

REVIEW

Location of end-of-life care of children with cancer: A systematic review of parent experiences

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This review highlights the importance of clear communication between families and healthcare providers to optimize conversations with children, young people, and families to ensure quality care is provided, goals of care are achieved, and opportunities to discuss the preferred location of care occur.

[Correction added on 12th May 2022, after first online publication: CAUL funding statement has been added.]

Abstract

Objective: To synthesize existing qualitative research exploring the experiences of parents caring for children with cancer during the end-of-life phase, and the factors that influence parental decision-making when choosing the location of end-of-life care and death for their child.

Results: This review included 15 studies of 460 parents of 333 children and adolescents who died from progressive cancer. Where reported, the majority (58%) of children died at home or in a hospital (39%), with only a small fraction dying in a hospice. Factors impacting decision-making for the location of care included the quality of communication and the quality of care available. Themes related to choosing home for end-of-life care and death included honoring the child's wishes, the familiarity of home, and parents' desire to be their child's primary carer. Preference for the location of death in the hospital included trust in hospital staff, practical logistics, and the safety of the hospital environment.

KEYWORDS

adolescent, child, decision making, neoplasms, parents, place of death, qualitative research, terminal care

1 | INTRODUCTION

During the past two decades, significant improvements in the treatment of childhood cancer mean 80% of children in developed nations can expect to be long-term survivors.¹ This means, however, approxi-

mately 20% of children will die from disease progression; indeed cancer remains the leading cause of non-accidental death in children.²

The end-of-life phase is defined as the period where cure is no longer possible and death appears imminent, although this phase can continue for days, weeks, or even months.³ Dying children receive end-of-life care either at home, supported by palliative care or home hospice services, in a hospital, or in some nations, a freestanding children's

Abbreviations: CASP, Critical Appraisal Assessment Programme; PICU, pediatric intensive care unit; PROSPERO, Prospective Register for Systematic Reviews.

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hospice.⁴ For many families, the preferred place for end-of-life care is at home, where there is a sense of security and normality.^{5–7} Some families however will prefer alternatives to home, including tertiary or local hospitals. If available, a free-standing children's hospice, or "hospice house" offers an alternative choice beyond the home or acute hospital setting, providing a home-like building with the additional support of health professionals on-site.⁵ Regardless of location, the opportunity for families to plan, prepare, and have flexibility in the timing and place of care may have a positive influence on distress at the time of their child's death and in longer term bereavement. For these reasons, the opportunity to plan for the location of care is considered a valid proxy measure of high-quality palliative care.⁸

Dying children endure a high burden of physical and psychological symptoms. Prevalent symptoms include pain, fatigue, poor appetite, dyspnea, irritability, sleep disturbances, anxiety, sadness, fear of being alone, and fear of dying.⁹ When symptoms are not optimally managed, suffering for the child and family is exacerbated.¹⁰ Suffering and other factors, such as understanding prognosis, parent perceived caregiving competence, and opportunities to extend time, can also impact the families' decision-making about the location of end-of-life care and death; these factors may also influence long-term bereavement.¹¹

Most studies that investigate end-of-life care for children with cancer are retrospective studies with epidemiological data, including disease type, symptom burden, location of care, and family experiences, with data retrieved from medical records and interpreted by health professionals.^{6,9,12–14} The few studies that address parental experiences of caring for children with advanced cancer and factors that influence decision-making about the location of care have not previously been synthesized.

This qualitative systematic review aimed to synthesize the available evidence that describes parent experiences and perceptions of the location of end-of-life care and death for children with advanced cancer. Specifically, this study seeks to better understand the experiences of parents by answering the following question:

What factors influence parental decision-making when choosing the location of end-of-life care and death for a child with cancer?

2 | MATERIALS AND METHODS

A research protocol was developed for this review and registered with the International Prospective Register for Systematic Reviews (PROSPERO), registration number CRD42021224413.

2.1 | Literature search and screen

A comprehensive search strategy was developed with assistance from a health librarian using keywords, including parents, mothers, fathers, caregivers, palliative care, end-of-life, terminal care, child, adolescent, pediatric, neoplasm, child neoplasm, place of death, and location of death. Customized searches were conducted in CINAHL, Medline, Embase, and PsycINFO databases in December 2020, and updated in December 2021. The search strategy is detailed in Table S1.

2.2 | Selection criteria

2.2.1 | Inclusion criteria

Studies utilizing qualitative methodology to investigate parents' experiences of providing end-of-life care to children aged 0–18 years with advanced cancer are included. Studies of mixed method methodology were eligible, but only qualitative data were synthesized. Studies with parents of children with malignant and nonmalignant diagnoses are included but only qualitative data on children with cancer were synthesized. The original search was undertaken in November 2020 and updated in December 2021 and included studies published between January 2000 and November 2021.

2.2.2 | Exclusion criteria

Studies reporting only quantitative data were excluded. Studies that investigated only the health professional experience of end-of-life care for children with cancer were excluded, and qualitative studies with no primary data (i.e., verbatim quotes from parents) were excluded. Studies not written in English and published before the year 2000 were also excluded.

2.2.3 | Screening

Titles and abstracts of all sourced articles were imported into EndNote with duplicates removed. Two reviewers (MN and NB) independently screened the titles and abstracts to identify studies that potentially met selection criteria. Differences in opinion were resolved through discussion. One reviewer (Michelle Noyes) screened full text. Where there was uncertainty about inclusion, the full text was reviewed by a second reviewer (NB) and both reviewers came to agreement through discussion. The reference lists of included studies were screened by one reviewer (MN) for potential studies not identified in the initial search strategy.

2.3 | Data extraction and analysis

Data from each included study were extracted by one reviewer (MN) into an Excel spreadsheet. Major categories of extraction included general study information, geographical location of study, research aim, participant characteristics, study design, data collection methods, ethical considerations, primary data (verbatim quotes), and study findings. Two types of analyses were used: (a) a narrative synthesis of the studies, including their aims, methods, population, and methodological quality; and (b) a thematic analysis of available data within included studies. Direct quotes from parents are presented in indented italics to distinguish quotes from written text, referenced by the study from which quotes were extracted.

Thematic analysis is an established method for systematic qualitative reviews to bring together and incorporate the findings of numerous qualitative studies.¹⁵ To facilitate analysis of raw data, one reviewer (MN) read all included papers at least twice to familiarize the reviewer with the data relevant to the aims of the review. Verbatim quotes directly addressing decision-making about the location of end-of-life care and death were grouped into categories. The same process was utilized to extract raw data about parental experiences of their child's end-of-life care and death. Themes were generated by organizing categories into groups. Discussion between reviewers and reflection on the categories and themes continued until consensus was reached.

2.4 | Quality appraisal

The quality appraisal of each included study was undertaken using the qualitative checklist from the Critical Appraisal Assessment Programme (CASP).¹⁶ This generic tool assists with appraising the strengths and limitations of qualitative research with 10 questions that focus on validity, results, and clinical relevance.¹⁶

Nine of the 10 CASP questions were used to evaluate the quality of each study, with an additional question added to identify if the study reported on the location of end-of-life care for children of study participants. A scoring system was followed to enable studies to be classified as low, moderate, or high quality. Each question was scored 0–2, with a score of 0 = no information, 1 = unclear, and 2 = complete to give a score out of 20, with higher scores indicating higher quality. No studies were excluded based on their quality appraisal.

3 | RESULTS

3.1 | Included studies

After searches and screening, 17 manuscripts were identified as meeting eligibility criteria from 15 unique studies representing experiences of 461 parents and 333 children (Figure 1). Four studies were undertaken in the United States,^{17–20} one from the United States and Canada,²¹ four from the United Kingdom,^{22–25} two from the Netherlands (four manuscripts),^{26–29} and one study each from France,³⁰ Greece,³¹ Japan,³² and Taiwan.³³ Nine studies were conducted in an individual cancer center and seven were multicenter studies. Table S2 summarizes the included studies. One study included data on adolescents and young adults aged 15–25 years, as over half represented adolescents were aged 15–18 years, the relevant data from this study was included.³⁰ Three studies^{23,29,31} included parents of children with malignant and nonmalignant conditions and only qualitative data from children who died from cancer were extracted and synthesized.

3.2 | Design and quality of included studies

Most studies (9/15, 60%) were rated as high quality according to the CASP appraisal tool,¹⁶ with the remaining six studies rated at a moderate quality. Table S3 details the quality ratings for each study. Most studies ($n = 12$, 71%) were retrospective in nature, with data collected from parents whose child had previously died. Two studies were mixed retrospective and prospective designs,^{28,29} including both bereaved parents and parents whose child was receiving palliative care at the time of study. One study was the first prospective interventional study to evaluate a communication intervention for parents of children with poor-prognosis brain tumors.¹⁷ The communication intervention, delivered by oncologist and specialist oncology nurse, included three sessions delivered shortly after diagnosis and during two sessions at clinic reviews. Content in the communication intervention focused on early palliative/end-of-life care discussions at diagnosis and after tumor response evaluations.

The range of years of follow-up after a child's death varied greatly across studies from 6 months to 12 years. Three studies^{18,20,30} did not report how many years follow-up occurred after the child's death. One study did restrict eligibility based on this criterion to reduce the bias of memory perception over time, only including parents whose child had died in the previous 2 years.²⁴ Another study recognized the limitation that participants were 3–12 years removed from their child's death and that parents' recount of events and emotions may be influenced by the coping mechanisms they have used.²⁵

3.3 | Participant characteristics of included studies

The demographic data reported varied significantly across studies. Three studies did not report numbers of mothers and fathers participating in studies, reporting participants as parents, families, or couples.^{19,22,29} Of the studies that did report these data, 232 mothers and 140 fathers were represented across 12 studies. The sample size was generally small, common to qualitative studies, with participant numbers varying from five to 131. The largest study of 131 participants utilized an online questionnaire.²⁰

There were 333 children represented with inconsistent reporting on ages of children at death. One study limited recruitment to parents of children who were over the age of 10 years at the time of death with the age limit intended to balance sampling variability homogeneity.¹⁸ The reporting on types of cancers was also inconsistent across studies, with five not providing any details of a cancer diagnosis. Of the studies that did report cancer type, 91 children died from brain tumors and 52 from blood cancers, including leukemia. This sample is reflective of international data with brain tumors and leukemia the leading cause of cancer death in children in developed nations.³⁴

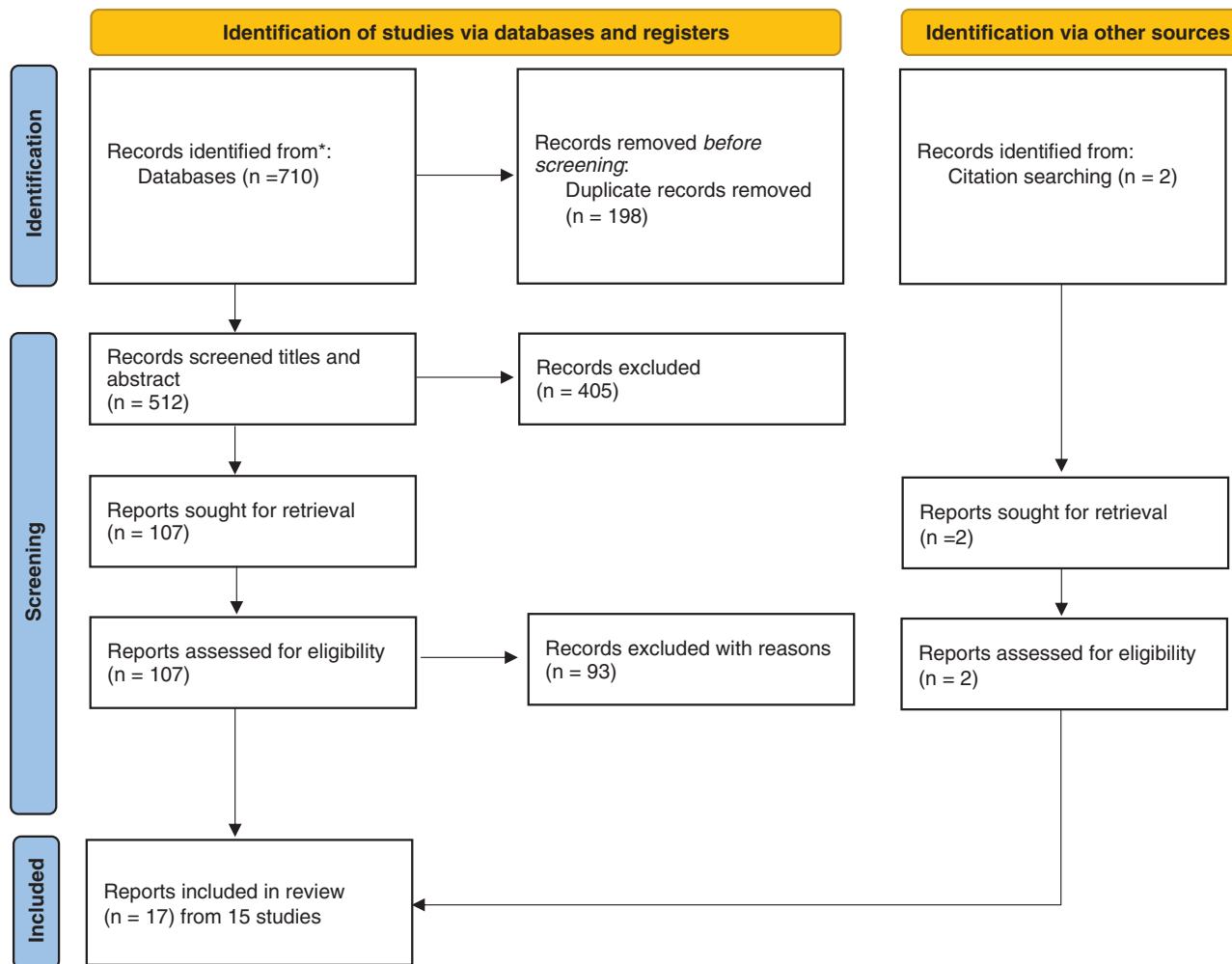


FIGURE 1 PRISMA flow diagram

3.4 | Method of data collection and analysis for included studies

Most studies ($n = 12$, 80%) used face-to-face semistructured interviews to obtain data. Interviews ranged in length of duration from 30 minutes to 2 hours. Only one study reported interviews less than 1 hour in duration; this study reported on a communication intervention for end-of-life care and therefore the interview was more structured with specific questions.¹⁷ Two studies used focus groups for data collection,^{18,25} with only one of these reporting facilitators of focus groups having expertise in focus group methods.¹⁸ One larger study collected data through the social media platform Facebook, conducting an online questionnaire to obtain quantitative and qualitative data.²⁰ Qualitative data were collected through a single open-ended question included in the questionnaire asking, "If you didn't feel prepared for the kind of medical and emotional problems the child experienced at end-of-life phase, what would have been helpful?"²⁰

A variety of qualitative methods were used to analyze data, including grounded theory analysis,^{26,28,29,31} thematic analysis,^{19,20,24,25,30}

content analysis,^{17,18,21} phenomenology,^{22,33} and use of a conceptual analytical framework.²³ Management of data was consistent across studies, with all reporting audio recording of interviews and transcription of interviews verbatim.

3.5 | Location of death

Eleven studies specifically explored parents' experiences of providing end-of-life care. The location of death was reported in 10 studies. Of these 224 deaths, 130 (58%) deaths occurred at home, 89 (39%) in hospital, and five (2%) in a free-standing hospice.^{19,20,22–24,28–31,33} Four studies had hospice as an option for location of death,^{20,22–24} with only single study reporting deaths in a hospice.²⁰ One further study included parent experiences of providing end-of-life care at home and in hospital but did not report the location of death.²⁵

Of the studies that did not report the location of end-of-life care or death, four addressed parents' experiences of providing end-of-life care, and their comments provided insight into decisions that impacted

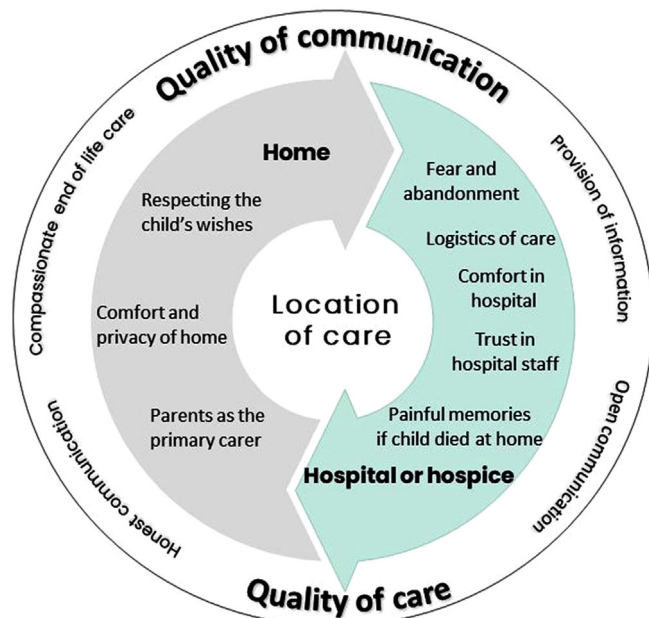


FIGURE 2 Thematic analysis of factors influencing the location of end-of-life care

the location of death, and therefore raw data from these studies are included.^{18,21,29,32}

3.6 | Thematic analysis of qualitative data of included studies

The overarching phenomena of how parents chose the location of end-of-life care for their child was influenced by (a) the quality of communication, and (b) the quality of care received. These factors were interwoven with eight themes that influence parents' decision-making and the overall experience of providing end-of-life care to their child. Each of these themes is presented with supporting quotes below and illustrated in Figure 2.

3.7 | Location of care

There were 76 parent quotes from 13 studies focussing on the choice of location of death, with 59 quotes directly addressing why parents did or did not choose home as the preferred location. Not all parents reported having a choice in the location for their child's end-of-life care and death, reasons included a lack of time for decision-making.^{30,31}

Things developed very fast, and we didn't know how to assume the care at home...I didn't expect this turnout. He died so suddenly, like in a road traffic accident.³¹

Through the synthesis of data from studies where parents did choose the location for end-of-life care, themes surrounding choice for home included respecting the child's wishes; familiarity of home, including presence of siblings; and parents' desire to be their child's primary carer.

3.7.1 | Respecting the child's wishes

He just wanted to be at home. We decided to go home because we didn't know how long we had. Just dismal, the thought of him being in a little room...there's nothing there to amuse him... you don't have his brothers and sisters around.²²

They gave me the option of letting [child] stay at the hospital if he wanted to, or if he wanted, to come to the house. And he told the doctor that he wanted to come home.¹⁹

3.7.2 | Comfort and privacy of home

Being at home with family was the best for her, I knew it. That's why I wouldn't let her stay in the hospital. It was the priority to think about what she wanted or hated. It was a big contradiction not to do it for the last time. It's nothing.³²

The day [another child] died, we were in for chemo, and I thought she's dying in there and there was nothing personal, there were kids running up and down and people laughing. There was no peace, how would they take the body out ... and the parents had nowhere to go to be alone, to hold each other.²⁴

The idea of your child dying in a strange setting, however, well they know everybody, is not the same as being at home, so I have got very mixed feelings about children's hospices.²⁴

3.7.3 | Parents as primary carer

When you are at home you can shut the door and no one is telling you that your child is ill, when we brought [child] home, that was our time.²⁴

I think if we'd have been in hospital, we would have lost that control. We'd have been told what to do instead of we are telling what to do; we had the choice of whether we had the nurse or not ... I think we'd done enough living by hospital rules.²⁴

Themes identified for not choosing home for end-of-life care included fear and abandonment and living with the memory of the child dying in the family home.

3.7.4 | Fear and abandonment

My other son had died at home, and I'd cocked it up a bit...I panicked at the end...so I didn't quite trust myself to do it right the second time, at home. I needed someone there...who would say it's alright for him to go.²²

I feared regretting not doing the right thing, not knowing what to do, anything could have happened, I wouldn't have known what to do.³⁰

Too frail to be at home; when he was really ill, we preferred him to be in hospital; I would have been worried to keep him at home in that condition. I didn't want to make a blunder.³⁰

When they suggested home care, we felt that there was no longer any hope of recovery. We felt rejected because there was no hope of recovery.³⁰

And the biggest thing I felt, I felt a little abandoned, not when we were in; this was when we were at home.²⁵

3.7.5 | Painful memories if the child died at home

I wouldn't have been able to stay in this house afterwards...there would have been too many memories... I didn't want to keep this image of a dead child in the house. What would I have done afterwards? Every day I would have had this image of the house, the time of his death, what could I do after that.³⁰

In synthesizing the data from studies reporting on parents' choice of a hospital as the location for their child's end-of-life care, themes included trust in hospital staff to manage symptoms, practical logistics of care, protecting siblings, and the ward environment. When the hos-

pital was the chosen location, two studies addressed the importance of the right location within the hospital setting.^{32,33} The opportunity to plan for the child's impending death is associated with favorable outcomes, including death in the desired location.⁸ The direct parent quotes provide examples of parental choice for hospital care for the location of end-of-life care and death.

3.7.6 | Trust in hospital staff

Everything about it was safe, 'cos we knew the nurses, Matthew knew the nurses, the nurses knew us.²²

I love [treating hospital]. They're really good with kids and also the parents...If I didn't have them there, I think I wouldn't have done anything or couldn't have survived that. When [child] passed away, all the doctors, the nurses, and everybody, they just came downstairs and they hugged me, and they kissed [child] goodbye. I keep that memory that they came for us. They didn't care they were busy at that time. They just came down to say goodbye.²¹

3.7.7 | Logistics of care

He was a huge boy... I'm only a scant 5 foot, 2 inches... if he had fallen, I couldn't even have picked him up.²²

We wouldn't be able to offer at home what professionals could offer at the hospital. I have no doubt about it. She underwent two mini surgeries at the end of her life because she couldn't urinate... I couldn't listen to her being in pain.³¹

We had to protect his brothers and sisters.³⁰

3.7.8 | Comfort in hospital

He would not be able to see his family as much as he was in PICU [pediatric intensive care unit]. So, I decided to let him move back to the general ward to be with friends, nurses, and doctors. It was the least I could do for him.³²

My wife and I both had a thought...that was to make every day as the last day, and to treasure the last moment we might spend with our child... We created a home at

*the hospital, almost the same as our home. *She started to ask for things; like her doll umbrella, nail polish, etc., and she kept saying that she would bring these with her. We left those items by her side for the last week, so she might have her beloved items by her side when she left the world.³³*

3.8 | Quality of communication

Communication was a key factor raised by parents in all 15 studies, in particular how information was communicated by healthcare providers during the child's end-of-life phase. This included the timing of communication, who delivered the information, and how it was delivered. There were more than 50 quotes addressing conversations and meetings with healthcare providers.

Parents requested open, honest, and direct communication from healthcare providers they trusted. Receiving open and honest communication helped parents to anticipate what was next and gave them time to prioritize what was important. Parents who received direct and honest information, spoke of being better able to prepare for their child's approaching death.

3.8.1 | Open and honest communication

At the end of the conference, I asked once again, doctor... you say a few weeks, but to me, a few weeks is two weeks, but also ten weeks. Which is it more likely to be?... Well, he says, think closer to two weeks. And at that moment I was very calm because I had an answer because I knew how to plan emotionally.... The time to say goodbye has begun. And saying these goodbyes, if you know ahead of time that you have two weeks or ten weeks, then you start to fill in that time differently.²⁸

I always wanted to know... if this happens where do we go, and if this happens where do we go.²¹

I wanted to get everything and be informed of everything. The communication was very good. I mean, they are very easy to understand, and they just say it in words that I can understand what is going on. It was like [MD-RN] asked if you have any questions and, 'What can I do to help in anything?'¹⁷

I liked the written session forms. It is something I can put into the binder and refer to and also it helped me explain to

my family about what's going on, in doctor terms versus my terms, what I remember, so these were helpful.¹⁷

I liked the MDs and RN's strong understanding and knowledge of what was going on they are there to help me, so it was very good.¹⁷

We needed information about what happens to the child's body... specific information about the things no one wants to talk about, but we face and need to know.²⁰

3.8.2 | Provision of information

Parents who reported receiving inadequate information from healthcare providers expressed feeling less able to prepare for their child's death, including the location of care and were uncertain of what to expect during the terminal phase.

When they tell you... There's nothing we can do, then you kind of wonder, 'What is it going to be like? What are the changes? ... It didn't seem like we had a lot of information about what it would be like.'²¹

We were prepared to talk about [death]. They were not ... We never got to the part where they said, would you want us to talk with [child]?¹⁸

Our son had lost the ability to talk and communicate. We pretty much knew where we were but no one ... told us. I finally called a time out and said, I'd like to speak to you, doctor ... I felt no one was ready and available. I had to ask the question We gotta [sic] know.¹⁸

We wanted to have family come but didn't have time because the team didn't talk with us about what to expect or tell us we should prepare family.²⁰

3.9 | Quality of care

In the reviewed studies, parents spoke of experiences at home and in hospitals that made caring for their child difficult and exacerbated their distress and suffering. These experiences were connected to the quality of end-of-life care parents perceived their child received from healthcare providers, the management of distressing symptoms, and coordination of care.

3.9.1 | Quality of end-of-life care in hospital

*Sometimes it was annoying... Nurses who don't know how to set up an infusion... It took four of them to do it.*³⁰

*Hospitals are busy with production. So, a nurse comes in, and basically jumps on the child to take his blood pressure, or give an injection, without paying attention to what it does to him. And I often wonder: How hard can it be to ask yourself beforehand how to approach this individual child, so that he understands the intervention?*²⁶

*The [inpatient nurses] were wonderful but ran ... from one patient to the next, ... going 90 miles an hour, trying to keep up.*¹⁸

*My child was heavily medicated during his final days. I had to seek them out (psychologist and other team members) to talk to not the other way around.*²⁰

*I think they were panicking a bit; they didn't quite know how to control it... we were all trying to hold him down - he was rearing up like a demon, it's absolutely horrendous.*²²

*Near the end of his life, [child] was in pain. The doctor came with a student, and asked, 'when do you think we should give him this amount or the other?' I was very disappointed. You have to consider that this child is in pain. If you want to ask this question [of the student], get out. It should be you and a doctor.*¹⁸

*We didn't know what to do, we were sitting at her bed, and we were panicking because she kept screaming, and we couldn't calm her down. So, the nurse suggested to wait in the hallway, but every time the door opened, we heard her screaming again. [...] and at that time, I didn't understand why they wouldn't do anything and kept thinking, how is it possible that we are in an ICU, and no one does anything?*²⁶

When end-of-life care was provided at home, four studies reported that parents experienced differences in the expertise of healthcare providers, with more generalist care provided in the home and specialist oncology care in hospital.^{19,22,25,28} Parents spoke of frustrations around access to staff and supply of medications at critical time points

during end-of-life care at home. The quotes demonstrate the importance of meticulous planning and coordination of care during the terminal phase of care.

3.9.2 | Quality of end-of-life care at home

*At home, I remember a few times being frustrated, being so far away, trying to reach somebody, and not being able to get [the doctor]. We didn't know who to call or talk to. We had emergencies about vomiting.*¹⁹

*I look back and I don't know what I was thinking. I would have hired private duty, but the response I got, 'Well you're the mother, you're the parents, don't you want to take care of your child?' Cause I was thinking I needed to bring her to the hospital because she was having trouble breathing. Her death was bad. I can't say she had a good death.*¹⁹

*Waiting for people to answer voicemails and to have the time to come assess her, is waiting too long. We needed the pain and sedation meds at my home BEFORE she needed them.*²⁰

Linked closely to parents' perception of healthcare providers' competence in delivering end-of-life care, was the constant reference by parents to how healthcare providers interacted with families and the need for compassionate end-of-life care in both hospital and home. In particular, compassionate care that focuses on the unique individual personality of each child and care that goes beyond just treating the symptoms of the disease.

3.9.3 | Compassionate end-of-life care

*In [ICU], ... you got a lot of special attention and that meant the world to us. The nurse could just sit there to make him comfortable, even though we were there.... That meant the most to us at that point in time—to have a lot of support right there, compassionate people.*¹⁸

*We need doctors, nurses, and social workers who truly understand what this is like for the child and family. Too often we were made to feel that we were being too demanding. My son suffered too much and was never treated as the courageous young man he was.*²⁰

*A father stated you don't want to think that your child is just a patient at a hospital. Treat them more as an individual... rather than just a patient on a clipboard.*²¹

*These kids are dying, and they know they are dying. Some of them [healthcare providers] need to be more compassionate.*²¹

*One physician had a big impact on me. We had to go home, and she said goodbye to my son. She started crying and apologized: 'I'm so sorry, I'm being very unprofessional.' And I: No, right now, you are human. I wonder if she knows that of all those doctors, she is the only one that crosses my mind frequently. Because she cared.*²⁶

4 | DISCUSSION

This review synthesized the available evidence that describes parents' experiences and perceptions of decision-making for the location of end-of-life care and death of children with advanced cancer. Across the 15 included studies, nine provided information regarding the location of death, with 58% of children dying at home, 39% in hospital, and just 2% in a free-standing hospice. Parents who chose to care for their child at home did so to respect their child's wishes and maintain their role as the primary caregiver in the comfort and privacy of their home, which included time spent with siblings. Other parents' preferred hospital for end-of-life care because of (a) the logistical challenges of home care, including difficult symptoms, which they perceived could be better and more safely managed in hospital; (b) fear of abandonment in the home setting when there were skilled healthcare providers parents trusted available at the hospital; and (c) avoidance of painful memories if the child died at home, including protecting siblings. For families with separated parents, hospital or care in a free-standing hospice may also offer a neutral territory and avoid challenges of moving the location of care between households.

Regardless of the location of end-of-life care, the provision of information with open and honest communication and compassionate and quality care delivered by known and trusted healthcare providers positively supported parents in their decision-making. Healthcare providers were commonly known to parents and included both oncology and palliative care clinicians. Optimal communication may be best facilitated when teams communicate both with each other as well as with families.³⁵ Parents were able to prioritize their goals and were better equipped to support the needs of their dying child and other family members. The factors that negatively impacted end-of-life decision-making for parents included poor communication and information exchange contributing to fears of the unknown, lack of services and available staff, leading to feelings of abandonment and poorly controlled symptoms.

These findings support and build on results from an earlier qualitative review by Heinze and Nolan (2012), which examined the research on parental decision-making at end-of-life, with communication, extending time, and understanding prognosis emerging as the themes of the published literature at that time.¹¹ Nearly 10 years on from this initial literature review on parental decision-making at end-of-life, there is a growing body of research emerging around the provision of direct and honest communication at the time of diagnosis for parents of children who have a poor chance of cure, including how the information about prognosis is used by parents.^{36,37} From this emerging research stems the recommendation for early referral to specialist pediatric palliative care services at the beginning of the child's cancer experience for those with high-risk disease and uncertain outcomes.^{37,38}

Access to palliative care services provides a time and space for information exchange, discussion of options, and clarification of goals of care, which may include preference of location for care.³⁰ This provides parents with time to prepare, as well as facilitating communication and decision-making, early referral provides healthcare providers time to plan and avoid a rapid hospital discharge, where there may be difficulties organizing home care services. Having adequate time to plan equipment required for home care, medication supply, and community nursing support can foster a sense of safety and confidence for the family who chooses end-of-life care for their child at home.¹⁴ For deaths in hospitals, involvement of palliative care teams is associated with fewer deaths in the intensive care unit, and better outcomes consistent with high-quality palliative care provision.⁸

There are, however, barriers to implementing early referral to palliative care for children with cancer, including healthcare provider and parent misconceptions of the philosophy of pediatric palliative care and parents' acknowledgment and acceptance of the child's disease and uncertain future.³⁸ Sociodemographic factors may also influence equity of access to pediatric palliative or hospice services. Additionally, there are also inherent differences between children with relapsed or progressive disease, where death may be anticipated and those who experience complications related to treatment that may rapidly deteriorate or not respond to supportive care. In such instances, there may be little opportunity to transfer to different settings.

The term palliative care is often misinterpreted as care given to those in the very terminal phase of the disease and those actively dying. Pediatric palliative care is coordinated interdisciplinary care delivered where possible in the environment of the child and family's choice. Importantly, the principles and philosophy of care can be delivered in parallel with treatment delivered with curative intent, providing physical, social, emotional, spiritual, and practical support for the child, their family, community, and friends.^{39,40} It is essential that healthcare providers working with children with cancer have accurate knowledge of the principles and philosophy of pediatric palliative care to provide advocacy for early referral to interprofessional palliative care teams and to assist in allaying misconceptions.^{41,42} It must also be acknowledged, however, that in certain geographical locations, even in developed nations, there may be very limited pediatric palliative or hospice

services available to support families, particularly in the home or community setting.⁴³

It is also important to recognize that every child and family is different and that each will have a different view on location for end-of-life care, with there being no right or wrong place. The importance of considering the needs of siblings was evident in several studies, with parents voicing their concerns about the short- and long-term impact of their child's death on siblings.^{18,19,21,30-32} Absent from the literature however were discussions about the impact of other socioeconomic factors, such as poverty or safety when geographically isolated. Moreover, it is important to distinguish between the location where most time is spent *before* death, and the location of death; health-care providers play an important role in supporting families to frame location in terms of what is important to each individual family context. Location is not the only determinant outcome; planning for the child's end-of-life, and creating memories with a focus on "no regrets" positively impacts the quality of end-of-life care the family receives.⁸ Where families do choose to care for their child at home, maintaining a connection to the hospital, treating oncologists and broader care teams may reduce potential feelings of abandonment and promote empowerment. This can be facilitated through home visits, phone calls, and increasingly through video calls and telehealth consultations.^{40,44} Resourcing for such care, including staff time and funds for home care support, has previously demonstrated value in terms of costs versus benefit and should be routinely offered.^{44,45}

The evidence from previously published literature and this current review suggests that children with oncology diagnoses are not frequent users of free-standing children's hospices.⁶ Free-standing children's hospices are not universally available, with the exception of the United Kingdom, where there are now over 40 operational facilities.⁴ In comparison, in Australia there are just three children's hospices,⁴⁶ and in the United States with few dedicated children's hospices, it is more common for children to receive home-based palliative care services.⁴⁷ As healthcare systems differ around the world, making direct comparisons between nations is thus difficult, and not necessarily appropriate.⁴⁸ The anecdotal experience of the authors, however, suggests more families of children with cancer are now utilizing free-standing children's hospices than what is currently reported in the literature. This may be due to relationships established between healthcare providers and the hospice, or because of unique facilities offered at the hospices. These facilities can include 24-hour nursing care, home-like accommodation for the whole family, and an after-death care suite. The provision of after-death care enables the family to continue to be with the deceased child, receive bereavement support, and if required, assistance to plan the child's funeral. None of these factors were described in any of the studies reviewed.

4.1 | Limitations and strengths

There are limitations to this systematic qualitative review. There was only a partial geographical representation of parents' experiences with studies from 10 high-income countries. There were no qualitative

studies from Australia, Africa, or South America. Further research is required to include a broader representation of parents' experiences of end-of-life care across all geographical locations, nations' wealth, and ethnic backgrounds.

A second limitation is the underrepresentation of parents who may access hospices for their child's end-of-life care. Further research is required to understand the role of children's hospices for end-of-life care for children with oncology diagnoses.

We included one study that was not a qualitative study, but that included one open-ended question within a survey.²⁰ While methodologically different to the other included studies, we elected to include this study as it provided relevant verbatim quotes from parents relevant to the study objectives.

While the search strategy was broad, we may have missed relevant studies, and as we only included studies published in English, there may be relevant studies not included. Despite this, this is the first review to systematically appraise and collate the qualitative evidence of parents' experience of end-of-life care for children with cancer. The narrative voice of parents provides an experience-based understanding of the important factors to consider when preparing for a child's end-of-life care.

4.2 | Clinical implications

Pediatric palliative care education programs are important strategies to expand understanding of the principles and philosophy of palliative care outside the hospital environments to the wider healthcare community. This includes communication training for healthcare providers caring for children with life-threatening diagnosis such as cancer, which is imperative to optimize conversations with children, young people, and families and ensure goals of care and choice in place of care are identified.⁴⁹ Empirical research highlights the importance of soliciting the families' agenda during consultations, as well as initiating and maintaining discussion about deterioration.⁵⁰ Utilizing technology-based communication is an increasingly acceptable mechanism to facilitate this.⁵¹

While there is an increasing focus on the development and delivery of pediatric palliative care training courses, these programs need to include a further emphasis on the importance of compassionate end-of-life care across different locations. This could be achieved through including bereaved parents and siblings in co-designing palliative care education training to give further voice to the lived experiences of children and their families.⁵²

5 | CONCLUSION

Important insights are gained through reflecting on the experiences of parents whose children have died, and these can help guide healthcare services and inform service development. Planning for the location of end-of-life care requires clear and honest communication between healthcare providers and parents, which includes information about

what supports are available in the home, hospice, or hospital. Early referral and implementation of palliative care for children with high-risk cancers may assist families to prioritize goals and provide additional interprofessional expertise to achieve optimal quality of life for the child and their family. This may contribute to improved communication regarding end-of-life decision-making, including planning for the location of end-of-life care.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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