Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) – primary research

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Scientific summary

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Background

Place of death (PoD) has been used as an outcome measure for end-of-life care. It is related to the quality of life of patients at the end of life, bereavement outcomes of caregivers, and costs of end-of-life care. Analysis of variations in PoD can improve understanding about the needs of service users, and help guide evidence-based service design and delivery. However, no in-depth individual-level analysis over time has been performed since 1994, and no study has investigated the temporal variations (e.g. seasons, specific holiday periods) in PoD.

Objectives

To:

- describe PoD in England by demographic, socioeconomic and temporal variables
- determine how much of the variation in PoD can be explained by potential explanatory variables at the area level, and building on this to develop individual-level multivariable regression models
- evaluate factors associated with PoD and to construct risk assessment models, for all causes combined and for selected causes of death.

Methods

The study was population based. All registered deaths that occurred between 1984 and 2010 in England, excluding those who died from external causes or those who died at the age of ≤ 24 years, were included in this report ($n = 13,154,705$). The outcome variable was the PoD, classified into four categories (hospital, home, other communal establishment, elsewhere) for the 1984–92 data, and six categories (hospital, own home, hospice, care home, other communal establishment, elsewhere) for the 1993–2010 data.

Explanatory variables include both individual- and area-level variables. Individual-level variables included age, gender, underlying cause of death (CoD), marital status, year of death, the region of usual residence; area-level variables were obtained through record linkage of the usual residence to measure at the lower layer super output area level or other appropriate geographic boundaries. Records with missing, illogical and invalid values on the key set of variables were deleted. Age was predominantly analysed as a categorical variable in five groups: 25–54, 55–64, 65–74, 75–84 and 85+ years. These age cut-off values are in line with commonly used age groupings to facilitate cross-study comparisons, and usefulness for policy development and targeting improvement. Gender was a binary variable (female vs. male). Marital status was included as an individual-level variable and grouped into five classes: married, widowed, divorced, single and not stated or unknown. The marital status was not available in the data before 1988, and until 1994 this variable was not universally consistent with those of post 1993; therefore, analysis using this variable was carried out for post-1993 data only. Year of death was directly extracted from the death certificate and was the year that death occurred. The location of usual residence was used to identify in which one of the 10 health authority regions the deceased lived: North East, North West, Yorkshire and the Humber, East Midlands, West Midlands, East of England, London, South East Coast, South Central and South West. The underlying CoD was identified using the *International Classification of Diseases* (ICD) coding system [ICD, Ninth Edition (ICD-9) for 1984–92; ICD, Tenth Edition (ICD-10) for 1993–2010] and grouped into seven classes: all CoDs, all non-cancer CoDs, cancer, cardiovascular diseases

(CVDs), cerebrovascular diseases (CBDs), neurological conditions and chronic obstructive pulmonary diseases (COPDs). The Index of Multiple Deprivation (IMD) was used as a proxy indicator for socioeconomic status. IMD 2000 was used for the 1984–2000 data and IMD 2010 for the 2001–10 data. Temporal variables for this report were defined as seasonal period (spring, summer, autumn, winter) and holiday period (Christmas, New Year and Easter). The seasonal period was defined by month of death according to the following cut-offs: spring (March to May), summer (June to August), autumn (September to November) and winter (December to February). The Christmas, New Year and Easter holiday period were defined as 3 days before and after the specified holiday. Before the analysis, data were checked for completeness, problems and errors.

Variations in PoD at the aggregate level were analysed and modelled using the weighted linear regression models. The dependent variable was the area-specific percentage of hospital deaths, with the total number of deaths at the selected area level as one of the adjusted variables. The proportion that can be explained by the model was derived from the model and measured using R^2. The explanatory variables were derived from the data and introduced into the models as the percentage of a defined subcategory for categorical data (e.g. gender) or average value for continuous data (e.g. age). The models were constructed using the 1993–2010 data, as the demographic variables in the pre-1993 data were limited and subject to a number of changes, and the geographic boundaries in the earlier period (1984–92) underwent significant changes. The explanatory variables included average age, percentage male, percentage married, year of death, average IMD score, percentage winter deaths or percentage deaths in the Christmas period. The area was defined at the primary care organisation (PCO) and local authority (LA) level, and modelled separately.

Factors associated with PoD at the individual level were investigated using either log-binomial regression models, or modified Poisson regression models in the case of convergence problems with the former. The dependent variable was a binary indicator of PoD. We considered the least preferred PoD [hospital (1)] compared with the second or the third most common PoD (0), which was determined by the CoD of interest. All selected independent variables, as informed by the area-level modelling analysis, were forced to stay in the model to adjust for their potential confounding effects.

We also constructed individual-level risk models for selected CoDs, to assess an individual's risk of dying in a hospital or a non-hospital setting. A non-hospital was a place other than a UK NHS- or non-NHS hospital. Given the changing patterns that we found in a recently published study on cancer deaths in England, we used the 2006–9 data as the training set to build the model, and the predictive performance was tested using the 2010 data (validation set). The model performance validation was evaluated using (1) a Wald chi-squared test and (2) the area under the receiver operating characteristic curve (AUC) and its 95% confidence interval (CI). An AUC of 0.5 indicates chance prediction (equivalent to flipping a coin), whereas a statistic of 0.7 indicates good discriminating ability. All analysis was undertaken separately for all causes, non-cancer, cancer, CVD, CBD, neurological conditions and COPD.

Results

Over the whole period 1984–2010, people died at an increasingly older age; the average age of death in 1984–92 was 75.3 years, in 1993–2000 it was 76.8 years and in 2001–10 it was 77.9 years. The proportion of those who died aged > 75 years increased from 58.2% in 1984–92 to 67.9% in 2001–10. Hospital was the most common PoD, regardless of CoD. Neurological conditions had the lowest proportion of hospital deaths (46.1% in 2001–10) and COPD most commonly occurred in hospital (68.3% in 2001–10). The second most common PoD for cancer deaths was at home (24.1%), whereas in non-cancer deaths the second most common PoD was a care home (20.0%). Neurological conditions had the highest proportion of care home deaths (35.2%); for other conditions, care home deaths accounted for around 10% of deaths. In total, 17.1% of all cancer deaths and 3.5% of the deaths from neurological conditions occurred in a hospice. For other causes of deaths the proportion of hospice deaths was < 1%.

Regional-level models using selected demographic and clinical variables together with a temporal variable explained a statistically significant ($p < 0.001$) proportion of variations in hospital deaths, ranging from 24.3% to 26.7% for all causes combined. The models constructed at the PCO level tended to perform slightly better than those at the LA level; models incorporating holiday periods marginally outperformed those incorporating the seasonal temporal variable. The disease-specific models varied widely between diseases. The selected variables explained the lowest proportion of PoD variations in cancer (5.4–6.9%), and the highest in CBDs (38.2–39.0%) for PCO-level models, and in non-cancer (36.5–37.2%) for LA-level models.

For all causes, the probability of a person dying at home decreased with increasing age across all time periods; however, the age gap reduced over time [proportion ratios (PRs) range 0.863–1.016], compared with patients who died aged 25–54 years. Home death was less likely among those who were aged 75+ years in all causes of deaths in the period 1993–2010 (PRs 0.938–0.962). Patients aged 85+ years had the lowest chance of dying at home (PRs 0.863–0.946). Male gender was associated with an increased chance of dying at home but this was more pronounced in earlier periods (PR 1.034, 95% CI 1.032 to 1.036) than in recent periods (PR 1.007, 95% CI 1.007 to 1.008 for 1993–2000; PR 1.009, 95% CI 1.008 to 1.009 for 2001–10). Divorced people were less likely to die in hospitals (PR 0.998, 95% CI 0.997 to 0.999) in 1993–2000 but more likely to die in hospital in 2001–10 (PR 1.027, 95% CI 1.024 to 1.030). Compared with people who were married, those who were widowed or single were more likely to die in hospital (PRs 0.992–0.998). Over the years, deaths in hospital became more likely (PR 1.001, 95% CI 1.000 to 1.002, in 2001–10 vs. PR 0.998, 95% CI 0.998 to 0.999, in 1993–2000). Living in a more deprived area was associated with a higher chance of hospital death; however, this was more pronounced in 1984–92 than in 1993–2010 (PRs 1.000–1.010 vs. PRs 1.030–1.076 for least deprived compared with most deprived). In all three periods, living in London was associated with the highest chance of dying in hospital (PRs 0.872–0.988 vs. North West) and those in the South West had the highest chance of home death (PRs 1.010–1.062 vs. North West).

Care home death was more likely among older people for all causes of death in 1993–2010 (PRs 0.941–0.996). Compared with care home death, men were more likely to die in hospital than women (PRs 1.008–1.010) in the whole period; those who were married had a higher chance of dying in hospital than those who were widowed, single, divorced or had unknown marital status (PRs 0.984–0.992) in recent periods; in the periods of 1993–2000 and 2001–10, widowed people had the highest chance of a care home death (PR 0.980, 95% CI 0.979 to 0.981, in 1993–2000; PR 0.985, 95% CI 0.985 to 0.986, in 2001–10). The number of care home deaths fell slightly in the period 1984 to 2000 (PRs 1.001–1.022) but remained stable for the period of 2001–10 (PR 1.000, 95% CI 0.999 to 1.000). Care home death was less likely among the least deprived (PRs 0.992 to 0.997 compared with the most deprived). Care home death was less likely in London than in the North West (PRs 1.012–1.016) but the regional gap reduced in 2001–10; South West areas had the highest chance of care home death (PRs 0.993–0.994).

Compared with the normal (i.e. non-holiday) period, there were slightly increased chances of dying in hospital rather than at home during the Christmas period for people from non-cancer conditions in 1993–2000 (PR 1.002, 95% CI 1.001 to 1.004); cancer in 1984–92 (PR 1.019, 95% CI 1.009 to 1.029) and 2001–10 (PR 1.003, 95% CI 1.000 to 1.006); CVD in 1993–2000 (PR 1.004, 95% CI 1.001 to 1.006) and neurological conditions in 1984–92 (PR 1.052, 95% CI 1.012 to 1.093). The probability of home death increased during the Christmas period for people who died from COPD in 1984–92 (PR 0.975, 95% CI 0.953 to 0.998). For CBD CoD, no statistically significant difference was found between Christmas and the normal period in any time periods ($p > 0.05$). A reduced chance of hospital death during the Easter period was observed for all causes of death in 2001–10 (PR 0.998, 0.997 to 0.999) and non-cancer deaths in 1984–92 (PR 0.994, 95% CI 0.987 to 1.000) and in 2001–10 (PR 0.998, 95% CI 0.997 to 1.000). The New Year period was associated with increased hospital deaths for the whole study period for deaths from all causes (PRs 1.002 to 1.016), non-cancer (PRs 1.007– 1.029) and CVD (PRs 1.010–1.035). With spring as the reference group, the chance of a hospital death was lower for all causes of deaths in the summer season in 1984–92 (PR 0.992, 95% CI 0.990 to 0.995) but the chance of a hospital death increased to a similar level as spring in 1993–2000 (PR 1.000, 95% CI 0.999 to 1.000). Up to the period 2001–10, the probability of hospital death in summer was higher than in spring for all causes of death (PR 1.002, 95% CI 1.001 to 1.002).

The AUC ranged from 0.552 (95% CI 0.551 to 0.554) for COPD CoD to 0.637 (95% CI 0.632 to 0.643) for CBD deaths. Although the performances of the model in the validation set were all significant at the level of $p < 0.0001$, none was deemed satisfactory.

Conclusions

This large-scale population-based study using 27 years of death registration data for England found that the most common PoD remains hospital, followed by home or care home, depending on the CoD. Hospices played an increasing role over time but primarily for people with cancer (17.1% of cancer deaths were in a hospice) but only 3.5% of neurological conditions, and < 1% of other conditions. There is regional variation in PoD: people from populated metropolitan areas (particularly London) were more likely to die in hospitals than elsewhere, which highlights a need to either plan for increased hospital deaths in these areas or examine ways to support more people to die in the community. PoD also varied slightly by season and holiday periods, with autumn and winter deaths (compared with spring deaths) having an increased chance of occurring in hospital, and a higher chance of home deaths during the Christmas period and hospital deaths during the New Year period than in the normal period. For all causes of death, there is evidence of inequality in PoD by age, marital status and deprivation. People who are aged 75+ years, single, divorced or widowed, and those living in more deprived areas were more likely to die in hospital. The predictive performance of our risk assessment models was not satisfactory and needs further development to take into account service provision and other important factors.

Recommendations for future research

This report has identified the following priority research questions:

- What is the pattern of health service utilisation in the last year of life and how is it related to where patients die?
- How are clinical characteristics in the last year of life related to where patients die?
- Is the distribution of end-of-life care facilities related to where patients die?

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