

Valuing friends' and family support for end of life cancer care: A national study of the economic costs of informal care-giving

Christine Rowland,
Barbara Hanratty, Bernard van den Berg,
Mark Pilling, Gunn Grande

Dimbleby Cancer Care funded project.

End of Life Programme: Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester

Background

- Patients prefer to stay at home at the end of life¹ and government policy supports this choice.²
- Family = prolonged caring roles, and are pivotal to ensuring that patients' needs are met⁴ including being able remain at home in their final illness.^{3,4}
- **BUT** the costs and consequences may be profound.^{5,6}



Background

The scale of family members' contributions are often overlooked in discussions of end of life caring.

Carers' time and out-of-pocket costs are consistently excluded from calculations.^{7,8}



Or, where cost is estimated:
It's based on secondary data & limited by level of detail
and/or small, unrepresentative samples.^{5, 9, 10}

Background

BUT, this type of information is used to canvas support for carers.
and is therefore vital as delivery of EoL service continues to move into the community.

This study aimed to provide **population-level** information on the **scale of cancer related caregiving** and its **economic contribution** to EoL care.



Post-bereavement, national survey

Survey developed in consultation with:

- Carer groups and bereaved individuals,
- ONS team.



Office for
National Statistics

This included:

- Discussing content and formatting with a lay research advisory group,
- Cognitive-debriefing interviews (n=5), and
- Pilot surveys (n=19).



Methods

Census sample:

N=5,271



Office for
National Statistics

relatives who registered a cancer death between 1st-16th May 2015.

Inclusion criteria:

- ✓ Decedent over 18 years old,
- ✓ Died of cancer,
- ✓ Death occurred in hospice, hospital, care home, or at home.

Exclusion criteria:

- ✗ Death reported to coroner,
- ✗ Age/sex of deceased not available,
- ✗ Person registering death not a relative.

Procedure

Survey packs:

- i) personalised covering letter (name, address, name of decedent),
- ii) information sheet emphasising the option to decline and avoid reminders,
- iii) decline slip;
- iv) survey, and
- v) reply-paid return envelope to the research team.

Reminders at one and two months later

- potentially, up to 8 months bereaved.

MANCHESTER
1824
The University of Manchester

Please remove this page before replying to us

If you would like to receive this information in large print, or if English is not your first language and you would like interpreter services, please call 0161 206 7831

FNAME SNAME
ADDRESS1
ADDRESS2
ADDRESS3
ADDRESS4
ADDRESS5
ADDRESS6
ADDRESS7

Dear FNAME SNAME
Val

We are writing to you because we understand that you would like to take part in our research. We know that you would like to be available for us to contact you if you wish. We will not share your information with anyone else.

We are writing to you because we understand that you would like to take part in our research. We know that you would like to be available for us to contact you if you wish. We will not share your information with anyone else.

195

4 How much time did you spend...?		How much time did this take in a typical week?	
Please do not count any activity twice		(please write in - your best guess is fine) Write 'Y' if you did not do this task	
HOUSEHOLD TASKS	HOURS	MINUTES	
a Preparing food and drink? (includes special diets, cooking)	<input type="text"/>	<input type="text"/>	<input type="text"/>
b Doing any cleaning? (includes emptying bins, washing-up, washing and ironing clothes, sewing)	<input type="text"/>	<input type="text"/>	<input type="text"/>
c Doing maintenance or 'odd jobs'? (e.g. gardening, hanging a picture)	<input type="text"/>	<input type="text"/>	<input type="text"/>
d Shopping for groceries or your relative's personal items?	<input type="text"/>	<input type="text"/>	<input type="text"/>
e Doing general administration for them? (e.g. paying bills, making phone calls, writing letters (do not include hospital appointments here))	<input type="text"/>	<input type="text"/>	<input type="text"/>
f Travelling outside the house with them? (e.g. walking, car, public transport, helping with wheelchair)	<input type="text"/>	<input type="text"/>	<input type="text"/>
PERSONAL CARE	HOURS	MINUTES	
g Helping your relative look after themselves? (e.g. eating and drinking, dressing, washing, using the toilet, etc.)	<input type="text"/>	<input type="text"/>	<input type="text"/>
HEALTH CARE AND MEDICINE	HOURS	MINUTES	
h Organising / attending health care appointments? (e.g. arranging appointments, working with care teams, organising help, etc.)	<input type="text"/>	<input type="text"/>	<input type="text"/>
i Helping with symptoms? (e.g. help with taking medicines, monitoring symptoms, making them comfortable, etc.)	<input type="text"/>	<input type="text"/>	<input type="text"/>
SOCIAL & EMOTIONAL CARE	HOURS	MINUTES	
j Providing social and emotional support? (e.g. providing companionship or reassurance/ support, 'see how they are doing', sitting with them, trips to see family or friends with them, etc.)	<input type="text"/>	<input type="text"/>	<input type="text"/>
OTHER	HOURS	MINUTES	
k Was there anything else that you did for them? (Please write in)	<input type="text"/>	<input type="text"/>	<input type="text"/>

Methods

Please remove this page before replying to us

MANCHESTER 1824
The University of Manchester
If you would like to receive this information in large print, or if English is not your first language and you would like interpreter services, please call 0161 206 7831

FNAME SNAME
ADDRESS1
ADDRESS2
ADDRESS3
ADDRESS4
ADDRESS5
ADDRESS6
ADDRESS7

Dear FNAME SNAME
Val

We are writing to you because we understand that you would like to be available for us to take part in our research. We would like to know how you feel about taking part in our research. If you feel that you would like to take part, please return this form to us.

How much time did you spend...? (Please do not count any activity twice)

How much time did this take in a typical week? (please write in - your best guess is fine) Write 'N' if you did not do this task

	HOURS	MINUTES
HOUSEHOLD TASKS		
a Preparing food and drink? (includes special diets, cooking)	<input type="text"/>	<input type="text"/>
b Doing any cleaning? (includes emptying bins, washing-up, washing and ironing clothes, sewing)	<input type="text"/>	<input type="text"/>
c Doing maintenance or 'odd jobs'? (e.g. gardening, hanging a picture)	<input type="text"/>	<input type="text"/>
d Shopping for groceries or your relative's personal items?	<input type="text"/>	<input type="text"/>
e Doing general administration for them? (e.g. paying bills, making phone calls, writing letters (do not include hospital appointments here))	<input type="text"/>	<input type="text"/>
f Travelling outside the house with them? (e.g. walking, car, public transport, helping with wheelchair)	<input type="text"/>	<input type="text"/>
PERSONAL CARE		
g Helping your relative look after themselves? (e.g. eating and drinking, dressing, washing, using the toilet, etc.)	<input type="text"/>	<input type="text"/>
HEALTH CARE AND MEDICINE		
h Organising / attending health care appointments? (e.g. arranging appointments, working with care teams, organising help, etc.)	<input type="text"/>	<input type="text"/>
i Helping with symptoms? (e.g. help with taking medicines, monitoring symptoms, making them comfortable, etc.)	<input type="text"/>	<input type="text"/>
SOCIAL & EMOTIONAL CARE		
j Providing social and emotional support? (e.g. providing companionship or reassurance/ support, 'see how they are doing', sitting with them, trips to see family or friends with them, etc.)	<input type="text"/>	<input type="text"/>
OTHER		
k Was there anything else that you did for them? (Please write in)	<input type="text"/>	<input type="text"/>

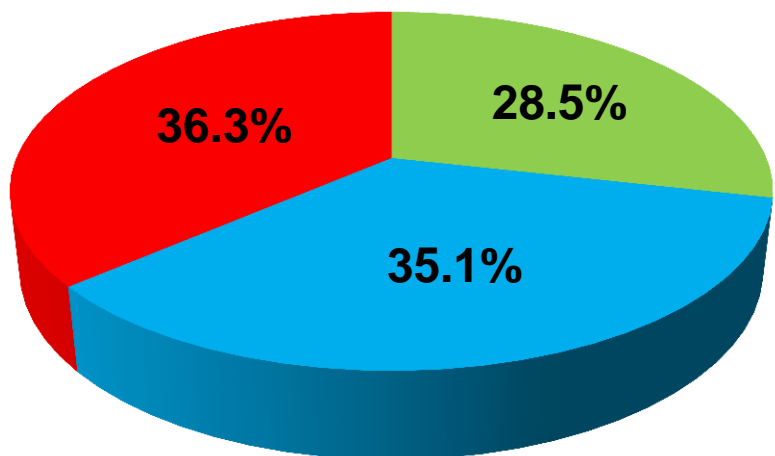
Asked about:

- Background generally – where lived in proximity to patient, employment and any changes, benefits received
- About the patient – symptoms, illness, where usually resident, where died - last three months of life
- Time on tasks – last three months of life
- Expenses – last three months, and large items over course of illness
- About caregiver – EQ-5D-5L / Vas and GHQ12 (retrospective and current)

Results

Carer population

Response (n=5270)



■ Participated N=1504
 ■ Declined N=1851
 ■ No response N=1915

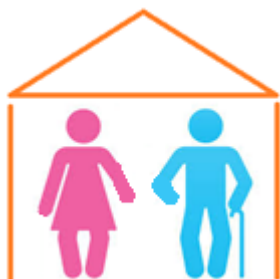
	Frequency (%)
Age (years) (Missing n= 24(1.6%))	
Mean (SD),	60.4 (12.28)
Median (min-max)	60 (21-94)
Gender	
Male	517 (34.4)
Female	966 (64.2)
Missing	21 (1.4)
Ethnicity	
White	1439 (95.7)
Mixed/ Multiple ethnic group	7 (0.5)
Asian/ British Asian	16 (1.1)
Black / African-Caribbean/ Black	7 (0.5)
British	
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)

Results

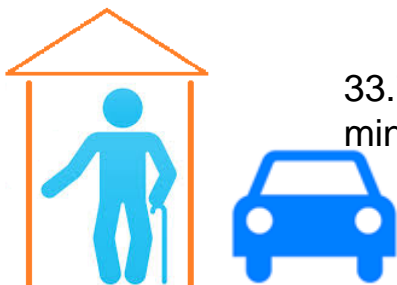
Carer population



44.5% (n=669) were the spouse/partner



50.6% (n=761) lived together



33.7% (n=507) within 30 mins



53.7% (n=808) were employed
36.4% were retired

2014/2015



September	October	November	December
Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
January	February	March	April
Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
May	June	July	August
Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	Sun Mon Tue Wed Thu Fri Sat 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

Contributions to care

90.0% (n=1,353) provided care during last three months of life.
Which is, 99.1% of those who answered the question.

They reported spending 'some' time providing care...

69 hours 30 mins* per week

OR

Almost 10 hours* per day.

Interquartile range (25-75) 28:37 - 115.15

*median figures

Mean(standard deviation): 94:59 (123:15)

Results

Contributions to care

Task	% participants(n)	Median time taken /week (Inter Quartile Range, 25-75)
Social /emotional support	82.9 (1247)	20 hours (8-40)
Shopping	79.1 (1190)	3 hours (2-6)
Cleaning	72.7 (1093)	7 hours (3-14)
Preparing food and drink	72.1 (1084)	10 hours (4.45-14.30)
General admin	72.1 (1084)	2 hours (1-4)
Organising /attending appointments	71.1 (1069)	3 hours (2-7)
Helping with symptoms	69.6 (1047)	5 hours (2-10)
Personal care	63.6 (956)	7 hours (3-14)
Travelling with patient	58.2 (876)	4 hours (2-8)
Maintenance /odd jobs	55.3 (831)	3 hours (1.30-6)

Results

Costs of care

76.1% (n=1,090) spent money as a result of providing care during last three months of life...

Results



National Institute for
Health Research

Task	% participants(n)	Median cost £GBP (Inter Quartile Range, 25-75)
Travel expenses	47.9 (720)	£100 (48.5-207.5)
Meals and snacks out	42.0 (631)	£50 (30-100)
Medical equip / care supplies	25.1 (377)	£100 (50-200)
Household bills (increase)	24.1 (363)	£129 (80-300)
Extra food / supplements / vitamins	19.7 (296)	£55 (30-120)
Odd jobs	16.2 (244)	£150 (60-337.50)
Other expenses	11.9 (179)	£150 (60-400)
Respite	8.3 (125)	£350 (150-1000)
Prescription / non-prescription drugs	7.9 (119)	£30 (20-80)
Nursing home / private care	4.9 (74)	£200 (487.50-5000)
Additional child care costs	1.4 (21)	£400 (100-852)

Conclusions

- Economic cost of informal care previously estimated at £3,265⁹, (based on 6-12 months before death).
- **But**, our data, from the last three months of life only, indicate that a financial value substantially larger than this estimate.
- Where expenses were reported this **facilitated vital care**
- This may represent an additional, sizable contribution to the caregiving process,
with **negative impact** for those who incur these costs?

This has important implications for the health and wellbeing of carers, and resource distribution

Conclusions

Informal caregiving represents a high value to society and is vital to the provision of end-of-life care.

These data indicate that the costs of replacing their contribution would be substantial **AND** considerably larger than previously estimated.

Therefore, we must ensure carers don't become invisible to policy makers & suitable care provision is made for them.

This study has yielded a unique data set –

Further analyses of these data are planned which, for the first time, will provide estimates of the full economic value of family care-giving based on population level data.

Thank you to:

- those who helped develop the survey
- relatives who responded to the survey
- the funders, Dimbleby Cancer Care and
CLAHRC GM

References

1. Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000; 3: 287–300.
2. Department of Health (2011). Palliative Care Funding Review: funding the right care and support for everyone. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf
3. Gomes B and Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: a systematic review. *BMJ* 2006;3332(7540): 515-521
4. Grande GE, Ewing G (2008). Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med*; 22: 971-972
5. Dumont S, Jacobs P, Turcotte, V, Anderson D, Harel F. The trajectory of palliative care costs over the last 5 months of life: a Canadian longitudinal study. *Palliat Med* 2010: 24(6) 630-640
6. Hanratty B, Holland P, Jacoby A, Whitehead M. Financial stress and strain associated with terminal cancer--a review of the evidence *Palliat Med.* 2007;21(7):595-607.
7. Smith S, Brick A, O'Hara S, Normand C (2013). Evidence on the cost and cost- effectiveness of palliative care: a literature review. *Palliative Medicine*; 28(2): 130-150
8. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews* 2013, Issue 6, Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2.
9. Round J, Jones L, Morris S. Estimating the cost of caring for people with cancer at the end of life: A modelling study. *Palliat Med* 2015; 29(10): 899-907
10. Hollander MJ, Liu G, Chappell NL. Who Cares and How Much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthc Q* 2009; 12(2):42-49