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## **What is the cost of palliative care in the UK? A systematic review**

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### KEYWORDS

Economic; palliative care; cost; resource utilisation; systematic review

Word count: 3421

## **ABSTRACT**

**Objectives:** Little is known about the cost of a palliative care approach in the UK, and there is an absence of robust activity and unit cost data. The aim of this study was to review evidence on the costs of specialist and generalist palliative care in the UK, and to explore different approaches used for capturing activity and unit cost data.

**Methods:** A systematic review with narrative synthesis. Four electronic databases were searched for empirical literature on the costs of a palliative care approach in the UK, and a narrative method was used to synthesis the data.

**Results:** Ten papers met our inclusion criteria. The studies displayed significant variation in their estimates of the cost of palliative care, therefore it was not possible to present an accurate aggregate cost of palliative care in the UK. The majority of studies explored costs from an NHS perspective and only two studies included informal care costs. Approaches to estimating activity and costs varied. Particular challenges were noted with capturing activity and cost data for hospice and informal care.

**Conclusion:** The data is limited, and the heterogeneity is such that it is not possible to provide an aggregate cost of palliative care in the UK. It is notable that the costs of hospice care and informal care are often neglected in economic studies. Further work is needed to address methodological and practical challenges in order to gain a more complete understanding of the costs of palliative care.

## INTRODUCTION

Palliative care, in common with other health disciplines, is forced to compete with other areas of health care for limited financial resources. Demographic trends in the UK indicate that the numbers of patients with palliative care needs are increasing year on year. [1] As a result health care systems, such as the NHS in the UK, are under increasing pressure to deliver cost effective care to an expanding population. Health care decision makers need to maximize 'value for money' when commissioning palliative care services, yet data which underpin these decisions are lacking.

The palliative care sector in England has developed in an unconventional and often ad hoc way, meaning that the role of the state in funding services has not been clearly defined. As a result there are large variations in the levels of state funding provided, geographically as well as between services. [2] A recent study by Lancaster (2017) [3] on the commissioning of palliative care services in England collected data from 29 Clinical Commissioning Groups (CCG's) on the budget they allocated to palliative care. They found a wide variation in the budget allocation, ranging from £51.83 to £2329.19 per patient per annum. [3] They also found limited correlation between the palliative care needs of the population and the budget allocated to palliative care services, supporting concerns about a 'postcode lottery'. They suggest further work is needed to inform how CCGs calculate their budget allocations. [3]

Understanding the cost of palliative care services has been identified as a key research priority. [4] The 2011 Palliative Care Funding Review identified a 'stunning lack of data on the costs of palliative care in England', leading to concerns over how commissioning decisions are made. [2] More recently, concerns have been raised around the funding of hospices in the UK who on average receive a third of their income from the Government, with the rest coming from charitable earnings. [5] A 2015 survey of 117 hospices found that more than two thirds had their statutory funding frozen or reduced in recent years. Hospice UK warn that the lack of fair and sustainable funding is already having an adverse effect on hospice services, potentially leading to more pressure on already overstretched NHS services if hospices are forced to reduce the level of care they provide. [6]

Another significant component of the cost of palliative care is informal care costs, or the costs borne by patients and their family caregivers. Evidence from Canada and Finland suggests that informal care costs account for a significant proportion of the total cost of palliative care [7,8,9], yet data on these costs are lacking [10,11,12] and are rarely included in economic evaluations. [13]

One of the difficulties inherent in palliative care research is the complexity of the care approach, with care commonly provided in a range of settings with different funding arrangements. This complexity means it is practically and methodologically difficult to collect accurate and comprehensive cost data. Evidence is also lacking on the most suitable and feasible methods for estimating the costs of palliative care in a way that accounts for the full range of specialist and generalist services. [13] In order to address these concerns, the aim of this study is to review evidence on the costs of palliative care in the UK and to explore different approaches used for capturing cost and activity data.

## METHODS

The study design was a systematic review with narrative synthesis. For the purposes of the review a palliative care approach was defined as a comprehensive package of palliative care incorporating specialist and/or generalist elements. Specialist palliative care is provided by professionals who have undergone recognised specialist palliative care training and generalist palliative care is palliative care provided as part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. [14]

Four electronic databases (CINAHL; Cochrane; PSYCHINFO; Medline) were searched from 1997 to Oct 2017. The search was limited to the last 20 years in recognition of the rapidly changing nature of funding for health and social care. We developed a search strategy in consultation with an information specialist which comprised MeSH headings and keywords related to the research question (table 1). An initial scoping search helped refine the search strategy. Appropriate wildcards were used to search for word ending truncations where necessary. We hand searched the reference lists of included studies for additional relevant evidence. We also undertook a comprehensive grey literature search of the following UK government, charity and advocacy organisations: Marie Curie Cancer Care; Nuffield Trust; UK Department of Health; National Institute for Health and Care Excellence (NICE); the Kings Fund; National Audit Office (NAO); Office for National Statistics; National Council for Palliative Care; National End of Life Care Intelligence Network. The searches were undertaken in Nov 2015 as part of a wider study [13], and were updated in Oct 2017.

Palliative search terms	Palliative care Terminal care Terminally ill End of life care Hospice Life limiting
Cost search terms	Health expenditure Health care costs Costs and cost analysis Economic assessment Economic evaluation Economic implications Resource utilization Resource consumption Health care utilization Financial burden Financial stress Financial strain

Table 1: Search terms

Inclusion and exclusion criteria were devised by the authors (table 2). Title and abstracts were screened by CG and full texts extracted for all potentially relevant articles. Full texts were then independently reviewed by two of four experienced academics (including MG and TR), and 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 on the economic perspective of the study, the patient group/diagnosis, the time period

over which costs were considered, costs inflated to 2017 prices, and the source of activity and unit cost data.

Study quality was evaluated using the ‘Weight of Evidence Framework’. This framework appraises quality and relevance according to three dimensions which involve both generic standards and review specific assessments. [15] This approach to quality appraisal is particularly recommended for reviews involving studies with diverse methodologies. The first dimension of ‘methodological quality’ is the quality of execution of the study according to generic and accepted standards associated with that type of study. The second dimension of ‘methodological relevance’ is the appropriateness of the study design for answering the review question. The third dimension of ‘topic relevance’ is how well matched the study is to the focus of the review. Studies were given a grading of 1-3 (low – high) for each dimension. Scores were totalled and a studies with a score < 4 were excluded in order that poor quality work would not dilute the usefulness of the findings.

Inclusion Criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Papers must report costs of a palliative care approach (defined as a comprehensive package of care incorporating specialist and/or generalist elements).</li> <li>• Papers must report on full economic costs of palliative care, OR costs in more than one setting or from the viewpoint of more than one provider.</li> <li>• Studies providing data from the UK or countries within the UK.</li> <li>• Original research (i.e. involving independent data collection)</li> <li>• Papers relating to adults (≥ 18 years)</li> <li>• English language papers</li> </ul>	<ul style="list-style-type: none"> <li>• Papers published before 1997 OR papers where all the cost data was collected pre-1997</li> <li>• Literature reviews</li> <li>• Unpublished manuscripts, conference abstracts, posters and other empirical work not published in full</li> <li>• Non-empirical articles e.g. discussion papers, letters, editorials</li> <li>• Papers only reporting on costs which relate to specific element of care or specific interventions e.g. costs of Advanced Care Planning/hospice care/home care etc.</li> <li>• Papers which report how much was paid for palliative care (by commissioners), as opposed to how much palliative care cost.</li> </ul>

Table 2: Inclusion and exclusion criteria

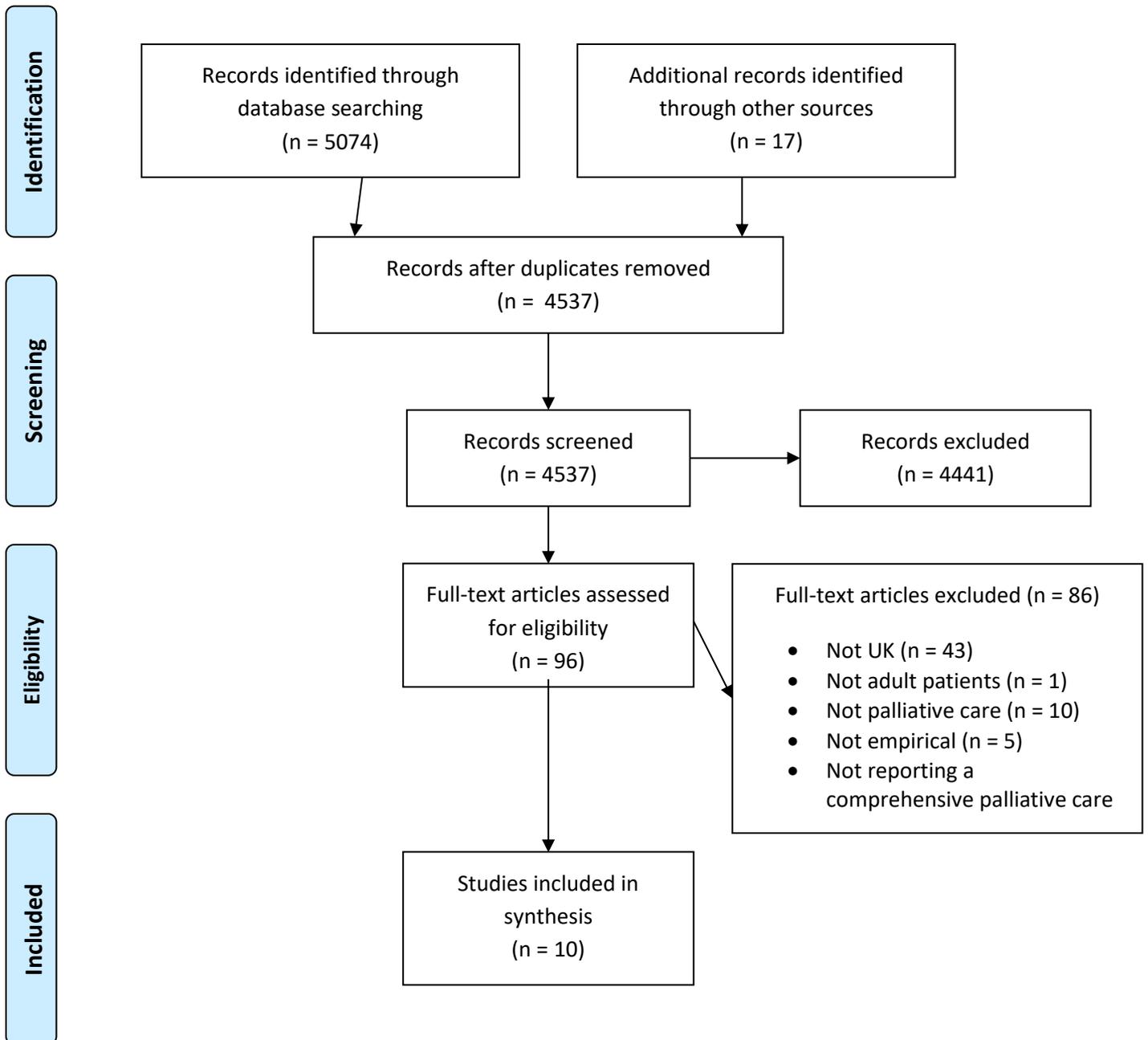
Whilst our original intention was to combine cost data from different studies to provide an aggregate estimate of the cost of palliative care in the UK, we found this was not possible because of heterogeneity in study design and reporting of data (as described in the results). These variations meant that it was not possible to combine quantitative cost data from different studies in any meaningful way. Instead, we provide a narrative summary of the studies alongside the cost estimates provided within each article, inflated to June 2017 prices. Prices were inflated using the GDP deflator index [16], and rounded up to the nearest pound. The GDP index is used rather than the Consumer Price Index (CPI) or CPI-Health (CPIH) Index as the GDP is more appropriate when adjusting for inflation in measures of national income and public expenditure where the focus is wider than consumer items alone. [17] In addition, the CPIH index is not appropriate in this instance

as some prices reflect non-health costs including informal care and social care. One study provided cost data in Euros [18], and this was converted to GBP using the currency conversion rate for 2012 derived from XE.com (<http://www.xe.com/currencytables/>).

## **RESULTS**

Search results are summarised in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart in Figure 1. [19] Ten papers met our inclusion criteria. Five of the studies were cross-sectional/cohort, four were modelling studies and one was secondary analysis of trial data. Quality scores of the included studies varied from four to nine and therefore no studies were excluded due to poor quality. Studies were often hampered by a lack of high quality data with which to estimate costs, which is reflected in lower scores in some dimensions. Table 3 provides a summary of key data from the ten studies including the economic perspective taken by the authors (i.e. from whose viewpoint were costs considered), the patient group/diagnosis, the time period over which costs were considered, and costs inflated to 2017 prices with breakdown by perspective/diagnosis if provided. Full details of study aims, methods, results are provided in the on-line supplementary information that accompanies this paper.

Figure 1: PRISMA flow diagram summarising search results



Author, date and country	Economic perspective	Patient group	Time period over which costs are considered	Per patient cost, inflated to 2017 prices
Round 2015 [10] (England & Wales)	NHS, Social care, Charitable sector, Informal carers	Cancer only	From initiation of strong opioids until death (expected survival 243 days)	Total cost £10,311 Health care: £4433 Social care: £1906 Charity care: £487 Informal care: £3396
Hatziandeu 2008 [20] (England)	NHS only	Cancer and organ failure	Last year of life	Total cost: £38,377 Cancer: £16552 Organ failure: £21825
Hollingworth 2016 [21] (England)	NHS only	Heart failure	Last three months of life	Total cost £9198
Dzingina 2017 [22] (England)	NHS, social care, informal care	Advanced disease and refractory breathlessness	A period of three months before entry into a trial	Total cost £12,444 Formal care £3518 Informal care £8926
Coyle 1999 [23] (UK)	NHS, social care	Any non-curative	One arbitrary week of life	Total cost £4140
Guest 2006 [24] (UK)	NHS only	Cancer	From initiation of opioids to death (mean=301 days)	Total cost £4237
McBride 2012 [25] (UK)	NHS, social care	Cancer and organ failure	Last year of life	Total cost £19,451 Cancer £16,952 Non-cancer £21,950
Georghiou 2014 [26] (England)	NHS, social care	Any palliative care patient	Last 90 days of life	Hospital <sup>1</sup> £4932 Social care £1096 Community nursing £305 GP £161
Bardsley 2010 [27] (England)	NHS, social care	Any palliative care patient	Last year of life	Total cost £10,318 Hospital £6957 Social care £3361
Johnston 2012 [18] (UK)	NHS only	Advanced malanoma	Three years post diagnosis or until death whichever first	Total cost £9091 Hospital £6875 Hospice £1737 Outpatient £479

Table 3: Costs of palliative care inflated to 2017 prices

<sup>1</sup> Costs for the four elements (hospital, social care, community nursing and GP) are from different cohorts so it was not appropriate to combine these into a total score.

The studies in this review displayed significant variation in their estimates of the cost of end of life care and ranged from £4140 for one week of life [23] to £38,377 for the last year of life. [20] A significant contributing factor to this variation is the heterogeneity in study design, however the disparity in cost estimates is much greater than might be expected as a result of variations in design alone and may reflect the complexity of the care approach and lack of reliable data.

Four studies only estimated the cost of palliative care from an NHS perspective [18, 20,21,24]; a further four studies included social care costs in addition to NHS costs. [23, 25, 26, 27] The studies by Round (2015) [10] and Dzingina (2017) [22] were the only two which attempted to capture comprehensive costs including informal care. Both of these studies found informal care to represent a significant percentage of the total cost of care (33% and 72% respectively).

Seven of the studies estimated costs for a specific patient group, for example advanced melanoma [18], heart failure [21] or cancer. [10,24] Only three papers estimated costs for any patient with palliative care needs regardless of diagnosis. [23, 26, 27] McBride (2011) [25] noted that although they examined the costs of end of life care for patients with organ failure, the lack of unit cost data for these conditions meant that results were based on costs for cancer patients and should therefore be treated as indicative only. There was also significant variation in the time period over which costs were estimated. Many provided an estimate for a finite period ending in death, commonly the last three months or the last year of life. However, other authors calculated costs over a specific time period not ending in death. For example Coyle (1999) [23] estimated costs for one week of life for a patient with a non-curative condition and Dzingina (2016) [22] estimated costs for three months before entry into a trial for patients with advanced disease and breathlessness. These differing time perspectives have implications for the way the findings are interpreted as costs are known to increase the nearer a person is to death. [28]

The included papers showed some consistency in the method used to derive and estimate the costs of palliative care, with all studies combining unit costs with estimates of resource/activity use. Using this approach the cost for an individual patient is calculated by summing the resources used during the specified time period and multiplying by the unit cost of the resource. Sources of unit cost and activity data varied widely and are noted in table four. Unit costs were derived from a variety of sources but most commonly from standardised national datasets including the Department of Health reference costs, the Department of Health payment by results (PbR) tariff and the Personal and Social Services Research Unit (PSS) unit costs of health and social care. Two studies [21, 24] estimated medication costs separately and derived costs from NHS Prescription cost analysis (PCA) data [21], or MIMS and the Drug Tariff data. [24]

Data on the costs of hospice and informal care were more difficult to acquire and were largely based on estimates. For example, in the study by Georghiou (2014) [26] hospice inpatient costs were estimated by commissioner charge per bed day, this reflects the amount paid for a hospice bed rather than the actual cost of a hospice bed. Round (2015) [10] derived their estimate of hospice care from data provided directly by a national hospice provide (Marie Curie Cancer Care). Data on informal care costs were similarly sparse and were derived using the Human Capital Approach [10] or by using the unit cost of a home care worker as a proxy for an informal care. [22]

Author & date	Source of activity data	Source of unit costs
Round 2015 [10]	Estimated using published literature; HES data; data provided directly by Marie Curie	<ul style="list-style-type: none"> <li>• Hospital and social care costs: NHS reference costs &amp; PSSRU Unit costs</li> <li>• Hospice costs: data provided directly from Marie Curie</li> <li>• Informal care costs: Office for National Statistics (ONS) average earnings</li> </ul>
Hatziandreu 2008 [20]	Hospital activity from HES; hospice use from National Council of Palliative Care Minimum Dataset (MDS)	<ul style="list-style-type: none"> <li>• All prices taken from Coyle (1999)</li> </ul>
Hollingworth 2016 [21]	Hospital Episode Statistics (HES) data	<ul style="list-style-type: none"> <li>• Hospital costs: NHS reference costs and PSSRU unit costs</li> <li>• Drug costs: NHS prescription cost analysis</li> </ul>
Dzingina 2017 [22]	Patients completed the Client Services Receipt Inventory	<ul style="list-style-type: none"> <li>• Hospital and social care costs: National Health Service (NHS) reference cost data and the Personal Social Services Research Unit (PSSRU) Unit Costs of Health and Social Care.</li> <li>• Informal care costs: PSSRU unit cost of a home care worker was used as proxy for informal care</li> </ul>
Coyle 1999 [23]	Service providers gave information on resource input into palliative care and length of visits	<ul style="list-style-type: none"> <li>• All prices from PSSRU Unit costs and where unit costs were not available other sources of information (Graves 1992) were used to estimate unit costs</li> </ul>
Guest 2006 [24]	Primary and secondary care resource utilization obtained from the DIN-Link database, which contains information on live patients managed by general practitioners.	<ul style="list-style-type: none"> <li>• Hospital costs: PSSRU Unit costs</li> <li>• Drug costs: MIMS and Drug Tariff</li> </ul>
McBride 2012 [25]	Hospital usage from HES; hospice usage from National Council for Palliative Care MDS	<ul style="list-style-type: none"> <li>• Hospital and hospice costs: prices taken from Coyle (1999)</li> <li>• Residential care and ambulance journeys: PSSRU Unit costs</li> <li>•</li> </ul>
Georghiou 2014 [26]	GP consultations estimated by READ code; use of community nursing based on local data recording contacts with district nurses (in absence of national dataset); social care use taken from linked HES/social care and mortality dataset; hospice care from Marie Curie estimates; hospital usage taken from HES	<ul style="list-style-type: none"> <li>• Hospital costs: NHS reference costs</li> <li>• GP, nursing &amp; social care costs: PSSRU Unit costs</li> <li>• Hospice costs: data from Marie Curie</li> </ul>

Bardsley 2010 [27]	Social care resource use from local authority client management systems; hospital use from NHS Secondary Users Service (SUS) data (information on inpatient admissions); GP use from GP register information.	<ul style="list-style-type: none"> <li>Hospital, social care, GP costs: all from PSSRU Unit costs</li> </ul>
Johnston 2012 [18]	Healthcare utilisation recorded directly from patients	<ul style="list-style-type: none"> <li>Hospital costs: NHS reference cost</li> <li>Hospice costs: Hatziandreu et al. (2010) and Consumer Price Indices</li> </ul>

Table 4: Sources of activity data and unit costs for included studies

## DISCUSSION

This study has presented a review of evidence on the cost of palliative care in the UK. We identified only ten papers which attempted to estimate the cost of palliative care, reflecting a limited evidence base. The heterogeneity of the studies we review here highlights a key challenge in undertaking research in this area, that is defining the parameters of what constitutes the ‘cost of palliative care’.

We have noted differences in the time period over which costs are considered, differences in patient group/diagnosis, differences in source of activity and unit cost data and differences in the choice of economic perspective. The lack of accurate and consistent data on palliative care costs has important implications for the way in which palliative care is funded. Decisions regarding commissioning and funding allocations need to be based on accurate and comprehensive data if they are to lead to fair and equitable funding across England and the UK. Concerns have already been raised in the literature regarding the ‘postcode lottery’ of palliative care funding and geographical variations in care provision. [2,3] A recent study comparing palliative care funding models across 13 countries reported that provider payment is rarely linked to population need and often perpetuates existing inequitable patterns in service provision. [29] In order to address these concerns greater focus and attention should be paid to identifying the costs of services which underpin funding decisions. In order for this to happen, innovative methodological developments are required that enable a more accurate and consistent approach to costing palliative care.

The choice of economic perspective for the majority of studies was either solely NHS, or NHS and social care. From these perspectives most studies found that hospital costs account for the greatest proportion of the overall cost of care. This finding reflects international research, for example Dumont (2009) [30] reported that hospital costs represent the largest cost component for palliative care patients in Canada. It is notable that only two of the studies in this review considered a comprehensive economic perspective including informal care costs. Both of these studies found informal care costs to represent a significant proportion of the overall cost of care. [10, 22] International research has produced similar findings, for example Chai et al (2013) report that 76.7% of the full economic cost of palliative care in Canada is borne by patients caregivers in the form of unpaid care. [8] More recently Brick et al. (2017) reported that informal care costs account for more than 22% of costs during the last year of life in Ireland. [31] Informal care costs are rarely included in economic evaluations in palliative care [13] so it is perhaps unsurprising that these costs are largely absent from the studies in this review. However, with mounting evidence emerging that informal

caregiving can lead to significant financial burden and can impact on health and wellbeing, [12, 32] more research is needed which fully accounts for the nature and extent of these costs.

Different approaches were used to estimate resource use and derive unit costs across the ten studies. Two studies collected resource use data directly from patients [18, 22], using tools such as the Client Services Receipt Inventory. [22] This approach is useful for collecting resource use data across a number of different settings but is susceptible to recall bias. Other studies utilised national datasets to capture resource use. Hospital Episode Statistics (HES) data was commonly used to capture hospital resource use for palliative care patients. HES data contains details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England [33], enabling researchers to capture a detailed picture of resource use for any patient group.

Capturing resource use in other care settings is more complex, particularly for hospice care and informal care where there is no 'standard' for estimating resource use. Consequently, different approaches to data collection were developed for each study. Round (2015) [10] estimated hospice resource use using data provided directly from a national hospice provider but it is not clear how these data were derived or how well they represent other independent hospices. Resource use for informal caregiving is even more difficult to accurately estimate due to a range of factors including the challenges of collecting the data, lack of proven methodological approaches [34] and inconsistent definitions of what constitutes 'informal caregiving'. [35] Dzingina (2017) [22] recorded the amount of informal care directly from patients using the Client Service Receipt Inventory. This tool captures basic data on caregiver time but does not include out of pocket costs and work related costs, despite evidence suggesting that these are significant. [12] The Cost of Family Caregiving in Palliative Care (COFAC) questionnaire was recently developed to capture comprehensive data on the costs of informal caregiving in palliative care, and this may be a useful tool for future research in this area. [36]

The majority of studies in this review combined estimates of resource use with unit cost data to provide an estimate of the cost of palliative care. The accuracy of unit cost data should be carefully scrutinised as these costs form the basis of the majority of cost analysis studies. Most of the studies in this review used PSSRU unit cost data, which is a standardised dataset updated annually providing costs on hospital services as well as community health care and social care services (<http://www.pssru.ac.uk/research/354/>). The other main sources of unit cost data in this review were the NHS Payment by Results (PbR) tariff and NHS reference costs. The PbR tariff specifies the currencies and national prices that make up the national tariff payment system, whilst NHS reference costs are the average unit cost to the NHS of providing defined services.

These national datasets provide standardised and readily available unit cost data for NHS and social care costs, however similar standardised unit cost data for informal care and hospice costs are not available, perhaps partly accounting for the lack of studies which attempt to include these costs. Following the publication of the independent Palliative Care Funding Review (PCFR) in July 2011 [2], a pilot data collection was undertaken to address the lack of robust cost and activity data within the sector. This data may provide answers to some of the questions that have arisen here, however due to its "sensitive nature" the data is not publicly accessible and "can never be used for any other purpose other than the development of the [palliative care] currency". [37]

## LIMITATIONS

Due to heterogeneity of study design and purpose, we were unable to combine costs into a single aggregate estimate of the cost of palliative care. This limits the usefulness of our findings from the perspective of commissioners and policymakers. Many of studies included in the review explored costs for a single condition (commonly cancer), this limits the generalizability of our findings for other conditions. We also acknowledge that the UK focus of this paper limits its international relevance.

## CONCLUSION

This review provides a descriptive overview of available literature on the costs of palliative care in the UK. The data is limited, and the heterogeneity is such that it is not possible to provide an aggregate cost of palliative care. It is notable from this review that the costs of hospice care and informal care are often neglected in economic and cost analysis studies. An evaluation of the sources of resource use and unit costs reveal some of the difficulties inherent in trying to accurately estimate costs in these settings, namely the lack of standardised national datasets, the lack of methodological guidance and definitions, and a complex picture of care provision in palliative care.

Further work is needed to address these methodological challenges in order to gain a more complete understanding of the costs of palliative care in the UK. Only then will funding allocations and commissioning decisions be able to respond to the needs of the population and ensure access is fair and consistent for all. International studies may provide us with some of these methodological innovations, and in turn other countries may benefit from new insights from the UK.

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