Hospital-based specialist palliative care compared with usual care for adults with advanced illness and their caregivers: a systematic review

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Scientific summary

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Scientific summary

Background

Serious illness is often characterised by physical/psychological problems, family support needs and high rates of health-care resource use. Hospital-based specialist palliative care has developed to assist in better meeting the needs of patients and their families, and, potentially, reduces hospital care expenditure. There is a need for clarity on the effectiveness and optimal models of hospital-based specialist palliative care, given that most people still die in hospital, and also to allocate scarce resources judiciously.

Objectives

The study had the following objectives:

- to determine the effectiveness of hospital-based specialist palliative care services compared with best usual care on –
    - patient and caregiver health-related quality of life
    - patient symptom burden
    - patient and caregiver satisfaction with care
    - achieving a patient's preferred place of care or death
    - patient mortality/survival
    - pain
    - patient symptoms such as anxiety, depression and breathlessness
    - caregiver burden, mental health and bereavement
- to determine the different models and out-of-hours arrangements of hospital-based specialist palliative care teams and their influence on effectiveness
- to assess whether or not hospital-based specialist palliative care services result in adverse effects
- to critically appraise and summarise current evidence on resource use and costs associated with hospital-based specialist palliative care services compared with best usual care services for adults with advanced illness and their caregivers/families.

Methods

A systematic review of randomised controlled trials assessing the impact of hospital-based specialist palliative care on outcomes for adults with advanced illness or their caregivers, or both, was undertaken.

Search strategy and data sources

We searched The Cochrane Library [Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects and Health Technology Assessment], MEDLINE, EMBASE, the Cumulative Index to Nursing and Allied Health Literature, PsycINFO, CareSearch, the NHS Economic Evaluation Database and trial registers to August 2019. Search terms included a combination of medical subject headings and free-text terms, refined with the assistance of the information specialist of the Cochrane Pain, Palliative and Supportive Care group. We checked reference lists of all included studies and of three relevant systematic reviews, searched citations and contacted 15 experts to identify additional studies.

Study selection

The inclusion and exclusion criteria used were as follows:

- Target population – patients with advanced illnesses and their unpaid caregivers.
- Target interventions – hospital-based specialist palliative care involving any of the following models: ward-based models, inpatient consulting models, outpatient models, hospital at home or hospital outreach models, and models involving multiple settings that included hospital. Hospital-based specialist palliative care consisted of the following essential elements –
    - care co-ordinated by a multiprofessional or multidisciplinary team
    - collaboration between specialist palliative care providers and generalist providers
    - holistic care.
- Control/comparators – usual care was the comparator. It was defined as inpatient or outpatient hospital care without any specialist palliative care input at the point of entry to the study (e.g. oncological care only), community care (e.g. primary or specialist care provided in a patient's place of residence) or hospice care provided outside the hospital setting. When usual care was compared with hospital-based specialist palliative care (plus or minus usual care), we extracted descriptive data on what was involved in the intervention.
- Outcome measures –
    - primary outcomes:
        - patient health-related quality of life, measured using validated assessment scales, which may be generic or disease-/condition-specific health-related quality-of-life measures
        - patient symptom burden, specifically, a collection of two or more symptoms, which could be physical (e.g. pain), psychological (e.g. anxiety, depression), social or spiritual, either patient- or proxy-reported through validated generalised assessment scales.
    - secondary outcomes:
        - patient satisfaction with care through validated assessment scales
        - caregiver satisfaction with care through validated assessment scales
        - achieving patient's preferred place of death
        - achieving patient's preferred place of care
        - patient mortality/survival
        - pain measured using validated assessment scales
        - patient anxiety and depression measured using validated assessment scales
        - patient breathlessness measured using validated assessment scales
        - adverse events among participants and unpaid caregivers
        - unpaid caregiver symptom control, specifically of physical, psychological (e.g. anxiety and depression), social or spiritual domains, reported through validated assessment scales and burden, including emotional strain, burden, distress, mastery or positive aspects of caregiving through validated assessment scales
        - unpaid caregiver pre- and post-bereavement outcomes, reported using validated outcome scales of multidimensional caregiving experiences (strain, distress, positive appraisals and family well-being), caregiver prolonged grief, multidimensional grief responses (despair, panic behaviour, blame and anger, detachment, disorganisation and personal growth) and quality of life.

Data extraction

Full texts of studies that met the inclusion criteria were read and data extraction was carried out by two independent reviewers. We resolved any disagreements by discussion and consensus.

Assessment of quality

Assessment of methodological quality was carried out by two independent reviewers using the criteria outlined in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins JPT, Green S, editors. *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.1 [Updated March 2011]*. London: The Cochrane Collaboration; 2011. URL: www.handbook.cochrane.org), with any disagreements resolved by discussion. We completed a 'risk of bias' table for each included study using the Cochrane Risk of Bias tool for randomised controlled studies.

Strength of the evidence

Two reviewers independently rated the quality of the evidence for each outcome using recommendations from the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system and guidelines provided in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins and Green, 2011). Four levels were specified: very low, low, moderate and high. Evidence of very low certainty means that we have very little confidence in the effect estimate. Evidence of low certainty means that our confidence in the effect estimate is limited; evidence of moderate certainty means that we are moderately confident in the effect estimate; and evidence of high certainty reflects high confidence in the effect estimate.

Data synthesis

If appropriate, we undertook meta-analyses of the primary and secondary outcomes using RevMan (The Cochrane Collaboration, The Nordic Cochrane Centre, Copenhagen, Denmark). We used a random-effects model for meta-analyses to incorporate the assumption of heterogeneity, as eligible studies were conducted with different populations, in different countries and years. To account for use of different scales across studies, we calculated standardised mean differences with 95% confidence intervals for continuous data. If the same scales were used, we calculated mean differences. We used an inverse variance random-effects model. For binary data, we calculated odds ratios with 95% confidence intervals.

Results

A total of 42 randomised controlled trials involving 7779 participants (6678 patients and 1101 caregivers/family members) were included. We included 13 economic studies (2103 participants). The designs included parallel, fast-track and cluster randomised controlled trials. Almost half (19) of the studies were set in the USA. Twenty-one studies were with cancer populations; 14 and seven studies were with non-cancer, and mixed cancer and non-cancer populations, respectively. Six of the 14 non-cancer studies were on heart failure. Hospital-based specialist palliative care was offered in different ways, and included the following models: ward based (one study), inpatient consult (10 studies), outpatient (six studies), hospital at home or hospital outreach models (five studies) and service provision across multiple settings that included hospital (20 studies). For our main analyses, we pooled data from studies reporting adjusted end-point values. Seven studies included multidisciplinary hospital-based specialist palliative care teams led by nurses, whereas none of the studies included physician-led hospital-based specialist palliative care teams. Multidisciplinary team members ranged from two to eight professionals, mainly comprising nurses, physicians and, sometimes, social workers. Five studies included hospital-based specialist palliative care that had provision for out-of-hours services. In 20 studies, usual care included involvement of palliative care professionals if needed; in one study, usual care incorporated hospice care. Early palliative care was evaluated in 19 studies.

Meta-analyses demonstrated improvement in patient health-related quality of life (10 studies, 1344 participants, standardised mean difference 0.26, 95% confidence interval 0.15 to 0.37; $I^2 = 3\%$) and patient satisfaction with care (two studies, 337 participants, standardised mean difference 0.36, 95% confidence interval 0.14 to 0.57; $I^2 = 0\%$), as well as a significant reduction in patient symptom burden (six studies, 761 participants, standardised mean difference –0.26, 95% confidence interval –0.41 to

–0.12; $I^2 = 0\%$) and patient depression (eight studies, 1096 participants, standardised mean difference –0.22, 95% confidence interval –0.34 to –0.10; $I^2 = 0\%$). There was a significant increase in the chances of patients dying in their preferred place (measured by number of patients with home death) (seven studies, 861 participants, odds ratio 1.63, 95% confidence interval 1.23 to 2.16; $I^2 = 0\%$), favouring hospital-based specialist palliative care.

Non-significant improvement in favour of the control group was observed for caregiver satisfaction with care: the mean satisfaction in the hospital-based specialist palliative care group was 81.1 (95% confidence interval 78.3 to 83.9) (range 0–100, 100 = best caregiver satisfaction), whereas that in the usual-care group was 84.3 (95% confidence interval 81.3 to 87.3). Non-significant improvement in favour of the hospital-based specialist palliative care group was observed for pain (four studies, 525 participants, standardised mean difference –0.16, 95% confidence interval –0.33 to 0.01; $I^2 = 0\%$), patient anxiety (five studies, 384 participants, mean difference –0.63, 95% confidence interval –2.22 to 0.96; $I^2 = 76\%$), caregiver depression (two studies, 413 participants, standardised mean difference –0.02, 95% confidence interval –0.21 to 0.18; $I^2 = 0\%$) and patient breathlessness (five studies, 616 participants, standardised mean difference –0.04, 95% confidence interval –0.19 to 0.12; $I^2 = 0\%$).

The evidence on mortality/survival in 36 studies (7103 participants) was inconsistent, as some studies showed an increase in mortality/survival, whereas others showed a decrease. One study showed that all the patients who died in the hospital-based specialist palliative care group [$n = 8$ (100%)] achieved their preferred place of care, compared with 11 patients (84%) in the control group who died by the end of the study. Two studies presented data on caregiver burden, but they could not be pooled in a meta-analysis. They both found non-significant differences between hospital-based specialist palliative care and usual care. One of the studies assessed caregiver burden using the Montgomery–Borgatta Caregiver Burden scale and presented results for three different subscales of the scale, namely the objective burden scale (range 6–30, 30 = worst), the stress burden scale (range 4–20, 20 = worst) and the demand scale (range 4–20, 20 = worst). On the objective burden scale of the Montgomery–Borgatta Caregiver Burden scale, the mean caregiver burden score was 0.3 points higher (range 6–30, 30 indicates worst) for the hospital-based specialist palliative care group than for the control group, with adjustment for patient death ($p = 0.64$). On the stress burden scale of the Montgomery–Borgatta Caregiver Burden scale, the mean caregiver burden score was 0.5 points lower (range 4–20, 20 indicates worst) for the hospital-based specialist palliative care group than for the control group, with adjustment for patient death ($p = 0.29$). There was no difference in the mean caregiver burden score with adjustment for patient death on the demand scale of the Montgomery–Borgatta Caregiver Burden scale ($p = 0.97$). The second study assessed caregiver burden using the Zarit Burden Interview (range 0–88; 88 = highest burden) and reported a mean caregiver burden of 12.9 (standard error 1.3) in the hospital-based specialist palliative care group and of 14.8 (standard error 1.4) in the control group at 12 months ($p = 0.30$).

One study reported non-significant worsening of caregiver anxiety with hospital-based specialist palliative care. The study assessed caregiver anxiety using the Hospital Anxiety and Depression Scale-Anxiety (seven items; scale of 0–21, 21 = maximum distress), and found higher mean caregiver anxiety in the hospital-based specialist palliative care group (mean 7.2, 95% confidence interval 6.6 to 7.9) than in the control group at 3 months (mean 6.4, 95% confidence interval 5.7 to 7.1); on adjusting for baseline and multiple respondents, the mean difference was 0.8 (95% confidence interval –0.1 to 1.8; $p = 0.09$). Adjustments for three variables (baseline, multiple respondents and study sites) and six variables (baseline, multiple respondents, study sites, race, sex and primary/additional surrogate) also produced similar results with *p*-values of 0.11 and 0.12, respectively. Another study found a non-significant reduction in caregiver grief in favour of hospital-based specialist palliative care. The study assessed caregiver grief using the Prigerson Inventory of Complicated Grief-Short Form and reported a mean caregiver grief score in the hospital-based specialist palliative care group that was 2.2 points lower (range 11–55, 55 indicates highest grief) than that of the control group ($p = 0.21$). There was no evidence of a difference on adjusting for religious preference ($p = 0.40$), baseline depression levels ($p = 0.51$) or patient hospice use ($p = 0.51$). One study reported non-significantly better caregiver quality of life in the hospital-based specialist palliative care group. The study assessed caregiver quality of life using the Caregiver Quality of Life Index (range 0–140, 140 = worse caregiver quality of life), and found a mean caregiver quality-of-life score in the hospital-based specialist palliative care group that was 2 points better than that of the control group at 3 months, with adjustment for patient death ($p = 0.39$). Among decedents' caregivers, a terminal decline analysis indicated a mean difference of −4.9 points between the hospital-based specialist palliative care group and the control group ($p = 0.07$).

Eight studies with 1252 participants reported on adverse events. Overall, hospital-based specialist palliative care showed no evidence of causing serious adverse events. One study reported a non-significant increase in adverse events in the hospital-based specialist palliative care group: 15 serious adverse events in 13 patients in the hospital-based specialist palliative care group (compared with seven adverse events in seven patients in the control group) ($p = 0.78$). Another study found that more patients in the hospital-based specialist palliative care group had the mild adverse event of poorer appetite compared with the control group ($p = 0.04$).

The evidence on cost-effectiveness of hospital-based specialist palliative care, compared with usual care, was not consistent among the four full economic studies and was, at best, equivocal. Other studies that used only partial economic analysis and those that presented resource use and more limited cost information also had inconsistent results.

Evidence from the 10 qualitative studies (322 participants) that explored views and experiences of hospital-based specialist palliative care by stakeholders suggested that hospital-based specialist palliative care was beneficial as it ensured personalised and holistic care for patients and their families, while also fostering open communication, shared decision-making, respectful and compassionate care and psychosocial support. These areas have been found to be important to patients and their families for end-of-life care in the hospital setting.

The quality of the evidence was judged to be low for patient health-related quality of life, patient satisfaction with care, caregiver grief, caregiver quality of life and achieving patient preferred place of death (measured by number of patients with home death). Evidence on patient symptom burden, patient depression, patient anxiety, patient pain, patient breathlessness, mortality/survival, achieving patient preferred place of care, caregiver satisfaction with care, caregiver burden, caregiver anxiety, caregiver depression, resource use, costs and cost-effectiveness, and adverse events in patients and caregivers was rated to be of very low quality. The quality of the evidence was downgraded for various reasons, for example high risk of bias and differences between studies that made it difficult to analyse the data.

Conclusions

Evidence suggests that, when compared with usual care, hospital-based specialist palliative care may offer benefits for several person-centred outcomes including health-related quality of life, symptom burden, and patient depression and satisfaction with care, while also increasing the chances of patients dying in their preferred place (measured by home death), with little evidence of harm. Although these are only small effect sizes, they may be clinically relevant at an advanced stage of disease with limited prognosis, and are person-centred outcomes important to many patients and families. It is not possible to draw firm conclusions from the limited and inconsistent evidence on survival nor on the most effective models of care. More well-conducted studies are needed of populations with non-malignant diseases and mixed diagnoses; of interventions of different models of hospital-based specialist palliative care; and of outcomes including achieving patient preferred place of care, patient satisfaction with care, unpaid caregiver outcomes (satisfaction with care, burden, depression, anxiety, grief, quality of life) and cost-effectiveness of hospital-based specialist palliative care.

Study registration

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