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Decision-making regarding place of end-of-life care for children with life-limiting and life-threatening conditions: a systematic integrative review

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Abstract

Background Due to medical advancements the number of children living with life-limiting and life-threatening conditions is rising, meaning more children and their families will require palliative and end-of-life care in the future. While 'home' is often the preferred place of end-of-life care, the evidence around best practice for decision-making about place of end-of-life care remains inadequate.

Aim To synthesise evidence on the factors influencing decision-making regarding place of end-of-life care for children with life-limiting and life-threatening conditions.

Design A systematic integrative literature review. The review protocol was registered in Prospero: CRD42023406800.

Data sources CINAHL, MEDLINE, EMBASE, PsycINFO, and Maternal and Infant Health were searched for studies published between 2013 and 2024. Any empirical, peer-reviewed journal articles published in English that included data pertaining to decision-making about place of end-of-life care for children (≤ 18 years) with life-limiting or life-threatening conditions were considered. Quality appraisal was conducted using the Mixed Methods Appraisal Tool.

Results Eleven eligible studies were included. Using an iterative process of constant data comparison, four themes were identified, highlighting that (i) consideration of the child, (ii) availability and suitability of end-of-life care services, (iii) parents' capacity and control in providing care, and (iv) family and sibling well-being were factors influencing decision-making about place of end-of-life care.

Conclusion There are a complex range of factors surrounding decision-making regarding place of end-of-life care for children with life-limiting and life-threatening conditions. Studies focused primarily on parents' perspectives. Further research is needed to identify how to best support decisions about place of end-of-life care for families of children with life-limiting and life-threatening conditions.

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Keywords Palliative care, Paediatrics, Pediatrics, End-of-life, Place of care, Decision-making, Life-limiting life-threatening conditions, Systematic integrative review

Background

There has been a marked increase in the number of children living with life-limiting and life-threatening conditions, e.g., cancer, genetic disorders, and neurological conditions [1, 2]. In England, for example, the prevalence of children with a life-limiting condition rose from 26.7 per 10,000 in 2001/02 to 66.4 per 10,000 in 2017/18 [2]. This is largely due to improvements in technology, treatments, and medical expertise [3]. Future predictions estimate that this trend will continue [2]. Thus, more children and their families will require palliative and end-of-life care in the future. Globally, there is growing recognition of the need to optimise information on available palliative care services and to enhance communication between acute and community-based services for children with life-limiting and life-threatening conditions and their families [4–6].

A child's death has a long-lasting and traumatic impact on families and healthcare professionals [7, 8]. Consequently, when death in childhood is anticipated, such as when a child is living with a life-limiting or life-threatening condition, it is important to provide high-quality care to maximise quality of life and facilitate end-of-life care and death in the preferred place [9]. 'Home' is often the preferred place for many families when their child needs palliative and end-of-life care, though this preference can change due to factors such as the child's condition, availability of palliative care services, and family circumstances [10]. However, the evidence around best practices for decision-making about the place of end-of-life care remains inadequate [11]; some families may prefer alternatives to home [11]. Additionally, most children with life-limiting and life-threatening conditions continue to die in hospital settings [11]. Papadatou et al. recommend that policymakers work to improve end-of-life care in all settings since home, hospital, and hospice, as places of care, are desirable to different families for different reasons at different times [12]. As a result, the place of end-of-life care has been identified as a research priority to guide healthcare services and inform service development [9, 13].

Several quantitative retrospective cohort studies to date have investigated end-of-life care for children with life-limiting and life-threatening conditions [11, 14–16]. While these studies have yielded important information about place of end-of-life care by retrieving data from medical records, gaps in knowledge remain in relation to understanding factors influencing decisions around why

a particular place (i.e., hospital, hospice, home) is chosen for end-of-life care [11, 14–16]. Other studies have focused on place of end-of-life care solely for children with advanced cancer [17–20]. The emphasis so far on advanced cancer is reflected in the qualitative systematic review by Noyes et al. which synthesised factors that influence parental decision-making when choosing place of end-of-life care and death for children with cancer [21]. This review provides valuable insights into decision-making around location of end-of-life care for children with cancer, however, it remains unknown whether the findings are transferable to a range of childhood life-limiting and life-threatening conditions. Another recent scoping review investigated the importance of place in paediatric palliative care for families (from the parent's perspective) [22]. This scoping review identified a broad range of factors that contribute to the choice of place for end-of-life care, including familial support, parent capabilities, access to resources, and proximity to medical care, but did not include health and social care professionals (HSCPs) perspectives [22]. However, to our knowledge, no systematic integrative review has been undertaken to examine decision-making about place of end-of-life care for children with a wider range of conditions from the perspectives of parents, children, and HSCPs. Therefore, this integrative review aimed to synthesise the evidence base on factors influencing decision-making on place of end-of-life care for children with life-limiting and life-threatening conditions.

Methods

The methodological guidelines and procedures for conducting systematic integrative reviews as outlined by Whittemore and Knafl [23] were followed. The review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) 2020 guidelines [24] (see Additional file 1 for PRISMA checklist). The protocol for this review was registered with PROSPERO (No. CRD42023406800) [25].

Search strategy

A systematic search of five databases (CINAHL, MEDLINE, EMBASE, PsycINFO, Maternal and Infant Health) was conducted with the last search being ran on August 01, 2024. A combination of controlled vocabulary (e.g., MeSH headings) and free-text search terms was

developed in consultation with a subject librarian and applied to each database as appropriate. These included the following categories and search terms for example, infant/child/paediatric/adolescent; place of death; terminally ill patients/terminal care/palliative care; and decision making/choice/decision support techniques. A search strategy for the CINAHL database, which was adapted for all databases, is provided in Additional file 2.

Systematic review repositories including Cochrane Database of Systematic Reviews, Database of Abstracts and Review Effects (DARE), PROSPERO, and JBI Evidence Synthesis were also searched for any existing reviews in progress and to screen and retrieve references from completed reviews. For unpublished research reports specific to the Irish and UK context, a grey literature search of resources from the two leading organisations promoting excellence in palliative care on the island of Ireland, Together for Short Lives (TFSL) and the All-Ireland Institute of Hospice and Palliative Care (AIHPC), was carried out.

Eligibility criteria

Inclusion and exclusion criteria are provided in Table 1.

Study selection

Search outputs were initially imported into the reference management system Endnote and subsequently imported into Covidence (www.covidence.org), where duplicates were removed, and title/abstract and full-text screening took place. Two reviewers (AC and FH) independently screened the titles and abstracts of retrieved studies against eligibility criteria. If no abstract was available, full-text studies were retrieved for screening. At full-text screening stage, studies that did not meet the eligibility criteria were excluded, with reasons for exclusion recorded (see Fig. 1). Any differences in opinion among the reviewers were resolved through discussion and consensus. A third reviewer (GK or HK) was consulted at any stage of the review to resolve discrepancies where a decision could not be reached.

Quality appraisal

The Mixed Methods Appraisal Tool (MMAT) [26], which permits appraisal of five different categories of study designs, was employed to assess the methodological quality of included studies. The criteria of each chosen study design category were rated by reviewers for each included study using yes, no, or can't tell. Assessment of methodological quality was independently carried out by two reviewers (FH and AC). Consensus was reached through discussion, and discrepancies were resolved through consultation with a third reviewer (GK or HK).

Data extraction

Data were extracted by two reviewers (FH and AC) using a predefined data extraction form. This included study characteristics (authors, year of publication, country, aim, study design), sample and demographic characteristics (sample size and parent/HSCP/child, place of end-of-life care, diagnosis), and findings related to factors influencing decision-making regarding place of end-of-life care. Two reviewers (AC and FH) each independently extracted data from half of the included studies. Once completed, they cross-checked each other's data extraction forms.

Data analysis and synthesis

Whittemore & Knafl's five stages of data analysis for integrative reviews were used to synthesise the evidence [23]. The analysis stages included data reduction, data display, data comparison, conclusion drawing, and verification [23]. Data reduction involved using a sub-group classification for participant source (i.e., parent, HSCP or child) to organise, extract and code data from primary sources. Initial data coding and matrix compilation was conducted by two reviewers (AC, FH). Next, data display involved converting and assembling the data extracted from primary sources into visual data displays. These data displays provided a starting point for comparison and interpretation through the visualisation of data patterns across the primary data sources. This led to an iterative process of constant data comparison to identify

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none">• Studies that include data pertaining to factors influencing decision-making about place of end-of-life care for children with life-limiting or life-threatening conditions• Studies that focused on parents'/guardians', health and social care professionals (HSCPs), and/or children's perspectives, including children's perspectives by proxy in retrospect• Studies that include children up to and including 18 years• Studies published in English• Empirical research studies• Studies published between January 2013 and August 2024	<ul style="list-style-type: none">• Studies that address unexpected or sudden death, for example, death from injury, trauma, or poisoning, or sudden infant death syndrome• Studies that included the views of family members other than parents/guardians and children with life-limiting and life-threatening conditions

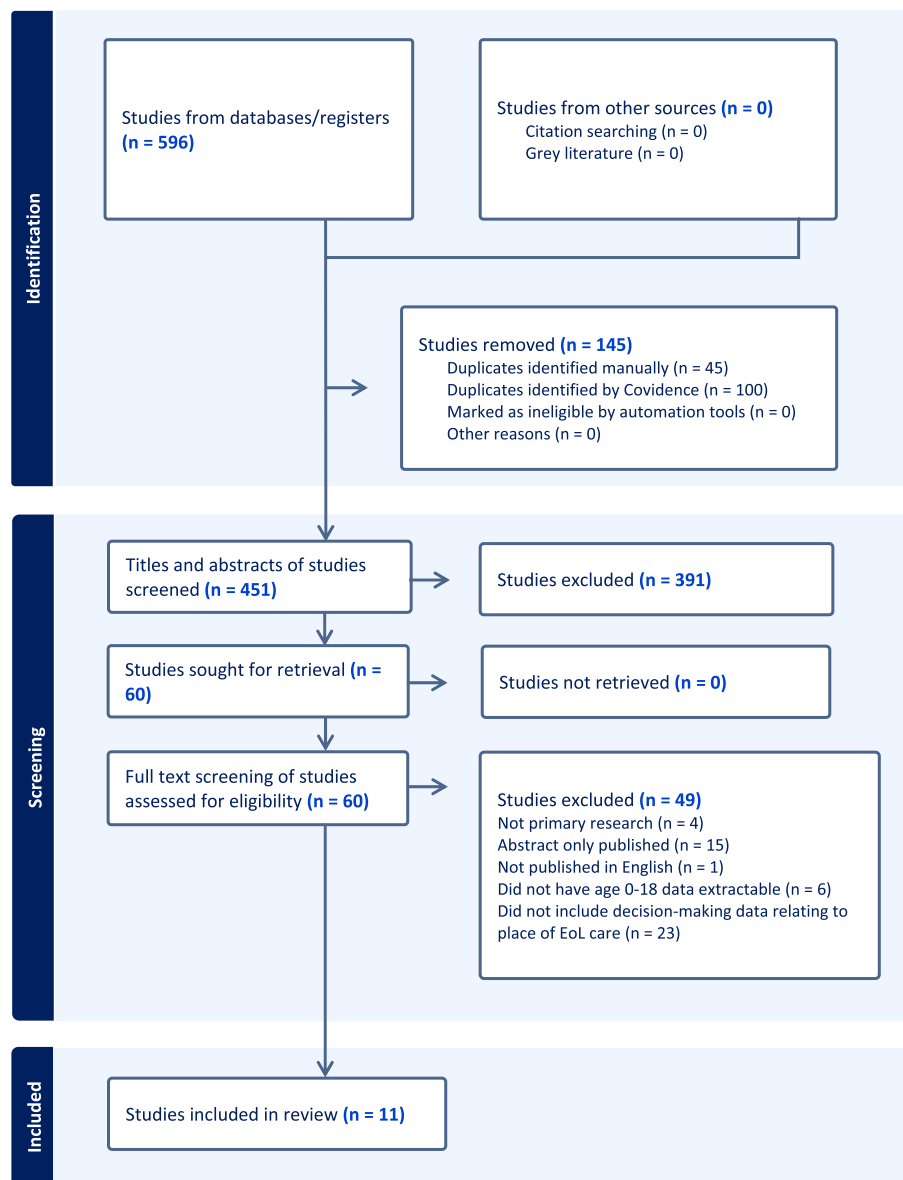


Fig. 1 PRISMA flowchart of study identification and selection process

patterns, sub-themes, and themes. Finally, conclusion drawing, and verification involved higher level abstraction and pattern representation with verification with primary source data for accuracy and confirmability.

Results

As illustrated in Fig. 1, database searches yielded 451 studies after duplicates were removed. Of these, 391 did not meet the eligibility criteria following title and abstract screening. A total of 60 studies met the criteria for full text review, and at this stage, a further 49 studies

were excluded, with reasons noted in Fig. 1. In total, 11 studies were deemed eligible for inclusion in this review.

Characteristics of included studies

As the grey literature search did not yield any evidence, the 11 studies included in the review were published studies. Studies originated from the United Kingdom ($n=3$), United States ($n=3$), Turkey ($n=1$), Switzerland ($n=1$), Spain ($n=1$), India ($n=1$), and Greece ($n=1$). The included studies were published between 2014 and 2023 and comprised findings from a combined total of

251 parents/caregivers, 191 HSCPs and 265 child case notes. Studies employed a qualitative ($n=5$), quantitative ($n=4$), or mixed-method ($n=2$) design. The studies primarily investigated: advance care planning for children [27, 28], experiences, needs, and factors affecting decisions about place of child death and end-of-life care [12, 29–34], experience of paediatric palliative transports and of transporting children home to die [35, 36], and experience of a palliative home care programme [12]. Ten studies reported on parent perspectives of decision-making (three of which were reflected in case notes), and one study reported on the perspectives of HSCPs decision-making. All studies revealed factors that influence decision-making regarding place of end-of-life care for children with life-limiting or life-threatening conditions. The life-limiting life-threatening conditions of children varied across samples, with five of the 11 studies explicitly focusing on children and young people with cancer (see Table 2).

Quality appraisal

Results of the MMAT quality appraisal are presented in Table 3. As included studies employed qualitative, quantitative descriptive and mixed method designs only, the MMAT criteria for these study types only were applied. Where two of the quantitative descriptive studies received ‘no’ or ‘can’t tell’ ratings, this was due to lack of information reported and for limitation in relation to sample representation. For one study, with a response rate of only 22%, the risk of nonresponse bias could not be ruled out. The quality appraisal was conducted to describe the quality of included studies to aid interpretation of the evidence rather than the exclusion of inadequately reported papers or studies that had less than perfect quality.

Main findings

Synthesis of findings from the 11 included studies identified four themes: (i) consideration of the child, (ii) availability and suitability of end-of-life care services, (iii) parents’ capacity and control in providing care, and (iv) family and sibling wellbeing, which were important factors influencing decision-making about place of end-of-life care.

Theme 1: consideration of the child

The theme ‘Consideration of the child’ was identified in nine studies [12, 28–33, 35, 36], and represents the child being placed at the forefront of decisions about place of end-of-life care.

The child’s condition was an important factor considered by parents and HSCPs when making decisions about place of end-of-life care [12, 28, 29, 31, 36]. When parents

had an awareness that their child was dying, they considered symptom severity and time to death when deciding on place of end-of-life care [12, 33]. Hospital was often chosen as the place of death due to observed child pain or poor symptom control in the home environment [12, 29, 31]. However, for some parents, home as the place of death was important despite the child’s symptoms [29].

Sudden deterioration in child health influenced the decision over place of death [12]. Papadatou et al. reported how parents resisted home care when the child’s condition suddenly deteriorated or when they felt they had limited time to develop the skills and confidence to care for the child with eventual emergencies at home [12]. In contrast, Thienprayoon et al. reported how Spanish families commonly emphasised the importance of being at home and did not focus on symptom management [29]. From health and social care professional perspectives, Morton et al. highlighted how clinical characteristics and subsequent instability of a child affected whether HSCPs would consider a transfer home, especially for children who were unstable and/or in need of cardiovascular support [36].

Parent decisions about their child’s place of end-of-life care took account of the quality of death they desired for their child [12]. For example, for some mothers, envisioning a peaceful death included performing religious rituals, such as reading the Quran at home [31], whereas other parents were distressed seeing their child experience IV access difficulties and repeated procedures [33].

Parents reported acting as advocates for their child’s wishes, especially to be at home for end-of-life care [12, 30, 35]. Some children wanted to be at home with family members, and others were afraid to go to hospital [33]. Parents felt obligated to decide to go home for their child’s end-of-life care due to promises made to the child, the child’s goals, or because the child preference was to be at home [29, 35].

Theme 2: availability and suitability of end-of-life care services

The theme ‘availability and suitability of end-of-life care services’ was identified in nine studies [12, 28–31, 33–36]. This theme describes how the availability and suitability of services were factors that influenced parents’ decisions on place of end-of-life care for their child. Specifically, lack of, or inadequate, home-oriented services and/or limited knowledge of such services affected parent’s decision-making [12, 29, 31, 33, 34, 36].

The availability of end-of-life services, and parents’ capacity to access them, had an impact on how and what decisions were made about place of end-of-life care for children [12, 30, 31, 36]. A study conducted in Spain found that families who had been visited at home by an

Table 2 Characteristics of Included Studies

Author	Country	Aim	Research Design	Sample	Child Condition	Place of Care
Beecham et al. 2017 [28]	UK	To investigate how parents of children and young people with life-limiting conditions approach and experience advance care planning	Qualitative Grounded Theory	18 parents 9 parents of children currently receiving palliative care 9 bereaved parents	Range of life-limiting and cancer conditions	Hospital Home Hospice
Bingöl et al. 2022 [31]	Turkey	To describe factors affecting place of death of children with cancer	Qualitative Phenomenology	18 bereaved mothers	Range of cancer diagnosis	Home Hospital
Eskola et al. 2017 [30]	Switzerland	To understand parents' experiences and needs during a child's end-of-life care at home and to identify systemic factors that influence its provision in Switzerland	Mixed Methods Concurrent Embedded Design	66 bereaved parents (quantitative survey) 10 parents (qualitative interviews)	Range of life-limiting and cancer conditions	Home
Friedrichsdorf et al. 2015 [32]	USA	To compare symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a paediatric palliative care home care program (PPC/Oncology) with those who died without exposure to the paediatric palliative care program (Oncology)	Quantitative Retrospective Survey	60 bereaved parents 50% (PPC/Oncology) 50% (Oncology)	Range of cancer diagnosis	Home Hospital
Heckford et al. 2014 [27]	UK	To review advance care planning for children with life-threatening or life-limiting conditions	Quantitative Descriptive Study	42 sets of case notes for 20 children	Range of life-limiting and cancer diagnosis	Hospital Home Hospice
Morton et al. 2019 [36]	UK	To examine (a) health care professionals (HCPs) views and experience of transferring babies/children home to die from intensive care, (b) patient clinical characteristics that HCPs would consider transferring home and (c) barriers to transferring home	Quantitative Descriptive Study	191 HCPs (doctors 48% and nurses 49%)	Not reported	Home Hospital
Nelson et al. 2015 [35]	USA	To understand parents' perspectives on experience of paediatric palliative transports	Qualitative Conventional Content Analysis	9 parents	Variety of medical and surgical diagnoses	Home Hospice

Table 2 (continued)

Author	Country	Aim	Research Design	Sample	Child Condition	Place of Care
Papadatou et al. 2021 [12]	Greece	To develop a model explaining how parents of a child with a life-threatening illness in Greece decide about place of end-of-life care and death and to identify factors affecting decision-making	Qualitative Grounded Theory	36 bereaved parents	Malignant and non-malignant cancers	Home Hospital
Peláez-Cantero et al. 2023 [34]	Spain	To analyse the characteristics of patients who die in the care of specific paediatric palliative care teams (PPCT) in Spain, and to determine what factors influence the place of death and compliance with family preferences	Ambispective, analytical observational, multicentre study (Quantitative Retrospective Survey)	Case notes for 164 children	Range of life-limiting and cancer conditions	Home Hospital
Sneha et al. 2023 [33]	India	To identify the choices of parents about the place of death of their children with cancer, reasons for the choices, and regrets if any of the choices were made	Retrospective mixed methods	Case notes for 59 children and their respective parents	Cancer diagnosis	Hospital Home
Thienprayoon et al. 2016 [29]	USA	To explore parental perspectives of hospice experience in children with cancer, and to explore how race/ethnicity impacts this experience	Qualitative Descriptive Study	34 adult caregivers	Cancer diagnosis	Hospice

Table 3 Results of quality appraisal of included study using Mixed Methods Appraisal Tool (MMAT) [26]

	Beecham et al	Bingol et al	Eskola et al	Friedrichsdorf et al	Heckford et al	Morton et al	Nelson et al	Papadatou et al	Peláez-Cantero et al	Sneha et al	Thienprayoon et al
Screening questions (for all types)											
S1. Are there clear research questions?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
S2. Do the collected data allow to address the research questions?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Qualitative											
1.1. Is the qualitative approach appropriate to answer the research question?	Y	Y					Y	Y			Y
1.2. Are the qualitative data collection methods adequate to address the research question?	Y	Y					Y	Y			Y
1.3. Are the findings adequately derived from the data?	Y	Y					Y	Y			Y
1.4. Is the interpretation of results sufficiently substantiated by data?	Y	Y					Y	Y			Y
1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Y	Y					Y	Y			Y
Quantitative descriptive											
4.1. Is the sampling strategy relevant to address the research question?				Y	Y	Y			Y		
4.2. Is the sample representative of the target population?				Y	C ^a	N ^b			Y		
4.3. Are the measurements appropriate?				Y	Y	Y			Y		
4.4. Is the risk of nonresponse bias low?				Y	Y	N ^c			Y		

Table 3 (continued)

	Beecham et al	Bingol et al	Eskola et al	Friedrichsdorf et al	Heckford et al	Morton et al	Nelson et al	Papadatou et al	Peláez-Cantero et al	Sneha et al	Thienprayoon et al
4.5. Is the statistical analysis appropriate to answer the research question?				Y	Y	Y			Y		
Mixed methods											
5.1. Is there an adequate rationale for using a mixed methods design to address the research question?			Y							Y	
5.2. Are the different components of the study effectively integrated to answer the research question?			Y							Y	
5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			Y							Y	
5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?			Y							N ^d	
5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			Y							Y	

^a No information provided on how cases were selected
^b Significant majority of PICU vs NICU staff
^c Only 22% response rate
^d That this is mixed methods study isn't specified and methods are not explicitly described for phone calls with parents

established paediatric palliative care team were more likely to choose for their child to die at home [34]. From HSCPs perspective, lack of access to community care was a barrier to parents being able to transfer their child home to die [36]. Likewise for parents in Turkey, Spain, and the UK, lack of home-oriented services hindered their choice of end-of-life care at home [31, 34, 36]. Availability of transfer home was described in two of the 11 studies [35, 36]. Parents were influenced by the distance the family lived from a treating hospital [30]. Families were facilitated in changing their mind about end-of-life care if transport services were available, even in the few hours prior to the child's death [12].

Suitability of services was also considered by parents, where parents perception of the environment impacted their decision of place for end-of-life care for their child [12, 28, 31, 35]. This included an environment simply being perceived as unsuitable, while other factors such as a lack of family rooms or privacy, also impacted on parent's decision-making of where end-of-life care should take place [31, 35]. How the child would feel in an environment was also an important consideration, for example, familiarity of place [12].

Theme 3: parents' capacity and control in providing care

Parents' capacity and control in providing care for their child were identified in ten studies [12, 28–31, 33–37] as factors influencing decision-making regarding place of end-of-life care. Parents' capacity to provide care mattered. However, several circumstances affected parents' control by either enhancing or restricting their capacity. When deciding about the place of care and death, parents reported that they considered their own capacity to care for the child [12, 28–31, 35]. Papadatou et al. reported that parents who chose hospital as the place for end-of-life care were uncertain of their ability to provide effective care and felt insecure about managing a health crisis or actual death at home [12].

The availability of support for parents played a significant role in shaping their decisions about where their child would die [31, 33]. In some instances, mothers and children were willing to be at home at the end of the child's life, but their wishes were not always fulfilled due to limited support [31]. As a result, parents' control over choosing the desired location for their child's end-of-life care was impacted. The most important facilitators of end-of-life care at home were parental readiness and social support [30]. Ready parents were described as strong-willed, had clear expectations about the provision of their child's end-of-life care, and were willing to learn the required skills to provide care [30]. Parents managed issues proactively and advocated for their child's wish to be cared for at home. Parents who had

the skills necessary for care felt more in control of their child's care [30]. One included study reported that parents who provide end-of-life care at home must make extraordinary efforts [30].

The relationship with health and social care professionals was also identified by parents in seven studies and affected parents' capacity and control [12, 27–31, 35]. In Beecham et al.'s study, all parents mentioned the interaction between clinicians and parents, including the need for clinicians to understand the holistic picture of the child's life and the life of the wider family [28]. Deciding about place of death requires consensus in a family-centred approach from HSCPs that involves parents, allowing parents to have some control [31]. Papadatou et al. explored parents' decisions regarding the place of end-of-life care and death, specifically home or hospital [12]. They suggested that the clinicians' ability to communicate honestly and relate with compassion affects parents' capacity to make decisions about the place of their child's dying and death, regardless of the chosen place. Thienprayoon et al. found that the decision to enrol in hospice at home was driven primarily by recommendations of the primary oncologist [29]. Variety in parental control was also reported in Thienprayoon et al.'s study, where English-speaking families often framed the decision to transition to hospice care at home as the only option, whereas Spanish-speaking families more commonly discussed hospice care at home as a choice provided by their oncologist [29].

Parents' capacity and control in decision-making over place of end-of-life care varied across the studies included in this review [12, 27–31, 34, 35]. Papadatou et al. reported that decisions regarding place of care and death were reached in four distinct ways: consensus, accommodation, imposition of professional decisions on parents, or imposition of parents' decisions without including professionals [12]. In some cases, this led to parents not being offered any options [12, 34]. The physician told parents what was going to happen, and parents acceded to the clinician's decisions [12]. Likewise, Heckford and Beringer found that fifty percent of families were not offered a choice regarding the place of death [27]. Some of the parents recalled asking the primary care team if going home was an option, whereas others remembered being presented options by the palliative care team [35]. Parents' decisions on the place of death occasionally changed, however this was reported in these included studies as the exception [27, 29]. In these uncommon situations, decisions were predominantly influenced by unsatisfactory symptom management and the need for additional support services, despite their initial preference to remain at home.

Theme 4: family and sibling wellbeing

Family impact was important when deciding where end-of-life care would take place, as was how accessible the place was, so that all family members could be present together at the end of the child's life. The right decision for the whole family was considered important. The theme of 'family and sibling well-being' in respect of decision-making for place of end-of-life care was identified in seven studies [12, 28–31, 35, 36]. Some parents made the decision to stay in hospital for end-of-life care to safeguard siblings [12, 31]. Bingöl et al. described how one mother made the decision to stay in the hospital [31]. The mother thought that her other child, at home, would be adversely affected by seeing their sibling with cancer, so the mother preferred to stay at the hospital for end-of-life care. Hospital care was also chosen by parents who perceived good parenting as 'sibling(s) protector' from exposure to dying and death [12]. Whereas home care was chosen by parents whose good-parent beliefs involved being a 'facilitator of sibling sharing' in a dignified death for the child [12]. When deciding about the place of death, parents reported that they considered maintaining family life [28, 30]. Bingöl et al. suggested that parents wanted to be together as a family [31].

Parents described comfort and support as outcomes of being at home. Comfort was mentioned not only for the child but also for the parents, siblings, and family [35]. For the parents of newborns, being home created a sense of normalcy [35]. Parents were able to hold their newborns without lines, tubes, and wires. Parents appreciated the chance to use things that were waiting at home for the newborn [35]. The ability to have extended family members present unhindered by time or travel was an important support for families. Eskola et al. suggested that opting for a child's end-of-life care at home was based on a deep conviction that it was the right thing for the child and the whole family [30].

Discussion

This integrative review systematically identified and synthesised the available evidence on factors influencing decision-making regarding place of end-of-life care for children (≤ 18 years) with life-limiting and life-threatening conditions. This review provides nuanced insights into multiple complex factors that influence decision-making on choosing place of end-of-life for a child.

Previous research indicated that home is the preferred place for end-of-life care for both children and parents [9, 34]. Our review findings suggest that the child's condition, including symptom severity, time to death, and risk of deterioration, is an influential factor considered by parents and HSCPs when choosing home as the place for the child's end-of-life care. Previous literature has

revealed that parents desire the child's pain and symptoms to be controlled, but parents may lack the confidence to manage this themselves at home [38–40]. The data in our review indicated that the child's preference was to be at home [12, 29, 35]. This created a complex balance for parents to strike between honouring the child's wishes whilst also considering the practicalities of pain and symptom control.

Our review also revealed that where there were limited home or community care services for end-of-life care, parental capacity and skill set to care for their child impacted whether the child could go, or remain at, home for end-of-life care. Previous research shows that limited access to services in some geographical areas is a significant issue that impacts on decision-making for place of end-of-life care [41]. This is further supported by an overview of palliative care in Europe which highlights inequality between countries and regions regarding policy and service provision [42]. This variation suggests varying opportunities for families to make meaningful decisions concerning place of palliative care for their child and place for a peaceful death. Our review highlights the need for system-wide improvements and policy strategies that empower parents to choose the most suitable end-of-life care setting for their child and family regardless of parental skill set.

Our review revealed situations where parents were given no choice about place of end-of-life care for their child or where a lack of information provided made parents feel as if there was no choice. In such situations, parents' control was obliterated, and their capacity was significantly diminished. Previous research has indicated that information provision to parents has clear value in helping them make informed decisions [43–47].

The wellbeing of siblings was considered alongside the wellbeing of the child receiving end-of-life care when choices were being made about place for end-of-life care. Key findings in this review were safeguarding siblings, facilitating sibling connectedness, maintaining family life, and familiarity and comfort of home. Previous research found that parents of children with life-limiting conditions often felt they prioritised their unwell child's needs, resulting in siblings sometimes feeling deprioritised [48]. Other research however has shown that siblings of unwell children receiving palliative care when directly spoken to consider themselves part of a special and happy family [49].

The findings of our review highlight a lack of research studies specifically investigating the impact of choice of place of end-of-life care on the wellbeing of siblings of children receiving palliative and end-of-life care. Furthermore, our review highlighted that there can be contrasting attitudes from parents in how to best meet the needs

of siblings, and that this is an influential factor in parent's decision-making. For instance, some parents desire to protect their children from death, or possibly from the suffering that their dying child is going through [12, 29]. Notwithstanding this, siblings often demonstrate an awareness that death is coming, and desire to be involved [49–51], illustrating that sibling inclusion in decision-making about place of end-of-life care requires further investigation. Future research to understand sibling perspectives to inform the development of bespoke family-focused interventions to support advanced care planning for place of end-of-life care for children with life-limiting and life-threatening conditions is required.

Our review highlighted that there are limited studies examining the child's experience of, and involvement in, deciding place of their end-of-life care. One existing research article largely focused on understanding children with cancer's decision-making about their care and treatment while undergoing palliative care [52], and one other article included a discussion to inform policy for prospective decision-making [53]. Strategies for communication with children about cancer diagnosis and treatment have for instance been highlighted in the literature, but these strategies are poorly implemented [54, 55]. This lack of children's voices regardless of diagnosis in deciding their place of end-of-life care supports previous research which has highlighted a gap in hearing children's voices in relation to healthcare provision, including end-of-life care [56]. It has been documented that including children's voices may present challenges given the nature of some conditions (e.g., curative possibility of cancer) [54], the sensitivity of discussing end-of-life care and parental desire to protect children from the possibility of death. Notwithstanding this future research might be of benefit to understand how to meaningfully and ethically involve children who are receiving end-of-life care in palliative care research.

Our review also highlighted the lack of evidence of HSCP experiences of decision-making about place of end-of-life care for children. Shared decision-making is recommended in international guidance documents written for HSCPs [44, 57]. HSCPs bring to shared decision-making an in-depth understanding of family values, and this helps them provide end-of-life care aligned to family need [57]. Positive relationships between HSCPs and parents have been shown to support parents making end-of-life decisions, both in our review and elsewhere [58]. Thus, HSCPs developing positive relationships with parents/families, would assist families in making decisions about the place of end-of-life care for their child. Further to this, what is unknown from the current synthesis is an understanding of HSCPs decision-making process when

considering where end-of-life care should take place. Ultimately there is the need for more empirical research studies to further investigate and understand the perspectives of children, parents, and HSCPs when deciding upon the place of end-of-life care for the child [59].

Strengths and limitations

There were limitations to this review. First, while a search strategy was systematically applied across multiple databases, the possibility that relevant studies were missed cannot be excluded. Second, searching for English language publications only may have resulted in publication bias. Third, included studies varied in the amount of contextual data presented, such as child demographic characteristics (e.g., specific life-limiting life-threatening diagnosis), place of care (e.g., hospice, hospital, home), and geographical data (e.g., rural, or suburban localities) which could determine available services. Hence, it was not possible to report on and synthesise contextual data for all included studies. There were also differences in end-of-life services, systems, and views on life and death across different countries and regions. This may limit transferability of findings. Also, five of the 11 studies included only cancer patients, and a further four included cancer patients, this limits the review recommendations for a broader range of life-limiting life-threatening conditions. Fourth, most evidence reported in this review represents parent perspectives. We did incorporate data about children (by proxy) and HSCPs where available in included studies. Ultimately, further research is needed with all stakeholders involved to build a comprehensive understanding of shared decision-making when choosing place of end-of-life care for children with life-limiting and life-threatening conditions and their families.

Conclusions

This review found that there are a complex range of factors to be considered in practice, largely by parents, when deciding on place of end-of-life care for children with life-limiting and life-threatening conditions. The evidence from this review demonstrates the need for guidance and policies to enable system-wide improvements and to empower parents to choose to be actively involved in deciding what place of end-of-life care is best for their child and family. This review found that some parents are not afforded a choice when it comes to decision-making about place of end-of-life care. It is important for parents to be involved in decisions about place of end-of-life care for their child and for parents to be provided with information to help them in the decision-making process. When this is not the case, families may feel unsupported, and the care provided may not reflect their preferences.

There are clear benefits to advance care planning, as sensitive, timely, and honest discussions can help facilitate the wishes of families and ensure better support during this challenging time. It is evident from this review that parents consider the impact on the whole family, including siblings, when making decisions. Thus, HSCPs should be mindful of the child's family when influencing decisions about place of end-of-life care. Finally, future research needs to evaluate HSCP experience of decision-making about place of end-of-life care, but also, crucially, consider how to meaningfully involve the child themselves.

Abbreviations

HSCPs	Health and social care professionals
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analysis
MMAT	Mixed Methods Appraisal Tool
DARE	Database of Abstracts and Review Effects
TFSL	Together for Short Lives
AIHPHC	All-Ireland Institute of Hospice and Palliative Care

Supplementary Information

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Additional file 1.

Additional file 2.

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Authors' contributions

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Not applicable.

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Competing interests

The authors declare no competing interests.

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