

Original Article

Advance Care Planning and Dying in Nursing Homes in Flanders, Belgium: A Nationwide Survey

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Abstract

Context. In Belgium, data on actual advance care planning (ACP) in nursing homes (NHs) are scarce.

Objectives. To investigate the prevalence and characteristics of documented advance directives and physicians' orders for end-of-life care in NHs, and the authorization of a legal representative in relation to the residents' demographic and clinical characteristics and care received.

Methods. This was a retrospective cross-sectional study, including all NH residents deceased during September and October 2006 in all 594 NHs in Flanders, Belgium. Structured mail questionnaires about the resident's characteristics, hospital transfers, palliative care delivery, ACPs, and authorization of legal representatives were completed via the NH administrators and nurses involved in the care of the resident.

Results. Administrators of 318 NHs (53.5%) reported 1303 deaths. Nurses provided information about 1240 (95.2%) of these deaths. At the end of life, NH residents often had dementia (65.2%) and were severely dependent (76.1%). Almost half (43.1%) had at least one hospital transfer during the last three months of life and two-thirds received palliative care. Half had an ACP, predominantly a physician's order and less often an advance directive. Having advance directives or physician's orders was associated with receiving palliative care. Residents with a physician's order more often died in the NH. Nine percent had an authorized legal representative.

Conclusion. Prevalence of ACPs and formal authorization of a legal representative was low among the deceased NH residents in Flanders, Belgium. There was a higher prevalence of physicians' orders, often established after the resident had lost capacity. Initiatives should be developed to stimulate more advance discussion on care options and making end-of-life decision with the

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Accepted for publication: February 14, 2012.

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Key Words

Advance care planning, advance directives, nursing homes, palliative care, end of life

Introduction

In Belgium and other Western countries, the population is living longer because of better living conditions, changing lifestyles, and advances in medical knowledge and technology, leading to improved early diagnosis and treatment of chronic conditions. Many people now live to be very old and die after a long period of chronic and degenerative disease,¹ whereas earlier, deaths occurred more suddenly and were often caused by infectious diseases.² During recent decades, awareness has grown that palliation of patient symptoms and improvement in quality of life for the patient and family may be preferable to futile life-prolonging treatment at the end of life.³

This new awareness has resulted in increasing attention being paid to advance care planning (ACP), especially in nursing homes (NHs) where residents often lack capacity to make decisions at the end of life.^{4–6} ACP is defined as the discussion with patients and/or their representatives about the goals and desired direction of care, particularly their end-of-life care, in the event that they lose the capacity to make decisions.⁷ This way, the patient's values, attitudes, and wishes can be taken into account as much as possible by the health care workers, and unwarranted, often burdensome, interventions can be avoided.^{8–10}

Since 2002, the Belgian Patients' Rights Act¹¹ has given patients the legal right to reject medical treatment and to authorize a legal representative to speak for them when they are unable to speak for themselves, like the Patient Self-Determination Act of 1991 in the U.S.^{12,13} ACPs outlining the patient's preferences concerning care and medical treatment can be either patient driven (advance directives) or physician driven (physician's orders).¹⁴ Advance directives are declarations made in advance of a situation in which the author may lack the capacity to make decisions about their own care, stating their treatment preferences

or authorizing a third party to make decisions for them.⁷ Physician's orders, on the other hand, are written by the physician, mostly with the consent and input of the NH resident or his/her representatives. In the U.S., the prevalence of ACPs among NH residents has increased since the Patient Self-Determination Act but is still low,¹² with the exception of the anticipatory decision not to hospitalize the resident (83.8% of NH residents).¹⁵

Within the health care system of Belgium, NHs provide skilled nursing care to elderly people who have serious problems undertaking the activities of daily living and/or lack mental capacity but who do not need daily medical supervision or full-time specialized medical treatment as in hospitals.¹⁶ However, because NHs in Belgium have developed from care homes for elderly people, it remains possible that they still include some less dependent people, but this number is diminishing. At the end of 2006, these institutions in Flanders, Belgium (with a population of approximately six million people) had a total 57,858 beds (a mixture of NH beds and traditional care home beds) and each institution had, on average, 97 residents.^{17,18}

Most NH residents are still supervised by their former general practitioners (GPs).¹⁹ Palliative care for these residents can thus be provided by these GPs, but also by other individual caregivers with specialized palliative care training, for example, the coordinating and advisory physician (CAP) of the NH, the palliative care reference nurse of the NH, or a Life End Information Forum physician. Since 2000, each NH is legally bound to have a CAP,²⁰ a GP, preferably with training in gerontology, whose tasks include some of those related to individual end-of-life care situations (consultancy, taking charge of care, or conflict mediation).¹⁷ It is also obligatory for each NH to appoint a palliative care reference nurse who, together with the CAP, is responsible for establishing a culture of

palliative care in the NH, making staff more aware of palliative care, formulating advice on individual palliative care situations and organizing training in palliative care.¹⁷ Life End Information Forum physicians offer a wide range of information and support for both professional caregivers and patients in all care settings who have questions about the end of life, including palliative care, and they help physicians confronted with euthanasia requests in finding a specifically trained, accessible, and independent physician for a formal second consultation as required by the euthanasia law.^{21,22} Palliative support also can be given by multidisciplinary palliative care teams, for example, the palliative care task group of the NH, the palliative home care team of the region where the NH is situated, or the palliative care support team or the team of the palliative care unit of a nearby hospital (mostly chosen for their experience with specialized palliative treatment techniques).

In Belgium, no data on ACP practices in NHs and related factors are available so far, and international results cannot be generalized to this particular setting. This study describes: 1) the demographic and clinical characteristics of those dying in NHs in Flanders, Belgium, and the care they received in the months before their death; 2) the prevalence and characteristics of documented ACPs (advance directives and physician's orders for end-of-life care) and of the authorization of a legal representative by the NH resident, and 3) the relationship between the prevalence of ACP and authorization of a legal representative and the characteristics of the residents and of the care received. Better understanding of these practices will be helpful in optimizing end-of-life care for an increasing proportion of the population.

Methods

Design

This study was conducted at the end of 2006 in Flanders, the Dutch-speaking part of Belgium, with approximately six million people (60% of the Belgian population). All care homes for elderly people in Flanders recognized as high care NHs were included ($N = 594$).

Addresses of these NHs were obtained from the Flemish Ministry of Health. The administrator of each NH was mailed a package of

identical, structured questionnaires with the request to report the number of residents who had died during September and October 2006 and to pass a questionnaire for each of these residents to the nurse most involved in the care of these residents, or to the head nurse in cases where it was not possible to identify this nurse.

To improve the response rate, a letter of recommendation signed by six organizations relevant to this setting was enclosed with the mailing. About one month after the first mailing, a follow-up letter was mailed to the administrator of nonresponding institutions. A telephone call was made after another three weeks to those who had still not responded; a call also was made to those who had reported more deceased residents during September and October 2006 than the number of completed questionnaires returned.²³

Approval for this study was received from the Medical Ethics Commission of the UZ Brussel (University Hospital of Brussels).

Questionnaire

The first part of the four-page questionnaire contained questions about characteristics of the NH resident at time of death, for example, sex, age, level of dependency in daily living, diagnosis of dementia, and whether or not the death was expected. The level of dependency was defined by means of a five-category scale (O: independent, A: little dependent, B: dependent, C: severely dependent, and Cd: severely dependent and with dementia), based on the Katz Index of Independence in Activities of Daily Living scale,²⁴ indicating the resident's overall level of independence/dependence in performing the six functions of bathing, dressing, toileting, transferring, continence, feeding, and orientation to place and time. Nurses were asked to answer, according to their own assessment, whether residents had received a diagnosis of severe, moderate, or no dementia and whether death was expected, neither expected nor unexpected, or unexpected.

The second part of the questionnaire asked for the number of hospital transfers during the last three months of life and whether palliative care had been delivered and by whom. The last part of the questionnaire explored whether the resident's file contained documented ACPs (advance directives and/or

physician's orders) and whether the resident had formally authorized a legal representative.

The questionnaire was pilot tested by 13 nurses working in 12 different NHs. This resulted in minor adaptations to avoid ambiguity and to improve understanding.

Statistical Analysis

The deceased NH resident was considered the unit of analysis. Descriptive results were presented in frequency tables and crosstabs, and differences in distribution (χ^2) were calculated. Logistic regression models (stepwise conditional) were performed to further investigate the bivariate relationships ($P < 0.1$), after analysis of covariance between variables. Delivery of palliative care was considered as a dichotomous variable (yes/no) in these models.

The statistical package PASW 17.0 (SPSS Inc., Chicago, IL) was used, and P -values of less than 0.05 were considered statistically significant.

Results

Response

The administrators of 345 (58.1%) NHs reported a total number of 1357 NH residents dying during September and October 2006. Nurses from 318 different NHs (53.5% of the total number of NHs) returned a questionnaire for 1240 of these residents (95.2% of the 1303 deceased residents reported in these 318 NHs; 91.4% of total reported number of deceased NH residents). Characteristics of these residents were compared with sex and age data of in-NH deaths from a representative death certificate study done in 2001 with no significant differences (data not shown in tables).²⁵

Characteristics of Deceased NH Residents

Two of three deceased NH residents were female and 80% were aged 80 years or older (mean 86 years; Table 1). Nurses reported cardiovascular (34.8%) and specific neurological (31.8%) diseases as the most frequently diagnosed problems, followed by respiratory diseases (20.1%) and malignancies (18.6%). More than 75% were severely dependent and 65.2% suffered from dementia (24.3% moderate and

Table 1
Characteristics of Deceased Nursing Home Residents, Hospital Transfers, and Palliative Care Received (N = 1240)

	n	%
Characteristics of deceased nursing home residents		
Sex		
Male	384	31.1
Female	852	68.9
Missing cases	4	
Age (years) (mean 86)		
<80	237	19.4
80–84	283	23.2
85–89	303	24.9
90–94	249	20.4
≥95	147	12.1
Missing cases	21	
Diagnosed diseases/disorders ^a		
Cardiovascular	413	34.8
Neurological	377	31.8
Respiratory	238	20.1
Malignant tumor	221	18.6
Urogenital system	100	8.4
Metabolic disorder	56	4.7
Other	115	9.7
Missing cases	54	
Diagnosis of dementia		
No	408	34.8
Yes, moderate dementia	285	24.3
Yes, severe dementia	479	40.9
Missing cases	68	
Level of dependency		
O: independent	47	4.1
A: little dependent	58	5.0
B: dependent	172	14.9
C: severely dependent	265	22.9
Cd: severely dependent and demented	615	53.2
Missing cases	83	
Length of stay		
≤6 months	267	21.7
0.5–2 years	286	23.3
3–4 years	281	22.9
>4 years	395	32.1
Missing cases	11	
Having a support person		
Yes	1167	94.7
No	65	5.3
Missing cases	8	
Having the coordinating and advisory physician of the nursing home as treating general practitioner		
Yes	229	18.6
No	1002	81.4
Missing cases	9	
Type of death		
Expected	723	58.8
Neither expected nor unexpected	268	21.8
Unexpected	239	19.4
Missing cases	0	
Place of death		
Nursing home	981	79.2
Hospital	244	19.7
Palliative care unit	10	0.8
Other	3	0.2
Missing cases	2	

(Continued)

Table 1
Continued

	n	%
Number of hospital transfers during the last 3 months of life		
0	696	56.9
1	381	31.1
≥2	147	12.0
Missing cases	16	
Palliative care delivered at the end of life ^a	789	67.2
By regular caregiver, with palliative care training	705	60.1
Treating general practitioner	546	46.5
Palliative reference nurse	461	39.3
Coordinating and advisory physician	115	9.8
LEIF physician	1	0.1
By multidisciplinary palliative care team	535	45.6
Palliative task group	494	42.1
Palliative home care team	34	2.9
Palliative support team of the hospital	34	2.9
Palliative care unit of the hospital	17	1.4
Missing cases	68	

LEIF = Life End Information Forum.

^aMultiple answers possible.

40.9% severe). Twenty-two percent had a length of stay of less than six months and more than half had a length of stay of three years or more. Most (94.7%) still had a support person, and in fewer than 20% of cases, the treating

GP was the CAP of the NH. For most of the NH residents (80.6%), death was not unexpected. One of five died in hospital, with fewer than 1% in a palliative care unit.

Hospital Transfers at the End of Life and Palliative Care Delivery

In the last three months of life, 31.1% of residents were transferred to a hospital once and 12.0% more than once (Table 1). Palliative care was delivered to 67.2%, in 60% of cases from regular caregivers with palliative care training (mostly their treating GP and/or the palliative reference nurse of the NH) and in 45.6%, from a multidisciplinary palliative care team (mostly from the NH). In 38.5% of cases, both regular and specialized palliative care were involved. Residents whose death was expected more often received palliative care (80.2%; $P < 0.001$) than those whose death was not unexpected (17.4%) or unexpected (2.4%; data not shown in table).

Prevalence of ACPs and Authorization of a Legal Representative

Documented ACPs (advance directives and/or physician's orders) were available for 51.8% of NH residents (Table 2). Five percent had

Table 2
Prevalence of Advance Care Plans and Authorization of a Legal Representative (N=1240)

	n	%
Advance care plans ^a	637	51.8
Advance directives	61	5.0
Do not hospitalize	48	3.9
Do not resuscitate	36	2.9
Withholding or withdrawing administration of artificial food and/or fluids	29	2.4
Withholding or withdrawing antibiotics	12	1.0
Withholding or withdrawing other treatments	21	1.7
Terminal sedation	2	0.2
Euthanasia	8	0.7
Physician's orders	622	50.6
Do not hospitalize	458	37.2
Do not resuscitate	352	28.6
Withholding or withdrawing artificial food	292	23.7
Withholding or withdrawing artificial fluids	291	23.7
Withholding or withdrawing antibiotics	211	17.2
Withholding or withdrawing chemotherapy	204	16.6
Withholding or withdrawing hemodialysis	155	12.6
Withholding or withdrawing blood transfusion	162	13.2
Alleviation of pain and symptoms knowing that this might shorten the patient's life	337	27.4
Terminal sedation, with administration of artificial food and fluids	66	5.4
Terminal sedation, without administration of artificial food and fluids	148	12.0
Euthanasia	9	0.7
Authorization of a legal representative ^b	102	8.6

^aTen missing cases, multiple answers possible.

^bFifty-nine missing cases.

documented advance directives. Four percent had an advance directive not to be hospitalized and 2.9% not to be resuscitated in case of a cardiopulmonary arrest. The wish not to receive artificial food or fluids was documented by 2.4% of the residents. Two residents (0.2%) documented their potential wish for terminal sedation and eight (0.7%) for euthanasia.

According to the nurses, half of the residents who died in this period had one or more physician's orders concerning end-of-life care documented in their file. For 37.2% of the residents, an order not to hospitalize was documented, and for 28.6%, there was an order not to resuscitate in case of a cardiopulmonary arrest. Withholding or withdrawing artificial food and fluids were each documented for almost one of four residents. For 5.4%, there was an order concerning terminal sedation with administration of artificial food and fluids, and for 12.0% without administration of food and fluids. For nine residents (0.7%), a physician had documented agreement concerning euthanasia. Almost 9% of the residents had authorized a legal representative.

Prevalence of ACPs and Authorization of a Legal Representative: Related Factors

Unadjusted analysis revealed that those residents diagnosed with malignancies had significantly more documented advance directives (8.6% vs. 4.2%; $P = 0.010$) and those with dementia had significantly fewer documented advance directives ($P < 0.001$) (Table 3). Six percent of residents whose death was expected had documented their wishes in advance directives compared with 1.7% ($P = 0.018$) of those who died unexpectedly. Residents who received palliative care significantly more often had advance directives than those who did not (6.5% vs. 2.6%; $P = 0.005$), especially those receiving palliative care from the CAP (9.6%), the palliative care task group from the NH (7.7%), and their treating GP (6.8%).

Physician's orders were documented significantly more often for residents with malignancies (63.2%; $P < 0.001$), a neurological diagnosis (57.2%; $P = 0.007$), and severe dementia (59.6%; $P < 0.001$). More dependent residents ($P < 0.001$) and those with a longer length of stay ($P = 0.018$) more often had physician's orders. Residents whose deaths were expected ($P < 0.001$) and who were not

transferred to hospital during the last three months of life ($P < 0.001$) and who died in the NH ($P < 0.001$) were more likely to have had physician's orders, as were those who received palliative care at the end of life (68.7% vs. 18.5%; $P < 0.001$).

Authorization of a legal representative occurred more often for residents with malignancies (13.0% vs. 7.8%; $P = 0.021$) and for those who received palliative care from a multidisciplinary palliative care team (10.6% vs. 6.9%; $P = 0.032$).

Multivariate Logistic Regression

Multivariate logistic regression showed that residents with severe dementia had documented advance directives six times less frequently (adjusted odds ratio [AOR] 0.182, 95% CI 0.088–0.377) and those with moderate dementia had half as many (AOR 0.516, 95% CI 0.270–0.988) as did those without dementia (Table 4). Residents who received palliative care four times more often had documented advance directives (AOR 4.160; 95% CI 1.933–8.950).

Residents who died in the NH had physician's orders almost three times more often than those who died in hospital (AOR 2.751; 95% CI 1.796–4.213). Residents whose death was expected had physician's orders more than twice as often as those who died suddenly (AOR 2.351; 95% CI 1.422–3.888). Residents who received palliative care had physician's orders documented five times more often than those who did not (AOR 4.957; 95% CI 3.322–7.396). Authorization of a legal representative occurred more often among residents with malignancies than among those diagnosed with other diseases (AOR 1.706; 95% CI 1.064–2.734).

Discussion

At time of death, residents of NHs in Flanders, Belgium are often severely dependent and often have a diagnosis of dementia. During the last three months of life, almost half of the residents had been transferred to a hospital at least once, and one of five died in the hospital. Most deaths were not unexpected, and two-thirds of all those who died received palliative care. Half of residents had an ACP (mostly

Table 3
Prevalence of Advance Care Plans According to Deceased Resident's Characteristics, Number of Hospital Transfers, and Palliative Care Delivery (N= 1240)

	Total	Advance Directive ^a		Physician's Orders ^a		Authorization of a Legal Representative ^b	
	N	Documented (%)	P-value ^c	Documented (%)	P-value ^c	Documented (%)	P-value ^c
Characteristics of deceased nursing home residents							
Sex							
Male	384	4.2	0.479	48.2	0.295	8.0	0.654
Female	852	5.3		51.4		9.0	
Missing cases	4						
Age (years)							
<80	237	6.0	0.543	52.8	0.504	9.8	0.670
80–84	283	5.3		46.6		9.2	
85–89	303	3.3		52.8		9.3	
90–94	249	4.9		49.0		8.0	
≥95	147	6.2		52.7		5.6	
Missing cases	21						
Diagnosed diseases/disorders							
Malignant tumor	221	8.6	0.010	63.2	<0.001	13.0	0.021
Cardiovascular	413	5.1	0.890	50.7	0.760	9.2	0.740
Respiratory	238	4.6	0.869	56.1	0.110	11.1	0.187
Neurological	377	2.9	0.031	57.2	0.007	8.3	0.736
Urogenital system	100	4.0	0.812	53.0	0.755	11.3	0.346
Metabolic disorder	56	1.8	0.522	53.6	0.785	5.7	0.617
Other	115	2.6	0.361	46.5	0.280	8.2	1.000
Missing cases	54						
Diagnosis of dementia							
No	408	8.4	<0.001	41.4	<0.001	8.2	0.341
Yes, moderate dementia	285	4.9		51.8		10.5	
Yes, severe dementia	479	2.1		59.6		7.4	
Missing cases	68						
Level of dependency							
O: independent	47	6.5	0.005	23.9	<0.001	4.7	0.440
A: little dependent	58	8.6		34.5		10.9	
B: dependent	172	6.4		34.3		7.2	
C: severely dependent	265	7.6		48.9		10.2	
Cd: severely dependent and demented	615	2.8		58.1		7.0	
Missing cases	83						
Length of stay							
≤6 months	267	5.7	0.478	49.1	0.018	10.0	0.774
0.5–2 years	286	5.7		43.3		8.7	
3–4 years	281	5.3		54.1		8.5	
>4 years	395	3.6		54.5		7.7	
Missing cases	11						
Having a support person							
Yes	1167	5.3	0.069	50.8	0.518	9.2	0.005
No	65	0.0		46.0		0.0	
Missing cases	8						
Treating general practitioner is the coordinating and advisory physician of the nursing home							
Yes	229	4.8	1.000	55.5	0.106	6.4	0.187
No	1002	5.0		49.3		9.2	
Missing cases	9						
Type of death							
Expected	723	6.0	0.018	65.2	<0.001	9.3	0.179
Neither expected nor unexpected	268	4.9		41.4		9.8	
Unexpected	239	1.7		16.5		5.7	
Missing cases	10						
Place of death							
Nursing home	981	5.6	0.205	59.1	<0.001	8.6	0.435
Hospital	244	2.5		18.1		8.8	
Palliative care unit	10	0.0		22.2		0.0	
Other	3	0.0		0.0		33.3	
Missing cases	2						

(Continued)

Table 3
Continued

	Total	Advance Directive ^a		Physician's Orders ^a		Authorization of a Legal Representative ^b	
	N	Documented (%)	P-value ^c	Documented (%)	P-value ^c	Documented (%)	P-value ^c
Number of transfers to the hospital during the last 3 months of life							
0	696	4.8	0.173	56.8	<0.001	8.8	0.550
1	381	4.2		42.4		7.8	
≥2	147	8.2		46.3		10.7	
Missing cases	16						
Palliative care delivered at the end of life ^d		6.5	0.005	68.7	<0.001	9.2	0.363
By individual regular caregiver, with palliative care training		7.0	0.001	71.3	<0.001	9.0	0.586
Treating general practitioner	546	6.8	0.025	71.7	<0.001	9.7	0.202
Palliative reference nurse	461	6.5	0.138	72.0	<0.001	6.7	0.081
Coordinating and advisory physician	115	9.6	0.042	77.2	<0.001	12.0	0.203
LEIF physician	1	0.0	1.000	100.0	1.000	0.0	1.000
By multidisciplinary palliative care team		7.3	0.004	67.9	<0.001	10.6	0.032
Palliative task group	494	7.7	0.001	69.1	<0.001	10.5	0.052
Palliative home care team	34	5.9	0.697	76.5	0.005	12.1	0.520
Palliative support team of the hospital	34	0.0	0.254	41.2	0.224	10.3	0.732
Palliative care unit of the hospital	17	0.0	1.000	52.9	1.000	12.5	0.641
Missing cases	66						

LEIF = Life End Information Forum.

^aTen missing cases.

^bFifty-nine missing cases.

^c χ^2 test.

^dMultiple answers possible.

physician's orders and rarely advance directives). Delivery of palliative care was positively related to having an ACP (either a physician's order or an advance directive). Dying in the NH, the expectation of imminent death, and suffering from dementia were associated with having physician's orders. Residents with dementia less often had advance directives. Nine percent had authorized a legal representative.

This study is the first in Flanders, Belgium, to describe the dying conditions and actual practice of ACP in NHs. Deceased NH residents were used as the denominator of the study because this population provided a more accurate estimate of ACP in those who were likely to need it. The characteristics of deceased NH residents in this study were compared with sex and age data of in-NH deaths from a representative death certificate study,²⁵ with no significant differences.

The study has some limitations. First, response bias cannot be ruled out as no direct

comparison with a cohort of dying residents in this setting is available. It is also possible that selection bias might have resulted in an overestimation of actual ACP completion by the NHs, as NHs doing a good job in provision of end-of-life care were perhaps more likely to complete the questionnaire. Second, this study neither investigated the quality of the process preceding the documentation of ACPs (timing, communication, and so on) nor the quality of the palliative care delivered. And third, this study provides no data about the final decisions made at the end of life, how far they complied with the ACPs, or whether or not the absence of an ACP would automatically have led to continuation of treatment.

Findings of this study confirm that the profile of NH residents at the time of death shows them to be most appropriate for having made anticipatory decisions concerning end-of-life care issues. More than 80% were found to be very old (aged 80 years or older)—with one

Table 4
Multivariate Logistic Regression Analysis of
Advance Care Plans and Authorization of a Legal
Representative (N = 1240)

	Advance Directives ^a	
	Odds Ratio ^b	
	Adjusted	95% CI
Diagnosis of dementia		
No	Ref	
Yes, moderate dementia	0.516	0.270–0.988
Yes, severe dementia	0.182	0.088–0.377
Palliative care delivered at the end of life	4.160	1.933–8.950
	Physician's Orders ^a	
	Odds Ratio ^b	
	Adjusted	95% CI
Place of death		
Nursing home	2.751	1.796–4.213
Hospital	Ref	
Palliative care unit	NS	
Other	NS	
Type of death		
Expected	2.351	1.422–3.888
Neither expected nor unexpected	1.709	1.020–2.864
Unexpected	Ref	
Palliative care delivered at the end of life	4.957	3.322–7.396
	Authorization of a Legal Representative ^c	
	Odds Ratio ^b	
	Adjusted	95% CI
Diagnosed diseases/disorders		
Malignant tumor	1.706	1.064–2.734

NS = not significant.

Only figures of significant variables are presented.

^aTen missing cases.

^bOdds ratio of logistic regression with having no advance care plan or not having authorized a legal representative as reference group.

^cFifty-nine missing cases.

of three being 90 years or older—and to have died relatively expectedly, which is a much higher proportion than among the general public. In previous studies, including all deaths of those aged one year or older in Flanders, Belgium, only half were found to be 80 years or older and two-thirds died nonsuddenly.^{2,26,27} In Flanders, Belgium, 28% of NH residents were found to die each year,¹⁶ of which 65% had dementia. Because of the degenerative character of dementia, those suffering from this disease can benefit especially from anticipatory discussion about their attitudes and wishes concerning the end of life.

Although dementia is one of the most frequent reasons for NH admission in Flanders, Belgium,²⁸ the possibility of some kind of communication might be expected at the time of admission or shortly afterward before the disease progresses. Moreover, more than half of the deceased NH residents had lived in the NH for more than three years before death (which is longer than in other countries),^{29,30} and it might be expected that during this time NH staff would have been in a position to stimulate advance communication about the resident's preferences concerning end-of-life care.

Despite the growing interest in ACP in general and more specifically for NH residents, documented ACPs were found in only half the cases of deceased NH residents in Flanders, Belgium, at the end of 2006. This is rather low considering that ACP can be of great benefit for qualitative end-of-life care,³¹ particularly for NH residents who may lose the capacity to make decisions when they near the end of life and whose death can be largely expected. Documentation of advance directives by NH residents in Flanders, Belgium (5%) lags far behind that in other countries like the U.S., where (in contrast with the Belgian Patients' Rights Act) the Patient Self-Determination Act obliges health care institutions, including NHs, to give patients information about advance directives at the time of admission and to encourage them to write them down.^{5,32} Most alarming is that those NH residents without a supportive relative (5.3% of deceased residents) were also without an advance directive, leaving them doubly dependent on staff to advocate in their best interests when they lose capacity. The fact that physician's orders occurred more often when death was expected, and that residents with dementia were less likely to have advance directives, seems to confirm other studies concluding that formal discussions about end-of-life care often do not occur before the onset of dementia or the loss of capacity resulting from serious illness near the end of life.^{12,31}

Most ACPs (advance directives and physician's orders) concern anticipatory decisions about nonhospitalization and/or the withholding or withdrawing of treatments. This should not be a surprise because previous research has shown that of all end-of-life decisions

preceding deaths in NHs, nontreatment decisions are the most frequent.^{2,26,27} However, the completion rate for ACPs among deceased NH residents (51.8%), including do-not-hospitalize (37.2%), remains substantially lower than among the deceased NH residents in the U.S. (more than 80%).^{15,33} Euthanasia, which is performed in 0.6% of all deaths in NHs,²⁶ was rarely documented in ACP (0.7%). However, based on this study, no conclusions can be made about levels of concordance between ACPs and actual end-of-life decisions made at the very end of life. A recent study in The Netherlands shows that the physicians often do not adhere to advance directives for euthanasia in patients lacking in capacity to make decisions.³⁴

Receiving palliative care seems to be linked to the existence of ACPs (physician's orders and advance directives). This finding might be expected because discussion of goals of care is inherent in palliative care.^{3,4,9} However, in one-third of all deceased NH residents or in one-fifth of NH residents whose death was expected, no palliative care initiatives were taken. There seems to be room for improvement in palliative care delivery in NHs, although previous research in Flanders, Belgium shows that decedents in NHs had received twice as much specialist palliative care than had those dying at home.³⁵ When palliative care was delivered by the CAP, independent of whether or not he/she was the resident's treating physician, this resulted in a higher rate of documented ACPs. Although the same trend was seen when palliative care was delivered by the resident's treating GP (not necessarily the CAP), documentation of advance directives by the NH resident was clearly higher for those who received palliative care from the CAP (9.6%) than for those who received it from their treating GP (6.8%). Because no difference in documentation of advance directives (or physician's orders) was found relating to whether or not the resident's treating GP was the CAP of the NH, it seems as if the specific training of the CAP has an impact on stimulating a resident to write an advance directive when care is defined as palliative care and not in other care situations. Appropriate training of physicians treating NH residents seems to be important. In The Netherlands, NH residents are treated by NH physicians who have completed a two-

year specialist training program in special skills and competencies relating to the characteristics of NH residents, and to the specific context of NHs. This training also includes the development of skills in communication, attitudes, and decision making in difficult ethical dilemmas about end of life and palliative care.³⁶ Dutch researchers consider such specialized training, as well as the continuous presence of NH physicians in NHs, as important facilitating factors for improved decision making and care planning, including ACP.³⁷

Almost half of deceased NH residents in the study had been transferred to a hospital during the last three months of life and one in five died in the hospital; these residents were less likely to have had physician's orders limiting life-sustaining treatments, although it remains unclear whether their transfers were aimed at curative treatment or at receiving adequate palliative care that was not available in the NH.

The authorization of a legal representative was documented by fewer than one in 10 NH residents. A person who is familiar with the resident's preferences regarding the end of life could be involved in end-of-life discussions about the sort of specific problems that were difficult to foresee in drawing up advance directives. Although there is discussion in the literature about whether relatives have an adequate understanding of the wishes of a dying person, it has been shown that appointing an authorized representative can avoid burdensome treatments at the end of life.^{10,38}

In conclusion, considering the profile of NH residents at the end of life, there are very few ACPs documented. Increased awareness of the role played by ACP in achieving a dignified dying process in line with a person's wishes can increase the awareness of specialized palliative care workers as well as regular health care workers (especially GPs and nurses)³⁹ of the value of the timely discussion of the direction of care at the end of life of NH residents. As many residents lose their capacity to make decisions during their stay at NHs, it is also important to encourage people to communicate their wishes, values, and worries to their caregivers and to write advance directives as early as possible, before or soon after NH admission, and/or to appoint a legal representative.

Disclosures and Acknowledgments

Research grants from the Research Council of the Vrije Universiteit Brussel funded this study, after approval of the study design that was proposed by the researchers. These funding sources had no role in developing the study design, in the data collection, data analysis, data interpretation, or presentation of the information. The authors declare no conflicts of interest.

The authors thank the four umbrella organizations for nursing homes in Flanders, Belgium (Vereniging van Vlaamse Steden en Gemeenten, Verbond der Verzorgingsinstellingen, Federatie Onafhankelijke Seniorenzorg, and the Federatie van Rustoorden van België), Crataegus, and the Federation Palliative Care Flanders for their support given to this study by signing the recommendation letter enclosed with the questionnaire.

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