

End-of-life communication in advanced cancer: international trends between 2009 and 2014

Abstract

Objective: To examine trends in end-of-life communication with cancer patients in general practice.

Methods: Mortality follow-back survey among GPs in representative epidemiological surveillance networks in Belgium (BE), the Netherlands (NL) and Spain (ES) in 2009-2010 (ES: 2010-2011) and 2013-2014. Using a standardized form, GPs registered all deceased adult patients in their practice and reported for five end-of-life care topics whether they had been discussed with the patient. Non-sudden cancer deaths were included (n=2306; BE: 1233; NL: 729; ES: 344).

Results: A statistically significant increase was found between 2009/2010 and 2014 in the prevalence of communication about diagnosis (from 84% to 94%) and options for end-of-life care (from 73% to 90%) in BE, and in GPs' awareness of patients' preferences for medical treatment and a proxy decision-maker in BE (from 41% and 20% up to 53% and 28%) and the NL (from 62% and 32% up to 70% and 52%). Communication about options for end-of-life care and psychosocial problems decreased in the NL (from 88% and 91% down to 73%) and ES (from 76% and 77% down to 26% and 39%).

Conclusion: Considerable change in GP-patient communication seems possible in a relatively short time-span, but communication cannot be assumed to increase over time. Increasing specialization of care and task differentiation may lead to new roles in communication for healthcare providers in primary and secondary care. Improved information sharing between GPs and other healthcare providers may be necessary to ensure that patients have the chance to discuss important end-of-life topics.

4.1 Introduction

Despite the progress made over the past decade in prevention and treatment, cancer remains the second leading cause of death in the European Union, accounting for more than one quarter of all deaths.^[1] With an aging population that continues to grow, it is anticipated that the cancer incidence and mortality will rise further in the coming years. As a result, more people with cancer will require palliative care.^[2]

High-quality palliative care requires that physicians engage in meaningful patient-centred communication,^[3,4] which has several aims including fostering an interpersonal relationship, exchanging appropriate information and responding to uncertainty and emotions.^[5] Effective physician-patient communication has been related to favourable patient outcomes, such as better understanding of the illness, care and treatment options,^[6] adherence to treatment,^[5,7] and satisfaction with end-of-life care.^[5,8] Inadequate communication is associated with adverse outcomes including emotional distress and worsening of symptoms.^[9]

Communication between healthcare providers and patients in oncology has often been shown to be infrequent and suboptimal.^[10,11] Possible barriers for physicians to engage in effective end-of-life communication include a natural reluctance to raise this subject, lacking knowledge or training in this area, and inadequate structural support for advance care planning (ACP).^[12,13] In Europe, patient-centred communication and ACP have received increasing policy attention over the last years, with efforts made in many countries to implement training, programmes and guidelines for palliative care.

In light of these developments, this study aims to examine trends in end-of-life communication between GPs and people with advanced cancer in three European countries – Belgium, the Netherlands, and Spain – from 2009 to 2014, based on data collected by general practitioner (GP) networks. Belgium, the Netherlands and Spain are all considered to be at the highest level of palliative care development, i.e., advanced integration into mainstream service provision.^[14] Since 2000, efforts have been made in Belgium and the Netherlands to increase opportunities for palliative care training, as well as implementing programs and constructing guidelines to improve end-of-life communication practices.^[14-16] In Spain, palliative care has continued to develop and has been integrated in educational programmes,^[14] but without such a specific focus on ACP or communication. However, it is likely that different cultural traditions, attitudes towards the end of life,^[17] health care systems, policies and available resources^[14,18] affect end-of-life communication practices. Cross-country comparative studies focusing on aspects of end-of-life communication among individuals with cancer are scarce, although previous research has indicated that European countries vary substantially with regard to the process and content of physicians' discussions with terminally ill patients.^[19]

Because GPs play a crucial role in the coordination and delivery of palliative care, they are well-placed to initiate end-of-life conversations with their patients. General practice is relatively easily accessible in the studied countries. In the Netherlands and Spain, GPs serve as gatekeepers for health care delivery – they act as referral and care coordinators.^[20,21] Patients are registered with a specific GP and do not have direct access to secondary or specialist care. In Belgium, GPs have a central coordinating role in patient care but do not have a gatekeeper function, but GPs are the ones who contact palliative home care teams when necessary.^[21]

Our study explores whether conversations about topics related to end-of-life care with people with cancer in primary care have become more frequent between 2009 and 2014. The specific research questions are:

1. Did the percentages of people with cancer with whom end-of-life topics (diagnosis, options for end-of-life care, psychological or social problems, preference for medical treatment in the final phase of life, preference for a proxy decision-maker) were discussed change between 2009 and 2014 in Belgium, the Netherlands and Spain, and in what direction?
2. Were there differences in the time trends in GP-patient end-of-life communication with respect to age, gender, longest place of residence, and place of death?

4.2 Methods

Study design

This study uses data from Belgium, the Netherlands, and Spain (Castile and León) collected as part of the European Sentinel Network Monitoring End-of-Life Care (EURO SENTIMELC) study, an ongoing mortality follow-back study designed to retrospectively monitor end-of-life care in population-based samples of deaths in different countries.^[21] Data were collected through existing representative GP Sentinel Networks, epidemiological surveillance networks consisting of GP practices or community-based physicians who voluntarily and continuously monitor health problems occurring in the population. In each country, GPs were selected to form a representative national sample of the total GP population and invited to participate in the networks by national public health and/or research institutes. By comparing the characteristics of GPs in the Sentinel Networks to the general population of GPs – such as age, gender and geographical distribution – the responsible institutes ensure continued representativity of the networks. Patient data was anonymized by the GPs; GP data was anonymized by the responsible institute during data cleaning. Participating GPs provided weekly reports on every adult patient in their practice who had died during the past week as part of a larger public health questionnaire. In the Netherlands, elderly care physicians who are responsible for the care of long-term care facility residents are not part of the GP Sentinel Network; this exact physician role does not exist in Belgium and Spain. Data used in this study were collected in 2009, 2010, 2013 and 2014 in Belgium and the Netherlands, and in 2010, 2011, 2013 and 2014 in Spain. More details on the data collection and study design are described elsewhere.^[21]

Study population

We included all people registered by the participating GP practices who died of cancer (according to ICD-10 code), for a total of n=2627. People whose death was classified by the GPs as ‘sudden and totally unexpected’ and those for whom this information was missing were excluded, leaving a sample that was eligible for palliative care (n=2306).

Questionnaire

Using a standardized registration form consisting of structured and closed-ended items, GPs collected demographic characteristics (age at death, gender, longest place of residence in the last year of life, place of death), cancer type (coded according to ICD-10), and whether or not death was sudden and unexpected. Additionally, the following questions were asked regarding end-of-life communication:

1. Were the following topics addressed during your conversations with the patient?
Diagnosis – the answer options were ‘yes’ or ‘no’.
Options for end-of-life care – the answer options were ‘yes’ or ‘no’. In 2009-2010, this item was phrased as ‘options for palliative care’, in 2013-2014 as ‘options in terms of end-of-life care’, to be more in line with quality indicator measurement tools developed for general palliative care.^[22]
Psychological or social problems – the answer options were ‘yes’ or ‘no’. In 2009-2010, these concepts were measured by two separate items which were combined for this analysis.
2. Did the patient ever express wishes about a medical treatment that he/she would or would not want in the final phase of life? The answer options were ‘yes’, ‘no’ or ‘don’t know’.
3. Did the patient ever express a wish about who was to make decisions regarding medical treatments or activities in his/her place, in the event he/she would no longer be able to speak for him/herself? The answer options (more than one possible) were ‘yes, in writing’, ‘yes, verbally’, ‘no’ or ‘don’t know’.

Statistical analyses

If the GP indicated ‘don’t know’ as an answer to question 2 or 3, this was coded as ‘no’.

Pearson’s chi-square tests, Fisher’s exact tests, or analysis of variance (ANOVA) were performed to test for differences in patient characteristics (age at death, gender, cancer type, longest place of residence in the last year of life, place of death) between years. Bivariate Mantel-Haenszel tests were calculated to detect linear trends in the proportion of people with cancer with whom any of the five studied end-of-life care topics were discussed between 2009 and 2014. Multivariable trend analyses controlling for age, gender, cancer type, longest place of residence in the last year of life, and place of death were used to test for linear trends in proportions through the SPSS UNIANOVA procedure, specifying a polynomial contrast for the variable *year*. A significant result on this test provides strong evidence for a linear relationship between year and topic discussed, as the number of patients with whom a topic was discussed in later years was significantly above what might be expected if there was no relationship between the variables. A power analysis was conducted for each variable in each country, assuming a medium effect-size, showing that power was above 95% for all variables in Belgium, preferences for medical treatment and a proxy decision-maker in the Netherlands and diagnosis in Spain. Power was between 68% and 78% for the remaining variables in the Netherlands, and below 55% for the remaining variables in Spain, suggesting the trend analysis for these variables may be underpowered. Statistical significance was set at $p < .05$. All analyses were performed using IBM SPSS Statistics version 24.0.

Ethics

For Belgium, ethics approval was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (VUB). Formal approval for this research project by a medical ethics committee was not required in The Netherlands according to the Medical Research (Human Subjects) Act (WMO), but permission for the study was sought and obtained from the board of the NIVEL network. The NIVEL Primary Care Database extracts data according to strict guidelines for the privacy protection of patients and GPs. Ethics approval was not required for posthumous collection of anonymous patient data in Spain, according to the legislation of this country.

4.3 Results

Characteristics of the study population

A total of 2306 cancer decedents were included (BE=1233; NL=729; ES=344; *Table 1*). The median age at death was between 73 and 78 years. In general, the most common cause of death was lung cancer (BE: 21-25%; NL: 22-29%; ES: 17-20%). The majority of people lived at home in the last year of life (BE: 81-88%; NL: 88-91%; ES: 92-97%) and in general home was the most common place of death (BE: 31-38%; NL: 54-62%; ES: 41-50%). In Spain, the percentage of women was considerably lower than the percentage of men (30-34% across years). Additional data analysis showed that this relatively large gender imbalance was present only for those who died of cancer, regardless of whether death was 'sudden and totally unexpected', possibly because in Spain, 60% of new cancers are diagnosed in men.^[23]

Table 1. Characteristics of the study population: people with cancer who died non-suddenly in Belgium, the Netherlands and Spain, 2009-2014 (*n*=2306)

	Belgium					The Netherlands					Spain				
	2009	2010	2013	2014	<i>p</i> ^a	2009	2010	2013	2014	<i>p</i> ^a	2010	2011	2013	2014	<i>p</i> ^a
	<i>N</i> =303	<i>N</i> =292	<i>N</i> =336	<i>N</i> =302		<i>N</i> =157	<i>N</i> =189	<i>N</i> =190	<i>N</i> =193		<i>N</i> =80	<i>N</i> =86	<i>N</i> =88	<i>N</i> =90	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Age at death (years) , median (95% CI)	74 (72-76)	75 (73-77)	77 (75-79)	77 (74-79)	.02	73 (70-75)	73 (72-76)	73 (71-75)	75 (72-76)	.23	77.5 (73-81)	77 (74-81)	78 (77-83)	76.5 (72-79)	.18
Gender , female	129 (43)	138 (47)	160 (48)	138 (46)	.58	83 (53)	76 (41)	89 (47)	93 (48)	.15	24 (30)	28 (33)	30 (34)	31 (34)	.93
Primary cancer site															
Lung	76 (25)	72 (25)	72 (21)	70 (23)	.69	34 (22)	46 (27)	40 (24)	52 (29)	.41	15 (20)	15 (19)	14 (17)	16 (18)	.96
Colorectal	33 (11)	36 (12)	47 (14)	42 (14)	.61	12 (8)	28 (16)	23 (14)	21 (12)	.12	21 (28)	12 (15)	7 (8)	3 (3)	<.001
Breast	22 (7)	29 (10)	37 (11)	19 (6)	.12	26 (17)	8 (5)	18 (11)	11 (6)	<.01	5 (7)	5 (6)	13 (15)	15 (17)	.05
Prostate	10 (3)	15 (5)	26 (8)	20 (7)	.09	11 (7)	13 (8)	14 (8)	6 (3)	.25	8 (11)	9 (11)	5 (6)	3 (3)	.18
Other	162 (54)	140 (48)	154 (46)	151 (50)	.26	74 (47)	78 (45)	75 (44)	89 (50)	.73	27 (36)	40 (49)	46 (54)	50 (58)	.03
Longest place of residence in last year^b															
Home	261 (87)	255 (88)	288 (86)	243 (81)	.10	143 (91)	166 (90)	167 (88)	173 (91)	.84	73 (92)	79 (94)	78 (92)	86 (97)	.55
Long-term care facility	34 (11)	31 (11)	38 (11)	51 (17)	.07	14 (9)	18 (10)	19 (10)	13 (7)	.68	6 (8)	2 (2)	5 (6)	2 (2)	.26
Place of death^b															
Home	94 (31)	102 (35)	126 (38)	95 (32)	.28	84 (54)	110 (58)	114 (60)	118 (62)	.45	39 (49)	42 (50)	30 (41)	37 (41)	.49
Hospital	103 (34)	98 (34)	95 (28)	90 (30)	.30	28 (18)	30 (16)	31 (16)	33 (17)	.96	23 (29)	27 (32)	23 (31)	24 (27)	.86
PCU/hospice	65 (22)	57 (20)	62 (19)	45 (15)	.20	27 (17)	27 (14)	23 (12)	23 (12)	.47	10 (13)	13 (16)	17 (23)	24 (27)	.08
Long-term care facility	38 (13)	33 (11)	51 (15)	68 (23)	<.01	17 (11)	22 (12)	21 (11)	15 (8)	.62	8 (10)	2 (2)	4 (5)	5 (6)	.23

Abbreviation: *PCU*, palliative care unit.

Missing data <1.5% for all variables.

^a Bivariate Pearson's chi-squared tests or Fisher's exact tests, except for age (ANOVA).

^b Categories 'living elsewhere' (Belgium: $n=25$; the Netherlands: $n=9$; Spain: $n=6$) and 'died elsewhere' (Belgium: $n=3$; the Netherlands: $n=4$) not shown in table. 'Home' indicates living in own home or with family. 'Long-term care facility' includes residential care home in Belgium, residential home for older people in the Netherlands and Spain, (infrequently) nursing home in the Netherlands. 'Hospital' excludes PCU and nursing home unit in hospital.

Trends in the proportion of people with whom end-of-life care topics were discussed

Belgium was the only country to see a significant increase in the percentage of people with whom their diagnosis was discussed between 2009 and 2014 (from 84% to 94%, $p<.01$) (*Table 2; Figure 1*). In multivariable regression models controlling for age, gender, cancer type, longest place of residence in the last year of life, and place of death, this increase was significant for all age groups, both genders, those who lived at home and in a long-term facility in the last year of life, and those who died at home, in a hospital, and in a long-term care facility (*Table 3*).

The percentage of people with whom options for end-of-life care were discussed showed an increasing trend in Belgium between 2009 and 2014 (from 73% to 90%, $p<.001$), but decreased significantly in the Netherlands between 2009 and 2014 (from 88% to 73%, $p<.001$) and in Spain between 2010 and 2014 (from 76% to 26%, $p<.001$) (*Table 2; Figure 1*). In multivariable regression, the increase in Belgium was significant for all age groups and both genders, for those who lived at home in the last year of life, and for those who died at home, in a hospital, and in a palliative care unit or hospice (*Table 3*). In the Netherlands, the decreasing trend was significant for those aged 65-84 and 85+, both genders, those who lived at home in the last year of life, and those who died at home and in a palliative care unit or hospice. In Spain, the decrease was significant for both genders, those aged 65-84, those who lived at home in the last year of life, and those who died at home.

The percentage of people with whom psychological or social problems were discussed decreased significantly over time in both the Netherlands (from 91% to 73%, $p<.001$) and Spain (from 77% to 39%, $p<.001$). In multivariable regression, this decrease was significant in the Netherlands for all age groups, both genders, those who lived at home and those who lived in a long-term care facility during the last year of life and for all place of death groups (*Table 3*). In Spain, the decrease was significant for those aged 18-64, females, those who lived at home in the last year of life, and those who died at home. While overall, no decreasing trend in communication about psychological or social problems was found in Belgium between 2009 and 2013 (*Table 2*), multivariable regression showed that there was a significant decrease for those aged 18-64, and those who died at home.

Table 2. Trends in communication between general practitioners (GPs) and people with advanced cancer about end-of-life care topics in Belgium, the Netherlands and Spain, 2009-2014 (*n*=2306)

	Belgium					The Netherlands					Spain				
	2009	2010	2013	2014	<i>p</i> ^a	2009	2010	2013	2014	<i>p</i> ^a	2010	2011	2013	2014	<i>p</i> ^a
	<i>N</i> =303	<i>N</i> =292	<i>N</i> =336	<i>N</i> =302		<i>N</i> =157	<i>N</i> =189	<i>N</i> =190	<i>N</i> =193		<i>N</i> =80	<i>N</i> =86	<i>N</i> =88	<i>N</i> =90	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Topics discussed															
Diagnosis	241 (84)	233 (84)	275 (86)	245 (94)	<.01	142 (96)	169 (94)	166 (97)	162 (96)	.45	54 (79)	52 (73)	45 (76)	51 (84)	.49
Options for end-of-life care	206 (73)	183 (67)	200 (77)	161 (90)	<.001	127 (88)	152 (87)	120 (70)	123 (73)	<.001	48 (76)	46 (66)	23 (39)	16 (26)	<.001
Psychological or social problems	227 (80)	204 (74)	168 (72)	---	.07	136 (91)	154 (89)	135 (79)	124 (73)	<.001	51 (77)	50 (69)	30 (51)	24 (39)	<.001
Preference for medical treatment	123 (41)	102 (35)	178 (54)	158 (53)	<.001	95 (62)	104 (55)	139 (74)	134 (70)	<.01	13 (17)	9 (11)	21 (24)	20 (22)	.06
Preference for proxy decision-maker	60 (20)	52 (18)	99 (30)	84 (28)	<.001	49 (32)	67 (36)	100 (53)	98 (52)	<.001	7 (9)	10 (12)	14 (16)	15 (17)	.08

Missing data: BE 5%, NL 6%, ES 20% for ‘diagnosis’; BE 17%, NL 6%, ES 21% for ‘options for end-of-life care’; BE 15%, NL 9%, ES 25% for ‘psychological or social problems’; BE 1%, NL 1%, ES 1% for ‘preference for medical treatment’; BE 0%, NL 1%, ES 1% for ‘preference for proxy decision-maker’.

^a Bivariate Mantel-Haenszel tests for linear trends.

Figure 1. Trends in communication between general practitioners (GPs) and people with advanced cancer about end-of-life care topics in Belgium, the Netherlands and Spain, 2009-2014. Showing percentages of patients with whom certain end-of-life care topics were discussed, according to the GP, per year. Blue line shows Belgium, red line shows the Netherlands, green line shows Spain.

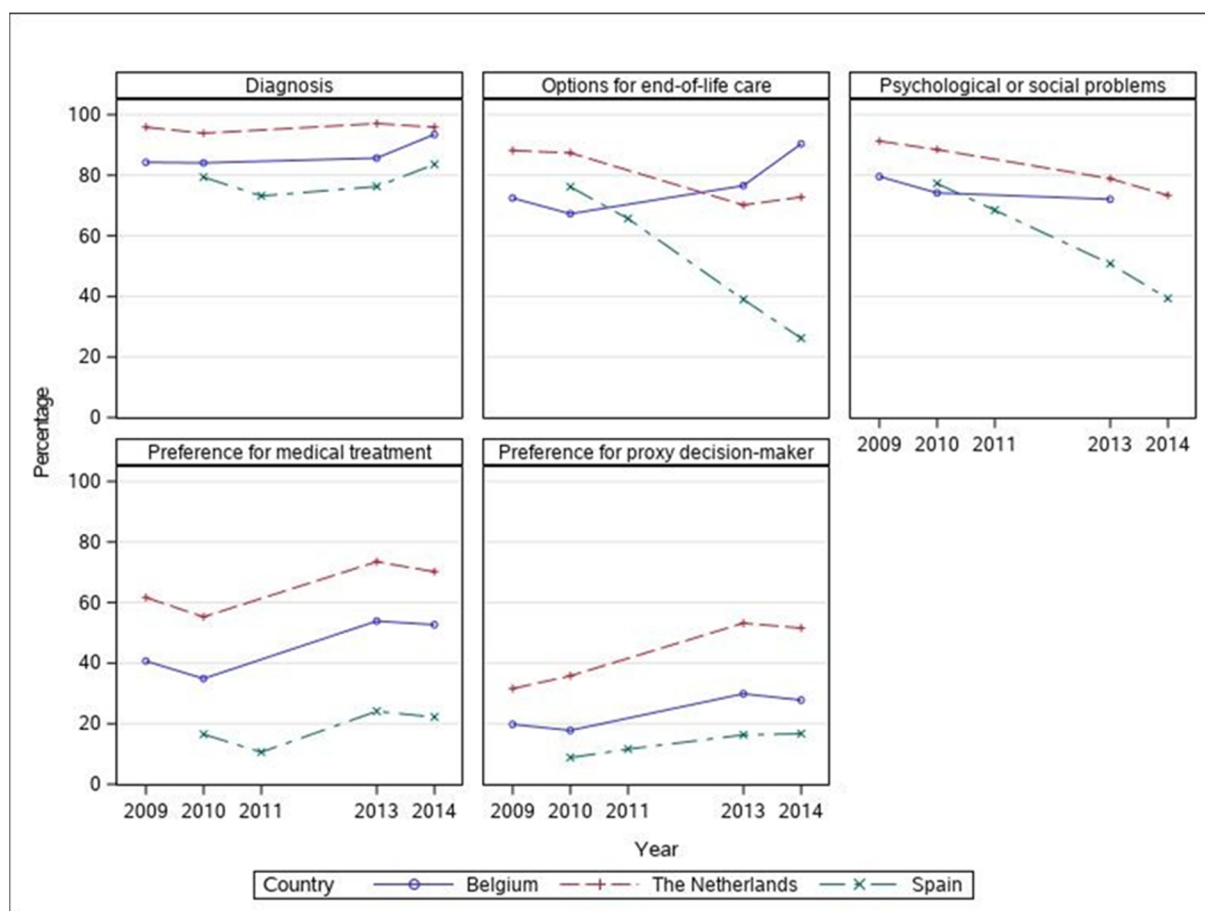


Table 3. Trends in communication between general practitioners (GPs) and people with advanced cancer about the diagnosis, options for end-of-life care and psychological or social problems by patient group in Belgium, the Netherlands and Spain, 2009-2014 (*n*=2306)

Patient group		Diagnosis				Options for end-of-life care				Psychological or social problems			
		2009 ^a	2014			2009 ^a	2014			2009 ^a	2014		
		BE: <i>N</i> =1201				BE: <i>N</i> =1194				BE: <i>N</i> =931			
		NL: <i>N</i> =710				NL: <i>N</i> =702				NL: <i>N</i> =729			
		ES: <i>N</i> =323	%-point			ES: <i>N</i> =320	%-point			ES: <i>N</i> =344	%-point		
		%	%	change	<i>p</i> ^b	%	%	change	<i>p</i> ^b	%	%	change	<i>p</i> ^b
Age (years)													
	18-64												
	Belgium	89	95	+6 pp	<.001	78	92	+14 pp	<.001	87	---	-21 pp	<.001
	The Netherlands	100	97	-3 pp	.68	85	74	-11 pp	.16	93	81	-12 pp	<.001
	Spain	75	94	+19 pp	.92	94	28	-66 pp	.07	81	44	-37 pp	<.01
	65-84												
	Belgium	89	95	+7 pp	<.001	78	92	+14 pp	<.001	78	---	-2 pp	.89
	The Netherlands	97	95	-1 pp	.16	90	69	-21 pp	<.001	91	71	-20 pp	<.001
	Spain	80	86	+7 pp	.61	77	31	-47 pp	<.01	78	39	-39 pp	.12
	85+												
	Belgium	64	89	+25 pp	<.001	46	85	+39 pp	<.001	68	---	-5 pp	.07
	The Netherlands	85	97	+12 pp	.55	85	83	-2 pp	.05	90	73	-17 pp	<.01
	Spain	84	43	-42 pp	---	50	---	---	---	71	29	-43 pp	---
Gender													
	Male												
	Belgium	84	93	+8 pp	<.001	73	89	+16 pp	<.001	78	---	-9 pp	.10
	The Netherlands	96	93	-3 pp	.07	96	93	-15 pp	<.01	87	75	-12 pp	<.001
	Spain	82	87	+5 pp	.47	76	26	-49 pp	.01	77	42	-35 pp	.74
	Female												

Belgium	84	95	+11 pp	<.001	71	93	+21 pp	<.001	82	---	-6 pp	.18
The Netherlands	96	99	+3 pp	.75	91	75	-16 pp	<.001	95	71	-24 pp	<.001
Spain	74	78	+3 pp	.69	78	26	-52 pp	<.01	79	35	-44 pp	<.001

Abbreviation: *PCU*, palliative care unit; *%-point* and *pp*: percentage point (calculated using the first and last available year). Missing data for independent variables <3%. Missing data for dependent variables: BE 5%, NL 6%, ES 20% for 'diagnosis'; BE 17%, NL 6%, ES 21% for 'options for end-of-life care'; BE 15%, NL 9%, ES 25% for 'psychological or social problems'. ^a The year 2010 is shown for Spain since data were not available for 2009. ^b Multivariable trend analysis controlled for age, gender, primary cancer site, longest place of residence in the last year of life, place of death. In some cases significance tests could not be performed due to small *n*. ^c 'Home' indicates living in own home or with family. 'Long-term care facility' includes residential care home in Belgium, residential home for older people in the Netherlands and Spain, (infrequently) nursing home in the Netherlands. 'Hospital' excludes PCU and nursing home unit in hospital.

Table 3 continued. Trends in communication between general practitioners (GPs) and people with advanced cancer about the diagnosis, options for end-of-life care and psychological or social problems by patient group in Belgium, the Netherlands and Spain, 2009-2014 (*n*=2306)

Patient group		Diagnosis				Options for end-of-life care				Psychological or social problems			
		2009 ^a	2014			2009 ^a	2014			2009 ^a	2014		
		BE: <i>N</i> =1201				BE: <i>N</i> =1194				BE: <i>N</i> =931			
		NL: <i>N</i> =710				NL: <i>N</i> =702				NL: <i>N</i> =729			
		ES: <i>N</i> =323	%-point			ES: <i>N</i> =320	%-point			ES: <i>N</i> =344	%-point		
		%	%	change	<i>p</i> ^b	%	%	change	<i>p</i> ^b	%	%	change	<i>p</i> ^b
Longest place of residence^c	Home												
	Belgium	86	95	+8 pp	<.001	75	92	+17 pp	<.001	81	---	-4 pp	.25
	The Netherlands	96	96	+1 pp	.39	87	72	-15 pp	<.001	91	76	-15 pp	<.001
	Spain	81	85	+4 pp	.60	81	27	-54 pp	<.001	77	41	-36 pp	.04
	Long-term care facility												
	Belgium	63	88	+25 pp	<.001	47	80	+33 pp	.08	67	---	-27 pp	.26
	The Netherlands	100	91	-9 pp	.45	100	82	-18 pp	---	92	36	-56 pp	.01
	Spain	60	50	-10 pp	---	20	---	---	---	80	---	---	---
Place of death^c	Home												
	Belgium	89	95	+6 pp	<.001	88	94	+6 pp	<.01	88	---	-10 pp	<.01
	The Netherlands	98	96	-1 pp	.08	91	78	-14 pp	<.001	90	80	-11 pp	<.001
	Spain	94	82	-12 pp	.32	88	41	-47 pp	<.01	82	50	-32 pp	.02
	Hospital												
	Belgium	87	96	+10 pp	<.001	62	92	+30 pp	<.01	79	---	-8 pp	.40
	The Netherlands	92	100	+8 pp	.15	77	39	-38 pp	.85	100	78	-22 pp	<.01
	Spain	65	89	+24 pp	.74	81	28	-54 pp	.13	61	28	-33 pp	.12
	PCU/hospice												

Belgium	84	91	+6 pp	.19	79	86	+6 pp	<.01	73	---	+6 pp	.43
The Netherlands	96	96	-17 pp	.39	88	82	-6 pp	.02	85	64	-21 pp	.05
Spain	67	88	+22 pp	.41	63	12	-51 pp	.97	100	47	-53 pp	.27
Long-term care facility												
Belgium	68	89	+22 pp	<.001	47	83	+36 pp	.79	74	---	-30 pp	.33
The Netherlands	94	85	-9 pp	.02	88	77	-11 pp	.77	94	39	-55 pp	<.001
Spain	67	50	-17 pp	---	29	---	---	---	72	---	---	---

Abbreviation: *PCU*, palliative care unit; *%-point* and *pp*: percentage point (calculated using the first and last available year). Missing data for independent variables <3%. Missing data for dependent variables: BE 5%, NL 6%, ES 20% for 'diagnosis'; BE 17%, NL 6%, ES 21% for 'options for end-of-life care'; BE 15%, NL 9%, ES 25% for 'psychological or social problems'. ^a The year 2010 is shown for Spain since data were not available for 2009. ^b Multivariable trend analysis controlled for age, gender, primary cancer site, longest place of residence in the last year of life, place of death. In some cases significance tests could not be performed due to small *n*. ^c 'Home' indicates living in own home or with family. 'Long-term care facility' includes residential care home in Belgium, residential home for older people in the Netherlands and Spain, (infrequently) nursing home in the Netherlands. 'Hospital' excludes PCU and nursing home unit in hospital.

Trends in preferences known for medical treatments at the end of life

The percentage of people for whom the GP was aware of a preference for medical treatment they would or would not want at the end of life increased in Belgium (from 41% to 53%, $p < .001$) and in the Netherlands between 2009 and 2014 (62% to 70%, $p < .01$). No significant trend was found for Spain (*Table 2; Figure 1*). In multivariable regression, the increase in Belgium was significant for those aged 18-64 and those aged 65-84, both genders, those who lived at home in the last year of life, and those who died at home and in a palliative care unit or hospice (*Table 4*). In the Netherlands, the increase was significant for those aged 18-64 and 65-84, males, those who lived at home in the last year of life, and those who died at home, in a hospital, and in a palliative care unit or hospice.

Trends in preferences known for a proxy decision-maker

The percentage of people for whom the GP was aware of a preference for a proxy decision-maker at the end of life increased in Belgium (from 20% to 28%, $p < .001$) and in the Netherlands between 2009 and 2014 (from 32% to 52%, $p < .001$). Spain did not show a significant trend (*Table 2; Figure 1*). In multivariable regression, the increase in the percentage of people for whom the GP was aware of a preference for a proxy decision-maker at the end of life in Belgium was significant in those aged 18-64, those who lived in a long-term care facility in the last year of life, and those who died at home (*Table 4*). In the Netherlands, the increase was significant in those aged 65-84 and 85+, males, those who lived at home in the last year of life, and those who died at home.

Table 4. Trends in awareness by general practitioners (GPs) of preferences of people with advanced cancer for medical treatment and for a proxy decision-maker by patient group in Belgium, the Netherlands and Spain, 2009-2014 (*n*=2306)

		Patient expressed preference for medical treatment				Patient expressed preference for proxy decision-maker			
		2009 ^a	2014			2009 ^a	2014		
		BE: <i>N</i> =1233				BE: <i>N</i> =1233			
		NL: <i>N</i> =729				NL: <i>N</i> =729			
		ES: <i>N</i> =344		%-point	<i>p</i> ^b	ES: <i>N</i> =344		%-point	<i>p</i> ^b
Patient group		%	%	change		%	%	change	
Age (years)	18-64								
	Belgium	42	48	+7 pp	<.001	19	37	+18 pp	.01
	The Netherlands	58	68	+10 pp	.05	36	39	+3 pp	.38
	Spain	29	36	+7 pp	.20	12	18	+6 pp	---
	65-84								
	Belgium	41	58	+18 pp	<.001	19	25	+7 pp	.62
	The Netherlands	63	67	+4 pp	<.01	29	51	+23 pp	.02
	Spain	17	20	+3 pp	.15	11	16	+5 pp	.51
	85+								
	Belgium	40	46	+5 pp	.10	23	26	+3 pp	.27
	The Netherlands	63	83	+20 pp	.06	32	63	+31 pp	.05
	Spain	---	12	---	---	---	18	---	---
Gender	Male								
	Belgium	39	54	+15 pp	<.001	21	35	+14 pp	.18
	The Netherlands	51	73	+22 pp	<.001	14	48	+35 pp	<.001
	Spain	20	17	-3 pp	.14	9	10	+1 pp	.40
	Female								
	Belgium	43	52	+9 pp	<.01	18	20	+2 pp	.60
	The Netherlands	72	67	-4 pp	.11	48	55	+7 pp	.86
	Spain	9	32	+26 pp	.83	8	29	+21 pp	.89

Abbreviation: *PCU*, palliative care unit; %-point and *pp*: percentage point (calculated using the first and last available year).

Missing data for independent variables <3%. Missing data for dependent variables: BE 1%, NL 1%, ES 1% for 'preference for medical treatment'; BE 0%, NL 1%, ES 1% for 'preference for proxy decision-maker'.

^aThe year 2010 is shown for Spain since data were not available for 2009.

^bMultivariable trend analysis controlled for age, gender, primary cancer site, longest place of residence in the last year of life, place of death. In some cases significance tests could not be performed due to small *n*.

^c'Home' indicates living in own home or with family. 'Long-term care facility' includes residential care home in Belgium, residential home for older people in the Netherlands and Spain, (infrequently) nursing home in the Netherlands. 'Hospital' excludes *PCU* and nursing home unit in hospital.

Table 4 continued. Trends in awareness by general practitioners (GPs) of preferences of people with advanced cancer for medical treatment and for a proxy decision-maker by patient group in Belgium, the Netherlands and Spain, 2009-2014 ($n=2306$)

Patient group		Patient expressed preference for medical treatment				Patient expressed preference for proxy decision-maker			
		2009 ^a	2014			2009 ^a	2014		
		BE: $N=1233$				BE: $N=1233$			
		NL: $N=729$				NL: $N=729$			
		ES: $N=344$	%-point			ES: $N=344$	%-point		
		%	%	change	p^b	%	%	change	p^b
Longest place of residence^c	Home								
	Belgium	41	57	+16 pp	<.001	19	29	+10 pp	.08
	The Netherlands	64	71	+7 pp	<.001	33	52	+19 pp	<.01
	Spain	18	23	+6 pp	.17	10	17	+8 pp	.51
	Long-term care facility								
	Belgium	32	35	+3 pp	.70	27	22	-5 pp	.04
	The Netherlands	43	69	+26 pp	.95	14	39	+24 pp	.80
	Spain	---	---	---	---	---	---	---	---
Place of death^c	Home								
	Belgium	55	73	+18 pp	<.001	20	41	+21 pp	<.01
	The Netherlands	76	82	+6 pp	<.001	41	66	+25 pp	<.01
	Spain	21	27	+7 pp	.02	8	16	+9 pp	.08
	Hospital								
	Belgium	33	33	0 pp	.71	15	14	0 pp	.20
	The Netherlands	50	39	-11 pp	.05	21	15	-6 pp	.26
	Spain	13	25	+12 pp	.60	4	21	+17 pp	.48
	PCU/hospice								
	Belgium	39	60	+21 pp	<.01	26	22	-4 pp	.13
	The Netherlands	35	68	+34 pp	<.01	23	46	+22 pp	.37
	Spain	20	17	-3 pp	.18	30	17	-13 pp	.74
	Long-term care facility								
	Belgium	29	44	+15 pp	.53	24	27	+3 pp	.18
	The Netherlands	53	60	+7 pp	.97	18	33	+16 pp	.14
	Spain	---	---	---	---	---	---	---	---

Abbreviation: *PCU*, palliative care unit; *%-point* and *pp*: percentage point (calculated using the first and last available year).

Missing data for independent variables <3%. Missing data for dependent variables: BE 1%, NL 1%, ES 1% for 'preference for medical treatment'; BE 0%, NL 1%, ES 1% for 'preference for proxy decision-maker'.

^a The year 2010 is shown for Spain since data were not available for 2009.

^b Multivariable trend analysis controlled for age, gender, primary cancer site, longest place of residence in the last year of life, place of death. In some cases significance tests could not be performed due to small *n*.

^c 'Home' indicates living in own home or with family. 'Long-term care facility' includes residential care home in Belgium, residential home for older people in the Netherlands and Spain, (infrequently) nursing home in the Netherlands. 'Hospital' excludes PCU and nursing home unit in hospital.

4.4 Discussion and conclusion

Discussion

Our findings show that there has been a significant increase between 2009 and 2014 in the percentages of people with cancer with whom certain end-of-life care topics were discussed (diagnosis, GPs' awareness of a preference for medical treatment at the end of life, GPs' awareness of a preference for a proxy decision-maker). This is in line with the overall enhanced attention to patient-centred communication and ACP initiatives, focusing on the process of discussing personal goals and wishes for care and treatment at the end of life.^[14-16] However, we also found some significant decreases for other topics (options for end-of-life care, psychological or social problems). In general, these trends were found across countries and across patient groups. Although some differences between groups persist, this study shows that changes in the likelihood of communication between GPs and people with cancer are widespread and indicative of a change in the general population. This may also mean that similar findings could be expected for other disease groups.

To our knowledge, this study is the first trend analysis on end-of-life communication practices in primary care in Europe for people with advanced cancer. In line with previous research^[19,24] and our expectations, the international comparison of Belgium, the Netherlands and Spain allowed us to see that while overall trends were similar in many ways, there are considerable cross-country differences in the prevalence and magnitude of change in communication related to end-of-life care, including the overall higher frequency of end-of-life conversations in the Netherlands and Belgium compared with Spain. Cultural variation may play a role in these overall differences, with Southern European cultures having a stronger tendency to avoid discussions that cause distress or discomfort, trying not to take away hope.^[25,26]

Diagnosis was the most commonly discussed end-of-life care topic in all three countries, a finding that is consistent with results from other cross-country attitudinal research.^[19] The high frequency of discussions of the diagnosis in all countries (between 84% and 96% in 2014) seems to reflect a commitment of GPs to providing people with advanced cancer with the information needed to understand their medical condition.^[27] Awareness of their diagnosis creates an opening for patients to engage in a conversation about other implications of their illness, allowing patients to exercise their autonomy. Only in Belgium, the increasing trend in the proportion of patients with whom the diagnosis was discussed was statistically significant; however, in the Netherlands a ceiling effect may have been at play, with communication already being at 96% in 2009. The increase in Belgium may have been due to several initiatives taking place during the 2009-2014 period, including the implementation of enhanced reimbursement to enable GPs to spend more time with patients on consultations in which the announcement of the diagnosis takes place, additional training for doctors on communication with patients, and the publishing of a protocol for disclosing the bad news about the diagnosis drafted by a group of experts.^[15,16]

We found that GPs awareness of preferences for medical treatment at the end of life and awareness of preferences for a proxy decision-maker clearly increased in Belgium (from 41% to 53%) and in the Netherlands (from 62% to 70%) between 2009 and 2014. Even though similar upward patterns were visible in Spain, these did not reach statistical significance, possibly due to low statistical power. These aspects of advance care planning have numerous benefits for patients, families and professional caregivers.^[28,29]

Besides increasing trends, this study also found unexpected declines over time for some variables. The percentage of people with whom options for end-of-life care were discussed dropped between 2009 and 2014 in the Netherlands (from 88% to 73%) and to an even more extreme extent in Spain (from 74% to 26%). Furthermore, again in the Netherlands and in Spain, a decline was seen in the percentage of people with whom psychological or social problems were discussed (from 91% to 73% and from 77% to 39%, respectively). These two items were the only items which have undergone minor modifications to their formulation. This could have influenced interpretation. However, the downward trends were already visible within the first wave (from 2009 to 2010 in the Netherlands and from 2010 to 2011 in Spain) and therefore the impact of changes in phrasing may have been limited. Additionally, the new formulation of the question (from 'palliative care' to 'end-of-life care'), which was explicitly intended to allow respondents to imagine a wider range of care provided beyond specialized palliative care, could equally have been expected to result in an increase in the response. A Belgian study found that medical oncologists perceive the term 'palliative care' as a barrier to communication about end-of-life care due to the stigma associated with the term, and in Belgium we indeed saw an increase in reported communication once this term had been removed from the questionnaire.^[30] However, there are also indications that the term 'end-of-life care' carries a stigma of its own in certain cultures, and is not well-defined in all contexts.^[31] As such, these conflicting pressures may be responsible for some of the changes over time.

Other explanations for these unexpected decreases exist. One possible interpretation is related to an increase in the specialization of cancer care and palliative care. Due to suboptimal information transmission between GPs and specialists, it is not uncommon for GPs and their patients to lose touch during ongoing treatment and in the post-treatment phases.^[32] In Spain for example, palliative care in hospitals has improved considerably over the course of this study, possibly leading to an increase in end-of-life conversations taking place in the hospital instead of the primary care setting.^[14] In the Netherlands, a recent study showed that GPs were more hesitant to engage in ACP with patients who were still being treated by specialists in hospital, as these patients are often less open to discussion.^[33] Numerous initiatives have been developed to make earlier integration of specialized palliative care services a reality.^[34-37] Consequently, certain topics may be more frequently discussed with palliative caregivers or nurses of the palliative homecare team rather than with GPs. An interesting example is the evolving role of the oncology nurse in clinical oncology departments.^[38,39] These nurses pay particular attention to the emotional impact of living with and beyond the diagnosis and its treatment through the cancer care pathway.^[40] However, this does not explain why these decreases were only found for the Netherlands and Spain, and not for Belgium, where the role of the oncology nurse is well-defined and highly appreciated.^[41] The way palliative care provision is organised may contribute to part of the differences. Belgium and the Netherlands are small countries where palliative care is often highly accessible, whereas in Spain, despite improvements in recent years, palliative care provision in rural areas is still lacking.^[14]

The mortality follow-back study design is a robust study design to measure end-of-life care on a population level.^[42] In this study recall bias was limited since GPs were instructed to complete the questionnaire within a week of the patient's death. A limitation is that although representative within this area, the Spanish Sentinel Network only covered a specific region resulting in a smaller sample and lower statistical power. Furthermore, this study only reports if topics were discussed according to the GP, and does not represent the totality of end-of-life communication with cancer patients. Perceptions of what constitutes the 'discussion' of a certain topic may differ between

patients and physicians.^[43] The present study examines the prevalence of discussions and can neither provide in-depth insights into patients' expectations or desires for such conversations – e.g., whether patients took the initiative for such communication themselves or whether they rely on their GP to initiate – nor into the quality of the communication process – e.g., whether communication about care preferences was started early enough that this could make a material difference to the quality of end-of-life care. Finally, due to the low statistical power for some analyses, particularly in Spain, it is possible that the significance of some results is underestimated.

This study shows that initiatives to increase end-of-life communication can be ambitious and aim at significant change in clinical practice in a short time. However, the prerequisites for successful interventions are still unknown, while challenges to continued high levels of communication between GPs and patients are also apparent. For instance, the ongoing increase in the specialization of cancer care and palliative care and subsequent task differentiation between healthcare professionals pave the way for new roles and responsibilities in primary and secondary care. This will require better communication between healthcare providers in order to maintain good communication with patients. Future research should provide a broader picture including ACP as a whole as well as including the various healthcare providers.

Conclusion

Broad changes, both increasing and decreasing, were found between 2009 and 2014 in the number of people with cancer with whom certain end-of-life care topics were discussed according to GPs in Belgium, the Netherlands and Spain. Despite international differences that appear to persist over time, end-of-life communication in primary care in Europe can change substantially in a relatively short period of time across patient groups.

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Competing interest

None declared.

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Data availability statement

Data may be made available upon request to the relevant national institute.

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