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

Lara Pivodic, Lieve Van den Block, Koen Pardon, Guido Miccinesi, Tomás Vega Alonso, Nicole Boffin, Gé A. Donker, Maurizio Cancian, Aurora López-Maside, Bregie D. Onwuteaka-Philipsen, Luc Deliens, on behalf of EURO IMPACT

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, 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 (The Netherlands and Italy) and 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.
look specifically at end-of-life care or the samples were limited to patients with particular diagnoses such as cancer or patients in receipt of specific health care services, 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:

1. How many family carers of people in their last 3 months of life feel physically or emotionally overburdened and are there differences between countries?
2. 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?
3. 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. 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 ≥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. 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.

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 3.6% (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 ≥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.

The participating GPs completed the registration form for each deceased patient aged ≥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. 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 ≥20% of the expected cell frequencies were <5. Age was grouped as 18–64, 65–84 and ≥85 years, corresponding to commonly applied definitions of the old and oldest old, 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 α < 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 N = 1604 | The Netherlands N = 635 | Italy N = 1839 | Spain N = 388 | P valuea |
|-------------------------|-----------------|-------------------------|----------------|---------------|----------|
|                        | n (%)           | n (%)                   | n (%)          | n (%)         |          |
| Sex                     |                 |                         |                |               |          |
| Women                   | 868 (54.3)      | 333 (53.0)              | 983 (53.5)     | 179 (46.1)    | 0.04     |
| 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. 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
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. 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, and using sentinel

### Table 2: Family carers feeling overburdened and difficulties 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, N = 1604 | The Netherlands, N = 635 | Italy, N = 1839 | Spain, N = 388 | P value<sup>a</sup> |
|---------------------------------------------|------------------|------------------------|----------------|---------------|------------------|
| 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>d</sup> | 207 (12.9) (11.3–14.5) | 55 (9.0) (6.7–11.3) | 125 (6.8) (5.6–8.0) | 0 (0) | |

### 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> |
|---------------------------------------------|--------------------------|------------------|
| n (%) | OR (95% CI)<sup>d</sup> | n (%) | OR (95% CI)<sup>d</sup> |
| N = 1182 | N = 1080 | | |
| Age (years) | | | |
| >85 | 106 (22.3) | 1.00 | 55 (12.8) | 1.00 |
| 65–84 | 194 (35.1) | 1.42 (1.05–1.92) | 91 (18.2) | 1.49 (1.01 to 2.21) |
| 18–64 | 72 (46.8) | 1.84 (1.19–2.83) | 56 (37.6) | 4.36 (2.63–7.23) |
| Sex | | | |
| Male | 191 (35.4) | 1.00 | 98 (20.1) | 1.00 |
| Female | 181 (35.4) | 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) | 0.65 (0.44–0.96) |
| Place of death | | | |
| Home | 135 (42.2) | 1.00 | 59 (19.9) | 1.00 |
| Care home | 55 (14.6) | 0.27 (0.18–0.40) | 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) | 1.39 (1.04–1.86) | 141 (19.2) | 1.23 (0.86–1.75) |

### Notes:

<sup>a</sup>P values based on multivariate analysis adjusted for age, sex, cause of death, place of death, and longest place of residence.

<sup>b</sup>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.

<sup>c</sup>Not included in multivariate analysis

<sup>d</sup>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 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

| Patient-, health- and care characteristics | Family carer(s) feeling physically or emotionally overburdened | Difficulties in covering costs |
|--------------------------------------------|---------------------------------------------------------------|--------------------------------|
|                                            | n (%) OR (95% CI)d                                              | n (%) OR (95% CI)d |
|                                            | N=476                                                          | N=370 |
| 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) 0.57 (0.38–0.86)                                     | 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) 0.51 (0.27–0.99) |
| Hospital                                   | 45 (39.1) 1.82 (1.07–3.11)                                     | 31 (36.9) 0.44 (0.24–0.79) |
| PCU/hospice                                | 23 (42.6) 0.82 (0.41–1.66)                                     | 15 (40.5) 0.34 (0.14–0.81) |
| Specialist palliative care                 |                                                                |        |
| Not received                               | 41 (31.5) 1.00                                                  | 40 (38.5) 1.00 |
| Received                                   | 119 (34.4) 3.04 (1.84–5.01)                                    | 135 (50.8) 1.86 (1.02–3.41) |

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

| Patient-, health- and care characteristics | Family carer(s) feeling physically or emotionally overburdened | Difficulties in covering costs |
|--------------------------------------------|---------------------------------------------------------------|--------------------------------|
|                                            | n (%) OR (95% CI)d                                              | n (%) OR (95% CI)d |
|                                            | N=1444                                                          | N=1444 |
| Age (years)                                |                                                                |        |
| ≥85                                        | 421 (71.6) 1.00                                                 | 277 (46.6) 1.00 |
| 65–84                                      | 549 (81.8) 2.07 (1.24–3.48)                                    | 337 (49.9) 1.43 (1.12–1.82) |
| 18–64                                      | 162 (87.6) 2.07 (1.24–3.48)                                    | 86 (49.1) 1.66 (1.13–2.43) |
| 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) 0.49 (0.38–0.64) |
| Place of death                             |                                                                |        |
| Home                                       | 554 (78.7) 1.00                                                 | 362 (51.6) 1.00 |
| Care home                                  | 65 (67.0) 0.57 (0.36–0.92)                                     | 53 (47.7) 0.78 (0.52–1.18) |
| Hospital                                   | 439 (78.8) 0.92 (0.70–1.22)                                    | 259 (47.4) 0.79 (0.63–0.99) |
| PCU/hospice                                | 74 (86.6) 0.83 (0.42–1.64)                                     | 26 (30.2) 0.37 (0.22–0.81) |
| Specialist palliative care                 |                                                                |        |
| Not received                               | 272 (71.0) 1.00                                                 | 182 (47.4) 1.00 |
| Received                                   | 860 (81.1) 2.26 (1.63–3.12)                                    | 518 (48.9) 1.62 (1.27–2.08) |

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.
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, 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.

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.

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

Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy. Interestingly, although family carers in Spain degree of physical or emotional overburden reported by GPs for carers in Italy.
devote a similar number of hours per week to care, which is considerably more than in Belgium and The Netherlands, while at the same time receiving less support. 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, 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.

Acknowledgements

The authors are grateful to all members of the sentinel general practice networks and particularly to all the GPs who provided the data for this study.

This analysis was undertaken as part of the European Intersectorial and Multidisciplinary Palliative Care Research Training (EURO IMPACT) project. EURO IMPACT aims to develop a multidisciplinary, multi-professional and intersectorial educational and research training framework for palliative care research in Europe. In recognition of the collaborative nature of EURO IMPACT, the authors thank the following EURO IMPACT members: Van den Block Lieve, De Groote Zeger, Brearley Sarah, Caraceni Augusto, Cohen Joachim, Francke Anneke, Harding Richard, Higginson Irene, Kaasa Stein, Linden Karen, Miccinesi Guido, Onwuteaka-Philipens Bregje, Pardoe Koen, Pasman Roelien, Pauet Sophie, Payne Sheila and Deliens Luc. EURO IMPACT is coordinated by Prof Luc Deliens and Prof Lieve Van den Block of the ‘End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, Brussels, Belgium. Other partners are: VU University Medical Center, EMGO Institute for health and care research, Amsterdam, The Netherlands; King’s College London, Cicely Saunders Institute, London; Cicely Saunders International, London and International Observatory on End-of-Life Care, Lancaster University, Lancaster, UK; Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, and Cancer Research and Prevention Institute, Florence, Italy; EUGMS European Union Geriatric Medicine Society, Geneva, Switzerland; Science and Business Media, Houten, The Netherlands.

The work described in this article was presented orally by L.P. at the 13th World Congress of the European Association for Palliative Care in Prague, Czech Republic, on 31 May 2013, and at the second International Seminar of the European Palliative Care Research Centre and the European Association for Palliative Care Research Network in Ghent, Belgium, on 19 October 2012.

Funding

This work was supported by the European Union Seventh Framework Programme (FP7/2007–2013 [264697]) and the Institute for the Promotion of Innovation by Science and Technology in Flanders as a Strategic Basic Research project [BOIWT 050158] (2006–10).

Conflicts of interest: None declared.

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.

References

1. Mathers CD, Loncar D. Projections of global mortality and burden of disease from 2002 to 2030. PLoS Med 2006;3:e442.
2. Hall S, Petkova H, Tsouros AD, et al. Palliative Care for Older People: Better Practices. Copenhagen: World Health Organization, Regional Office for Europe, 2011.
3. Levine C, Halper D, Peist A, et al. Bridging troubled waters: family caregivers, transitions, and long-term care. Health Aff 2010;29:116–24.
4. Gomes B, Calanzani N, Gyseys M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013;12:7.
5. Department of Health. End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life. London: Department of Health, 2008.
6 Francke AL. Palliative Care for Terminally Ill Patients in the Netherlands. Dutch Government Policy. The Hague: Ministry of Health, Welfare and Sport (Ministerie van volksgezondheid welzijn en sport), 2003.

7 The National Health System Palliative Care Strategy: Strategy approved by the National Health System Interterritorial Council on March 14, 2007.

8 Buckner L, Yeandle S. Valuing carers 2011: calculating the value of carers’ support. 2011. Available at: http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011___Carers_UK.pdf (13 January 2014, date last accessed).

9 OECD. Health at a Glance 2011: OECD Indicators. Paris: OECD, 2011.

10 Tarricone R, Touros AD. The Solid Facts: Home Care in Europe. Copenhagen: World Health Organization, Regional Office for Europe, 2008.

11 Lee R. The outlook for population growth. Science 2011;333:569–73.

12 Talley RC, Crews JE. Framing the public health of caregiving. Am J Public Health 2007;97:224–8.

13 Dumont S, Jacobs P, Fassbender K, et al. Costs associated with resource utilization during the palliative phase of care: a Canadian perspective. Palliat Med 2009;23: 708–17.

14 Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers’ needs in providing home-based end-of-life care to people with cancer. J Clin Nurs 2009;18: 1379–93.

15 Assun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: at what cost? Palliat Med 2005;19:551–5.

16 Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. Ann Intern Med 2000;132:451–59.

17 Shahly V, Chatterji S, Gruber MJ, et al. Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. Psychol Med 2013;43:865–79.

18 Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. CMAJ 2004; 170:1795–801.

19 Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. J Pain Symptom Manage 1999;17:418–28.

20 Harding R, Higgins JJ, Donaldson N. The relationship between patient characteristics and carer psychological status in home palliative cancer care. Support Care Cancer 2003;11:638–43.

21 Van den Block L, Onwuteaka-Philipsen B, Meuissen K, et al. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract 2013;14:73.

22 Costantini M, Beccaro M, Merlo F. The last three months of life of Italian cancer patients. Methods, sample characteristics and response rate of the Italian Survey of the Dying of Cancer (ISDOC). Palliat Med 2005;19:628–38.

23 Gomes B, McCrone P, Hall S, et al. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALCARE study. BMC Cancer 2010;10:400.

24 Meuissen K, Van den Block L, Echteld MA, et al. End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. J Clin Oncol 2011;29: 4327–34.

25 Ko W, Beccaro M, Miccinesi G, et al. Awareness of general practitioners concerning cancer patients’ preferences for place of death: evidence from four European countries. Eur J Cancer 2013;49:1967–74.

26 Evans N, Pasman HR, Vega Alonso T, et al. End-of-life decisions: a cross-national study of treatment preference discussions and surrogate decision-maker appointments. PLoS One 2013;8:e57965.

27 Borgsteede SD, Deliens L, Francke AL, et al. Defining the patient population: one of the problems for palliative care research. Palliat Med 2006;20:63–8.

28 National Institute on Aging. National Institutes of Health. U.S. Department of Health and Human Services. Why population aging matters. A global perspective. 2007. Available at: http://www.nia.nih.gov/health/publication/why-population-aging-matters-global-perspective/trend-3-rising-numbers-oldest-old (13 January 2014, date last accessed).

29 Bockstaele P, De Graaf P. Primary care and care for older persons: position paper of the European forum for primary care. Qual Prim Care 2011;19:369–89.

30 Teno JM. Measuring end-of-life care outcomes retrospectively. J Palliat Med 2005;8: s42–9.

31 Schäfer W, Kroneman M, Boerma W, et al. The Netherlands: health system review. Health Syst Transit 2010;12:1–228.

32 Garcia-Armesto S, Abadia-Taira MB, Durán A, et al. Spain: health system review. Health Syst Transit 2010;12:1–295.

33 Gerkens S, Merkur S. Belgium: health system review. Health Syst Transit 2010;12: 1–266.

34 Lo Scalo A, Donatini A, Orzella L, et al. Italy: health system review. Health Syst Transit 2009;11:1–216.

35 Colombo F, Llena-Noxal A, Mercier T, Tjadens F. Help wanted! Providing and paying for long-term care. 2011.

36 Riedel M, Kraus M. Informal care provision in Europe: regulation and profile of providers. ENEPRI Research; Report No. 96. Brussels: Centre for European Policy Studies (CEPS), 2011.

37 Rossi PG, Beccaro M, Miccinesi G, et al. Dying of cancer in Italy: impact on family and caregiver. The Italian survey of dying of cancer. J Epidemiol Commun Health 2007;61:547–54.

38 Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian Survey of the Dying of Cancer (ISDOC). BMC Public Health 2007;7:66.

39 Abashir E, Echteld M, Van den Block L, et al. Transitions between care settings at the end of life in the Netherlands: results from a nationwide study. Palliat Med 2010; 24:166–74.

40 García J, Carretero S, Ródenas F, Vivancos M. The care of the informal caregiver’s burden by the Spanish public system of social welfare: a review. Arch Gerontol Geriatr 2010;50:250–3.