Original Article

PALLIATIVE MEDICINE

Palliative Medicine
2018, Vol. 32(4) 891–901

DOI: 10.1177/0269216317743961
journals.sagepub.com/home/pmj
SAGE

Risk factors for hospital death in conditions needing palliative care: Nationwide population-based death certificate study

Barbara Gomes[1,2], Maria João Pinheiro[3], Sílvia Lopes[3,4], Maja de Brito[2], Vera P Sarmento[2,5], Pedro Lopes Ferreira[6,7] and Henrique Barros[8]

Abstract

Background: Most people would prefer to die at home as opposed to hospital; therefore, understanding mortality patterns by place of death is essential for health resources allocation.

Aim: We examined trends and risk factors for hospital death in conditions needing palliative care in a country without integrated palliative care.

Design: This is a death certificate study. We examined factors associated with hospital death using logistic regression.

Setting/participants: All adults (1,045,381) who died between 2003 and 2012 in Portugal were included. We identified conditions needing palliative care from main causes of death: cancer, heart/cerebrovascular, renal, liver, respiratory and neurodegenerative diseases, dementia/Alzheimer's/senility and HIV/AIDS.

Results: Conditions needing palliative care were responsible for 70.7% deaths ($N = 738,566$, median age 80); heart and cerebrovascular diseases (43.9%) and cancer (32.2%) accounted for most. There was a trend towards hospital death (standardised percentage: 56.3% in 2003, 66.7% in 2012; adjusted odds ratio: 1.04, 95% confidence interval: 1.04–1.04). Hospital death risk was higher for those aged 18–39 years (3.46, 3.25–3.69 vs aged 90+), decreasing linearly with age; lower in dementia/Alzheimer's/senility versus cancer (0.13, 0.13–0.13); and higher for the married and in HIV/AIDS (3.31, 3.00–3.66). Effects of gender, working status, weekday and month of death, hospital beds availability, urbanisation level and deprivation were small.

Conclusion: The upward hospital death trend and fact that being married are risk factors for hospital death suggest that a reliance on hospitals may coexist with a tradition of extended family support. The sustainability of this model needs to be assessed within the global transition pattern in where people die.

Keywords

Mortality, health facilities, epidemiology, palliative care

What is already known about the topic?

- The global scenario of where people die is changing as some high-income countries shift towards death in the community.

[1]Faculty of Medicine, University of Coimbra, Coimbra, Portugal
[2]Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, UK
[3]National School of Public Health, Universidade Nova de Lisboa, Lisbon, Portugal
[4]Public Health Research Centre, National School of Public Health, Universidade Nova de Lisboa, Lisbon, Portugal
[5]Hospital Espírito Santo de Évora, Évora, Portugal
[6]Centre for Studies and Health Research of the University of Coimbra, Coimbra, Portugal
[7]Faculty of Economics, University of Coimbra, Coimbra, Portugal
[8]EPIUnit, Institute of Public Health of the University of Porto, Oporto, Portugal

Corresponding author:
Barbara Gomes, Faculty of Medicine, University of Coimbra, Polo III, Azinhaga de Santa Comba 3000-548 Coimbra, Portugal.
Emails: barbara.gomes@uc.pt; barbara.gomes@kcl.ac.uk

- Little is known about regions that still lack integrated palliative care and where hospitalisation trends persist.
- These regions constitute the majority worldwide and Portugal is an example in Europe.

What this paper adds?

- Based on death certificate data on over 1 million adults who died in Portugal, we found the prevalence of palliative care need in this country is higher than in England, using the same methodology (71% compared to 63%).
- Opposite to most evidence, in Portugal the risk of hospital death is higher for people dying from cancer and the married.
- The risk of dying in hospital decreased linearly with age and there were wide disparities in place of death according to cause of death.

Implications for practice, theory or policy

- Our findings suggest that a reliance on hospitals as best available care may coexist with a tradition of extended family support towards the end of life.
- The model of care we found in Portugal is likely to occur in many other countries with similar trends and may not be sustainable in the future.
- There is a need to strengthen home support if dying at home is to be a real option for more persons and their families.

Introduction

Where people die is a vital indicator of end-of-life care, important in relation to patient preference and with clear implications for health resources allocation in view of the most vulnerable.[1,2] There is a human rights concern with the stark incongruence between preferred and actual place of death. Most people would prefer to die at home but the majority die in hospital.[3,4] Furthermore, there are social variations suggesting inequity.[5,6] Palliative care provision increases the odds of home death.[7] However, the level of palliative care development differs worldwide, from countries with 'no known activity' to 'advanced health system integration'.[8–10] Most research focuses on countries in the latter group.

A combination of factors plays a role in where people die, including illness-related, individual and environmental factors.[5] However, we know very little about how this complex web of factors applies to countries with poor integration of palliative care into mainstream health services. These countries constitute the majority worldwide.[6,10] Knowledge of their reality would help understand what shapes place of death in a context that may offer less formal support to home death. Therefore, this study aims to examine trends and some critical risk factors for hospital death from conditions needing palliative care in a country lacking integrated palliative care – Portugal.

Methods

Study design and data source

This is a death certificate study using data for all individuals deceased with ⩾18 years old in Portugal (2003–2012), provided by the National Statistics Institute. We used an anonymised dataset; therefore, no ethical approval was required.

Identification of conditions needing palliative care

We used a well-established method for estimating palliative care need from death certificate data, recently used to project future palliative care need.[11,12] This is based on the selection of specific chronic diseases that are likely to have complex physical, psychological, social and/or spiritual problems that can be improved by either specialist or generalist palliative care services. The conditions included cancer, heart and cerebrovascular, renal, liver, respiratory and neurodegenerative diseases, dementia/Alzheimer's/senility and HIV/AIDS (Supplementary Appendix 1). These were identified from the main cause of death using the *International Statistical Classification of Diseases and Related Health Problems* – 10*th Revision* (ICD-10).

Classification of place of death

Place of death was classified in death certificates as follows: 'domicile' (any non-public or non-clinical place), 'hospital/clinic' (any clinical facility) or 'other place' (any public space). We recoded into hospital/clinic (called from now onwards 'hospital') versus elsewhere.

Independent variables

Gender, age at death (grouped for comparability with similar research in 18–39, 40–49, 50–59, 60–69, 70–79,

80–89, 90+),[6,13] country of birth (Portugal vs. others), residence of the deceased (nomenclature of territorial units for statistics (NUTS) II and III regions, 2002 definition), temporal variables (weekday, month and year of death), marital and working status and main cause of death were chosen based on the literature as potential explanatory variables from those available in death certificates.[5] We also analysed information regarding area of residence: urbanisation level (predominantly urban, mid-urban and predominantly rural), public hospital beds per 1000 inhabitants and deprivation level (European deprivation index).[14] Supplementary Appendix 2 shows further information about these variables.

Statistical analysis

We calculated crude and standardised percentages of deaths by place of death (direct standardisation, decedent population of 2003 as standard). In bivariate analysis, we explored associations between hospital death and independent variables, drawing attention to factors producing at least a five-point difference in percentages, a difference we believe healthcare and policy will be interested to explore further. We analysed variance inflation factor (VIF) values to examine multicollinearity, guided by the rule of thumb that if VIF $>$ 10, multicollinearity is high.[15] We then ran a multivariate logistic regression model using backwards likelihood-ratio elimination of variables, retaining those with p value $<$ 0.05. Interaction effects between age, gender and marital status were added to the models; we examined whether this changed the findings and improved the R^2. As sensitivity analysis, we ran models using forward selection to check if altering the variable selection procedure impacted on findings. We reported missing data, unadjusted and confounder-adjusted odds ratios (AORs) with 95% confidence intervals (CIs). To judge the influence of the different factors, we examined the magnitude of associations through differences in the percentages of hospital deaths (in bivariate analysis) and AORs for hospital death (in multivariate analysis). Analysis was performed with complete cases in IBM SPSS version 23.

Results

Death caused by conditions needing palliative care

There were 1,052,754 registered deaths in Portugal (2003–2012), of which 1,045,381 occurred at ages ⩾18 (7220 occurred at ages <18, age was unknown for 153). Of the included persons, 738,566 died due to a condition needing palliative care, representing 70.7% of adult deaths (72.9% in 2003, 70.2% in 2012). In addition, 10.4% of all adult deaths were caused by signs, symptoms and ill-defined conditions (ICD-10 codes R00-R99), 4.3% had external causes and 14.7% had other causes.

Annual numbers of adult deaths caused by conditions needing palliative care fluctuated between 70,006 and 78,840 without a clear overall time trend; they declined over time until the age of 80 and increased thereafter (10.2% increase in the aged 80–89, 23.8% in the 90+). Median age at death rose from 79 (interquartile range (IQR), 69–86) to 81 (72–87) years old (Table 1). Men died at median age of 77 (67–84) and mostly married (63%), while women died at median age of 82 (75–88) and mostly widowed (58%). The majority (61.3%) lived in predominantly urban areas (Supplementary Appendix 3). Heart diseases including cerebrovascular (43.9%) and cancer (32.2%) accounted for most deaths from conditions needing palliative care (Table 1). While cancer became more common over time (28.7% to 34.1%), heart diseases reduced (48.8% to 40.7%).

Trends in hospital death

Hospital was the most common place of death in conditions needing palliative care (61.9%), with percentages increasing linearly from 56.3% in 2003 to 65.1% in 2012. This increase was not explained by changes in decedents' age and gender as it maintained with standardised percentages (Figure 1). Annual numbers of hospital deaths increased by 10.6% during the 10 years studied (44,384 to 49,073; mean increase of 1.3% per year).

The increase in hospital death was more evident in cancer (69.1% hospital deaths in 2003 to 77.1% in 2012), respiratory diseases (68.7%–78.5%) and neurodegenerative diseases (50.2%–58.4%). It was also more evident in the oldest old (90+), although this remained the group with the lowest percentage of hospital deaths (Figure 2).

Factors associated with hospital death

Bivariate analysis showed associations between hospital death and all examined factors (Table 2) and there was no multicollinearity (all VIF values <3). The strongest associations with place of death concerned individual characteristics. Among these, the largest variations were observed for age and cause of death and the smallest for gender and country of residence. There was a gradual and large decrease of hospital deaths as age advanced; 83.5% of those aged 18–39 died in hospital compared to 43.2% of the aged 90+. Hospital death was more common in cancer (74.2%) than in non-malignant conditions (56.0%); within the latter group, it varied from 19.5% in dementia/Alzheimer's/senility to 92.2% in HIV/AIDS.

The smallest differences concerned temporal variations; hospital death ranged from 59.6% in January to 64.4% in September and from 61.1% on Sundays to 62.3% on Tuesdays (Supplementary Appendix 4). In contrast, there was wide regional variation; hospital death ranged from 58.0% in the North to 79.6% in the Madeira Islands. Urbanisation level was the most influential area-level

Table 1. Characteristics of all adults deceased due to conditions needing palliative care in Portugal.

	2003–2012	2003	2012
	N = 738,566	*N* = 78,840	*N* = 75,360
Gender			
Male	378,172 (51.2)	40,044 (50.8)	38,229 (50.7)
Female	360,394 (48.8)	38,796 (49.2)	37,131 (49.3)
Age			
Median (IQR; min–max)	80 (70–86; 18–114)	79 (69–86; 18–109)	81 (72–87; 18–110)
18–39	10,872 (1.5)	1608 (2.0)	711 (0.9)
40–49	23,774 (3.2)	2721 (3.5)	2023 (2.7)
50–59	48,948 (6.6)	5131 (6.5)	4772 (6.3)
60–69	88,883 (12.0)	10,306 (13.1)	8625 (11.4)
70–79	193,062 (26.1)	22,327 (28.3)	17,381 (23.1)
80–89	269,570 (36.5)	26,782 (34.0)	29,516 (39.2)
90+	103,457 (14.0)	9965 (12.6)	12,332 (16.4)
Underlying cause of death			
Malignant neoplasm	237,516 (32.2)	22,652 (28.7)	25,693 (34.1)
Heart disease including cerebrovascular	324,536 (43.9)	38,497 (48.8)	30,705 (40.7)
Renal disease	15,727 (2.1)	1644 (2.1)	1323 (1.8)
Liver disease	19,675 (2.7)	2208 (2.8)	1678 (2.2)
Respiratory disease	85,762 (11.6)	7123 (9.0)	10,791 (14.3)
Neurodegenerative disease	7134 (1.0)	647 (0.8)	889 (1.2)
Dementia/Alzheimer's/senility	40,880 (5.5)	5095 (6.5)	3778 (5.0)
HIV/AIDS	7336 (1.0)	974 (1.2)	503 (0.7)
Place of death			
Hospital/clinic	456,900 (61.9)	44,384 (56.3)	49,073 (65.1)
Domicile	237,015 (32.1)	29,864 (37.9)	21,437 (28.4)
Other place	44,651 (6.0)	4592 (5.8)	4850 (6.4)
Marital status			
Married	335,556 (45.6)	34,839 (44.3)	33,627 (44.7)
Single	80,420 (10.9)	9275 (11.8)	7669 (10.2)
Widowed	291,815 (39.6)	32,005 (40.7)	30,290 (40.3)
Divorced	28,344 (3.9)	2448(3.1)	3567 (4.7)
Working status			
Non-active	675,560 (91.5)	72,780 (92.3)	69,749 (95.8)
Unemployed	1489 (0.2)	61 (0.1)	147 (0.2)
Working	47,543 (6.4)	5999 (7.6)	2878 (4.0)
Country of birth			
Portugal	713,399 (96.6)	76,330 (96.8)	75,591 (96.3)
Other	25,141 (3.4)	2510 (3.2)	2767 (3.7)
Country of residence			
Portugal	736,454 (99.7)	78,645 (99.8)	75,183 (99.8)
Other	2088 (0.3)	195 (0.2)	171 (0.2)

IQR: interquartile range.
Table presents numbers of deaths and percentages calculated in columns. Missing data: marital status unknown (*N* = 2431, 0.3%); working status unknown (*N* = 13,974, 1.9%); country of birth unknown (*N* = 26, 0.0%); country of residence unknown (*N* = 24, 0.0%).

factor but the differences were small (Supplementary Appendix 5); hospital death was less common in rural regions (58.1%), increasing slightly in mid-urban regions (58.6%) and further in urban regions (64.0%).

The multivariate model of factors associated with hospital death retained all variables except country of birth. Aligned with bivariate results, the most influential factors during the decade in analysis were age and cause of death, followed by year of death, region of residence (NUTS II) and marital status. Accounting for other factors had no impact on the year of death effect; the odds of hospital death increased 4% per year (Table 3).

The age effect remained strong and linear but decreased in magnitude. Notwithstanding, people aged 18–39 had

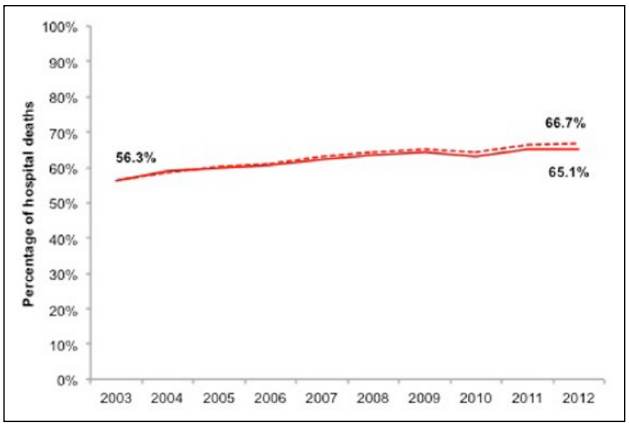

Figure 1. Crude and standardised percentages of hospital deaths.
Dashed line shows age- and gender-standardised percentages.

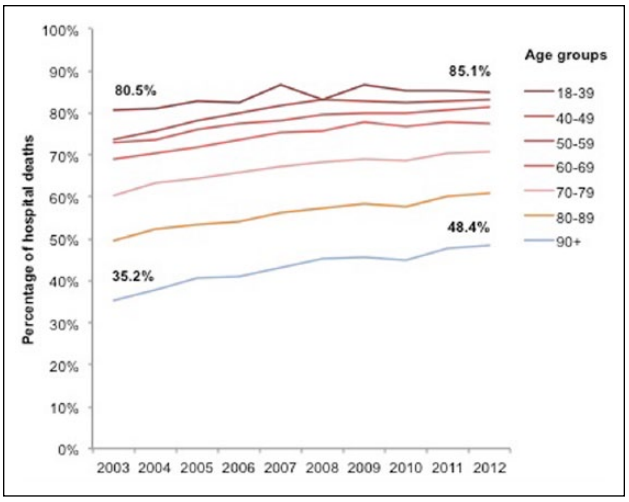

Figure 2. Trends in percentages of hospital deaths by age group.

three times greater odds of dying in hospital compared to those aged 90+. The direction of differences by cause of death also remained the same. Compared to cancer, the odds of hospital death were higher in respiratory, liver and renal diseases and HIV/AIDS and lower in heart and neurodegenerative diseases and dementia/Alzheimer's/senility. Hospital death odds were three times higher for HIV/AIDS patients compared to cancer patients and reduced by 87% for those dying from dementia/Alzheimer's/senility. Hospital death odds remained lowest in the North (adjusted odds ratio (AOR): 0.83, 95% confidence interval (CI): 0.82–0.84) and highest in the Madeira Islands (2.15, 2.06–2.24), compared to the capital region.

The association with marital status changed once confounders were controlled for. People who were married had higher odds of dying in hospital than all others (single AOR: 0.67, 95% CI: 0.65–0.68; widowed: 0.81, 0.80–0.82; divorced: 0.80, 0.78–0.82). The effects of gender, working status, weekday and month of death, hospital beds availability, urbanisation level and deprivation remained small (Table 3).

Using forward selection rather than backwards elimination of variables produced the same results. Interaction terms (involving gender, age and marital status) were statistically significant. However, adding them did not improve the R^2 (0.18) nor changed substantially the parameter estimates for main effects. Gender lost statistical significance when the interaction between gender and marital status was accounted for but remained statistically significant in the model including the three-way interaction between gender, age and marital status (Supplementary Appendix 6).

Discussion

How many people need palliative care

We found that nearly three in every four deaths in Portugal (70.7%) are caused by conditions that would benefit from the provision of palliative care. The estimate falls between figures in England (63%) and Ireland (80%) using the same methodology.[11,16] It is higher than that obtained in a study of 14 other countries (range, 25%–49%),[6] but this used a more conservative classification of palliative care need which excluded several diseases where palliative care is beneficial, for example, multiple sclerosis.

Hospitalisation of dying trend and clinical heterogeneity

Most deaths caused by conditions needing palliative care took place in hospital (61.9%), with annual numbers increasing by 1% a year. This trend is opposite to countries such as England,[17] the United States[2] and Canada[18] where palliative care is well developed and home deaths are increasing. It also differs from other countries in advance stages of palliative care integration; in Germany, the Netherlands and Belgium, there has been a shift away from hospitals into care homes, with home deaths reducing in Germany and remaining stable in the Netherlands and Belgium.[19–21] Greece (where there is only 'isolated palliative care provision')[10] presents a trend towards hospitalised dying in cancer that is similar to Portugal but not as rapid.[22]

In contrast with most international findings,[6,13] in Portugal dying from cancer (as opposed to a non-malignant disease) acts as a risk rather than protective factor for death in hospital. Nearly 8 in 10 cancer deaths took place in hospital in 2012. This is surprising as cancer shows a more predictable disease trajectory and cancer patients have better access to palliative care.[23] Our finding could be explained by a combination of factors: cancer care is generally centralised in specialist hospitals, aggressive therapies are often pursued until late in the disease course[24] and palliative care services reach very few as capacity is low, especially in home care.[25]

Table 2. Individual variation in place of death: bivariate analysis.

	Place of death		Tests	
	Hospital	Elsewhere	Test and result	*p*-value
Gender				
Male	251,600 (66.5)	126,572 (33.5)	$\chi^2 = 7156.22$	<0.000
Female	205,300 (57.0)	155,094 (43.0)		
Age				
Median (IQR; min–max)	77 (67–84; 18–110)	83 (75–88; 18–114)		
18–39	9078 (83.5)	1749 (16.5)	M-W = −192.825	<0.000
40–49	19,045(80.1)	4729 (19.9)		
50–59	38,142 (77.9)	10,806 (22.1)		
60–69	66,084 (74.3)	22,799 (25.7)		
70–79	128,535 (66.6)	64,527 (33.4)		
80–89	151,300 (56.1)	118,270 (43.9)		
90+	44,716 (43.2)	58,741 (56.8)		
Underlying cause of death				
Malignant neoplasm	176,327 (74.2)	61,189 (25.8)	$\chi^2 = 75{,}719.22$	<0.000
Heart disease including cerebrovascular	168,743 (52.0)	155,793 (48.0)		
Renal disease	12,250 (77.9)	3477 (22.1)		
Liver disease	16,321 (83.0)	3354 (17.0)		
Respiratory disease	64,761 (75.5)	21,001 (24.5)		
Neurodegenerative disease	3747 (52.5)	3387 (47.5)		
Dementia/Alzheimer's/senility	7986 (19.5)	32,894 (80.5)		
HIV/AIDS	6765 (92.2)	571 (7.8)		
Marital status				
Married	231,341 (68.9)	104,215 (31.1)	$\chi^2 = 16{,}251.01$	<0.000
Single	48,034 (59.7)	32,386 (40.3)		
Widowed	156,517 (53.6)	135,298 (46.4)		
Divorced	19,528 (68.9)	8816 (31.1)		
Working status				
Non-active	406,916 (60.2)	268,644 (39.8)	$\chi^2 = 6468.76$	<0.000
Unemployed	1224 (82.2)	265 (17.8)		
Working	37,280 (78.4)	10,263 (21.6)		
Country of birth				
Portugal	439,697 (61.6)	273,702 (38.4)	$\chi^2 = 463.79$	<0.000
Other	17,183 (68.3)	7958 (31.7)		
Country of residence				
Portugal	455,411 (61.8)	281,043 (38.2)	$\chi^2 = 62.57$	<0.000
Other	1467 (70.3)	621 (29.7)		

IQR: interquartile range; M-W: Mann–Whitney *U* test (standardised result shown).
Table presents numbers of deaths and percentages calculated in rows.

Cultural issues may also play a role. Disclosure of cancer diagnosis and prognosis occurs less often than in other countries,[26] which may hinder conversations about critical end-of-life decisions including place of death.

The group of non-malignant conditions showed wide clinical heterogeneity. Only one in five patients who died from dementia/Alzheimer's/senility died in hospital. It is known the dwindling disease trajectory leads many to move to a care home where the level of under-reporting of these causes of death seems to be lower.[27] This place of death is recorded in Portugal as 'domicile', therefore care must be taken when interpreting data. Our percentage of hospital death for this group is the lowest found in Europe, except for the Netherlands where only 1.6% of dementia deaths occur in hospital, probably due to the existence of specialised nursing home physicians.[28]

In contrast, 9 in 10 deaths due to HIV/AIDS took place in hospital. Although there might be under-reporting due to stigma (possibly biased towards hospital), an uncertain disease trajectory, marked with sudden episodes of illness and infections, is likely to lead to death in hospital. Notwithstanding, United States trends during the HIV epidemic showed a reduction in hospital deaths among AIDS patients from 92% in 1983 to 57% in 1991.[29] Although the

Table 3. Factors associated with hospital death: logistic regression.

	Hospital death			
	Bivariate		Multivariate	
	OR	95% CI	AOR	95% CI
Gender				
Male	1.50	1.49–1.52	1.02	1.01–1.03
Female	1.00	–	1.00	–
Age group				
18–39	6.65	6.31–7.00	3.46	3.25–3.69
40–49	5.29	5.11–5.47	2.94	2.82–3.07
50–59	4.64	4.52–4.75	2.67	2.58–2.75
60–69	3.81	3.73–3.88	2.41	2.35–2.46
70–79	2.62	2.58–2.66	1.95	1.92–1.99
80–89	1.68	1.66–1.70	1.45	1.43–1.48
90+	1.00	–	1.00	–
Underlying cause of death				
Malignant neoplasm	1.00	–	1.00	–
Heart disease including cerebrovascular	0.38	0.37–0.38	0.49	0.49–0.50
Renal disease	1.22	1.18–1.27	1.66	1.59–1.72
Liver disease	1.69	1.62–1.75	1.55	1.49–1.61
Respiratory disease	1.07	1.05–1.09	1.48	1.46–1.51
Neurodegenerative disease	0.38	0.37–0.40	0.42	0.40–0.44
Dementia/Alzheimer's/senility	0.08	0.08–0.09	0.13	0.13–0.13
HIV/AIDS	4.11	3.77–4.48	3.31	3.00–3.66
Marital status				
Married	1.00	–	1.00	–
Single	0.67	0.66–0.68	0.67	0.65–0.68
Widowed	0.52	0.52–0.53	0.81	0.80–0.82
Divorced	1.00	0.97–1.02	0.80	0.78–0.82
Working status				
Non-active	1.00	–	1.00	–
Unemployed	3.05	2.67–3.48	1.09	0.94–1.25
Working	2.40	2.34–2.45	1.04	1.01–1.07
Country of birth				
Portugal	1.00	–	–	–
Other	1.34	1.31–1.38	–	–
Country of residence				
Portugal	1.00	–	–	–
Other	1.46	1.33–1.60	–	–
Year	1.04	1.04–1.04	1.04	1.04–1.04
Month				
January	1.00	–	1.00	–
February	1.03	1.01–1.05	1.03	1.01–1.05
March	1.05	1.03–1.08	1.04	1.01–1.06
April	1.10	1.07–1.12	1.07	1.04–1.09
May	1.12	1.10–1.15	1.07	1.04–1.10
June	1.17	1.15–1.20	1.12	1.09–1.15
July	1.18	1.16–1.21	1.12	1.10–1.15
August	1.18	1.15–1.20	1.12	1.10–1.15
September	1.22	1.20–1.25	1.15	1.12–1.18
October	1.15	1.12–1.18	1.08	1.06–1.11
November	1.09	1.07–1.12	1.06	1.04–1.09
December	1.02	1.00–1.04	1.01	0.99–1.03

(Continued)

Table 3. Continued

	Hospital death			
	Bivariate		Multivariate	
	OR	95% CI	AOR	95% CI
Weekday				
Monday	1.02	1.00–1.03	1.01	0.99–1.03
Tuesday	1.05	1.04–1.07	1.04	1.02–1.06
Wednesday	1.05	1.03–1.07	1.04	1.02–1.06
Thursday	1.05	1.03–1.07	1.04	1.02–1.06
Friday	1.04	1.03–1.06	1.04	1.02–1.06
Saturday	1.03	1.01–1.04	1.02	1.00–1.04
Sunday	1.00		1.00	
NUTS II region of residence				
Lisbon	1.00	–	1.00	–
North	0.76	0.75–0.77	0.83	0.82–0.84
Algarve	1.27	1.24–1.31	1.65	1.60–1.70
Centre	0.85	0.84–0.87	1.08	1.06–1.10
Alentejo	0.81	0.80–0.83	1.07	1.04–1.09
Autonomous Region of Azores (islands)	1.53	1.48–1.59	1.71	1.65–1.78
Autonomous Region of Madeira (islands)	2.15	2.07–2.24	2.15	2.06–2.24
Urbanisation level				
Predominantly urban	1.28	1.27–1.30	1.16	1.14–1.17
Mid-urban	1.02	1.00–1.03	1.00	0.98–1.02
Predominantly rural	1.00	–	1.00	–
EDI score (quintile)				
1 (least deprived)	1.00	–	1.00	–
2	0.95	0.93–0.96	1.01	0.99–1.02
3	0.86	0.84–0.87	0.97	0.95–0.98
4	0.85	0.84–0.86	0.96	0.94–0.97
5 (most deprived)	0.87	0.86–0.89	1.03	1.01–1.05
Public hospital beds availability (tercile)				
1 (<1.677 beds per 1000 inhabitants)	1.00	–	1.00	–
2	1.07	1.06–1.09	1.02	1.01–1.03
3 (>2.409 beds per 1000 inhabitants)	1.23	1.22–1.25	1.12	1.10–1.13

OR: odds ratio; CI: confidence interval; AOR: adjusted odds ratio; EDI: European deprivation index; NUTS: nomenclature of territorial units for statistics.
The multivariate logistic regression model was run using backwards likelihood-ratio elimination of variables.
Factors were retained if p-value < 0.05. Model statistics: 715,727 cases included (96.9%). Nagelkerke $R^2 = 0.176$, Hosmer–Lemeshow $\chi^2(8) = 231{,}531$, $p < 0.001$. Correctly classified 83.9% of hospital deaths and 41.3% of deaths elsewhere, with an overall success rate of 67.4%.

way and reasons why people die today with HIV infection are very different from before antiretroviral therapy was available, the establishment of outpatient clinics, greater access to nursing home programmes and hospice care, and increasing numbers of community-based HIV specialists are likely to have played a role in that striking reduction of hospital death in the United States. This demonstrates that more can be done, even in high-risk groups, to overturn hospitalisation trends and improve choice on place of death.

Social factors

The effects on place of death of a 'social triangle' constituted by gender, marital status and age may reveal how end-of-life care is handled in a given society. In Portugal, men, younger and married people are at higher risk of hospital death. The typical situation of when all variables of this triangle combine to achieve the lowest risk of hospital death is that of a very old woman who is usually widowed and lives with family or in a care home (both considered 'domicile'). The typical high risk of hospital death situation is a young married man likely to have a young wife and children.

The findings for gender and age are not surprising, an analysis of 14 countries found the same results in most.[6] The findings on marital status, however, are opposite to what most other studies find. The married are a group that usually has increased chances of dying at home;[5,6] it is

thought that this happens because being married often means that there is a live-in relative who helps care at home. However, it is possible that spousal caregiver fatigue and burnout might be higher than those of other caregivers (family or formal when no family is involved). Spouses are older than offspring and therefore more likely to experience health problems, which may impact on their ability to care at home. It is also plausible that the patient is more concerned with the burden that death at home might impose on his wife or her husband and possibly the long-lasting consequences as many will keep living in the same home after the patient dies. However, these potential explanations apply to other countries too and therefore do not fully explain the differential finding on the relationship between marital status and place of death. Contextual factors, such as the particularly advanced age people die in Portugal, the tradition of extended family support, the lack of home palliative care and the hospital-centric culture, might be potential reasons that shape the relationship between marital status and place of death. Caregivers (usually daughters) often live with the patient or take the patient to their home to be able to provide care.[30]

Still, the 'gold standard' of formal care continues to be seen as provided in hospitals. The population is likely to perceive that there is more support in hospitals than at home. Findings from a survey in 2010 showed a lower preference for home death in Portugal compared to six other European countries (51% vs. 64% in England to 84% in the Netherlands).[31] Despite having hospital bed availability below the average across Organisation for Economic Co-operation and Development (OECD) countries and cuts in bed numbers, Portugal has the highest use of emergency departments across OECD countries[32] and its length of stay in acute care is also among the highest. The creation of a national network of continuing care in 2006, which included continuing and palliative care inpatient units and home teams, seemed unable to counteract this hospital culture, as seen in Figure 1. In 2013 (1 year after the last in study), there were only 24 palliative care units and 9–14 home palliative care teams in the country (10 million residents), an offer which is insufficient and disparate across regions.[33] Furthermore, family doctors rarely visit patients at home and this is a critical barrier to supporting patients to die at home.[34] An expansion of specialist and non-specialist home palliative care is needed.

Our finding on the effect of socio-economic conditions (deprivation) also differs from most literature.[5] The results suggest that the level of poverty of the area someone lives in has limited influence on the risk of hospital death. However, this should be interpreted with caution as the deprivation index used is still in early stages of development, derives from 2001 Census data and may underestimate severe material deprivation.[13] The finding warrants further investigation.

Geography

Geography appears to be an important factor. Hospital death percentages ranged from 58.0% to 69.7% in mainland and were highest in the islands (73.5% in Azores, 79.6% in Madeira). This was not explained by urbanisation level and hospital beds availability, although other factors such as the greater distance from hospitals in sparsely populated areas and the availability of other local care providers and social support may play a role. The high hospital death percentages in the islands are difficult to explain. The migration and emigration exodus from relatives of patients in the islands could be a potential explanation but a negative migration balance is also present in the mainland, particularly in the North region, where hospital death percentages are lowest. The geographical, population and health services distribution within the two island groups may play a role. Madeira consists of three islands (one not inhabited) with 98% of the population living in the main one (334 km^2), where the hospital is based. There is a well-established regional palliative care network providing home care since 2012 but also a lack of generalist home support and few alternatives to hospital (e.g. care homes). Azores, however, consists of nine islands with 430 to 137,699 inhabitants in each and a distance between them that ranges from 9 to 602 km. Three of the nine islands have hospitals and during the study period there was no specialist palliative care service in Azores. There is a dearth of evidence on place of death and its determinants in regions with small islands but our findings suggest islanders appear to be at greater risk of dying in hospital, hence we call for further research on this matter.

Limitations

The limitations of analysing routinely collected mortality data include the possibility of filling and coding errors, as well as changes in diagnostic and coding processes. The fact that the data are filled in by the doctor who certifies the death and that coding systems remained the same during the study period provides reassurance that the information is correct and consistent over time. The percentage of deaths caused by signs, symptoms and ill-defined conditions (10.4%) is much lower than in earlier times and very close to the $<10\%$ threshold proposed by Mathers et al.[35] for high-quality mortality data.

An important limitation is that the coding of place of death in Portuguese death certificates includes only three categories (domicile, hospital/clinic, other place). In this classification, deaths taking place in care homes are coded as 'domicile' and deaths taking place in palliative care units that are based within hospitals are coded as 'hospital/clinic'. However, dying in a palliative care unit may be very different from dying in another hospital service, for example, the emergency department. Also, dying in a care

home is not necessarily the same as dying at one's own home. Aligned with a recent call for standardising records of place of death,[1] we highlight the need for categories that are clearly distinguished in preference surveys,[31] mainly 'palliative care unit', 'home' and 'care home'.

Other limitations include unmeasured confounding (e.g. preferences), potential for measurement bias on marital status (de facto unions were not captured, though they account for <3% of the population), possibility of ecological fallacy (i.e. generalising area information to all individuals within) and of changes in the area descriptors analysed (most derived from 2001 Census data).

Conclusion

Our findings show that the reality for place of death in Portugal is different to countries where palliative care is well established: there is a steady upward hospital death trend and dying from cancer, a disease with a more predictable trajectory than others, acts as a risk rather than protective factor for hospital death. This may apply to other aged countries with high-level of need but without integrated palliative care.

While a cultural pattern of extended family support may persist, it seems to coexist with a reliance on hospitals as providers of the best available care in a hospital-centric health system. This may shape the fact that younger patients and married people are at higher risk of dying in hospital. In this context, hospital beds availability, urbanisation level and deprivation do not seem very influential.

The sustainability of this model needs to be assessed in light of the global emerging transition pattern in where people die and taking into account future challenges. As the population ages further and older people are more likely to die out of hospital, the current hospitalisation of dying trend may attenuate but only if the observed patterns of family caregiving persist. This is unlikely as families are becoming smaller and more disperse. Home support must therefore develop so that dying at home is a real option in response to people's preferences, supported with the best quality care, available in a fair manner to more persons and their families in the future.

Acknowledgements

This work was supported by the Calouste Gulbenkian Foundation as part of the DINAMO Project, which aims to enhance advanced training and research to optimise home palliative care in Portugal (Principal Investigator – Barbara Gomes, Scientific Director – Irene J. Higginson, other members – Pedro L. Ferreira, Helder Aguiar, Ana F. Lacerda, Vera P. Sarmento, Duarte Soares, Rita Canario, Maja de Brito, Catarina Ribeiro, Diogo M. Branco). We thank the National Institute of Statistics in Portugal for providing the mortality database, access to the safe centre and on-site support; Ana Isabel Ribeiro and all other authors of the European Deprivation Index for providing scores and quintiles for Portugal; and Natalia Calanzani for helping with the preparation of area-level variables. B.G. is principal investigator and conceived the study with M.J.P. and S.L. B.G. and V.P.S. negotiated data access with the National Institute of Statistics in Portugal. B.G. and M.d.B. analysed the data and interpreted the results together with S.L. and with contributions from all other authors. B.G. drafted the manuscript; all authors read and approved the final manuscript.

Data availability

The data that support the findings of this study are available from National Statistics Institute (https://www.ine.pt) but restrictions apply to the availability of these data, which were used under license for this study and so are not publicly available.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This study was funded by the Calouste Gulbenkian Foundation.

Research ethics and patient consent

We used an anonymised dataset, therefore no ethical approval was required.

References

1. Pivodic L, Higginson IJ, Sarmento VP, et al. Health metrics: standardize records of place of death. *Nature* 2013; 495(7442): 449.
2. Rothman DJ. Where we die. *N Engl J Med* 2014; 370(26): 2457–2460.
3. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12(1): 7.
4. Broad JB, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health* 2013; 58(2): 257–267.
5. Gomes B and Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332(7540): 515–521.
6. Pivodic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health* 2016; 70(1): 17–24.
7. Gomes B, Calanzani N, Curiale V, et al. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev* 2013; 6(6): CD007760.
8. World Health Organization (WHO). *Strengthening of palliative care as a component of comprehensive care throughout the life course*. Report no. WHA67.19, WHO, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (2014, accessed 1 July 2016).

9. Knaul FM, Farmer PE, Bhadelia A, et al. Closing the divide: the Harvard Global Equity Initiative-Lancet Commission on global access to pain control and palliative care. *Lancet* 2015; 386(9995): 722–724.
10. Worldwide Palliative Care Alliance (WPCA). *Global atlas of palliative care at the end of life*. London: WPCA, 2014.
11. Murtagh FE, Bausewein C, Verne J, et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014; 28(1): 49–58.
12. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017; 15: 102.
13. Cohen J, Houttekier D, Onwuteaka-Philipsen B, et al. Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol* 2010; 28(13): 2267–2273.
14. Guillaume E, Pornet C, Dejardin O, et al. Development of a cross-cultural deprivation index in five European countries. *J Epidemiol Community Health* 2016; 70(5): 493–499.
15. Kutner MH, Nachtsheim CJ and Neter J. *Applied linear regression models*. 4th ed. New York: McGraw-Hill Education, 2004.
16. Kane PM, Daveson BA, Ryan K, et al. The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. *J Pain Symptom Manage* 2015; 49(4): 726–733.
17. Gomes B, Calanzani N and Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med* 2012; 26: 102–107.
18. Wilson DM, Truman CD, Thomas R, et al. The rapidly changing location of death in Canada, 1994-2004. *Soc Sci Med* 2009; 68(10): 1752–1758.
19. Dasch B, Blum K, Gude P, et al. Place of death: trends over the course of a decade: a population-based study of death certificates from the years 2001 and 2011. *Dtsch Arztebl Int* 2015; 112(29–30): 496–504.
20. Van der Velden LF, Francke AL, Hingstman L, et al. Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data. *BMC Palliat Care* 2009; 8: 4.
21. Houttekier D, Cohen J, Surkyn J, et al. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health* 2011; 11: 228.
22. Mystakidou K, Parpa E, Tsilika E, et al. Where do cancer patients die in Greece? A population-based study on the place of death in 1993 and 2003. *J Pain Symptom Manage* 2009; 38(2): 309–314.
23. Goncalves F, Almeida A, Antunes C, et al. A cross-sectional survey of the activity of palliative care teams in Portugal. *Am J Hosp Palliat Care* 2013; 30(7): 648–651.
24. Braga S, Miranda A, Fonseca R, et al. The aggressiveness of cancer care in the last three months of life: a retrospective single centre analysis. *Psychooncology* 2007; 16(9): 863–868.
25. Sarmento VP, Higginson IJ, Ferreira PL, et al. Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliat Med* 2016; 30(4): 363–373.
26. Ferraz Goncalves J and Castro S. Diagnosis disclosure in a Portuguese oncological centre. *Palliat Med* 2001; 15(1): 35–41.
27. Romero JP, Benito-Leon J, Louis ED, et al. Under reporting of dementia deaths on death certificates: a systematic review of population-based cohort studies. *J Alzheimers Dis* 2014; 41(1): 213–221.
28. Reyniers T, Deliens L, Pasman HR, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. *J Am Med Dir Assoc* 2015; 16(2): 165–171.
29. Kelly JJ, Chu SY and Buehler JW. AIDS deaths shift from hospital to home. AIDS Mortality Project Group. *Am J Public Health* 1993; 83(10): 1433–1437.
30. Ribeiro O, Araújo L, Teixeira L, et al. Health status, living arrangements, and service use at 100: findings from the Oporto Centenarian Study. *J Aging Soc Policy* 2016; 28(3): 148–164.
31. Gomes B, Higginson IJ, Calanzani N, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, The Netherlands, Portugal and Spain. *Ann Oncol* 2012; 23(8): 2006–2015.
32. Berchet C. *Emergency care services: trends, drivers and interventions to manage the demand*. OECD Health working paper 83, http://dx.doi.org/10.1787/5jrts344crns-en (2015, accessed 1 July 2016).
33. Gomes B, Sarmento VP, Ferreira PL, et al. [Epidemiological study of place of death in Portugal in 2010 and comparison with the preferences of the Portuguese population]. *Acta Med Port* 2013; 26(4): 327–334.
34. Gomes B, Calanzani N, Koffman J, et al. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Med* 2015; 13: 235.
35. Mathers CD, Fat DM, Inoue M, et al. Counting the dead and what they died from: an assessment of the global status of cause of death data. *B World Health Organ* 2005; 83(3): 171–177.