



JAMDA

journal homepage: www.jamda.com

Original Study

Formal and Informal Costs of Care for People With Dementia Who Experience a Transition to Hospital at the End of Life: A Secondary Data Analysis

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A B S T R A C T

Keywords:

Cost of illness
health care costs
informal care
dementia
health care utilization
end-of-life
transitions of care
hospital admissions

Objectives: To explore formal and informal care costs in the last 3 months of life for people with dementia, and to evaluate the association between transitions to hospital and usual place of care with costs. **Design:** Cross-sectional study using pooled data from 3 mortality follow-back surveys.

Setting and Participants: People who died with dementia.

Methods: The Client Service Receipt Inventory survey was used to derive formal (health, social) and informal care costs in the last 3 months of life. Generalized linear models were used to explore the association between transitions to hospital and usual place of care with formal and informal care costs. **Results:** A total of 146 people who died with dementia were included. The mean age was 88.1 years (SD 6.0), and 98 (67.1%) were female. The usual place of care was care home for 85 (58.2%). Sixty-five individuals (44.5%) died in a care home, and 85 (58.2%) experienced a transition to hospital in the last 3 months. The mean total costs of care in the last 3 months of life were £31,224.7 (SD 23,536.6). People with a transition to hospital had higher total costs (£33,239.2, 95% CI 28,301.8–39,037.8) than people without transition (£21,522.0, 95% CI 17,784.0–26,045.8), mainly explained by hospital costs. People whose usual place of care was care homes had lower total costs (£23,801.3, 95% CI 20,172.0–28,083.6) compared to home (£34,331.4, 95% CI 27,824.7–42,359.5), mainly explained by lower informal care costs. **Conclusions and Implications:** Total care costs are high among people dying with dementia, and informal care costs represent an important component of end-of-life care costs. Transitions to hospital have a large impact on total costs; preventing these transitions might reduce costs from the health care perspective, but not from patients' and families' perspectives. Access to care homes could help reduce transitions to hospital as well as reduce formal and informal care costs.

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Funding sources: J.L. is funded by a Royal Marsden Partners Pan London Research Fellowship Award and the Programa Formacion de Capital Humano Avanzado, Doctorado Becas Chile, 2018 (folio 72190265). D.Y. is supported by Cicely Saunders International. K.E.S. is the Laing Galazka Chair in Palliative Care at King's College London, funded by an endowment from Cicely Saunders International and the Kirby Laing Foundation. I.J.H. is an NIHR Senior Investigator Emeritus. I.J.H. is supported by the NIHR Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. I.J.H. leads the Palliative and End of Life Care theme of the NIHR ARC South London, and co-leads the national theme in this. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, or the funding charities.

The authors declare no conflicts of interest.

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<https://doi.org/10.1016/j.jamda.2022.06.007>

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With the increasing number of people dying with dementia projected for the United Kingdom and worldwide,^{1,2} understanding how to provide good quality end-of-life care to these patients becomes imperative. People dying with dementia are at high risk of experiencing multiple transitions to hospital.³ These transitions have been associated with markers of overaggressive care⁴ and poor health outcomes,^{5–7} and suggested as an indicator of poor-quality end-of-life care.^{8,9}

Preventing unnecessary transitions to hospital is a priority for health care systems, as detailed in health and social care policy documents in the United Kingdom.¹⁰ Health and social care government strategies propose reorganizing services enhancing community care to improve quality of care, reducing hospital admissions and health care costs, with a strong emphasis on supporting unpaid carers.¹⁰

Although reducing multiple transitions to hospital is likely to result in lower hospital costs,¹¹ it is not clear how this would affect community or residential care, or the cost for families.

Current estimated costs of dementia care per person are significant. In England, these are projected to increase 68% by 2040, with social care costs projected to increase by 92%.¹² Informal care costs are defined as the cost of the time spent by family or friends caring for a person without payment and they can include the costs of stopping or reducing work.¹³ Informal care constitutes an important component of dementia care.^{14,15} It has been estimated that informal care costs account for around 40% of all total costs in this population¹² and can result in a significant and multidimensional caregiver burden.^{16,17} Although end-of-life care costs have been investigated in other populations,^{18–20} and dementia care costs have been previously explored,^{12,14,21,22} fewer studies have focused specifically on the end-of-life period for people with dementia, in particular considering informal care costs.²³

The aim of this study is to explore formal and informal care costs in the last 3 months of life for people with dementia and to evaluate the association between a transition to hospital and usual place of care, with costs, to understand the effect of transitions to hospital on formal and informal care costs.

Methods

Study Design

Cross-sectional study using pooled data from 3 mortality follow-back postal surveys: the International Access Rights and Empowerment studies I (IARE-I)¹⁷ and II (IARE-II),¹ and OPTCare Elderly study.²⁴ Adults 65 years or older with and without access to palliative care services were identified from hospital records in the IARE-I and IARE-II studies, respectively.^{1,17} In the OPTCare Elderly study, decedents 75 years or older with causes of death common in advanced age and suitable for palliative care were identified from death registration records by the Office of National Statistics.²⁴ The 3 surveys were sent by post 3 to 10 months after the participant died to their next of kin in IARE-I and IARE-II, or the person who registered the death in the OPTCare Elderly study (Supplementary Table 1).

Ethical approvals were granted by the respective local authority (IARE-I: 12/LO/0044; IARE-II: 16/LO/2048; OPTCare Elderly: 12/LO/1367). Only anonymized data were used for this study.

Population

We included people with dementia as underlying or contributing cause of death.

Outcome

The primary outcome was total costs of care in the last 3 months of life. Costs were calculated using a bottom-up approach.²⁵ The Client Service Receipt Inventory was used to collect information on health and social care services use and informal time spent caring for the participant.²⁶ We calculated the costs of services by multiplying the number of specific services used and 2020 unit costs according to the Client Service Receipt Inventory (Supplementary Table 2). When unit costs were only available for previous years, values were inflated to year 2020. When a service was reported as used but not the quantity, we imputed the median costs of the sample.

Secondary outcomes were cost components, calculated by aggregating the costs into 5 categories based on Gardiner et al¹³:

Formal Costs

- Hospital costs: in-hospital, intensive care, emergency room visits, ambulance services, and outpatients hospital contacts
- Care home costs: care home stays with nursing (nursing home) or without nursing (residential care home)
- Community costs: primary [general practitioner (GP) face-to-face and telephone contacts], community (community nurses, physiotherapists, occupational therapists), spiritual care, social care services, and formal carer
- Palliative care costs: specialist palliative care services in hospital, hospice, or community based (including Macmillan and Marie Curie nurses)

Informal Care Costs

- Time spent by family or friends caring for the participant including helping with household tasks, going to medical appointments, and providing personal care to the decedent

Explanatory Variables

Transition to hospital was defined as 1 or more days in hospital during the last 3 months of life for people whose usual place of care was home or care home, or people whose usual place of care was reported as hospital but spent less than 90 days in hospital.

Usual place of care was derived from respondents' answers to the question "Where did the decedent spend most of his/her last 3 months?" and were grouped by home (including own home or a relative/friend home), care home (including nursing home or residential home), and hospital.

Covariables

We included sociodemographic information collected in the surveys on age at death, gender, ethnicity, marital and financial status, having a key contact in the last 3 months of life, and whether proximity to death was discussed with the decedent or their family. Categories of ethnicity were grouped as White or non-White. Marital status was recorded as married or with partner, widowed, divorced, or single. Financial status was collected using the question "How well would you say she/he was managing financially during the last 3 months of life?" and recoded as living comfortably or doing alright, just about getting by, or finding it quite or very difficult.

We calculated the EQ5D index based on the value set for England in Devlin et al.²⁷ The EQ5D is a standardized measure of health status developed for clinical and economic appraisal.²⁸ The instrument measures self-perceived health status in 5 dimensions: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. The EQ5D-5L version measures each dimension using a 5-level Likert-type scale. The EQ5D index can be calculated from the answers to these 5 dimensions, and it is used to represent people's values of different health states. The index ranges from less than 0 to 1, where 0 is the value of a health state equivalent to dead, negative values represent values worse than dead, and 1 the value of full health.²⁷

Analysis

We reported the proportion of people receiving services in the last 3 months of life and the mean number of days (for hospital and care home care), contacts (for other services), or hours per week (for informal care) for the whole sample, and people with and without a transition to hospital.

We calculated costs by cost components (hospital, care home, community, palliative care and informal care costs) and total costs in the last 3 months of life. We calculated the proportion of the total costs that are hospital, community, care home, palliative care, and informal care costs by dividing the mean costs for each cost component by the mean total costs.

We used a generalized linear model with a gamma family and log link to explore the association between a transition to hospital, usual place of care, total, formal (hospital, community, care home and palliative care) and informal care costs, adjusted by covariables. We did not include ethnicity in the models as most people were White. We reported the adjusted estimated mean of total, formal and indirect costs and 95% CIs for transition of care and usual place of care, with covariables at mean.

We used generalized linear models with a gamma family and log link, adjusted by covariables to explore the effect of transition to hospital on the different cost components. We reported the adjusted estimated means and 95% CIs for transition to hospital as main explanatory variable, for the main model and by usual place of care (home or care home), with covariables at mean. Palliative care costs were included in total costs but were not analyzed as a secondary outcome, as costs were small.

Missing values in covariables were assumed missing at random and were imputed using chain multiple imputations to minimize bias and maximize available information. A sensitivity analysis was performed for the total costs and subgroup analysis including covariables without imputation.

The analysis was performed using Stata MP 16.1.

Results

Characteristics of the Study Sample

We identified 146 decedents (IARE-I $n = 27$; IARE-II $n = 22$; OPT-Care Elderly $n = 97$) with a diagnosis of dementia. The mean age was 88.1 years (SD 6.0), 137 (93.8%) were White, 98 (67.1%) female, 110 (75.3%) reported to live comfortably, and 93 (63.7%) were widows or divorced. The place of death was hospital for 57 (39.0%) people and care home for 65 (44.5%) (Table 1). The mean EQ5D index was 0.68 (SD 0.13), with a response of slight or moderate to most of the 5 EQ5D dimensions. Twenty-three respondents (15.8%) reported the decedent experienced moderate pain or discomfort, and 31 (21.2%) reported anxiety or depression in the last 3 months of life.

Respondents had a mean age of 64.9 years (SD 9.8), 64.4% were the decedent's son or daughter, 67.1% female, and 89.0% had secondary school or higher level of education (Table 1).

Transition to Hospital and Usual Place of Care

Of 146 people, 85 (58.3%) experienced a transition to hospital in the last 3 months of life. The usual place of care was reported as care home for 85 (58.2%), or their own home or a relative's or friend's home for 58 (39.7%). In addition, 74.1% of people whose usual place of care was home experienced a transition to hospital vs 45.9% among those in care homes.

Service Use in the Last 3 Months of Life

The average number of days in hospital for the whole cohort was 6.9 (SD 14.0). People had on average 0.8 (SD 1.2) visits to the emergency department (ED), 0.8 (SD 1.2) ambulance calls, and 0.3 (SD 1.1) outpatient appointments. Ninety people (61.6%) spent at least 1 day in a care home [average number of days 39.9 (SD 42.8) for total cohort]. Among the 85 people reporting care home as their usual place of care, the average number of days spent in a care home was 67.4 (SD 35.8).

Overall, 128 (87.7%) and 95 (65.1%) had at least 1 face-to-face contact with GPs and community nurses, and the average number of contacts with GP was 0.6 (SD 1.7) and 2.7 (12.7) for community nurses. Contacts with other health care professionals in the community were less frequent. Forty-five people (30.8%) had a paid carer for an average of 8.0 (SD 48.0) hours per week. Only 3 people in this cohort spent a day in a hospice, and 22 (15.1%) and 10 (6.8%) had at least 1 contact with a palliative care physician or nurse. Ninety-two people (63.0%) received some sort of informal care related to personal care, support with medical procedures, appointments, or household tasks, and 125 people (85.6%) had a relative spending time with them (Table 2).

People with a transition to hospital had a higher average number of ED visits, ambulance calls, outpatient appointments, contacts with community nurses, GPs and palliative care specialists. A higher proportion of people with a transition to hospital had a paid carer (35.3% vs 24.6%), but they had a lower average number of hours per week of paid care (3.5 vs 14.3) than people without a transition to hospital. Both the proportion of people with informal care and number of hours per week of informal care received was higher among people with a transition to hospital than people without transition (Table 2).

Costs of Care

The average total cost of care in the last 3 months of life was £31,224.7 (SD 23,536.6). Unadjusted total costs were higher for people with a transition to hospital than without transition (£39,605.5 vs £19,546.6) (Table 2). In people with a transition to hospital, 39.2% of the total cost was explained by informal care costs, followed by hospital costs (29.6%) and care home costs (22.1%). In people without transition to hospital, most of the total cost was explained by care home costs (45.6%), followed by informal care costs (37.1%) (Figure 1).

After adjusting for confounders, total costs were significantly higher for people with a transition to hospital (£33,239.2, 95% CI 28,301.8–39,037.8) than without transition (£21,522.0, 95% CI 17,784.0–26,045.8). People whose usual place of care was a care home had lower total costs (£23,801.3, 95% CI 20,172.0–28,083.6) compared with people whose usual place of care was home (£34,331.4, 95% CI 27,824.7–42,359.5). This was mainly explained by lower informal care costs for care home residents (Table 3 and Supplementary Table 3).

Transition to hospital was associated with higher hospital costs but not with the other cost components. The analysis by subgroup showed that people with a transition to hospital had higher total costs for people whose usual place of care was home, but not for those in care homes. Informal care costs were higher for people whose usual place of care was home than care home but did not differ according to whether patients had a hospital transition (Figure 2 and Supplementary Table 4).

The sensitivity analysis with complete-case analysis (without imputation) shows similar results (Supplementary Table 5).

Discussion

In a sample of people who died with dementia in England, we described total costs of care in the last 3 months of life from a societal perspective, including formal and informal care costs, and explored the effect of transition to hospital on total costs and cost components. We found that the estimated average total cost per person was £31,224.7 and informal care costs represent 35% of the total costs of care. After adjusting for confounders, people with a transition to hospital had higher costs than people without transition, mainly explained by hospital costs. People whose usual place of care was care homes had lower total costs compared to home, mainly explained by lower informal care costs.

Informal care costs formed a major component of total costs in our study (35% of all costs). A similar pattern is observed in the USA, with

Table 1
Decedents and Respondent Characteristics by Transition to Hospital

	Total Sample (N = 146)	Transition to Hospital	
		No (n = 61)	Yes (n = 85)
Decedent's characteristics			
Age, y, mean ± SD	88.09 ± 6.02	89.43 ± 4.75	87.13 ± 6.65
Ethnicity			
White	137 (93.8)	60 (98.4)	77 (90.6)
Non-White	8 (5.5)	0 (0.0)	8 (9.4)
Missing	1 (0.7)	1 (1.6)	0 (0.0)
Gender			
Male	48 (32.9)	16 (26.2)	32 (37.6)
Female	98 (67.1)	45 (73.8)	53 (62.4)
Financial status			
Living comfortably or doing alright	110 (75.3)	45 (73.8)	65 (76.5)
Just about getting by	20 (13.7)	8 (13.1)	12 (14.1)
Finding it quite or very difficult	8 (5.5)	4 (6.6)	4 (4.7)
Missing	8 (5.5)	4 (6.6)	4 (4.7)
Marital status			
Married or with partner	45 (30.8)	13 (21.3)	32 (37.6)
Widowed, divorced, or single	93 (63.7)	44 (72.1)	49 (57.6)
Missing	8 (5.5)	4 (6.6)	4 (4.7)
Usual place of care in last 3 mo			
Home	58 (39.7)	15 (24.6)	43 (50.6)
Hospital	3 (2.1)	0 (0.0)	3 (3.5)
Care home	85 (58.2)	46 (75.4)	39 (45.9)
Place of death			
Home	23 (15.8)	15 (24.6)	8 (9.4)
Hospital	57 (39.0)	0 (0.0)	57 (67.1)
Care home	65 (44.5)	46 (75.4)	19 (22.4)
Missing	1 (0.7)	0 (0.0)	1 (1.2)
Proximity to death discussed			
No	102 (69.9)	46 (75.4)	56 (65.9)
Yes	44 (30.1)	15 (24.6)	29 (34.1)
Having a key contact			
No	48 (32.9)	13 (21.3)	35 (41.2)
Yes	78 (53.4)	42 (68.9)	36 (42.4)
Missing	20 (13.7)	6 (9.8)	14 (16.5)
EQ5D index, mean ± SD	0.68 ± 0.13	0.70 ± 0.06	0.66 ± 0.16
Pain or discomfort in last 3 mo (EQ5D)			
No or slight problems	110 (75.3)	49 (80.3)	61 (71.8)
Moderate problems	23 (15.8)	7 (11.5)	16 (18.8)
Severe problems	1 (0.7)	0 (0.0)	1 (1.2)
Missing	12 (8.2)	5 (8.2)	7 (8.2)
Anxiety or depression in last 3 mo (EQ5D)			
No or slight problems	96 (65.8)	46 (75.4)	50 (58.8)
Moderate problems	31 (21.2)	12 (19.7)	19 (22.4)
Severe problems	3 (2.1)	0 (0.0)	3 (3.5)
Missing	16 (11.0)	3 (4.9)	13 (15.3)
Source			
IARE-I	27 (18.5)	6 (9.8)	21 (24.7)
IARE-II	22 (15.1)	0 (0.0)	22 (25.9)
OPTCare elderly	97 (66.4)	55 (90.2)	42 (49.4)
Respondent characteristics			
Age, y, mean ± SD	64.86 ± 9.84	63.60 ± 8.41	65.76 ± 10.70
Relationship			
Husband or wife	28 (19.2)	5 (8.2)	23 (27.1)
Son or daughter	94 (64.4)	43 (70.5)	51 (60.0)
Other	24 (16.4)	13 (21.3)	11 (12.9)
Sex			
Male	48 (32.9)	19 (31.2)	29 (34.1)
Female	98 (67.1)	42 (68.8)	56 (65.9)
Education			
No education	3 (2.1)	1 (1.6)	2 (2.4)
Secondary school	86 (58.9)	32 (52.5)	54 (63.5)
University	44 (30.1)	25 (41.0)	19 (22.4)
Missing	13 (8.9)	3 (4.9)	10 (11.8)
Ethnicity			
White	136 (93.2)	58 (95.1)	78 (91.8)
Non-White	10 (6.8)	3 (4.9)	7 (8.2)

Unless otherwise noted, values are n (%).

Table 2
Service Use and Costs for People With Dementia With and Without Transition to Hospital in the Last 3 Months of Life by Cost Component

	Total Sample (N = 146)			Transition to Hospital					
				No (n = 61)			Yes (n = 85)		
	No. of People With ≥1 Contact (%)	Mean Number of Contacts (SD)	Mean Cost in £ (SD)	No. of People With ≥1 Contact (%)	Mean Number of Contacts (SD)	Mean Cost, £ (SD)	No. of People With ≥1 Contact (%)	Mean Number of Contacts (SD)	Mean Cost, £ (SD)
Hospital care									
In-hospital, d	73 (50.0)	6.9 (14.0)	6285.3 (10,791.2)	0 (0.0)	0.0 (0.0)	0 (0)	73 (85.9)	11.9 (16.7)	10,795.9 (12,318.2)
ICU, d	17 (11.6)	1.5 (6.7)	2656.5 (10,620.2)	0 (0.0)	0.0 (0.0)	0 (0)	17 (20.0)	2.7 (8.6)	4562.9 (13,634.3)
ED visits	71 (48.6)	0.8 (1.2)	95.8 (134.3)	4 (6.6)	0.1 (0.3)	9.3 (37.4)	67 (78.8)	1.3 (1.3)	157.9 (144.3)
Ambulance calls	78 (53.4)	0.8 (1.2)	120.6 (140.9)	8 (13.1)	0.2 (0.5)	23.3 (67.6)	70 (82.4)	1.3 (1.3)	190.5 (138.4)
Outpatient hospital appointment	24 (16.4)	0.3 (1.1)	55.8 (171.1)	3 (4.9)	0.0 (0.2)	9.8 (46.2)	21 (24.7)	0.5 (1.4)	88.8 (215.3)
Psychiatrist appointment	14 (9.6)	0.1 (0.6)	29.9 (100.8)	5 (8.2)	0.1 (0.6)	24.9 (88.9)	9 (10.6)	0.1 (0.6)	33.5 (108.9)
Total hospital costs			9243.8 (15087.0)			67.2 (173.9)			15,829.4 (16,966.1)
Care home									
Nursing home, d	64 (43.8)	29.7 (40.8)	4406.4 (5465.9)	39 (63.9)	52.5 (44.7)	7191.7 (5709.2)	25 (29.4)	13.3 (28.2)	2407.5 (4314.2)
Residential care home, d	34 (23.3)	10.2 (27.0)	2508.3 (4915.6)	9 (14.8)	8.9 (26.9)	1713.5 (4401.9)	25 (29.4)	11.1 (27.2)	3078.6 (5204)
Any care home, d	90 (61.6%)	39.9 (42.8)	6914.7 (5720.2)	44 (72.1)	61.5 (42.2)	8905.3 (5224.1)	46 (54.1)	24.4 (36.1)	5486.1 (5660.9)
Total care home costs			6914.7 (5720.2)			8905.3 (5224.1)			5486.1 (5660.9)
Community care									
Contacts with community nurses	95 (65.1)	2.7 (12.7)	163 (427.1)	46 (75.4)	2.2 (12.8)	164.8 (437.8)	49 (57.6)	3.1 (12.7)	161.7 (421.8)
GP face-to-face contacts	128 (87.7)	0.6 (1.7)	89.8 (50.6)	59 (96.7)	0.2 (0.9)	97.6 (24.9)	69 (81.2)	0.8 (2.1)	84.2 (62.5)
GP telephone contacts	51 (34.9)	0.2 (0.9)	6.4 (9.8)	24 (39.3)	0.1 (0.9)	7.3 (10.6)	27 (31.8)	0.2 (0.9)	5.7 (9.3)
Contacts with physiotherapist	17 (11.6)	0.3 (1.0)	9.7 (32.6)	6 (9.8)	0.2 (1.0)	9.3 (32.3)	11 (12.9)	0.3 (1.1)	10.1 (33.0)
Contacts with occupational therapist	26 (17.8)	0.3 (1.2)	12.4 (37.8)	8 (13.1)	0.3 (1.6)	12.4 (47.8)	18 (21.2)	0.3 (0.9)	12.5 (28.9)
Contacts with social care worker	32 (21.9)	0.3 (1.0)	15.4 (38.3)	10 (16.4)	0.1 (0.5)	8.9 (23)	22 (25.9)	0.4 (1.2)	20.1 (45.8)
Day care	3 (2.1)	0.0 (0.2)	2.6 (18.2)	0 (0.0)	0.0 (0.0)	0 (0)	3 (3.5)	0.0 (0.2)	4.5 (23.8)
Contacts with psychologists	3 (2.1)	0.0 (0.0)	0 (0)	1 (1.6)	0.0 (0.0)	0 (0)	2 (2.4)	0.0 (0.0)	0 (0)
Spiritual care	28 (19.2)	0.5 (1.7)	9.1 (25.3)	19 (31.1)	0.9 (2.5)	16.6 (35.4)	9 (10.6)	0.1 (0.6)	3.8 (11.6)
Other professionals	24 (16.4)	0.5 (3.3)	104.4 (493.9)	9 (14.8)	0.2 (1.5)	68.6 (246.5)	15 (17.6)	0.8 (4.1)	130.2 (613.3)
Paid carer, hpw	45 (30.8)	8.0 (48.0)	1891.2 (5539.6)	15 (24.6)	14.3 (73.7)	2294.3 (7995.2)	30 (35.3)	3.5 (7.0)	1602 (2666.5)
Total community care costs			2304.2 (5679.9)			2679.7 (8040.7)			2034.7 (3054.9)
Palliative care									
In-hospice, d	3 (2.1)	0.1 (0.7)	62.9 (440)	1 (1.6)	0.1 (0.6)	41.8 (326.7)	2 (2.4)	0.1 (0.8)	78 (507.3)
Contacts with palliative care nurses	10 (6.8)	1.1 (9.4)	92.6 (486)	7 (11.5)	2.2 (13.6)	114.9 (585.3)	3 (3.5)	0.0 (0.0)	76.6 (402.9)
Contacts with palliative care physician	22 (15.1)	1.5 (9.6)	360.7 (1855.9)	10 (16.4)	1.9 (11.9)	481.9 (2286.8)	12 (14.1)	1.2 (7.7)	273.7 (1480.5)
Total palliative care costs			516.2 (2117.4)			638.6 (2372.0)			428.3 (1924)
Informal care									
Time spent in personal care, hpw	63 (43.2)	9.4 (17.6)	3505.1 (6340.9)	19 (31.1)	7.2 (16.2)	2579 (5845.3)	44 (51.8)	11.1 (18.5)	4169.6 (6627.9)
Time spent in medical procedures, hpw	60 (41.1)	6.6 (14.7)	3120.5 (6852.8)	17 (27.9)	4.7 (12.9)	2194.2 (6036.1)	43 (50.6)	7.9 (15.7)	3785.3 (7346.3)
Time spent in appointments, hpw	54 (37.0)	1.9 (6.6)	307 (1003.9)	12 (19.7)	0.3 (0.9)	80.7 (164.5)	42 (49.4)	3.1 (8.4)	469.3 (1287.1)
Time spent helping with household, hpw	56 (38.4)	9.3 (16.7)	1575.3 (2728.9)	14 (23.0)	4.2 (11.4)	694.3 (1864.8)	42 (49.4)	12.9 (18.8)	2207.5 (3066.4)
Time spent with decedent, hpw	125 (85.6)	22.1 (34.3)	3738 (5577.9)	49 (80.3)	9.6 (17.7)	1707.5 (2887.3)	76 (89.4)	31.1 (40.1)	5195.2 (6527.6)
Total informal care costs			12,245.8 (18,415.1)			7255.8 (15,226.2)			15,826.9 (19,715.9)
Total costs			31,224.7 (23,536.6)			19,546.6 (17,899.2)			39,605.5 (23,607.4)

ED, emergency department; hpw, hour per week; ICU, intensive care unit.

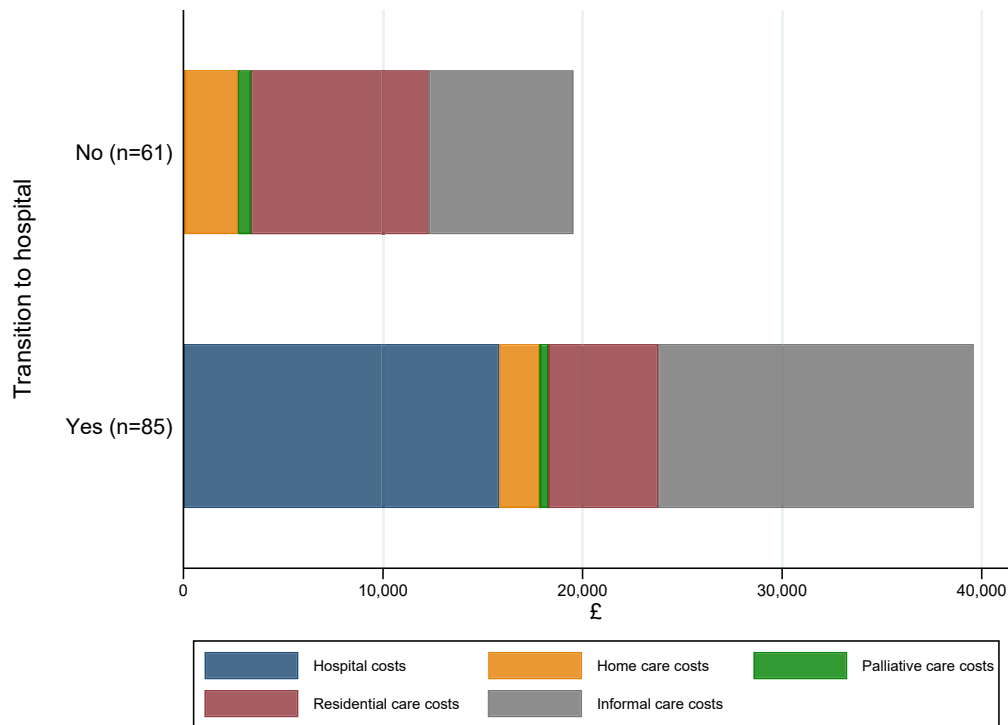


Fig. 1. Observed mean costs by cost components in the last 3 months of life by transition to hospital.

informal care costs representing approximately 30% of the total costs of dementia care in the last 5 years of life.²⁹ In England, an audit of 9 people who had died of dementia reported an average cost of formal care in the last 6 months before death of £25,000 per patient, with high estimated informal care costs for people living at home.³⁰

We found that people with a transition to hospital in the last 3 months have higher total costs than people without transitions. This was mainly explained by hospital costs. In fact, people with a transition to hospital had similar community care, care home, and informal care costs than people without transition after adjusting for confounders. This suggests reducing admissions to hospital might lead to lower total costs and has important implications for policy. Further research exploring the cost-effectiveness of interventions aiming at reducing end-of-life transitions to hospital in this population is needed.

We found that people whose usual place of care was care homes had significantly lower total costs than people at home, even considering the cost of the care home. This is explained by people living in care homes being less likely to transition to hospital and also having lower levels of informal care. Our findings support evidence suggesting care home expenses act as substitute for hospital and informal care costs in older adults.^{31–33} There is some evidence suggesting that people dying

in care homes might have better access to health care support,³⁴ advance care planning,^{35,36} and symptom control³⁷ than people living at home, which might contribute to reducing transitions to hospital in this population. There is evidence suggesting the number of older people living at home needing informal care will rise by 63% in the next decade.³⁸ It is therefore critical to improve the level of support for people living at home with dementia and their informal carers. Interventions such as multidisciplinary home care,³⁹ community-based integrated palliative care services,⁴⁰ and advance care planning^{31,41} have been associated with lower risk of transitions of care and lower costs in people dying with dementia.

This study only considered costs in the last 3 months of life, and the number of days spent in care homes was low. Care home costs might increase significantly and exceed hospital costs if a longer end-of-life period is considered⁴² and, therefore, future research with a longer time frame might be important. However, when exploring the effect of transitions to hospital, the last 3 months of life is particularly relevant as hospital admissions and ED visits increase exponentially during this period.^{43,44}

In this cohort, people without a transition to hospital had similar informal care costs to people with transition. This is likely to be explained because care provided by family does not stop when

Table 3

Adjusted Estimates of Predicted Total, Formal, and Informal Care Costs by Transition to Hospital and Usual Place of Care in the Last 3 Months of Life

	Total Costs			Formal Care Costs			Informal Care Costs		
	Adjusted Mean*	95% CI	P Value [†]	Adjusted Mean*	95% CI	P Value [†]	Adjusted Mean*	95% CI	P Value [†]
Transition to hospital									
No	21,522.0	(17,784.0–26,045.8)		11,517.0	(9500.0–13,962.2)		6744.3	(3865.9–11,765.8)	
Yes	33,239.2	(28,301.8–39,037.8)	.002	23,006.7	(19,586.7–27,023.8)	<.001	7271.0	(4568.0–11,573.5)	.85
Usual place of care									
Home	34,331.4	(27,824.7–42,359.5)		14,351.7	(11,755.4–17,521.3)		18,316.9	(9952.5–33,710.9)	
Care home	23,801.3	(20,172.0–28,083.6)	.016	19,321.4	(16,499.2–22,626.4)	.038	3667.4	(2280.1–5898.8)	<.001

*All models were adjusted by age, gender, marital status, financial status, having a key contact, end-of-life discussions, EQ5D index, and study.

[†]P values correspond to the P value for the coefficient using “no” and “home” as reference categories, respectively.

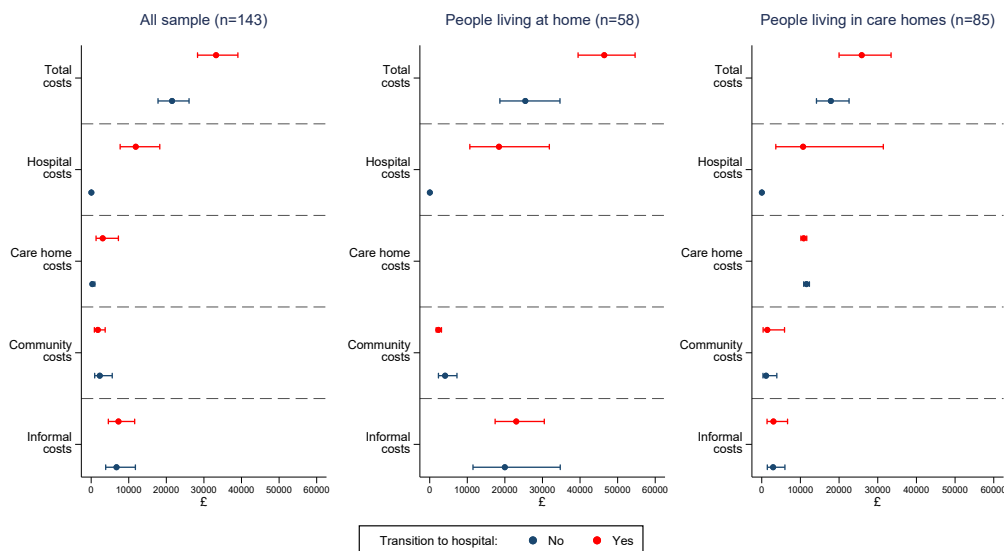


Fig. 2. Estimated mean of total costs and cost components for people with and without transition to hospital in the last 3 months of life adjusted by covariables for the whole sample and by place of care. All models were adjusted by age, gender, marital status, financial status, place of care, having a key contact, end-of-life discussions, EQ5D index, and study.

someone is admitted to hospital. Hospital admissions are burdensome not only for the patient but also for their carers who still need to be involved.⁴⁵ Admissions to hospital do not provide “respite” for carers, and traveling and adaptations to their routine can be stressful.⁴⁶

Strengths and Limitations

This study has some limitations. We used information from 3 mortality follow-back surveys that had different recruitment strategies. However, we adjusted by study in the analysis. Surveys were completed 3–10 months after death by proxies, who were generally the next of kin. This could lead to recall bias, under- or overreporting, and missing information due to memory issues. However, there is evidence suggesting the Client Service Receipt Inventory questionnaire has a good level of agreement with administrative sources in terms of health care utilization⁴⁷ and that proxies close to the person can reliably report on the use of services and observable symptoms.⁴⁸

Our small sample size (146 people) might have led to a low power to detect differences in sociodemographic variables related to total costs. However, the study had enough power to detect a statistically significant difference in total costs for our main explanatory variables. Our method might overestimate hospital costs, as we only had information on the number of days in hospital but not the length of stay per admission. In addition, 93.8% of the sample was White and 75.3% referred to living comfortably; hence, more research is needed to understand if these results apply to more ethnically diverse and socioeconomically deprived populations.

Nevertheless, this study has important strengths, such as reporting informal care as well as formal care costs, which has been highlighted in the literature as an important component of total costs among people with dementia at the end of life.

Conclusions and Implications

Total and informal care costs are high among people with dementia at the end of life. Our results highlight the importance of informal care costs in this population. Considering informal care costs in policy evaluations is key, as the pattern of informal care costs differs depending on the place of care. Preventing transitions to hospital in people with dementia might reduce overall costs from the health care perspective, but

not from patients' and families' perspectives. Transitions to hospital have an important impact on total costs, mainly explained by higher hospital costs. Access to care homes could help reduce transitions to hospital transitions, as well as reduce formal and informal care costs.

Acknowledgments

We thank BuildCARE (International Access Rights and Empowerment studies I) and the OPTCare Elderly research teams and all collaborators and advisors.

BuildCARE (Building Capacity, Access, Rights and Empowerment) is an international research program that aims to create a “sea change” in the way palliative and end of life care is regarded, implemented, and prioritized internationally. The following are members of the BuildCARE team: Emma Bennett, Francesca Cooper, Barbara Daveson, Susanne de Wolf-Linder, Mendwas Dzingina, Clare Ellis-Smith, Catherine Evans, Taja Ferguson, Lesley Henson, Irene J. Higginson, Bridget Johnston, Paramjote Kaler, Pauline Kane, Lara Klass, Peter Lawlor, Paul McCrone, Regina McQuillan, Diane Meier, Susan Molony, R. Sean Morrison, Fliss Murtagh, Charles Normand, Caty Pannell, Steve Pantilat, Anastasia Reison, Karen Ryan, Lucy Selman, Melinda Smith, Katy Tobin, Rowena Vohora, Gao Wei, Deokhee Yi.

OPTCare Elderly aims to develop and evaluate the feasibility of a short-term integrated palliative and supportive care service for frail elderly people with nonmalignant conditions living at home or in a care home. OPTCare Elderly is a joint project between King's College London and Sussex Community NHS Foundation Trust. The following are members of the OPTCare Elderly Team: Catherine J. Evans, Irene J Higginson, Myfanwy Morgan, Paul McCrone, Wei Gao, Juliet Wright, Sue Hall, Barbara Gomes, Emma Gordon, Fiona Lindsay, Carla Bruni, Shamim Taherzadeh, Richard Harding, Katherine E. Sleeman, Matthew Maddocks, Helen Harris, Anita Wright, Sue Guerrier, John Barry, Lesley Talmey, Colin Vincent, Mike Bojczuk, Jack Hazelgrove, Anna E. Bone, Deokhee Yi, Rowena Vohora, Katie Stone, Mark Philips, Nina Walters, Kate Porter, and Claire Cox.

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Supplementary Table 1

Characteristics of the Included Studies

	IARE-I	IARE-II	OPTCare Elderly
Setting	London	London	Southern England
Data collection period	2012	2017-2018	2012
Recruitment	2 hospitals	3 hospitals	Death certificates, ONS
Inclusion criteria	Decedent ≥65 y old Accessed (≥1 contact) palliative care team	Decedent ≥65 y old Rockwood Clinical Frailty Score (CFS) ≥5	Decedent ≥75 y old
Exclusion criteria	Unable to give informed consent	Receiving specialist palliative care	Causes of death unlikely to be suitable for palliative care (eg, accidental deaths). Individuals with no contact address
People with dementia as underlying or contributing cause of death/total sample	27/245	22/80	97/443

IARE, International Access Rights and Empowerment studies.

Supplementary Table 2
Sources for Costing and Unit Cost

Item (Source)	Cost per Unit (£)	Unit in Source	Year From Source	Unit in Survey	Cost per Unit in Survey (£)	Adjusted for Inflation (£)	Method
Hospital care							
Inpatient hospital*	757	Days	2018-2019	Days	757	778.0	Median of the national average unit costs per day for all HRG codes by section, excluding pediatric services and transplant codes: - Day cases: median of national average unit cost - EL: median of national average unit cost/median average length of stay - NEL short stay: median of national average unit cost - NEL long stay: median of national average unit cost/median average length of stay
ICU*	1534	Days	2018-2019	Days	1534	1576.6	Critical care section; median of the national average unit costs for all service codes.
AE*	110	Visits	2018-2019	Events	110.0	113.0	Emergency medicine section; median of the national average unit costs for all service codes, excluding pediatric services
Ambulance*	115	Visits	2018-2019	Events	115	118.2	Ambulance section NHS reference costs; median of all activity descriptions
Outpatient*	146	Visits	2018-2019	Events	145.5	149.5	Outpatient attendance data; median of the national average unit costs for all service codes, excluding pediatric services
Hospice†	450	Days	2012	Days	450.0	510.3	Information on section "Inpatient Hospice Care"
Nursing home‡	907	Weeks	2019-2020	Days	129.6	129.6	Information in section 1 (Services for Older People Age 65+); establishment cost plus personal living expenses and external services per permanent resident per week
Residential‡	1026.5	Weeks	2019-2020	Days	146.6	146.6	Information in section 1 (Services for Older People Age 65+); median of private and LA establishment; establishment cost plus personal living expenses and external services per permanent resident week
Day care‡	64	Days	2019-2020	Events	64.0	64.0	Information in section 1 (Services for Older People Age 65+); cost per attendance, including capital costs and total expenditures
Nurses							
District nurses‡	89	Hours	2019-2020	Events	44.5	44.5	Information in section 10.1 (Nurses); band 6 cost per hour of patient-related work; assuming 30 min per contact
Marie Curie nurses‡	89	Hours	2019-2020	Events	44.5	44.5	Information in section 10.1 (Nurses); band 6 cost per hour of patient-related work; assuming 30 min per contact
McMillan nurses‡	89	Hours	2019-2020	Events	44.5	44.5	Information in section 10.1 (Nurses); band 6 cost per hour of patient-related work; assuming 30 min per contact
Other nurses‡	63	Hours	2019-2020	Events	31.5	31.5	Information in section 10.1 (Nurses); band 5 cost per hour of patient-related work; assuming 30 min per contact
Nurse practitioner‡	120	Hours	2019-2020	Events	60.0	60.0	Information in section 10.1 (Nurses); band 7 cost per hour of patient-related work; assuming 30 min per contact
GP							
GP face-to-face contact‡	33	Per contact	2019-2020	Events	33.0	33.0	Information in section 10.3b (General Practitioner—Unit Costs); per surgery consultation lasting 9.22 min, including direct care staff costs without qualification costs
GP telephone contact‡	8.41	Per contact	2019-2020	Events	8.4	8.4	Information in section 10.4 (The Cost of Online Consultations); average cost per GP telephone calls data
Physiotherapist‡	58	Hours	2019-2020	Events	29.0	29.0	Information in section 9 (Scientific and Professional Staff); median cost per working hour for bands 4-8c, assuming 1 h per contact
Occupational therapist‡	58	Hours	2019-2020	Events	29.0	29.0	Information in section 9 (Scientific and Professional Staff); median cost per working hour for bands 4-8c, assuming 1 h per contact
Palliative care*	186.3	Per contact	2018-2019	Events	186.3	191.5	National average unit cost for service code 315 (Palliative medicine) from the Outpatient NHS Reference Cost publication
Psychiatrist*	246	Sessions	2018-2019	Events	246.1	252.9	National average unit cost for service code 710 (Adult mental illness) from the Outpatient NHS Reference Cost publication
Psychologist‡	105	Hours	2019-2020	Events	105.0	105.0	Information in section 9 (Scientific and Professional Staff); median cost per working hour for bands 8c-8d, assuming 1 h per contact
Spiritual care‡	522.9	Weeks	2020	Events	13.9	13.9	Information from the Agenda for Change—pay rates in NHS; median wage band 5, assuming 37.5 working hours per week
Other professionals*	146	Visits	2018-2019	Events	145.5	149.5	Median of the national average unit costs for all service codes from the Outpatient NHS Reference Cost publication
Social care							
Social worker‡	45	Hours	2019-2020	Events	45.0	45.0	Information in section 11.1 (Social Worker, Adult Services); cost per hour (excluding qualifications), assuming 1 h per contact

Paid carer [‡]	30	Hours	2019-2020	hpw	30	30.0	Information in section 11.5 (Home Care Worker); median cost per hour for face-to-face contacts during weekdays day- and nighttime, and withing weekends day- and nighttime; the cost is based on the price multipliers for independent sector home care provided for private purchasers
Indirect costs							
Personal care [‡]	30	Hours	2020	hpw	30.0	30.0	Information in section 11.5 (Home Care Worker); median cost per hour for face-to-face contacts during weekdays day- and nighttime, and withing weekends day- and nighttime; the cost is based on the price multipliers for independent sector home care provided for private purchasers
Medical procedures [‡]	39	Hours	2020	hpw	39.0	39.0	Information in section 10.1 (Nurses); band 5 cost per working hour
Appointment	13.68	Hours	2020	hpw	13.68	13.68	Information from the ASHE from ONS; median hourly earnings (£)
Household	13.68	Hours	2020	hpw	13.68	13.68	Information from the ASHE from ONS; median hourly earnings (£)
On-call	13.68	Hours	2020	hpw	13.68	13.68	Information from the ASHE from ONS; median hourly earnings (£)
Time spent with patient	13.68	Hours	2020	hpw	13.68	13.68	Information from the ASHE from ONS; median hourly earnings (£)

ASHE, Annual Survey of Hours and Earnings; EL, elective; GP, general practitioner; hpw, hours per week; HRG, Healthcare Resource Group; LA, local authority; NEL, nonelective; NHS, National Health Service; ONS, Office for National Statistics.

^{*}Reference Cost Collection: National Schedule of Reference Costs - Year 2017-18 - NHS trust and NHS foundation trusts.

[†]Georghious T, Bardsley M. Exploring the cost of care at the end of life. Nuffield Trust; 2014.

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^{||}ONS. Guide to time series from the Annual Survey of Hours and Earnings (ASHE). <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsandworkinghours/bulletins/annualsurveyofhoursandearnings/previousReleases>.

Supplementary Table 3

Models With Multiple Imputation for Total, Formal, and Indirect Costs

	Total Costs (n = 143)			Formal Costs (n = 143)			Indirect Costs (n = 143)		
	Coefficient	SE	P Value	Coefficient	SE	P Value	Coefficient	SE	P Value
Transitions to hospital (ref: no)									
Yes	0.333	0.138	.016	0.695	0.141	<.001	0.076	0.408	.85
Age	−0.006	0.011	.60	0.014	0.011	.22	−0.023	0.031	.46
Marital status (ref: married or with partner)									
Widowed, divorced, or single	−0.143	0.185	.44	0.093	0.170	.59	−0.468	0.532	.38
Financial status (ref: living comfortably or doing alright)									
Just about getting by	0.060	0.174	.73	−0.021	0.163	.90	0.295	0.508	.56
Finding it quite or very difficult	0.196	0.255	.44	−0.018	0.251	.94	0.142	0.719	.84
Having a key contact (ref: no)									
Yes	−0.145	0.138	.30	−0.052	0.148	.73	−0.195	0.380	.61
Gender (ref: male)									
Female	0.115	0.165	.48	0.038	0.160	.81	0.159	0.464	.73
Place of care (ref: home)									
Care home	−0.575	0.153	<.001	0.300	0.143	.036	−1.613	0.449	<.001
Proximity to death discussed (ref: no)									
Yes	0.222	0.139	.11	0.092	0.139	.51	0.347	0.392	.38
EQ5D index	−0.285	0.511	.58	0.266	0.510	.60	−0.674	1.451	.64
IARE-I	0.432	0.171	.011	0.165	0.173	.34	0.895	0.483	.06
IARE-II	0.118	0.228	.60	0.122	0.227	.59	0.216	0.613	.72

IARE, International Access Rights and Empowerment studies.

Supplementary Table 4

Models With Multiple Imputation for Total Cost by Subgroup of Usual Place of Residency

	Total Costs, All Sample (n = 143)			Total Costs for People Living at Home (n = 58)			Total Costs for People Living in Residential Care (n = 85)		
	Coefficient	SE	P Value	Coefficient	SE	P Value	Coefficient	SE	P Value
Transitions to hospital (ref: no)									
Yes	0.333	0.138	.016	0.399	0.185	.031	0.306	0.193	.112
Age	−0.006	0.011	.593	0.008	0.012	.480	−0.014	0.017	.397
Marital status (ref: married or with partner)									
Widowed, divorced, or single	−0.143	0.185	.438	−0.261	0.181	.149	0.067	0.289	.818
Financial status (ref: living comfortably or doing alright)									
Just about getting by	0.060	0.174	.731	0.197	0.223	.377	0.067	0.236	.778
Finding it quite or very difficult	0.196	0.255	.442	0.387	0.315	.219	0.174	0.371	.640
Having a key contact (ref: no)									
Yes	−0.145	0.138	.293	−0.137	0.159	.389	−0.172	0.207	.406
Gender (ref: male)									
Female	0.115	0.165	.484	−0.008	0.203	.969	0.088	0.238	.712
Place of care (ref: home)									
Care home	−0.575	0.153	.000	—	—	—	—	—	—
Proximity to death discussed (ref: no)									
Yes	0.222	0.139	.109	0.169	0.158	.284	0.229	0.213	.282
EQ5D index	−0.285	0.511	.577	−0.473	0.466	.310	−1.381	1.118	.217
IARE-I	0.432	0.171	.011	0.306	0.181	.090	0.580	0.279	.038
IARE-II	0.118	0.228	.603	0.088	0.216	.684	−0.871	0.640	.174

IARE, International Access Rights and Empowerment studies.

Supplementary Table 5

Models for Total Costs Without Multiple Imputation for Covariables

	Total Costs, All Sample (n = 92)			Total Costs for People Living at Home (n = 32)			Total Costs for People Living in Residential Care (n = 60)		
	Coefficient	SE	P Value	Coefficient	SE	P Value	Coefficient	SE	P Value
Transitions to hospital (ref: no)									
Yes	0.294	0.186	.11	0.622	0.318	.05	0.245	0.245	.32
Age	−0.011	0.016	.50	−0.021	0.026	.42	−0.016	0.022	.47
Marital status (ref: married or with partner)									
Widowed, divorced, or single	−0.072	0.241	.77	−0.331	0.289	.25	0.145	0.357	.68
Financial status (ref: living comfortably or doing alright)									
Just about getting by	0.208	0.256	.42	0.737	0.476	.12	0.202	0.313	.52
Finding it quite or very difficult	−0.009	0.505	.99				0.074	0.559	.90
Having a key contact (ref: no)									
Yes	−0.221	0.183	.23	−0.204	0.240	.40	−0.255	0.252	.31
Gender (ref: male)									
Female	0.172	0.224	.44	0.855	0.516	.10	0.045	0.283	.87
Place of care (ref: home)									
Care home	−0.604	0.217	.005	—	—	—	—	—	—
Proximity to death discussed (ref: no)									
Yes	0.287	0.194	.14	0.101	0.259	.70	0.323	0.264	.22
EQ5D index	−0.352	0.705	.62	0.398	0.791	.61	−2.059	1.377	.14
IARE-I	0.338	0.247	.17	−0.077	0.367	.84	0.497	0.358	.17
IARE-II	0.065	0.312	.84	0.139	0.387	.72	−0.962	0.786	.22

IARE, International Access Rights and Empowerment studies.