

Policymakers overlook improving end of life care across all places

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Added value of the study

- One of very few qualitative cross-national studies on policy approaches to end-of-life (EoL) care, examining places of care and death, which is a key EoL indicator.
- The study shows there are health policies on EoL care that do not discuss places of care and death.
- In contrasting world regions, we identified critical gaps in EoL care provision across places.
- The recommendations can help policymakers to improve care.

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What is the issue and why is it important?

Place of death and its concordance with patient preference is a key indicator for EoL care, studied internationally and flagged as a priority by the OECD.(1) However, it is unclear if and how 'place' is considered in health policy on EoL care. This cross-national analysis can inspire policy-making to open new ways to improve care for people at the EoL.

Study methods

We analyzed health policies across the US, the Netherlands, Portugal, and Uganda, following the READ systematic approach for document analysis in health policy research.(2) Documents were analyzed using directed content analysis.(3) Timelines for document publication were country-specific, based on local health policy developments relevant to EoL care in the last 2 decades. Backdates ranged from 2001 in Uganda to 2015 in the Netherlands; the most recent publication year was 2024 for all countries.

Summary of findings

Type of policy documents included per country

	 n = 12	 n = 42	 n = 25	 n = 10	Total n = 89
Legal documents	2	0	12	1	15
Formal policies & governmental documents	5	15	11	4	35
Non-governmental documents	2	21	2	3	28
Statistical reports or publications	3	6	0	2	11

Main results

- Less than half of potentially relevant policies on EoL care (89/205) discussed places of EoL care or death and were included.
- In all countries, home was prioritized while inpatient facilities (especially hospitals) were most problematized. Consequently, policy measures and recommendations focused on home care.
- The rural-urban divide, workforce shortages, waitlists, and financial considerations were identified as critical gaps in EoL care delivery across places.
- In the identified policy measures, there was a key tension in the extent to which countries invest in professional expertise versus community empowerment.

Main implications

Health policy documents on EoL care tend to focus on the population at large, overlooking the needs of distinct subpopulations (e.g., rural communities, ethnic groups). There is a notable lack of emphasis on discussing preferences for places of end-of-life care and death and ways to address potential shifts in preferences in a patient trajectory. Moreover, it is important to consider the reasons why countries invest in civic engagement, as this is key to interpreting the drivers and implications of community-based approaches. While the use of volunteers is valued, volunteers require professional supervision and system support, and do not fully address staff shortages.

Recommendations

1. Policymakers must consider the potential benefits of all EoL care settings and offer flexible care solutions that promote choice and continuity of care.
2. Policy documents must emphasize the importance of discussing preferences for places of EoL care and death and include the needs and preferences of diverse subpopulations.
3. Further research into the determinants and impact of policy developments on EoL care.

References

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Disclaimer

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