

TITLE:

Factors Associated with Transition from Community Settings to Hospital as Place of Death for Adults Aged 75 Years or Older: A Population-Based Mortality Follow-back Survey

Anna E. Bone, MPH,¹ Dr Wei Gao, PhD,¹ Dr Barbara Gomes, PhD¹, Dr Katherine E. Sleeman, PhD,¹ Dr Matthew Maddocks, PhD,¹ Dr Juliet Wright, PhD,³ Dr Deokhee Yi, PhD,¹ Professor Irene J. Higginson, PhD,¹ and Dr Catherine J. Evans, PhD,^{1,2} on behalf of OPTCare Elderly

¹King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

²Sussex Community National Health Service Trust, Brighton and Hove, United Kingdom

³University of Sussex, Brighton and Sussex Medical School, Brighton, United Kingdom

Corresponding Author: Dr Catherine Evans

Email: catherine.evans@kcl.ac.uk

Address: Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, King's College London, London, SE5 9PJ, United Kingdom

Tel: +44 (0) 207 848 5579

Alternate Corresponding Author: Anna Bone

Email: anna.bone@kcl.ac.uk

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Address: As above

Tel: +44 (0) 207 848 0128

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ABSTRACT

OBJECTIVE: To identify factors associated with end of life (EoL) transition from usual place of care to hospital as place of death for people aged 75 years or older (75+).

DESIGN: Population-based mortality follow-back survey.

SETTING: Deaths over six months in 2012 in two unitary authorities in England, covering 800 square miles with over one million residents.

PARTICIPANTS: A random sample of people aged 75+ who died in a care home or hospital and all those who died at home or in a hospice unit. Cases were identified from death registrations. The person who registered the death (a relative for 98.9%) completed the survey.

MEASUREMENTS: Our main outcome was EoL transition to hospital as place of death versus no EoL transition to hospital. We used multivariable modified Poisson regression to examine factors (illness, demographic and environmental) related to EoL transition to hospital.

RESULTS: 443/882 (50.2%) responded, describing the care received by people who died from mostly non-malignant conditions (76.3%) at mean age 87.4 years (SD=6.4). 32.3% transitioned to hospital and died there (n=146). Transition was more likely in respiratory disease compared to cancer (Prevalence Ratio [PR] =2.07, 95%CI 1.42- 3.01) and for people with severe breathlessness (PR=1.96, 95%CI 1.12-3.43). Transition was less likely if EoL preferences had been discussed with a healthcare professional (PR=0.60, 95%CI 0.42-0.88) and when there was a key healthcare professional (PR=0.74, 95%CI 0.58-0.95).

CONCLUSION: To reduce EoL transition to hospital for older people this study suggests a need to improve the symptom management of breathlessness in the community and better access to a key healthcare professional skilled in coordinating care, communication, facilitating complex discussions and in planning for future care.

Key words: Frail elderly; Palliative care; Terminal care; Cross-sectional survey; Mortality follow-back survey

INTRODUCTION

People aged 75 years or older (75+) are a rapidly growing demographic worldwide.¹ This group account for approximately two-thirds of deaths in more developed countries.² As people die increasingly in advanced age the patterns of diseases and causes of death change.³ Older people commonly live with multi-morbidities and frailty and die from a combination of conditions.⁴ It is imperative that we understand how end-of-life (EoL) care is delivered to this expanding and complex population group to inform health policy and optimise service provision.

Most older people die in hospital in developed countries^{5, 6} despite knowledge that the majority wish to remain at home or their usual place of care at the EoL.⁷ With advanced age a care home increasingly forms the usual place of care.⁸ Older people's overall preference is to remain in an environment that is safe and secure with autonomy preserved and their loved ones nearby.⁹ Transition from usual place of care at the EoL is often challenging for patients and families. Transition disrupts the continuity of care at the EoL and threatens the quality of care received.^{11,10} Patient safety is also compromised as hospitalisation for older people is associated with physical and cognitive decline, and an increased risk of mortality.¹²

A major cost driver in the provision of EoL care is inpatient hospital stay.¹³ In most high-income countries there is an overreliance on acute hospital care at the EoL.¹³ In the United Kingdom (UK), there has been a reduction in hospital deaths, which may be attributed to policy initiatives to increase home based care at the EoL¹⁴, including specialist palliative care services or home hospice (receipt of which does not affect eligibility to hospital care in the UK). However, improvements have been seen mainly for those dying from cancer.¹⁵

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Studies have explored transitions between care settings in the months before death^{10, 20,16}, place of death using national death registration data that precludes understanding on preceding care and concerns,^{3, 17} and outcomes of care by place of death.¹⁸ However, such studies rarely consider patient or carer reported symptoms and concerns or preferences for care, and their impact on transition at the EoL to place of death. This study aims to identify explanatory illness, individual and environmental factors in the last three months of life associated with transition from community settings to hospital as place of death for people aged 75+.

METHODS

Population-based mortality follow-back survey.¹⁹

Ethics Statement

An NHS Research Ethics Committee (REC no. 12/LO/1367) approved the study. The Office for National Statistics (ONS) agreed the Data Access Agreement and individual access for researchers (CJE, WG, AEB, DY and IJH). Return of a completed questionnaire was taken as consent. All data were anonymized and stored securely.

Setting

The study included two contrasting geographical areas in Southern England (rural/urban, and city) with a total population of over one million and geographical area of 800 square miles.²⁰

Sample

We first identified the sampling frame comprising people aged 75+ who had died at home, in a care home, hospital, or inpatient hospice unit from ONS death registration data. We included decedents who died from a cancer or non-malignant illness in the two study areas. We selected all underlying causes of death common in advanced age and suitable for palliative care²¹ excluding causes of death unlikely to be suitable for palliative care (e.g. accidental deaths). Participants were those who registered the death (a relative in 98.9% of cases). We also excluded participants involved in a national post-bereavement survey,²² cases where officials registered the death (e.g. a solicitor) and registrations with no contact address.

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Based on our sample size calculation, we planned to include 310 deaths in our study (80% power and significance of 0.05 [two-sided]). We estimated standardised differences between death in hospital and community settings from findings on home deaths versus deaths elsewhere (hospital, care home, inpatient hospice) for cancer patients, the best data available to inform the calculation.^{23, 24} We examined three variables: patient preference for death at home (yes/no; standardised difference 0.866), help of community nurse (yes/no; standardised difference 0.795), and satisfaction with GP care (poor vs. fair/good/excellent; standardised difference 0.225). Using 80% power and significance of 0.05, we estimated the sample sizes to be n=22, n=26 and n=310 respectively. We aimed to achieve the largest sample size to ensure detection of difference for each considered variable. To accommodate the older age of respondents we anticipated a lower response rate (35%) and higher missing data (30%) compared to similar follow-back surveys. Hence to get the 310 we needed, we planned to approach 882 people. The sample was stratified by geographical area in the study site (rural/urban, and city) and place of death. For the city area we included all eligible deaths in each care setting. However for the rural/urban area we included all home and inpatient hospice deaths and a random sample of hospital and care home deaths (45% and 44% respectively) to counter their high frequency.¹⁹

Procedures

The person who registered the death was invited to participate by the ONS four to ten months after death registration. The ONS posted the QUALYCARE survey¹⁹ to eligible participants as a single wave in October 2012 with postal reminders at three

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weeks (letter) and six weeks (letter and survey). We provided a survey helpline to support participants and a research nurse for participants requiring face-to-face assistance e.g. due to visual impairment.

The QUALYCARE survey is an adapted short form of the Cartwright survey developed in the 1960s to measure bereaved relatives' perspectives of patients' experiences in the last year of life.²⁵ The survey includes validated measures of palliative symptoms and concerns experienced in the last week of life (Palliative care Outcome Scale - POS)²⁶ and of health and social care services use and informal care in the last three months of life (Client Service Receipt Inventory - CSRI).²⁷ It also asks about the decedent's preferences for place of death (as far as the respondent knows), the respondent's preferences (looking back at 3 months before death) and if preferences had been discussed. The original QUALYCARE survey was designed for adults with cancer.^{19, 28} We modified the survey to tailor for older people with cancer or non-malignant conditions e.g. to capture relevant healthcare input. Our Steering Group and Lay Project Advisory Group oversaw this process. The ONS provided data on cause of death; contributing causes of death; place of death; age; and a national composite measure of area deprivation (Indices of Multiple Deprivation [IMD] 2010) using decedents' usual residence at the Lower Super Output Area and analysed in quintiles.²⁹

Main outcome

Our main outcome was EoL transition to hospital as the place of death versus no EoL transition to hospital. Usual place of care was identified by the informant and defined as the place where the decedent spent most of their last three months of life.

The 'at home' group comprised decedents who had usual care 'at home' or 'friend/relative own home'; and 'care home' group those with nursing care (nursing home) or with personal care only (residential care).

Explanatory variables

We examined factors associated with EoL transition to hospital as place of death, selecting explanatory variables based on previous research and clinical judgement.^{3, 17, 30} We used an explanatory model³⁰ to categorise variables as: 1) illness factors (underlying cause of death, symptom distress [e.g. pain], psychological distress [e.g. anxiety], and carer anxiety); 2) individual factors (e.g. age, gender); and 3) environmental factors at the individual level (e.g. healthcare input). Underlying cause of death was grouped into ICD-10 top level disease codes e.g. respiratory ICD-10 J. We defined 'frailty' using ICD-10 R53-R54 (malaise and senility) and collapsed with Alzheimer's (ICS10-F01, F03) and dementia (ICD-10 G30), and 'other' causes of death. We used a count of contributing causes of death (including underlying cause of death).

We used POS data on decedents' symptoms and concerns in the last week of life with five response options ranging from *not at all* to *overwhelmingly* and imputed missing data using median values. Service use (CSRI) was analysed as a continuous variable for frequently used services (e.g. GP) and dichotomous yes/no for specialist services. We imputed missing data on number of contacts using the lower quartile number of contacts that showed a positively skewed distribution. We imputed missing data (17.5 %) for the variable "*Do you feel he/she had a key contact*

person (healthcare professional) to rely on to get things done” using a proxy variable of contact with a specialist palliative care team or a specialist nurse (e.g. respiratory nurse) as this group as commonly perform a key worker role^{31, 32} and explored with sensitivity analyses.

Data analysis

To compare EoL transition to hospital as place of death (defined 1) to no EoL transition or transition to a care home or inpatient hospice unit (defined 0), we conducted univariate analysis by illness related, individual, and environmental factors, using Chi² test/Mann Whitney test as appropriate.

We used multivariable modified Poisson regression with robust error variance to estimate prevalence ratios (PRs) for EoL transition to hospital.³³ Modified Poisson regression was favoured over logistic regression as a prevalence ratio was considered a preferable measure of risk than an odds ratio, which may overestimate effect size.³³ We generated a propensity score (probability of participation) using factors significantly associated with participation (age and place of death: see supplementary table 1). The inverse propensity score was used in the regression model to adjust for response bias.³⁴ Findings from the univariate analysis and clinical consideration informed candidate variables for regression modelling (supplementary table 2). We assessed collinearity between explanatory variables to inform variable inclusion using Spearman’s rank correlation coefficient and chi² test as appropriate. We used backwards selection to determine variables entered into the final parsimonious model. Age, gender and place of usual care were forced to remain as

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potential confounders. We used sensitivity analyses on the dependent variable to explore case inclusion (supplementary table 3), and variables that were significant in the univariate analysis e.g. specialist palliative care variable (supplementary table 4). Analyses used Stata SE 13.

RESULTS

The sample

Informants

443 informants completed the survey (50.2% response rate); 438 (98.9%) were related to the deceased; mostly a son or daughter (n=303, 68.4%) or a spouse/partner (n=68, 15.8%). Their mean age was 62.3 years (SD= 10.7), most were women (n=279, 63.0%); 44% were in paid employment (n=195), 38.4% retired (n=170). Half were from area 1 (n=223, 50.3%, rural/urban) and half from area 2 (n=220, 49.7%, city) (table 1).

Decedents

The decedents' age ranged from 75 years to 104 years (mean 87.4 years, SD=6.4). The majority were women (n=262, 59.1%) and widowed (n=237, 53.5%) and White British (n=410, 92.5%). The main underlying causes of death were circulatory diseases (n=144, 32.5%), respiratory conditions (n=90, 20.3%), cancer (n=105, 23.7%), and dementia/frailty (n=88, 19.9%) (table 1). 39.7% of decedents had a mention of frailty or dementia (or both) on the death certificate. Frailty was a contributing cause of death for 21.9% (n=97) and dementia for 6.7% (n=30).

Transition to hospital at the end of life

A third (32.3%) of our sample transitioned to hospital at the EoL as their place of death. Only 2% of respondents expressed a known preference of the patient to die in hospital, and 9.7% of respondents expressed a preference for the decedent to have died in hospital. Most patients wished to die at home (67.9%), while family members,

looking back at the 3 months before death, expressed a lower preference for home (42%) but higher for care home (25.1% compared to 9.5% for patients) (table 1).

The majority of the patients who transitioned at the EoL to hospital as place of death did so from home (71.9%) and the remainder transitioned from a care home (28.1%) (figure 1). Nearly half transitioned to hospital a week to a month prior to death (47.3%). A quarter (26.7%) moved in the last week of life and 10.3% in the last 24 hours of life. 14.4% spent one to six months in hospital prior to death.

Over half of the decedents (n=240, 54.2%) remained in their usual place of care in a community setting; this was mainly home (n=120, 27.1%) or care home (n=118, 26.6%). A small number transitioned in the last weeks of life to an inpatient hospice unit (n=21, 4.7%) or a care home (n=20, 4.5%). For a few, usual place of care in the last three months and place of death comprised a hospital (n=16, 3.6%) (figure 1). We considered these cases anomalies and thus excluded them in our analysis.

Adjusted associations with EoL transition to hospital

We found that an EoL transition to hospital was associated with factors relating to the patient's illness and symptom distress, carer's anxiety and the type and volume of healthcare receipt (supplementary table 2). Seven variables were included in our final multivariable model of factors related to EoL transition to hospital (table 2).

These included factors related to the patient's illness factors and health care receipt.

Dying from respiratory or circulatory diseases was independently associated with EoL transition to hospital. Patients dying from a respiratory disease were twice as likely to transition to hospital at the EoL (PR 2.07, 95%CI 1.42-3.01) and patients

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dying from circulatory disease 53% more likely (PR 1.53, 95% CI 1.06-2.20) as those dying from cancer. Patients experiencing severe/overwhelming breathlessness in their last week of life were almost twice as likely to transition to hospital at the EoL as those who experienced no breathlessness (PR 1.96; 95%CI 1.12-3.43).

Patients who discussed their preferred place of care with a healthcare professional were less likely to transition to hospital (PR 0.60, 95% CI 0.42-0.88). Similarly, patients with the identified presence of a key worker (healthcare professional) 'to rely on to get things done' were less likely to transition to hospital (PR 0.74, 95% CI 0.58-0.95). Sensitivity analyses to explore the impact of imputed values for included variables (i.e. complete cases) demonstrated consistent findings. Specialist palliative care was not significantly associated with transition to hospital and excluded from the model (OR 0.79, 95% CI 0.56 – 1.13) (supplementary table 4). This finding may be attributed to the significant associations between specialist palliative care and the covariates cause of death, presence of a key worker, and discussions about preferred place of care with a health professional (chi squared test $p < 0.001$ for each).

DISCUSSION

In this population-based study of the EoL care experienced by older people we found that over a third transitioned to hospital at the EoL and died there, even though very few (2.0%) wished to die in this setting. There is an apparent reliance on hospitals to provide EoL care for older people, particularly for those living at home who accounted for 71.9% of those who transitioned. Very few (4.7%) older people transitioned to an inpatient hospice unit at the EoL. Almost half (47.3%) of the older people who transitioned to hospital were inpatients for several weeks to a month before death. Irrespective of their usual place of care, the likelihood of transition to hospital was greater for people with respiratory and circulatory disease and with severe breathlessness. The likelihood of transition was lower among people who had discussed EoL care preferences with a health professional, and those with an identified key healthcare professional.

Breathlessness is a prominent symptom for patients across advanced illnesses^{53,35} and is a common symptom in emergency department attendance.³⁶ Severe breathlessness is distressing for patients and carers³⁷ which may explain the observed association with transition to hospital. Our findings suggest that there is a need to better alleviate the symptom of breathlessness for older people at the EoL. There is growing evidence that innovative breathlessness services improve patient outcomes of mastery of breathlessness and distress.^{38, 39} Improved breathlessness services provided by specialist health professionals in the community may reduce the incidence of transition to hospital for older people.

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Transition to hospital as place of death was more likely among people with certain non-malignant illnesses (i.e. respiratory and circulatory diseases). Patients who died from non-malignant respiratory disease were twice as likely to transition to hospital at the EoL compared to those with cancer and the association remained after adjusting for breathlessness. Studies consistently report the association between respiratory disease and dying in hospital.^{3, 40, 41} For patients with respiratory disease, such as chronic obstructive pulmonary disease, end of life is often hard to recognise and inadequately anticipated.⁴² This may preclude timely access to palliative care interventions and services. With prognostic uncertainty, indicators of unstable or deteriorating symptoms and concerns, notably unplanned hospital attendance, may better indicate requirement for palliative interventions.⁴² Most older people who died in hospital had been admitted several weeks prior to death, suggesting there was opportunity for anticipation of end of life, palliative care input, and discussions about wishes for future care.

We found that discussion of preferences for future care with a health professional and the presence of a key worker – a healthcare professional ‘to rely on to get things done’- were both protective factors against transition to hospital. A key worker with clinical expertise may augment continuity of care through improved care coordination and timely access to services.^{31, 43} Continuity is a central component of quality of health care comprising both relational continuity between a patient and a clinician, and management continuity between clinicians e.g. information sharing.⁴⁴ Relational continuity with a key healthcare professional may facilitate discussions with patients and families on preferences for future care. We found that few patients (22.3%) were reported to have had discussions about preferences for future care

with health professionals. Our findings suggest that EoL discussions and wider provision of advance care planning may be important to facilitate patients to remain in their usual place of care at the EoL or to shorten length of hospital stay.

It is clinically challenging to manage older people nearing the EoL as they often have multiple debilitating conditions with complex needs including physical, emotional, psychological and spiritual.⁴⁵ It is important that a key worker has the clinical skills and training to effectively assess and anticipate care needs and coordinate timely care, and discuss sensitively with older people and their families about preferences for future care at the EoL.⁴⁶ Older patients with multiple non-malignant conditions have similar palliative care need to patients with advanced cancer.^{36,45} Home palliative care services have been effective for cancer patients in improving symptom management including alleviation of breathlessness and in over doubling the incidence of home deaths.⁴⁷ There is a need for similar service and treatment innovation applied to older people living in the community and for evaluation using robust trials to provide high quality evidence of potential effect.

The study's strengths are the focus on people aged 75 years or older across care settings, including care homes, and across multiple conditions and the comparatively high response rate (50.2%).^{22, 48} The linkage of national death registration data with bereaved relatives' accounts has enabled detailed and unique reporting as few studies have examined in detail factors associated with EoL transition to hospital for older people.⁴⁹

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A limitation of the study is the use of a follow-back mortality survey reliant on proxy accounts. However the majority of proxy informants were close family members, mainly sons or daughters. While expected, the high non-response rate and ethnic homogeneity of the sample limit the generalisability of the findings. However, we accounted for known differences in the decedents' age and place of death between participants and non-participants in the analyses to minimise the effect of systematic non-response on our findings. We oversampled home and inpatient hospice deaths including all cases to enable analysis of these less common places of death. The proportion that transitioned to hospital at EoL is therefore likely to be underestimated. We acknowledge that we did not differentiate between appropriate and inappropriate hospital admission at the EoL.

In conclusion, our findings suggest that to reduce reliance on hospital care at the EoL for older people with non-malignant conditions requires timely and coordinated services responsive to increasing symptom distress, and greater anticipatory care planning. Policy imperatives are improved management of breathlessness in the community and greater emphasis on an assigned key healthcare professional skilled in coordinating care, communication, facilitating complex discussions and in future care planning. Further research is required on evaluating service innovations to improve palliative and end of life care provision and access for older people with non-malignant conditions in community settings.

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Conflict of Interest:

We declare no conflicts of interest.

Author Contributions:

Obtained research funding: CJE and IJH. Wrote protocol: CJE, IJH, WG and BG. Data entry, checking, recoding and analysis: AEB and CJE. Statistical guidance:

WG, IJH and DY. Interpretation of statistical findings: AEB, CJE, WG, IJH, MM, KS, DY, JW, BG. Wrote first draft of the manuscript: AEB and CJE. Commented on, revised draft of the manuscript for critical content and approved final version: AEB, CJE, IJH, WG, BG, JW, KS, MM, DY.

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REFERENCES

1. United Nations Department of Economic and Social Affairs. World Population Prospects: The 2010 Revision. United Nations 2011.
2. National End of Life Care Intelligence Network. Deaths in Older Adults in England. South West Public Health Observatory 2010.
3. Evans CJ, Ho Y, Daveson BA, et al. Place and Cause of Death in Centenarians: A Population-Based Observational Study in England, 2001 to 2010. *PLoS Med.* 2014;11(6):e1001653.
4. Gomes B CJ, Deliens L, Higginson IJ. International trends in circumstances of death and dying among older people. In Gott M, (Ed). *Living with Ageing and Dying: Palliative and End of Life Care for Older People.* Oxford: Oxford University Press 2011:3-18.
5. National End of Life Care Intelligence Network. Variations in Place of Death in England. Inequalities or appropriate consequences of age, gender and cause of death? National End of Life Care Intelligence Network 2010.
6. Davies E, Higginson I. *The Solid Facts: Palliative Care.* WHO Europe 2004.
7. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care.* 2013;12:7.
8. Houttekier D, Cohen J, Bilsen J, et al. Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc.* 2010;58(4):751-757.
9. Gott M, Seymour J, Bellamy G, et al. Older people's views about home as a place of care at the end of life. *Palliative Medicine.* 2004;18(5):460-467.

10. Hanratty B, Holmes L, Lowson E, et al. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *J Pain Symptom Manage*. 2012;44(1):74-83.
11. Klinkenberg M, Visser G, van Groenou MI, et al. The last 3 months of life: care, transitions and the place of death of older people. *Health Soc Care Community*. 2005;13(5):420-430.
12. Merino Martín S, Cruz-Jentoft AJ. Impact of hospital admission on functional and cognitive measures in older subjects. *European Geriatric Medicine*. 2012;3(4):208-212.
13. Georghiou T, Bardsley M. Exploring the cost of care at the end of life Research report. Nuffield Trust 2014.
14. Department of Health. End of Life Care Strategy - promoting high quality care for adults at the end of life. Crown 2008.
15. Gomes B, Calanzani N, Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliative medicine*. 2012;26(2):102-107.
16. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*. 2013;309(5):470-477.
17. Sleeman KE, Ho YK, Verne J, et al. Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010. *BMC Neurol*. 2014;14:59.
18. 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(1):1-14.

19. Gomes B, McCrone P, Hall S, et al. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer*. 2010;10:400.
20. Office for National Statistics. Neighbourhood statistics Available: <http://www.neighbourhood.statistics.gov.uk/>. Accessed 2nd February, 2015.
21. 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*. 2013;28(1):49-58.
22. Department of Health. First national VOICES survey of bereaved people: key findings report. Department of Health 2012.
23. Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliative medicine*. 1995;9(4):295-305.
24. Karlsen S, Addington-Hall J. How do cancer patients who die at home differ from those who die elsewhere? *Palliative medicine*. 1998;12(4):279-286.
25. Cartwright A, Hockey L. *Life Before Death*. London: Routledge 1973.
26. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. *Qual Health Care*. 1999;8(4):219-227.
27. McCrone P. Capturing the costs of end-of-life care: Comparisons of multiple sclerosis, Parkinson's disease, and dementia. *J Pain Symptom Manage*. 2009;38(1):62-67.
28. Pivodic L, Harding R, Calanzani N, et al. Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors. *Palliat Med*. 2015.

29. Mclennan D, Barnes H, Noble M, et al. The English Indices of Deprivation 2010. Department for Communities and Local Government 2011.
30. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*. 2006;332(7540):515-521.
31. Epiphaniou E, Shipman C, Harding R, et al. Coordination of end-of-life care for patients with lung cancer and those with advanced COPD: are there transferable lessons? A longitudinal qualitative study. *Prim Care Respir J*. 2014;23(1):46-51.
32. Goodwin N SL, Thiel V, Kodner DL. Co-ordinated care for people with complex chronic conditions. The King's Fund 2013.
33. Zou G. A Modified Poisson Regression Approach to Prospective Studies with Binary Data. *American Journal of Epidemiology*. 2004;159(7):702-706.
34. Kreuter F, Olson K, Wagner J, et al. Using Proxy Measures and Other Correlates of Survey Outcomes to Adjust for Non-Response: Examples from Multiple Surveys. *Journal of the Royal Statistical Society*. 2010;173(2):389-407.
35. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage*. 2006;31(1):58-69.
36. Beynon T, Gomes B, Murtagh FE, et al. How common are palliative care needs among older people who die in the emergency department? *Emerg Med J*. 2010;28:491-495.
37. Malik FA, Gysels M, Higginson IJ. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. *Palliative medicine*. 2013;27(7):647-656.
38. Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory

breathlessness: a randomised controlled trial. *The Lancet Respiratory medicine*. 2014;2(12):979-987.

39. Farquhar MC, Prevost AT, McCrone P, et al. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial. *BMC Med*. 2014;12:194.

40. Cohen J, Bilsen J, Addington-Hall J, et al. Population-based study of dying in hospital in six European countries. *Palliat Med*. 2008;22(6):702-710.

41. Public Health England. Patterns of End of Life care in England, 2008 to 2010. 2013.

42. Pinnock H, Kendall M, Murray SA, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ*. 2011;342:d142.

43. Oishi A, Murtagh FEM. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals. *Palliat Med*. 2014.

44. Freeman G, Hughes J. Continuity of care and the patient experience. The King's Fund 2010.

45. Hall S, Petkova H, Tsouros A, et al. Palliative care for older people: better practices. World Health Organisation Regional Office for Europe 2011.

46. Woo JA, Maytal G, Stern TA. Clinical Challenges to the Delivery of End-of-Life Care. *Primary Care Companion to The Journal of Clinical Psychiatry*. 2006;8(6):367-372.

47. 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:Cd007760.
48. Burt J, Shipman C, Richardson A, et al. The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. *Age and ageing.* 2010;39(1):86-91.
49. Dixon J, King D, Matosevic T, et al. Equity in the Provision of Palliative Care in the UK: Review of Evidence. Personal Social Services Research Unit, London School of Economics and Political Science 2015.

TABLES

Table 1: Characteristics of Decedents and Informants (N=443)

Variable	Characteristic	n	%
Decedent's relationship to informant	Husband/wife or partner	68	15.4
	Son or daughter	303	68.4
	Other relative	67	15.1
	Friend or staff (e.g. care home)	5	1.1
Decedent gender	Male	181	40.9
	Female	262	59.1
Decedent age (years)	Mean (Standard deviation)	87.4(6.4)	
	75-79	51	11.5
	80-84	103	23.3
	85-89	111	25.1
	90-94	117	26.4
	95+	61	13.8
Decedent ethnicity	White	410	92.6
	White other/ other ethnicity	18	4.1
Deprivation quintile of decedent's area of residence (Indices of Multiple Deprivation)	1 Most deprived	51	11.5
	2	69	15.6
	3	111	25.1
	4	90	20.4
	5 Least deprived	121	27.4

End of Life Transition to Hospital

Underlying cause of death (ICD10 codes)	Cancer (C)	105	23.7
	Ischaemic heart disease (I20-125)	69	15.6
	Other circulatory (I [others])	52	11.7
	Cerebrovascular (I60-169)	23	5.2
	Respiratory (J [others])	90	20.3
	Dementia (F01-F03, G30)	67	15.1
	“Frailty” (R54)	21	4.7
	“Others”	16	3.6
Place of death	Home*	120	27.1
	Care home †	138	31.2
	Inpatient Hospice	23	5.2
	Hospital	162	36.6
Usual place of care in the last three months of life	Home*	254	57.3
	Care home †	160	36.1
	Inpatient Hospice	2	0.5
	Hospital	27	6.1
Decedent’s preferred place of death (as far as respondent knows)	Home*	301	68.0
	Care Home †	42	9.5
	Inpatient Hospice	14	3.2
	Hospital	9	2.0
	2 or more preferences	5	1.14
	No preference	21	4.74
Don’t know	37	8.35	
Informant’s preferred	Home*	186	42.0

End of Life Transition to Hospital

place of death (3 months before death)	Care Home †		111	25.1
	Inpatient Hospice		27	6.1
	Hospital		43	9.7
	No preference		58	13.1
	2 or more preferences		7	1.6
End of life (EoL) transition	Patients with EoL transition to	Patients with EoL transition to	146	33.0
	community institution	care home†	20	4.5
		EoL transition to inpatient hospice	21	4.7
	Patients without EoL transition	EoL in home*	120	27.1
		EoL in care home†	118	26.6
		EoL in inpatient hospice	2	0.5
		EoL in hospital	16	3.6

Column percentages that do not sum to one hundred percent are due to missing data;

*Own home or home of friend or relative; † Nursing or residential home

Table 2: Multivariable Regression Analysis: EoL Transition to Hospital versus No Transition or Transition to Community Setting

Variable	Variable levels	Prevalence Ratio (PR)	95% CI	P value
Age (years)	(continuous)	1.00	0.98-1.02	0.90
Gender	Male	1.00*		
	Female	1.21	0.94-1.55	0.13
Usual place of care	Institutional setting†	1.00*		
	Home	1.80	1.35-2.40	<0.001
Cause of death	Cancer	1.00*		
	Circulatory disease	1.53	1.06-2.20	0.024
	Respiratory disease	2.07	1.42-3.01	<0.001
	Other including frailty and dementia	1.01	0.60-1.70	0.98
Breathlessness	Not at all	1.00*		
	Slightly/Moderately	1.46	0.83-2.56	0.19
	Severely/Overwhelmingly	1.96	1.12-3.43	0.018
Discussed preferred place of care with health professional	No/ Don't know	1.00*		
	Yes	0.60	0.42-0.88	0.008
Key health professional	No	1.00*		
	Yes	0.74	0.58-0.95	0.019

N= 424 (3 excluded for missing data on key contact variable). Regression model is weighted by the inverse propensity score; CI=Confidence interval; EoL= end of life.

* Reference group; †Institutional setting includes care home (n=160), inpatient hospice (n=2), hospital with transition (n=11) (see figure 1). A PR of greater than one indicates higher probability of EoL transition to hospital.

SUPPLEMENTARY MATERIAL FOR ONLINE ONLY

Supplementary table 1: Comparison of decedent characteristics for participants and non-participants

	Non- participants N=439 n(col %)	Participants N=443 n(col %)	p value
Patient's gender			Chi2 p=0.70
Male	185(42.1)	181(41.1)	
Female	254(57.9)	262(59.1)	
Patient's age (years)			
Median (IQR)	86 (10)	88 (9)	MW p=0.001*
Mean (SD)	86.1(6.5)	87.4 (6.4)	
75-79	84(19.1)	51(11.5)	Chi2 p=0.014*
80-84	107(24.4)	103(23.3)	
85-89	107(24.4)	111(25.1)	
90-94	94(21.4)	117(26.4)	
95+	47(10.7)	61(13.8)	
Patient's cause of death			Chi2 p=0.28
Cancer	125(28.5)	105(23.7)	

End of Life Transition to Hospital

Ischaemic heart disease	54(12.3)	69(15.6)	
Cerebrovascular	27(6.2)	23(5.2)	
Other Circulatory	63(14.4)	52(11.7)	
Respiratory	70(15.9)	90(20.3)	
Dementia	61(13.9)	67(15.1)	
Frailty	18(4.1)	21(4.7)	
Other	21(4.8)	16(3.6)	
Place of death			Chi2 p=0.005*
Home	84(19.1)	120(27.1)	
Care home	124(28.2)	138(31.2)	
Inpatient Hospice	36(8.2)	23(5.2)	
Hospital	195(44.4)	162(36.6)	
Indices of Multiple Deprivation†			Chi2 p=0.09
1 (most deprived)	54(12.3)	51(11.5)	
2	98(22.3)	69(15.6)	
3	96(21.9)	111(25.1)	
4	73(16.6)	90(20.4)	
5 (least deprived)	118(26.9)	121(27.4)	

MW= Mann Whitney Test; SD= standard deviation; IQR= interquartile range

*Significant at p<0.05 level; † missing value for 1 participant

Supplementary table 2: Unadjusted Univariate Analysis of Illness and Environmental Factors by EoL Transition

		EoL transition to hospital (N=146)		No EoL transition or transition to inpatient hospice/care home (N=281)		p value	Missing
		n	col%	n	col%		n (%)
Illness Factors							
Cause of death	Cancer	25	17.1	77	27.4	<0	
						.001	
	Circulatory disease	53	36.3	83	29.5		
	Respiratory disease	48	32.9	37	13.2		
	Other including dementia and frailty	20	13.7	84	29.9		
Number of mentioned causes of death	1	17	11.6	74	26.3	<0.001	
	2	30	20.6	107	38.1		
	3	28	19.2	54	19.2		
	4+	71	48.6	46	16.4		

End of Life Transition to Hospital

Pain	Not at all	52	41.6	103	40.6	0.27	48(11.2)
	Slightly/	62	49.6	114	44.9		
	Moderately						
	Severely/	11	8.8	37	14.6		
	Overwhelmingly						
Breathlessness	Not at all	10	7.3	44	17.5	<0.001	38(8.9)
	Slightly/	51	37.0	120	47.8		
	Moderately						
	Severely/	77	55.8	87	34.7		
	Overwhelmingly						
Depression	Not at all	51	39.2	99	39.1	0.77	44(10.3)
	Occasionally/	47	36.2	99	39.1		
	Sometimes						
	Most of the	32	24.6	55	21.7		
	time/ Definitely						
Anxiety	Not at all	39	28.1	87	33.3	0.55	27(6.3)
	Occasionally/	77	55.4	133	51.0		
	Sometimes						
	Most of the	23	16.6	41	15.7		
	time/Thought of nothing else						
Family anxiety	Not at all	11	7.6	37	13.5	0.019	8(1.9)
	Occasionally/	31	21.5	81	29.5		
	Sometimes						

End of Life Transition to Hospital

	Most of the time/ Always	102	70.8	157	57.1		
Felt at peace	All /Most of the time	64	49.6	154	58.1	0.27	33(7.7)
	Some of the time/Occasionally	31	24.0	51	19.3		
	Not very often/ Not at all	34	26.4	60	22.6		

Environmental Factors

Usual place of care	Home	105	71.9	149	53.0	N/A ‡	
	Care home	41	28.1	119	42.4		
	Inpatient	0	0	2	0.7		
	Hospice						
Discussed preferred place of care with clinician	Hospital	0	0	11	3.9		
	No/ Don't know	123	85.4	197	71.6	0.002	8(1.9)
Key healthcare professional*	Yes	21	14.6	78	28.4		
	No	85	58.6	110	39.4	<0.001	3(0.7)
GP face-to-face contacts	Yes	60	41.4	169	60.6		
	Mean/ SD	3.60	4.6	4.45	4.5	0.002†	2(0.5)
Community nurse contacts	Mean/ SD	3.82	9.9	4.75	12.4	0.80†	9(2.1)

End of Life Transition to Hospital

Specialist	No/ Don't know	113	77.4	188	66.9	0.024
Palliative Care §						
	Yes	33	22.6	93	33.1	

N=427. SD= Standard Deviation; GP= General Practitioner; EoL=End of Life; P values pertain to chi 2 test of association unless indicated otherwise; † Mann-Whitney test. ‡ Chi square test not performed due to zero cell counts. Symptoms relate to last week of life and health service to the last three months of life. § Specialist palliative care in all settings, including hospice care, palliative care, Marie Curie or Macmillan or any other specialist palliative care service. *Missing values for key healthcare professional (n=76, 17%) have been imputed using specialist palliative care/specialist nurses variable.

Supplementary table 3: Sensitivity Analysis on Dependent Variable										
		Model 1 (N=424)			Model 2 (N=413)			Model 3 (N=383)		
		PR	95% CI	P value	PR	95% CI	P value	PR	95% CI	P value
Age (years)	(continuous)	1.00	0.98-	0.90	1.00	0.98-	0.87	1.00	0.98-	0.79
			1.02			1.02			1.02	
Gender	Male	1.00*	-	-	1*	-	-	1*	-	-
	Female	1.21	0.94-	0.13	1.18	0.92-	0.18	1.22	0.97-	0.09
			1.55			1.51			1.54	
Usual place of care	Institutional setting	1.00*	-	-	1*	-	-	1*	-	-
	Home	1.80	1.35-2.4	<0.001	1.66	1.24-	0.001	1.78	1.34-	<0.00
						2.21			2.36	1
Cause of death	Cancer	1.00*	-	-	1*	-	-	1*	-	-

End of Life Transition to Hospital

	Circulatory disease	1.53	1.06-2.2	0.024	1.45	1.01-2.09	0.046	1.15	0.84-1.57	0.37
	Respiratory disease	2.07	1.42-3.01	<0.001	1.99	1.37-2.89	<0.001	1.53	1.11-2.1	0.010
	Other including frailty and dementia	1.01	0.6-1.7	0.98	0.92	0.54-1.57	0.77	0.73	0.45-1.2	0.22
Breathlessness	Not at all	1.00*	-	-	1*	-	-	1*	-	-
	Slightly/ Moderately	1.46	0.83-2.56	0.19	1.44	0.82-2.53	0.20	1.58	0.91-2.77	0.11
	Severely/ Overwhelmingly	1.96	1.12-3.43	0.018	1.93	1.11-3.38	0.021	2.12	1.22-3.7	0.008
Discussed preferred place of death with	No/ Don't know	1.00*	-	-	1*	-	-	1*	-	-
	Yes	0.60	0.42-0.88	0.008	0.60	0.42-0.87	0.007	0.64	0.45-0.9	0.010

End of Life Transition to Hospital

health

professional

Key health	No	1.00*	-	-	1*	-	-	-	-
professional	Yes	0.74	0.58-	0.019	0.73	0.57-	0.013	0.77	0.61- 0.024
			0.95			0.93			0.97

*Reference; PR=prevalence ratio; CI= confidence interval. Model 1: Final model with EoL transition to hospital (1) vs no EoL transition/ transition to care home or inpatient hospice (0); Model 2: Excluded EoL transition to community from hospital (n=11)
 Model 3: Excluded EoL transition to community from hospital and other community settings (n=41).

Supplementary Table 4: Sensitivity Analysis for Multivariable Regression of EoL Transition to Hospital versus No Transition or Transition to Community Setting

Variable	Variable levels	Prevalence Ratio (PR)	95% CI	P value
Age (years)	(continuous)	1.00	0.98-1.02	0.96
Gender	Male	1.00*		
	Female	1.22	0.96-1.56	0.12
Usual place of care	Institutional setting†	1.00*		
	Home	1.86	1.34-2.50	<0.001
Cause of death	Cancer	1.00*		
	Circulatory disease	1.37	0.91-2.06	0.127
	Respiratory disease	1.88	1.25-2.82	0.002
	Other including frailty and dementia	0.93	0.54-1.58	0.78
Breathlessness	Not at all	1.00*		
	Slightly/Moderately	1.45	0.82-2.56	0.19
	Severely/Overwhelmingly	1.97	1.11-3.47	0.020

End of Life Transition to Hospital

Discussed preferred place of care with health professional	No/ Don't know	1.00*		
	Yes	0.64	0.44-0.93	0.021
Key health professional	No	1.00*		
	Yes	0.76	0.59-0.97	0.029
Specialist palliative care†	No/ Don't know	1.00*		
	Yes	0.79	0.56-1.13	0.192

N= 424 (3 excluded for missing data on key contact variable). Regression model is weighted by the inverse propensity score; CI=Confidence interval; EoL= end of life.

* Reference group; †Institutional setting includes care home (n=160), inpatient hospice (n=2), hospital with transition (n=11) (see figure 1). ‡Specialist palliative care in all settings, including hospice care, palliative care, Marie Curie or Macmillan or any other specialist palliative care service. A PR of greater than one indicates higher probability of EoL transition to hospital.
