

Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain

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Background: Cancer end-of-life care (EoLC) policies assume people want to die at home. We aimed to examine variations in preferences for place of death cross-nationally.

Methods: A telephone survey of a random sample of individuals aged ≥ 16 in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. We determined where people would prefer to die if they had a serious illness such as advanced cancer, facilitating circumstances, personal values and experiences of illness, death and dying.

Results: Of 9344 participants, between 51% (95% CI: 48% to 54%) in Portugal and 84% (95% CI: 82% to 86%) in the Netherlands would prefer to die at home. Cross-national analysis found there to be an influence of circumstances and values but not of experiences of illness, death and dying. Four factors were associated with a preference for home death in more than one country: younger age up to 70+ (Germany, the Netherlands, Portugal, Spain), increased importance of dying in the preferred place (England, Germany, Portugal, Spain), prioritizing keeping a positive attitude (Germany, Spain) and wanting to involve family in decisions if incapable (Flanders, Portugal).

Conclusions: At least two-thirds of people prefer a home death in all but one country studied. The strong association with personal values suggests keeping home care at the heart of cancer EoLC.

Key words: Europe, health care surveys, neoplasms, palliative care, public health

introduction

End-of-life care (EoLC) imposes considerable costs on health systems [1, 2] and is a public health priority particularly relevant for clinical oncology. About a third of cancer care expenditure is incurred in patients' last year of life and projections show rising costs, as cancer deaths increase and cohorts of 'baby-boomers' reach older age [3–5].

These challenges require clinicians working in cancer care to be prepared to provide good EoLC. Presently, most patients die in hospital but this may soon change [6, 7, 8]. National policies, such as the USA hospice benefit programme and the UK 2008 EoLC strategy, are seeking to increase home death rates, assuming people want to die at home [9, 10]. Studies on preferences for place of death come mainly from the USA or the UK, are usually conducted with selected samples and are difficult to compare, with questions asked in different ways and to different sources [11, 12]. Moreover, little is known on how exposure to illness, caregiving and age may affect preferences. Evidence from Europe is needed to appraise and

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inform national and international cancer EoLC. The present study is the first to examine variations in people's preferences for where to die in a scenario of advanced cancer cross-nationally.

methods

design

We undertook a population-based telephone survey based on a theoretical model on preferences for place of death in a hypothetical scenario of advanced cancer, grounded in social psychological and ecological theories [13, 14]. The model postulated that such preferences are socially patterned and result from three groups of factors: facilitating circumstances, prior experiences and personal values (supplemental Figure A, available at *Annals of Oncology* online) [13, 14].

questionnaire

development. We took a multi-method approach to questionnaire development to enhance validity and comparability. This included: (i) review of studies and questions on EoLC preferences and priorities; (ii) review of cross-national social surveys; and (iii) three consultation rounds with 27 EoLC experts.

content. The questionnaire included 28 questions on preferences, personal values related to EoLC (most important goals, importance attributed to dying in preferred place, most concerning symptoms and problems, preferences for decision making), experience with illness, death and dying, general health and sociodemographics. Most of the latter were adapted from the European Social Survey Round 4 (2008) [15]. Participants indicated where they preferred to die in a scenario of advanced cancer by answering the question in Table 1.

translation. We undertook systematic and culture-sensitive translations of the questionnaire into the countries' dominant language following EORTC translation procedures [16]. This involved forward independent translations by two native speakers with EoLC knowledge, backward professional translation and harmonization of all versions.

testing. The resulting questionnaire (in supplementary data, available at *Annals of Oncology* online) was piloted using cognitive interviewing with 30 volunteers in England and Germany [17].

setting

The survey covered Flanders (the Dutch speaking part of Belgium) and all regions in England, Germany, Italy, the Netherlands, Spain and Portugal.

Table 1. Question on preferences for place of death

'In a situation of serious illness like cancer with less than 1 year to live where do you think you would prefer to die if circumstances allowed you to choose?'

- in your own home
- in the home of a relative or friend
- in a hospice or palliative care unit^a—places with specialized care and beds for dying patients
- in a hospital—but not in a palliative care unit
- in a care home^a
- somewhere else

^aThese categories were phrased differently across countries according to language and service availability. The description of a hospice or palliative care unit was kept the same across all countries.

These countries have contrasting cultural, political contexts and sociodemographic profiles [5, 6, 18, 19], and different proportions of cancer home deaths [6, 7, 20].

participants

Individuals aged ≥ 16 residing in a household were invited to participate in a computer-assisted telephone interview (CATI) by selection of households using random digit dialling (RDD). Once an eligible participant was identified, no substitution was allowed. Exclusion criteria were incapacity to hear or understand the information and provide informed consent (assessed by interviewers) and poor language skills (of country's dominant language).

To be able to detect previous age differences in preferences for home death in England between those aged 16–44 (60%) and those aged 45+ (51%) [21], we needed a minimum of 1278 completed interviews (power 0.90, significance 0.05). Modelling calculations to other countries resulted in overall minimum needed interviews being 8946. No oversampling, strata or quota were applied.

procedures

We trained 149 interviewers (95% native speakers) with experience in telephone surveys on social and health issues on how to administer the questionnaire. Interviews were conducted from May to December 2010 with at least four call attempts (at least one after 6 pm). Interviewers entered answers into a database with missing data checks at entry; 10% of interviews were checked by *in situ* supervisors.

statistical analysis

We described the sample and preferences for place of death and then focused the analysis on a preference to die at home (one's own or of a relative or friend), as this is of utmost interest for policy and care planning. We calculated crude and standardized percentages of preferences for home death in all countries applying England's gender and age sample distribution (first comparing the 16–44 age group with the 45+ to allow comparisons with data from the previous survey in England [21] and then pursuing a more detailed analysis in 5-year age categories) with 95% confidence intervals (CIs). We compared crude percentages using χ^2 tests and tested for differences in ordinal variables using Mann–Whitney tests and in parametric data using *t*-tests (supplemental Table A, available at *Annals of Oncology* online).

We used generalized estimating equations (GEE) [22] to examine factors associated with a preference for home death. GEE (a multivariate regression-based technique) takes into account the effect of country as a cluster, and the fact that participants from the same country are likely to have more similar preferences than participants from other countries. We entered in the model variables which were either (i) associated with a preference for home death ($P \leq 0.05$) in at least two countries and for which the direction of the effect was consistent across countries or (ii) associated with a preference for home death ($P \leq 0.05$) using data from all countries together and for which the direction of the effect was consistent across all. We used a fixed-effects model with the logit link function, exchangeable correlation and model-based method for estimating variance, as the number of clusters was small (< 20) [23]. We estimated odds ratios (OR) with 95% CIs for variables in the final model. As the main aim of the study was to examine variations rather than to make population estimates, and given that GEE controlled for country effects, we used and report unweighted data.

Logistic regressions were then conducted in each country, entering factors which were entered in the GEE model (to confirm applicability to individual countries) and any other country-specific factors associated with preferences for home death in the bivariate analysis ($P \leq 0.05$). We undertook all analyses using SPSS 18 for Windows. Cases with missing data were excluded. Tests were two-tailed and $P \leq 0.01$ was deemed significant in the final models to allow for multiple testing.

ethics

The research ethics committee of the lead academic centre approved the study (ref: BDM/08/09-48). We obtained local ethics approvals and/or notified data protection agencies in all countries.

results

From a total of 45 242 randomly selected households with a known eligible person, 9344 people (21%) agreed to participate in the study. Response was highest in Germany (29%), followed by Portugal (28%), Spain (21%), Italy (21%), England (21%), Flanders (16%) and the Netherlands (16%). Overall, 1% were excluded due to language difficulties, 1% due to hearing problems and 1% were deemed incapable of providing informed consent.

Main reasons for refusal were lack of interest (59%), lack of time (17%) and refusal to take part in telephone surveys (3%). In addition, 3% ($n = 1251$) stated reasons for refusal to participate related to the topic: 385 due to its sensitive nature, 497 because they had a physical disability or illness, 223 because a relative or friend had a physical disability or illness and 146 due to a recent household bereavement/death. In 3%, reasons for refusal were not specified. In addition, 7% were asked to be called back but the interview was never concluded, 8% broke-off the interview at early stages and less than 1% chose to stop and withdraw the information.

The interview took 15.4 min on average to complete. The oldest person interviewed was 98 years old, 13% participants were 70 years or older and 93% were born in the country where they lived in. Ten per cent reported having been seriously ill in the past 5 years and 53% had cared for a close relative or friend in their last months of life (Table 2).

In all but one country, 64–84% of participants said they would prefer to die at home if they were to die with advanced cancer and if circumstances allowed them to choose, except for Portugal where 51% preferred this. Standardization made little difference in estimates and CIs (Figure 1).

A preference for home death was more frequent amongst people aged 16–44 years than amongst those aged 45+ years (74 versus 67%; $P < 0.01$); differences were significant in all countries except Portugal ($P = 0.07$). Table S1 (available as supplementary data in *Annals of Oncology* online) shows variables where significant differences and linearity appeared when using data from all countries together (age, financial hardship and health) and sociodemographics with opposite country effects (gender, marital status and religion/denomination).

Nine factors were independently associated with a preference for home death cross-nationally (Figure 2). The influence of religion/denomination, being in paid work, being in education, level of concern with being alone and general health was examined but lost significance to other factors. The resulting model covered two groups of factors in our theoretical model—facilitating circumstances and personal values—but did not support the influence of prior experiences of illness, death and dying. Age was the strongest cross-national factor, ‘washing out’ the effect of health and co-existing with a retirement factor. The ORs of preferring to die at home decreased with age up to 60 years old and increased in the age

groups 60–69 and 70+ (although odds were still lower in these groups than in the reference group: 16–29). This U-shaped relationship and tailing up of preferences for home death in the older groups, particularly the 70+, was observed in all countries (to a greater or lesser extent) except England (Tables 2 and 3) where the preference fell slightly.

Country models added 11 country-specific factors and confirmed the influence of four factors in more than one country (Tables 3 and 4). Younger age up to 70+ (Portugal, Spain, the Netherlands, Germany), increased importance of dying in preferred place (England, Portugal, Spain, Germany), top goal being to keep a positive attitude (Spain, Germany) and wanting to involve family in decisions in a scenario of incapacity (Portugal, Flanders) were associated with a preference for home death. Country models explained 5% (Flanders and Portugal) to 13% (the Netherlands) of the variance in individual countries and correctly predicted 57% (Portugal) to 84% (the Netherlands) of preferences for home death.

discussion

Until now, evidence on preferences for place of death has been mainly from the USA or the UK and difficult to compare. In this first European Union (EU) population-based survey, we found that in all but one of the countries studied, at least two-thirds of people have a preference for home death if they were to die with a serious illness like advanced cancer. This prevalence is high but still varies and the most important factors are age and personal values.

These findings derive from a robust cross-national comparison. We used standard methodologies and asked identical questions across countries (reducing differential biases). The results not only provide country-specific factors (important since most policies are made at national level), but also cross-national data to inform international policymaking—while also taking into account local preferences.

The interview successfully explored an area of high sensitivity corroborating findings from pilot studies [17], validating the methods and the data. The study also has some limitations. The survey questionnaire gradually and sensitively directed participants towards a scenario of cancer; however, the framing also allowed them to draw on experiences from other advanced illnesses. Notwithstanding, cancer was the only single serious illness named and the word ‘cancer’ was used seven times in total throughout the questionnaire. This ensured the focus on cancer but we were not able to identify differences between illnesses. Our response rate is typical of the declining rates of RDD surveys [24] though in some countries, it is higher than the rates in the 2002 Picker Institute Europe survey of public views on health care responsiveness [25]. Our sample presents well-known selection biases excluding those living in households without a fixed telephone (29% of households in the EU-27) [26] and over-representing women and older people due to selective non-response. The selection bias towards women is unlikely to change estimates except in Germany (the only country where we found a gender effect; as men were more likely to prefer to die at home, the frequency of this preference in the German population is likely to be higher

Table 2. Preferences for place of death and participant characteristics by country

Variables ^{a,b}	England, N = 1351 n (%)	Flanders, N = 1269 n (%)	Germany, N = 1363 n (%)	Italy, N = 1352 n (%)	Netherlands, N = 1356 n (%)	Portugal, N = 1286 n (%)	Spain, N = 1367 n (%)	All countries, N = 9344 n (%)
Preferred place of death								
Own home	829 (63.0)	883 (71.6)	863 (66.0)	1007 (76.1)	1110 (83.1)	619 (50.3)	848 (66.1)	6159 (68.2)
Home of a relative or friend	15 (1.1)	16 (1.3)	16 (1.2)	8 (0.6)	12 (0.9)	11 (0.9)	13 (1.0)	91 (1.0)
Hospice or palliative care unit	381 (29.0)	122 (9.9)	324 (24.8)	159 (12.0)	140 (10.5)	440 (35.7)	215 (16.8)	1781 (19.7)
Hospital—but not palliative care unit	42 (3.2)	145 (11.8)	45 (3.4)	73 (5.5)	43 (3.2)	101 (8.2)	147 (11.5)	596 (6.6)
Care home	26 (2.0)	65 (5.3)	8 (0.6)	23 (1.7)	22 (1.6)	27 (2.2)	35 (2.7)	206 (2.3)
Elsewhere	23 (1.7)	3 (0.2)	52 (4.0)	54 (4.1)	9 (0.7)	33 (2.7)	24 (1.9)	198 (2.2)
Age								
Mean in years (SD)	54.2 (16.3)	52.2 (14.3)	47.1 (15.7)	48.7 (15.9)	54.5 (14.6)	50.1 (16.9)	48.1 (16.5)	50.7 (16.0)
16–29	107 (8.0)	88 (7.5)	213 (15.8)	177 (15.0)	61 (4.7)	169 (13.8)	204 (15.4)	1019 (11.5)
30–39	151 (11.3)	119 (10.2)	197 (14.6)	166 (14.1)	126 (9.7)	176 (14.4)	213 (16.1)	1148 (12.9)
40–49	255 (19.1)	261 (22.3)	361 (26.8)	241 (20.4)	289 (22.3)	231 (18.9)	279 (21.0)	1917 (21.6)
50–59	258 (19.4)	315 (27.0)	273 (20.3)	272 (23.1)	313 (24.2)	246 (20.1)	294 (22.2)	1971 (22.2)
60–69	317 (23.8)	256 (21.9)	184 (13.7)	209 (17.7)	306 (23.6)	226 (18.5)	198 (14.9)	1696 (19.1)
70+	244 (18.3)	129 (11.0)	119 (8.8)	115 (9.7)	199 (15.4)	175 (14.3)	139 (10.5)	1120 (12.6)
Gender								
Female	863 (63.9)	832 (65.6)	790 (58.0)	974 (72.0)	891 (65.8)	893 (69.4)	935 (68.4)	6178 (66.1)
Living arrangements								
Living alone	325 (24.2)	197 (15.6)	281 (20.8)	142 (10.5)	294 (21.8)	136 (10.6)	156 (11.5)	1531 (16.5)
Urbanization level								
Big city or suburbs/outskirts	500 (37.1)	289 (22.8)	556 (40.9)	269 (19.9)	363 (26.8)	643 (50.0)	324 (23.7)	2944 (31.5)
Town or small city	495 (36.7)	224 (17.7)	419 (30.8)	526 (39.0)	311 (23.0)	368 (28.6)	589 (43.1)	2932 (31.4)
Country village	287 (21.3)	591 (46.6)	301 (22.1)	521 (38.6)	578 (42.7)	221 (17.2)	401 (29.4)	2900 (31.1)
Farm or home in countryside	66 (4.9)	165 (13.0)	85 (6.2)	34 (2.5)	103 (7.6)	54 (4.2)	52 (3.8)	559 (6.0)
Marital status								
Married or with a partner	822 (61.3)	951 (75.7)	784 (58.1)	860 (63.8)	932 (69.2)	814 (63.6)	847 (62.2)	6010 (64.8)
Divorced or separated	175 (13.1)	100 (8.0)	152 (11.3)	86 (6.4)	110 (8.2)	91 (7.1)	100 (7.3)	814 (8.8)
Widowed	131 (9.8)	96 (7.6)	83 (6.2)	92 (6.8)	142 (10.5)	109 (8.5)	113 (8.3)	766 (8.3)
Single	212 (15.8)	110 (8.8)	330 (24.5)	310 (23.0)	162 (12.0)	265 (20.7)	301 (22.1)	1690 (18.2)
Religion/denomination								
With a religion or denomination	778 (57.9)	664 (52.9)	771 (57.0)	1094 (81.6)	616 (45.6)	1017 (79.6)	959 (71.0)	5899 (63.6)
Activities in last 7 days								
In paid work	637 (47.3)	649 (51.4)	871 (64.4)	590 (43.7)	709 (52.6)	561 (43.8)	562 (41.3)	4579 (49.2)
In education	88 (6.5)	101 (8.0)	178 (13.2)	135 (10.0)	80 (5.9)	98 (7.7)	155 (11.4)	835 (9.0)

Table 2. (Continued)

Variables ^{a,b}	England, N = 1351 n (%)	Flanders, N = 1269 n (%)	Germany, N = 1363 n (%)	Italy, N = 1352 n (%)	Netherlands, N = 1356 n (%)	Portugal, N = 1286 n (%)	Spain, N = 1367 n (%)	All countries, N = 9344 n (%)
Retired	480 (35.6)	362 (28.7)	289 (21.4)	330 (24.5)	342 (25.4)	353 (27.6)	245 (18.0)	2401 (25.8)
Unemployed	63 (4.7)	53 (4.2)	65 (4.8)	106 (7.9)	48 (3.6)	99 (7.7)	185 (13.6)	619 (6.7)
Permanently sick or disabled	64 (4.7)	46 (3.6)	159 (11.8)	12 (0.9)	108 (8.0)	38 (3.0)	54 (4.0)	481 (5.2)
Housework, looking after children or others	389 (28.9)	320 (25.3)	477 (35.3)	338 (25.1)	372 (27.6)	222 (17.3)	378 (27.8)	2496 (26.8)
Other	123 (9.1)	23 (1.8)	185 (13.7)	7 (0.5)	51 (3.8)	31 (2.4)	16 (1.2)	436 (4.7)
Financial hardship								
Living comfortably on present income	585 (43.8)	689 (55.2)	608 (45.5)	430 (32.2)	813 (60.9)	222 (17.5)	440 (32.6)	3787 (41.1)
Coping on present income	576 (43.1)	497 (39.8)	618 (46.2)	677 (50.7)	441 (33.0)	681 (53.6)	633 (46.9)	4123 (44.8)
Difficult on present income	136 (10.2)	60 (4.8)	85 (6.4)	203 (15.2)	62 (4.6)	239 (18.8)	203 (15.0)	988 (10.7)
Very difficult on present income	38 (2.8)	3 (0.2)	26 (1.9)	25 (1.9)	20 (1.5)	129 (10.1)	73 (5.4)	314 (3.4)
Health								
Very good	565 (42.0)	490 (38.6)	310 (22.9)	305 (22.6)	302 (22.3)	170 (13.3)	293 (21.5)	2435 (26.1)
Good	535 (39.8)	583 (46.0)	699 (51.5)	642 (47.6)	748 (55.3)	488 (38.1)	560 (41.1)	4255 (45.7)
Fair	191 (14.2)	176 (13.9)	289 (21.3)	377 (28.0)	254 (18.8)	558 (43.6)	437 (32.0)	2282 (24.5)
Bad	47 (3.5)	16 (1.3)	53 (3.9)	21 (1.6)	43 (3.2)	46 (3.6)	67 (4.9)	293 (3.1)
Very bad	7 (0.5)	3 (0.2)	5 (0.4)	3 (0.2)	5 (0.4)	19 (1.5)	7 (0.5)	49 (0.5)
Experience of illness, death and dying								
Diagnosed with serious illness in last 5 years	172 (12.8)	190 (15.2)	107 (8.0)	113 (8.4)	137 (10.1)	99 (7.8)	119 (8.8)	937 (10.1)
Close relative/friend seriously ill in last 5 years	849 (63.1)	760 (60.6)	862 (64.1)	900 (67.4)	969 (71.8)	728 (57.5)	923 (68.2)	5991 (64.8)
Death of close relative/friend in last 5 years	949 (70.6)	876 (69.9)	933 (69.4)	928 (69.3)	1036 (76.7)	771 (60.9)	1006 (74.4)	6499 (70.3)
Cared for close relative/friend in last months of life	679 (50.6)	625 (49.9)	647 (48.0)	815 (60.8)	702 (52.0)	673 (53.2)	771 (57.0)	4912 (53.1)

^aSums may not always amount to the total sample number because of missing values on variables. Percentages may not always add up to 100 because of rounding. SD = standard deviation.

^bThe percentage of missing data was 3.3% for preferred place of death, 5.1% for age, 0.03% for gender, 0.6% for living arrangements, 0.1% for urbanisation level, 0.7% for marital status, 1.1% for religion/denomination, 0.4% for each activity in last 7 days, 1.4% for financial hardship, 0.3% for health and 1.0% for each of the experiences of illness, death and dying. Missing data include 'don't know', refusals, interview break-offs and data missing from the CATI system.

than in our sample). The impact of over-representing older people is uncertain (a preference for home death is more frequent in younger people but increases in the oldest group). Notwithstanding, these limitations have little effect on cross-national comparisons (main study aim).

respecting diversity within Europe

Although more than two-thirds of our sample expressed a preference for home death, this percentage was lower in Portugal (51%) and others varied from 64% to 84%. This country variation is not explained by differences in age and gender distributions, as shown by standardized results. Explanations could relate to local EoLC or macro social, economic and cultural factors. For example, the Portuguese findings may reflect concerns with the limited availability of home care and resources in the community (e.g. equipment, access to drugs); this could also help explain why Portugal has the highest percentage of hospice/palliative care unit preferences and the third for hospital (after Spain and Belgium). Poorer economic circumstances [lowest gross domestic product at purchasing power parity per capita (GDP PPP) of the seven countries] [27] and a culture strong on traditional values such as the importance of religion, obedience to authority and conventional family values (versus secular-rational) and survival values giving priority to economic and physical security (versus self-expression) might also play a role. According to the World Values Survey, traditional and survival values are higher in Portugal than in most EU countries, including other Catholic countries such as Spain and Italy [18]. The strong respect for authority and the need to feel safe might help explain the higher preferences for hospital and hospices. In contrast, the highest preference for home death in the Netherlands may reflect the availability of home care, good economic circumstances (highest GDP PPP of the seven countries) [27] and a culture with a Protestant tradition where

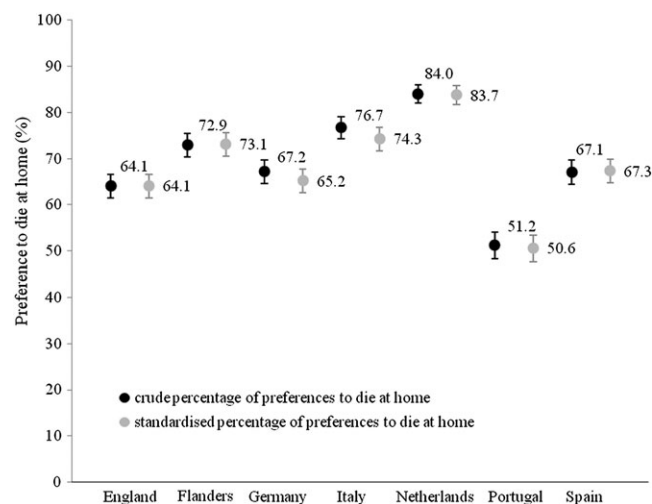


Figure 1. Crude and standardized percentages of preferences to die at home by country. Vertical bars are 95% confidence intervals. Standardized percentages were based on the age and gender distribution of the sample in England.

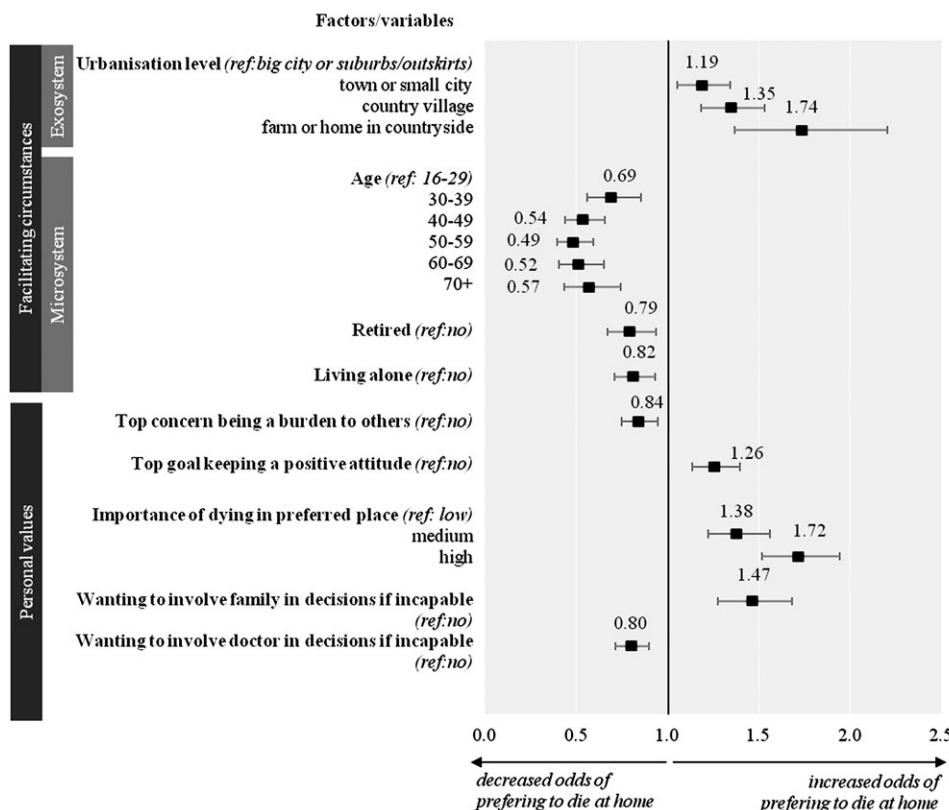


Figure 2. Factors influencing a preference for home death cross-nationally.

Table 3. Influence of cross-national factors on preferences for home death in each country

Cross-national factors	England OR (95% CIs)	Flanders OR (95% CIs)	Germany OR (95% CIs)	Italy OR (95% CIs)	Netherlands OR (95% CIs)	Portugal OR (95% CIs)	Spain OR (95% CIs)
Urbanization level (ref: big city or suburbs/outskirts)							
Town or small city	NS ^a	1.49 (1.01–2.19)	NS	NS	NS	NS	NS
Country village	NS	1.94 (1.41–2.66)	NS	NS	NS	NS	NS
Farm or home in countryside	NS	1.63 (1.06–2.52)	NS	NS	NS	NS	NS
Age (ref: 16–29)							
30–39	NS	NS	0.50 (0.31–0.79)	NS	0.78 (0.25–2.43)	0.79 (0.51–1.23)	0.53 (0.33–0.86)
40–49	NS	NS	0.50 (0.33–0.77)	NS	0.49 (0.18–1.31)	0.51 (0.33–0.78)	0.53 (0.33–0.84)
50–59	NS	NS	0.47 (0.31–0.73)	NS	0.29 (0.11–0.77)	0.46 (0.30–0.70)	0.39 (0.24–0.61)
60–69	NS	NS	0.33 (0.21–0.53)	NS	0.19 (0.07–0.51)	0.57 (0.37–0.87)	0.37 (0.22–0.61)
70+	NS	NS	0.46 (0.27–0.79)	NS	0.25 (0.09–0.71)	0.78 (0.48–1.24)	0.45 (0.25–0.80)
Retired (ref: no)	0.57 (0.45–0.73)	NS	NS	NS	NS	NS	NS
Top goal keeping a positive attitude (ref: no)	NS	NS	1.56 (1.21–2.02)	NS	NS	NS	1.73 (1.30–2.30)
Importance of dying in preferred place (ref: low)							
Medium	1.64 (1.23–2.19)	NS	1.47 (1.08–2.01)	NS	NS	1.47 (1.09–1.99)	1.63 (1.17–2.27)
High	2.56 (1.91–3.43)	NS	1.62 (1.21–2.18)	NS	NS	1.83 (1.37–2.43)	2.44 (1.77–3.36)
Wanting to involve family in decisions if incapable (ref: no)	NS	1.81 (1.32–2.48)	NS	NS	NS	1.70 (1.21–2.38)	NS
Wanting to involve doctor in decisions if incapable (ref: no)	NS	NS	NS	0.63 (0.48–0.83)	NS	NS	NS

^aExcluded from logistic regression because of non-significance.

NS, non-significant; OR, odds ratio; CIs, confidence intervals.

Table 4. Country-specific factors influencing a preference for home death

Country-specific effects ^a	England OR (95% CIs)	Flanders OR (95% CIs)	Germany OR (95% CIs)	Italy OR (95% CIs)	Netherlands OR (95% CIs)	Portugal OR (95% CIs)	Spain OR (95% CIs)
Top concern feeling as want to be sick (ref: no)	0.34 (0.16–0.73)	–	–	–	–	–	–
Health (ref: very good)							
Good	–	0.71 (0.54–0.95)	–	–	–	–	–
Fair	–	0.54 (0.36–0.79)	–	–	–	–	–
Bad	–	0.51 (0.18–1.46)	–	–	–	–	–
Very bad	–	0.17 (0.02–1.87)	–	–	–	–	–
Gender (ref: male)	–	–	0.63 (0.50–0.81)	–	–	–	–
In education in last 7 days (ref: no)	–	–	–	3.24 (1.75–5.97)	–	–	–
Country region (ref: North West)							
North East	–	–	–	0.93 (0.66–1.32)	–	–	–
Centre	–	–	–	1.08 (0.73–1.60)	–	–	–
South	–	–	–	2.07 (1.38–3.11)	–	–	–
Islands	–	–	–	1.99 (1.22–3.27)	–	–	–
Religion/denomination (ref: no)	–	–	–	–	0.55 (0.39–0.78)	–	–
Marital status (ref: married or with a partner)							
Divorced or separated	–	–	–	–	0.56 (0.31–0.99)	–	–
Widowed	–	–	–	–	0.31 (0.19–0.52)	–	–
Single	–	–	–	–	0.29 (0.18–0.47)	–	–
Top concern having no appetite at all (ref: no)	–	–	–	–	0.37 (0.20–0.70)	–	–
Wanting information about care options (ref: yes, always)							
Yes, but only if ask for it	–	–	–	–	0.51 (0.34–0.78)	–	–
No	–	–	–	–	1.52 (0.50–4.60)	–	–
Wanting information about symptoms and problems (ref: yes, always)							
Yes, but only if ask for it	–	–	–	–	–	–	0.96 (0.63–1.44)
No	–	–	–	–	–	–	0.37 (0.20–0.66)
Financial hardship (ref: living comfortably on present income)							
Coping on present income	–	–	–	–	–	–	0.62 (0.46–0.84)
Difficult on present income	–	–	–	–	–	–	0.91 (0.60–1.38)
Very difficult on present income	–	–	–	–	–	–	0.48 (0.26–0.88)

^aOnly significant factors are shown.

OR, odds ratio; CIs, confidence intervals.

secular–rational and self-expression values are amongst the highest in the world [18]. This country has the highest cancer home death rate of all seven studied [7].

Results from logistic regressions conducted separately in each country helped understand within-country diversity. These country models confirmed the influence of four factors in more than one country and added 11 country-specific factors to which national policies and clinical practice should be responsive. Some of these factors identify groups with a preference different from the majority (e.g. those with a religion or denomination in the Netherlands) that must be respected; others suggest inequity and circumstances that can hinder free choice (e.g. financial hardship in Spain) [28]. It is also important to note that across all countries, there is a substantial minority who prefer to die elsewhere, most often in hospices and palliative care units, thus provision of these services must develop to meet preferences for this group.

planning for ageing nations with more cancer deaths and EoLC needs

One of the major contributions from this study is its detailed examination of the influence of age, which was found to be the strongest factor influencing preferences. Across countries, a preference for home death becomes less frequent with age but this linearity reverses in the oldest age groups. It is difficult to isolate age and birth effects [29]. Is it because as people get older they calibrate their preference having witnessed others dying and experiencing cancer themselves? Or is it because different generations, born at different times, think differently about this issue? Our findings that experiences of illness, death and dying have no effect and that preferences for home death increase amongst the oldest suggest that both conditions may be involved but a definite answer is only possible through longitudinal cohort studies [29]. When planning future cancer EoLC careful consideration needs to be given to how baby-boom generations born after the Second World War (now in their 60's) will still have a strong preference for home death in 10–30 years time, to how public opinion is likely to evolve towards more recent cohorts [18] increasing the prevalence of a preference for home death, and to the impact of existing and new cancer EoLC policies on patients' preferences and actual place of death.

early assessment of values and preferences

Although public preferences are largely hypothetical and may change when people are faced with a diagnosis, 10% of those surveyed had been diagnosed with cancer or another serious illness in the last 5 years. We found no difference between their preferences and those of healthier counterparts. Better health was associated with preferences only in Flanders. For some of the healthier participants, it might have been difficult to imagine the actual circumstances surrounding the dying process and preceding months. This might have been easier for people with a previous experience of caring for someone close to them in the last months of life (53% of our sample). Yet, we found no influence of experiences of recent bereavement and caring for a close relative or friend in their last months of life. Although these are cross-sectional findings, they indicate that

a preference for home death may be an orientation more stable than previously thought [30] and unrelated to experiences of illness, death and dying. Replicating the survey with cancer patients at different stages of illness would help determine if and how hypothetical and 'real' preferences differ. Strong associations with aspects related to personal values (increased importance of dying in preferred place, wanting to keep a positive attitude above other things, wanting to involve family in decisions in a scenario of incapacity) suggest that preferences for place of death are intrinsically held and dependent largely on the individual's beliefs and value system. As people come closer to death, preferences may, however, change. Prospective studies showed that a minority of advanced cancer patients change their minds regarding where to die as they become sicker [31, 32], but to the best of our knowledge only one study commented on the significance of differences (found to be non-significant) [30]. As patients come closer to death, they may feel safer in institutional settings, particularly if care at home is difficult to manage in terms of support and resources for patients or caregivers, or both [33]. In these situations, it is even more important to address concerns and improve home care, so people can achieve their first choice.

Although knowing patients' values, wishes and preferences is central to practicing good EoLC in cancer, clinicians are often unaware of patients' preferences and bereaved families express concerns with the way clinicians communicate about shared decision making, as found in recent nationwide surveys in the USA and Belgium [34, 35]. The latter study demonstrated that patients' chances of dying at their preferred place improve substantially if their doctors are aware of their preferences. This stresses the need for a prompt assessment of patients' values and preferences in clinical practice as soon as a cancer with poor prognosis (or any other serious illness with poor prognosis) is identified [36]. Knowing the preferences of different population groups may help clinicians caring for advanced cancer patients to understand the baseline expectations of their patients and to approach, address or adjust these expectations as need be and as feasible. It is important to note that the people enquired in the survey are potentially future patients as a quarter of all deaths in Europe are caused by cancer and that despite falls in cancer mortality rates, absolute numbers of cancer deaths are predicted to have increased in Europe from 1.26 million in 2007 to 1.28 million in 2011 [37, 38].

policy focus on home care

The high prevalence of a preference for home death and the strong association with personal values suggest keeping home care at the heart of cancer EoLC in Europe. A continued focus on home care in national policies, such as the UK EoLC strategy [10], is therefore aligned with the preferences of populations. The consistent prevailing preference for home death across all the countries studied calls for an international cancer EoLC strategy focused on home care to better meet preferences within the European Region and beyond. A strong international research partnership now needs to address the dearth of evidence on home-based models of EoLC in Europe [39, 41], learning with successful local experiences [42] and

finding ways to maximize effectiveness and cost-effectiveness to inform policies and future care.

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disclosure

The authors declare no conflict of interest.

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