

*Original Article*

# End-of-Life Communication: A Retrospective Survey of Representative General Practitioner Networks in Four Countries

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**Abstract**

**Context.** Effective communication is central to high-quality end-of-life care.

**Objectives.** This study examined the prevalence of general practitioner (GP)-patient discussion of end-of-life topics (according to the GP) in Italy, Spain, Belgium, and The Netherlands and associated patient and care characteristics.

**Methods.** This cross-sectional, retrospective survey was conducted with representative GP networks. Using a standardized form, GPs recorded the health and care characteristics in the last three months of life, and the discussion of 10 end-of-life topics, of all patients who died under their care. The mean number of topics discussed, the prevalence of discussion of each topic, and patient and care characteristics associated with discussions were estimated per country.

**Results.** In total, 4396 nonsudden deaths were included. On average, more topics were discussed in The Netherlands (mean = 6.37), followed by Belgium (4.45), Spain (3.32), and Italy (3.19). The topics most frequently discussed in all countries were “physical complaints” and the “primary diagnosis,” whereas “spiritual and existential issues” were the least frequently discussed. Discussions were most prevalent in The Netherlands, followed by Belgium. The GPs from all

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countries tended to discuss fewer topics with older patients, noncancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim, and patients for whom their GP had not provided palliative care.

**Conclusion.** The prevalence of end-of-life discussions varied across the four countries. In all countries, training priorities should include the identification and discussion of spiritual and social problems and early end-of-life discussions with older patients, those with cognitive decline if possible, and those with non-malignant diseases. *J Pain Symptom Manage* 2013;■:■-■. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### **Key Words**

*Patient-physician communication, palliative care, terminal illness, patient participation, cross-national*

## **Introduction**

Palliative care involves the “identification and impeccable assessment of physical, psychosocial, and spiritual suffering.”<sup>1</sup> Such high-quality assessment requires the discussion of a range of end-of-life topics, such as diagnosis, prognosis, treatment preferences, and psychosocial and spiritual issues. These end-of-life discussions enable health care professionals to recognize their patients’ values and preferences and are an important step in the provision of care commensurate with patients’ wishes.<sup>2</sup>

Good end-of-life communication enhances patients’ understanding of their condition and care and treatment options,<sup>2</sup> facilitates informed participation in decision making,<sup>2</sup> and is repeatedly identified as important for patient and caregiver satisfaction with end-of-life care.<sup>3,4</sup> Suboptimal communication, in contrast, may result in poor pain and symptom management,<sup>5</sup> psychological and spiritual distress,<sup>6,7</sup> and a lack of knowledge concerning patients’ preferences.<sup>6</sup> Considering the centrality of communication in high-quality end-of-life care, it is important to understand how often physicians discuss different end-of-life issues with patients and the factors that influence discussions.

There is, however, little evidence concerning the topics that are discussed between physicians and patients at the end of life and even less from a cross-country perspective. International comparisons draw attention to factors that are universally important and those that are country specific, highlight examples of

“best practice,” and inform policy nationally and internationally.

Previous cross-national research has been mostly limited to attitudinal or prevalence studies focusing on diagnosis, prognosis, and treatment discussions.<sup>8–11</sup> These studies revealed differences between countries, differences that were ascribed to cultural, social, and institutional influences.<sup>8–11</sup> Furthermore, a study by Cartwright et al.<sup>12</sup> estimated the topics that, in principle, physicians from Australia and six European countries discuss with patients at the end of life.<sup>12</sup> However, Cartwright et al.<sup>12</sup> did not examine the topics that were actually discussed with individual patients. There is, therefore, no cross-country empirical research on the actual prevalence of physician-patient discussion of end-of-life topics in Europe.

This study examines the prevalence of general practitioner (GP)-patient discussion of different end-of-life topics in Italy, Spain, Belgium, and The Netherlands. The GPs were chosen because, although complex cases are often referred for a time to specialist care, much end-of-life care is provided in primary care settings.<sup>13,14</sup> The GP’s role in end-of-life care provision, together with related laws, policy, and training in each country, is detailed in [Table 1](#). The study draws on data collected by representative GP networks as part of the European Sentinel Network Monitoring End-of-Life Care (EURO SENTIMELC) project, which aims to describe and compare care provided to patients in the last three months of life. Specific objectives of this study are: to estimate and compare the prevalence of GP-patient

Table 1  
**General Practitioners' (GPs') Role in Palliative Care Provision: Law, Policy, Practice, and Training**

GPs' Role	Italy	Spain	Belgium	The Netherlands
Law	Access to palliative care has been recognized as a right under Italian law since 2010. <sup>15</sup>	Access to palliative care in primary and secondary settings has been recognized as a basic right under Spanish law since 2003. <sup>16</sup>	Access to palliative care has been recognized as a right under Belgian law since 2002. <sup>17,18</sup>	There is no specific legislation in The Netherlands with regard to access to palliative care. Access is, however, covered by general legislation on health care insurance. <sup>19</sup>
Policy	Palliative care featured in the Italian National Health Plan for 2011–2013. <sup>20</sup> The plan acts as a guideline for regional authorities' health care provision. <sup>21</sup> Furthermore, the National Collective Agreement for GPs includes care for the dying at home. <sup>21</sup>	Spain has had a comprehensive National Palliative Care Strategy since 2007 <sup>22,23</sup> and clinical practice guidelines for palliative care. <sup>24</sup> The strategy acts as a guideline for autonomous communities. Most communities have developed their own palliative care plans. <sup>25</sup> There is consensus across autonomous communities on an organizational model of care: A basic level of palliative care is provided in primary settings, whereas specialist care is provided for those with complex needs. <sup>25</sup>	Belgium has had a comprehensive national palliative care plan since 2005. <sup>26,27</sup> In Belgium, there is a policy focus on the provision of multidisciplinary palliative home care under the supervision of the GP rather than care in specialist settings. <sup>26,27</sup>	In 2011, the Ministry of Health, Welfare, and Sport issued a policy brief that stated that palliative care should be accessible for all those who need it. <sup>28</sup> The brief from the Ministry stated that palliative care should principally be provided by primary care professionals. <sup>28</sup> There are also guidelines available for generalist end-of-life care provision. <sup>29</sup>
Practice	In Italy, local health authorities autonomously plan and provide services, leading to variation. <sup>30</sup> In general, GPs have a role in the coordination and provision of palliative care in primary and home care settings. The GPs coordinate and participate in primary care–based home care teams <sup>30,31</sup> but not hospital-based home care teams. <sup>30</sup> The 2010 law on access to care makes specific reference to the need for GP palliative care. <sup>32</sup>	In Spain, each autonomous community plans and provides its own health care, leading to variation. <sup>33</sup> In both the Valencian community and Castile and León, primary care is the first level of access to palliative care. Care is provided by GPs in the primary or home care settings. Home support teams are also coordinated by the GP.	Belgian GPs often share the provision of palliative care with a multidisciplinary home team (physicians, pharmacists, nurses, physiotherapists, psychologists, and social workers). <sup>34</sup> The GP, however, remains entirely responsible for the care and supervision of the patient. <sup>26,27</sup>	Dutch GPs have a high degree of personal responsibility for end-of-life care provision. <sup>35</sup> Care is often provided solely by the GP or in consultation with a mobile palliative care consultation team. <sup>36</sup>
Training	Palliative care is not a medical specialty in Italy, <sup>37</sup> but has recently been recognized as an autonomous medical discipline. <sup>38</sup> Palliative care is not an obligatory part of undergraduate medical training, and until recently there were no official postgraduate courses in palliative care, although there were	Palliative care is not a recognized medical specialty in Spain. <sup>37</sup> The need for palliative care education in undergraduate curricula is, however, recognized. <sup>40</sup> The National Strategy describes three levels of training: basic (20–40 h), intermediate (40–80 h), and advanced (Masters courses or	Palliative care is not a recognized medical specialty. <sup>37</sup> Although palliative care is not an obligatory part of undergraduate medical training, GPs can undertake optional advanced postgraduate courses. <sup>42</sup>	Palliative care is not recognized as a medical specialty in The Netherlands. <sup>37</sup> Dutch medical students receive a small amount of palliative care education during their medical training; <sup>43</sup> however, the GPs can choose to undertake further specialist palliative care training ( <i>palliatieve kaderopleiding</i> ).

(Continued)

Table 1  
Continued

GPs' Role	Italy	Spain	Belgium	The Netherlands
	<p>some unofficial ones.<sup>21,37</sup> The 2010 law on access to care, however, outlined the need for postgraduate courses in palliative care.<sup>38</sup> Proposed Masters courses suitable for GPs included the Master degrees "Pain" (1 y) and "Palliative Care" (2 y).<sup>32</sup></p>	<p>3 months in a PCU). The 2012 evaluation report of the strategy states that intermediate training courses have mostly been directed at primary health professionals.<sup>41</sup></p>		

PCU = palliative care unit.

discussion of different end-of-life topics before patients' deaths in four European countries, and to analyze associations between discussions and patient and care characteristics for each country.

## Methods

### Study Design and Procedure

The study followed a cross-sectional, retrospective design. The GPs from representative networks in each of the four countries recorded the demographic, health, and care characteristics using a standardized registration form in the last three months of life of all practice patients who died. The GPs registered deaths weekly from January 1, 2009 to December 31, 2010, except for Spanish GPs who registered deaths from January 1, 2010 to December 31, 2010. Participants were asked to include information received from hospital physicians and patient records. Completed forms were sent to national coordinating institutions. Received forms were checked for missing data, which were retrieved via telephone, if possible. Researchers entered data into SPSS (SPSS, Inc., Chicago, IL), double entering 5% of data as a quality check.

### Settings and Study Population

Existing Spanish, Belgian, and Dutch GP sentinel networks participated.<sup>44–47</sup> A sentinel network is a monitoring system based on a representative sample of health care professionals reporting all cases of one or more conditions to study disease prevalence and associated factors.<sup>46</sup> In Italy, a representative network of GPs was created specifically for this end-of-life surveillance in nine health districts.<sup>48</sup> To avoid selection bias, Italian GPs were unaware of the aim of the surveillance when recruited.<sup>48</sup>

The nationwide Belgian and Dutch networks covered 1.75% and 0.8% of the population, respectively. The Spanish network operated in two autonomous communities: Castile and León and the Valencian Community, covering 3.8% and 2.2% of the respective regional populations. The Italian network operated in nine local health districts and covered 4% of each district's population.

The GPs were instructed to record the deaths of all patients aged older than 18 years.

To include only patients who could have received end-of-life care, deaths registered as sudden and totally unexpected, or for which this information was missing, were excluded. As the study examines patient-GP end-of-life discussions, only patients who could have received care from a GP in the last year of life were included. This was determined from the patient's main place of residence in the last year of life; Dutch nursing home residents, cared for by a specially trained elder care physician, were excluded, as were patients whose main place of residence was "unknown" or "other" (these were often institutions outside of the GP's remit, e.g., hospitals or psychiatric institutions). Comparing the data with national place of death data (excluding Dutch nursing home deaths in The Netherlands) verified the representativeness of all deaths (except for a slight underrepresentation of nonsudden hospital deaths and people aged younger than 65 years in Belgium, and women in The Netherlands).<sup>48</sup>

#### *Measurement Instrument*

The 22-item 2009/2010 EURO SENTIMELC registration form contained questions on patients' demographic, health, and end-of-life care characteristics in the last three months of life (Appendix; available at [jpsmjournal.com](http://jpsmjournal.com)). Specific aspects of care included the main place of care, place of death, communication, palliative care provision, and symptoms in the last week of life. A question on whether the following topics had ever been addressed during the GP's conversations with the patient was included (Question 11, Appendix), namely primary diagnosis, incurability of disease, life expectancy, possible medical complications, physical complaints, psychological problems, social problems, spiritual/existential problems, options for palliative treatment, and the possible burden of treatments.

Independent variables collected were: age; sex; cause of death; dementia diagnosis; main place of residence in the last year of life; place of death; average monthly number of contacts with the patient (face to face) in the second and third months before death; provision of palliative care by the GP (as defined by the GP); and the importance of curative, life-prolonging, and palliative care as treatment

aims in the second and third months before death (rated on a five-point Likert scale).

Most questions had been piloted and used in previous studies.<sup>44,45,49–53</sup> New questions were agreed collaboratively by all partners. The questionnaire underwent forward and backward translations from Dutch into English, from English into Italian and Spanish, and from Dutch into French. The final form was piloted in each country (minimum 10 GPs).<sup>48</sup>

#### *Data Analysis*

Patient characteristics in each country were assessed using descriptive statistics. Differences between countries were assessed using Pearson's Chi-squared test. Prevalence of discussion of each topic was assessed using descriptive statistics. Differences between countries were examined using logistic regression analyses (controlling for variables that differed significantly in the Pearson's Chi-squared tests). The mean number of topics discussed was estimated per country and differences between countries were assessed using a Kruskal-Wallis test.

Multiple ordinal regressions were conducted separately by country to explore associations between patient and care characteristics and the discussion of end-of-life topics. The dependent variable was a score of topics discussed between the GP and the patient (possible scores between zero and 10). Ordinal regression takes into account the rank ordering of the 11-level score. Odds ratios from ordinal regressions provide an estimate of the odds for a unit increase when changing levels on the dependent variable scale.

Continuous variables (age and number of GP contacts) were converted into categorical variables. Cause of death was recategorized as cancer or noncancer. Furthermore, treatment aims were dichotomized: "important" and "very important" were separated from other responses. All analysis was carried out in SPSS version 18.

#### *Results*

A total of 6858 deaths were recorded. After the removal of sudden and totally unexpected deaths ( $n = 2243$ ), deaths for which this information was missing ( $n = 97$ ), Dutch nursing home residents ( $n = 22$ ), and patients with

an “unknown” ( $n=28$ ) or “other” ( $n=72$ ) main place of residence, the final sample comprised 4396 deaths (Italy  $n=1808$ , Spain  $n=379$ , Belgium  $n=1556$ , and The Netherlands  $n=653$ ).

### Sample Characteristics

Although characteristics varied between countries, most deaths occurred in those aged older than 85 years (32–44%) and the most common cause of death was cancer

(37–52%). Just less than a third of patients in Italy, Spain, and Belgium had dementia (29–31%), compared with 13% of Dutch patients (Table 2). Approximately half of Italian, Spanish, and Dutch patients died at home (44–50%), compared with less than a quarter of Belgian patients (24%). A quarter to one-third of patients (24–32%) in the last week of life and 8–20% of patients in the second and third months before death had no contact with their GP.

Table 2  
Patients' Personal and Care Characteristics ( $N=4396$ )<sup>a</sup>

Characteristics	Italy	Spain	Belgium	The Netherlands	P-value <sup>b</sup>
	( $N=1808$ )	( $N=379$ )	( $N=1556$ )	( $N=653$ )	
	n (%)				
Age (y)					
≤64	227 (13)	43 (11)	214 (14)	119 (18)	<0.001
65–74	293 (16)	47 (12)	212 (14)	125 (19)	
75–84	556 (31)	124 (33)	516 (33)	198 (30)	
85+	732 (40)	165 (44)	602 (39)	211 (32)	
Mean	79.6	80.5	79.0	77.0	
Sex					
Male	844 (47)	202 (53)	712 (46)	304 (47)	0.075
Female	964 (53)	177 (47)	840 (54)	342 (53)	
Cause of death					
Cancer	820 (46)	147 (39)	581 (37)	339 (52)	<0.001
Cardiovascular disease	371 (21)	63 (17)	226 (15)	101 (16)	
Respiratory disease	129 (7)	53 (14)	168 (11)	50 (8)	
Diseases of the nervous system	104 (6)	17 (5)	113 (7)	20 (3)	
Stroke	177 (10)	40 (11)	103 (7)	28 (4)	
Other	163 (9)	56 (15)	363 (23)	112 (17)	
Dementia diagnosed					
Yes	520 (29)	112 (31)	478 (31)	84 (13)	<0.001
No	1262 (71)	255 (69)	1050 (69)	544 (87)	
Place of death					
Hospital	697 (39)	124 (33)	556 (36)	171 (28)	<0.001
Residential or care home	163 (9)	46 (12)	479 (31)	112 (18)	
Home (including service flat) or with family	842 (47)	186 (50)	365 (24)	273 (44)	
Palliative care unit/hospice (Other, $n=41$ ) <sup>c</sup>	100 (6)	16 (4)	147 (10)	65 (10)	
Average GP-patient monthly contacts in the second and third months before death					
0	145 (8)	73 (19)	127 (8)	130 (20)	<0.001
1 or 2	972 (54)	222 (59)	1227 (79)	369 (57)	
3 or more	691 (38)	84 (22)	202 (13)	154 (24)	
GP provision of palliative care					
Yes	995 (55)	232 (65)	787 (51)	374 (60)	<0.001
No	807 (45)	126 (35)	768 (49)	251 (40)	
Curative treatment an important treatment aim					
Yes	322 (18)	91 (24)	468 (31)	141 (24)	<0.001
No	1449 (82)	288 (76)	1028 (69)	459 (76)	
Life prolongation an important treatment aim					
Yes	747 (42)	91 (24)	573 (39)	165 (28)	<0.001
No	1036 (58)	288 (76)	914 (61)	435 (72)	
Palliative care an important treatment aim					
Yes	749 (42)	182 (48)	733 (51)	390 (65)	<0.001
No	1022 (58)	197 (52)	714 (49)	212 (35)	

GP = general practitioner.

Valid percentage reported. Percentages have been rounded to whole numbers; therefore, some totals are not exactly 100%.

<sup>a</sup>Percent of missing observations ranged from 0.3% to 4.5%.

<sup>b</sup>Test of association: Pearson's Chi-square.

<sup>c</sup>Not included in statistical analyses.

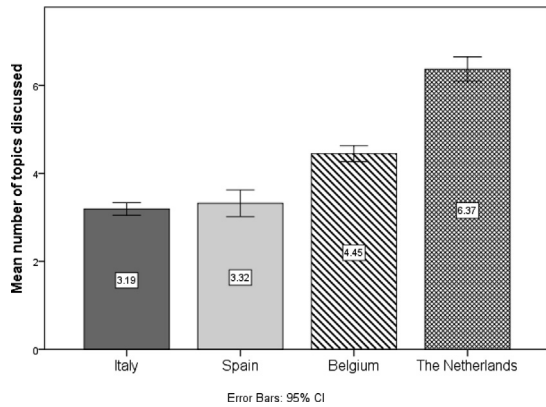


Fig. 1. Mean number of topics discussed by country.

### GP-Patient Discussion of End-of-Life Topics

The mean number of end-of-life topics discussed between patients and physicians differed significantly between countries ( $P < 0.001$ ). On average, more topics were discussed in The Netherlands (mean = 6.37), followed by Belgium (4.45), Spain (3.32), and Italy (3.19) (Fig. 1).

Discussion of all topics was most prevalent in The Netherlands, followed by Belgium, and then either Spain or Italy (depending on the topic; Fig. 2). “Physical complaints” was the most prevalent topic of discussion in all countries (61–82%). “Primary diagnosis,” the second most prevalent topic, was discussed with 49–78% of the patients. The topic “spiritual and existential problems” was least discussed (with 7–37% of patients). “Social problems” was the second least frequently discussed topic

in Spain, Belgium, and The Netherlands (with 18%, 35%, and 52% of patients, respectively), whereas “options for palliative treatment” was the second least frequent in Italy (with 18% of patients). Furthermore, the incurability of disease, life expectancy, medical complications, options for palliative treatment, and the burden of treatment were discussed with less than 50% of patients from all countries except for The Netherlands. In Italy and Spain, there was a particularly low prevalence of GP-patient discussion about the incurability of disease (28% and 34%, respectively), life expectancy (23% in both countries), and social problems (23% and 18%, respectively) compared with The Netherlands and Belgium.

Prevalence of discussion of each topic differed significantly between the four countries (Table 3). The odds of discussing each of the 10 topics were higher for Dutch and Belgian patients than Italian patients. There were no significant differences between Spain and Italy in the odds of discussion of four topics. The odds, however, of a Spanish patient having discussed the primary diagnosis, incurability of disease, medical complications, physical complaints, options for palliative treatment, and the burden of treatment with their GP were significantly higher than those of an Italian patient.

### Associations Between the Score of Topics Discussed and Patient and Care Characteristics

Older age was negatively associated with the discussion of more end-of-life topics in Italy

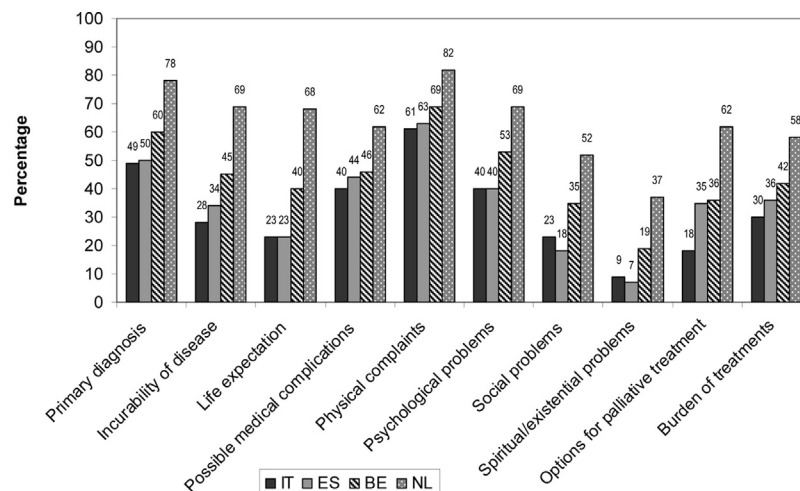


Fig. 2. Prevalence of general practitioner-patient discussion of the end-of-life topics. IT = Italy; ES = Spain; BE = Belgium; NL = The Netherlands.

Table 3  
GP-Patient Discussion of 10 End-of-Life Topics (N = 4396)<sup>a,c</sup>

End-of-Life Topic Discussed	Italy (N = 1808)		Spain (N = 379)		Belgium (N = 1556)		The Netherlands (N = 653)	
	n	Multivariable OR (CI) <sup>b</sup>	n	Multivariable OR (CI) <sup>b</sup>	n	Multivariable OR (CI) <sup>b</sup>	n	Multivariable OR (CI) <sup>b</sup>
Primary diagnosis	880	1	172	<b>1.38 (1.04–1.84)</b>	932	<b>2.51 (2.01–3.05)</b>	498	<b>5.11 (3.83–6.80)</b>
Incurability of disease	496	1	119	<b>1.88 (1.40–2.53)</b>	701	<b>3.62 (2.98–4.40)</b>	440	<b>7.61 (5.85–9.91)</b>
Life expectation	422	1	77	1.18 (0.86–1.63)	614	<b>3.29 (2.70–3.99)</b>	431	<b>8.96 (6.91–11.62)</b>
Possible medical complications	711	1	153	<b>1.49 (1.13–1.98)</b>	712	<b>1.75 (1.46–2.10)</b>	394	<b>2.61 (2.05–3.33)</b>
Physical complaints	1087	1	222	<b>1.41 (1.05–1.89)</b>	1065	<b>2.27 (1.85–2.79)</b>	521	<b>3.71 (2.73–5.05)</b>
Psychological problems	720	1	139	1.23 (0.94–1.63)	822	<b>2.30 (1.92–2.75)</b>	439	<b>3.53 (2.76–4.51)</b>
Social problems	413	1	62	0.88 (0.63–1.21)	550	<b>2.47 (2.05–2.97)</b>	327	<b>3.88 (3.08–4.88)</b>
Spiritual/existential problems	166	1	23	0.83 (0.52–1.32)	299	<b>2.80 (2.21–3.56)</b>	237	<b>5.26 (4.03–6.86)</b>
Options for palliative treatment	326	1	119	<b>4.65 (3.35–6.46)</b>	566	<b>5.68 (4.51–7.14)</b>	394	<b>12.44 (9.30–16.63)</b>
Burden of treatments	535	1	119	<b>1.90 (1.41–2.56)</b>	647	<b>2.54 (2.10–3.07)</b>	370	<b>3.55 (2.78–4.54)</b>

GP = general practitioner; OR = odds ratio; CI = confidence interval.

Values for which  $P < 0.05$  are highlighted in bold.

<sup>a</sup>Percent of missing observations ranged from 1.4% to 2.2%.

<sup>b</sup>Multivariable logistic regressions (forced enter). The dependent variable was if the topic had or had not been discussed. Independent variables included country (OR and CI shown); age; cause of death; dementia diagnosis; place of death; GP palliative care provision; the number of contacts with the GP in the last week, and in the second and third months before death; and the importance of curative, life-prolonging and palliative care as treatment aims. The results of the multivariable logistic regressions were compared with equivalent univariate analyses (not shown) to check for any major differences in the magnitude or direction of associations.

and Belgium. Also, in The Netherlands, the age groups 65–74 and 75–84 were associated with the discussion of more end-of-life topics compared with the group aged 85 years or older (Table 4).

Cancer as a cause of death was positively associated with the discussion of end-of-life topics compared with noncancer deaths in all countries. Furthermore, diagnosis of dementia was negatively associated with the discussion of end-of-life topics compared with patients without dementia in all countries.

Place of death was associated with end-of-life discussions in Italy and Belgium. In Italy, dying at home was negatively associated with the discussion of end-of-life topics compared with dying in hospital, whereas in Belgium, home and palliative care unit deaths were positively associated with the discussion of end-of-life topics compared with hospital deaths. In addition, residential home deaths were negatively associated with the discussion of end-of-life topics compared with hospital deaths in Belgium.

The personal provision of palliative care by the GP was positively associated with the discussion of end-of-life topics in Italy, Belgium, and The Netherlands. Furthermore, more contact with the GP in the second and third months before death was positively associated with the discussion of end-of-life topics in Italy, Belgium, and The Netherlands.

The identification of curative care as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in Italy only. The identification of life prolongation as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in Italy and The Netherlands. The recognition of palliative care as an important or very important treatment aim was positively associated with the discussion of end-of-life topics in all countries.

## Discussion

This cross-national study maps the occurrence of end-of-life discussions related to 10 physical, psychosocial, or spiritual issues and examines associated factors in The Netherlands, Belgium, Italy, and Spain. The topics most frequently discussed in all countries



Table 4  
Ordinal Regression Examining Associations Between Patient and Care Characteristics and the Discussion of More End-of-Life Topics

Characteristics	Italy (n = 1808)	Spain (n = 379)	Belgium (n = 1556)	The Netherlands (n = 653)
	Multivariable OR (95% CI) <sup>a</sup>	Multivariable OR (95% CI) <sup>a</sup>	Multivariable OR (95% CI) <sup>a</sup>	Multivariable OR (95% CI) <sup>a</sup>
Age (y)				
≤64	<b>1.96 (1.43–2.68)</b>	0.98 (0.47–2.05)	<b>1.89 (1.36–2.65)</b>	1.64 (0.96–2.79)
65–74	<b>1.92 (1.45–2.53)</b>	0.91 (0.47–1.79)	<b>1.53 (1.11–2.12)</b>	<b>2.45 (1.46–4.12)</b>
75–84	1.23 (0.98–1.53)	1.13 (0.70–1.81)	<b>1.33 (1.05–1.68)</b>	<b>1.63 (1.07–2.49)</b>
85+	1	1	1	1
Sex				
Male	1.13 (0.94–1.35)	1.05 (0.70–1.57)	0.96 (0.79–1.18)	0.87 (0.62–1.20)
Female	1	1	1	1
Cause of death				
Cancer	<b>1.46 (1.18–1.81)</b>	<b>2.12 (1.31–3.42)</b>	<b>2.03 (1.59–2.58)</b>	<b>1.91 (1.31–2.81)</b>
Noncancer	1	1	1	1
Dementia diagnosed				
Yes	<b>0.16 (0.12–0.20)</b>	<b>0.23 (0.14–0.37)</b>	<b>0.20 (0.15–0.25)</b>	<b>0.37 (0.22–0.60)</b>
No	1	1	1	1
Place of death				
Care home/residential home	0.77 (0.54–1.09)	0.66 (0.32–1.37)	<b>0.56 (0.42–0.75)</b>	0.62 (0.36–1.08)
Family or own home	<b>0.71 (0.58–0.87)</b>	1.39 (0.87–2.22)	1.25 (0.95–1.65)	0.93 (0.57–1.51)
PCU or hospice	1.33 (0.90–1.97)	1.17 (0.43–3.16)	<b>1.57 (1.10–2.25)</b>	1.64 (0.90–2.97)
Hospital	1	1	1	1
GP provided palliative care				
Yes	<b>1.67 (1.38–2.02)</b>	1.39 (0.89–2.19)	<b>1.75 (1.38–2.21)</b>	<b>11.98 (7.68–18.68)</b>
No	1	1	1	1
GP-patient second to third months before death				
0	1	1	1	1
1–2	1.36 (0.93–1.98)	1.66 (0.96–2.85)	<b>2.64 (1.78–3.90)</b>	<b>3.86 (2.43–6.12)</b>
≥3	<b>2.17 (1.48–3.20)</b>	1.39 (0.74–2.63)	<b>4.86 (3.06–7.69)</b>	<b>6.43 (3.77–10.96)</b>
Importance of curative treatment				
Likert scale score				
4–5	<b>1.47 (1.15–1.87)</b>	1.33 (0.81–2.18)	0.96 (0.76–1.22)	0.89 (0.57–1.38)
1–3	1	1	1	1
Importance of life prolongation				
Likert scale score				
4–5	<b>1.37 (1.12–1.66)</b>	1.01 (0.61–1.66)	<b>1.36 (1.09–1.69)</b>	1.10 (0.73–1.67)
1–3	1	1	1	1
Importance of palliative care				
Likert scale score				
4–5	<b>1.50 (1.24–1.81)</b>	<b>2.04 (1.35–3.07)</b>	<b>1.28 (1.05–1.57)</b>	<b>2.14 (1.50–3.04)</b>
1–3	1	1	1	1

OR = odds ratio; CI = confidence interval; PCU = palliative care unit; GP = general practitioner; PC = palliative care.

Values for which  $P < 0.05$  are highlighted in bold.

<sup>a</sup>Multivariable ordinal regressions (forced enter). The dependent variable was a score of the number of topics discussed between the GP and the patient (possible scores between zero and 10). Independent variables included: age; sex; cause of death; dementia diagnosis; place of death; GP provision of PC; the number of contacts with the GP in the second and third months before death; and the importance of curative, life-prolonging and palliative care as treatment aims. The results of the multivariable ordinal regressions were compared with equivalent univariate analyses (not shown) to check for any major differences in the magnitude or direction of associations. Results were also compared with univariate and multivariable logistic regressions for which dependent variables were “no topics discussed vs. any topic discussed” and “five or less topics vs. more than five topics discussed” (analyses not shown) to check the robustness of the associations.

were physical complaints and the primary diagnosis; spiritual and existential issues were the least frequently discussed. This is the first study to provide robust and comparable data on the prevalence of GP-patient end-of-life discussions with patients nearing death in the four countries.

Important between-country differences in the mean number of topics discussed and the prevalence of discussion of all topics were identified: a gradient from low prevalence in Italy to high prevalence in The Netherlands was revealed. However, despite these between-country differences, the overall associations between patient and care characteristics and the discussion of more end-of-life topics were remarkably similar across countries.

### *Topics Discussed*

The frequent discussion of physical complaints and primary diagnosis in all countries, compared with social problems and spiritual and existential issues, reflects findings of cross-country attitudinal<sup>12</sup> and non-cross-country practice<sup>44,45,54</sup> surveys. Qualitative and survey studies examining patients' spiritual and psychosocial well-being at the end of life, however, report considerable unmet needs.<sup>55–58</sup> Physicians' avoidance of spiritual and social problems has been attributed to a lack of appropriate training, time pressure, and difficulties identifying patients who wish to discuss spiritual issues.<sup>59–61</sup>

Although some topics were more frequently discussed, most were still only discussed with less than half of patients from all countries except The Netherlands. Similarly, previous qualitative<sup>62,63</sup> and survey<sup>64–66</sup> studies also have found physician-patient end-of-life communication to be limited.

### *Between-Country Differences*

The greater discussion of end-of-life issues in The Netherlands, and to a lesser extent in Belgium, than other European countries has been partially attributed to the open public debate of all aspects of end-of-life care brought about by the process of legalization of euthanasia.<sup>67,68</sup> Dutch GPs also are said to have a discussion-led practice, prioritizing discussion of problems and associated psychosocial issues.<sup>69</sup> Less frequent end-of-life discussions in Italy and Spain, and to a lesser extent in Belgium,

also may be partially explained by more limited diagnosis disclosure, hindering the discussion of other end-of-life topics.<sup>12,66,69–72</sup> Limited disclosure in Italy and Spain has been attributed to the greater importance given to beneficence than autonomy in clinical practice; physicians avoid discussions that cause patients distress and prioritize the maintenance of hope.<sup>71,73,74</sup>

Between-country differences also may reflect country-specific differences in service organization. In The Netherlands, GPs have a high degree of personal responsibility for end-of-life care, which they provide alone or in consultation with a mobile palliative care team.<sup>28,36</sup> In Belgium and Spain, however, provision is more often shared with palliative care home teams.<sup>30,33,34</sup> In Italy, multidisciplinary home teams provide most palliative care.<sup>30,75</sup> Italian GPs coordinate and provide palliative care in primary care–based home teams<sup>30,31</sup> but not in hospital-based teams<sup>30</sup> (Table 1). Access to and provision of end-of-life care is strongly supported by law or health care policy in The Netherlands, Belgium, and Spain (Table 1). In contrast, access to palliative care only became a legal right in Italy in 2010;<sup>15</sup> and, although palliative care is mentioned in the National Health Plan,<sup>20</sup> there is no national strategy.

Finally, an additional explanation for the between-country variation concerns physicians' training in palliative care. A survey of physicians from Belgium, Denmark, Italy, The Netherlands, Sweden, and Switzerland revealed that 48%, 63%, and 91% of Italian, Belgian, and Dutch GPs, respectively, had ever had any specific palliative care training.<sup>76</sup> Training in palliative care is not, however, compulsory for GPs in any of the four countries, and the amount of training undertaken can vary greatly among GPs.

### *Patient and Care Characteristics*

Although the frequency of end-of-life communication differed between countries, the overall significance, magnitude, and direction of patient and care factors associated with discussions were remarkably similar. The GPs from all countries tended to discuss fewer topics with older patients, noncancer patients, patients diagnosed with dementia, patients for whom palliative care was not an important

treatment aim, and patients for whom the GP had not provided palliative care.

These findings resonate with those of previous studies: qualitative studies show that older patients receive less time and information during the patient-physician encounter;<sup>77,78</sup> survey studies reveal that dementia patients are less likely to receive timely end-of-life discussions;<sup>45,49</sup> and reviews of the literature highlight that patients suffering from non-malignant conditions receive less end-of-life information, primarily because of their less predictable illness trajectories and difficulties prognosticating the end-of-life phase.<sup>2,79</sup>

The results also reflect broader problems of the recognition of palliative care needs and access to palliative care for older patients and those with nonmalignant diseases.<sup>80,81</sup> Indeed, the most important care characteristics across the four countries associated with end-of-life discussions were GP palliative care provision and the importance of palliative care as a treatment aim. The effect of GP palliative care provision was particularly pronounced in The Netherlands and may reflect the greater individual responsibility Dutch GPs have in the provision of palliative care.

### *Strengths and Limitations*

As more than 95% of the population in each of the four countries surveyed is registered with a GP,<sup>82,83</sup> registrations by GP networks provided a population-based sample of nonsudden deaths. Furthermore, the retrospective, cross-sectional design enabled the identification of patients nearing the end of life, which is difficult if not infeasible in a prospective study.<sup>84</sup> The data were representative in terms of place of death when compared with national death certificate data. Cause of death was not compared because of concerns about the reliability of cause of death recording in death certificates;<sup>85,86</sup> place of death was considered a more objective measure. The use of an identical methodology in each country enabled direct comparison of data.

There are, however, several limitations. Although representative within those areas, the Spanish and Italian sentinel networks only covered specific regions. The Italian network was created especially for the end-of-life surveillance; therefore, members were less familiar with the data collection procedure. The

Spanish network collected data for one year only, resulting in a smaller sample and lower statistical power. Dutch nursing home residents were excluded from analyses, and there was a slight underrepresentation of nonsudden hospital deaths and people aged younger than 65 years in Belgium and women in The Netherlands. Some sudden deaths in hospitals also may have been missed by GPs in Spain and Italy. However, because of a lack of national data on place of death, this could not be tested.

In addition, socially desirable answers may have been provided for items that reflect on GPs' care competencies; high levels of GP provision of palliative care were reported in all four countries. Furthermore, what is understood by "palliative" care may differ not only between countries,<sup>87</sup> but also among GPs.<sup>88</sup> It is not possible to discern whether the provision of palliative care was, for example, understood as pain and symptom management or the holistic treatment of the patient's "total pain," encompassing psychosocial and spiritual aspects of suffering. Other limitations include the lack of GPs' characteristics, possible recall bias, and a reliance on GPs to report care in other settings (such as hospitals).

Furthermore, the study only reports which topics were discussed, and, indeed, what constitutes a discussion, according to the GP. Patients and physicians may differ in their perception of what constitutes the "discussion" of a certain topic. An issue reflected in previous research that has found that patients' and physicians' recall of topics discussed differs.<sup>89</sup> Patients also may have discussed some topics with other health, social, or spiritual care professionals. This article does not, therefore, represent the totality of end-of-life communication with patients. The findings do, however, support those of Cartwright et al.<sup>12</sup> whose survey of physicians from a range of specialties (anesthesiology, geriatrics, oncology, general practice, and so on) found that all end-of-life topics were discussed, in principle, most by Dutch and least by Italian physicians.

Finally, the study only examines the prevalence of discussions and provides no information on the quality of discussions or patients' desire for such discussions. Surveys, such as this one, are appropriate tools for mapping large-scale variations between countries and

over time. Such instruments can neither provide in-depth insights into the process of patient-physician communication nor the expectations and experiences of the actors involved within the context of their social and cultural realities; this is the territory of qualitative rather than quantitative research. This epidemiological approach to the study of social phenomena, however, can reveal differences that deserve further investigation in future research of both a qualitative and quantitative nature.

### **Conclusions**

Most end-of-life topics had been discussed with less than half of all patients in all countries, with the exception of The Netherlands. Dutch GPs discussed more topics on average and all topics more frequently than GPs from other countries. Across all four countries, there was a particularly low prevalence of discussion of spiritual/existential and social problems. To improve the discussion of these topics, it is essential that GPs are provided training on identifying and discussing spiritual and social problems.

The GPs from all countries tended to discuss fewer topics with older patients, noncancer patients, patients diagnosed with dementia, patients for whom palliative care was not an important treatment aim, and patients for whom their GP had not provided palliative care. Because of cognitive decline in patients with dementia, and difficulties prognosticating the end-of-life phase for patients with nonmalignant conditions, early and sensitive discussion of end-of-life issues is recommended.

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*Appendix***2009/2010 EURO SENTIMELC Registration Form****End-of-life care in Europe**

**a descriptive mortality follow-back study via  
representative Networks of General Practitioners**

**The standardized weekly registration form  
of the EURO SENTI-MELC study 2010**

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**BELGIUM**

Research Partner End-of-Life Care Research Group, Vrije Universiteit Brussel

In collaboration with the Huisartsenpeilpraktijken i.e. the Belgian Sentinel Network of General Practitioners, coordinated by the Institute of Public Health, Department of Epidemiology

**THE NETHERLANDS**

Research Partner VU University Medical Center, and EMGO Institute

In collaboration with the Huisartsenpeilstations, the Dutch Sentinel Network of General Practitioners, coordinated by the NIVEL Institute

**ITALY**

Research Partner ISPO, University of Florence

In collaboration with the Italian Society for General Medicine

**SPAIN**

Sentinel Network of General Practitioners of Junta de Castilla y León,  
co-ordinated by Consejería de Sanidad

Please contact the EURO SENTIMELC Research Group Coordination  
if you want to use this instrument, in full or individual items,  
or if you want to adapt it to your local circumstances:

Contact address:

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Tel +32 2 477 43 10 - Fax +32 2 477 47 11 - [www.endoflifecare.be/ZrL](http://www.endoflifecare.be/ZrL)

[lvdblock@vub.ac.be](mailto:lvdblock@vub.ac.be)

**REGISTRATION OF ALL DEATHS OF PATIENTS (aged 1 year or older) WHO ARE PART OF YOUR (GROUP) PRACTICE**

1. Your reference (e.g. initials) : .....

2. Date of birth : . . . / . . . / . . . . .

3. Date of death : . . . / . . . / 2 0 1 0

4. Gender :  M  F

5. Postal code of patient's usual place of residence

6. Where did the patient reside the longest in his/her last year of life?  
 at home or living with family  care home(nursing home/home for elderly persons)  other (namely) .....

7. Cause of death\*: Illness or disorder that was the direct cause of death: State below under (a) the logical association of the illnesses/disorders that resulted in the immediate cause of death. If more than one illness, state the illness that was the "original cause of death" last. \*This is not the way in which the patient died, e.g. heart failure, syncope, etc. ... but the illness, the trauma or the complication that caused the death. Please mention only one cause per line.  
 (a) .....  
 Caused by : (b) .....  
 Caused by : (c) .....  
 Caused by : (d) .....

see instructions for examples

8. Did you or another doctor determine the diagnosis of dementia ?  yes, severe dementia  yes, mild dementia  no  unknown

9a. The **place of death** of the patient and **place(s) of residence** during the **last 3 months (=90 days) before death**, as well as the duration of stay in **days** (approximately if not precisely known). If the patient remained in the same place until death, only fill in Place 1.

	see instructions for examples	at home or living with family (incl. service flat)	care home : home for the elderly / nursing home	hospital (excl. pall. care unit, and excl. nursing home unit in hospital)	palliative care unit	elsewhere please specify
the last 3 months before death		<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days
1 place of <b>déath</b> and duration of stay		<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days
2 place of <b>déath</b> and duration of stay		<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days
3 place of <b>déath</b> and duration of stay		<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days
4 place of <b>déath</b> and duration of stay		<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days	<input type="checkbox"/> . . . . days

9b. To be filled in **ONLY IF THE PATIENT WAS MOVED** one or more times during the final three months of life: for what reason(s) was the patient **moved to the place where s/he died?** (More than one answer can be given)  
 it was the wish of the patient  
 it was the wish of the patient's family or significant other(s)  
 the patient needed (more) palliative care or palliative treatment(s)  
 the patient needed curative or life-prolonging treatment(s)  
 the patient did not need further treatment in that setting  
 other (please specify) : .....

10. How often, on average, did you have **contact** (consultations, home visits, excl. telephone contact) with the patient or with significant others regarding the patient?  

<b>last week before death</b>	<b>2<sup>nd</sup> to 4<sup>th</sup> week before death</b>	<b>2<sup>nd</sup> and 3<sup>rd</sup> month before death</b>
. . . x per <b>week</b>	. . . x per <b>week</b>	. . . x per <b>month</b>

11. Were the following topics addressed during **your conversations with the patient?** (1 answer per line)

	yes	no	not applicable
A primary diagnosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B incurability of the illness .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C life expectation .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D possible medical complications .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E physical complaints .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F psychological problems (i.e., sadness, worry, fear) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G social problems (i.e., relationship problems, lack of social support from family/friends, family unable to accept situation, etc.) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H spiritual/existential problems (i.e., difficulty in accepting the situation, trouble with the meaning of life, angry at God, etc.) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I options for palliative care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J burden of treatments .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. How **important** do you think the following aspects were in the care of this patient?

	1=not at all important	5=very important	?=unknown
	1	2 3 4 5 ?	?
treatment aimed at <b>cure</b> .....		1 2 3 4 5 ?	1 2 3 4 5 ?
treatment aimed at <b>prolonging life</b> .....		1 2 3 4 5 ?	1 2 3 4 5 ?
treatment aimed at <b>comfort/palliation</b> .....		1 2 3 4 5 ?	1 2 3 4 5 ?

13. Within the **last week** of life, was the patient capable of making decisions?  
 yes  sometimes  no  unknown

14a. Did **you** provide palliative care to this patient?  yes, until death  yes, but not until death  no

14b. Which **palliative care initiatives** were involved in the last 3 months of this patient's life?  
*(More than one answer can be given)*

- palliative homecare team
- mobile palliative care support team in a hospital
- palliative care unit (hospital)
- reference persons\* for palliative care in a care home
- palliative day care centre
- other (namely) : .....
- none
- unknown

14c. Estimate the number of days between the **first palliative intervention and the moment of death**  ..... days

\*(coordinating and advisory physician and/or reference nurse)

15. How difficult was it for the **patient and his/her family** to cover the **costs** of the care in the last three months of the patient's life?  
 very difficult  somewhat difficult  not difficult at all  don't know  patient did not need care

16. Did the **informal caregivers** feel **overburdened** (physically or emotionally) in the last three months of the patient's life?  
 yes  no  don't know  there were no informal caregivers

17. Were you informed (verbally or in writing) of the patient's preference regarding place of death? *(More than one answer can be given)*

- YES  by the patient him/herself
- by the patient's family or significant other
- other (namely) : .....

If **YES**, where did this patient prefer to die?

- at home or living with family (incl. service flat)
- in a care home
- in hospital (excl. palliative care unit, and excl. nursing home unit in hospital)
- palliative care unit (hospital)
- elsewhere (namely) : .....

NO

18. Did the **patient** ever express specific **wishes** about a medical treatment that he/she would or would not want in the final phase of life?  
 yes  no  unknown

If **YES**,

a) Did you ever speak to the patient about these wishes?  yes  no

b) Within the last week of life, was there any medical procedure or treatment that was inconsistent with previously stated wishes?  
 yes  no  unknown

19. 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**? *(More than one answer can be given)*

- yes, in writing
- yes, verbally
- no
- unknown

If **YES**,

a) Did **you** ever speak to the patient about these wishes?  yes  no

b) If the situation did arise, was this person consulted?  yes  no  unknown  situation did not arise

20. Did the patient have the following symptoms during the last week prior to death?  
*(Please circle the most appropriate answer)*

	Yes No Unknown			If <b>YES</b> , <b>how much</b> did that <b>distress</b> the patient?					
				not at all	a little bit	somewhat	quite a bit	very much	unknown
A lack of appetite .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
B lack of energy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
C pain .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
D feeling drowsy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
E constipation .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
F dry mouth .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>
G difficulty breathing .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	<input type="checkbox"/>

If **YES**, **how often** did the patient appear to feel this way?

	rarely	occasionally	frequently	almost constantly	unknown
H feeling sad .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worrying .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J feeling irritable .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K feeling nervous .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. Was **death sudden and totally unexpected**?  yes  no

22. Was the patient suffering from a life-threatening illness or condition (incl. coma) OR from serious health problems associated with old age?  
 yes  no