

Review Article

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Hospital, hospice, or home: A scoping review of the importance of place in pediatric palliative care

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Abstract

Background. Palliative care necessitates questions about the preferred place for delivering care and location of death. Place is integral to palliative care, as it can impact proximity to family, available resources/support, and patient comfort. Despite the importance of place, there is remarkably little literature exploring its role in pediatric palliative care (PPC).

Objectives. To understand the importance and meaning of place in PPC.

Methods. We conducted a scoping review to understand the importance of place in PPC. Five databases were searched using keywords related to “pediatric,” “palliative,” and “place.” Two reviewers screened results, extracted data, and analyzed emergent themes pertaining to place.

Results. From 3076 search results, we identified and reviewed 25 articles. The literature highlights hospital, home, and hospice as 3 distinct PPC places. Children and their families have place preferences for PPC and place of death, and a growing number prefer death to occur at home. Results also indicate numerous factors influence place preferences (e.g., comfort, grief, cultural/spiritual practices, and socioeconomic status).

Significance of results. Place influences families’ PPC decisions and experiences and thus warrants further study. Greater understanding of the importance and roles of place in PPC could enhance PPC policy and practice, as well as PPC environments.

Introduction

Medical advancements have significantly improved the length of life for children with serious and complex illnesses and, correspondingly, increased this group’s population size over recent decades (Cohen and Patel 2014). However, many childhood conditions are still life-threatening and significantly shorten the lives of some children (Cohen and Patel 2014; Rapoport and Liben 2015). Approximately one million children die from a life-limiting terminal illness each year (Boucher et al. 2014; Himmelstein et al. 2004). Pediatric palliative care (PPC) has emerged as an end-of-life care model that has advanced the care provided to children with life-limiting illnesses. PPC is specifically focused on improving quality of life (QoL) for these children and their families (Rapoport and Liben 2015).

PPC has evolved into an established field of medical expertise and practice (Feudtner et al. 2003; Widger et al. 2007, 2016). PPC clinicians aim to offer care that is collaboratively centered around the unique and evolving needs of infants, children, and young adults (Feudtner et al. 2003). Further, their provision of PPC is intended to align with the wishes of the child and their family (Muskat et al. 2020; Rapoport and Liben 2015; Widger et al. 2016). To carry out their work, PPC practitioners require specific knowledge and expertise pertaining to childhood and developmental stages (Himmelstein et al. 2004; Jennings 2005; Schmidt 2003). In turn, they are trained to consider a child’s physical, psychological, social, emotional, practical, and existential needs (Feudtner et al. 2003; Himmelstein et al. 2004). PPC typically begins as early as a child’s diagnosis and then continues and evolves throughout a disease’s trajectory until the end of life (Delgado-Corcoran et al. 2020).

Providing care in a patient’s physical place of choice can contribute to the quality of care they experience (Higginson and Thompson 2003). The location of PPC plays a critical role in how a PPC team delivers care, as well as how a child and their family experience it. The 3 locations where PPC is most often delivered are the hospital, hospice, and home (Bender et al. 2017). A family’s preference for choosing one of these locations may be attributed to a combination of cultural preferences, geographical settings, and resource accessibility (Bender et al. 2017). While the importance of location in the planning and provision of palliative care has been explored in relation to adults, it has received remarkably little attention in relation to children (Jones 2011).

Place is highly contested in the literature, with little consistency shown across academic discourse. By “place,” we are considering the personal and cultural meanings that individuals and groups ascribe to a specific physical location (Cresswell 2004). As people personalize, connect, and associate feelings with and ascribe meaning to specific sites, they are making physical spaces social – i.e., they are making them into places. Place plays a critical role in how individuals come to view, experience, shape, create, value, and feel belonging in communities and institutions. The purpose of this scoping review is to explore how place and its importance are understood and approached in the PPC literature. We do this with a view to advancing a fuller understanding of PPC–place relations so that we can work toward leveraging place and its meanings to help improve the quality of PPC. To do this, we engage the following review question: “What is known about the importance of place in PPC?”

Methods

Our scoping review drew upon Arksey and O’Malley’s (2005) scoping review framework to gather and identify the literature pertaining to the importance of place as it relates to PPC. Using scoping review principles, a comprehensive list of search terms was generated and compiled into a search string, 5 key databases were identified and searched, and inclusion and exclusion criteria were identified and then applied to search results. The search strategy was developed with support from a health sciences research librarian working within a pediatric rehabilitation academic health sciences center.

Literature search process

With input from the health sciences research librarian, we selected 5 databases to search based on their relevance to health sciences: (1) Medline via Ovid, (2) APA PsycInfo via Ovid, (3) Embase via Ovid, (4) CINAHL Plus via EBSCO, and (5) Scopus. We crafted a search function comprising terms related to “pediatric,” “palliative,” and “place” to capture the peer-reviewed literature pertaining to our topic. As shown below, this search function comprised 6 pediatric terms, 8 palliative care terms, and 6 place/location terms:

((child OR youth* OR life* OR teen* OR adolescen* OR p#ediatric* OR “baby”) AND (end-of-life* OR life-limit* OR palliat* OR “dying” OR terminal* OR “mortality” OR “spphc” OR “pphc”) AND (place* OR location* OR setting* OR hospice* OR hospital* OR home*))*

This search function includes Boolean operators (AND, OR) to carefully combine key and alternate search terms. It also includes truncated terms (i.e., the use of asterisks) to capture terms in their singular and plural forms, and with different suffixes (e.g., “adolescen*” will capture “adolescent,” “adolescents,” and “adolescence”). In June 2021, 2 research team members applied the search over a 47-year period (1974–2021) across the 5 identified databases. The year 1974 was selected as the starting date of our search period because it marks the emergence and development of palliative care in Canada (Loscalzo 2008). Two researchers downloaded the search result records from each database and loaded them into a Covidence database. Covidence is software specifically designed to support the management of systematic/scoping review records and to facilitate different stages of review screening (i.e., first screening of titles and abstracts, resolving first screening conflicts, second screening of articles in full, resolving second screening conflicts). Inclusion and exclusion criteria were then applied to each article to help ensure that our search led to the

comprehensive collection of a full range of literature concerning the importance of place in PPC.

Inclusion and exclusion criteria

Documents were considered as part of this review if they met the following inclusion criteria:

1. Published between 1974 and 2021;
2. Available in English;
3. Full text was accessible online;
4. Focused on children under 18 years old receiving palliative care;
5. Considered the experience, importance, and/or significance of place in PPC in some capacity;
6. Peer-reviewed empirical study (not a literature review) or relevant legislation; and
7. Study was geographically located in the Global North.

The decision to restrict review materials to those considering children under 18 years was made to align with the transition of pediatric health care to adult care, which typically occurs at 18 years of age. To help us understand what the literature tells us about the meaning and importance of place in PPC, the included documents were required to focus on experience, importance, and/or significance of place.

Documents were excluded from the review if they met the following exclusion criteria:

- a. Dissertation;
- b. Conference proceeding;
- c. Position statement or commentary; and
- d. Literature review.

These exclusion criteria were determined to help ensure that the review is largely focused on empirical and rigorous studies that have undergone peer review processes prior to publication.

Study selection

The initial search of the 5 databases yielded 3706 results. Once duplicates were removed, there were 2964 results. Two independent reviewers screened the titles, abstracts, and keywords of the 2964 results for inclusion and exclusion criteria. Any conflicts between the 2 reviewers were resolved through consultation with this paper’s 2 other co-authors. The first stage of screening led to the identification of 77 documents. These 77 documents underwent a second stage of screening involving a full-text screening to determine if they should be included in the review. The 2 screeners independently reviewed the text of the 77 documents in this second stage, which yielded a total of 22 documents to be included in the review. The remaining 55 documents were excluded because they did not satisfy inclusion criteria (e.g., wrong study scope, population, and geographical location). We had initially excluded 3 literature reviews but opted to include them after the screening due to their relevance to this paper’s topic, which led to us including a total of 25 documents in this review. Figure 1 presents a PRISMA diagram that outlines our review process and its results.

Data extraction

Working with input from research team members, 2 co-authors reviewed the 25 documents, extracted data, and populated an extraction table. Table 1 below presents a summary of each reviewed study’s author, year, and location; study aims and methods; population and study setting; key findings; and themes.

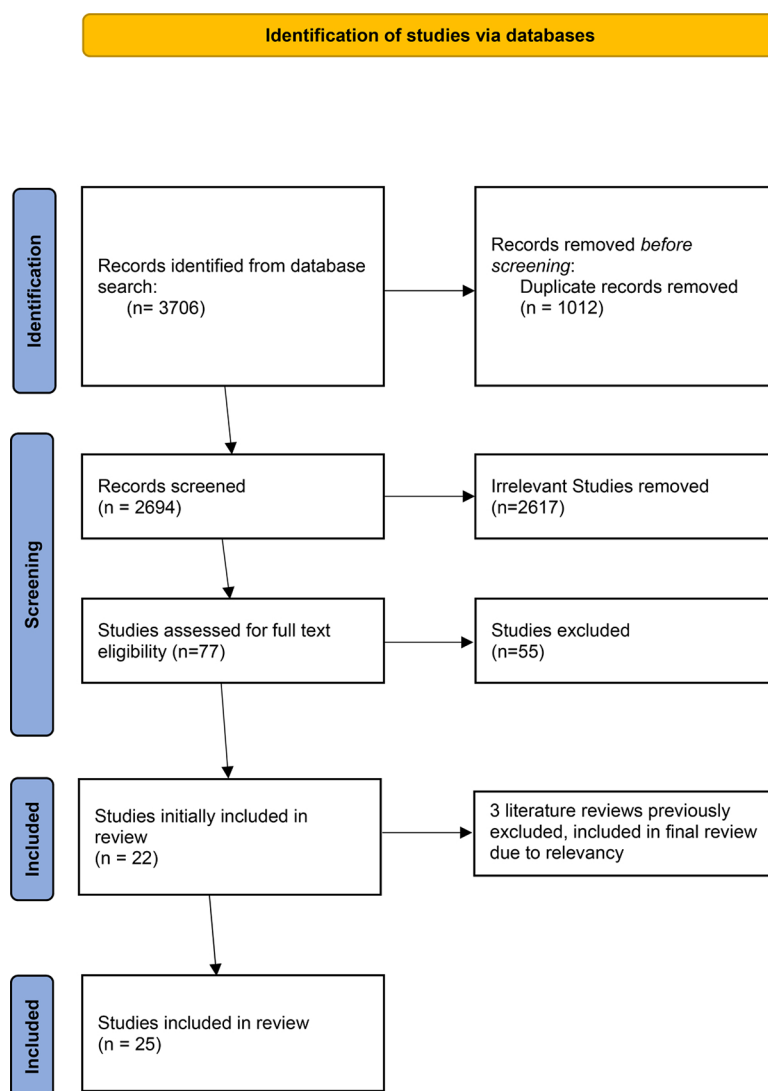


Figure 1. PRISMA diagram.

Results

Of the 25 articles included in this review, 21 presented findings from studies geographically located in the United States. The remaining 4 presented findings from studies located in the United Kingdom. Regarding the studies' specific PPC locations, 8 considered hospice-based PPC, 20 examined home-based PPC, and 17 were focused on hospital-based PPC (some studies examined more than one location where children receive PPC.). Three key themes emerged from our review of the literature concerning PPC and place: (1) factors influencing decisions about the place of PPC, (2) preferences for at-home PPC, and (3) impacts of PPC places on identity and family dynamics.

Factors contributing to place-related PPC decisions

Various complex and intersecting factors contribute to how parents and children make decisions about place of PPC and death. The impending death of a child generates a multitude of individual and family needs, emotional reactions, and shifts in priorities that together impact care planning and decisions about place of care and

death (Johnston et al. 2017). Internal family factors (e.g., comfort, familial support, and parent capabilities) and those that are external to the immediate family unit (e.g., access to resources, proximity to medical care, and extended family) all feed into a family's decision about the place where they want their child to receive PPC.

In a study by Martinson et al. (1978), primary caregivers indicated that their key priority was to provide the most comfort possible for their children and that they often desired PPC at home to help with achieving this priority (Martinson et al. 1978). These parents found the home to be a place where they could more easily create comfortable spaces for their children throughout the dying process. In a different study, the impacts of parents' belief in their own medical caregiving capabilities were explored (Martinson et al. 1977). The skills and confidence that a parent feels they possess and can apply in providing care to their dying child played a critical role in deciding where their child should receive care (Edwardson 1983; Martinson et al. 1977). Edwardson et al. (1983) found that parents' feelings of competency concerning the provision of medical care to their child led some to choose home as the place of death, while parents who felt less comfortable providing medical care to their child had a stronger preference for hospital or hospice-based care (Edwardson 1983).

Table 1. Summary of reviewed documents

Study and location	Description	Population and setting	Key findings	Themes
<i>Empirical studies</i>				
1. Bender et al. (2017), Germany	<i>Aim:</i> Examine the characteristics of patients receiving pediatric palliative home care and the frequency of parents wanting to bring their child home for end-of-life care	<i>Population:</i> 213 children with life-limiting conditions	Families of children with diagnoses other than cancer reported a lack of support services. Specialized home care services were developed to meet the needs of families who wished for death to occur at home.	1, 2
	<i>Methods:</i> Retrospective analysis of electronic record charts of pediatric patients in palliative care	<i>Setting:</i> Home, hospital, and hospice		
2. Bettini (2020), United States	<i>Aim:</i> Examine barriers to PPC communication created by Covid-19 care restrictions	<i>Population:</i> 7-month-old infant, family of patient	Telehealth approaches are not a perfect replacement for in-person interactions, though they were found to be useful in delivering difficult conversations during end-of-life care.	3
	<i>Methods:</i> Case study using observations and interviews in which communication occurred via telehealth	<i>Setting:</i> Hospital		
3. Castor et al. (2018), Sweden	<i>Aim:</i> Describe lived experiences of PPC patients and their families when care is delivered at home	<i>Population:</i> 15 families of PPC patients	Delivery of care at home was found to strengthen relationships within and outside the family unit. Home care provided an environment conducive to promoting well-being of patients and their family members.	2, 3
	<i>Methods:</i> Qualitative interviews with PPC patients and their families	<i>Setting:</i> Home and hospital		
4. Dabbs, Butterworth and Hall (2007), United States	<i>Aim:</i> Explore challenges and barriers associated with increasing access to hospice care	<i>Population:</i> 225 families of children who died from terminal conditions	Pain/symptom management of children in care posed a challenge in the hospice setting. Parents often lacked various types of support when care was delivered at home.	1, 2, 3
	<i>Methods:</i> Questionnaire and interviews completed by parents of children with life-threatening conditions	<i>Setting:</i> Home, hospital, and hospice		
5. Edwardson (1983), United States	<i>Aim:</i> Explore decision-making process of physicians and parents in choosing between hospital and home care for children in terminal phase of cancer	<i>Population:</i> 123 deceased pediatric cancer patients and 103 parents of deceased patients	Physicians' influence and their dominant care delivery method is a key influence on decisions about location of death during the terminal phase.	1
	<i>Methods:</i> Interviews with parents and data collection from patient records	<i>Setting:</i> Home and hospital		
6. Feudtner, DiGuseppe and Neff (2003), United States	<i>Aim:</i> Describe hospital care received by children and young adults in their last year of life	<i>Population:</i> 8893 deceased patients aged 25 years and younger	Infants who died spent most of their lives in hospital care, while older children and young adults spent more time outside of the hospital when not receiving care. It is critical that PPC is available and accessible to patients in both hospitals and home community settings.	1
	<i>Methods:</i> Analysis of patient record information and death certificates	<i>Setting:</i> Hospital		
7. Gao et al. (2016), England	<i>Aim:</i> Describe factors associated with what denotes a "good death" and how it relates to location of end-of-life care	<i>Population:</i> 12,774 deceased pediatric patients with cancer	Home and hospice were found to be preferred locations of pediatric cancer patients and their families in facilitating good-quality end-of-life care. However, hospital deaths were found to be the most common.	1, 2
	<i>Methods:</i> Analysis of patient record information	<i>Setting:</i> Home, hospital, and hospice		
8. Higginson and Thompson (2003), England	<i>Aim:</i> Examine the factors that influence the place of death for children dying of cancer	<i>Population:</i> 3197 deceased cancer patients aged 0–24 years	Home was identified as a preferred location of death for children dying of cancer. Death at home was found to be less likely for those of a lower social class.	1, 2

(Continued)

Table 1. (Continued.)

Study and location	Description	Population and setting	Key findings	Themes
	<i>Methods:</i> Analysis of patient record information and death certificates	<i>Setting:</i> Home, hospital, and hospice		
9. Lauer et al. (1985), United States	<i>Aim:</i> Describe experiences of siblings of children who died at home versus in hospital	<i>Population:</i> 36 siblings of children who died	Siblings reported higher levels of preparation for a child's impending death when care was delivered at home. When death occurred in hospital, siblings reported feelings of isolation and lack of support during end-of-life process.	2, 3
	<i>Methods:</i> Questionnaires and interviews completed by siblings of children who died	<i>Setting:</i> Home and hospital		
10. Lindley, Mixer and Mack (2016), United States	<i>Aim:</i> Examine the factors influencing the use of home care versus hospice care at the end of life	<i>Population:</i> 989 deceased PPC patients	Use of home care at the end of life for children with chronic complex conditions was low. The role of hospice care services in providing symptom management was associated with higher rates of hospice care delivery.	1, 2
	<i>Methods:</i> Analysis of patient record information	<i>Setting:</i> Home and hospice		
11. Martinson et al. (1978), United States	<i>Aim:</i> Examine the process of facilitating home care for children dying of cancer and coordinating care	<i>Population:</i> 32 families of children dying of cancer	Primary caregivers' key concern was providing the most comfort as possible for their children. Facilitating support and care from nurses was crucial to allowing for end-of-life home care.	1, 2, 3
	<i>Methods:</i> Analysis of patient records/notes; interviews with families of children dying of cancer	<i>Setting:</i> Home and hospital		
12. Martinson et al. (1977), United States	<i>Aim:</i> Determine the feasibility and favorability of home care for children dying of cancer	<i>Population:</i> 29 children dying of cancer and their families	Most families expressed a desire for care to occur at home. Pain management was found to be well controlled in the home, making it an appropriate care alternative for families.	1, 2, 3
	<i>Methods:</i> Interviews and observations of families of children dying of cancer being cared for at home	<i>Setting:</i> Home and hospital		
13. Meert et al. (2008), United States	<i>Aim:</i> Describe how the experience of the environment impacts parents at the time of their child's death	<i>Population:</i> 33 parents of 26 children who died in a pediatric intensive care unit	Positive environmental memories were associated with feelings of comfort and ease during bereavement. Negative environmental memories were associated with devastation throughout the process.	3
	<i>Methods:</i> Interviews with parents 2 years after their child's death	<i>Setting:</i> Hospital		
14. Needle (2010), United States	<i>Aim:</i> Describe the benefits and limitations of home extubation using a pediatric critical care team	<i>Population:</i> 6-month-old indigenous infant with down syndrome, parents of child, critical care team members	Home extubation can be a feasible option for families wishing for death to occur at home. Home extubation allowed for privacy, spiritual connection, and preservation of familial roles.	2, 3
	<i>Methods:</i> Case study using observations and interviews of a pediatric home extubation	<i>Setting:</i> Home		
15. Nelson and Mott (2017), United States	<i>Aim:</i> Describe the process and reasoning used to develop a structured system for PPC transport	<i>Population:</i> 9 parents of deceased children	Parents shared positive experiences with pediatric palliative transport services, as they offered families an option to have end-of-life care delivered in their preferred location.	1, 2, 3
	<i>Methods:</i> Interviews with parents of critically ill children transported for end-of-life care delivery	<i>Setting:</i> Home, hospital, hospice		

(Continued)

Table 1. (Continued.)

Study and location	Description	Population and setting	Key findings	Themes
16. Noje et al. (2017), United States	<i>Aim:</i> Examine the experiences of children and their families during transport home for the end of life	<i>Population:</i> 3 PPC patients, their families, critical care team members	Despite logistical challenges associated with transporting a critically ill patient home, each family strongly preferred an at-home death.	2
	<i>Methods:</i> Data collection from patient records and transport notes as well as interviews with families and care team members	<i>Setting:</i> Home and hospital		
17. Sanderson and Burns (2017), United States	<i>Aim:</i> Describe the benefits and limitations of home-based PPC	<i>Population:</i> Literature reviewing home-based PPC	Consistent benefits of home-based care include privacy and familiarity. Limitations include care provider incompetency and lack of palliative care experience.	2, 3
	<i>Methods:</i> Review literature on home-based PPC	<i>Setting:</i> Home		
18. Shah et al. (2011), England	<i>Aim:</i> Evaluate patterns in palliative care delivery and factors influencing place of death for children who died of cancer	<i>Population:</i> 1864 deceased pediatric oncology patients	Associations were found between place of death and type of cancer as well as length of care. A substantial number of children from ethnic minority groups were found to die in hospital.	1
	<i>Methods:</i> Data collection of patient record information and death certificates	<i>Setting:</i> Home, hospital, and hospice		
19. Tang et al. (2011), Taiwan	<i>Aim:</i> Examine trends in aggressive end-of-life care for PPC patients in Taiwan	<i>Population:</i> 1208 deceased pediatric oncology patients	Parents were willing to continue aggressive end-of-life treatment to avoid death. Aggressive treatments at end of life were associated with professionals' reluctance to stop treatment.	1, 3
	<i>Methods:</i> Analysis of patient record information	<i>Setting:</i> Home and hospital		
20. Taylor et al. (2021), United Kingdom	<i>Aim:</i> Describe merit of consulting young people on palliative care provision to inform practice/policy	<i>Population:</i> 14 patients with life-threatening conditions aged 12–18 years	Young people emphasized a desire to be involved in their care planning, noting they have the “lived experience” of their condition. The needs of young people in PPC planning were often left unmet.	1, 3
	<i>Methods:</i> Focus group interviews and individual patient interviews	<i>Setting:</i> Home, hospital, and hospice		
21. Thienprayoon et al. (2015), United States	<i>Aim:</i> Examine the impact location has on the quality of end-of-life care for children with cancer	<i>Population:</i> 202 pediatric oncology patients	Parental satisfaction with quality of care was higher when children were able to die at home. Hospice care was associated with lower rates of acute tertiary health-care use.	1, 2
	<i>Methods:</i> Analysis of patient record information	<i>Setting:</i> Home, hospital, and hospice		
22. Vickers et al. (2007), United Kingdom	<i>Aim:</i> Evaluate the efficacy of an outreach palliative care model in allowing children with incurable cancer diagnoses to die at home	<i>Population:</i> 185 families of children with incurable cancer	Home was found to be the principal location of end-of-life care. Families clearly preferred for death to occur at home and found having this option to be emotionally significant.	1, 2
	<i>Methods:</i> Questionnaires completed by families of a child with incurable cancer	<i>Setting:</i> Home, hospital, and hospice		
<i>Literature reviews</i>				
23. Ziegler and Kuebelbeck (2021), United States	<i>Aim:</i> Evaluate the definition of perinatal palliative care and the population it serves	<i>Population:</i> n/a (Literature review of perinatal palliative care)	A community-based hospital setting for the provision of perinatal palliative care can provide families with the benefits of customizing the end-of-life care experience.	1, 3
	<i>Methods:</i> Literature review of perinatal palliative care, focusing on case study on a perinatal community program	<i>Setting:</i> Hospital		

(Continued)

Table 1. (Continued.)

Study and location	Description	Population and setting	Key findings	Themes
24. Johnston et al. (2017), United States	<i>Aim:</i> Examine the differences between the quality measure in the delivery of adult end-of-life care versus pediatric end-of-life care	<i>Population:</i> n/a (Literature review of end-of-life care quality measures in adult and pediatric settings)	Adult end-of-life care quality measures are unable to address the needs of pediatric patients. End-of-life care quality measures for adult palliative care tends to be more well developed and systematic than that of PPC.	1, 3
	<i>Methods:</i> Review literature on quality care measures for adult palliative care and PPC	<i>Setting:</i> Home and hospital		
25. Jones (2011), United States	<i>Aim:</i> Describe barriers to accessing pediatric hospital and PPC	<i>Population:</i> n/a (literature review of barriers facing children with terminal conditions)	Nurses and physicians require more training on the specialized delivery of PPC to make end of life as painless as possible for children and their families.	1
	<i>Methods:</i> Review literature on PPC delivery options, focusing on impact of care on the needs of children and families	<i>Setting:</i> Home, hospital, and hospice		

Access and proximity to resources have also been found to contribute to parents' decisions about where their child receives PPC. Access to necessary medical equipment that allows for safe and comfortable care at home was highlighted as a large contributing factor to being cared for at home versus a hospital (Taylor et al. 2021). Meert et al. (2008) found that families having access to Health Care Providers while at home was a key factor in decisions about the place of PPC and death, as access to these professionals can create a feeling of security while caring for a child at home (Meert et al. 2008). Gao et al. (2016) suggested that while home deaths are often preferred, many families at times experience limited access to the services, equipment, and staff needed to adequately and safely support their child at home (Gao et al. 2016). For this reason, some families deem the home as an impractical and infeasible place for children's PPC.

While parents' preferences for place of PPC must be considered as part of care planning, so too must the preferences of children. However, only 1 (Taylor et al. 2021) out of the 25 reviewed studies considered children's preferences regarding their end-of-life care. Taylor et al. (2021) found that children valued the quality of care they received more, so than the place where the care was provided. Child participants identified some key aspects of care that they associated with good quality care, irrespective of place, which helped them to feel cared for and safe. These factors included having familiar and accessible specialists with knowledge of their condition, being treated as an individual with autonomy, care providers taking adequate time to understand and meet their unique care needs, and the continuity of relationships with their care providers (Taylor et al. 2021).

Preferences for at-home PPC

The preference for death at home rather than in hospital-based or hospice-based end-of-life care was evident across the examined literature for a myriad of reasons (Castor et al. 2018; Edwardson 1983; Gao et al. 2016; Martinson et al. 1978; Needle 2010; Sanderson and Burns 2017; Vickers et al. 2007). Across studies, privacy, cultural background, grief and bereavement, spirituality, and family life are commonly noted as contributing to families' preference to receive PPC at home (Castor et al. 2018; Needle 2010).

Privacy was among the highest cited factors contributing to parents' desire for home-based PPC (Meert et al. 2008; Needle 2010;

Sanderson and Burns 2017). The home fulfills a specific parental need when navigating a child's end-of-life care, as it offers exclusive physical closeness and comfort with their child and allows for private family conversations (Meert et al. 2008; Needle 2010; Sanderson and Burns 2017). Across studies, families highlighted the importance of having privacy during end-of-life care to allow for grieving and difficult discussions with family members without having to deal with lacking privacy and scheduling constraints, both of which are often present in hospital environments (Meert et al. 2008; Needle 2010; Sanderson and Burns 2017). Having the privacy of a home throughout, PPC can also add to feelings of comfort and safety when engaging in cultural and religious practices (Sanderson and Burns 2017; Tang et al. 2011). For example, a family's home serves as a familiar and comfortable physical environment that allows for an intimate, non-judgmental space to practice faith and spirituality and to carry out religion-/culture-specific end-of-life rituals (Needle 2010; Sanderson and Burns 2017; Tang et al. 2011). Having the comfort of a home environment to carry out rituals and traditions can add to a family's closeness and feelings of comfort and safety during the vulnerable end-of-life care period (Needle 2010). Home environments and the real and perceived privacy and safety they offer promote a peaceful atmosphere for the child, as well as for family members' grieving, healing, and psychosocial recovery from a dying child (Castor et al. 2018).

While numerous studies have shown that home is the preferred place for a child to receive PPC, having PPC and a child's death occur at home can alter how a family views and relates to their home. This, in turn, may affect family dynamics and how a family uses different spaces of their home following a child's death. In the following section, we consider implications of receiving PPC at home on family dynamics and the grieving process following a child's death.

Impacts of PPC places on identity and family dynamic

Place plays a critical role in the ways in which family members come to understand their own roles and relationships within the family. Castor et al. found that siblings of children who died at home were more readily able to engage in their typical activities, rather than their lives being strictly governed by their siblings being hospitalized (Castor et al. 2018). This ability for siblings to partake in normal aspects of their lives (e.g., their recreational activities,

play dates, sports) as a child receives PPC at home allows for them to experience some degree of normalcy in their everyday lives while also processing anticipatory grief. Siblings of children dying at home have also reported feeling greater connection to their dying sibling and family, as well as feeling more involved in the death process (Castor *et al.* 2018; Lauer *et al.* 1985). Further, siblings of children who have died at home have also reported that the home environment enabled more adequate preparation for the impending death, direct communication, and parental support (Lauer *et al.* 1985). Alternatively, families of children who have received PPC in hospitals have reported feeling poorly prepared for the impending death, a lack of involvement in the care and dying process, and a sense of isolation from death-related events and the death itself (Lauer *et al.* 1985). Siblings of dying children in home environments appreciated that home care services allowed their family unit to stay together (Castor *et al.* 2018). Siblings' feelings of separation from a child's in-hospital death has been found to lead them to feeling less connected to their family following the death and feeling that their role and presence in the death process was less significant as those whose siblings died at home (Lauer *et al.* 1985). Receiving PPC at home not only strengthened family connections but also provided more opportunities to be together and contribute to care (Castor *et al.* 2018; Lauer *et al.* 1985). This is because less time and energy was expended traveling back and forth to hospitals, and at home family members are often more involved in supporting PPC (Castor *et al.* 2018).

Receiving PPC at home has been found to impact the ways in which parents perceive themselves and their ability to provide medical care for their child (Castor *et al.* 2018; Martinson *et al.* 1977). Parents whose children received PPC at home were found to have stronger ties and connections to relatives and friends (Castor *et al.* 2018). At-home PPC can enable families to continue nurturing relationships with family and their surrounding community. Moreover, it can help families to carry on with some regular activities that help to maintain a degree of normalcy within their day-to-day lives and to find reprieves from the remarkable difficulties of a child's dying process and death (Castor *et al.* 2018). One study also found that children whose siblings died at home reported the same, or stronger, family cohesion following the death of their sibling compared to children whose siblings died in hospital (Lauer *et al.* 1985). Home-based PPC can also allow for more opportunities to preserve the roles of the parent and sibling (Sanderson and Burns 2017). In their examination of parents of children who died at home versus those who died in a hospital, Thienprayoon *et al.* (2015) found that parents whose children died at home were

quicker to adapt to "normal" social functioning, felt less isolated and less strain on their marriage, and experienced considerably less guilt.

The meanings that we ascribe to a place of PPC and death extend beyond those that are considered and felt during the dying process and at death. That is, the place of PPC and death can impact a family's relations, QoL, and grieving long after the child has died. Vivid memories of the place where death occurs can affect how feelings of grief are processed long after the child's death, and revisiting where the death occurs (e.g., the location in one's home) may affect how those memories are experienced and processed. Meert *et al.* explored this notion and reported that positive associations with the environment, or aspects of the environment, can comfort parents and ease their bereavement process. Parents who spoke of negative associations with the environment reported more difficult and convoluted grieving processes (Meert *et al.* 2008).

The themes that emerged through our analysis of the literature and that are discussed in this paper led us to develop a list of key questions that families of children receiving PPC can ask themselves, reflect upon, and discuss with their health-care practitioners. The questions are intended to help families make an informed decision about the place of PPC that is tailored to their specific circumstances (e.g., their capabilities, preferences, values, rituals, and more). Figure 2 presents the 6 questions.

While research has begun to explore the impact of place on palliative care for children, and their families, many gaps persist. There was a scarcity of research exploring children's perspectives and desires on where they receive palliative care. It is essential that the views of children are integrated into research that directly impacts their well-being. Further, most of the research to date has focused on hospital-based or home-based PPC, with little focus on hospice care for children. While the literature highlights the preference for PPC to be received at home, to our knowledge, no research has been conducted to explore how a child's death at home can affect how families experience home after the death. Future research exploring the resultant relationship with the home following the death of a child is warranted. Further, while the preference for PPC at home is evident in the literature, it is imperative that future research explores ways to best provide optimal palliative care at home. Lastly, our literature review explored studies conducted in the Global North. It would be beneficial for future research to consider Global South perspectives and practices pertaining to PPC and place, as they will likely offer further helpful knowledge on this topic.

1. Do I/we have the capability (and feel confident in my/our ability) to provide care at home for my/our child?
2. What place-related considerations (e.g., proximity to family, familiarity, proximity to health care staff, privacy, social/play opportunities) matter to my/our child during the dying process?
3. What place-related considerations do I/we want for my/our child (and their siblings) during the death and dying process?
4. What will dying at home versus the hospital look and feel like for my/our child?
5. How might my/our child dying at home impact the ways our family views and experiences our home after the death?
6. What pediatric palliative care health care support options can I/we access in relation to each potential place of care?

Figure 2. Questions to aid decisions about the place of PPC.

Conclusion

The place of PPC (typically at home, in hospital, or in hospice) plays a critical role in how PPC is provided and experienced. In this review of 25 articles that explore the relationship between place and PPC, as well as how families experience navigating PPC and the dying process, we have identified some key findings and considerations that can help to inform families' decisions about the place of PPC.

The literature makes it clear that the place of PPC does not only affect the dying child; rather, it affects how the entire family unit operates, copes, grieves, and manages PPC and a child's impending death. The place of PPC and death can affect how both parents and siblings come to understand their own role and position within a family, how they interact with/relate to a dying child, how they carry out religious and cultural practices (e.g., end-of-life rituals), and how the family is able to grieve before, during, and after a child's death. When making decisions about place of PPC, it is important to acknowledge that it represents more than just where care is received. Place of PPC represents and affects the privacy a family is granted, the freedom to practice and adhere to spiritual, religious, and cultural practices, and the ability to be empowered and integrated, in a meaningful way, into the death process. While many families may prefer to receive end-of-life care at home due to a multitude of factors (e.g., comfort for the child, greater involvement in care provision, and easier for siblings), this is not always possible (e.g., if parents are not capable of/confident about providing the necessary support, if at-home PPC supports are unavailable).

It is important that families undergoing PPC are able to experience privacy, the freedom to carry out spiritual/religious/cultural practices and be involved in the PPC provision and dying process regardless of where PPC is received. It therefore may be practical for some pediatric hospitals to consider redesigning a selection of rooms for PPC purposes so that they provide a place of PPC that better accounts for the needs of not only the dying child but also the child's siblings and parents. For example, attention could be given to creating some fully private rooms with ample space and comfortable seating for family members, offering religious/cultural symbols and services upon request in multiple languages, providing lounge space where family members can grieve and have private discussions away from the child, as well as support programming for siblings.

The place of a child's death may impact how families come to recognize their own roles within the family dynamic. When navigating the dying process, families are not only processing the impending death of their loved one in the place they choose for the child's care and death. The place – that is, its privacy, comfort, PPC supports – all become part of the family's coping and grieving process. For example, a child's death at home may bring about difficult emotions associated with entering and using the room or space where the child died, which could warrant consideration for some when making decisions about place of PPC and death.

Alarmingly, among the 25 reviewed studies, only one study included the voices of children. In pediatric research, it is still common for parents' voices to be prioritized and viewed as representative of the opinions and perspectives of the child. However, it is essential that we recognize the value and agency of children's input in care-related decisions (Harcourt and Einarsdottir 2011; James et al. 1990), including those pertaining to PPC. Children are experts on their own lives, needs, and desires, and it is critical that

the ways and places in which they want to receive care and experience life, at the end of life, is planned in alignment with their values and desires (Taylor et al. 2021).

While place has largely been considered in geography, architecture, and urban planning research, this scoping review highlights the importance of considering place in health care and, specifically, PPC. The meanings we ascribe to physical spaces impact the ways in which care is experienced for children receiving palliative care and their families. We hope this paper acts as a catalyst for future research in this area to further advance our knowledge of ways in which place and PPC are experienced so we can best support this vulnerable population. Further, we encourage readers to use Figure 2 as a takeaway tool that can help families to make informed and meaningful decisions regarding the place and PPC. This review represents an important first step in understanding the importance of and preferences for place when receiving PPC, and it offers a strong foundation to impact clinical care and drive future studies.

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References

- Arksey H and O'Malley L (2005) Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology* 8(1), 19–32 doi:10.1080/1364557032000119616.
- Bender HU, Riester MB, Borasio GD, et al. (2017) "Let's bring her home first." Patient characteristics and place of death in specialized pediatric palliative home care. *Journal of Pain and Symptom Management* 54(2), 159–166. doi:10.1016/j.jpainsymman.2017.04.006
- Bettini EA (2020) COVID-19 pandemic restrictions and the use of technology for pediatric palliative care in the acute care setting. *Journal of Hospice and Palliative Nursing* 22(6), 432–434. doi:10.1097/NJH.0000000000000694.
- Boucher S, Downing J and Shemilt R (2014) The role of play in children's palliative care. *Children* 1(3), 302–317. doi:10.3390/children1030302
- Castor C, Landgren K, Hansson H, et al. (2018) A possibility for strengthening family life and health: Family members' lived experience when a sick child receives home care in Sweden. *Health & Social Care in the Community* 26(2), 224–231. doi:10.1111/hsc.12512
- Cohen E and Patel H (2014) Responding to the rising number of children living with complex chronic conditions. *Canadian Medical Association Journal* 186(16), 1199–1200. doi:10.1503/cmaj.141036
- Cresswell T (2004) *Place: a Short Introduction*, Malden M (ed). Malden, Massachusetts, USA: Blackwell Ltd.
- Dabbs D, Butterworth L, and Hall E (2007) Increasing Access to Hospice Services for Children With Life-Threatening Conditions. Retrieved from <https://www.Childrenshospice.org>
- Delgado-Corcoran C, Wawrzynski S, Bennett E, et al. (2020) Palliative care in children with heart disease treated in an ICU. *Pediatric Critical Care Medicine* 21(5), 423–429. doi:10.1097/PCC.0000000000002271
- Edwardson S (1983) The choice between hospital and home care for terminally ill children. *Nursing Research* 32(1), 29–34.
- Feudtner C, Digiuseppe DL and Neff JM (2003) Hospital care for children and young adults in the last year of life: A population-based study. *BMC Medicine* 1, 1–9. doi:10.1186/1741-7015-1-3
- Gao W, Verne J, Peacock J, et al. (2016) Place of death in children and young people with cancer and implications for end of life care: A population-based study in England, 1993–2014. *BMC Cancer* 16(1). doi:10.1186/s12885-016-2695-1

- Harcourt D and Einarsdottir J** (2011) Introducing children's perspectives and participation in research. *European Early Childhood Education Research Journal* **19**(3), 301–307. doi:10.1080/1350293X.2011.597962
- Higginson IJ and Thompson M** (2003) Children and young people who die from cancer: Epidemiology and place of death in England. *British Medical Journal* **327**, 478–479. doi:10.1136/bmj.327.7413.478
- Himmelstein BP, Hilden JM, Morstad Boldt A, et al.** (2004) Pediatric palliative care. *The New England Journal of Medicine* **350**(17), 1752–1762 doi:10.1056/NEJMra030334.
- James A, A. P. and Prout A** (1990) *Contemporary Issues in the Sociological Study of Childhood*, 3rd edn. Abingdon, Oxfordshire: Routledge.
- Jennings PD** (2005) Providing pediatric palliative care through a pediatric supportive care team. *Pediatric Nursing* **31**(3), 195–200.
- Johnston EE, Rosenberg AR and Kamal AH** (2017) Pediatric-specific end-of-life care quality measures: An unmet need of a vulnerable population. *Journal of Oncology Practice* **13**, e874–e880. doi:10.1200/JOP.2017.021766
- Jones BW** (2011) The need for increased access to pediatric hospice and palliative care. *Dimensions of Critical Care Nursing* **30**(5), 231–235. doi:10.1097/DCC.0b013e3182276ded
- Lauer M, Mulhern R, Bohne J, et al.** (1985) Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. *Cancer Nursing* **8**(1), 21–28.
- Lindley LC, Mixer SJ, and Mack JW** (2016) Home care for children with multiple complex chronic conditions at the end of life: The choice of hospice versus home health. *Home Health Care Services Quarterly*, **35**(3–4), 101–111. doi:10.1080/01621424.2016.1208133
- Loscalzo MJ** (2008) Palliative care: An historical perspective. *Hematology, ASH Education Program* **2008**(1), 465. doi:10.1182/asheducation-2008.1.465
- Martinson I, Armstrong G, Geis D, et al.** (1978) Facilitating home care for children dying of cancer. *Cancer Nursing* **1**(1), 41–45.
- Martinson IM, Geis D, Anglim MA, et al.** (1977) Home care for the child. *The American Journal of Nursing* **77**(11).
- Meert K, Briller S, Myers Schim S, et al.** (2008) Exploring parents' environmental needs at the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine* **9**(6), 623–628. doi:10.1097/PCC.0b013e31818d30d5
- Muskat B, Greenblatt A, Anthony S, et al.** (2020) The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital end-of-life care in a pediatric acute-care hospital. *Death Studies* **44**(2), 105–116. doi:10.1080/07481187.2018.1526829
- Needle J** (2010) Home extubation by a pediatric critical care team: Providing a compassionate death outside the pediatric intensive care unit. *Pediatric Critical Care Medicine* **11**(3), 401–403. doi:10.1097/PCC.0b013e3181c0143f
- Nelson H and Mott S** (2017) Translating research to practice: Providing critically ill children the opportunity to go home or to hospice for end-of-life care. *Dimensions of Critical Care Nursing*, **36**(3), 174–181. doi:10.1097/DCC.0000000000000249
- Noje C, Bernier ML, Costabile PM, Klein BL, and Kudchadkar SR** (2017) Pediatric Critical Care Transport as a Conduit to Terminal Extubation at Home: A Case Series. *Pediatric Critical Care Medicine*, **18**(1), e4–e8. doi:10.1097/PCC.0000000000000997
- Rapoport A and Liben S** (2015) Paediatric palliative care: There is always more we can do. *Pediatric Child Health* **20**(3), 123–125. doi:10.1093/pch/20.3.123
- Sanderson A and Burns JP** (2017) Withdrawal of life-sustaining therapy at home: Broadening the view of end-of-life care in the PICU...Even in children's homes. *Pediatric Critical Care Medicine* **18**(1), 92–93. doi:10.1097/PCC.0000000000001005
- Schmidt L** (2003) Pediatric end-of-life care: Coming of age? *Caring* **12**(5), 20–22.
- Shah A, Diggins N, Stiller C, Murphy D, Passmore J, and Murphy MFG** (2011) Place of death and hospital care for children who died of cancer in England, 1999–2006. *European Journal of Cancer*, **47**(14), 2175–2181. doi:10.1016/j.ejca.2011.03.030
- Tang ST, Hung YN, Liu TW, et al.** (2011) Pediatric end-of-life care for Taiwanese children who died as a result of cancer from 2001 through 2006. *Journal of Clinical Oncology* **29**(7), 890–894. doi:10.1200/JCO.2010.32.5639
- Taylor J, Murphy S, Chambers L, et al.** (2021) Consulting with young people: Informing guidelines for children's palliative care. *Archives of Disease in Childhood* **106**(7), 693–697. doi:10.1136/archdischild-2020-320353
- Taylor J, Murphy S, Chambers L, and Aldridge J** (2021) Consulting with young people: Informing guidelines for children's palliative care. *Archives of Disease in Childhood*, **106**(7), 693–697. doi:10.1136/archdischild-2020-320353
- Thienprayoon R, Lee SC, Leonard D, et al.** (2015) Hospice care for children with cancer: Where do these children die? *Journal of Pediatric Hematology/Oncology* **37**(5), 373–377. doi:10.1097/MPH.00000000000000331
- Vickers J, Thompson A, Collins GS, et al.** (2007) Place and provision of palliative care for children with progressive cancer: A study by the paediatric oncology nurses' forum/United Kingdom children's cancer study group palliative care working group. *Journal of Clinical Oncology* **25**(28), 4472–4476. doi:10.1200/JCO.2007.12.0493
- Widger K, Davies D, Drouin DJ, et al.** (2007) Pediatric patients receiving palliative care in Canada. *Archives of Pediatric and Adolescent Medicine* **161**, 597–602. doi:10.1001/archpedi.161.6.597
- Widger K, Davies D, Rapoport A, et al.** (2016) Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study. *Canadian Medical Association Journal* **4**(4), 562–568. doi:10.9778/cmajo.20160054
- Ziegler TR and Kuebelbeck A** (2021) Close to home: Perinatal palliative care in a community hospital. *Advances in Neonatal Care* **20**(3), 196–203. doi:10.1097/ANC.0000000000000732