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## Burden on family carers and care-related financial strain at the end of life: a cross-national population-based study

Lara Pivodic<sup>1</sup>, Lieve Van den Block<sup>1</sup>, Koen Pardon<sup>1</sup>, Guido Miccinesi<sup>2</sup>, Tomás Vega Alonso<sup>3</sup>, Nicole Boffin<sup>4</sup>, Gé A. Donker<sup>5</sup>, Maurizio Cancian<sup>6</sup>, Aurora López-Maside<sup>7</sup>, Bregje D. Onwuteaka-Philipsen<sup>8</sup>, Luc Deliens<sup>1,8</sup>, on behalf of EURO IMPACT

1 End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, Brussels, Belgium

2 Cancer Prevention and Research Institute (ISPO), Florence, Italy

3 Public Health Directorate, Ministry of Health, Autonomous Community of Castile and Leon, Valladolid, Spain

4 Scientific Institute of Public Health, Brussels, Belgium

5 NIVEL, Netherlands Institute for Health Services Research, Utrecht, The Netherlands

6 SIMG, Italian College of General Practitioners, Florence, Italy

7 Public Health General Directorate, Health Department, Valencian Community, Valencia, Spain

8 Department of Public and Occupational Health, EMGO+ Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

**Correspondence:** Lara Pivodic, End-of-Life Care Research Group, Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Laarbeeklaan 103, 1090 Brussels, Belgium, Tel: +32 2 477 4754, Fax: +32 2 477 4752, e-mail: [lara.pivodic@vub.ac.be](mailto:lara.pivodic@vub.ac.be)

**Background:** The rising number of deaths from cancer and other life-limiting illnesses is accompanied by a growing number of family carers who provide long-lasting care, including end-of-life care. This population-based epidemiological study aimed to describe and compare in four European countries the prevalence of and factors associated with physical or emotional overburden and difficulties in covering care-related costs among family carers of people at the end of life. **Methods:** A cross-national retrospective study was conducted via nationwide representative sentinel networks of general practitioners (GPs). Using a standardized form, GPs in Belgium, The Netherlands, Italy and Spain recorded information on the last 3 months of life of every deceased adult practice patient (1 January 2009–31 December 2010). Sudden deaths were excluded. **Results:** We studied 4466 deaths. GPs judged family carers of 28% (Belgium), 30% (The Netherlands), 35% (Spain) and 71% (Italy) of patients as physically/emotionally overburdened ( $P < 0.001$ ). For 8% (Spain), 14% (Belgium), 36% (The Netherlands) and 43% (Italy) patients, GPs reported difficulties in covering care-related costs ( $P < 0.001$ ). Patients <85 years of age (Belgium, Italy) had higher odds of having physically/emotionally overburdened family carers and financial burden. Death from non-malignant illness (vs. cancer) (Belgium and Italy) and dying at home compared with other locations (The Netherlands and Italy) were associated with higher odds of difficulties in covering care-related costs. **Conclusion:** In all countries studied, and particularly in Italy, GPs observed a considerable extent of physical/emotional overburden as well as difficulties in covering care-related costs among family carers of people at the end of life. Implications for health- and social care policies are discussed.

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### Introduction

The number of deaths from cancer and other life-limiting illnesses is rising.<sup>1</sup> As a consequence, a growing number of people experience multiple and complex symptoms towards the end of life and require care over extended periods.<sup>2</sup> Taking into account economic factors, population ageing and critical shortages of professional resources,<sup>3</sup> it is unlikely that the need for palliative and end-of-life care in the population can be borne entirely by formal care. As a result, increasing demands will be put on family carers of people at the end of life, and their role will be further strengthened by the prevailing wish among people to die at home<sup>4</sup> and the implementation of health policies aimed at facilitating end-of-life care in the community.<sup>5–7</sup> Already today the economic value of the contribution of family carers in the UK is estimated to be considerably more than the cost of the National Health Service.<sup>8</sup>

The availability of and burden on family carers are increasingly pressing concerns for public health given the rising old-age dependency ratio, increasing geographic mobility, changes in traditional family structures, urbanization and the growing participation of women in the labour market.<sup>9–12</sup> The trend towards end-of-life care in the community may also put additional financial strain on patients at the end of life and on their families, as it is likely to cause a shift in cost burden away from public health care systems and towards patients and families.<sup>13</sup> Research indicates that family carers of dying people experience a wide range of unmet needs, physical and emotional strains and financial burden.<sup>14–16</sup>

Despite these challenges, population-based cross-national data on the extent of physical or emotional overburden and financial strain among family carers of people at the end of life are absent. This creates an obstacle for the nationwide planning and implementation of policies and programmes to support these families.<sup>12</sup> Existing population-based studies of the burden on family carers did not

look specifically at end-of-life care<sup>17</sup> or the samples were limited to patients with particular diagnoses such as cancer<sup>18</sup> or patients in receipt of specific health care services,<sup>13,18–20</sup> thereby excluding other large groups of people who also provide care for their dying family members.

Using nationwide representative epidemiological surveillance networks of general practitioners (GPs) in Belgium, The Netherlands, Italy and Spain, our study allowed us to evaluate the burden on family carers cross-nationally at a population-based level. International comparisons facilitate the identification of factors that are common across countries or country-specific, highlight where improvement is possible and guide policymaking nationally and internationally. This study addressed the following three research questions from the perspective of GPs in four European countries:

How many family carers of people in their last 3 months of life feel physically or emotionally overburdened and are there differences between countries?

How many patients and families experience problems in covering the costs of care in the last 3 months of life and are there differences between countries?

Are physical and emotional burdens on family carers and patients' and families' problems in covering the costs of care associated with patient-, health- and care-related characteristics?

## Methods

### *Study design and procedure*

This analysis is part of a cross-national, epidemiological, retrospective study monitoring end-of-life care in Belgium, The Netherlands, Italy and Spain.<sup>21</sup> From 1 January 2009 to 31 December 2010 (in Spain from 1 January 2010 to 31 December 2010), GPs belonging to sentinel general practice networks (epidemiological surveillance systems based on a representative sample of GPs) weekly registered all deaths of patients (aged  $\geq 18$  years) in their practice and described their demographic, health and care characteristics in the last 3 months of life using a standardized registration form. The GPs were asked to also include any information from hospital physicians and patient records. The last 3 months of life are widely accepted as a relevant period for studying end-of-life care.<sup>22,23</sup> The GPs of the Belgian and Dutch sentinel networks received a small annual fee for conducting the registrations on several topics; the GPs of the Italian network received a fee per completed registration form. The suitability of this study protocol for collecting population-based epidemiological data on end-of-life care has been demonstrated in previous studies, among which several reported cross-national comparisons.<sup>24–26</sup>

### *Study population*

The networks in Belgium and The Netherlands were nationwide with a population coverage of 1.8% and 0.8% in 2009 and 1.5% and 0.8% in 2010, respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of nine health districts spread across the country. The Spanish networks operated in two autonomous communities, the Valencian Community and Castile and Leon, covering 2.2% and 3.8%, respectively, of the respective regional populations aged  $\geq 18$  years. The participating GPs of all four countries had an adequate geographical distribution and were representative of the general population of GPs in the respective country (or region in Spain) with regard to sex and age.<sup>21</sup>

The participating GPs completed the registration form for each deceased patient aged  $\geq 18$  years. We excluded deaths that GPs had classified as sudden and totally unexpected to obtain a sample of people for whom end-of-life care was a realistic option.<sup>27</sup> We also excluded nursing home deaths from The Netherlands, as nursing

home residents in this country are not attended by GPs but by specialized nursing home physicians.

### *Measurement*

The standardized registration form consists of 21 structured closed-ended items and is available in Dutch, French, Italian, Spanish and English. Family carers' physical or emotional overburden was assessed with the question, 'Did the family carers feel overburdened (physically or emotionally) in the last 3 months of the patient's life?' (a) yes, (b) no, (c) don't know and (d) there were no family carers. Difficulty in covering costs of care was determined from the question, 'How difficult was it for the patient and his/her family to cover the costs of care in the last 3 months of the patient's life?' (a) very difficult, (b) somewhat difficult, (c) not difficult at all, (d) don't know and (e) the patient did not need care. We also collected information on the patient's age, sex, cause of death, longest place of residence in the last year of life, place of death and whether they had been attended to by specialist palliative care providers.

### *Statistical analysis*

We compared the characteristics of the samples in the four countries using Pearson's chi-squared tests or Fisher's exact tests if  $\geq 20\%$  of the expected cell frequencies were  $< 5$ . Age was grouped as 18–64, 65–84 and  $\geq 85$  years, corresponding to commonly applied definitions of the old and oldest old,<sup>28</sup> and cause of death was dichotomized as cancer and non-cancer. For each country, we calculated the percentage of carers feeling physically or emotionally overburdened and the percentage of patients and families experiencing difficulties in covering the costs of care. Differences between countries in carers' physical or emotional overburden (yes vs. no) and financial difficulties (not difficult vs. somewhat/very difficult) were examined using multivariate logistic regression analyses, adjusted for the sample characteristics that differed between countries. For each country, two multivariate logistic regression analyses were performed to determine whether age, sex, cause of death, place of death and specialist palliative care provision were associated with family carers feeling physically or emotionally overburdened (yes vs. no) on the one hand and difficulty in covering costs of care (not difficult vs. somewhat/very difficult) on the other. For all outcome variables, binomial 95% confidence intervals (CIs) were calculated, and all statistical tests were performed with a significance level of  $\alpha < 0.05$ . Analyses were performed in IBM SPSS Statistics version 20 and Microsoft Excel 2010.

### *Ethics*

The participating GPs gave written informed consent at the beginning of each registration year. Strict procedures were followed to ensure the anonymity of patients and physicians. Ethics approval for this study was obtained from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium (2004), and from the Local Ethical Committee 'Comitato Etico della Azienda U.S.L. n. 9 di Grosseto' in Tuscany, Italy (2008). Ethics approval was not required for the posthumous collection of anonymous patient data in The Netherlands and Spain.

## Results

The GPs reported 6858 deaths in the four countries and classified 4518 (65.9%) as expected or non-sudden. The percentage of non-sudden deaths was 67% in Belgium, 62% in The Netherlands, 66% in Italy and 69% in Spain. The exclusion of nursing home deaths from The Netherlands ( $n = 52$ , 7.6% of non-sudden deaths registered in The Netherlands) resulted in a sample of 4466 deaths of which

**Table 1** Characteristics of non-sudden deaths in Belgium, The Netherlands, Italy and Spain, *N* = 4466

Patient characteristics	Belgium <i>N</i> = 1604 <i>n</i> (%)	The Netherlands <i>N</i> = 635 <i>n</i> (%)	Italy <i>N</i> = 1839 <i>n</i> (%)	Spain <i>N</i> = 388 <i>n</i> (%)	<i>P</i> value <sup>a</sup>
Sex					0.04
Women	868 (54.3)	333 (53.0)	983 (53.5)	179 (46.1)	
Men	731 (45.7)	295 (47.0)	856 (46.5)	209 (53.9)	
Age at death (years)					<0.001
18–64	219 (13.8)	117 (18.4)	233 (12.7)	43 (11.1)	
65–84	753 (47.3)	318 (50.1)	860 (46.8)	174 (44.8)	
≥85	620 (38.9)	200 (31.5)	746 (40.6)	171 (44.1)	
Cause of death					<0.001
Cancer	595 (37.1)	335 (52.9)	830 (46.3)	149 (38.8)	
Non-cancer	1007 (62.9)	298 (47.1)	964 (53.7)	235 (61.2)	
Longest place of residence					<0.001
Home/with family	1048 (65.6)	491 (78.1)	1697 (92.7)	339 (88.3)	
Care home	508 (31.8)	135 (21.5)	111 (6.1)	40 (10.4)	
Other	42 (2.6)	3 (0.5)	22 (1.2)	5 (1.3)	
Place of death					<0.001
Home	367 (23.0)	276 (43.5)	846 (46.1)	188 (49.0)	
Care home	499 (31.2)	114 (18.0)	164 (8.9)	48 (12.5)	
Hospital	577 (36.1)	177 (27.9)	716 (39.0)	128 (33.3)	
PCU/Hospice	150 (9.4)	66 (10.4)	101 (5.5)	17 (4.4)	
Other	4 (0.3)	1 (0.2)	9 (0.5)	3 (0.8)	
Specialist palliative care					<0.001
Received	717 (46.6)	172 (29.0)	683 (38.9)	174 (44.8)	
Not received	822 (53.4)	422 (71.0)	1073 (61.1)	214 (55.2)	

a: Pearson chi-squared test.

Abbreviations: PCU = palliative care unit.

Missing values: sex: *n* = 12 (0.3%), age: *n* = 12 (0.3%), cause of death: *n* = 53 (1.2%), longest place of residence: *n* = 25 (0.6%), place of death: *n* = 15 (0.3%) and specialist palliative care: *n* = 189 (4.2%).

Percentages are within-country percentages. Percentages are rounded and therefore may not add up to 100.

1604 were registered in Belgium, 635 in The Netherlands, 1839 in Italy and 388 in Spain. The registered deaths were representative of all deaths in the countries studied, except for the excluded nursing home deaths in The Netherlands, a slight underrepresentation of hospital deaths and people <65 years of age in Belgium and women in The Netherlands.<sup>21</sup> Table 1 shows the characteristics of the samples of the four countries.

### Family carers feeling physically or emotionally overburdened

Of all patients who had a family carer according to the GP, GPs described the carers of 28% (Belgium), 30% (The Netherlands), 35% (Spain) and 71% (Italy) as physically or emotionally overburdened (Table 2). The percentages differed significantly between countries (adjusted *P* < 0.001).

### Difficulty for patients and family in covering the costs of care

GPs in Italy reported the highest (8%) and GPs in Spain the lowest (0.3%) proportion of families for whom covering the costs of care was 'very difficult' (Table 2). The highest percentage of families for whom GPs said that they did not have difficulties in covering the costs of care was found in Spain (73%).

### Characteristics associated with family carers feeling physically or emotionally overburdened and with difficulties in covering care-related costs

In Belgium and Italy, carers of patients <85 years of age had higher odds of being described as physically or emotionally overburdened

and as having difficulties in covering the costs of care (Table 3–6). Dying from cancer vs. non-malignant disease was not associated with GPs' reports of the physical or emotional overburden on carers in any of the countries studied. However, in Belgium and Italy, cancer patients and their families had lower odds than non-cancer patients of having difficulties in covering the costs of care. Furthermore, in Belgium and Italy, family carers were less likely to be described as physically or emotionally overburdened if the patient died in a care home as opposed to home. Difficulties in covering the costs of care were more frequently reported for patients who died at home as opposed to other locations in The Netherlands, and for patients who died at home or in a care home rather than in other locations in Italy. Involvement of specialist palliative care providers was associated with higher physical or emotional carer burden in all countries except in Spain and with higher financial burden for patients and families in The Netherlands and Italy.

## Discussion

This study found that GPs judged family carers of 28% (Belgium) to 72% (Italy) of patients at the end of life as feeling physically or emotionally overburdened. Difficulties in covering the costs of care were reported for 8% (Spain) to 43% (Italy) of patients. Patients' age, cause of death, place of death and specialist palliative care provision were associated with physical or emotional and financial burden, although these associations were not statistically significant in each of the four countries studied.

This is the first cross-national population-based study that described and compared the prevalence of physical or emotional overburden and financial strain among family carers of patients at the end of life, as reported by GPs. A recent position paper of the

**Table 2** Family carers feeling overburdened and difficulties for patient and family in covering the costs of care in the last 3 months of the patient's life according to the GP, *N* = 4466

Physical/emotional burden and financial strain	Belgium <i>N</i> = 1604		The Netherlands <i>N</i> = 635		Italy <i>N</i> = 1839		Spain <i>N</i> = 388		<i>P</i> value <sup>a</sup>
	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	
Family carer(s) feeling physically or emotionally overburdened according to GP <sup>b</sup>									<0.001
Yes	387	27.8 (25.4–30.2)	169	30.2 (26.4–34.0)	1205	70.9 (68.7–73.1)	125	34.8 (29.9–39.7)	
No	840	60.3 (57.8–62.9)	333	59.6 (55.5–63.7)	329	19.4 (17.5–21.3)	200	55.7 (50.6–60.8)	
Unknown <sup>c</sup>	165	11.9 (10.2–13.6)	57	10.2 (7.7–12.7)	166	9.8 (8.4–11.2)	34	9.5 (6.5–12.5)	
No family carer <sup>c</sup>	207	12.9 (11.3–14.5)	55	9.0 (6.7–11.3)	125	6.8 (5.6–8.0)	0	(0)	
Difficulties in covering costs of care according to GP <sup>d</sup>									<0.001
Very difficult	35	2.3 (1.5–3.1)	20	4.0 (2.3–5.7)	138	7.8 (6.6–9.0)	1	0.3 (0–0.9)	
Somewhat difficult	182	11.9 (10.3 to 13.5)	160	32.2 (28.1 to 36.3)	619	34.9 (32.7 to 37.1)	23	7.6 (4.6 to 10.6)	
Not difficult at all	901	58.9 (56.4–61.4)	215	43.3 (38.9–47.7)	775	43.7 (41.4–46.0)	220	72.6 (67.6–77.6)	
Unknown <sup>c</sup>	413	27.0 (24.8–29.2)	102	20.5 (17.0–24.0)	242	13.6 (12.0–15.2)	59	19.5 (15.0–24.0)	

a: *P* values based on multivariate analysis adjusted for age, sex, cause of death, place of death, and longest place of residence.

b: The denominator on which the percentages for 'yes', 'no' and 'unknown' are based is the number of patients who had family carers according to the GP.

c: Not included in multivariate analysis

d: Patients who did not need care according to the GP (BE: *n* = 69, 4.3%; NL: *n* = 120, 18.9%; IT: *n* = 49, 2.7%; and ES: *n* = 60, 15.5%) are not included.

Missing values: family carers overburdened: *n* = 69 (1.5%); difficulties in covering costs of care: *n* = 63 (1.4%).

Percentages are within-country percentages. Percentages are rounded and therefore may not add up to 100.

**Table 3** Belgium: factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last 3 months of life; two multivariate logistic regression analyses<sup>a</sup>

Patient-, health- and care characteristics	Family carer(s) feeling physically or emotionally overburdened <sup>b</sup>		Difficulties in covering costs <sup>c</sup>	
	<i>n</i> (%) <i>N</i> = 1182	OR (95% CI) <sup>d</sup>	<i>n</i> (%) <i>N</i> = 1080	OR (95% CI) <sup>d</sup>
Age (years)				
≥85	106 (22.3)	1.00	55 (12.8)	1.00
65–84	194 (35.1)	<b>1.42 (1.05–1.92)</b>	91 (18.2)	<b>1.49 (1.01 to 2.21)</b>
18–64	72 (46.8)	<b>1.84 (1.19–2.83)</b>	56 (37.6)	<b>4.36 (2.63–7.23)</b>
Sex				
Male	191 (35.4)	1.00	98 (20.1)	1.00
Female	181 (28.2)	0.96 (0.74–1.26)	104 (17.6)	0.99 (0.72–1.38)
Cause of death				
Non-cancer	193 (26.6)	1.00	117 (17.9)	1.00
Cancer	179 (39.2)	0.96 (0.70–1.31)	85 (19.9)	<b>0.65 (0.44–0.96)</b>
Place of death				
Home	135 (42.2)	1.00	59 (19.9)	1.00
Care home	55 (14.6)	<b>0.27 (0.18–0.40)</b>	40 (12.1)	0.69 (0.42–1.12)
Hospital	136 (36.1)	0.83 (0.61–1.14)	82 (24.0)	1.34 (0.90–1.99)
PCU/hospice	46 (42.2)	0.83 (0.52–1.32)	21 (18.6)	0.87 (0.48–1.57)
Specialist palliative care				
Not received	98 (25.7)	1.00	61 (17.7)	1.00
Received	274 (34.2)	<b>1.39 (1.04–1.86)</b>	141 (19.2)	1.23 (0.86–1.75)

a: Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

b: Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

c: Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

d: Odds ratios >1 indicate higher odds of carers feeling overburdened/higher odds of financial burden. Odds ratios in bold indicate statistically significant associations.

Abbreviations: OR = odds ratio.

Missing values: family carers overburdened: *n* = 69 (1.5%); difficulties in covering costs of care: *n* = 63 (1.4%), age: *n* = 12 (0.3%), sex: *n* = 12 (0.3%), cause of death: *n* = 53 (1.2%), place of death: *n* = 15 (0.3%), specialist palliative care: *n* = 189 (4.2%).

Percentages indicate proportions within the predictor variable.

European Forum for Primary Care stated that primary care practitioners have a crucial role in detecting, discussing and managing the burden of care for family carers.<sup>29</sup> Therefore, it is highly relevant for the planning and implementation of health and social care policies

and programmes to know how many families of patients at the end of life GPs identify as overburdened. Retrospective surveys are a well-established methodology for obtaining population-based information on a consistent period before death,<sup>30</sup> and using sentinel

**Table 4** The Netherlands: factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last 3 months of life; two multivariate logistic regression analyses<sup>a</sup>

Patient-, health- and care characteristics	Family carer(s) feeling physically or emotionally overburdened <sup>b</sup>		Difficulties in covering costs <sup>c</sup>	
	n (%) N=476	OR (95% CI) <sup>d</sup>	n (%) N=370	OR (95% CI) <sup>d</sup>
Age (years)				
≥85	41 (27.7)	1.00	46 (42.2)	1.00
65–84	92 (37.7)	1.38 (0.82–2.32)	93 (50.8)	1.67 (0.95–2.93)
18–64	27 (32.1)	1.11 (0.56–2.19)	36 (46.2)	1.40 (0.70–2.81)
Sex				
Male	91 (40.1)	1.00	74 (42.5)	1.00
Female	69 (27.7)	<b>0.57 (0.38–0.86)</b>	101 (51.5)	1.76 (0.13–2.75)
Cause of death				
Non-cancer	72 (34.8)	1.00	70 (46.7)	1.00
Cancer	88 (32.7)	0.78 (0.48–1.27)	105 (47.7)	0.68 (0.40–1.15)
Place of death				
Home	69 (30.4)	1.00	102 (54.8)	1.00
Care home	23 (28.7)	1.15 (0.60–2.20)	27 (42.9)	<b>0.51 (0.27–0.99)</b>
Hospital	45 (39.1)	<b>1.82 (1.07–3.11)</b>	31 (36.9)	<b>0.44 (0.24–0.79)</b>
PCU/hospice	23 (42.6)	0.82 (0.41–1.66)	15 (40.5)	<b>0.34 (0.14–0.81)</b>
Specialist palliative care				
Not received	41 (31.5)	1.00	40 (38.5)	1.00
Received	119 (34.4)	<b>3.04 (1.84–5.01)</b>	135 (50.8)	<b>1.86 (1.02–3.41)</b>

a: Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

b: Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

c: Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

d: Odds ratios >1 indicate higher odds of carers feeling overburdened/higher odds of financial burden. Odds ratios in bold indicate statistically significant associations.

Missing values: family carers overburdened: *n* = 69 (1.5%); difficulties in covering costs of care: *n* = 63 (1.4%), age: *n* = 12 (0.3%), sex: *n* = 12 (0.3%), cause of death: *n* = 53 (1.2%), place of death: *n* = 15 (0.3%), specialist palliative care: *n* = 189 (4.2%).

Percentages indicate proportions within the predictor variable.

**Table 5** Italy: factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last 3 months of life; two multivariate logistic regression analyses<sup>a</sup>

Patient-, health- and care characteristics	Family carer(s) feeling physically or emotionally overburdened <sup>b</sup>		Difficulties in covering costs <sup>c</sup>	
	n (%) N=1444	OR (95% CI) <sup>d</sup>	n (%) N=1444	OR (95% CI) <sup>d</sup>
Age (years)				
≥85	421 (71.6)	1.00	277 (46.6)	1.00
65–84	549 (81.8)	<b>1.56 (1.17–2.07)</b>	337 (49.9)	<b>1.43 (1.12–1.82)</b>
18–64	162 (87.6)	<b>2.07 (1.24–3.48)</b>	86 (49.1)	<b>1.66 (1.13–2.43)</b>
Sex				
Male	564 (80.7)	1.00	322 (46.7)	1.00
Female	568 (76.2)	0.88 (0.68–1.14)	378 (50.1)	1.15 (0.92–1.42)
Cause of death				
Non-cancer	563 (74.4)	1.00	406 (53.6)	1.00
Cancer	569 (82.8)	0.94 (0.69–1.28)	294 (42.9)	<b>0.49 (0.38–0.64)</b>
Place of death				
Home	554 (78.7)	1.00	362 (51.6)	1.00
Care home	65 (67.0)	<b>0.57 (0.36–0.92)</b>	53 (47.7)	0.78 (0.52–1.18)
Hospital	439 (78.8)	0.92 (0.70–1.22)	259 (47.4)	<b>0.79 (0.63–0.99)</b>
PCU/hospice	74 (86.0)	0.83 (0.42–1.64)	26 (30.2)	<b>0.37 (0.22–0.61)</b>
Specialist palliative care				
Not received	272 (71.0)	1.00	182 (47.4)	1.00
Received	860 (81.1)	<b>2.26 (1.63–3.12)</b>	518 (48.9)	<b>1.62 (1.27–2.08)</b>

a: Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

b: Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

c: Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

d: Odds ratios >1 indicate higher odds of carers feeling overburdened/higher odds of financial burden. Odds ratios in bold indicate statistically significant associations.

Missing values: family carers overburdened: *n* = 69 (1.5%); difficulties in covering costs of care: *n* = 63 (1.4%), age: *n* = 12 (0.3%), sex: *n* = 12 (0.3%), cause of death: *n* = 53 (1.2%), place of death: *n* = 15 (0.3%), specialist palliative care: *n* = 189 (4.2%).

Percentages indicate proportions within the predictor variable.

**Table 6** Spain: factors associated with GPs' reports of family carers feeling overburdened and with difficulties in covering the costs of care in the last 3 months of life; two multivariate logistic regression analyses<sup>a</sup>

Patient-, health- and care characteristics	Family carer(s) feeling physically or emotionally overburdened <sup>b</sup>		Difficulties in covering costs <sup>c</sup>	
	n (%) N=318	OR (95% CI) <sup>d</sup>	n (%) N=239	OR (95% CI) <sup>d</sup>
Age (years)				
≥85	46 (33.6)	1.00	9 (8.8)	1.00
65–84	62 (41.9)	1.38 (0.80–2.38)	13 (11.8)	2.59 (0.93–7.26)
18–64	14 (42.4)	1.32 (0.54–3.27)	1 (3.7)	1.10 (0.11–10.79)
Sex				
Male	75 (43.6)	1.00	12 (9.3)	1.00
Female	47 (32.2)	0.62 (0.39–1.01)	11 (10.0)	0.84 (0.34–2.12)
Cause of death				
Non-cancer	72 (37.9)	1.00	18 (12.3)	1.00
Cancer	50 (39.1)	0.80 (0.47–1.36)	5 (5.4)	0.34 (0.11–1.09)
Place of death				
Home	69 (41.3)	1.00	16 (12.1)	1.00
Care home	7 (24.1)	0.42 (0.17–1.07)	1 (5.6)	0.32 (0.04–2.69)
Hospital	42 (39.6)	0.82 (0.49–1.38)	5 (6.2)	0.41 (0.13– 1.24)
PCU/hospice	4 (25.0)	0.38 (0.11–1.29)	1 (11.1)	1.58 (0.15–16.39)
Specialist palliative care				
Not received	19 (24.1)	1.00	4 (7.1)	1.00
Received	103 (43.1)	1.30 (0.78–2.15)	19 (10.4)	0.48 (0.17–1.39)

a: Missing values on the predictor variables resulted in a reduced number of cases included in the multivariate logistic regression analyses.

b: Deaths were not included in analysis if carer burden was unknown or if there were no family carers according to the GP.

c: Deaths were not included in analysis if cost burden was unknown or if patient did not need care according to the GP.

d: Odds ratios >1 indicate higher odds of carers feeling overburdened/higher odds of financial burden.

Missing values: family carers overburdened: *n* = 69 (1.5%); difficulties in covering costs of care: *n* = 63 (1.4%), age: *n* = 12 (0.3%), sex: *n* = 12 (0.3%), cause of death: *n* = 53 (1.2%), place of death: *n* = 15 (0.3%), specialist palliative care: *n* = 189 (4.2%).

Percentages indicate proportions within the predictor variable.

general practice networks as observational units increased the comparability of data across countries. The GPs in the networks are representative of the total GP population in each country,<sup>21</sup> and they reported a representative sample of non-sudden deaths, with the exception of nursing home deaths in The Netherlands. Furthermore, GPs are usually well informed of their patients' care, as they are the coordinators of most of the care delivered in the countries studied and the vast majority of people have a GP whom they consult regularly.<sup>31–34</sup>

However, our study has limitations. Firstly, information on physical or emotional burden and financial strain was not obtained from the family carers themselves, and GPs may not be able to report the precise degree of the burden experienced by carers. However, these data indicate the primary care physicians' perception of the extent of the overburden and thereby facilitate conclusions about the number of family carers for whom the GPs may decide to initiate support mechanisms. Secondly, GPs' judgments of physical or emotional overburden and financial strain are based on their subjective perceptions rather than valid measures of burden. This subjectivity can be problematic if it leads to systematic differences between countries, e.g. in case of cultural differences in people's expression of feeling overburdened. Thirdly, it is possible that the GPs were not aware of the specific family circumstances and the particulars of the caring role of the different family members of all of their patients. Fourthly, based on our data, we cannot determine the type of burden (e.g. physical or emotional) experienced by the carers. Fifthly, owing to the retrospective data collection, recall bias cannot be ruled out but it was likely limited, as the GPs were instructed to register deaths immediately after being informed of them. Lastly, owing to the exclusion of nursing home deaths in The Netherlands, we did not have information from this country on the family carers of a group of patients of whom many are very old and have complex health problems.<sup>6</sup>

Italy is among the European OECD countries with the highest percentage of carers devoting >20 hours a week to care for a

dependent relative.<sup>9</sup> Compared with Belgium, The Netherlands and Spain, Italy has fewer nursing homes, which means that a large number of people with complex conditions and symptoms (e.g. dementia) stay at home for a relatively long period at the end of life. These aspects might have contributed to the particularly high degree of physical or emotional overburden reported by GPs for carers in Italy.<sup>35</sup> Interestingly, although family carers in Spain devote similar amounts of time to care and the majority of older people are cared for at home,<sup>9,35</sup> a much smaller percentage was judged physically or emotionally overburdened by GPs.

The results of this study also suggest that financial burden remains an issue for a considerable proportion of people at the end of life and their families, particularly in The Netherlands and Italy. Both the dependent person and the family carer are entitled to allowances in all four countries.<sup>35,36</sup> However, of the OECD countries, Belgium offers the longest publicly paid care leave (maximum of 12 months),<sup>35</sup> which could explain the relatively low percentage of financially overburdened families reported by GPs in Belgium. However, the relatively high proportion of families with unknown financial burden in Belgium complicates the interpretation of this result. The high number of financially burdened families in Italy is consistent with reports that one-fourth of families of cancer patients have to use all their savings to pay for care at the end of life and that 44% of family carers of cancer patients have difficulties in managing their regular employment.<sup>37</sup> The relatively higher financial burden of families of patients who died at home in The Netherlands and at home or care home in Italy indicates a need to evaluate whether the health and social care policies in these countries are suited to meet the family carers' needs for work leave and allowances given the large number of patients staying at home towards the end of life.<sup>38,39</sup> The findings concerning physical and emotional burdens and difficulties in covering care-related costs in Spain are rather surprising. As in Italy, long-term care in Spain is mainly delivered by relatives at home, and, on average, carers in Spain and Italy

devote a similar number of hours per week to care, which is considerably more than in Belgium and The Netherlands,<sup>9</sup> while at the same time receiving less support.<sup>35,40</sup> It is possible that GPs in Spain underestimated the burden experienced by carers. Just as well they could have had a broader definition of who family carers are and may have considered people who helped with care only occasionally and therefore felt less burdened than close relatives who are living with the patient. This assumption could also explain why the Spanish GPs reported the lowest proportion of patients without a family carer (0%).

The higher odds of physical or emotional overburden among family carers of patients receiving palliative care are likely to be the result of these patients' lower functional status,<sup>19</sup> but also underline the need for a more thorough evaluation of the support mechanisms for family carers of people who are very ill. In Belgium and Italy, carers of patients <85 years of age had higher odds of being described by GPs as physically or emotionally and financially overburdened. Carers of younger patients are usually younger themselves and might therefore experience a particularly big impact of the caring role on their social, occupational and financial domains. Furthermore, caring for a younger family member might carry an additional emotional burden if the person is perceived as dying prematurely. The lower financial burden for cancer patients as opposed to non-cancer patients in Belgium and Italy may suggest that non-cancer patients and their families do not request or are not offered the financial support they are entitled to, such as the Belgian 'palliative lump-sum' that requires a predicted survival of between 24 hours and 3 months. This may be due to the less predictable illness progression in non-cancer patients. We acknowledge that these potential explanations are speculative and that they do not explain why these associations were not found in all countries we studied.

Efforts to shift end-of-life care from institutions to the community need to be accompanied by health and social care policies that are better aligned with the needs of family carers. A formal recognition of family carers as care recipients and a stronger focus in general practice on identifying and supporting carers at risk should be part of these measures. Continuous epidemiological monitoring of overburden in family carers on national levels is crucial, as this is the level on which these policies and programmes are implemented.<sup>12</sup>

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## Key points

- The rising number of deaths from cancer and other life-limiting illnesses confronts society with growing difficulties in terms of care organization. As a result, considerable responsibilities for long-lasting care, including end-of-life care, are taken on by family carers.
- This retrospective, population-based, epidemiological study found that GPs in Italy perceived family carers of 71% of patients as feeling physically or emotionally overburdened, whereas this applied to around one-fourth of patients in Belgium and one-third in The Netherlands and Spain. Furthermore, GPs reported that 43% of patients and families in Italy, 36% in The Netherlands, 14% in Belgium and 8% in Spain had difficulties in covering the costs of care at the end of life.
- Family carers of patients <85 years of age and of patients who died at home rather than in a care home had higher odds of feeling physically or emotionally overburdened in Belgium and Italy. Dying at home rather than in other locations was associated with higher odds of having difficulties in covering care-related costs in The Netherlands and Italy.
- The considerable degree of overburden and difficulties in covering care-related costs among family carers of people at the end of life emphasizes that efforts to shift end-of-life care from institutions to the community need to be accompanied by health- and social care policies that are better aligned with the needs of family carers.

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