



CME: Palliative Medicine

Palliative care: what's the evidence? ☆

Sophie Pask, Fliss E.M. Murtagh, Jason W. Boland*

Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, HU6 7RX, United Kingdom

ARTICLE INFO

Keywords:

Palliative care
Specialist palliative care
Symptoms
Dying
Quality of life
Healthcare costs

ABSTRACT

Palliative care is essential for people with an advanced life-limiting illness. Most palliative care is delivered by healthcare professionals who do not specialise in palliative care ('non-specialists'). Multidisciplinary specialist palliative care services manage more complex problems, providing more comprehensive support when needed. Both 'non-specialist' and specialist palliative care improve patient and family outcomes and reduce formal healthcare costs. However, there are inconsistencies in the delivery of, and access to, 'non-specialist' and specialist palliative care. These inconsistencies and inequities lead to unrecognised and unmet palliative care needs. There is also inconsistent referral to specialist palliative care services.

Unless there are greater resources and training, these issues will be exacerbated by an increasing need for palliative care with changing population demographics.

Palliative care is delivered by a range of professionals: i) some 'non-specialists' in palliative care (eg primary/community care professionals, and also secondary care professionals specialised in other areas) and ii) specialists in palliative care (ie multiprofessionals working predominantly in palliative care). Both 'non-specialist' and specialist palliative care improve patient and family outcomes, and reduce formal healthcare costs.¹⁻³ 'Non-specialist' palliative care is the first line of holistic care (including pain/symptom/psycho/social/spiritual assessment and management), identification of the last year/months/weeks/days of life, advance care planning and identification of specialist palliative care need and referral. It should be the business of almost all health and care professionals. However, there are currently often unrecognised and unmet palliative care needs, due to inconsistencies in 'non-specialist' palliative care resource, expertise, delivery and referral to specialist palliative care.⁴ There are also inconsistencies in specialist palliative care resource and delivery.

It is predicted that palliative care demand will increase by up to 47% (from 2014 to 2040) due to 25% more annual deaths (England and Wales), with more deaths at older ages and from chronic disease and dementia.⁵ Healthcare systems must respond to and adapt to meet age-related multimorbidity increase in palliative care needs, developing robust non-specialist and specialist palliative care infrastructure to ensure high-quality care and support for those with advanced life-limiting illness.⁵⁻⁸ With more people dying at home and the policy ambition to pivot care to community from hospital, palliative care is paramount.⁹ Enough appropriately skilled staff to support community-based pallia-

tive and end-of-life care, as well as health and care system infrastructure, are needed to meet current and evolving demand.⁹

The role of non-specialist palliative care and where does specialist palliative care fit in?

Non-specialist and specialist palliative care are both characterised by the holistic care of individuals, which aims to improve quality of life by addressing physical, psychosocial and emotional needs.¹⁰ Non-specialist palliative care is mostly delivered by primary and community care providers (eg GPs and community/district nurses) and family and informal carers in home and community settings, and also by a range of hospital healthcare professionals specialised in other areas.^{10,11} Specialist palliative care providers tend to manage more complex problems and provide more targeted and comprehensive support when needed.¹⁰ In view of individualised and variable needs of people with advanced or life-limiting illness, it is necessary to identify those with more complex needs for referral to specialist palliative care.¹²

Both non-specialist and specialist palliative care have been shown to improve outcomes for patients and their families, reduce costs, and enhance end-of-life care experiences.¹⁻³ However, the way in which care is delivered varies greatly; from the professionals involved (non-specialist or specialist palliative care or both), to the setting where the care is delivered, and the mode of delivery (eg in-person/telehealth).³ There remains limited understanding of which models and components of care work best and for whom, and under which circumstances.^{3,13-15} A re-

☆ This article has an accompanying continuing medical education (CME) activity. Completion of this CME activity enables RCP members to earn two external CPD credits. The CME questions are available at: <https://cme.rcp.ac.uk/>

* Corresponding author.

E-mail address: jason.boland@hymms.ac.uk (J.W. Boland).

cent systematic review on palliative and end-of-life care for adults living at home found that evidence largely supports in-home palliative care, including both non-specialist palliative care and integrated care with specialist palliative care.³

Using a novel methodology to convert outcomes into minimally clinically important difference (MID) units and number needed to treat (NNT), a recent meta-analysis and meta-regression pooled 20 years of robust evidence for specialist palliative care across outcomes for quality of life and emotional wellbeing.¹⁶ Specialist palliative care, provided in addition to usual care, demonstrates significant clinically important improvements to both quality of life and emotional wellbeing, with moderate to substantial effect (ie a standardised mean difference (minimally clinically important difference) of 0.4 for quality of life), regardless of the underlying illness.¹⁶ The NNT is similar to, or better than, many other well-accepted interventions, such as cardiac rehabilitation.¹⁶

The importance of timing specialist palliative care

Specialist palliative care has optimal benefit when care is received at least 3 months before death, although there is benefit with less.¹⁶ However, referrals to specialist palliative care currently occur within weeks of death, too late for maximal benefit.^{16,17} A UK retrospective cohort study reported the median time from referral to hospice-based inpatient or community specialist palliative care and death was on average 48 days,¹⁷ and even less (27 days) for those with non-cancer conditions.¹⁷ Referral time for people with dementia or stroke to specialist palliative care was a median of 9 days before they died.¹⁷ Increasing age and being male were also significant predictors of late referral.¹⁷ Reduced access by non-cancer diagnosis, older age and lower socioeconomic status were evident in an England/Wales bereavement survey for specialist palliative care received at home, care home or hospital.¹⁸

As well as the need for 'timely' (ie based on need, and likely notably earlier than at present) specialist palliative care, there remain challenges with how 'timely' is defined and identifying appropriate triggers for referral (ie criteria and screening).⁴ Patients receiving 'earlier' specialist palliative care show an improvement in a range of outcomes, including better physical symptom control, improved mood, better quality of life and longer survival.^{19,20} 'Early' palliative care led to decreased depression, less chemotherapy at the end of life, and increased social support.^{19,21} To provide 'timely' and 'early' specialist palliative care for all patients with advanced illness will need redirection of resources.⁴

What are the challenges?

Most palliative care is delivered by primary and community care providers, as well as hospital healthcare professionals, for whom palliative care is just one aspect of the care that they provide.^{9,22-24} Their role includes identifying those who are dying, providing first-line symptom management, and enabling access of additional services, such as specialist palliative care, where needed.²³ Barriers include limited time to deliver care, large workload, staff shortages, poor knowledge of policy developments in palliative care (eg Gold Standards Framework) and lack of palliative care skills.²²⁻²⁴ Specialist palliative care addresses the most complex cases, reduces hospital admissions and bed days in hospital.^{25,26} However, its ability to do this is also reducing, as much of the funding (about two-thirds) for specialist palliative care comes from charitable funding; third sector providers are experiencing severe financial and workforce challenges – and subsequently having to reduce the number of people seen.²⁷

This raises a question around who care then falls to. Family and friends play an important role in supporting those with advanced and life-limiting illness. The costs of care provided by family and friends, including *personal care* (eg washing or dressing) and *other help* (eg providing transport or doing laundry), would mean an estimated national replacement cost of £28.7 billion (England).¹¹ This echoes the challenges with accessing timely specialist palliative care, where those with non-cancer

causes of death and increasing age were associated with increased costs among other factors (eg those in more deprived areas).¹¹ Multiple barriers to 'timely' palliative care include a lack of awareness of symptoms or needs, inconsistent referral thresholds, stigma surrounding palliative care and limited resources.⁴

What are the solutions?

To be most effective, specialist palliative care services need to be multidisciplinary and integrated across different healthcare settings, delivering multiple components (ie symptom control, psycho-social-spiritual care and advance care planning).¹⁶ Both non-specialist and specialist palliative care need to be sufficiently resourced to enable timely and effective intervention (especially as this is a statutory requirement) and to relieve hospital pressures.^{9,16,25,27}

It requires timely referral to ensure benefits are achieved.^{16,17} For this to occur, there needs to be better identification of people with difficult-to-manage palliative care needs, consistent referral criteria, and education and support for the whole workforce who deliver non-specialist palliative care to be able to achieve this.^{4,6} Policy and commissioning should drive a needs-based referral at least 3–6 months before death as the optimal standard of care.¹⁶

Summary/conclusions

It is counterproductive to leave palliative care and specialist palliative care under-resourced, as it risks ill-equipped and ineffective services that do not deliver for people or the NHS.^{16,26,27} This is especially important for community-based palliative care services, if the high levels of unplanned hospital admissions near end-of-life care are to be reduced,²⁸ and the proposed pivot from acute care to community-based care is to be achieved.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. FM is a UK National Institute for Health and Care Research (NIHR) senior investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Sophie Pask: Writing – original draft, Writing – review & editing, Conceptualization. **Fliess E.M. Murtagh:** Conceptualization, Writing – review & editing. **Jason W. Boland:** Conceptualization, Writing – original draft, Writing – review & editing.

References

1. de Wolf-Linder S, Dawkins M, Wicks F, *et al.* Which outcome domains are important in palliative care and when? An international expert consensus workshop, using the nominal group technique. *Palliat Med.* 2019;33:1058–1068. doi:10.1177/0269216319854154.
2. Bausewein C, Daveson BA, Currow DC, *et al.* EAPC White Paper on outcome measurement in palliative care: improving practice, attaining outcomes and delivering quality services – recommendations from the European Association for Palliative Care (EAPC) task force on outcome measurement. *Palliat Med.* 2016;30:6–22. doi:10.1177/0269216315589898.
3. Pask S, Okwuosa C, Mohamed A, *et al.* Models, components, and outcomes of palliative and end-of-life care provided to adults living at home: A systematic review of reviews. *medRxiv.* 2025. doi:10.1101/2025.02.14.25322267.

4. Hui D, Heung Y, Bruera E. Timely palliative care: personalizing the process of referral. *Cancers*. 2022;14:1047.
5. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med*. 2017;15:102. doi:10.1186/s12916-017-0860-2.
6. Hocaoglu MB, Siegert RJ, Sandham M, et al. Editorial: public health in the context of life-limiting illnesses: patient-centered care in advanced and life-limiting illnesses. *Front Public Health*. 2024;12:1454805. doi:10.3389/fpubh.2024.1454805.
7. Pati S, MacRae C, Henderson D, et al. Defining and measuring complex multimorbidity: a critical analysis. *Br J Gener Pract*. 2023;73:373–376. doi:10.3399/bjgp23X734661.
8. Whitty CJM, MacEwen C, Goddard A, et al. Rising to the challenge of multimorbidity. *BMJ*. 2020;368:l6964. doi:10.1136/bmj.l6964.
9. Baylis A, Chikwira L, Robertson R, Tiratelli L. *Dying well at home-commissioning quality end-of-life care overview*. London, UK: The King's Fund; 2023.
10. Radbruch L, De Lima L, Knaul F, et al. Redefining palliative care—A new consensus-based definition. *J Pain Symptom Manage*. 2020;60:754–764. doi:10.1016/j.jpainsymman.2020.04.027.
11. Johnson MJ, Currow DC, Chynoweth J, et al. The cost of providing care by family and friends (informal care) in the last year of life: A population observational study. *Palliat Med*. 2024;38:725–736. doi:10.1177/02692163241259649.
12. Murtagh FEM, Guo P, Firth A, et al. A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme. *Programme Grants Appl Res*. 2023;11. doi:10.3310/PLRP4875.
13. Bajwah S, Oluyase AO, Yi D, et al. The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*. 2020;9(Cd012780):20200930. doi:10.1002/14651858.CD012780.pub2.
14. Oluyase AO, Higginson IJ, Yi D, et al. *Health Services and Delivery Research*. Hospital-based specialist palliative care compared with usual care for adults with advanced illness and their caregivers: a systematic review. Southampton (UK): NIHR Journals Library; 2021.
15. Hughes MC, Vernon E, Hainstock A. The effectiveness of community-based palliative care programme components: a systematic review. *Age Ageing*. 2023;52. doi:10.1093/ageing/afad175.
16. Johnson MJ, Rutterford L, Sunny A, et al. Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. *PLOS Med*. 2024;21:e1004436. doi:10.1371/journal.pmed.1004436.
17. Allsop MJ, Ziegler LE, Mulvey MR, et al. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliat Med*. 2018;32:1322–1333. doi:10.1177/0269216318781417.
18. Johansson T, Pask S, Goodrich J, et al. *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales (Research Report)*. London, UK: Marie Curie; 2024.
19. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New Engl J Med*. 2010;363:733–742. doi:10.1056/NEJMoa1000678.
20. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet*. 2014;383:1721–1730. doi:10.1016/S0140-6736(13)62416-2.
21. Irwin KE, Greer JA, Khatib J, et al. Early palliative care and metastatic non-small cell lung cancer: potential mechanisms of prolonged survival. *Chronic Respirat Dis*. 2013;10:35–47. doi:10.1177/1479972312471549.
22. Offen J. The role of UK district nurses in providing care for adult patients with a terminal diagnosis: a meta-ethnography. *Int J Palliat Nurs*. 2015;21:134–141. doi:10.12968/ijpn.2015.21.3.134.
23. Polak L, Hopkins S, Barclay S, Hoare S. The difference an end-of-life diagnosis makes: qualitative interviews with providers of community health care for frail older people. *Br J Gen Pract*. 2020;70:e757–e764. doi:10.3399/bjgp20X712805.
24. Walshe C, Luker KA. District nurses' role in palliative care provision: a realist review. *Int J Nurs Stud*. 2010;47:1167–1183. doi:10.1016/j.ijnurstu.2010.04.006.
25. Imison C, Curry N, Holder H, et al. *Shifting the balance of care: great expectations. Research report*. London, UK: Nuffield Trust; 2017.
26. McCarroll S, Avsar P, Moore Z, et al. The impact of specialist community palliative care teams on acute hospital admission rates in adult patients requiring end of life care: A systematic review. *Eur J Oncol Nurs*. 2022;59:102168. doi:10.1016/j.ejon.2022.102168.
27. All-Party Parliamentary Group Hospice and End-of-Life Care. *Government funding for hospices*. London, UK: Hospice UK; 2024.
28. Pask S, Davies JM, Mohamed A, et al. *Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Research*. London, UK: Marie Curie; 2022.