Title: The complex relationship between household income of family caregivers, access to palliative care services and place of death: a national household population survey.

Running Title: Caregiver household income, access to palliative care services and place of death.

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Word count 2,871

ABSTRACT

Background: Previous work shows that more affluent patients with cancer are more likely to die at home. Whereas those with non-cancer conditions are more likely to die in hospital. Family caregivers are an important factor in determining place of death.

Aim: To investigate associations between family caregivers' household income, patients' access to specialist palliative care and place of patients' death, by level of personal end-of-life care.

Design: A cross-sectional community household population survey.

Setting and participants: Respondents to the Household Survey for England.

Results: One third of 1265 bereaved respondents had provided personal end-of-life care (caregivers) (30%). Approximately half (55%) of decedents accessed palliative care services and 15% died in a hospice. Place of death and access to palliative care were strongly related (p<0.001). Palliative care services reduced the proportion of hospital deaths (p<0.001), and decedents accessing palliative care were more likely to die at home (p<0.001). Respondents' income was not associated with palliative care access (p=0.233). Overall, respondents' income and home death were unrelated (p=0.106), but decedents with *caregivers* in the highest income group were *least* likely to die at home (p=0.069).

Conclusions

Decedents' access to palliative care services was associated with fewer deaths in hospital and more home deaths. Bereaved respondents' income was unrelated to decedents' place of death when adjusted for palliative care access. For *caregivers* only, decedents with more affluent caregivers were the *least* likely to die at home. Higher income caregivers are likely to be powerful patient advocates; information needs must be addressed with regard aim of care.

Keywords: caregivers; palliative care; socio-economic status; place of death; household income; carers; population survey

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Word Count: 253

Key Statements

What is already known about the topic?

- More affluent people who die from cancer are more likely to die at home.
- More affluent people who die from non-malignant conditions are more likely to die in hospital.

What this paper adds?

- This study of *those who had someone close die,* (providing personal care or not) found no relationship between the bereaved person's income and decedent's death at home.
- However, if *personal end-of-life care* was provided by those from higher income quartiles, decedents from *any* cause were the *least* likely to die at home.
- Decedents with identified palliative care service use were more likely to die at home.

Implications for practice, theory or policy?

- The interplay between place of care and income is more complex than being able to pay for care.
- Family caregivers from higher income brackets are likely to be powerful patient advocates.
- Caregiver information needs must be addressed especially with regard to stage of disease, aim of care and appropriate interventions at the end of life.

Introduction

Socio-economic factors (education, household income, area of residence) are some of the social determinates of health outcomes including place of death. In the United Kingdom, people who die from cancer are more likely to die at home than an institution if of higher socioeconomic status (SES).[1] However, people of higher SES dying from cardiovascular or respiratory diseases are more likely to die in an institution.[1]

In Australia, access to specialist palliative care services reduces the likelihood of dying in hospital, but not home death.[2] Several groups (older people, people with non-malignant diseases, people with lower SES) are consistently under-referred to specialist palliative care services.[2-7]

The interplay between SES, access to specialist palliative care and place of death is complex. A systematic review of the worldwide literature examined whether access to specialist palliative care modified the effect of patients' SES on place of death for adults with cancer.[8] The review found some evidence to suggest that use of specialist palliative care might modify the unfavourable effect of lower SES on home death. The presence of a family caregiver adds further complexity: another systematic review found that patients without a home caregiver are less likely to access community palliative care services.[9]

In 2013, questions about providing informal care for '*someone close*' at the end of life were included in the Health Survey for England (HSE).[10] The questions were adapted from the South Australia Health Omnibus Survey (HOS), allowing comparisons with different service, funding and social care models in this study.[3] Importantly, these are data about people who did and did not access palliative care services at the end of life, and whether or not the person *"close"* had provided care, irrespective of health service contact.

The aim of this study is to investigate whether access to specialist palliative care services ameliorates the effects of respondents' SES on decedents' place of death. The null hypothesis was that there was no relationship between these three variables by level of respondents' care.

Methods

A population-based, observational study was conducted. Detailed methods of the Health Survey for England (HSE) are described elsewhere.[11] In summary, it is an annual, face-to-face, cross-sectional survey measuring health and health-related behaviours. Core socio-demographic data are included yearly and specific topics added by researchers buying 'space' to incorporate researchers' questions. Consolidated de-identified data are supplied to researchers of core data and researchers' specific data.

HSE is commissioned by the NHS Information Centre for Health and Social Care for the Department of Health. Addresses were issued between January and December, 2013, and fieldwork completed in March 2014. A random probability sample of households (9,408 addresses in 588 postcode sectors) was surveyed. Adults (age 16 or over) and children were interviewed at households identified at the selected addresses followed by a visit from a specially trained nurse for those consenting. Data were weighted by HSE weights with the aim of the weighting to reduce non-response bias resulting from differential non-response at the household level. [11] The dataset included 10,980 respondents, of whom 2,165 (20%) stated *that someone close to them had died of a terminal illness in last five years* (hereafter referred to as 'respondents) and, as a subsequent question so as not to pre-empt questions about care, whether or not they had accessed palliative care services. The HSE included the question set in their ethics approval processes (including consent) for the 2013 survey, obtained from the Oxford A Research Ethics Committee (reference 12/SC/0317).

Measure of socioeconomic status

In this current study, household income was used as the surrogate measure of SES. Income in the Australian dataset was grouped into four $20,000 income bands. In the HSE dataset the variable used was derived equivalised income. Equivalised income adjusts household income to take account of the number of persons in the household. It should be noted that in the HSE dataset around 19% of adults live in households where no information is provided on income, and are therefore excluded from the breakdown by equivalised household income. This was summarised into quartiles based on the quartiles from this equivalised income: 25%= £14,701, 50%=£24,700, 75% =£44,094.

Provision of care

In the Australian HOS, respondents were asked if they had provided “hands on care” and its level. In the HSE question, this was phrased as “personal care”, and defined as “things like helping with washing, dressing, going to the toilet, or eating.” In the HSE, respondents were also asked if they had provided company, errands, laundry, shopping, giving lifts, taking to appointments or out for recreation.

Palliative Care Services

In both surveys, the question “Was a palliative care service used?” was asked alongside an explanation from the interviewer that a palliative care service aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief.” Examples of service providers were given in the English survey.

Place of death

The deceased’s place of death was reported as home, hospital, hospice, residential aged care facility, or ‘other’.

Statistical analysis

The main analysis conducted was a comparison of survey respondents who stated *that someone close to them had died of a terminal illness in the last five years* and whether or not they had access to palliative care services (hereinafter referred to as respondents).

Demographic characteristics of the respondents and place of death of the deceased were described. Univariate analyses were undertaken comparing groups using a Chi-square test for categorical data and a t-test for continuous data.

Logistic regression was undertaken to explore the relationship between home death and SES, adjusting for access to palliative care, age, gender and educational and marital status. A Hosmer and Lemeshow Test was used to assess model fit. In view of the relationship between educational level and SES, findings were adjusted for educational status. Sensitivity analyses quantified the effect of dying at home by income, adjusting for access to palliative care with the exclusion of non-cancer patients. This analysis was repeated substituting the provision of personal care by the respondent. Analyses were undertaken using SPSS (v.22, SPSS Inc., Chicago, IL).

Findings were reported in accordance with the STrengthening the Reporting of OBservational (STROBe) studies in Epidemiology statement.[13]

Results

Household survey participation was 64%. Demographic characteristics of the respondents who stated that '*someone close to them had died of a terminal illness in last 5 years*', by access to palliative care services are shown (Table 1) together with the characteristics associated with patients' access to palliative care. Of interest, respondents' household income was not associated with access to palliative care (p=0.233). Household income was missing for 402 of respondents and 52% of those had access to palliative care. As a quality check, there was no significant difference in the proportion who had access to palliative care compared to those who had income recorded (p=0.164).

Age and gender of respondents were similar between groups. Hands-on care was provided by 30% of the bereaved (hereon referred to as "caregivers"), one half of decedents (55%) had accessed palliative care services and 15% died in a hospice. The majority died from cancer (72%).

Access to palliative care and place of death

Decedents who accessed palliative care services were less likely to die in hospital (31% without, 61% with; p<0.001). (Table 1) The proportion of people dying in hospices *and* at home increased and those who accessed palliative care services were more likely to die at home (36%, 26%, p<0.001).

<<insert Table 1 about here>>

Respondent’s income and decedent’s place of death

There was no statistically significant difference between income groups regarding place of death (p=0.099), nor any relationship between household income and dying at home (p=0.106; Table 2).

<<insert Table 2 about here>>

This finding stands even when adjusted for access to palliative care and, separately, excluding non-cancer patients in sensitive analyses (Table 3).

<<insert Table 3 about here>>

Analysis of data from those who had provided care (caregiver)

The intensity of hands-on care provided by the caregiver was associated with access to palliative care (p<0.001). One third of people who accessed palliative care services had provided hands-on care, compared to one quarter of those who had not.

For caregivers, income and place of death were associated (p=0.147) and income and death at home compared with elsewhere (p=0.069; Table 4).

<<insert Table 4 about here>>

Caregivers in the highest income group were *least* likely to provide care for someone who died at home (25%), although this did not reach statistical significance (p=0.069) even after adjusting for diagnosis (0.108). For those who had died from a non-cancer condition (p=0.180) and cancer (p=0.378), those with caregivers in the highest income group were *least* likely to die at home (Figure 1).

<<insert Fig 1 about here>>

Discussion

Main findings

Decedents who died from *any cause* with identified access to palliative care services were least likely to die in hospital (p<0.001), and were more likely to die at home. This study found no relationship between the *respondent's* income and *decedent's* death at home once adjusted for palliative care service access. However, people with *caregivers* from higher income quartiles were the *least* likely to die at home irrespective of identified access to palliative care services.

How does this compare with other findings?

This survey found a reduction in hospital deaths in people with identified access to palliative care services and an increase in home deaths. In contrast, in Australia, with access to palliative care services, the deaths moved from hospital to hospice but did not change levels of death in the community.[2] This may be due to a variety of factors including the wide cultural diversity and extreme rurality in Australia coupled with a community expectation to go to hospital. However, although in both countries palliative care services are provided at no cost to the patient, there are also important differences in Australian and English primary care with regard to caring for the dying. In England there is widespread implementation of systems of care such as Gold Standards Framework, the palliative care register as part of the Quality Outcomes Framework which embeds this into their system of remuneration, and the maintenance of a clinical culture of visiting the patient in their own homes. The quality of primary care is known to be crucially important with regard to supporting people to die at home if that is their wish across a variety of countries [14] and responsibility for community palliative care supported by early integration with specialist teams[15] and home visits by the family practitioner have been highlighted as important factors.[16, 17] However, in Australia, home visits are less frequent and there is variable practice with regard to the composition of the multi-disciplinary primary and palliative care teams across settings and the level of integration with palliative care teams.

The intensity of hands on care provided by the caregiver was associated with increased access to palliative care ($p<0.001$). Those referred to palliative care services may be those assumed to have sufficient support to sustain home care. Family and friends involved in providing care may more effectively advocate for additional help. A recent mortality follow-back study of place of death in people with cancer found that patients' and relatives' preferences, home palliative care, and district/community nursing explained over 90% of home deaths.[18]

Although there was no association between respondents' household income and care recipients' place of death, when only those who had provided hands on, personal care were considered, income did play a part. Those with caregivers from higher income quartiles were the *least* likely to die at home. This is consistent with the National End of Life Care Intelligence Network (NEoLCIN) 2012 report for people dying of *non-cancer* disease but in contrast to the data regarding death due to cancer.[19] The NEoLCIN data are mainly sourced from NHS and social care *patient* data. The HSE caregiver dataset is therefore not directly comparable with NEoLCIN data as household income of patient and caregivers before and after the death may be different. Gomes *et al* found that people with cancer were more likely to die at home if family members were aware that the disease was no longer curable, and preferences for place of care had been discussed with patients and families.[18] However, as more educated, higher income caregivers are likely to be effective using their health literacy to advocate for those for whom they care,[20] then if the caregiver believes that best care is hospital, even in very advanced disease, then this might help to explain the caregiver income effect on home deaths.[18] However, we did not have data on the caregivers' employment status. These caregivers may be those in employment and may be less able to increase the level of personal care around the time of death, especially if they have used leave entitlement prior to this point.

With non-cancer conditions there are particular challenges of a disease trajectory with episodic deteriorations and periods of recovery, poorer professional skills in determining and communicating prognosis reflected in lower rates of advance care planning.[21, 22] There is poorer public understanding of the terminal nature of such conditions and conversations about prognosis are less likely than for cancer.[23] This issue is complicated by the fact that for people with advanced non-cancer conditions, hospital admission may be beneficial during deteriorations, any of which may lead to death. As there is emerging evidence that a palliative approach alongside appropriate disease-modifying treatment does not appear to shorten survival[24, 25] and may even prolong it,[26] our findings may indicate clinically important disadvantage to patients.

There is a need for clear communication with patients *and* their caregivers about the implications of advanced disease and the need for advance care planning including informed preferences for place of death. There is increasing emphasis on the importance of advanced care discussions between clinicians and *patients* to encourage a realistic understanding of their stage of disease. However, there is no systematic approach to ensure patients' family caregivers have an up-to-date understanding of the stage of disease, aim of care and viable treatment options. The family member or friend usually seen with the patient in the clinic, or at home, or visiting in hospital may not be the person who is the most health literate or strongest patient advocate. If information is not passed accurately on by the patient or accompanying person, or expressly communicated by clinical staff then the family member/friend acting as the main patient advocate may influence place of care and interventions from a basis of incomplete understanding.

The issue of providing care for *someone close* at the end of life and the relationship with socioeconomic status is therefore complex and not simply a matter of being able to pay for help in the home.

Limitations

As the numbers with a spousal relationship were small, there is no sub-group analysis. Spousal household income is a measure that may change with the death of the spouse but this paper focuses on *respondents' (not decedent)* household income acknowledging that this may be different to the patients'. Previous work with caregivers more broadly showed people with lower household incomes were more likely to become caregivers, to carry a higher caregiver burden and experience poorer health. This work found that caregivers who are less deprived are likely to have greater health, knowledge and skills, and greater material resources with which to support the care recipient.[27] Findings were adjusted for educational status but our lack of data regarding employment status limits our ability to draw conclusions, given the issues highlighted above. SES is more complex than household income alone, each aspect highlighting differing aspects of access to health services.

Implications for policy and practice

Despite government policy urging more care in the community, in part driven by a desire to save hospital costs, good care of the dying at home requires excellent (and costly) nursing, medical and social supports, without accounting for the care provided by family and friends. Dying at home is perceived by bereaved caregivers as having poorer symptom control than inpatient care suggesting that community care is still sub-optimal.[28]

Caregivers can play a powerful advocacy role for the care recipient and their own needs, especially when the patient is too sick to convey their own wishes. If the caregiver believes that the best place of care is hospital, especially if due to a lack clear explanation and honest discussion regarding treatment futility, then health literate caregivers will continue to push for hospital admission.

Conclusions

This study examined data concerning people in England who had *someone close* to them die. For study respondents, access by the decedent to palliative care services was strongly associated with a reduction in deaths in hospital and an increase in home deaths. Respondents' household income and decedents' place of death were not associated when adjusted for palliative care use. However, when only caregivers were considered, decedents with caregivers from higher income quartiles were the *least* likely to die at home.

There is a complex relationship between caregivers' SES, ability to provide personal care, and health literacy that is likely to have an impact on a patient's place of death. Further research is needed to help interpret these findings, inform tailored and relevant support, and provide appropriate resources for caregivers for someone at the end of life.

Declarations

Ethics approval and consent to participate: The HSE included the question set in their ethics approval processes (including consent) for the 2013 survey, obtained from the Oxford A Research Ethics Committee (reference 12/SC/0317). For the elements involved in this report, verbal consent only was sought. Verbal consent was not recorded assuming that those who took part in the survey, and provided data had consented to do so.

Consent to publish

This article does not publish individual participant data.

Availability of data: The HSE data used in this analysis are available at the UK Data Archive: NatCen Social Research and University College London. Department of Epidemiology and Public Health, Health Survey for England, 2013 [computer file]. Colchester, Essex: UK Data Archive [distributor], January 2015. SN: 7649, http://dx.doi.org/10.5255/UKDA-SN-7649-1.

Competing interests: The authors have declared that no competing interests exist.

Funding: The work was funded by palliative care speciality group lead (MJ) support funding provided by the North East Yorkshire, North Lincolnshire (NEYNL) Local Clinical Research Network who were completely independent of the study.

Author contribution: MJ and DC; conception and design, acquisition of data - VA, MJ, DC; analysis and interpretation of data - MJ: drafting of the manuscript - MJ, DC, VA, HC, LD, UM; critical revision of the manuscript for important intellectual content - MJ, DC, VA, HC, LD, UM read and approved the final manuscript - VA; statistical analysis - MJ; obtaining funding.

Acknowledgements. With thanks to: the members of the public and Lisa Dikomitis, Research Fellow, University of Hull and to Annie Jones, patient and public representative to the Hull York Medical School who contributed to the focus groups to adapt the Australian question set for an English setting; to Amy Abernethy from Duke University, N. Carolina for her work developing the original question set for the HOS, and for her comments on the adaptation for English use; to Rachel Craig Senior Research Director, and Sally Bridges, Research Director, Health Survey for England for providing excellent liaison assistance and advice; Tessa Ing, Head of End of Life Care and Death Certification Department of Health and Barbara Hanratty, Senior Lecturer in Primary Care Research, NIHR Career Development Fellow. Hull York Medical School for valuable comments on question adaptation

Figure legend.

Figure 1: Proportion who died at home by income, for caregivers by cancer death or not.

Reference List

(1) Pring A, Verne J. Deprivation and death: Variation in place and cause of death - National End of Life Care Intelligence Network. http://www endoflifecare-intelligence org uk/resources/publications/deprivation_and_death 2012 February 1;Available from: URL: http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death

(2) Currow DC, Burns CM, Abernethy AP. Place of death for people with noncancer and cancer illness in South Australia: a population-based survey. *J Palliat Care* 2008;**24**(3):144-50.

(3) Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 2004 September;**18**(6):525-42.

(4) Grande GE, Farquhar MC, Barclay SI, Todd CJ. The influence of patient and carer age in access to palliative care services. *Age Ageing* 2006 May;**35**(3):267-73.

(5) Davidson PM, Abernethy AP, Newton PJ, Clark K, Currow DC. The caregiving perspective in heart failure: a population based study. *BMC Health Serv Res* 2013;**13**:342.

(6) Gadoud A, Kane E, Macleod U, Ansell P, Oliver S, Johnson M. Palliative Care among Heart Failure Patients in Primary Care: A Comparison to Cancer Patients Using English Family Practice Data. *PLoS One* 2014;**9**(11):e113188.

(7) Walshe C, Todd C, Caress A, Chew-Graham C. Patterns of access to community palliative care services: a literature review. *J Pain Symptom Manage* 2009 May;**37**(5):884-912.

(8) Chen H, Nicolson DJ, Macleod U, Allgar V, Dalgliesh C, Johnson M. Does the use of specialist palliative care services modify the effect of socioeconomic status on place of death? A systematic review. *Palliat Med* 2015 September 1.

(9) Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998 September;**47**(5):565-79.

(10) Johnson MJ, Allgar V, Macleod U, Jones A, Oliver S, Currow D. Family Caregivers Who Would Be Unwilling to Provide Care at the End of Life Again: Findings from the Health Survey for England Population Survey. *PLoS One* 2016;**11**(1):e0146960.

(11) Boodhna G, Bridges S, Darton R et al. Methods and Documentation. Household Survey for England 2013. HSE 2013. Department of Epidemiology and Public Health, UCL; 2013. Report No.: Volume 2.

(12) Organisation for economic co-operation and development (OECD). Prices and Purchasing Power Parities:Monthly comparative price levels. http://stats oecd org/Index aspx?DataSetCode=CPL# 2016 April 7;Available from: URL: http://stats.oecd.org/Index.aspx?DataSetCode=CPL#

(13) Observational studies: getting clear about transparency. *PLoS Med* 2014 August;**11**(8):e1001711.

(14) De Roo ML, Miccinesi G, Onwuteaka-Philipsen BD et al. Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators. *PLoS One* 2014;**9**(4):e93762.

(15) Costa V, Earle CC, Esplen MJ et al. The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliat Care* 2016;**15**:8.

(16) Bell CL, Somogyi-Zalud E, Masaki KH. Factors associated with congruence between preferred and actual place of death. *J Pain Symptom Manage* 2010 March;**39**(3):591-604.

(17) Brogaard T, Neergaard MA, Sokolowski I, Olesen F, Jensen AB. Congruence between preferred and actual place of care and death among Danish cancer patients. *Palliat Med* 2013 February;**27**(2):155-64.

(18) Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Med* 2015;**13**:235.

(19) National End of Life Care Intelligence Network. Deprivation and death: Variation in place and cause of death. 2012 Feb.

(20) Sorensen K, Van den BS, Fullam J et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;**12**:80.

(21) McIlvennan CK, Allen LA. Palliative care in patients with heart failure. *BMJ* 2016;**353**:i1010.

(22) Boland J, Martin J, Wells AU, Ross JR. Palliative care for people with non-malignant lung disease: summary of current evidence and future direction. *Palliat Med* 2013 October;**27**(9):811-6.

(23) Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *Br J Gen Pract* 2011 January;**61**(582):e49-e62.

(24) Sidebottom AC, Jorgenson A, Richards H, Kirven J, Sillah A. Inpatient palliative care for patients with acute heart failure: outcomes from a randomized trial. *J Palliat Med* 2015 February;**18**(2):134-42.

(25) Farquhar MC, Prevost AT, McCrone P et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. *Trials* 2016;**17**(1):185.

(26) Higginson IJ, Bausewein C, Reilly C et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 14 A.D. October 29;**http://dx.doi.org/10.1016/S2213-2600(14)70226-7**.

(27) Bruhn JG, Rebach HM. Socioeconomic status and caregiving. *The Sociology of Caregiving. Clinical Sociology: research and practice.* Heidelberg, New York, london: Springer Dordrecht, 2014. p86.

(28) Colvin H, Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. Quality of care delivered in the last 3 months of life for adults who died in England. 2016 Apr 22.

Table 1: Demographic characteristics of respondents who stated that *someone close to them had died of a terminal illness in last 5 years* by access to palliative care

	HSE respondents Access to pall care missing for 3 responders			
	Total n=2165	PCS n=1190	No PCS n=975	p-value
Age (Mean (sd)) (n=2165)	47.7 (18.6)	47.0 (18.0)	48.6 (19.3)	0.042
Sex (n=2165)				
Female	1174 (54%)	662 (56%)	512 (53%)	0.147
Male	991 (46%)	528 (44%)	463 (47%)	
Marital Status (n=2163)				0.018
Single	478 (22%)	280 (24%)	198 (20%)	
Married	1032 (48%)	555 (47%)	477 (49%)	
Co-habiting	286 (13%)	162 (14%)	123 (13%)	
Separated/Divorced	182 (8%)	104 (9%)	78 (8%)	
Widowed	186 (9%)	88 (7%)	98 (10%)	
Household Income* (n=1763)				0.233
Q1	440 (25%)	254 (26%)	186 (24%)	
Q2	447 (25%)	250 (26%)	197 (25%)	
Q3	436 (25%)	225 (23%)	211 (27%)	
Q4	440 (25%)	253 (26%)	187 (24%)	
Qualifications† (n=2160)				0.050
No qualifications	462 (21%)	241 (20%)	221 (23%)	
Trade qualification,/certificate/diploma	1138 (53%)	616 (52%)	522 (54%)	
Degree	560 (26%)	332 (28%)	228 (23%)	
Relationship to deceased (n=2164)				0.033
Spouse/Partner	133 (6%)	72 (6%)	61 (6%)	
Parent	425 (20%)	226 (19%)	199 (20%)	
Child	73 (3%)	42 (4%)	31 (3%)	
Sibling	209 (10%)	100 (8%)	109 (11%)	

Other relative	1009 (47%)	551 (46%)	458 (47%)	
Friend	275 (13%)	173 (45%)	102 (11%)	
Other	40 (2%)	26 (2%)	14 (1%)	
Provided hands on care (n=2141)				<0.001
Daily	306 (14%)	197 (17%)	109 (11%)	
Intermittent	251 (12%)	154 (13%)	97 (10%)	
Rare	87 (4%)	52 (4%)	35 (4%)	
No care	1497 (70%)	773 (66%)	724 (75%)	
Place of death (n=2153)				<0.001
Home	686 (32%)	432 (36%)	254 (26%)	
Hospital	952 (44%)	369 (31%)	583 (61%)	
Hospice	316 (15%)	284 (24%)	32 (3%)	
Residential, hostel or other	199 (9%)	104 (9%)	95 (10%)	
Place of death (Home) (n=2153)	686 (32%)	432 (36%)	254 (26%)	<0.001
Cause of death (Cancer) (n=2165)	1552 (72%)	997 (84%)	555 (57%)	<0.001

PCS –palliative care services; HSE – Health Survey for England: *NB *respondent's* household income. Figures represent income quartiles: 25%= £14,701, 50%=£24,700, 75% =£44,094. † Trade qualification, certificate, diploma or higher = Below degree or NVQ4/NVQ5

Table 2: Household income quartiles and place of death

	Income Quartiles†			
Place of death	Q1	Q2	Q3	Q4
Home	147 (34%)	160 (36%)	137 (31%)	124 (28%)
Hospital	196 (45%)	189 (42%)	194 (45%)	187 (43%)
Hospice	60 (14%)	65 (15%)	62 (14%)	69 (16%)
Residential, hostel or other	35 (8%)	32 (7%)	42 (10%)	57 (13%)

† Figures represent income quartiles: 25%= £14,701, 50%=£24,700, 75% =£44,094.

Table 3: Logistic regression for odds of dying at home compared to elsewhere

	Unadjusted Odds Ratio (95% CI)	**p-value**	**Adjusted Odds* Ratio (95% CI)**	**p-value**
	All patients (Unadjusted model: n=1791, Adjusted model: n=1790)			
Palliative care (Yes)	1.52 (1.24, 1.87)	<0.001	1.52 (1.24, 1.87)	<0.001
Income		0.102		0.055
Q1	1.28 (0.96, 1.71)	0.095	1.35 (0.98, 1.86)	0.065
Q2	1.43 (1.07, 1.90)	0.015	1.53 (1.13, 2.08)	0.006
Q3	1.19 (0.89, 1.60)	0.235	1.25 (0.93, 1.68)	0.148
Q4	1.00		1.00	
	Cancer only patients (Unadjusted model: n=1283, Adjusted model: n=1283)			
Palliative care (Yes)	1.66 (1.29, 2.13)	<0.001	1.68 (1.31, 2.17)	<0.001
Income		0.639		0.386
Q1	1.06 (0.76, 1.47)	0.734	1.16 (0.81, 1.68)	0.418
Q2	1.20 (0.86, 1.66)	0.284	1.32 (0.93, 1.88)	0.118
Q3	1.19 (0.85, 1.67)	0.300	1.28 (0.91, 1.81)	0.155
Q4	1.00		1.00	

*Adjusted for age, gender, marital status and educational status

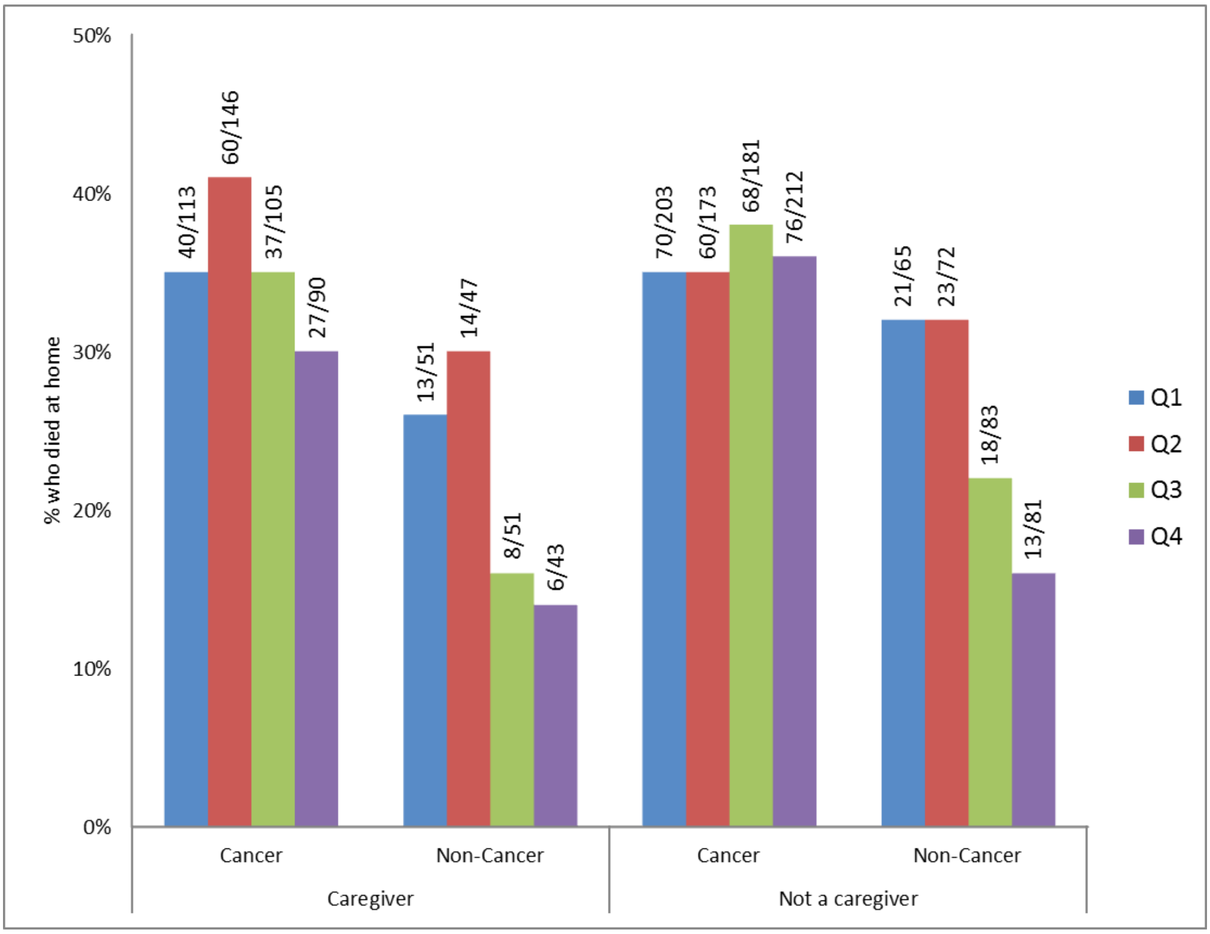
Table 4: Income and place of death for those who provided personal care

Caregiver **n=648, p=0.147**	**Q1**	**Q2**	**Q3**	**Q4**
Home	53 (32%)	73 (38%)	46 (29%)	33 (25%)
Hospital	74 (45%)	78 (41%)	64 (41%)	58 (43%)
Hospice	25 (15%)	25 (13%)	27 (17%)	22 (16%)
Residential, hostel or other	12 (8%)	16 (8%)	21 (13%)	21 (16%)

There was an association for the caregivers (p=0.069) between place of death and income, after adjusting for access to palliative care. (Table 5) The Hosmer and Lemeshow Test demonstrated a good model fit and was not seen for non-caregivers.

Table 5: Logistic regression for odds of dying at home compared to elsewhere by caring status

	Odds ratio (95% CI)	**p-value**
Caregiver (n=682)		
Palliative care (Yes)	2.39 (1.65, 3.47)	<0.001
Income		0.069
Q1	1.53 (0.91, 2.57)	0.111
Q2	1.91 (1.16, 3.15)	0.011
Q3	1.31 (0.77, 2.22)	0.323
Q4	1.00	
Not a caregiver (n=1066)		
Palliative care (Yes)	1.23 (0.95, 1.60)	0.110
Income		0.778
Q1	1.17 (0.82, 1.67)	0.389
Q2	1.19 (0.83, 1.71)	0.353
Q3	1.13 (0.79, 1.62)	0.510
Q4	1.00	


50%
40%
30%
20%
10%
0%
% who died at home
40/113
60/146
37/105
27/90
13/51
14/47
8/51
6/43
70/203
60/173
68/181
76/212
21/65
23/72
18/83
13/81
Cancer
Non-Cancer
Caregiver
Cancer
Non-Cancer
Not a caregiver
Q1
Q2
Q3
Q4