








Emerging health and social policy considerations for safe and quality end-of-life care in Australia – the evidence, gaps and challenges

Deb Rawlings^{A,*}  (MPH, Senior Lecturer), Raechel Damarell^A  (PhD, Senior Research Fellow), Paul Tait^A  (PhD, Project Pharmacist), Amal Chakraborty^{A,B}  (PhD, Research Fellow), Angie Dalli^C  (Dip Health Sci, Masters Bioethics, Senior Policy Advisor, Partnering with Consumers at the ACSQHC), Kim Devery^A  (B Soc Sci, Associate Professor) and Jennifer Tieman^A  (PhD, Professor)

For full list of author affiliations and declarations see end of paper

*Correspondence to:

D. Rawlings
Research Centre for Palliative Care, Death and Dying, College of Nursing and Health Sciences, Flinders University, Adelaide, SA 5042, Australia
Email: deborah.rawlings@flinders.edu.au

Received: 20 July 2023
Accepted: 24 August 2023
Published: 12 September 2023

Cite this:

Rawlings D et al. (2023)
Australian Health Review
47(5), 586–588. doi:10.1071/AH23166

© 2023 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of AHHA. This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (CC BY-NC-ND)

OPEN ACCESS

ABSTRACT

Recognition of the importance of end-of-life care will enable improvements in the quality of care delivered to patients and their families. Australia is experiencing an increasing number of deaths, (many expected), with an aging population who are living longer, often with multimorbidity. This makes end of life care a priority. The last year of someone's life takes place in a complex healthcare system, with increasing pressures on care delivery, placing the spotlight on health service providers to ensure that teams and individuals are supported and enabled to provide such care. Two rapid literature reviews identified best practice principles and processes for delivering safe and high-quality end-of-life care in acute care, aged care and community settings. The reviews identified that end-of-life care is experienced within the whole health and social care system, including hospital admissions interspersed with care in the community, outpatient and emergency department visits and potentially admission to a hospice. Much of this last year of life is spent at home, which may be a personal residence, an aged care facility, prison, supported accommodation or even on the streets. Transitions across settings requires seamless care, as well as organisational readiness to deliver safe and culturally appropriate care. This is more important now with end-of-life care subject to quality assurance mechanisms within the National Safety and Quality Health Service Standards (2nd edn): Comprehensive care. This requires all sectors to work collaboratively when caring for someone at the end of their life in order to see positive changes in care outcomes.

Keywords: aged care, end-of-life, evidence base, health policy, literature reviews, palliative care, primary health care, quality and safety.

Introduction

There were 190 394 deaths in Australia in 2022,¹ with the majority requiring healthcare in the last 12 months of life, and health care professionals (HCPs) working across acute, community and aged care services all having a role in managing anticipated deaths. Most of this last year is spent at home with an average of 2.6 admissions to hospital,² potentially frequent visits to a hospital emergency department,³ to a general practitioner (GP) or other health-related appointments. The complexity of providing end-of-life (EOL) care across various settings is compounded by the multidisciplinary workforce, different funding models,⁴ and reliance on caregiver support amidst the deterioration of the patient.⁵

With an increasingly older population living longer, often with multimorbidity or frailty, the need for quality EOL care is rising.⁶ For the health and aged sectors (i.e. the context in which care is provided) the reality is one of relentless demands for care from population groups with different needs who are supported by an imperfect, fragmented care system.⁴ With diverse funding models and sources, a lack of clarity around

individual, service and jurisdictional responsibilities; a perfect storm is being created for patients and families requiring EOL care.

In 2015, the Australian Commission on Safety and Quality in Health Care (the Commission) developed the *National Consensus Statement: Essential Elements for Safe and High-quality End-of-life Care* (CS) in collaboration with stakeholders.⁷ The CS described essential elements for safe and high-quality care for anyone approaching the EOL in an acute healthcare setting. The CS's scope has been expanded to all settings where EOL care is provided to align with the Commission's broadened focus on primary, community and residential aged care. This includes response to the coronavirus disease 2019 (COVID-19) pandemic, the Royal Commission into Aged Care Quality and Safety, and to significant issues in healthcare delivery.⁸ Interviews and focus groups were held with users of the Commission's EOL care audit toolkit throughout 2020 and 2021 to identify gaps in the current CS. Discussions were held with the Commission's standing committees, identifying issues that informed the revision approach, the scope of literature for review and the changes to be tested.

To inform the revision of the CS, two literature reviews were undertaken by the Research Centre for Palliative Care, Death and Dying at Flinders University, dealing respectively with acute hospitals⁹ and community and aged care settings.¹⁰ They aimed to determine current best practices, identify emerging issues and risks, and highlight gaps in the current CS. This perspective will summarise the recommendations (five from review one and 10 from review two) relevant to policy and health system considerations.

Those at EOL with diverse needs often traverse care settings including hospital and community, private and public sectors with an urgent need for integrated healthcare systems¹¹ and EOL care pathways¹² (e.g. for people living with chronic obstructive pulmonary disease or dementia).¹⁰ Many health and social care organisations, and the individual HCPs working within them lack awareness of, or do not acknowledge, that death and dying are core business and that they need to be prepared to support quality EOL care. Both reviews emphasised that without changes to the way in which care is currently delivered (team, individual and organisational level) safe, quality care will be harder to achieve.^{9,10}

Addressing and responding to such EOL care concerns is urgent, given drivers such as the Commission's broadened scope, increasing demand, increasing costs and changing consumer expectations. Encouragingly there are facilitators for change. First, there is implementation of national standards (e.g. aged care, palliative care, safety and quality), stakeholder interest, an enhanced technology focus, policy sensitivity, and existing legislation, policies and programs.^{10,13} Second, there have been increasing death awareness, consumer advocacy, and innovative community models.¹⁴ Additionally, the different players in a complex

system and their roles in enabling, facilitating or underpinning change also need consideration.

In order to enable positive change towards high quality EOL care, we need quality guidance, integrated systems (e.g. between hospital and primary care with selective involvement of specialist palliative care),¹⁵ and a commitment and willingness to engage. People with palliative care needs who require hospital admissions for symptom management, can experience multiple transitions between the acute and community sectors. Coordination of care¹² (e.g. shared documentation, medication management), shared care arrangements (e.g. decision-making), and health and social care collaborations (including relevant early referrals) can help in providing consistent EOL care, prevent hospitalisations and improve transition experiences.¹⁰ An organisations' readiness to provide EOL care (e.g. ongoing support to prevent burnout) and each HCPs capacity to deliver quality EOL care (e.g. recognising dying and changing the focus of care) are paramount.

Standards, a nationally shared idea of quality, based on evidence are one mechanism that can influence healthcare safety and quality across systems. However, not all are mandatory, which impacts adherence and therefore effectiveness. Relevant here are mandatory National Safety and Quality Health Service Standards¹⁶ and the Draft Revised Aged Care Quality Standards (which includes an EOL component),¹⁷ to which all health care organisations and HCPs have a responsibility, namely the National Palliative Care Standards (self-reported),¹⁸ and the National Safety and Quality Primary and Community Healthcare Standards (voluntary).¹⁹ One example of a mechanism for standardisation of care is via audit,²⁰ such as the Commissions' EOL care audit that can highlight targets to improve care.²¹

Conclusion

In highlighting the evidence-based recommendations from two EOL care literature reviews the focus is firmly placed on policy priorities with implications relative to care practice in the Australian healthcare context going forward. Given care is commonly experienced over time and across settings, accessibility, affordability, and optimal EOL care pathways are needed to ensure consistent and quality care.

Having an evidenced-based approach at the policy level is critical in guiding how to deliver EOL care however adopting and adhering to EOL standards and a national CS at both the individual and organisational level is key. The impetus is on everyone working in healthcare to recognise EOL care as a priority and to consider how to achieve safe and high-quality care for patients and families.

References

- 1 Australian Bureau of Statistics. Provisional Mortality Statistics Jan to Dec 2022. ABS; 2023. Available at <https://www.abs.gov.au/statistics/health/causes-death/provisional-mortality-statistics/latest-release> [verified 22 May 2023].

- 2 Australian Institute of Health and Welfare. The last year of life: patterns in health service use and expenditure. AIHW; 2022. Available at <https://www.aihw.gov.au/reports/life-expectancy-deaths/the-last-year-of-life-health-service-use-patterns/contents/study-background> [verified 22 May 2023].
- 3 Buck D, Tucker S, Roe B, Hughes J, Challis D. Hospital admissions and place of death of residents of care homes receiving specialist healthcare services: A systematic review without meta-analysis. *J Adv Nurs* 2022; 78(3): 666–697. doi:10.1111/jan.15043
- 4 Angeles MR, Crosland P, Hensher M. Challenges for Medicare and universal health care in Australia since 2000. *Med J Aust* 2023; 218(7): 322–329. doi:10.5694/mja2.51844
- 5 Lindt N, van Berkel J, Mulder BC. Determinants of overburdening among informal carers: a systematic review. *BMC Geriatr* 2020; 20: 304. doi:10.1186/s12877-020-01708-3
- 6 Bourke C, Verhoeven A. Deeble Institute Perspectives Brief no.16. Translating aged care reform recommendations to action. Deeble Institute, Australian Healthcare & Hospitals Association; 2021. doi:10.25916/35s4-0728
- 7 Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC; 2015. Available at www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf [verified 22 May 2023].
- 8 Rawlings D, Damarell R, Chakraborty A, Devery K, Tieman J. Rapid review of the literature on end-of-life care in aged care and community settings. Supplementary report: COVID-19. Sydney: ACSQHC; 2022. Available at <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/rapid-review-literature-end-life-care-aged-care-and-community-settings> [verified 22 May 2023].
- 9 Rawlings D, Devery K, Tieman J, Tait P, Chakraborty A. A rapid review of the literature: end-of life care Sydney: ACSQHC; 2021. Available at <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/rapid-review-literature-end-life-care> [verified 22 May 2023].
- 10 Rawlings D, Damarell R, Chakraborty A, Devery K, Tieman J. Rapid review of the literature on end-of-life care in aged care and community settings. Sydney: ACSQHC; 2022. Available at <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/rapid-review-literature-end-life-care-aged-care-and-community-settings> [verified 22 May 2023].
- 11 Douglas KA, Dykgraaf SH, Butler DC. Harnessing fast and slow thinking to ensure sustainability of general practice and functional universal health coverage in Australia. *Med J Aust* 2023; 218(7): 288–290. doi:10.5694/mja2.51883
- 12 Chan RJ, Webster J, Bowers A. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database Syst Rev* 2016; 2(2): CD008006. doi:10.1002/14651858.CD008006.pub4
- 13 Australian Government. National Palliative Care Strategy; 2018. Canberra. Available at <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018?language=en> [verified 22 May 2023].
- 14 Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, Doble B, Dullie L, et al. Report of the Lancet Commission on the Value of Death: Bringing death back into life. *Lancet* 2022; 399: 837–884. doi:10.1016/S0140-6736(21)02314-X
- 15 Jennings LA, Turner M, Keebler C, Burton CH, Romero T, Wenger NS, et al. The effect of a comprehensive dementia care management program on end-of-life care. *J Am Geriatr Soc* 2019; 67(3): 443–448. doi:10.1111/jgs.15769
- 16 Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. Sydney: ACSQHC; 2017. Available at www.health.gov.au/initiatives-and-programs/comprehensive-palliative-care-in-aged-care-measure [verified 22 May 2023].
- 17 Australian Government. Revised Aged Care Quality and Safety Commission: Aged Care Quality Standards. Available at <https://www.health.gov.au/sites/default/files/documents/2022/10/revised-aged-care-quality-standards-detailed-draft-for-public-consultation-revised-aged-care-quality-standards-detailed-draft-for-public-consultation.pdf> [verified 12 July 2023].
- 18 Palliative Care Australia. National Palliative Care Standards, 5th edn. Canberra: PCA. Available at <https://palliativecare.org.au/publication/standards/> [verified 22 May 2023].
- 19 Australian Commission on Safety and Quality in Health Care. National Safety and Quality Primary and Community Healthcare Standards. Sydney: ACSQHC; 2021. Available at <https://www.safetyandquality.gov.au/standards/primary-and-community-health-care> [verified 22 May 2023].
- 20 Saunders R, Seaman K, Glass C, Gullick K, Andrew J, Davray A. Improving the safety and quality of end-of-life in an Australian private hospital setting: An audit of documented end-of-life care. *Australas J Ageing* 2021; 40(4): 449–456. doi:10.1111/ajag.12986
- 21 Australian Commission on Safety and Quality in Health Care. End-of-Life Care Audit Toolkit. Sydney: ACSQHC; 2021. Available at <https://www.safetyandquality.gov.au/our-work/end-life-care/end-life-care-audit-toolkit> [verified 17 August 2023].

Data availability. The two rapid reviews from which this perspective are drawn are listed as follows: ACSQHC: Rapid review of the literature on end-of-life care in aged care and community settings. Supplementary report: COVID-19. Sydney: ACSQHC; 2022. Available at: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/rapid-review-literature-end-life-care-aged-care-and-community-settings> [verified 22 May 2023]. ACSQHC: A rapid review of the literature: end-of life care. Sydney: ACSQHC; 2021. Available at: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/rapid-review-literature-end-life-care> [verified 22 May 2023].

Conflicts of interest. The two rapid literature reviews by RePaDD authors (DR, RD, PT, AC, JT, KD) were commissioned and funded by the ACSQHC (author AD). The ACSQHC had no role in study design, data collection, analysis and interpretation of the two rapid literature reviews. Author AD was involved in contributing to this perspective piece.

Declaration of funding. The two rapid literature reviews were commissioned and funded by the Australian Commission on Safety and Quality in Health Care.

Author affiliations

^AResearch Centre for Palliative Care, Death and Dying, College of Nursing and Health Sciences, Flinders University, Adelaide, SA 5042, Australia.

^BThe University of Sydney, University Centre for Rural Health, 61 Uralba Street, PO Box 3074, Lismore, NSW 2480, Australia.

^CAustralian Commission on Safety and Quality in Health Care, Level 5, 255 Elizabeth Street, Sydney, NSW 2000, Australia.