Original Article

PALLIATIVE MEDICINE

Palliative Medicine
2015, Vol. 29(10) 899–907

DOI: 10.1177/0269216315595203
pmj.sagepub.com
SAGE

Estimating the cost of caring for people with cancer at the end of life: A modelling study

Jeff Round[1], Louise Jones[2] and Steve Morris[3]

Abstract

Background: People with advanced cancer require a range of health, social and informal care during the final phases of life. The cost of providing care to this group as they approach the end of their lives is unknown, but represents a significant cost to health and social care systems, charities patients and their families.

Aim: In this study, we estimate the direct and indirect costs for lung, breast, colorectal and prostate cancer patients at the end of life (from the start of strong opioids to death) in England and Wales.

Methods: We use a modelling-based approach to estimate the costs of care. Data are estimated from the literature and publicly available data sets. Probabilistic sensitivity analysis is used to reflect uncertainty in model estimates.

Results: Total estimated costs for treating people with these four cancers at the end of life are £641 million. Breast and prostate cancer patients have the highest expected cost per person at £12,663 (95% credible interval (CI): £1249–£38,712) and £14,859 (95% CI: £1391–£46,424), respectively. Lung cancer has the highest expected total cost (£226m). The value of informal care giving accounts for approximately one-third of all costs.

Conclusion: The cost to society of providing care to people at the end of their lives is significant. Much of this cost is borne by informal care givers. The cost to formal care services of replacing this care with paid care giving would be significant and demand for care will increase as the demographic profile of the population ages.

Keywords

Palliative care, cancer, costs, burden of illness, economics

What is already known about the topic?

- Only a small number of studies have considered the cost to society of providing end of life care.
- The costs of providing care to people with cancer at the end of their lives is significant.
- No single study has considered the broad range of health, social and informal care that is provided to people at the end of life.

What this paper adds?

- This study is the first to include the costs of health and social care as well as the cost of informal care giving when estimating the cost to society of providing care at the end of life.
- Using a modelling-based approach, we estimate a total cost to society of caring for people with cancer as they approach the end of life.

[1]Comprehensive Clinical Trials Unit at UCL, University College London, London, UK
[2]Marie Curie Palliative Care Research Department, University College London, London, UK
[3]Department of Applied Health Research, University College London, London, UK

Corresponding author:
Jeff Round, Comprehensive Clinical Trials Unit at UCL, University College London, 175-176 Tottenham Court Road (Entrance in Capper Street), London W1T 7NU, UK.
Email: j.round@ucl.ac.uk

- We find that the costs of providing care are significant, with up to one-third of that cost being borne by informal care givers.
- Sensitivity analysis reveals the limitations of the available data for estimating costs and planning services.

Implications for practice, theory or policy

- Replacing informal care giving with formal services would represent a significant cost to public service providers.
- Service planners should be aware of the role of informal care giving in meeting the care needs of people at the end of their lives.
- Improved data collection and categorisation would allow for more informative international comparisons to drive service improvements.

Background

Cancer is responsible for over 141,000 deaths in England and Wales every year.[1] It is a significant burden to individuals and society in terms of morbidity and mortality. The cost of providing care to people who die with and from cancer as they approach the end of their lives is unknown, yet clearly represents a significant cost to the health care systems, social services, charities and, importantly, patients and their families. In this study, we estimate the cost to society of providing care at the end of life to patients who die from lung, colorectal, breast or prostate cancer. The four cancers included here account for approximately 45% of all cancer-related deaths in England and Wales.[1]

Care for people with cancer in the advanced stages is provided by a wide range of specialist and generalist providers of health and social services.[2] Health care will usually focus on maximising symptom control.[3,4] It may encompass courses of palliative chemotherapy to reduce tumour size and spread, radiotherapy for localised bone pain or to manage acute emergencies such as superior vena caval obstruction or spinal cord compression. Drugs are commonly used to control the more widespread symptoms such as pain and nausea and vomiting. As illness progresses, fatigue and frailty lead to falls in global functioning and assistance with daily living may be needed. As death approaches, general nursing care support may be required provided by a mixture of generalist and specialist nursing services, either in the patient's home or other care settings. Additional supportive care may be offered by a broad range of physicians with advice from specialist palliative care providers or perhaps sharing care between palliative and oncology specialists. Individuals or their families may be required to pay for residential or nursing home care, imposing significant financial burden and may also provide informal care at significant personal cost, particularly through foregone employment.[5]

The aim of this study is to estimate the total direct and indirect costs of the broad range of care described above provided to lung, colorectal, breast and prostate cancer patients in England and Wales during the end-of-life period – that is, the period in people's lives where death is expected in the near future and the primary aims of treatment are no longer curative.

Methods

Systematic review

To understand what is already known on this topic and to plan the methodology for our model-based approach, we began with a systematic review of the literature. We searched MEDLINE, Embase, PsycINFO, EconLit, CINAHL and NHSEED databases for studies published between 1990 and 1 April 2015. Grey literature was also searched for UK government or statutory agency reports, reports by non-governmental agencies or academic working papers. The review search strategy and further details are provided in the supplemental material.

We chose UK-based studies that included cancer patients for detailed review given the UK National Health Service (NHS) cancer care was the focus of our analysis. We included four UK-based studies that considered the cost of providing any type of care to patients with cancer at the end of life.[6–9] All of the studies included in the review estimated the costs of providing health care, while three also included estimates of the costs of providing social care[6,7,9] and none included the costs of privately provided care, charity provided care or informal care provision (Table 1). What little evidence is available suggests that there are significant direct and indirect costs in caring for patients at the end of their lives that are not met by public health and social care providers.[5] These additional costs are a significant burden to individuals and society and need to be counted.

Defining the end-of-life period

Defining what constitutes end-of-life care is difficult, with different views taken at times by health service planners, researchers and the wider public.[10–12] Within England and Wales, the definition used in practice is that contained in the Gold Standards Framework guidance document produced by the Royal College of General Practitioners[10] and the National Institute for Health and Care Excellence (NICE) Quality Standards[11] for end-of-life care. These state that a person is approaching the end of life when it is considered by health care professionals that they are likely to die within the next 12 months. This includes 'People

Table 1. Overview of studies included in review.

Study	Population, study type	Direct costs	Indirect costs	Results (mean cost)
Nuffield (2014)[9]	All deaths, with cancer sub-group analysis. Retrospective cohort analysis.	Primary and community care, social care, inpatient hospice care, secondary care used in the 90 days prior to death.	None	Per death – £6015 Per cancer death – £7287
Nuffield (2012)[6]	Patients with long-term conditions (including cancer, chronic obstructive pulmonary disease, ischaemic heart disease, organ failure and mental disorders). Retrospective cohort analysis	Inpatient care, nursing care, residential care, home care, respite care, equipment, day care and direct payments in the 12 months prior to death.	None	Per death – £10,130 Per cancer death – £10,844
RAND (2008)[7]	Incidence-based population of patients who died from cancer or organ failure. Modelling study.	Hospital inpatient stays; hospice inpatient stays; home care costs per day in the 12 months prior to death.	None	Cancer, per patient: £14,236 Organ failure, per patient: £18,771
Guest et al. (2006)[8]	Incidence-based population of patients with advanced cancer. Retrospective cohort analysis.	Prescriptions, GP use; palliative physician use (home and outpatient) and hospital admissions from the time of strong opioid use being instigated until death.	None	Per patient: Breast – £1.75 k Colon – £1.54 k Lung – £2.24 k Uterus – £2.69 k Ovaries – 4.79 k Prostate – £3.77 k Stomach – 3.49 k

GP: general practitioner.

whose death is imminent … as well as those with advanced, progressive, incurable conditions, general frailty and co-existing conditions that mean they are expected to die within 12 months …'.[12]

This definition has limitations for research purposes. In our view, in order for a definition of the end of life period to be useful in a research context where service use or costs are to be estimated, it must satisfy two criteria, at least partially. First, there must be a defined period of time over which the research will be conducted. Second, it should reflect as far as possible the clinical needs of the patient. Using the 12 month time frame as above fails to satisfy this second criterion, as it may lead to an:

- underestimate of costs for patients who may have palliative needs longer than 12 months, yet
- overestimate of costs for those patients who are expected to die in under 12 months.

For this study, we consider that the most appropriate definition of the end of life should include patients who are at increased risk of death during the time period measured and should account for the varying lengths of time patients with different illnesses may spend with palliative care needs. This approach also has the advantage that it is based on the clinical needs of the patient, rather than an indiscriminate fixed length of time, which reflects the recommendations of the Palliative Care Funding Review.[13] We have chosen to follow the approach of Guest et al.[8] in defining the end of life period as the point at which a patient begins the use of strong opioids. The use of strong opioids is the principal treatment for pain associated with advanced, progressive cancer.[14] At this stage of disease, the primary intention of treatment is often the management of symptoms as cure is no longer likely.

The model

This analysis takes a novel approach to estimating a population estimate of the cost of an illness. Using data available in the literature, a model has been developed to estimate the cost of providing care to a typical patient during the end of life period. This estimate (along with associated estimates of uncertainty) is then aggregated to derive a population-level estimate. The model comprises counts of the resources used by an individual in the last period of life combined with an estimate of the unit cost for each of those resources. An estimated cost for an individual patient is calculated by summing the resources used during the end of life period multiplied by the unit cost of the resource. Monte Carlo simulations are conducted to generate an expected mean cost for an individual patient, reported with associated Bayesian credible intervals (posterior probability interval).[15] We conduct 10,000 simulations for each of the four cancers studied. This approach generates a plausible estimate of the overall cost based on the existing data; this is an improvement over existing cost of care methods,

as it gives a fuller account of the uncertainty inherent in the underlying data.

Because of the diffuse nature of the care provided, in diverse settings, and the need to include an estimate of informal care, we have chosen to estimate costs from the bottom-up.[16] This approach requires detailed information on resource use and unit costs. Although this approach is more resource intensive than the alternative top-down approach (which aggregates data at the system level), it is the only practical way to arrive at a meaningful estimate of the costs of providing end of life care. Details of how we derived the estimates used in our analysis are provided in the supplementary material.

Unit costs

Unit costs have been estimated using publicly available data where possible. Both direct and indirect costs are considered in this study. Direct costs are those borne directly by the health or social care services, or patients and their carers. We include direct costs only for health and social care providers, as no data of sufficient quality were identified to include the direct costs to patients and their carers. Indirect costs are those costs arising from the illness but where a payment is not made, such as lost wages due to time off work. The key indirect cost included in this study relates to value of the provision of informal care. This has been valued using the human capital approach.[17]

Sensitivity analysis

The approach we took to estimating the cost of care relies on a number of parameter values that are uncertain. The role of sensitivity analyses is to demonstrate the degree to which results may be affected by this uncertainty in the data. Probabilistic sensitivity analysis combined with Monte Carlo simulation is used to address the uncertainty in the parameter estimates used in the model.

Results

Results are presented in Tables 5 and 6. As would be expected, the patients with the longest expected survival (breast and prostate cancers) are those who have the highest average expected cost per person during the last period of their lives (Table 5). Lung cancer leads to the most deaths and has the highest expected total cost of the four cancer types (Table 6). The total estimated cost of providing care to people with these four cancers is £642 million (Table 6). Health care and informal care provision represent the highest cost areas across all four cancer types. The financial value of charity care provision is low in our estimation, although this is probably an underestimate due to the way we have classified charity care.

Discussion

Our results show that the costs of providing care to people with breast, prostate, colorectal or lung cancer at the end of their lives are significant. Our expected total direct and indirect costs for treating people at the end of life for these four cancers alone is nearly £650 million. This is clearly a significant cost to health and social care services directly, as well as indirectly to patients and their carers. About 33% (£219 million) of the total costs of care are borne by informal carers in terms of the value of the care they provide and lost employment income. Direct health care costs during the end of life period for these four cancers alone are estimated at £275.3 million, compared to total health care costs for all cancer care provision in the United Kingdom of £5.24 billion.[24]

Our estimated costs differ from those studies included in our review (Table 1). In our study, the expected cost of care for each cancer across all four cancer types considered and resource categories is £9914, with expected costs of health and social care of £4254 and £1829, respectively. By comparison, the Nuffield study of 2012[6] estimated an average cost per cancer patient in the 12 months prior to death of £10,844, with health care accounting for £9498 and social care £1346. The Nuffield estimate of overall cost per patient is higher than our overall estimate despite the fact that we included the value of a wider range of care (the Nuffield study did not include primary, informal or hospice care provision). The difference in costs appears to be driven largely by the estimated health care costs in each analysis. This in turn appears to be largely due to the way the end of life period is defined. Results from our simulation show that patients across all four cancer types have an expected survival of 243 days from when they enter the end of life period as defined for our study, compared with the 365-day period considered as end of life in the Nuffield study. The fact that this survival time accounts for much of the difference between estimates highlights how important defining the end of life period is for undertaking analysis is in this area, whether for estimates of cost or for other service planning purposes.

The value of care provided by charities was lower than we anticipated. This is most likely an underestimate, as charities provide care through multiple avenues and identifying spending in each case is difficult. Our results suggest that charities provide just £30 million pounds of care per year through hospice provision – this reflects the fact that just 5% of the population will die in a hospice and will spend a relatively short period of time there. But charities also provide care through other means, often paid for in part by local authorities and the health service – these costs will have been captured where possible in the social care element of spending, and though charity provided and subsidised, it will not be included in the estimate of charitable provision.

Table 2. Estimates of resource use.

Category	Mean	Distribution	α	β	Source
Expected survival (days)					
Breast cancer	372	Gamma	1.00	372	Guest et al.[8]
Colorectal cancer	201	Gamma	1.00	201	Guest et al.[8]
Lung cancer	180	Gamma	1.00	180	Guest et al.[8]
Prostate cancer	360	Gamma	1.00	360	Guest et al.[8]
Health care resource use					
Estimates used for all cancers					
Probability any hospital care	0.99	Beta	19,828	106	Georghiou et al.[6]
Mean annual elective inpatient admissions[a]	2.51	Gamma	1.00	2.51	Georghiou et al.[6]
Mean annual non-elective inpatient admissions[a]	1.95	Gamma	1.00	1.95	Georghiou et al.[6]
Outpatient attendances	10.80	Gamma	1.00	10.80	Georghiou et al.[6]
A&E attendances	1.39	Gamma	1.00	1.39	Georghiou et al.[6]
Breast cancer					
Probability non-emergency admission[a]	0.97	Beta	172,504	5010	Hospital Episode Statistics (C50)[18]
Probability emergency admission[a]	0.03	Beta	4810	172,704	Hospital Episode Statistics (C50)[18]
Mean days per inpatient admission	3.00	Gamma	1.00	3.00	Hospital Episode Statistics (C50)[18]
GP contacts (at surgery)	15.75	Gamma	1.00	15.75	Guest et al.[8]
District Nurse contacts	15.75	Gamma	1.00	15.75	Guest et al.[8]
Colorectal cancer					
Probability non-emergency admission[a]	0.92	Beta	128,811	11,464	Hospital Episode Statistics (C18-C20)[18]
Probability emergency admission[a]	0.08	Beta	11,464	128,811	Hospital Episode Statistics (C18-C20)[18]
Mean days per inpatient admission	9.80	Gamma	1.00	9.80	Hospital Episode Statistics (C18-C20)[18]
GP contacts (at surgery)	10.43	Gamma	1.00	10.43	Guest et al., 2006[8]
District Nurse contacts	10.43	Gamma	1.00	10.43	Guest et al., 2006[8]
Prostate cancer (C61)					
Probability non-emergency admission[a]	0.91	Beta	51,566	5090	Hospital Episode Statistics (C61)[18]
Probability emergency admission[a]	0.09	Beta	5090	51,566	Hospital Episode Statistics (C61)[18]
Mean days per inpatient admission	5.60	Gamma	1.00	5.60	Hospital Episode Statistics (C61)[18]
GP contacts (at surgery)	14.97	Gamma	1.00	14.97	Guest et al.[8]
District Nurse contacts	14.97	Gamma	1.00	14.97	Guest et al.[8]
Lung cancer (C34)					
Probability non-emergency admission[a]	0.81	Beta	68,340	16,536	Hospital Episode Statistics (C34)[18]
Probability emergency admission[a]	0.19	Beta	16,536	68,340	Hospital Episode Statistics (C34)[18]
Mean days per inpatient admission	8.80	Gamma	1.00	8.80	Hospital Episode Statistics (C34)[18]
GP contacts (at surgery)	21.76	Gamma	1.00	21.76	Guest et al.[8]
District Nurse contacts	21.76	Gamma	1.00	21.76	Guest et al.[8]
Social care resource use					
Probability of any home care use	0.13	Beta	0.75	3574.00	Georghiou et al.[6]
Mean days of home care use[a]	57.25	Gamma	1.00	57.25	Georghiou et al.[6]
Hours per day of home care use	1.20	Gamma	1.00	1.20	Georghiou et al.[6]
Probability of being in a nursing home	0.03	Beta	519.00	19,415.00	Georghiou et al.[6]

(Continued)

Table 2. (Continued)

Category	Mean	Distribution	α	β	Source
Days in nursing home[a]	55.28	Gamma	1.00	55.28	Georghiou et al.[6]
Probability of being in a residential home	0.04	Beta	794.00	19,140.00	Georghiou et al.[6]
Days in residential home[a]	66.77	Gamma	1.00	66.77	Georghiou et al.[6]
Probability of 'Other Social Care' use	0.02	Beta	0.96	43.34	Georghiou et al.[6]
Units of 'Other Social Care' used[a]	5.00	Gamma	1.00	5.00	Georghiou et al.[6]
Charity provided care					
Probability hospice inpatient stay	0.05	Beta	0.91	18.37	Marie Curie Cancer Care data
Hospice inpatient days[a]	22.91	Gamma	1.00	22.91	Marie Curie Cancer Care data
Probability hospice outpatient contact	0.05	Beta	0.91	18.37	Marie Curie Cancer Care data
Hospice outpatient visits[a]	5.85	Gamma	1.00	5.85	Marie Curie Cancer Care data
Informal care					
Probability of receiving any informal care	0.34	Beta	0.32	0.62	Hayman et al.[19]
Hours of informal care received (weekly)[a]	15.00	Gamma	1.00	15.00	Macmillan Cancer Support[5]
Hours of employment lost by carer (weekly)[a]	2.18	Gamma	10.06	0.22	Macmillan Cancer Support[5]
Probability carer's allowance received by carer[a]	15.00	Beta	0.90	17.10	Macmillan Cancer Support[5]

GP: general practitioner.
[a]These parameters are set equal to 0 where the individual did not use a resource.

Our study is the only one to date to acknowledge and capture, using probabilistic sensitivity analysis, the full extent of the uncertainty surrounding the level of resources used by patients at the end of life. The wide 95% credible intervals indicate that our results are highly uncertain and thus how uncertain knowledge of the cost of providing end of life care is. This uncertainty is driven by two things. The first is that many of the estimates we were able to identify for resource use are themselves highly uncertain. In many cases, only a point estimate was reported in the existing research – for example, while Guest et al.[8] report in some detail the different categories of resources used, they did not report confidence intervals or any other measure of dispersion. As a result, it was necessary in some cases to make highly conservative assumptions about the variability of patient resource use in the model. It is a necessary consequence of making such conservative assumptions that we increase the uncertainty in our results. The second is that in many cases, it was not possible to find data that applied specifically to patients at the end of life. This again leads to conservative assumptions and greater uncertainty in results. Better collection of routine data would enable analysts and service planners to understand better patterns of resource use, including at the end of life.

Additionally, there is a lack of distinction in recorded statistics between care that happens because a patient is at the end of life that is primarily palliative in intent, and all other care a patient receives during this time. This makes estimation of a cost of care for people at the end of life difficult. This is a problem faced by many researchers interested in establishing what care individuals receive towards the end of life. We have taken the pragmatic approach, which is to consider all care at the end of life. But in some cases, patients with co-morbidities would be receiving care irrespective of their cancer diagnosis. However, as data are not coded to indicate whether or not care is because of the end of life being reached, it is not possible to take any other approach. This lack of data may also present problems to those in charge of commissioning or designing services.

A lack of widely available data also restricts comparisons between countries. In the systematic review, we identified an additional six studies which estimated the cost of providing care to patients at the end of life in non-UK countries.[6–11] In addition to not being UK-based, none of these studies focused exclusively on cancer patients and so were excluded from the review. Direct comparisons of costs between different health economies are difficult – palliative and end of life care can constitute a wide range of different services and patient needs can be met in a wide range of ways. Yet, without reliable data on who gets what care, when and where, and at what cost, it is difficult to make a comparative assessment of outcomes internationally. For example, a recent study from Canada found that the cost of caring for an individual was approximately CAD34,000 (£185,000).[25] However, given differences in the structure of the care system and definitions of the end of life period, it is not possible to

Table 3. Unit costs (all costs adjusted to 2013–2014 prices).

Category	Unit cost	Source
Health care resources		
Breast cancer		
Elective inpatient admission (initial spell)	£362	2013–14 Tariff, JA12C Malignant breast disorder without CC[20]
Elective inpatient admission (excess day)	£227	2013–14 Tariff, JA12C Malignant breast disorder without CC[20]
Non-elective inpatient admission	£964	2013–14 Tariff, JA12C Malignant breast disorder without CC[20]
Non-elective inpatient admission (excess day)	£227	2013–14 Tariff, JA12C Malignant breast disorder without CC[20]
Colorectal cancer		
Elective inpatient admission (initial spell)	£1756	2013–14 Tariff, FZ46B Malignant Large Intestinal Disorders with length of stay 2 days or more without Major CC[20]
Elective inpatient admission (excess day)	£218	2013–14 Tariff, FZ46B Malignant Large Intestinal Disorders with length of stay 2 days or more without Major CC[20]
Non-elective inpatient admission	£2829	2013–14 Tariff, FZ46B Malignant Large Intestinal Disorders with length of stay 2 days or more without Major CC[20]
Non-elective inpatient admission (excess day)	£218	2013–14 Tariff, FZ46B Malignant Large Intestinal Disorders with length of stay 2 days or more without Major CC[20]
Lung cancer		
Elective inpatient admission (initial spell)	£761	2013–14 Tariff, DZ17C Respiratory Neoplasms without CC[20]
Elective inpatient admission (excess day)	£195	2013–14 Tariff, DZ17C Respiratory Neoplasms without CC[20]
Non-elective inpatient admission	£2071	2013–14 Tariff, DZ17C Respiratory Neoplasms without CC[20]
Non-elective inpatient admission (excess day)	£195	2013–14 Tariff, DZ17C Respiratory Neoplasms without CC[20]
Prostate cancer		
Elective inpatient admission (initial spell)	£1421	2013–14 Tariff, LB06F Kidney, Urinary Tract and Prostate Neoplasms with length of stay 2 days or more without CC[20]
Elective inpatient admission (excess day)	£205	2013–14 Tariff, LB06F Kidney, Urinary Tract and Prostate Neoplasms with length of stay 2 days or more without CC[20]
Non-elective inpatient admission	£1915	2013–14 Tariff, LB06F Kidney, Urinary Tract and Prostate Neoplasms with length of stay 2 days or more without CC[20]
Non-elective inpatient admission (excess day)	£205	2013–14 Tariff, LB06F Kidney, Urinary Tract and Prostate Neoplasms with length of stay 2 days or more without CC[20]
Common health care unit costs		
Outpatient appointment (Initial)	£223	2013–14 Tariff, Clinical Oncology, Multi-Prof[20]
Outpatient appointment (follow-up)	£105	2013–14 Tariff, Clinical Oncology, Multi-Prof[20]
A&E visit	£102	VB05Z Category 2 investigation with category 3 treatment[20]
District nurse	£64	PSSRU 2011[21]
GP	£36	PSSRU 2011[21]
Social care resources		
Home care per hour	£17	PSSRU via Nuffield[6]
Nursing home per day	£646	PSSRU via Nuffield[6]
Residential home per day	£529	PSSRU via Nuffield[6]
Unit of 'Other Social Care' (day care, direct payments and respite care)	£2698	Nuffield[6]
Charity provided resources		
Hospice inpatient per day	£419	Marie Curie Cancer Care data provided to the authors
Hospice outpatient visit	£104	Marie Curie Cancer Care data provided to the authors
Informal care		
Hour of lost employment	£13	ONS 2011 Annual Survey of Hours and Earnings[22]
Carer's allowance per week	£61	https://www.gov.uk/carers-allowance/overview

GP: general practitioner; CC: cancer care; PSSRU: Personal Social Services Research Unit; ONS: Office of National Statistics.

Table 4. Annual deaths by cancer type.

Cancer type	Annual deaths
Breast	10,311
Colorectal	14,441
Lung	30,273
Prostate	9698

Source: Office of National Statistics.[23]

make a direct comparison between studies. This restricts further development of cost-effective services and prevents others from drawing on knowledge and experience gained elsewhere. A more useful comparison would be to explore resource use differences between countries; however, there are insufficient data from the identified studies to conduct such an analysis. We expect that the costs of caring for people at the end of life are likely to be significant in all countries, yet differences in the structure

Table 5. Mean estimated cost per patient, by cancer type and resource use category, with Bayesian credible intervals.

Cancer type	Health care	Social care	Charity care	Informal care	Total
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
Breast	£4346 (£395 to £12,545)	£2843 (£84 to £10,170)	£480 (£7 to £1845)	£4868 (£18 to £21,818)	£12,663 (£1249 to £38,712)
Colorectal	£4854 (£413 to £14,485)	£1489 (£44 to £5350)	£470 (£6 to £1833)	£2850 (£10 to £13,350)	£9760 (£1037 to £29,545)
Lung	£3157 (£332 to £8944)	£1358 (£39 to £4838)	£459 (£6 to £1775)	£2420 (£9 to £11,153)	£7467 (£855 to £21,663)
Prostate	£6687 (£535 to £20,257)	£2728 (£83 to £9588)	£482 (£6 to £1906)	£4814 (£18 to £21,981)	£14,859 (£1391 to £46,424)
Mean[a]	£4254	£1829	£468	£3265	£9914

CI: credible interval.
Based on 10,000 Monte Carlo simulations.
[a]Mean weighted by proportion of deaths due to each cancer in the total population (Table 4).

Table 6. Mean estimated total cost of care, by cancer type and resource category (millions), with Bayesian credible intervals.

Cancer type	Health care	Social care	Charity care	Informal care	Total
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
Breast	£44.82 (£4.07–£129.35)	£29.31 (£0.86–£104.86)	£4.95 (£0.07–£19.02)	£50.20 (£0.19–£224.97)	£130.57 (£12.88–£399.16)
Colorectal	£70.10 (£5.96–£209.18)	£21.51 (£0.64–£77.25)	£6.79 (£0.09–£26.47)	£41.16 (£0.15–£192.79)	£140.95 (£14.98–£426.66)
Lung	£95.57 (£10.05–£270.78)	£41.11 (£1.18–£146.47)	£13.90 (£0.17to £53.72)	£73.25 (£0.27–£337.65)	£226.06 (£25.90–£655.81)
Prostate	£64.85 (£5.19–£196.45)	£26.46 (£0.81–£92.98)	£4.68 (£0.06–£18.49)	£46.69 (£0.17–£213.17)	£144.11 (£13.49–£450.22)
Sub-totals	£275.33	£118.39	£30.32	£211.29	£641.68

CI: credible interval.
Based on 10,000 Monte Carlo simulations.

of health and social care systems require analysis to be conducted on a country by country basis. The methods we describe in this analysis could be adapted to a range of settings in future research focusing on other health systems.

One of our most important findings is the value of the care provided to people at the end of life by informal carers. The cost to the health and social care services to replace informal unpaid care giving with formal paid care giving would be significant. This has important policy implications. If current demographic trends continue, the proportion of older people requiring care will continue to increase, with fewer people capable of providing it. This also has implications for hospice services, which are highly dependent on volunteers at present.[26] If the pool of capable informal carers and volunteers shrinks relative to the population needing care, a greater need for state funding will arise. Commissioners and payers of formal care services should be aware of this, as it may lead to greater pressure on resources than are currently expected.

Conclusion

As we have shown, the cost to society of providing care to people with one of the four studied cancers at the end of life is significant. For the individual patient, the mean expected cost of care to society is nearly £13,000. Across the roughly 140,000 people who die from cancer each year, this is a considerable sum. If we then consider that between 69% and 82% of the nearly 500,000 deaths in England and Wales will have palliative care needs, it is clear that providing this care is a great cost to society directly and indirectly. Much of this cost is borne by informal care givers. As populations age, there will be a greater demand for care and a decrease in the supply of informal care givers. Service planners should account for these issues when considering the future cost of providing end of life care.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Funding

The work has been conducted as part of the PhD research of author J.R., whose PhD fees are supported by Marie Curie Cancer Care, a registered charity. L.J.'s post is supported by Marie Curie Cancer Care core grant funding (grant no. MCCC-FCO-11-U). MCCC has had no input in the design, analysis or reporting of the results of the study or the decision to submit for publication. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. Office for National Statistics. *Mortality statistics: deaths registered in England and Wales* (Series DR). 2012, http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics–deaths-registered-in-england-and-wales–series-dr-/2012/index.html
2. NHS Choices. *End of life care*. 27 April 2015, http://www.nhs.uk/Livewell/cancer/Pages/Endoflifecare.aspx
3. National Institute for Health and Care Excellence. *Guidance on cancer services: improving supportive and palliative care for adults with cancer*. London: NICE, 2004.
4. Royal College of Physicians. *Palliative care services: meeting the needs of patients*. Royal College of Physicians, 2007, https://www.rcplondon.ac.uk/sites/default/files/documents/palliative-care-services.pdf
5. Macmillan Cancer Support. *More than a Million*. 2012, http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf
6. Georghiou T, Davies S, Davies A, et al. *Understanding patterns of health and social care at the end of life*. London: The Nuffield Trust, 2012.
7. Hatziandreu E, Archontakis F and Daly A. *The potential cost savings of greater use of home- and hospice based end of life care in England*. Cambridge: The RAND Corporation, 2008.
8. Guest JF, Ruiz FJ, Greener MJ, et al. Palliative care treatment patterns and associated costs of healthcare resource use for specific advanced cancer patients in the UK. *Eur J Cancer Care* 2006; 15(1): 65–73.
9. Georghiou T and Bardsley M. *Exploring the cost of care at the end of life*. London: Nuffield Trust, 2014.
10. Royal College of General Practitioners (RCGP). *Full guidance on using QOF to improve palliative/end of life care in primary care*. London: RCGP, 2006.
11. National Institute for Health and Care Excellence. *Quality standard for end of life care for adults*. London: NICE, 2011.
12. Royal College of General Practitioners (RCGP). *Palliative care and the GMS contract Quality and Outcomes Framework (QOF)*. London: RCGP, 2006.
13. Hughes-Hallett T, Craft A and Davies C. *Palliative care funding review*, 2012, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf
14. National Institute for Health and Clinical Excellence. *Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults*. NICE clinical guideline 140, May 2012. Manchester: NICE.
15. O'Hagan A and Stevens JW. Bayesian methods for design and analysis of cost-effectiveness trials in the evaluation of health care technologies. *Stat Methods Med Res* 2002; 11(6): 469–490.
16. Morris S, Devlin NJ and Parkin D. *Economic analysis in health care*, 1st ed. Chichester: John Wiley & Sons, Ltd, 2007.
17. Segel JE. *Cost of illness studies: a primer*. 2006, https://www.rti.org/pubs/coi_primer.pdf
18. Department of Health. *Hospital episode statistics, 2012–2013*. London: Department of Health, 2014.
19. Hayman JA, Langa KM, Kabeto MU, et al. Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol* 2001; 19(13): 3219–3225.
20. Department of Health. *Payment by Results (PbR) tariff for payment of healthcare providers over 2013 to 2014*. 2014, https://www.gov.uk/government/publications/payment-by-results-pbr-operational-guidance-and-tariffs
21. Curtis L. *Unit costs of health and social care*. Canterbury: Personal Social Services Research Unit, University of Kent, 2011.
22. Office for National Statistics. *2011 annual survey of hours and earnings*. London: Office for National Statistics, 2013, http://ons.gov.uk/ons/rel/ashe/annual-survey-of-hours-and-earnings/index.html
23. Office for National Statistics. *Deaths registered in England and Wales in 2010, by cause*. 2011, http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics–deaths-registered-in-england-and-wales–series-dr-/2012/sty-causes-of-death.html
24. Luengo-Fernandez R, Leal J, Gray A, et al. Economic burden of cancer across the European Union: a population-based cost analysis. *Lancet Oncol* 2013; 14(12): 1165–1174.
25. Yu M, Guerriere DN and Coyte PC. Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health Soc Care Community*. Epub ahead of print 2 December 2014. DOI: 10.1111/hsc.12170.
26. Burbeck R, Low J, Sampson EL, et al. Volunteers in specialist palliative care: a survey of adult services in the United Kingdom. *J Palliat Med* 2014; 17(5): 568–574.