



The monetary valuation of informal care to cancer decedents at end-of-life: Evidence from a national census survey

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Abstract

Background: Carers' end-of-life caregiving greatly benefits society but little is known about the monetary value of this care.

Aim: Within an end-of-life cancer setting: (1) to assess the feasibility and content validity of a post-bereavement measure of hours of care; and (2) to obtain a monetary value of this informal care and identify variation in this value among sub-groups.

Design and setting: A census based cross-sectional survey of all cancer deaths from a 2-week period in England collected detailed data on caregiving activity (10 caregiving tasks and the time spent on each). We descriptively analyse the information carers provided in 'other' tasks to inform content validity. We assigned a monetary value of caregiving via the proxy good method and examined variation in the value via regression analysis.

Results: The majority of carers (89.9%) were able to complete the detailed questions about hours and tasks. Only 153 carers reported engaging in 'other' tasks. The monetary value of caregiving at end-of-life was £948.86 per week with social and emotional support and symptom management tasks representing the largest proportion of this monetary valuation. Time of recall did not substantially relate to variation in the monetary value, whereas there was a stronger association for the relationship between the carer and recipient, carer gender and recipient daily living restrictions.

Conclusion: The monetary valuation we produce for carers' work is substantial, for example the weekly UK Carers' Allowance only amounts to 7% of our estimated value of £948.86 per week. Our research provides further information on subgroup variation, and a valid carer time instrument and method to inform economic evaluation and policy.

Keywords

Caregivers, cancer, palliative care, health economics

What is already known about this topic?

- The contribution of carers at end-of-life is crucial but often overlooked, yet our reliance on carers during this time is likely to increase in the future.
- We lack validated methods for comprehensive collection of all the tasks that carers perform during the end-of-life period.

What this paper adds?

- We obtained caregiving activity information retrospectively (post-bereavement) and found evidence that this information was comprehensive, feasible to obtain and was not significantly affected by recall bias.
- This study produced a monetary valuation of end-of-life cancer informal care at £948.86 per week using population-based information on caregiving activity.

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- We identified that female compared to male carers and spousal carers compared to non-spousal had a higher monetary valuation of caregiving.

Implications for policy, theory and practice?

- Our study demonstrated that retrospective data collection was feasible in an end-of-life setting. This can be used in future work to help understand and/or support the contribution of end-of-life carers.
- Monetary valuations of the sort we produced, can increase the visibility of carers to policy makers, and identify which subgroups of carers require more support.

Introduction

The monetary value of cancer was estimated to be 199 billion euros (which included cancer related healthcare, cancer drugs, informal care and productivity loss) across 31 countries in Europe in 2018 with informal care making up 22 billion euros of this total.¹ Important aspects of informal care are often not taken into account when estimating the monetary value of caregiving and this figure is likely to vary greatly depending on the stage of cancer. A frequently overlooked stage is at end-of-life where caregiving hours substantially increase.²

The number of deaths has been projected to increase worldwide, including those related to cancer.^{3,4} Combined with a preference from both patients and policy makers for those with cancer to remain at home during the end-of-life stage, caregivers will become even more important in the future.^{5,6} Caregivers make a substantial contribution to the care of those at end-of-life,² but where they are unable to provide this service, increased formal care use is necessary. It is therefore essential to establish the monetary value of informal care to inform healthcare interventions, policy and a greater understanding of the economic burden of cancer, in particular in end-of-life care, where informal care has largely been excluded to date.^{7,8}

Derivation of a monetary value first requires appropriate measurements of time and activities suited to the type of caregiving.⁹ There are many instruments used to collect informal care information. The validity and reliability of caregiving time instruments has been assessed in various settings,^{10,11} but instruments that have been developed for collecting data on end-of-life caregiving are limited. They are not conducive to collecting data longitudinally, as is needed for prospective cohort studies, due to resource intensity¹² and difficulties defining when the end-of-life period will occur.¹³ Furthermore, it is not clear if they capture all activities conducted during end-of-life caregiving.¹⁴

The literature which covers the monetary value of cancer informal care typically use the proxy good or opportunity cost method.¹⁵ These studies cover select European countries^{13,16–20} or North America^{21–24} and also focus mainly on specific types of cancer^{16–20,22} (such as head and

neck cancer or colorectal cancer) or cover a variety of types.^{13,21,23,24} There is a lack of studies that focus solely on end-of-life caregiving and use nationally representative data. This may in part be due to the challenges of prospective means of data collection at end-of-life. Prospective data collection through cohort studies yield small samples of carers ($N < 200$) due to the recruitment of patients from a hospital at the end-of-life stage.^{23,24} Consequently, little is known about what factors (i.e. carer and recipient characteristics) are associated with variation in the monetary value. An exception analysed variation in the monetary value (derived via the opportunity cost method) through regression analysis, although there were only 144 carers of those at the terminal phase.²² Retrospective data collection may be more feasible in an end-of-life context to obtain a substantial number of carers and as a result enable a greater insight into carers' contributions overall and by sub-group.

In this study, we aim to establish the content validity and feasibility of our time instrument with post bereavement (retrospective) data collection. This is crucial for two main reasons: (1) it is important to include all caregiving related tasks in an end-of-life cancer setting (due to the few studies in this area) and (2) show that the collection of information post-bereavement produces enough quality information for meaningful analysis that is not influenced by recall bias. These data can then be used to design support for, and generate awareness of, the contribution of carers. We aim to produce a monetary valuation of end-of-life cancer caregiving using a census-based survey and examine variation in this value by characteristics of the carer and recipient via regression analysis. Variation in monetary values by particular characteristics can help identify certain sub-groups who may require further support with caregiving and can be targeted by interventions.

Methods

Design and sample

We use data from a retrospective cross-sectional census survey of informal family caregivers of people who had died ($N = 5271$) from cancer between the 1st and 16th of

Table 1. Content of the informal care time instrument.

Category	Items
Household tasks	Preparing food and drink
	Doing any cleaning
	Doing maintenance or 'odd' jobs
	Shopping for groceries or your relative's personal items
	Doing general administration for them
Personal care tasks	Travelling outside the house with them
	Helping your relative look after themselves
Health care and medicine tasks	Organising/attending healthcare appointments
	Helping with symptoms
Social and emotional care	Providing social or emotional support
Other tasks	Anything else

May 2015. The Office of National Statistics (ONS) identified people who registered a death and sent a postal questionnaire for the carer to complete 4 months after the registered death date (post bereavement) with two reminders at 1-month intervals. To be included in the sample, the cancer patient in receipt of end-of-life care had to have been older than 18 years of age, have cancer as an underlying or contributory cause of death and have died in England. Recipients were invited to pass the survey to a main carer if they did not feel they met this role.

Previous work on the measurement of informal care was used to obtain an initial list of caregiving tasks^{11,25,26} which was then refined alongside development of the questionnaire. The questionnaire was developed in collaboration with an ONS team and local carer groups including bereaved individuals. Carer groups assisted through think aloud exercises and gave feedback on the pilot survey.

The final questionnaire contains a detailed set of information which covered the carer's socio-demographic background (e.g. age, gender and relationship to the descendant), contribution (e.g. time) and general demographic information, symptoms and function of the decedent (see Rowland et al.² for more details on questionnaire design and content).

The University of Manchester's Research Ethics Committee approved the study (Ref: 14430).

Time measurement

The questionnaire asked carers to recall from a list of 11 tasks how many hours they spent on informal caregiving in a typical week during the last 3 months of their care recipient's life. We collapse these 11 tasks into five groupings of tasks shown in Table 1. These questions explicitly acknowledge that there may not be a typical week when

providing informal care. We also asked respondents to record and add up their hours of sleep, leisure and work, and further remind carers that there is 168 h in a week to help ensure hours are not overestimated.

Analysis

First, we establish the content validity of our time instrument through descriptive analysis of the 'other' category (Table 1). If this category is: (1) rarely used by our sample of carers and (2) makes little difference to the total hours; then we can claim the other 10 categories are comprehensive and appropriate, in terms of content, for use in end-of-life cancer informal caregiving. We perform a basic thematic analysis of written responses to the 'other tasks' to further understand what types of tasks may have been missed by the instrument. We derive our total hour's variable from the sum of each of the 10 informal care tasks (Table 1). We include carers who indicate that they provide a positive value for at least one of the 10 informal care tasks from the 1504 completed questionnaires. We recode missing hour's values as zeros.

Second, we use the proxy good method (or sometimes referred to as the replacement cost method) to assign a monetary valuation to informal care. This method requires hours of informal care for each task and an assigned wage rate intended to be the monetary value of a market substitute. We assign the gross wage rate of a home care worker at £8.20 per hour to household tasks, personal care tasks and social and emotional care tasks. The gross wage rate of a (Band 6) community nurse at £21.24 per hours (assuming a salary of £32,563 and 1 573 h of annual working time) is assigned to health care and medicine tasks as these types of task require technical knowledge. Both costs are obtained from the Personal Social Services Research Unit (PSSRU) who provide unit costs at 2019 prices.²⁷

We derive a proxy good monetary value for caregiving per hour (equation (1)) and per week (equation (2)).

$$\text{Hourly Cost} = \frac{8.20 * \text{Household}_i + 8.20 * \text{Personal Care}_i + 21.24 * \text{Health care}_i + 8.20 * \text{Social}_i}{\text{Household}_i + \text{Personal Care}_i + \text{Health care}_i + \text{Social}_i} \quad (1)$$

$$\text{Weekly Cost} = 8.20 * \text{Household}_i + 8.20 * \text{Personal Care}_i + 21.24 * \text{Health care}_i + 8.20 * \text{Social}_i \quad (2)$$

Both formulas include the four activity groups (which excludes 'other' tasks) outlined in Table 1, for caregiver, i , which are multiplied by their respective market substitute.

Equation (1) is the weekly cost (shown in equation (2)) divided by the total hours of provision, which results in an hourly monetary value bounded between £8.20 and £21.24. The more hours of health care tasks a carer provides relative to all other types of tasks the closer the hourly monetary value will be to £21.24.

As some carers may report substantially more than 168 h in a week, we provide sensitivity analysis which caps total hours at 168 (provided in the appendix). Among carers with capped total hours the distribution of each task is identical to pre-capped hours which indicates carers provided the correct distribution of hours but over-reported the number of hours.

Third, we explore what characteristics of the carer and recipient are related to variation in the monetary value of caregiving, which is possible due to the sample size. We include the number of days between the deceased date and questionnaire completion date (recall date difference), where variation in the monetary value by the recall date would provide a suggestion of recall bias in (and threaten the feasibility of) post bereavement data collection.

We use ordinary least squares regression (OLS)²⁸ with the weekly monetary valuation as the outcome and sequentially include three sets of variables: (1) relationship to the recipient (spouse, parent and other), residence of the recipient (co-residing or not) and the recall date difference; (2) carer age, gender, education (none, exams at 16 years old, college/equivalent, university degree and other), employment prior to caregiving (employed, retired and homemaker/unemployed/other) and marital status (married/living as married, divorced/separated and single/other); (3) recipient age, gender and activities of daily living (ADL) restrictions (the sum of six ADLs scored zero (not at all) to three (very much): eating, dressing, walking, washing, going to the toilet and getting up at night). We estimate these regressions on a sample of 923 carers with complete information on all characteristics. Sensitivity analysis performs these regressions using a log transformed outcome which accounts for extreme monetary values which could be considered as outliers.

Results

Out of 1504 completed questionnaires, 1352 (89.9%) carers provide information on caregiving hours and 923 carers provide information on all characteristics included in the regression analysis (Table 2). Our sample used for regression analysis contains 923 carers, of which, 65% of carers are female, 59% are employed prior to caregiving, the average age of a provider and recipient is 59 and 79 years old, respectively. Table 2 shows that the monetary valuation sample and regression sample are very similar in terms of carer and recipient characteristics.

There are 330 carers in our sample that report a value in the 'other' category for caregiving tasks and spend

9.94 h per week on this type of task on average (Table 3). Of these 330 carers, 153 report a value greater than zero. Under the assumption of missing values recoded as zeros, the average hours per week of 'other' tasks are 2.18 and 2.09 h for the monetary valuation and regression samples respectively. Given the recoding of missing values to zero only 11.3% of 1352 carers report a value greater than zero for 'other' tasks, hence why the 75th percentile of this variable produces a value of zero hours. Carers could indicate in the survey what 'other' tasks they perform that were not captured in the 10 tasks and only 129 carers used this to provide a written answer.

Carers provide on average 93.07 h per week in the monetary valuation sample (Table 3). This is equivalent to 55.5% of the total hours in a week. Within this sample, 348 carers (25.7%) report providing over 112 h of care in a week, and 149 (11.0%) report over 168 h in a week.

Inclusion of 'other' tasks increases the average number of caregiving hours per week by roughly 2 h across both samples. Further analysis does not include 'other' tasks as it makes only minor differences to the reported hours.

The survey enables carers to indicate what 'other' tasks they perform that were not captured in the 10 tasks. We performed a basic thematic categorisation of $n = 129$ written responses. Eighty-eight responses were re-codable into existing categories, for example, 'love them', 'reading', 'contacting friends and relatives' could be re-codable into the Social and Emotional Care category, 'gardening', 'dog walking' into the Household category (under maintenance/odd jobs) and 'toileting' into Personal Care tasks. Eighteen responses could be considered extensions of existing categories. For example, 'funeral planning', 'advance care planning', 'will writing' and 'organising house move' ($n = 10$) are end-of-life specific falling under the Household (general administration) category. Fifteen responses were arguably extensions requiring further research which were providing care support for another (i.e. dependent of the patient) ($n = 8$) and respondent's own travel (e.g. 'travelling from my home to hers and back') ($n = 7$). A total of eight people gave general care information which lacked specificity (e.g. 'looked after', 'fetched and carried so they didn't have to') and a small number of items were unique, such as charity fundraising, helping up stairs and research/decision making.

We show the mean weekly hours for each caregiving tasks and the associated monetary valuation in Table 4 (equivalent figures for the regression sample are provided in Supplemental Table A1). Across 1352 carers provision of social and emotional support makes up the largest of this total at 33.28 h (95% CI: 30.45–36.12). Other tasks consisted of a mean of only 2.42 h (95% CI: 1.58–3.26). The mean of the total weekly hours of informal care are monetarily valued at £948.86 (95% CI: £879.63–£1018.09). Social and emotional support accounts for the largest proportion of this total at £272.92 (95% CI: £249.67–£296.17) followed by both

Table 2. Characteristics of the carer and recipient.

	Monetary valuation sample		Regression sample	
	Carers (N)	% (mean (SD))	Carers (N)	% (mean (SD))
Co-resided with the recipient	1352	50%	923	49%
Recall date difference (number of days)	1348	160.2 (25.2)	923	159.7 (22.7)
Age (years)	1338	60.2 (12.1)	923	59.2 (12.1)
Female	1341	65%	923	65%
Relationship to recipient:	1352		923	
Partner	595	44%	390	42%
Parent	581	43%	431	47%
Other	162	12%	102	11%
Education	1272		923	
No qualification	191	15%	138	15%
Exams at 16 years	382	30%	268	29%
College/equivalent	305	24%	231	25%
University degree	343	27%	268	29%
Other	51	4%	28	3%
Employment prior to caregiving:	1337		923	
Employed	735	55%	545	59%
Retired	481	36%	305	33%
Other	120	9%	74	8%
Marital status:	1352			
Married	1014	75%	692	75%
Divorced	68	5%	46	5%
Other	284	21%	185	20%
Recipient information:			923	
Age (years)	1352	74.4 (12.4)	923	74.3 (12.4)
Female	1352	48%	923	48%
ADL score	1000	11.6 (5.6)	923	11.6 (5.6)

SD: standard deviation.

Recall date difference refers to the number of days between the deceased date and questionnaire completion date.

tasks valued at £21.84 per hour. The hourly monetary value of £21.84 for helping with symptoms and organising/attending healthcare appointments drives the large mean weekly monetary valuations of each respective task at £105.87 (95% CI: £92.84–£118.90) and £196.53 (95% CI: £166.08–£226.99) relative to all the other tasks. We obtain a mean hourly monetary valuation of £10.01 (95% CI: £9.93–£10.09) for a typical hour of caregiving. Hours capped at a total of 168 h per week produce a monetary value of £757.31 (95% CI: £727.81–£786.82) shown in Supplemental Table A2.

Regression analysis in Table 5 shows that the monetary value of caregiving is £503.04 (CI: £–898.99; £–107.80; $p < 0.05$) lower for those who care for their parent compared to their spouse, on average (from the full specification). Those who co-reside with their recipient have a higher although not statistically significant monetary value of caregiving compared to non-co-residing carers. For each additional day increase in the recall date difference, the monetary value is £0.61 (CI: £–2.07; £3.29; $p > 0.05$) greater but not statistically significant (from the full specification). Female carers and recipients have higher monetary values than male carers and recipients,

respectively. For each extra ADL score, the monetary value is £30.35 (CI: £17.08; £43.62; $p < 0.001$) higher. Regression results including ‘other’ tasks (provided in Supplemental Table A2) in the total aggregated hours and log transforming the outcome (provided in Supplemental Table A3) are similar to results in Table 5.

Discussion

Main findings and implications

Our results, using a census sample, show that the monetary value of informal care for people with cancer at end-of-life is £948.86 per week. Social and emotional care and symptom management tasks have the highest monetary valuations at £272.92 and £196.53, respectively. To put this into perspective, benefits given by the state to carers in the UK (known as carers allowance) are £66.15 per week²⁹ and the maximum state pension amount is £134.24 per week³⁰ (both at 2019 prices) which amount to less than 10% and 15%, respectively, of the weekly monetary value we derive in this study. A further perspective is the national monetary value

Table 3. Descriptive statistics of caregiving hours provided per week.

	N	Mean hours per week	95% CI: Lower	95% CI: Upper	Min	25th percentile	Median	75th percentile	Max
Other tasks									
Raw hours	330	9.94	6.62	13.27	0	0	0	6	168
Hours > 0	153	21.44	14.68	28.2	1	3	6	14	168
Missing recoded to 0	1352	2.18	1.43	2.94	0	0	0	0	168
Missing recoded to 0: <i>regression sample</i>	923	2.09	1.17	3.02	0	0	0	0	168
Aggregated tasks									
Valuation sample	1352	93.07	86.65	99.5	1	28	68	114.5	2107
Including 'other': <i>valuation sample</i>	1352	95.49	88.92	102.07	1	29	70	116	2107
Regression sample	923	90.56	83.73	97.38	2	29	68	113	1234
Including 'other': <i>regression sample</i>	923	92.65	85.66	99.64	2	30	70	115	1234

CI: confidence interval.

Table 4. Proxy good monetary valuations GBP (2019 prices).

	Mean weekly hours (95% CI)	Hourly monetary value (95% CI)	Mean weekly monetary value (95% CI)
Preparing food and drink	10.89 (9.53–12.25)	£8.20	£89.3 (£78.16–£100.45)
Doing any cleaning	8.82 (7.63–10)	£8.20	£72.29 (£62.6–£81.98)
Doing maintenance or 'odd' jobs	3.06 (2.68–3.44)	£8.20	£25.1 (£22.01–£28.2)
Shopping for groceries or your relative's personal items	4.8 (3.71–5.89)	£8.20	£39.36 (£30.45–£48.28)
Doing general administration for them	3.3 (2.82–3.77)	£8.20	£27.02 (£23.09–£30.95)
Travelling outside the house with them	4.66 (3.83–5.5)	£8.20	£38.23 (£31.4–£45.07)
Helping your relative look after themselves	10.03 (8.95–11.11)	£8.20	£82.22 (£73.39–£91.06)
Organising/Attending healthcare appointments	4.98 (4.37–5.60)	£21.24	£105.87 (£92.84–£118.90)
Helping with symptoms	9.25 (7.82–10.69)	£21.24	£196.53 (£166.08–£226.99)
Providing social or emotional support	33.28 (30.45–36.12)	£8.20	£272.92 (£249.67–£296.17)
Total	93.07 (86.65–99.5)	£10.01 ^a (£9.93–£10.09)	£948.86 ^b (£879.63–£1018.09)
Other	2.42 (1.58–3.26)		

CI: confidence interval.

Values obtained are from the monetary valuation sample of 1352 individuals.

^aDerived using equation (1).

^bDerived using equation (2).

of the end-of-life caregiving. If we apply the weekly proxy good values per-person of caregiving (of £948.86) to the 163,444 cancer deaths per year in the UK,³¹ assuming the end-of-life period is 3 months, we derive a national annual monetary valuation of £1.861 billion. The magnitude of this national level figure for end-of-life care is substantial. It contrasts with estimates of the monetary value of annual UK informal cancer care in 2018, of 3.213 billion euros (or £2.827 billion at the average 2018 exchange rate).¹

We find that our weekly monetary valuation varies by the relationship to the recipient, gender of the carer and recipient and health of the recipient, demonstrating criterion validity. For example, previous evidence has found that females tend to provide more informal care than males³² and that those with a higher dependency require more caregiving input.³³ To put this into context, if the

variation of the monetary valuation of informal care is indicative of future demographic trends, then policy and support must account for the needs of these groups.

The recall date difference variable coefficient is small, although a one standard deviation increase in this variable is associated with a £13.85 higher monetary value but is not statistically significant at the 5% level. This suggests that recall bias has little impact on our monetary valuations.

We find that our time instrument exhibits some degree of content validity. This is due to the 'other' tasks category being used by a small number of carers ($N = 153$) and inclusion of these tasks in the aggregated hours variable only increasing the mean by roughly 2 h per week. Therefore, we consider our time instrument to include the majority of tasks undertaken by end-of-life cancer caregivers. Thematic analysis of the tasks suggests that future work should still

Table 5. Regression on the weekly (level) monetary value of caregiving using OLS.

	Basic specification coefficient (95%CI)	Carer specification coefficient (95%CI)	Full specification coefficient (95% CI)
Relationship of recipient: Parent	-440.28*** (-669.63 to -210.93)	-676.57*** (-964.38 to -388.75)	-503.40* (-898.99 to -107.80)
Relationship of recipient: Other	-431.03** (-702.51 to -159.55)	-680.78*** (-990.80 to -370.76)	-631.36*** (-953.85 to -308.87)
Co-residing carer	189.41 (-18.80 to 397.62)	132.21 (-98.51 to 362.93)	116.96 (-97.70 to 331.61)
Recall date difference (number of days)	1.37 (-1.38 to 4.11)	1.18 (-1.51 to 3.87)	0.61 (-2.07 to 3.29)
Age		9.01 (-31.28 to 49.30)	21.17 (-16.34 to 58.68)
Age squared		-0.12 (-0.47 to 0.24)	-0.15 (-0.49 to 0.19)
Female		259.36*** (128.28 to 390.45)	338.04*** (191.99–484.10)
Education: Exams at 16 years		183.15 (-49.04 to 415.34)	223.38 (-7.99 to 454.74)
Education: College/equivalent		32.02 (-162.68 to 226.72)	51.92 (-140.64 to 244.48)
Education: University degree		-142.57 (-322.59 to 37.44)	-107.18 (-286.36 to 72.00)
Education: Other		210.18 (-222.50 to 642.85)	221.99 (-194.24 to 638.22)
Employment: Retired		-86.07 (-289.10 to 116.97)	-71.12 (-267.43 to 125.18)
Employment: Other		210.55 (-158.73 to 579.84)	203.33 (-164.86 to 571.52)
Marital status: Divorced		-44.13 (-228.92 to 140.67)	-44.59 (-219.62 to 130.45)
Marital status: Other		234.64* (10.48 to 458.79)	290.69** (75.31–506.08)
Recipient: Age			19.77 (-26.62 to 66.17)
Recipient: Age squared			-0.22 (-0.57 to 0.13)
Recipient: Female			183.01* (21.17–344.86)
Recipient: ADL sum			30.35*** (17.08–43.62)
Constant		728.31 (-691.39 to 2148.01)	-613.36 (-2666.62 to 1439.91)
Carers	923	923	923

The outcome excludes 'other' tasks. Reference categories for relationship, education and employment variables are spouse, no education qualification and employed, respectively. 95% CI are reported in parentheses: * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$

measure whether or not adding the other tasks to the questionnaire results in a substantial difference to total hours. Carers, however, may also wish to use a written space to provide extra detail about their responsibilities.

It is feasible to use retrospective (post bereavement) data collection methods in order to understand carer contribution during the terminal phase of cancer. Nearly 90% of carers were willing and able to provide detailed information on hours of care provided over a range of activities. Further, we show evidence of feasibility through the ability to produce a monetary valuation and through the face validity of the regression results. This is hugely important for estimating the value of caregivers' contribution to end-of-life care, as retrospective post bereavement data collection may often be the only feasible method, due to the difficulty of estimating patients' closeness to death and thus prospective identification of an end-of-life population. As end-of-life caregivers experience a distressing and intensive caregiving period, this adds additional challenges to prospective data collection.

Limitations

One limitation of our work, is that we do not use other monetary valuation methods such as the opportunity cost

approach (which considers the forgone time displaced for caregiving) or the wellbeing valuation method (which considers the wellbeing impacts of caregiving into a valuation of caregiving). Both methods require income, which is poorly completed in our data. The proxy good method we estimate is an approach that is used to assign monetary valuations to other non-market tasks such as housework or childcare by using a market equivalent wage.³⁴

Most of the carers in our survey completed the questionnaire 4 to 6 months post bereavement. Therefore, our test of recall bias is mainly applicable to this time window. However, it would be difficult to obtain detailed information from a carer earlier in bereavement for two reasons. First, the emotional state of respondents may be such that they would not wish to fill out a questionnaire or potentially mis-remember aspects of caregiving. Second, processing death data, identifying carers and sending questionnaires within a short time period may not be feasible. We show that over a 3-month period that there is no evidence of recall bias. In general, there is little evidence on the optimal recall period from which to collect of informal caregiving information.

Our large monetary values may be driven, in part, by extreme estimates of informal care provision, due to some carers reporting more than 168 h of provision. Although we

find that only 11.02% of our sample report hours over 168 h. The weekly monetary valuation using hours capped at 168 are £757.31 compared to £948.86 from our main results. Many studies have also capped hours to 112 h allowing for 8 h of sleep per night.¹⁵ We do not favour the capped hours approach as our time instrument collects most tasks considered caregiving and inclusion of 'other' tasks has no impact on our findings. Further, capping hours involves making extra assumptions about the data such as the amount of sleep, which carers may have little of, and the degree to which carers performed multiple tasks at the same time. It was unclear the degree to which carers conducted more than one task simultaneously (jointly produced) which could explain values over 168 h per week.

It was also unclear whether carers reported the additional hours that were due to the needs of the recipient in our setting, for example, the time spent cooking over and above the cooking they would do anyway pre-caregiving. This is a potential avenue for future research. Non-co-residing carers may be less likely to over-report caregiving hours as it may be easier for them to distinguish the time spent cooking or cleaning in their care recipient's home from their own. As we find no statistically significant difference between co and non-co-residing carers in the monetary valuation, this provides some evidence that over-reporting may not be common in our sample.

Conclusion

This study produces a monetary value for end-of-life cancer caregiving as well as subgroup differences for use in further research and in policy. Post-bereavement retrospective data collection, based on our evidence, is a feasible means to collect information. Through these aims, we hope to increase the visibility of this overlooked group of caregivers. Their contribution will be further called upon to a greater extent in light of global pandemics which place substantial pressure on health and social care systems worldwide, such as Covid-19.

Declaration of conflicting interests

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Supplemental material

Supplemental material for this article is available online.

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