A literature review of randomized controlled trials of the organization of care at the end of life

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CRD summary
This review concluded that despite methodological flaws and limitations, randomised controlled trials of end-of-life (EOL) care suggest that home- or community-based interventions compare favourably with conventional hospital or medical care. The review findings are supported by the data provided, but the unclear review methodology and the poor quality of the review data suggest that they should be interpreted with caution.

Authors' objectives
To review randomised controlled trials (RCTs) that assess the organisation of end-of-life (EOL) care for persons who are terminally ill, near death, or dying.

Searching
EMBASE, MEDLINE, CINAHL, AHMED, PsycINFO, ERIC, HealthSTAR, Sociological Abstracts and the Cochrane Library were searched using the listed search terms.

Study selection
RCTs of palliative patients, that considered any outcome for the organisation of EOL care, excluding studies of medications, were eligible for inclusion. Studies where data for palliative and other patients could not be separated, or where medical and surgical interventions were studied, were excluded from the review. Similarly, studies of relatives which did not include the palliative patients themselves were also excluded. The included studies focused on the advanced planning of EOL care, making data available (patient-held records and providing quality-of-life data to patients and physicians), grief education for relatives, palliative care education for nurses and care for specific groups of patients (e.g. dementia). The outcomes included quality of life, management of symptoms, satisfaction with care, duration of palliative period and place of death.

The authors did not state how many reviewers performed the selection.

Assessment of study quality
Two reviewers independently assessed the validity of studies according to four types of bias: selection, performance, attrition and detection bias. In addition, the reviewers assessed whether a sample size calculation was used, whether analyses were based on intention-to-treat data, and whether appropriate statistical methods of analysis were used. Differences between the two reviewers were discussed until issues were resolved.

Data extraction
Effect sizes and levels of statistical significance were reported where available. The authors did not state how the data were extracted for the review, or how many reviewers performed the data extraction.

Methods of synthesis
The studies were grouped according to intervention type (care provided by dedicated community teams and specific palliative care interventions) and outcome, and a narrative synthesis with accompanying data tables was used to summarise the findings.

Results of the review
Twenty-three RCTs (n=6,321) were included in the review.

None of the trials met all of the methodological criteria, and most had methodological flaws and potential biases. Only 10 RCTs performed a sample size calculation, five described their method of randomisation, five used concealed allocation methods, two assessed whether the intervention was delivered according to protocol, three assessed attrition
bias, three used patient blinding and only six used intention-to-treat data.

Six studies reported that quality of life and perceived management of symptoms were improved by palliative care. However, three trials, at least one of which had methodological flaws, found no improvement in symptoms.

One study found higher levels of patient satisfaction with home- or hospice-based care compared with standard hospital-based care, whereas two studies found no increase in patient satisfaction and a further trial found no significant differences between hospital and telephone support. However, three trials reported increased caregiver satisfaction where palliative care teams were used.

One trial reported that hospital-at-home palliative care did not increase the likelihood of dying at home, whereas a second trial reported an increase in survival duration. There were also more deaths at home and fewer deaths in nursing homes in the EOL intervention group than in the control group.

Three trials assessed advanced planning interventions and one reported that patients in the intervention group, when compared with those receiving conventional care, were less likely to undergo life-sustaining treatment for new serious health problems.

One RCT of portable records found no differences in pain control, satisfaction with care or mood compared with standard care. Another RCT of patient care records compared with control also found no improvement in the provision of information to patients, or in family involvement or patient satisfaction, with information provided by health professionals.

Of the two RCTs assessing the provision of quality-of-life data to patients and physicians, one reported that, compared with control, health related quality-of-life issues were discussed significantly more frequently in the intervention group; the second trial found that there were no statistically significant differences in SF-36 scores.

One trial of palliative education for nurses found no effect on nurses’ attitudes to EOL care or their intentions to provide care, but their perceptions of how others might perceive their provision of EOL care were improved compared with control. Another RCT comparing palliative workshops given by video conference or face-to-face methods found no significant difference in learning between the two methods.

One trial of in-hospital palliative care for dementia patients found little difference in the care provided to intervention patients in comparison with control.

Cost information
Three studies, two of which assessed Veterans Affairs home-based EOL care services, reported higher costs for EOL care in comparison with conventional care. Two further studies found no differences between palliative and conventional care, while two more studies reported lower costs for palliative care. Further details were provided in the review.

Authors’ conclusions
It was difficult to synthesise an accurate overview of EOL given the limited number of RCTs available, many of which had methodological flaws and were conducted in various settings, with differing participants, interventions and outcomes. However, in general, community- or home-based EOL appears to compare favourably with conventional care.

CRD commentary
This review answered a clear, but broad research question, with no apparent attempts to define outcomes or patient populations. A large number of databases were searched for potential studies, but it appears that no attempts were made to locate unpublished studies and so publication bias may be a problem. Without further information it is also difficult to assess the risk of language bias and the risk of reviewer error and bias when selecting the studies and extracting the data. The methodological quality of the included studies was, however, assessed and found to be poor in most instances. The wide range of included interventions, participants and outcomes precluded any statistical synthesis and the authors’ use of narrative methods appears appropriate. Overall, the authors’ findings are supported by the data provided, but the
unclear review methodology and the poor quality of the review data suggest that they should be interpreted with caution.

**Implications of the review for practice and research**

**Practice:** The authors stated ‘a key finding of the review is that community or home-based EOL care compares favourably with more traditional or conventional hospital-based and episodic medical care in improving symptoms and in the opinions of patients and caregivers’.

**Research:** The authors stated that there ‘is a need for research about patients with palliative care needs who do not have cancer’. They also stated that future studies should include patients before the palliative stage; carry out sample size calculations; use validated and reliable outcome scales; work sympathetically with patients and caregivers; include an appropriate representation of different cultural groups; use reliable and valid methodologies; and use trialists and statisticians in their research groups.

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