Palliative medicine can be called the ‘heaven for the few’: how can we improve access to good palliative care?

--

for the APM Undergraduate Palliative Medicine Essay Prize 2024

Word count (excluding citations): 1888

Introduction

Palliative medicine, as defined by the World Health Organization is a discipline concerned with the relief of health-related suffering, extending far beyond the management of physical symptoms alone (1). The field comprises expertise bridging many disciplines, including pain management, psychology and psychiatry, and spirituality. It can be accurately described as 'heaven for the few' because the present – and future – demand for this crucial service unfortunately far outstrips supply, with only 14% of the global population estimated to have adequate access to end of life care (2,3).

A 'good death' may be regarded as the end result of 'good' palliative care, but what constitutes such a death is highly dependent on the individual. Researchers have previously highlighted the difficulty in exploring this concept (4–6), however certain core areas of importance to patients approaching the end of life have been well elucidated in the existing literature (7). Improving access to 'good' palliative care to facilitate a 'good death' for all who need it, in a timely and culturally-sensitive fashion, is of the utmost importance.

The following essay will approach this question predominantly through the lens of palliative care delivery in the United Kingdom (UK), however, points raised may also be applicable to other settings.

Palliative medicine provision in the UK

Hospices represent the cornerstone of palliative care provision in the UK. Since the establishment of the UK's first hospice in 1967 by Dame Cicely Saunders (8), these settings have been delivering necessary end of life care to patients in need. Their functioning relies upon a complex combination of government and charitable funding, and a multidisciplinary team of professionals (9–11).

With demand for palliative care projected to rise significantly in the coming years, there is an inherent need to maintain, and ideally bolster funding to ensure these needs are met. In England and Wales alone, for example, it is anticipated that there will be a 25-47% increase in need for these services by 2040 (12). Unfortunately, current investigations demonstrate that these critical services have seen a millions-strong reduction in their real-terms funding in recent years (13). Reports suggest that there will be a compensatory reduction in staff numbers and services provided (14).

This predicament offers an area in which a significant improvement can be made, with the first step being to ensure that these funding needs are met to maintain current services. Subsequently, increasing funding beyond what is required for service maintenance will facilitate the expansion of services in preparation for the expected increase in demand. Furthermore, a *sustainable* increase in funding could facilitate enhanced staffing and training, targeted approaches to reach underserved populations, and new, innovative approaches to palliative care delivery.

The palliative care workforce

Presently, the palliative and hospice workforce consists of large numbers of healthcare professionals, such as doctors and nurses, allied staff, and a substantial network of volunteers (9). The above discussion highlights the need for an expansion of this workforce to meet the future needs of the population. Importantly, there is a growing international body of research exploring fatigue and burnout among workers in palliative care (15–17), so in addition to the expansion of the workforce, there should be efforts to ensure support to those providing these services.

Palliative medicine has historically been a popular choice among medical graduates selecting their area of specialisation. In England in 2020, for example, 100% of the available training positions in the specialty were filled by interested applicants, of whom there were 2.8 for each post offered (18). However, there has been a recent reversal of this trend, such that only 31.7% of training positions were filled in 2022, without any significant increase to training post numbers (19). Despite this figure recovering somewhat to 63% in the most recent UK-wide application cycle (20), this presents a concerning trend, as it hints at the potential for a future shortage of palliative care specialists in the UK.

This fall in popularity coincided with the launch of the new training curriculum (21), which introduced a requirement for palliative medicine trainees to also pursue higher training in general medicine. These changes align with the goal of the Chief Medical Officer of England: ensuring that specialist doctors maintain their generalist knowledge to better serve patients (22). This is a noble aim, but it appears to have had an impact on interest in palliative medicine among medics. Therefore, it would be prudent to take steps to limit the number of training vacancies in the specialty.

Under the new curriculum, to become a specialist in palliative medicine will take a newly qualified doctor a minimum of nine years of training (including the mandatory two-year Foundation Programme), up from eight years under the previous curriculum (21,23,24). It may be an option to investigate reducing the length of training to line up with systems overseas, for example the United States or Canada, whose minimum training lengths are four and six years respectively (25,26). Alternatively, it could be feasible to transition to a competency-based training curriculum akin to one newly introduced for ophthalmology specialty training in the UK (27). These changes may make palliative medicine a more attractive career option for those with an interest in the specialty, and provide the added benefit of accelerating the throughput of palliative medicine trainees.

Another important avenue to explore is garnering interest among medical students and early-career doctors. Integrating formal palliative medicine experience into medical curricula can have a meaningful impact on students' understanding and perception of the specialty (28). Extracurricular opportunities relating to the palliative medicine are also an excellent way of encouraging students to engage with the specialty, such as student-led societies and specialist society membership (29,30).

The importance of a robust workforce of palliative medicine specialists cannot be understated, however current demands on palliative care services mean that a majority of UK palliative care practitioners feel there is insufficient capacity to deliver high-quality end of life care (31). Doctors of all specialisms, at all levels, will encounter, and often deliver care to, patients with palliative care needs (32). To relieve stresses on the system, there is a need for the broad acquisition of 'primary palliative care' skills among medics: basic skills which enable them to care for patients with end of life needs (33). Specialist palliative physicians may then be called upon to deliver care to patients with more complex needs. This expansion of palliative medicine skills will greatly enhance access to end of life care.

Although a core competency defined by the General Medical Council (34), there is significant variation in how students are exposed to the specialty between medical schools, with some institutions placing less emphasis on palliative care than others (35). As such, previous research has highlighted that newly qualified doctors are not always sufficiently equipped to deal with end of life care for patients. To achieve widespread acquisition of 'primary palliative care' skills, it is critical to introduce palliative medicine to medical students during their studies. An enlarged, upskilled workforce will be better equipped to care for people of all groups approaching the end of life, and hence improve access to this care. However, though medical staff play an important role, the services themselves must be designed to be accessible.

Serving the underserved

Though the UK's palliative care system is regarded among the best in the world (36,37), access to care is distributed unequally across the country and between demographic groups. For instance, it is well documented that people's eventual place of death is significantly influenced by their location, due to inconsistent access to services (38). Patients from more deprived parts of the UK are also more likely to die in hospital, even though most patients reportedly wish to be at home as they approach the end of their life (39,40). It has been suggested that this outsized burden of disease among people living in areas of socioeconomic deprivation leads to higher rates of hospital admission towards the end of life, thus impeding access to quality end of life care (39,41). This illustrates the interplay between socioeconomic factors – the "postcode lottery" – and access to palliative care.

Unfortunately, inequalities in access are not limited only to people from different socioeconomic backgrounds. People with certain medical conditions, perhaps most notably heart disease and dementia, are also less likely to access the end of life care that they deserve (42). The Care Quality Commission (CQC) point out that this may be due to difficulties in recognising when people are in the last 12 months of life (43). Tools have been developed in pursuit of better outcomes in this area (44), but it is clear that there is still room for improvement.

In a similar vein, there are challenges in accessing end of life care among people from minoritsed communities. Patients for whom English is not their first language, for instance, may be hindered by language barriers. Indeed, there are many other minoritised groups whose access to this care has also been limited due to flaws in the system (43). Researchers have called for thorough data collection in this area relevant to palliative medicine to better address inequalities (45).

There are growing calls to increase the role of devolved, locally-administered approaches to health in the UK (46). This could better enable services to be tailored to the specific communities they serve. In the context of palliative medicine, local decision-makers are more likely to be cognisant of inequalities in accessing end of life care and can therefore direct resources accordingly. For instance, embedding palliative care navigators in the community – such as in primary care and hospices – could support patients in accessing these services. In conjunction with this, where speakers of specific languages are concentrated, interpreters could be employed locally to support patients to advocate for the care they need and deserve. These local efforts can be reinforced by measures taken on the national level, such as developing a national staff education scheme to improve the recognition of the end of life in conditions where this is more challenging. Patient information materials should also be offered in a wide range of languages. Local services can also report outcome data into large national datasets, the analysis of which could educate funding strategies and further staffing or educational adjustments.

Conclusion

The need for ‘good’ palliative care is evident, as are the reasons for the expected increase in demand for these services in years to come. For now, the UK provides some of the best end of life care in the world, its shortcomings notwithstanding, but we may be sleepwalking into a crisis by not effectively futureproofing these services.

Real-terms loss of funding, staffing vacancies, and insufficient staff education threaten the future of palliative care provision. It is also probable that existing inequalities in access to these services will be exacerbated by such losses. To maintain – and expand – palliative care provision, we must take a proactive approach to the service. A sustainable boost to funding is a necessary first step, followed by inspiring and educating the next generation of health professionals in palliative care. These actions will improve access to this expertise across the board, with the potential for targeted approaches to be taken to support groups for whom accessing such care has historically been challenging.

Ultimately, it is true that palliative care can be regarded ‘heaven for the few’, however we have the power to shift this narrative. We have the opportunity to offer ‘heaven for all who need it’. This is a lofty ambition, but it is what our patients deserve, and what we would want for those close to us should the time come.

References

1. World Health Organization. Palliative care [Internet]. [cited 2024 Nov 18]. Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care

2. Lupu D, Quigley L, Mehfoud N, Salsberg ES. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? J Pain Symptom Manage. 2018;55(4):1216–23.

3. Clark D, Baur N, Clelland D, Garralda E, López-Fidalgo J, Connor S, et al. Mapping Levels of Palliative Care Development in 198 Countries: The Situation in 2017. J Pain Symptom Manage. 2020;59(4):797-807.e4.

4. Kendall M, Harris F, Boyd K, Sheikh A, Murray SA, Brown D, et al. Key challenges and ways forward in researching the “good death”: qualitative in-depth interview and focus group study. BMJ. 2007 Feb 28;334(7592):521.

5. Meier EA, Gallegos JV, Thomas LPM, Depp CA, Irwin SA, Jeste DV. Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. Am J Geriatr Psychiatry. 2016 Apr 1;24(4):261–71.

6. Clark J. Patient centred death: We need better, more innovative research on patients’ views on dying. BMJ. 2003 Jul 26;327(7408):174.

7. Cottrell L, Duggleby W. The “good death”: An integrative literature review. Palliat Support Care. 2016 Dec;14(6):686–712.

8. Richmond C. Dame Cicely Saunders. BMJ. 2005 Jul 23;331(7510):238.

9. Hospice UK. Hospice UK Strategy 2024-2029: Hospice care for all, for now and forever [Internet]. 2024. Available from: https://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2024-04/Hospice%20Strategy%20Document%2022April2024_0.pdf

10. All-Party Parliamentary Group on Hospice and End of Life Care. Government funding for hospices [Internet]. 2024 Jan. Available from: https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2024-02/APPG%20Report%20-%20Government%20funding%20for%20Hospices%20HUK.pdf?VersionId=0l8T4jC5V2C0zRKQLFs9ClZ5QZ5xEiOs

11. National Health Service. NHS UK. 2023 [cited 2024 Nov 18]. Hospice care. Available from: https://www.nhs.uk/conditions/end-of-life-care/where-you-can-have-care/hospice-care/

12. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017 May 18;15(1):102.

13. Hospice UK. Hospice UK. 2023 [cited 2024 Nov 18]. Hospice funding falls short by £47m. Available from: https://www.hospiceuk.org/latest-from-hospice-uk/hospice-funding-falls-short-ps47m

14. Pym H, Loader V. BBC News. 2024 [cited 2024 Nov 18]. Hospices hit by funding crisis. Available from: https://www.bbc.com/news/articles/c4gl5dxzyrdo

15. Slocum-Gori S, Hemsworth D, Chan WW, Carson A, Kazanjian A. Understanding Compassion Satisfaction, Compassion Fatigue and Burnout: A survey of the hospice palliative care workforce. Palliat Med. 2013 Feb 1;27(2):172–8.

16. Gómez-Urquiza JL, Albendín-García L, Velando-Soriano A, Ortega-Campos E, Ramírez-Baena L, Membrive-Jiménez MJ, et al. Burnout in Palliative Care Nurses, Prevalence and Risk Factors: A Systematic Review with Meta-Analysis. Int J Environ Res Public Health. 2020 Oct 21;17(20):7672.

17. Koh MYH, Gallardo MD, Khoo HS, Hum A. Burnout in Palliative Care - Difficult Cases: Qualitative Study. BMJ Support Palliat Care. 2023 Dec 1;13(e3):e1383–9.

18. NHS England. NHS England - Workforce, training and education. [cited 2024 Nov 18]. 2020 England Recruitment Fill Rates. Available from: https://medical.hee.nhs.uk/medical-training-recruitment/medical-specialty-training/fill-rates/2020-fill-rates/2020-england-recruitment-fill-rates

19. NHS England. NHS England - Workforce, training and education. [cited 2024 Nov 18]. 2022 Recruitment England Fill Rates. Available from: https://medical.hee.nhs.uk/medical-training-recruitment/medical-specialty-training/fill-rates/2022-recruitment-england-fill-rates-round-1-and-round-2

20. NHS England. NHS England - Workforce, training and education. [cited 2024 Nov 18]. 2024 England Recruitment Fill Rates. Available from: https://medical.hee.nhs.uk/medical-training-recruitment/medical-specialty-training/fill-rates/2024-fill-rates/2024-england-recruitment-fill-rates

21. Joint Royal Colleges of Physicians Training Board. Curriculum for Palliative Medicine Training (Implementation August 2022) [Internet]. Available from: https://www.gmc-uk.org/-/media/documents/palliative-medicine-2022-curriculum-final-v1_0_pdf-92050272.pdf

22. Generalist skills are vital to serve ageing population, says England's CMO | The BMJ [Internet]. [cited 2024 Nov 18]. Available from: https://www.bmj.com/content/383/bmj.p2640

23. UK Foundation Programme. UK Foundation Programme Curriculum 2021 [Internet]. 2021. Available from: https://foundationprogramme.nhs.uk/wp-content/uploads/sites/2/2024/05/UKFP-Curriculum-2021_Oct22-update.pdf

24. Joint Royal Colleges of Physicians Training Board. Specialty Training Curriculum for Palliative Medicine 2010 (Amendments 2014) [Internet]. 2014. Available from: https://www.gmc-uk.org/-/media/documents/dc10694-app-palliative-medicine-curriculum-75606940.pdf

25. Accreditation Council for Graduate Medical Education. ACGME Program Requirements for Graduate Medical Education in Hospice and Palliative Medicine [Internet].

2022. Available from: https://www.acgme.org/globalassets/pfassets/programrequirements/540_hospicepalliativemedicine_2022.pdf

26. Royal College of Physicians and Surgeons of Canada. Subspecialty Training Requirements In Adult Palliative Medicine [Internet]. 2017. Available from: https://www.royalcollege.ca/content/dam/documents/ibd/palliative-medicine/palliative-medicine-adult-str-e.html

27. The Royal College of Ophthalmologists. Curriculum for Ophthalmic Specialist Training (OST). 2024.

28. Head BA, Earnshaw LA, Greenberg RB, Morehead RC, Pfeifer MP, Shaw MA. “I Will Never Forget”: What We Learned from Medical Student Reflections on a Palliative Care Experience. J Palliat Med. 2012 May;15(5):535–41.

29. West Midlands Palliative Care [Internet]. 2024. Starting Early: Student Activism. Available from: https://www.westmidspallcare.co.uk/starting-early-student-activism/

30. Assocation for Palliative Medicine of Great Britain and Ireland [Internet]. Medical Student Membership. Available from: https://apmonline.org/medical-student-membership/

31. Association for Palliative Medicine of Great Britain and Ireland, Marie Curie. Association of Palliative Medicine and Marie Curie survey of palliative care practitioners 2021 [Internet]. 2021. Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-and-apm-survey-analysis-12.01.22-1.pdf

32. Gibbins J, McCoubrie R, Maher J, Wee B, Forbes K. Recognizing that it is part and parcel of what they do: teaching palliative care to medical students in the UK. Palliat Med. 2010 Apr 1;24(3):299–305.

33. Quill TE, Abernethy AP. Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. N Engl J Med. 2013 Mar 28;368(13):1173–5.

34. General Medical Council. Outcomes for graduates 2018 [Internet]. Available from: https://www.gmc-uk.org/-/media/documents/outcomes-for-graduates-2020_pdf-84622587.pdf

35. Walker S, Gibbins J, Paes P, Adams A, Chandratilake M, Gishen F, et al. Palliative care education for medical students: Differences in course evolution, organisation, evaluation and funding: A survey of all UK medical schools. Palliat Med. 2017 Jun 1;31(6):575–81.

36. Woitha K, Garralda E, Martin-Moreno JM, Clark D, Centeno C. Ranking of Palliative Care Development in the Countries of the European Union. J Pain Symptom Manage. 2016 Sep;52(3):370–7.

37. Finkelstein EA, Bhadelia A, Goh C, Baid D, Singh R, Bhatnagar S, et al. Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. J Pain Symptom Manage. 2022 Apr 1;63(4):e419–29.

38. Gao W, Chukwusa E, Verne J, Yu P, Polato G, Higginson IJ. The role of service factors on variations in place of death: an observational study. Health Serv Deliv Res. 2019 Feb 26;7(8):1–58.

39. Davies JM, Maddocks M, Chua KC, Demakakos P, Sleeman KE, Murtagh FEM. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. Lancet Public Health. 2021 Mar 1;6(3):e155–63.

40. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol Off J Eur Soc Med Oncol. 2012 Aug;23(8):2006–15.

41. Marmot M. Health equity in England: the Marmot review 10 years on. BMJ. 2020 Feb 25;368:m693.

42. Johansson T, Pask S, Goodrich J, Budd L, Okamoto I, Kumar R, et al. Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales [Internet]. 2024. (Better End of Life 2024). Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf

43. Care Quality Commission. A different ending: addressing inequalities in end of life care [Internet]. 2016. Available from: https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf?msclkid=5cf24948c63b11ec9240cca339e854b3

44. The Gold Standards Framework Centre CIC. The GSF Prognostic Indicator Guidance: the National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life [Internet]. 2011. Available from: https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%2002011.pdf

45. Clarke G, Hussain JA, Allsop MJ, Bennett MI. Ethnicity and palliative care: we need better data – five key considerations. BMJ Support Palliat Care. 2023 Dec 1;13(4):429–31.

46. Buck D, Tiratelli L. The King's Fund. 2024. The latest proposals on health devolution: solution or provocation? Available from: https://www.kingsfund.org.uk/insight-and-analysis/blogs/proposals-health-devolution-solution-provocation