

Supporting the supporters: a national study of family carers' contributions to end-of-life cancer care.

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SUPPORTING PATIENT CHOICE

Patients
want to die
at home¹.

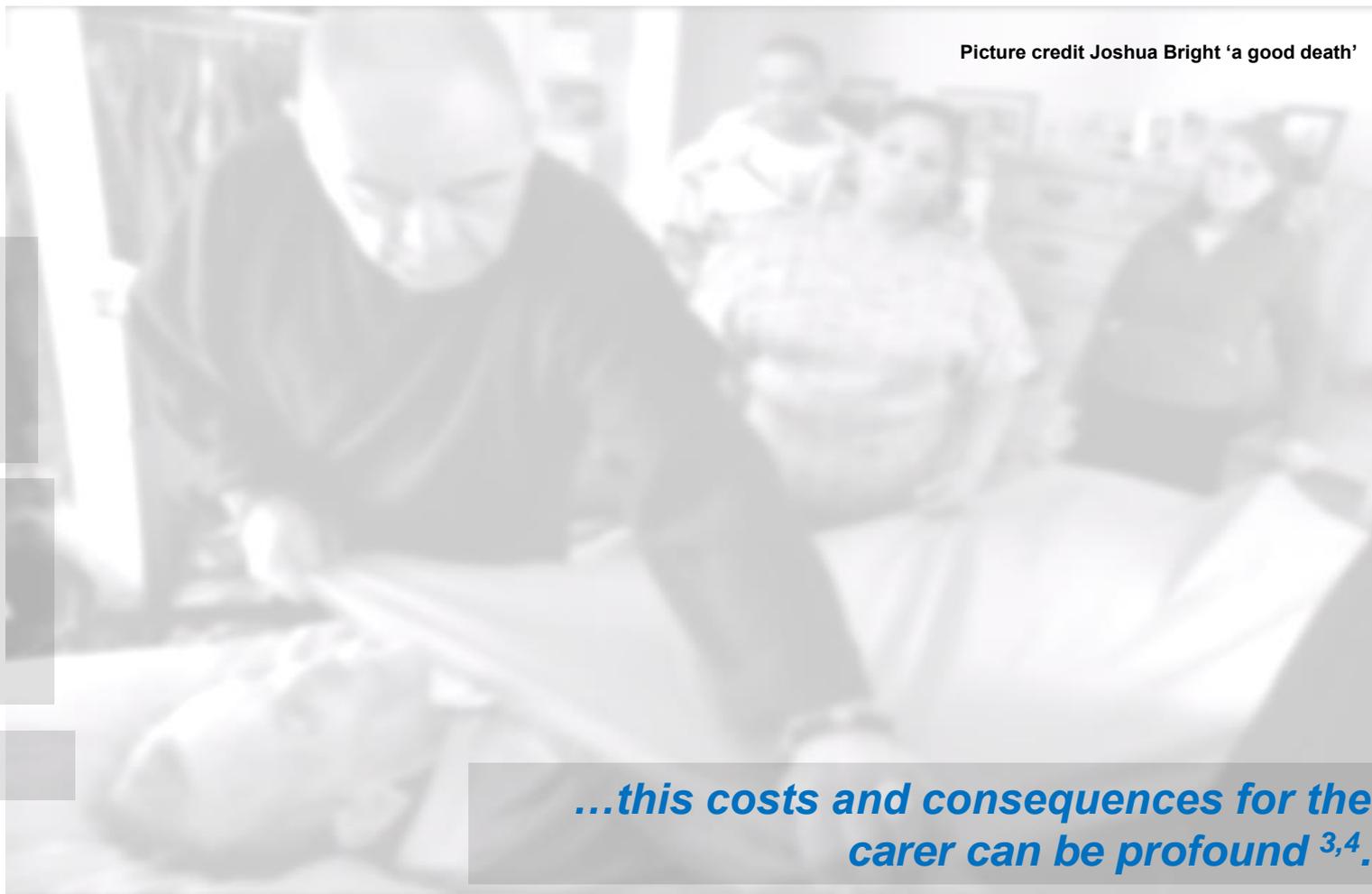
The
Government
wants this
too².

Family are
essential in
helping this
to happen...

... but ...

*...this costs and consequences for the
carer can be profound^{3,4}.*

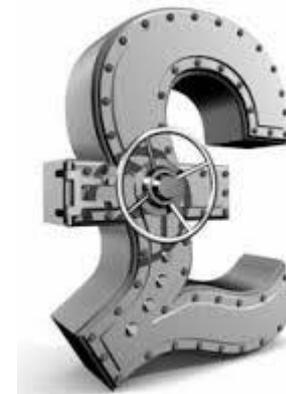
Picture credit Joshua Bright 'a good death'



Background

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

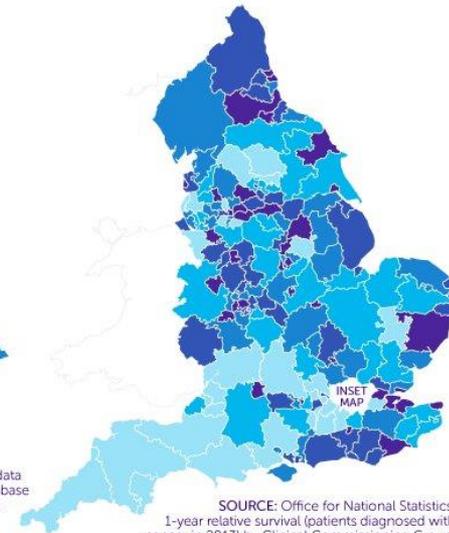
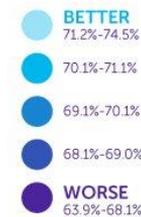
Carers' time and out-of-pocket costs are consistently excluded from calculations^{5,6}.



Or, where cost is estimated:
It's based on secondary data, limited by level of detail, and/or small, unrepresentative samples⁷⁻⁹.



LOCAL VARIATION IN 1-YEAR CANCER SURVIVAL IN ENGLAND



Contains National Statistics data
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SOURCE: Office for National Statistics
1-year relative survival (patients diagnosed with
cancer in 2013) by Clinical Commissioning Group.

LET'S BEAT CANCER SOONER
cruk.org/localstats



To provide **POPULATION LEVEL** information on
the **EXTENT OF** cancer related **CARING** and
its **ECONOMIC** contribution to end of life care.

Methods

Post-bereavement, national survey

This included:

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



@visualminutes

METHODS



National Institute for Health Research

Office for National Statistics

Please remove this page before replying to us

MANCHESTER 1824
The University of Manchester

If you would like to receive this information you would like interpret

FNAME SNAME
ADDRESS1
ADDRESS2
ADDRESS3
ADDRESS4
ADDRESS5
ADDRESS6
ADDRESS7

Dear FNAME SNAME

Valuing family and friends

We are writing to you as you recently replied to our survey. We understand that this might be a difficult time for you.

We know that families and friends are important to you. We would like to know more about how you spend your time with families of caring for people with cancer. UK to take part in a survey.

We realise that it may be difficult to take part. Before you decide to take part, please take time to think about how you would like to take part. If you do not think you would be best able to take part, please do not take part.

If you would like to help us, please complete the enclosed survey.

- Complete the enclosed survey
- Complete the survey online
- Complete the survey over the phone

If you decide that you would like to take part, please return the enclosed survey to the address below (no stamp needed).

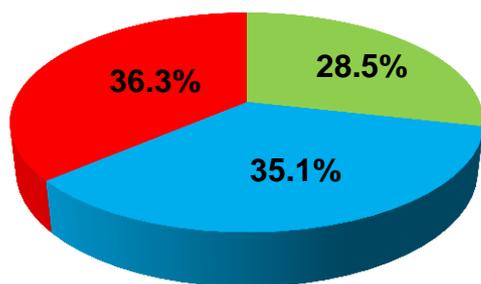
4 How much time did you spend...? <i>Please do not count any activity twice</i>		How much time did this take in a typical week? <i>(please write in - your best guess is fine) Write '0' if you did not do this task</i>			
HOUSEHOLD TASKS		HOURS		MINUTES	
a	Preparing food and drink? <i>(includes special diets, cooking)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
b	Doing any cleaning? <i>(includes emptying bins, washing-up, washing and ironing clothes, sewing)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
c	Doing maintenance or 'odd' jobs? <i>(e.g. gardening, hanging a picture)</i>	<input type="text"/>	<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"/>	<input type="text"/>
e	Doing general administration for them? <i>(e.g. paying bills, making phone calls, writing letters (do not include hospital appointments here))</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
f	Travelling outside the house with them? <i>(e.g. walking, car, public transport, helping with wheelchair)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
PERSONAL CARE		HOURS		MINUTES	
g	Helping your relative look after themselves? <i>(e.g. eating and drinking, dressing, washing, using the toilet, etc.)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
HEALTH CARE AND MEDICINE		HOURS		MINUTES	
h	Organising / attending health care appointments? <i>(e.g. arranging appointments, working with care teams, organising help, etc.)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
i	Helping with symptoms? <i>(e.g. help with taking medicines, monitoring symptoms, making them comfortable, etc.)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
SOCIAL & EMOTIONAL CARE		HOURS		MINUTES	
j	Providing social and emotional support? <i>(e.g. providing companionship or reassurance/support, 'see how they are doing', sitting with them, trips to see family or friends with them, etc.)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
OTHER		HOURS		MINUTES	
k	Was there anything else that you did for them? <i>(Please write in)</i>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



Results

Carer population

Response (n=5270)



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



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



50.6% (n=761) lived together



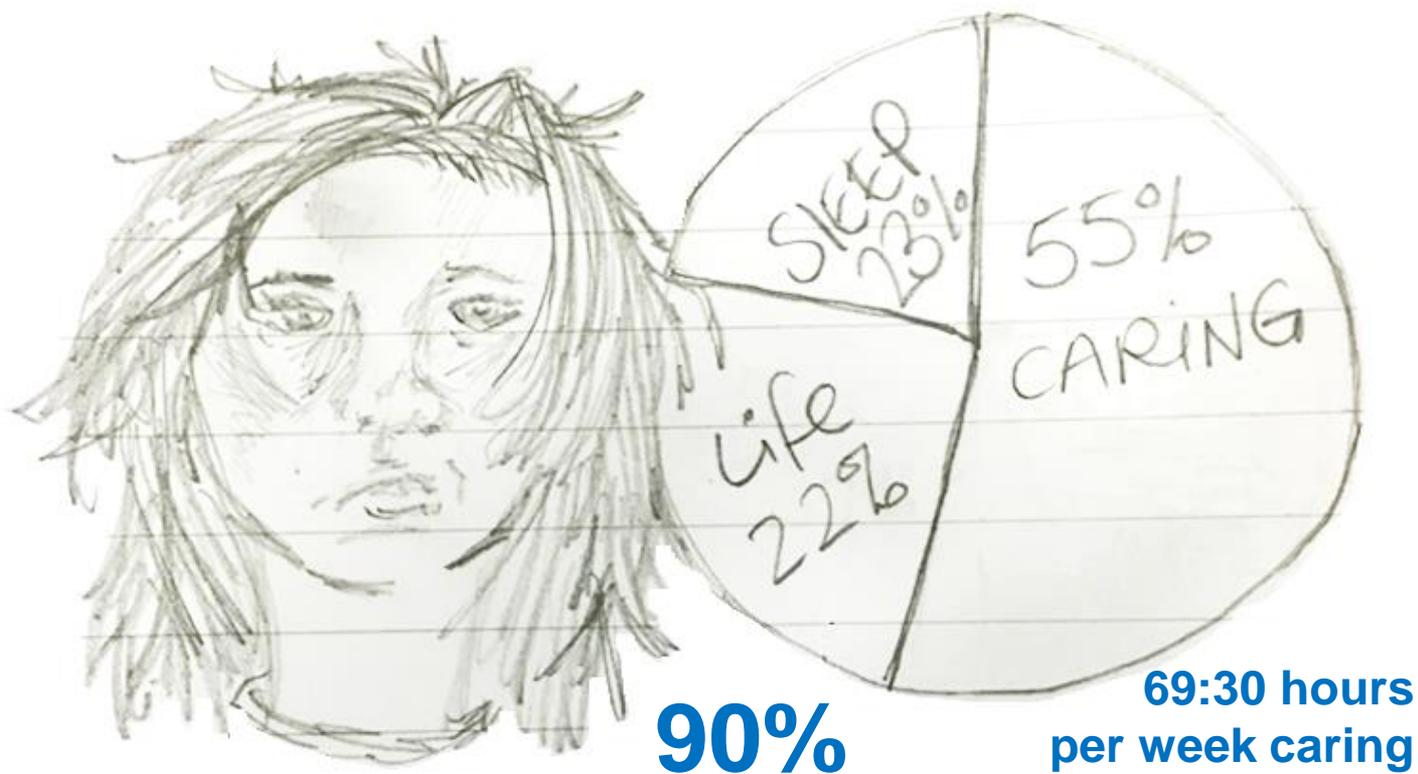
33.7% (n=507) within 30 mins

	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)

FINDINGS N=1504 / 5270 (28.5%) responded

NHS
National Institute for
Health Research

In last three months of life:



73% spent
£370
on related
expenses

CONCLUSIONS

- For the first time we can estimate the contribution and expenses based on a UK census sample of bereaved carers.
- Previous research has estimated 15⁶ and 24.5⁷ hours of care. Therefore value of care is likely to be much higher than previous estimates based on our finding of 69.30 hours.
- Informal care represents a substantial and vital contribution to society. Economic valuations should be routinely undertaken to ensure those who support those at end-of-life are in turn adequately supported.



Forthcoming analyses:

Economic estimates of cost to society

Associations between hours of care and carer well-being.

FIND UPDATES OF OUR WORK AT
<http://clahrc-gm.nihr.ac.uk/our-work/end-of-life/dimbleby/>

Thank you to:

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



References

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