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Demographic, Health, and Social Predictors of Place of Death in England, 2004-2013: Identifying barriers to dying in the community

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ABSTRACT

The reduction of hospital deaths is a policy priority in most developed countries. However, health and social care systems experience difficulties in delivering this outcome. Moreover, studies of place of death fail to identify barriers to dying in the community. To address this gap, this study estimates the unique effects of disease diagnosis and care provider type on the probability that ill adults aged 50 and older die in a private home, care home, hospital, or hospice. It does so by applying multinomial logistic regression analysis to data from the English Longitudinal Study of Ageing. Crucially, the analysis controls for sociodemographic factors, disability, and prognostic uncertainty by accounting for whether relatives anticipated the death. Cancer predicts hospice death, while non-cancer diagnosis and care provision by a partner predict hospital death. Dementia is a barrier to dying in a private home, while it is associated with a care home death. This suggests that community palliative care referral pathways cater to cancer diagnoses, while private home-based palliative care services struggle to support adults with dementia to die at home, regardless of prognostic accuracy. Including cancer-free adults in community palliative care referral pathways, and supporting their partners in care provision, would likely reduce hospital deaths.

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Community palliative care; dementia; end of life care; old adults; place of death; prognostic uncertainty

Introduction

As the global population ages, most people die aged 70 or over, having spent an average of 5 years in ill-health and receiving help from a relative or paid carer (Cambois et al., 2023, p. 14). Governments in many developed countries have cultivated national palliative care policies which are designed to improve the quality of life of people reaching the end of life (Pivodic et al., 2021). Such policies argue that community-based palliative care should be prioritized over

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hospital care, based on patients' preference to die at home (Driessen et al., 2021), the suboptimal quality of hospital palliative care provision (Binda et al., 2021), the futility of invasive hospital treatment at the end-of-life (Carter et al., 2017), and cost-effectiveness (Robinson et al., 2016).

In England, where this study is set, palliative care policy is underpinned by the *End of Life Care Strategy: Promoting High Quality Care for Adults at the End of Their Life* (DoH, 2008). The right to choose is central to this document, with the Government's Long-Term Plan for the National Health Service (NHS) promising personalized care planning for those in their final year of life with the aim of reducing emergency hospital admissions so that more people are, "able to die in a place they have chosen" (NHS England, 2019, para 1.42). Acknowledging the limited hospice bed capacity (see Huntley & Thompson, 2022), English policy promotes private homes and care homes as the most suitable places for death, according to where the patient already lives (Driessen et al., 2021; Teggi, in press). Research evidence supports English and international policy contentions that most people prefer to die at home, with a systematic review by Gomes et al. (2013) indicating that 75% of participants gave this preference across 130 studies. Although individuals generally prefer to die in a private home, some hospital, hospice, and care home deaths are appropriate. Individuals are more likely to opt for institutional deaths as care needs increase with aging and disease progression (Gomes et al., 2013). High levels of carer burden and the inability to safely care at home may mean that the dying person or their carer opts for end-of -life care in an institution (Chapple et al., 2011; Gomes et al., 2013; Gott et al., 2008). Similarly, most English care home residents prefer to die in the care home as opposed to in hospital (Watson, 2017). Preferences for hospital and hospice deaths are also affected by a recognition that a dignified death at home may not be possible in the later stages of illness (Chapple et al., 2011). Additionally, a hospital death may be unavoidable where necessary care is not provided outside of hospital settings (Shalev Many et al., 2023) and dying is not anticipated by the clinicians or carers of the deceased (Sweeny et al., 2024; Teggi, 2018).

Previous research has identified disease diagnoses and disability levels as significant determinants of place of death (PoD) in old age (Smith et al., 2013; Wiese et al., 2024). These studies attribute the association between disease diagnoses and disability level, on one side, and PoD, on the other side, to the prognosis associated with the disease. The expected progression of a disease influences the ability of family carers as well as health and social care professionals (HSCPs) to predict an accurate timeframe for dying (Murray & McLoughlin, 2012). Prognostic uncertainty is associated with dying from non-cancer diagnoses, especially dementia and multiple chronic conditions (Murray & McLoughlin, 2012). However, no studies of PoD have accounted for prognostic uncertainty to date. This shortcoming is compounded by most studies' limited focus on dying from cancer (Cohen et al., 2010; Gomes & Higginson, 2006), dying aged 80+ (Evans et al., 2014;

Fleming et al., 2010), dying in private home or hospital settings (Cohen et al., 2010; Gágyor et al., 2016), dying in care home or hospital settings (Connoly et al., 2014), and the scarcity of controls for sociodemographic factors and care provider type (Evans et al., 2014; Fleming et al., 2010; Van Rensbergen et al., 2006).

This study is the first to test the hypotheses that disease diagnosis and care provider type determine the place of death in old age (defined as private home, hospital, care home and hospice), independently of prognostic uncertainty and sociodemographic factors. By identifying the diagnoses and care provider types predicting each PoD, the study delivers actionable insight to policymakers, with respect to their objective to reduce hospital deaths and enable more people to die in a place of their choosing.

Methods

Design

This study tests two hypotheses:

1. Primary Hypothesis: Disease diagnosis determines the PoD of ill adults aged 50+, regardless of care provider type, prognostic uncertainty, age, gender, wealth, education, and disability level.
2. Secondary Hypothesis: Care provider type determines the PoD of ill adults aged 50+, regardless of disease diagnosis, prognostic uncertainty, age, gender, wealth, education, and disability level.

It does so by applying a multinomial logistic regression analysis to data from the English Longitudinal Study of Ageing (ELSA), including only those respondents whose deaths could be anticipated due to being ill and requiring some form of social care – defined as receiving help with one or more Activities of Daily Living (ADLs) by a paid or unpaid carer.

Sample

The ELSA is the largest survey of adults aged 50+ in England. The core waves, collected biennially between 2005 and 2013, address various aspects of an old adult’s life course. The EOL waves are an abridged version of the core surveys, focussing on the respondents’ final year of life through proxy interviews with the bereaved close relative or companion. We use the core waves 2 to 5 and end-of-life (EOL) waves 2 to 4 and 6. EOL information was not collected in waves 1 and 5, and core wave 1 was not included in the analysis as it omitted care home residents. To exploit the full potential of the ELSA datasets, age 50 was adopted as the threshold to define old age. The analysis dataset was constructed to include a representative sample of the English population aged 50+ who received social care, lived with chronic illness, and were observed at the time of death (Figure 1). Deaths that were classed as “sudden” were excluded (Figure 1) to focus on those deaths announced by physical and cognitive deterioration, which is the usual pattern of death in old adults and allows for palliative care need to be planned for (Murray & McLoughlin, 2012).

Crucially, the constructed analysis dataset allows us to estimate the unique effects of disease diagnosis and care provider type on PoD, controlling for prognostic uncertainty, age, gender, disability level, education, and wealth. These are original features of the constructed dataset that combines core and EOL variables (see Table 1). In particular, the constructed dataset reports on whether the close relative or companion of the deceased expected the death, providing an indicator of HSCPs’ ability to anticipate the time of death. Palliative care provision in community and hospital settings is well-established in England and involves open communication with the next-of-kin about disease prognosis and death expectation (Gott et al., 2013; Teggi & Woodthorpe, 2024; Wilkin et al., 2024). Although lacking a clinical measure of prognostic accuracy and information on advance directives and preferred PoD, the constructed analysis dataset is the richest available source of data on the end-of-life circumstances of old English adults.

Place of death was categorized using EOL variables to target the four most common places of death in the UK, namely private home, hospital, nursing or residential care home, and hospice (PHE, 2024). Seven respondents who died in a place other than a private home, hospital, care home and hospice were deleted (Figure 1). Three respondents dying in sheltered housing were recorded as dying in private homes as, unlike care homes, these settings do not provide 24 h/7 care in the UK (Age UK, 2024). Two respondents dying in an ambulance en route to hospital were recorded as dying in hospital. Place of residence was not included as a covariate to avoid multicollinearity with the care provider variable. Arguably, strong associations between residing and dying in a private home or care home are expected. By contrast, testing whether care provision by a relative who cohabited with the deceased before death or care home transfer affects PoD has the potential to deliver valuable insight. This applies especially to partners and adult children who were found to continue providing support to old adults in care home and hospice settings (Borgstrom et al., 2019; Coe &

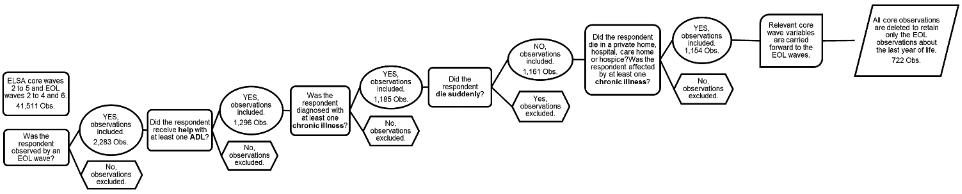

Figure 1. Sample selection criteria.

Table 1. Predictors.

Predictor's Type	Predictor	Predictor Description	ELSA Waves
Age These are mutually exclusive categories.	Adulthood	50–64 y/o	Core 2 to 5.
	Young-Old	65–79 y/o	
	Old-Old	80–84 y/o	
	Oldest-Old	85+ y/o	
Gender	Gender	Man = 0 Woman = 1	
Education These are mutually exclusive categories.	< GCSE	Less than a General Certificate of Secondary Education (GCSE) or equivalent qualification.	
	GCSE	GCSE or equivalent qualification.	
	A-level+	A-level or higher qualification.	
Wealth	Wealth	Respondent's total non-pension wealth The sum of savings, investments, physical wealth and housing wealth after financial debt and mortgage debt has been subtracted, adjusted for inflation (base year 2023) and divided by 10,000.	
Disability Level These are mutually exclusive categories. The ADLs include shopping, cooking, walking, getting dressed, bathing/showering, going in/out of bed, going to the toilet, eating, and taking medication.	Light Disability	Received help with 1 to 3 ADLs.	EOL 2 to 4 and 6.
	Mild Disability	Received help with 4 to 6 ADLs.	
	Severe Disability	Received help with 7 to 9 ADLs.	

(*Continued*)

Table 1. (Continued).

Predictor's Type	Predictor	Predictor Description	ELSA Waves
Disease Diagnoses These are independent variables.	Cancer	Died from or with a diagnosis of cancer.	EOL 2 to 4 and 6.
	Heart Condition	Died from or with a diagnosis of one (or more) conditions among heart attack, congestive heart failure, angina, heart murmur and arrhythmia.	
	COPD	Died from or with a diagnosis of chronic obstructive pulmonary disease.	
	Dementia	Died from or with a diagnosis of Alzheimer's disease or another type of dementia.	
	Stroke	Died from or with having had a stroke.	
	Arthritis	Died with a diagnosis of arthritis.	
	Psychiatric Condition	Diagnosed with a psychiatric condition.	
	Multimorbidity	Diagnosed with at least two (2+) conditions counted among cancer, heart condition, COPD, dementia, stroke, arthritis, diabetes, hypertension, osteoporosis, and asthma.	
	Number of Chronic Illnesses	Number of diagnosed conditions counted among cancer, heart condition, COPD, dementia, stroke, arthritis, diabetes, hypertension, osteoporosis, and asthma.	

(*Continued*)

Table 1. (Continued).

Predictor's Type	Predictor	Predictor Description	ELSA Waves
Care Provider Types These are independent variables. A deceased could receive help with ADLs by multiple providers at the same time. The partner care and the child care variables have three and four mutually exclusive categories respectively.	Partner Care	Whether the deceased received help with ADLs by a cohabiting spouse or partner.	Combination of two ELSA variables: living partner (Core 2 to 5) and partner helping with ADLs (EOL 2 to 4 and 6).
	Partner No Care	Whether the deceased had a cohabiting spouse or partner who did not help with ADLs.	
	No Partner	Whether the deceased had no cohabiting spouse or partner.	
	Living-in Child Care	Whether the deceased received help with ADLs by a cohabiting adult child.	Combination of three ELSA variables: living adult child (Core 2 to 5), cohabiting adult child (Core 2 to 5), adult child helping with ADLs (EOL 2 to 4 and 6).
	Living-in Child No Care	Whether the deceased lived with an adult child who did not help with the ADLs.	
	Living-out Child Care	Whether the deceased received help with ADLs by an adult child who lived outside the household.	
	Living-out Child No Care	Whether the deceased had an adult child who did not provide help with ADLs and lived outside the household.	
	No Child	Whether the deceased had no adult children.	
	Other Relative Care	Whether the deceased received help with ADLs by a relative other than the partner and adult child.	EOL 2 to 4 and 6.
	Friend Care	Whether the deceased received help with ADLs by a neighbor or friend.	
	Paid Care	Whether the deceased received help with ADLs by a paid care worker (other than a care home or hospice staff member).	
Prognostic Uncertainty	Unexpected Death	The close relative or companion of the deceased did not anticipate the time of death.	EOL 2 to 4 and 6.

Werner, 2022). As detailed in Table 1, the variables for education and wealth, and part of the variables defining care provision by a partner and adult child are carried forward from the core waves, dating on average 2 years before death. Wealth is a better indicator than income of the socioeconomic position of adults aged 50+ (Torres et al., 2016) hence its inclusion as a control variable.

Variables

The outcome variable is place of death (PoD), categorized as private home, hospital, nursing and residential care home, or hospice. The independent variables are defined as follows: the key predictors for the primary hypothesis are the disease diagnoses; the key predictors for the secondary hypothesis are the care provider types; the control variables include: age, gender, wealth, education, and disability level; and the key confounding variable is prognostic uncertainty, measured through the variable capturing whether the death was expected or not (see Table 1). Table 2 and the supplementary materials provide an overview of the distribution of the predictor (Table 2) and outcome variables (Supp. Mat. Table S4). Table 2 reveals patterns of association between the predictor variables and PoD – i.e., very few adults with dementia die at home, and those with partners providing care are most likely to die in hospital. However, these are unconditional correlations and given the complex relationships between characteristics, diagnoses, and care provision, a more formal modeling strategy is required to identify the individual contribution of the different factors at play.

Analytical strategy

To test both hypotheses, we employed a series of multinomial logit models with a progressive inclusion of variables. This sensitivity analysis allowed us to evaluate the independent and joint effects of disease diagnosis and care provider type on PoD, while controlling for sociodemographic factors and prognostic uncertainty. Predictive power and model fit were assessed using the adjusted McFadden's pseudo R^2 and the Hosmer–Lemeshow test, respectively. In addition, Wald tests were conducted at each stage of the analysis to assess whether the addition of new variables (disease diagnoses, care provider type, and unexpected death) significantly improved model fit. The analytical strategy comprised two parts:

Part 1: testing the primary hypothesis (disease diagnoses)

To test the primary hypothesis, we progressively added the control, predictor, and confounding variables to assess whether disease diagnoses determine PoD, independent of other factors. Model 1 establishes the baseline

Table 2. Predictors by place of death.

Predictor	Private Home Death (%)	Hospital Death (%)	Care Home Death (%)	Hospice Death (%)	Total (%) (count)
Adulthood	29.87	29.87	29.87	29.87	10.60 (81)
Young-Old	19.56	56.32	16.69	7.42	17.41 (133)
Old-Old	24.80	53.60	13.60	8.00	34.82 (266)
Oldest-Old	11.65	61.65	23.31	3.38	37.17 (284)
					100.00 (722)
Gender	Men: 22.81	Men: 55.97	Men: 13.00	Men: 8.22	Men: 52.21 (377)
	Women: 18.84	Women: 53.04	Women: 18.55	Women: 9.57	Women: 47.78 (345)
					100.00 (722)
< GCSE	18.09	57.52	17.48	6.91	68.14 (492)
GCSE	26.85	52.78	12.04	8.33	14.95 (108)
A-level+	27.05	44.26	11.48	17.21	16.89 (122)
					100.00 (722)
Wealth (in £10,000s)	Mean: 65.10	Mean: 56.79	Mean: 56.19	Mean: 64.91	Mean: 59.14
	SD: 80.75	SD: 71.41	SD: 82.21	SD: 78.88	SD: 75.74
Light Disability	14.95	72.16	5.67	7.22	26.86 (194)
Mild Disability	18.75	62.50	11.46	7.29	26.59 (192)
Severe Disability	25.60	39.88	23.81	10.71	46.53 (336)
					100.00 (722)
Cancer	26.96	45.51	9.28	18.26	47.78 (345)
Heart Condition	18.16	62.82	16.43	2.59	48.06 (347)
COPD	25.41	56.22	14.59	3.78	25.62 (185)
Dementia	6.90	48.28	42.24	2.59	16.06 (116)
Stroke	13.07	61.44	22.22	3.27	21.19 (153)
Arthritis	19.46	55.25	18.29	7.00	35.59 (257)
Psychiatric Condition	21.82	52.73	21.82	3.64	7.61 (55)
Multimorbidity	21.22	54.67	16.30	7.81	81.58 (589)
Number of Chronic Illnesses	One: 19.55	One: 54.14	One: 12.78	One: 13.53	One: 18.42 (133)
	Two: 22.44	Two: 51.71	Two: 16.59	Two: 9.27	Two: 28.11 (205)
	Three: 25.38	Three: 52.79	Three: 15.23	Three: 6.60	Three: 27.28 (197)
	Four: 14.95	Four: 57.94	Four: 17.76	Four: 9.35	Four: 14.82 (107)
	Five: 16.36	Five: 63.64	Five: 14.55	Five: 5.45	Five: 7.61 (55)
	Six: 20.00	Six: 55.00	Six: 20.00	Six: 5.00	Six: 2.77 (20)
	Seven: 0.00	Seven: 80.00	Seven: 20.00	Seven: 0.00	Seven: 0.69 (5)
					100.0% (722)

(*Continued*)

Table 2. (Continued).

Predictor	Private Home Death (%)	Hospital Death (%)	Care Home Death (%)	Hospice Death (%)	Total (%) (count)
Partner Care	25.00	56.18	9.12	9.71	49.09 (340)
Partner No Care	12.73	58.18	18.18	10.91	7.61 (55)
No Partner	18.04	52.29	22.02	7.65	45.29 (327)
					100.0% (722)
Living-in Child Care	20.55	56.16	16.44	6.85	10.66 (73)
Living-in Child No Care	11.76	64.71	17.65	5.88	4.70 (34)
Living-out Child Care	22.01	55.21	15.06	7.72	35.87 (259)
Living-out Child No Care	21.43	55.16	11.51	11.90	34.905 (252)
No Child	20.19	47.12	25.96	6.73	14.40 (104)
					100.00 (722)
Other Relative Care	22.07	54.19	14.80	8.94	49.58 (358)
Friend Care	23.94	47.89	18.31	9.86	9.83 (71)
Paid Care	25.00	51.56	17.19	6.25	8.86 (64)
Unexpected Death	17.77	66.53	9.92	5.79	33.51 (242)

relationships between the control variables age, gender, wealth, education, and disability level and PoD. Model 2 adds disease diagnoses to determine whether they predict PoD after controlling for sociodemographic factors. Model 3 adds care provider types to assess whether the significance of disease diagnoses persists when accounting for the type of care provision. Model 4 includes prognostic uncertainty to evaluate whether the disease diagnoses (and care provider types) remain significant predictors when accounting for whether the death was expected or unexpected.

Part 2: testing the secondary hypothesis (care provider types)

To test the secondary hypothesis, we fitted a fifth model. Model 5 estimates the unique effects of care provider types along with the control variables age, gender, wealth, education, and disability level. This allows us to evaluate whether care provider types significantly predict PoD after controlling for sociodemographic factors, before potentially interacting with disease diagnoses in Model 3 and both prognostic uncertainty and disease diagnoses in Model 4. Similarly, we fitted a sixth model including just prognostic uncertainty and the control variables to assess the impact of prognostic uncertainty when other confounders are not in the model. To further assess the model specification, we calculated the Variance Inflation Factors (VIFs) for all independent variables in Model 4.

Data preparation

The sample's selection criteria (Figure 1) delivered a dataset comprising 722 observations with 16 missing data points (2.21%). Little's test was non-significant ($\chi^2 = 16.993$, DF = 18, $p = .523$); therefore, data missing completely at random (MCAR) was inferred. Missing data was replaced using hot-deck imputation, which is suitable for dealing with small quantities (<10%) of MCAR data (Myers, 2011). This operation delivered a complete dataset of 722 cases. As a robustness check, we ran the models excluding the observations with imputation and the results remain qualitatively and quantitatively the same (available from the authors on request).

Statistical analysis

The six multinomial logit regression models were formulated as follows:

$$Pr(y_i = j) = \frac{exp\left(X_i \cdot \beta_{ij}\right)}{\sum_{k=1}^{4} exp\left(X_i \cdot \beta_{ik}\right)}$$

In the above equation, y_i represents the place of death of a deceased person i, with j taking four outcome values: a private home; hospital; care home, and hospice. X_i is the vector of the deceased person's characteristics, with β_{ij} and β_{ik} being vectors of coefficients. Average marginal effects (AMEs) were computed for each of the four outcomes for the six models. In non-linear probability models, AMEs are better summary estimates of each predictor's unique effect than both regression coefficients and Marginal Effects at the Means (MEMs) (Wooldridge, 2013). Therefore, AMEs were used to compare the unique effects of disease diagnoses and care provider types across the six models. Robust standard errors were applied in all models to account for violations of model assumptions.

Results

Model diagnostics

Pseudo R^2 and the Hosmer–Lemeshow test indicated improved predictive power and model fit as additional variables were included to the models. Testing the primary hypothesis, the adjusted pseudo R^2 increased almost steadily from 0.056 in Model 1 to 0.118 in Model 2, 0.112 in Model 3, and 0.113 in Model 4. Testing the secondary hypothesis, the adjusted pseudo R^2 remained fairly stable from 0.056 in Model 1 to 0.050 Model 5, then increasing in Model 3 and 4 as mentioned above. This evidences that the inclusion of disease diagnoses has the largest impact on the explanatory power of the model, as anticipated by the primary hypothesis.

The Hosmer–Lemeshow test confirmed that all models provided a good fit, with p-values ranging from 0.109 to 0.854 – all failing to reject the null hypothesis that observed and model-predicted values of the outcome are the same. The Wald tests substantiated that the addition of disease diagnoses, care provider types, and unexpected death significantly improved model fit at each stage, except when care provider types were added to the baseline Model 1.

Testing the primary hypothesis, the Wald test for Model 2 vs. Model 1 yielded a χ^2 value of 104.77 ($p < .000$), the test for Model 3 vs. Model 2 yielded a χ^2 value of 29.72 ($p < .040$), and the test for Model 4 vs. Model 3 yielded a χ^2 value of 7.83 ($p < .049$). Testing the secondary hypothesis, the Wald test for Model 5 vs. Model 1 produced a χ^2 value of 26.96 ($p < .079$), and the test for Model 5 vs. Model 3 produced a χ^2 value of 108.28 ($p < .000$). Finally, VIFs analysis confirmed that multicollinearity was not a concern for the models, with all VIF values well below the acceptable threshold of 5 (Supp. Mat. Table S10).

Table 3. Model 4 AMEs – control variables, disease diagnoses, care provider types, and prognostic uncertainty (unexpected death).

Predictors	Outcomes											
	Private Home Death			Hospital Death			Care Home Death			Hospice Death		
	dx/dy[1]	SE	95% CI	dx/dy	SE	95% CI	dx/dy	SE	95% CI	dx/dy	SE	95% CI
50–64 y/o	.139*	.055	.031 .246	−.107	.075	−.253 .039	−.097	.063	−.221 .027	.066	.037	−.000.139
65–79 y/o	.091*	.046	.000.180	−.155**	.054	−.261 .048	.008	.040	−.070.086	.056	.033	−.008 .120
80–84 y/o	.104**	.038	.029 .179	−.124**	.043	−.209 .039	−.007	.028	−.062 .049	.027	.031	−.033 .087
85+ y/o	Reference category											
Gender	−.023	.037	−.085–.039	.023	.038	−.051. 097	−.015	.026	−.065 .037	.015	.022	−.028 .058
< GCSE	.074	.040	−.147 .010	.112*	.050	.015 .210	−.002	.037	−.074 .071	−.037	.023	−.082 .008
GCSE	.012	.047	−.115 .072	.069	.063	−.054 .191	−.000	.050	−.097 .096	−.056	.031	−.117 .005
A-level+	Reference category											
Wealth (in £10,000)	.000	.000	−.000.000	−.000	.000	−.000.000	−.000	.000	−.000.000	.000	.000	−.000.000
Light Disability	−.113**	.037	−.185–.040.	.269***	.041	.189 .350	−.146***	.036	−.217–.076	−.010	.024	−.057 .037
Mild Disability	−.077*	.034	−.144–.009	.195***	.040	.116 .273	−.096**	.029	−.153–.039	−.022	.024	−.070.025
Severe Disability	Reference category											
Cancer	−.016	.042	−.097 .065	−.173**	.052	−.274–.071	−.040	.030	−.100.020	.129**	.067	.097 .360
Heart Condition	.021	. 038	−.053. 094	.056	.043	−.027 .142	.011	.030	−.047 .069	−.089**	.030	−.149–.030
COPD	. 065	.038	−. 009. 140	−.016	.045	−.105 .073	.007	.034	−.060.074	−.056	.032	−.119 .006
Dementia	−. 144 *	. 059	−. 259–.029	−.029	.059	−.143 .085	.183***	.029	.125 .241	−.010	.041	−.090.070
Stroke	−. 074	. 046	−. 165. 017	.065	.052	−.037 .167	.069*	.034	.001 .136	−.059	.040	−.138 .019
Arthritis	. 011	.040	−.067 .089	−.050	.046	−.140.040	.057*	.028	.001 .114	−.017	.029	−.075 .039
Psychiatric Condition	.016	.058	−.099 .130	.035	.067	−.097 .165	.034	.042	−.049 .115	−.083	.049	−.178 .013
Multimorbidity	.064	.048	−.030.159	.025	.024	−.180.042	−.037	.018	−.071 .002	−.033	.030	−.093 .027
Number of Illnesses	−.016	.020	−.055 .022	.025	.024	−.021 .071	−.037*	.018	−.071–.002	.028	.014	.000.056
Partner Care	.012	.036	−.058 .083	.149**	.044	.063 .235	−.120***	.032	−.184–.058	−.041	.026	−.091 .009
Partner No Care	−.106	.072	−.246 .035	.141	.0077	−.011 .230	−.058	.050	−.155 .039	.023	.035	−.047 .092
No Partner	Reference category											
Living-in Child Care	.004	.067	−.128 .135	.104	.076	−.045 .253	−.076	.051	−.176 .025	−.032	.41	−.113 .049
Living-in Child No Care	−.095	.063	−.218 .028	.197*	.087	.027 .367	−.103	.060	−.220.014	.000	.0631	−.123 124
Living-out Child Care	.016	.051	−.085 .118	.046	.062	−.076 .167	−.034	.045	−.121 .054	−.028	.038	−.103 .047
Living-out Child No Care	.010	.052	−.091 .111	.067	.058	−.047 .181	−.106**	.039	−.182–.030	.029	.042	−.054 .112
No Child	Reference category											
Other Relative Care	.023	.046	−.068 .113	.030	.055	−.079 .138	−.087**	.033	−.152–.022	.034	.029	−.023 .091
Friend Care	.030	.050	−.068 .128	−.005	.056	−.115 .105	−.023	.039	−.099 .053	−.002	.033	−.066 .062
Paid Care	.050	.055	−.057 .158	−.002	.061	−.121 .117	−.028	.039	−.104 .047	−.020	.042	−.101 .062
Unexpected Death	−.020	.031	−.083 .041	.099**	.037	.026 .172	−.062*	.028	−.118–.006	−.016	.022	−.06 .027

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$.

[1] dx/dy denotes the average marginal effect (AME), representing the change in the predicted probability of the outcome for a one-unit increase in the predictor, averaged across all observations.

Disease diagnoses: cancer and dementia

Assessing the primary hypothesis, cancer, dementia, heart condition, and number of chronic illnesses showed significant and consistent AMEs across all models (Supp. Mat. Tables 5 to 7; Table 3). This highlights the diseases' robust association with PoD regardless of prognostic uncertainty, care provider type, age, gender, wealth, education, and disability level. Dementia was the strongest predictor of a care home death, and the strongest barrier to death in a private home (Table 3): adults living with dementia were on average 18.3% points (ppts) more likely than dementia-free adults to die in a care home as opposed to other settings. Conversely, dementia-free adults were on average 14.4 ppts more likely than adults living with dementia to die at home as opposed to other settings. Cancer was the strongest predictor of a hospice death and a barrier to a hospital death. Adults with a cancer diagnosis were 28.8 ppts more likely than cancer-free adults to die in a hospice as opposed to other settings. Conversely, cancer-free adults were 17.2 ppts more likely than adults with a cancer diagnosis to die in a hospital as opposed to elsewhere. Adults with a heart condition were 8.9 ppts less likely than adults without a heart condition to die in hospice, as opposed to other settings. Finally, each addition to the number of chronic illnesses increased the likelihood of dying in a care home as opposed to other settings by 3.7 ppts (Table 3).

Care provider type: partner, adult child, and other relatives

Assessing the secondary hypothesis, care provision by a partner, having an adult child not involved in care provision and care provision by a relative (other than the partner or adult child) predicted PoD across all models consistently (Sup. Mat. Tables 5, 7 and 8 and Table 3). This evidences that partner and relative involvement in care provision as well as the presence of an adult child are associated with PoD regardless of prognostic uncertainty, other care provider type, age, gender, wealth, education, and disability level. As compared to single or bereaved adults, adults with a partner who helped with ADLs were 14.9 ppts more likely to die in hospital and 12 ppts less likely to die in a care home as opposed to other settings (Table 3). Similarly, as compared to childless adults, adults cohabiting with an adult child who did not help with the ADLs were 19.7 ppts more likely to die in a hospital. By contrast, adults who received help from a relative (someone other than a partner or child) were 8.7 ppts less likely than adults who did not receive help by such a relative to die in a care home as opposed to other settings. Likewise, as compared to childless adults, adults with an adult child who lived independently and was not involved in their care were 10.6 ppts less likely to die in a care home as opposed to other settings. Finally, it is notable that comparing Supp. Mat. Table S9 and Table 3, prognostic uncertainty has a slightly stronger effect when disease diagnoses and care provider type are not included in the model, but differences are small – reflecting again that the impact of disease diagnoses in particular is not just picking up prognostic uncertainty, the effect of which is largely independent of these other confounders.

Discussion

The study highlights three key findings. First, a cancer diagnosis leads to increased probability of hospice death and decreased probability of hospital death, regardless of HSCPs' ability to anticipate the time of death. Second, dementia diagnoses increase the chances of dying in a care home and decrease the chances of dying at home, independently of whether HSCPs predicted the timing of death accurately. Third, all else equal, a partner's active involvement in the care of the deceased increases the likelihood of dying in a hospital and is a barrier to dying in a care home, regardless of prognostic accuracy and disease diagnosis. The first two key findings confirm previous findings that disease diagnosis is the main determinant of PoD and add to the original finding that this is *not* simply reflecting the predictability of the underlying disease trajectory.

Cancer is the strongest predictor of a hospice death, while it is a barrier to a hospital death. Additionally, a heart condition is a barrier to a hospice death. This mirrors the mainstreaming of specialist community palliative care services (SCPCS) in private home and hospice settings for cancer patients in the UK and internationally. Cancer patients are overrepresented in hospice settings in the UK (Dixon et al., 2015) and USA (Carlson et al., 2010). A recent review of the English-speaking literature found that cancer patients using SCPCS were less likely to die in hospital than cancer patients failing to use SCPCS (Sharafi et al., 2022). Moreover, a recent evaluation of an Electronic Palliative Care Coordination System (EPaCCS) in England found that cancer patients were more likely than non-cancer patients to have an EPaCCS record, and patients with an EPaCCS record were more likely than patients without an EPaCCS record to die in a private home or care home as opposed to in hospital (Pocock et al., 2024). The dominant provision of SCPCS to people with a cancer diagnosis is often attributed to the relative predictability of dying from cancer as opposed to dying with or from frailty or dementia (Teggi, 2018; Tobin et al., 2022). However, this study challenges this explanation by adjusting for the effect of prognostic uncertainty on PoD across disease groups. The fact that hospital death remains unlikely for adults with cancer, even controlling for prognostic uncertainty, is consistent with the evidence that cancer diagnoses follow community palliative care referral pathways that make hospital death unlikely regardless of HSCPs' ability to predict dying accurately. Consistently, the fact that hospital death is likely for non-cancer diagnoses, and hospice death is unlikely for heart condition diagnoses, even controlling for prognostic uncertainty suggests that non-cancer diagnoses do *not* follow community palliative care referral pathways that make hospital death unlikely regardless of HSCPs' capacity to anticipate dying.

A dementia diagnosis favors a different palliative care route. Dementia is the strongest barrier to dying in a private home and the strongest predictor of dying in a care home, independently of HSCPs' ability to identify an accurate timeframe for dying. This is in line with the patterns of long-term care provision to adults aged 50+ in England (Teggi, 2020). It also reflects international evidence that care homes are the dominant setting for the palliative care of adults dying with or from dementia (Connoly et al., 2014; Houttekier et al., 2009, 2010). That dementia poses challenges to dying at home, while it is positively correlated with dying in a care home regardless of prognostic accuracy is consistent with the disease profile. As dementia severity progresses, people require increasing supervision and help to perform activities of daily living (Giebel et al., 2020). Consequently, dementia is associated with high levels of stress in partner and family carers, with the stress leading to increased likelihood of transfer to a care home (Cole et al., 2018).

Family support also plays a role in shaping PoD. A partner's provision of social care increases the chances of dying in hospital, while it decreases the chances of dying in a care home, regardless of prognostic accuracy and the disease(s) that the individual dies with or from. These findings contradict those of other studies of PoD, evidencing that the presence of a cohabiting relative facilitates a home death as compared to death in an institution (Gágyor et al., 2016, Gomes & Higginson, 2006; Houttekier et al., 2009). However, these studies do not differentiate between a partner's presence and their provision of practical support to the deceased (Gágyor et al., 2016, Gomes & Higginson, 2006; Houttekier et al., 2009). This study is the first to reveal that, as compared to single adults, adults with a partner who is involved in their care are more likely to die in hospital. Similarly, adults cohabiting with an adult child are more likely than childless adults to die in hospital as opposed to other PoDs, even if the child is not involved in care provision. This points to the support needs of family carers and cohabiting family members. Strain on family carers and cohabiting relatives may lead to avoidable hospital admissions at the end of life (Chapple et al., 2011; Gomes et al., 2013; Gott et al., 2008). By contrast, care provision by a partner and by a relative other than the partner and adult child as well as a non-carer and non-cohabiting adult child decrease the chances of a care home death. This is in line with the English patterns of long-term care provision to adults aged 50+ (Teggi, 2020). Adults with low family support due to being single or childless are more likely to enter residential care (Ibid.) and, this study adds, also to die there.

Implications for service delivery

The findings of this paper have implications for the provision of palliative care. Our findings point to the need for Integrated Care Boards to create clear community palliative care referral pathways for cancer-free adults aged 50+ living with social care needs. The findings also point to the need to increase palliative care provision in private homes to old adults with dementia. The latter enjoy limited opportunities to age and die in their own homes as they are very likely to do so in a care home (Teggi, 2020; Table 3). This questions whether the right to choose one's PoD, which British policy upholds, applies to adults with dementia. Reviews of end-of-life care policy in England have highlighted a lack of effective community services for older adults with complex conditions, a fragmented health and social care system, and a need for better home-based service provision if policy narratives around choice are to be meaningful (Barker et al., 2023; Henry et al., 2015). A clear community palliative care pathway for cancer-free adults and better private home-based palliative care services for adults with dementia would mean ensuring that multi-disciplinary care is properly co-ordinated, with family physicians and social care workers being engaged in palliative care plans from the outset and options alternative to emergency care being available in-situ (Stienstra et al., 2012).

Our results also indicate that hospital deaths are more likely when there is a partner involved in the care. The current literature highlights that two things are needed to enable family carers to support the deceased to die at home. First, information and training about providing palliative care need to be made available to family carers, as a systematic review of the literature has shown that a lack of confidence in providing care leads carers to conclude that an admission to hospital is necessary (Wahid et al., 2018). Resources such as decision-making tools may aid carers to provide support in accordance with the patient's wishes (Davies et al., 2021). Second, support from carers needs to be supplemented by community support and periods of respite care as a lack of support from services or other family members may lead to exhaustion, which in turn may lead to hospital admission (Davies et al., 2021). Cases where partners care for adults living with dementia at home have an extra layer of complexity due to the carer burden of the syndrome. Research shows that regular partners' contact with health and care professionals, effective pain management, and the availability of appropriate aid adaptations (such as continence aids or wheelchairs) are all crucial elements to maintaining palliative care within home settings for this group (Mogan et al., 2018).

The importance of family carers' involvement in advance care planning (ACP) and anticipatory prescribing (AP) has also been highlighted for people living with dementia. ACP is particularly important for this population, as many people with advanced-stage dementia lack the capacity to make decisions regarding their care and treatment (Nakanishi et al., 2024, van der Steen et al., 2024). A systematic review of the evidence shows that engaging adults with dementia and their carers in ACP reduces hospital admissions from both private home and care home settings (Dixon et al., 2018). Where no advanced care plans exist and a person living with dementia lacks capacity, then HSCPs should act in the person's "best interests," which may include consultation with partners and informal carers, as defined by section 4 of the Mental Capacity Act. In such cases, there is growing evidence that AP helps HSCPs provide palliative care in-situ and forego emergency care, which often leads to hospital admission (Teggi & Woodthorpe, 2024).

Limitations

The limitations of this study concern ethnicity, sample size, and the coarseness of our proxy measure for prognostic accuracy. First, this study could not consider ethnic differences because the ELSA did not oversample ethnic minority groups (Steptoe et al., 2013). Second, this study is based on a sample size of only 722 respondents because the ELSA EOL waves were collected inconsistently between 2005 and 2013, when they stopped. This reflects the scarcity of representative surveys on the dying circumstances of adults aged 50+ at the English national and international levels. Third, the proxy measure for prognostic uncertainty cannot distinguish whether death was unexpected due to clinical inaccuracy or miscommunication between HSCPs and the deceased's close companions. A finer-grained and clinical measure would be preferable to capture the degree of prognostic accuracy. However, the proxy measure establishes when the next-of-kin failed to anticipate the timing of death that the close relative, partner, or friend was not aware of the deceased impending death reflects the uncertainty surrounding clinical prognosis. This is particularly true as the study excludes sudden deaths and focuses on old adults who were ill and frail enough to receive social care, limiting the possibility that failure to recognize dying stems from a lack of visible deterioration. The limitations of this study are typical of secondary analyses of panel surveys such as the ELSA, which were tailored for multipurpose use rather than the authors' research question.

Conclusion

This study is the first to test that disease diagnosis and care provider type determine the place of death (PoD) of adults aged 50+ who are ill enough to need social care. Based on data from the ELSA, this study isolates the unique effects of nine disease diagnoses and five care provider types on the likelihood that ill adults aged 50+ die in a private home, hospital, care home, or hospice, controlling for prognostic uncertainty, age, gender, education, wealth, and disability level. Crucially, the study controls for prognostic uncertainty using relatives' ability to anticipate the time of death as a proxy measure. The study identifies non-cancer diagnosis, care provision by a partner, and cohabiting with a non-carer adult child as positive predictors of hospital death and dementia as negative predictors of dying in a private home. These findings suggest a lack of effective community palliative care referral pathways for dying cancer-free and insufficient private home-based support for dying with dementia as well as partner carers and cohabiting adult children not actively involved in the care of their old parents. Advanced care planning and, as evidenced by emerging research, anticipatory prescribing, are known to decrease hospital transfers from private home and care home settings, and subsequent hospital deaths. This study supports the provision of both interventions to cancer-free adults and adults with dementia, and the active involvement and support of the partner and cohabiting adult child in their delivery and planning, with the aim of meeting the government's policy objective of allowing more people to die in the place of their choosing.

Key points

- To reduce hospital deaths is an unrealized policy priority in developed countries.
- No previous studies of the place of death provide actionable insight to policymakers.
- This study isolates the unique effects of disease diagnosis on place of death.
- Non-cancer diagnosis predicts hospital death regardless of prognostic uncertainty.
- Including cancer-free adults in palliative care would reduce hospital deaths.

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Author contributions statement

DT designed the study, conducted the study, and wrote the first draft of the abstract, key points, introduction, methods, results, discussion, limitations, and conclusion sections. JD wrote the second draft of the introduction section and the first draft of the implications for the service delivery section. DT and MD revised the paper's methods, results, and discussion sections considering the reviewers' comments. All authors reviewed subsequent drafts of the manuscript. All authors read the final manuscript.

Data availability statement

This paper employed core waves 2 to 5 and the end-of-live waves 2 to 4 and 6 of the English Longitudinal Study of Ageing (ELSA). The dataset can be accessed through the UK Data Service at http://doi.org/10.5255/UKDA-SN-5050-15.

Ethics approval and consent to participate

The University of Bath Social Science Research Ethics Committee (SSREC) approved this study (reference number S18–010). Requirement for consent was waived by the committee as the study employs anonymous data publicly available through the UK Data Service.

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