

RESEARCH PROTOCOL

Uncovering the contribution, costs and economic value of family care-giving at end of life: putting carers on the agenda.

[Short Title: Valuing family and friends' support for people with cancer at end of life]

Background and rationale

Family carers provide vital support for patients with cancer towards the end-of-life¹. Their contribution is essential to enable patients to remain at home in their final illness² and thus fulfil patients' preferences³ and government policy⁴.

The economic value of carers' contribution in general is estimated to be greater than the budget of the NHS^{5, 6}. However, there is a clear gap in our knowledge of the contribution made by carers towards end-of-life, when the complexity and intensity of their input is likely to substantially increase⁷.

Without quantification of the size and economic impact of carers' contribution to end-of-life care, it remains largely 'invisible' and unrecognised at government, commissioner and service provider level, with negative consequences for all stakeholders. The National End of Life Care Programme (NEoLCP)⁸ estimates that end-of-life community care is likely to be cheaper than acute hospital care, but this calculation only considers health and social care costs, not carers' contribution. Literature reviews indicate that the cost of palliative care is lower than standard care, but these economic evaluations consistently fail to consider carers' time and out-of-pocket costs^{9, 10}. Support for carers is explicitly excluded from the NHS Palliative Care Tariff recommended by the Palliative Care Funding Review⁴, despite the PCFR's emphasis on enabling patient death at home. NEoLCP¹¹ list the critical success factors that enable people to die in their preferred place of death, but omit family carers from the list, in the face of clear empirical evidence that carers are a crucial factor and that home care is not feasible without their input^{2, 12}.

Guidance on carer support appears to have had little effect on the services provided. Department of Health (2008) and NICE (2004) guidance stipulates that carers' needs should be assessed and addressed^{13, 14}, without describing how services should deliver this in practice¹. Our research¹⁵ indicates that EOL carers feel unheard and unsupported, a situation that has changed little over recent decades. Furthermore, despite having family support as their explicit remit, palliative home care services normally have no established procedures for identifying and consulting patients' family carer(s), and identifying, recording and following up their support needs¹⁶. They do not recognise the importance of carers as co-workers and of supporting them to support the patient.

The lack of basic information on the characteristics of end-of-life care-giving - who carers are, what they contribute to end-of-life care and to the economy - is likely to be a major barrier to enhancing carer support. Data are needed for appropriate planning and investment, to enable carers to continue supporting patients, and ensure that their contribution is part of any economic evaluation, particularly as delivery of services continues to move into the community.

This study will be the first to provide population-based information on the scale of cancer related carer activity and its economic contribution to end-of-life care in the UK. We will collect detailed data directly from carers and identify participants based on support provided for the patient. This approach will avoid limitations of earlier UK population studies on general care-giving that utilised limited secondary data^{5, 6}.

Whilst carer population data have been used to canvass for improved support for carers in general¹⁷, the intensity and distress of end-of-life care-giving demands specific

consideration. Carers of patient dying from cancer - characterised by progressive, rapid decline - are likely to require more rapid and flexible support arrangements than carers of people with other, longer term conditions.

Our roles in the Greater Manchester and Yorkshire & Humber CLAHRC-2 (Collaborations for Leadership in Applied Health Research and Care between the University, commissioners and service providers) will enable us to engage local commissioners and service providers in the assessment of implications of findings for service investment and planning, raise carers' profile within provider organisations and facilitate introduction of carer support into regular practice procedures. Findings will be disseminated nationally to carer organisations, providers, commissioners and government to ensure that future developments in end-of-life care are sensitised to carers' contribution, and increase the likelihood that future health economics evaluations take a broader societal perspective to include carers.

Whilst this project will provide an overview of cancer carers in England, the work will form the basis for further national and European surveys comparing contribution and costs at end-of-life for other disease groups and other countries.

Aim

To investigate the costs, contribution and economic value of family care-giving in end-of-life cancer care.

Objectives

- To describe carers' demographic characteristics
- To determine carers' contribution in terms of time, nature of care and support provided
- To characterize the economic and other costs to carers of providing end-of-life cancer care
- To investigate the association between carer characteristics and time spent caring, costs to carers and carer wellbeing.
- To estimate the economic value of end-of-life care provided by family carers of people with cancer

Design

We will conduct a cross-sectional population survey of N=2000 family carers of people who died from cancer, employing procedures used by the national VOICES bereavement survey¹⁸. After pre-testing and piloting, the survey will be sent to family members of people who died from cancer identified from death certificates by the Office for National Statistics (ONS). We will obtain ethical approval for all study procedures and materials.

Pre-testing and piloting

Preparatory work with carer advisors will be essential to ensure that procedures and study materials are sensitive, relevant and understandable. The survey questionnaire will be designed in partnership with people who have experience as carers. It will undergo retesting using cognitive interviews with 4-5 carers, and piloted with 10-15 carers using feedback interviews.

We will work with the Lancaster Research Partner Forum (patients and carers with experience of palliative research) as advisors to develop and revise recruitment and survey materials. Carers to help with pre-testing and piloting will be recruited through carer groups in the Greater Manchester, *North West and North East regions of the UK* and through a bereavement counselling service for care givers in Greater Manchester.

Sampling and recruitment of population survey sample

The sample will be family members of people who died from cancer, 4-6 months post-bereavement, identified from death certificates by the Office for National Statistics (ONS).

Inclusion criteria:

Cancer as underlying or contributory cause of death

Patient \geq age 18

Death not registered by a coroner

Death registered in England

Our sample will be derived from all death registrations that meet the above criteria, occurring on specified days. Not enough is known about the composition of the target study population of carers to conduct proportional stratified random sampling in a meaningful way and simple random sampling may introduce bias by chance. In contrast to other causes of death, cancer does not display seasonal variation^{19 20}. Data supplied by the ONS furthermore show no variation in cancer deaths depending on day of week or time of month, although some weekend variation may be observed for other causes²¹. We will therefore sample all cancer deaths over 14 consecutive days. This 'census' approach should ensure that our sample is as representative of the English carer population as possible.

Previous ONS VOICES bereavement surveys indicate that a survey with two reminders should give a response rate of 40-46%¹⁸. Therefore 5000 surveys will be sent out to achieve a sample of at least $n=2000$. This would match the size of previous general carer surveys and improve sample sizes for carer groups that are few in number (e.g. black and minority ethnic groups). This sample would also allow the estimation of carer traits (e.g. gender) using a 95% confidence interval to have a precision of at least $\pm 2\%$ and be large enough to undertake multivariable analysis to model predictors of carer activity. There were over 135,000 deaths from cancer in England in 2012^{22 23}, approximately 370 per day, suggesting the total number of deaths over 14 days would be approximately $N=5180$.

The ONS will send a survey pack (invitation letter, questionnaire, response slip, return envelopes) to the person who reported the death. In over 90% of cases this is a spouse or other relative²⁴. The recipient will be invited to pass the survey onto the person most involved in supporting the patient if they are not the right person. The response slip enables recipients to opt out of receiving reminders if they do not wish to take part. Completed questionnaires will be returned to the research team in a pre-paid envelope. Questionnaires may also be completed online or by telephone if preferred. A follow-up reminder letter and another survey pack will be sent by the ONS at four and eight weeks, respectively.

ONS will provide anonymised data contained in the death certificate for the total sampling frame to enable assessment of the representativeness of our respondent sample.

Data collection

Consultation with carer advisors will ensure that the final survey is relevant and understandable with an acceptable response burden. The questions will encompass:

- Length of time spent in care-giving role, impact on work, wages and leisure activities
- Daily or weekly hours spent caring, care tasks, out of pocket expenses (including travel) during the last 3 months of the patient's life
- Location of patient (home versus elsewhere and when) during last 3 months of life
- Impacts of care-giving on carer wellbeing including loss of sleep, care giver burden, quality of life
- Factors likely to influence hours spent caring and costs to the carer, including demographic variables (age, sex, relationship to patient, ethnicity, geographical location, employment status and care leave opportunities); use of services; patient condition and symptom burden
- Number of others involved in family care-giving, their relationship and contribution
- Carers' perception of factors that would improve their care-giving situation

Some recall bias in retrospective data can be expected, but can to some extent be accounted for²⁵ and should be weighed against the substantial advantages of gaining population data for an ‘anchored’ time period. Prospective measurement would require a resource intensive study with a small, selective sample, and probably yield data from varying time periods before death.

Analysis

Our analysis will provide the following information

- A profile of the cancer carer population, derived from descriptive analyses of carer characteristics, hours and type of care provided, costs, impact on employment and carer burden/ wellbeing
- Estimates of costs of caregiving for society, services and carers themselves:
 - replacement costs for carers’ contribution (i.e. how much it would cost health and social care services to provide this care)²⁶
 - opportunity costs for carers’ time (based on type of paid employment for carers originally or currently in work)²⁶
 - loss of tax revenue and productivity for society
- Identification of factors influencing hours of care, costs and impacts on carer wellbeing to identify which carers may be most in need of support, using multivariable regression analyses

Dissemination

Our final dissemination strategy will be developed in partnership with our research partners and local user groups involved in the pre-testing/piloting, but will encompass:

- Local dissemination: We will engage with our CLAHRC-2 commissioner and service provider partners in four workshops to agree study implications and plans for implementation. Implementation of research evidence is a CLAHRC remit, and CLAHRC-2 Greater Manchester has family carers in end-of-life care as a specified focus, providing clear pathways and mechanisms for translating study implementation targets into practice.
- National dissemination: we will produce press releases, executive summaries and brief reports to fit lay, practitioner, commissioner and policy audiences. Targets include national carer groups (Carers UK, Carers Trust, Carers Federation); palliative provider organisations (Help the Hospices, National Association for Hospice at Home, National Council for Palliative Care); NHS (NHS England; NHS Improving Quality) and Government organisations (Public Health England, including the National End of Life Care Intelligence Network). We will also present at a national conference (Palliative Care Congress) and publish findings in a peer reviewed open access journal.

References

¹ Ewing G, Grande GE (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. *Palliative Medicine*; **27**(3):244 - 256. DOI: 10.1177/0269216312440607

² Gomes B, Higginson IJ (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*; 332:515-21

³ Higginson IJ and Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000; 3: 287–300.

⁴ 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

⁵ Buckner L, Yeandle S (2007). Valuing carers – calculating the value of unpaid care. Carers UK report.

- ⁶ Buckner L, Yeandle S (2011). Valuing carers 2011: calculating the value of carers' support. Carers UK report. <http://circle.leeds.ac.uk/files/2012/08/110512-circle-carers-uk-valuing-carers.pdf>
- ⁷ Corden A, Hirst M (2011). Partner care at the end of life: identity, language and characteristics. *Ageing and Society*; 31: 217-242.
- ⁸ National End of Life Care Programme (2012a). Reviewing end of life care costing information to inform the QIPP End of Life Care Workstream. Whole systems partnership. September 2012. http://www.thewholesystem.co.uk/docs/EoLC_QIPP_Costings_Report.pdf
- ⁹ 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.
- ¹⁰ 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.
- ¹¹ National End of Life Care Programme (2012b). Critical success factors that enable individuals to die in their preferred place of death. February 2012. <http://www.nhs.uk/resources/publications/eolc-critical-success-factors.aspx>
- ¹² Grande GE, Ewing G (2008). Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliative Medicine*; 22: 971-972
- ¹³ Department of Health (2008). End of life care strategy: promoting high quality care for all adults at the end of life. London: DH.
- ¹⁴ National Institute for Clinical Excellence (2004). Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. London: NICE.
- ¹⁵ Hanratty B, Grande G, Payne S, Seymour J et al (in press). Transitions at the end of life for older adults: patient and provider perspectives. *Health Serv Deliv Res*. <http://www.nets.nihr.ac.uk/projects/hsdr/081809232>
- ¹⁶ Ewing G, Austin L, Grande G (2014). Challenges to implementing comprehensive carer assessment in palliative home care: findings from a cluster trial. *BMJ Supportive & Palliative Care*; 4 (1): 115.
- ¹⁷ Yeandle S, Buckner L (2007). Carers, employment and services: time for a new social contract? Report No 6. Carers, Employment and Service (CES) Report Series, Carers UK. <http://circle.leeds.ac.uk/files/2012/08/carers-uk-report-6.pdf>
- ¹⁸ Office for National Statistics (2012). National Bereavement Survey (VOICES), 2011. ONS Statistics Bulletin. <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/national-bereavement-survey--voices---2011.html>
- ¹⁹ Mackenbach JP, Kunst AE, Looman CWN (1992). Seasonal variation in mortality in The Netherlands. *Journal of Epidemiology and Community Health*; 46: 261-265.
- ²⁰ Rossum CTM van, Shipley MJ, Hemingway H, Grobbee DE, Mackenbach JP, Marmot MG (2001). Seasonal variation in cause-specific mortality: are there high-risk groups? 25-year follow-up of civil servants from the first Whitehall study. *International Journal of Epidemiology*; 30: 1109-1116.
- ²¹ Dr Foster Health (2011). Reducing mortality at nights and weekends. In: Inside your hospital 2011. http://drfosterintelligence.co.uk/wpcontent/uploads/2011/11/Hospital_Guide_2011.pdf
- ²² Office for National Statistics (2013). Deaths Registered in England and Wales (Series DR), 2012. ONS Statistics Bulletin <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/index.html>
- ²³ Office for National Statistics (2014) Mortality Statistics: Deaths Registered in England and Wales by Area of Usual Residence, 2012. <http://www.ons.gov.uk/ons/rel/vsob1/deaths-registered-area-usualresidence/2012/index.html>

- ²⁴ Gomes B, McCrone P, Hall S, Kofman J, Higginson IJ (2010). Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer*; 10:400. <http://www.biomedcentral.com/1471-2407/10/400>
- ²⁵ Berg B van den, Spauwen P (2006). Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health Economics*; 15: 447-460.
- ²⁶ Faria R, Weatherly H, van den Berg B (2012). A review of approaches to measure and monetarily value informal care. In L Curtis, "Unit Costs of Health and Social Care 2012"; PSSRU; <http://www.pssru.ac.uk/project-pages/unit-costs/2012/>