



This is a repository copy of *Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature.*

White Rose Research Online URL for this paper:  
<http://eprints.whiterose.ac.uk/90853/>

Version: Accepted Version

---

**Article:**

Gardiner, C., Brereton, L., Frey, R. et al. (2 more authors) (2014) Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. *Palliative Medicine*, 28 (5). 375 - 390. ISSN 0269-2163

<https://doi.org/10.1177/0269216313510588>

---

**Reuse**

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.



[eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk)  
<https://eprints.whiterose.ac.uk/>

**Exploring the financial impact of caring for family members receiving palliative and end of life care: A systematic review of the literature**

Clare Gardiner, Louise Brereton, Rosemary Frey, Laura Wilkinson-Meyers, Merryn Gott

Dr Clare Gardiner (corresponding author)

Senior Lecturer

School of Nursing

The University of Auckland

Private Bag 92019, Auckland

C.gardiner@auckland.ac.nz, Tel: +64 9373 7599 ext 89573

Dr Louise Brereton

Research Fellow

School of Health & Related Research (SchARR)

The University of Sheffield, Sheffield, UK

Dr Rosemary Frey

Research Fellow, The University of Auckland, Auckland, New Zealand

Dr Laura Wilkinson-Meyers

Lecturer in Health Services Research, The University of Auckland, Auckland, New Zealand

Prof Merryn Gott

Professor of Health Sciences

The University of Auckland, Auckland, New Zealand

Keywords: palliative care; family caregiver, informal carer; financial impact; economic impact

### **What is already known about the topic?**

- To date, research regarding the economic dimension of palliative and end of life care provision has been relatively limited.
- The importance of family care givers has long been recognised within palliative care.
- The economic repercussions of caring within a palliative care context remain 'relatively neglected' at a policy and research level.

### **What this paper adds?**

- Evidence relating to the costs and implications of caregiving is relatively limited.
- The review identified 21 studies relating to the costs and implications of caregiving in a palliative care context
- The financial costs of caring for someone at the end of life are substantial.
- Financial costs can result in significant and multidimensional caregiver burden; various factors mediate the extent of financial burden.

### **Implications for practice, theory or policy?**

- This review identified a significant gap in the evidence base regarding the economic implications of providing care to a family member within a palliative care context.
- Further research is required to explore these economic costs
- Policy initiatives across much of the developed world to move the provision of palliative care from hospital to community settings should be mindful of the significant costs incurred by family caregivers.

### **Background**

Most developed countries will face a common challenge over coming decades in terms of how to improve palliative and end of life care provision to meet the needs of rapidly ageing populations. An almost two-fold increase in the number of people dying globally is predicted over the next 40 years; people are also expected to live longer and experience more complex health and social care needs as they approach the end of their lives. [1] It is therefore unsurprising that developing new models of palliative and end of life care to meet the needs of ageing populations has been identified as a global public health priority by the World Health Organisation. [2] A key challenge will be developing models of care which are sensitive to global concerns about the future funding of health care in the face of a worldwide economic recession. [3]

To date, research regarding the economic dimension of palliative and end of life care provision has been relatively limited. Indeed, 'a weak and often inconsistent evidence base' has been identified as a barrier to developing optimal cost-effective palliative care services internationally. [4] Moreover, efforts to date have largely been concentrated on capturing the costs of statutory service provision

at the end of life, particularly those related to public hospital use. This is to be expected given that hospitalisations at the end of life are costly for health budgets. [5, 6]

There is also mounting evidence from the UK to suggest that reducing hospital use at the end of life, and supporting people to die at home, results in significant cost savings from the hospital perspective. [6, 7, 8, 9] However, the extent of the resulting financial trade-off in terms of increased community care costs is less certain. Indeed, no full economic evaluation of the costs of caring for someone with palliative care needs at home has been published. This would require an understanding not only the costs of community services, such as hospice and community nursing, but also of the costs incurred by family caregivers, a group for whom reducing end of life hospitalisations will have significant financial implications. [10,11]

Family caregivers have been defined as: 'Carers, who may nor may not be family members, who are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management'. [12] Family include 'those related through committed heterosexual or same sex partnership, birth and adoption, and others who have strong emotional and social bonds with a patient'. [10] The importance of family care givers has long been recognised within palliative care; however, the implications of undertaking a caring role have only recently begun to receive sustained research attention. [10] In particular, the economic repercussions of caring within a palliative care context remain 'relatively neglected' at a policy and research level. [13]

That significant economic costs are incurred by informal carers has been demonstrated within other contexts. For example, a review of the costs of informal caregiving for frail older people in Australia, the US, the UK, Canada and Germany concluded that 'the output informal carers provide (...) may be as high as the value recorded for formal care provision'. [14] The economic losses incurred by carer non-participation in formal employment were also identified as 'non-negligible'. Moreover, it has been estimated that annual costs of family caregiving in England and Wales account for between 50-160% of gross personal expenditure, and costs of family care in the USA may constitute twice that of nursing home care and more than six times that of formal care. [14]

It is within this context that a need to map and synthesise the current research evidence base regarding the economic costs of family caregiving within a palliative and end of life care context was identified in order to inform future research in this field.

## **Research aim**

1. To explore the financial costs of caring for family members receiving palliative/end of life care.
2. To explore the impact of financial costs on family members caring for those receiving palliative/end of life care.

## **Methods**

For the purposes of this review 'financial costs' are defined as any costs paid for by family caregivers of patients receiving palliative/end of life care, as a result of their caregiving responsibilities. Costs may be direct (e.g. medications) or may be incurred (e.g. loss of earning through absence from work). 'Financial impact' is defined as the impact or implications of the financial costs, to family caregivers. 'Family caregivers' are defined in line with the UK National Institute for Clinical Governance definition. [12]

We searched seven electronic databases (AMED; Cinahl; Cochrane; Econlit; Embase; Medline; Web of Knowledge) from inception to April 2012 using a search strategy devised by an Information Specialist in consultation with the authors (table 1). The strategy included MeSH headings and keywords related to the financial impact of caregiving at the end of life, search terms were refined following an initial scoping search. Reference lists of included studies were hand searched. Grey literature searches of the following organisations also took place: World Health Organisation, European Association of Palliative Care, Macmillan cancer care; Dimpleby cancer care; Cancer research UK; UK Department of Health; Kings Fund; NHS Carers Direct; Marie Curie Cancer Care.

**Table 1: Search terms**

1 palliative.mp. (51863) 2 Terminally ill/ or terminal illness.mp. (5985) 3 terminal ill\$.mp. (1385) 4 end of life.mp. (9165) 5 end-of-life.mp. (9165) 6 last year of life.mp. (292)	Palliative search terms
8 home based.mp. (3949) 9 home nursing.mp. or Home Nursing/ (8541) 10 informal care giv\$.mp. (41) 11 lay carers.mp. (43) 12 informal support.mp. (348) 13 community based support.mp. (83) 14 personal assistance.mp. (209) 15 spousal support.mp. (130) 16 spousal caregiving.mp. (25) 17 ((spous\$ or family or home) and care\$).mp.	Home based search terms
19 financial cost\$.mp. (1368) 20 economic cost\$.mp. (2620) 21 financial burden.mp. (1479) 22 financial stress.mp. (198) 23 financial strain.mp. (310) 24 cost assessment.mp. (137) 25 economic assessment.mp. (409) 26 economic evaluation.mp. (4174) 27 economic implication\$.mp. (1289) 28 cost implication\$.mp. (811) 29 cost of care.mp. (2626) 30 indirect cost\$.mp. (3085) 31 direct cost\$.mp. (3724) 32 illness cost.mp. (37)	Financial search terms
<b>Total</b>	458
<b>Duplicates removed</b>	<b>252</b>

CG and LB independently screened titles and abstracts of all articles to identify those which met the study inclusion criteria. Study inclusion criteria were: papers relating to the financial costs and implications of caring for family members receiving palliative/end of life care; English language papers; empirical research or systematic reviews published in full (including research articles, theses and other grey literature); papers relating to adults (paediatrics excluded as the implications of palliative caregiving for children are complicated by the expected financial implications of caregiving for healthy children). After initial sifting 'publication date within the last 20 years' was added as a further inclusion criteria, in recognition that articles published before this time were unlikely to have financial relevance today.

Full texts of all included articles, and any where there was disagreement, were further independently screened by two of the five authors (CG, LB, MG, RF, LW-M). Studies were again assessed to identify those which met the inclusion criteria, where there was lack of consensus a third person acted as arbitrator. Details of included studies were extracted onto pre-defined forms. Data were extracted regarding the financial costs of caring for family members receiving palliative/end of life care, and the financial implications of caring for family members receiving palliative/end of life care. This paper presents data on the financial costs and financial impact of caring for a family member at the end of life, a second paper will present data on the tools and methods of data collection.

As it was anticipated that the included studies would have diverse methodologies, the review was conducted using a descriptive thematic method for systematically reviewing and synthesising research from different paradigms. Advantages of thematic analysis include allowing clear identification of prominent themes, and providing organised and structured ways of dealing with the literature. [15] The thematic approach was based on predefined categories relating to the two research aims, but also allowed a data driven approach identifying other major or recurrent themes relating to economic costs and implications of family caregiving. Within each theme, both supporting and conflicting data were reported if available

The process of evaluating overall quality of studies is the cause of some debate in the literature, particularly when integrating evidence from diverse study designs. [16] In this review, quality appraisal of studies was undertaken according to principles laid out by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI). EPPI provide a framework for comparing diverse subject matter and varied study design. Studies were assessed according to trustworthiness (methodological quality), methodological relevance (appropriateness of study design for the review question) and topic relevance (the extent to which the paper addressed the review topic) [17]. Quality appraisal is detailed in table 2.

Many papers reported actual costs of caregiving, in local currency. Costs are not reported in this paper due to the significant variation in currencies, and changes in exchange rates since the research was undertaken.

## **Results**

Search results are summarised in the adapted PRISMA flowchart in figure 1. Twenty one studies met our inclusion criteria, 15 of these were quantitative research, three were qualitative research, two were systematic reviews, and one study used mixed methods. The studies were set in a range of countries with differing healthcare systems and different funding mechanisms for healthcare. The 21 articles presented data from 17 studies. Quality appraisal indicated variable relevance and rigour amongst the studies, however all met acceptable standards and none were excluded from the review. The studies by Dumont 2009 [18], Dumont 2010 [19] and Jacobs 2011 [20] should be singled out as demonstrating the highest relevance, with good methodological rigour. The studies by Covinsky 1994 [21], Covinsky 1996 [22] and Emmanuel 2000 [23] also used rigorous methods with relevant aims, however data were collected during the 1990's and this limits relevance. The characteristics of these studies are described in table 2. The results are presented under three key themes relating to the research aims: financial costs of caregiving; financial implications of caregiving; and factors mediating financial burden.

### *Financial costs of caregiving*

Numerous financial costs related to caregiving were identified. Costs can be categorised into three main areas: work related costs (costs related to changes in the caregivers employment); out of pocket expenses (direct outlays of money by caregivers); and carer time costs (costs related to time investment required by carers). In terms of work related costs, a number of papers reported that carers had either given up work, reduced hours at work, or used annual leave or sick leave to cope with the demands of caregiving. [24,25,26,27,28,22,29,30] Only one paper presented conflicting evidence; in their large Australian study of bereaved carers Abernathy et al., (2009) reported that carers rarely had to give up work and less than 10% reduced work hours. However, financial burden was reported by one quarter of those providing high intensity care, and this burden was found to be related to intensity of caregiving. [31]

Out of pocket expenses were identified by many of the included studies. A wide range of out of pocket expenses were described as a result of caregiving including costs of medical equipment, prescription and non-prescription drugs, nursing home expenses, private home care, travel expenses, and child care costs. [24, 25, 27, 30, 32, 33, 18, 20, 23, 34 ] The nature and extent of these costs varied significantly by country, depending on the funding system for palliative care. Some studies from the US for example, reported costs including the payment of insurance premiums, as well as some physician and medication costs. [27, 32] Some studies described carers selling assets or taking out loans to cope with the cost burden of providing care. [21, 23] In contrast, studies from countries with comprehensive public funding reported less medication, physician and home care costs. [35]

Significant time investment is required by any carer of a patient at the end of life, and some studies attempted to quantify and cost this 'time investment' element. Dumont (2009) estimated that 66.4% of costs supported by the family were attributable to caregiving time. [18] Studies that attempted to quantify the proportion of total care costs met by informal caregivers varied widely in their reported costs, with estimates of caregiving ranging from 26.6% - 80% of total costs, again with wide variation across different countries. [31, 18, 34, 35 ] It is also worth noting that cost estimates may vary depending on the method used to capture costs. Andersson (2002) reported that the cost of

informal care calculated using a 'friction cost model' only amounted to 18% to 44% of the cost when a 'human capital approach' was used. [36]

### *Financial impact of caregiving*

The financial costs of caring for a loved one at the end of life had a significant impact on caregivers. Covinsky (1994) reported that severe caregiving burden was experienced by many families as a result of financial issues. Major life changes were often required due to the cost of the illness including moving house, delaying education, or delaying medical care for other family members. The financial burden often resulted in an inability to function 'normally'. [21] Other reported effects of financial burden included increased worry [28], difficulties coping [24], family conflict [27], and caregiver strain [32]. Covinsky (1996) explored the relationship between economic burden and preferences for care, and reported that economic hardship on the family was associated with family preferences for comfort care over life-extending care for their loved one [22]. Brazil (2010) reported on the impact of reducing work hours or stopping work due to caregiving, and described a resultant increase in work related stress. [37] The burden of providing care could also have a negative impact on the patient/caregiver relationship. [24] In an exploration of how a stress process model relates to care giving at the end of life, Waldrop et al., (2005) identified 'financial issues' as a secondary stressor in the model. Secondary stressors are those that flow from caregiving to other aspects of life, but do not entail the provision of care directly. [27]

### *Factors mediating financial burden*

Various factors were identified which mediated the impact or magnitude of financial burden. A number of studies reported that financial strain was associated with disease stage, with financial strain reported as worst in the end stages of disease. [25, 27, 23, 19] Financial burden was also related to intensity of caregiving, with the greatest financial burden seen in the carers of those with greatest care requirements. [31, 23 ] A number of studies explored the impact of ethnicity on the financial burden of caregiving. The majority of these studies reported that ethnic minority groups were more vulnerable to financial hardship than white Caucasian groups [28, 32]; however one study exploring differences between African-American carers and White caregivers reported no difference in the proportion of carers suffering from financial strain. [26 ]

Financial strain was also found to be associated with socio-economic status. Phipps (2003) reported that the more highly educated caregivers were, the more likely they were to say caregiving required work adjustments. [26] McGarry (2005) reported that those in the bottom quarter of the income distribution spent the largest proportion of their income on caring related out of pocket expenses. [38] Age of caregiver was also found to impact on financial burden. [21, 33] Increasing age offered increased protection from loss of family savings until the age 65 when it plateaued. [21] The major concerns for older people were losing the care recipient's pension after death and coping with nursing home costs. However they had fewer concerns about losing income as the caregiver had normally already retired. For younger caregivers concerns were focused on issues including losing out on work, increasing child care costs and difficulties managing a full time job with caring. [33 ]

## **Discussion**



This review used systematic methods to synthesise the current research evidence base regarding the costs of caring for family and friends within a palliative care context. Whilst a number of studies reporting data relevant to the costs and impact of family caregiving at the end of life were identified, none of the papers had this issue as their central focus. Indeed, all studies addressed the wider economic impact of palliative and end of life care, including costs borne by the patients themselves, the health care system, and insurers or charitable/voluntary providers. This indicates a considerable gap in the existing literature.

Nevertheless, and despite the variable quality of the evidence base, the papers identified by the review provide us with a considerable breadth of evidence relating to the significant economic impact of family caregiving at the end of life. The review clearly demonstrates that caring for a family member at the end of life is financially costly. Costs were identified across a wide range of domains but were focused in three main areas: work related costs, out of pocket expenses, and carer time costs. There was evidence that, for many caregivers, economic costs have significant negative implications for their own health and wellbeing. In some cases financial strain was even associated with family preferences for comfort care over life extending care [22]. It is not clear from this review if all out of pocket expenses were essential, or whether any could have been avoided. Those caring for a patient at the end of life may be financially and emotionally vulnerable, and willing to pay costs which may not actually be of benefit to the patient (e.g. non-prescription medications). This evidence supports a considerable body of literature which describes caregiving for a family member at the end of life as having negative outcomes for family care givers, although it is important to recognise that positive dimensions to caregiving have also been reported. [39]

The review also identified considerable inequity in the financial impact of caring for a family member at the end of life. Carers providing the highest intensity of caregiving and to those in the most advanced stages of disease were the most vulnerable to significant financial burden. The amount and type of care given by family caregivers is not generally static and often changes and develops throughout the disease trajectory. [40] Financial costs are likely to mirror these fluctuations in caregiving intensity. Careful monitoring of changes in caregiving over time may help in anticipating particularly intense periods of caring and financial strain, and subsequently enable early intervention to provide appropriate support and reduce carer burden. Carers from ethnic minority groups, those with low socio-economic status, and those from particular age groups may also be more vulnerable to financial burden. Inequity with relation to age [41], and ethnicity [42] are well documented in the palliative care literature. Older patients, patients from ethnic minorities, and patients from other minority groups are less likely to access palliative care services. This may have a knock-on effect for family caregivers who may be required to provide greater intensity of care to these patients, with resultant financial burden. Whilst this review identified a universal dearth of research relating to the financial costs of family caregiving within a palliative care context, specific gaps could also be identified. Most studies to date have been undertaken within a North American context; differences in funding models for palliative and end of life care limits applicability to other countries. It is important to recognise that any costs related to caregiving will be mediated by the system for health care funding in a particular country. Whilst the percentage of healthcare costs paid by the government in the UK and Sweden is over 81%, in the USA this falls to 45.1% [43]. This has clear implications for financial burden, whilst we were unable to make direct monetary comparisons in this review, the evidence did suggest that caregivers in countries with comprehensive public health care funding had fewer financial costs and burdens than those in the US. Further research should

explore cross country comparisons in more depth, including the impact of caregiving in low/middle income countries with developing health systems. More prospective, longitudinal data are needed to capture the fluctuating costs of caring across the disease trajectory, including costs following bereavement such as funeral costs and costs related to on-going health problems incurred by the experience of care-giving. The implications for practice should also be considered, on-going assessment of the financial impact on family caregivers may enable earlier intervention and provision of support, and prevent carer breakdown. Early interventions could include financial planning as part of a palliative care package of services, to aid family caregivers in planning and managing finances, and accessing sources of financial support. Finally, future research needs to be more cognisant of the differing approaches available to capture the economic costs of caring, and acceptable validated methods of capturing costs are required.

### **Strengths and limitations**

Whilst this review was undertaken rigorously using systematic methods, certain limitations must be acknowledged. Only English language papers were included in the review, therefore we cannot be completely confident that our searches were comprehensive. Whilst grey literature searches included the WHO and the EAPC, most sources were UK based, which may mean some international grey literature was missed. Rigour and relevance varied between studies, therefore generalisations should be considered with caution.

### **Conclusion**

This review has identified a significant gap in the evidence base regarding the economic implications of providing care and support to a family member within a palliative and end of life care context. Research to address this gap is urgently needed, particularly given policy initiatives in a number of developed countries to move the provision of such care from hospital to community settings. [44] So doing will place further pressure upon family caregivers who, according to the research reported in this review, already incur significant economic costs as a result of their caregiving role.

### **Funding**

This research was funded by the University of Auckland

### **Declaration of Conflicting Interests**

None

## References

1. Gomes B, Cohen J, Deliens L and Higginson IJ. International trends in circumstances of death and dying. In Gott M and Ingleton C (eds), *Living with Ageing and Dying: Palliative and End of Life Care for Older People*. Oxford: Oxford University Press, 2011, pp.3-18.
2. World Health Organisation (WHO). Cancer control knowledge into action: WHO guide for Effective Programmes. 2007. WHO, Geneva, Switzerland.
3. Hughes-Hallett T, Craft A, Davies C, Mackay I, Nielsson T. (2011). *Creating a fair and transparent funding system; the final report of the palliative care funding review*. London; The Palliative Care Funding Review.
4. Evans CJ, Harding R, Higginson IJ and on behalf of MORECare. 'Best practice' in developing and evaluating palliative and end-of-life care services: A meta-synthesis of research methods for the MORECare project. *Palliat Med*, 2013 doi: 0269216312467489
5. Holman A, Mandal U. *An assessment of the costs of end of life care for people with dementia. Full Technical Report*. Available at: <http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/technical-report-0210.pdf> (accessed 10.5.13)
6. Ward S, Gardiner C, Gott M, Cobb M, Ingleton C, Richards N. Economic Analysis of Potentially Avoidable Hospital Admissions in Patients with Palliative Care Needs. *Progress in Palliative Care* 2012; 20(3): 147-153
7. Chitnis X, Georghiou T, Steventon A, Bardsley M. *The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life*. 2012. The Nuffield Trust, London.
8. National Audit Office. *Identifying alternatives to hospital for people at the end of life*. London: NAO, 2008 National Audit Office. End of Life Care Report 2008 Accessed at [http://www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx) (accessed 10.5.13)
9. Abel J, Rich A, Griffin T, Purdy S. End of life care in hospital: a descriptive study of all inpatient deaths in 1 year. *Palliative Medicine* 2009;23:616-622.
10. Payne S. *The changing profile of the family caregivers of older people: a European perspective*. In: *Living with Ageing & Dying: Palliative and End of Life Care for Older People*. Eds: M. Gott & C. Ingleton. 2011 (p 149-157). Oxford University Press, Oxford, UK.
11. Robinson J, Boyd M, O'Callaghan A, Laking G, Frey R, Raphael D, Snow B, Gott B. The extent and cost of potentially avoidable admissions in hospital in-patients with palliative care needs. *BMJ Supportive & Palliative Care* (under review)
12. NICE (2004) *Guidance on cancer services: improving supportive and palliative care for adults with cancer: the manual*. London: NICE.
13. Hanratty B. (2011) *Costs of family caregiving*. In: Gott M, Ingleton C ed(s). *Living with ageing and dying: End of life care for older people*. Oxford, Oxford University Press.
14. Casey B. The Value and Costs of Informal care. Paper submitted to the Commission on Funding of Care and Support in response to its call for evidence. Available from: [http://www2.warwick.ac.uk/fac/soc/ier/news/casey\\_-\\_dilnot\\_commission\\_evidence\\_-\\_as\\_sent.pdf](http://www2.warwick.ac.uk/fac/soc/ier/news/casey_-_dilnot_commission_evidence_-_as_sent.pdf) (accessed 19.4.13)
15. Health Development Agency. *Integrative Approaches to Qualitative and Quantitative Evidence*. 2004 London: NHS Health Development Agency.
16. Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from [www.cochrane-handbook.org](http://www.cochrane-handbook.org). (accessed 5.5.13)
17. Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI). EPPI Centre Methods for Conducting Systematic Reviews. 2010, EPPI, London

18. Dumont S, Jacobs P, Fassbender K, Anderson D, Turcotte V, Harel F. Costs associated with resource utilisation during the palliative phase of care: a Canadian perspective. *Palliative Medicine*. 2009, 23(8): 708-717.
19. 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. *Palliative Medicine* 2010, 24(6):630-40.
20. Jacobs P, Dumont S, Turcotte V, Anderson D. Evaluating the economic loss of caregiving for palliative care patients. *Journal of Palliative Care* 2011, 27(3):210-5.
21. Covinsky, K.E, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Medical Association*, 1994; 272(23), 1839–1844.
22. Covinsky KE, Landefeld CS, Teno J, et al. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? *ArchIntern Med*. 1996;156:1737-1741.
23. Emmanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med* 2000; 132:451-459
24. Jo S, Brazil K, Lohfeld L, Willison K et al., Caregiving at the end of life: perspectives from spousal caregivers and care recipients. *Palliative & Supportive care*. 2007, 5(1): 11-17
25. Grunfeld E. Coyle. Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal* 2004, 170(2):1795- 1801
26. Phipps EB. Family care giving for patients at life's end: report from the cultural variations study (CVAS). *Palliative & Supportive Care*, 2003, 1(2): 165-170
27. Waldrop DP, Kramer, B.J., Skrentny, J.A., Milch, R.A., & Finn, W. Final transitions: family caregiving at the end of life. *Journal of Palliative Medicine* 2005 Jun;8(3):623-38
28. Hanratty B, Holland P, Jacoby A, Whitehead M. Financial stress and strain associated with terminal cancer - a review of the evidence. *Palliative Medicine* 2007;21(7):595-607
29. Chan AT, Jacobs P, Yeo W et al., The cost of palliative care for hepatocellular carcinoma in Hong Kong. *Pharmacoeconomics*. 2001; 19:947-953.
30. Guerriere DN, Coyte PT. The Ambulatory and Home Care Record: A Methodological Framework for Economic Analyses in End-of-Life Care. *Journal of Ageing Research* 2011. Article ID 374237, 11 pages, 2011. doi:10.4061/2011/374237
31. Abernethy A, Burns C, Wheeler J, Currow D. Defining distinct caregiver subpopulations by intensity of end-of-life care provided. *Palliative Medicine* 2009 Jan;23(1):66-79
32. Tilden VP. Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *Journal of the American Geriatrics Society*. 2004 52(4): 532-539
33. Parker D, Grbich C, Maddocks I. Financial issues in caring for someone with terminal cancer at home. *Aust J Prim Health* 2001; 7(2): 37–42.
34. Guerriere DN, Zagorski B, Fassbender K, Masucci L, Librach L, Coyte PC. Cost variations in ambulatory and home-based palliative care. *Palliative Medicine* 2010 Jul;24(5):523-32
35. McCrone P. Capturing the costs of end-of-life care: Comparisons of Multiple Sclerosis, Parkinson's disease, and Dementia. *Journal of Pain and Symptom Management* 2009 Jul;38(1):62-7

36. Andersson A. The economic burden of informal care. *International Journal of Technology Assessment in Health Care* 2002 18(1):46-54
37. Brazil K, Bainbridge D, Rodriguez C. The stress process in palliative cancer care: a qualitative study on informal caregiving and its implication for the delivery of care. *American Journal of Hospice and Palliative Care* 2010. 27(2):111-116.
38. McGarry K, Schoeni RF. Widow(er) poverty and out-of-pocket medical expenditures near the end of life. *J Gerontol B Psychol Sci Soc Sci* 2005; 60: S160–8.
39. Hudson P. Positive aspects and challenges associated with caring for a dying relative. *International Journal of Palliative Nursing*. 2004, 7(1): 19-25
40. Smith P & Skilbeck J. *Working with family caregivers in a palliative care setting*. In: Palliative Care Nursing: Principles and Evidence for Practice. 2008. 2<sup>nd</sup> Edition Eds: Payne S, Seymour J, Ingleton C. McGraw Hill, Maidenhead, UK.
41. Gardiner C, Cobb M, Gott M, Ingleton C. Barriers to the provision of palliative care for older people in acute hospitals. *Age & Ageing* 2011, 40: 233-238
42. N Ahmed, J E Bestall, S H Ahmedzai, S A Payne, D Clark, B Noble. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*. 2004 vol. 18 no. 6 525-542
43. The Organisation for Economic Co-operation and Development (OECD). Physicians and hospital beds per 1000 inhabitants vs Health Care Spending in 2008 for OECD Countries. 2008 <http://www.oecd.org>
44. Department of Health. *The End of Life Care Strategy for England*. 2008 Department of Health, London, UK.
45. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review: a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy*. 2005 10(Suppl 1): 2134

**Figure 1: Adapted PRISMA flowchart of studies**

Total number of titles identified through searches = 252

Excluded on basis of title/abstract = 225

Full text articles reviewed = 27

New texts identified through reference lists = 50

Total number of full text articles reviewed = 77

Excluded = 56  
*Excluded as full text unavailable = 1*  
*Excluded as not meeting criteria = 55*

**Articles included in review = 21**  
*Systematic reviews = 2*  
*Qualitative studies = 3*  
*Quantitative studies = 15*  
*Mixed methods studies = 1*

**Table 2: Characteristics of included papers**

Author, year, country of origin	Type of publication	Aims	Setting	Sample & sample size	Methods & analysis	Quality Appraisal	Relevant findings
Abernethy et al., 2009, Australia [31]	Research	To define caregiver subpopulations by intensity of care provided	General population, Australia	Random sampling of households. 5302 adults included who had lost a loved one to terminal illness in the previous 5 years. Data collected from 2001 to 2005.	General population cross-sectional survey, using a questionnaire tool previously developed/validated for palliative care service planning. Administered by face to face interview. Descriptive and analytical analyses.	Appropriate large cross-sectional study design. Data collected from up to 5 years previously so potential for significant recall bias. Limited relevance as of the complete survey only one question related to financial burden.	Financial burden is closely related to intensity of caregiving. A qu hands-on caregiving group indicated they had experienced financial this concern was less likely for the intermittent hands-on caregivers (6-9.2%) reported that caregiving had a severe financial impact on Caregivers rarely reported giving up work as a result of caregiving of all active caregivers reduced their working hours, and 3% in bo they used vacation or sick leave. 10% had to draw on savings/ sell caregiving.
Andersson A et al.,2002, Sweden [36]	Research	To discuss different models for estimating the cost of informal care in the home care setting in economic appraisals.	Hospital based homecare, Sweden.	All patients registered in a hospital based home care programme at one hospital during a one week period in Nov 1999. 39 patients and caregivers included.	Data collected via standardized form. Data collected on length of time and amount of time per day spent providing care. Different economic models used to estimate indirect costs.	Small opportunistic sample. Not including people not receiving formal homecare. Limitations in data, but sophisticated analysis.	Informal care is an important component of home care. Indirect c by the 'friction cost model' only amount to 18% to 44% of the cos 'human capital approach' is used. Regardless of the model used to costs, the cost of informal care in evaluations of home care progr underestimated due to the exclusion of indirect costs.
Brazil K et al., 2010, Canada. [37]	Research	To examine how the comprehensive nature of the Stress Process Model could elucidate on the stressors associated with caring for a palliative cancer patient	Community setting, Ontario, Canada	12 bereaved family caregivers of people aged >50 years who had received home based palliative cancer care.	Qualitative semi-structured interviews. Topics included formal services used; informal supports; and caregiving experience. Constant comparative analysis, informed by the domains of the Stress Process Model.	Small qualitative study, therefore generalizability of findings unlikely. Reasonable relevance although focus of study was 'stressors' not financial burden.	Financial & work related stress identified as a secondary stressor. reported financial stress associated with caring for the recipient. financial stress with purchase of private home care to supplement Several caregivers reported the stress of continuing to work while caregiver. In 2 instances carers reduced work hours or stopped w altogether.
Grunfeld et al.,2004, Canada [25]	Research	To measure the psychological, occupational and economic impact of caring for a person with a terminal illness.	Two regional cancer centres, Canada	89 family caregivers of breast cancer patients receiving palliative care	Prospective survey of caregivers. Assessments every 3 months, and every 2 weeks when patients entered the terminal phase. Followed until death or study completion at 3yrs. Economic data collected administered questionnaire	Prospective design a strength, but high attrition limiting power of stats to detect small changes over time. Good relevance although economic impact only one component of three, and only included cancer	No significant change in caregiver employment status between pa and terminal period. But more caregivers missed work in the term than in the palliative period. Caregivers reported an increased ina regular hours in terminal phase. Prescription drugs were the mos source of economic burden. Higher financial burden for those with health insurance than those with.

Guerriere DN et al., 2010, Canada [34]	Research	1) To assess the societal costs of home-based palliative care; 2) to examine socio-demographic and clinical factors accounting for variations in costs	Community palliative care centre, Toronto, Canada	136 family caregivers of patients with cancer	Prospective cohort study. Participants interviewed every 2 weeks from admission to death, and asked to report on resource utilisation over previous 2 weeks. The Ambulatory & Homecare Record (AHCR) was used to collect data.	Questionable accuracy of methods used to derive costs (some approximations were used), otherwise strong prospective design. Good relevance although focus was societal costs rather than caregiver costs, and only included cancer	Mean total monthly costs of care were \$25,549 per patient. Broken down into public expenditure, \$698 (private out of pocket costs), \$172 (3 <sup>rd</sup> party) and \$17452 (caregiver time costs). Total costs incurred by family caregivers represented the largest proportion (71%) of total costs. Regression analysis identified predictors of total cost; living alone; poor functional status; and time spent in hospital.
Guerriere DN et al., 2011, Canada [30]	Systematic Review	To address methods used to assess end of life costs.	No geographical restrictions on systematic review	n/a	Systematic review to identify all studies between 1998 and 2009 that have assessed economic outcomes in end of life care.	Strong review design, but aim was to explore methods, rather than actual impact or burden.	18 papers identified, but few included costs incurred by family members. Those that did were not comprehensive. Only 1 study included costs of time losses from labour market, and 3 studies costs of out of pocket expenses. The review highlights a lack of standardised methods for capturing costs as time lost from labour market, lost income etc. Many studies failed to report costs.
Hanratty et al., 2007, UK [28]	Systematic review	To review evidence of the financial stress & strain for people with terminal cancer & their caregivers, to determine how common it is & identify consequences for health of the patient or caregiver	Review of international literature (13 papers from USA & 11 papers from outside USA.)	n/a	Systematic review of 4 databases from 1966 to June 2006, for studies that provided data on illness associated financial burden (stress), or perceived financial hardship (strain), from patients with terminal cancer.	Strong review design, but less relevance as focus is illness costs not costs of caring, and no inclusion of non-cancer carers.	24 papers identified. All US studies measured financial stress. Financial implications of illness included carer giving up job (10-40%). African-American carers reported higher levels of financial hardship than their white counterparts on all measures. One Australian study reported on financial burden of carers – more than half the carers had incurred extra costs. Loss of pension and costs of nursing home were potent sources of worry for spouses.
Jo S et al., 2007, Canada [24]	Research	To examine the perspectives of both the spousal caregiver and care recipient on the caregiving experience in home-based palliative care.	Home settings, Canada	10 spousal caregiver and care recipient dyads. Care recipients > 50 years and receiving palliative care. Recruited over 6 months in 2001.	Qualitative study. Separate home based interviews with caregiver and care recipient using 2 parallel interview guides. Analysed using predetermined coding template based on literature.	Small qualitative study, therefore generalizability of findings unlikely. Very limited detail on the financial costs & implications.	Caregivers reported financial stresses as one of many negative reasons for caregiving. Caregivers noted costs of medical equipment and drugs were common expenses. Some had difficulties/frustrations coping with the costs. Care recipients were aware of financial strain spouses were under.
McCrone P. 2009, UK [35]	Research	To examine the cost impact of providing care for people with advanced disease and to demonstrate these costs using data from studies of Multiple Sclerosis (MS), Parkinson's disease (PD), and dementia.	Various settings across the UK	Study 1 - 1942 members of MS Society. Study 2 – People with PD recruited from community based cohort (no numbers given). Study 3 – 132 people with moderate/severe dementia recruited with carers.	Secondary analyses of data from 3 studies. Study 1 – questionnaire survey Study 2 – service use costs recorded at 2 time points Study 3 – interviews at 3 time points to record service use and caregiver activity	Secondary reporting of existing studies, but reporting is poor. No details on numbers for study 2, no details of sampling for study 3. Difficult to ascertain relevance due to reporting issues.	Study 1 - People with more advanced MS had 'far higher' informal care costs. Study 2 – informal care accounted for 80% of total costs. Secondary care showed costs of both formal services and informal care increased with disease stage. Study 3 - Informal care amounted to 4 hrs/week for those in supported accommodation; 24 hrs/week for those living alone & 75 hrs/week for those living with carer. Mean costs at baseline (in 1997/8) were £542 (in supported accommodation). Informal care costs accounted for 6% of costs respectively.
Phipps et al.,	Research	To investigate	Cancer centre	37 African-American &	Caregivers interviewed at	Strong prospective	At baseline financial strain was similar in White and African-American caregivers.



2003, USA [26]		differences between African American and White caregivers in self-reported health, use of social support and resources, and emotional and financial strain when caring for a family member with advanced cancer.	in Philadelphia , USA	32 white family caregivers of patients with advanced lung or colon cancer, between Dec 1999 & July 2001.	baseline & at 8 month follow up. Interviews addressed caregiver emotional and financial strain, and various other measures. Quantitative statistical analysis	comparative design. Focus was comparison between groups rather than recording financial impact, but some financial data collected. Limited relevance to non-cancer.	(p=0.88). The more highly educated the caregivers were, the more likely they were to say caregiving required work adjustments. (p=0.006). At 8 months, 44% among caregivers of survivors, similar percentages of African-American and White caregivers reported care caused financial strain. Among caregivers of patients who had died, 44% reported having to quit work to provide care for the patient. 25% of family caregivers reported using most of their family's saving in caring for the patient.
Tilden VP. et al. 2004, USA [32]	Research	To examine the end-of-life experiences of elderly decedents dying out of the hospital and their family caregivers	Community setting in Oregon , USA	1189 family caregivers of decedents aged 65 and older who died of natural deaths in community settings between 2000 and 2002.	Quantitative telephone interviews 2-5 months post death. Two scales constituting Financial Burden and Hardship (Financial Hardship and Out-of-Pocket Expenses) in addition to a variety of other scales.	Large prospective design, but only 53% of the target population were interviewed when considering refusals and those who could not be located. Only explored community settings and focus was 'experiences' rather than financial impact	66.1% of caregivers experienced at least one financial hardship event. Out-of-pocket expenses were common for families, especially for medical services. 44% of ethnic minority decedents experienced more financial hardship than whites (P=0.007) but the same frequency of out-of-pocket expenses. Financial burden was associated with greater caregiver strain.
Waldrop DP et al. 2009, USA [27]	Research	To understand how caregivers make the transition to end-stage caregiving and to illuminate its unique aspects using a stress process model.	Hospice setting, USA	74 caregivers of a family member > 50 years who had been receiving hospice care for at least 2 weeks.	Qualitative semi-structured interviews exploring various areas including caregiving stressors, and resources. Continued until theoretical saturation.	Qualitative design limits generalizability, but large sample achieved saturation. Focus was transition to end stage caregiving and application of model, financial impact was secondary to this.	Financial strain was identified as a secondary stressor in the stress process model. All employed caregivers faced conflicts due to work and caregiving demands. Causes of financial strain compounded during the end of life. Unpaid deductibles and the cost of prescription drugs contributed to financial strain. Some family members left their job or moved house to become a caregiver. Some family conflict about who would support caregiver.
Chan ATC et al., 2001, Hong Kong [29]	Research	To determine patient-specific costs of palliative care of Hepatocellular carcinoma; and to identify factors that drive patient costs.	Teaching Hospital, Hong Kong	All patients (n=204) who presented to the hospital with inoperable HCC between June 1996-May 1997.	Patients prospectively tracked until death. Informal services and indirect costs were measured using personal interviews once/month until death or last follow-up.	Strong prospective design. Data collected 1996-1997 therefore costs and impact may have changed. Focus was a specific cancer, relevance to other conditions unclear. Setting Hong Kong and may have less relevance in Western settings.	11 caregivers reported loss of income, with a mean value of \$HK800. All other cost related to patients rather than caregivers.
Emmanuel EJ, 2000, USA [23]	Research	To determine the mechanism for economic and non-economic burdens of terminal illness and to identify potential ameliorating	Outpatient settings in six randomly selected US sites	988 terminally ill patients (<6 months prognosis) and 893 of their caregivers.	Surveys (by interview) of patients and caregivers. Questions on a range of topics including economic burden. Questions regarding economic burdens and financial expenditures on	Strong prospective design. Focus was economic burden of illness rather than of caregiving per se. Over 10yrs old so relevance may be reduced.	Substantial need for care was strongly associated with economic hardship. Caregivers with moderate/high care needs were significantly more likely to report moderate or great economic hardship for their family (44.9% vs 35.3%; P = 0.001); 10% of their household income was spent on health care costs other than insurance premiums (28.0% vs 17.0%; P <= 0.001); and that they/their family had to sell assets, take out a loan, or obtain an additional job to pay for care costs (16.3% vs 10.2%; P = 0.004).

		interventions.			health care were taken from previous studies.		
Dumont S et al., 2009, Canada [18]	Research	(a) identify and measure prospectively the goods and services used during the palliative phase; (b) estimate their costs; and (c) determine who paid.	Five urban centres in Canada	248 patients receiving palliative care and 243 of their informal caregivers.	Prospective questionnaire study with interviews on cost utilisation every 2 weeks until death or for 6 months. Questions on types and number of goods and services used, and who paid for them.	Strong prospective multi-site design with relevant focus on financial impact during palliative phase.	26.6% of all costs incurred by participants were paid by the family or public health care, 1.6% by charities, and 0.5% by other payers. (66.4%) of costs supported by the family was attributable to caregivers. The family also absorbed out-of-pocket cost (17.0%), and a part of cost for home medical equipment or aids (6.7%), and home care (4.4%).
Parker D et al., 2001, Australia [33]	Research	To examine the financial concerns of caring for someone with terminal cancer at home.	South Australia	Data collated from 136 carers and bereaved carers of cancer patients.	Mixed methods study involving interviews with carers, focus groups with bereaved carers and service providers, and a quantitative bereaved carer survey.	Recall based design may be subject to recall bias. Cancer focus so relevance to other conditions unclear.	59% of carers had incurred additional medication costs, 34% travel costs, 30% dietary supplements, and 21% other items. Many carers reported incontinence aids of up to \$10/wk, and increased laundry costs. Impact on lifestyle differed by age. For older people major concerns were: loss of recipients pension after death; concerns over nursing home costs. For younger people concerns included: increased child care costs; loss of income etc.
Covinsky KE et al., 1994, USA [21]	Research	To examine the impact of illness on the families of seriously ill adults and to determine the correlates of adverse economic impact.	5 hospital centres in the US	179 patients & 1950 surrogates of patients (total = 2129) presenting at hospital with a terminal diagnosis defined as <6 months life expectancy.	Prospective quantitative study. Patients/surrogates interviewed on admission to collect data on impact of illness and financial burden. Family Impact Interview also administered 2 and 6 months post discharge.	Strong prospective design, large sample and multi-site. Focus was caregiving burden rather than financial impact, nonetheless useful data was collected.	Severe caregiving burdens reported by many families. 31% of families lost part of their savings, and 29% lost their major source of income. Costs of care required 17% of families to change personal plans. Families who reported loss of savings to lose all or most of the family savings were younger (P<.001) and non-white (P<.05), had lower incomes (P<.001), and had worse functional status (P<.01) than patients not reporting loss of savings. Increasing age was associated with increasing protection on loss of family savings until age 65 years where it plateaued.
Covinsky KE et al., 1996, USA [22]	Research	To explore whether economic hardship resulting from a serious illness is associated with preferences to forgo life-prolonging care.	5 hospital centres in the US	3158 patients & surrogates of patients presenting at hospital with a terminal diagnosis defined as <6 months life expectancy.	Cross sectional design, two months following hospitalization interviews were conducted with patients and surrogates to learn about the financial impact on the patient's family, and patient's preference for goal of care.	Strong prospective design, large sample and multi-site. Focus was mediators of preferences for life-prolonging care, not financial impact.	Loss of most or all of the family savings was reported by 24% of subjects. Change in family plans because of the cost of the illness was reported by 27% of subjects. 27% of subjects reported at least 1 of these impacts and were considered to have suffered economic hardship. Economic hardship was associated with preferences for comfort care over life-extending care.
Dumont S et al., 2010, Canada [19]	Research	This study aimed to highlight the trajectory of palliative care costs over the last five months of life in five urban centres across Canada	5 urban centres in Canada	160 terminally ill patients and their main informal caregiver	Prospective questionnaire study. First interview in the patient's home, follow-up interviews by telephone at 2 week intervals until death. Information collected on goods and services used related to the patients' health condition, and on	Strong prospective multi-site design with relevant focus on financial impact during palliative phase.	Regarding informal care (defined as caregiving time provided by the family) there was an increase starting at the fifth month to the third month preceding death. The mean total cost related to caregiving time was about 10% higher in the third month preceding death, as compared to that of the fifth month preceding death. Thereafter a slight decrease (-2.0%) in the third to the last month of life.

Jacobs P et al., 2011, Canada [20]	Research	To provide a unified measure of economic burden faced by families during the palliative phase of care, and to compare this measure to Statistics Canada low income cut-off	5 Canadian urban regions	192 palliative care patients and their informal caregivers	informal caregiving time. Quantitative interviews every 2 weeks up until the patients death, or for 6 months. Details on expenses, time off work etc. Economic burden defined as normal income before caregiving, minus a monetary evaluation of time lost from work, and out of pocket expenses .	Strong prospective multi-site design with relevant focus on financial impact during palliative phase.	About 9% (n=17) of families incurred economic losses of 10% of their gross annual income. Low income status changed from 27 participants to 40 participants (after). Costs broken down into: out of pocket costs, and total loss. Most families (n=142, 74%) reported no loss of income. A majority of families (n=147, 77%) reported out of pocket costs between \$1-\$999, 127 (66.1%) families reported total losses of \$1-\$999, only 3 (1.6%) reported losses of >\$10,000.
McGarry K & Schoeni RF, 2005 USA [38]	Research	To investigate the gap in poverty, income, and wealth between elderly widows and older married people, with a focus on the role played by medical out-of-pocket (MOOP) expenditures spent on dying spouses	Community dwelling elders, USA	Community dwelling people >70 years and their spouses/partners. 271 widows and 3550 married couples.	Panel Survey of individuals and spouses/partners. Interviews in 1993 and then biannually. An exit interview undertaken for partners of individuals who have died, including medical expenses up until death.	Strong longitudinal design. Limited relevance as focus was older people (less relevance to younger caregivers) and on differences between widowed and married.	44% of the difference in economic status between widows and married persons was due to disparities in economic status that existed prior to widowhood. The remaining 56% was due to factors more directly related to the death of a spouse, including loss of income, nursing home costs, pharmaceuticals, drugs, physician charges & insurance premiums. On average, MOOP in the final 2 years of life were equal to 30% of a couple's annual income. For couples in the bottom quarter of the income distribution, expenditures exceeded income.