

Review Article

Patient and Family Preferences About Place of End-of-Life Care and Death: An Umbrella Review



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Abstract

Context. The place where people are cared towards the end of their life and die is a complex phenomenon, requiring a deeper understanding. Honoring preferences is critical for the delivery of high-quality care.

Objectives. In this umbrella review we examine and synthesize the evidence regarding preferences about place of end-of-life care and death of patients with life-threatening illnesses and their families.

Methods. Following the Joanna Briggs Institute methodology, we conducted a comprehensive search for systematic reviews in PsycINFO, MEDLINE, EMBASE, CINAHL, Epistemonikos, and PROSPERO without language restrictions.

Results. The search identified 15 reviews (10 high-quality, three with meta-analysis), covering 229 nonoverlapping primary studies. Home is the most preferred place of end-of-life care for both patients (11%–89%) and family members (23%–84%). It is also the most preferred place of death (patient estimates from two meta-analyses: 51%–55%). Hospitals and hospice/palliative care facilities are preferred by substantial minorities. Reasons and factors affecting preferences include illness-related, individual, and environmental. Differences between preferred places of care and death are underexplored and the evidence remains inconclusive about changes over time. Congruence between preferred and actual place of death ranges 21%–100%, is higher in studies since 2004 and a meta-analysis shows noncancer patients are at higher risk of incongruence than cancer patients (OR 1.23, 95% CI: 1.01–1.49, I² = 62%).

Conclusion. These findings are a crucial starting point to address gaps and enhance strategies to align care with patient and family preferences. To accurately identify patient and family preferences is an important opportunity to change their lives positively. J Pain Symptom Manage 2024;67:e439–e452. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Key Words

Patient preference, hospice care, palliative care, terminal care, systematic review

Key Message

This review emphasizes a broad spectrum of preferred places for end-of-life care and death. Home is the preferred place, while some choose hospitals or

hospice/palliative care facilities. Differences between the preferred place of care/death and changes over time are limited. Congruence varies, being higher since 2004 and lower for noncancer patients.

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Introduction

The place where people are cared towards the end of their life, and where they eventually die, is a complex phenomenon that depends on several factors, including resources availability, sociodemographic factors, people's experiences of illness and care.^{1–2} A deeper understanding of this phenomenon is urgently needed.

Honoring the patient's preference on this matter and involving them in decisions are not only a moral duty but also a critical factor for the delivery of high-quality care. As highlighted by the Organisation for Economic Co-operation and Development,³ end-of-life care (EOLC) often does not reflect patient's wishes (including preferences for place of care (POC) and place of death (POD)), which are rarely recorded in routine clinical practice. One of the potential explanations of why this happens is that assessing and understanding patients' preferences for POC and POD is often challenging, but this limits the provision of patient-centered care, which is particularly important at the end-of-life (EOL).⁴ In addition to the patient's preference, it is also important to reflect on family preferences, since decision-making at the EOL is commonly a shared process.⁵ Family members are pivotal in EOLC, providing most of the caregiving in critical moments, particularly at home where professional support may be lower and may not cover 24 hours a day. Hence, family members are at increased risk of stress.^{5–6}

Considering the new patterns and challenges for EOLC, it is timely to reflect about people's preferences for POC and POD, and the way in which these are assessed, with a view to help improve care. A scoping search identified several systematic reviews,^{7–11} but they have not yet been appraised together to understand the full spectrum of preferences, nuances and commonalities worldwide.

This umbrella review aims to examine and synthesize the available evidence from systematic reviews regarding preferences about place of EOLC and death of patients with life-threatening illnesses and their families at a global level. Such new data will contribute to identify the strengths and gaps in the scientific knowledge and to fully capture the diversity of places that are meaningful for individuals.

More specifically, our review questions are:

- (1) What is the full spectrum of places where people with life-threatening illnesses and their families prefer to be cared for at the EOL and/or die, and what are the underlying reasons?
- (2) Do preferences vary according to sociodemographic and clinical variables (including illness type and age), and between patients and their family members?
- (3) Do preferences for place of EOLC and POD differ and, if so, why?
- (4) Do preferences change over time and, if so, why?
- (5) Are preferences met and, if not, why?

Methods

Umbrella Review Methods

We prospectively registered the review in PROSPERO (CRD42022339983), and published the protocol.¹² We followed the Joanna Briggs Institute (JBI) methodology for umbrella reviews^{13–14} and report according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines.¹⁵

Literature Search

On October 11, 2022, we searched five databases: PsycINFO (since 1806), MEDLINE (since 1950), EMBASE (since 1980), CINAHL (since 1981), Epistemonikos (since 2012). In the same date, we also searched PROSPERO for review registrations (since 2011). We developed the search strategy with the support of a Medical Library Specialist and included both controlled and free-text vocabulary ([Appendix I](#)). We checked the references lists and contacted the authors of all included reviews as well as other key investigators conducting research in this topic for further systematic reviews. In addition, we searched for grey literature, namely for systematic review reports of governments and nongovernmental organizations in the following websites: CORDIS (primary source of results from European Commission funded research), the National Institute for Health and Care Research (NIHR) and the Agency for Healthcare Research and Quality (AHRQ).

Eligibility Criteria

We included systematic reviews of studies that assessed the preferences about place of EOLC and/or death of patients diagnosed with life-threatening illnesses and/or their family members (of any age, gender and race/ethnicity). We considered participants in all care settings, including but not limited to palliative care units/hospices, long-term care facilities, acute care settings and community care. We excluded systematic reviews that exclusively focused on the preferences of healthy participants or patients with diseases that are not life-threatening, or of professionals and/or formal or informal carers other than family (e.g., volunteers acting on behalf of charities). For reviews that included different populations, we report data on the preferences of patients and family members only. We excluded systematic reviews that exclusively focused on the actual place of EOLC and/or death since actual places do not always reflect preferences.

We included qualitative, quantitative, comprehensive or mixed-methods systematic reviews with or without meta-analysis. We excluded narrative reviews, scoping reviews, rapid reviews and other nonsystematic reviews as well as primary research studies. There were no language restrictions.

Eligible reviews needed to include a description of the review question, eligibility criteria, a clear and comprehensive search strategy in at least two databases, and critical appraisal by at least one reviewer and confirmed by another or discussed among the team, using a standardized tool. These items were considered critical for inclusion, aligning with JBI guidelines for systematic reviews.^{13–14} Whenever necessary, we contacted review authors for clarification before exclusion.

Screening, Data Extraction and Quality Assessment

Two reviewers (SP and ABS/MD) independently screened all retrieved citations for eligibility, extracted data from each included review onto a piloted data extraction form and assessed their methodological quality using the JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses.¹³ This tool consists of 11 questions, each question scored as met (“yes”), not met (“no”), “unclear” or “not applicable.” We based the overall appraisal of each review on predefined quality thresholds,¹² considering JBI recommendations:^{13–14} low quality (0%–49% of criteria met), moderate quality (50%–74%) and high quality ($\geq 75\%$). Disagreements between reviewers were solved by consensus or with a third reviewer (BG/SL). Reviewers did not screen, extract data or assess the quality of systematic reviews in which they were involved in.

Data Summary

We reported the screening process using the PRISMA flow diagram,¹⁵ and used the Graphical Representation of Overlap for OVERviews (GROOVE) tool¹⁶ to calculate double counting of primary studies in the included reviews. We appraised overlap according to the percentage of corrected covered area (CCA): 0%–5% (slight overlap), 6%–10% (moderate overlap), 11%–15% (high overlap), and above 15% (very high overlap).^{16–17}

We described the key characteristics of the included reviews and their critical appraisal in a tabular form and through narrative synthesis.¹⁸ A summary table listed all preferred places, with preference estimates (range of percentages by place and pooled estimates from meta-analyses whenever possible and as extracted from the reviews). We narratively reported the results on each of our review questions.¹⁸ We organised the reasons and factors associated with preferences and the factors influencing congruence according to the groups proposed in an early model of POD in terminally ill patients with cancer, developed by Gomes and

Higginson,¹⁹ and adopted by others in populations with cancer and noncancer conditions.^{11,20,21}

Changes to Protocol

We relaxed the criteria of independent critical appraisal (from two reviewers to at least one reviewer and confirmed by another or discussed among the team) to include relevant reviews (particularly the oldest), and we appraised the strength of the evidence (considering its quantity, quality and consistency) without applying GRADE tools^{22–23} which are focused on interventional research.

Patient and Public Involvement

Representatives of patients and carers from the International Alliance of Patients' Organizations (IAPO) and Eurocarers contributed to the protocol and will help disseminate the results.

Results

Review Selection

Searches of electronic databases identified 1712 hits excluding duplicates (Fig. 1). After screening, 1697 hits were excluded, which identified 14 eligible systematic reviews. Searches in PROSPERO yielded 4471 entries but added no new reviews. Searches of grey literature yielded 3150 records and one additional review.²¹ This resulted in 15 included systematic reviews.

Study Overlap

The 15 systematic reviews covered 229 nonoverlapped primary studies. Overall, the CCA demonstrated a slight degree of overlap (2.6%) between primary studies. Overlap between reviews ranged 0.0%–22.2%. The highest degree of overlap (22.2%) was between two reviews on the congruence between preferred and actual POD.^{11,26} The two reviews shared eight primary studies (of 18 studies in Bell et al.¹¹ and of 26 studies in Billingham et al.²⁶ (Appendix II).

Methodological Quality

Of the 15 included reviews, 10 were deemed of high quality ($\geq 75\%$ or more criteria met),^{7–10, 20–21, 27–31} three of moderate quality (50–74%),^{11,26,32} and two of low quality (0%–49%).^{9,33} All reviews were clear about their review question, the inclusion criteria and the critical appraisal of primary studies (Table 1). The lack of policy/practice recommendations and research directives for new research were the weakest criteria across studies.

Characteristics of Systematic Reviews

The 15 reviews were published from 2000³¹ to 2022³³ (Appendix III). In two reviews it was not

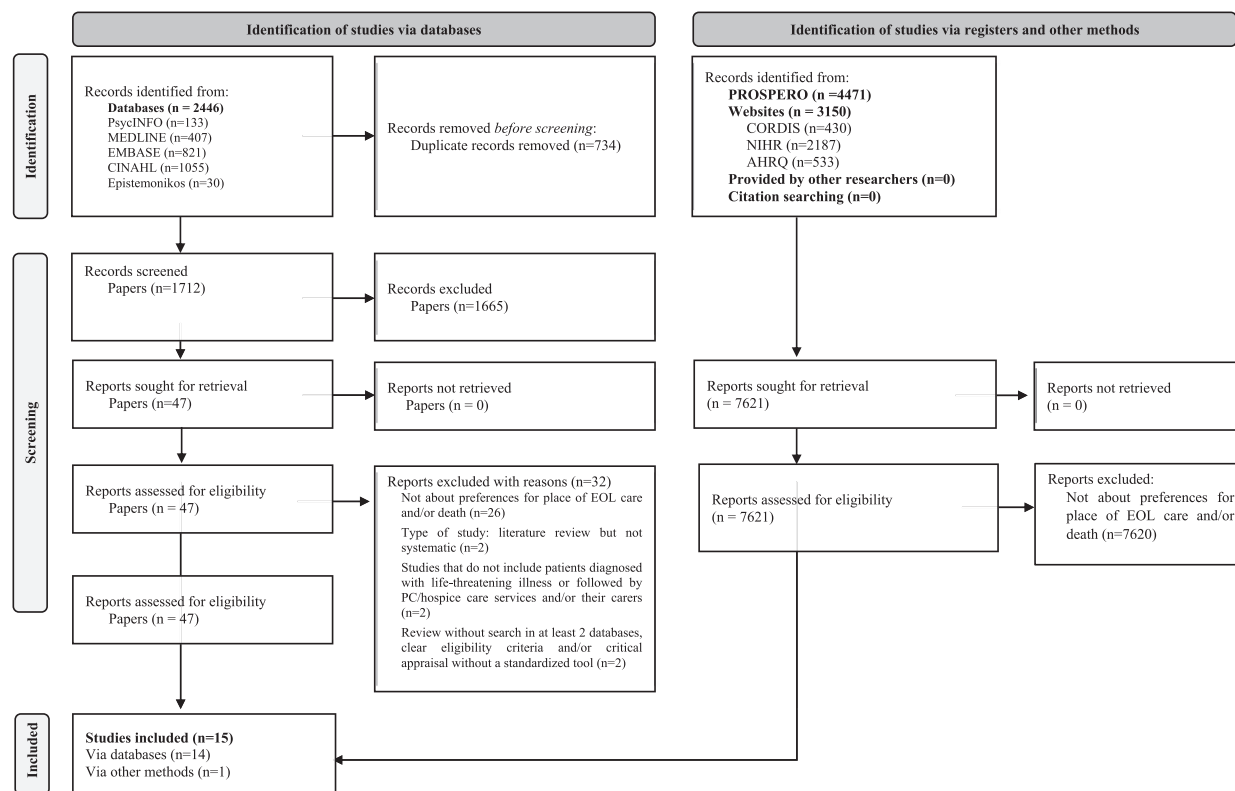


Fig. 1. PRISMA flow diagram. AHRQ = Agency for Healthcare Research and Quality, CORDIS = Community Research and Development Information Service, EOL = end-of-life, NIHR = National Institute for Health and Care Research, PC = palliative care. Of note, two relevant reviews were excluded as they did not meet the minimum quality criteria: Nilsson et al.²⁴ did not search in at least two databases, critical appraisal was conducted only by one reviewer and the authors did not describe if a standardized tool was used for critical appraisal; Johnston et al.²⁵ did not provided a clear description of the eligibility criteria and did not use a standardized critical appraisal tool.

possible to determine all countries in which the primary studies were conducted.^{10,20} However, considering the information available, most primary studies were conducted in European countries (158 studies), followed by North America (82 studies), Asia (33 studies), Latin America (19 studies), Oceania (eight studies) and Africa (seven studies). Most studies came from the United Kingdom (117 studies) and the United States (63 studies).

Six reviews were quantitative,^{7–8,11,20,26,30} (two with meta-analysis),^{7,26} three were qualitative,^{29,31,33} and six were mixed-methods^{9–10,21,27–28,32} (one with meta-analysis).²⁷

Although in four reviews it was not possible to calculate the number of participants included across all primary studies,^{8–9,28,30} considering the information available, the studies reported on the preferences for place of EOLC and/or POD of at least 110,984 patients and 30,175 family members.

Thirteen reviews focused on adult patients and/or their family members.^{7–9,11,20–21,26–28,29,30–32} Two reviews focused on paediatric patients and/or their family members.^{9,33} In the latter, most study participants were parents reporting on the preferences of

their children and/or their own. Ten reviews included patients with cancer and noncancer conditions.^{8–11,20,26–29,32} Three reviews focused on cancer,^{7,31,33} one review on dementia,³⁰ and one review covered any nonmalignant condition.²¹

All reviews provided data on at least one of our review questions. The full spectrum of places (question 1) was the most described (15 reviews) and the differences between place of EOLC and POD (question 3) was the least described (two reviews) (Appendix IV). We now describe the findings on each of the review questions.

Full Spectrum of Preferred Places

We identified a wide spectrum of preferred places, including home, several types of hospitals, hospice/palliative care facilities, and other care facilities. As the reviews included studies from several countries, the terminology varied (Fig. 2). Four reviews provided data on preferred place of EOLC^{21,28–29,31} and eleven reviews provided data on preferred POD.^{7–9,11,20–21,26–28,30–31} Seven reviews aggregated data on preferred place of EOLC and death.^{8,10,21,28,31–33}

Table 1
Methodological Quality of Systematic Reviews

Review (authors, publication date and reference)	1. Review Question	2. Inclusion criteria	3. Search strategy	4. Sources and resources	5. Appraisal criteria	6. Critical appraisal by 2 or more reviewers independently	7. Methods to minimize errors	8. Methods used to combine studies appropriately	9. Publication bias	10. Recommendations for policy and/or practice	11. Specific directives for new research	OVERALL APPRAISAL
Badrakalimuthu et al. (2014) ⁽³⁰⁾	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Bell et al. (2010) ⁽¹¹⁾	Yes	Yes	Unclear	Unclear	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Moderate
Gomes et al. (2013) ⁽¹⁰⁾	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	High
Billingham et al. (2013) ⁽²⁶⁾	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Unclear	No	No	Moderate
Bluebond et al. (2013) ⁽⁹⁾	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	No	Unclear	Unclear	No	Low
Hoare et al. (2015) ⁽⁸⁾	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	High
Rainsford et al. (2016) ⁽²⁸⁾	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Unclear	High
Woodman et al. (2016) ⁽²⁹⁾	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	High
Dittborn et al. (2021) ⁽³²⁾	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Moderate
Noyes et al. (2022) ⁽³³⁾	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Unclear	No	Unclear	Low
Gonzalez et al. (2020) ⁽²⁷⁾	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	No	No	High
Fereidouni et al. (2021) ⁽⁷⁾	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	No	No	High
García-Sanjuán et al. (2021) ⁽²⁰⁾	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	No	Unclear	High
Higginson et al. (2000) ⁽³¹⁾	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	High
Murtagh et al. (2012) ⁽²¹⁾	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	High

Preference for Home

Home preferences were reported in all 15 reviews. Quantitative data showed that home was the most commonly preferred place of EOLC both for adult patients (11%–89%) and their family members (23%–84%). No quantitative data were provided for pediatric patients or their family members (Appendix V).

Regarding home as the preferred POD among patients, the highest level of evidence comes from two meta-analyses.^{7,27} In Gonzalez et al.'s²⁷ review of older patients with multimorbidity, the authors performed a meta-analysis of three studies and found similar percentages of a home preference facing patient's current state of health (52%; 95% CI: 47–56, $I^2 = 0\%$) compared with hypothetical scenarios (51%; 95% CI: 45–56, $I^2 = 0\%$). In the review by Fereidouni et al.⁷ of cancer patients, a meta-analysis of 27 studies found 55% (95% CI: 49–61, $I^2 = 98\%$) preferred home death. The only study reporting paediatric patient preferences for POD comes from a low-quality review⁹ in which a study conducted with 40 adolescents with HIV in the United States revealed that 60% preferred to die at home.³⁴

Regarding home as preferred POD among family members, while in family members of adult patients a home preference ranged 17%–100%, in family members of children and young people the range was

narrower (25%–89%), though the number of studies was lower.

Rainsford et al.²⁸ assessed preferences considering the option “not home,” with some patients choosing this (21% in rural patients vs. 43% in city patients).

Preference for Hospital

Hospital preferences were reported in 12 reviews,^{7–10,20,21,27–31,33} 10 of high quality.^{7,8,20,21,27–31} Hospital was described as a preferred place of EOLC in seven reviews.^{8,10,21,28,29,31,33} Patients' preference for hospitals as place of EOLC ranged 2%–54% (Appendix V), while the preferences of family members of adult patients for this care setting were reported in a single study within Higginson et al.³¹ review (42%).

With regard to POD, the strongest evidence comes from the meta-analysis conducted by Fereidouni et al.,⁷ in cancer patients. The pooled prevalence of hospital as preferred POD in 21 studies was 17% (95% CI: 12–23, $I^2 = 99\%$). In paediatric patients a hospital preference ranged 14%–39%.⁹

Family preferences for hospital death ranged 0%–66% for families of adult patients. The perspectives of families of pediatric patients were captured only in qualitative data and the findings were conflicting: some showed that in retrospect no families intended a

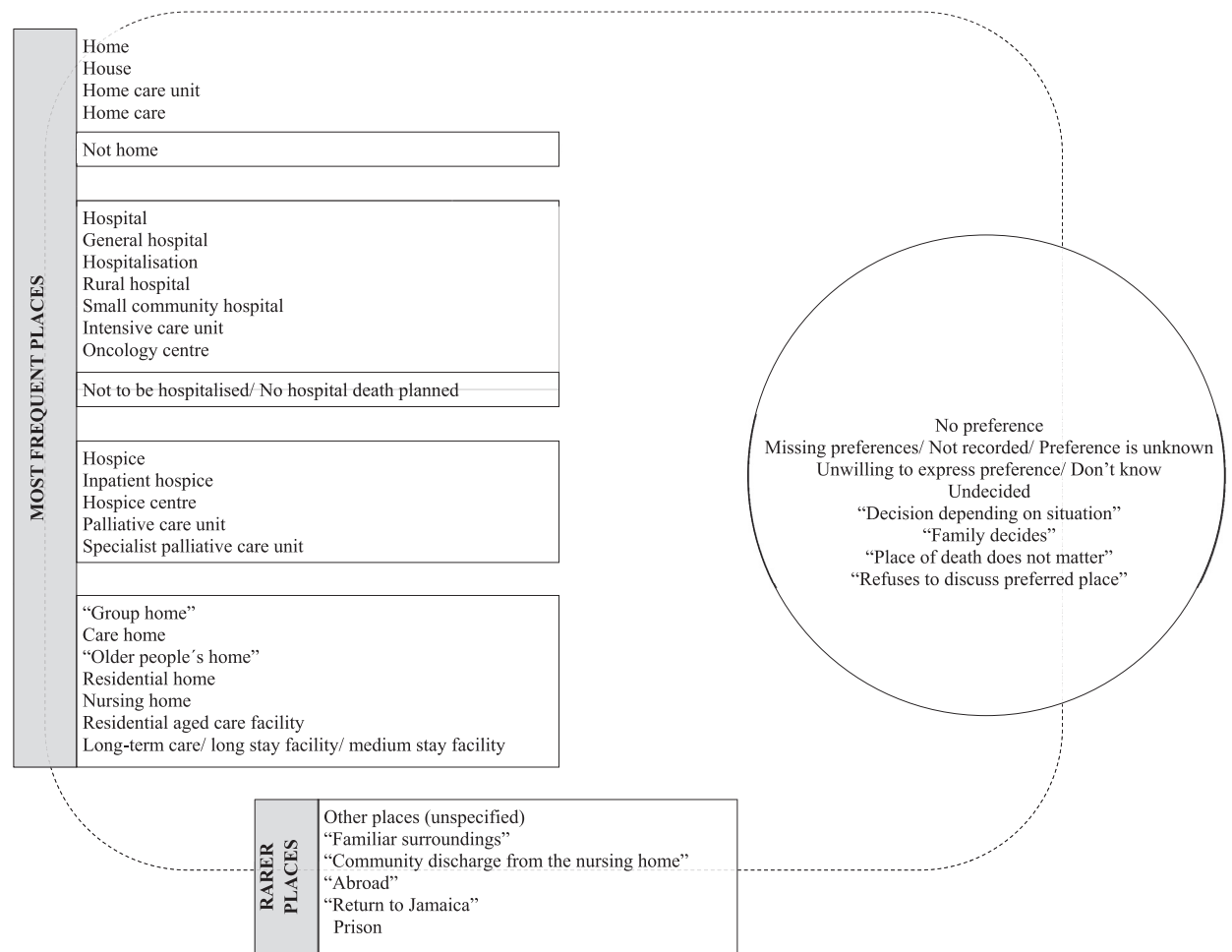


Fig. 2. Full spectrum of preferred places. The figure is organized into most frequent places and rarer places. Within most frequent places, home was the most common preference, followed by hospital, hospices/palliative care facilities and other care facilities, described using different terminologies. Rarer places included other places, some unspecified. The circle represents situations in which preferences were undefined (dependent on situation, family decides, missing preferences, unreported, indecisions or refusal to discuss).

hospital death, while others preferred a hospital death for their child, particularly during the last month of life.⁹

Rural and community hospitals were pointed out as preferred places of death for patients in two reviews.^{8,28} Preferences ranged 9%–21% in Rainsford et al.’s²⁸ review and 2%–16% (when reported by patients themselves) vs. 4% (when reported by proxies), in Hoare et al.⁸ Data on family preferences for community hospitals were mainly qualitative, describing these hospitals as preferred places of care and death, especially when hospices were not available.²⁹

Preference for Hospice/Palliative Care Facilities

A preference for hospice/palliative care facilities was reported in nine reviews,^{7–10,21,28–29,31,33} all with high quality except the two pediatric reviews, which were considered low quality.^{9,33} Across studies, hospice facilities were preferred places to receive EOLC for

3%–30% of adult patients (Appendix V). There was only one quantitative study that captured the views of family members of adult patients (43 in 1142 participants; 11%).⁸ Palliative care units were also pointed by patients as preferred places to receive EOLC in two reviews, and the estimates ranged 3%–30%.^{8,31}

Concerning preferences for POD, the strongest evidence comes from Fereidouni et al.⁷ meta-analysis of 12 studies reporting a pooled prevalence of a hospice preference among cancer patients of 10% (95% CI: 8–13, I² = 95%). Other reviews^{7,9,21,28,31} found higher estimates of preferences among adult patients (1%–73%), compared with pediatric patients (5%–59%) or with family members of adult patients (9%–40%)⁸ (Appendix V).

Preference for Other Care Facilities

Several other care facilities were reported as preferred places in six reviews,^{8,10,20–21,30–31} all of high

quality. Some reviews^{8,21,31} described “other places” as preferential places of EOLC or death but in many studies the exact places were not specified. When the information was available, uncommon places were revealed, mostly reported by one or few participants. For example, in one study conducted with migrants reviewed by Hoare et al.⁸ the preferred POD of 10% of family members was “return to Jamaica.”

Decision Dependent on Situation, No Preference and Missing Preferences

This was an important group of categories found across 10 reviews.^{8–11,21,26–28,31,33} Several expressions were used, most revealing that patients and/or their family members are not always prepared or able to report a preference (Fig. 2).

Underlying Reasons

Reasons for patient and/or family members’ preferences were described in eight reviews,^{9–10,21,27–29,32,33} five of high quality.^{10,21,27–29} Reasons related mostly to home, hospital, and hospice/palliative care facilities, with limited data for other care facilities and missing preferences. There were individual, family and environmental reasons for and against each place (Fig. 3).

Underlying reasons for a home preference included several positive aspects, most of them individual

reasons reported by the patients, as the possibility to be surrounded by family and friends,^{10,28,32–33} more autonomy and dignity.^{10,21,32}

With regard to POD, home was associated with a peaceful death.¹⁰ With regard to family members’ perspectives, studies shown that caregiving at home was considered meaningful and a unique opportunity to demonstrate love and to accompany their relatives until the end.^{29,33} Important reasons against home preference included imminent death and symptom distress,^{9,21,33} family burden,^{10,29,32} and lack of support or inability to provide care at home.^{21,29,32–33}

Reasons behind a preference for hospital included a perception of greatest chance of survival/disease reversibility from treatments,^{10,21,33} and better symptom management.^{28,33} Regarding community/rural hospitals, these were seen as alternatives to hospice facilities, especially in remote areas where hospices were not available.^{28,29} Reasons against hospital focused in their impersonal nature.²⁹ As with hospices, hospitals were not always readily available locally, with some patients preferring to remain in their community.²⁸

With regard to missing preferences, main reasons included lack of time to plan the place of EOLC and death due to sudden death or rapid illness progression^{21,33} and the perception that choices are limited.²¹

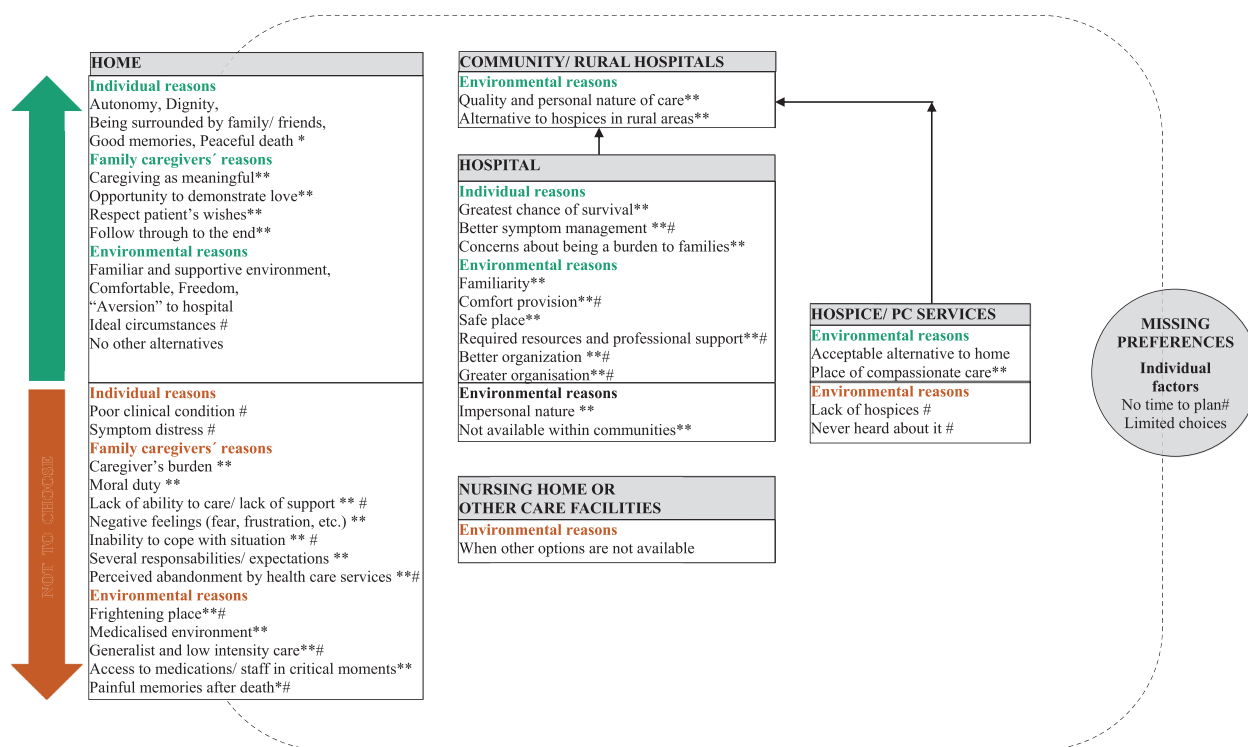


Fig. 3. Underlying reasons for preferences. *Place of death. **Place of care. #Also reported within pediatric reviews.^{9,33}

Factors Affecting Preferences

Factors affecting preferences (Appendix VI) were reported in nine reviews, seven of high quality^{7–8,10,21,28–29,31} and two of low quality.^{9,33} All nine reviews provided information related to factors affecting preferences about POD, with two reviews also reporting on factors affecting preferences about place for EOLC: Higginson et al.³¹ in cancer and Murtagh et al.²¹ in noncancer. Four reviews provided only qualitative data and/or descriptive quantitative data;^{8–9,29,33} five reviews reported results from studies that tested associations.^{7,10,21,28,31}

The factors were grouped into illness-related, individual and environmental factors. In addition to these, several studies examined the influence of sex,^{7,10,31} age,^{7,10,31} functional status,^{7,10,21} and diagnosis,^{8,21} but the findings were inconclusive or inconsistent.

Differences Between POC and POD Preferences

Only two high quality reviews^{10,29} provided information regarding differences between preferred POC and preferred POD. Gomes et al.¹⁰ reported inconclusive evidence, for both patients (four studies) and family members (four studies), with only one study (of advanced cancer patients under a home palliative care team) carried out statistical testing of differences, showing the majority preferred to be cared for at home and fewer preferred to die at home (89% vs. 80%, $P < 0.001$). The review authors also described qualitative results showing a conceptual distinction between preferences for POC and POD, as a “definite” or “desperate” desire to remain at home as long as possible, with the ultimate goal to die at home, was reframed if an admission was required (found acceptable if the person was not aware of it anymore). A home care preference was limited by the family’s ability to care, whereas a home death preference was limited by the consequences of witnessing death at home (e.g., for children). For some surviving spouses satisfied at having mastered the time spent at home, the greatest value was on the place where most care was provided, rather the actual POD. Woodman et al.²⁹ p.426 referred to “potentially different preferences surrounding POC and POD”, reporting to one single study, but provided no further information.

Changes in Preferences Over Time

Eight reviews (seven of high quality) described changes in preferences over time.^{8–10,21,27–29,31} Gomes et al.¹⁰ analyzed findings from 15 studies on the matter, reporting that it was not clear cut whether preferences change significantly over time, as no study with patients and family members reported the statistical significance of the observed changes. Still, changes were documented for 20% of patients across 10 studies

(ranging 2%–80%) and less than a third of family members across three studies. The direction of changes varied but was commonly from hospital to home, home to hospice and home to hospital (patient and family members did not feel anymore care should be at home due to uncontrolled symptoms, acute medical events, patient falls and imminent death). In light of changing circumstances, they reprioritised and treatment of reversible situations for comfort became more important than staying at home. In another study, patients also reframed their initial preference to be cared for at home, due to increasing illness and dependency (“better be where could be looked after”). Preferences are described as rarely a definite feeling, as events may change and influence choice.

The other reviews provided more limited data on changes. Reporting on cancer, Higginson et al.³¹ described the findings of two earlier longitudinal studies in the UK, stating that the observed changes in patient and family preferences (decrease of home preference) happened possibly as a result of increasing family burden, but were not statistically significant. Reporting on noncancer, Murtagh et al.²¹ stated that preferences may change over time according to circumstances, referring to one study with older people where wishes changed even in short time during interview. However, the review authors also stated there was no indication from studies with COPD patients that preferences changed according to stage of illness. Hoare et al.⁸ referred to two studies with bereaved relatives in the UK where 1% had changed their mind. Woodman et al.²⁹ in their review of qualitative evidence, described several findings related to changes or stability of preferences: while preferences could change from home to hospital, particularly if distressing symptoms made home care difficult, family members often reported how their preferences for POC had not changed; instead they simply felt unable to cope at home any longer.

The remaining two reviews referred to single studies. Reporting on the pediatric population, Bluebond et al.⁹ referred to one study showing that preferences for home increased from study entry to the last month of life (from 98 to 120 family members), whilst the preference for hospice increased (from zero to four family members) and the hospital preference remained constant. With regard to the option “had yet to express preference” the percentage decreased from 18% at study entry to 13% in the last month of life. Gonzalez et al.²⁷ referred to one study that examined stability of preferences about place of EOLC of older patients with multimorbidity and advanced diseases, finding that, at one-year follow-up, 61% of patient had changed their preference at least once (reasons not explained).

Congruence

Six reviews (three of high quality,^{20–21,30} two moderate^{11,26}, and one low quality⁹) reported on the congruence between preferred and actual places. Across primary studies, congruence between preferred and actual POD ranged 21%–100%, with differences between the estimates reported by three reviews: 30%–91% in Bell et al.'s¹¹ review, 30%–89% in Billingham et al.'s²⁶ review, and 21%–100% in García-Sanjuán et al.'s²⁰ review. Results from other reviews were more limited. Murtagh et al.²¹ reported two US studies where 35% and 47% of patients died in their preferred place. Badrakalimuthu et al.³⁰ reported that among 14 patients with dementia from a “group home” in Japan, only six died at their preferred place but location was not described. Bluebond et al.⁹ p.708 described that one study on the preferences of adolescents, reported by their parents, found that “the ‘majority’ of the 13 subjects preferred a death at home, ‘two-thirds’ of the 13 young adults...were able to die at home, and one wished to do so but died in a hospice.” The review authors also reported findings from another study showing that 48% of parents whose child died at home would not, in retrospect, choose another place, and 34% of those whose child died in hospital would not have preferred another place.

Congruence between family members' preference and the patient's actual POD was reported in the review on dementia by Badrakalimuthu et al.³⁰ The authors referred to one study in which the patient's actual POD matched the preferences of family

members in 32 out of 33 cases (but with no information about the locations preferred).

Factors Associated With Congruence

Factors associated with the congruence between preferred and actual POD were described in five reviews,^{9,11,20,26,30} one with meta-analysis.²⁶ The factors are synthesized in Fig. 4, organized into illness-related, individual and environmental. Rapid illness progression was the only factor pointed out both in paediatric⁹ and adult patients,¹¹ negatively associated with congruence. In addition to these, there was conflicting evidence on the influence of several factors.

The highest level of evidence comes from Billingham et al.'s²⁶ review, in which the authors examined incongruence according to the presence of cancer or noncancer disease and by preferred POD, through meta-analysis. Patients with a noncancer diagnosis (illness-related factor) were found to be at greater risk of incongruence (weighted risk ratio; 1.23, 95% CI: 1.01–1.49, $I^2 = 62\%$) compared to cancer patients. Patient's preferred POD (personal factor) was not found to be associated with incongruence. The authors also reported a significant overall increase of congruence in studies published since 2004 (macrosocial factor), with the improvement being more pronounced for cancer patients when compared with noncancer patients ($P = 0.0095$).

Discussion

This umbrella review allowed a comprehensive examination and synthesis of quantitative and

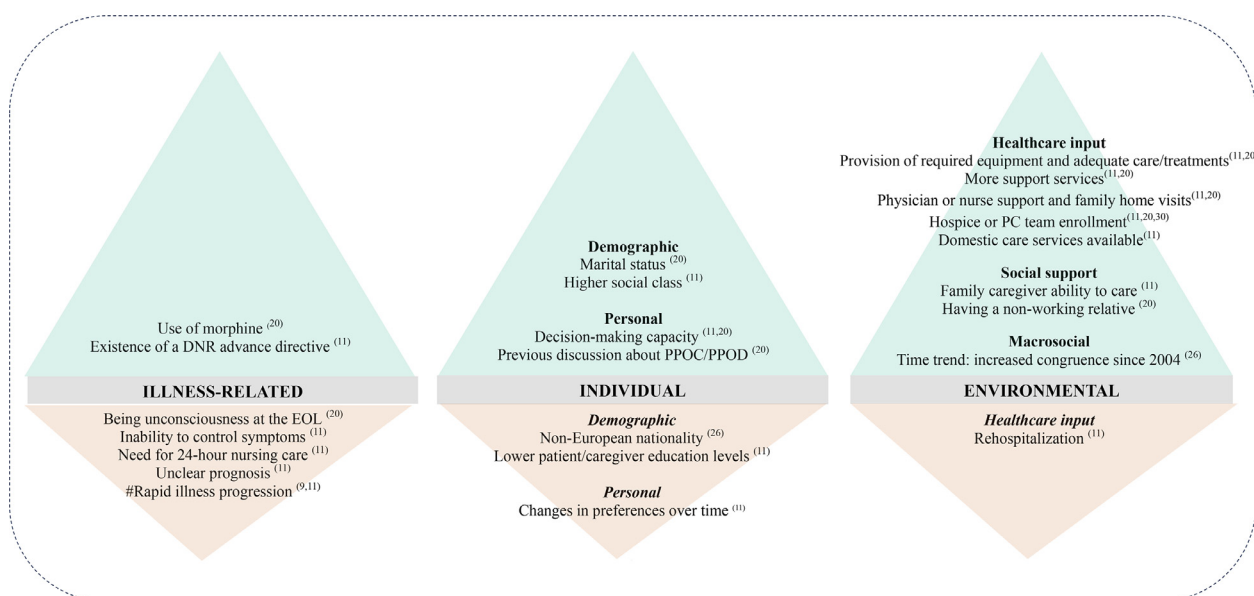


Fig. 4. Summary of factors associated with congruence. DNR = do not resuscitate, HCP = healthcare professional, PC = palliative care, PPOC = preferred place of care, PPOD = preferred place of death. Δ Enhanced congruence. ∇ Decreased congruence. #Factor also found in pediatric populations.⁹

qualitative evidence on patient and family member's preferences for place of EOLC and death, both for adult and pediatric patients. The first systematic review on this subject was published in 2000³¹ and the last one in 2022,³³ with the evidence going back as far as 1974, showing there were concerns about addressing preferences for place of EOLC and death nearly 50 years ago.³⁵ Despite the wide geographical coverage of the primary studies, most were conducted in European and North-American countries, limiting the extent to which our results can be widespread to lower and middle-income countries, where the number of studies identified was low.

We explored preferences for both place of EOLC and POD, and found that most reviews focused on preferences for POD, with only four providing data on preferences for place of EOLC. Despite the importance of preferences for POD, understanding preferences for POC is also needed, in order to ensure best care at the right place (for patients and families) and to enable better decision-making towards the EOL.

Although research on EOLC has been growing, there are still gaps to tackle, namely with regard to specific populations, such as children and family members (the latter are commonly seen as proxies or studied with a focus on their "attitudes" instead of their own needs or preferences).^{36–37} We saw the research gap on preferences is especially evident regarding the preferences of children and young people, as nearly all studies interviewed parents instead of patients themselves. The reasons for this were not described, but international studies emphasize complex limitations to the conduct of research with pediatric patients at the EOL, not only for ethical reasons but also due to lack of funding and, above all, due to clinicians and parents' gatekeeping.³⁸

Regarding the full spectrum of preferred places, we identified a wide range, including home, hospitals and hospice/palliative care facilities as the most preferred. There was consistency that home is the most favored place for EOLC and death, both for patients and their families. However, it is important to note that as the reviews included primary studies from several countries worldwide, different concepts and wording were found to describe places that represent similar settings. This prompts a broader comprehension of the political, organizational, and cultural richness and variability worldwide, which is critical to inform the development of an international classification of dying places, currently underway.

As reported across reviews, ensuring care at home, particularly at the EOL and until the end may sometimes be a struggle or even not possible. Important reasons to express a preference against home or to switch to another place include the poor clinical condition of the patient, symptom distress, and family burden. Although

we found that home care and death are most commonly preferred, hospitals and hospice/palliative care facilities are places preferred by substantial minorities, the extent of which may vary worldwide. This aligns with previous studies, which flagged that while home remains an important and preferred place, respecting global diversity is pivotal, since several local, macrosocial, economical, political and cultural factors play a role.¹⁹

Also, some patients decide to sacrifice their preferences and move to another place, commonly to hospitals and hospice/palliative care facilities. However, these care facilities are not available everywhere,^{28,39} especially in remote or rural areas, and the lack of support at home is critical to the decision. Thus, small community hospitals and other care facilities are important alternatives to consider, despite having little expression in people's preferences. Since palliative care is not the usual focus of the care provided in these places, it is important to provide education and training to their workforce, to ensure good quality EOLC. As reported in a recent systematic review,⁴⁰ the provision of EOLC within nursing homes is challenging due to the lack of effective educational interventions, and this is important because 20% of the population are estimated to die in nursing homes, though the percentage varies across countries.

Another important finding was the considerable amount of missing and unreported data or indecisions around preferences. This suggests that some patients and their family members are not prepared or able to report a preference, while for others it may not be appropriate to approach the matter in advance. Respect for diversity must be considered in conversations and care delivery.⁸ Regardless the reasons, the extent of missing data has major implications for clinical practice, policy and research, as it may impact on the distribution of preferences.^{8,41} However, it is difficult to predict in which direction, without knowing more about the reasons and the "hidden" direction of the missing preferences.

Several illness-related, individual and environmental factors were found to be significant. Environmental factors were the largest group, which is consistent with the data reported by Gomes and Higginson¹⁹ in their earlier model on actual POD, with the model fitting well our findings on factors affecting preferences. This provides a greater understanding about the influence of this group of factors.

Differences between place of EOLC and POD, changes over time and congruence are other topics deserving attention, especially considering the challenges posed by care transitions at the EOL. A previous qualitative meta-synthesis about transitions as experienced by patients in palliative care and their families⁴² found that maintaining normality during transitions was a central topic. However, the difficulties around

prognostication and defining illness and care trajectories (particularly in noncancer) may limit the time patients and families have to consider their options and preferences.²⁶ Thus, to ascertain congruence it is pivotal to accurately measure preferences.

Strengths and Limitations

To our knowledge, this is the first umbrella review concerning preferences about place of EOLC and death of patients with life-threatening illnesses and their families. We have undertaken several efforts to ensure quality, namely through five clear and well-articulated research questions, appropriate inclusion criteria, comprehensive search in six databases and grey literature with no time/language restrictions, as well as other methods to minimize errors, as analysis by two independent reviewers at all stages of screening, extraction, quality assessment and analysis.

Despite our efforts to avoid methodological and publication biases, some relevant reviews may have been missed and others were excluded based on criteria considered pivotal for quality. Some reviews had limitations in their search strategies, in the extent they searched for grey literature, or had language limitations, leaving scope for publication bias. Consequently, the quality of the reviews varied (from high to low, although 10/15 were considered high quality) and of the primary studies too. Findings on pediatrics should be read with caution as the two reviews were of low quality. In the reviews by Bell et al.,¹¹ by Gomes et al.¹⁰ and by Noyes et al.³³ the quality assessment was conducted by only one reviewer, confirmed by another or discussed among the team; this should be considered when appraising their findings.

The way preferences were assessed in the primary studies is another important limitation to consider when appraising the findings. The strategies and questions that the researchers used to capture preferences varied greatly among studies and sometimes were not clearly reported. Caution is also needed depending on "when" preferences were asked (earlier vs. later disease, ideal vs. actual circumstances, hypothetical vs. real scenarios) and "who" were the respondents (patients vs. family members as proxies or extracting information from clinical records). Another limitation is the high heterogeneity among reviews and the primary studies included in them. Studies were conducted in different countries, settings (sometimes multiple or unstated settings) and populations.

Conclusions and Recommendations

This umbrella review deepens the understanding of the available evidence on preferences about place of EOLC and death among patients and their family members. A full capture of the diversity of places that are meaningful for individuals and of the concepts

used to describe these places across studies, as well as the underlying reasons and factors affecting preferences and congruence were analyzed and synthesized in an updated state-of-the-art.

Home is the most common patient's preferred POC and death, and this is an important finding considering the rise of home death observed during the COVID-19 pandemic in 23 countries.⁴³ However, it should be noted that hospitals and hospice/palliative care facilities are preferred by substantial minorities, especially when home is no longer possible, often due to family burden or symptom distress. However, these facilities are not available in many locations, particularly in rural and remote areas, where small community hospitals and nursing homes can be alternatives. Reasons underlying and factors affecting preferences are several, including illness-related, individual, and environmental. Differences between preferred POC and preferred POD are relatively underexplored and the evidence remains inconclusive on changes in preferences over time, although these may happen. Congruence between preferred and actual POD is higher in studies published since 2004 and meta-analysis results showed noncancer patients are at higher risk of incongruence than cancer patients. No study reported congruence between preferred and actual POC.

Our results can underpin the creation of guidelines to systematically assess and record preferences for place of EOLC and death, can help improve care across settings according to patients and family members preferences for and against, and can help develop strategies to increase congruence between preferred and actual POD.

Recommendations for Policy and Practice

Policy-makers and healthcare professionals should consider the need to recognize home as the most commonly preferred place of EOLC and death, both for patients and their family members, followed by hospitals and hospices/palliative care facilities. However, the several difficulties surrounding EOLC at home (the generally low intensity and frequency of care, the struggle to access relevant medication, equipment and support in critical moments, the family burden) require strategic planning to allow the required conditions and put in place alternatives. Thus, it is also important to allow care and death in places other than home, especially if we consider that home is not the unique preferred place to be cared for at the EOL and to die. While in some countries the planning may be local (at the level of regions and institutions), in others it may be necessary to develop a national strategy. Policy-makers can take proactive measures to align healthcare services with patient preferences at the end-of-life. This may involve promoting community-based palliative care programs,

expanding hospice services to underserved areas, and implementing standardized procedures for recording and regularly updating patient and family preferences in health records.

As an action to help reduce the family burden reported both by families and patients, it is important to prepare and train family members. If strong support is not available at home, family members may be unable to cope with the situation and undesired admissions may happen, representing important costs to patients, families and healthcare services. Thus, recognizing that end-of-life decisions often impact the entire family, healthcare professionals can foster open discussions through facilitated family meetings. This approach encourages questions, addresses concerns, and enhances understanding, creating a supportive environment for shared decision-making.

Another important recommendation is the need to be prepared to systematically assess and record preferences, as our findings highlighted an important share of missing preferences. For this reason, we recommend that assessing and recording preferences for POC and POD should be a quality EOLC indicator and a mandatory item in clinical records for patients with advanced diseases. This documentation should be easily accessible to all members of the healthcare team to facilitate consistent and patient-centered care. This may include, for example, an advance directive, living will, or other legal documents that outline the patient's preference for POC and POD. Thus, it is important to encourage healthcare professionals to guide discussions that delve into the values and preferences of patients and their families. Understanding the reasons behind patient's preferences can help tailor care plans to better align with their goals and expectations.

Yet, it is also necessary to recognize that preferences may change over time, as the illness progresses and death approaches. Thus, the education and training of healthcare professionals on this matter remains an important goal, particularly for those who work in places that are more likely to receive patients in advanced disease stages, but whose main focus of action would not be EOLC. This is the case of hospitals and nursing homes, since findings from our umbrella review also showed evidence that, in some circumstances and for some people, these are preferred places of care or death. Therefore, it is crucial to routinely revisit discussions and preferences, as well as to explore potential scenarios, to support informed decision-making. Creating an open and supportive clinical environment is vital for patients and families to express concerns and preferences comfortably, fostering a constructive dialogue.

While there are several factors influencing preferences for POC and POD, the significance of this review lies in recognizing and helping to address modifiable

factors, particularly within the healthcare system. We have shown the complexity of preferences which cannot be oversimplified. We have also identified actionable factors that can be improved upon, such as healthcare infrastructure, access to palliative care services, and effective communication to align care with patient and family preferences. Addressing preferences for place of EOLC and death will contribute to enhancing the adaptability and responsiveness of healthcare systems to better meet the diverse needs of individuals at the end-of-life.

Recommendations for Research

Although the review has international coverage, most of the studies were conducted in Europe or the United States. Therefore, further studies must seek to clarify preferences and their variation elsewhere, particularly in low and middle-income countries. Considering the wide spectrum of concepts found to express preferred places of care and death, it is important to have these variations in mind when conducting future research.

While there is a considerable amount of evidence on preferences regarding POD, preferences on POC are less explored, with potential differences between preferred POC and POD. These are important aspects to explore, since the evidence is limited and findings could be pivotal to a better understanding and management of patient's transitions towards the EOL.

Regarding target population groups, the greatest need for future research falls clearly on children and young people, since the evidence is scarce, of low quality, and focused on parental perspectives.

Further studies and reviews aiming to explore preferences about place of EOLC and death need also to carefully consider and explicitly define the role of family members in the research, improving efforts to clarify whether they are acting as proxies or reporting their own perspectives.

Considering possible changes over time, an early assessment of preferences must be addressed. This process should be dynamic and preferences should be prospectively measured, since our findings suggest differences between hypothetical vs. real scenarios and, within real scenarios, differences between ideal and actual circumstances. For these reasons, longitudinal studies are much needed.

In addition to these research directives, other methodological issues surrounding the assessment of preferences should be considered. For example, the way in which researchers choose the questions to assess preferences could influence the answers they get. Thus, we advise implementing strategies to improve preference assessments and study designs. To accurately identify

patient and family preferences is an important opportunity to change their lives positively.

Author Contributors

SP, SL and BG designed the study, developed the search strategy and implemented it. SP, ABS and MD screened the retrieved studies for eligibility, extracted the data from the eligible studies and conducted the quality assessment. BG and SL acted as third reviewer when needed. SP performed the analysis and drafted the paper with contributions from all authors. All authors approved the version for publication. BG is the guarantor of the review.

Data Sharing

The list of all retrieved citations and primary studies is available if needed.

Disclosures and Acknowledgments

All authors have completed the Unified Competing Interest form (available on request from the corresponding author) at www.icmje.org/disclosure-of-interest/. BG is first author of one included systematic review. She did not take part in the selection, quality assessment, data extraction, analysis or conclusions in relation to this study. The authors thank Edoardo Aromataris (Director of Synthesis Science at the JBI, University of Adelaide), Kawaldip Sehmi (Chief Executive Officer of IAPO), Stecy Yghemonos (Director of Eurocarers), Isabel Andrade (Head Librarian at Nova National School of Public Health, Universidade Nova de Lisboa) and Barbara Antunes (Visiting Researcher at the University of Cambridge) for their contribution to the protocol and review development. This work is part of the project EOLinPLACE: Choice of where we die: a classification reform to discern diversity in individual end of life pathways, which has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No 948609). The funder had no role in the protocol development and in the review execution, analysis, interpretation of the data, or decision to submit results. BG (the guarantor of the review) declares that the manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted and any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2024.01.014](https://doi.org/10.1016/j.jpainsymman.2024.01.014).

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