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End-of-life care for people dying with dementia in general practice in Belgium, Italy and Spain: A cross-sectional, retrospective study

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Aim: To describe and compare end-of-life care for people with mild or severe dementia in general practice in Belgium, Italy and Spain, in terms of place of care, place of death, treatment aims, use of specialized palliative care and communication with general practitioners (GPs).

Methods: Cross-sectional retrospective survey was carried out of nationwide networks of GPs in Belgium, Italy and Spain, including patients who died aged 65 years or older in 2009–2011 and were judged by the GP to have had dementia ($n = 1623$).

Results: GPs reported a higher proportion of older people with severe dementia in Belgium (55%) than in Spain (46 %) and Italy (45 %), and a higher proportion of patients living in care homes (57% vs 18% and 13%, respectively). A palliative treatment aim was common in the last 3 months of life in all three countries. Specialized palliative care services were provided in 14% (Italy, severe dementia) to 38% (Belgium, severe dementia) of cases. Communication between GP and patient about illness-related topics occurred in between 50% (Italy) and 72% (Belgium) of cases of mild dementia, and 10% (Italy) to 32% (Belgium) of cases of severe dementia. Patient preferences for end-of-life care were known in a minority of cases. Few people (13–15 %) were transferred between care settings in the last week of life.

Conclusions: Although overall treatment aims at the end of life are often aligned with a palliative care approach and transfer rates are low, there is room for improvement in end-of-life care for people with dementia in all countries studied, especially regarding early patient–GP communication. *Geriatr Gerontol Int* 2017; 17: 1667–1676.

Keywords: dementia, end-of-life, international perspectives, primary care, public health.

Introduction

Over the next 15 years, it is expected that the number of people with dementia worldwide will grow to more than 65 million.¹ Because of the nature of the condition, there can be a prolonged “dwindling” and long-term survival with severe physical and cognitive impairments and behavioral problems.^{2,3} These dementia-specific disease trajectories warrant targeted end-of-life care

strategies with a particular focus on advance care planning, communication in the event of loss of decision-making capacity and anticipating future health issues.^{4–6} A recent white paper from the European Association of Palliative Care has also advised that palliative care, including advance care planning, is the preferred approach to care for all people with dementia starting from diagnosis onwards.⁷ However, many national dementia strategies cover only part of the recommendations made in this white paper, and often do not include explicit mention of palliative care or preparation for the last phase of life.⁸

So far, there is little population-based knowledge about the extent to which palliative care is provided to people dying with dementia at various stages of their illness. Existing research focuses primarily on those with severe

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dementia who live in nursing homes. We know little about the sizeable group of community-dwelling people with dementia and those whose dementia is in the early stages; that is, mild dementia.⁹ These previous studies have shown that residents with advanced dementia are at risk of undergoing burdensome interventions at the end of life, potentially avoidable hospitalizations from nursing homes and of dying with great suffering.^{10–14}

Cross-country comparisons regarding dying with dementia are limited. Those that exist focus on nursing home residents, and find some differences in quality of care and quality of life as judged by proxy respondents, but provide no details of the type of care received, such as the provision of palliative care or communication between patient and care providers.^{15–18} Detailed cross-country comparisons on end-of-life care, such as those on patients with cancer, can shed light on which aspects of care are universally difficult or, alternatively, managed well in a variety of settings and cultural contexts; and draw attention to those areas where improvements can be made.¹⁹

Comparing Belgium, Italy and Spain is interesting, as all three countries have achieved either preliminary or advanced integration of palliative care in the healthcare system.²⁰ Additionally, in all three countries, general practitioners (GPs) are important primary caregivers responsible for the provision of end-of-life care to people with dementia.² Apart from this, the countries differ in their approach to end-of-life care: in Italy and Spain, palliative care consists mostly of home-based support services; whereas in Belgium, more hospital-based palliative care services exist.²⁰ In Belgium, people generally want to be informed about issues such as diagnosis and options for end-of-life care, whereas in Mediterranean countries such as Italy and Spain there has traditionally been resistance to disclosure of health information by physicians.^{21–24} Another difference regards long-term care: in Spain and Italy, few long-term care facilities are available; whereas in Belgium, these are the most frequent place of residence of people who die from dementia, though here too the situation with respect to people with mild dementia is still unknown.^{25,26} Previous research has shown that in Spain, quality of life of people with dementia recently admitted or at risk of admission to a care home was rated lower than in other countries, such as Sweden and England, but Belgium and Italy were not included in that study.¹⁸

The present study aims to investigate differences between Belgium, Italy and Spain with regard to the following research questions:

- How many people dying with dementia have a palliative treatment aim, and how many use specialized palliative care?
- With how many people dying with dementia did GPs communicate about end-of-life issues?
- How frequently are people dying with dementia transferred between care settings at the end of life, and what is their place of death?

Methods

Study design

The present study used data from Belgium, Italy and Spain (Castile and León and Valencian Community regions) collected as part of the EURO SENTIMELC (European Sentinel Network Monitoring End-of-Life Care) study, designed to retrospectively monitor end-of-life care in population-based samples of deaths in different countries.²⁷ Data were collected through existing GP Sentinel Networks, epidemiological surveillance networks consisting of GP practices or community-based physicians. Deaths were registered weekly from 1 January 2009 to 31 December 2010, except for Spain (from 1 January 2010 to 31 December 2011).²⁷

Sample

All patients of the participating GP practices who died aged 65 years or older and who were judged by their GPs to have had either mild or severe dementia (between 30–32 % of decedents) were included in the study ($n = 1623$). The definitions of “mild dementia” and “severe dementia” were left to the interpretation of the GP. We included both those who died suddenly and non-suddenly.

Measurements

The GP Sentinel Networks collect demographic characteristics, cause of death, and whether death was sudden and unexpected for every deceased patient in the practice of participating GPs. In addition, the following questions were asked:

- Treatment aims: whether there was a palliative, curative or life-prolonging main treatment aim in the last 3 months, the last 2–4 weeks and the last week of life.
- Palliative care services: whether any of a number of specialized palliative care services²⁸ provided care, and how many days before death this was initiated.
- Communication: whether the GP and patient ever communicated about 11 aspects of illness and care; for example, primary diagnosis, social problems and the burden of treatments; and whether the patient ever expressed any preference about a medical end-of-life treatment, place of death or a proxy decision-maker.
- Transitions and place of death: how often the patient was transferred between care settings in the last 3 months of life and to where; place of death and whether place of death was in accordance with the patient’s preference.

Ethics approval

For Belgium, ethics approval was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (2004), and for Italy from

the Local Ethical Committee “Comitato Etico della Azienda U.S.L. n. 9 di Grosseto” in Tuscany (2008). Posthumous collection of anonymous patient data does not require ethics approval according to Spanish law.

Statistical analysis

Differences between countries were calculated using ANOVA, Pearson's χ^2 -tests or Fisher's exact tests. Multivariable logistic regression was used to analyze between-country differences controlling for the longest place of residence and cause of death. Robust error clustering was used to account for clustering of individuals within GP practices. All analyses were carried out using STATA Statistical Software: Release 12 (StataCorp, College Station, TX, USA).

Results

Patient characteristics

We studied 1623 patients with mild or severe dementia (Table 1). In Belgium, severe dementia was more common (55%) than mild dementia (45%), whereas the reverse was true for Italy (45% and 55%, respectively) and Spain (46% and 54% respectively, $P = 0.002$). We stratified for this difference in subsequent analyses, as certain aspects of care (e.g. communication) might differ significantly for these two groups.

In the last year of life, 40% of patients with dementia in Belgium resided at home, 81% in Spain and 87% in Italy ($P < 0.001$). The most common cause of death was

cardiovascular disease: 20% in Belgium, 23% in Spain and 31% in Italy ($P = 0.38$). Between 22% and 26% of deaths were classified as sudden ($P = 0.18$).

Treatment aims in the last 3 months of life

Two to three months before death, a palliative treatment aim was considered important for 66% of patients with mild dementia in Belgium, 75% in Spain and 64% in Italy (Fig. 1). A curative treatment aim was considered important for 58% in Belgium, 52% in Spain and 37% in Italy (OR 0.39, 95% CI 0.26–0.59). A life-prolonging treatment aim was considered important for 62% of patients in Belgium 55% in Spain and 74% in Italy (non-significant). Patients with severe dementia showed the same pattern of treatment aims, although in their case a palliative treatment aim was significantly more likely in Belgium (77%) than in Italy (59%; OR 0.34, 95% CI 0.19–0.63).

In the last week of life, for people with mild dementia, a palliative treatment aim was considered important less often in Italy (68%) than in Spain (87%) and Belgium (84%; OR 0.36, 95% CI 0.2–0.64), whereas a life-prolonging treatment aim was more common in Italy (58%) than in Belgium (35%) and Spain (32%; OR 2.46, 95% CI 1.62–3.74). There was no significant difference in the frequency of a curative treatment aim in the last week of life for people with mild dementia, but patients with severe dementia were more likely to have a curative treatment aim in Belgium (22%) than in Italy (14%; OR 0.53, 95% CI 0.3–0.94).

Table 1 Characteristics of the study population

	Belgium ($n = 621$)		Spain ($n = 295$)		Italy ($n = 707$)		P^{\dagger}
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Mean age at death, years (SD)	85.9	(6.8)	85.8	(6.4)	86.5	(7.1)	0.62
Female	402	65 (61–68)	170	58 (52–63)	460	65 (62–69)	0.07
Severity of dementia							0.002
Mild	282	45 (41–49)	160	54 (49–60)	392	55 (52–59)	
Severe	339	55 (51–59)	135	46 (40–51)	315	45 (41–48)	
Longest place of residence in last year							
Home	247	40 (36–44)	234	81 (76–85)	611	87 (84–89)	<0.001
Care home	355	57 (54–61)	54	19 (14–23)	91	13 (11–15)	<0.001
Elsewhere	16	3 (1–4)	2	1 (0–2)	3	0 (0)	0.002
Cause of death							
Malignancies	61	10 (8–12)	38	13 (9–17)	76	12 (9–14)	0.36
Cardiovascular disease	124	20 (17–23)	66	23 (18–28)	209	31 (27–34)	0.38
Respiratory disease	70	11 (9–14)	38	13 (9–17)	64	10 (7–12)	0.26
Disease of nervous system	92	15 (12–18)	49	17 (13–22)	115	17 (14–20)	0.58
Stroke (CVA)	68	11 (9–14)	37	13 (9–16)	117	17 (15–20)	0.008
Other	205	33 (30–37)	61	21 (16–26)	90	13 (11–16)	<0.001
Sudden death	134	22 (18–25)	63	23 (18–28)	183	26 (23–29)	0.18

Study population, $n = 1623$ (missing for place of residence, 10; cause of death, 43; sudden death, 24).[†]Bivariate P -value. SD, standard deviation; CI, confidence interval; CVA, cerebrovascular accident.

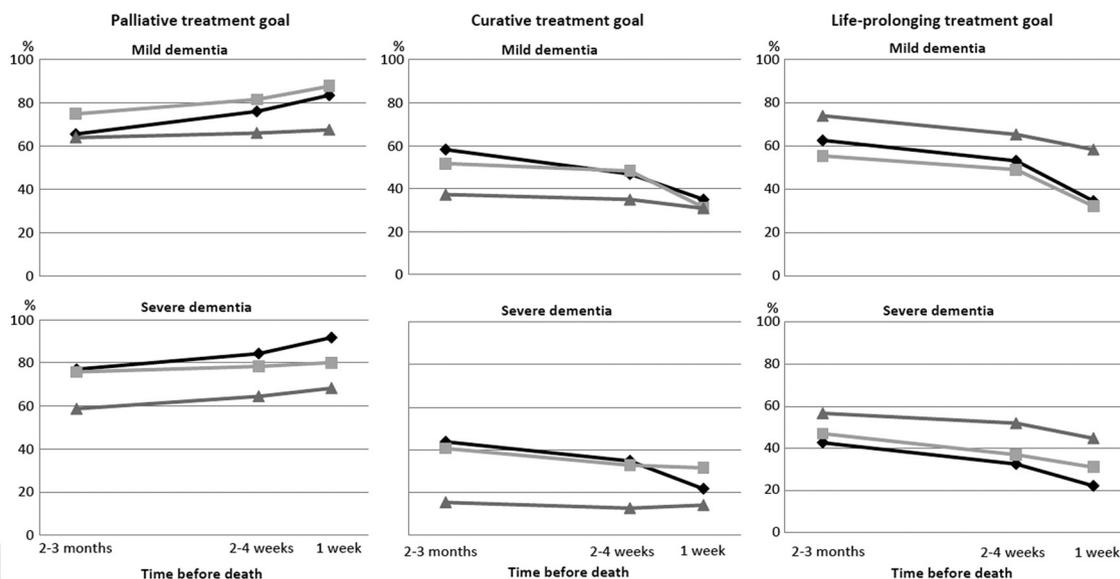


Figure 1 Percentage of patients for whom the general practitioner judged a palliative, curative and life-prolonging treatment goal to be important during the last 3 months of life in Belgium (black diamond), Spain (grey square) and Italy (grey triangle).

Palliative care provision

In Belgium, 35% of patients with mild dementia received some form of specialized palliative care, compared with 32% in Spain and 21% in Italy (OR 0.47, 95% CI 0.3–0.72; Table 2). In Belgium, specialized palliative care services were most often provided by an in-house palliative care service in a care home (19%, compared with 6% in Spain). Care provided by a palliative home care team was less likely in Belgium (7%) than in Spain (19%; OR 2, 95% CI 1.07–3.77), though the difference with Italy (13%) was not significant. Specialized palliative care was initiated a median of 14 days before death in Belgium for patients with mild dementia, 12 days in Spain and 50 days in Italy. Multivariate analysis showed that specialized palliative care is in fact initiated longer before death in Spain (OR 1.01, 95% CI 1.001–1.01) and Italy (OR 1.04, 95% CI 1.02–1.05) than in Belgium. There was no significant difference in the initiation of specialized palliative care for patients with severe dementia between Belgium and Spain, though in Italy specialized palliative care was initiated less frequently (OR 0.28, 95% CI 0.16–0.48), but longer before death than in Belgium (OR 1.02, 95% CI 1.01–1.05).

Communication at the end of life between GP and patients

Communication about at least one of the illness-related topics occurred with 72% of patients with mild dementia in Belgium, compared with 61% in Spain (OR 0.5, 95% CI 0.29–0.89) and 50% in Italy (OR 0.32, 95% CI 0.2–0.52; Table 3). Patients with severe dementia showed the same pattern, though overall communication was

lower in all countries (32% communicated about any of the topics in Belgium, 26% in Spain and 10% in Italy).

A preference for place of death for people with mild dementia was known by the GP in 29% of cases in Belgium, 34% in Spain and 24% in Italy. Preferences for a proxy decision-maker were expressed in 17% of cases of mild dementia in Belgium, 8% in Spain (OR 0.42, 95% CI 0.19–0.92) and 8% in Italy (OR 0.42, 95% CI 0.22–0.78). For patients with severe dementia, there was no significant difference between the countries in expressed preference for a proxy decision-maker (9% in Belgium, 5% in Spain and 4% in Italy), but a significant difference between Belgium and Italy in an expressed preference for place of death (29% *vs* 21%; OR 0.55, 95% CI 0.34–0.91).

Transfers at the end of life and place of death

Patients with mild dementia were less likely to be transferred between care settings in the last 3 months in Spain (47%, OR 0.5, 95% CI 0.32–0.78) and Italy (48%, OR 0.49, 95% CI 0.35–0.7) than in Belgium (55%; Table 4). There were no significant differences between the countries in terms of transfers between care settings in the last week of life (15–17% of cases). Patients were most often transferred to hospital in 47% of cases with mild dementia in Belgium, 34% in Spain (OR 0.43, 95% CI 0.1–0.27) and 41% in Italy (OR 0.52, 95% CI 0.36–0.74). Patients with severe dementia showed a similar pattern of transfers.

Place of death of patients with mild dementia was most often a care home in Belgium (43% for mild dementia), and at home in Spain (48%) and Italy (52%). Patients with mild dementia were less likely to die in hospital in Italy (31%, OR 0.61, 95% CI 0.42–0.89) than in Belgium

Table 2 Palliative care for people with mild or severe dementia in Belgium, Spain and Italy

	Mild dementia						Severe dementia					
	Belgium (n = 282)		Spain (n = 160)		Italy (n = 392)		Belgium (n = 339)		Spain (n = 135)		Italy (n = 315)	
	%	Ref.	%	OR (95 % CI)	%	OR (95 % CI)	%	Ref.	%	OR (95% CI)	%	OR (95% CI)
Received any specialist palliative care	35	-	32	0.85 (0.52–1.37)	21	0.47 (0.3–0.72)	38	-	28	0.65 (0.37–1.13)	14	0.28 (0.16–0.48)
Specifically from:^{‡#}												
Palliative home care	7	-	19	2 (1.07–3.77)	13	1.13 (0.63–2.05)	6	-	16	1.66 (0.84–3.29)	14	1.2 (0.61–2.39)
team/assistance at home												
Palliative care unit in a hospital	7	-	8	0.94 (0.39–2.27)	NA	NA	3	-	4	0.8 (0.23–2.8)	NA	NA
In-house palliative care service in care home	19	-	6	0.61 (0.25–1.52)	NA	NA	27	-	10	0.47 (0.17–1.3)	NA	NA
Initiation of palliative care in days before death (median)	14	-	12	1.01 (1.001–1.01) [#]	50	1.04 (1.02–1.05) [#]	14	-	9	0.999 (0.98–1.01) ^{#†}	40	1.02 (1.01–1.05) [†]

Study population, n = 1623 (missing for received any specialist palliative care, 41). [†]Largest three categories shown; specialist palliative care also included hospice care, day centers and others. [#]In increments of 1 day. Controlled for longest place of residence in the last year and cause of death (stroke vs other causes). CI, confidence interval; OR, odds ratio; Ref., reference category.

Table 3 Communication between general practitioner and people with mild or severe dementia in Belgium, Spain and Italy

	Mild dementia						Severe dementia					
	Belgium (n = 282)		Spain (n = 160)		Italy (n = 392)		Belgium (n = 339)		Spain (n = 135)		Italy (n = 315)	
	%	Ref.	%	OR (95% CI)	%	OR (95% CI)	%	Ref.	%	OR (95% CI)	%	OR (95% CI)
Communication between GP and patient on												
Primary diagnosis	41	-	35	0.61 (0.35-1.08)	28	0.44 (0.29-0.68)	14	-	11	0.44 (0.18-1.06)	4	0.15 (0.06-0.37)
Incurability of illness	23	-	32	1.38 (0.79-2.42)	10	0.36 (0.21-0.62)	10	-	11	0.81 (0.33-2.01)	2	0.16 (0.06-0.43)
Life expectancy	21	-	22	0.97 (0.56-1.7)	11	0.41 (0.24-0.7)	8	-	10	0.75 (0.31-1.8)	2	0.13 (0.04-0.41)
Possible medical complications	24	-	37	1.51 (0.8-2.85)	20	0.63 (0.38-1.05)	9	-	13	0.9 (0.34-2.36)	3	0.18 (0.07-0.48)
Physical symptoms	63	-	53	0.54 (0.32-0.92)	45	0.38 (0.24-0.62)	28	-	20	0.39 (0.2-0.76)	8	.14 (0.08-0.27)
Psychological symptoms	41	-	37	0.8 (0.47-1.37)	24	0.47 (0.3-0.74)	19	-	12	0.33 (0.16-0.68)	5	0.16 (0.08-0.32)
Social problems	27	-	20	0.62 (0.35-1.11)	17	0.54 (0.32-0.89)	11	-	10	0.59 (0.27-1.3)	4	0.2 (0.09-0.47)
Existential problems	12	-	8	0.67 (0.3-1.48)	5	0.47 (0.23-0.98)	6	-	2	0.22 (0.05-1.1)	1	0.17 (0.05-0.61)
Options for palliative care	18	-	25	1.2 (0.68-2.13)	5	0.2 (0.1-0.38)	9	-	11	0.9 (0.38-2.12)	1	0.05 (0.01-0.23)
Burden of treatments	22	-	21	0.87 (0.46-1.63)	11	0.43 (0.26-0.73)	6	-	9	0.94 (0.32-2.77)	1	0.12 (0.02-0.6)
Any communication at all	72	-	61	0.5 (0.29-0.89)	50	0.32 (0.2-0.52)	32	-	26	0.46 (0.24-0.87)	10	0.15 (0.08-0.27)
Patient had ever expressed preference												
about a medical end-of-life treatment	16	-	4	0.16 (0.06-0.41)	6	0.26 (0.15-0.48)	7	-	2	0.17 (0.04-0.75)	2	0.17 (0.06-0.45)
For place of death	29	-	34	1.09 (0.67-1.79)	24	0.63 (0.4-1.01)	29	-	39	1.39 (0.72-2.69)	21	0.55 (0.34-0.91)
For proxy decision-maker	17	-	8	0.42 (0.19-0.92)	8	0.42 (0.22-0.78)	9	-	5	0.59 (0.18-1.92)	4	0.48 (0.19-1.21)

Study population, n = 1623 (missing for communication between physician and patient <4%; preference expressed about treatment, 47; place of death, 27; proxy decision-maker, 387). Controlled for longest place of residence in the last year and cause of death (stroke vs other causes). CI, confidence interval; OR, odds ratio; Ref., reference category.

Table 4 Transitions between care settings of people with mild or severe dementia in Belgium, Spain and Italy

	Mild dementia						Severe dementia					
	Belgium (n = 282)		Spain (n = 160)		Italy (n = 392)		Belgium (n = 339)		Spain (n = 135)		Italy (n = 315)	
	%	Ref.	%	OR (95% CI)	%	OR (95% CI)	%	Ref.	%	OR (95% CI)	%	OR (95% CI)
Transferred between care settings in last 3 months	55	-	47	0.5 (0.32-0.78)	48	0.49 (0.35-0.7)	37	-	44	0.66 (0.37-1.15)	36	0.44 (0.28-0.7)
Transferred in last 3 months to												
Hospital	47	-	34	0.43 (0.1-0.27)	41	0.52 (0.36-0.74)	32	-	30	0.54 (0.3-0.96)	32	0.56 (0.36-0.87)
Home	7	-	10	0.89 (0.41-1.92)	14	1.26 (0.66-2.44)	4	-	16	2.02 (0.87-4.68)	8	0.9 (0.42-1.92)
Care home	16	-	4	0.25 (0.11-0.54)	8	0.52 (0.29-0.92)	20	-	8	0.21 (0.09-0.45)	5	0.15 (0.08-0.28)
Transferred between care settings in last week	15	-	17	0.98 (0.56-1.72)	17	0.93 (0.59-1.46)	10	-	18	1.57 (0.81-3.06)	12	0.83 (0.46-1.49)
Place of death												
Home	18	-	48	2.55 (1.55-4.18)	52	2.61 (1.68-4.05)	12	-	52	3.62 (2.03-6.45)	56	3.63 (2.25-5.86)
Care home	43	-	16	0.61 (0.32-1.17)	14	0.79 (0.47-1.33)	69	-	25	0.3 (0.16-0.56)	17	0.21 (0.13-0.35)
Hospital	33	-	34	0.72 (0.45-1.15)	31	0.61 (0.42-0.89)	18	-	21	0.84 (0.45-1.57)	27	1.02 (0.61-1.72)
Palliative care unit/hospice	6	-	2	-	3	-	1	-	1	-	-	-
Died at place of preference ^{††}	72	-	89	5.14 (1.68-15.68)	74	1.87 (0.82-4.25)	88	-	95	3.25 (0.7-14.96)	86	0.99 (0.34-2.89)

Study population, n = 1623 (missing for transfers, 57; place of death, 5). [†]Only those for whom a preferred place of death was known, n = 438. Controlled for longest place of residence in the last year and cause of death (stroke vs other causes). CI, confidence interval; OR, odds ratio; Ref., reference category.

(33%). Patients with severe dementia were more likely to die in a care home in Belgium than in Spain (OR 0.3, 95% CI 0.16–0.56) or Italy (OR 0.21, 95% CI 0.13–0.35). Most people for whom a preferred place of death was known (between 24% in Italy and 34% in Spain for people with mild dementia; Table 3) died at their place of preference: 72% of patients with mild dementia in Belgium, 89% in Spain (OR 5.14, 95% CI 1.68–15.68) and 74% in Italy. Although people with severe dementia died at their place of preference more often than people with mild dementia (between 86% of cases in Italy and 95% of cases in Spain), there were no differences between countries for this group.

Discussion

We showed that there are both cross-country differences and similarities in treatment aims, communication about illness-related topics, provision of specialized palliative care, transfers at the end of life and place of death of people dying with dementia, with more differences between Belgium and Italy than between Belgium and Spain. Although most patients had a palliative treatment aim in the last week of life, communication between the GP and patient about care, illness or preferences was relatively low in all countries. Specialized palliative care was provided in approximately one-fifth (Italy) to one-third (Belgium and Spain) of cases for people with mild dementia. Transfers in the last week of life were relatively infrequent, but still between 10% (Belgium) and 18% (Spain).

This research adds to our current knowledge of the circumstances of people dying with dementia by providing an international population-based overview of several important end-of-life care issues, both for people with severe dementia and the less-often studied group of people with mild dementia. A limitation of our research was that the presence and severity of dementia is based on an overall judgment by a GP and not by a specialist. Although specificity in dementia diagnosis by GPs is excellent, meaning there is little chance of false positives in our sample, there might have been an underreporting of people with mild dementia.²⁹ The possibility of recall bias on the part of GPs was limited by having questionnaires completed within 1 week of the patient's death. The low percentages of communication with people with severe dementia are understandable given the cognitive decline inherent in the disease; however, as no time period was specified in the questions regarding communication, this also tells us that communication took place infrequently earlier in the disease trajectory. Alternatively, GPs might have communicated with relatives of patients instead of patients themselves in case dementia was prohibitive to clear communication, as other research has shown that communication with relatives of older patients is frequent in Belgium and Italy at least.³⁰

The present study showed that the importance of a palliative treatment aim was recognized for most people with dementia, both mild and severe, and that relatively few people were transferred between care settings in the last week of life compared with, for example, cancer patients.³¹ The low transfer rates indicate a low likelihood of unnecessary or inappropriate transitions between care settings at the end of life. These encouraging results follow the recommendations of the European Association of Palliative Care white paper on palliative care for people with dementia.⁷

However, there is also room for improvement in all three countries, particularly regarding awareness by the GP about preferences for end-of-life care. Preferences for medical treatments at the end of life or a proxy decision-maker were frequently known in fewer than one-quarter or even 10% of cases. Advance communication about preferences regarding end-of-life care and dying is especially important in the case of dementia patients, who might not be able to communicate about such matters close to death.⁷ Previous research found that advance care planning is considered important by most older people, that it decreases the likelihood of unnecessary hospitalizations; is associated with a higher mean rating of emotional well-being during the dying process for both patients and family; and improves knowledge of and compliance with the patient's wishes.^{17,32,33} In the present study, we also found that the majority of people died at their preferred place when this was known.

In addition to an improvement in communication, specialized palliative care could perhaps be called upon more frequently, particularly for those with advanced dementia who have complex problems.⁷ Specialized palliative care is still provided primarily to cancer patients, and there are several barriers to providing the same care for other patient groups, despite their complex problems and high palliative care needs.^{32,34} For example, the lack of clarity about prognosis, strong emphasis on a curative approach and reluctance to talk about death were identified as barriers in Spain;³⁵ whereas in Belgium, there are systemic issues, such as a much lower likelihood of non-cancer patients receiving a palliative home care allowance.³⁶ Overcoming such barriers both in practice and on a policy level is important for the continued improvement of end-of-life care for people with dementia.

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Disclosure statement

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