

Original Article

Advance Care Planning in Belgium and The Netherlands: A Nationwide Retrospective Study Via Sentinel Networks of General Practitioners

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Abstract

Context. Advance care planning (ACP) is an important part of patient-centered palliative care. There have been few nationwide studies of ACP, especially in Europe.

Objectives. To investigate the prevalence and characteristics of ACP in two European countries and identify the associated factors.

Methods. A mortality follow-back study was undertaken in 2007 via representative nationwide Sentinel Networks of general practitioners (GPs) in Belgium and The Netherlands using similar standardized procedures. All GPs reported on each non-suddenly deceased patient in their practice. Our main outcome measure was whether or not ACP, that is, an agreement for medical treatment and/or medical decisions in the last phase of life in the case of the patient losing competence, was present.

Results. Among 1072 non-sudden deaths, ACP was done with 34% of patients and most often related to the forgoing of potential life-prolonging treatments in general (24%). In 8% of cases, ACP was made in consultation with the patient and in writing. In 23% of cases, care was planned with the patient's family only. Multivariate analysis revealed that ACP was more often made with patients if they were capable of decision making during the last three days of life (odds ratio [OR] 3.86; 95% confidence interval [CI] 2.4–6.1), received treatment aimed at palliation in the last week (OR 2.57; 95% CI 1.6–4.2), had contact with a GP in the last week (OR 2.71; 95% CI 1.7–4.1), died of cancer (OR 1.46; 95% CI 1.1–2.0), or died at home (OR 2.16; 95% CI 1.5–3.0).

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Conclusion. In these countries, ACP is done with approximately one-third of the studied terminally ill patient population. Most agreements are made only verbally, and care also is often planned with family only. ACP relates strongly both to patient factors and to health care measures performed at the very end of life. *J Pain Symptom Manage* 2011;42:565–577. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

End-of-life care, terminal care, palliative care, advance care planning

Introduction

An important aspect of the quality of end-of-life care is the congruence between the care and the patient's wishes. A patient's inability to participate in decision making could hinder the provision of good quality end-of-life care if their exact preferences remained unknown. One way of shaping future clinical care to fit each patient's wishes and values is by engaging in advance care planning (ACP), a process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient is unable to make decisions about his or her care.¹

With the passage of the Patient Self-Determination Act² in the U.S. in 1991, much attention was given to the right of patients to be involved in decision making. This resulted in the formalization of advance directives, such as living wills and the durable power of attorney. Research shows that more than a decade after the enactment, most (71%) of those U.S. citizens who experienced a nontraumatic death had completed an advance directive, and this was perceived by family members as being associated with better quality end-of-life care.^{3,4} However, most of the literature suggests that merely between 18% and 30% of the U.S. general population have completed an advance directive, which may be considered as a low percentage in view of the widespread support for ACP.⁵

In contrast to the research conducted in the U.S., relatively few studies have addressed the topic of ACP in Europe.⁶ Little research has been undertaken even as the patient's right to self-determination concerning the end of life has increasingly received attention in Western Europe within recent decades.

In this study, the prevalence and characteristics of ACP in both Belgium and The Netherlands were investigated. These neighboring countries are situated in the center of Western Europe and have between 100,000 (Belgium) and 135,000 (The Netherlands) deaths annually, which is approximately 1% of the total population.^{7,8} Both countries place high value on patient autonomy in their legal frameworks concerning end-of-life issues; for example, both have specific laws on patient rights,^{9,10} and a law on euthanasia,^{11,12} the first worldwide. In both countries, palliative care has been well developed and integrated within the national health care system,^{13,14} and in a recently published Quality of Death Index, which measures the current end-of-life health care environment, availability, cost, and quality across 40 countries, Belgium and The Netherlands ranked fifth and seventh,¹⁵ respectively.

Using an identical study design, we aimed to address the following research questions among a representative sample of terminally ill patients:

- 1) What is the prevalence and what are the characteristics of ACP within a non-suddenly deceased population in Belgium and The Netherlands?
- 2) Which patient and health care characteristics are associated with the occurrence of ACP?

Methods

Study Design, Setting, and Participants

In Belgium and The Netherlands, we set up a nationwide mortality follow-back study in 2007 aimed at monitoring end-of-life care in collaboration with the national Sentinel Networks of general practitioners (GPs) (SENTI-MELC

study). Both networks have a long history of nationwide surveillance of a wide variety of health-related topics,^{16–22} with a turnover rate that, from year to year, remains low. This means that participating GPs did not enroll because of specific interest in the field of end-of-life care.

The Belgian network covers 1.6% of the total patient population and is representative of all GPs in the country in terms of age, gender, and geographical distribution.^{19,23} The coverage in The Netherlands approximates to 1% of the registered patient population, and the network is nationally representative by gender, age, geographical distribution, and population density.^{24,25} The Belgian Scientific Institute of Public Health (IPH) and NIVEL (The Netherlands Institute for Health Services Research) acted as coordinators of the respective national Sentinel Networks. In 2007, the Belgian network comprised 156 regularly participating practices, compared with 45 in The Netherlands.

Participating GPs register each death in their practice of anyone aged one year or older on a standardized form within a week of its occurrence.²¹ The GPs certify the deaths of their patients themselves or are notified by the certifying GP or hospital colleague after death. To identify a sample of terminally ill patients who could benefit the most from having an advance care plan, we asked the GP, “Was this death sudden and totally unexpected?” Only those patients whose death was non-sudden and expected, as judged by the GP, were included in this study. The design has been used previously in several other studies on end-of-life care and decision making.^{21,26–29}

In Belgium, the study protocol and anonymity procedures were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel. An approval from the Ethical Review Board was not required for this study in The Netherlands because of the nature of the data collection (post-mortem). In both countries, patient anonymity was preserved and physician confidentiality maintained through the registration and data entry processes.

Data Collection

The registration form comprised structured closed-ended questions surveying sociodemographic patient information, the patient’s

place of longest residence during the last year of life, the place and cause of death, and the GP’s appraisal as to whether or not the patient was capable of making decisions in the last three days of life.

A major part was aimed at measuring the existence and content of an advance care plan. Definitions of ACP vary between countries and studies. We based our question on Teno et al.,¹ who defined ACP as a process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient is unable to make decisions about his or her care. ACP in this article covers a range of preferences—without being exhaustive—related to the withholding or withdrawal of potentially life-prolonging procedures that are common in end-of-life care decision making; it clarifies preferences to receive certain care or treatment rather than to have it withheld. We focus not only on ACP made with patients themselves, but also on agreements about the patient’s situation that are made with the patient’s family only.

In a first set of questions, GPs were asked to indicate whether or not they were aware of “a previous agreement, with the patient or his/her family, not to initiate or to stop one of the following potentially life-prolonging treatments under certain circumstances: chemotherapy, artificial food administration, artificial fluid administration, blood transfusion, artificial respiration, cardiopulmonary resuscitation, dialysis, antibiotics, vasopressors, and hospital transfer.” If yes, then GPs were asked to indicate whether or not the agreement also was “made in writing” (advance directive) and/or “made in consultation with the patient.” A second group of questions measured the GP’s knowledge of any previous agreement with patient or family to perform, under certain circumstances, the following medical practice: 1) an overall agreement to forgo any potential life-prolonging treatments (when testing the questionnaire, some GPs indicated that patients do not always plan for specific treatments but use more general statements), 2) intensifying the alleviation of pain and/or symptoms with a possible life-shortening effect, 3) keeping the patient unconscious until death using medication with/without artificial feeding or hydration

(continuous deep sedation), and 4) prescribing, supplying, or administering a drug with the explicit intention of hastening the end of life (physician-assisted death). If yes, GPs were asked to indicate whether or not the agreement was “made in writing” and/or “in consultation with the patient.”

Other care characteristics measured included the following: whether or not GP contacts with the patient or with relatives concerning the patient had occurred during the last week of life, whether or not a specialist palliative care service had been involved within the last three months of life, and the main treatment goal in the last week of life (cure, prolonging life, or comfort/palliation; in cases in which the treatment goal had changed during the last week, we relied on the GP’s judgment to indicate the most important goal). The wording of these questions was identical to that used in previous research.^{27,28} The selection of patient and health care characteristics was based on their possible influence on end-of-life care and communication in both countries, as stated in previous research.^{6,26}

Several procedures were used to ensure data quality: the registration form was originally developed in Dutch, then translated via a forward-backward procedure into French, as the study covered both language regions of Belgium; the study design was subjected to an extensive pilot study in 2004³⁰ and was used in previous registration years (2005 and 2006);^{21,26–29,31} the 2007 questionnaire was pretested by 10 GPs from each country for readability and comprehensibility; an automatic follow-up and telephone contact with the GPs were used to prevent missing data; and on data entry, the registration forms were closely scrutinized for errors, and several quality control measures were used to ensure optimal data quality (e.g., data entry checking for consistency and whether GPs followed the correct route in the questionnaire).

Analyses

We calculated the proportion of patients for whom the GPs indicated that—for at least one particular medical practice—there was 1) an advance care plan made in consultation with patient, 2) an advance care plan made both in consultation with the patient and in writing,

and 3) a care plan made with the patient’s family without consulting the patient.

With StatXact6 (Cytel, Inc., Cambridge, MA), 95% confidence intervals (CIs) were calculated on the percentages shown. SPSS 17.0 (SPSS Inc., Chicago, IL) and STATA 10 (StataCorp LP, College Station, TX) were used for other statistical computations: logistic regression analysis was used to explore bivariate associations between patient/health care characteristics and binary outcome measures. Variables that were significantly associated were included in multivariate logistic regression models to investigate their independent predictive value. Multilevel analyses (by means of a marginal Generalized Estimating Equations model) accounted for clustering of the data by physician practices. If missing data for an independent variable were higher than 5% of cases, these also were entered as a separate category in the multivariate analyses to increase statistical power of the model.

Results

The Belgian and Dutch Sentinel GPs reported 1191 and 520 deaths, respectively. Of these 1711 deaths, 20 cases were excluded because of too much missing data. Of all remaining deaths, 63.4% were non-sudden ($n = 1072$). In both countries, the characteristics of the non-sudden deaths were compared with those of a group of non-sudden deaths identified in a nationwide, representative, large-scale, death certificate study (for Belgium, this covered only the Dutch-speaking part). The Belgian sample was representative for age, gender, and place of death ($n = 2128$).³² In The Netherlands, representativeness was reached for age and gender. However, nursing home deaths were underrepresented ($n = 9965$)³³ (analyses not shown). The characteristics of the study population are presented in Table 1.

An overview of the types and characteristics of ACP within the total sample of terminally ill patients is shown in Table 2. Advance agreements about a medical practice were made with 34% of patients. More specifically, percentages of ACP concerning the withholding or withdrawing of a particular life-prolonging treatment varied between 4% (about vasopressors) and 20% (about hospital transfer).

Table 1
Characteristics of the Non-Sudden Deaths Studied in Belgium and The Netherlands

Characteristics	All Non-Sudden Deaths (<i>n</i> = 1072) ^a			Belgium (<i>n</i> = 755)	The Netherlands (<i>n</i> = 317)
	<i>n</i>	%	95% CI ^b	%	%
Age at death					
<65 years	176	16.8	(14.2–19.7)	15.9	19.0
65–79 years	313	29.9	(26.5–33.4)	29.2	31.6
≥80 years	559	53.3	(49.6–57.1)	54.9	49.3
Gender					
Male	489	46.5	(43.1–50.0)	45.3	49.7
Female	562	53.5	(50.0–46.9)	54.7	50.3
Level of education ^c					
Elementary or lower	419	44.5	(40.6–48.4)	42.2	50.4
Lower/higher secondary	427	45.4	(41.5–49.3)	48.6	37.3
Higher education/university	95	10.1	(7.9–12.6)	9.2	12.3
Capacity for decision making three days before death ^{c,d}					
Totally incapable (worst case possible)	310	36.1	(32.2–40.1)	42.1	20.6
Not entirely capable	281	32.8	(29.0–36.7)	30.3	39.1
Capable of making decisions	267	31.1	(27.4–35.0)	27.6	40.3
Main treatment goal in the last week of life ^c					
Cure/prolonging life	188	18.8	(16.1–21.7)	22.7	8.6
Comfort/palliation	812	81.2	(78.3–83.9)	77.3	91.4
Specialist palliative care services used ^c					
Yes	348	33.2	(30.0–36.5)	38.3	21.2
No	700	66.8	(63.5–70.0)	61.7	78.8
Patient-GP contact during the last week of life					
None	290	27.1	(24.1–30.2)	27.8	25.2
At least one	782	72.9	(69.8–76.0)	72.2	74.8
Cause of death					
Malignancies	449	42.0	(38.0–46.0)	40.2	46.3
Cardiovascular disease	189	17.7	(14.7–20.9)	17.2	18.7
Respiratory disease	89	8.3	(6.3–10.8)	8.6	7.6
Disease of nervous system	50	4.7	(3.2–6.6)	4.5	5.1
Stroke	74	6.9	(5.0–9.2)	6.6	7.6
Other	218	20.4	(17.2–23.8)	22.8	14.6
Longest place of residence in last year					
Home	750	72.5	(69.7–76.0)	71.5	75.2
Institution ^e	272	27.5	(24.0–30.3)	28.0	24.8
Elsewhere (<i>n</i> = 6) ^f					
Place of death ^c					
Home	298	28.5	(25.1–32.1)	24.5	38.6
Hospital	382	36.5	(32.8–40.3)	39.0	30.2
Care home	271	25.9	(22.6–29.4)	25.3	27.4 ^g
Palliative care unit/hospice	95	9.1	(7.0–11.5)	11.2	3.7

^aMissing values <5% for age at death, gender, specialist palliative care services, patient-GP contact, cause of death, longest place of residence, place of death; <10% for treatment goal; <15% for level of education; and 20% for decision-making capacity.

^bMultinomial CIs, exact method.

^cDifference between countries was significant at alpha 0.05 (Fisher's exact test).

^dScores could range from 0 to 10: capable of making decisions (score 0–4); not entirely capable (score 5–9); and totally incapable (score 10).

^eFor Belgium: care homes (28.0%); for The Netherlands: residential homes for older people (22.9%) and nursing homes (1.9%).

^fNot included in analysis.

^gResidential homes for older people (19.3%) and nursing homes (8.1%).

Prevalence figures of ACP to perform a medical decision at the end of the patient's life varied a good deal between the different types of decisions. The highest proportion was found for an agreement made with patients about forgoing any potentially life-prolonging treatment

(24% of patients) followed by the decision to intensify pain or symptom alleviation despite a possible life-shortening effect (16%).

The GPs indicated that, in 8% of all non-sudden deaths, a written advance agreement was made with the patient. As such, the outcomes

Table 2
Prevalence of Advance Care Planning (ACP) ($n = 1072$)^a

Advance Care Planning (ACP)	ACP with Patient		ACP with Patient and in Writing		Care Planning with Family Only	
	%	95% CI ^b	%	95% CI ^b	%	95% CI ^b
Any type of ACP	33.6	(30.7–36.6)	7.7	(6.1–9.5)	22.7	(20.2–25.4)
ACP to withhold/withdraw a potentially life-prolonging treatment	26.2	(23.6–29.0)	3.6	(2.6–5.0)	18.4	(16.1–20.9)
Chemotherapy/radiotherapy	13.4	(11.4–15.7)	1.2	(0.6–2.0)	8.1	(6.5–9.9)
Artificial food administration	10.5	(8.7–12.5)	1.3	(0.7–2.2)	11.6	(9.7–13.7)
Artificial fluid administration	9.6	(7.9–11.6)	1.5	(0.9–2.5)	12.2	(10.3–14.3)
Blood transfusion	7.0	(5.5–8.7)	0.9	(0.4–1.6)	6.2	(4.9–7.9)
Artificial respiration	9.8	(8.1–11.8)	1.4	(0.8–2.4)	9.9	(8.1–11.9)
Cardiopulmonary resuscitation	13.0	(11.0–15.2)	1.7	(1.0–2.7)	13.3	(11.3–15.6)
Dialysis	6.8	(5.4–8.5)	0.8	(0.3–1.5)	6.9	(5.5–8.6)
Antibiotics	4.9	(3.7–6.4)	0.5	(0.2–1.1)	6.4	(5.0–8.1)
Vasopressors	3.6	(2.5–4.9)	0.6	(0.2–1.3)	6.0	(4.6–7.6)
Hospital transfer	19.7	(17.3–22.2)	2.2	(1.4–3.3)	12.9	(10.9–15.1)
ACP to perform a medical end-of-life decision	27.2	(24.5–30.0)	6.3	(4.9–8.0)	20.6	(18.2–23.2)
Forgoing potential life-prolonging treatments in general	24.3	(21.7–27.0)	4.7	(3.5–6.2)	18.0	(15.8–20.5)
Intensifying pain/symptoms alleviation with a possible life-shortening effect	16.4	(14.2–18.8)	2.3	(1.5–3.4)	14.5	(12.4–16.8)
Continuous sedation with artificial feeding or hydration	1.8	(1.1–2.8)	0.6	(0.2–1.3)	3.1	(2.1–4.3)
Continuous sedation without artificial feeding and hydration	3.9	(2.8–5.3)	0.9	(0.4–1.6)	3.6	(2.6–5.0)
Administration, prescription, or supply of drugs with the explicit intention of shortening the patient's life	5.5	(4.2–7.0)	3.4	(2.4–4.6)	1.2	(0.6–2.0)

^aDenominator is all non-sudden deaths; 30 cases (2.8%) were excluded from all analyses on ACP as all the involved questions were left unanswered.

^bBinomial CI; exact method.

of the ACP were committed to paper in 23% of patients with whom an ACP had been discussed (not shown in table). Regarding most of the treatments and decisions, a written advance agreement was made with 1% or 2% of cases. Comparatively speaking, ACP about forgoing potential life-prolonging treatments in general (5%) and about the use of drugs with the explicit intention of shortening the patient's life (3%) were most often documented.

In 23% of cases, care planning was made with the patient's family without involvement of the patient. Most agreements concerned forgoing potential life-prolonging treatments in general (18%), intensifying the alleviation of pain or other symptoms despite a possible life-shortening effect (15%), cardiopulmonary resuscitation (13%), hospital transfer (13%), and artificial food or fluid

administration (12%). Agreements about the use of drugs with the explicit intention of shortening the patient's life that were made with the family occurred in 1% of cases.

Multivariate analyses indicated that ACP was more often made when patients had had contact with their GP in the last week of life (three times more often) (Table 3), when patients were capable to some extent to make decisions in the last three days of life as opposed to totally incompetent patients (two to four times), when treatment was aimed at palliation as opposed to cure or the prolongation of life during the last week of life (2.5 times), when patients died from cancer as opposed to non-cancer diseases (1.5 times), and when patients died at home as opposed to in an institution (two times).

Table 3
Factors Associated with the Prevalence of Advance Care Planning (ACP) (n = 1072)

Characteristics	ACP with Patient			ACP with Patient and in Writing			Care Planning with Family Only		
	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b
Age at death									
≤64 years	33.3	Reference category	—	11.9	Reference category	Reference category	18.5	Reference category	Reference category
65–79 years	38.4	1.25 (0.84–1.85)	—	9.6	0.79 (0.43–1.44)	1.22 (0.60–2.50)	17.5	0.94 (0.58–1.54)	0.82 (0.48–1.40)
≥80 years	30.1	0.86 (0.60–1.25)	—	4.9	0.38 (0.21–0.70)	0.72 (0.33–1.57)	27.6	1.68 (1.09–2.59)	1.01 (0.61–1.66)
Gender									
Male	36.8	Reference category	Reference category	8.5	Reference category	—	19.9	Reference category	Reference category
Female	30.5	0.75 (0.58–0.98)	0.78 (0.60–1.02)	6.9	0.81 (0.51–1.28)	—	25.7	1.40 (1.04–1.88)	1.17 (0.86–1.58)
Country									
The Netherlands	37.4	Reference category	—	13.1	Reference category	Reference category	16.1	Reference category	Reference category
Belgium	32.0	0.79 (0.60–1.04)	—	5.4	0.38 (0.24–0.60)	0.50 (0.26–0.98)	25.5	1.79 (1.26–2.53)	1.41 (0.91–2.18)
Level of education									
Elementary or lower	29.4	Reference category	Reference category	5.1	Reference category	Reference category	22.3	Reference category	—
Lower/higher secondary	36.8	1.40 (1.04–1.87)	1.17 (0.81–1.69)	9.0	1.81 (1.04–3.16)	1.39 (0.71–2.70)	22.3	1.00 (0.72–1.39)	—
Higher education/university	43.5	1.85 (1.16–2.94)	1.00 (0.62–1.61)	16.3	3.59 (1.77–7.28)	2.02 (0.93–4.39)	28.3	1.37 (0.82–2.29)	—
Cause of death									
Noncancer	24.3	Reference category	Reference category	5.3	Reference category	Reference category	27.1	Reference category	Reference category
Cancer	46.7	2.73 (2.10–3.56)	1.46 (1.08–1.96)	11.1	2.24 (1.40–3.56)	0.81 (0.42–1.55)	16.9	0.55 (0.40–0.74)	0.60 (0.41–0.87)
Treatment goal last week									
Cure/prolonging life	14.8	Reference category	Reference category	1.1	Reference category	Reference category	13.1	Reference category	Reference category
Comfort/palliation	40.2	3.88 (2.52–5.98)	2.57 (1.58–4.17)	9.6	9.58 (2.33–39.37)	4.94 (1.16–20.98)	26.1	2.34 (1.48–3.69)	2.83 (1.74–4.60)
Capacity for decision making three days before death									

(Continued)

Table 3
Continued

Characteristics	ACP with Patient			ACP with Patient and in Writing			Care Planning with Family Only		
	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b	%	OR (95% CI) Bivariate ^a	OR (95% CI) Multivariate ^b
Totally incapable	22.7	Reference category	Reference category	4.9	Reference category	Reference category	37.8	Reference category	Reference category
Not entirely capable	39.8	2.25 (1.57–3.23)	2.10 (1.37–3.19)	7.5	1.57 (0.79–3.11)	1.42 (0.71–2.84)	19.0	0.39 (0.18–0.41)	0.47 (0.32–0.71)
Capable of making decisions	55.9	4.31 (2.99–6.21)	3.86 (2.42–6.14)	14.1	3.15 (1.68–5.90)	2.08 (1.00–4.32)	14.1	0.27 (0.26–0.56)	0.33 (0.22–0.51)
Contacts in last week of life									
No	12.7	Reference category	Reference category	1.8	Reference category	Reference category	19.2	Reference category	—
Yes	41.1	4.81 (3.28–7.05)	2.71 (1.66–4.41)	9.8	5.88 (2.35–14.70)	4.83 (1.38–16.97)	24.0	1.33 (0.95–1.87)	—
Place of death									
Institution	24.5	Reference category	Reference category	4.7	Reference category	Reference category	24.9	Reference category	Reference category
Home	57.6	4.20 (3.15–5.60)	2.16 (1.53–3.03)	14.8	3.54 (2.21–5.68)	1.64 (0.94–2.86)	18.3	0.67 (0.48–0.95)	0.79 (0.54–1.15)
Specialist palliative care initiative used in last three months of life									
No	28.3	Reference category	Reference category	5.2	Reference category	Reference category	21.4	Reference category	—
Yes	45.3	2.10 (1.60–2.75)	1.32 (0.97–1.79)	12.6	2.66 (1.67–4.25)	2.21 (1.31–3.72)	25.6	1.27 (0.93–1.72)	—

^aOR with 95% CIs from a logistic regression analysis (“no ACP made in consultation with the patient,” “no ACP made both in writing and in consultation with the patient,” and “no care planning made with the patient’s family without consulting the patient” as respective reference categories). Significant values ($P \leq 0.05$) are shown in bold print.

^bOR with 95% CIs from a multivariate regression analysis (“no ACP made in consultation with the patient,” “no ACP made both in writing and in consultation with the patient,” and “no care planning made with the patient’s family without consulting the patient” as respective reference categories), performed for all bivariately tested significant associations; if missing data for an independent variable were higher than 5% of cases (level of education, treatment goal, and decision-making capacity), these also were entered as a separate category in the regression model to increase statistical power (not shown in table). Significant values ($P \leq 0.05$) are shown in bold print.

Multivariate analyses also showed that patients in Belgium were half as likely to have an ACP made in writing compared with those in The Netherlands. Additionally, patients had about five times more chance of having a documented ACP when treatment was aimed at palliation or when they had had contact with their GP during the last week of life and double the chance when specialist palliative care initiatives had been delivered over the last three months of life or when they were still fully capable of making decisions in the last three days of life.

Results of the multivariate analyses further indicated that patient care was three times more likely to be planned with the patient's family only (without consulting the patient) in cases where treatment was aimed at palliation in the last week of life and, respectively, three times and two times less likely if patients remained competent until the end of life or died of a noncancer disease.

Discussion

In general, ACP on at least one medical practice concerning the end of life occurred with about one-third of all non-suddenly deceased patients in Belgium and The Netherlands and most often related to the forgoing of potential life-prolonging treatments in general. Only in a small part of the sample was an ACP made in writing. For a quarter of all patients, care had been planned with the family without patient involvement. The factors associated with the outcome measures but varying according to type of care planning were the following: country, dying at home, dying of cancer, having GP contacts within the last week of life, being capable of decision making in the last three days of life, having a palliative treatment aim during the last week of life, and the involvement of specialist palliative care services within the last three months of life.

To our knowledge, this study is the first to provide European data on the prevalence of ACP within a robust terminally ill population, irrespective of setting, country, or diagnosis. This has been made possible by the use of an identical and dependable methodology across countries: a nationwide representative Sentinel

Network of GPs, each with a long history of registration research not selected on the basis of a specific interest in end-of-life research. Because the observation unit of this study was the GP, knowledge of whether the patient had an ACP was based on the report of the GP only. However, several control mechanisms were used to ensure reporting quality. Registrations were made within a week after death to limit recall bias as much as possible, and GPs were generally instructed to use the patient's records while completing the form. However, because detailed information concerning the care provided is not always available from the patient's medical files (e.g., verbal agreements), surveying GPs directly has an important surplus value. We also took several measures that contributed to the reliability of data: the use of an identical jointly developed and pretested questionnaire and strict research procedures, such as data entry with consistency, range, and skip checks. The surveyed sample of non-sudden deaths is well representative of the national population of non-sudden deaths by age, gender, and place of death in the Dutch-speaking part of Belgium and by age and gender in The Netherlands. The lack of representativeness for place of death in The Netherlands is a limitation resulting from an underrepresentation of nursing home patients because of the fact that nursing home physicians take over the care from GPs once patients are admitted for long-term care.^{34,35} Additionally, because our reports were limited to the perceptions of GPs, ACP done within a hospital might not always have been fully communicated to GPs.

Consequently, although representativeness is reached for the general practice population in both Belgium and The Netherlands, there might be some underestimation of the prevalence of ACP for all non-sudden deaths in both countries. This study has other limitations as well. Because of the retrospective design of the study, a possible memory bias could never be excluded. It also was not possible to explore cause and effect relationships, only associations between characteristics and the prevalence of ACP. Additionally, definitions of ACP may vary between countries, which makes comparison of results with previous studies difficult. Finally, the timing of the agreement was not measured.

ACP is documented only in a small proportion of patients but verbally occurs with many more. This finding is in line with the prevailing consensus in the present literature that ACP may not be narrowed to the formulation of a written advance directive but must be regarded as a continuous process of communication, of which a written declaration may be an outcome.³⁶ Nevertheless, to provide care in correspondence with the patient's wishes, a written advance directive may be very important when the decision making is urgent, without time for consultation; to use as a foundation for future updating and reviewing; or to ensure continuity of care—end-of-life care transitions occur rather frequently in Belgium and The Netherlands.^{29,37} Furthermore, ACP only has a legal status when it is made in writing.

Possible reasons for the low prevalence are that preferences may change, that physicians prefer to remain free to act according to their own medical judgment at the moment of decision making,³⁸ or that ACP is seen as a social process between physician and patient, and documenting it formally is regarded as unnecessary.³⁹

Remarkably, ACP is documented considerably more often in The Netherlands than in Belgium, even after controlling for country differences in patient or care characteristics. This country-specific effect might be rooted in a general difference in medical culture between the two countries, as physicians in The Netherlands tend more toward the formalization of practices.^{40,41} Also, the political and societal debate concerning euthanasia and other end-of-life decisions has a longer history in The Netherlands than in Belgium, and the Dutch Medical Treatment Contracts Act,¹⁰ in which the importance of the patient's written authority for medical treatments has to be made explicit to them, has been in place several years longer than the Belgian Law on Patient Rights.⁹ As a result, advance directive forms in The Netherlands (widely promoted by the Dutch Association for Voluntary Euthanasia) are more widespread compared with Belgium, which also may be part of the explanation.

However, compared with findings from the United States (71% of nontraumatic deaths), the prevalence of advance directives in both our study samples remains very low.³ Also, in

the United Kingdom, a study concluded that discussions related to ACP are very rarely initiated among a group of chronically ill patients.⁴² It seems safe to suggest that advance directives are still more prevalent in the United States than in Europe. A reason for this may be that advance directives have a much longer tradition in the United States and the fact that advance directives, which usually limit treatment, are considered more necessary in the United States because American physicians are more inclined to more aggressive treatment options than their European colleagues.⁴³ Also, in most European countries, it is not compulsory for hospitals or nursing homes to inform admitted patients of their right to draft a treatment directive, in contrast to the United States, where studies have shown that the prevalence of advance directive documentation in nursing home medical records has increased significantly since the implementation of the Patient Self-Determination Act.⁴⁴ The relatively high rate of care planning with the family of the patients without the latter's involvement in our study also might reflect these differences in legislation. This finding was particularly surprising because in both Belgium and The Netherlands, a great value is being placed on patient autonomy in health care as is the case in most Western countries.

Our results further show that cancer patients are more often involved in the process of ACP than noncancer patients, as the opposite is true for patient care planning that occurs with family only. It is known that cancer patients have a relatively more predictable dying course with often a short period of evident decline at the very end compared with other chronic diseases.⁴⁵ This also might mean that cancer patients may be more aware of the life-threatening consequences of their disease and thus possibly engage in ACP more proactively compared with others.

Another key finding is that ACP relates strongly to the provision of palliative care. A core value of the palliative care philosophy from its inception has been in enabling people to make genuine choices about their own care;⁴⁶ this is very reconcilable with what is intended by ACP. Although palliative care has much to offer from the early stages of a progressive disease,⁴⁷ previous research demonstrated that palliative care is often initiated

relatively close to death.^{26,48} This might suggest that end-of-life care planning also is initiated rather late in the dying process, when death is imminent and end-of-life decision making comes to the fore.

That end-of-life care agreements are relatively often made without consulting the patient supports this thought, as it possibly means that discussions about future medical care take place at a time when the patient has already become incompetent or is unable to express his/her wishes and advice from family members is needed, which is in line with our results. The finding that many patients are unable to make decisions at the very end of life points to the importance of exploring patient wishes beforehand so that physicians can take them into account when making end-of-life decisions. Also, the strong relationship between having one or more GP consultations within the last week of life and the chance of having made an ACP might further suggest that ACP is initiated and discussed at these late contacts, rather than before. This may be because some GPs feel constrained timewise or are uncertain about when to initiate end-of-life discussions.^{49–51} Previous studies have shown that patients are more satisfied with their GP when advance directives are discussed.⁴⁹ Moreover, it could be a satisfactory experience for the physician as well.⁵² Altogether, the extent to which ACP truly occurs in advance of future medical decision making is questionable.

In conclusion, ACP is present in one-third of the studied terminally ill patient population, but these end-of-life care agreements are very often left undocumented. This study supports the idea that advance directives are more widespread and prevalent in the United States than in European countries, although differences did occur between Belgium and The Netherlands as well. Our results further suggest that ACP strongly relates to the provision of palliative care and that it is often done ad hoc in the patient's terminal phase of life rather than earlier in the course of the illness. The high rate of care planning with the family without patient involvement further supports this thought. Initiatives to encourage GPs to document the ACP discussions and agreed outcomes, and to do this in a timely fashion, could assist to ensure that a person's wishes are followed.

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