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Awareness of General Practitioners concerning cancer patients' preferences for place of death: Evidence from four European countries

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Abstract

Background: General Practitioners (GPs) are at the first level of contact in many European healthcare systems and they supposedly have a role in supporting cancer patients in achieving their desired place of death. A four-country (Belgium, the Netherlands, Italy and Spain) study was carried out exploring current practices.

Patients and Methods: EURO SENTI-MELC adopted a retrospective study design and data for this study were collected in 2010 through representative GPs' networks in four countries. In the current study all non-sudden cancer deaths were included with weekly GP registrations.

Results: The main study sample included 930 deceased cancer patients: preference for place of death was known by GPs for only 377. GP awareness on the preferred place of death varied across countries, 27% in Italy, 36% in Spain,

45% in Belgium and 72% in the Netherlands ($p < 0.01$). The general level of preferences met was high, from 68% (Italy) to 92% (Spain).

Conclusions: Despite the importance of being able to die in a preferred location, GPs were often unaware about patient preferences, especially in Italy and Spain. If GPs were informed, the preference was often met in all countries, indicating room for improvement in end-of-life care.

1. INTRODUCTION

Cancer is a leading cause of death in Europe with standardised statistics demonstrating more than 169 deaths per 100,000 inhabitants annually died from malignancies.¹ Therefore, offering quality cancer care is crucial and palliative care is one element. Achieving patients' preference is a marker in assessing quality of care¹ and place of death deserves attention because it gives patients and their families a sense of control and thus improving the quality of death.² Meeting patients' preferences of place of death enhances the quality of cancer care in addition to other goals such as symptom control and spending time with family at the end-of-life.³ Existing literature shows that from 44% to 90% of individuals (both cancer patients and healthy population) worldwide desire to die at home^{4, 5, 6 and 7} while these wishes often remain unfulfilled. Hospital deaths account for 35% to 65% cancer deaths in the United Kingdom (UK) and 45% in the Netherlands.^{8, 9 and 10} Information on how well this preference is met (congruence between actual and preferred place of death) is less known. One Italian survey reports an overall 67% of sampled patients died in their preferred place of death¹¹ whereas the proportion drops to just over 50% in an Irish study.¹² A recent study shows an increase of home deaths in Britain, from 18% in 2004 to 21% in 2010, the rise is more pronounced among cancer patients.¹³ This might be related to the introduction of the End-of-Life Care Strategy in 2008,¹⁴ which includes place of death as a quality indicator, demonstrating the potential benefits of integrating palliative care into public health.¹⁵

This study uses General Practitioners (GPs) as proxies for information. Though precise statistics on GPs' coverage are not available, previous studies highlight their role in improving palliative care services.^{10, 16 and 17} Abarshi shows that four-fifths of patients had their preference met when Dutch GPs knew them¹⁰ while Meeussen et al. show that only 46% of Belgian GPs knew the preferred place of death of their cancer patients,¹⁷ indicating room for improvements.

An international study on preference met with regard to GPs' involvement in end-of-life care for cancer patients would add to the knowledge on improving GP-patient communications.

The study aims of this article are:

1. To report GPs' awareness of preferred place of death of a sample of deceased cancer patients in four European countries (Belgium, the Netherlands, Italy and Spain).

2. To estimate the distribution of actual and preferred place of death from a sample of deceased cancer patients in the four countries.
3. To describe preference met in the sampled cancer patients.

2. METHODS

2.1. The EURO SENTI-MELC study

The European Sentinel Network of the GPs to Monitor End-of-Life Care (EURO SENTI-MELC) is a large scale epidemiological descriptive study conducted in four European countries in 2009–2010 based on continuous full-year registration of all patients who died in the participating GP sentinel networks. The study started in Belgium in 2004 and expanded to the Netherlands in 2005 and has continued since then.

2.2. Observational unit

General practices are the observational units. The GP network covers 1.8% and 0.8% of the Belgian and Dutch national patient populations respectively.¹⁸ and ¹⁹ The Spanish Sentinel Network has existed for more than 15 years²⁰ and engaged in end-of-life care study since 2010, representing 3.8% of the patient population in Castilla and León (northwest) and 3% in Valencia (east). Italian data are available from 2009 with a new GP network constituted for this study.²¹ Data were collected from nine out of 146 health districts and cover about 4% of the patient population.

2.3. Study population

All deceased aged 18 or above who were part of a GPs' practice were included. Since this study examines the care delivered at the end-of-life (i.e. those theoretically receiving palliative care as their GPs identified them as terminally ill), all deaths occurred 'suddenly and totally unexpectedly' were excluded.¹⁸

2.4. Retrospective data collection

GPs reported place of death and circumstances of end-of-life care of deceased cancer patients weekly on a standardised questionnaire. They first identified the 'place of death of patient', and secondly indicated, 'Were you informed (verbally or in writing) of the patient's preference regarding place of death?': where the answer is YES, the GP would be asked where did this patient prefer to die. For both questions, five options were given, at home or living with family, in a care home (Belgium and Italy)/elderly home (the Netherlands and Spain), in hospital, palliative care unit (PCU)/hospice or elsewhere (namely). Dutch nursing home deaths were excluded since these patients were cared for by nursing home physicians once transferred.²² Further information on the selection procedures of GP Sentinel Networks in Belgium and the Netherlands has been published.¹⁸ and ²³

2.5. Ethical approval

The protocol of the study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel and the local ethics committee in Grosseto, Italy. No specific ethical approvals were needed in the Netherlands or Spain because of the retrospective anonymous data collection.

2.6. Analyses

This is a cross-sectional study. Heterogeneity tests were conducted on cross-country differences (controlling for the types of malignancy) and *p*-values are shown. Numbers and proportions are reported on the variables: age, gender, cause of death and place of death. Analyses were completed using PASW Statistics 18, Release Version 18.0.0 (SPSS, Inc., 2009, Chicago, IL). The variable preference met was constructed based on information of actual and preferred place of death and a multivariate analysis (adjusting for age, gender and types of malignancy) was done to assess cross-country differences. Binomial proportion confidence intervals were estimated for preference met with MedCalc, Release Version 12.2.1. (MedCalc Software, 2012, Mariakerke, Belgium) Patients whose preferred place of death was unknown were excluded in this part of the analysis.

3. RESULTS

3.1. Selection of sample (Fig. 1)

A total of 3336 deaths were reported from the four countries with 938 'non-sudden' cancer deaths. Preference met on place of death was analysed for 377 patients whose 'preferred' and 'actual' place of death were known.

[FIGURE 1]

3.2. Patient characteristics

There was no difference between cancer patients in terms of age but more male patients were included. (Table 1). One fourth of patients aged between 18 and 64 (except in Italy), 60% of patients aged between 65 and 85; the very old (aged 85 or above) comprised another 15%. Forty percent of cancer patients had malignancies other than the four main sites (lung, breast, colorectal and prostate).

[TABLE 1]

3.3. Actual place of death

Home was the most common place of death among 930 patients in all countries (Table 2). More than half of Dutch (61%) and Spanish (53%) died at home while only 35% of Belgian and 45% of Italian patients did so. Except in the Netherlands, more than one-third of patients died in hospitals in all countries. Care home or hospice deaths were higher in the Netherlands and Belgium (23–31% in total) than in the other two countries (13–17% in total).

[TABLE 2]

3.4. GP awareness of preferred place of death

Cross-national differences were observed on GPs' awareness of their patients' preferred place of death (41% in the four countries together, Table 3). Dutch physicians were the most informed (72%) and Italians the least (27%). When asked about the informants about preferred place of death, Belgian and Dutch GPs were mainly informed by patients (63 and 72%) whereas family members were the informants (53% and 54%) in Italy and Spain. Furthermore, one in five GPs in Belgium and the Netherlands were informed by both the patient and a family member compared to 6% in Italy and 13% in Spain.

[TABLE 3]

There were a high percentage of 'unknown' preferences, hinting a lack of GPs' awareness. Only 389 (42%) of patients' preferences on place of death were documented. For known preferences, most were for dying at home, marked by the strong preference in Italy and Spain, where nearly nine out of 10 cancer patients preferred home deaths. Almost 70% of cancer patients in Belgium and the Netherlands had the same preference. 20% of Belgian patients opted for a care home/PCU and a PCU was the second most (12%) preferred place of death in the Netherlands. There was no prominent second preferred place of death in Italy and Spain.

3.5. Preference met between actual and preferred place of death (Table 4)

Spain and the Netherlands had the highest level of overall preference met (92% and 91% respectively), followed by Belgium (81%) and Italy (68%). Results from a multivariate analysis ($p < 0.05$) confirmed this: the Netherlands (odds ratio (OR): 5.7 [2.43–13.54]) and Spain (OR: 5.7 [1.56–20.55]), with Italy as reference category (not shown in table).

[TABLE 4]

One-third of Italian patients ($N = 23$, 32%) preferring home deaths died in hospitals. Reviewing deaths in PCUs or hospices, Dutch patients ($N = 14$, 93%) had a higher proportion of preference met than Belgian patients ($N = 13$, 77%). There was complete preference met for Italian and Spanish patients in care home and PCU/hospice, though the number was small.

3.6. Comparison of actual place of death with regard to GP awareness of preferences

We also found group differences when patients were dichotomised by GPs' awareness of the preference were found except in Italy (Table 5). In all countries, between 40% and 53% patients died in hospitals when their preferred place of death was unknown. Home deaths decreased substantially when GPs did not know the

preferred place of death, reductions ranged from 11% in Italy to 42% in the Netherlands.

[TABLE 5]

4. Discussions

This is the first cross-European study to measure preference met on place of death for cancer patients from a general practice population. For actual place of death, home deaths varied from one-third in Belgium to over 60% in the Netherlands. 70–90% of GPs reported home as the preferred location of their cancer patients. The proportion of preference met was high (over 80%), except in Italy. Both results are supported by the existing literature.^{6, 10, 11 and 17}

One finding is the large cross-country difference in GPs' awareness. Only one-third of Italian and Spanish GPs knew the preferred place of death of cancer patients compared to more than two-thirds of Dutch GPs. There were more hospital deaths and fewer home deaths when GPs lacked the information. The differences amounted to over 40% in Belgium and the Netherlands, and more than 35% for Spain. Understanding the causes of these variations is vital for effective interventions. Possible explanations for GPs not knowing the preference include sudden deterioration of a patient's physical state^{24, 25 and 26} and patients remaining silent on their preference due to worries about burdening caregivers.⁹ Unequal access to healthcare resources also implies patients from a lower socioeconomic class would die in hospitals.^{9, 27 and 28} Data from the World Health Organization (WHO) and others demonstrate a slightly higher overall cancer mortality rate (with lung, breast, prostate and colorectal combined) in the Netherlands (16%) than in Belgium (13%), Italy (12%) and Spain (13%), and larger cross-country mortality differences on specific cancer types, e.g. lung (5.7% Italy to 7.6% the Netherlands), breast (1.7% Spain to 2.3% Belgium), colorectal (3.2% Italy to 3.8% the Netherlands) and prostate (1.3% Italy to 1.9% the Netherlands).^{29 and 30} However, these differences in cancer death burden do not seem large enough to explain the observed differences in GPs' awareness of patient preferences and the multivariate analyses controlling for different frequencies in cancer type confirm this. Hence, differences might be more related to GP training and culture than to cancer death burden. Training effective communications in these sensitive issues may enhance a favourable outcome as discussing end-of-life care is perceived as challenging.³¹ For instance, the proportion of Dutch GPs' awareness of preferred place of death increased from 54% in 2005/06 to 72% 2009/2010, the change could be due to increased discussions.³² Moreover, evidence shows preferences are more stable than we assume,³³ encouraging healthcare professionals not only to elicit that preference regularly, but also consider the available social and healthcare support. On the other hand, the different sources of informant might be a sign of cultural differences. The response for both patient and family was around 20% in the Netherlands and Belgium, the figure was lower in Spain (13%) and Italy (6%). Spanish and Italian GPs often learned about the preference from family members, opening up a speculation about cultural differences in communicating end-of-life issues.^{34, 35 and 36}

However, the questionnaire only captured a categorical preference from proxies, and knowing the 'strength' of that preference could help delineate the weight of place of death in comparisons with other goals of care.¹ One should remember that some patients do not have a preference on place of death or regard it as unimportant.

5. Strengths and limitations

This is a European-wide study on preference met on place of death among cancer patients, using GPs as proxies. The same methodology was applied in four countries, allowing comparisons across territories. The choice of countries, Belgium, the Netherlands, Italy and Spain reflects the diversity of healthcare systems and cultures. Furthermore, efforts have been made to achieve the best representativeness possible and GPs reported weekly to minimise recall bias.

Nevertheless there are limitations with employing GPs as proxies. The reported preference was based on GPs' own observation which could be affected by their concept of 'good death'. One possible bias is that the sampled patients maintained more contact with their GPs and thus making their preference better known than patients who had less contact with GPs.

Another weakness is that GPs did not know all the details and preferences of their patients. For instance, Dutch GPs were not the primary care providers for nursing home residents,²² and many Italian GPs were not informed about a preferred place of death.

Though GP practice is highly accessible in the countries surveyed, we risked excluding patients outside the practice who might be socially deprived and could benefit from the care. These all imply further caution in interpreting the results.

Last but not least, the prompt question of 'non-sudden death' was used as a criterion in identifying the theoretical sample of palliative care group which means preferences of palliative care patients who died suddenly were unavoidably omitted.

6. Conclusions

It has been repeatedly reported that patients wish to die at home.^{4, 5, 6 and 7} The article describes the current situation and explores conditions related to the preferred place of death in four European countries. Except in the Netherlands, the majority of GPs surveyed were not aware of the preferred place of death of patients and where this was the case, patients usually died in hospitals. Nonetheless, by offering training to GPs on end-of-life care communication, better arrangements can be made to enable people dying in their chosen location.

Achieving the desired place of death is a component of quality supportive care for our cancer patients but has also been shown to be contingent upon many other conditions such as family support and physical status in the final days. Further qualitative research would increase our understanding of the complexities of achieving the preference as well as the genuine preference of patients.

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Conflict of interest statement

None declared.

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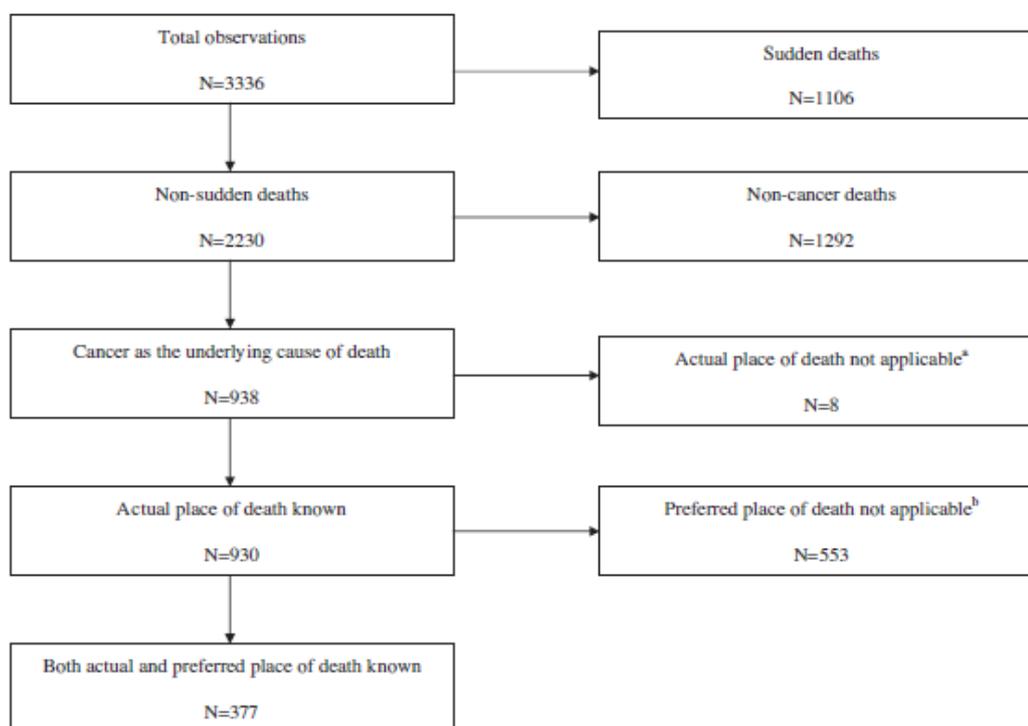
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TABLES

Fig. 1. Overview of the obtained study sample.



^a nursing home deaths from the Netherlands

^b preferred place of death not known by GPs or being nursing home in the Netherlands

Table 1
Cancer patients' characteristics ($N = 930$).

| | Belgium ($N = 292$) N (%) | The Netherlands ($N = 181$) N (%) | Italy ($N = 308$) N (%) | Spain ($N = 149$) N (%) | p -Value ^a |
|----------------------------------|-------------------------------------|---|-----------------------------------|-----------------------------------|-------------------------|
| Gender ^b | | | | | |
| Male | 154 (53) | 106 (59) | 157 (51) | 98 (66) | 0.013 |
| Female | 138 (47) | 73 (41) | 151 (49) | 51 (34) | |
| Age at death, years ^c | | | | | |
| 18-64 | 71 (25) | 47 (26) | 67 (22) | 35 (24) | 0.912 |
| 65-85 | 171 (59) | 108 (60) | 185 (60) | 88 (59) | |
| 86 or above | 47 (16) | 26 (14) | 56 (18) | 26 (17) | |
| Types of malignancy ^d | | | | | |
| Lung | 72 (25) | 46 (28) | 74 (28) | 32 (22) | 0.024 |
| Breast | 29 (9.9) | 8 (4.8) | 16 (6.1) | 6 (4.1) | |
| Colorectal | 36 (12) | 28 (17) | 37 (14) | 32 (22) | |
| Prostate | 15 (5.1) | 13 (7.8) | 8 (3.1) | 13 (9.0) | |
| Others ^e | 140 (48) | 75 (45) | 127 (49) | 62 (43) | |

Note: percentages may not add up to 100 due to round off.

^a Chi-square test used.

^b Not answered: two in the Netherlands.

^c Missing: three in Belgium.

^d Not answered: 15 in the Netherlands, 46 in Italy and four in Spain.

^e For others, the site of tumour is noted qualitatively and beyond the four main categories.

Table 2
Actual place of death of cancer patients ($N = 930$).

| | Belgium ($N = 292$) N (%) | The Netherlands ($N = 181$) N (%) | Italy ($N = 308$) N (%) | Spain ($N = 149$) N (%) | p -Value ^a |
|------------------------------|-------------------------------------|---|-----------------------------------|-----------------------------------|-------------------------|
| Actual place of death | | | | | |
| Home | 102 (35) | 110 (61) | 137 (45) | 78 (53) | <0.01 |
| Care home ^a | 33 (11) | 14 (7.7) | 17 (5.5) | 8 (5.4) | |
| Hospital | 98 (34) | 30 (17) | 118 (38) | 49 (33) | |
| Palliative care unit/hospice | 57 (20) | 27 (15) | 36 (12) | 12 (8.2) | |
| Total ^b | 290 (100) | 181 (100) | 308 (100) | 147 (100) | |

Note: percentages may not add up to 100 due to round off.

^a Care home in the Netherlands and Spain is residential home for elderly.

^b Not answered: two in Belgium and one in Spain; one indicated as elsewhere in Spain.

^c test for heterogeneity used, controlling for the five categories of malignancies (lung, breast, colorectal, prostate and others).

Table 3
GPs' awareness and preferred place of death of cancer patients.

| Characteristics | Belgium N (%) | The Netherlands N (%) | Italy N (%) | Spain N (%) | p-Value ^f |
|---|------------------|--------------------------|----------------|----------------|----------------------|
| Whether GPs are informed about patients' preferred place of death ^a (N = 930) | (N = 292) | (N = 181) | (N = 308) | (N = 149) | |
| Informed | 130 (45) | 129 (72) | 83 (27) | 47 (36) | |
| Not informed | 162 (56) | 50 (28) | 225 (73) | 84 (64) | <0.01 |
| GPs informed by ^{b,c} (N = 389) | (N = 130) | (N = 129) | (N = 83) | (N = 47) | |
| Patient himself/herself only | 80 (63) | 91 (72) | 33 (40) | 15 (32) | <0.01 |
| A family member only | 22 (17) | 8 (6.3) | 45 (54) | 25 (53) | <0.01 |
| Both | 26 (20) | 26 (21) | 5 (6.0) | 6 (13) | 0.057 |
| Others | – (–) | 1 (0.0) | – (–) | 1 (2.1) | 0.202 |
| Preferred place of death of patients ^d (N = 389) | (N = 130) | (N = 129) | (N = 83) | (N = 47) | |
| Home | 92 (71) | 100 (78) | 73 (90) | 35 (90) | |
| Care home ^e | 14 (11) | 12 (9.4) | 1 (1.2) | 2 (5.1) | |
| Hospital | 6 (4.7) | 1 (0.8) | 5 (6.2) | 1 (2.6) | |
| Palliative care unit/hospice | 17 (13) | 15 (12) | 2 (2.5) | 1 (2.6) | <0.01 |

Note: Percentages may not add up to 100 due to round off.

^a Not answered: two in Belgium and 18 in Spain.

^b Multiple answers possible.

^c Not specified: two in Belgium and three in the Netherlands.

^d Not applicable: one in Belgium, one in the Netherlands, two in Italy and seven in Spain; one Spanish GP reported 'elsewhere' for preferred place of death.

^e Care home in the Netherlands and Spain is residential home for elderly.

^f Test for heterogeneity used, controlling for the five categories of malignancies (lung, breast, colorectal, prostate and others).

Table 4
Preference met of place of death for deceased cancer patients in four European countries (N = 377).

| Preferred place of death | Actual place of death | | | | Total N (%) | Preference met N(%); 95% confidence interval (CI) ^e |
|---------------------------|-----------------------|--------------------------------|-------------------|------------------------------------|----------------|---|
| | Home N (%) | Carehome ^a N (%) | Hospital N (%) | PCU ^b /hospice N (%) | | |
| Belgium (N = 129) | | | | | | 105/129 (81%; 73.6–87.7) |
| Home | 74 (80) | 1 (1.1) | 6 (6.5) | 11 (12) | 92 (100) | |
| Care home | – (–) | 14 (100) | – (–) | – (–) | 14 (100) | |
| Hospital | – (–) | – (–) | 4 (67) | 2 (33) | 6 (100) | |
| PCU/hospice | – (–) | – (–) | 4 (24) | 13 (77) | 17 (100) | |
| The Netherlands (N = 128) | | | | | | 117/128 (91%; 85.1–95.6) |
| Home | 92 (92) | – (–) | 3 (3.0) | 5 (5.0) | 100 (100) | |
| Care home ^a | 2 (15) | 10 (77) | – (–) | – (–) | 12 (100) | |
| Hospital | – (–) | – (–) | 1 (100) | – (–) | 1 (100) | |
| PCU/hospice | – (–) | – (–) | 1 (6.7) | 14 (93) | 15 (100) | |
| Italy (N = 81) | | | | | | 55/81 (68%; 56.6–77.8) |
| Home | 47 (64) | 1 (1.4) | 23 (32) | 2 (2.7) | 73 (100) | |
| Care home | – (–) | 1 (100) | – (–) | – (–) | 1 (100) | |
| Hospital | – (–) | – (–) | 5 (100) | – (–) | 5 (100) | |
| PCU/hospice | – (–) | – (–) | – (–) | 2 (100) | 2 (100) | |
| Spain (N = 39) | | | | | | 36/39 (92%; 79.1–98.4) |
| Home | 32 (91) | – (–) | 3 (8.6) | – (–) | 35 (100) | |
| Care home ^a | – (–) | 2 (100) | – (–) | – (–) | 2 (100) | |
| Hospital | – (–) | – (–) | 1 (100) | – (–) | 1 (100) | |
| PCU/hospice | – (–) | – (–) | – (–) | 1 (100) | 1 (100) | |

Note: percentages may not add up to 100 due to round off.

^a Care home in the Netherlands and Spain is residential home for elderly.

^b PCU refers to palliative care unit.

^c Binomial proportion confidence interval estimated.

Table 5

Actual place of death of cancer patients whose preferred place of death is known ($N = 377$) versus unknown ($N = 553$) by GPs.

| | Belgium | | The Netherlands | | Italy | | Spain | |
|-------------------------------------|-------------------------------|--|-------------------------------|-----------------------------|------------------------------|---------------------------------|------------------------------|--|
| | Known ($N = 130$) (%) | Unknown ($N = 162$) ^b (%) | Known ($N = 129$) (%) | Unknown ($N = 52$) (%) | Known ($N = 83$) (%) | Unknown ($N = 225$) (%) | Known ($N = 47$) (%) | Unknown ($N = 102$) ^b (%) |
| Home | 58 | 17 | 73 | 31 | 57 | 40 | 81 | 43 |
| Care home ^a | 12 | 11 | 7.8 | 7.7 | 4.8 | 5.8 | 8.5 | 4.0 |
| Hospital | 11 | 53 | 3.9 | 48 | 34 | 40 | 8.5 | 45 |
| Palliative care unit/ hospice | 20 | 19 | 16 | 14 | 4.8 | 14 | 2.1 | 11 |
| <i>p</i> -Value ^c | $p < 0.01$ | | $p < 0.01$ | | $p = 0.01$ | | $p < 0.01$ | |

Note: Percentages may not add up to 100 due to round off.

^a Care home in the Netherlands and Spain is residential home for elderly.

^b Not answered: two in Belgium and one in Spain, one Spanish patient died elsewhere.

^c Test for heterogeneity used, controlling for the five categories of malignancies (lung, breast, colorectal, prostate and others).