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Primary palliative care for older people in three European countries: a mortality follow-back quality study

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ABSTRACT

Background Many older people with serious chronic illnesses experience complex health problems for which palliative care is indicated. We aimed to examine the quality of primary palliative care for people aged 65–84 years and those 85 years and older who died non-suddenly in three European countries.

Methods This is a nationwide representative mortality follow-back study. General practitioners (GPs) belonging to epidemiological surveillance networks in Belgium (BE), Italy (IT) and Spain (ES) (2013–2015) registered weekly all deaths in their practices. We included deaths of people aged 65 and excluded sudden deaths judged by GPs. We applied a validated set of quality indicators.

Results GPs registered 3496 deaths, of which 2329 were non-sudden (1126 aged 65–84, 1203 aged 85+). GPs in BE (reference category) reported higher scores than IT across almost all indicators. Differences with ES were not consistent. The score in BE particularly differed from IT on GP–patient communication (aged 65–84: 61% in BE vs 20% in IT (OR=0.12, 95% CI 0.07 to 0.20) aged 85+: 47% in BE vs 9% in IT (OR=0.09, 95% CI 0.05 to 0.16)). Between BE and ES, we identified a large difference in involvement of palliative care services (aged 65–84: 62% in BE vs 89% in ES (OR=4.81, 95% CI 2.41 to 9.61) aged 85+: 61% in BE vs 77% in ES (OR=3.1, 95% CI 1.71 to 5.53)).

Conclusions Considerable country differences were identified in the quality of primary palliative care for older people. The data suggest room for improvement across all countries, particularly regarding pain measurement, GP–patient communication and multidisciplinary meetings.

INTRODUCTION

There is a rising number of deaths in old age¹ accompanied by serious chronic conditions, such as cardiovascular diseases, cancer and dementia.² Many older people are affected by multimorbidity, which

is the simultaneous presence of multiple chronic conditions.³ The end of life of older people is thus often characterised by complex health problems, symptoms and disabilities that require palliative care.⁴ According to the WHO, palliative care aims to improve the quality of life of patients with a life-threatening disease.⁵ Yet, concerns have been raised about the access to palliative care for older people, especially in primary care, as most approaching the end of life wish to be cared for and to die in their usual place of care.^{6–8} Evidence shows that older people who are dying from serious chronic conditions may be receiving poor end-of-life care, such as poor communication regarding wishes and preferences for care and care planning.^{1 4 9–13} Similarly, access to palliative care and symptom control is increasingly problematic in old age.¹⁰

Despite these concerns, there is insufficient population-based data to assess the quality of palliative care for older people dying from serious chronic conditions and to determine whether there are specific patient groups or care domains where improvements in quality can be made. In particular, there are few cross-national studies that permit comparison of the quality of palliative care in different healthcare systems. This precludes evidence-informed policy-making to ensure high-quality palliative care for older people. Existing population-based studies assessing the quality of palliative care for older people focus on the last week of life only¹⁴ or are limited to a particular diagnosis such as cancer¹⁴ or dementia,¹⁵ thereby excluding large groups of older people for whom palliative care may also be relevant.

Measuring the quality of palliative care is complicated because palliative care often involves multiple healthcare professionals

in various disciplines and healthcare settings, has a multidimensional nature and is integrated within a larger spectrum of healthcare services.^{16 17} In many countries, general practitioners (GPs) have a good view of the care their patients received from them and other healthcare providers, hence our use of representative epidemiological surveillance networks based on general practice provides an important opportunity for evaluation.¹⁸

The systematic evaluation of quality can be achieved by using a core set of quality indicators defined as 'measurable items referring to the outcomes, processes, or structure of care'¹⁹ judged as critical in the evaluation of the quality of palliative care.^{16 20} The quality indicators assessed in general practice can therefore measure quality across different settings as delivered by various healthcare professionals and can be used to capture the quality of care on an aggregated, for example, national, level.¹⁹

We conducted this study in three countries, Belgium, Italy and Spain. All three countries have legislation and/or national strategies for primary palliative care provision,^{21–23} but there are also important differences in the way primary palliative care is organised. For instance, GPs in Spain fulfil a gatekeeping function to specialist palliative care services.¹⁸ In Belgium and Italy, GPs have a partial gatekeeping function in that their referral is required for certain specialist palliative care services (such as specialist palliative home care in Belgium) but not for others (eg, involvement of a mobile palliative care team in the hospital).¹⁸ GPs in Belgium and Italy still have an important coordinating role within healthcare, and most people in these countries have a GP whom they consult regularly.¹⁸ Furthermore, there are differences between these countries in how certain aspects of dying and palliative care are approached that may impact on the quality of primary palliative care.²⁴ This includes, but is not limited to, communication about end-of-life, disclosure of diagnosis and prognosis and reliance on family care.²⁴

The overall aim of this study was to answer the following research question: what is the quality of primary palliative care for people aged 65–84 years and those 85 years and above who died non-suddenly in Belgium, Italy and Spain?

METHODS

Study design and procedure

The data were collected as part of the European Sentinel General Practitioner Networks Monitoring End-of-Life Care (EURO-SENTIMELC) study, which was a cross-national mortality follow-back study that monitored end-of-life care in population-based samples of deceased people.¹⁸ The data were collected through nationwide sentinel networks of GPs. In Belgium and Spain, these are existing regional and national epidemiological surveillance networks consisting of representative samples of GP practices or community-based

physicians. In Italy, a new network was formed for this study by the Italian Society of General Practitioners through a procedure similar to that in the other countries; GPs were only informed about the procedure and not about the subject of the surveillance in order to avoid over-representation of those with a particular interest in palliative care. The networks in Belgium and Italy were nationwide; in Spain we collected data only from two autonomous regions: the Valencian Community and Castile and Leon.

All deaths of patients aged 18 years or older were registered weekly by the participating GPs using a standardised registration form and classified as sudden and totally unexpected or non-sudden, a common method in palliative care research for retrospectively identifying people for whom palliative care was a realistic option.^{25 26} In Belgium and Spain, this was done from January 2013 to December 2014 and in Italy from June 2013 until May 2015.

Setting and participants

We included deaths of patients who were 65 years or older which were non-sudden as judged by the GP.

Measurements

The standardised registration form consisted of open-ended and closed-ended items. As well as assessing quality indicators, it asked about patient characteristics such as age, sex, primary cause of death, dementia diagnosis, main place of residence in the last year of life and place of death.

Main outcome measure: quality indicators

The quality indicators used in this study are based on the work of Leemans *et al.*²⁷ They measured the quality of palliative care services by assessing nine important domains of palliative care (ie, physical, psychosocial, communication with patients, communication with relatives, multidisciplinary consultation, type of end-of-life care, continuity of care, support for relatives and structure of care). From that set, the EURO-SENTIMELC consortium selected those applicable to primary care and reformulated them into questions suitable to be answered by GPs. The questions underwent review by primary palliative care experts from Belgium, Italy, Spain, France and the Netherlands and were then ranked; those with a score of at least 7.5 (scale 1–10) remained, ensuring that there was at least one question per domain of quality indicators of palliative care. The quality indicators were selected through a multistep process which can be found elsewhere.^{15 28} The final core set consisted of nine quality indicators, of which two (3.1 and 4) cover the third palliative care domain:

1: Percentage of patients whose pain was known by the GP to be monitored regularly during the last 3 months of life.

2: Percentage of patients known by the GP to have accepted that they were nearing the end of life.

3.1 and 4: Extent to which patients and relatives receive information from the GP about diagnosis, prognosis, disease progression, advantages and disadvantages of treatments and palliative care options.

3.2: Percentage of patients who expressed a specific wish about a medical treatment.

5: Repeated (on several occasions) formal multidisciplinary consultation with and between care providers (between settings, including GP) about care goals and palliative care option.

6: Percentage who received palliative care services²⁹ involved in last 3 months of life.

7: Percentage who did not die in a regular hospital unit.

8: Percentage for whom the GP contacted or planned to contact the relatives regarding bereavement counselling.

Statistical analyses

Differences between countries in characteristics and quality indicator scores of those aged 65–84 years

and those aged 85 years or older were analysed by using generalised linear mixed models (GLMMs) with country and potential confounders (patient characteristics that differed significantly between countries) as fixed effects and GP practice as random effect. Using GLMMs allows us to account for clustering of patient data within GP practices (possibility that one GP provided data on several patients). All analyses were completed with SPSS V.25.0.

Patient characteristics

GPs registered 3496 deaths, of which 2329 were non-sudden. The people aged 65–84 years (n=1126) were predominantly male and those aged 85 years and older (n=1203) were predominantly female (table 1). In both age groups, the majority did not have a diagnosis of dementia and significant differences between the countries were only found among those aged 65–84 years (p=0.003). In the last year of life, between 77% in Belgium and 93% in Spain of those aged 65–84 years resided at home (p=0.000), and 45% in Belgium to 88% in Italy of those aged 85 years and older resided at home (p=0.000). The most

Table 1 Patient characteristics (n=2329)

Patient characteristics	People aged 65–84 years (n=1126)			P value*	People aged 85 years and older (n=1203)			P value*
	Belgium (n=718)	Italy (n=254)	Spain (n=154)		Belgium (n=690)	Italy (n=342)	Spain (n=171)	
	n (%)	n (%)	n (%)		n (%)	n (%)	n (%)	
Mean age at death (SD)	76.7 (5.7)	77.7 (5.3)	77.3 (5.5)	0.080	90.1 (4.2)	90.5 (4.0)	90.7 (4.3)	0.140
Gender, female	337 (47.1)	123 (49.2)	55 (35.7)	0.020	462 (67.2)	230 (68.0)	103 (60.2)	0.320
Dementia diagnosis								
None	467 (69.5)	182 (72.2)	130 (86.1)	0.003	328 (50.2)	164 (48.8)	87 (52.1)	0.799
Mild	83 (12.4)	35 (13.9)	13 (8.6)		136 (20.8)	79 (23.5)	39 (23.4)	
Severe	122 (18.2)	35 (13.9)	8 (5.3)		190 (29.1)	93 (27.7)	41 (24.6)	
Longest place of residence in the last year of life								
At home	515 (77.3)	231 (92.0)	136 (92.5)	0.000	290 (45.0)	300 (88.2)	129 (75.9)	0.000
Care home†	151 (22.7)	20 (8.0)	11 (7.5)		354 (55.0)	40 (11.8)	41 (24.1)	
Main cause of death								
Cancer	348 (51.4)	121 (50.2)	104 (68.0)	0.015	160 (24.4)	53 (15.6)	39 (22.8)	0.014
Cardiovascular disease	89 (13.1)	40 (16.6)	14 (9.2)		172 (26.2)	126 (37.1)	45 (26.3)	
Nervous system disease	75 (11.1)	21 (8.7)	7 (4.6)		75 (11.4)	32 (9.4)	21 (12.3)	
Respiratory disease	54 (8.0)	26 (10.8)	6 (3.9)		72 (11.0)	43 (12.6)	9 (5.3)	
Stroke (CVA)	39 (5.8)	12 (5.0)	3 (2.0)		61 (9.3)	34 (10.0)	18 (10.5)	
Other	72 (10.6)	21 (8.7)	19 (12.4)		116 (17.7)	52 (15.3)	39 (22.8)	

People aged 65–84 years: Missing data, n (%): gender, 6 (0.5), dementia diagnosis, 51 (4.5), longest place of residence in the last year of life, 62 (5.5), main cause of death, 55 (4.9).

People aged 85 years and older: Missing data, n (%): gender, 7 (0.6), dementia diagnosis, 46 (3.8), longest place of residence in the last year of life, 49 (4.1), main cause of death, 36 (3.0).

*Tested for differences between countries using generalised linear mixed models to account for clustering at general practitioner level.

†Includes care/nursing homes, 'elsewhere' not included in the analysis.

CVA, cerebrovascular accident; SD, standard deviation.

common cause of death in those aged 65–84 years was cancer ($p=0.015$) and of those aged 85 years and older was cardiovascular diseases ($p=0.014$).

Quality of primary palliative care in Belgium, Italy and Spain

Higher quality indicator scores were reported in Belgium than in Italy in both age groups (table 2). Exceptions are discussions between GPs and family of illness-related topics (aged 65–84: 76% in Belgium vs 82% in Italy (OR=1.50, 95% CI 0.90 to 2.49); aged 85+: 81% in Belgium vs 83% in Italy (OR=1.17, 95% CI 0.72 to 1.90)) and bereavement counselling (aged 65–84: 68% in Belgium vs 68% in Italy (OR=1.29, 95% CI 0.73 to 2.29); aged 85+: 64% in Belgium vs 69% in Italy (OR=0.93, 95% CI: 0.54 to 1.63)). We found a difference in discussions between GPs and patients regarding illness-related topics for more patients in Belgium than in Italy (aged 65–84: 61% in Belgium vs 20% in Italy (OR=0.12, 95% CI 0.07 to 0.20); aged 85+: 47% in Belgium vs 9% in Italy (OR=0.09, 95% CI 0.05 to 0.16)). Among those aged 65–84 years, we also found a difference for the quality indicator regarding GP awareness of patient preferences about medical treatments (44% in Belgium vs 15% in Italy (OR=0.16, 95% CI 0.10 to 0.27)). Among those aged 85 years and older, there were differences in the quality indicators on involvement of palliative care services in the last month of life (61% in Belgium vs 18% in Italy (OR=0.18, 95% CI 0.11 to 0.30)) and pain measurement in the last 3 months of life (45% in Belgium vs 15% in Italy (OR=0.20, 95% CI 0.11 to 0.39)).

We also identified important differences between Belgium and Spain in involvement of palliative care services in the last 3 months of life (aged 65–84: 62% in Belgium vs 89% in Spain (OR=4.81, 95% CI 2.41 to 9.61); aged 85+: 61% in Belgium vs 77% in Spain (OR=3.1, 95% CI 1.71 to 5.53)) (table 2). In those aged 65–84 years, we found differences for the quality indicator on GP awareness of patient preferences about medical treatments (44% in Belgium vs 18% in Spain (OR=0.18, 95% CI 0.11 to 0.31)) and in those aged 85 years and older on multidisciplinary consultations during the last month of life (38% in Belgium vs 10% in Spain (OR=0.15, 95% CI 0.08 to 0.30)).

DISCUSSION

In both age groups, for almost all quality indicators, higher scores were found for Belgium than Italy, and fewer consistent differences were found between Belgium and Spain. GPs in all countries reported relatively low scores on pain measurement in the last 3 months of life, discussions between GPs and patient, and multidisciplinary consultations during the last month of life. At the same time, relatively high scores were reported in all countries regarding discussions

between GP and family of illness-related topics and bereavement counselling.

The three countries in the study have palliative care frameworks and strategies that specify standards and aims regarding the organisation and provision of palliative care^{21–23}; however, having frameworks and strategies alone is not enough to achieve high-quality palliative care. We identified that the overall quality of primary palliative care for the older population in Italy was considerably lower than in Belgium. The relatively high scores in Belgium may be explained by the well-established palliative home care teams and region-wide palliative care networks that promote collaboration and sharing of knowledge and expertise with GPs.^{30 31} In Italy, on the other hand, palliative home care is still mainly provided to people with cancer,³² which may contribute to lower quality indicator scores for the population included in this study. The differences between Belgium and Spain were not consistently in the same direction. In Spain, we identified relatively high-quality indicator scores on the involvement of specialised palliative care services in the last 3 months of life. In the last decade, considerable efforts have been made in Spain to expand palliative care services from patients with cancer to patients without cancer,^{33 34} with a close collaboration between GPs and palliative care services.³³ The differences in the scores on the involvement of specialised palliative care services are not necessarily concerning; GPs often provide palliative care themselves. However, this needs further research as we can expect exacerbations and complex situations among an older population where specialised advice and collaboration with the GP can be highly beneficial.

In all three countries, there is room for improvement in the quality of primary palliative care for the older population. This is an urgent matter given the rising number of people who are in need of palliative care, the current ageing of populations and trends in chronic morbidity.¹ We identified that pain was not regularly measured in the older population. This is concerning given that poor pain assessment has been cited as an important barrier to adequate pain control.³⁵ Research shows that pain is an important symptom in around a third of the older population,^{4 35 36}; it is therefore crucial that frequent comprehensive pain assessment is provided.³⁷

We found that in all countries more than half of GPs did not communicate with the patient (except for those aged 65–84 years in Belgium) regarding illness-related topics and were not aware of their preferences about medical treatments. These low scores may be influenced by the difficulty of prognosis in older people,³⁸ something seen as an important barrier to the initiation of discussion with the patient, that is, difficulties in deciding the ‘right’ time to broach the topic.³⁸ Decline in, for example, speech and cognition could also hinder communication³⁹ and cultural factors are also

Table 2 Quality indicator scores for people aged 65–84 years and people aged 85 years and older between Belgium, Italy and Spain (n=2329)

	People aged 65–84 years (n=1126)						People aged 85 years and older (n=1203)					
	Belgium (n=718)		Italy (n=254)		Spain (n=154)		Belgium (n=690)		Italy (n=342)		Spain (n=171)	
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	OR (95% CI)
1. Pain measured often or very often in last 3 months of life	318 (46.2)	58 (23.2)	87 (64.9)	2.75 (1.41 to 5.37)	303 (45.1)	50 (14.8)	75 (46.6)	0.20 (0.11 to 0.39)	1.94 (1.00 to 3.77)			
2. GP thinks that patient was able to accept their approaching end completely or for the most part*	393 (55.4)	98 (39.2)	69 (49.6)	0.70 (0.40 to 1.22)	423 (62.8)	167 (49.1)	64 (38.8)	0.44 (0.25 to 0.76)	0.27 (0.15 to 0.49)			
3.1. GP discussed at least three illness-related topics† with patient	381 (60.8)	50 (19.7)	44 (44.0)	0.28 (0.16 to 0.48)	254 (46.9)	32 (9.4)	21 (32.8)	0.09 (0.05 to 0.16)	0.49 (0.25 to 0.96)			
3.2. GP was aware of patient preferences about medical treatments	309 (43.5)	37 (14.6)	28 (18.4)	0.18 (0.11 to 0.31)	235 (34.3)	39 (11.6)	19 (11.2)	0.21 (0.12 to 0.35)	0.20 (0.11 to 0.37)			
4. GP discussed at least three illness-related topics† with family	492 (76.4)	209 (82.3)	114 (86.4)	1.92 (1.03 to 3.57)	514 (81.2)	282 (82.5)	127 (82.5)	1.17 (0.72 to 1.90)	1.19 (0.67 to 2.10)			
5. Multidisciplinary consultation at least once a week during the last month of life	246 (35.2)	46 (18.5)	35 (25.9)	0.38 (0.23 to 0.63)	259 (38.4)	44 (13.1)	16 (10.0)	0.29 (0.17 to 0.52)	0.15 (0.08 to 0.30)			
6. Palliative care services involved in last 3 months of life	407 (62.3)	113 (48.1)	112 (88.9)	4.81 (2.41 to 9.61)	376 (60.5)	57 (18.3)	102 (77.3)	0.18 (0.11 to 0.30)	3.1 (1.71 to 5.53)			
7. Patient did not die in hospital‡	468 (66.5)	162 (63.8)	88 (61.1)	0.94 (0.59 to 1.48)	507 (74.9)	246 (72.4)	109 (67.3)	1.71 (1.18 to 2.48)	1.02 (0.66 to 1.57)			
8. GP contacted or plans to contact relatives about bereavement counselling	482 (68.2)	170 (67.7)	109 (72.7)	1.29 (0.73 to 2.29)	436 (64.1)	229 (68.6)	112 (67.1)	0.93 (0.54 to 1.63)	0.97 (0.55 to 1.73)			

Reference group=Belgium.

Tested for the differences between countries using generalised linear mixed models to account for clustering at general practitioner level and to adjust for patient characteristics that differed between the countries. People aged 65–84 years: Missing data, n (%): Pain measured, 53 (4.7), accepted death, 27 (2.4), discussion with patient, 145 (12.9), preference medical treatments, 10 (0.9), discussion with family, 96 (8.5), multidisciplinary consultation, 44 (3.9), palliative care services involved, 112 (9.9), place of death, 24 (2.1), bereavement counselling, 18 (1.6).

People aged 85 years and older: Missing data, n (%): Pain measured, 32 (2.7), accepted death, 24 (2.0), discussion with patient, 255 (21.2), preference medical treatments, 11 (0.9), discussion with family, 74 (6.2), multidisciplinary consultation, 31 (2.6), palliative care services involved, 138 (11.5), place of death, 24 (2.0), bereavement counselling, 22 (1.8).

*Excluded 'don't know' (people aged 65–84 years, 293, people aged 85 years and older, 387).

†Regular hospital wards excluding palliative care units.

‡CI, confidence interval; GP, general practitioner; OR, odds ratio.

likely to influence it; in several countries, including Italy, partial or non-disclosure in advanced diseases is still common.²⁴

GPs in all countries reported relatively high scores on communication with the family carer. As most people resided at home in the last year of life, especially in Italy and Spain, it seems that the family carer was highly involved in care and that GPs tend to communicate with them as an alternative to communicating with the patient.

The complex needs and problems of older people require joint working and interdisciplinary collaboration between different healthcare professionals.⁴ In our study, we identified that for most people there were no regular multidisciplinary meetings conducted in the last month of life (ie, fewer than one a week). As multidisciplinary meetings are crucial in facilitating interdisciplinary collaboration,⁴⁰ they should be conducted regularly. In Spain and Belgium, efforts have been made to encourage and provide guidance in facilitating interdisciplinary collaboration.^{41,42} The Spanish Association of Palliative Care (SECPAL) developed a model recommending multidisciplinary meetings, but does not yet provide a clear guidance on how to organise such meetings.⁴¹ The Belgian Healthcare Knowledge Centre (KCE) has developed a position paper that makes recommendations for organising these meetings in an efficient manner, such as by using a shared care plan or a shared patient medical record.⁴² In addition, appointing a key person responsible for organising such multidisciplinary meetings could improve their quality.⁴⁰

Strengths and limitations

To our knowledge, this is the first cross-national population-based study using a validated minimum quality indicator set to measure the quality of primary palliative care for older people. We used existing sentinel networks of GPs in the three European countries and therefore obtained samples of deaths representative for the GP population in the three countries.¹⁸ Another strength is that GPs conducted registrations weekly, limiting recall bias.¹⁸ The identification of non-sudden deaths as denominator is an advantage compared with including patients who died suddenly and unexpectedly because the patients who died non-suddenly were likely to have received palliative care. Our study also has limitations. We used only GP estimations of the care provided by themselves and not by others, so misclassifications might have occurred. Future studies should consider to also include the views of other healthcare professionals who are important providers of generalist palliative care, such as district and community nurses.

CONCLUSION

This study found that there are considerable cross-country differences in the quality of primary palliative

care for older people, probably reflecting different healthcare systems and cultures. Our findings show that the overall quality of primary palliative care for older people could be improved. Initiatives are needed to support regular pain measurement, communication between GP and patient and frequent multidisciplinary meetings in the last month of life. These focal points should become a priority for policy-makers and healthcare professionals, given the rising number of older people in need of palliative care.

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