


Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study

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Abstract

Background: Nursing homes are among the most common places of death in many countries.

Aim: To determine the quality of dying and end-of-life care of nursing home residents in six European countries.

Design: Epidemiological survey in a proportionally stratified random sample of nursing homes. We identified all deaths of residents of the preceding 3-month period. Main outcomes: quality of dying in the last week of life (measured using End-of-Life in Dementia Scales – Comfort Assessment while Dying (EOLD-CAD)); quality of end-of-life care in the last month of life (measured using Quality of Dying in Long-Term Care (QoD-LTC) scale). Higher scores indicate better quality.

Setting/participants: Three hundred and twenty-two nursing homes in Belgium, Finland, Italy, the Netherlands, Poland and England. Participants were staff (nurses or care assistants) most involved in each resident's care.

Results: Staff returned questionnaires regarding 1384 (81.6%) of 1696 deceased residents. The End-of-Life in Dementia Scales – Comfort Assessment while Dying mean score (95% confidence interval) (theoretical 14–42) ranged from 29.9 (27.6; 32.2) in Italy to 33.9 (31.5; 36.3) in England. The Quality of Dying in Long-Term Care mean score (95% confidence interval) (theoretical 11–55) ranged from 35.0 (31.8; 38.3) in Italy to 44.1 (40.7; 47.4) in England. A higher End-of-Life in Dementia Scales – Comfort Assessment while Dying score was associated with country ($p = 0.027$), older age ($p = 0.012$), length of stay ≥ 1 year ($p = 0.034$), higher functional status ($p < 0.001$). A higher Quality of Dying in Long-Term Care score was associated with country ($p < 0.001$), older age ($p < 0.001$), length of stay ≥ 1 year ($p < 0.001$), higher functional status ($p = 0.002$), absence of dementia ($p = 0.001$), death in nursing home ($p = 0.033$).

Conclusion: The quality of dying and quality of end-of-life care in nursing homes in the countries studied are not optimal. This includes countries with high levels of palliative care development in nursing homes such as Belgium, the Netherlands and England.

Keywords

Nursing home, terminal care, palliative care, quality of health care, epidemiologic research design

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What is already known about the topic?

- The number of deaths in nursing homes is growing in many countries worldwide.
- Many nursing home residents are affected by multiple chronic progressive illnesses, including frailty and dementia, and thus have complex care needs and high levels of disability and dependence towards the end of life.
- Although there are indications that nursing home residents are underserved by palliative care, the existing epidemiological data on quality of dying in this setting are vastly insufficient to assess needs and guide policy-making.

What this paper adds

- We conducted an epidemiological study of the quality of end-of-life care and quality of dying of nursing home residents as reported by nurses and care assistants in Belgium, Finland, Italy, the Netherlands, Poland and England.
- Although countries differed significantly regarding quality of dying and quality of end-of-life care, all revealed room for improvement, particularly with regard to physical and emotional distress, advance care planning and helping residents achieve closure.
- These findings also applied to countries with relatively high levels of palliative care development in nursing homes (i.e. England, Belgium, the Netherlands).

Implications for practice or policy

- The quality of end-of-life care and quality of dying of nursing home residents in the six European countries studied can potentially be improved.
- The findings suggest that a strong policy base may be an important but not sufficient precondition for high-quality end-of-life care and quality of dying in nursing homes.
- Additional palliative care guidelines and practice tools may be needed.

Introduction

As the world's population is ageing, a rapidly growing number of people will die in old age, affected by chronic progressive illnesses and with complex care needs.^{1,2} In many countries, a large number of older people are admitted to nursing homes or care homes as they near the end of life.³⁻⁵ In some countries, up to one-third of people in need of palliative care die in these settings,⁶ and this figure is expected to rise.⁷ This article uses the term 'nursing home' to refer to 'collective institutional settings where care, on-site provision of personal assistance in daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 h a day, 7 days a week, for an undefined period of time.^{8,9}

While previous research has studied aspects of end-of-life care in nursing home residents (e.g. hospital admissions, hospice use in the United States, resident level outcomes), it has important limitations. Studies included data from only one or two countries at a time and used different outcome measures which prevented comparisons between countries and hence points of reference to judge where improvement may be necessary.^{5,10} Other studies sampled prospectively which means they could not obtain population-based samples of deaths in nursing homes,^{11,12} and yet others reported process measures of care (e.g. hospice use, hospital admissions) but did not report resident level outcome measures.^{13,14} We can conclude that there is insufficient epidemiological data to evaluate the quality of

dying and quality of end-of-life care in nursing homes and to guide policy-making and clinical practice. This is concerning given that research suggests that nursing home residents may be underserved by palliative care,^{3,15} although it is indicated given the life-limiting nature and complex symptoms of the chronic diseases, including dementia, which affect many residents.¹⁶ Quality of end-of-life care reflects elements of the setting in which dying takes place whereas quality of dying refers to symptom burden and other resident outcomes that can be influenced by care and various resident-related factors.^{17,18} Methodological difficulties in obtaining population-based data on the end of life have hampered research on the end of life of nursing home residents. This includes difficulties in determining suitable population denominators, non-response due to poor functional or cognitive status, and ethical concerns about burdening people who are very ill.¹⁹ Several authors have proposed retrospective studies of deaths as a valuable solution, in particular for large-scale epidemiological studies,^{12,19} and the number of such studies in palliative care research is growing.²⁰⁻²²

We report the main outcomes of the European PACE study in nursing homes in six European countries.^{16,23} The research questions were as follows:

1. What is the quality of dying and quality of end-of-life care of nursing home residents in six European countries according to staff members (nurses and care assistants) most involved in care, and are there differences between countries?

2. To what extent are country, resident or nursing home characteristics associated with quality of dying and quality of end-of-life care in nursing homes?

Methods

Study design

PACE (Palliative Care for Older People in Care and Nursing Homes in Europe) is an epidemiological survey study of deceased residents of nation-wide representative samples of nursing homes in Belgium (Flanders), Finland, Italy, the Netherlands, Poland and England.²³ We identified all deaths of residents that occurred over the period of 3 months prior to the distribution of questionnaires. The main outcome was quality of dying and quality of end-of-life care as reported by the staff member most involved in each deceased resident's care. The study methods are described in detail elsewhere.²³

Setting

The data were collected in 2015. The selected countries represent various stages of palliative care development in nursing homes in terms of policies and activities regarding palliative care in this sector. Previous research has described higher levels of palliative care development in nursing homes in Belgium, the Netherlands and England compared to Finland, Italy and Poland.²⁴

Sampling

Based on an expected minimum of four deaths per nursing home over 3 months, we determined that we needed to sample 48 facilities per country to achieve a sufficiently large sample for this analysis. Details of the sample size calculation have been published with the study protocol.²³ We sampled nursing homes in each country through proportional stratified random sampling to obtain representative samples in terms of region within country, nursing home type and bed capacity. We sampled from national lists of nursing homes in all countries except Italy, where no national lists exist and a previously created cluster of nursing homes with interest in research participation was used.²⁵ The English team additionally recruited through ENRICH, a network of nursing homes with interest in research participation, to improve the participation rate.

Participants

Questionnaires concerning the deceased resident's care were distributed to (1) the nurse most involved in the care of the deceased resident or a care assistant in case a nurse could not be identified (both henceforth termed 'staff member'); (2) the nursing home administrator/manager/

head nurse (henceforth termed 'administrator'); (3) the resident's treating physician (general practitioner (GP) or elderly care physician).

Procedure

Assisted by a researcher, the administrator identified all deaths, assigned anonymous codes to questionnaires and mailed the questionnaires and up to two reminders (ethics committees allowed one reminder in Poland and England). Respondents mailed the questionnaires directly to the research team.

Measurements

The main outcomes, quality of dying and quality of end-of-life care, were reported by the staff member most involved in care through two validated questionnaires: End-of-Life in Dementia Scales – Comfort Assessment while Dying (EOLD-CAD)²⁶ and Quality of Dying in Long-Term Care (QoD-LTC)²⁷, respectively. The EOLD-CAD assesses quality of dying by measuring symptom burden in the *last week of life* on four subscales: physical distress, dying symptoms, emotional distress, well-being. The QoD-LTC assesses quality of end-of-life care in the *last month of life* on three subscales: personhood, closure, preparatory tasks.¹⁷ Previous reviews have recommended these scales as the most appropriate instruments for measuring quality of dying in mixed nursing home populations (with various levels of cognitive and physical functioning).^{18,28} Functional status 1 month before death was also reported by the staff member and assessed using the Bedford Alzheimer Nursing Severity-Scale (BANS-S).²⁹ The underlying cause of death was based on the clinical judgement of the treating physician, or the staff member, if no information was available from the physician. Dementia was determined as present if *either* the treating physician or the staff member most involved in care indicated so. Dementia was determined as not present if both the treating physician and the staff member indicated that the resident did not have dementia. If neither respondent provided information, the response was recorded as missing. Nursing home administrators reported residents' age, gender, length of stay in the nursing home and place of death, and the nursing home type and status (i.e. public, private non-profit, private for profit).

Analysis

The non-response analysis involved comparing administrator-reported sociodemographic characteristics, place of death and length of stay of residents for whom staff did and did not return questionnaires. Sample characteristics, quality of dying and quality of end-of-life care were reported per country. We reported frequencies for all

items of the EOLD-CAD and QoD-LTC along with estimated marginal means for subscale scores and total scores. The scores were calculated using generalised linear mixed models with nursing home as random factor, and country and residents' sociodemographic and clinical characteristics that differed significantly between countries as covariates.

To determine associations between quality of dying and quality of end-of-life care on one hand, and country, resident and nursing home characteristics on the other hand, we computed two generalised linear mixed models with the total scores of EOLD-CAD and QoD-LTC as dependent variables and nursing home as random factor. Covariates were country, resident characteristics (age, gender, cause of death, functional status, length of stay in the nursing home, place of death, presence of dementia) and nursing home characteristics (nursing home type, nursing home status). All generalised linear mixed models were calculated with random intercepts and without random slopes. We checked all multivariable models for collinearity using variance inflation factors. Hypothesis tests were two-sided. Statistical significance was set at $\alpha < 0.05$. Analyses were conducted in IBM SPSS statistics version 24.

Ethics

The research teams in all participating countries obtained ethical approval from their respective ethics committees or waivers for the collection of data of deceased residents (Netherlands, Italy). All respondents participated on a voluntary basis and remained anonymous. The return of a questionnaire was taken as consent to participate.

Results

Sample and response rates

In 322 participating nursing homes in six countries, we identified 1707 deceased residents, 342 in Belgium, 283 in Finland, 229 in Italy, 329 in the Netherlands, 356 in Poland and 168 in England. A staff member most involved in the resident's care was identified for 1696 residents, and they returned questionnaires for 1384 residents (response rate of 81.6% overall; 85.1% in Belgium; 95.1% in Finland; 91.7% in Italy; 67.5% in the Netherlands; 87.4% in Poland; 54.2% in England). The responding staff member was a nurse for 75% of residents. The non-response analysis did not reveal significant differences between residents for whom staff did or did not return questionnaires in terms of age, gender, place of death or length of stay in the nursing home (see Supplementary Table S1).

The median age at death was lowest in Poland (83 years) and highest in England (89 years) ($p < 0.001$;

Table 1). Between 60% in England and 83% in Finland were judged as having had dementia ($p < 0.001$). The difference between countries in length of stay was significant ($p < 0.001$) with the longest lengths of stay in Netherlands (70% stayed 1 year or more) and particularly short stays in Poland (53% stayed for 6 months or less).

Quality of dying in nursing homes: symptoms in the last week of life (EOLD-CAD)

The estimated marginal means of the EOLD-CAD total score ranged from 29.9 in Italy to 33.9 in England, on a theoretical scale range of 14 through 42 (Table 2).

Pain, discomfort, difficulty swallowing and lack of well-being were the most frequent symptoms within each of the countries studied (Table 2). Between 52% (England) and 90% (Finland) of residents experienced pain in the last week of life. Between 62% (England) and 90% (Finland) experienced discomfort, and between 58% (England) and 81% (Finland) were reported as having had difficulty swallowing. Items of the 'well-being' subscale (i.e. serenity, peace, calm) were reported as 'not at all' or 'somewhat' present in the last week of life in 65% (calm, England) to 97% (serenity, Poland) of residents.

Quality of end-of-life care in nursing homes: personhood, closure and preparatory tasks in the last month of life (QoD-LTC)

The estimated marginal means of the QoD-LTC total score ranged from 35.0 in Italy to 44.1 in England, on a theoretical scale range of 11 through 55 (Table 3). In each of the countries studied, staff reported significantly lower scores (as shown by non-overlapping confidence intervals (CIs)) on the 'preparatory tasks' subscale (estimated means 18.1 in Italy to 39.7 in England) than on the 'personhood' subscale (44.7 (Belgium) to 49.1 (England)). Furthermore, in Belgium, Italy, the Netherlands and England, staff rated 'closure' (33.5 (Italy) to 39.4 (England)) significantly worse than personhood.

Four aspects of quality of end-of-life care were consistently rated as poorest within each of the countries studied (according to aggregated percentages for 'not at all/a little/a moderate amount'): the resident having treatment preferences in writing (35% (England) to 91% (Italy)) the resident's funeral having been planned (41% (England) to 91% (Finland)) the resident indicating that they were prepared to die (54% (Netherlands) to 87% (Italy)), and the resident maintaining their sense of humour (39% (England) to 74% (Belgium)) (Table 3).

Table 1. Characteristics of deceased nursing home residents in six European countries.

Resident characteristics	BE (N = 291)	FI (N = 269)	IT (N = 200)	NL (N = 222)	PL (N = 311)	ENG (N = 91)	p value ^a
Age at time of death, median (IQR)	88 (83–92)	86 (82–91)	87 (81–91)	87 (83–92)	83 (74–89)	89 (85–94)	<0.001
Gender, female, n (%)	174 (64)	169 (64)	136 (68)	138 (67)	195 (64)	66 (75)	0.38
Underlying cause of death, n (%)							<0.001
Cancer	30 (11)	32 (12)	18 (9)	25 (12)	16 (5)	13 (16)	
Cardiovascular disease (excl. CVA)	71 (25)	38 (14)	38 (20)	23 (11)	154 (51)	3 (4)	
Stroke/CVA	30 (11)	20 (8)	31 (16)	11 (5)	45 (15)	9 (11)	
Dementia	61 (22)	118 (45)	22 (11)	61 (28)	25 (8)	22 (27)	
Respiratory disease	38 (13)	15 (6)	27 (14)	2\4 (11)	11 (4)	10 (12)	
Other	53 (19)	42 (16)	58 (30)	74 (34)	51 (17)	26 (31)	
Resident had dementia, n (%)	183 (63)	222 (83)	154 (77)	135 (61)	207 (68)	53 (60)	<0.001
Functional status 1 month before death (BANS-S), median (IQR) ^b	19 (15–22)	20 (17–23)	22 (19–25)	18 (14–21)	23 (20–25)	18 (14–21)	<0.001
Place of death, n (%)							
Nursing home	227 (83)	226 (86)	170 (87)	185 (94)	249 (80)	71 (82)	0.014
Length of stay in nursing home, n (%)							<0.001
Up to 6 months	55 (19)	80 (30)	68 (34)	49 (22)	163 (53)	26 (30)	
6–12 months	33 (12)	20 (8)	21 (11)	18 (8)	23 (8)	8 (9)	
1 year or more	200 (69)	166 (63)	111 (56)	153 (70)	122 (40)	54 (61)	
Respondent for resident, n (%)							<0.001
Nurse most involved in care	245 (85)	251 (94)	197 (100)	97 (44)	212 (70)	36 (40)	
Other staff most involved in care	45 (16)	15 (6)	1 (1)	123 (56)	92 (30)	53 (60)	
Type of nursing home in which resident lived, n (%) ^c							<0.001
Type 1	0 (0)	0 (0)	48 (25)	117 (56)	184 (59)	0 (0)	
Type 2	276 (100)	267 (100)	141 (75)	94 (45)	127 (41)	49 (54)	
Type 3	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	42 (46)	
Status of nursing home in which resident lived, n (%)							0.960
Public non-profit (reference)	135 (49)	211 (80)	66 (35)	211 (100)	201 (65)	2 (2)	
Private non-profit	124 (45)	24 (9)	44 (23)	0 (0)	104 (34)	10 (11)	
Private for profit	17 (6)	28 (11)	79 (42)	0 (0)	4 (1)	79 (87)	

IQR: inter-quartile range; BANS-S: Bedford Alzheimer Nursing Severity-Scale; CVA: cerebrovascular accident.

Missing data: age: n = 55 (4%); gender: n = 57 (4.1%); cause of death: n = 39 (2.8%); length of stay in nursing home: n = 14 (1%); presence of dementia: n = 11 (0.8%); functional status: n = 32 (2.3%); place of death: n = 55 (4.0%); respondent: n = 17 (1.2%); type of nursing home: n = 39 (2.8%), status of nursing home: n = 45 (3.2%).

Percentages are rounded.

^aCalculated using generalised linear mixed model, adjusted for correlation within clusters (nursing homes); 'other' categories not included in calculation of p-values.

^bA higher BANS-S score represents lower functional status (i.e. more problems).

^cType 1: nursing homes with care provided by on-site physicians, nurses and care assistants (present in Italy, Netherlands, Poland); Type 2: nursing homes with care provided by on-site nurses and care assistants and off-site physicians (present in all countries); Type 3: nursing homes with care provided by on-site care assistants and off-site-based nurses and physicians (only in England).

Table 2. Quality of dying in the last week of life (EOLD-CAD items) as judged by nursing home nurses or care assistants in six countries.

EOLD-CAD		BE (N = 291)	FI (N = 269)	IT (N = 200)	NL (N = 222)	PL (N = 311)	ENG (N = 91)	p-value ^a
Subscale	Item	Present 'somewhat' or 'a lot', n (%) ^b						
Physical distress	Discomfort	179 (66)	225 (90)	120 (64)	150 (70)	233 (84)	53 (62)	<0.001
	Pain	188 (69)	230 (90)	116 (61)	175 (80)	258 (89)	45 (52)	<0.001
	Restlessness	181 (66)	164 (65)	126 (67)	149 (68)	203 (71)	55 (65)	0.668
	Shortness of breath	142 (52)	167 (66)	96 (51)	111 (51)	203 (70)	33 (38)	<0.001
Dying symptoms	Choking	167 (61)	42 (17)	54 (29)	92 (42)	171 (61)	4 (5)	<0.001
	Gurgling	120 (44)	178 (70)	70 (37)	107 (50)	128 (46)	13 (16)	<0.001
	Difficulty swallowing	203 (74)	207 (81)	148 (78)	131 (61)	226 (77)	49 (58)	0.003
	Fear	174 (63)	131 (53)	107 (58)	143 (66)	200 (71)	31 (37)	<0.001
Emotional distress	Anxiety	173 (63)	147 (59)	117 (62)	122 (57)	223 (77)	47 (55)	0.149
	Crying	57 (21)	60 (24)	59 (32)	68 (31)	76 (28)	19 (23)	0.034
	Moaning	97 (35)	137 (54)	127 (67)	119 (55)	121 (43)	25 (30)	<0.001
Subscale	Item	Present 'not at all' or 'somewhat', n (%) ^c						
Well-being	Serenity	217 (81)	177 (71)	181 (96)	175 (81)	273 (97)	67 (82)	<0.001
	Peace	211 (77)	167 (66)	180 (96)	149 (69)	253 (91)	56 (66)	<0.001
	Calm	210 (77)	177 (70)	178 (95)	163 (75)	245 (89)	55 (65)	<0.001
Total and subscales ^d								
Estimated marginal means and 95% CIs ^a (theoretical scale range 14 through 42)								
Total score		31.2 (28.9–33.4)	31.1 (28.9–33.3)	29.9 (27.6–32.2)	30.7 (28.5–32.9)	30.2 (28.0–32.4)	33.9 (31.5–36.3)	n/a
Physical distress		31.1 (28.2–34.0)	27.7 (24.9–30.6)	30.9 (27.9–34.0)	29.4 (26.5–32.3)	29.1 (26.2–31.9)	32.2 (29.1–35.4)	
	Dying symptoms	30.5 (27.3–33.6)	30.0 (26.9–33.0)	32.7 (29.5–35.9)	31.1 (28.0–34.1)	29.6 (26.6–32.7)	35.7 (32.4–39.1)	
Emotional distress		33.6 (30.7–36.4)	33.6 (30.7–36.4)	31.5 (28.6–34.4)	32.0 (29.2–34.9)	33.7 (30.8–36.5)	36.0 (32.9–39.1)	
	Well-being	29.8 (26.5–33.2)	33.6 (30.3–36.9)	23.9 (20.4–27.3)	30.6 (27.3–33.9)	27.7 (24.4–31.0)	31.7 (28.1–35.3)	

EOLD-CAD: End-of-Life in Dementia Scales – Comfort Assessment while Dying; CI: confidence interval.

Missing data: EOLD-CAD items: between n = 70 (5.1%) for pain and n = 100 (7.2%) for discomfort; EOLD-CAD total score: n = 92 (6.6%). Percentages are rounded.

^aCalculated using general linear mixed model; adjusted for correlation within clusters (nursing homes) and significant sample differences between countries (age, cause of death, dementia, functional status, place of death, length of stay in nursing home, respondent nurse vs other).

^bn (%) of residents who experienced symptom 'somewhat' or 'a lot' (vs 'not at all'). We report the frequencies for the three response options aggregated to two categories with a view to contrast scores representing very good quality of dying (i.e. all categories above the middle category) with scores that represent poor quality of dying and the middle category. Frequencies for the non-aggregated response categories are reported in Supplementary Table S2.

^cn (%) of residents who experienced state 'not at all' or 'somewhat' (vs 'a lot').

^dTotal scores are averages per subscale/whole scale multiplied by total number of items (i.e. 14). Cases with missing data on more than 25% of items per scale/subscale were excluded from the calculation of the total scores; higher scores indicate higher quality of dying.

Table 3. Quality of end-of-life care in the last month of life (QoD-LTC items) as judged by nursing home nurses or care assistants in six countries.

QoD-LTC	BE (N = 291)	FI (N = 269)	IT (N = 200)	NL (N = 222)	PL (N = 311)	ENG (N = 91)	p-value ^a
Subscale	Not at all/a little/a moderate amount, n (%) ^b						
Personhood	83 (29)	45 (17)	64 (32)	44 (20)	86 (29)	10 (11)	<0.001
There was a nurse or aide with whom resident felt comfortable							
Resident received affectionate touch daily	75 (26)	33 (12)	20 (10)	39 (18)	37 (13)	7 (8)	<0.001
Resident's physician knew her or him as a whole person including life and personality	76 (27)	171 (65)	100 (52)	53 (25)	133 (46)	38 (44)	<0.001
Closure	35 (12)	37 (14)	18 (9)	16 (7)	28 (9)	0 (0)	<0.001
Resident's dignity was maintained	11 (4)	8 (3)	10 (5)	11 (5)	8 (3)	1 (1)	0.003
Resident's clothes and body were kept clean	118 (41)	76 (29)	96 (49)	69 (32)	95 (32)	15 (18)	<0.001
Resident appeared to be at peace	177 (62)	157 (61)	168 (87)	116 (54)	244 (83)	59 (71)	<0.001
Resident indicated that she or he was prepared to die	210 (74)	153 (59)	133 (68)	120 (56)	201 (71)	35 (39)	<0.001
Resident maintained her or his sense of humour	159 (56)	178 (69)	176 (91)	123 (58)	211 (74)	30 (35)	<0.001
Preparatory tasks	195 (70)	225 (91)	153 (81)	97 (48)	196 (71)	35 (41)	<0.001
Resident had treatment preferences in writing	132 (47)	145 (58)	134 (71)	44 (21)	140 (50)	8 (10)	<0.001
Resident's funeral was planned							
Resident had named a decision-maker in the event that she or he was no longer able to make decisions							
Total and subscales ^c	Estimated marginal means and 95% CIs ^a (theoretical scale range 11 through 55)						
Total score	37.7 (34.5–40.8)	38.3 (35.2–41.3)	35.0 (31.8–38.3)	41.3 (38.2–44.5)	39.4 (36.3–42.4)	44.1 (40.7–47.4)	n/a
Personhood	44.7 (41.9–47.6)	45.2 (42.4–48.0)	45.6 (42.6–48.5)	46.4 (43.5–49.2)	45.1 (42.3–47.9)	49.1 (46.1–52.2)	
Closure	35.0 (30.7–39.3)	40.1 (35.9–44.3)	33.5 (29.0–37.9)	39.0 (34.7–43.4)	39.1 (34.8–43.3)	39.4 (34.8–44.0)	
Preparatory tasks	27.6 (21.7–33.4)	23.5 (17.9–29.2)	18.1 (12.1–24.1)	34.3 (28.5–40.1)	29.6 (23.9–35.3)	39.7 (33.6–45.8)	

QoD-LTC: Quality of Dying in Long-Term Care; CI: confidence interval.

Missing data: QoD-LTC items: between n = 34 (2.5%) for resident received affectionate touch and n = 101 (7.3%) for funeral planned; QoD-LTC total score: n = 48 (3.5%).

Percentages are rounded.

^aCalculated using general linear mixed model; adjusted for correlation within clusters (nursing homes) and significant sample differences between countries (age, cause of death, dementia, functional status, place of death, length of stay in nursing home, respondent nurse vs other).^bn (%) of residents for whom respondent answered 'not at all/a little/a moderate amount' (vs 'quite a bit'/'completely'). We report the frequencies for the five response options aggregated to two categories with a view to contrasting scores representing very good or good quality of dying (i.e. all categories above the middle category) with scores that represent poor or very poor quality of dying and the middle category. The frequencies for the non-aggregated response categories are reported in Supplementary Tables S3a and S3b.^cTotal scores are averages per subscale/whole scale multiplied by total number of items (i.e. 11). Cases with missing data on more than 25% of items per scale/subscale were excluded from the calculation of the total scores; higher scores indicate higher quality of dying.

Table 4. Associations between quality of dying (EOLD-CAD and QoD-LTC) and country, resident and nursing home characteristics^a (N = 1384^b).

Country, staff and nursing home characteristics (independent variables)	p-value		Coefficient b (95% CI)	
	EOLD-CAD	QoD-LTC	EOLD-CAD	QoD-LTC
Intercept	<0.001	<0.001	28.31 (24.49 to 32.13)	29.48 (24.55 to 34.40)
Country	0.027	<0.001	ref	ref
BE (reference)	ref	ref	ref	ref
FI	0.692	0.366	0.23 (-0.89 to 1.34)	0.83 (-0.96 to 2.62)
IT	0.098	0.006	-1.16 (-2.53 to 0.21)	-3.23 (-5.53 to -0.93)
NL	0.539	0.001	-0.44 (-1.87 to 0.98)	4.02 (1.68 to 6.36)
PL	0.092	0.138	-1.13 (-2.44 to 0.18)	1.61 (-0.52 to 3.74)
ENG	0.062	0.003	2.16 (-0.11 to 4.44)	5.42 (1.90 to 8.94)
Resident characteristics				
Age	0.012	<0.001	0.05 (0.01 to 0.09)	0.13 (0.08 to 0.17)
Female gender	0.203	0.711	0.44 (-0.23 to 1.10)	0.15 (-0.66 to 0.97)
Cause of death				
Cancer (reference)	ref	ref	ref	ref
Non-cancer	0.069	0.154	1.05 (-0.08 to 2.18)	-1.01 (-2.39 to 0.38)
Length of stay in nursing home	0.095	<0.001	ref	ref
Up to 6 months	ref	ref	ref	ref
6–12 months	0.647	0.048	0.27 (-0.89 to 1.44)	1.45 (0.01 to 2.89)
1 year or more	0.034	<0.001	0.79 (0.06 to 1.52)	1.96 (1.04 to 2.88)
Resident had dementia	0.368	0.001	-0.34 (-1.08 to 0.40)	-1.57 (-2.50 to -0.65)
Functional status 1 month before death (BANS-S) ^c	<0.001	0.002	-0.17 (-0.24 to -0.10)	-0.14 (-0.23 to -0.05)
Resident died in nursing home (vs elsewhere)	0.498	0.033	0.34 (-0.64 to 1.31)	1.28 (0.10 to 2.45)
Nursing home characteristics				
Nursing home type ^d	0.733	0.876	ref	ref
Type 1 (reference)	ref	ref	ref	ref
Type 2	0.923	0.558	0.05 (-1.04 to 1.14)	-0.54 (-2.35 to 1.27)
Type 3	0.448	0.840	1.13 (-1.80 to 4.07)	-0.44 (-4.75 to 3.86)
Nursing home status	0.929	0.080	ref	ref
Public non-profit (reference)	ref	ref	ref	ref
Private non-profit	0.800	0.113	-0.17 (-1.51 to 1.17)	1.27 (-0.30 to 2.83)
Private for profit	0.841	0.057	0.10 (-0.85 to 1.04)	2.06 (-0.06 to 4.17)

EOLD-CAD: End-of-Life in Dementia Scales – Comfort Assessment while Dying; QoD-LTC: Quality of Dying in Long-Term Care; CI: confidence interval; BANS-S: Bedford Alzheimer Nursing Severity-Scale.

^aGeneralised linear mixed models with total scores of EOLD-CAD and QoD-LTC as dependent variable, country, staff and nursing home characteristics as covariates, nursing home as random factor. There was no multicollinearity among independent variables according to variance inflation factors (VIFs) and variance proportions of linear combinations of variables (highest VIF was 1.29; no variables with variance components above 0.5 per linear combination).

^bCases included: for EOLD-CAD: N = 1130 (81.6%); for QoD-LTC: N = 1171 (84.6%); exclusions due to missing data on one or more independent variables per model.

^cHigher BANS-S scores represents lower functional status (i.e. more problems).

^dType 1: nursing homes with care provided by on-site physicians, nurses and care assistants (present in Italy, Netherlands, Poland); Type 2: nursing homes with care provided by on-site nurses and care assistants and off-site physicians (present in all countries); Type 3: nursing homes with care provided by on-site care assistants and off-site-based nurses and physicians (only in England).

Factors associated with quality of dying and quality of end-of-life care in the nursing home

Country was significantly associated with both quality of dying (EOLD-CAD, $p = 0.027$) and quality of end-of-life care (QoD-LTC, $p < 0.001$; Table 4) in the multivariable models. Among resident characteristics, better quality of dying was associated with older age ($p = 0.012$), length of stay in the nursing home of 1 year or more compared with up to 6 months ($p = 0.034$) and better functional status 1 month before death ($p < 0.001$). Better quality of end-of-life care was associated with older age ($p < 0.001$), length of stay in the nursing home of 6 months or longer (compared with up to 6 months; 6–12 months: $p = 0.048$; 1 year or more: $p < 0.001$), better functional status 1 month before death ($p = 0.002$), absence of dementia ($p = 0.001$), and the resident having died in the nursing home compared with another location ($p = 0.033$).

Discussion

Main findings of the study

The responses of nursing home staff on the EOLD-CAD indicate that quality of dying of nursing home residents in all countries studied may require improvement. For considerable proportions of residents, staff reported burden in several symptoms that indicate physical or emotional distress. Staff responses on the QoD-LTC showed that the quality of end-of-life care in the last month of life can also be improved in all countries, in particular with regard to achieving closure and completing preparatory tasks. Country was significantly associated with both the quality of dying and quality of end-of-life care. Staff reported better quality of dying and quality of end-of-life care for residents with a longer stay in the nursing home, residents with a higher functional status 1 month before death and older residents. In addition, staff reported better quality of end-of-life care for residents without dementia and residents who died in the nursing home as opposed to elsewhere.

Quality of dying: symptom burden in the last week of life

A first notable finding of this study is the similarity in the symptoms that staff in different countries reported for large proportions of residents in the last week of life. This concerns pain, discomfort, difficulty swallowing and lack of serenity, peace and calm. These symptoms have also been described in previous studies of the end of life of people with dementia,^{5,30} who make up a large proportion of nursing home residents (in our study between 60% and 83%). A considerable percentage of residents in all countries are thus perceived by staff as

dying with physical and emotional distress. This finding points to an urgent need to determine whether improvements can be made in the systematic assessment, recognition and management of end-of-life symptoms in this population.

Quality of end-of-life care: personhood, closure and preparatory tasks in the last month of life

Across countries, staff consistently rated end-of-life care in terms of personhood (e.g. resident's body and clothes were kept clean) relatively well. Poorer quality of end-of-life care was reported with regard to preparatory tasks (e.g. resident had treatment preferences in writing) and closure (e.g. resident indicated that she or he was prepared to die). This suggests that aspects of general good nursing home care (e.g. preserving dignity, hygiene) may be better established than care that is more closely linked to palliative care and the dying process, such as advance care planning. This is in line with existing literature indicating a low prevalence of advance care plans for nursing home residents.^{31,32} These findings further highlight the need for the integration of a palliative care approach into regular nursing home care.

Factors associated with quality of dying and quality of end-of-life care

Country was significantly associated with both the quality of dying and quality of end-of-life care, independent of sociodemographic and clinical characteristics. Differences between countries may therefore be reflections of differences in the organisation of nursing home care, and particularly integration of palliative care in the nursing home sector.¹⁶ Several resident characteristics were associated with better quality of dying and end-of-life care, for instance a longer stay in the nursing home. This is consistent with findings of previous research showing that residents with a longer stay were more likely to be prescribed drug treatment that can be classified as palliative³³ and less likely to experience undertreatment of non-pain symptoms.³⁴ Staff were also more likely to report poorer quality of end-of-life care in the last month of life (QoD-LTC) for residents with dementia than for residents without dementia, a difference not found on the EOLD-CAD (i.e. symptom burden in the last week of life). This association may reflect the particular challenges related to communication and care planning in dementia.

Implications for policy and practice

The findings of this study highlight the need to recognise 'dying well in nursing homes' as an issue of utmost

importance for clinical practice and public health. Deaths in nursing homes will increase substantially over the coming years and decades, and nursing homes will be the most frequent place of death in England by 2040.³⁵ Our study showed that many nursing home residents were very old and affected by dementia or other diseases that considerably limit physical and cognitive functioning. Many experienced distressing symptoms at the end of life. Residents' length of stay in the facilities is relatively short and will likely continue to decrease, considering that policy in many countries aims to keep older people at home until they reach very high levels of disability.³⁶ The fact that a shorter length of stay was associated with poorer quality of end-of-life care and quality of dying will further complicate the delivery of high-quality care in this population. Countries with a high level of palliative care development in nursing homes (i.e. Belgium, the Netherlands, England) did not perform better in terms of quality of dying and quality of end-of-life care than countries with lower levels of palliative care development (i.e. Poland, Italy, Finland).²⁴ This suggests that palliative care policies or practice frameworks for nursing homes may be an important but not sufficient precondition for high quality of end-of-life care. Next to a strong policy base, additional practice tools and guidelines for nursing homes may be needed.

Strengths and limitations of the study

We obtained nation-wide representative samples of nursing homes in six European countries and cross-nationally comparable data by employing standardised research methods. Retrospective data collection through proxy respondents is the most accurate and feasible method for large-scale population-based epidemiological studies on the end of life and for a uniform time frame (e.g. last month of life).^{12,19} It avoids potential bias inherent in prospective sampling that is caused by underrepresentation of people who live longer than the study follow-up period or who are affected by certain conditions whose terminal phase is often not recognised.³⁷ Our data collection resulted in high staff response rates in all countries except England, where it was satisfactory. As data were collected after death, some might have been difficult for staff to remember. Although we cannot exclude the possibility of recall bias, we did attempt to limit it by including deaths that occurred at most three months before data collection. Studying a 3-month period retrospectively is an established approach in end-of-life care research.^{5,38–40} Although our outcome measures are validated questionnaires, they have not been validated cross-nationally. Differences between countries in staff members' reports of quality of dying and end-of-life care therefore need careful interpretation. Finally, averaging scores of quality of dying and quality of end-of-life care across facilities

means that important differences in quality between facilities cannot be seen.

Conclusion

A considerable proportion of nursing home residents are perceived by staff as dying with physical and emotional distress. Staff rated aspects of general nursing home care at the end of life as being of high quality for the vast majority of residents. However, they rated the quality of end-of-life care as poorer in areas related to palliative care and dying. These problems were reported in all countries, including those with high levels of palliative care integration in nursing homes such as Belgium, the Netherlands or England. The study findings point to an urgent need to review whether improvements can be made in the systematic assessment, recognition and management of end-of-life symptoms and underline the importance of further integration of palliative care in nursing home care.

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Data management and sharing

Data can be obtained from the authors upon reasonable request.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

The research teams in Belgium, Finland, Poland and England obtained ethical approval from their respective ethics committees: Ethics Committee of Brussels University Hospital (143201422845); Committee for Research Ethics of the Ministry for Health and Wellbeing (THL/116/6.02.01/2015); Ethics Committee of Jagiellonian University (122.6120.11.2015); NHS Health Research Authority (15/NW/0205). The research teams in the Netherlands (Medical Ethics Commission of VU University (2014.587) and Italy (Ethics Committee of Università Cattolica del Sacro Cuore; no identification number) obtained waivers for the collection of data of deceased residents.

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References

1. Van Den Block L, Albers G, Martins Pereira S, et al. *Palliative care for older people: a public health perspective*. Oxford: Oxford University Press, 2015.
2. Global elderly care in crisis. *Lancet* 2014; 383: 927.
3. Hall S, Petkova H, Tsouros AD, et al. *Palliative care for older people: better practices*. Copenhagen: World Health Organization, 2011.
4. 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.
5. Vandervoort A, Van Den Block L, Van Der Steen JT, et al. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. *J Am Med Dir Assoc* 2013; 14: 485–492.
6. Pivodic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health* 2016; 70: 17–24.
7. Houttekier D, Cohen J, Surkyn J, et al. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health* 2011; 11: 228.
8. Froggatt K and Reitlinger E. Palliative care in long-term care settings for older people. EAPC Taskforce 2010–2012 Report, http://www.eapcnet.eu/Portals/0/Organization/Long%20term%20care%20settings/FinalReportLongTermCareSettings_2013.pdf
9. Sanford AM, Orrell M, Tolson D, et al. An international definition for 'nursing home'. *J Am Med Dir Assoc* 2015; 16: 181–184.
10. Van Uden N, Van den Block L, Van Der Steen JT, et al. Quality of dying of nursing home residents with dementia as judged by relatives. *Int Psychogeriatr* 2013; 25: 1697–1707.
11. Thompson SA, Bott M, Gajewski B, et al. Quality of care and quality of dying in nursing homes: two measurement models. *J Palliat Med* 2012; 15: 690–695.
12. Earle CC and Ayanian JZ. Looking back from death: the value of retrospective studies of end-of-life care. *J Clin Oncol* 2006; 24: 838–840.
13. Mukamel DB, Caprio T, Ahn R, et al. End-of-life quality-of-care measures for nursing homes: place of death and hospice. *J Palliat Med* 2012; 15: 438–446.
14. Li Q, Zheng NT and Temkin-Greener H. Quality of end-of-life care of long-term nursing home residents with and without dementia. *J Am Geriatr Soc* 2013; 61: 1066–1073.
15. Pivodic L, Pardon K, Van Den Block L, et al. Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners. *PLoS ONE* 2013; 8: e84440.
16. 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 Dir Assoc* 2017; 18: 550.e7–550.e14.
17. Van Soest-Poortvliet MC, Van Der Steen JT, Zimmerman S, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res* 2012; 21: 671–684.
18. Van Soest-Poortvliet MC, Van Der Steen JT, Zimmerman S, et al. Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manage* 2011; 42: 852–863.
19. Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med* 2005; 8: s42–s49.
20. Van Den Block L, Onwuteaka-Philipsen B, Meeussen K, et al. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. *BMC Fam Pract* 2013; 14: 73.
21. Gomes B, McCrone P, Hall S, et al. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer* 2010; 10: 400.
22. Beccaro M, Costantini M, Merlo DF, et al. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *BMC Public Health* 2007; 7: 66.
23. 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.e1–566.e7.
24. 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 Dir Assoc* 2017; 18: 550.e7–550.e14.

25. Onder G, Carpenter I, Finne-Soveri H, et al. 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.
26. Kiely DK, Volicer L, Teno J, et al. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord* 2006; 20: 176–181.
27. Munn JC, Zimmerman S, Hanson LC, et al. Measuring the quality of dying in long-term care. *J Am Geriatr Soc* 2007; 55: 1371–1379.
28. Van Soest-Poortvliet MC, Van Der Steen JT, Zimmerman S, et al. Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. *J Am Med Dir Assoc* 2013; 14: 179–186.
29. Galindo-Garre F, Hendriks SA, Volicer L, et al. The Bedford Alzheimer Nursing-Severity Scale to assess dementia severity in advanced dementia. *Am J Alzheimers Dis Other Demen* 2014; 29: 84–89.
30. Sternberg S, Bentur N and Shuldiner J. Quality of care of older people living with advanced dementia in the community in Israel. *J Am Geriatr Soc* 2014; 62: 269–275.
31. Teno JM, Gozalo PL, Bynum JPW, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013; 309: 470–477.
32. Vandervoort A, Houttekier D, Van Den Block L, et al. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. *J Pain Symptom Manage* 2014; 47: 245–256.
33. Jansen K, Schaufel MA and Ruths S. Drug treatment at the end of life: an epidemiologic study in nursing homes. *Scand J Prim Health Care* 2014; 32: 187–192.
34. Rodriguez KL, Hanlon JT, Perera S, et al. A cross-sectional analysis of the prevalence of undertreatment of nonpain symptoms and factors associated with undertreatment in older nursing home hospice/palliative care patients. *Am J Geriatr Pharmacother* 2010; 8: 225–232.
35. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliat Med* 2018; 32: 329–336.
36. Maarse JAM and Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy* 2016; 120: 241–245.
37. Van Der Steen JT, Deliëns L, Ribbe MW, et al. Selection bias in family reports on end of life with dementia in nursing homes. *J Palliat Med* 2012; 15: 1292–1296.
38. Pivodic L, Harding R, Calanzani N, et al. Home care by general practitioners for cancer patients in the last 3 months of life: an epidemiological study of quality and associated factors. *Palliat Med* 2016; 30: 64–74.
39. Van Den Block L, Deschepper R, Bossuyt N, et al. Care for patients in the last months of life: the Belgian sentinel network monitoring end-of-life care study. *Arch Intern Med* 2008; 168: 1747–1754.
40. De Gendt C, Bilsen J, Stichele R, et al. Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *J Pain Symptom Manage* 2013; 45: 223–234.