Background: The aim of this study is to discover how many nursing homes (NHs) in Flanders (Belgium) have policies on advance care planning (ACP) and their content regarding different medical end-of-life decisions. Methods: A structured mail questionnaire was sent to the NH administrators of all 594 NHs in Flanders (Belgium) at the end of 2006. The questionnaire asked about the existence, timing of implementation and content of ACP policy documents (guidelines and patient-specific planning forms), and on NH characteristics related to end-of-life care. Results: The response rate was 58.1%. The development of ACP policy documents began in 1989 with major increases in implementation taking place from 2000. In 2006, ACP policy documents were available in 95.1% of NHs. Most of these NHs had ACP guidelines as well as ACP patient-specific planning forms. Almost all patient-specific planning forms included anticipatory do-not-hospitalize (90.0%) and do-not-resuscitate decisions (83.2%). Anticipatory decisions about terminal sedation (29.2%) and euthanasia (19.7%) were mentioned less often and these decisions were not permitted to be made in all NHs. One out of three NHs had policies on the appointment of a patient’s representative. Conclusion: By the end of 2006, almost all NHs in Flanders (Belgium) had an ACP policy. The implementation of ACP policies in Flemish NHs lagged behind other countries, but has developed rapidly since 2000. However, some NHs appear to ban some end-of-life options which are actually legal in Belgium. Further research is needed to investigate whether ACP policies have much impact on the quality of end-of-life care in NHs.

Keywords: advance care planning, nursing homes, policy.
traditional care home beds) and each institute has on average 97 elderly residents.\textsuperscript{13,14} The medical care in Flemish NHs (including end-of-life care) is provided by general practitioners (GPs) chosen by the individual resident. These GPs are not part of the management of the institution. Each NH is also obliged by law to have one coordinating and advisory physician, also a GP, who participates in the management of the NH. This coordinating and advisory physician has the task of facilitating the cooperation between the NH management and the visiting GPs, coordinating and streamlining medical care, and organizing training for GPs and nurses. He/she can also be consulted for a second opinion by the other GPs and can intervene in care-related conflicts (e.g., a conflict between resident, next of kin and professional caregivers concerning decisions at the end of life)\textsuperscript{15,16}

The addresses of the 594 NHs included in this study, their characteristics such as ownership (‘public’/’private, non-profit’/’private, profit’) and bed capacity were obtained from the Flemish Ministry of Health. The NH administrator of each NH was sent a structured mail questionnaire requesting information about the ACP policy of his/her institution, together with a letter of recommendation signed by six relevant organizations for this setting. About 1 month later a follow-up letter was mailed to the non-responders. A telephone call was made after another three weeks to those who had still not responded.

**Questionnaire**

The first part of the four-page questionnaire was about NH characteristics related to end-of-life care: (i) How much time per week did the coordinating and advisory physician visit the NH (excluding any time spent acting as the treating GP of an individual resident)? (ii) How many full-time equivalent (FTE) reference nurses for palliative care are there? (iii) How many residents died in the past 12 months? (iv) How many residents died in the past 12 months received palliative care in the NH? (e.g., palliative care delivered in the NH by a multidisciplinary palliative support team or by the resident’s GP) (v) How many residents who died in the past 12 months were transferred to a palliative care unit? To make useful comparisons between NHs, the answer to question (iii) was reassessed per 100 beds, and to questions (iv) and (v) per 100 deaths.

The second part of the questionnaire explored two possible aspects of the ACP policy of the NH namely (i) written institutional ACP guidelines and (ii) individual, patient-specific planning forms. These were defined in the questionnaire as follows:

(i) Written institutional ACP guidelines: generally accepted agreements of the NH to guide physicians and nurses in advance care planning regarding the end-of-life of patients;

(ii) Individual patient-specific planning forms: standardized forms to document anticipatory instructions from the physician and/or the patient (regarding hospitalization, treatments and other medical end-of-life acts) concerning the individual patient.

Key questions were: ‘Are written institutional ACP guidelines regarding the end of life available in the NH’ (‘Yes’/’No’) and ‘Are individual patient-specific planning forms available in the NH’ (‘Yes’/’No’). When these documents were available, respondents were asked at what stage they were enacted and about their content differentiating several medical end-of-life decisions. The questionnaire was partly inspired by an existing questionnaire on policies and guidelines on medical end-of-life decision making in health care in The Netherlands\textsuperscript{17} and by another regarding do-not-resuscitate policies on acute geriatric wards in Flanders.\textsuperscript{18}

The questionnaire was pilot-tested by 10 NH administrators in all five provinces of Flanders, resulting in minor adaptations to avoid ambiguity and to improve understanding.

**Data analysis**

To test the representativity of the response sample, it was compared with the non-response sample using the NH characteristics of the database from the Flemish Ministry of Health (ownership and number of beds). For characteristics with significant differences in distribution, the response sample was weighted to the distribution of the population.

The NH was considered the unit of analysis. Descriptive results were presented in frequency tables and crosstabs, and differences in distribution (Chi-square and Rao-Scott Chi-square tests taking into account design correction) were calculated using the statistical package SPSS 16.0 (SPSS Inc., Chicago, IL) and SAS Enterprise Guide 4.1 (SAS Institute Inc., Cary, NC). Confidence intervals of 95\% were used.

**Results**

**Nursing home characteristics**

In total 345 of the 594 NH administrators (58.1\%) completed and returned the questionnaire; 189 (31.8\%) were returned after sending the original questionnaire, 91 (15.3\%) after the follow-up letter was sent and 65 (10.9\%) after the follow-up telephone call. Ownership (‘public’/’private, non-profit’/’private, profit’) and number of beds of the 345 responding NHs were compared with the non-response sample. Since there was an overrepresentation of public NHs in the response sample (41.7 vs. 30.1\% in the non-response sample; \(P = 0.006\)), results were weighted for ownership of all NHs in Flanders (table 1).

In 25.9\% of the NHs the coordinating and advisory physician spent \(\leq 1\) h per week in the NH, 26.5\% spent between 1 and 2 h, 20.4\% between 2 and 3 h and 27.2\% \(>3\) h. This was positively related to the bed capacity of the NH (\(P < 0.001\); not shown in table 1). Most NHs (41.4\%) had one FTE reference nurse for palliative care and 23.5\% had less than one FTE.

**Dying and care for the dying in nursing homes**

The mean proportion of NH residents per 100 beds who died in the past year was 28 (table 1). Of the residents who had died in the last year, NHs had been given palliative care on average to 53 per 100 and had transferred on average 1 per 100 to a palliative care unit in the last phase of life. In the majority of NHs (86.9\%) no transfers to a palliative care unit had taken place.

**Development of ACP policy**

At the end of 2006, 95.1\% of the NHs had a policy regarding ACP (figure 1). Institutional ACP guidelines were available in 66.6\% of NHs and individual patient-specific planning forms in 93.0\%. Both institutional guidelines and individual patient-specific planning forms were available in 64.5\% of NHs. No significant differences were found for NH characteristics (not shown in the table or figure).

The first ACP policy documents were implemented in 1989 in two NHs, and it took until 1993 before other NHs began to implement institutional ACP guidelines and/or individual patient-specific planning forms. Since 1998, more than half of the NHs with ACP policy documents had institutional
NH characteristics

**Ownership**
- Public: 144 (41.7) 36.9
- Private, non-profit: 171 (49.6) 52.2
- Private, profit: 39 (10.7) 10.9

**Number of beds**
- 60: 72 (20.9) 21.4
- 61–90: 113 (32.8) 32.6
- 91–120: 74 (21.4) 21.8
- >120: 86 (24.9) 24.2

**Average time spent per week in the NH by the coordinating and advisory physician**
- ≤1 h: 85 (25.9) 25.9
- 1–2 h: 88 (26.8) 26.5
- 2–3 h: 66 (20.1) 20.4
- >3h: 89 (27.1) 27.2

**FTE reference nurse for palliative care**
- <1 FTE: 75 (23.4) 23.5
- 1 FTE: 131 (40.9) 41.4
- 1.01–2 FTE: 60 (18.8) 18.4
- >2 FTE: 54 (16.9) 16.6

**Dying and care for the dying in NHs**

**Number of deaths per year (per 100 beds)**
- ≤20: 53 (15.6) 15.7
- 21–25: 80 (23.5) 23.5
- 26–30: 98 (28.8) 28.3
- 31–35: 48 (14.1) 14.4
- >35: 61 (17.9) 18.1

**Mean 28 (SD 8); median 27; range 2–60**

**Number of deaths with palliative care per year (per 100 deaths)**
- ≤60: 107 (31.8) 32.0
- 61–80: 93 (27.7) 27.4
- >80: 37 (11.0) 11.3

**Mean 53 (SD 23); median 52; range 0–100**

**Number of transfers to a palliative care unit per year (per 100 deaths)**
- 0: 298 (87.1) 87.1
- 1–5: 24 (7.0) 6.9
- 6–10: 9 (2.6) 2.6
- >10: 11 (3.2) 3.4

**Mean 1 (SD = 5); median 0; range 0–40**

SD: standard deviation

Content of individual patient-specific planning forms regarding different medical end-of-life decisions

In 90.0% of the NHs anticipatory do-not-hospitalize decisions could be documented on individual patient-specific planning forms (table 3). In 82.1–84.6% of NHs other kinds of non-treatment decisions could be documented on individual patient-specific planning forms. A space to document anticipatory instructions about intensifying pain and symptom alleviation which might shorten the patient’s life was provided less often. In 29.4% of the NHs a standardized document was available for the appointment of a representative (not shown in the table).

Discussion

The development of ACP policy in NHs in Flanders, Belgium, started gradually in 1989 and increased more rapidly from 2000. At the end of 2006, almost all NHs had an ACP policy, consisting predominantly of individual patient-specific planning forms often accompanied by institutional guidelines. Anticipatory do-not-hospitalize and do-not-resuscitate decisions are almost always included in these policy documents, while anticipatory decisions about terminal sedation and euthanasia are often not mentioned, and when mentioned often specifically excluded. In addition, this study shows that about half of residents who had died had previously received palliative care in the NH and that 1 out of 10 was transferred to a palliative care unit in the last phase of life.

Content of institutional ACP guidelines regarding different medical end-of-life decisions

Anticipatory decisions about whether or not to transfer a resident to hospital at the end of life were the most (59.2%) common medical end-of-life decisions covered by institutional ACP guidelines (table 2). These guidelines make it possible to

make do-not-hospitalize decisions in 58.6% of the NHs, more often according to legal criteria (38.0%) as according to legal as well as additional institutional criteria (20.6%).

Institutional guidelines about anticipatory do-not-resuscitate decisions (not to start resuscitation in case of a cardiopulmonary arrest) were somewhat less frequently found (55.1%). About the same figures were found concerning institutional guidelines for anticipating decisions to withhold or withdraw artificial food and fluids, antibiotics or other treatments.

Intensifying pain and symptom alleviation, in the knowledge that this might shorten the patient’s life, was mentioned less often in the institutional ACP guidelines (47.4%). In 29.4% of NHs this was allowed according to legal criteria and in 17.7% there were additional institutional criteria.

Institutional guidelines about terminal sedation or euthanasia were found in one third of NHs, and in respectively 2.3 and 6.2% of the NHs these guidelines did expressly not allow these medical decisions in the institution.

Physician-assisted suicide was mentioned in institutional ACP guidelines in one to five NHs. In 15.2% of the NHs this practice was explicitly prohibited in their guidelines.

About a quarter (26.2%) of NHs had institutional guidelines about the appointment of a representative for the resident (not shown in the table).

Institutional guidelines about euthanasia were more frequently (but not significantly, \( P = 0.064 \)) implemented in private, non-profit NHs which are mostly of Catholic denomination (42.0 vs. 34.7% in public and 27.8% in private, for profit NHs). These institutions were also significantly more likely to have guidelines allowing euthanasia according to legal as well as institutional criteria (17.6 vs. 9.7% in public and 2.8% in private, for profit NHs; \( P = 0.043 \); not shown in the table).
This is the first nationwide study in Flanders to investigate ACP policies regarding different kinds of medical end-of-life decisions in NHs rather than focussing on euthanasia alone, and the first to describe both individual patient-specific planning forms and institutional guidelines. Furthermore, it gives for the first time some insight into the existence of palliative care initiatives in NHs. Results were weighted for the slight overrepresentation of public NHs in the response sample and can be considered to be representative for all NHs in Flanders.

Nevertheless, there are some limitations related to this study. First, in spite of the satisfactory response rate (58.1%) and weighted figures, possible non-response bias cannot be totally ruled out. It remains possible that NH with ACP policies were more likely to respond to the questionnaire, resulting in an overestimation of NH with ACP policies. Second, although a substantial impact of ACP on actual practices in the NHs can be expected, this is currently debated in literature since medical crisis often can not be predicted in detail, making most prior instructions difficult to use, irrelevant or even misleading. The current study does not provide information on this issue.

The development of ACP policies in NHs in Flanders has recently expanded rapidly. This might be an indirect consequence of the public debate about the laws on euthanasia and patients’ rights (both enacted in 2002) which formally began in 2000.12,21

There is little information available about ACP policies in other European countries. In The Netherlands, where the public debate on end-of-life decisions began much earlier than in Belgium and the rest of Europe, an important step towards policy development on euthanasia and physician-assisted

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**Figure 1** Cumulative percentages of NHs with ACP policy documents by year of implementation (N = 345)

**Table 2** Availability and content of institutional ACP guidelines regarding different medical end-of-life decisions (N = 345)

<table>
<thead>
<tr>
<th>Content of available institutional ACP guidelines</th>
<th>Available</th>
<th>Decision allowed according to legal criteria</th>
<th>Decision allowed according to legal as well as additional institutional criteria</th>
<th>Decision not allowed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available</td>
<td>66.6</td>
<td>Decision allowed according to legal criteria</td>
<td>Decision allowed according to legal as well as additional institutional criteria</td>
<td>Decision not allowed</td>
</tr>
<tr>
<td>Institutional ACP guidelines (total)</td>
<td>66.6</td>
<td>20.6</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Institutional ACP guidelines regarding decisions concerning...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do-not-hospitalization</td>
<td>59.2</td>
<td>38.0</td>
<td>20.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Do-not-resuscitation</td>
<td>55.1</td>
<td>36.7</td>
<td>17.5</td>
<td>0.9</td>
</tr>
<tr>
<td>Withholding or withdrawing artificial food and fluids</td>
<td>56.9</td>
<td>36.8</td>
<td>20.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Withholding or withdrawing antibiotics</td>
<td>57.7</td>
<td>37.3</td>
<td>20.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Withholding or withdrawing other treatments</td>
<td>57.1</td>
<td>37.4</td>
<td>19.5</td>
<td>0.3</td>
</tr>
<tr>
<td>Pain and symptom alleviation, which may shorten the patient's life</td>
<td>47.4</td>
<td>29.4</td>
<td>17.7</td>
<td>0.3</td>
</tr>
<tr>
<td>Terminal sedation</td>
<td>33.5</td>
<td>20.9</td>
<td>10.3</td>
<td>2.3</td>
</tr>
<tr>
<td>Euthanasia</td>
<td>37.7</td>
<td>18.4</td>
<td>13.1</td>
<td>6.2</td>
</tr>
<tr>
<td>Physician-assisted suicide</td>
<td>19.7</td>
<td>3.5</td>
<td>0.9</td>
<td>15.2</td>
</tr>
</tbody>
</table>

*Note: Percentages are weighted for ownership of all NHs in Flanders

a: From 4 to 9 missing cases
suicide was taken in 1995 (in 74% of the Dutch NHs), but on DNR and the withholding or withdrawing of other life-sustaining treatments to a lesser degree (in about 20% of the Dutch NHs).17

In short, one can say that the development of ACP policy in NHs in Europe is still incomplete and lags behind the situation in the USA. Almost half of the US NHs had implemented an ACP policy before enactment of the Patient Self-Determination Act (1991) and the rest did so shortly afterwards.21,22 ACP policies, especially those concerning do-not-resuscitation and living wills, are also commonplace in health care institutions in Canada and Australia.23

For a country like Belgium which has had a law on euthanasia since 2002, it seems strange that by 2006 only 37.7% of NHs in Flanders had guidelines on euthanasia in their ACP policies. An earlier study of 2003 showed that about 30% of Catholic NHs in Flanders had guidelines on euthanasia.24 Since the current study has not found any relationship between the ownership of a NH and the inclusion of euthanasia in its ACP guidelines, only a slight increase of this specific kind of policy is assumed in a 3-year period after enactment of the euthanasia law. However, as euthanasia is only performed in 0.6% of deaths in NHs, it might be necessary to put into perspective the lower prevalence of guidelines on euthanasia.25 Perhaps more remarkable is the fact that in 6.2% of NHs euthanasia is not allowed, although it is not possible to discover from this study whether this means that euthanasia requests from residents of these NHs will be ignored, or that these NHs will refer to another institution in the event of such a request. It is also not clear whether existing additional institutional criteria (besides the legal ones) allowing euthanasia, more often imposed in private non-profit NHs, are actually intended to improve carefulness in decision making or rather to deter such decisions. This may possibly be a leftover from the so-called palliative filter procedure. During the public hearings in the Belgian Senate before the enactment of the euthanasia law, there was a lot of discussion about whether or not to include an obligatory palliative filter procedure in the law. This procedure would require the consultation of a specialized palliative care team before a euthanasia request could be honoured (from a point of view that palliative care can forestall such requests), but in the end this obligation was not included in the law. Although the law stipulates that patients requesting euthanasia must be informed of the possibilities of palliative care, the palliative filter procedure might still persist in some health care institutions.25,27,28

Table 3 Availability of individual patient-specific planning forms concerning different medical end-of-life decisions (N = 345)

<table>
<thead>
<tr>
<th>Individual patient-specific planning forms</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual patient-specific planning form available (total)</td>
<td>93.0</td>
</tr>
<tr>
<td>Do-not-hospitalization</td>
<td>90.0</td>
</tr>
<tr>
<td>Do-not-resuscitation</td>
<td>83.2</td>
</tr>
<tr>
<td>Withholding or withdrawing artificial food and fluids</td>
<td>84.6</td>
</tr>
<tr>
<td>Withholding or withdrawing antibiotics</td>
<td>82.3</td>
</tr>
<tr>
<td>Withholding or withdrawing other treatments</td>
<td>82.1</td>
</tr>
<tr>
<td>Pain and symptom alleviation, which may shorten the patient’s life</td>
<td>56.4</td>
</tr>
<tr>
<td>Terminal sedation</td>
<td>29.2</td>
</tr>
<tr>
<td>Euthanasia</td>
<td>19.7</td>
</tr>
</tbody>
</table>

Note: Percentages are weighted for ownership of all NHs in Flanders
a: From 4 to 17 missing cases

Less than one-third of NHs had policy documents on the appointment by the resident of a representative. Since NH residents are often lacking in capacity due to dementia or other illness, it is important to investigate further whether and how this could be encouraged e.g. by obliging NHs under law to draw up guidelines and formalized documents. Finally, this study showed that only half of residents who had died in NHs had previously received palliative care and that very few were transferred to palliative care units in order to get adequate care. Because of the high mortality rate in NHs and since the majority of NH residents die non-suddenly, it can be assumed that palliative care delivery in the NH has not yet reached the optimal quality of end-of-life care for these residents. This might be subject for improvement by placing more financial means and manpower at their disposal.

In conclusion, this study provides an insight into the present state of ACP policies regarding the different kinds of end-of-life decisions in NHs in Flanders, Belgium. By the end of 2006, almost all NHs in Flanders had an ACP policy. Compared with other countries, implementation had started rather slowly but developed rapidly during recent years. Further research is needed to investigate actual ACP practices and the extent to which the existence of ACP policy documents impacts on actual medical practice at the end-of-life and on the quality of end-of-life care in NHs. Differences in legal regulations, organization of care and cultural factors should be taken into account in international comparisons.

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**Conflicts of interest:** None declared.

**Key points**

- Compared with other countries, implementation of ACP policies in Flemish NHs lagged behind but attained near completion at the end of 2006.
- Anticipatory do-not-hospitalize and do-not-resuscitate decisions are almost always included in ACP policy documents, while anticipatory decisions about terminal sedation and euthanasia are often not mentioned.
- Less than one-third of Flemish NHs had policy documents on the appointment by the resident of a representative, which is rather low since NH residents are often lacking in capacity.
- Based on this study, it can be assumed that palliative care delivery in NHs has not yet reached the optimal quality of end-of-life care, and might be subject for improvement by placing more financial means and manpower at the disposal of NHs.
References


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