



The  
University  
Of  
Sheffield.

# Costs of family caregiving in palliative care

Dr Clare Gardiner  
School of Nursing & Midwifery  
The University of Sheffield

[c.gardiner@sheffield.ac.uk](mailto:c.gardiner@sheffield.ac.uk)  
Twitter: [@claregardiner8](https://twitter.com/claregardiner8)



# Work to date

- Systematic review exploring financial impact of caring for family members receiving palliative and end of life care
  - Limited evidence base
  - Financial costs are substantial
  - Results in multi-dimensional caregiver burden

“

Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. "Exploring the financial impact of caring for family members receiving palliative and end of life care: A systematic review of the literature". *Palliative Medicine* 2014; 28(5): 375 – 390



The  
University  
Of  
Sheffield.

# Areas of cost

- Work related costs
- Carer time costs
- Out of pocket costs





The  
University  
Of  
Sheffield.

# Impact of costs

- Major life changes
- Worry, conflict, relationship, carer strain
- Work related stress





The  
University  
Of  
Sheffield.

# What mediates financial burden?

- Disease stage
- Intensity of caregiving
- Ethnicity
- Socio-economic status
- Carer age





# Methods work

- Most previous research has used structured questionnaires
- No single tool available for measuring costs
- Most research based on recall and/or objective measures of cost
- Prospective, retrospective, longitudinal





# Methods work

- No overwhelming consensus on preferred methods, although on-line favoured by majority.
- Some sensitivities around discussing finances
- When does financial burden begin?

Research

## Methodological considerations for researching the financial costs of family caregiving within a palliative care context

Clare Gardiner,<sup>1</sup> Ruth Allen,<sup>2</sup> Tess Moeke-Maxwell,<sup>3</sup> Jackie Robinson,<sup>3,4</sup>  
Merryn Gott<sup>3</sup>

Gardiner C, Allen R, Moeke-Maxwell T, Robinson J, Gott M. Methodological considerations for researching the financial costs of family caregiving within a palliative care context. *BMJ Supportive & Palliative Care* 2016;6:445–451

Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Approaches to capturing the financial cost of family caregiving within a palliative care context: a systematic review. *Health & Social Care in the Community* 2015 doi: 10.1111/hsc.12253.



# Methods work

- Development of the COFAC questionnaire
- Work related costs; carer time costs; out of pocket costs; own health
- Versions for patients and carers

Research

## Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: development and piloting of a new survey tool

Clare Gardiner,<sup>1</sup> Chris McDermott,<sup>2,3</sup> Claire Hulme<sup>4</sup>

**ABSTRACT**

**Background** Family caregivers play an important role in the care of patients receiving palliative care, yet little is known about the financial impact of family caregiving in this context. A lack of existing validated tools for collecting data on the costs of family caregiving in palliative care has resulted in a weak and limited evidence base. The aim of the study was to describe the development and initial piloting of a new survey tool which captures data on the costs of family caregiving in palliative care: the Costs of Family Caregiving (COFAC) questionnaire.

**Methods** Development and piloting of the COFAC questionnaire involved 2 phases: (1) questionnaire development based on published evidence and cognitive interviews with service users; and (2) validity testing involving expert review and piloting with bereaved caregivers.

**Results** Questionnaire content was generated from previously published research and related to work-related costs, carer time costs and out-of-pocket expenses. 2 group cognitive interviews with 15 service users refined content of the draft questionnaire. Face validity was established through expert review with 9 academics and clinicians. Piloting with 8 bereaved caregivers established acceptability and feasibility of administration.

**Conclusions** The COFAC tool has been shown to be valid, acceptable to bereaved caregivers and feasible to administer. The COFAC questionnaire is recommended for economic research in palliative care which seeks to capture data from a broad societal perspective which includes family caregiver costs.

**Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjspcare-2016-001202>).**

<sup>1</sup>The School of Nursing and Midwifery, The University of Sheffield, Sheffield, UK  
<sup>2</sup>Sheffield Teaching Hospitals, Sheffield, UK  
<sup>3</sup>Sheffield Institute for Translational Neuroscience, University of Sheffield, Sheffield, UK  
<sup>4</sup>Academic Unit of Health Economics, University of Leeds, Leeds, UK

**Correspondence to** Dr Clare Gardiner, The School of Nursing and Midwifery, The University of Sheffield, Barber House Annex, 3A Clarkehouse Road, Sheffield S102UA, UK; [cgardiner@sheffield.ac.uk](mailto:cgardiner@sheffield.ac.uk)

Revised 13 July 2016  
Revised 18 January 2017  
Accepted 29 January 2017

**To cite:** Gardiner C, McDermott C, Hulme C. *BMJ Supportive & Palliative Care* 2017; doi:10.1136/bmjspcare-2016-001202

**BACKGROUND**  
Family caregivers play an important role in the care of patients approaching the end of life. Factors including demographic shifts, policy directives and a focus on home as the preferred place of death have resulted in an increasing proportion of palliative care provision shifting from inpatient facilities to community and family caregivers.<sup>1-3</sup> The expertise offered by family carers and wider communities is widely acknowledged; however, little is known about the financial impact of family caregiving specifically within a palliative care context. The financial costs of caregiving are known to be substantial; a recent UK report estimated that the economic value of the contribution made by carers is now £132 billion/year.<sup>4</sup> A recent systematic review on the costs of family caregiving at the end of life identified a limited evidence base but suggested that costs could be significant. These costs comprised direct financial costs as well as assumed or indirect costs incurred through lost employment, caregiver time investment and lost opportunities for leisure.<sup>4</sup> A review of financial stress and strain in terminal cancer found that financial stress was a common consequence of terminal cancer and featured in the top three concerns of patients.<sup>5</sup> The effects of financial burden are notable and have been found to include increased worry, difficulties coping, family conflict, caregiver strain and an inability to function “normally”.<sup>6</sup> Despite this mounting evidence base, research on the economic impact of family caregiving in palliative care remains limited. A recent study from Canada noted the narrow viewpoint that the majority of economic analyses in palliative care have taken, highlighting that they are generally limited to the measurement of publicly financed care without consideration of the considerable costs

**BMJ** Gardiner C, et al. *BMJ Supportive & Palliative Care* 2017;0:1-7. doi:10.1136/bmjspcare-2016-001202 **1**



© The University of Sheffield 2017. Cite as: Gardiner C, McDermott C, Hulme C. Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: development and piloting of a new survey tool BMJ Supportive & Palliative Care 2017 doi:10.1136/bmjspcare-2016-001202

### Costs of Family Caregiving (COFAC) Questionnaire:

A questionnaire to explore the financial and emotional costs of caregiving in palliative care

Carer Questionnaire (to be completed by caregivers with a researcher to assist): Baseline Interview

*'Carers may or may not be family members, they are lay people in a close supportive role who share in the illness experience of the patient and undertake vital care work and emotional management'*

Participant ID: \_\_\_\_\_  
Date of completion: \_\_\_\_\_

© The University of Sheffield 2017

### Section 3: Caregiver Time costs

19. Do you live with [patient]?

Yes  No

If no, how much did you spend over the last month on travel to visit [patient]?

Cost of Public Transport	£
Cost of taxis	£
Cost of parking	£
Miles travelled in your own car	Miles:

20. Over the last month, how many hours of care have you provided each week for [patient]?

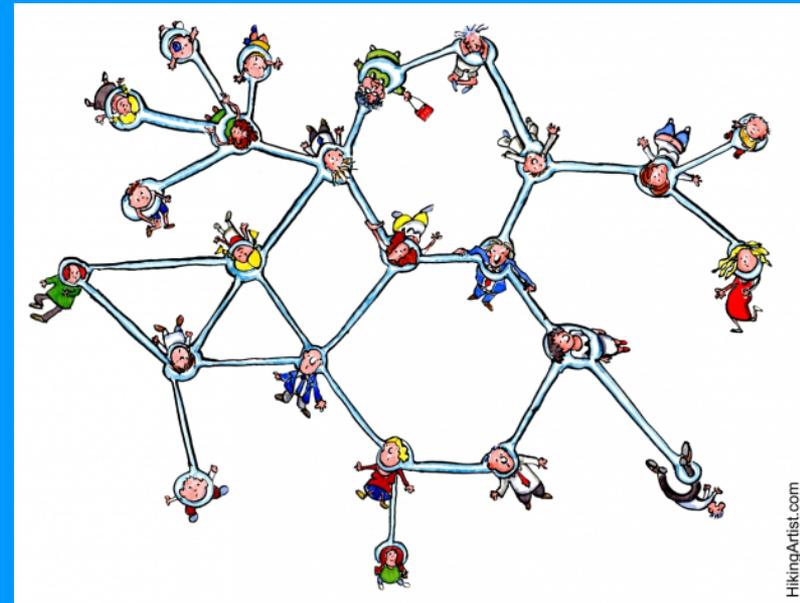
Type of caregiving	Hours per week, over the last month
Personal care (washing, feeding, moving etc)	
Making appointments and taking to/from appointments	
Household tasks (washing, cleaning, shopping etc)	
Managing finances or other paperwork	
Collecting prescriptions	
Spending time together/with family	
Other	



The  
University  
Of  
Sheffield.

# Costs related to a palliative care approach

- Four broad domains:
  - hospital care,
  - community or home-based care
  - hospice care
  - informal care
- Three economic viewpoints:
  - Government
  - Insurers/third-party/not-for-profit
  - Patient and family and/or society



**Table 4.** Framework outlining perspectives of economic evaluations in palliative care and components of their related costs.

Perspective	Types of cost	Components of cost	References	
Patient and family and/or societal State/publicly funded health services Third-party/private sector/not-for-profit organisations	Hospital	Inpatient hospital admissions/bed days	8, 11–21, 23–26, 28–34, 40, 42–47	
		Personnel costs	13, 14, 40, 46	
		Medical supplies, equipment and aids, etc.	8, 13, 14, 29	
		Inpatient procedures (surgery, chemo, etc.)	13, 14, 17, 29	
		Investigations, laboratory and diagnostic costs	8, 13–15, 17, 29, 43	
		Drugs and medications	8, 12–15, 40, 46	
		Outpatient hospital admissions	8, 12, 13, 15–17, 21, 29, 30, 32–35, 38, 47	
		ER visits	8, 12–14, 16, 21, 23, 30, 32, 43, 46, 47	
		Ambulatory costs and transport	8, 13, 14, 18–20, 43, 44	
		Hospital day care	12–14, 17	
		Outpatient procedures (chemotherapy, etc.)	12–14, 43	
		Chinese and herbal medicines	15	
		Overhead costs (building costs and capital depreciation)	40	
		Palliative care unit admission	38, 46, 49	
		Palliative care outpatient clinics	24, 38, 49	
	Community/ home-based	GP/family physician surgery visits	8, 13, 14, 17, 21, 23–26, 31, 34, 39–41	
		Medical and nursing home visits (GP, DN, etc.)		
		Allied health home visits (physio, OT, mental health)	8, 13, 14, 17, 21, 24, 26, 29, 30, 38, 40	
		Other home visits (social services, home care, other carers)	8, 13, 14, 26, 29, 30, 38	
		Drugs and medications	8, 11, 13, 14, 17, 26, 29, 30, 31, 33, 45	
		Medical equipment, aids and adaptations	8, 13, 14, 18–21, 24, 29, 31, 34, 40, 44	
		Day care services	8, 11, 13, 14, 18–20, 45	
		Stays in long-term care facilities, care homes, nursing homes, skilled nursing facilities	12–14	
		Transportation	8, 11, 18, 21, 28, 29, 32, 34, 44–46	
		Diagnostic tests, laboratory costs	13, 14, 18–20, 40	
		Personal support (bathing, feeding, dressing, home help)	8, 13, 14, 31	
		Other social services (meals on wheels, etc.)	13, 14, 26, 31	
		Nutritional counselling	11, 26	
		Dental services	31	
		Communication costs	29	
		Residential respite care and rehabilitation	40	
		Overhead costs	11	
	Direct payments made to users so they can 'buy' their own services			
	Hospice and specialist palliative care	Inpatient hospice stays/bed days	8, 13–16, 21, 29, 30, 32, 34, 45	
		Personnel costs	13, 14	
		Medical supplies	13, 14, 31	
		Inpatient procedures	13, 14	
		Investigations, laboratory and diagnostic costs	13, 14	
		Drugs and medications	13, 14, 31	
		Equipment and aids	13, 14, 31	
		Outpatient appointments and visits	13, 14, 16	
		Home hospice	12–14	
		Home visits from specialist palliative care	13, 14, 21, 24	
		Start-up costs, e.g., for new community palliative care nursing service	40	
		Informal care	Home caregivers	8, 13, 14
			Household help	13, 14
	Equipment, aids, home adaptations		8, 13–15	
Medications	8, 13, 14			
Insurance payments	8, 13, 14, 9			
Travel and accommodation expenses	8, 13, 14			
Out-of-pocket expenses (parking, food/drink)	8, 13, 14, 18–20, 29, 47			
Income lost from work	8, 13–15, 18–20			
Caregiver time costs	8, 13, 14, 18–20, 47			
Co-payments, e.g., shared with insurer/other	33			

ER: emergency room; GP: general practitioner; OT: occupational therapist.



The  
University  
Of  
Sheffield.

# Costs of palliative care in the UK

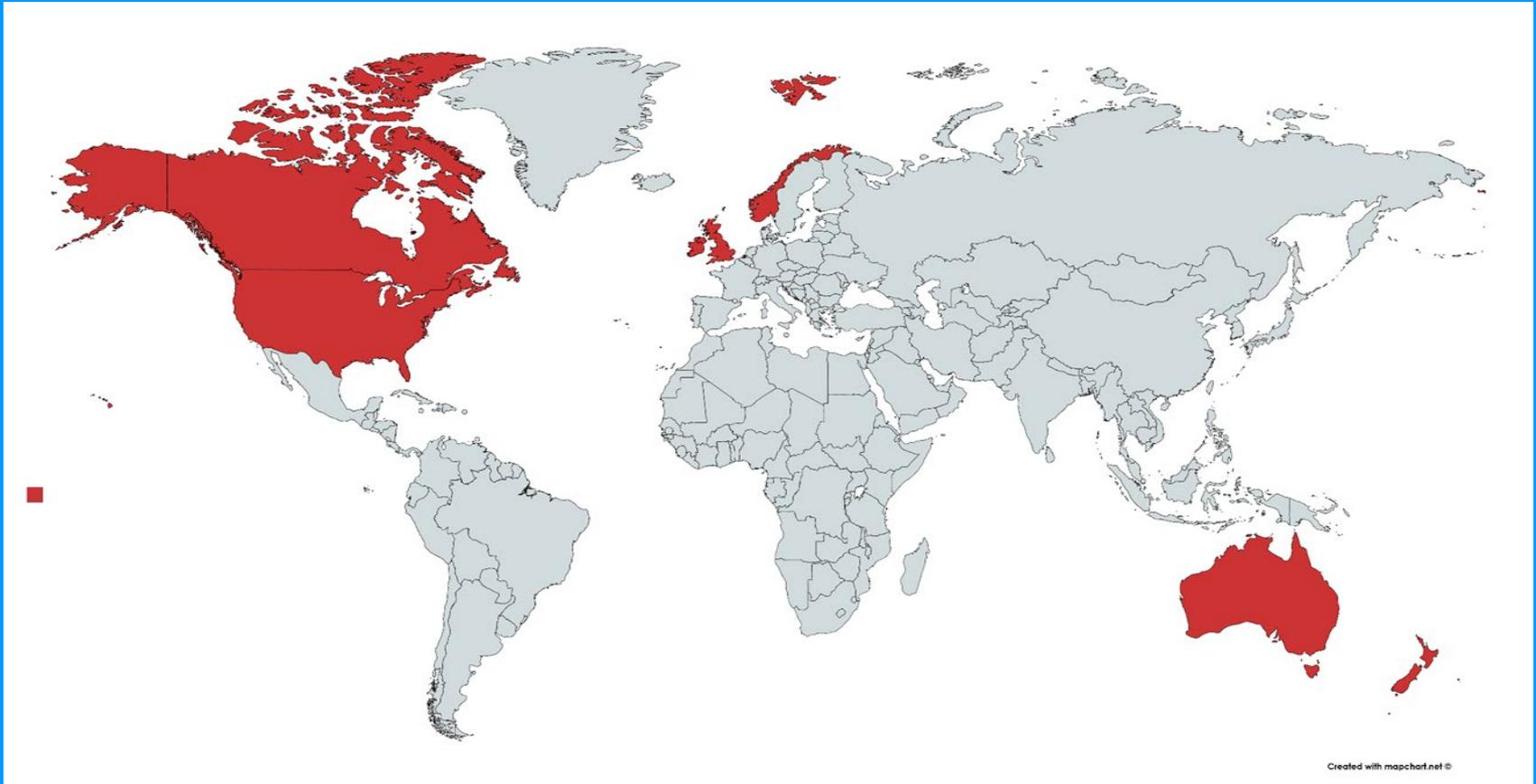
- Costs ranged from £4237 - £38 377 for last year of life
- Ten studies, only two included informal costs
- Both of these found informal care to represent a significant % of the total cost



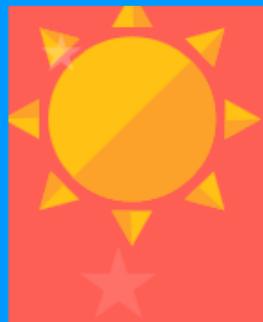


The  
University  
Of  
Sheffield.

# Availability of financial support



Gardiner C, Taylor B, Robinson J, Gott M. Comparison of financial support for family caregivers of people at the end of life across six countries: a descriptive study. Palliative Medicine (in press)



# Support for the time commitment of caring



## Financial Support for Patient

Some form of disability allowance available in **all countries**. Can be fast-tracked but applications complex.



## Financial Support for Carer

Only in **Australia, Canada, UK, Ireland**. Canada only country to offer specific end of life benefit. Applications complex.



## Bereavement/Funeral Support

Some support available, but usually means tested.

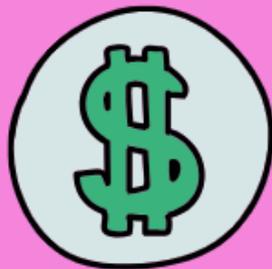
"There are numerous constraints and requirements for any of the benefits listed here"

# Support with employment related rights & support



## Protection of Employment Rights

In Ireland, Canada, UK and the USA carers have employment protection, but conditions apply.



## Pension/Tax Credits

Very variable, many schemes are potentially available but eligibility criteria are numerous and complex.



## Working Carers

Supporting working carers to remain in the workforce has many benefits, yet currently **support structures are not adequately configured** to support this

# Support with out of pocket costs



## Home Adaptations

Available in all countries, but conditions apply. Significant variation between and within countries e.g. in **Canada/UK** variations between province/region



## Energy/Utility Bills

Very limited coverage. Grants do not usually cover full cost.



## Grants

Available in all countries, aimed at those facing financial hardship. Often cancer focused.



## Travel Costs

Most generous in countries with large rural/remote populations e.g. **New Zealand, Canada, Australia**. Does not always include carer.



## Food & Accommodation

Similar to 'travel costs'. Mainly restricted to those living considerable distance from healthcare provider

# Support with costs of healthcare



## Costs of Healthcare

'Safety nets' in countries without free healthcare, if deemed 'palliative'.



## Carer Respite

Generally very limited capacity, and variable by region.

"Respite home care is very limited and many carers miss out"



## Prescription & Medication Costs

Usually free for those deemed 'palliative' or with very high usage.



# Work I haven't done...

- Prospective study of costs of caring in the UK
- Carers tracked over 6 months, monthly assessments of costs using COFAC
- Qualitative arm to explore impact of costs



# What perspectives do I bring?

- Breadth of prior knowledge in area
- Interest derived from research into 'inequalities'
- Qualitative/mixed methods expertise



The  
University  
Of  
Sheffield.

# What do I hope to achieve from the workshops?

- Ideas for bids
- Collaborative relationships
- Opportunity to develop international networks



# References

- Gardiner C, Allen R, Moeke-Maxwell T, Robinson J, Gott M. Methodological considerations for researching the financial costs of family caregiving within a palliative care context. *BMJ Supportive & Palliative Care* 2016;6:445–451
- Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L, Gott M. Approaches to capturing the financial cost of family caregiving within a palliative care context: a systematic review. *Health & Social Care in the Community* doi: 10.1111/hsc.12253.
- Gardiner C, McDermott C, Hulme C. Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: development and piloting of a new survey tool *BMJ Supportive & Palliative Care* 2017 doi:10.1136/bmjspcare-2016-001202
- Gott M, Gardiner C, Alen R, Moke-Maxwell T, Robinson J. No matter what the cost: A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context. *Palliative Medicine* 2015 Jun;29(6):518-28
- Gardiner C, Ingleton C, Ryan T, Ward S, Gott M. What cost components are relevant for economic evaluations of palliative care, and what approaches are used to measure these costs? A systematic review. *Palliative Medicine*. 2017 31(4):323-337.
- Gardiner C, Ryan T, Gott M. What is the cost of palliative care in the UK? A systematic review. *BMJ Supportive & Palliative Care* 2018. 8(3):250-257
- Gardiner C, Taylor B, Robinson J, Gott M. Comparison of financial support for family caregivers of people at the end of life across six countries: a descriptive study. *Palliative Medicine* (in press)



The  
University  
Of  
Sheffield.

# Thank you

[c.gardiner@sheffield.ac.uk](mailto:c.gardiner@sheffield.ac.uk)

[@claregardiner8](https://www.instagram.com/claregardiner8)