# Original Article

# Agreement of Nursing Home Staff With Palliative Care Principles: A PACE Cross-sectional Study Among Nurses and Care Assistants in Five European Countries



Elisabeth Honinx, PhD, Tinne Smets, MSc, PhD, Ruth Piers, MD, PhD, Luc Deliens, MSc, MA, PhD, Sheila Payne, MSc, PhD, Marika Kylänen, Msc, PhD, Ilona Barańska, MPH, H. Roeline W. Pasman, MSc, PhD, Giovanni Gambassi, MD, and Lieve Van den Block, MA, PhD, on behalf of PACE, European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe Department of Family Medicine & Chronic Care (E.H., T.S., L.D., L.V.d.B.), Vrije Universiteit Brussel (VUB) & Ghent University, Brussels; Department of Geriatric Medicine (R.P.), Ghent University Hospital, Ghent, Belgium; Faculty of Health and Medicine, Lancaster University (S.P.), Lancaster, UK; National Institute for Health and Welfare (M.K.), Helsinki, Finland; Unit for Research on Aging Society (I.B.), Department of Sociology of Medicine, Epidemiology and Preventive Medicine Chair, Faculty of Medicine Jagiellonian University Medical College, Kraków; Faculty of Health Sciences, Jagiellonian University Medical College (I.B.), Kraków, Poland; Department of Public and Occupational Health (H.R.W.P.), Vrije Universiteit, Amsterdam Medisch Centrum, BT Amsterdam, the Netherlands; and Department of Internal Medicine (G.G.), Istituto di Medicina Interna e Geriatria, Università Cattolica del Sacro Cuore Largo F, Rome, Italy

#### Abstract

**Context.** To provide high-quality palliative care to nursing home residents, staff need to understand the basic principles of palliative care.

**Objectives.** To evaluate the extent of agreement with the basic principles of palliative care of nurses and care assistants working in nursing homes in five European countries and to identify correlates.

**Methods.** This is a cross-sectional study in 214 homes in Belgium, England, Italy, the Netherlands, and Poland. Agreement with basic principles of palliative care was measured with the Rotterdam MOVE2PC. We calculated percentages and odds ratios of agreement and an overall score between 0 (no agreement) and 5 (total agreement).

**Results.** Most staff in all countries agreed that palliative care involves more than pain treatment (58% Poland to 82% Belgium) and includes spiritual care (62% Italy to 76% Belgium) and care for family or relatives (56% Italy to 92% Belgium). Between 51% (the Netherlands) and 64% (Belgium) correctly disagreed that palliative care should start in the last week of life and 24% (Belgium) to 53% (Poland) agreed that palliative care and intensive life-prolonging treatment can be combined. The overall agreement score ranged between 1.82 (Italy) and 3.36 (England). Older staff (0.26; 95% confidence interval [CI]: 0.09-0.43, P=0.003), nurses (0.59; 95% CI: 0.43-0.75, P<0.001), and staff who had undertaken palliative care training scored higher (0.21; 95% CI: 0.08-0.34, P=0.002).

Conclusions. The level of agreement of nursing home staff with basic principles of palliative care was only moderate and differed between countries. Efforts to improve the understanding of basic palliative care are needed. J Pain Symptom Manage 2019;58:824–834. © 2019 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

#### Key Words

Palliative care, nursing homes, care homes, opinions, attitudes

Address correspondence to: Elisabeth Honinx, PhD, Researcher, End-of-Life Care Research Group, Department of Family Medicine & Chronic Care, Vrije Universiteit Brussel (VUB)

& Ghent University, Laarbeeklaan 103, 1090 Brussels, Belgium. E-mail: elisabeth.honinx@vub.be

Accepted for publication: June 13, 2019.

## Introduction

Over the past century, populations have aged; more and more people will die in older age, often after having lived with multiple chronic diseases and agerelated disabilities for many years.<sup>1</sup> Numerous older people will move into nursing homes at some point, and most of those who do will eventually die there.<sup>2</sup> Given the rise of chronic diseases and the increasingly complex care needs among residents of nursing homes,<sup>3–7</sup> providing optimal palliative care in this setting is essential.<sup>2,6–8</sup> Hence, nursing home staff need to be able to provide high-quality care to residents at the end of life.

Studies have shown, however, that palliative care provided to nursing home residents is often inadequate, sometimes resulting in hospital transfers. 9-11 In a Norwegian study, up to 57% of residents were transferred to a hospital at the end of life. 12 According to a systematic review in 14 countries, <sup>13</sup> transfers are mostly due to infections, trauma after falling, and altered mental status. Otherwise, also socialstructural factors such as care planning, staffing levels, lack of support, and family expectations can contribute to hospital transfers. <sup>14–19</sup> An earlier PAlliative Care for older people in care and homes in Europe (PACE) study indicated that the knowledge of end-of-life care staff working in this setting is insufficient;<sup>17</sup> having adequate understanding of the principles and practices of end-of-life care and palliative care is indeed an important component of high-quality palliative care. 16-19 Studies in demonstrated that homes nursing communication, understanding, and teamwork of staff led to improved quality of care, including palliative care.

To help improve care, the World Health Organization (WHO) definition of palliative care states that the skills, attitudes, and competences of palliative care should be incorporated into general health care. This means that staff in the nursing home setting need to be able to provide basic palliative care to residents at the end of life. This requires at least that they understand the basic principles of palliative care such as that it is applicable early in the course of a life-limiting illness; that it can be combined with life-prolonging treatments; that it is holistic in nature including physical, emotional, spiritual, and social aspects of care; and that it also includes care for those close to the patient. The course of palliative care such as that it also includes care for those close to the patient.

Until now, it has been relatively unknown to what extent nurses and care assistants working in nursing homes in different European countries have a common understanding of these basic principles. Earlier studies in Greece, Spain, and Australia assessed understanding of and attitudes toward palliative care principles using the palliative care quiz for nursing. 21–23 However, the present study is the first large-scale international study to describe and compare the extent to which staff in nursing homes in different European countries share a basic understanding of palliative care.

This study is part of the PACE project, a Europeanfunded project that compares palliative care in nursing homes in six European countries (Belgium, England, Italy, Finland, the Netherlands, and Poland). These countries were selected to represent a diversity of geographic regions in Europe, comprising Southern, Western, Northern, and Eastern Europe. 24,25 Another PACE study conducted by Froggatt et al.<sup>26</sup> showed that in England, Belgium, and the Netherlands, palliative care in the nursing homes is highly developed with a variety of initiatives on micro, meso, and macro level, whereas mainly in Finland and Italy, but also in Poland, palliative care development in nursing homes is limited. Also, there are few palliative care initiatives or nursing homes providing palliative care in these countries. The participating countries thus reflect different levels of development and implementation of palliative care in nursing homes, providing the optimal sample for an international comparative study.<sup>26,27</sup> We expect staff's understanding of the basic principles of palliative care to be insufficient and to differ between countries. We hypothesize that in countries with lower development of palliative care in nursing homes (Finland, Italy, and Poland), staff less often agree with and understand the basic principles than staff in countries with higher levels of palliative care development (Belgium, the Netherlands, and UK).

To test this hypothesis, the research questions of this articles are as follows:

- To what extent do nurses and care assistants working in nursing homes in the participating countries agree with the basic principles of palliative care?
- 2) Which country-related, nursing home—related, and staff-related factors are associated with the level of agreement with the basic principles of palliative care?

#### Methods

Design and Sampling

In 2015, a cross-sectional study among staff was conducted in nursing homes in five European countries: Belgium (Flanders), the Netherlands, England, Poland, and Italy. Finland was eventually excluded from this article because in the Finnish questionnaires, the term terminal care (saattohoito) was used instead of palliative care. Even though

terminal care is part of palliative care, this conceptual difference might lead to biased results. Nursing homes were selected using proportional stratified random sampling: stratified by region (province or large regions), then by bed capacity (higher or lower than the median number of beds in each country) and facility type. Subsequently, homes were sampled randomly and proportionally from each stratum, that is, cluster sampling. If a nursing home did not want to participate, another home from the same stratum was sampled to ensure that the selected homes would be representative for the country. This method was based on publicly available lists of homes in each country. In Italy, no public lists are available, and therefore, a sample based on a previously constructed cluster of nursing homes, also used in earlier Italian studies such as the EU SHELTER project, was used, covering all regions in Italy.<sup>24</sup> In England, the enabling research in care homes research network for nursing homes was used to enhance recruitment.<sup>28</sup>

## Setting and Participants

In this article, the term nursing home refers to "collective institutional settings where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time.<sup>26</sup> There were three types of nursing homes: Type 1 with 24/7 on-site care from physicians and nurses/care assistants; Type 2 with 24/7 on-site care from nurses/care assistants, but off-site from physicians; and Type 3 with 24/7 onsite care from care assistants and off-site care from nurses and physicians. Type 1 exists in Poland, Italy, and the Netherlands, Type 2 exists in all countries, and Type 3 only exists in the Netherlands and England. In Type 1 homes, dementia rates are higher, length of stay is shorter, and functional and cognitive status is poorer than those in Type 2 nursing homes.<sup>29</sup> The staff we surveyed consisted of care assistants and nurses. Care assistants provide direct personal care and work under the supervision of a nurse in a team and are generally educated to a lower level than nurses. 19

#### Data Collection

A letter introducing the PACE project and asking for voluntary participation was sent to the nursing homes. In each participating home, a contact person was appointed by the manager. This person listed all staff on duty at the time of the visit by a study researcher. The contact person distributed the questionnaires to these staff in a prestamped envelope together with an information leaflet, which

mentioned that full anonymity was guaranteed by using unique anonymized number codes instead of names. It was also guaranteed that their answers would be treated in the strictest confidentiality not accessible by the homes because the questionnaires were sent straight back to the researchers. The researchers registered the received questionnaires in an excel file and contacted each contact person to send up to two reminders to nonresponding staff. The data collection is described in detail in the protocol of the PACE study.<sup>24</sup> The protocol was approved by the ethics committee in each country in 2015. In the Netherlands and Italy, no approval by an ethics committee was needed, and waivers for the collection of data of deceased residents were obtained. A completed questionnaire was considered as valid informed consent.

## Measurements

The following variables were used: age, gender, professional role (i.e., care assistant or nurse), having undertaken formal training in palliative care, and nursing home type. Training included training in palliative care as part of the degree, additional training after the degree, or any other training in palliative care. Agreement with palliative care principles was measured by using a subscale of the validated Rotterdam MOVE2PC instrument. 25,30 The MOVE2PC (Assessment of Knowledge, and Opinions of Nurses Regarding to Palliative Care) is constructed to assess the opinions and knowledge of nurses and the perceived difficulties and educational needs regarding the provision of palliative care. It is a 66-item questionnaire, including 11 items on opinions. These are based on guidelines for palliative care in the Netherlands, which are in turn based on the WHO guidelines. Of these 11 items, five measure the extent to which nurses agree with the WHO definition of palliative care.<sup>30</sup> In our study, these five were used to measure the extent to which staff members of nursing homes agree with basic principles of palliative care: "the aim of palliative care is treatment of pain only", "palliative care starts in the last weeks of life", "palliative care and intensive life prolonging treatment can be combined", "palliative care includes spiritual care and palliative care includes care for resident's family/relatives". Agreement with the principles was scored on a 3-point scale with anchors "disagree", "neither agree nor disagree", and "agree". The MOVE2PC questionnaire was developed in the Netherlands. All items of the instrument were tested for validity regarding six measurement properties. It proved to be a valid instrument for assessing nurses' knowledge and opinions related to palliative care.<sup>30</sup> For our study, we forward-backward translated the five items in all participating country languages according to European Organisation for Research and Treatment of Cancer guidelines,<sup>31</sup> with English as

the source language. For more details on the translation procedure, we refer to the protocol of the PACE study.  $^{24}$ 

## Statistical Analyses

Multilevel models were used for the analyses because of the clustering of data in homes. To calculate the extent of agreement with each principle, the 3-point ordinal scale was converted into a 2-point dichotomous scale ("agree with the principle" and "disagree with the principle") because we were primarily interested in staff with understanding of the principles. The neutral category "neither agree nor disagree" was thus combined with the answer that was not consistent with the WHO definition, that is if expected to agree with a principle, the neutral answer was combined with "disagree"; if expected to disagree with a principle, the neutral answer was combined with "agree". For each item, we accounted for the clustering at the level of nursing homes and adjusted for the following possible confounders: age, gender, professional role of the staff member, and formal training. Country was entered as a fixed effect to detect differences in the extent of agreement between countries. Nursing home was entered as a random effect. Results on the extent of agreement are presented as percentages and odds ratios, based on the dichotomous scale, with Belgium as reference category.

Then, we calculated an overall score of agreement with the principles of palliative care. The individual principles were first scored 0 (disagreement or neither agree nor disagree) or 1 (agreement). Then, the scores on the five individual principles were summed. The total score of agreement ranged on a 5-point scale, between 0 and 5, with a higher score indicating more agreement with the principles.

To determine factors associated with a staff member's level of agreement (i.e., the overall score of agreement), we conducted a multiple linear mixed model analysis. Factors entered into the model were country, age, gender, professional role, formal training, and type of nursing home. The associations between the overall score of agreement of staff and their characteristics were computed as estimated means. The statistical significance is presented by an alpha level of P < 0.05. All analyses were performed using SPSS version 24.

#### Results

In 214 participating homes, 2719 staff members were identified and 1716 responded to the questionnaire (overall response rate 63.1%). Of these, 39.9% of the respondents were nurses and 60.1% were care assistants. Fig. 1 shows the response rates per country.

# Characteristics of the Study Sample

All characteristics, that is, age, gender, professional role, formal training, and nursing home type, differed significantly between the countries (P < 0.001). In Belgium, England, and Italy, the age group 17-35 years was the largest (range between 40.4% and 55.5%) (Table 1). Staff in the Netherlands and Poland were significantly older, with the majority aged between 36 and 50 years (range between 38% and 52.9%). In all countries, most of the participating staff were women, the percentage differed significantly among countries from a low of 67.3% in Italy to a high of 94.3% in the Netherlands. In Italy, most of the responding staff were nurses (99.4%); in the other countries, the majority were care assistants (between 53.1% and 85.8%). In most countries except England, a substantial proportion of the staff had undertaken formal training in palliative care (46.2%-60.9%).

The extent to which staff agree with the basic principles of palliative care in the different countries

The overall score of agreement ranged between 3.36 in England and 1.82 in Italy (scale 0 to 5; Table 2). Staff in Belgium, the Netherlands, and Poland had overall scores of 2.91, 2.87, and 2.48, respectively.

In all countries except Italy, most of the staff rightly disagreed that the aim of palliative care is treatment of pain only (Table 2). The percentage of staff disagreeing with this statement varied from 58% in Poland to 82% in Belgium (odds ratio: 0.12, 95% confidence interval [CI]: 0.07-0.19). Just over half of the staff in Belgium, England, Poland, and Italy rightly disagreed that palliative care starts in the last weeks of life (51% -64%). In the Netherlands, only 46% disagreed with this statement (odds ratio: 0.35, 95% CI: 0.24-0.51). In all countries, most of the staff agreed that palliative care includes spiritual care (62%-76%, P = 0.006) and that palliative care includes care for residents' family/relatives (56%-92%, P < 0.001). For these four statements, staff in Belgium showed a higher level of agreement with the palliative care principles than the staff in the other countries. With the exception of the staff in England (50%) and Poland (53%), only a minority agreed that palliative care and intensive life-prolonging treatment can be combined (24%-44%). For this statement, staff in Belgium showed the lowest level of agreement with the palliative care principles, resulting in a higher overall score for England than for Belgium.

# Characteristics Associated With the Overall Score of Agreement

Characteristics significantly associated with the overall score of agreement were country, professional role, and

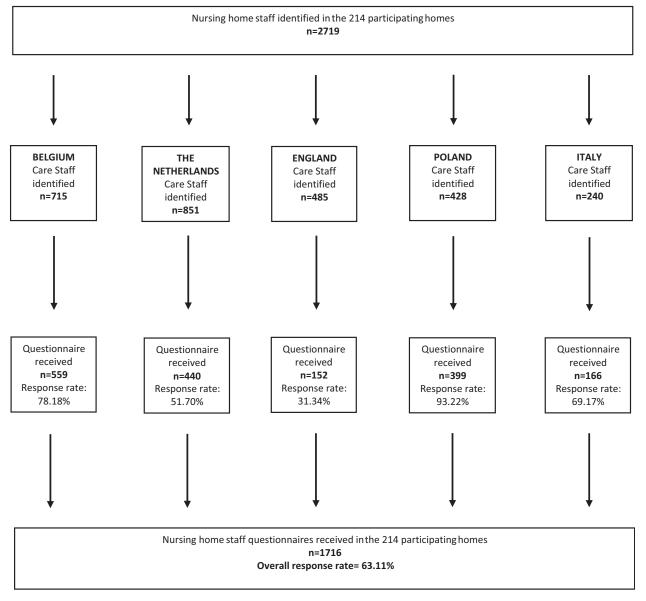


Fig. 1. Flowchart of identified respondents (nursing home care staff) in the 6 countries.

formal training (Table 3). Compared with those in Belgium, staff in England more often agreed with the basic palliative care principles (estimated difference: 0.45; 95% CI: 0.10–0.81, P=0.01), whereas staff in Poland and Italy agreed less often. No significant difference was found between Belgium and the Netherlands. Furthermore, we found that nurses more often agreed with the basic palliative care principles than did care assistants (0.59; 95% CI: 0.43–0.75, P<0.001) and thus had higher overall scores of agreement.

Staff who had undertaken formal training were more likely to agree with the principles than those who had not (estimated difference: 0.21; 95% CI: 0.08-0.34, P=0.002). Staff older than 35 years more often agreed as well (estimated difference: 0.26; 95% CI: 0.09-0.43, P=0.003), also those

aged between 36 and 50 years (estimated difference: 0.28; 95% CI: -0.08-0.48, P=0.006). Gender and type of nursing home were not associated with agreement.

## Discussion

Overall, we found large heterogeneity in the extent to which nursing home staff (nurses and care assistants) agreed with the basic principles of palliative care but with room for improvement in all countries, especially in Italy and Poland. The level to which staff agreed with the principles was significantly associated with country, age, professional role, and formal training, with older staff having a higher score of agreement than younger staff, as had nurses

 Table 1

 Characteristics of the Participating Nursing Home Staff

Characteristics	Belgium $n = 559 (\%)$	The Netherlands $n = 440 \ (\%)$	England $n = 152 (\%)$	Poland n = 399 (%)	Italy n = 166 (%)	Bivariate <i>P</i> -value <sup>a</sup>
Age						<0.001
17–35 years	224 (40.4)	128 (29.5)	61 (41.2)	67 (17.1)	86 (55.5)	<b>\0.001</b>
36–50 years	201 (36.3)	165 (38)	46 (31.1)	207 (52.9)	59 (38)	
>50 years	129 (23.3)	141 (32.5)	41 (27.7)	117 (30)	10 (6.5)	
Gender	()	()	( ,	(/	( , , , ,	< 0.001
Female	495 (88.6)	412 (94.3)	139 (92.7)	371 (94.2)	107 (67.3)	
Male	64 (11.4)	25 (5.7)	11 (7.3)	23 (5.8)	52 (32.7)	
Professional role	,		,			< 0.001
Care or nursing assistant	297 (53.1)	374 (85.8)	115 (77.2)	235 (58.9)	1 (0.6)	
Nurse	262 (46.9)	62 (14.2)	34 (22.8)	164 (41.1)	156 (99.4)	
Formal training in palliative care			( )	,	,	< 0.001
No	232 (44.2)	182 (41.7)	121 (82.3)	151 (39.1)	86 (53.8)	
Yes <sup>b</sup>	293 (55.8)	254 (58.3)	26 (17.7)	235 (60.9)	74 (46.2)	
Working in which type of nursing						< 0.001
home						
Type 1	NA	172 (42.6)	NA	130 (32.6)	63 (38)	
Type 2	537 (100)	232 (57.4)	101 (67.8)	269 (67.4)	103 (62)	
Type 3	NA	NA	48 (32.2)	NA	NA	

NA = not available in that particular country.

Significant results are indicated in bold.

compared with care assistants and staff who had undertaken palliative care training compared with those who had not.

Although all countries had room to improve, the level of agreement varied greatly across countries. Staff in England more often agreed with the principles. Not surprising given that the UK ranked first in the 2015 Quality of Death Index and reached a top score in quality of palliative care globally.<sup>32</sup> On the other hand, the extent to which staff in Italy and Poland agreed with the principles was lower than that in the other countries. This finding corroborates what was found in another PACE study: staff working in nursing homes in these countries often lack basic knowledge of end-of-life care.<sup>17</sup> Froggatt et al. showed<sup>26</sup> that in these countries, there are few initiatives on development of palliative care in nursing homes. The extent to which nursing homes engage with palliative care initiatives and the degree of national investment in palliative care development in the nursing home setting seems to be related to the level of understanding of the basic principles of palliative care in nursing home staff.

Nevertheless, in the other countries, a substantial number of staff also did not completely agree with the principles of palliative care, a finding in line with earlier studies. <sup>21–23</sup> This means that either they were not familiar with, or they disagreed with, the essence of palliative care. It is quite alarming that staff lack a basic level of understanding of palliative care, considering that nursing home residents spend the last months and years of their lives there and stays are becoming shorter also. The finding is in line with more general studies that found that among all

types of health-care professionals, many are not familiar with the meaning and availability of palliative care. <sup>33,34</sup> Our study confirms that palliative care is in some cases (25%) still perceived as "terminal care" (cfr. Table 4: *Palliative care starts in the last week of life*). Lack of understanding of the meaning of palliative care may have negative implications for the quality of care for residents with serious conditions receiving inadequate pain and symptom treatment and psychosocial support throughout their illness trajectory.

The fact that nurses agreed more often with the principles of palliative care than did care assistants is probably due to the difference in education and expertise between the two groups. A previous PACE article<sup>17</sup> showed that nurses have better knowledge of end-of-life care than care assistants. In most countries, care assistants are responsible for direct patient care. 19 Considering budgetary constraints and shortage of personnel, this group will become more and more crucial in the future. Therefore, it is most important to train them in basic palliative care. Besides education, cultural diversity can play a role in the difference in agreement between nurses and care assistants because cultural diversity can not only explain the difference between countries but possibly also between professions. In the United States, for example, many care assistants have a minority or immigrant background. 35,36 A cultural background influences end-of-life decision-making and may result in inconsistency with values of traditional Western-based medicine.<sup>37</sup>

Additionally, we found that staff who had undertaken training in palliative care more often agreed with the principles of palliative care than those who

<sup>&</sup>lt;sup>a</sup>Generalized linear mixed model reporting *P*-value for country as a fixed effect,  $\alpha = 0.05$ .

<sup>&</sup>lt;sup>b</sup>Training in palliative care as part of degree or as additional training after degree.

Extent to Which Nursing Home Staff Agree With Basic Principles of Palliative Care (Percentages and Odds Ratios) and Overall Score of Agreement With the Principles of Palliative Care

Measurements         N(%)         Ref         N(%)         OR (95% CI)         N(%)         N(%)		Belgium $n = 559$		The Netherl	The Netherlands $n = 440$	Engl	England $n = 152$	Pol	Poland $n = 399$	Ita	Italy $n = 166$
related to the WHO definition of palliative care 450 (82) — 344 (79) 0.74 (0.41–1.32) 119 (81) 0.83 (0.37–1.87) 226 (58) 0.12 (0.07–0.19)  st 353 (64) — 201 (46) 0.35 (0.24–0.51) 92 (63) 0.85 (0.5–1.44) 201 (51) 0.41 (0.28–0.60)  n 415 (76) — 297 (68) 0.81 (0.56–1.77) 104 (73) 1.16 (0.70–1.90) 292 (75) 0.91 (0.62–1.34) 1  503 (92) — 372 (86) 0.58 (0.34–0.99) 112 (80) 0.39 (0.21–0.75) 245 (63) 0.11 (0.07–0.18)  e 2.91 — 2.87 — 3.36 — 2.48	Measurements	N(%)	Ref	N (%)	OR (95% CI)	N (%)	OR (95% CI)	N (%)	OR (95% CI)	N (%)	OR (95% CI)
st 353 (64) — 201 (46) <b>0.35 (0.24—0.51)</b> 92 (63) 0.85 (0.5—1.44) 201 (51) <b>0.41 (0.28—0.60)</b> 129 (24) — 140 (33) <b>1.51 (1.07—2.12)</b> 72 (50) <b>3.41 (2.21—5.26)</b> 208 (53) <b>3.48 (2.49—4.86)</b> 415 (76) — 297 (68) 0.81 (0.56—1.77) 104 (73) 1.16 (0.70—1.90) 292 (75) 0.91 (0.62—1.34) 1  503 (92) — 372 (86) <b>0.58 (0.34—0.99)</b> 112 (80) <b>0.39 (0.21—0.75)</b> 245 (63) <b>0.11 (0.07—0.18)</b> e 2.91 — 2.87 — 3.36 — 2.48	Opinions toward the principles rela a. The aim of palliative care is	ited to the WHO def 450 (82)	finition —	_	care 0.74 (0.41–1.32)	(119 (81)	0.83 (0.37–1.87)	226 (58)		(137)	0.08 (0.04–0.14)
st 353 (64) — 201 (46) <b>0.35 (0.24—0.51)</b> 92 (63) 0.85 (0.5—1.44) 201 (51) <b>0.41 (0.28—0.60)</b> 129 (24) — 140 (33) <b>1.51 (1.07—2.12)</b> 72 (50) <b>3.41 (2.21—5.26)</b> 208 (53) <b>3.48 (2.49—4.86)</b> 1415 (76) — 297 (68) 0.81 (0.56—1.77) 104 (73) 1.16 (0.70—1.90) 292 (75) 0.91 (0.62—1.34) 11  503 (92) — 372 (86) <b>0.58 (0.34—0.99)</b> 112 (80) <b>0.39 (0.21—0.75)</b> 245 (63) <b>0.11 (0.07—0.18)</b> c 2.91 — 2.87 — 3.36 — 2.48	treatment of pain only (DISAGREE)										
129 (24)	b. Palliative care starts in the last weeks of life (DISAGREE)	353 (64)	I	201 (46)	$0.35 \ (0.24-0.51)$	92 (63)	0.85 (0.5-1.44)	201 (51)		81 (51)	$0.56 \ (0.34-0.94)$
and 415 (76) — 297 (68) 0.81 (0.56–1.77) 104 (73) 1.16 (0.70–1.90) 292 (75) 0.91 (0.62–1.34) (503 (92) — 372 (86) <b>0.58 (0.34–0.99)</b> 112 (80) <b>0.39 (0.21–0.75)</b> 245 (63) <b>0.11 (0.07–0.18)</b> (2.91	c. Palliative care and intensive	129 (24)	I	140 (33)	$1.51 \ (1.07 - 2.12)$	72 (50)	3.41 (2.21 - 5.26)	208 (53)	3.48 (2.49-4.86)	73 (44)	3.25 (2.07-5.10)
415 (76) — 297 (68) 0.81 (0.56–1.77) 104 (73) 1.16 (0.70–1.90) 292 (75) 0.91 (0.62–1.34)  503 (92) — 372 (86) <b>0.58 (0.34–0.99)</b> 112 (80) <b>0.39 (0.21–0.75)</b> 245 (63) <b>0.11 (0.07–0.18)</b> 2.91	life-prolonging treatment can be combined (AGREE)										
503 (92) — 372 (86) <b>0.58 (0.34—0.99)</b> 112 (80) <b>0.39 (0.21—0.75)</b> 245 (63) <b>0.11 (0.07—0.18)</b> ss 2.91 2.87 3.36 2.45	d. Palliative care includes	415 (76)		297 (68)	0.81 (0.56-1.77)		1.16 (0.70-1.90)			100 (62)	$0.32 \ (0.19-0.53)$
503 (92) — 372 (86) <b>0.58 (0.34—0.99)</b> 112 (80) <b>0.39 (0.21—0.75)</b> 245 (63) <b>0.11 (0.07—0.18)</b> ss 2.91 2.87 3.36 2.48	spiritual care (AGREE)										
2.91 2.87 3.36 e	e. Palliative care includes care	503 (92)		372 (86)		112 (80)	0.39 (0.21 - 0.75)	245 (63)		92 (56)	0.06 (0.03 - 0.11)
e 2.91 2.87 3.36	for resident's family/relatives (AGREE)										
the principles of palliative care	Overall score of agreement with	2.91		2.	87	33.	98	2.	.48	Τ.	1.82
	the principles of palliative care										

Generalized linear mixed model reporting Pvalue for country as a fixed effect,  $\vec{\alpha} = 0.05$ . The model accounted for the clustering at the level of homes and adjusted for age, gender, professional role, and training in palliative care. Numbers in bold represent statistically significant differences with Belgium. Abbreviations: Ref., reference category; OR, odds ratio; WHO, World Health Organization.

had not. Similar results were reported in earlier studies; taking part in training has a positive influence on the opinions of staff, and a lack of training can lead to negative attitudes, which can affect care outcomes. 38–40

Currently, effective palliative care training is not always included in curricula for nurses and care assistants. 19 Some training and online courses exist; however, these are often limited to certain communities. 41,42 The following training elements are shown to be the most effective ones: a hands-on approach, innovative training strategies, managerial support, and the use of role modeling. 43-46 More and better education and training is thus needed to promote the better understanding of palliative care and to encourage its timely use for nursing home residents. A second important strategy is to bring about a cultural shift regarding palliative care in nursing homes. Initiatives such as the PACE Steps to Success Programme can contribute to making such a shift by integrating palliative care into mainstream care and can raise awareness of palliative care in nursing home staff.47

# Strength and Limitations

This study has several strengths. First, this is the first large-scale international study to describe and compare the extent to which nursing home staff across five European countries agree with the basic principles of palliative care. We were able to include 1716 staff members from 214 homes in five countries, providing cross-country comparable data. Second, this is the first international study that analyses the characteristics associated with the overall score of agreement. Third, the overall response rate was 63%. For all countries, except England (31%), the response rates were high, ranging from 52% to 93%.

This study also has some limitations. We must acknowledge that when speaking of levels of agreement, it is implied that people know something about the topic and agree or disagree with it. However, in this study, it is also possible that staff might disagree with the principles of palliative care because of a lack of understanding. Second, staff who had undertaken formal training in palliative care might be more disposed to answer the questionnaire than those who did not, resulting in a possible response bias. Third, although response rates were high in most countries, the response rates were low in England (31%) and the Netherlands (51.7%), which might have caused bias. Finally, although multiple studies have linked staff attitudes to negative implications for the quality of care, it remains uncertain how attitudes regarding palliative care translate into actual care practices.

Table 3

Association of Overall Score of Agreement With Principles of Palliative Care of Nursing Home Staff and Their Characteristics

	Agreement With the Principles of Palliative Care								
Measurements	Estimated Difference (95% CI)	Adjusted <i>P</i> -Value <sup>a</sup>							
Predictors									
Intercept	$2.91\ (2.55 - 3.28)$	< 0.001							
Country									
Belgium	Ref								
The Netherlands	-0.04 (-0.30  to  0.22)	0.75							
England	0.45 (0.10-0.81)	0.01							
Poland	$-0.43 \ (-0.69 \ \text{to} \ -0.17)$	0.001							
Italy	-1.09 (-1.42  to  -0.75)	< 0.001							
Age	,								
17–35 years	Ref.								
36-50 years	$0.26 \ (0.09 - 0.43)$	0.003							
>50 years	$0.28 \ (-0.08 \ \text{to} \ 0.48)$	0.006							
Gender	,								
Male	Ref.								
Female	-0.12 (-0.33  to  0.10)	0.28							
Professional role	,								
Care or nursing	Ref.								
assistant									
Nurse	0.59 (0.43 - 0.75)	< 0.001							
Training in	,								
palliative care									
No	Ref.								
Yes <sup>b</sup>	$0.21 \ (0.08 - 0.34)$	0.002							
Nursing home type									
Type 1	Ref.								
Type 2	$0.07 \ (-0.17 \ \text{to} \ 0.30)$	0.58							
Type 3	-0.27 (-0.83  to  0.29)	0.35							
Variances									
Residual effect	1.38 (1.27-1.49)	< 0.001							
Random effect—	0.14 (0.08-0.24)	0.001							
nursing home									
ICC	0.09								

ICC = intraclass correlation coefficient.

Missing data in analysis: 219 (9.6%).

Significant results are indicated in bold.

"Multiple linear mixed model analysis with nursing home as random effect and country, age, gender, professional role, type of nursing home, and training in palliative care as covariates.

# Conclusion

Given the rise of chronic diseases and complex care needs among nursing home residents, optimal palliative care in this setting is essential. To be able to provide high-quality palliative care to a growing number of nursing home residents, nursing home staff need to possess at least a basic level of understanding of palliative care. This study shows that the extent of agreement of nursing home staff with the basic principles of palliative care differs between countries, with room for improvement in all. For that reason, palliative care needs to become an integral part of all nursing school curricula and health-care trainings, as well as of continuing education programme offerings. Also, a cultural shift regarding palliative care in nursing homes is needed.

# Disclosures and Acknowledgments

Ms. Honinx reports receiving a fee from Polish Ministry of Science and Higher Education based on the decision no 3202/7PR/2014/2 and a grant from European Union's Seventh Framework Programme (FP7/2007e2013), during the conduct of the study.

Ethics approval and consent to participate: Ethics approval from the relevant ethics committees were obtained in all participating countries—Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: National Health Service—National Research Ethics Service Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; the Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, general practitioners) have to give their prior informed consent in writing. If residents are unable to give informed consent, they will not be involved in the study. In some countries, such as Poland and the Netherlands, a separate informed consent is not required if questionnaires are filled in anonymously.

Consent for publication: Not applicable.

Availability of data and material: The data sets used and/or analyzed during the present study are available from the corresponding author on reasonable request.

Funding: Project has been cofunded by Polish Ministry of Science and Higher Education in the years 2014–2019 based on the decision no 3202/7PR/2014/2 dated November 25, 2014. This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis, or interpretation of the data, nor in writing and the decision to submit this article for publication.

The authors thank all participating physicians, nurses, patients, and their families for providing data for this study; Roos Colman for her advice on data analysis; and Jane Ruthven for her language editing.

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Nele Van Den Noortgate, Katherine Froggatt, Bregje Onwuteaka-Philipsen, Katarzyna Szczerbińska, Mariska Oosterveld-Vlug, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo

<sup>&</sup>lt;sup>b</sup>Training in palliative care as part of degree or additional training after degree.

Table 4

Extent to Which Long-Term Care Nursing Home Nurses and Care Assistants Agree or Disagree With the Principles of Palliative Care (Percentages)

Principles Related to the WHO Definition		Belgium $n = 559$		The	Netherla $n = 440$	nds		England $n = 152$			Poland $n = 399$			Italy $n = 166$		_	Total $N = 1716$	;
of Palliative Care	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)
a. The aim of palliative care is treatment of pain only	82	13	5	79	15	7	81	13	6	58	10	32	37	33	30	71	15	14
b. Palliative care starts in the last weeks of life	64	20	16	46	21	33	63	17	18	51	18	30	51	25	22	55	20	25
c. Palliative care and intensive life- prolonging treatment can be combined	42	32	24	34	32	33	16	31	72	19	27	53	18	37	44	31	32	37
d. Palliative care includes spiritual care	3	20	76	7	25	68	6	19	73	8	17	75	8	30	62	6	22	72
e. Palliative care includes care for resident's family/ relatives	2	5	92	4	10	86	8	11	80	15	21	63	11	33	56	7	14	79

D = disagree; N = neither agree nor disagree; A = agree; WHO = World Health Organization.

Hockley, Suvi Leppäaho, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Paula Andreasen, Outi Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud 10 Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

# References

- 1. Marengoni A, Angleman R, Melis R, et al. Aging with multimorbidity: a systematic review of the literature. Ageing Res Rev 2011;10:430–439.
- 2. Wowchuk MS, McClement S, Bond J Jr. The challenge of providing palliative care in the nursing home part II: internal factors. Int J Palliat Nurs 2007;13:345–350.
- 3. World Health Organization. Strengthening of palliative care as a component of integrated treatment within the continuum of care, EB134/R7, 134th session, Geneva, 2014:1–6.
- 4. Szczepura A. Residential and nursing homes: how can they meet the challenge of an aging population? Aging health 2011;7:877–887.
- 5. Spilsbury K, Hanratty B, McCaughan D. Supporting nursing in care homes 2015. Available from https://www.kingsfund.org.uk/sites/files/kf/media/Karen Spilsbury pres.pdf. Accessed May 22, 2019.
- 6. Connor SR, Bermedo MCS. Global atlas of palliative care at the end of life, Worldwide hospice palliative care alliance. 2014 2017. Available from <a href="http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care">http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care</a>. Accessed May 23, 2017.
- 7. Onder G, Carpenter I, Finne-Soveri H, et al. the SHEL-TER project. Assessment of nursing home residents in Europe: the Services and health for Elderly in long TERm care (SHELTER) study. BMC Health Serv Res 2012;12:5.
- 8. Norton SA, Ladwig S, Caprio TV, Quill TE, Temkin-Greener H. Staff experiences forming and sustaining palliative care teams in nursing homes. Gerontologist 2018;58: e218–e225.
- 9. Temkin-Greener H, Mukamel DB, Ladd H, et al. Impact of nursing home palliative care teams on end-of-life outcomes. Med Care 2018;56:11—18.
- 10. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization, License: CC BY-NC-SA 3.0 IGO, 2018:5—52.
- 11. Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. Lancet Oncol 2018;19:e588—e653.
- 12. Krüger K, Jansen K, Grimsmo A, Eide GE, Geitung JT. Hospital admissions from nursing homes: rates and reasons. Nurs Res Pract 2011;2011:247623.
- 13. Lemoyne SE, Herbots HH, De Blick D, Remmen R, Monsieurs KG, Van Bogaert P. Appropriateness of transferring nursing home residents to emergency departments: a systematic review. BMC Geriatr 2019;19:17.

- 14. Hanson LC, Reynolds KS, Henderson M, Pickard CG. A quality improvement intervention to increase palliative care in nursing homes. J Palliat Med 2005;8:576–584.
- 15. Hanson LC, Ersek M. Meeting palliative care needs in post-acute settings: "To help them live until they die". JAMA 2006;295:681–686.
- **16.** Brazil K, Bédard M, Krueger P, et al. Barriers to providing palliative care in long-term care homes. Can Fam Physician 2006;52:472–473.
- 17. Smets T, Pivodic L, Piers R, et al. The palliative care knowledge of nursing home staff: the EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries. PalliativeMedicine 2018;32:1487—1497.
- 18. Brazil K, Brink P, Kaasakainen S, Kelly ML, McAiney C. Knowledge and perceived competence among nurses caring for the dying in long-term care homes. Int.J Palliat Nurs 2012;18:77–83.
- 19. Stillman D, Strumpf N, Capezuti E, Tuch H. Staff perceptions concerning barriers and facilitators to end-of-life care in the nursing home. Geriatr Nurs 2005;26:259–264.
- **20.** Gamondi C, Larkin P, Payne S. Core competencies in palliative care: an EAPC White paper on palliative care education part 1. Eur J Palliat Care 2013;20:86—145.
- 21. Maria K, Evanthia V, Petros KA, Dimitris N. Assessment of knowledge and associated factors towards palliative care among Greek nurses. World J Social Sci Res 2016;3:381.
- 22. Ronaldson S, Hayes L, Carey M, Aggar C. A study of nurses' knowledge of a palliative approach in residential aged care facilities. Int J Old People Nurs 2008;3:258–267.
- 23. Chover-Sierra E, Martínez-Sabater A, Lapeña-Moñux Y. Knowledge in palliative care of nursing professionals at a Spanish hospital. Rev Lat Am Enfermagem 2017;25:e2847.
- 24. Van den Block L, Smets T, van Dop N, et al. Comparing palliative care in care homes across Europe (PACE): protocol of a cross- sectional study of deceased residents in 6 EU countries. J Am Med Dir Assoc 2016;17:566.
- 25. Reitlinger E, Froggatt K, Brazil K, et al. Palliative care in long-term care settings for older people: findings from an EAPC taskforce. Eur J Palliat Care 2013;20:251—253.
- **26.** Froggatt K, Payne S, Morbey H, et al. Palliative care development in European care homes and nursing homes: application of a typology of implementation. J Am Med Directors Assoc 2017;18. 550.e7–550.e14.
- 27. Froggatt K, Reitinger E, Heimerl K, et al. Palliative care in long-term care settings for older people. Milan, Italy: EAPC Onlus, 2012:2010–2012.
- 28. Research Ready Care Home Network | ENRICH. Available from http://www.enrich.nihr.ac.uk/pages/research-ready-care-home-network. Accessed May 22, 2019.
- 29. Honinx E, Van Dop N, Smets T, et al. Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries, Belgium. Manuscript accepted for publication with *BMC Public Health*, 2019:1–24.
- 30. Witkamp FE, van Zuylen L, van der Rijt CCD, van der Heide A. Validation of the Rotterdam MOVE2PC questionnaire for assessment of nurses' knowledge and opinions on palliative care. Res Nurs Health 2013;36:512—523.
- **31.** Dewolf L, Koller M, Velikova G, Johnson C, Scott N, Bottomley A. EORTC quality of life group translation procedure. Brussels: EORTC, 2009:1–24.

- 32. The Economist Intelligence Unit. The 2015 Quality of Death Index Ranking: palliative care across the world. EIU Perspectives. Available from https://eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf. Accessed March 4, 2019.
- 33. Berry LL, Castellani R, Stuart B. The branding of palliative care. J Oncol Pract 2016;12:48–50.
- 34. Buss MK, Rock LK, McCarthy EP. Understanding palliative care and Hospice. Mayo Clinic Proc 2017;92:280–286.
- **35.** Sloane PD, Williams CS, Zimmerman S. Immigrant status and intention to leave of nursing assistants in U.S. Nursing homes. J Am Geriatr Soc 2010;58:731–737.
- **36.** Smiley RA, Lauer P, Bienemy C, et al. The 2017 national nursing workforce survey. J Nurs Regul 2018;9:S1–S88.
- **37.** Bullock K. The influence of culture on end-of-life decision making. J Soc Work End Life Palliat Care 2011;7:83—98.
- 38. Janssen AL, MacLeod RD, Walker ST. Recognition, reflection, and role models: Critical elements in education about care in medicine. Palliat Support Care 2008;6: 389–395.
- **39.** Kassa H, Murugan R, Zewdu F, Hailu M, Woldeyohannes D. Assessment of knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospitals, Addis Ababa, Ethiopia. BMC Palliat Care 2014;13:6.
- **40.** Vejlgaard T, Addington-Hall JM. Attitudes of Danish doctors and nurses to palliative and terminal care. Palliat Med 2005;19:119–127.

- 41. Pesut B, Robinson CA, Bottorff JL. Among neighbours: an ethnographic account of responsibilities in rural palliative care. Palliat Support Care 2013;12:127–138.
- 42. Kaasalainen S, Brazil K, Wilson D, et al. Palliative care nursing in rural and urban community settings: a comparative analysis. Int J Palliat Nurs 2011;17:344–352.
- 43. Callahan MF, Breakwell S, Suhayda R. Knowledge of palliative and end-of-life care by student registered nurse anesthetists. AANA J 2011;79:S15—S20.
- 44. Saylor J, Vernoony S, Selekman J, Cowperthwait A. Interprofessional education using a palliative care simulation. Nurse Educ 2016;41:125—129.
- 45. McDonnell MM, McGuigan E, McElhinney J, McTeggart M, McClure D. An analysis of the palliative care education needs of RGNs and HCAs in nursing homes in Ireland. Int J Palliat Nurs 2009;15:446. 448-455.
- 46. Pennbrant S, Tomaszewska M, Lorentzson Penttilä G. Nurses' experience of caring for palliative-stage patients in a hospital setting in Sweden. Clin Nurs Stud 2015;3, https://doi.org/10.5430/cns.v3n2p97.
- 47. Smets T, Onwuteaka-Philipsen BBD, Miranda R, et al. PACE trial group. Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the "PACE Steps to Success" intervention in seven countries. BMC Palliat Care 2018; 17:47.