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The cost of providing care by family and friends (informal care) in the last year of life: A population observational study

MJ Johnson

DC Currow

Jade Chynoweth *Peninsula Medical School*

H Weatherly

G Keser

et al. *See next page for additional authors*

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Authors

MJ Johnson, DC Currow, Jade Chynoweth, H Weatherly, G Keser, A Hutchinson, A Jones, L Dunn, and V Allgar



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Title: The cost of providing care by family and friends (informal care) in the last year of life: a population observational study

Authors:

Johnson MJ; Professor of Palliative Medicine, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull

Currow DC; Deputy Vice-Chancellor (Research and Sustainable Futures), Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, NSW, Australia

Chynoweth J; Research Fellow in Medical Statistics, University of Plymouth

Weatherly H; Professor, Centre for Health Economics, University of York

Keser G; Undergraduate MBBS medical student, Hull York Medical School, University of Hull

Hutchinson A; Research Fellow in Palliative Care, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull

Jones A; Patient and Public Representative, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull

Dunn L; Research Fellow in Primary Care, Hull York Medical School, University of Hull

Victoria Allgar; Professor of Medical Statistics, University of Plymouth

Author for correspondence: Johnson MJ, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, HU6 7RX. Email: miriam.johnson@hyms.ac.uk

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ABSTRACT

Introduction: Little is known about replacement costs of care provided by informal carers during the last year of life for people dying of cancer and non-cancer diseases.

Aim: To estimate informal caregiving costs and explore the relationship with carer and decedent characteristics.

Design: National observational study of bereaved carers. Questions included informal end-of-life caregiving into the 2017 Health Survey for England including estimated recalled frequency, duration, and intensity of care provision. We estimated replacement costs for a decedent's last year of life valuing time at the price of a substitutable activity. Spearman rank correlations and multivariable linear regression were used to explore relationships with last year of life costs.

Setting/Participants: Adult national survey respondents - England.

Results: 7,997 adults were interviewed from 5,767/9,612 (60%) of invited households. Estimated replacement costs of *personal care* and *other help* were £27,072 and £13,697 per carer and a national cost of £13.2 billion and £15.5 billion respectively. Longer care duration and intensity, older age, death at home (lived together), non-cancer cause of death and greater deprivation were associated with increased costs. Female sex, and not accessing 'other care services' were related to higher costs for *other help* only.

Conclusion: We provide a first adult general population estimate for replacement informal care costs in the last year of life of £41,000 per carer per decedent and highlight characteristics associated with greater costs. This presents a major challenge for future universal care coverage as the pool of people providing informal care diminish with an ageing population.

Key words caregivers; informal carers; end-of-life; costs and cost analysis; survey

Key messages

What is already known about the topic?

- Informal (unpaid) care from family or friends is a critical contribution, supporting people at the end of their lives to live at home.
- Globally, care provided by informal caregivers is thought to save billions annually in social and health care costs.
- The costs of informal caregiving costs at the end-of-life are unknown.

What this paper adds

- We provide a first estimate for replacement informal care costs in the last year of life of £41,000 per carer per decedent and highlight characteristics associated with greater costs.
- We identify that longer care duration and intensity, older age, death at home (lived together), non-cancer cause of death and greater deprivation were associated with increased costs.
- We identify a relationship between carers from non-Christian religions and costs of care which requires further exploration.

Implications for practice, theory or policy

- Our findings present a major challenge for future universal care coverage, both in the UK and elsewhere in the world, as the pool of family and friends providing informal care diminish with an ageing population.
- The relationships between longer care duration and intensity, older age, death at home (lived together), non-cancer cause of death and greater and increased costs highlight situations where better recognition and provision of statutory support needs are required even if informal carers are available.

INTRODUCTION

People at the end of their lives use a range of statutory and non-statutory support. Informal (unpaid) care from family or friends is a critical contribution, supporting people at the end of their lives to stay in their own homes.¹ Less use of formal social and health care reduces statutory service costs, but the full economic impact of caring on individuals, communities and societies is difficult to estimate.^{2,3} There is no agreement on reasonable out-of-pocket costs for family or friends caring for someone dying at home and estimating these is difficult.^{3,4} Globally, care provided by informal caregivers is thought to save billions annually in social and health care costs.⁵ Informal caregiving costs during the last year of life are unknown for the general adult population. To date, estimates were based on surveys of carers of decedents known to specialist palliative care (United States, UK, Ireland- last three months; Ireland – last year of life)^{6,7} or, nationally, of carers of cancer decedents only (England and Wales, last three months).^{3,8,9}

Data from the 2013 Health Survey for England (HSE) identified that 25% of respondents had *'someone close to them die from a terminal illness'* within the previous five years, of whom one third had provided care.¹⁰ This dataset included data on duration and intensity of care (personal or other care), and if palliative care or other services were accessed. These were data about people who did *and did not* access palliative care or other services, whether or not the respondent had provided care, and irrespective of cause of death. Although the data provided useful characterisation of people providing this informal care, they lacked detail for estimating costs. This paper reports on an expanded question set from the 2017 HSE survey estimating hours of informal care in the last year of life.

In this study, the replacement costs of informal caregiving in the last year of life are estimated, and the relationship with carer and decedent characteristics (including cause and place of death) is explored. We hypothesise that higher overall costs of informal care will reflect less formal care access (specialist palliative care services, other support services), a non-cancer diagnosis, death at home, younger caregivers' ages and being female.

METHODS

Health Survey for England (HSE)

HSE is an annual, face-to-face, cross-sectional survey conducted on behalf of the Department of Health and Social Care using a multi-stage, stratified, random probability, nationally representative sample of private households. A random sample of postcode-based sampling units, are selected from which a random sample of postal addresses are drawn and the household invited to participate. At each responding household a maximum of ten per household for adults aged 16 years

and over, and maximum of four children are invited to be interviewed. Health and health-related behaviours in adults and children are surveyed by a trained interviewer and a nurse. Annual core elements include socio-demographic data. Researchers may submit their own questions, such as our carer question set (see below). Data pertaining to this study were collected by the interviewer visiting the participant's household. Detailed survey methods have been described (Health Survey England 2017 Methods report).¹¹ Addresses were issued from January to December 2017 and fieldwork was completed in March 2018.

Health Survey England carer questions

We included previously used informal carers' end-of-life questions¹⁰:

- i) had someone close to them died of a terminal illness in the previous five years?;
- ii) had they had provided personal care or other help?; and in addition
- iii) the duration (how long prior to death), frequency (how often care) and intensity (how long per day) of care.

The survey used skip logic so only those replying 'yes' to the first question had the rest of the carer question set administered.

The development of the original carers' end-of-life questions is described elsewhere.¹⁰ We further adapted the questions to include estimated recalled frequency, duration and intensity of care provision in the last year of life. (See Supplement Appendix 1 for the final question set). Two stakeholder groups (one rural, one urban) were held in their respective communities to ensure the wording of the questions was clear for the new question content. Consenting members of the public were included. People bereaved in the previous 6 months were excluded.

Groups were facilitated by AH/MJ (urban; n= 4, female 75%, median age 47.5, range 44-50) and LD/AJ/MJ (rural; n = 9; female 66%; median age 64, range 47-73). Groups were guided through each proposed question. Changes were agreed by consensus during each session where possible, then by the research team and the Health Survey England team.

Ethical approval for the question adaptation was given by the Hull York Medical School ethics committee (Reference 1615). The questions were included in the Health Survey England's 2017 ethics submission and approved by the East of England Research Ethics Committee (Reference 15/EE/0229).

Variables

Dependent variables: Total cost of: i) personal care; and ii) general help provided in the last year of life by the carer to the person who had died (most recent experience if more than one).

For both personal (hands-on) care and other help, we estimated the total cost of care provided by each respondent in the last year of life from the duration (“For how long?”: days/weeks/months given as minimum to maximum ranges (e.g., 1 – 6 days; 1 – 4 weeks; 1 – 3 months etc), frequency (“how often?”: days/weeks [‘roughly how many days per week’] /months [‘roughly how many days per month’]) and intensity (hours per day’ estimated from part of day stated e.g., assuming ‘half a day’ = 6 hours) of care. All assumptions were agreed by GK, MJJ, JC and VA. All hours (and therefore cost) variables were independently checked by two researchers (GK, JC).

We used a proxy (or replacement) good method valuing informal care time at the price of a substitutable activity.¹²⁻¹⁴ We assumed that personal care would be proxied by the cost for a community-based home care worker (wages, on-costs, overheads, antisocial hours and face-to-face multipliers; average £24 per hour¹⁵). General help, likewise was valued as a substitutable support worker (average £25 per hour¹⁵). Assuming hours of care would be reasonably stable, costs for 2019-2020 (the year the dataset was received and analysis commenced) were used.

We did not include carer burden, out-of-pocket expenses such as travel to provide care or additional heating or power at home. Receiving statutory benefits, such as carers’ allowances, were not considered.

Independent variables and their rationale are shown in Box 1.

Box 1. Independent variables, and their rationale

Variable	Rationale
Age and sex of the carer.	Older carers may be less physically able to provide care, or conversely more likely to have family members requiring care. Women are more likely to provide informal care ¹⁶ and the person they care for therefore receive less formal care support.
Cause and place of death.	The end of life is better recognised in cancer compared with non-cancer causes of death, with those dying of non-cancer causes accessing fewer support services, including specialist palliative care. ¹⁷⁻¹⁹ For people dying at home, more informal care – if available - may be required.
Socio-economic status (Index of Multiple Deprivation [IMD]).	Those from more deprived quintiles may be less able to fund additional formal care. Lower socio-economic status is also associated with lower health literacy; in this situation, people may be less able to advocate and access state provided health and social care support. ²⁰

Religious affiliation and ethnicity.	Religious teaching and cultural norms regarding caring for the sick within family and communities may be related to provision of informal care. Minoritised ethnic groups have reduced access to health and social care systems and culturally congruent care. ²¹
Access to specialist palliative care.	Our previous work showed that access to specialist palliative care ameliorated the adverse impact of lower socio-economic status on home death. ^{10,22}
Willingness to care again.	In informal carers of those dying from cancer and known to specialist palliative care teams, higher informal care costs are associated with a more positive perception of caregiving. ⁶ Our previous work showed that younger carers caring for those accessing specialist palliative care were more likely to be willing to care again. ¹⁰

Statistical analysis

Demographic characteristics of the respondents, and place and cause of death of the deceased were described. Cause of death was listed as cancer if cancer was marked as cause of death, regardless of other causes mentioned.

Hours of care were derived from duration, frequency and intensity responses. As respondents reported care duration with minimum and maximum limits, total hours reflect these ranges. The costs were then applied to the hours of care provided.

Ethnicity was grouped into two categories: 'White' and 'Other' containing: Black; Asian; Mixed and Other.

Religion was grouped into three categories: 'Christian', 'Other religion' or 'None'.

The data were weighted using Health Survey England individual weighting variable, hence base sizes may not correspond. Weighting is applied to HSE 2017 data to correct for probabilities of selection and to minimise bias from non-response. From 2003 a non-response adjustment was also incorporated into the weighting strategy.¹¹

A multivariable linear regression model was created to explore any relationship between independent variables and costs in the last year of life. Cost of care was log transformed as data were positively skewed. A p-value <0.05 was accepted as statistical significance using backwards and forwards stepwise selection. Point estimates are presented with 95% confidence intervals (CIs). No adjustments were made for multiple significance testing. Length

and intensity of care were not included in the model as costs were calculated from these two variables, but Spearman rank correlations with costs were conducted. All analysis used a complete case analysis with the assumption that data in this large population-based survey was missing at random; missing data were not imputed.

Examination of residuals vs fitted values assessed model fit. Analyses used StataSE Version 17.

Findings were reported in accordance with the STrengthening the Reporting of OBservational (STROBe) studies in Epidemiology guidance.²³

RESULTS

The survey was sent to 9,612 household addresses in 543 postcode sectors. A household response rate was 60% (5,767/9,612) generating 7997 interviews with adults. The end-of-life set of questions was administered to adults (age 16 or over; the age of competent consent), generating 7,997 analysable responses.

Experienced close bereavement

One quarter of respondents (2163/7997; 27%) reported that someone '*close to them had died of a terminal illness in the previous five years*' (Table 1). The most common cause of death was cancer (1443/2083; 69%) and the decedent's relationship to the carer was most commonly their parent, a non-first degree relative or a friend. Most decedents died in hospital (840; 40%), or at home (31%/2083; 646). Palliative care services were involved in over half of decedents' care (1177; 57%), and other health and social care services by one quarter (534; 26%).

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

Variable	N (%)
Number of respondents reporting death of someone close to them	2163 (27)
Age (years) (n=2083)	
16-24	140 (7)
25-34	243 (12)
35-44	338 (16)
45-54	367 (18)
55-64	403 (19)
65-74	370 (18)
75+	302 (14)
Sex (n=2083)	
Female	1295 (62)
Male	868 (38)

Ethnicity (n=2080)		
	White	1896 (91)
	Black	46 (2)
	Asian	108 (5)
	Mixed	18 (1)
	Other	12 (1)
Religion (n=1911)		
	No religion	656 (34)
	Christian – Catholic	373 (20)
	Christian – Protestant	747 (39)
	Buddhist	9 (1)
	Hindu	25 (1)
	Jewish	4 (1)
	Muslim	65 (3)
	Sikh	8 (1)
	Other*	24 (1)
Relationship to deceased; this person was my... (n= 2083)		
	Spouse/Partner	137 (7)
	Parent	466 (23)
	Child	46 (2)
	Sibling	256 (12)
	Other relative	858 (41)
	Friend	2978 (14)
	Other	23 (1)
Place of death (n=2083)		
	Home (lived together)	57 (3)
	Home (deceased's)	570 (27)
	Home (respondent's)	19 (1)
	Hospital	840 (40)
	Hospice	329 (16)
	Nursing care home	175 (8)
	Residential care home	43 (2)
	Other [#]	36 (2)
	Unknown	14 (1)
Cause of death** (n=2083)		
	Emphysema/other lung disease	189 (9)
	End stage heart failure	134 (6)
	End stage liver failure	37 (2)
	Cancer	1443 (69)
	Motor neuron disease/multiple sclerosis	44 (2)
	End stage kidney failure	45 (2)
	Other, including HIV/AIDS	259 (12)
	Don't know illness	44 (2)

Whether palliative care service was used (n=1983)	Yes	1177 (59)
	No	806 (41)
Whether any other care services were used (n=1949)	Yes	534 (27)
	No	1415 (73)

**Numbers do not add up to 2083 as some participants died of multiple causes; * Other religion contained the categories: Buddhist; Hindu; Jewish; Muslim; Other. There were no Sikhs with a care cost calculated.

Provision of care - personal

One quarter (521/2083; 25%) of bereaved respondents provided personal care to someone who had died (Table 2). Two-thirds (343; 66%) were women. Half of the carers had provided personal care for more than 6 months in the last year of life. Half of all carers had provided care daily and a further 168 (32%) provided care at least once a week. Whilst most would provide personal care again under the same circumstances, some would not (46; 9%).

Other help

Nearly half of respondents (1,010/2083; 48.5%) reported providing other help (Table 2). There was still a female preponderance (616; 61%), but more men were involved than giving personal care. Duration and frequency of care provided in general mirrored that of personal care provision.

Cost of care – personal care

Based on the hourly replacement costs, the total estimated cost of care in the last year of life (number of min/max total hours of care in last year of life x £24/hour) was £9,668,256 to £11,469,648 (~£18,557 to £22,072 average per carer). This represents national costs for informal personal care in the last year of life of £10.8 to £12.9 billion, assuming i) an English population ≥16 years of 44,981,459 (2017); ii) the study population is representative, and 521/7997 (6.5%) of the general adult population provided an episode of care; ii) and care episodes of care were evenly distributed over five years (Online Supplement Table 5.).

Other help

The estimated cost of other help in the last year of life (24 hours a day x number of min/max total hours of care in last year of life x £25/hour) was £11,772,725 to £13,833,800 (~£11,656 to £13,697 per carer). This represents national costs of £13.2 to £15.5 billion assuming i) an English population ≥16 years of 44,981,459 (2017); ii) the study population is representative, and 1010/7997 (12.6%) of the general adult population provided an episode of care; ii) and care episodes of care were evenly distributed over five years (Online Supplement Table 5.).

Table 2. Characteristics of respondents, amount and estimated of care by care provided

CHARACTERISTICS OF RESPONDENTS BY CARE PROVIDED				
	Provided personal care		Provided other help	
	Yes n (%)	No n(%)	Yes n (%)	No n(%)
Age (n=2083)				
16-24	18 (3)	115 (7)	45 (4)	88 (8)
25-34	51 (10)	182 (12)	101 (10)	132 (12)
35-44	88 (17)	244 (16)	161 (16)	171 (16)
45-54	123 (24)	236 (15)	201 (20)	158 (15)
55-64	110 (21)	279 (18)	211 (21)	178 (17)
65-74	72 (14)	283 (18)	191 (19)	164 (15)
75+	59 (11)	223 (14)	100 (10)	182 (17)
Sex (n=2083)				
Male	178 (34)	657 (42)	394 (39)	441 (41)
Female	343 (66)	905 (58)	616 (61)	632 (59)
Self-assessed general health (n = 2082)				
Very good	180 (35)	432 (28)	330 (33)	282 (26)
Good	199 (38)	651 (42)	411 (41)	439 (41)
Fair	100 (19)	317 (20)	188 (19)	229 (21)
Bad	33 (6)	104 (7)	53 (5)	84 (8)
Very bad	9 (2)	57 (4)	28 (3)	38 (4)
Marital Status (n=2083)				
Single	76 (15)	255 (16)	151 (15)	180 (17)
Married	240 (46)	849 (54)	537 (53)	552 (51)
Separated	10 (2)	32 (2)	14 (1)	28 (3)
Divorced	40 (8)	113 (7)	73 (7)	80 (7)
Widowed	92 (18)	111 (7)	121 (12)	82 (8)
Cohabitees	63 (12)	202 (13)	114 (11)	151 (14)
Index of multiple deprivation (n=2083)				
Q1	107 (21)	302 (19)	208 (21)	201 (19)
Q2	114 (22)	340 (22)	239 (24)	215 (20)
Q3	106 (20)	300 (19)	196 (19)	210 (20)
Q4	96 (18)	287 (18)	169 (17)	214 (20)
Q5	98 (19)	333 (21)	198 (20)	233 (22)
Qualifications (n=2078)				
None	85 (16)	342 (22)	164 (16)	263 (25)
Trade qualification/certificate/diploma	295 (57)	872 (56)	588 (58)	579 (54)
Degree	140 (27)	344 (22)	256 (25)	228 (21)
Able to carry on with life (n = 2081)				
I have been able to	424 (81)	1463 (94)	876 (87)	1011 (94)
I am starting to	75 (14)	76 (5)	102 (10)	49 (5)
I have not been able to	22 (2)	21 (1)	32 (3)	11 (1)
Would take on caring role again (n =518)				

definitely would	401 (77)	N/A
probably would	71 (14)	
probably would not	19 (4)	
would not	27 (5)	
AMOUNT AND COSTS OF CARE BY TYPE PROVIDED IN THE DECEDENT'S LAST YEAR OF LIFE		
	Provided personal care	Provided other help
Provided care (Length of time) (n= 1531)		
≤ 1 week	45 (9)	59 (6)
>1 week, ≤ 1 month	52 (10)	103 (10)
> 1 month, ≤ 3 months	67 (13)	128 (13)
> 3 months, ≤ 6 months	79 (15)	128 (13)
> 6 months, ≤ 9 months	48 (9)	97 (10)
> 9 months, ≤ 1 year	35 (7)	85 (8)
> 1 year, ≤ 2 years	79 (15)	158 (16)
> 2 years, ≤ 5 years	67 (13)	142 (14)
> five years	49 (9)	110 (11)
Provided care (frequency) (n= 1531)		
Every day	278 (53)	336 (33)
At least once a week	167 (32)	449 (44)
At least once a month	43 (8)	126 (12)
Less than once a month	20 (4)	59 (6)
It varied too much to say	15 (3)	40 (4)
Estimated hours of care provided: total (median; Q1, Q3; range)		
Minimum	403,616 (186; 26, 730; 1 to 8760)	470,909 (104; 24, 365; 1 to 8760)
Maximum	477,902 (288; 52, 936; 1 to 8760)	553,352 (175; 49, 459; 1 to 8760)
Estimate costs of care last year of life nationally		
Minimum	£9,668,256	£11,772,725
Maximum	£11,469,648	£13,833,800

Variables associated with costs of care

The minimum and maximum weighted costs for *personal care* and *other help* are presented in Table 2. Spearman rank correlations were produced for intensity and length of care against costs (Supplement Tables 1 and 2).

Personal care

Length of care was strongly (0.88), and intensity of care moderately (0.46), correlated with costs (Supplement Table 1). Table 3 presents the “best” model for maximal costs. Compared to carers aged 16-24 years, costs of carers aged 65-74 or 75+ years, were 4.0 (95% CI: 1.6 to 10.0)

and 6.7 (95% CI: 2.5 to 17.7) times greater respectively. Carer costs of those dying at home (not the carer's home), hospital, or hospice, were 72.2% (95% CI: 87.1 to 39.9), 61.1% (95% CI: 81.4 to 18.8) and 66.2% (95% CI: 85.5 to 21.6) less respectively than those who lived with the decedent. Costs were greater for carers from more deprived areas. People who died from non-cancer diseases had maximum costs; 1.8 (95% CI: 1.2 to 2.6) times greater than for people with cancer. Maximum costs of carers of other religions were 58.6% (95% CI: 87.6 to 23.5) less than Christian or 'no religion' carers. Similar patterns were seen using minimum costs (Supplement Table 3).

Table 3. 'Best' multivariable linear model for the log transformed maximum personal care costs

Log maximum cost	Factor levels	n	Exp (Coefficient)	95% CI	Std. error	p-value
Age Ref: 16-24 (n=18)	25-34	45	2.022	[0.855, 4.782]	0.886	0.109
	35-44	81	2.461	[1.095, 5.528]	1.013	0.029
	45-54	114	2.906	[1.328, 6.359]	1.158	0.008
	55-64	100	3.541	[1.562, 8.030]	1.475	0.003
	65-74	69	3.981	[1.657, 9.562]	1.775	0.002
	75+	52	6.129	[2.355, 15.950]	2.983	0.0002
Place of death Ref: Home (we lived together) (n=38)	Home (theirs)	126	0.297	[0.139, 0.636]	0.115	0.002
	Home (yours)	10	1.310	[0.265, 6.476]	1.065	0.740
	Hospital	177	0.362	[0.175, 0.748]	0.134	0.006
	Hospice	62	0.379	[0.163, 0.880]	0.162	0.024
	Nursing care home	51	0.506	[0.212, 1.205]	0.223	0.124
	Residential home	10	0.236	[0.056, 0.989]	0.172	0.048
	Other	5	1.487	[0.298, 7.410]	1.215	0.628

Log maximum cost	Factor levels	n	Exp (Coefficient)	95% CI	Std. error	p-value
Deprivation	2	100	0.496	[0.281, 0.874]	0.143	0.016
Ref: Least deprived (n=96)	3	99	0.964	[0.546, 1.701]	0.279	0.900
	4	89	1.971	[1.096, 3.547]	0.589	0.024
	Most deprived	95	1.349	[0.756, 2.405]	0.397	0.310
Cause of death	Non-cancer	157	1.760	[1.184, 2.616]	0.355	0.005
Ref: Cancer (n=322)						
Religion	Other religion	40	0.414	[0.224, 0.765]	0.129	0.005
Ref: Christian (n=282)	None	157	0.938	[0.618, 1.423]	0.129	0.762

R squared = 12.75%

Other help

Length of care was moderately (0.46), and intensity fairly (0.38), correlated with costs (Supplement Table 2).

The 'best' multivariable linear model for the log transformed maximum costs included age, sex, place of death, cause of death, deprivation and other care services used as explanatory variables (Table 4). Compared to those aged 16-24 years, the maximum costs of carers aged 45-54, 65-74 or 75+, were 1.8 (95% CI: 1.1 to 2.8), 2.0 (95% CI: 1.2 to 3.0) and 2.7 (95% CI: 1.5 to 4.6) times greater respectively.

Female carers had maximum costs 1.3 (95% CI: 1.1 to 1.7) times higher than males.

Carer costs for those dying at home (but not the carer's home), hospital, hospice, nursing care home or residential home were 82.2% (95% CI: 89.8 to 69.0), 74.7% (95% CI: 85.2 to 56.6), 76.1% (95% CI: 87.1 to 68.9), 70.8% (95% CI: 84.2 to 46.1) and 78.4% (95% CI: 90.3 to 50.6) lower respectively than for carers who lived with decedents.

Maximum costs changed in a non-linear way with deprivation levels. Compared to the least deprived people, the maximum costs of people with a deprivation level of 4, were 1.9 (95% CI: 1.4 to 2.7) times greater.

Carers that did not use other care services had maximum costs 21.3% (95% CI: 36.4 to 3.1) lower than carers that did. People who died from non-cancer diseases had maximum carer costs 1.4 (95% CI: 1.1 to 1.8) times greater than people who died from cancer. Again, similar patterns were seen for minimal costs. (Supplement Table 4).

Table 4. Multivariable regression model with weighted maximum costs for general help (n=989)

Log maximum cost	Factor levels	n	exp(Coefficient)	95% CI	Std. error	p-value
Age Ref: 16-24 (n=43)	25-34	99	1.069	[0.657, 1.739]	0.265	0.788
	35-44	159	1.069	[0.674, 1.698]	0.252	0.776
	45-54	197	1.792	[1.144, 2.806]	0.409	0.011
	55-64	204	1.543	[0.980, 2.428]	0.357	0.06
	65-74	188	1.918	[1.207, 3.049]	0.453	0.006
	75+	99	2.653	[1.545, 4.557]	0.731	0.0004

Log maximum cost	Factor levels	n	exp(Coefficient)	95% CI	Std. error	p-value
Sex Ref: Male (n=386)	Female	603	1.347	[1.091, 1.663]	0.145	0.006
Place of death Ref: Home (we lived together) (n=45)	Home (theirs)	254	0.178	[0.102, 0.310]	0.050	<0.0001
	Home (yours)	12	0.705	[0.207, 2.403]	0.440	0.576
	Hospital	368	0.253	[0.148, 0.434]	0.070	<0.0001
	Hospice	162	0.231	[0.129, 0.411]	0.068	<0.0001
	Nursing care home	105	0.292	[0.158, 0.539]	0.091	0.0001
	Residential home	28	0.216	[0.097, 0.484]	0.089	0.0002
	Other	15	0.491	[0.187, 1.290]	0.242	0.149
Deprivation Ref: Least deprived (n=203)	2	236	0.968	[0.703, 1.333]	0.158	0.841
	3	193	0.959	[0.688, 1.338]	0.163	0.807
	4	165	1.928	[1.359, 2.734]	0.343	0.0002
	Most deprived	192	1.299	[0.923, 1.827]	0.226	0.133
Other care services Ref: Yes (n=351)	No	638	0.797	[0.636, 0.997]	0.091	0.048
Cause of death Ref: Cancer (n=673)	Non-cancer	316	1.439	[1.136, 1.822]	0.173	0.003

R squared = 10.59%

DISCUSSION

Main findings

The replacement costs of *personal care* and *other help* for the last year of life were estimated at £27,072 and £13,697 per carer and a total cost of £12.9 billion and £15.5 billion respectively nationally (financial year 2020). Older age, death at home, a non-cancer cause of death and greater deprivation were associated with increased costs of care. Religion was associated with personal care costs (no difference between 'Christian' and 'no religion'; lower costs for 'non-Christian'). Female sex, and not accessing 'other care services' were related to higher costs for *other help* only.

What this study adds

Other reported replacement costs are for people with cancer, include nursing replacement costs, and relate to the last three months of life only. This makes direct comparison difficult as monthly informal care costs will increase towards the end of life. However, *assuming a uniform cost over time*, our three months care cost estimation per carer (personal care and other help) is £10,192, which is comparable to Urwin and colleagues⁹ (£11,400; care assistants and nursing replacement costs) but lower than Higginson and colleagues (£28,530; nursing replacement costs).⁶

Age (all care) and sex (*other help* only). Consistent with other literature older age was associated with higher costs.²⁴ This may be due to the higher likelihood of spouses living together, with consequent longer duration and intensity of caregiving and greater frailty of the decedent. Hospitalisation at the end of life is also less for older adults,²⁵ which increases informal caregiving. The female preponderance and increased costs are consistent with the literature,¹⁶ but the distinction by *personal care* or *other help* is novel.

Place of death. Care costs are highest in the last three months of life, driven by hospital admissions.^{24, 25} Our data confirm carer costs were less for hospital, hospice or care home deaths, consistent with fewer direct 'care-hours'. This finding was less marked if the person died in a nursing care home, where informal carers may help with personal care.

Cause of death. People dying from cancer are more likely to access supportive and palliative care services than others.^{27,28} Unmet care needs are more likely in people with non-cancer conditions, and end-stage illness less often recognised.^{19, 26} Our findings suggest a greater burden on people providing informal care for those dying from non-cancer conditions. By exploring general population costs for the whole last year of life, we find a difference unseen only exploring the last three months of life in people accessing palliative care.²⁴ Interestingly, given dementia is a common cause of death (most common for women) in England, 'other' causes did not appear as the most common. These data are from informal caregivers and therefore not representatives of population deaths. However, perhaps women dying from dementia are less likely to have an available family member – particularly spousal - to provide care. In addition, respondents were asked to give only one cause of death, and named

conditions on the response options more likely to be given for decedents with multiple conditions including dementia.

Deprivation. The relationship between healthcare need and deprivation is complex. Population age structure, funding and staffing, health inequities in deprived areas,²⁶ and social action healthcare initiatives²⁷ often directed to areas of high need, play their part. Navigation of the social and healthcare system by non-professionals varies by socioeconomic status; lower education and income being associated with lower health literacy.²⁸ This effects a ‘double jeopardy’ for people in more deprived areas – fewer services, and greater difficulty in accessing those they have. Our observation that the most deprived carers (level 5) had fewer care costs than the next level may reflect better recognition of ‘very obvious’ unmet need by professionals, and targeted improvement and social action projects.

Religion. Given the small numbers and the complex interplay between culture, religion and ethnicity our findings are exploratory. Ethnicity did not appear in the final model, perhaps indicating ‘religion’ to be a cultural proxy cutting across ethnic boundaries, e.g., differences in faith as an expressed motivation for caregiving between Black and White Christians.²⁹ The lower costs for carers from non-Christian religions contrast with the literature and common assumptions about the impact of non-Western and non-Christian cultures on informal caregiving, such as filial responsibility and collectivist versus individualist motivation.³⁰ Formal services may be seen as inaccessible or culturally inappropriate, leading to routine expectations and practice of increased informal caregiver provision.³¹ Possible explanations include: i) the carer’s response related to *one* decedent thereby not accounting for multiple carer roles common in collectivist cultures; ii) respondents were not asked about other involved informal caregivers; iii), carers from non-Western cultures may not view themselves as caregivers, although the question was clearly defined and was interviewer-delivered; iv) we could not explore differences between non-Christian religions due to small numbers, and common caregiving practice should not be assumed; v) we could not account for traditional approaches modified by acculturation; and vi) ‘individualist-collectivist’ is not dichotomous and ethnicity intersects with other health determinants.³¹ Most previous work relates to caregiving in general; there is little information about informal care provision at the *end of life* across cultures³² An increased likelihood of hospital death for people from minoritized ethnic communities is documented,³³ which may contribute to our observed reduced costs,³⁴ noting religion is not synonymous with ethnicity.

Strengths and Limitations

Our national population level approach looking at care during the last year of life, and for people dying of cancer *and* non-cancer diseases is novel. Our primary outcomes required recall potentially over five years, and used time-based minimum and maximum estimates (e.g., three

to six months) and assumptions ('morning' = 6-hours). Nevertheless, we identify issues beyond duration and intensity of caring which resonate with other findings and raise new concerns. The limits of recall in this field has been noted³ and although a new validated Costs of Family Caregiving is an important addition, it is recall-based.³⁵ Although total care costs (professional and informal) increase in the last three months of life, we could not explore changes over time. The replacement good method is one of a number of methods for estimating the monetary value of informal care time. Different methods for the monetary valuation of care give different results; replacement cost approach give higher values than for the other approaches to cost informal care time.³⁶ This is why I think it is also worth highlighting the time spent on caregiving. Time spent is not affected by the method used to value time.

The goodness of fit of the models are relatively weak (R^2 : 12.75% and 10.59%), but this is expected given the strong associations between duration and intensity with costs, therefore excluding these from the model. The findings about religion should be interpreted cautiously.

Our analyses assume that decedents received the appropriate care. Evaluation of this will be important in future work. We used a conservative replacement proxy good method, valuing time at the price of a substitute (community-based homecare worker). However, some informal carers may provide skilled nursing care irreplaceable with unqualified help. We have also not considered carer burden or the effects on quality of life, wellbeing and health or caregiver mortality.

We also assumed hours of care provided would be reasonably stable, and applied unit costs from the year we received the dataset (2020).[15] Therefore the estimated costs would have been slightly less in 2017, the year in which they were incurred.

Importantly, the survey response rate was 60%. Whilst this is a relatively good response rate to a survey, it brings limitations regarding generalisability.

Finally, due to the sampling methods, we do not know the total number of adults per household; a maximum of 10 adults per household were interviewed which makes it unlikely that eligible adults were not invited to interview, but we do not know how many individual adults were invited but declined. As some of the adults declining participation might have also provided care, our findings might be an underestimate.

Implications for clinical practice and research

Little systematic support is provided for informal carers. Services dedicated to their wellbeing and health are urgently needed considering the changing demographics and increasing needs of society.³⁷ The under-estimated cost of informal care is a serious challenge to statutory providers; *current* services are inadequately resourced. We highlight that social and healthcare

providers will be expected to pick up minimum costs of £41,000 per decedent for the last year of life.

Although data are from 2017, the proportions of those bereaved and providing end-of-life care, and those unwilling to care again are similar to figures from the 2013 survey¹⁰ indicating a stable relevance. Prospective data collection on duration and intensity of care is needed, and the complex impact of religion, ethnicity and culture on providing care at the end of life further explored.

Although data are from England, the issues demonstrated are applicable to other healthcare models around the world with an ageing population. In countries with no universal health and social care, the demand on informal carers will be greater, especially for those with no financial resource to pay for care.

CONCLUSION: Estimated replacement informal care costs in the last year of life are £41,000 per decedent. Costs are greater for older carers, home deaths, deaths due to non-cancer diseases, longer care duration and intensity, and greater carer deprivation. This presents a major challenge for future universal care coverage as the pool of family and friends providing informal care diminish with an ageing population.

DECLARATIONS

Authorship

Concept; MJJ, DCC, HW; question set adaptation; all authors; statistical analysis; JC, VA, MJJ, HW, GK; first draft of manuscript; MJJ; revisions for intellectual content: all authors; agreement of final manuscript; all authors

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Conflicts of interest

The authors declare no conflicts of interest

Ethics and consent

Ethical approval for the question adaptation was given by the Hull York Medical School ethics committee (Reference 1615). The questions were included in the Health Survey England's 2017 ethics submission and approved by the East of England Research Ethics Committee (Reference 15/EE/0229). All participants provided informed verbal consent for taking part in the survey at all, for answering modules of questions (and any individual question), for completing the self-completion booklet, and for measurements such as height, weight, blood pressure and waist and hip circumference. Written consent was required for: taking biological measurements; passing on information to others, for instance sending biological sample results to the participant's GP; storing blood samples for future use; using personal details for matching to administrative data.

Data management and sharing. Data are available from University College London, Department of Epidemiology and Public Health, National Centre for Social Research. (2023). *Health Survey for England, 2017*. [data collection]. 3rd Edition. UK Data Service. SN: 8488, DOI: <http://doi.org/10.5255/UKDA-SN-8488-3>

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