# BMJ Open Hospitalisation in the last month of life and in-hospital death of nursing home residents: a cross-sectional analysis of six European countries

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#### **ABSTRACT**

**Objectives** To examine the rate and characteristics of hospitalisation in the last month of life and place of death among nursing home residents and to identify related care processes, facility factors and residents' characteristics. Setting A cross-sectional study (2015) of deceased residents in 322 nursing homes in six European countries. **Participants** The nursing home manager (N=1634), physician (N=1132) and primary nurse (N=1384) completed questionnaires.

Outcome measures Hospitalisation and place of death were analysed using generalised linear and logistic mixed models. Multivariate analyses were conducted to determine associated factors.

**Results** Twelve to 26% of residents were hospitalised in the last month of life, up to 19% died in-hospital (p<0.001). Belgian residents were more likely to be hospitalised than those in Italy, the Netherlands and Poland. For those dying in-hospital, the main reason for admission was acute change in health status. Residents with a better functional status were more likely to be hospitalised or to die in-hospital. The likelihood of hospitalisation and in-hospital death increased if no conversation on preferred care with a relative was held. Not having an advance directive regarding hospitalisations increased the likelihood of hospitalisation.

**Conclusions** Although participating countries vary in hospitalisation and in-hospital death rates, between 12% (Italy) and 26% (Belgium) of nursing home residents were hospitalised in the last month of life. Close monitoring of acute changes in health status and adequate equipment seem critical to avoiding unnecessary hospitalisations. Strategies to increase discussion of preferences need to be developed. Our findings can be used by policy-makers at governmental and nursing home level.

### INTRODUCTION

In Europe, up to 38% of people over 65 years die in a nursing home. Older people living in nursing homes have a high level of comorbidity, frailty and complex health needs; hospitalisation comes with a number of drawbacks like low satisfaction with care, rapid functional

# Strengths and limitations of this study

- Large-scale representative study with data from 1384 deceased residents from 322 nursing homes in six European countries.
- Overall response rate from nurses was high (81.6%).
- However, physician response rate for England was
- Although nurses were instructed to consult patient records when filling in the questionnaire, we cannot exclude recall bias.
- Hospital records or hospital medical and nursing staff were not consulted about hospitalisationrelated factors.

decline, low survival rates and a suboptimal quality of end-of-life care and should thus be avoided without strong clinical indication.3-7 Nevertheless, in many countries hospitalisation of nursing home residents at the end of life is not infrequent and some die there, even if they would had preferred not to.8-13

Most studies on hospitalisation of nursing home residents in the last month of life have been conducted in the USA and many focused on place of death;<sup>14</sup> only a few looked at associated factors, mainly limited to resident-level factors such as age or gender, and reported inconsistent results, with highly variable hospitalisation rates. 15 The PAlliative Care for older people in Europe (PACE) project, which studied palliative care in nursing homes in six European countries (Belgium, England, Finland, Italy, the Netherlands and Poland), conducted a large-scale representative, crossnational survey of deceased nursing home residents to study the characteristics of hospitalisations in the last month of life, place of death, and the country-related, resident-related, care processes-related, and facility-related factors associated with them and with in-hospital death.





Studying cross-national variation can provide useful information for the development of end-of-life care policies and targeted interventions to meet the needs of nursing home residents, their relatives and society as a whole.

Thus, the aims of this study were to provide an answer to two different research questions:

- 1. What are the characteristics of hospitalisations of nursing home residents in the last month of life and what is the place of death in Belgium, England, Finland, Italy, the Netherlands and Poland?
- 2. Which factors are associated with hospitalisations of nursing home residents in the last month of life and with in-hospital death?

### **METHODS**

# Study design and sampling

A cross-sectional study of deceased residents in nursing homes was conducted in 2015 in six European countries: Belgium, England, Finland, Italy, the Netherlands and Poland. A proportional stratified random sampling procedure was applied in each country which included a stratification of the nursing homes by type, region/province and number of beds. Homes were proportionally and randomly sampled from each stratum resulting in representative samples. More details about the study design and protocol have been published elsewhere. We used the Strengthening the Reporting of Observational Studies in Epidemiology cross-sectional checklist when writing our report. <sup>16</sup>

# **Setting and participants**

In this paper, we define nursing homes as 'collective institutional settings where care and on-site personal assistance with activities of daily living, and on-site or off-site nursing and medical care, is provided for older people who live there, 24 hours a day, 7 days a week, for an undefined period of time'. 17 We distinguish between three types: 24/7 care from on-site physicians and nurses/care assistants (type 1), 24/7 care from on-site nurses/care assistants and off-site physicians (type 2), and 24/7 care from on-site care assistants and off-site physicians and nurses (type 3). Type 2 nursing homes are present in all countries, whereas type 1 is only present in Italy, the Netherlands and Poland and type 3 only in England. Nursing home staff included in the study were the staff member who was most involved in the care of the resident (nurse/ care assistant), the physician and the nursing home administrator for each identified deceased resident.

# **Recruitment procedure**

Publicly available regional or national lists were used as a basis for recruitment. In Italy, no such lists were available, and therefore a previously composed cluster of eligible homes was used that reflected the three main regions and different types and sizes of nursing homes. <sup>18</sup> To enhance recruitment in England, we collaborated with the Enabling Research in Care Homes (ENRICH) research network for nursing homes. <sup>19</sup> A letter introducing the PACE project

and an invitation to participate was sent to every sampled nursing home. If a nursing home declined participation, another from the same stratum was selected.

# **Data collection**

If a nursing home agreed to participate, a contact person was appointed by the manager. He/she listed all deaths both inside and outside the home (eg, in hospital), of residents over the preceding 3 month and their attending physician and staff member that is, nurse or care assistant most involved in their care. This contact person then distributed precoded envelopes containing the paper questionnaire and a document guaranteeing full anonymity to the identified staff and physician, ensuring strict confidence through direct return of the completed questionnaires to the researchers who registered the returned envelopes in an excel file. Up to two reminders were sent in case of non-response, after 3 and 6 weeks.

# **Patient and public involvement**

No patient involved.

### Measurements

For each resident, information on demographic, clinical, nursing home stay and care process characteristics was collected.

The administrator of each participating home provided information on age, gender and nursing home characteristics: type of ownership (public-nonprofit/private-nonprofit/private-profit), type and size (number of beds) of nursing home and length of stay of the resident (in days). The administrator also reported whether or not the nursing home included 24/7 availability of opioids, and an assigned contact person who maintained regular contact with the residents and relatives to ensure coordinated delivery of health and social care.

The physician reported on the presence of illness at time of death and whether or not they had expected the death.

The nurse provided data on the functional and cognitive status of the resident during the last month of life, measured with the Bedford Alzheimer Nursing Severity Scale (BANS-S),<sup>20</sup> with scores ranging between 7 (low) and 28 (high).

Presence of dementia at time of death was estimated by the physician, the nurse or both and coded as 'yes' if either indicated its presence.

The nurse also reported on care processes: presence of a written 'do not transfer to hospital' advance directive and whether there had been—prior to a decision—a conversation with a relative about the resident's preferred medical treatment and course of care in the last phase of life.

To describe the characteristics of hospitalisation and place of death, we included questions on hospital use in the last month of life in the nurse questionnaire and about place of death in the questionnaire for the nursing home administrator. We surveyed: the number of visits to the emergency room (ER), hospital admissions, total days spent in hospital if admitted, admission to the intensive care unit (ICU),



whether the hospital palliative care team was involved, place of death and, if death occurred in hospital, the reason for the final admission and at whose request it took place.

To analyse which factors related to hospitalisation during the last month of life and in-hospital death, variables from all three questionnaires were selected based on the authors' clinical experience and extensive literature search. <sup>14</sup> <sup>21-24</sup>

# Statistical analysis

All variables were calculated at the level of the resident; we included only those for whom a questionnaire was filled in by the nurse. Demographic, clinical, nursing home stay and care process characteristics are presented as count and percentages for categorical variables and mean and SD for continuous variables (table 1). Generalised linear and logistic mixed models were used to calculate the differences in these characteristics between countries, with country as a fixed effect and nursing home as a random effect in each model to account for data clustering at country and nursing home level.

To analyse the characteristics of hospitalisation and place of death, generalised linear and logistic mixed models were conducted (table 2). Country was again included as a fixed effect. Nursing home was included as a random effect in each model. We also included age, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases), functional/cognitive status, length of stay, type of ownership and type nursing home and nursing home size as fixed effects to correct for differences in demographic, clinical and nursing home stay characteristics. With this risk adjustment procedure, a fair comparison between countries was made possible. We excluded missing values for each characteristic from the analyses.

To analyse which factors related to hospitalisation in the last month and in-hospital death, selected variables (demographic, country, resident, nursing home and care process characteristics) were first included in univariate analyses. Next, variables that proved to be significantly associated with hospitalisation during the final month and in-hospital death were subsequently included as fixed effects into two multivariate logistic mixed regression models with nursing home as random factor and either hospitalisation in the final month (yes/no) or in-hospital death (yes/no) as dependent variable (table 3). Due to low numbers of complete cases in England, we excluded data from England from the multivariate analyses. Statistical significance was represented by an alpha level of p<0.05. All analyses were performed with IBM SPSS V.25.

### **RESULTS**

In 322 participating nursing homes, 1707 deceased residents were identified. For 11, no nurse could be contacted (figure 1). From the 1696 nurse questionnaires that were sent out, 1384 were completed and returned (overall

response rate 81.6%). Response rates per country are reported in the footnotes of figure 1.

# Demographic, clinical, nursing home stay and care process characteristics of deceased nursing home residents

Residents' mean age at time of death ranged from 81 years in Poland to 87 years in Belgium and England (table 1). Most residents were female (64% in Poland -75% in England) and the majority had dementia (60% in England - 83% Finland). Polish residents had the poorest functional and cognitive status (BANS-S mean score of 22), whereas those in England had the highest (BANS-S mean score of 18). Between 41% (Poland) and 100% (Belgium) of residents were in type 2 nursing homes (care from on-site nurses and off-site physicians). The size of the nursing homes varied, ranging between 41 beds (England and Finland) to 126 beds (Belgium). The majority of deceased residents resided in nursing homes where opioids were available 24/7 for all residents with palliative care needs (69% in Italy - 88% in Belgium and England), except in Poland (48%; p=0.002). For most residents (61%-85%), a contact person was available to ensure coordinated health and social care (p<0.001). However, in Italy and Poland, such a person was not available for 37% and 53% of residents respectively. In the majority of cases across the countries (52% in Poland - 72\% in Finland; p=0.001), the physician expected the resident's death. A third of residents in Belgium (33%) had a 'do not transfer to hospital' advance directive while barely anyone had in Italy (0.5%; p<0.001). In most countries, the resident's primary nurse had discussed with a relative the resident's preferred medical treatments or course of care in the last phase of life (58% in Italy –75% in the Netherlands), but that happened less often in Poland (28%; p<0.001).

# Hospitalisations and place of death of nursing homes residents

Between 8% (the Netherlands) and 20% (England) of the residents visited the ER—for less than 24 hours in the last month of life (p<0.001; table 2). Up to 26% were hospitalised in the last month of life (12% in Italy - 26% in Belgium; p<0.001), most of them only once. Nevertheless, up to 33% (Poland) of those were hospitalised multiple times. The average length of stay ranged between 7 days in Poland and Italy and 14 days in Finland. The hospital palliative care team was involved in the care of 4% of those admitted in Italy and 15% in England. The percentage of residents dying in-hospital ranged from 6% in the Netherlands to 19% in Poland (p<0.001). Among those who died during hospitalisation, the reason for the final admission was in the majority of cases a sudden onset or an exacerbation of symptoms or a lifethreatening situation (65% in the Netherlands – 92% in England). For these, the decision to hospitalise was made by the physician (25% in Italy – 66% in Belgium) and the nurses (19% in the Netherlands – 69% in Italy). The rate

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	Belgium (n=291)	England (n=91)	Finland (n=269)	Italy (n=200)	The Netherlands (n=222)	Poland (n=311)	P value*
Demographic characteristics							
Age - years† Mean (SD) years old at time of death	87 (7)	(6) 28	85 (9)	86 (8)	(6) 98	81 (11)	<0.001
Gender†							
Female count (%)	174 (64.0)	66 (75.0)	169 (64.3)	136 (68.3)	132 (66.7)	195 (63.5)	0.387
Male count (%)	98 (36.0)	22 (25.0)	94 (35.7)	63 (31.7)	66 (33.3)	112 (36.5)	
Clinical characteristics							
Dementia at time of death (yes)दCount (%)	183 (62.9)	53 (60.2)	222 (82.5)	154 (77.0)	135 (61.4)	207 (67.9)	<0.001
Functional/cognitive status 1 month before death (BANS-S)‡**†† (Mean (SD))	18.5 (4.9)	17.5 (4.2)	19.6 (4.3)	21.8 (3.7)	17.7 (4.7)	21.9 (4.6)	<0.001
Diseases at time of death§**							
Malignant cancer§	30 (15.5)	9 (42.9)	41 (19.4)	26 (17.2)	27 (18.5)	10 (4.0)	<0.001
Severe cardiovascular disease§	67 (34.7)	2 (9.5)	79 (37.4)	71 (47.0)	45 (30.8)	141 (55.7)	<0.05
Severe pulmonary disease§	33 (17.1)	3 (14.3)	17 (8.1)	40 (26.5)	17 (11.6)	18 (7.1)	<0.001
Other severe disease§	31 (16.1)	3 (14.3)	51 (24.2)	33 (21.9)	4 (2.7)	33 (13.0)	<0.001
Nursing home stay characteristics							
Type of ownership†							
Public-nonprofit	135 (48.9)	2 (2.2)	211 (80.2)	66 (34.9)	211 (100.0)	201 (65.0)	<0.001
Private-nonprofit	124 (44.9)	10 (11.0)	24 (9.1)	44 (23.3)	Ϋ́	104 (33.7)	
Private-profit	17 (6.2)	79 (86.8)	28 (10.6)	79 (41.8)	ΑN	4 (1.3)	
Type of nursing home†							0.960
Type 1 (care from on-site physicians and nurses)	NA A	NA A	NA V	48 (25.4)	117 (55.5)	184 (59.2)	
Type 2 (care from on-site nurses and off-site physicians)	276 (100)	49 (53.8)	267 (100)	141 (74.6)	94 (44.5)	127 (40.8)	
Type 3 (care from off-site physicians and nurses)	NA VA	42 (46.2)	NA A	NA	NA	NA A	
Nursing home size† (Mean (SD) number of beds)	126 (50)	41 (23)	41 (30)	101 (50)	124 (64)	72 (41)	<0.001
Length of stay† Median (min-max) number of days	745 (2–9706)	600 (2-4952)	581 (1–9218)	416 (2–10171)	710 (1–6290)	145 (1–12365)	<0.05
Opioids available 24/7 for residents with PC?†							
Yes, for all residents	236 (88.1)	73 (88)	224 (84.2)	130 (68.8)	171 (81)	149 (48.4)	<0.001
Yes, for most residents	9 (3.4)	4 (4.8)	17 (6.4)	36 (19)	26 (12.3)	2 (0.6)	
Yes, for some residents	21 (7.8)	4 (4.8)	20 (7.5)	6 (3.2)	9 (4.3)	66 (21.4)	
No, never	2 (0.7)	4 (2.4)	5 (1.9)	17 (9)	5 (2.4)	91 (29.5)	
Care process characteristics							
Resident had a written advance directive with regard to 'do not transfer to a hospital'	96 (33)	18 (19.8)	21 (7.8)	1 (0.5)	NA	6 (1.9)	<0.001
							:

Table 1 Continued							
	Belgium (n=291)	England (n=91)	Finland (n=269)	Italy (n=200)	The Netherlands (n=222)	Poland (n=311)	P value*
Conversation between nurse and relative about preferred course of care was held	215 (74.9)	52 (63.4)	158 (60.5)	114 (58.2)	167 (75.2)	81 (27.8)	<0.001
Contact person for residents/relatives to ensure coordinated health and social care	ealth and social	care					
Yes, for all residents	159 (60.7)	75 (85.2)	194 (72.7)	86 (45.5)	162 (76.8)	133 (42.8)	0.002
Yes, for most residents	31 (11.8)	1 (1.1)	17 (6.4)	0.0) 0	4 (1.9)	0.0) 0	
Yes, for some residents	25 (9.5)	8 (9.1)	10 (3.7)	34 (18)	0.0) 0	13 (4.2)	
No, never	47 (17.9)	4 (4.5)	46 (17.2)	69 (36.5)	45 (21.3)	165 (53.1)	
Physician's level of expectation about death							
Death was expected	107 (55.7)	14 (63.6)	155 (72.1)	105 (68.2)	(99) 26	130 (51.6)	0.001
Death was expected, yet sooner than anticipated	42 (21.9)	4 (18.2)	43 (20)	23 (14.9)	29 (19.7)	55 (21.8)	
Death was neither expected nor unexpected	16 (8.3)	4 (18.2)	12 (5.6)	20 (13)	10 (6.8)	35 (13.9)	
Death was unexpected	27 (14.1)	0) 0	5 (2.3)	6 (3.9)	11 (7.5)	32 (12.7)	

Percentages may not always add up to 100 because of rounding. Missing values: age=13, gender=13, dementia=11, BANS-S=86 (missing data on at least one item), diseases=12, type of ownership=2, We only included residents for whom a questionnaire was filled in by a nurse (total n=1384). All variables are calculated at the level of the resident. type of nursing home=0, size=5, length of stay=15, advance directive=66, contact person=4, physician's expectation=7.

Data in bold indicate statistically significant p-values.

Heported by administrator/manager of nursing home. For 44 out of 1384 residents, no questionnaire was returned by the nursing home administrator; these are not included as missing values below. tReported by the nurse/care assistant most involved in care.

Generalised linear and logistic mixed models reporting p value for country as a fixed effect and nursing home as random effect in each model, α<0.05.

SReported by the physician. For 397/1384 residents, no questionnaire was returned by physician; these are not included as missing values below. IWhen either the physician or the nurse (or both) considered the resident to have dementia, this was coded as yes.

\*\*Multiple answers possible. TTScores on BANS-S range from 7 to 28; higher scores indicate greater severity.

BANS-S, Bedford Alzheimer Nursing Severity Scale; NA, not applicable; PC, palliative care.

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Table 2         Hospitalisation and place of death of nursing homes residents in six countries	esidents in six co	untries					
	Belgium (n=291)	England (n=91)	Finland (n=269)	Italy (n=200)	The netherlands (n=222)	Poland (n=311)	P value*
Hospitalisation in the last month of life							
Did the resident visit the emergency room in the last month of life (for less than 24	24 hours)?†						
Yes (total)	37 (13.3)	17 (20.2)	40 (15.4)	31 (16.7)	17 (7.9)	25 (9.2)	<0.001
Once	35 (94.6)	15 (88.2)	28 (70)	28 (90.3)	12 (70.6)	19 (76)	0.02
Twice or more	2 (5.4)	2 (11.8)	12 (30)	3 (9.7)	5 (29.4)	6 (24)	
Was the resident admitted to a hospital for more than 24 hours during the last mo	month of life?†						
Yes (total)	72 (25.8)	20 (23.3)	58 (22.2)	22 (11.6)	34 (15.7)	66 (25.1)	0.001
Once	67 (93.1)	18 (90)	44 (75.9)	17 (77.3)	24 (70.6)	44 (66.7)	<0.001
Twice or more	5 (6.9)	2 (10)	14 (24.1)	5 (22.7)	10 (29.4)	22 (33.3)	
If admitted to hospital in last month of life, average length of stay in hospital in days† mean	10.5	6.4	14.4	7	7	8.4	0.35
If admitted to the hospital, was the resident admitted to an ICU in the last month of life?†‡ (yes)	6 (75)	(0) 0	2 (28.6)	2 (33.3)	2 (12.5)	4 (16.7)	0.93
Was the Hospital Palliative Care Team involved in the care of the resident in the hospital?† (yes)	11 (14.5)	10 (15.4)	36 (15.1)	6 (3.6)	2 (3.8)	29 (15.5)	0.08
Place of death							
Place of death§¶							
Nursing home (%)	226 (82.2)	71 (81.6)	224 (84.8)	170 (86.7)	176 (89.3)	248 (80.0)	<0.001
Hospital (%)	48 (17.5)	16 (8.6)	24 (9.1)	26 (13.3)	12 (6.1)	60 (19.4)	
If the resident died in hospital, what were the medical reasons for the last hospital admission? $\uparrow^{+*}$	admission?†**						
A specific diagnosis was required for further decisions	3 (7.5)	(0) 0	1 (2.4)	(0) 0	3 (17.6)	7 (10.9)	
For specific treatment Sudden onset or	5 (12.5)	1 (7.7)	9 (22)	4 (18.2)	3 (17.6)	8 (12.5)	
Exacerbation symptoms or a life-threatening situation	32 (80)	12 (92.3)	31 (75.6)	18 (81.8)	11 (64.7)	49 (76.6)	
If the resident died in the hospital, at whose request did the last admission to the I	he hospital take place?†**	*					
Resident	2 (4.5)	1 (6.7)	2 (4.2)	(0) 0	3 (18.8)	2 (3.1)	0.99
Relatives	3 (6.8)	(0) 0	6 (12.5)	1 (6.3)	(0) 0	7 (10.8)	
Physician	29 (65.9)	6 (40)	18 (37.5)	4 (25)	10 (62.5)	25 (38.5)	
Nurses/carers NH	10 (22.7)	8 (53.3)	22 (45.8)	11 (68.8)	3 (18.8)	31 (47.7)	

We only included residents for whom a questionnaire was filled in by a nurse (total n=1384). All variables are calculated at the level of the resident. Data in bold indicate statistically significant p-values.

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<sup>\*</sup>Generalised linear and logistic mixed models reporting p value with country as a fixed effect and nursing home as a random effect in each model. Age, length of stay, place of death, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases) and functional/cognitive status were also included as fixed effects to correct for differences in demographic, clinical and nursing home stay characteristics, α<0.05.

Heported by the nurse/care assistant most involved in care.
‡Total number of answers to this question per country: 8 (Belgium), 2 (England), 7 (Finland), 6 (Italy), the Netherlands (16), Poland (24).
§Reported by administrator/manager of nursing home. For 44 out of 1384 residents, no questionnaire was returned by the nursing home administrator.
¶Other places not in table include: LTCF/hospice/Pall care unit/other.

<sup>\*\*</sup>Multiple answers possible. ICU, intensive care unit; NH, nursing home.



Table 3 Factors associated with (1) hospitalisation of nursing home residents in last month of life and (2) in-hospital death

	Hospitalisation*		In-hospital death*	
	Exp(Coefficient)†; (95% CI)	P value for factor	Exp(Coefficient)†; (95% CI)	P value for factor
Country, resident and nursing home characteristic	s (independent variable	es)		
Intercept‡ Country §	8.02 (1.90 to 33.8)	0.005	1.37 (0.19 to 9.82)	0.75
Belgium (reference)	Ref		Ref	Ref
Finland	0.51 (0.24 to 1.11)	0.09	0.35 (0.11 to 1.23)	0.08
Italy	0.36 (0.16 to 0.85)	0.02	1.55 (0.50 to 4.81)	0.45
The Netherlands	0.27 (0.12 to 0.62)	0.002	0.33 (0.10 to 1.17)	0.09
Poland	0.39 (0.16 to 0.97)	0.04	1.33 (0.40 to 4.43)	0.64
Clinical characteristics				
Dementia at time of death¶	0.86 (0.55 to 1.37)	0.53	0.78 (0.43 to 1.41)	0.41
Functional/cognitive status 1 month before death (BANS-S) ¶	0.90 (0.86 to 0.95)	<0.001	0.89 (0.84 to 0.95)	<0.001
Nursing home stay characteristics				
Type of nursing home§				
Type 1 (reference)	Ref	Ref	Ref	Ref
Type 2	0.91 (0.47 to 1.75)	0.77	1.90 (0.73 to 4.94)	0.19
Nursing home size§	1.00 (0.99 to 1.00)	0.23	0.99 (0.99 to 1.00)	0.10
Opioids available 24/7 for residents with PC needs§				
Yes, for all residents	Ref	Ref	Ref	Ref
Yes, for most residents	2.73 (1.25 to 5.95)	0.01	1.85 (0.49 to 6.92)	0.36
Yes, for some residents	1.84 (0.84 to 3.99)	0.13	1.30 (0.44 to 3.86)	0.64
No, never	1.01 (0.43 to 2.38)	0.98	0.40 (0.10 to 1.55)	0.18
Care process characteristics				
Conversation between nurse and relative about preferred course of care was held¶	0.47 (0.31 to 0.72)	<0.001	0.54 (0.31 to 0.95)	0.03
Resident had a written advance directive with regard to 'do not transfer to a hospital'¶	0.17 (0.06 to 0.50)	0.001	0.40 (0.12 to 1.34)	0.14
Contact person for residents/relatives to ensure coordinated health and social care §				
Yes, for all residents	Ref	Ref	Ref	Ref
Yes, for most residents	0.87 (0.29 to 2.62)	0.80	0.73 (0.12 to 4.64)	0.74
Yes, for some residents	0.43 (0.13 to 1.39)	0.16	0.94 (0.22 to 4.00)	0.93
No, never	1.24 (0.73 to 2.11)	0.42	0.90 (0.40 to 2.00)	0.74
Physician's level of expectation about death**				
Death was expected	Ref	Ref	Ref	Ref
Death was expected, yet sooner than anticipated	1.18 (0.73 to 1.93)	0.50	2.82 (1.48 to 5.39)	0.002
Death was neither expected nor unexpected	1.04 (0.53 to 2.03)	0.91	3.90 (1.78 to 8.55)	0.001
Death was unexpected	0.45 (0.19 to 1.04)	0.06	5.21 (2.22 to 12.23)	<0.001

We were able to include 790 residents for analysis of hospitalisation and 814 residents for analysis of in-hospital death in the complete-case multivariate analysis. Due to low numbers of complete cases in England, we excluded data from England from the multivariate analyses. Therefore, also type 3 nursing homes were not included.

Data in bold indicate statistically significant p-values.

Multivariate logistic mixed-effect regression models reporting p value with hospitalisation in the last month of life and place of death as independent variables and nursing home as random factor,  $\alpha$ <0.05.

<sup>\*</sup>Hospitalisation 'no' and in-hospital death 'no' are reference categories.

<sup>†</sup>Exponentiation of the coefficient, which is an OR.

<sup>‡</sup>Expected mean value of the dependent variables (hospitalisation and in-hospital death) when all factors equal zero.

<sup>§</sup>Reported by administrator/manager of nursing home. For 44 out of 1384 residents, no questionnaire was returned by the nursing home administrator.

<sup>¶</sup>Reported by the nurse/care assistant most involved in care.

<sup>\*\*</sup>Reported by the physician. For 397/1384 residents, no questionnaire was returned by physician.

BANS-S, Bedford Alzheimer Nursing Severity Scale; PC, palliative care.

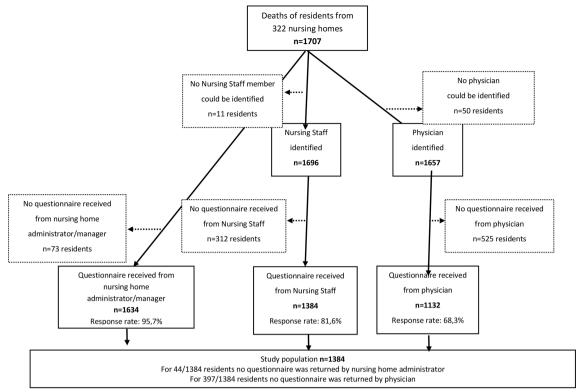


Figure 1 Numbers of questionnaires (distributed and returned) regarding residents per respondent in six countries.

of hospitalisation in the last month of life was highest for residents in type 3 nursing homes and more for type 2 than for type 1 (online supplemental appendix table A1). A similar pattern was observed for in-hospital deaths. The highest rates were found in Polish type 2 nursing homes: 33% was hospitalised and 38% died in-hospital.

# Factors associated with hospitalisation during the last month of life and in-hospital death

In Belgium, residents had a significantly greater likelihood of being hospitalised at the end of life than those in Italy (OR=0.36; p=0.02), the Netherlands (OR=0.27; p=0.002) or Poland (OR=0.39; p=0.04) (table 3). Those with higher functional status 1 month before death (lower BANS-S score) were more likely to be hospitalised then those with a high BANS-S score (OR=0.90; p<0.001). Although dementia was not associated with hospitalisation, additional analysis (not in tables) showed that residents with early stage dementia were more likely to be hospitalised than those with very severe or advanced dementia. In nursing homes where opioids were available to most residents, the odds of hospitalisation increased (OR=2.73; p=0.01) compared with those where they were available to all residents. Not having a 'do not transfer to hospital' advance directive increased the likelihood of hospitalisation compared with having one (OR=0.17; p=0.001). It was also more likely if there had been no conversation between the nurse and a relative about preferred medical treatments and course of care in the last phase of life than if there had (OR=0.47; p<0.001).

# Factors associated with in-hospital death

Residents were more likely to die in-hospital if the nursing home physician did not expect the death (OR=5.21; p<0.001), if it was sooner than they expected (OR=2.82; p=0.002) or if it was neither expected nor unexpected (OR=3.90; p=0.001). A resident was more likely to die in-hospital if they had a good functional status than a poor one (OR=0.89; p<0.001) (table 3). Again, in-hospital deaths were also more likely if the nurse had not had a conversation with a relative about medical treatments or the preferred course of care in the last phase of life than if they had (OR=0.54; p=0.03). No significant additional association was found.

# DISCUSSION Main findings

Between 12% (Italy) and 26% (Belgium) of residents were hospitalised at least once in the last month of life. Besides country differences, residents were also more likely to be hospitalised if they had a high functional status, no advance directive regarding hospitalisation, and if there had been no conversation with a relative about preferences at the end of life. Between 6% (the Netherlands) and 19% (Poland) died while in hospital. For these residents, the reason for the last hospital admission was in the majority of cases the acute onset or exacerbation of symptoms or the sudden appearance of a life-threatening situation. Residents were more likely to die in-hospital than in the nursing home if they had a better functional



status, if the physician did not expect the death and if no end-of-life conversations had been held with a relative.

# **Strengths and limitations**

We conducted a large-scale study on the hospitalisation of nursing home residents in the last month of life and on place of death, identifying the country-related, residentrelated, care processes-related, and facility-related factors associated with such events in six European countries. We were able to include data from 1384 residents from 322 representative nursing homes (figure 1). Overall response rate across all countries was high (figure 1). Earlier studies included only resident-level variables, whereas our study went beyond resident-level and included variables related to the care process and to the nursing home.<sup>14</sup> The analysis of associations on different levels enables us to hypothesise about which palliative care practices may result in better nursing home outcomes. Further, the retrospective design of this study is most suitable to examine hospitalisations of nursing home residents in the last month of life and place of death. Nevertheless, it is important to mention some limitations: the physician response rate for England was low so data from England were not considered in the multivariate analyses; we did not review hospital records or interview hospital medical and nursing staff about hospitalisation-related factors, which could have been a useful addition to the information provided by nursing home staff, specially where they were little involved in the hospitalisations. Finally, although nurses were instructed to consult patient records where necessary, we cannot exclude recall bias.

# Hospitalisations in the last month of life

Our finding that 12% to 26% of nursing home residents are hospitalised at least once in the last month of life is comparable with numbers found in previous studies from European countries. Two systematic reviews on hospitalisations in the last month of life of nursing home residents in Europe reported a range from 8% to 34%, with up to 50% in Germany. Studies from the US reported higher rates of hospitalisation in the last month of life than ours, ranging between 25% and 35%, which might be partly attributable to a more cure-oriented culture for terminally ill people there than in most European countries, in combination with the Medicare fee-forservice system that offers financial incentives to nursing homes for hospitalising residents.

We found that residents in Belgium were more likely to be hospitalised than those in Italy, the Netherlands and Poland; the rate in Poland was almost as high as in Belgium. Across all countries, type of nursing home was not significantly related to hospitalisation, though additional analysis showed that type 2 nursing homes—the only type in Belgium—had more hospitalisations and in-hospital deaths than type 1, suggesting nursing home organisation could be a possible explanation for Belgium's high hospitalisation rate and the high rate in

type 2 nursing homes in Poland. Another reason could be that Belgian family physicians usually coordinate the end-of-life care of their patients, which would make them essential in avoiding hospitalisations in the last month of life;<sup>29</sup> this gate-keeping role is however limited so that hospitalisation can be requested more easily by family members without consulting them.<sup>30 31</sup> On top of that, there is the institutionalised nature of the final phase in Belgium;<sup>32</sup> in the Netherlands, where hospitalisation in the last month of life was least common, care in nursing homes is not managed by the family physician but by the elderly care physician in the nursing home.<sup>4 33</sup> This model is less hospital centric and has the potential to decrease hospitalisation in the last month of life.

Apart from country, other factors increased the likelihood of hospitalisation. Residents were more likely to be hospitalised in the last month of life if they had a better functional status and were not suffering from very severe or advanced dementia. This suggests that primarily residents with a better state of health and a better prognosis are hospitalised. This finding seems plausible and was confirmed by a US study on hospitalisations of dying nursing home residents.<sup>34</sup> Hospitalisations were also more likely if no conversation on medical treatments and the course of care had been held between the nurse and a relative and if residents did not have a written 'do not transfer to hospital' advance directive. A study on avoiding hospitalisations of nursing home residents identified both having advance directives and discussing residents' preferences as two strategies for reducing hospital transfers.<sup>35</sup> In general, very few of the residents had such an advance directive (0.5%-33%). Since many suffer from dementia and thus do not have the capacity to make decisions themselves, written advance directives would be crucial. In the USA, written advance directives are more common (72%), possibly due to support from governments, healthcare providers and insurers in completing them. 36 37 Hospitalisation is however sometimes needed and is not always avoidable; even though a resident prefers not to be transferred, nursing home staff may not feel equipped to provide the care required. Sometimes, high-quality palliative care cannot be provided in the nursing home, which can be a reason for referral to another setting.

# In-hospital death

The percentage of residents dying in-hospital ranged between 6% in the Netherlands and 19% in Poland. The average number of in-hospital deaths in our study lies well below that in other studies from Europe, the US, Asia and Canada which reported a median of one in five residents dying in-hospital. In Belgium and Poland, the percentage of in-hospital deaths was highest. For Poland, this was especially the case in type 2 nursing homes with off-site physicians (38%). In the Netherlands, in-hospital deaths were less common, in all types, and happened more often at a resident's request than in the other countries. Earlier studies also report lower in-hospital



deaths and more residents with a palliative care goal on the day of death in the Netherlands than in other countries. 36'38 39 These findings might suggest that in the Netherlands close attention is paid to the preferences of the resident regarding place of death. Further, discontinuing life-prolonging medical treatments is accepted practice there and quality of life is an important aspect of end-oflife decisions and often outweighs prolongation of life. 40 Hendriks et al<sup>41</sup> found that there were several contact moments during a nursing home stay between physicians, nursing staff and relatives in which care goals and treatment decisions were discussed. 41 42 This implies an organisational focus on facilitating end-of-life discussions. We found that in the majority of cases, the main reason for the last hospital admission was a sudden onset or exacerbation of symptoms or a life-threatening situation and that admission had usually been requested by a physician or nurse. This suggests that most last hospitalisations were a reaction to what staff perceived as an urgent medical situation. Furthermore, physicians indicated they usually expected the resident to die. Not expecting death increased the likelihood of in-hospital death. Which suggest that staff are more inclined to transfer residents to the hospital (for a treatment or diagnosis) if they assume the residents is not dying. In-hospital deaths were also more likely if the conversation about preferences on medical treatments and the course of care between a nurse and a relative had not taken place. These findings suggest that involvement of staff and their knowledge of a resident's preferences might have a strong impact on place of death. Interestingly, not having an advance directive regarding do not transfer to hospital was associated with a higher likelihood of hospitalisation in the last month, but not with a higher likelihood of dying in-hospital. Given that the main reason for the final hospitalisation was an acute medical situation, having an advance directive appears not to make a difference in such a case. This seems to indicate that in such situations very complex decision-making takes place, with hospitalisation as the default option.

# **Implications**

Not having a do not transfer to hospital advance directive increased the likelihood of hospitalisations in the last month of life. In addition to a continuing commitment to advance care planning, our findings indicate the need to improve management of acute changes in symptoms—through staff training and support—before they worsen and require hospital stays. Hospitalisations also increased if the physician did not expect a resident's death, which highlights the importance of recognition of the terminal phase.

### **CONCLUSIONS**

In the European countries participating in the PACE project, between 12% and 26% of nursing home

residents were hospitalised in the last month of life and up to 19% died in-hospital. This indicates that although the participating countries vary in hospitalisation and in-hospital death, a minority of the residents were hospitalised in the last month of life. For those who died in-hospital, the main reason for hospital admission was an acute change in health status, those with a higher functional status being more likely to be hospitalised or to die in-hospital. The likelihood of hospitalisation in the last month of life and of in-hospital death increased if no conversation about the preferred course of care was held with a relative. Having no advance directive regarding hospitalisations increased the likelihood of hospitalisation in the last month of life but not of in-hospital death. Close monitoring of acute changes in a resident's health status reinforced by staff training and support—and adequate equipment to manage these changes are critical in the nursing home setting to avoid unnecessary hospitalisations. In addition, strategies to increase discussion about individual preferences and advance care planning need to be developed and adapted locally. Our findings can be used by policymakers—at government and nursing home level—to follow-up on the effects of their policies.

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Ethics approval Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES 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; 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. If no approval for collection of data of deceased residents was needed, which was the case for Italy and the Netherlands, waivers were acquired. All participants took part on a voluntary basis, meaning that completed (anonymous) questionnaires were regarded as valid informed consents.

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**Data availability statement** Data are available upon reasonable request. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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#### REFERENCES

- 1 Broad JB, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health 2013;58:257–67.
- 2 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. BMC Public Health 2019;19:1199.
- 3 Ouslander JG, Lamb G, Perloe M, et al. Potentially avoidable hospitalizations of nursing home residents: frequency, causes, and costs: [see editorial comments by Drs. Jean F. Wyman and William R. Hazzard, pp 760-761]. J Am Geriatr Soc 2010;58:627–35.
- 4 Houttekier D, Cohen J, Bilsen J, et al. Place of death of older persons with dementia. A study in five European countries. J Am Geriatr Soc 2010;58:751–6.
- 5 Verhofstede R, Smets T, Cohen J, et al. Improving end-of-life care in acute geriatric hospital wards using the care programme for the last days of life: study protocol for a phase 3 cluster randomized controlled trial. BMC Geriatr 2015;15:13.
- 6 Giezendanner S, Bally K, Haller DM, et al. Reasons for and frequency of end-of-life hospital admissions: general practitioners' perspective on reducing end-of-life Hospital referrals. J Palliat Med 2018;21:1122–30.
- 7 De Korte-Verhoef MC, Pasman HRW, Schweitzer BPM, et al. How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of general practitioners, nurses and family carers. PLoS One 2015;10:e0118971.

- 8 Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013:12:7.
- 9 Leadbeater C, Garber J. Dying for change. Demos, 2010.
- 10 Wheatley VJ, Baker JI. "Please, I want to go home": ethical issues raised when considering choice of place of care in palliative care. Postgrad Med J 2007;83:643–8.
- 11 Bell CL, Somogyi-Zalud E, Masaki KH. Factors associated with congruence between preferred and actual place of death. J Pain Symptom Manage 2010;39:591–604.
- Menec VH, Nowicki S, Blandford A, et al. Hospitalizations at the end of life among long-term care residents. J Gerontol A Biol Sci Med Sci 2009;64:395–402.
- 13 Intrator O, Grabowski DC, Zinn J, et al. Hospitalization of nursing home residents: the effects of states' Medicaid payment and bedhold policies. Health Serv Res 2007;42:1651–71.
- 14 Allers K, Hoffmann F, Schnakenberg R. Hospitalizations of nursing home residents at the end of life: a systematic review. *Palliat Med* 2019;33:1282–98.
- 15 Carter MW, Porell FW. Variations in hospitalization rates among nursing home residents: the role of facility and market attributes. *Gerontologist* 2003;43:175–91.
- 16 von Elm E, Altman DG, Egger M, et al. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008:61:344–9.
- 17 Froggatt K, Reitinger E. Palliative care in term care settings for older people. Report of an EAPC Taskforce 2010-2012. European Association of Palliative Care 2013.
- 18 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.
- 19 ENRICH. Research ready care home network. Available: http:// www.enrich.nihr.ac.uk/pages/research-ready-care-home-network [Accessed 22 May 2019].
- 20 Galindo-Garre F, Hendriks SA, Volicer L, et al. The Bedford Alzheimer nursing-severity scale to assess dementia severity in advanced dementia: a nonparametric item response analysis and a study of its psychometric characteristics. Am J Alzheimers Dis Other Demen 2014;29:84–9.
- 21 Wagman S, Rishpon S, Kagan G, et al. Variables correlated with elderly referral from nursing homes to general hospitals. *Isr J Health Policy Res* 2014;3:2.
- 22 Grabowski DC, Stewart KA, Broderick SM, et al. Predictors of nursing home hospitalization: a review of the literature. Med Care Res Rev 2008;65:3–39.
- 23 Young Y, Inamdar S, Dichter BS, et al. Clinical and nonclinical factors associated with potentially preventable hospitalizations among nursing home residents in New York state. J Am Med Dir Assoc 2011:12:364–71
- 24 Becker M, Boaz T, Andel R, et al. Predictors of avoidable hospitalizations among assisted living residents. J Am Med Dir Assoc 2012;13:355–9.
- 25 IBM Corp. IBM SPSS statistics for MacIntosh; 2017.
- Dzeng E, Dohan D, Curtis JR, et al. Homing in on the social: system-level influences on overly aggressive treatments at the end of life. J Pain Symptom Manage 2018;55:282–9.
- 27 Lamberg JL, Person CJ, Kiely DK, et al. Decisions to hospitalize nursing home residents dying with advanced dementia. J Am Geriatr Soc 2005;53:1396–401.
- 28 Temkin-Greener H, Zheng NT, Xing J, et al. Site of death among nursing home residents in the United States: changing patterns, 2003-2007. J Am Med Dir Assoc 2013;14:741–8.
- 29 Keirse E, Beguin C, Desmedt M. Organisation of palliative care in Belgium;214.
- 30 Abarshi E, Echteld MA, Van den Block L, et al. Use of palliative care services and general practitioner visits at the end of life in the Netherlands and Belgium. J Pain Symptom Manage 2011;41:436–48.
- 31 Meeussen K, Van den Block L, Echteld MA, et al. End-Of-Life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. J Clin Oncol 2011;29:4327–34.
- 32 Van den Block L, Deschepper R, Drieskens K, et al. Hospitalisations at the end of life: using a sentinel surveillance network to study Hospital use and associated patient, disease and healthcare factors. BMC Health Serv Res 2007;7:69.
- 33 Helton MR, Cohen LW, Zimmerman S, et al. The importance of physician presence in nursing homes for residents with dementia and pneumonia. J Am Med Dir Assoc 2011;12:68–73.



- 34 Cai S, Miller SC, Mukamel DB. Racial differences in hospitalizations of dying Medicare-Medicaid dually eligible nursing home residents. J Am Geriatr Soc 2016;64:1798–805.
- 35 Unroe KT, Hickman SE, Carnahan JL, et al. Investigating the Avoidability of hospitalizations of long stay nursing home residents: opportunities for improvement. Innov Aging 2018;2:igy017.
- 36 Hendriks SA, Smalbrugge M, Deliens L, et al. End-Of-Life treatment decisions in nursing home residents dying with dementia in the Netherlands. Int J Geriatr Psychiatry 2017;32:e43–9.
- 37 Silveira MJ, Wiitala W, Piette J. Advance directive completion by elderly Americans: a decade of change. *J Am Geriatr Soc* 2014;62:706–10.
- 38 Pivodic L, Pardon K, Miccinesi G, et al. Hospitalisations at the end of life in four European countries: a population-based study via epidemiological surveillance networks. *J Epidemiol Community Health* 2016;70:430–6.
- 39 Cohen J, Pivodic L, Miccinesi G, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. Br J Cancer 2015:113:1397–404.
- 40 Helton MR, van der Steen JT, Daaleman TP, et al. A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. Ann Fam Med 2006;4:221–7.
- 41 Hendriks SA, Smalbrugge M, Hertogh CMPM, *et al.* Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* 2014;47:710–20.
- 42 van Soest-Poortvliet MC, van der Steen JT, Gutschow G, et al. Advance care planning in nursing home patients with dementia: a qualitative interview study among family and professional caregivers. J Am Med Dir Assoc 2015;16:979–89.