0 )    | 27 (13.70)         | 51 (44.0)        |             |
| 36-50 years   | 132 (43.6)    | <b>153 (36.4)</b>  | 196 (38.9)         | <b>41 (38.0)</b>     | 132 (43.6)    | <b>107 (54.3)</b>  | <b>32 (27.6)</b> |             |
| >50 years   | 77 (25.4)     | <b>100 (23.8)</b>  | 175 (34.7)         | <b>8 (7.4)</b>       | 77 (25.4)     | <b>63 (32.0)</b>   | <b>33 (28.4)</b> |             |
| <b>Gender (Female)</b>  | 285 (93.1)    | <b>373 (88.4)</b>  | 487 (95.9)         | <b>71 (64.0)</b>     | 285 (93.1)    | 182 (91.9)         | 111 (94.1)       | <.001       |
| <b>Professional role</b>  |               |                    |                    |                      |               |                    |                  | <.001       |
| Care assistant (ref.)   | 252 (82.6)    | 182 (43.1)         | 20 (3.9)           | 0 (0.0) <sup>b</sup> | 252 (82.6)    | 88 (44.2)          | 84 (71.8)        |             |
| Nurse   | 53 (17.4)     | <b>240 (56.9)</b>  | <b>491 (96.1)</b>  | 110 (100.0)          | 53 (17.4)     | <b>111 (55.8)</b>  | <b>33 (28.2)</b> |             |
| <b>Education level<sup>a</sup></b>  |               |                    |                    |                      |               |                    |                  | <.001       |
| Primary or lower<br>secondary (ref)   | 130 (42.5)    | 36 (9.1)           | 49 (9.7)           | 5 (4.5)              | 130 (42.5)    | 6 (3.0)            | 36 (32.4)        |             |
| Higher secondary  | 159 (52.0)    | <b>171 (43.4)</b>  | <b>302 (59.7)</b>  | 7 (6.3)              | 159 (52.0)    | <b>133 (66.8 )</b> | 31 (27.9)        |             |
| Tertiary  | 17 (5.6)      | <b>187 (47.5)</b>  | <b>155 (30.6)</b>  | <b>99 (89.2)</b>     | 17 (5.6)      | <b>60 (30.2)</b>   | <b>44 (39.6)</b> |             |
| <b>Formal training in<br/>palliative care (Yes, as<br/>part of degree or<br/>additional education after<br/>degree)</b> | 188 (61.6)    | 228 (57.1)         | 278 (54.8)         | <b>59 (52.7)</b>     | 188 (61.6)    | 126 (65.3 )        | <b>25 (21.4)</b> | <.001       |
| <b>Number of years working<br/>in direct resident care</b>  |               |                    |                    |                      |               |                    |                  | <.001       |
| More than 10 years (ref. 10<br>years or less)   | 197 (65.9)    | 241 (60.0)         | <b>279 (56.0)</b>  | <b>27 (25.7)</b>     | 197 (65.9)    | <b>129 (68.6 )</b> | <b>48 (42.)</b>  | <.001       |
| <b>Working in which type of<br/>facility<sup>a</sup></b>  |               |                    |                    |                      |               |                    |                  | <.001       |
| Onsite physicians,<br>nurses and care assistants<br>(ref.)  | 123 (39.8)    |                    |                    | 53 (46.1)            | 123 (39.8)    | 59 (29.6)          |                  |             |
| Onsite nurses and care<br>assistants, offsite<br>physicians   | 186 (60.2)    | <b>422 (100.0)</b> | <b>515 (100.0)</b> | 62 (53.9)            | 186 (60.2)    | <b>140 (70.4)</b>  | 83 (69.2)        |             |
| Onsite care assistants,<br>offsite nurses and<br>physicians   |               |                    |                    |                      |               |                    | 37 (30.8)        |             |
| <b>Working in facility with<br/>specific guidelines<br/>regarding palliative care</b>                                   | 161 (59.2)    | <b>330 (89.7)</b>  | 358 (72.3)         | <b>46 (40.0)</b>     | 161 (59.2)    | <b>25 (13.1)</b>   | 83 (79.0)        | <.001       |
| <b>Working in facility where<br/>palliative care team is<br/>available</b>  | 57 (20.0)     | 172 (46.9)         | <b>40 (8.2)</b>    | 28 (24.3)            | 57 (20.0)     | <b>7 (3.5)</b>     | <b>4 (3.6)</b>   | <.001       |

|   |            |                   |                   |           |            |             |                  |       |
|---|------------|-------------------|-------------------|-----------|------------|-------------|------------------|-------|
| <b>Working in facility where specialist palliative care advice is available</b> | 162 (58.3) | <b>365 (96.1)</b> | <b>176 (35.3)</b> | 59 (52.7) | 162 (58.3) | 118 (61.1 ) | <b>98 (85.2)</b> | <.001 |
|---|------------|-------------------|-------------------|-----------|------------|-------------|------------------|-------|

221 BE=Belgium, FI=Finland, IT=Italy, NL=the Netherlands, PL=Poland, EN=England

222 Univariate GEE models, NL = reference category (based on self-efficacy scores, see table 2)

223 **In bold** = significant difference compared to the Netherlands

224 No. of missing values: Age: 32; Gender: 17; Professional role:16; Education level: 53; Formal PC training: 47; Years

225 working: 75; PC guidelines: 134; PC team available in facility: 113; Specialist PC advice available: 103.

226 a: Nominal regression analysis, as GEE analysis did not fit the data,

227 b: Due to separation in data, Italy was not included in analysis on variable 'professional role'

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In the Netherlands, the majority of staff rated a high level of self-efficacy (>5) on each item (range 59.2%-72.5%), in all other countries these proportions were significantly smaller (31.7%-67.6%) and in Italy it was the smallest(10.4%-30.4%) (see table 3). Over three-quarters of the staff in the Netherlands, and over half of the staff in Finland, England, Poland and Belgium had a self-efficacy scale score > 5, opposed to less than one-third in Italy.

In most countries, a high self-efficacy level was indicated 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup> least often (ranking 8-6) on the statements ‘Discussing the likely course of a life-limiting illness with the resident’, ‘Discussing the likely course of a life-limiting illness with the resident's family’ and ‘Responding to the resident's question: "How long have I got to live?"’. Staff also less often scored a high level of self-efficacy on the item ‘Providing emotional support to the family upon bereavement’ in Finland and on the item ‘Responding to the resident's question: "Will there be much suffering or pain?"’ in Poland and Italy.

Staff indicated high levels of self-efficacy most often (ranking 1) on the following items: ‘Providing emotional support to the family upon bereavement’ in Belgium; ‘Discussing general issues related to dying and death’ in Finland, Italy, Poland and England; and ‘Having a discussion with the family about their specific concerns about the resident's dying and death’ in the Netherlands and Italy.

248 **Table 3. Percentage of care staff with high self-efficacy scores (>5) on discussing end-of-**  
 249 **life topics, based on the Self-Efficacy in Palliative Care (SEPC) communication subscale**  
 250 **(n=1680)**

|  | NL<br>(n=309)            | BE<br>(n=422)         | FI<br>(n=515)         | IT<br>(n=115)          | PL<br>(n=199)         | EN<br>(n=120)       | p-<br>value |
|--|--------------------------|-----------------------|-----------------------|------------------------|-----------------------|---------------------|-------------|
|  | n (%) [rank per country] |                       |                       |                        |                       |                     |             |
| <b>a. Discussing the likely course of a life-limiting illness with the resident</b>                              | 183<br>(59.2)<br>[8]     | 139<br>(32.9)*<br>[8] | 195<br>(37.9)*<br>[8] | 17<br>(14.8)*<br>[7]   | 63<br>(31.7)*<br>[8]  | 46 (38.3)*<br>[8]   | <.001       |
| <b>b. Discussing the likely course of a life-limiting illness with the resident's family</b>                     | 195<br>(63.1)<br>[6]     | 171<br>(40.5)*<br>[6] | 206<br>(40.0)*<br>[6] | 29<br>(25.2)*<br>[4]   | 92<br>(46.2)*<br>[5]  | 48 (40.0)*<br>[7]   | <.001       |
| <b>c. Discussing general issues related to dying and death</b>   | 204<br>(66.0)<br>[4]     | 187<br>(44.3)*<br>[5] | 348<br>(67.6) [1]     | 35<br>(30.4)*<br>[1/2] | 123<br>(61.8)*<br>[1] | 69 (57.5)<br>[1]    | <.001       |
| <b>d. Having a discussion with the resident about his/her specific concerns about dying and death</b>            | 217<br>(70.2)<br>[3]     | 208<br>(49.3)*<br>[2] | 296<br>(57.5)*<br>[2] | 25<br>(21.7)*<br>[5]   | 104<br>(52.3)*<br>[4] | 63 (52.5)*<br>[3]   | <.001       |
| <b>e. Having a discussion with the family about their specific concerns about the resident's dying and death</b> | 224<br>(72.5)<br>[1]     | 203<br>(48.1)*<br>[3] | 259<br>(50.3)*<br>[3] | 35<br>(30.4)*<br>[1/2] | 113<br>(56.8)*<br>[3] | 61 (50.8)*<br>[5/4] | <.001       |
| <b>f. Providing emotional support to the family upon bereavement</b>   | 223<br>(72.2)<br>[2]     | 244<br>(57.8)*<br>[1] | 201<br>(39.0)*<br>[7] | 34<br>(29.6)*<br>[3]   | 117<br>(58.8)*<br>[2] | 67 (55.8)*<br>[2]   | <.001       |
| <b>g. Responding to the resident's question: "How long have I got to live?"</b>                                  | 190<br>(61.5)<br>[7]     | 158<br>(37.4)*<br>[7] | 221<br>(42.9)*<br>[5] | 12<br>(10.4)*<br>[8]   | 79<br>(39.7)*<br>[7]  | 53 (44.2)*<br>[6]   | <.001       |
| <b>h. Responding to the resident's question: "Will there be much suffering or pain?"</b>                         | 197<br>(63.8)<br>[5]     | 201<br>(47.6)*<br>[4] | 258<br>(50.1)*<br>[4] | 20<br>(17.4)*<br>[6]   | 80<br>(40.2)*<br>[6]  | 61 (50.8)*<br>[5/4] | <.001       |
| <b>Scale score self-efficacy</b>   | 236<br>(76.4)            | 236<br>(55.9)*        | 309<br>(60.0)*        | 34<br>(29.6)*          | 116<br>(58.3)*        | 71 (59.2)*          | <.001       |

251 BE=Belgium, FI=Finland, IT=Italy, NL=the Netherlands, PL=Poland, EN=England

252 \*Significant difference compared to the Netherlands

253 [= ranking 1 (item on which staff most often indicated a SE>5) to 8 (item on which staff least often indicated a SE>5) in  
 254 each country

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259 Univariable analysis showed that self-efficacy towards end-of-life communication was  
260 associated with age, professional role, level of education, formal training in palliative care,  
261 years working in direct care and country (see table 4). The final multivariable model showed  
262 that care staff were more likely to have a high self-efficacy scale score if they: were over 50  
263 years of age (OR 1.86 95%CI[1.30-2.65]); were nurses (1.75 [1.20-2.54]); had completed  
264 higher secondary or tertiary education (respectively 2.22 [1.53-3.21] and 3.11 [2.05-4.71]); had  
265 formal training in palliative care (1.71 [1.32-2.21]); had worked more than 10 years in direct  
266 care (1.53 [1.14-2.05]); worked in a facility with care from onsite nurses and care assistants  
267 and offsite physicians (1.86 [1.30-2.65]); and worked in a facility where guidelines for  
268 palliative care were available (1.39 [1.03-1.88]). Staff were less likely to have a high level of  
269 self-efficacy if they were working in countries other than the Netherlands.

270

271 **Table 4. Characteristics associated with the level of self-efficacy towards end-of-life**  
 272 **communication.**

|  | Scale score self-efficacy ≤5 | Scale score self-efficacy >5 | Univariable<br>n=1680<br>≤5 = 678 (40.4%)<br>>5 = 1002 (59.6%) |                     | Multivariable<br>n=1411<br>≤5 n= 556 (39.4%)<br>>5 n= 855 (60.6%) |         |
|--|------------------------------|------------------------------|--|---------------------|---|---------|
|  | N (%)                        | N (%)                        | OR (95% CI)  | p-value             | OR (95% CI)   | P-value |
| <b>Country</b>   |                              |                              |  |                     |   |         |
| The Netherlands (ref)  | 73 (23.6)                    | 236 (76.4)                   | 1  |                     | 1   |         |
| Belgium  | 186 (44.1)                   | 236 (55.9)                   | .383 (.273-.535)   | <.001               | .154 (.092-.258)  | <.001   |
| Finland  | 206 (40.0)                   | 309 (60.0)                   | .450 (.323-.628)   | <.001               | .145 (.085-.249)  | <.001   |
| Italy  | 81 (70.4)                    | 34 (29.6)                    | .127 (.068-.240)   | <.001               | .064 (.030-.134)  | <.001   |
| Poland   | 83 (41.7)                    | 116 (58.3)                   | .449 (.283-.711)   | .001                | .209 (.119-.368)  | <.001   |
| England  | 49 (40.8)                    | 71 (59.2)                    | .449 (.283-.711)   | .001                | .410 (.189-.894)  | .025    |
| <b>Age</b>   |                              |                              |  |                     |   |         |
| 17-35 years (ref)  | 271 (51.0)                   | 260 (49.0)                   | 1  | <.001               | 1   |         |
| 36-50 years  | 261 (39.5)                   | 400 (60.5)                   | 1.567 (1.200-2.047)  | .001                | 1.062 (0.762-1.479)   | .723    |
| >50 years  | 131 (28.7)                   | 325 (71.3)                   | 2.527 (1.932-3.304)  | <.001               | 1.856 (1.302-2.646)   | .001    |
| <b>Gender</b>  |                              |                              |  |                     |   |         |
| 73 (47.4)  | 81 (52.6)                    | 1                            |  | 1                   |   |         |
| <b>Male</b>  |                              |                              |  |                     |   |         |
| <b>Female</b>  |                              |                              |  |                     |   |         |
| 594 (39.4)   | 915 (60.6)                   | 1.275 (0.918-1.772)          | .147   |                     |   |         |
| <b>Professional role</b>   |                              |                              |  |                     |   |         |
| 275 (43.9)   | 351 (56.1)                   | 1                            |  | 1                   |   |         |
| <b>Care assistant (ref)</b>  |                              |                              |  |                     |   |         |
| <b>Nurse</b>   |                              |                              |  |                     |   |         |
| 394 (38.0)   | 644 (62.0)                   | 1.585                        | <.001  | 1.746 (1.202-2.537) | .003  |         |
| <b>Education level</b>   |                              |                              |  |                     |   |         |
| <b>Primary + lower secondary (ref)</b>                             |                              |                              |  |                     |   |         |
| <b>Higher secondary</b>  |                              |                              |  |                     |   |         |
| 327 (40.7)   | 476 (59.3)                   | 1.513 (1.151-1.989)          | .003   | 2.216 (1.531-3.208) | <.001   |         |
| <b>Tertiary</b>  |                              |                              |  |                     |   |         |
| 201 (35.8)   | 361 (64.2)                   | 2.199 (1.598-3.024)          | <.001  | 3.106 (2.048-4.711) | <.001   |         |
| <b>Formal training in palliative care</b>                          |                              |                              |  |                     |   |         |
| <b>No (ref)</b>  |                              |                              |  |                     |   |         |
| <b>Yes, as part of degree or additional education after degree</b> |                              |                              |  |                     |   |         |
| 340 (46.6)   | 389 (53.4)                   | 1                            |  | 1                   |   |         |
| 314 (34.7)   | 590 (65.3)                   | 1.679 (1.351-2.086)          | <.001  | 1.707 (1.317-2.214) | <.001   |         |
| <b>Number of years working in direct resident care</b>             |                              |                              |  |                     |   |         |
| <b>10 years or less (ref)</b>                                      |                              |                              |  |                     |   |         |
| <b>More than 10 years</b>  |                              |                              |  |                     |   |         |
| 291 (31.6)   | 630 (68.4)                   | 2.203 (1.758-2.762)          | <.001  | 1.530 (1.142-2.049) | .004  |         |
| <b>Working in which type of facility</b>                           |                              |                              |  |                     |   |         |
| <b>Onsite physicians, nurses</b>                                   |                              |                              |  |                     |   |         |
| 100 (42.6)   | 135 (57.4)                   | 1                            |  | 1                   |   |         |

|   |            |            |                     |      |                     |      |
|---|------------|------------|---------------------|------|---------------------|------|
| and care assistants (ref)   |            |            |                     |      |                     |      |
| Onsite nurses and care assistants, offsite physicians                         | 560 (39.8) | 848 (60.2) | 1.134 (.744-1.727)  | .559 | 1.735 (1.045-2.882) | .033 |
| Onsite care assistants, offsite nurses and physicians                         | 18 (48.6)  | 19 (51.4)  | 0.771 (.376-1.582)  | .479 | 1.842 (.597-5.683)  | .288 |
| <b>Working in facility with specific guidelines regarding palliative care</b> |            |            |                     |      |                     |      |
| no (ref)  |            | 305 (56.2) | 1                   |      | 1                   |      |
| yes   | 238 (43.8) | 616 (61.4) | 1.242 (0.942-1.638) | .124 | 1.393 (1.034-1.876) | .030 |
| <b>Working in facility where palliative care team is available</b>            |            |            |                     |      |                     | -    |
| no (ref)  | 496 (39.4) | 763 (60.6) | 1                   |      | 1                   |      |
| yes   | 133 (43.2) | 175 (56.8) | 0.915 (0.687-1.218) | .524 |                     |      |
| <b>Working in facility where palliative care advice is available</b>          | 245 (40.9) | 354 (59.1) | 1                   |      | 1                   | -    |
| no (ref)  |            |            |                     |      |                     |      |
| yes   | 388 (39.7) | 590 (60.3) | 1.079 (0.832-1.400) | .567 |                     |      |

273 OR= Odds Ratio, CI= Confidence Interval.

274 Logistic GEE analyses. Dependent variable: mean self-efficacy level towards end of life communication (0 –self-efficacy scale score ≤ 5, 1 – self-efficacy scale score > 5)

275 Collinearity between independent variables was not present.

276 Missings: gender:17, professional role:16, formal palliative care training:47, years in direct care:75, guidelines palliative care:134, specialist palliative care team: 113, specialist palliative care advice:103, age:32, education level:53

280

281

## 282 **Discussion**

283 In this study care staff's level of perceived self-efficacy towards end-of-life  
284 communication differed largely between countries, with mostly high levels of self-efficacy in  
285 the Netherlands and low levels of self-efficacy in Italy. Furthermore, care staff more often had  
286 a high mean level of perceived self-efficacy if they: were older, were nurses (compared to  
287 care assistants), followed higher secondary or tertiary education or formal palliative care  
288 training, worked in direct care for over 10 years, worked in a facility with onsite nurses and  
289 offsite physicians or where palliative care guidelines were available, or worked in the  
290 Netherlands.

### 291 **Self-efficacy theory**

292

#### 293 Factors related to care staff's self-efficacy towards end-of-life communication

294 The facility and staff characteristics which we found to be associated with care staff's  
295 sense of self-efficacy, can be linked to the four sources of influence in Bandura's self-efficacy  
296 theory: mastery experiences; vicarious experiences; social persuasion; and physical and  
297 emotional states. First, the relation between self-efficacy and age, work experience,  
298 professional role, educational level and country seems to be connected to mastery  
299 experiences. Older staff may generally have more personal experience with death and dying  
300 and discussing difficult topics and more years of work experience provide more opportunities  
301 to practice end-of-life communication. Previous research found that care assistants are less  
302 likely to engage in a conversation with a nursing home resident's family about death and  
303 dying, compared to nurses (Johnson and Bott, 2016). Care assistants also have expressed  
304 difficulty in responding to existential matters, for which they often used non-verbal  
305 communication strategies such as gentle touches, instead of discussing the topic (Ahsberg and  
306 Carlsson, 2014). Additionally, care staff's professional roles show a tendency for focus on  
307 ADL assistance in lower educational levels and care assistants roles (Mistiaen et al., 2011,  
308 Wöpking, 2016), while higher educational levels and nurses' professional roles could have  
309 more focus on the importance of end-of-life discussions. Moreover, in the Netherlands care  
310 staff could be expected to work more independently, compared to other countries (de Veer et  
311 al., 2004). This in turn could mean that in the Netherlands care staff carry out more tasks  
312 themselves, such as discussing end-of-life topics, instead of this being allocated to other care  
313 providers such as the physician.

314 Variation in vicarious experiences could also play a role in country differences.  
315 Previous studies found, for instance, that discussions of end-of-life topics by general  
316 practitioners occur most often in the Netherlands and least often in Italy (Evans et al., 2014),  
317 which could indicate how common it is for healthcare providers discuss end-of-life matters  
318 with patients. Furthermore, in Mediterranean countries such as Italy healthcare providers  
319 often practice partial- or non-disclosure of end-of-life issues, due to wishes of family who are  
320 often involved in care (Gysels et al., 2012) and to the importance of maintaining patient's  
321 hope and not causing them distress (Toscani and Farsides, 2006).

322 Availability of palliative care guidelines and facilities where physicians are available  
323 offsite while nurses provide care onsite, could be optimal environments for end-of-life  
324 discussions and raising staff's self-efficacy (social persuasion in Bandura's theory). Oncology  
325 nurses in the United States have reported difficulty in not being able to make autonomous  
326 decisions about having certain conversations, without consent from the medical team  
327 (Banerjee et al., 2016). Staff working in facilities with onsite physicians may experience a  
328 similar struggle, while staff in facilities where the physician is offsite may be more used to  
329 working independently and having these discussions themselves. Availability of guidelines  
330 can facilitate healthcare providers' participation in palliative care improvement projects (van  
331 Riet Paap et al., 2014) and might contribute to a care culture in which staff are expected to  
332 provide palliative care, including end-of-life discussions, and where they are supported by the  
333 facility.

334 Considering the 4<sup>th</sup> factor of influence in self-efficacy theory, negative emotional  
335 states could have contributed to lower levels of perceived self-efficacy of younger, less  
336 experienced staff, care assistants and staff without palliative care education. Other research  
337 showed that younger and less experienced nurses indicated a stronger fear of death (Peters et  
338 al., 2013) (Lange et al., 2008), which is linked to feeling less comfortable in discussing death  
339 with patients and families (Deffner and Bell, 2005). Moreover, nursing assistants have  
340 reported that talking about death with residents or families felt unnatural and emotionally  
341 demanding and they felt a lack of competency to do so (Beck et al., 2012). Finally, nurses  
342 considered palliative care training to be an important strategy to reduce anxiousness about  
343 caring for terminally ill patients (Sommerbakk et al., 2016) and nurses who received palliative  
344 care education reported less death anxiety (Zyga et al., 2011).

345

#### 346 Discussing prognosis: most often low self-efficacy

347 In all countries fewer staff indicated high levels of perceived self-efficacy on items

348 concerning discussion of disease course or prognosis, which could be due to lack of mastery  
349 and vicarious experiences and to negative emotions. Care staff could lack experience in  
350 informing residents about their prognosis, as this may be a task for physicians instead for care  
351 staff. However, prognosis or disease course could be a topic of discussion for care staff once  
352 residents have been informed. Most residents in long-term care have multiple chronic diseases  
353 which can make it difficult to establish an accurate prognosis (Murray et al., 2005) and care  
354 staff could evaluate their efforts to discuss prognosis as unsuccessful when they cannot  
355 provide a definite prognosis. Limited discussions of prognoses by other healthcare providers  
356 may also play a role, as studies have shown that physicians in French nursing homes did not  
357 discuss prognosis with 36.5% of residents or their families (Morin et al., 2016). Also, in only  
358 13.6% of long-term care residents in five European countries the physician established an  
359 accurate prognosis and informed the resident about this (Ten Koppel et al., 2018).  
360 Furthermore, healthcare providers have indicated discussing prognosis feels uncomfortable  
361 because they are afraid it will have a negative impact on their patients, such as taking away  
362 their hope (Hancock et al., 2007). However, most older people would like to be informed  
363 about their prognosis because it helps them to make the most of life and prepare for death  
364 (Ahalt et al., 2012), indicating that discussing prognosis can be considered an important skill  
365 for care staff.

### 366 **Country differences**

367 As mentioned above, differences in the sources of influence – such as the level of  
368 independency in work roles and how common end-of-life discussions are- may partly explain  
369 the observed differences between countries, However, in light of the international character of  
370 the current study a more in-depth reflection of country differences –mainly the high scores in  
371 the Netherlands- deserves attention. It is possible that among Dutch staff end-of-life matters-  
372 life matters are more normalised, which makes them feel that they should be able to discuss  
373 matters openly and therefore should have high self-efficacy. This would result in staff  
374 indicating higher levels of self-efficacy than they actually experience. It is also possible that  
375 the Dunning-Kruger effect, where low-ability people lack the self-awareness to objectively  
376 evaluate their competence (Kruger and Dunning, 1999), is more pronounced in the  
377 Netherlands than in other countries. This means that Dutch staff could more often  
378 underestimate the difficulties or overestimate their own abilities in end-of-life discussions,  
379 which has been found to play a role in pain treatment and assessment (Zwakhalen et al.,  
380 2007). Cultural differences between countries could play a role in this. Markus and Kitayama

381 proposed that cultural dimensions such as individualism and collectivism can shape self-  
382 phenomena, such as self-efficacy (Markus and Kitayama, 1991). Earley et al. (1999)  
383 concluded that for individualists self-efficacy is mainly shaped by feedback of individual  
384 performance, while self-efficacy of collectivists is influenced both by individual and group  
385 performance feedback (Earley et al., 1999). Furthermore, a review conducted by Klassen  
386 (2004) suggests that on average, self-efficacy levels are lower among collectivists compared  
387 to individualists. However, congruence between self-efficacy beliefs and subsequent  
388 behaviour seems more accurate among collectivists than among individualists (Klassen,  
389 2004). This means that individualists would usually overestimate their skills, as could be the  
390 case for Dutch nurses in the current study. Data from cross-country research conducted by  
391 Hofstede et al. shows the following country rankings on individualism (0-100): Great Britain  
392 89, the Netherlands 80, Italy 76, Belgium 75, Finland 63 and Poland 60 (Hofstede et al., 2010,  
393 Hofstede et al., 2015). While those data do not point towards the Dutch being extremely more  
394 individualistic than the other countries, we have not assessed individualism in this study and it  
395 is possible that in our sample individualism was more pronounced among staff in the  
396 Netherlands.

### 397 **Implications for practice, policy and research**

398 Communication training strategies for healthcare providers can improve self-efficacy  
399 towards communicating with patients and increase communication performance (Banerjee et  
400 al., 2017, Brown et al., 2009, Gulbrandsen et al., 2013, Hsu et al., 2014, Liu et al., 2007).  
401 Furthermore, our results indicate that palliative care education could also be beneficial in  
402 increasing care staff's self-efficacy and could be further supported by establishing national  
403 policies to ensure availability of palliative care guidelines in facilities.

404 In all countries staff could benefit from training and education on discussing  
405 prognoses and disease course. Such training could highlight the importance of informing  
406 patients when a prognosis is uncertain (Ahalt et al., 2012), allowing care staff to feel less  
407 prohibited by the fact that they cannot provide an exact prognosis. It is also important to  
408 highlight that patients can maintain hope after they acknowledged their condition is terminal  
409 (Clayton et al., 2008), to reduce negative feelings associated with discussing prognosis.  
410 Additionally, communication training and education can be tailored to each country. For  
411 example, in Finland training could focus on including relatives in palliative care and  
412 improving emotional intelligence skills, as self-efficacy was often low for providing family  
413 emotional support. In Italy and Poland training could also focus on pain (management) at the

414 end of life.

415 While care staff with higher levels of self-efficacy are generally more likely to engage  
416 in end-of-life discussions, we cannot infer with certainty that in practice they do, since this  
417 was not researched. Furthermore, it is unknown whether a higher self-efficacy leads to end-of-  
418 life discussions of better quality. Therefore, future research could focus on the relationship  
419 between self-efficacy and performance quality in end-of-life discussions across countries,  
420 potentially by conducting a mixed-methods study.

### 421 **Strengths and limitations**

422 This is the first study comparing long-term care staff's perceived self-efficacy towards  
423 end-of-life communication across six European countries and analysing factors associated  
424 with this specific self-efficacy. This study included a large sample of 1680 care staff  
425 members.

426 While recruitment in the PACE study was random, there is some selection bias in the  
427 current study sample, as participants who filled in all self-efficacy items differed from those  
428 with missing items. Based on findings in this study, participants with missing values are likely  
429 to have lower levels of self-efficacy, based on their characteristics (see table 1). Therefore the  
430 proportion of care staff with high self-efficacy could be an overestimation and the  
431 associations found between staff and facility characteristics could be stronger.

### 432 **Conclusion**

433 In the Netherlands most staff have a high level of perceived self-efficacy, while in Italy  
434 most staff have a low level of perceived self-efficacy towards end-of-life communication. In  
435 all countries high self-efficacy scores are found least often for discussing prognosis. High  
436 self-efficacy shows associations with older age, more years of working in care, profession as a  
437 nurse, completion of a higher level of education, working in facilities with onsite nurses and  
438 offsite physicians, availability of palliative care guidelines and employment in the  
439 Netherlands. Communication training, palliative care education and guidelines for palliative  
440 care could be adjusted to country-specific needs in order to help improve care staff's self-  
441 efficacy.

442

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