

## **Approaches to capturing the financial cost of family caregiving within a palliative care context: a systematic review**

### Abstract

The economic burden faced by family caregivers of people at the end of life is well recognised. Financial burden has a significant impact on the provision of family caregiving in the community setting, but has seen limited research attention. A systematic review with realist review synthesis and thematic analysis was undertaken to identify literature relating to the financial costs and impact of family caregiving at the end of life. This paper reports findings relating to previously developed approaches which capture the financial costs and implications of caring for family members receiving palliative/end of life care.

Seven electronic databases were searched from inception to April 2012, for original research studies relating to the financial impact of caregiving at the end of life. Studies were independently screened to identify those which met the study inclusion criteria and methodological quality of included studies was appraised using realist review criteria of relevance and rigour. A descriptive thematic approach was used to synthesise data. Twelve articles met the inclusion criteria for the review. Various approaches to capturing data on the financial costs of caregiving at the end of life were noted, however no single tool was identified with the sole purpose of exploring these costs. The majority of approaches used structured questionnaires and were administered by personal interview, with most studies using longitudinal designs. Calculation of costs was most often based on recall by patients and family caregivers, in some studies combined with objective measures of resource use.

Whilst the studies in this review provide useful data on approaches to capturing costs of caregiving, more work is needed to develop methods which accurately and sensitively capture the financial

costs of caring at the end of life. Methodological considerations include study design and method of administration, contextual and cultural relevance, and accuracy of cost estimates.

What is known about this topic

- Family carers play a pivotal role in supporting and caring for people in the community towards the end of life
- Caring for someone at the end of life in the community can place heavy demands on the financial resources of the caregiver and family
- Research regarding the economic dimension of palliative and end of life care provision is relatively limited.

What this paper adds

- Various approaches to capturing data on the financial costs of caregiving at the end of life were identified, however no single tool was identified with the sole purpose of exploring these costs.
- There was significant variation in design, method of administration and cost data.
- More work is needed to develop methods which accurately and sensitively capture the financial costs of caring at the end of life.

## **Background**

Research regarding the economic dimension of palliative and end of life care provision is relatively limited. A recent systematic review identified that one of the main challenges in developing and evaluating palliative care interventions was a poor understanding of economic impact beyond cost savings (Evans et al. 2013). The majority of research to date has focused on reducing costs relating to the use of statutory services (e.g. service costs/resource use). The extent to which savings for statutory services are shifted to increases in informal care costs is not known, and has received little research attention. However research from other disciplines including gerontology and mental health suggests that policy-driven increases in informal caring may be exploiting 'carers' as an economic resource (Molyneaux, 2011).

Family carers play a pivotal role in supporting and caring for people in the community towards the end of life. Whilst such a role is a rewarding experience for many, it is well recognised that caring can also bring about considerable burden (Grande & Keady 2011). A recent review of home based family caregiving at the end of life reported moderate to high carer needs in a range of areas including emotional and psychological difficulties, financial strain, and occupational disruption (Stajduhar et al. 2010). Caring for someone at the end of life can place heavy demands on the financial resources of the caregiver and family (Hanratty 2011). Our previous recent systematic review on costs of family caring at the end of life identified a lack of literature regarding this perspective, but nonetheless reported that the financial costs of caregiving were significant. Costs were identified in three main areas: work related costs; out of pocket expenses; and carer time costs. The burden of these costs was also significant, and a range of negative outcomes were associated with the financial burden of caring. The review concluded that there is a gap in the evidence base regarding the economic implications of caring for someone at the end of life (Gardiner et al. 2014).

The importance of assessing financial issues as part of a comprehensive assessment of carer support needs has been acknowledged (Ewing et al. 2013). Whilst tools such as the validated Carer Support

Needs Assessment Tool (CSNAT) can be used to identify carers at risk of financial burden and other issues, little attention has been paid to an accurate quantifiable assessment of these costs (Ewing et al. 2013). Our previous systematic review reported data on the financial costs and the financial impact of caring for family members receiving palliative/end-of-life care (Gardiner, 2014). This second systematic review with thematic analysis utilises the same data to report on previously developed approaches that aim to capture the financial costs from a carer perspective, and the implications of caring for family members receiving palliative/end of life care.

## **Methods**

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. 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 (table 1). Reference lists of included studies were hand searched. Grey literature searches of the websites of key international organisations also took place (e.g. World Health Organisation; European Association of Palliative Care; Marie Curie Cancer Care; The Kings Fund).

[inset table 1 here]

For the purposes of this review family caregivers were defined as: 'Carers, who may or 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' (NICE 2004, p55).

Family includes 'those related through committed heterosexual or same sex partnership, birth and adoption, and others who have strong emotional and social bonds with a patient' (Payne 2011, p150).

CG and LB independently screened titles and abstracts of all articles to identify those which met the study inclusion criteria (table 2). Full texts of all included articles, as well as those 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, and where there was lack of consensus a third person acted as arbitrator. Details of included studies were extracted onto pre-defined forms and data were extracted that related to approaches/tools that aim to capture the financial costs and implications of caring for family members receiving palliative and end of life care. This paper presents data on the tools and methods of data collection, a previous paper presented data on financial costs and financial impact of caring (Gardiner et al. 2014).

Initial scoping had indicated a diverse evidence base using a range of methodological approaches.

Therefore the review was conducted using a descriptive thematic method for systematically reviewing and synthesising research from different paradigms. There are various advantages of thematic analysis including allowing clear identification of prominent themes, and providing organised and structured ways of dealing with the literature (Health Development Agency 2004).

The thematic approach was based on predefined categories relating to the research aim, and other major or recurrent themes relating to these approaches. Within each theme, both supporting and conflicting data were reported if available

The methodological quality of the studies was assessed using realist review principles. These principles can be incorporated into systematic review methods (Pawson, 2005), and are able to take into account the value of multiple methods in the appraisal of diverse subject matter. The approach focuses on judgements regarding fitness for purpose. Studies were independently assessed according to relevance (the extent to which the paper addressed the review topic) and rigour (whether inferences drawn by the original researchers had sufficient weight to make methodologically credible contributions) (Pawson et al. 2005). Relevance and rigour are dimensions of fitness for purpose for a particular synthesis, in our case each paper was assessed and scored 0

(failed to meet criteria) or 1 (met criteria) for both relevance and rigour. Studies scoring 0 for either criteria were excluded as they were not deemed to demonstrate sufficient fitness for purpose.

[insert table 2 here]

## **Findings**

Search results are summarised in the PRISMA flowchart in figure 1. Fourteen studies met our inclusion criteria, 12 of these used quantitative research, one used mixed methods and one was a literature review. The majority of studies were from North America (six from Canada and four from the USA), with two from Australia, one from the UK and one from Hong Kong. The fourteen articles presented data relating to 11 approaches to capturing the costs of family caregiving. Following quality appraisal two studies were dismissed due to insufficient relevance to the research aim (Abernathy et al. 2009) and poor methodological rigour with regard to reporting (McCrone 2009). The remaining 12 studies met acceptable standards for relevance and rigour, with little variation between studies. The studies by Dumont et al. 2009, Dumont et al. 2010 and Jacobs et al. 2011 should be singled out as demonstrating the highest relevance to the research question. These studies also demonstrated good methodological rigour, using prospective longitudinal designs. The characteristics of all included 12 studies are described in table 3.

[insert figure 1 here]

### *Summary of different tools*

The review identified various approaches to capturing data on the financial costs and impact of caregiving for a family member at the end of life. However, no single tool was identified with the sole purpose of exploring these costs. All of the approaches were aimed at capturing the wider costs related to ill-health or end of life care, rather than costs related specifically to family caregiving at the end of life. As a consequence, most approaches only explored family caregiving costs in the context of a wider financial impact. Nonetheless, many of the approaches outlined useful techniques

for collecting data relevant to the financial impact of caregiving for someone at the end of life. These are summarised below.

Many authors developed new tools for capturing costs. The US SUPPORT study developed the Family Impact Scale (FIS) to explore the impact of terminal illness on the families of seriously ill adults. The FIS is a short questionnaire which captures caregiving burden but also explores financial impact. No information is given on the psychometric properties of this tool, however a previous article is referenced for more details of the methods (Covinsky et al. 1994). Guerriere et al. (2010, 2011) proposed the use of the Ambulatory and Homecare Record in the end of life context. This tool was developed by the authors to capture comprehensive costs on the provision and receipt of end of life care, from a societal perspective. It captures costs borne by the health care system as well as those borne by the patient and family caregiver. The psychometric properties were evaluated in previous research and AHCR is standardised and validated. Dumont et al. (2009, 2010) developed a Resource Utilisation Questionnaire which has been used in a number of studies (Dumont et al. 2009, Dumont et al. 2010, Jacobs et al. 2011). Whilst survey questions are in line with validated items from the Canadian Community Health Survey, no details are given about the psychometric properties of the questionnaire itself. The tool aims to capture resource utilisation and related costs at the end of life, estimate these costs and determine who paid. A study by Grunfeld & Coyle (2004) exploring the burden of caring for someone with terminal cancer used a range of standardized and validated tools to measure domains of burden. However as no existing tool existed to capture financial burden they developed a new additional questionnaire for this, which was the only component of their tool without psychometric testing (Grunfeld & Coyle 2004).

Some authors adapted or refined existing tools, rather than develop new approaches. For example Phipps et al. (2003) adapted questions from the Robinson Caregiver Strain Index, a previously validated tool for exploring caregiver burden. The Index was adapted to explore caregiver strain at the end of life in three specific areas: emotional burden; financial burden; and adjustments at work,

but did not undergo further testing for psychometric properties. Similarly Tilden et al. (2004) developed a 69 item questionnaire from existing sources including those used in the SUPPORT study. These items were combined with new items to gather data about a range of caregiver and decedent issues including caregiver burden and financial burden. The questionnaire was piloted but no further psychometric testing was undertaken. Emmanuel et al. (2000) developed a carer questionnaire using economic and financial items from The Boston Health Survey and the SUPPORT study, to explore a range of topics related to caring for a loved one at the end of life. Reliability and validity testing was undertaken prior to its use. A personal interview approach was developed by Chan et al. (2001), involving interviews with cancer patients in hospital. Whilst financial data were captured, few details were given about the nature of the interview and no data are presented on psychometric properties. Similarly Parker used a bereaved carer questionnaire, but few details were given about the psychometric properties or development of the questionnaire (Parker et al. 2001).

#### *Data collection methods*

The review identified various approaches to exploring costs related to family caregiving. The majority of studies used a structured questionnaire format to collect data from patients, current caregivers, or bereaved caregivers (Grunfeld & Coyle 2004, Guerriere et al. 2010 & 2011, Phipps et al. 2003, Tilden et al. 2004, Emmanuel 2000, Dumont et al. 2009 & 2010, Jacobs et al. 2011). As noted above, the majority of these questionnaires addressed the wider costs of caregiving rather than costs specific to end of life care. Some studies used personal interviews to ascertain financial costs and impact of caregiving. For example in a study on hepatocellular carcinoma, patient data were collected during personal interviews with nurses (Chan et al. 2001). The studies by Covinsky et al. (1994) and Parker et al. (2001) used a combined approach with personal interviews implemented alongside existing questionnaire tools to collect data on the costs of caregiving. Whilst Covinsky et al. (1994) used a structured quantitative interview in combination with a questionnaire, Parker used a



qualitative approach and combined focus groups and semi-structured interviews with a quantitative survey.

All of the questionnaires were administered by face to face interview with a researcher, rather than self-administered (Grunfeld & Coyle 2004, Guerriere et al. 2010 & 2011, Phipps et a. 2003, Tilden et al. 2004, Emmanuel 2000, Dumont et al. 2009 & 2010, Jacobs et al. 2011). However, some of the questionnaires had been developed with an option to be self-administered. (Guerriere et al. 2010 & 2011). All qualitative and personal interview approaches to collecting financial data were delivered via face to face interview (Parker et al. 2001, Covinsky et al. 1994, Chan et al. 2001).

The different approaches varied in when they were administered, and how often. While some approaches used a cross-sectional design and collected data at a single timepoint (Tilden et al. 2004, Emmanuel 2000), the majority adopted a longitudinal approach and collected data over a period of weeks or months (Grunfeld & Coyle 2004, Guerriere et al. 2010 & 2011, Covinsky et al. 1994, Dumont et al. 2009 & 2010, Jacobs et al. 2011). A common approach was to identify patients with life-limiting illness (and their family caregivers), and collect data at regular time points until the patients' death. For example Dumont et al. (2009 & 2010) and Jacobs (2011) conducted interviews with informal caregivers every two weeks up until a patients' death or for 6 months. Another notable variation was that some approaches collected data prospectively through the caregiving phase and sometimes into bereavement (Grunfeld & Coyle 2004, Guerriere & Coyte 2011, Phipps et al. 2003, Chan et al. 2001, Emmanuel 2000, Dumont et al. 2009 & 2010, Jacobs et al. 2011, Covinsky et al. 1994) whereas others gathered data retrospectively after a patient had died (Tilden 2004, Parker et al. 2001).

The approach used to record cost data also varied between different studies. The most common approach was based on recall and cost estimates by family members or patients, rather than the collection of actual cost data in real time. For example, in a study on hepatocellular carcinoma, patients were requested to estimate healthcare resources during personal interviews with nurses,

including estimates of the amount spent on medicine and supplies related to their illness, and the loss of income from work for both patients and carers (Chan et al. 2001). In studies using recall based approaches, the frequency of data collection varied. Whilst some designs collected data from patients and/or carers every two weeks (Dumont et al. 2009 & 2010, Jacobs 2011, Guerriere et al. 2010), in other studies cost data were not collected until some months after a patients' death (Tilden et al. 2004, Parker et al. 2001). In some studies, patient and/or carer recall data were combined with more objective sources of financial data such as resource utilisation costs and income (Dumont et al. 2009 & 2010, Jacobs et al. 2011).

[insert table 3 here]

## **Discussion**

It is notable from this review that no single instrument exists to accurately capture the financial impact of caring for a family member at the end of life. Despite this, the studies identified give valuable evidence regarding approaches and methods which may be appropriate, in addition to useful information about how such tools should be administered. The lack of research focus on family caregiving costs at the end of life indicates that the financial burden faced by informal carers in the community may have been overlooked to date.

The majority of tools used in these studies were administered by personal interview, either over the telephone or face to face. This method of data collection has been shown to result in higher response rates, more complete population sampling (Bowling 2005), and fewer missing data (Addington-Hall et al. 1998). However, the increased cost of personal interview methods and the possibility of positive response bias means that choice of administration method requires careful consideration (Addington-Hall et al. 1998). The majority of studies also adopted a longitudinal design, and collected data over a period of weeks or months. The discipline of palliative care has been criticised for its lack of longitudinal research with appropriate study design (Kaasa & DeConno

2001). Studies of this nature are often challenging in palliative care as attrition rates are high, and family carers may be facing considerable burden and distress (Higginson 2011). Nonetheless, prospective longitudinal designs have methodological advantages and are likely to result in the most robust and accurate data, therefore they should be considered as the first choice of design for financial impact studies.

The wide range of methods, study designs, and data collection tools used in the reviewed studies emphasise the complexity of financial considerations at the end of life. The lack of consensus regarding appropriate methods may also indicate that data collection techniques and tools are highly context specific, and that methods should be adapted so they are contextually and culturally appropriate. One such example relates to the definition of family caregivers in palliative care. The term 'carer' is not consistently defined within a palliative care context, not least by carers themselves who often do not perceive themselves to be in a caring role (Barnes et al. 2005). The studies included in this review had varied definitions for this term including 'informal carer' (Dumont et al. 2009 & 2010), 'family caregiver' (Emmanuel 2000) and 'home carer' (Parker et al. 2001). This highlights some of the difficulties that are faced when capturing data about a population who are ill-defined, and emphasises a need to ensure tools are locally validated and contextually relevant in order to accurately measure financial burden.

A further consideration with the tools described in this review is the assumption that a single person takes responsibility for the financial burden of family caregiving. However, for many patients the cost is spread across a large number of family, friends, and community members. This is a particular issue in cultures which place greater emphasis on the role of the wider family. For example in New Zealand, Māori (indigenous people of New Zealand) are supported and cared for by a large whānau (extended family group) at the end of life, with the cost burden often spread amongst group members (Moeke-Maxwell et al. 2014). Tools to capture costs at the end of life should be cognisant of this, and should attempt to capture data from all relevant parties. This may require a more

comprehensive data collection strategy involving a range of family and friends, but is important for ensuring accuracy of the cost estimate.

Methods for quantifying the cost of 'carer time' varied between the reviewed studies. The time investment required by family caregivers is often significant, and many carers give up work or leisure time to take on caring responsibilities. How this time investment is translated into a monetary cost is a subject of some debate. Estimations are often based on standard costs rather than on actual spend. For example Dumot et al. (2009 & 2010) estimated the cost of caregiver time by multiplying days of lost work by the average hourly wage for women in Canada, based on the assumption that most carers are women. However, the true cost burden of such time investment varies enormously across individuals according to factors including gender, income, resources, dependents and other time commitments. Research from carers of people with dementia recommends the measurement of time should also consider the associated satisfaction or utility of caring, and valuations of time should consider aspects of the caregiving experience which influence the valuation of time spent caring (McDaid 2001). More empirical work is required to elicit information on both the positive and negative satisfaction associated with caregiving and to incorporate this into valuations of the costs related to informal care, which acknowledge and capture significant individual variation.

## **Conclusion**

Whilst the studies in this review provide useful data on approaches to capturing the cost of caregiving at the end of life, no single instrument was identified which was aimed at specifically capturing these costs. More work is needed to develop methods which accurately and sensitively capture the financial costs of caring at the end of life. Methodological considerations include study design and method of administration, contextual and cultural relevance, and accuracy of cost estimates. These approaches should also be acceptable and feasible to use within this potentially vulnerable population.

## **Limitations**

Whilst this review used systematic search methods, some limitations should be acknowledged. It is possible that some research may have been overlooked during the searches, and as non-English language papers were excluded the findings may not be truly reflective of international literature. A non-traditional realist review approach involving judgements was used to assess methodological quality, therefore it is possible there may be some bias in the reporting of study quality.

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