Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers

Protocol information

Authors

Barbara Gomes¹, Irene J Higginson¹, Paul McCrone²

¹Palliative Care, Policy and Rehabilitation, King's College London, London, UK
²Institute of Psychiatry, King's College London, London, UK

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Contact person

Barbara Gomes

Palliative Care, Policy and Rehabilitation
King's College London
Weston Education Centre
Cutcombe Road
London
SE5 9RJ
UK

E-mail: barbara.gomes@kcl.ac.uk

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What's new

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Background

Extensive international evidence shows that well over 50% of people prefer to be cared for and to die at home (Higginson 2000; Agar 2008). Most patients and caregivers facing advanced illness also prefer this. However, their choices depend on the quality of the care received (Thomas 2004; Choi 2005). At present, in many developed countries of the world, most have their wishes unfulfilled, as the majority die in hospital (WHO 2004). The importance of providing optimal care that supports patients and caregivers who wish to stay at home is particularly topical in ageing populations (Khaw 1999; WHO 2004). With the number of deaths predicted to rise in the future due to longer life expectancy and baby boom generations reaching older age, an expansion of palliative care services will need to take place across the board – in hospitals, hospices, nursing and residential homes, and at home (Gomes 2008). However, in order to care for more people at home and thus meet the preferences of more patients and caregivers, home palliative care services will need to increase exponentially.

Strong evidence ought to be used to develop more and better home palliative care services. These are complex interventions. An understanding of what models of care best enable patients to die at home and their associated costs will allow for the provision of sustainable, cost-effective and high quality home palliative care for more people in the future (Robinson 1996).

Existing reviews of the effectiveness of home palliative care services (including homecare hospice teams, hospital-based community support teams, hospital at home services) have often been part of wider reviews of the effectiveness of palliative care models and/or have referred to populations of patients with cancer only (Smeenk 1998), although palliative care has now expanded beyond cancer (Addington-Hall 2001). Two non-Cochrane systematic reviews have looked at palliative care services regardless of patient diagnosis and included economic studies (Higginson 2003; Zimmermann 2008). Of the 22 studies of home teams reviewed in Higginson 2003, seven had some analysis of costs or resource use but only one was a full economic evaluation. This one pilot study showed overall health care cost savings of 6 to 7% and an increase in well-being detectable shortly after the beginning of care from a multidisciplinary home palliative care service (hospital-based, including doctors, nurses, a psychologist, a social worker, infectious disease specialists and volunteers) providing an integrated model of home care to patients with AIDS in northern Italy (Tramarin 1992). Five other RCTs were identified in the latest review by Zimmermann 2008, three which contained some economic data, but the findings were contradictory for both costs and outcomes. Only one study identified in the later systematic review demonstrated home palliative care was more effective and cost saving (Brumley 2007). Patients with cancer, congestive heart failure or COPD randomised to receive care from multidisciplinary home palliative care teams providing pain and symptom relief, patient and family education and training, and an array of medical and social support services in Hawaii and Colorado were more likely to die at home than patients on Medicare (75% died at home compared to 51%, P < 0.001), were more satisfied with care (P < 0.05) and their overall costs of care were 33% lower (P < 0.03).

Exploration of variation in the findings, particularly in relation to service components or configurations that may have better or equal outcomes and equal or lower costs were beyond the broad scope of both of the previous systematic reviews (Higginson 2003; Zimmermann 2008). At present and until such work is done, there is insufficient evidence to inform the development of better home palliative care services. By providing a comprehensive and critical appraisal of the available body of evidence and its heterogeneity, this review will help improve the evidence-base for the development, implementation and evaluation of home palliative care services in the future.

Objectives

The objectives of this review are:

1. to determine the clinical effectiveness of different types of home palliative care services for adult patients with advanced illness and their caregivers;
Effectiveness and cost-effectiveness of home palliative care services for adults...

2. to compare the resource use and costs associated with these services; and
3. to determine their cost-effectiveness.

Additional objectives are to compare different disease groups, to examine other sources of heterogeneity in the findings and to ascertain the appropriateness for meta-analysis.

Methods

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCTs) (patient or cluster trials), controlled clinical trials (CCTs) (patient or cluster trials), controlled before and after studies (CBA) or interrupted time series analyses (ITS) that evaluate the impact of home palliative care services on at least one of the outcomes listed below. For CBA there needs to be at least two intervention sites and two control sites, contemporaneous data collection both before and after the intervention, and comparable sites as comparators. For ITS, there needs to be a clearly defined point in time when the intervention occurred and at least three data points before and three after the intervention.

The economic component of the review will be restricted to health economics studies which are conducted alongside the studies meeting eligibility criteria for the effectiveness component of the review and that evaluate the impact of intervention(s) versus comparator(s) on at least one of the costs (resource use) listed below. We will include:

1. full economic evaluations, i.e. comparative analyses of intervention(s) versus comparator(s) in terms of both costs (resource use) and consequences (outcomes) that use cost-effectiveness analyses, cost-utility analyses or cost-benefit analyses (Drummond 2005; Shemilt 2008);
2. partial economic evaluations, i.e. cost analyses, cost-comparison studies or cost-outcome descriptions of intervention(s) and comparator(s);
3. analyses reporting more limited information, such as estimates of resource use or costs associated with intervention(s) and comparator(s).

Types of participants

Participants aged 18 year or over and/or caregivers in receipt of a home palliative care service (as described below). To be included the majority of the participants will be required to be experiencing a severe or advanced malignant and/or non-malignant disease which is no longer responding to curative/maintenance treatment and is symptomatic (e.g. lung/brain tumours or metastatic cancers, chronic obstructive pulmonary disease (COPD)).

Types of interventions

Home palliative care is a generic term that can involve the use of a range of physical and psycho-social interventions. The precise boundaries of home palliative care services for the present review are defined by the presence of four elements described below:

1. primarily for patients with a severe or advanced malignant or non-malignant disease, or both, which is no longer responding to curative/maintenance treatment and is symptomatic, or their caregivers, or both;
2. aiming to support patients or caregivers, or both, outside hospital and other institutional settings as far as possible and to enable them to stay at home;
3. providing either specialist or intermediate palliative/hospice care, as defined in a previous systematic review (Higginson 2003):
   a. specialist palliative/hospice care is defined as health and social care provided by:
      i. one or more doctors who have undergone higher specialist training in palliative medicine, and
ii. one or more nurses who have undergone higher specialist training, and
iii. one or more professionals attached to the team from a profession allied to medicine who have had further training in palliative care;

b. intermediate palliative/hospice care is defined as health and social care provided by:
   i. professionals from differing clinical disciplines working full-time or most of the time in palliative care, who have not undergone any higher specialist training but developed much clinical experience over the years and had in-service training for their job, or
   ii. a uni-disciplinary team of professionals (e.g. nurses) working full-time or most of the time in palliative care, in which one or more members may have had some further training;

c. providing comprehensive care and aiming at different physical and psycho-social components of palliative care.

Studies evaluating the impact of services exclusively provided to caregivers after the patient has deceased (bereavement only) and services delivered in skilled nursing facilities, day care centres or residential homes will be excluded. Studies evaluating the impact of only one component of palliative care (e.g. pain medication, psychotherapy) will be excluded as this does not encompass the holistic nature of palliative care.

**Types of outcome measures**

**Primary outcomes**
Whether the patient died at home or not.

**Secondary outcomes**
These will include:
- proportion of time the patient spent at home,
- satisfaction with care,
- pain control,
- control of other symptoms,
- physical function,
- quality of life,
- caregiver pre and post bereavement outcomes.

**Costs (resource use)**
These will include:
- hospital costs;
- other institutional care costs (including costs of stay in other institutional settings funded by the public, private or voluntary sectors, or both, and of inpatient consultations with health and social care professionals);
- home care costs (costs of care to support the patient staying at home, including consultations with health and social care professionals such as family doctor/general practitioner, and of outpatient and day care attendances, funded by the public, private or voluntary sectors, or both);
- informal care costs (including costs of lost production, patient and caregiver’s out-of-pocket expenses, travel and child care costs);
- equipment and medication prescribed.

**Measures of cost-effectiveness**
Incremental cost-effectiveness ratios (ICERs) using condition specific outcome measures and incremental
Effectiveness and cost-effectiveness of home palliative care services for adults... 13-Feb-2009

cost-effectiveness ratios (ICERs) using Quality-Adjusted Life Years (QALYs) as outcome measures.

**Search methods for identification of studies**

**Electronic searches**

Studies will be identified from a search of the following databases:

- Cochrane Pain, Palliative and Supportive Care Trials (PaPaS) Register;
- Cochrane Effective Practice and Organisation of Care (EPOC) Group Register;
- The Cochrane Central Register of Controlled Trials (CENTRAL) (current issue);
- The Cochrane Database of Systematic Review (CDSR) (current issue);
- Database of Abstracts of Reviews of Effectiveness (DARE) (current issue);
- Health Technology Assessment (HTA) Database (current issue);
- MEDLINE (1950 to present);
- EMBASE (1980 to present);
- CINAHL (1981 to present);
- PsychINFO (1806 to present).

Searches of the following two specialist health economics databases will be conducted to identify further economic studies for potential inclusion in the review and to check for structured abstracts of economic analysis conducted alongside the included effectiveness studies:

- NHS Economic Evaluation Database (NHS EED) (current issue);
- EURONHEED (1980 to present).

**Search strategy**

The search strategy will use a combination of controlled vocabulary (MeSH) terms and free text terms. Three groups of terms will be combined with AND: terms to capture palliative/hospice/terminal/end of life care, terms on home/community/outreach services and a methodological search filter to identify evaluation studies. Additional filters for excluding studies focusing on children will be used. The MEDLINE search strategy (see Appendix 1) will model strategies in other databases.

**Searching other resources**

**Hand searching**

The reference lists of selected studies, key textbooks, previous systematic reviews and conference proceedings will be checked for additional studies.

**Personal contact**

Investigators who are known to be carrying out research in this area will be contacted for unpublished data or knowledge of the grey literature.

**Language**

The search will attempt to identify all relevant studies irrespective of language. Non-English papers will be assessed and, if necessary, translated.
Effectiveness and cost-effectiveness of home palliative care services for adults...

Data collection and analysis

Selection of studies

One review author (BG) will screen the titles and abstracts for relevance, to judge eligibility and to remove duplicates. Full text of all potentially relevant studies will be assessed by BG and a second review author. Disagreement will be resolved by consensus and with a third review author. A QUOROM flow chart will describe graphically the sequence of steps and reasons for exclusion of the studies (Moher 1999).

Data extraction and management

Data from each selected study will be entered on a data extraction form by two review authors independently (BG and PMc/IJH). Disagreement will be resolved by consensus and with a third review author. A data extraction form specifically designed for the review will be developed (Appendix 2).

Abstracts of full economic evaluations included in the review will be obtained from the NHS EED. These detail the economic study type (e.g. descriptive, cost-effectiveness, cost utility), resource use data, outcome data, description of the intervention/comparator, duration of follow-up, analysis and synthesis methods, and the main results (Craig 2007). Analytic viewpoints, time horizons, point estimates of measures of resource use or costs, or both, incremental costs or cost-effectiveness, or both, with associated measures of uncertainty for intervention(s) and comparator(s), country, region, reimbursement system, currency and price year will also be extracted. We will request NHS EED to produce abstracts for full economic evaluations for which we find there is no NHS EED abstract. Abridged versions will be added in the appendix if the abstracts are provided by the NHS EED within the review's timescale; otherwise they may be added in later updates.

If possible, authors of studies will be contacted to provide unpublished data if essential for the analysis. Data provided within the review’s timescale will be included or otherwise added in later updates.

Assessment of methodological quality of included studies

All selected studies will be assessed for methodological quality by two review authors independently (BG and PMc/IH). The quality of the studies will be assessed using standard EPOC criteria for RCTs/CCTs, CBAs and ITS (see methods used in reviews under editorial information in group details). Each criterion will be scored as 0 (not done), 0.5 (not clear) and one (done).

The quality of full economic evaluations will be assessed using the BMJ ‘35 item checklist for authors and peer reviewers of economic submissions’ (Drummond 1996) and partial economic evaluations will be appraised using the subset of applicable items from the checklist. A scoring system will be applied to the checklist to discriminate low quality economic evaluations. We will calculate an average score with all items weighted equally (Gonzalez Perez 2002). Each item will be scored 0 (no), 0.5 (not clear) and one (yes); evaluations with an average score below 0.6 will be considered of low quality (Gonzalez Perez 2002). Not applicable items will be omitted from the calculation of the average.

Measures of treatment effect

The characteristics and results of the clinical effectiveness studies included in the review will be tabulated and the data will be analysed and combined using RevMan 5. The main analysis will use the primary outcome measure (home death) within each study. This will be in the form of binary data. We will calculate the home death rates observed in intervention(s) and comparator(s) using data from the papers if provided or requested from the authors. We will calculate odds ratios (OR) if appropriate, with a 95% confidence interval (CI) to show the effect of the intervention(s). A P value of < 0.05 will be considered as statistically significant. Numbers needed to treat to benefit (NNT), i.e. the expected number of people who need to receive intervention(s) rather than comparator(s) for one additional person to die at home, as opposed to in hospital, will be calculated.
For secondary outcomes, we will focus on the optimal type of measure used (i.e. used most widely and validated). For measures in the form of binary data we will calculate OR if appropriate. For continuous data, we will calculate standardized mean differences (SMDs) with 95% CIs (as we anticipate use of different scales across the studies). We will treat ordinal data as binary data when scales are short and as continuous data when scales are long.

We will describe and compare the direction and size of the effect on outcomes of different intervention types (e.g. specialist versus intermediate), conduct sub-group analysis, describe and statistically evaluate heterogeneity. We will explore the effect of different intervention components such as contact frequency, duration of intervention, hours of operation, caregiver support. These components have been suggested in the literature as factors with influence on death at home or as key components of home mental health interventions (Burns 2001; Gomes 2006). Study design and quality, comparator type (institutional-control or home-control) and disease group will also be explored as other potential sources of heterogeneity.

We will conduct a meta-analysis of the primary outcome measure if appropriate. As we anticipate heterogeneity we plan to use a random-effects model. Sensitivity analyses will examine the effect of intervention and comparator type, study design and quality and disease group. We will comment on the direction, magnitude and precision of the results and will grade the evidence (strong, moderate, limited, conflicting or no evidence) using criteria developed by the Cochrane Collaboration Back Review Group (van Tulder 2003).

**Measures of resource use and costs**

The characteristics and results of the health economic studies included in the review will be tabulated by sub-groups (full economic evaluations, partial economic evaluations, analysis reporting more limited information). Analytic viewpoints, time horizons, point estimates of measures of resource use and/or costs, incremental costs and/or cost-effectiveness with associated measures of uncertainty for intervention(s) and comparator(s), country, region, reimbursement system, currency and price year will be presented (if reported). We will narratively summarize the critical appraisal and main findings. Abridged NHS EED abstracts will be provided in the appendix.

Resource use data will be analysed and combined if appropriate using RevMan 5. If possible and appropriate cost data from each study will be converted into a common price year (2008 or above) and a common currency (of most of the economic evaluations included for meta-analysis) by applying the cost conversion tool developed and piloted by The Campbell & Cochrane Economics Methods Group and The Evidence for Policy and Practice Information and Co-ordinating Centre. The main analysis will take total healthcare costs within each study. This will be in the form of continuous data. If the data are at least approximately normally distributed, we will calculate the mean number of hospital days per a defined time unit (e.g. week), both in intervention(s) and comparator(s) and mean differences with 95% CIs, using data from the papers or requested from the authors. If the data are found to be skewed, we will present medians (with interquartile ranges) and median differences instead. Secondary resource use/cost measures will be listed and findings will be narratively reported.

We will describe and compare the direction and size of the effect on costs/resource use of different intervention types, conduct sub-group analysis, and describe and statistically evaluate heterogeneity. Quality of economic evaluation, comparator type and disease group will also be explored as other potential sources of heterogeneity.

We will conduct meta-analyses for resource use and cost measures if appropriate and if a common continuous metric is used by two or more studies and time horizons are comparable. Cost data for meta-analyses will be converted into a common price year (2008 or above) and a common currency. As we anticipate heterogeneity we plan to use a random-effects model. If the data are skewed and if appropriate we will request from the authors the original data to transform on a log scale for meta-analysis. Sensitivity analyses will examine the effect of intervention and comparator type, study design and low quality, and disease group. We will comment...
Effectiveness and cost-effectiveness of home palliative care services for adults...

Cost-effectiveness
Incremental cost-effectiveness ratios (ICERs), incremental cost-per QALYs or cost-benefit ratios of individual studies provided in the papers or by the authors will be reported. If the data allow, the authors will calculate the above measures for each study that supplies suitable data for a common outcome.

Acknowledgements

Contributions of authors

For the protocol
All review authors: contributed to the development of the idea and of the protocol.

BG: developed and wrote the protocol, developed the search strategies and the data extraction form.

PMc and IJH: discussed the protocol with BG, contributed to the development of the search strategy and the data extraction form, discussed and approved the protocol, the search strategy and the data extraction form.

For the review
BG: to search for studies, obtain copies of the studies, extract data from studies, enter data in to RevMan, carry out quality assessment and analysis, draft the review and finalise it after discussion with the other review authors.

PMc: to extract data from studies, carry out quality assessment and analysis, discuss the outcomes with the other review authors and revise the manuscript.

IJH: to extract data from studies, carry out quality assessment and analysis, discuss the outcomes with the other review authors and revise the manuscript.

All review authors will: select which studies to include, interpret analysis, draft the final review and be involved with the update of the review.

Declarations of interest
None known

Published notes

Additional tables

Other references

Additional references

Addington-Hall 2001

Agar 2008
Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP. Preference for place of care...
and place of death in palliative care: are these different questions? Palliative Medicine 2008;22:787-95.

**Brumley 2007**

**Burns 2001**

**Choi 2005**

**Craig 2007**

**Drummond 1996**

**Drummond 2005**

**Gomes 2006**

**Gomes 2008**

**Gonzalez Perez 2002**

**Higginson 2000**

**Higginson 2003**
**Khaw 1999**

**Moher 1999**

**Robinson 1996**

**Shemilt 2008**

**Smeenk 1998**

**Thomas 2004**

**Tramarin 1992**

**van Tulder 2003**

**WHO 2004**

**Zimmermann 2008**

Other published versions of this review

**Figures**

**Sources of support**

**Internal sources**
- Department of Palliative Care, Policy and Rehabilitation, King's College London, UK
Effectiveness and cost-effectiveness of home palliative care services for adults...

External sources
- Cicely Saunders International, Not specified

Feedback

Appendices

1 MEDLINE search strategy

1. exp. palliative care/
2. exp. terminal care/
3. exp. terminally ill/
4. palliat*.mp
5. terminal* and (care or caring or ill*).mp
6. ((advanced or end stage or terminal*) adj4 (disease* or illness* or cancer* or malignan*)).mp
7. last year of life or LYOL or life's end or end of life.mp
8. or/1-7
9. exp. home care services/
10. exp. home care agencies/
11. exp. mobile health units/
12. exp. community health nursing/
13. home adj4 (hospital or palliat*).mp
14. (macmillan or marie curie or district) adj nurs*.mp
15. (home or in-home or domicile or outreach or residential or housing or posthospital or post-hospital or communit* or mobile or ambulatory or door to door) adj2 (team* or center* or centre* or treat* or care or interven* or therap* or management or model* or program or programs or programme* or service* or base* or nurs*).mp
16. homecare or home-care or homebased or home-based.mp
17. or/9-16
18. hospice*.mp
19. 18 or (8 and 17)
20. (child* or adolescent* or infant* or baby or babies or neonat* or juvenil* or pediatric* or paediatric* or young person* or young people or youth* or young adult* or matern*).ti.
21. 19 not 20
22. randomized controlled trial.pt.
23. controlled clinical trial.pt
24. randomized.ab
25. randomly.ab
Footnotes:

Line 14 - Macmillan, Marie Curie and district nurses provide care in a home setting in the UK. Macmillan nurses support patients with cancer and their caregivers. Marie Curie nurses support patients with cancer and those with other terminal illnesses in their own homes, and their caregivers. District nurses provide primary care in the community to all kinds of patients in need and support their caregivers.

Line 18 - The general search on hospice* combines palliative care with home setting for US studies, accounting for the fact that hospice care in the US is predominantly provided at home and thus the home setting is often implicit in the term hospice.

2 Items to be included in the data extraction form

Study ID and publication details, including:

- study country and region;
- data collection time period;
- study publication year;
- study aim.

Study design and methods, including:

- study design,
- study setting,
- allocation sequence procedure,
- allocation concealment,
- power calculation,
- baseline measurement,
- time horizon of the study,
- reliable primary outcome measurement,
- details of blinding,
- exclusion and attrition details,
- number and time of follow-ups,
- handling of missing data,
- selective reporting,
- bias,
- analysis details.

Patient and/or caregiver characteristics, including:

- number of patients and/or caregivers in the intervention and comparator groups,
Effectiveness and cost-effectiveness of home palliative care services for adults...

- socio-demographics,
- diagnosis,
- baseline staging of illness,
- baseline symptoms,
- baseline patient function,
- baseline quality of life,
- survival,
- place of death.

**Intervention(s) and comparator(s), including:**

- setting of intervention,
- type of intervention,
- staff composition,
- staff training and experience,
- components of intervention,
- frequency of intervention,
- duration of intervention,
- resource use and/or costs of intervention.

**Primary outcome:**

- number of patients who died at home.

**Secondary outcomes, including:**

- proportion of time that the patient spent at home,
- measurement and change in symptoms,
- measurement and change in patient function,
- measurement and change in quality of life,
- measurement of satisfaction with care,
- measurement and change in caregiver pre and post bereavement outcomes.

**Costs (resource use):**

- measurement and change in hospital costs.
- measurement and change in other institutional care costs,
- measurement and change in community care costs,
- measurement and change in informal care costs,
- measurement and change in equipment and medication prescribed.

**Additional, including:**

- adverse effects,
- number and reason of withdrawals,
- modification to intervention,
- patient and/or caregiver comments of intervention.