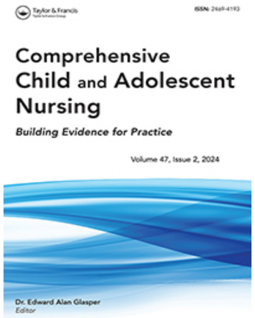

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Places of Farewell: A Scoping Review Exploring Factors Influencing the Choice of Place of Death for Children when Death is Expected

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ABSTRACT
Progression of ill health and death trajectories is different for children with a non-oncology diagnosis. As previous research has focused primarily on children with cancer diagnoses, this scoping review explored what factors influence the parent and/or child's choice of place of death for a child with a non-oncological complex care condition, when death is expected. Eighteen papers were identified considering the preferred place of death. The findings were themed into 1. Diagnostic Factors; 2. Home Factors; 3. Socio-economic Factors; 4. Parent Factors. In conclusion, informed discussions with families that recognize the reason for, and the impact of their choices, are necessary not only for the preferred place of death but also end of life care.

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KEYWORDS
Place of death; expected death; child; complex care; non-oncology

Introduction

Good death

Place of death is considered a key indicator in evaluating the quality of end of life (EoL) care (Håkanson et al., 2017; Renton et al., 2018). For health care professionals (HCPs) working in palliative care, the importance of enabling the dying person to be in their preferred place of death is understood as a fundamental factor in the experience of a good death, a view which appears to have global acceptance (for example, De Roo et al., 2014, Hakanson et al., 2017; Malcolm et al., 2020; TomooIkari et al., 2022). Whilst there appears to be little agreement about what defines a good death (Meier et al., 2016), core elements include being free from pain, in control of symptoms and in an environment that is in accordance with the wishes of the dying person and their family (Gustafson, 2007; Krikorian et al., 2020). It is also generally accepted that the concept of a good death refers to a series of events rather than a single occurrence (Cottrell & Duggleby, 2016; McNamara et al., 1994). These factors strongly influence the choice of the preferred place of death, and whilst the physical place of death is a fundamental factor, its importance is variable depending upon the level of symptom control (Seal et al., 2015; Waghorn

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et al., 2011). Kellehear's (1990) exploration of good death is understood to include the time prior to death, rather than just the actual death, and begins with "their dawning awareness that they are dying" (Kellehear, 1990, p. 73). Kellehear's (1990) considered adults who were dying of cancer and were aware that they had less than 12 months to live and highlighted five features that constitute a good death: 1. Awareness of dying; 2. Private life (social adjustments and personal preparations); 3. Public preparation; 4. Work life; 5. Farewells. This "social role" is the responsibility of the dying person (Kellehear, 1990, p. 73, 2007). For the child, the fourth factor of "work life" could be replaced with "school life." When considering this 4th stage, Kellehear found that, for many people, a form of their work life continues throughout the dying process, but that to enable the specific needs of the dying individual to be accommodated, it is not unusual for their work pattern to be altered. For the child and young person in full time education, the same accommodation is also made to enable them to continue to access the normality of their education and peer group for as long as they are able (Lister & Alley, 2015).

While there is an established international body of evidence in the literature about the preferred place of death of a child or young person, where death is expected, studies predominantly focus on the child with cancer and very few studies consider the child with a non-oncology diagnosis (Bluebond-Langner et al., 2013; Duc et al., 2017; Johnston et al., 2020). This sparsity of studies considering place of death for children with a non-oncology diagnosis is important, as the progression of ill health and death trajectories are different, with periods of acute illness and plateaus of stable health occurring over longer periods of time, often years (Dunbar et al., 2019; Johnston et al., 2020). For children and young people death is expected because of a life limiting or life-threatening condition (LLC and LTC, respectively). LLCs and LTCs refer to the curative options and life expectancy of the person. LLCs have no curative treatments and the child is unlikely to reach adult life (for example, child onset batten disease; severe cerebral palsy; some chromosomal disorders, e.g., trisomy 13 and trisomy 18), whereas LTCs have possible curative treatments and whilst the child may live into adulthood, premature death remains a probability (e.g., organ failure such as heart, liver, kidney) (Duc et al., 2017; T. Mitchell et al., 2016).

This paper presents a scoping review, which aimed to explore what factors influence the parent and/or child's choice of place of death for a child with a non-oncological complex care condition, when death is expected. The two main objectives were to consider the extent of the evidence and identify key factors in relation to the choice of place of expected death.

Acronyms used in this paper and in the papers reviewed

HCP	Health Care Professional
LLC	Life Limiting Condition
LTC	Life Threatening Condition
LTCCC	Life Threatening Complex Chronic Condition
EoL	End of Life
PICU	Paediatric Intensive Care Unit
NICU	Neonatal Intensive Care Unit
CDOP	Child Death Overview Panel

Method

A scoping literature review (Arksey & O'Malley, 2005; Levac et al., 2010) was carried out to establish what evidence was available about the factors affecting the choice of place of death for children with a non-oncological complex care condition. A scoping review is a "preliminary assessment of potential size and scope of available research literature" (Grant & Booth, 2009, pp. 95, 101). Conversely a scoping review can also be considered an independent project (Arksey & O'Malley, 2005) or as "reconnaissance" (Peters et al., 2015, p. 141). The purpose of this scoping review was "to identify key characteristics or factors related to a concept" (Munn et al., 2018, p. 4). Initial explorations indicated that a systematic review would identify a limited number of studies (as previously found by Duc et al., 2017). A scoping review method was chosen to allow for the relevant literature to be gathered from a broad base, include non-research articles.

This scoping review followed a five stage framework (Arksey & O'Malley, 2005), which encourages a broad search by not (initially) including limitations, enabling the potential to gather a wide range of evidence:

Stage 1: Identifying the research question;
Stage 2: Identifying the relevant studies;
Stage 3: Study Selection;
Stage 4: Charting the data;
Stage 5: Collating, summarizing, and reporting the results.

Identifying the research question

This review asked: "what factors influence the parent and/or child's choice of place of death for a child with a non-oncological complex care condition, when death is expected?"

Identifying the relevant studies

The literature search was carried out during August 2023. Using the search terms (Table 1), within CINAHL, MEDLINE, APA PsycINFO, APA PsycArticles, and Academic Search Complete databases produced 308 papers. Widening the database search to include Cochrane and SSOAR gave no additional results. A library search including all databases with full university library accesses produced 27 results; however, just two papers were relevant, and those had been found on previous searches (Coombs et al., 2022; Renton et al., 2018). No limits were added to the searches (e.g., date, gray literature, peer reviewed) and Boolean operators were applied (Table 1).

Nine papers were identified from other sources. Three papers (Bender et al., 2017; Håkanson et al., 2017; Wolff et al., 2022) came from a previous search (December 2022)

Table 1. Search terms 1.

	Children or adolescents or youth or child or teenager
AND	Expected death or palliative care or end of life
AND	Place or location
AND	Place or space
AND	Preference or choice

Table 2. Search terms 2.

	Child death
AND	Place
OR	Space

where the search terms used were kept simple (Table 2) and produced a result of 500 sources, most of which were not relevant. The remaining six articles came from different citation searches, including backward and forward citation checking (Bogetz et al., 2020; Chang et al., 2013; DeCourcey et al., 2018; Duc et al., 2017; Fraser et al., 2020; Johnston et al., 2020).

Study selection

Article duplicates were removed, after which the remaining papers were scanned by title and abstract. Inclusion criteria were applied (Table 3). This left 19 papers to be assessed. One paper was subsequently excluded due to content. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used to ensure quality reporting for the scoping review process (Peters et al., 2015) (Figure 1). JBI tools were used to assess the papers (Aromataris et al., 2015; Lockwood et al., 2015; McArthur et al., 2015; Moola et al., 2020; Munn et al., 2020) (Tables 4 and 5).

Charting the data

To appraise the appropriateness of the papers included, a data extraction process was utilized, referred to as "charting" (Peters et al., 2015, p. 144), where the data was charted in a descriptive-analytical format (Arksey & O'Malley, 2005). This involved mapping a logical summary in a table (Arksey & O'Malley, 2005; Peters et al., 2015). For ease of reading, primary data studies and secondary data studies have been charted separately (Tables 4 and 5).

Of the 18 papers considered eligible for inclusion, 12 were primary studies and consisted of eight quantitative studies and four qualitative studies (Table 4). These 12 studies acknowledge the global perspective, as just five studies were carried out in the UK. The remaining six papers were secondary studies of which one was a systematic review (Bluebond-Langner et al., 2013), one was a scoping review (Walker et al., 2023), one was

Table 3. Inclusion criteria.

Inclusion criteria
Expected death of person <18 years old
Place of death
Preferred place for the location of death
The actual place of death
Non-oncology diagnosis
Oncology diagnosis where other non-oncology diagnosis are also considered.
Experiences of family
All types of study (e.g. qualitative, quantitative, and mixed methods)
Non-research literature including grey literature and commentaries

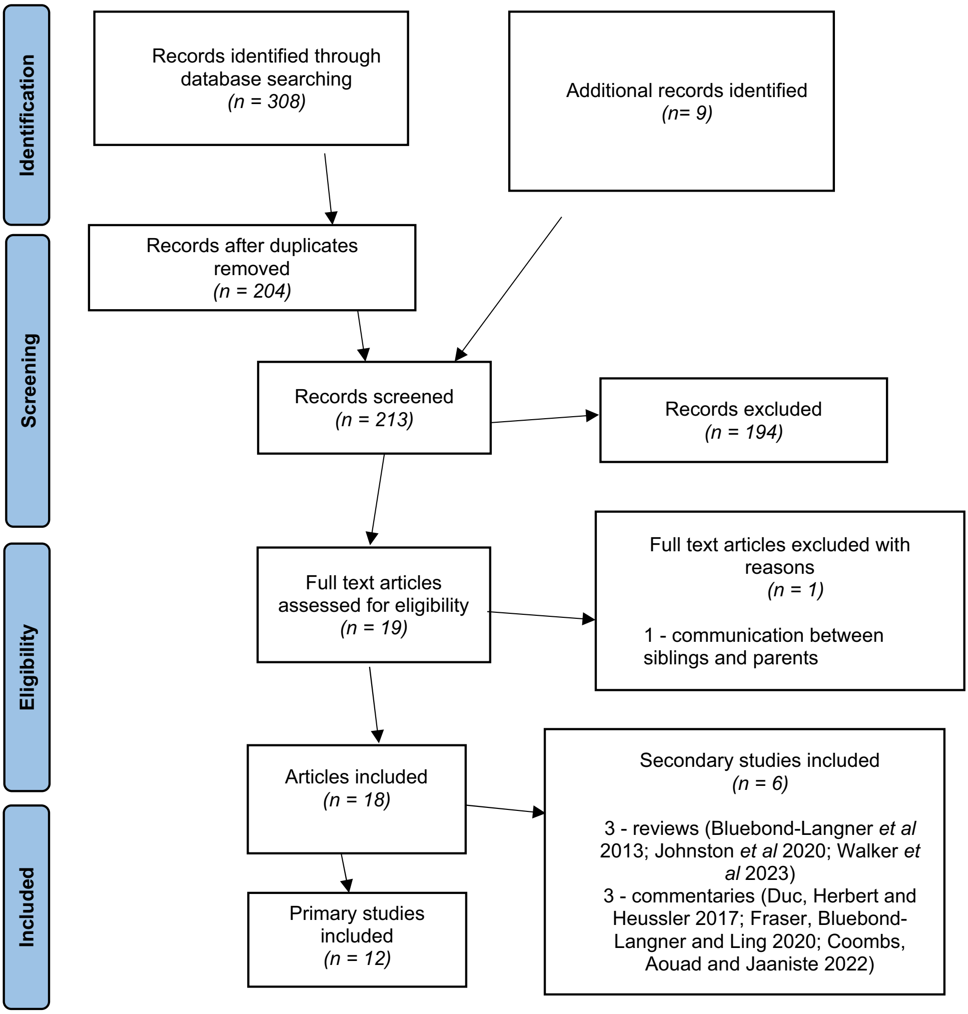

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for the scoping review process (Peters et al., 2015).

a narrative review (Johnston et al., 2020) and three were commentaries (Coombs et al., 2022; Duc et al., 2017; Fraser et al., 2020) (Table 5).

Bluebond-Langner et al's (2013) systematic review considered the preferred place of death for children with LLCs and LTCs, reviewing nine studies from six countries (UK, USA, Australia, Canada, France and Germany), of which six studies focused on cancer. Duc et al. (2017) found that when searching for palliative care of children with an intellectual disability to undertake a systematic review, too few studies could be identified. Johnston et al.'s (2020) review into the preferred location of a child's death identified 34 relevant studies. Whilst it is not specified how many of the studies reviewed focused either fully or partially on children with a cancer diagnosis, Johnston et al., 2020. state that most of the studies involved children with cancer. Walker et al. (2023) also reviewed location of death but considered the importance of place rather than preference. Twenty-two studies and three reviews were explored in their scoping review, and whilst Walker *et al.* did not

Table 4. Primary studies included in the scoping review.

	Author and year (date order)	Research question/aim of study	Participants	Method	Country	Key findings/results
1	Chang et al. (2013)	To determine whether demographic and diagnostic characteristics were associated with the place of death of children with LLCs.	The case notes of children with LLCs (*n* = 494), 28 days to 18 yrs old who died 2006–2009	Case note review 2006–2009.	New Zealand	(1) Children referred to the PPC more likely to die at home. (2) Asian and Pacific children are more likely to die in hospital than European children.
2	Håkanson et al. (2017)	To examine where children with chronic complex conditions die and associations with country, cause of death and gender.	Death certificate data of children 1–17 yrs (*n* = 40,624) who died in 2008	Population based study over 11 countries	Belgium Canada Czech Republic France Italy Korea Mexico New Zealand Spain Sweden USA	(1) Large cross-national variations in place of death (2) Variations related to health systems and cultural values related to place of death.
3	Bender et al. (2017)	To explore whether the population of service users accessing a specialised paediatric palliative home care team at a specific centre, representative of the national mortality statistics, the TfSL categories and care, diagnosis and place of death.	Case notes of children accessing the centre (*n*= 212)	Case note review.	Germany	(1) Significant differences with TfSL categories in relation to care needs and survival. (2) High prevalence in children with neurological problems (3) Large majority of children dying at home.
4	DeCourcey et al. (2018)	To characterise patterns of care at EoL of children LTCCC (non-oncology and non-cardiac)	Bereaved parents (*n* = 114)	Cross sectional survey.	USA	Significant differences in EoL support depending on LTCCC type.
5	Fraser et al. (2018)	To assess trends in place of death and identify characteristics of children who die in the community after discharge from PICU	All children resident in England and Wales admitted to PICU January 1, 2004– December 31, 2014 (*n* = 110,328)	National data study over 11 years.	England and Wales	(1) Proportion of children dying in the community after discharged from PICU has increased, most children continue to die in hospital. (2) Children who die after the involvement of a palliative care team are 8 times more likely to die in the community than children who were discharged from PICU but not palliative care team.

(*Continued*)

Table 4. (Continued).

	Author and year (date order)	Research question/aim of study	Participants	Method	Country	Key findings/results
6	Renton et al. (2018)	To identify and describe trends in place of death for children in South Yorkshire.	Data from 5 CDOP databases of child deaths between 2008–2015 (*n* = 748)	Retrospec-tive cohort study over 7 years.	England	(1) Hospital is the most common place for expected and unexpected child death. (2) Pediatric palliative medicine should be expanded into hospital settings
7	S. Mitchell et al. (2019)	To gain an insight into the experiences and perceptions of bereaved parents about end of life care decision making for with LLC or LTC in PICU	17 parents of 11 children who had died in PICU in a tertiary children's hospital.	Semi-structured interviews. Parents bereaved within 12 months prior to the start of the study.	England	5 inter-related themes: (1) Parents have significant knowledge and experiences that influence the decision-making process (2) Trusted relationships with HCPs are key to supporting parents making end of life decisions (3) Verbal and non-verbal communication with HCPs impacts upon the family experience (4) Engaging with end of life care decision making can be emotionally overwhelming, but becomes possible if parents reach a "place of acceptance" (5) Families perceive benefits to receiving end of life care for their child in PICU
8	Bogetz et al. (2020)	To explore aspects important to parent preparedness for EoL care of their child	Bereaved parents (*n* = 110) from a single children's hospital. The children (1 month – 35 years) had complex chronic conditions and had died between 2006–2015	Qualitative element of a larger survey.	USA	Most parents felt unprepared for their child's EoL care and death, despite palliative planning and advance care planning.
9	Gibson-Smith et al. (2020)	To assess trends in place of death for children and the factors associated with the choice	Data from children aged 0–25yrs who died between 2003–2017 (*n* = 39,349)	Observati-onal cohort study over 14 years.	England	(1) Most children with LLC continue to die in hospital. (2) Further study needed on preferences for place of death especially in children with a non-oncology diagnosis
10	Malcolm and	To explore the perception of bereaved parents about the values and	13 bereaved parents of 10 children	Descriptive study using semi-	Scotland	Home EoL care enabled:

(*Continued*)

Table 4. (Continued).

	Author and year (date order)	Research question/aim of study	Participants	Method	Country	Key findings/results
	Knighting (2021)	effectiveness of home-based end of life care		structured interviews.		(1) Ability to facilitate changes in preferred place of death (2) Trusted relationships with care providers (3) Provision of family centered care (4) Specialist care support (from service) when needed
11	Papadatou et al. (2021)	To develop a model explaining how parents with LLC decide about place of EoL and death, and to identify factors affecting decision-making.	36 bereaved parents of 22 children	Grounded theory. Semi-structured interviews.	Greece	(1) 6 factors affecting decision-making about place: (a) Awareness of dying (b) Perceived professional competence (c) Parents' perceived competence to deliver care at home (d) Parents' view of symptom management (e) Timing of decision making (f) Being a "good parent" (2) 4 distinct processes through which decisions are made: (a) Mutual consensus (b) Accommodation (c) Acceding to professional decisions (d) Imposing decisions by excluding professionals (3) Explanatory model articulated.
12	Wolff et al. (2022)	To identify predictors of home death for dying children in Denmark, considering socio-demographic factors	Children aged 1–17yrs who died between January 1, 2006–December 31, 2016 (n = 938)	National registry in a cohort of deceased children.	Denmark	(1) Household income is not a factor – this could be specific to the healthcare system in Denmark. (2) Non-cancer diagnosis, immigrant families and living in a rural area are associated with less potential of dying at home.

Table 5. Secondary studies included in scoping review.

	Author and year (date order)	Country	Aim of paper	Method	Results	Key findings
1	Bluebond-Langner et al. (2013)	UK	To review the literature on preference for place of death for children and young people with LLCs or LTCs	Systematic review	Nine studies from six countries: USA UK Australia Germany France Canada	The evidence supporting the preference for home death is inadequate and further research is needed.
2	Duc et al. (2017)	Australia	To describe the care of children with LLCs and intellectual disabilities.	Literature synthesis and commentary	Evidence drawn from studies in adult palliative care and children with cancer	Absence of literature considering children with a non-oncology diagnosis, and particularly children with an intellectual disability LLC.
3	Johnston et al. (2020)	USA	A review of literature exploring the arguments supporting and against home deaths of children ≤18 years old in North America	Literature review	34 studies from two countries: USA Canada	Resources to support the choice made by children and their families needed. Further research to understand death location preference needed.
4	Fraser et al. (2020)	UK and Belgium	To discuss challenges and advances in children's palliative care in Europe	Commentary		● Inequity in service provision. ● The routine collection of high quality standardized data is needed. ● Further research around decision making, communication, pain and symptom management are needed.
5	Coombs et al. (2022)	Australia	To review the factors associated with the place of death of children with LLCs	Commentary		● Inequity in service provision ● The opportunity to be involved in the planning of EoL care may be a more important indicator of good care than the choice of a particular place.
6	Walker et al. (2023)	Canada	To understand the importance and meaning of place in children's palliative care	Scoping review	25 studies from five countries: Germany USA Sweden UK Taiwan	Factors affecting choice: ● impact on family ● symptom management ● socioeconomic status ● cultural and spiritual practices

distinguish which studies being reviewed focus on children with a cancer diagnosis, a reexamination of the papers (for this review) showed that 14 of the 25 papers concentrated on children with cancer diagnoses. Not making this distinction is important, as Walker *et al.* conclude that although there are factors that influence the decision on place (including access to resources, family dynamics, cultural concerns and socio-economic concerns), home is the choice for death (Walker et al., 2023). Johnston et al. (2020), however, found that diagnosis is an important factor, influencing the choice of place, and that a preference to die at home was chosen particularly by children with cancer. Three of the secondary studies comment on the lack of qualitative knowledge on the preferred place of death for children with a non-oncology diagnosis (Bluebond-Langner et al., 2013; Duc et al., 2017; Johnston et al., 2020).

Of the remaining 12 primary studies, there is general agreement that, whilst there has been a decrease in the number of children dying in hospital, most deaths still occur in an acute hospital area (these units include pediatric intensive care unit [PICU], neonatal intensive care unit [NICU], and high and low dependency wards). Potential reasons for this include child, parent, or wider family choice; the child is considered too unstable to transfer home or to the hospice; there are no community services available, or, where they are available, they cannot be set up in time to facilitate care in the home. Other reasons for most child deaths occurring in hospitals include the impact of the sociodemographic characteristics of the child and family (Chang et al., 2013; Renton et al., 2018; Wolff et al., 2022) and the cultural value attached to the place of death (Håkanson et al., 2017).

Collating, summarizing and reporting the results

Four key themes emerged from the review of the literature considering the factors influencing the parent and/or the child's choice of place of death for a child with a non-oncological complex care condition, when death is expected: Diagnostic factors; Home factors; Socio-economic factors; Parent factors (Table 6). Each of these will be explored in turn. To provide a greater clarity and context, a short, general discussion has also been included within each theme.

Diagnostic factors

One characteristic that appears to impact upon place of death is that of the diagnosis (DeCourcey et al., 2018) and, more specifically, if that diagnosis is oncology related (Chang et al., 2013; Gibson-Smith et al., 2020; Renton et al., 2018; Wolff et al., 2022). The point

Table 6. Thematic summary of papers.

Theme	Study
Diagnostic factors	Bluebond-Langner et al. (2013); Chang et al. (2013); DeCourcey et al. (2018); Fraser et al. (2018); Renton et al. (2018); Gibson-Smith et al. (2020); Johnston et al. (2020); Malcolm and Knighting (2021); Papadatou et al. (2021); Coombs et al. (2022); Wolff et al. (2022).
Home factors	Bluebond-Langner et al. (2013); Bender et al. (2017); Håkanson et al. (2017); Fraser et al. (2018); Renton et al. (2018); S. Mitchell et al. (2019); Malcolm and Knighting (2021).
Socio-economic factors	Chang et al. (2013); Fraser et al. (2018); Wolff et al. (2022); Walker et al. (2023).
Parent factors	S. Mitchell et al. (2019); Bogetz et al. (2020); Fraser et al. (2020); Johnston et al. (2020); Malcolm and Knighting (2021); Papadatou et al. (2021).

raised by Wolff et al. (2022), that children with a cancer diagnosis are more likely to die at home has been previously evidenced (Bluebond-Langner et al., 2013; Coombs et al., 2022; Dussel et al., 2009; Hannan & Gibson, 2005; Johnston et al., 2020; Wolff et al., 2020) and is supported by Chang et al. (2013), Renton et al. (2018), Fraser et al. (2018), Gibson-Smith et al. (2020), Malcolm and Knighting (2021). Diagnostic factors does not appear to be limited to the UK; Wolff et al.'s (2022) study was undertaken in Denmark, and Chang et al. (2013) in New Zealand, with similar findings, and is supported by Coombs et al. (2022). Noyes et al. (2022) systematic review of parental experiences of children with cancer, found that parents who chose home as their preferred place of death, did so because their children were able to communicate a choice and the choice was home. It is worth considering how this relates to Papadatou et al.'s (2021) Greek study, where they found that all the verbally competent children (*n* = 16) interviewed (except one) chose home as their preferred place to die. The study does not explicitly state the diagnosis of this group of children, but out of the 22 families who participated, 16 children had a cancer diagnosis and 16 of children were verbally competent. Bluebond-Langner et al.'s (2013) systematic review explored whether caring for a child with cancer is more compatible to the home environment, pointing out that, for oncology, "home outreach is extensively developed" (p. 710).

Further research is needed to ascertain whether the choice of home death based on diagnosis is related, for example, predominantly to the ability of the child to communicate effectively; on how well the home death service is developed within the specialty (e.g., cancer, cardiac, neurodisability); or the geographical location. Research is also needed to specifically consider the choice of preferred place of death for children with a non-oncological LLC.

Home factors

The effect of "home," the significance of familiarity, the recognition of a place as safe and the acknowledgment of the impact of "home" was initially explored in the 1970s and is closely tied with the concept of ontological security (Dunbar et al., 2019; Giddens, 1984). Ontological security refers to the routine of personal and daily life, the order and continuity that alleviate anxiety and create an individual's sense of identity and routine (Atkinson, 2007; Giddens, 1984; Possamai-Inesedy, 2002). Changes to this, such as a palliative care diagnosis, can disrupt individual "selfhood" (Possamai-Inesedy, 2002, p. 27), leading to ontological insecurity (Ellingsen et al., 2014; Giddens, 1984; Possamai-Inesedy, 2002). Home can be both a physical place and somewhere that is based on the "particular, familiar, meaningful" and is "the essence of place" (Relph, 1976, p. iv). It is the familiarity, the ontological security of home, that makes it the assumed preferred place of death for adults and children (Hannan & Gibson, 2005; Pollock, 2015), a belief that appears to be held internationally (for example, Ellingsen et al., 2014; Rainsford et al., 2018). This observation, however, is based on adult studies (Bluebond-Langner et al., 2013, 2015), and both Pollock (2015) and Rainsford et al. (2018) argue that the assertion that home is the preferred place of death for adults and children is not supported by current evidence. In exploring the importance of home in end of life care, Rainsford et al. (2018) found that the preferred place of death was a "safe" place which may or may not be home (Dunbar et al., 2019; Rainsford et al., 2018). Where home is not felt to be a safe place, a hospice can be considered as such (Price et al., 2017; Rainsford et al., 2018; Simpson & Penrose, 2011). In the UK, children's hospices actively encourage a home-like environment through the use of furnishings and the use of rooms as shared living spaces, to try to create a positive welcoming environment to where families can feel they belong (Dunbar et al., 2019; Holdsworth, 2015; T. Mitchell et al., 2016). Dunbar et al. (2019) refer to this as place bonding; where a place (children's hospice in this study) can be perceived as somewhere the child and family can feel safe and to where they can "come home" (p. 101); a place which can offer ontological security by enabling the family to maintain their usual daily routines, whilst providing a feeling of safety with the presence of health care professionals (Dunbar et al., 2019; Ellingsen et al., 2014).

To enable a child to die safely at home, the availability of appropriate community services is necessary, however the differences in the pediatric palliative care services varies considerably between regions and countries (Håkanson et al., 2017; S. Mitchell et al., 2019; Renton et al., 2018) and where these services are available the provision is not consistent (Fraser et al., 2018; Malcolm & Knighting, 2021; S. Mitchell et al., 2019). In contrast to the UK, Bender et al. (2017) found that, due to the routine use of a specialized pediatric palliative home care team in Germany, most parents (84% of parents of children with LLC) choose home as the place of death. This included a high proportion of children with complex neurological disorders.

Further research is needed in the UK to ascertain the extent of variability of community pediatric palliative care services and to identify strategies to improve consistency and reduce health inequalities in the choice of place of death. For example, exploring how this choice has been decided and whether this choice can be accommodated when the child requires end of life care.

Socio-economic factors

As discussed above, the geographical location of the family and whether the family home is in a rural area or has a proximity to the support services needed can impact upon the choices parents make about their preferred choice of place of death (Rainsford et al., 2018; Walker et al., 2023; Wolff et al., 2020, 2022). Wolff et al. (2022) found that household income was not a factor (due, they suggest, to the Danish health care system) and that there was little difference between low and high income families about whether their children died at home or in hospital. This finding is contrary to previous studies (Cf. Fraser et al., 2018). However, Wolff et al. (2022) did find that children of immigrant families are more likely to die in hospital and suggest that one of the contributory factors for this may include housing, but this is not explored in their study. Chang et al. (2013) also found ethnic differences in location of death, suggesting that this is due to societal norms and cultural attitudes to healthcare. Whilst the studies considered in Wolff et al.'s (2020) systematic review and meta-analysis focus primarily on the location of death of children with an oncology diagnosis (only five out of the 14 studies reviewed included non-oncology child deaths), socio-economic factors were found to be relevant in the location of death, with children considered to be economically deprived and from low income families being more likely to die in hospital (Wolff et al., 2020).

Further research is needed to explore who chooses the place of death and how socio-economic factors are considered within this choice. Although the UK has guidance that considers the preferred place of death and end of life care of children with LLCs, the guidance is general, and does not consider socio-economic factors. Whilst the guidance is aimed at the management of end-of-life care of children with LLCs, its evidence is taken primarily from studies that have focused on children with an oncology diagnosis (NICE, 2017, 2019). The findings and recommendations from this scoping review can be used to inform future updates and policies.

Parent factors

Other factors affecting the preferred place of death are identified by the four qualitative studies from the literature search (Bogetz et al., 2020; Malcolm & Knighting, 2021; S. Mitchell et al., 2019; Papadatou et al., 2021). These studies focused on parents and primary care givers, including the relationship with, trust of, and perceived competence of health care professionals both in the community and hospital settings; the availability of and ease of access to symptom management support when needed; the acknowledgment of health care professionals of the experience of the parent about their child; and parents' perception of their own competence to deliver care.

The confidence of a parent in caring for their dying child is highlighted by S. Mitchell et al. (2019) and Bogetz et al. (2020), where parents of children with complex chronic conditions, felt themselves "unprepared" (Bogetz et al., 2020, p. 1160) and "vulnerable" (Mitchell et al., 2019, p. 6) for their child's EoL care and death, despite having planned for their child's palliative care and have been involved in the delivery of such care. This involvement, in theory, covers four of the five features of a good death: 1. Awareness of dying; 2. Private life; 3. Public preparation; 4. School life (adapted from Kellehear, 1990). However, Bogetz et al. (2020) found that despite the child's chronic condition, the child was viewed by the parents as "healthy" (p. 1156), as this level of health is the child's normality; and that having recovered from previous events where death was expected, the actual death, when it occurs, is unexpected and shocking. Bogetz et al. (2020) also report parents feeling that "the notion of preparedness was really a pretence or illusion" (p. 1157). This can lead practitioners to question whether having these difficult conversations with parents detracts them from time with their child. However, whilst parents engage with these conversations, they do not distract the parent from the hopes and beliefs in their child's survival. Thus, creating a duality of preparing for a good death, in the knowledge that the parents and family may well also feel unprepared when death occurs (Bogetz et al., 2020; Johnston et al., 2020; Papadatou et al., 2021). This duality can also impact upon the location of death, even where conversations about it have taken place, as recovery (though improbable) is still expected by the parents (Bogetz et al., 2020).

Being a "good parent," is raised by Papadatou (2021, p. 225), and Fraser et al. (2020). Papadatou et al. (2021) refers to the role as the sometimes conflicting influences of parental "values, priorities and sense of duty to act on behalf of their dying child" (p. 225). These influences are portrayed in the roles of "saviour," "guardian," "advocate," "sibling protector" and "facilitator of sibling sharing." Parents who perceived their role as "sibling protector," shielded their other children by choosing death in hospital; whereas, parents who viewed their role as "facilitator of sibling sharing" chose home (in Papadatou *et al.*'s study the choice was hospital or home, as a hospice service was not available). This concept of the good parent is seen also in S. Mitchell et al. (2019) and Bogetz et al. (2020), with parents trying to make the best and the right decisions for their dying child, other children in the family and, lastly, themselves.

Further research could incorporate an exploration of the effect on the family and people emotionally close to dying children, if the choice of place of death is not achieved. The findings from this scoping review emphasize the importance of conversations HCPs have with children, parents and families, when discussing not only the preferred place of death but also end of life care. The HCP needs to consider the wants, needs and concerns of the families, whilst managing their expectations. Tools such as Advance Care Plans can be used to support this. Whilst the use of Advance Care Plans is familiar to practitioners in the UK, there is growing evidence to suggest their use internationally, however research into this is in its infancy (Fraser et al., 2010; Khalid et al., 2021; Liberman et al., 2016; Namisango et al., 2019; Paediatric Palliative Care, 2024; Rapoport, 2024), and further research is needed into this as these findings cannot be generalized to cultures beyond Westernized health care systems.

Conclusion

It is evident that, despite positive progress in supporting the dying child and their family to choose a place of death that enables the child to have a good death, other factors complicate this process. These factors include feeling safe and supported; parents needing to protect themselves, and their children (the dying child and siblings); and the level and quality of provision of services. These can be considered within four broad areas of: Diagnostic factors; Home factors; Socio-economic factors; Parent factors. There is a deficit of information about how parents of children with non-oncological complex care needs make these choices and it is clear from the evidence that these deaths continue to primarily occur in hospitals. Whilst this maybe the choice of the parents, it cannot be assumed that this is so, any more than it can be assumed that the choice is home or hospice.

Limitations of the review

Whilst the body of evidence about the choice of place of death is limited regarding children with a non-oncology diagnosis, it can be seen from the literature search that this is beginning to change. The use of a scoping review was appropriate for this study and has highlighted four areas of influencing factors. However, it did not allow for an in-depth exploration of these influencing factors. This is considered further in Recommendations.

Recommendations

This scoping review has highlighted areas for further research, including who chooses the place of death for children with a non-oncological LLC, and how the child who can communicate verbally impacts on this choice; whether this choice can be accommodated at end of life and when the child dies, and the effect on the family if that choice is not achieved.

Implications for practice

This scoping review impacts upon the conversations HCPs have with children, parents and families, when discussing not only the preferred place of death but also end of life care. The HCP needs to consider the wants, needs and concerns of the families, whilst managing their expectations. Tools such as Advance Care Plans, for example, from the UK and Australia (Child and Young Person's Advance Care Plan Collaborative, 2023; Paediatric Palliative Care, 2024), and guidance from groups such as Together for Short Lives, and the Canadian Paediatric Society (Rapoport, 2024) can be used to support this, enabling the choices to be informed, and encouraging meaningful discussions both with professionals and within the family unit. Within the UK, NICE developed guidance to support the preferred place of death end of life care of children with LLCs, however the guidance is general (NICE, 2017, 2019). The findings and recommendations from this scoping review can be used to inform future updates and policies.

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