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Places of end-of-life care and death in health policies of four countries (EOLinPLACE Project)

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ABSTRACT

Background: Place of death and its concordance with patient preference is a key indicator for end-of-life care, studied cross-nationally and flagged as a priority by the OECD. However, it is unclear if and how 'place' is considered in health policy in relation to end-of-life care. This study aims to examine if and how health policies in different nations consider places of end-of-life care and death.

Methods: We conducted a comparative qualitative study across the US, the Netherlands, Portugal, and Uganda, of health policy documents following the READ (i.e., Ready materials, Extract data, Analyze data, Distill findings) systematic approach for document analysis in health policy research. Documents were analyzed using directed content analysis following Hsieh and Shannon (2005). Timelines for document publication were country-specific, based on local health policy developments relevant to end-of-life care in the last two decades. Backdates ranged from 2001 in Uganda to 2015 in the Netherlands; the most recent publication year was 2024 for all countries.

Findings: We identified 89 policy documents relevant to end-of-life care mentioning preferred or actual places of end-of-life care or death. The first topic was '*Narratives around places*', where home was prioritized while inpatient facilities were most problematized. A second topic '*Policy measures acting on places*' included: i) *Availability of services across places*, where the rural-urban divide, workforce shortages, waitlists and financial considerations challenged availability of end-of-life care across places; and ii) *Professional expertise vs. community empowerment*, which highlighted a key tension in the extent to which countries invest in professional expertise versus community empowerment.

Conclusions: While improving care at home is prioritized with evidence-based reasons to support it, our study shows that policymakers overlook the potential benefits of other care settings and flexible care solutions that promote continuity of care. This comparative analysis unveiled implications to improve end-of-life care across care settings.

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1. Introduction

End-of-life care is a public health priority due to the escalating global burden of severe health-related suffering experienced by people of all ages towards the end of their life. This impacted over 26 million families worldwide in 2016 and the number is expected to increase to 46 million in 2060 (Sleeman et al., 2019). Where people spend the end of their life is therefore a complex phenomenon relevant to health policy (Bone et al., 2018; Orlovic et al., 2017). A recent umbrella review found home is the most preferred place of end-of-life care and death among patients and family caregivers (Pinto et al., 2024). However, the realization of preferences depends on multiple factors including illness-related, individual and environmental (e.g., healthcare input, and social support). Also, many people prefer to die in other places, namely hospice and palliative care (HPC) facilities and hospitals (Pinto et al., 2024; Lee and Lee, 2022). Place of death and its concordance with patient preference has therefore become a key end-of-life care indicator, studied cross-nationally and flagged as a priority in the "Health at a Glance" report by the Organization of Economic Co-operation and Development (OECD) (Orlovic et al., 2017; Adair, 2021; Lopes et al., 2024; OECD, 2023a). Recently, the largest international study of trends in place of death to date (32 countries) showed an increase in home deaths during the COVID-19 pandemic in most countries analyzed (Lopes et al., 2024). Such vital statistics can help guide policymakers in deciding where to allocate resources for end-of-life care by showing where people die and therefore where services and support are most needed, flagging gaps between preferences and reality (Jiang and May 2021; Pivodic et al., 2013).

Despite this evidence and its relevance for policy-making, it is unclear how health policies in different nations have considered places of end-of-life care and death. Our study examined health policy documents in countries with contrasting healthcare systems with regard to end-of-life care and death (Orlovic et al., 2017; Lopes et al., 2024; OECD, 2023a; Jiang and May 2021; Pivodic et al., 2013; Böhm et al., 2013). The objectives were: i) to identify relevant health policy documents from each of the countries; ii) to compare countries on the places of end-of-life care and death considered (e.g., home, hospital); iii) to describe how places of end-of-life care and death were discussed; and iv) to describe the policy measures taken or proposed to act on places of end-of-life care and death.

2. Methods

2.1. Study design and study setting

The study is part of the EOLinPLACE Project, which aims to design and test an international classification of dying places (Namukwaya et al., 2024). The project, including this study, targets four countries: the United States (US), the Netherlands, Portugal and Uganda. These countries were selected to capture variation in five criteria: (i) different ranks in Quality of Death Index (Unit, 2015); (ii) low and high preference for dying at home (Gomes et al., 2012a, 2013); (iii) different place of death trends (Lopes et al., 2024; Gomes et al., 2012b, 2018; Flory et al., 2004); (iv) rudimentary and finer place of death classifications (Lopes et al., 2024); and (iv) variation between continents and healthcare systems (Supplementary Table 1) (Lopes et al., 2024). We followed the READ (i.e., Ready materials, Extract data, Analyze data, Distill findings) systematic approach for document analysis in health policy research (Dalglish et al., 2021; Assarroudi et al., 2018; Hsieh and Shannon, 2005; Elo and Kyngäs, 2008). We defined health policy as "*a broad statement of goals, objectives and means that create the framework for activity*" (Buse et al., 2012), that affects the set of institutions or organizations, services and funding arrangements related to healthcare.

2.2. Document search and eligibility criteria

We searched for diverse documents relevant to end-of-life care health policy (Table 1) between August 01, 2023 and February 29, 2024. Additionally, we searched for grey literature and identified documents through snowballing and experts.

The search had a national scope except in the US, where we included federal and state documents specific to Kansas, a middle-ranked state in palliative care provision (Morrison et al., 2011), where our project recruitment site is based. We defined country-specific timelines for document publication considering local health policy developments relevant to end-of-life care: 01/01/2012-29/02/2024 (US, 12 years), 01/01/2015-29/02/2024 (Netherlands, 9 years); 01/01/2006 -29/02/2024 (Portugal, 18 years); and 01/01/2001-29/02/2024 (Uganda, 23 years). We made an exception for current death certificates and associated materials (e.g., manuals), as their publication dates might predate this timeline.

Documents were included if they mentioned preferred or actual places of end-of-life care or death for patients with life-threatening illnesses of any age, sex/gender, race/ethnicity and diagnosis. Country reviewers (BS, DAO, KE, ND, SHB, SP) knowledgeable of HPC locally, executed data collection and analysis. They screened the documents using a list of search terms (Supplementary Table 2). Documents were excluded with reasons documented if: i) their full version could not be retrieved; or ii) the reference to places was not explicitly about people with life-threatening illnesses. Decisions were reviewed by other researchers in each country (BG, EB, EN, JTS, JVB). Characteristics of included documents were extracted into a piloted data extraction form in MS Excel (Supplementary Table 3).

2.3. Data analysis

We used directed qualitative content analysis to interpret and present the data (Hsieh and Shannon, 2005). Text and figures fitting the inclusion and exclusion criteria were imported into Atlas.ti (version 24) for analysis. We coded deductively, with codes derived from an interview study of the EOLinPLACE Project (van de Beek et al., 2024). We inductively added and changed codes as needed while reading the documents and through team discussions. Together, we built a common codebook allowing country-specific codes, due to differences in healthcare systems and culture. We revised the codebook iteratively until we reached consensus about its exhaustiveness. Country reviewers kept memos to record and reflect on important findings. We developed codes into (sub-)topics through discussion until consensus. To structure our analysis, we adopted a dual framework. First, we examined the data through the lens of the different places where end-of-life care occurs (i.e., hospital facilities, homes, HPC and LTC facilities). Second, to assess how each of these places were characterized in the policy documents, we applied the six domains of healthcare quality as defined by the Agency for Healthcare Research and Quality: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity (Quality AfHRa). This approach allowed us to analyze all the settings of care and the quality dimensions attributed to each of them. Additionally, to further address our research objectives, we analyzed the policy measures described in the documents, with a view to identify and compare the approaches taken in shaping end-of-life care across different countries and care settings.

3. Results

We included 89/205 (43.4%) of the identified potentially relevant documents (Table 2). Most had a pragmatic and direct tone, except in Portugal where the tone was more strategic and normative. Of the included US documents (n=12), 11(92%) were federal health policies and 1 (8%) was Kansas-state specific – this was a 5-year palliative care state plan which offered valuable insight into how an individual state

discusses places of end-of-life care and death and related preferences. The targeted readership of US documents was mainly formal (e.g., government and healthcare professionals), addressing care regulations, payment restrictions, and procedural aspects of care, with a focus on the delivery of services as part of the Medicare Hospice Benefit. Dutch documents mainly targeted healthcare professionals, and some targeted patients and families (e.g., information leaflets). The focus was on the organization of care and its cost-effectiveness, while identifying needs and emphasizing aspects related to access to and quality of care. Portuguese documents primarily targeted professionals in the (public) healthcare system and had a strong emphasis on patient rights and policy planning. The focus was on equitable access to healthcare, the 'right' of patients to choose the place of end-of-life care and death, and the development, proposal and approval of national palliative care laws and strategies. The targeted readership of Ugandan documents varied, ranging from healthcare professionals to policymakers. The focus was on practical strategies to overcome systemic challenges (e.g., training community members) – with fewer references to financial implications. More characteristics and details of the documents can be found in Supplementary Material (Table 4a, 4b, 4c, 4d).

We identified two topics. The first topic was '*Narratives around places*', describing how included health policy documents view and position places of end-of-life care and death. The second topic '*Policy measures acting on places*' includes: i) *Availability of services across places*, describing challenges in availability of end-of-life care across places; and ii) *Professional expertise vs. community empowerment*, highlighting a key tension in the extent to which countries invest in professional expertise versus community empowerment.

Table 1
Illustrative list of websites and document types to guide document acquisition, 2023

	Type of document	Examples of documents	Examples of potential sources
1.	Legal documents	Laws and regulations	National law repository
2.	Formal policies & governmental documents	Policy directives, national strategies, plans, mandated national formats (e.g., death certificate & instruction manuals)	Websites of government institutions (e.g., Department of Health or Health Ministry)
3.	Non-governmental documents	Strategies, guidelines, plans, position statements, and publications	Websites of non-governmental health care organizations or patient/carer associations
4.	Statistical reports or publications about statistics	Statistics, graphs, surveys, publications	National statistics office

Table 2
Type of documents included per country, 2001–2024.

	US n=12	Netherlands n=42	Portugal n=25	Uganda 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

3.1. Topic 1: Narratives around places

A variety of places were considered in the included documents (Supplementary Table 5). The documents frequently described specific places of end-of-life care and death around what they may offer in terms of care quality dimensions, often in contrast with other places. The emphasis was on places of end-of-life care more than on places of death, with a focus on the categories home, hospital, LTC and HPC facilities. This topic was more salient in Dutch and Ugandan documents.

Home Receiving care at home was described as most preferred in all countries, associated with higher patient satisfaction, and considered to represent the best quality of care (compared to hospitals and LTC

Text box 1

Contextual background of the four countries

US: The US healthcare system is classified as a Private Health System, market-driven and dominated by private insurers and private, for-profit healthcare providers (Böhm et al., 2013). Financing is dependent upon private insurance, deductibles, out-of-pocket payments and federal programs like 'Medicare' and 'Medicaid' (Böhm et al., 2013; Niles, 2023; Barr, 2023). The main causes of death are ischemic heart disease and dementia (2019) (WHO). While many people prefer to die at home (86%; 2004) (Barnato et al., 2009), only 34% do (2020–21) (Lopes et al., 2024). The other large portion dies in hospitals (36%) and hospice- and long-term care (LTC) facilities (27%; 2018) (OECD, 2023a; QuickStats).

Netherlands: The Dutch healthcare system is classified as an Etatist Social Health Insurance System (Böhm et al., 2013). All residents are required to have basic insurance from competitive, private, not-for-profit insurers under government regulation. Premiums are independent of income with a healthcare benefit to support people with lower incomes (Böhm et al., 2013). The main causes of death are ischaemic heart disease, cancer and dementia (2019) (WHO). There is a strong preference for home death (84%; 2023) (OECD, 2023b) and nursing homes are the most common least preferred places to die (42%; 2010) (Calanzani et al., 2014). However, only 34% (2020–21) died at home (Lopes et al., 2024) and 23% (2023) in the hospital (OECD, 2023a). 34% of people with palliative care needs die in nursing- and care homes (2022) (IKNL).

Portugal: The Portuguese healthcare system is classified as a tax-funded National Health Service system, providing universal and extensive coverage with some out-of-pocket payments. Care is mostly provided by public healthcare facilities (government) (Böhm et al., 2013). The main causes of death are ischemic heart disease and stroke (2019) (WHO). Most people prefer to die at home (51%) (OECD, 2023a; OECD, 2023b) and the most common least preferred place to die is hospital (29%) (Calanzani et al., 2014). The majority dies in a hospital (63%) (OECD, 2023a) and only 23% (2020–21) died at home (Lopes et al., 2024).

Uganda: The Ugandan healthcare system has private, not-for-profit, faith-based and public government funded facilities, and delivers decentralized health services. Private companies invest in hospitals, clinics, and pharmacies. There is no national health insurance coverage, but there is private health insurance provided by insurance companies. Some hospitals run their own health insurance schemes (Okunade et al., 2023; Department of Commerce USoA, 2024). The main causes of death are communicable diseases like tuberculosis and HIV/AIDS (2019) (WHO). While dying at home is not found important by all patients (only 25%) (Campbell et al., 2018), most people prefer to die at home (70%; 2000) (Kikule, 2003). The most common place of death is home (48%) and 35% die in health institutions (2020–21) (Lopes et al., 2024).

facilities). In the Dutch and Ugandan documents, home was seen as a familiar, secure and safe place, easily accessible for loved ones. Ugandan documents also highlighted advantages such as minimizing costs (e.g., transport) and the privacy and safety to express distress. Portuguese documents described home as the preferred place conditionally; only if adequate community care is available. In all countries, documents explicitly described challenges around end-of-life care and death at home (e.g., staffing shortages, lack of a single contact point, and the burden on informal caregivers risking burnout). Ugandan documents additionally discussed concern about uncertainties regarding the quality of care provided at home after discharge, by family and other members of the community. In summary, home as a place of end-of-life care and death was generally viewed as responsive, safe, and (cost-)effective. However, the challenges mentioned highlighted areas for improvement. These issues could compromise timely, patient-centered (responsive), and safe care, which indicated the need for better support and coordination in home care.

Hospital facilities In Dutch and Ugandan documents, hospitals were considered the best place only for pediatric care due to the available expertise, feasibility, and sustainability. For adult care, documents across all countries described hospitals as a less preferred place, both by the system and patients. The potential negative impact of hospital admissions was a cross-country concern, especially regarding the utilization of acute settings (e.g., emergency departments, intensive care units) during the dying phase because these were viewed as not cost-effective, not preferred and not best suited for end-of-life care. Therefore, documents in all countries stressed the need to prevent hospital (re-)admissions. The Kansas palliative care state plan specifically highlighted the overall lack of access to palliative care and disparity in access between rural-urban communities. Several documents underscored the importance of discussing preferences for or against hospital admissions, especially in the Netherlands. In Uganda, government health facilities were viewed favorably for their free services but were generally described as poorly equipped. Additionally, in Uganda, staff in hospital facilities focus on curable diseases due to time and capacity constraints. In summary, patient-centeredness, safety, efficiency, equity and (cost-) effectiveness were key care quality dimensions discussed when considering hospitals; most commonly in a negative way, except for pediatric care.

LTC facilities Across the US, the Netherlands and Portugal, LTC facilities (including nursing homes - NHs) were described as places one goes to when it is not feasible to remain at home (e.g., due to severe physical decline, informal caregiver burnout, or the need for round-the-clock care that exceeds home care capacity). US documents indicated that LTC facilities are often held to quality standards that promote life-prolonging care, describing that these may not align with the principles of HPC. Additionally, US documents highlighted the limited bed capacity, staffing challenges and volunteer shortages. Potential positive aspects of NHs were described by Dutch documents such as round-the-clock care, homeliness, gardens, and privacy. However, staffing shortages, high costs, and waitlists were viewed as potentially compromising the quality of care. In Portugal, LTC facilities were described as a place of end-of-life care available only for dependent patients and complex cases. Ugandan documents did not mention LTC facilities. In summary, although LTC facilities were viewed as capable of providing patient-centered and safe care, these facilities were not considered a preferred place. Arguments for and against focused on safety, efficiency, equity and timeliness as quality aspects of care.

HPC facilities Inpatient hospices and palliative care units (PCUs) were positioned differently in the four countries. US documents did not describe hospice facilities or PCUs in detail, only why and when these places are utilized (e.g., pragmatic guidelines). Dutch documents referred to 'hospices' as the second-best option to home, as they minimize patient burden. However, waitlists limit access to hospices. Portuguese documents also recognized PCUs as an alternative care setting, particularly for patients with complex needs facing clinical decompensation or social emergencies, such as caregiver burden. In Ugandan documents, there was limited detail on the description of hospice facilities and PCUs. In summary, quality aspects of HPC facilities most described were patient (or family) centeredness (minimization of patient and family caregiver burden) and effectiveness (in handling clinical decompensation), with a tension around timeliness (waitlists).

3.2. Topic 2: Policy measures acting on places

There were distinct approaches to policy measures acting on places of end-of-life care and death, including recommendations for the future. This topic captures two subtopics: 1) Availability of services across places; and 2) Professional expertise vs. community empowerment.

Availability of services across places Documents across all countries considered the need to ensure timely and equitable availability of services across places, each country highlighting different challenges and actions. US documents flagged issues around the rural-urban divide, including challenges in providing consistent HPC in rural areas (Kansas-document), limited healthcare infrastructure, and workforce shortages. Telehealth and community-based palliative care programs were emphasized as critical measures to bridge these gaps. Nationally, reimbursements for telehealth were implemented during the COVID-19 pandemic. This measure was planned to expire at the end of 2024, and several documents recommended extension. Specifically in Kansas, licensure requirements were modified to permit interstate telehealth to help address workforce shortages. The Kansas palliative care state plan also recommended to improve palliative care knowledge of citizens (including medically underserved groups, specifically ethnic and racial minorities, Spanish-speaking populations and individuals with hearing/vision and other disabilities) and advocated for reimbursement and provision of home-based personal care services, and the federal level recommendation to engage underused personnel in HPC services (e.g., occupational therapists). Dutch documents flagged the issue of waitlists to access NHs, consequently leading to residents entering NHs with more complex care needs, which can change the nature of NHs from LTC to terminal care. Recommendations to address these challenges emphasized civic engagement, financial investments, and writing and executing policies aimed at enabling individuals to remain at home as long as possible. In Portuguese documents, enhancing the availability of palliative care was a priority, focusing on training professionals to identify and refer patients promptly. There were recommendations to update admission-criteria to palliative care services, to improve accessibility. Ugandan documents described that availability issues are compounded by long distances to health facilities and transportation costs. Additionally, rural areas were described as lacking basic services, which exacerbates the rural-urban disparity. Measures to close gaps in care access were described, such as educating community-based palliative care teams.

Professional expertise vs. community empowerment In all countries, most measures were directed toward home as an important place of end-of-life care and death (Table 3). In US documents, there was a focus on improving professional expertise (e.g., training medical staff). Recommendations revolved around improving the organization of community- and home-based palliative care workforces, fostering collaboration among organizations involved in providing these services, broadening eligibility for reimbursement of respite services to include informal caregivers, and establishing a benefit that would give unpaid caregivers access to adequately trained respite care providers (the latter two measures in the Kansas palliative care plan). In contrast, Dutch documents focused on engaging volunteers with recommendations to continue and expand these ongoing measures, alongside investing in formal providers (e.g., in spiritual care at home). Portuguese documents focused on better integration of the existing national palliative care network, aiming to deliver palliative care closer to or in patients' homes. There were recommendations to enhance network management through new tools and formalized referral processes. One Portuguese document

Table 3
Examples of policy measures acting on places of end-of-life care and death, 2001–2024.

	US	Netherlands	Portugal	Uganda
Home	- Audio-only services (telehealth) as a covered expense; - Increased availability of hospice services by for-profit hospices; - CBPC[a] programs; - Improved communication technologies; - Expert HBPC[b] teams; - Medicare Hospice Benefit; - Accountable care organizations; - Measure home health care utilization.	- Investing in volunteers (recruitment, training and support); - Investing in case managers; -Investing in spiritual care at home; - Increased use of technology; - Guidelines how NH[e] residents can return home to die there; - HBPC[b] teams (i.e.,PaTz[h]); - Improved handover, and have timely and structured transmural discussions to optimize HBPC[b].	- New informal caregiver statute that formalizes support (including financial) for caregivers; - Training in PC[g] for professionals of primary care teams and community-based continuous care teams; - Investing in the expansion of domiciliary teams (generalist and specialist).	- Family members can pick up medicine at Hospice Africa Uganda if patient is not able to; - Guidelines to adjust medication to possibilities at home; - Training family members to provide PC[g] for the patient; - HBPC[b] programs; - Research to improve the quality of life of the dying; - Community volunteers.
Hospital facility	- Creating and expanding high-risk clinics.	- Mobile hospices.	- Establishing one intra-hospital PC[g] support team per general hospital or local health unit.	-Village teams to help with referral to hospital facilities. - Better discharge planning;
LTC[d] facility	- PC[g] consultants: Access to PC[g] for residents who are not enrolled in hospice care; - Training staff to provide PC[g].		- Articulation of specialist PC[g] teams with units of the National Network for Integrated Continuing Care.	
HPC[c] facility	- Public measures of hospice quality.		- Increase in the number of beds in PC[g] units and teams.	
Other measures	- Documents that explain payment models to navigate care.	- NPPZ II[f]: A national PC[g] program to improve end-of-life care and create awareness; - Laymen documents on options around dying and place of death; - Implementing end-of-life 'care pathways'.	- Constitution of a working group to establish national referral criteria for PC[g] services (adults and children); - Establishing the National Network for Integrated Continuing Care, with a strong role in the continuity of care across services and places; - Establishing the National Network of PC[g] (separated but in articulation with the National Network for Integrated Continuing Care), as a collaborative and integrated model, centered on the needs of patients and families at all levels and places; - Supporting professionals to issue death certificates through a new national death certification system which is fully electronic; - National framework law for PC[g]; - Different levels of PC[g] training (basic, generalist, specialized).	- Guidelines to facilitate travel across the border; - Checklists for conversations with families, including place of death; - Hospice Africa Uganda open in weekend and public holidays; - Measures to improve death registration (professionals and community members).

Empty cells represent no existing measures acting on that specific place.
[a] CBPC: Community-Based Palliative Care.
[b] HBPC: Home-Based Palliative Care.
[c] HPC: Hospice and Palliative Care.
[d] LTC facility: Long-Term Care facility.
[e] NH: Nursing Home.
[f] NPPZ II: Nationaal Programma Palliatieve Zorg II.
[g] PC: Palliative Care.
[h] PaTz: Palliatieve Thuiszorg (Palliative Home Care).

on pediatric care recommended to empower the community through volunteer activities. In Uganda, there was a strong focus on community involvement through local solutions (successful and ongoing), partly to reduce staffing issues, but also to strengthen communication between hospital and the community – to send patients home as soon as possible. Additionally, Ugandan documents referred to needs for research and education more often than other countries; describing the need to train, select, and supervise more community care providers, to support healthcare professionals not only in providing care but also in registering community deaths (under-reported).

4. Discussion

A variety of places of end-of-life care and death were discussed, spanning all six domains of healthcare quality according to the Agency for Healthcare Research and Quality (safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity). (Quality AfHRa) In all four countries, inpatient facilities (especially hospitals) were most problematized and home was prioritized. Consequently, policy measures and recommendations primarily focused on keeping the patient home or facilitating their return as soon as possible. The rural-urban divide, financial considerations, workforce shortages, and waitlists were flagged as critical challenges affecting the availability of services relevant for end-of-life care across places and countries. A key tension in the enacted measures and recommendations is the extent to which countries invest in strengthening professional expertise versus community empowerment to support the healthcare system, aiming to enable patients to be cared for and to die where they prefer.

The variety of places considered in the analyzed documents match those identified in a recent umbrella review on patient and family preferences for places of end-of-life care and death, which identified home as the most common preference (Pinto et al., 2024). The review also highlighted substantial minorities preferring other places, most notably hospitals and HPC facilities (Pinto et al., 2024). Whereas home was recognized as the most preferred place in the documents included in this study, the minorities reportedly preferring places other than home did not surface in our analysis. This suggests a potential discrepancy between the diversity of preferences reported in literature and the focus of the health policy documents on 'home', which may result in the preferences of minority groups being overlooked in policy considerations. These places (especially hospitals) were more often described flagging negative aspects of quality of care. The 'problematization' of hospital care, also identified in a previous exploratory review of the role of acute hospitals in palliative care policies of five countries (Switzerland, England, Singapore, Australia and Ireland) (Robinson et al., 2016), is now understood in greater detail. Namely, based on our findings we identified four explicit reasons for problematizing hospitals: 1) patient-centered care (i.e., lack of responsiveness to the preferred place of care of patients and family members), 2) safety (e.g., unnecessary treatments and burdensome transfers), 3) efficiency (e.g., unnecessary re-admissions), and 4) cost-effectiveness. Prior research has warned that by problematizing hospitals, health policies may undervalue potential benefits of a hospital setting and patient priorities such as 'minimizing burden on family members', and 'protecting the privacy of the domestic space' (Pollock et al., 2024; MacArtney et al., 2016). These priorities are not explicitly addressed in the health policies we reviewed, but are nonetheless important considerations. Additionally, while several health policy documents - particularly in the Netherlands - emphasize discussing patient preferences for hospital admission at the end-of-life, there is a notable lack of emphasis on addressing preferences for places of end-of-life care and death within advanced care planning and using preferred versus actual place of death as a quality indicator. Expanding this focus could help align care more closely with patient wishes. Furthermore, the included documents did not discuss potential shifts in preferences (e.g., to hospitals) or ways to address them. The existing evidence is not consistent on the stability or dynamic nature of preferences, so changes over time cannot be overruled (Pinto et al., 2024; van et al., 2021; McMahan et al., 2021; Ali et al., 2019). While policymakers may wish to prioritize home – especially in the face of reality with the rise of home deaths (Lopes et al., 2024) – they should avoid concentrating all resources in one setting.

A study of 23 European Economic Area countries found that modifiable policy choices (including strong HPC provision and generous government finance of LTC) were associated with decreased in-hospital mortality (Jiang and May 2021). Another study, of 13 European countries and Israel found that dying in hospital was associated with settings where end-of-life care is predominantly privately funded (Orlovic et al., 2017). Both studies demonstrate the impact of health policy on place of death. In our study, health policies across all four contrasting countries (two European and two non-European, one of which a low-income country) identify significant shortcomings in the availability of services across places such as the rural-urban divide, workforce shortages, financial constraints, and waitlists. While measures already implemented were seldom subjected to official evaluation in the included documents, the recommendations to continue suggest these measures may yield benefits. For instance, US telehealth solutions can offer improvements around availability of care (especially in rural areas). However, alternative strategies are needed for countries and regions where telehealth is not feasible. While the Kansas 5-year palliative care state plan explicitly addressed challenges and needs of specific subpopulations (i.e., accessibility issues of the rural population and recommendations around health literacy of the medically underserved), national health policy documents of all four countries discussing places of end-of-life care and death rarely address this (only the pediatric population in need of palliative care as minority group and rural populations). Rather than focusing on the specific needs of distinct population groups or minorities (e.g., rural communities or ethnic groups), national health policy documents tend to focus on the population at large. This identifies a gap in national health policies around places of end-of-life care and death in addressing the varying end-of-life care needs of increasingly diverse and multicultural populations.

Finally, results from our study suggest that investing in civic engagement could help alleviate pressure on the healthcare system. Not only by investing in family caregivers (like suggested by US policies), but also by investing in community members (i.e., volunteers). Policy measures from the Netherlands and Uganda around training volunteers to support care networks, have been positively evaluated in these policy documents. Hence, policymakers could consider policy measures that include communities, approaching end-of-life care as a public health issue. As a result from our analysis, it is relevant to explore what might explain the cross-country differences in the emphasis on civic engagement in end-of-life care and death. Countries with stronger government regulation, a history of community-based care, or countries that prioritize empowering people to be involved in decision-making combined with public dialogue about end-of-life care may naturally put more emphasis to civic engagement. Additionally, cultural values around death and dying may play a role. Whereas several studies support the increased use of volunteers (often seen in hospices but not only), in response to the growing pressure on the healthcare system (Abel and Kellehear, 2016; Finucane et al., 2019), it should be noted that volunteers require professional supervision and system support, and do not fully address staff shortages. Therefore, it is important to consider the reasons why certain countries invest in civic engagement. In Uganda, it may reflect limited resources to build the professional healthcare structure, while in the Netherlands a well-established basic healthcare infrastructure may allow for community involvement (e.g., volunteers) serving a complementary role. Recognizing this distinction is key to interpreting the drivers and implications of community-based approaches. These findings and interpretations, while tentative, highlight the need for further research into the socio-political and cultural determinants of policy development in this area, given that they are likely to shape outcomes at the end of life.

5. Limitations

Document analyses are prone to biased selections (Cardno, 2018) since there is risk of missing important documents and selection can be influenced by the researcher. We mitigated this by consulting experts in the field locally to ensure we included key documents. Additionally, as a qualitative method, content analysis risks overinterpretation (Elo and Kyngäs, 2008). We reduced this by continuously grounding the work in our objectives, analytical and interpretative steps, and reflexivity (details in Supplementary Table 6).

6. Conclusion

This comparative analysis identified key areas for consideration regarding policy decisions on places of end-of-life care and death between countries, an issue in the political spotlight globally. While improving care at home is prioritized with evidence-based reasons to support it, policymakers must, alongside, consider the potential benefits of other care settings (HPC, LTC and hospital facilities) and flexible care solutions that promote continuity of care for individual end-of-life care pathways. In contrasting world regions, we saw critical gaps in end-of-life care provision. We also saw policy measures with potential to strengthen healthcare across and within specific places of end-of-life care and death. The results can inspire policy-making to open new ways to improve care for people at the end-of-life.

CRediT authorship contribution statement

Sifra H. van de Beek: Writing – original draft, Visualization, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Barbara Gomes:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Krista Eckels:** Writing – review & editing, Validation, Software, Resources, Methodology, Investigation, Formal analysis. **Sara Pinto:** Writing – review & editing, Validation, Software, Resources, Methodology, Investigation, Formal analysis. **Beatriz Sanguedo:** Writing – review & editing, Validation, Software, Resources, Methodology, Investigation, Formal analysis. **Dorothy A. Olet:** Writing – review & editing, Validation, Software, Resources, Methodology, Investigation, Formal analysis. **Elizabeth Namukwaya:** Writing – review & editing, Validation, Supervision, Resources, Methodology, Conceptualization. **Joanna V. Brooks:** Writing – review & editing, Supervision, Methodology. **Emmanuelle Belanger:** Writing – review & editing, Validation, Supervision, Resources, Methodology, Conceptualization. **Jenny T. van der Steen:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Conceptualization.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.healthplace.2025.103534.

Data availability

Data will be made available on request.

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