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Effectiveness of Home-based End-of-life Care

Commentary on:

Shepperd, S., Gonçalves-Bradley, D. C., Straus, S. E., & Wee, B. (2021). Hospital at home: home-based end-of-life care. *The Cochrane database of systematic reviews*, *3*(3), CD009231. https://doi.org/10.1002/14651858.CD009231.pub3

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Abstract:

When a person has been diagnosed with a terminal illness and has less than six months to live, and curative treatments are no longer effective, end-of-life care or hospice care may be initiated. Studies suggest that approximately seven million people a year are given this type of care, which strives to reduce suffering and improve quality of life for patients and their families by providing comprehensive physical, psychosocial, and spiritual support. Surveys show that most individuals would prefer to receive this care at home when given the option. However, there are still some uncertainties regarding the effects of end-of-life care at home on a range of important patient outcomes. As a result, a Cochrane review was conducted/updated to study the effects of receiving end-of-life care at home, looking at these outcomes. The aim of this commentary is to critically appraise this Cochrane review and expand upon the findings of the review in context to practice.

Key points

- High quality evidence suggests that end-of-life care at home may increase the risk of an individual dying in their place of home compared to combined services.
- Low quality evidence suggests that end-of-life care at home may have reduced costs compared to combined services.
- There is still much uncertainty regarding the effect of end-of-life care at home on unplanned admissions to hospital, caregiver outcomes and staff views on the provision of services.
- Future research should focus on home-based end-of-life care programs in different patient populations and provide more information on important aspects, such as unplanned admissions to hospital and health outcomes, to facilitate easier decision making for patients and relatives.

Introduction

When a person has been diagnosed with a terminal illness and has less than six months to live, and curative treatments are no longer viable, end-of-life care or hospice care is initiated (Huffman and Harmer 2022). It is estimated that approximately seven million people per year receive this type of care (Connor et al. 2021). The aim of this care is to reduce suffering and improve the quality of life for patients and their families by providing comprehensive support with physical, psychosocial, and spiritual needs of the individual (Rome et al. 2011). Survey data suggest that most individuals prefer to receive end-of-life care at home when given the choice (Ali et al. 2019; Arnold et al. 2015; Higginson et al. 2017). However, even when end-of-life care is provided, there are still uncertainties regarding the effect on the risk of likelihood of dying in hospital and what effect providing this service has on patients' symptoms and quality of life (Shepperd et al. 2021). Subsequently a Cochrane review was conducted/updated to assess the effects of receiving end-of-life care at home on these outcomes (Shepperd et al. 2021).

Aim of commentary

This commentary aims to critically appraise the methods used within the review by Shepperd et al and to expand upon its findings in the context of clinical practice (Shepperd et al. 2021).

Methods

A comprehensive multi-database search was undertaken from date of inception until March 2020. No restrictions on publication type, or language were applied to the search. In addition, forward (using ISI Web of Science) and backward citation searches were undertaken for all included studies. Additional hand searching was also undertaken. Only randomised controlled trials or cluster random controlled trials which included adults who received end-of-life care at home compared with inpatient hospital or hospice care were included. End-of-life care at home was defined as a service offered by healthcare professionals which provides active treatment for extended periods in the patient's home, thus avoiding the need for hospital or hospice inpatient end-of-life care. Title and abstract screening were undertaken by a single reviewer. Full paper screening, data extraction and risk of bias (Cochrane Risk of Bias Tool) was carried out by two reviewers independently. Additional evaluation of confidence in the estimation of effect was undertaken using the GRADE criteria (Guyatt et al. 2008). When feasible a fixed-effect Mantel-Haenszel meta-analysis was undertaken for dichotomous data to calculate a risk ratio (RR) and corresponding 95% confidence interval (Cl 95%). To assess the variance in observed effects rather than sampling error the I^2 statistic was assessed. To test the null hypothesis that all studies in the analysis share a common effect size the Q statistic was utilized.

Results

For this current update 2,984 citations were identified after duplicate removal. After screening no additional papers were identified resulting in four RCTs being currently included in this Cochrane systematic review. Of these four RCTs two were conducted in the US, one in England and one in Norway. Three out of the four RCTs used a multidisciplinary team approach with the remaining RCT using a single disciplinary nursing care approach.

When home-based end-of-life care was provided it increased the risk of the place of death being home (RR 1.31; 95% CI, 1.12 to 1.52, GRADE: High) compared to combined services (this could include routine [not specialized] home care, acute inpatient care, primary care services and hospice care). Low quality evidence from two RCTs indicate that there was a cost reduction in healthcare services for end-of-life care at home of between 18 to 30%.

For the outcome of unplanned admission to hospital (GRADE: Low) there was a wide variation of individual study estimates of relative risk ranging from 2.61 (95% CI, 1.50 to 4.55) to 0.62 (95% CI, 0.48 to 0.79). Low quality evidence demonstrated similar inconsistencies regarding the effect of home-based end-of-life care on combined services on satisfaction. With one RCTs reporting a small increase in satisfaction and one RCT reporting no evidence of difference. Very low-quality evidence suggests that there could be a small reduction in pain control assessed by caregivers (0.48 points, 95% CI –0.93 to –0.03, four-point scale). There is very low-quality evidence from one RCT suggesting that caregivers of participants receiving home-based end-of-life care exhibited a decrease in psychological well-being and a little or no difference in the questionnaire assessing bereavement. District nurses reported within one RCT (very low quality) that there was less of a need for carer support (1.36 vs 1.81, $P \leq 0.01$) and additional help with night nursing (1.43 Vs 2.03, $P < 0.0001$) in the home-based end-of-life care group compared to control [three-point scale negative scores represent less of a problem].

Commentary

Using the AMSTAR 2 critical appraisal tool for systematic reviews 14 out of 16 criteria were judged to be satisfactory for this review (Shea et al. 2017). The only two criteria that were not achieved was the authors failed to explain why only randomized control trials were used and did not conduct duplicate screening for titles and abstracts. Due to the limited evidence within this area, taking a more expansive approach (including nonrandomised studies) may provide a more comprehensive overview of the current evidence base on the effects of home-based end-of-life care. However, when including non-random controlled trials within a systematic review it can lead to additional bias regarding sample allocation and affect the certainty in any type of recommendation being made (Deeks et al. 2003). Regarding title and abstract screening there is a possibility that studies/studies were missed during the screening process as title and abstract screening was undertaken by a single reviewer (Waffenschmidt et al. 2019). Overall, the systematic review provides a comprehensive synthesis of the included studies.

The findings from this review indicate with high certainty that home-based end-of-life care may increase the likelihood that the place of death is at home. Based upon these estimates, it would result in an increase of 163 deaths per 1000 deaths occurring at the individual's place of home when receiving home-based end-of-life care compared to combined services. However it is important to note that dying at home is not just the only outcome to indicate good end-of-life care (Age UK 2019).

Unfortunately, the other outcomes assessed in the review produced notable uncertainties regarding the outcomes assessed, which makes it difficult for any specific recommendations to practice being made based upon this evidence alone. There was very low-quality evidence suggesting that home-based end-of-life care may provide small improvement in pain management assessed by care givers. When care givers are required to deliver pain relief, qualitative evidence suggests that care givers need specialist training on pain management (Chi and Demiris 2017) . This training should focus on individual knowledge related to pain management, assessment, interpretation, and use of pain medications (Chi and Demiris 2017). This training may be provided through face-to-face education supported with written or multimedia resources (Latter et al. 2016).

Regarding the support of carers, this Cochrane systematic review found that there was very low evidence that home-based end-of-life care resulted in the perception that home-based end-of-life care intervention required less carer support than the control group. However, this was based upon a three-point scale and despite this being a significant difference, the actual means difference was minimal suggesting that both groups could require additional support (Grande et al. 2000). As highlighted in the NICE guideline on end-of-life care for adults, the emotional and practical needs of carers should be evaluated and reassessed when required (National Institute for Health and Care Excellence 2019). These needs are often multifaceted, in such areas as emotional support, knowledge related to the disease, taking on responsibilities as a career, caring for themselves, and general practical assistance (Marco et al. 2022). These needs can be met by providing access professional services, communication with health professionals and educational opportunities (Marco et al. 2022). Finally, the review suggested that receiving home-based end-of-life care may result in reduced service costs of between 18 to 30% compared to combined services. However, this is based upon low certainty evidence therefore these estimates should be viewed with caution.

End-of-life care at home versus hospital is a difficult decision for patients and their relatives and can present a significant source of confusion and anxiety (Gomes and Higginson 2004). Future research should focus on aspects that would help patients and their relatives when making this decision. Further exploration should be undertaken focusing on the effects of home-based end-of-life care, on frequency and type of unplanned admissions to hospitals which can disrupt continuity of care and patients end-of-life goals. Another avenue of focus for future research should be on effects of home-based end-of-life care on patient specific outcomes. There is currently no overall core outcome set for end-of-life care (Zambrano et al. 2020). However, one is currently being developed and when published the recommendation should be followed regarding which outcomes are important for patients (Zambrano et al. 2020). Future research should investigate the effect of the hospital-at-home program on various subgroups of patients with terminal illness or distinct demographics, with the aim of providing personalized end-of-life care to particular patient groups.

CPD reflective questions

1. What can home-based end-of-life care provide for patients?
2. What are the benefits of using the Cochrane Risk of Bias tool?
3. What still needs to be identified before home-based end-of-life care can be recommended?

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