

The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures

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Abstract

Background: Family members provide vital care at end of life, enabling patients to remain at home. Such informal care contributes significantly to the economy while supporting patients' preferences and government policy. However, the value of care-givers' contributions is often underestimated or overlooked in evaluations. Without information on the activities and expenditures involved in informal care-giving, it is impossible to provide an accurate assessment of carers' contribution to end-of-life care.

Aim: The aim of this study was to investigate the contributions and expenditure of informal, family care-giving in end-of-life cancer care.

Design: A national census survey of English cancer carers was conducted. Survey packs were mailed to 5271 people who registered the death of a relative to cancer during 1–16 May 2015. Data were collected on decedents' health and situation, care support given, financial expenditure resulting from care, carer well-being and general background information.

Results: In all, 1504 completed surveys were returned (28.5%). Over 90% of respondents reported spending time on care-giving in the last 3 months of the decedent's life, contributing a median 69 h 30 min of care-giving each week. Those who reported details of expenditure (72.5%) spent a median £370 in the last 3 months of the decedent's life.

Conclusion: Carers contribute a great deal of time and money for day-to-day support and care of patients. This study has yielded a unique, population-level data set of end-of-life care-giving and future analyses will provide estimates of the economic value of family care-givers' contributions.

Keywords

Informal care-giving, cancer, palliative care, care-givers, cost analysis

What is already known about the topic?

- Family carers make a substantial contribution to end-of-life care, but few studies have considered the hours of care-giving provided and carers' out-of-pocket expenditure.
- Estimates of end-of-life care-giving contributions and/or out-of-pocket expenditures are mainly derived from studies that are either small in size or lack detailed information on this issue.

What this paper adds?

- This study is the first to provide population-based information on the scale of cancer-related carer activity and out-of-pocket expenditures to enable the economic value of carers' contribution to end-of-life care to be calculated.

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- We have collected detailed data directly from carers using a bespoke census survey, overcoming many limitations of previous work.
- We find that carers' contribution to end-of-life care is substantial and could be much higher than some previous estimates suggest.

Implications for practice, theory or policy

- These data provide important information for policy makers and service planners who should take into account carers' contributions, both in terms of hours worked and out-of-pocket expenditure, and the value of these contributions to the economy.

Introduction

A majority of patients prefer to stay at home at the end of life¹ and government policy supports this choice.² For many people with cancer, the final period of illness is characterised by increasingly complex and intense care needs.³ Family members often take on prolonged caring roles and are pivotal to ensuring that patients' needs are met.⁴ Without family support, many people would be unable to remain at home in their final illness.^{5,6} Indeed, national-level data from countries worldwide indicate that married patients are able to die at home more frequently than those who are divorced, widowed or unmarried, indicating the importance of family carers.^{7,8}

The scale of family members' contribution and the financial burden on families are often overlooked in considerations of end-of-life caring although costs and consequences may be profound.^{9,10}

Support for carers was explicitly excluded from the NHS Palliative Care Tariff recommended by the Palliative Care Funding Review 4 (PCFR) for England, despite its emphasis on enabling patient death at home.² The National End of Life Care Programme (NEnd-of-lifeCP)¹¹ identified critical success factors that enable people to die in their preferred place of death, but omitted family carers from the list, despite empirical evidence that carers play a crucial role in this respect.⁵ NEnd-of-lifeCP¹² estimated end-of-life community care to be cheaper than acute hospital care, but this calculation only considered health and social care costs, not carers' contribution. Evidence syntheses suggest that palliative care is cheaper than standard care, but carers' time and out-of-pocket costs are consistently excluded from economic evaluations.^{13,14}

Within the current literature, important aspects relating to carer contributions (hours of care given, type of task and out-of-pocket expenditure) are routinely omitted from estimates, or where they are included, samples are small and unrepresentative. Specifically for UK cancer carers, much evidence has been from analysis of secondary data, which were not designed to consider these issues in detail, and has omitted both carer time and out-of-pocket expenditure.^{15–17} Round et al.¹⁸ estimated that informal care during the end-of-life period (defined as time since patient began using

strong opioids – 243 days) equates to £3265 GBP per patient (approximately \$4641USD). However, this relied on secondary data, where out-of-pocket or other expenses were not included. Some international studies have included carer time and out-of-pocket expenditure in their estimations of the value of carers' contributions. Van Houtven et al.¹⁹ estimated the value of 24.5 h of care per week at \$2164USD per month per patient (approximately £1774GBP/\$2877CAD). This estimate was calculated at 2005 prices and does not account for inflation. Based on more recent data, estimates have valued care hours at \$5077CAD²⁰ and \$11334CAD²¹ per patient per month (approximately £3148GBP/\$3808USD (2012 data);²⁰ £7027GBP/\$8501USD (2011 data)²¹ (number of care hours not defined)), while monthly out-of-pocket expenditure ranged from \$209USD¹⁹ to \$839CAD²⁰ (approximately £171GBP/\$278CAD–£520GBP/\$629USD). However, these studies were small scale ($n = 129$;²¹ $n = 138$;²⁰ $n = 144$)¹⁹ and not based on nationally representative data.

While the above studies provide much needed estimates, they all have limitations, and comprehensive figures for informal carer contributions and their associated economic value are still absent from the literature. This could lead to cost-shifting and overburdening of family and friends, ultimately compromising care quality.²² While broad population estimates of hours of care exist for carers in general,²³ the intensity of end-of-life care-giving demands specific consideration. As a first step to address the need for comprehensive information on family care contributions at end of life, and given the predominance of cancer within palliative care literature, we focus our research on cancer care.

In this article, we report data from a population-based study of cancer-related family care-giving activity at end of life in England. Working with the Office for National Statistics (ONS), we are uniquely able to report a comprehensive national overview of carers and their care-giving context, detailed information on the time spent on care tasks during patients' last 3 months of life and out-of-pocket expenditure. This extensive data set will form the basis for future, more in-depth analyses of the economic value of carers' contributions, impact of care-giving on carers' situation and well-being, and factors related to these.

Methods

Design

Post-bereavement, cross sectional and national postal survey.

Sample

The ONS drew a census sample of everyone (5271 people) who registered a cancer death in England over a 2-week period, that is, 1–16 May 2015. Unlike other causes of death, cancer does not display seasonal variation^{24,25} and ONS data show no variation in cancer deaths by day of week or time of month.²⁶ Dates were chosen to avoid other ONS post-bereavement surveys while allowing appropriate time post-bereavement for those contacted.

Inclusion criteria were as follows: death occurred during the designated period, in England, was caused by cancer (International Classification of Diseases, 10th revision (ICD)-10 codes C000-C979) and the decedent was aged over 18 years. Exclusion criteria were as follows: death occurred somewhere other than home, hospital, care home or hospice, was reported to the coroner, the person who registered the death was not a relative, the address of the person registering the death was missing, or sex or age of deceased was missing.

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

Procedure

The research team worked with the ONS team, carer groups and bereaved individuals to develop the survey content and ensure materials were sensitive, relevant and understandable. This included discussing content and formatting with a lay end-of-life research advisory group, carer cognitive-debriefing interviews ($n = 5$) and pilot surveys ($n = 19$).

ONS mailed surveys to the identified sample. No personal information was shared with the research team. People received (1) personalised covering letter (name, address, name of decedent), (2) information sheet emphasising the option to decline and avoid reminders, (3) decline slip, (4) survey and (5) reply-paid return envelope to the research team. Survey packs were sent to the person registering the death, who was invited to pass the survey to the person who provided most care, if appropriate.

Surveys were mailed to participants 4 months after registering a death (September 2016). Non-responders (no survey or decline slip returned) were sent a reminder letter 1 month later and another full survey the following month.

Participants could respond via online survey or telephone interview. Large print or non-English version of the survey was available on request.

Questionnaire

Questions were predominantly closed, single response from multiple choices. We report here the following items:

1. *General background.* Demographic information, work status, and relationship and proximity to the decedent.
2. *Decedent's health and situation.* Date and type of diagnosis.
3. *Carer contribution – care tasks.* Types of care tasks were presented under the headings: household tasks (six items), personal care (one item), health care and medicine (two items) and social and emotional care (one item). Participants estimated how much time (hours:minutes) they spent on each task in a typical week in the last 3 months of the decedent's life. The list was derived from survey development work and previous publications.^{27–29} Participants were instructed not to count any activity twice and to write '0' if they had not done a particular task.

We conceptualised care-giving as any task the participant undertook which provided care and/or assistance. While many respondents may have been the patient's spouse and may therefore have undertaken some tasks as part of this role, distinct from the impact of illness, we reasoned that had the spouse been unable to perform those tasks, then the state/another person would have to fulfil those duties. Given this logic, we incorporated all associated care-giving tasks within our estimates.

4. *Carer contribution – Out-of-pocket expenditure.* Participants were asked to estimate financial expenditure resulting from care provision for the decedent during the last 3 months of life. Items were presented under the headings: help from others, social activity and direct expenses. Details about any large, one-off expenses as a result of diagnosis (i.e. moving home) were also collected.

ONS provided anonymised data for the whole sampling frame linked by study identification (Study ID) number on the following variables: age and sex of deceased, date of death, date of death registration, final underlying cause of death by ICD-10 codes, place of death and index of multiple deprivation (IMD).³⁰

Analysis

Analyses were conducted using SPSS v22.³¹ Descriptive data are presented for respondent and decedent characteristics, types of care tasks and time taken, and care-related expenditure. Differences between decedent demographics,

as supplied by ONS, were explored by response type (survey, decline, no response) using chi-square for categorical variables and analysis of variance (ANOVA) for continuous data. Due to non-homogeneous variance (indicated by Levene's statistic), the Brown–Forsythe *F* statistic is reported for ANOVAs as it is robust to violations of this assumption. Post hoc comparisons of significant chi-square tests were made using *z*-tests to compare column proportions, with Bonferroni adjustment for multiple testing. The responder by cancer type chi-square had expected frequencies <5 in 12.8% of cells, which was acceptable given the large number of variables.³²

These data did show evidence of non-normality (skew and kurtosis) but as sample sizes were large and groups roughly equal data were not transformed to achieve normality.³² We did not make adjustments where data were missing, but have reported the number of missing values within the tables. We refer to median values throughout the results unless otherwise specified.

Results

Response rates

Surveys were completed by 28.5% ($n=1504$), 1851 (35.1%) declined to participate and $n=1915$ (36.3%) made no response.

Table 1 presents the differences in response rates and shows statistically significant differences in demographic characteristics of decedents between those who completed the survey (participants/responders), those who declined and those who made no response. Participants were significantly more likely to have registered the death of someone who died at home (35.9%; 29.6% non-responders, 28.1% decliners), who was older (76 years) than for non-responders (74 years) and younger than for decliners (78 years). Participants were also significantly more likely to be from less deprived areas (IMD 5: 24.6% participants, 19.9% decliners, 14.9% non-responders). There was no significant difference in the cancer site of decedent by responder group.

Participant characteristics

The majority of participants were female (64.2%), White (95.7%), with a median age of 60 years (mean: 60.4 (SD: 12.28)) and were qualified at school-leaver level (16 years) or higher (74.4%; Table 2).

Just under half of participants (44.5%) were the spouse/partner of the decedent and many had cared for their parent (43.2%). Half of decedents and respondents lived together (50.6%) and 33.7% lived within a 30-min journey of each other. A majority of participants (53.7%) were employed and 36.4% were retired when the decedent first became ill (Table 3).

In the last 3 months of life, three-quarters (75.3%) of decedents were 'usually resident' at home, 9.7% were

'usually resident' in hospital, 7.0% in care home, 2.3% in hospice (2.3%) and 2.8% in other locations (e.g. sheltered accommodation, someone else's home, palliative care unit; Table 3).

Contributions and costs of care-giving

During the last 3 months of life, 90.0% of participants reported spending time on care-giving which is 99.1% of those who responded to this question. These carers spent a median total of 69 h 30 min each in a typical week on care-giving – representing a mean of 9:56 h/day, every day of a typical week (Table 4).

The majority of participants (82.9%) reported providing social and emotional support, for a median of 20 h/week. This was followed by shopping (79.1%; 3 h), cleaning (72.7%; 7 h) and preparing food and drink (72.1%, 10 h). Fewest participants helped with maintenance and odd jobs (55.3%, 3 h).

In total, 76.1% of participants reported out-of-pocket expenditure which arose as a result of care-giving in the last 3 months of life (Table 5). Not everyone who reported a cost gave expenditure amount and as such data in Table 5 are calculated including only those who supplied figures (72.5%).

The most frequent expenditure was for travel expenses (47.9%) at a median cost of £100 per person over the last 3 months of life, followed by expenditure on meals and snacks while out with the patient (42.0%, £50), medical equipment and care supplies (25.1%, £100), and increased household bills (24.1%, £129). The biggest expenditure was nursing home/private care home (4.9%, £2000). Participants had a median total of £370 of out-of-pocket expenditure during the last 3 months of care-giving.

Additionally, 16.9% had 'one-off expenses' during their whole time care-giving. The median reported cost was £2000 and included payment for car, mobility equipment, furniture, house adaptations, cashing endowments/drawing on house capital, private medical care – including Swiss clinics/'Dignitas' and funeral costs.

Discussion

Our study provides national estimates of the contributions and out-of-pocket expenditure of family care-giving at end of life using a census survey completed by recently bereaved cancer carers.

Furthermore, our methods demonstrate that it is feasible to retrospectively collect very detailed data on carers' contributions and that carers find this acceptable. A substantial proportion of those we approached made some response to the survey invite (63.7%). Those who reported the death of a younger person and who were from more disadvantaged areas were less likely to respond, which is commensurate with survey response theory.³³

Table 1. Differences in decedent characteristics between responders, non-responders and decliners (N = 5270^a).

	Total sample	Non-responders	Responders	Decliners	Test (df)	p value
n	5271	1915	1504	1851		
Patient age (years) (SD)	74.41 (12.27)	72.56 (12.5) _A	74.36 (12.4) _B	76.35 (11.6) _C	F ^b (25,087) = 45.58	<0.001
Median (min–max) (SD)	76 (18–102)	74 (18–99)	76 (19–100)	78 (25–102)		
Patient gender					$\chi^2 = 5.254 (2)$	0.072
Males	2775 (52.6)	969 (50.6)	802 (53.3)	1003 (54.2)		
Place of death					$\chi^2 = 40.989 (6)$	<0.001
Hospital	1863 (35.3)	715 (37.3) _A	448 (29.8) _B	699 (37.8) _A		
Care home	766 (14.5)	256 (13.4) _A	219 (14.6) _A	291 (15.7) _A		
Home	1627 (30.9)	566 (29.6) _A	540 (35.9) _B	521 (28.1) _A		
Hospice	1015 (19.3)	378 (19.7) _A	297 (19.7) _A	340 (18.4) _A		
Multiple indices of deprivation (decedent)					$\chi^2 = 126.384 (8)$	<0.001
1 (most deprived)	1059 (20.1)	491 (25.6) _A	204 (13.6) _B	363 (19.6) _C		
2	981 (18.6)	407 (21.3) _A	255 (17.0) _B	319 (17.2) _B		
3	1146 (21.7)	388 (20.3) _A	335 (22.3) _A	423 (22.9) _A		
4	1062 (20.1)	344 (18.0) _A	340 (22.6) _B	378 (20.4) _{A,B}		
5 (least deprived)	1023 (19.4)	285 (14.9) _A	370 (24.6) _B	368 (19.9) _C		
Primary cause of death: cancer site (ICD-10 classification)					$\chi^2 = 60.004 (50)$	0.157
Lung (C33–34)	1139 (21.6)	444 (23.2)	302 (20.1)	393 (21.2)		
Colorectal (C18–20)	499 (9.5)	161 (8.4)	152 (10.1)	186 (10.0)		
Prostate (C61)	401 (7.6)	134 (7.0)	119 (7.9)	147 (7.9)		
Breast (C50)	375 (7.1)	143 (7.5)	110 (7.3)	122 (6.6)		
Pancreas (C25)	284 (5.4)	110 (5.7)	82 (5.5)	92 (5.0)		
Oesophagus (C15)	265 (5.0)	76 (4.0)	93 (6.2)	96 (5.2)		
All other malignant cancers (excl. C44) ^c	2308 (43.8)	847 (44.2)	646 (42.9)	815 (44.0)		

NB: un-matching subscripts (along the row) (e.g. A, B) denote statistically significant difference, whereas matching subscripts denote no significant difference (e.g. A, A).

Values are represented in frequencies (%) or means and standard deviations.

^aDue to researcher error, one participant's response status could not be determined (non-response or decline). Therefore, their ONS-linked data were excluded from analyses by response type as it could not be attributed to a response category. However, their data are included in descriptives of the sample overall.

^bMean (SD). Browne–Forsythe statistic reported due to non-homogeneity of variance.

^cAnalysis was conducted by individual cancer category. The largest groups are detailed and other cancer types are presented as a summary category 'All other ...' for conciseness. Includes other cancer categories – lip oral and pharynx, C00–14; stomach, C16; liver, C22 and C25; larynx, C32; melanoma of skin, C43; skin (other malignant neoplasm), C44; mesothelioma, C45; cervix, C53; uterus, C54–55; ovary, C56–57.4; testis, C62; kidney, C64–66 and 68; bladder, C67; brain, including other central nervous system (CNS) and intracranial tumours, C70–72, C75.1–C75.3, D32–D33, D35.2–D35.4, D42–D43, D44.3–D44.5; thyroid, C73; Hodgkin's disease, C81; non-Hodgkin's lymphoma, C82–85; multiple myeloma, C90; leukaemia, C91–95; and all other malignant cancers.

Non-surprisingly, almost all participants provided informal care in a typical week in the last 3 months of life. The median hours of care provided by each individual totalled 69:30 h (almost 10 h/day) and 25% of participants provided 115:15 h of care, or more, per week; over 16 h/day.

The main type of care provided was social/emotional support. The majority reported contributing to the very practical tasks of everyday living and to the medical care of the patient. Those who helped with personal care spent a high number of hours doing so. These data were supplied as a 'typical' week; a greater volume and intensity of care may occur in the final weeks or days before death.

We also hypothesise that intensity of care-giving would vary by care-giver context and we plan to explore this in future analyses. Round et al.¹⁸ estimate informal care provision of 15 h/week and Van Houtven et al.¹⁹ estimate 24.5 h. Given the number of hours of care identified in our study, the financial value of care-giving is likely to be greater than these estimates, even without out-of-pocket expenditure.

Fewer people reported out-of-pocket expenditure than care tasks, but the expenditure reported facilitated vital care for patients. For example, to provide care 50.6% incurred costs travelling, 44.6% spent money on sustenance while they were doing this and 25.1% spent money

Table 2. Participant characteristics ($N = 1504$).

	Frequency (%)
Age (years) (missing $n = 24$ (1.6%))	
Mean (SD)	60.4 (12.28)
Median (min-max)	60 (21–94)
Gender	
Male	517 (34.4)
Female	966 (64.2)
Missing	21 (1.4)
Ethnicity	
White	1439 (95.7)
Mixed/multiple ethnic group	7 (0.5)
Asian/British Asian	16 (1.1)
Black/African-Caribbean/Black British	7 (0.5)
Other ethnic group	6 (0.4)
Missing	29 (1.9)
Educational level	
None	226 (15.0)
Exams at 16 years/equivalent	405 (26.9)
'A'/'AS' Levels/college/equivalent	334 (22.2)
University degree	381 (25.3)
Other	51 (3.4)
Missing	107 (7.1)
Mode of response	
Paper	1395 (92.8)
Online	88 (5.9)
Telephone	21 (1.4)

Frequencies (%) unless otherwise stated.

on medical equipment and care supplies in addition to those supplied by the National Health Service. Participants also reported spending money on one-off costs which may have included care home expenses, house moves or funerals. In adopting a wide definition of care-related costs, such as these, a comprehensive picture of the types of financial expenditure that families are exposed to emerges. Although some of these costs may be seen as outside the remit of care-giving (e.g. funeral expenses), ultimately, these costs are often borne by the family of the dying person and may form part of the contribution a carer makes to support a dying person.

It has been estimated that out-of-pocket expenditure in the last month of life could total \$379CAD (approximately £235GBP/\$284USD)²¹ or \$839CAD (approximately £520GBP/\$629USD).²⁰ Converted to a 3-month estimate of £705, or £1561, these figures are much higher than the £370 we report over 3 months. Differences between the Canadian and UK health systems are likely to lead to different resource needs for carers which may explain some variation in out-of-pocket expenditure reported (e.g. insurance payments). This expenditure represents a sizable contribution to the care-giving process and may have a considerable negative impact for those who incur these costs.

Table 3. Care-giving context ($n = 1504$).

	Frequency (%)
Decedent's relationship to respondent	
Spouse/partner	669 (44.5)
Parent	650 (43.2)
Someone else	157 (10.4)
Missing	28 (1.9)
Proximity to decedent	
In the same house	761 (50.6)
Within walking distance	145 (9.6)
Within 10-min drive/bus or train journey	177 (11.8)
Within 30-min drive/bus or train journey	185 (12.3)
Within 1-h drive/bus or train journey	77 (5.1)
Over 1-h drive/bus or train journey	142 (9.4)
Missing	17 (1.1)
Decedent's primary location in last 3 months of life	
Home	1133 (75.3)
Hospice	34 (2.3)
Hospital	146 (9.7)
Care home	105 (7.0)
Other (including combinations of above categories)	42 (2.8)
Missing	44 (2.9)
Employment status when decedent became ill	
Employed full time	488 (32.4)
Employed part time	202 (13.4)
Self-employed	118 (7.8)
Homemaker	45 (3.0)
Unemployed	25 (1.7)
Retired	548 (36.4)
Other	59 (3.9)
Missing	19 (1.3)

Frequencies (%) unless otherwise stated.

Implications and recommendations

Informal care-giving represents a substantial contribution to society and is vital to the provision of end-of-life care. However, many informal care-givers would be unwilling to provide care again.³⁴ It is therefore essential that appropriate support, particularly palliative support, is available for family members to ensure the continued provision of care.³⁵ Our data indicate that carers provide care beyond the safe working hours recommended to preserve health and well-being.³⁶ It behoves us as a society to support informal care-givers, provide respite when needed and otherwise ensure that hours of care-giving entail the minimum distress and strain. Given the hours that informal care-givers invest in care, and subsequent savings to society, society should invest in them.

Our work suggests that economic analyses of interventions and location of care should, as a matter of course, include contributions given by care-givers in terms of time

Table 4. Time spent on care-giving tasks in a typical week in last 3 months of life ($n = 1504$) (hours:minutes – calculations based on 'n responded > 0').

	<i>n</i> responded '0 h' (%)	<i>n</i> responded > '0 h' (%)	Mean (SD)	Median	Inter-quartile range (25–75)	Missing <i>n</i> (%)
Household tasks						
Preparing food and drink	163 (10.8)	1084 (72.1)	13:30 (27:47)	10:00	04:45–14:30	257 (17.1)
Cleaning	159 (10.6)	1093 (72.7)	10:51 (24:09)	07:00	03:00–14:00	252 (16.8)
Maintenance/odd jobs	307 (20.4)	831 (55.3)	04:55 (08:29)	03:00	01:30–06:00	366 (24.3)
Shopping	84 (5.6)	1190 (79.1)	05:23 (21:38)	03:00	02:00–06:00	230 (15.3)
General administration	159 (10.6)	1084 (72.1)	04:02 (09:52)	02:00	01:00–04:00	261 (17.4)
Travelling with patient	286 (19.0)	876 (58.2)	07:09 (18:56)	04:00	02:00–08:00	342 (22.7)
Personal care	231 (15.4)	956 (63.6)	14:07 (22:47)	07:00	03:00–14:00	317 (21.1)
Organising/attending appointments	148 (9.8)	1069 (71.1)	06:14 (12:37)	03:00	02:00–07:00	287 (19.1)
Helping with symptoms	169 (11.2)	1047 (69.6)	11:52 (30:01)	05:00	02:00–10:00	288 (19.1)
Social and emotional support	26 (1.7)	1247 (82.9)	36.03 (54:25)	20:00	08:00–40:00	231 (15.4)
Other	177 (11.8)	153 (10.20)	21:23 (42:20)	06:00	02:30–14:00	1174 (78.1)
Total time spent on care-giving	12 (0.8)	1353 (90.0)	94:59 (123:15)	69:30	28:37–115.15	139 (9.2)

Table 5. Money spent as a result of care-giving ($n = 1504$) (£GBP – calculations based on 'n responded > 0').

	Indicated <i>n</i> [^] (%)	Reported <i>n</i> ⁺ (%)	Mean (SD)	Median	Inter-quartile range (25–75)	Missing <i>n</i> (%)
In last 3 months of life						
Help from others						
Nursing home/private care home	82 (5.5)	74 (4.9)	3138.58 (3384.28)	2000.00	487.50–5000	1422 (94.5)
Privately employing nurse/carer	67 (4.5)	63 (4.2)	1785.90 (2979.05)	500.00	160–1500	1437 (95.5)
Child care	22 (1.5)	21 (1.4)	545.90 (566.73)	400.00	100–852	1482 (98.5)
Odd jobs not normally paid for	250 (16.6)	244 (16.2)	371.74 (901.14)	150.00	60–337.5	1254 (83.4%)
Respite/holidays/day trips	129 (8.6)	125 (8.3)	780.08 (1085.06)	350.00	150–1000	1375 (91.4)
Direct expenses						
Medical equipment/care supplies	390 (25.9)	377 (25.1)	289.10 (907.79)	100.00	50–200	1114 (74.1)
Prescription/non-prescription drugs	128 (8.5)	119 (7.9)	107.47 (279.26)	30.00	20–80	1376 (91.5)
Household bills	410 (27.3)	363 (24.1)	235.62 (395.03)	129.00	80–300	1094 (72.7)
Travel expenses	760 (50.6)	720 (47.9)	208.20 (424.17)	100.00	48.5–207.5	744 (49.5)
Meals/snacks while out	670 (44.6)	631 (42.0)	113.10 (213.40)	50.00	30–100	834 (55.5)
Extra food/supplements/vitamins	323 (21.5)	296 (19.7)	123.03 (313.98)	55.00	30–120	1181 (78.5)
Other	194 (12.8)	179 (11.9)	602.27 (1481.12)	150.00	60–400	1310 (87.1)
Total spend (sum) ^a	–	1090 (72.5)	1025.00 (2024.75)	370.00	150–919	414 (27.5)
Any time since diagnosis						
One-off expense	254 (16.9)	240 (16.0)	8759.84 (44902.50)	2000	756.25–5875	1250 (83.1)

[^]NB: Indicated *n* – participants who indicated they *did* spend money on that item. Total who indicated spending money in last 3 months of life is $n = 1145$ (76.1%); total missing data $n = 359$ (23.9%).

⁺Reported *n* – participants who reported the amount they spent on that item – for 'one-off expenses' respondents reported up to three expenses, which were totalled.

A large proportion of missing data is likely to be systematic, rather than missing due to incomplete reporting, as participants were not asked to indicate if they had *not* spent money.

^aOnly those who reported spending money were included.

and expenditure and our data provide a basis for economic estimates of carer contributions. We adopted, and would recommend, a strong programme of participant engagement in the development of further economic evaluation work in order to maximise response rates among this vulnerable group.

Strengths and limitations

To our knowledge, this study is the first to provide detailed population-based information on the scale of cancer-related care activity and its contribution to end-of-life care. We collected data directly from respondents, using a

bespoke survey with a census sample, thereby overcoming limitations of other estimates of carer contributions, and consequently the economic value of informal care, within the UK which have utilised secondary data.

Some post-bereavement surveys of quality of care have achieved response rates of 39%–46%.^{37,38} Our survey, which was arguably more cognitively demanding and of a potentially more sensitive nature due to the level of care-giving detail required, reached 28.5% participation. Furthermore, comparisons between participants, decliners and non-responders indicate that our sample was representative of the general population, with only minor differences, which may be partially accounted for by the self-selecting nature of self-report surveys. However, there may be potential bias in reported care-giving by targeting only relatives who reported a death, as they may have provided different support compared to non-relatives.

A lot of palliative care research and economic evaluations rely on retrospective recall and this is also a limitation of this study. Retrospective recall can introduce bias due to inaccuracy in reporting past events, selective memory of the events and double counting or joint production of tasks – where tasks completed simultaneously are reported several times under multiple headings.³⁹ While it is in principle possible to control for joint production to a certain extent during analyses,^{27,40} we added to the survey the instruction to participants not to count any task twice in order to minimise this type of bias at source. Due to these effects, the data we report on hours of care may be inflated, but to not include certain aspects of care at all to minimise the risk of joint production would involve underestimation.⁴⁰ We also tried to overcome bias by being specific about the time frame that tasks were completed, referring to a typical week during the last 3 months of life. However, at end of life few weeks are ‘typical’ and as such challenging for some participants to conceptualise and report. Retrospective data collection does have disadvantages, but it does elicit more complete data compared with other methods such as diaries.³⁹ Furthermore, these limitations should be weighed against the advantage of obtaining population-level data for an ‘anchored’ time period, rather than alternative methods which may have involved a much smaller, resource intensive, less representative sample which would probably include data that vary in time relative to death.

Future research

This article provides a national census overview of cancer care-giving. Further analyses will consider the socio-demographic patterns of care-giving, the impact of care on carers’ well-being and estimate the full economic value of end-of-life care provided by family carers of people with cancer comparing different methods for estimation.

We hope that the results of this study will form the basis for further national and international research comparing contribution and costs at end of life for other disease groups and other countries.

Conclusion

The contributions by informal care-givers of cancer patients within the UK may be higher than estimates previously indicated given that we report 69:30 median hours of care compared to previous research based on 15–24.5 h. This study has yielded a unique data set which will allow, for the first time, estimates of the full economic value of family care-giving for cancer patients at end of life based on population-level data within the UK.

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