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## Experiences with the end-of-life decision-making process in children with cancer, their parents, and healthcare professionals: A systematic review and meta-ethnography

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## ABSTRACT

**Background:** Decision-making during the end-of-life (EOL) phase for children with cancer is extremely difficult for parents. We synthesized the qualitative experiences of children with cancer, parents, and healthcare professionals (HCPs), and their social interactions during the EOL decision-making process in the pediatric oncology setting.

**Methods:** Meta-ethnography was used to conduct a systematic review and meta-synthesis. We searched four online databases to identify original studies published in English and Japanese and examined 21 relevant studies. Two Japanese reviewers discussed the differences/relationships and included studies that synthesized the translated qualitative findings. A conceptual model of social interactions was created.

**Results:** We identified four themes regarding children's, parents', and HCPs' experiences: hope and confrontation with the child's death, guidance and support during uncertainty, awareness of being protected and having hope, and mutual unspoken integration of values.

**Conclusions:** These themes evince the experiences of children, parents, and HCPs during the EOL decision-making process and suggests a complex three-way social interaction model. While considering such distinctive social interactions during a child's EOL, this study revealed the sharing of prudent information and psychosocial support by HCPs. The findings indicate that hope and uncertainty are key elements for effectively understanding the experiences of children and parents and that EOL decision-making should not be rushed but should be supported by leaving room for uncertainty and acknowledging parents' emotional needs and fostering new hope. Further research into how hope can be further supported in situations that are rife with uncertainty is needed.

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## Introduction

Over the past 30 years, the five-year survival rate for pediatric cancers has improved to 70–80% in advanced countries (Katanoda et al., 2017). However, cancer remains the leading cause of death among children aged 1–19 years worldwide; approximately 350 cancer-related deaths were reported in Japan in 2021, the most recent year for which data are available (Ministry of Health, Labour and Welfare, 2021).

Dying children require attentive end-of-life (EOL) care since they experience several unbearable symptoms in a situation wherein death is inevitable (Heath et al., 2010; Hongo et al., 2003; Montgomery et al., 2020). Parents are also in a state of extreme psychological and physical distress (Boyden et al., 2021; Collins et al., 2016). Daily anxiety

about child loss, confrontation with loss, and tension regarding EOL decisions were reported as a source of prominent distress during the child's EOL phase (Verberne et al., 2019), with parents facing considerable challenges in making EOL decisions (Matsuoka & Narama, 2012). The provision of support for decision-making is of paramount importance in this context (Hirata & Kobayashi, 2020). EOL decision-making entails the consideration of various domains and scopes, including treatment and symptom management that affect the duration of survival and the child's quality of life (QOL) (Michelson & Steinhorn, 2007; Nagoya, Shiwaku, & Suzuki, 2014; van Loenhout et al., 2015); decisions about whether a painful procedure and examination should be performed (Mariyana et al., 2018); choosing the location for the child's EOL phase and last moments (Gao et al., 2016); engaging in daily life events that can improve growth and QOL (Friedrichsdorf et al., 2015); having a conversation with the dying child and his/her siblings about the truth of the patient's condition and prognosis (Hudson et al., 2019; Rosenberg et al., 2017); and discussing family, life, and role

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changes (Nakano, 2013). Therefore, decisions parents make have a significant impact on the comfort and QOL of their dying child (Kars et al., 2011; Tomlinson et al., 2011) and the well-being of surviving family members (Jalmsell et al., 2010; Kreicbergs et al., 2004).

Decision-making during the EOL period for children with cancer is the most challenging aspect for parents (Carroll et al., 2012; Hinds et al., 2001). Wyatt et al. (2015) indicated that shared decision-making interventions, based on a partnership with the children and families, significantly improved knowledge and reduced decisional conflict. However, in their review, Wyatt et al. (2015) reported that interventions rarely targeted patients (i.e., children) and focused mainly on parents; the number of shared decision-making interventions in pediatrics was small and did not show consistent effects on child-centered outcomes. Despite statements from the United Nations affirming a child's right to express their views and be involved in decisions, shared decision-making interventions still did not attempt to empower children with a voice.

In the EOL context, honestly telling the child that severe medical ramifications and death are inevitable could be difficult. That both parents and healthcare professionals (HCPs) would directly ask the child's opinion regarding important decisions in this context is unlikely. Both the parents and HCPs believe that if they honestly tell the child about their poor prognosis or severe medical conditions, the child will lose the will to live or will not be able to cope with the situation (Bates & Kearney, 2015; van der Geest et al., 2015). In addition, several barriers have been reported as reasons for the difficulties encountered by HCPs, such as the lack of communication skills and training, limited time available to prepare for discussions, and the feeling that patients or parents are not ready for discussion (Stein et al., 2019). Additionally, understanding how children's experiences impact shared decision-making between HCPs and parents is often difficult.

A systematic review of the barriers and facilitators of shared decision-making in pediatric care (Boland et al., 2019) found that the features of the treatment options, poor quality of information, emotional state of parents and the child, power dynamics, and insufficient time were the most common obstacles. Therefore, implementing shared decision-making remains particularly challenging in the EOL context. Parents and children are required to make difficult treatment decisions related to survival or death.

Our research questions were as follows:

1. What are the experiences related to the EOL decision-making process for children with cancer?
2. What are the experiences related to the parents' EOL decision-making process as surrogate decision-makers for children with cancer?
3. What are the experiences related to EOL decision-making for HCPs responsible for the treatment and/or nursing care for children with cancer?
4. Is there a distinctive social interaction between the experiences of children, parents, and HCPs in the EOL decision-making process?

## Methods

### Study design

We used the meta-ethnography technique for the synthesis of qualitative evidence. Meta-ethnography is a seven-phase, theory-based, and potentially theory-generating interpretive methodology for qualitative evidence synthesis, which was developed by two sociologists, Noblit and Hare (1988). It enables a more interpretive literature review; critical examination of multiple accounts of an event or situation; systematic comparison of case studies to facilitate cross-case conclusions; and discussion of a single study and its comparison with prior research. The process of meta-ethnography aims to facilitate a greater understanding of a social phenomenon by synthesizing the findings of

qualitative studies and retaining the rich context of the data through a seven-stage process (Noblit & Hare, 1988). It is designed to develop new overarching concepts and theories with an emphasis on preserving original contexts within the synthesis of data from multiple studies (France, Cunningham, et al., 2019). Because of these methodological strengths, meta-ethnography is among the most frequently used and influential methodologies for qualitative evidence synthesis in health and social care research (Dixon-Woods et al., 2005; France, Uny, et al., 2019). The volume of published meta-ethnographies has increased rapidly in recent years since this research methodology has improved the understanding of patient experiences regarding various health conditions and services (France, Cunningham, et al., 2019). Therefore, meta-ethnography is appropriate for the profound process entailing interpretation and integration of the experiences of the child, parents, and HCPs in the context of EOL decision-making.

### Eligibility criteria

This review comprised qualitative studies published in peer-reviewed journals in English and Japanese between January 1990 and March 2019. We used the "population," "phenomena of interest," and "context" (PICo) framework for the selection process since it is recommended for the meta-synthesis of qualitative studies according to the JBI (Aromataris & Munn, 2020), as the research questions in qualitative studies do not prove the effectiveness of an intervention.

### Types of study populations

In our review, we included studies that targeted children with cancer at the EOL stage, who were aged below 18 years (except for neonates and including adolescents aged 12–17 years), their parents, and HCPs responsible for the treatment and/or nursing of children with cancer at the EOL stage.

### Phenomena of interest and context

We focused on the experiences of the child, parents, and HCPs during the EOL decision-making process. We included the context of EOL discussions and the EOL decision-making experiences related to daily life events, family life and familial roles, treatment and symptom management, place of death, and telling the dying child the truth about their condition and prognosis.

### Information sources

We searched four online databases (PubMed, CINAHL, PsycINFO, and Ichushi) to identify primary peer-reviewed studies that explored experiences related to the EOL decision-making process.

### Search strategy and screening

The Medical Subject Headings terms (pediatric OR children OR child) AND (tumor OR lymphoma OR leukemia OR malignant OR hematology OR oncology OR cancer) AND (dying OR hospice OR terminal OR palliative OR end-of-life) AND (decision making) were used for the database search. Additionally, we employed citation tracking and manual searching. Two Japanese reviewers, M.H. and K.K., independently screened the titles and abstracts, followed by full-text screening. Disagreements during the selection process were resolved by discussion between M.H. and K.K. until a consensus was reached.

### Quality assessment

All eligible qualitative studies that met the inclusion criteria were independently appraised by two reviewers, M.H. and K.K., using the Critical Appraisal Skills Programme (CASP) qualitative research

checklist (CASP, 2018). This assessment tool has been used in numerous published reviews of qualitative studies (Bootsma et al., 2019; De Souza et al., 2020; Kelly et al., 2018).

#### Data extraction and synthesis

The primary reviewer extracted the following data from the selected studies: title, authors, year of publication, research objectives, design/method, samples, country of origin (of study), and critical findings. Two reviewers enumerated and discussed the differences/relationships between studies; translated the studies into English (if required); and separately synthesized the translated qualitative findings regarding the experiences of children, parents, and HCPs. Subsequently, three-way social interactions were interpreted from each experience, and a conceptual model of the interaction was created. Any disagreements regarding the themes, categories, and subcategories were discussed until an agreement was reached. In the review process, member checking was undertaken by doctoral students and qualitative researchers to ensure reliability. This study was approved by our institutional review board, and no informed consent was required as this was a systematic review of previously published research.

#### Ensuring trustworthiness

This review integrated qualitative research, interpreted the results of each study, and extracted new findings. However, the experiences, values, and cultures of different researchers may influence their interpretation. The primary reviewer has worked in EOL care for over 25 years in Japan and in the U.K. as a certified nurse specialist in child health nursing. Clinical experience is advantageous since it lends depth to interpretation and the selection of included studies. The second reviewer, a senior researcher with more than five years of pediatric oncology nursing experience in the clinical setting as well as 15 years of experience in pediatric oncology nursing research, with specific experience in research using meta-ethnography, had an in-depth understanding of the methodology and focused on this aspect of the literature review. Therefore, we capitalized on the strengths of the two reviewers while conducting the selection of the studies and the data analysis to address the research questions and attempted to ensure the trustworthiness of the data by implementing member checking (Morse et al., 2002).

## Results

#### Search and study characteristics

A total of 511 potentially relevant studies were identified by the electronic search, and 49 duplicate studies were eliminated. Of the remaining 462 studies, 403 were excluded during the title and abstract review. The remaining 59 studies were perused independently by the two reviewers, and 39 studies were excluded since they did not meet the inclusion criteria. Further, one review was added after citation tracking and manual searching. Finally, 21 studies, which included 19 published in English and two published in Japanese, were included in this systematic review (Fig. 1).

The CASP scores for quality assessment were satisfactory: all studies scored over 17 (maximum possible score: 20) points, and no study had a fatal flaw. The characteristics of the studies and their CASP scores are shown in Table 1. A summary of the focus, methods, sample size, and country of origin of these studies is presented in Table 2. More than half of the studies focused on the experiences of parents, and only two involved children as participants: one study included children aged 7–17 years, and the other included children aged 10–20 years (average age: 17 years, 4 months). Therefore, younger children below seven years of age were not included in these studies.

#### Synthesis

We synthesized the findings and identified three new themes regarding children's, parents', and HCPs' experiences with EOL decision-making: "hope and confrontation with the child's death" as parents' experiences, "guidance and support during uncertainty" as HCPs' experiences, and "awareness of being protected and having hope" as children's experiences (Table 3). Another new theme was found during further investigation, which involved a three-way social interaction between the children, parents, and HCPs, "mutual unspoken integration of values" (Table 3, Fig. 2, Table 4).

#### Experiences involved in the EOL decision-making process

Parents' experiences: Hope and confrontation with the child's death. The main translated theme of the parents' experiences with EOL decision-making was "hope and confrontation with the child's death," which means that the manner of dealing with the life and death of their child was partly in conflict with the primary parental role regarding the child's growth and development, daily life support, future independence of the child, and the child's best interests. Importantly, the parents' own hopes played a significant role during EOL decision-making. This theme was subdivided into four categories: "being a parent," "parental hope," "avoiding confrontation with the child's death," and "awareness of reality and new hope" (Table 3, Table 4).

#### Being a parent

"Being a parent" included two subcategories: *attempting to be a good parent* and *the need to fulfill parental roles*.

The essence of being a parent is threatened in the context of the inevitability of the child's death. *Attempting to be a good parent* implies that the parents of dying children continue to seek and find the meaning of being a parent. Parents always consider their child's preferences and best interests (Maurer et al., 2010; van der Geest et al., 2015). They also try to protect their children from things that remind them of death and often continue to explore hope for their child's survival without apprising them of the seriousness of their condition and impending death (van der Geest et al., 2015). Parents want to be good providers for their ill children, their other children, and other family members. For example, parents continue to work for their family because of concerns about the financial burden, and sometimes leave the ill child for the care of healthy child. Moreover, they struggle to balance their social roles and responsibilities toward their ill child and other family members (Zelcer et al., 2010). Such experiences influence the decision of where the child will die and the manner and place in which the child's EOL phase will be spent (Tomlinson et al., 2006; Zelcer et al., 2010).

Parents view being the EOL decision-maker for their child as their moral responsibility. "The need to fulfill the parental role" requires that parents be provided with high-quality, honest, and factual information about their child's condition and prognosis to fulfill their role, and to prevent them from making wrong decisions as guardians (Bluebond-Langner et al., 2007; Hinds et al., 2009; Sullivan et al., 2015; Yoshida et al., 2010). However, they feel that there is a lack of information from HCPs (Tomlinson et al., 2006; Yoshida et al., 2014). Parents wish HCPs to be partners in the decision-making process and for them to gain a thorough understanding of their child and family (Badarau et al., 2017).

These findings indicate the importance of providing parents with accurate information so that they can fulfill their parental obligations during the EOL decision-making process. Importantly, they emphasize the importance of presenting parents with a variety of options so that they can make decisions that will enable them to feel like they were good parents to their children both during their treatment and after their death, working together with the HCPs to identify the best possible decision for their child rather than leaving it solely to the parents.

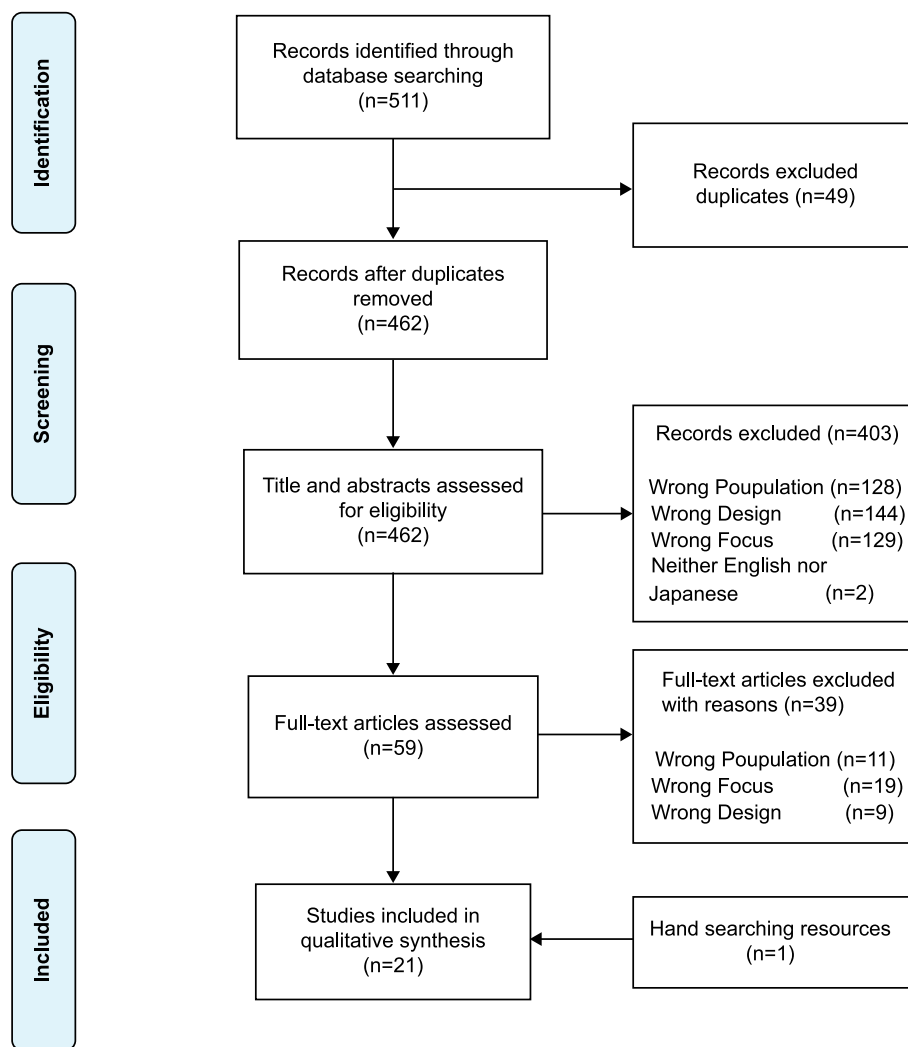


Fig. 1. PRISMA flow diagram.

### Parental hope

“Parental hope” is further subdivided into three subcategories: *hope of being with the child*, *hope for no pain or suffering*, and *conflict due to incompatible hope*. Parental hope has been indicated to be complex, ambivalent, and variable in relation to parents who have children with cancer.

The role of an individual as a parent is existential and controlled by the *hope of being with the child*, which implies that the loss of a child means that the parent loses some part of themselves and that life without the child would be meaningless (Mekelenkamp et al., 2020; Nagoya, Shiwaku, Suzuki, Tsuchiya, et al., 2014). This leads to decisions that ensure that the parents never miss any chances of treatment that would prolong the child’s survival and that they wish to do everything possible in the hope of spending more time with the child (Granek et al., 2013; Hinds et al., 2005; Tomlinson et al., 2006). Therefore, parents make decisions that tenaciously pursue chances of survival; opt for aggressive treatments; refuse to use or increase the doses of some drugs, such as morphine, to accelerate death (Kars et al., 2011); and request additional medical tests that cause distress and strain to the child (Bluebond-Langner et al., 2007).

However, when parents witness their child’s distress due to treatment, they instinctively stay beside them and convey their love (Hinds et al., 2009) and want to comply with the child’s wishes (Hinds et al., 2005). We translated this experience of parents into *hope for no pain or suffering*.

Parents continue to ask themselves what is best for their child when death is imminent. Hence, parents struggle with incompatible hope (Kars et al., 2011) because the length of their child’s survival is uncertain (Hannan & Gibson, 2005). These experiences were translated into *conflict due to incompatible hope*. Several parents admit that their hope is disproportionate and express difficulty in reigning it in, even though they have understood the HCPs’ prediction of the child’s medical condition (Kars et al., 2011; Zelcer et al., 2010). Zelcer et al. (2010) showed that parents simultaneously hold onto two dichotomous beliefs: the realism that their child’s prognosis is poor and the search for a miracle. It is noteworthy that parents who choose active treatment do not necessarily expect a cure for the child. Further, even after understanding the reality of the situation, the *hope of being with their child* creates belief in a miracle and leads parents to choose active treatment (Maurer et al., 2010; Mekelenkamp et al., 2020; Yoshida et al., 2010).

When *hope for no pain or suffering* exceeds the *hope of being with their child*, a transformation of hope occurs. However, the transformation itself creates a feeling of guilt and diminishes the transformation, as if experiencing incompatible hope (Granek et al., 2013; Kars et al., 2011; Mekelenkamp et al., 2020; Yoshida et al., 2010). Therefore, *parental hope* refers to the hope of living with the child for as long as possible, which makes the parent distressed from fear of losing the child. These parental experiences have a significant influence on EOL decision-making. It also indicates that parental hope fluctuates depending on their child’s situation and their readiness to let them go. It can be seen

**Table 1**  
Characteristics of the included studies and quality assessment scores.

No.	Title	Author, Year	Objectives	Design, Method	Samples	Setting, Country	Key findings	CASP Score*
1	Decision-making in pediatric oncology: views of parents and physicians in two European countries	Badarau et al. (2017)	To examine the perspectives of parents of children with cancer and the children's physicians on their experiences with participation in decision-making	A qualitative design using group interviews and thematic analysis	37 parents of children with cancer 26 physicians	8 pediatric oncology centers, in Switzerland 3 pediatric oncology centers, in Romania	Three main categories describe the decision-making process: 1. Heterogeneous decision-making at diagnosis, 2. Elective decisions, 3. Decisions outside the standard protocol. Parents' and sometimes children's participatory role increased when the prognosis was poor, or patients were diagnosed with rare cancers without standard treatment. Typically, oncologists believed that the decision depended more on the parents and patients in complex situations. However, the grim circumstances and improbability of a cure were not always openly discussed with patients. Interdependency between oncologists, parents, and children was always present.	18/20
2	Preparing pediatric healthcare professionals for end-of-life care discussions: an exploratory study	Henderson et al. (2017)	To identify what pediatric healthcare professionals consider important when preparing for an EOL discussion	A qualitative design using group interview	36 HCPs including medical, nursing, and allied health professionals working in pediatric palliative care settings	Major tertiary hospitals, General practice, Community, and non-government organizations, in Australia	Seven themes were identified while preparing for EOL discussion as HCPs: 1. Communication (general communication skills, language, cultural awareness, managing conflict); 2. HCPs' perspectives (acknowledge anxiety, ability, and expertise); 3. Interdisciplinary team role (team pre-briefing, working collaboratively across settings, information provision); 4. Patient and family perspectives; 5. Practical issues (timing of the discussion, space for discussion, HCP etiquette); 6. Addressing mistakes; 7. Healthcare professional education	18/20
3	Children with cancer share their views: tell the truth but leave room for hope	Jalmsell et al. (2016)	To explore how children with cancer want to receive bad news about their disease, such as when no future treatment options are available	The qualitative study comprised individual semi-structured interviews/Inductive and descriptive approach	10 children with cancer, aged 7–17 years	Pediatric oncology unit, in Sweden	Three important aspects were founded regarding how the children wished to receive bad news: 1. All children expressed that they wanted honest and straightforward information and they did not want to be excluded from bad news regarding their illness. 2. Children wanted to be informed as positively as possible, allowing them to maintain hope, and in words that they could understand. 3. Children wanted to receive any bad news at the same time as their parents.	19/20
4	Parental hope for children with advanced cancer	Kamihara et al. (2015)	To understand what hope means to parents of children with advanced cancer, or the extent to which parents can feel hopeful even while facing the child's impending death	Qualitative study using audiotaped conversations between parents, clinicians, and children when informing about recurrence or refractory cancer	32 parents and 32 clinicians	A single children's hospital in the USA	During parent–clinician EOL discussions, several clinicians used non-specific statements to convey worry, including “we are running out of options” or “I think we are not in a very good situation.” Although clinicians often used	19/20

(continued on next page)

Table 1 (continued)

No.	Title	Author, Year	Objectives	Design, Method	Samples	Setting, Country	Key findings	CASP Score*
5	Parents and end-of-life decision-making for their child: roles and responsibilities	Sullivan et al. (2015)	To examine the views and experiences of bereaved parents in end-of-life decision-making for their child and to clarify the ethical question of how decision-making should be approached with parents at end-of-life.	Qualitative design, semi-structured individual interviews, thematic analysis	25 bereaved parents of children who had a life-limiting condition aged between 3 months and 12 years when they died	Hospital and hospice in Australia	language referring to their own personal hopes during conversations ("I really do hope this may be the treatment that keeps his tumor stable or shrinks it for a very, very long time"), they did not ask parents directly about their hopes. Despite concerns about prognosis, parents expressed a range of hope for their children: cure, treatment response, quality of life, normalcy, minimal suffering, love and relationships for the child, hope for others in the family, hope for future research, and/or better treatment of children in the future. Many parents' hopes differed from their expectations of the likely occurrence. Parents described several ways of balancing hope with more difficult expectations, including playing a mental game of pushing it away. Three types of decision-making roles were identified: self-determined, guided, and acquiescent (passive). The majority of parents had been active in the decision-making process and perceived themselves as the ultimate EOL decision-maker. Parents viewed being the EOL decision-maker for their child as their moral responsibility as a parent. It was not simply something they wanted to do, but something that they felt they had to do to fulfill their role as a parent. Several parents thought there would be parents who would prefer not to make an EOL decision for their child. A doctor should take the required course of action when parents cannot decide.	20/20
6	Talking about death with children with incurable cancer: perspectives from parents	van der Geest et al. (2015)	To investigate the rationale and consequences associated with a parent's decision to discuss death with a child with incurable cancer	Qualitative retrospective study using a descriptive questionnaire	86 parents of 56 children with incurable cancer; 54 mothers and 32 fathers	A single children's hospital, Department of Pediatric Oncology/Hematology, in the Netherlands	Fifty-five of the 86 parents did not discuss impending death with their children. The following themes impacted this decision: parents' inability to discuss the impending death, parents' desire to protect their child, view regarding talking with children, parents' views of child characteristics, the child's unwillingness to discuss the subject, lack of opportunities to talk, and the child's disability. Thirty-one parents of 21 children talked with their child about death. Several parents used a symbolic story to talk with their child. Most parents reflected positively on their decision either to discuss or not discuss death with their child. Twenty-nine of the responding 47 parents who did not talk with their child about death reflected	19/20

7	How do parents of children with incurable cancer make treatment decisions?	Nagoya, Shiwaku, Suzuki, Tsuchiya, et al. (2014)	To clarify how mothers and fathers of children with cancer who were told that a cure was not inevitable chose a treatment option	A qualitative descriptive study using semi-structured interviews	6 bereaved parents: 3 mothers and 3 couples	A single children's hospital and a single university hospital, in Japan	positively on their decision and some of them indicated that their child clearly did not want to talk about death or avoided the conversation. The thoughts of parents who chose cancer-directed therapy fell into four categories: a strong belief in a cure, the expectation for a slight possibility, less damage caused by previous treatment, and difficulty in giving up active treatment. The thoughts of parents who chose to stop cancer-directed therapy fell into four categories: preparation before receiving notification, focus on the QOL of children, severe damage caused by previous treatment, and low survival rate with active treatment. Factors affecting cessation of active treatment: progressive illness/condition, the limit of the physical strength of the child, deterioration, and recommendation of trusted doctors.	18/20
8	Barriers of health-care providers against end-of-life discussions with pediatric cancer patients	Yoshida et al. (2014)	To describe the contents of EOL discussion in the pediatric setting and the barriers to EOL discussion for pediatric patients, as perceived by pediatric healthcare providers.	A qualitative design using two focus group interviews and two one-on-one interviews: semi-structured interviews	10 HCPs: 4 pediatric oncologists, 4 adult oncologists, 2 pediatric nurses, 1 pediatric clinical psychologist, 1 medical ethics expert	A single national cancer center, in Japan	EOL discussions with children included: disease name, recurrence, metastasis, treatment-resistant condition, the purpose of treatment, death, and afterlife in general terms, how the sick child recognizes death, what the child wants to do in the remaining time, the child's anxiety, fear, and concern. However, the estimated prognosis, estimated 5-year survival rate, estimated 1-year survival rate, lack of further effective anticancer treatment options, do not attempt resuscitation order, the child's impending death, and the child's will to the disclosure of their terminal condition were rarely discussed with sick children. Barriers to EOL discussion with children were: HCP factors (lack of knowledge about how to discuss EOL with patients, lack of confidence to face patients after the discussion, lack of experience, uncertain patient preference on the discussion), patient factors (inability of patients to comprehend the terminal condition, lack of patient readiness, patient willingness to protect their parent by ignoring the terminal condition, and never imagined the possibility of death), parent factors (parental opposition to EOL discussion, lack of parental readiness, lack of parent acknowledgment of terminal conditions, and unrealistic parental expectations), and institutional or cultural factors.	19/20
9	Trajectory of parental hope when a child has difficult-to-treat cancer: a	Granek et al. (2013)	To understand parental hope when a child has difficult-to-treat cancer	A qualitative prospective and longitudinal study, grounded theory	35 parents of children with cancer	A single children's hospital, in Canada	Two categories for hope as a positive inner source were identified: 1. Future-oriented hope: hope for cure and	18/20

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Table 1 (continued)

No.	Title	Author, Year	Objectives	Design, Method	Samples	Setting, Country	Key findings	CASP Score*
	prospective qualitative study						treatment success, hope for the child's future, hope for a miracle, and hope for more quality time with child; 2. Present-oriented hope: hope for day-to-day/moment-to-moment, hope for no pain and suffering and hope for no complications. The only hope that remained consistent for all parents throughout the study period was hope for a cure and hope for recovery. Hope functioned as a motivator to soldier through the tremendous affective and physical work associated with caring for a child with cancer.	
10	Parental experiences at the end-of-life in children with cancer: preservation and letting go in relation to loss	Kars et al. (2011)	To identify the process undergone when a cure is not obtainable, and to explore the influence of parental processes on the choices they make regarding their child's treatment and care	Grounded theory approach, individual in-depth open interviews	44 parents during the EOL process and/or after the death of their children; 23 mothers and 21 fathers	5 oncology centers, in the Netherlands	Parents experience an internal struggle between the wish for preservation and the willingness to let the child go. The dominating feeling of parents is that they cannot let the child go; life is meaningless without their child. They lose a part of their parenthood. Parents' loss occurred in separate stages and was characterized by moments of decision-making, making them feel that they were influencing the course of loss. Preservation goals were "as long as possible, as well as possible," with an emphasis on "long." Letting go was demonstrated by parental willingness to subordinate their needs to avoid loss to the child's well-being and comfort, which take precedence over prolonging life. For parents, "letting go" meant they recognized the inevitability of death and gave up their resistance to loss. The transition from "preservation" to "letting go" required a switch in the source of control. However, preservation and letting go coexist, and the transition is not linear. Parents with a strong sense of preservation showed the greatest tendency to withdraw from their social and health systems.	19/20
11	"I want to live, until I don't want to live anymore": Involving children with life-threatening and life-shortening illnesses in decision-making about care and treatment	Bluebond-Langner et al. (2010)	To clarify HCPs' ethical and meaningful role for children and children's role in decision-making	Case review	5 cases	A hospital in the UK	Age is not necessarily predictive of what children know. Children's experiences with their illnesses play a major role in their understanding. Children, like parents, hold onto the possibility of cure, stabilization, or, at least, a reasonable amount of time even in the face of phase 1 trials, despite explanations to the contrary. The interaction between adults and children was a mutual pretense, which could be an obstacle in assessing or eliciting the child's wishes or knowledge, which they may not express	N/A



12	Factors influencing parental readiness to let their child with cancer die	Kars et al. (2010)	To identify, from a parental perspective, the main factors that influence the parents' position between preservation and letting go	Grounded theory approach, individual in-depth open interviews	44 parents during the EOL process and/or after the death of their children: 23 mothers and 21 fathers	5 Oncology centers, in the Netherlands	Factors supporting preservation: Uncertainty about the course of the illness, the effect of interventions, and time left. Fragmentation, or parents pushing back signals of approaching death by focusing on details, allowed parents to avoid reading the signs and created ambiguity. Anxiety: most parents feared the dying process and the child's deterioration and tried to avoid or delay threats. Anxiety was a strong modulator and resulted in a move toward preservation. Factors supporting letting go: certainty, which can be defined as the parents' conviction that the malignant process is unstoppable or certain aspects of the child's life are irreversibly lost. Postponing grief: parents postponed grief to care for their child and to continue family life. Perception of suffering: once parents had begun to let go, they started to interpret the former, existing, or expected symptoms as suffering and used this to legitimize this attitude. The ability to disentangle needs or interests: the ability to parent meaningfully. Factors supporting both: hope, maintaining a peaceful parent-child relationship, and professionals	19/20
13	Decision making by parents of children with incurable cancer who opt for enrollment on a Phase 1 trial compared with choosing a do not resuscitate/terminal care option	Maurer et al. (2010)	To compare the self-reported rationale, good parent definition, and behaviors of clinical staff desired by parents who recently decided to opt for phase 1 chemotherapy with parents who chose the DNR or terminal care option	A qualitative study using individual interviews, semantic content analysis	58 parents of 58 children at the EOL stage	A single research hospital in the USA	Parents expressed the need to make a decision that did right by their child, took account of the medical facts, and preserved their child's legacy. Parents desired or received the endorsement of their decisions from clinicians or sympathetic figures. Parents believed that a good parent would do right, provide support and presence, and sacrifice for the child. The DNR/terminal care group mentioned a desire to protect the child from suffering.	20/20
14	Difficulties experienced by families of children with refractory childhood cancer	Yoshida et al. (2010)	To identify the difficulties that the families of children with cancer face after they were told that death is inevitable and what to expect from HCPs when experiencing difficulties	A qualitative design using semi-structured interviews of bereaved parents and focus group interviews of HCPs	6 bereaved parents: 2 fathers and 4 mothers; 13 HCPs: 5 physicians and 8 nurses	Hospital in Japan	Parents' difficulties were divided into 11 themes and 32 categories: The most frequent difficulties were questioning their decision-making, preparing for death, timing of gear change, and differences in recognition and preparation between couples. HCPs' difficulties were divided into 8 themes and 23 categories: The most frequent difficulties were the decision to stop active treatment, shift to home care,	18/20

(continued on next page)

Table 1 (continued)

No.	Title	Author, Year	Objectives	Design, Method	Samples	Setting, Country	Key findings	CASP Score*
15	Palliative care of children with brain tumors	Zelcer et al. (2010)	To explore the EOL experience of children with brain tumors and their families	Qualitative analysis of focus group interviews, thematic analysis	25 parents of 17 children who died of brain tumors	A single children's hospital in the UK	preparing parents for the child's death, talking with children about death, different hopes of the child and parents, and balancing between maintaining hope and recognizing reality. Three major themes regarding the EOL experience were identified: 1. The dying trajectory: neurological deterioration, loss of the ability to communicate, striving to maintain normality, and sources of spiritual strength; 2. Parental struggle: competing responsibilities and conversation about death and dying; 3. Dying at home: 3 barriers to planning for a home death were identified (optimal symptom control, financial and practical hardship, and support within the community). The loss of communication was highlighted by parents as a significant turning point in the dying trajectory. These parental experiences indicated parents' needs for anticipatory guidance and patients' and families' educational needs during the course of illness for optimal decision-making.	19/20
10	16 Trying to be a good parent as defined by interviews with parents who made phase 1, terminal care, and resuscitation decision for their children	Hinds et al. (2009)	To clarify the definition of a good parent to a child with incurable cancer and how clinicians could help them fulfill this role	A descriptive study using semi-structured face-to-face interviews	62 parents of 58 children who made one of three decisions (enrollment in a phase 1 study, DNR statutes, or terminal care within 72 h)	A single children's hospital in the USA	The qualitatively derived definition of "being a good parent" to a child with incurable cancer is as follows: a good parent makes informed, unselfish decisions in the child's best interest; provides basic food, shelter, and clothing; remains at the child's side regardless of the circumstances; shows the child that they are cherished; tries to prevent suffering and protect health; teaches the child to make good choices, to respect and have sympathy for others, and to know God; advocates for the child with staff; and promotes the child's health. Most commonly helpful staff: all that can be done is being done, the staff respects me and my decisions, the staff knows our special needs, the staff likes our child, the staff tells us we are good parents, and the staff gives us time to decide, etc.	18/20
17	Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed	Bluebond-Langner et al. (2007)	To examine American and British parents' approaches to care and treatment when standard therapy has failed and consider the implication for clinical practice	A prospective ethnographic study using participant observation, open-ended semi-structured interviews, review of medical records, constant and continuous comparison	34 parents of pediatric oncology patients: 17 in the USA and 17 in the UK	A Pediatric Oncology center in the USA and the UK	Parents do not see cancer-directed therapy and symptom-directed care as mutually exclusive, alternative approaches, and parents will not be constrained by what the oncologist offers. In most cases, at the last recurrence studied, parents pursued cancer-directed therapy. In 28 of 34 cases, the parents accepted the cancer-directed therapy that had been offered by their child's primary	18/20

18	Parental decision making in pediatric cancer end-of-life care: using focus group methodology as a pre-phase to seek participant design input	Tomlinson et al. (2006)	To seek parental options about five issues: (1) the general experience of choosing between palliative cytotoxic chemotherapy and supportive care alone; (2) the factors that parents regard as important when making this decision; (3) the proposed threshold technique	Qualitative study using focus group interview	7 bereaved parents: 5 mothers and 2 fathers	A single children's hospital in Canada	Factors parents believe to be important when choosing palliative chemotherapy: hope, time, child-centered, family dynamics, other parents' advice, or pressure from other parents. Factors parents believe to be important when choosing supportive care alone: quality of life of the whole family, marital relationship, financial burden, other support systems that may be necessary for continued hospitalization, family dynamics, and HCPs. Parents' view of how HCPs could help decide: be honest, adapt to each unique situation, be aware of the whole situation, be caring, and show media awareness.	18/20
19	Advanced cancer in children: how parents decide on final place of care for their dying child	Hannan and Gibson (2005)	To retrospectively explore the decisions made by parents regarding their choice of place of care at the time of death for their child with advanced cancer	A cross-sectional descriptive study using individual semi-structured interviews, Interpretive phenomenological analysis	5 bereaved parents of 5 children (aged 1–19 years) who had died of advanced cancer	A single pediatric oncology center in the UK	Four themes were extracted regarding how parents decide on the final place: Valuing time left: reaction not a decision; normality and family life; and the child's views and previous experience. Needing to feel safe and secure: control, not wanting to do it alone, place where families did and did not feel safe. We did not know what to expect: uncertainty, expected duration of the palliative phase, symptoms, and expectations. Difference between specialists and non-specialists: difference in approach, specialist care out of hours, non-specialist staff. Families' decisions were instinctive or intuitive rather than a calculated weighing of options	17/20
20	End-of-life care preferences of pediatric patients with cancer	Hinds et al. (2005)	To identify the preferences of children and adolescents with advanced cancer about their end-of-life care and the factors that influenced their decisions and to compare the factors considered by patients, parents, and physicians	A qualitative descriptive study by interviewing children and adolescents within 7 days of their participation in EOL decision-making	20 children aged 10–20 years (mean, 17 years and 4 months) with cancer, 18 parents, and 14 physicians	A single oncology center in the USA A single children's hospital in Australia	Seven factors influenced the patients' EOL decisions: thinking about relationships with others, avoiding adverse events, the desire to stop therapy, being ready to die and go to heaven, seeing others die, believing treatment now is futile, and seeing a chance for a cure. Nine factors influenced the parents' EOL decisions: deciding as my child prefers, trusting staff and being supported by them, deciding as a good parent would, avoiding negative outcomes, being helped by my faith, having nothing more to do, still trying for a cure or longer life, wanting time left to be good, wanting to help others. Six factors that influenced the HCPs' decisions: being influenced by patient	19/20

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Table 1 (continued)

No.	Title	Author, Year	Objectives	Design, Method	Samples	Setting, Country	Key findings	CASP Score*
21	An international feasibility study of parental decision making in pediatric oncology	Hinds et al. (2000)	To describe parental decision-making for treatment options for children with cancer in three hospitals in different countries and determine the feasibility of a similar but larger international hospital	A descriptive, cross-sectional design, open-ended interview, and content analysis	43 parents who performed decision-making for their children within 3 weeks; 38 mothers and 5 fathers	A single pediatric research center in the USA A single children's hospital in Australia A single children's hospital in Hong Kong	and family preferences, considering the prognosis and comorbid conditions, wanting to benefit my patients and others, wanting to avoid harm, patient/family understanding and acceptance, lack of other options Factors in parents' decision-making: wanting to minimize suffering, considering likely adverse effects of treatment, nothing more left to do, believing that my child could not survive, feeling that we did all we could, knowing my child's preference. Helpful care by HCPs: getting information, being supported by staff, trusting staff. Lack of helpful care by HCPs: feeling forced, care involving interferences	18/20

EOL: end-of-life; HCPs: healthcare professionals.

\* Critical Appraisal Skills Programme score: Yes: 2 points; Uncertain: 1 point; No: 0 points.

Table 2

Summary of study focus, method, sample size, and country of origin of the included studies.

Study focus	
Children's experiences	2 studies
Parents' experiences	15 studies
HCPs' experiences	7 studies
Children under 7 years of age	No study
Method	
Semi-structured individual interview	16 studies
Focus group interview	5 studies
Recording of daily conversation	1 study
Participant observation	1 study
Sample size	
Children	n = 10 and n = 20
Parents	n = 4–62
HCPs	n = 10–36
Country of origin	
The U.S.A.	7 studies
Australia	4 studies
The U.K.	4 studies
Japan	3 studies
The Netherlands	3 studies
Canada	2 studies
Switzerland	2 studies
Romania	2 studies
Hong Kong	2 studies
Multiple countries	4 studies

HCPs: healthcare professionals.

that such parental experiences, particularly the embraced hope and transformation of hope, influence parental EOL decision-making.

#### Avoiding confrontation with the child's death

"Avoiding confrontation with the child's death" is one of the coping strategies used by parents during the child's EOL phase that includes two subcategories: *maintaining control* and *unrealistic expectations*.

While this parental coping strategy can sometimes alleviate parents' fear of the death of a child, HCPs often have difficulty understanding and supporting parents who exhibit this behavior. One of the reasons why parents try to avoid confronting death is to *maintain control*. Parents require honest and open information to fulfill their parental responsibilities (Badarau et al., 2017; Sullivan et al., 2015). At the same time, they pretend not to recognize what they see, such as their child's condition, deterioration of function, and imminent death, so that they can delay the experience of loss. Parents cope with difficult situations by focusing on one part of the situation instead of the whole to avoid confronting their child's death. For example, parents subdivide the child's complaints into isolated symptoms, thus loosening the connection with the overall process of dying. Isolated problems can be treated more easily. Pain can be controlled, fever managed, and tightness of the chest relieved. Thus, the holistic picture of these symptoms caused by an uncontrollable tumor growth is kept out of sight. By fragmenting the signs, parents can maintain their status quo (Kars et al., 2010). This coping strategy helps the parent maintain control by tenaciously clinging to the hope that denies the possibility of their child's death while admitting the contradiction between these hopes and their understanding of the medical condition (Barrera et al., 2013; Bluebond-Langner et al., 2007; Kamihara et al., 2015; Kars et al., 2011).

HCPs tend to misunderstand such coping strategies by thinking that parents ignore the child's distress, avoid communication with HCPs, and have *unrealistic expectations* (Kars et al., 2011). When the deterioration of the child's condition accelerates, considerable energy is needed to avoid being confronted with death (Kars et al., 2011), and these coping

**Table 3**  
Synthesized themes, categories, and subcategories in the review.

Themes	Categories	Subcategories
Parents' experiences Hope and confrontation with the child's death	Being a parent	Attempting to be a good parent The need to fulfill parental roles Hope of being with the child Hope for no pain or suffering Conflict due to incompatible hope
	Parental hope	Maintaining control Unrealistic expectations
	Avoiding confrontation with the child's death	Accumulation and acceleration of the loss Awareness of inevitable death
	Awareness of reality and new hope	
HCPs' experiences Guidance and support during uncertainty	Maintaining the child's and parents' hope	Compassionate information-sharing Child's and parents' unconfirmed hope Child- and family-centered decisions Difficulties and bemusement as a guide
	Uncertainty as a barrier	
Child's experiences Awareness of being protected and having hope	Provided with filtered information	Desire for truth Maintaining hope Being a good child Hope for peace Altruism to bolster hope
	Pretending and being silent Child's unconfirmed hope	
Interaction between child, parents, and HCPs Mutual unspoken integration of values	Communication mix-ups among children, parents, and HCPs	Caring for each other Pretending and misunderstanding Parent-HCP alliance to keep hope afloat
	Preserving hope in uncertainty	

HCPs: healthcare professionals.

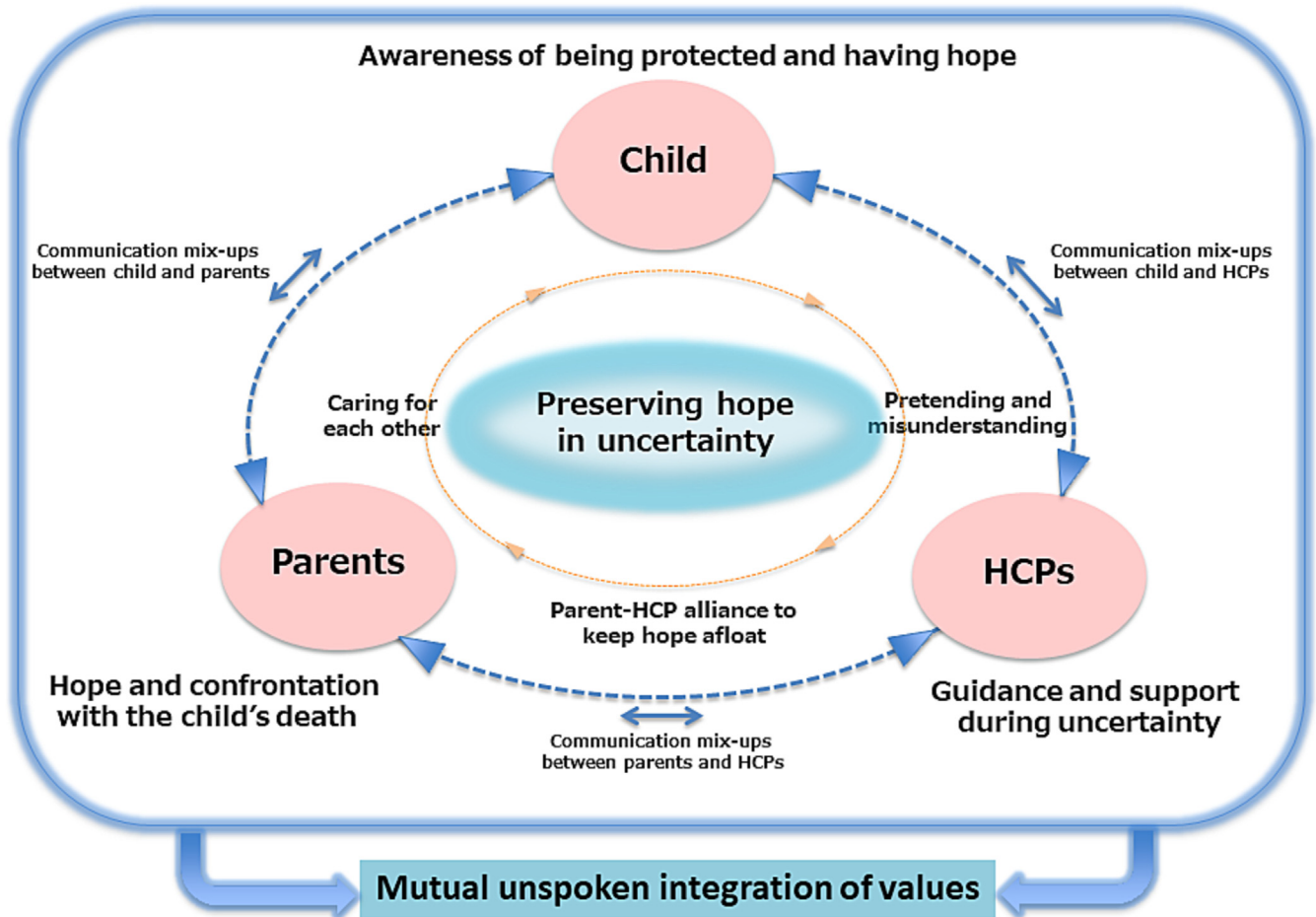


Fig. 2. Interaction among children, parents, and healthcare professionals during end-of-life decision-making.

**Table 4**  
Themes, categories, and subcategories identified in each study in the review.

Themes	Categories	Subcategories	Badarau 2017	Henderson 2017	Jalmsell 2016	Kamihara 2015	Sullivan 2015	van der Geest 2015	Nagoya 2014	Yoshida 2014	Granek 2013	Kars 2011	Bluebond-Langner 2010	Kars 2010	Maurer 2010	Yoshida 2010	Zelcer 2010	Hinds 2009	Bluebond-Langner 2007	Tomlinson 2006	Hannan 2005	Hinds 2005	Hinds 2000	
Parents' experiences																								
Hope and confrontation with the child's death	Being a parent	Attempting to be a good parent	✓			✓	✓	✓	✓	✓	✓							✓	✓	✓		✓	✓	
		The need to fulfill parental roles	✓			✓	✓		✓	✓	✓								✓	✓	✓		✓	✓
		Parental hope	✓			✓	✓		✓	✓	✓									✓	✓		✓	✓
	Avoiding confrontation with the child's death	Hope of being with the child	✓			✓	✓		✓	✓	✓										✓	✓	✓	
		Hope for no pain or suffering	✓			✓	✓		✓	✓	✓											✓	✓	✓
		Conflict of incompatible hope	✓			✓	✓		✓	✓	✓											✓	✓	
		Maintaining control				✓				✓	✓	✓								✓				
	Awareness of reality and new hope	Unrealistic expectations	✓			✓				✓	✓	✓									✓		✓	
		Accumulation and acceleration of the loss				✓				✓		✓											✓	✓
		Awareness of inevitable death				✓				✓		✓											✓	✓
HCPs' experiences																								
Guidance and support during uncertainty	Maintaining the child's and parents' hope	Compassionate information-sharing	✓	✓		✓				✓								✓	✓	✓	✓	✓	✓	
		Child's and parents' unconfirmed hope	✓	✓		✓		✓		✓														
	Uncertainty as a barrier	Child- and family-centered decisions	✓	✓		✓	✓	✓	✓	✓	✓										✓	✓	✓	
		Difficulties and bemusement as a guide	✓	✓		✓		✓		✓													✓	
Child's experiences																								
Awareness of being protected and having hope	Provided with filtered information	Desire for truth			✓	✓		✓		✓			✓										✓	
		Maintaining hope	✓		✓	✓		✓		✓			✓						✓					
	Pretending and being silent	Being a good child			✓					✓			✓										✓	
		Child's unconfirmed hope			✓	✓							✓										✓	

Note. "✓" indicates that these are authors' results related to each category. HCPs: healthcare professionals.

strategies are used to preserve the status quo (as if keeping the flood-gates shut) (Kars et al., 2011; Maurer et al., 2010).

Parents often act as if they are unaware that their child's death is imminent to cope with a distressing situation during the EOL decision-making process. They choose to implement experimental treatments or further testing for treatment evaluation, distressing the child even if the HCPs explain the lack of curative treatment. Such parental experiences confuse HCPs who are collaborative decision-makers and hinder the decision-making process (Badarau et al., 2017; Hannan & Gibson, 2005; Maurer et al., 2010; Yoshida et al., 2014).

#### *Awareness of reality and new hope*

"Awareness of reality and new hope" is a category that indicates the changes in parents from witnessing the deterioration in the child's condition. This category comprises two subcategories: *accumulation and acceleration of the loss* and *awareness of inevitable death*.

While coping strategies are employed for "avoiding confrontation with the child's death" as the parents gradually witness the loss of the child's bodily function, the child's death, which the parents could have avoided facing because of the uncertainty, becomes inevitable. Recognizing certainty during this process could drive a transformation in parental hope (Kars et al., 2010; Kars et al., 2011; Zelcer et al., 2010). The *accumulation and acceleration of the loss experience* piece together daily loss that confirms imminent death. Further, parents become aware that avoiding confrontation with the child's death is difficult. As a result, parents acquire an *awareness of inevitable death* (Kars et al., 2011). Therefore, during the process wherein numerous uncertainties gradually become clearer, the focus of the parents' hope changes from hope for a cure, to hope for stabilization, slower course of deterioration, maintenance of communication, lack of suffering, and finally, peaceful death (Granek et al., 2013). Such hope is translated into a *new hope*.

Consequently, a shift occurs from hope for survival to renewed hope when parents can distinguish their needs, which include their responsibilities and instinct, from the needs of the children themselves, such as the need to be free from pain and distress, and when they recognize that being a good parent means fulfilling the child's needs (Hannan & Gibson, 2005; Hinds et al., 2009). The shift to a new hope, which is determined by the parents' own internal mechanisms, is less likely to occur if the avoidance of confrontation with the child's death is strong. This transformation of hope through the parents' internal mechanisms is closely linked to all EOL decisions for children with cancer, from the small, routine decisions to larger, treatment-related ones.

#### *HCPs' experiences: Guidance and support during uncertainty*

The principal theme of the HCPs' experiences was "guidance and support during uncertainty." This category indicates how HCPs support children and their parents in the event of uncertainty and inability to face all facts and emotions. This category comprises two aspects: "maintaining the child's and parents' hope" and "uncertainty as a barrier" (Table 3, Table 4).

#### *Maintaining the child's and parents' hope*

"Maintaining the child's and parents' hope" comprises the subcategories *compassionate information-sharing* and *the child's and parents' unconfirmed hope*. This category presents difficulties in communicating and confirming children's and parents' thoughts and emotions during decision-making at the EOL stage.

HCPs consider imparting information to children and parents as a part of their professional role during the EOL decision-making process. However, HCPs are hesitant to talk about death and rarely inform the children about the lack of effective treatment (Henderson et al., 2017; Yoshida et al., 2014). They often carefully select their words and do not directly use phrases such as "there is no cure," even with the parents. These HCPs' experiences were interpreted as *compassionate information-sharing* (Henderson et al., 2017; Kamihara et al., 2015), which implies that they do not want to deprive the children and their

families of hope and want to maintain their motivation to live (Hinds et al., 2005). Although HCPs wish to preserve the child's and parents' hope in this manner, they do not directly ask about it (Kamihara et al., 2015). Therefore, they try to predict the hope of the children and parents (van der Geest et al., 2015; Yoshida et al., 2014) and make EOL decisions in the context of the *child's and parents' unconfirmed hope*.

Regardless of whether the wishes of the child and/or parents regarding how they would like to spend their remaining days have been confirmed, HCPs make the remaining days more memorable and valuable for the child and parent by inferring their hopes and wishes and fulfilling them. This is challenging and requires specific experience and sensitivity on the part of the HCPs during the EOL period.

#### *Uncertainty as a barrier*

"Uncertainty as a barrier" indicates that uncertainty sometimes makes it difficult for HCPs to guide children and parents while making EOL-related decisions. This category comprises two subcategories: *child- and family-centered decisions* and *difficulties and bemusement as a guide*.

At the time of diagnosis, the HCPs' guiding role is dominant, as they can identify a clear direction (Badarau et al., 2017). However, during the EOL phase, consultation with different specialists and an increase in the number of discussions with children and their families are required to make *child- and family-centered decisions* (Badarau et al., 2017; Henderson et al., 2017). During the EOL decision-making process, HCPs experience *difficulties and bemusement as a guide*.

HCPs consider guiding and supporting children and parents during decision-making to be a part of their professional role. However, they experience uncertainty as a barrier, such as the duration for which treatment can prolong life and the amount of time left, the extent to which parents and children wish to participate in the decision-making, and children's and parents' hopes (Badarau et al., 2017; Henderson et al., 2017; Kamihara et al., 2015; Yoshida et al., 2014). Furthermore, some HCPs consider it best to exclude the children from the decision-making process. They believe that there is no legal reason to involve the children, that children are not prepared to participate in EOL discussions, and that children do not understand their situation (van der Geest et al., 2015; Yoshida et al., 2014). However, there is still a strong sense of responsibility to protect children and act in their best interests.

#### *Children's experiences: Awareness of being protected and having hope*

The central theme of the children's experiences was "awareness of being protected and having hope," which consists of three categories: "provided with filtered information," "pretending and being silent," and "child's unconfirmed hope" (Table 3, Table 4).

#### *Provided with filtered information*

"Provided with filtered information" means that the information provided to a child with cancer in the EOL period is often manipulated and likely to be limited by HCPs and/or parents. In such circumstances, children may or may not be able to participate in the decision-making process. This category includes two subcategories: *desire for truth* and *maintaining hope*, clearly described in the following children's experiences.

During daily communication with the children, parents think that children do not want to talk about death and instead want to talk about joyous things (Hinds et al., 2000). Simultaneously, parents do not want their children to lose hope for a cure, and thus, they control information (van der Geest et al., 2015). In this way, the children are somehow aware of the current scenario, but are *provided with filtered information*, and are unable to estimate the future. Jalmself et al. (2016) found that children aged 7–17 years wanted true and fact-based information. They did not want to be excluded from bad news regarding their illness and wanted to be informed as positively as possible, allowing them to maintain hope. Notably, the parents recognized that

their children were aware of the situation and impending death, even when given filtered information (van der Geest et al., 2015).

Simultaneously, HCPs, akin to parents, want children to be positive even during the EOL stage (Hinds et al., 2000; Yoshida et al., 2014). Therefore, although they reveal some facts to the children, such as the diagnosis, recurrence, metastasis, and treatment resistance, the negative prospects, such as the expected prognosis, one- and five-year survival rates, and death, are rarely communicated to the children (Yoshida et al., 2014).

#### *Pretending and being silent and child's unconfirmed hope*

The children did not directly express the facts they were aware of and kept "pretending and being silent" (Bluebond-Langner et al., 2010; Hinds et al., 2005). "Pretending and being silent," an interpreted category in the synthesis, refers to the fact that the children wanted to be "good" in the same way that parents aimed to be good parents. It can be said that this is a distinctive social interaction between the dying children and their parents. Opportunities to talk about the child's hope and feelings were limited in this context because the HCPs and parents were not confident about the best approach to deal with dying children without disclosing the prognosis (Kamihara et al., 2015). Therefore, the "child's unconfirmed hope" continues to exist. "Child's unconfirmed hope" consisted of the following two subcategories: *hope for peace* and *altruism to bolster hope*.

Hinds et al. (2005) indicated that children did not want more treatment even if it may extend their life; rather, they wanted to be relieved of the pain, symptoms, and hospitalization. This was translated as a *hope for peace*. Additionally, adolescents focused on their relationships with others and continued treatment for the sake of their parents and siblings, who believed in a cure and potential recovery. Furthermore, participation in a challenging phase I of the study was sometimes viewed as having the potential to help and benefit others (Hinds et al., 2005). This was interpreted as *altruism to bolster hope*, which was a child-specific experience in the context of EOL that was not experienced by HCPs or parents. Therefore, it was found that participating in experimental treatment when the death of the child is imminent is not just a painful experience but may also be beneficial for a child who wants to help others.

#### *Interaction between children, parents, and HCPs: mutual unspoken integration of values*

The central theme of the social interaction between the children, parents, and HCPs was "mutual unspoken integration of values," which comprised two categories: "*communication mix-ups among children, parents, and HCPs*" and "*preserving hope in uncertainty*."

This review interpreted the EOL decision-making experiences of children, parents, and HCPs, and the three-way social interaction that emerged from each result was highly complex. The complexity of this social interaction can best be described in the form of three subcategories: *caring for each other*, *pretending and misunderstanding*, and *the parent-HCP alliance to keep hope afloat*. These interactions lead to consequences such as "*communication mix-ups*" and "*preserving hope in uncertainty*," which were translated categories (Table 3, Table 4, Fig. 2).

#### *Communication mix-ups between parents and HCPs*

The social interaction between the parents and HCPs sometimes led to the following communication mix-ups. First, parents sought more information to perform their parental role and discharge their parental responsibilities (Bluebond-Langner et al., 2007; Hinds et al., 2000; Kamihara et al., 2015; Tomlinson et al., 2006; Yoshida et al., 2020), although the HCPs were hesitant to share uncertain information (Henderson et al., 2017; Tomlinson et al., 2006; Yoshida et al., 2014). Second, misunderstandings arise as HCPs tend to think that the parents are unaware of the current situation, as observed from their coping behavior, which is misconstrued as a lack of awareness of reality and a wish to escape from it (Kamihara et al., 2015; Kars et al., 2011; Zelcer

et al., 2010). Third, the parents conversely expect the HCPs to guide them through the decision-making process. The HCPs believe that their role is to make decisions for the children and parents without imposing their own thoughts (Badarau et al., 2017; Hinds et al., 2005). Fourth, there is a misunderstanding that the parents fear being confronted with the child's death and maintain distance from the HCPs in a situation where they require more supportive care (Kars et al., 2010; Yoshida et al., 2014). The HCPs feel alienated and helpless (Kars et al., 2010; Kars et al., 2011; Yoshida et al., 2014). This interaction makes it difficult to meet the parents' needs.

#### *Communication mix-ups between parents and the child*

Communication mix-ups arise between parents and the child since the former believe that good parents protect children from information that reminds them of death and that excluding children from decision-making is right (Bluebond-Langner et al., 2010; Yoshida et al., 2014). On the other hand, children know that the information is controlled and pretend that they have adapted to the situation, as is expected of a "good" child (Hinds et al., 2005; Jalmsell et al., 2016). Parents who witness such behavior in their children mistakenly believe that withholding information related to death from them could allow the children to live their remaining days better and that this is the preferable way to make decisions. Moreover, the child wants to be free from pain and symptoms and does not want further treatment. However, children pretend for the sake of their parents and siblings that they have not given up the challenge of surviving (Jalmsell et al., 2016). This makes it difficult for parents to understand the real needs of their children. This social interaction interferes with the transformation from the *hope of being with the child* to the *hope of no pain or suffering*.

#### *Communication mix-ups between children and HCPs*

The communication mix-ups resulting from the social interaction between the child and HCPs were similar to those between the parents and HCPs. The perspectives of younger children have not been clarified in existing studies; however, older children hope that information is not hidden from them (Jalmsell et al., 2016). At the same time, the HCPs are not ready to talk to the children and misunderstand that they are too young to understand and cope with serious information (Badarau et al., 2017; Yoshida et al., 2020). Consequently, a gap exists between the children's actual needs and those assessed by the HCPs. Therefore, parents and HCPs have similar ideas and use similar communication styles to protect their children. Parents and HCPs share a strong desire to give the children filtered information and as much hope as possible in the EOL period. This aspect of parents and HCPs working together to maintain their child's hope is translated in this review as the *parent-HCP alliance keeps hope afloat*.

#### *Preserving hope in uncertainty*

Complex three-way social interactions occur between the child with cancer, parents, and HCPs in the context of uncertainty during the EOL decision-making process. Such interactions may lead to communication mix-ups. These interactions could have a negative impact because the child, parents, and HCPs do not fully understand each other. Conversely, uncertainty for children and parents can delay facing death, which can be painful to accept or allow them to have hope, including unfulfilled hope (Barrera et al., 2013). Further, this leads to the HCPs being reassured that the children and parents still retain the willingness to live. Notably, studies have reported that children and parents wish to remain hopeful, in addition to the existence of the *preservation of hope in uncertainty* (Barrera et al., 2013; Bluebond-Langner et al., 2010; Kars et al., 2010; Kars et al., 2011). These interactions between the children, parents, and HCPs during the EOL decision-making process imply the mutual unspoken integration of values, a new concept derived from this review. When the goal or hope for a cure is clear, the ideal form of social interaction is to look ahead and move forward, with all parties involved being honest and open, moving toward the same direction.



However, when hope for a cure is diminished and the goal is invisible, daring not to look ahead, turning away from the painful reality, and leaving some uncertainty will instill some hope and protect those involved. In this review, we found that social interactions in the EOL decision-making process of children with cancer are evinced as the mutual silent integration of values, which comprises the communication between the child, parents, and HCPs and preserving hope during uncertainty.

## Discussion

We conducted a synthesis of qualitative evidence and identified children's experiences with cancer, their parents' and HCPs' experiences during the EOL decision-making process, and the social interactions between these three groups of individuals. Complex and characteristic interactions were observed, and the three-way interaction lent both positive and negative meaning to each experience. Children with cancer and their parents spend the EOL period caring for each other, seeking to perform their respective roles well. The weight of the minimal time available during the EOL stage increases concern for others, leading to *pretending and misunderstanding*. Consequently, communication mix-ups arise in the relationships among the children, parents, and HCPs, complicating the experience of the EOL decision-making process.

Only two studies in this review included children as participants, while the remaining studies reported the children's experiences from the parents' perspectives. However, the children's experiences derived from this review through the parents' lens; that is, *awareness of being protected and having hope*, and *pretending and being silent*, are consistent with the work of Bluebond-Langner (1978) on dying children. Therefore, we consider these to be significant representations of the children's experiences. Further, the subcategories "*altruism to bolster hope*" and "*hope for peace*," interpreted as the child's experience, are vital findings from the child's perspective. If it is known that the child would be distressed because of treatment during the EOL decision-making process, choices that could help future patients and their families and siblings rather than themselves are not always harmful to the child.

The difficulties encountered by parents and HCPs during the EOL decision-making process are thought to be caused by the complexity of the decisions and social interactions between those involved, such as caring for each other, pretending, and misunderstanding. In particular, parents and HCPs do not understand the real hope of children who do not express their innermost feelings, which hinders the realization of child-centered care.

The formation of the parent-HCP alliance to protect the child indicates that the former ensures that children are provided with filtered information, while simultaneously excluding them from EOL decision-making. Five of the included studies were conducted in Asian countries, while the remaining were conducted in Western countries. Western culture emphasizes honest and open communication and respect for the child's autonomy so that parents and HCPs understand the child's real hope, and the child can be involved in decision-making (Rosenberg et al., 2016). Studies that described cultural differences reported that Asian families often decide against conveying the diagnosis of death to the child for fear that this will erode their hope and result in a poorer prognosis (Chittem et al., 2013; Ni & Alræk, 2017).

A systematic review that described the role of the cultural context in pediatric EOL care reported that multiple studies underscored the differences in acceptable practices but did not describe cross-cultural similarities and differences in preferred parent-child EOL communication (Wiener et al., 2013). We found no evidence to support the integration of qualitative research from different cultures. However, we considered that despite differences in cultures, values, and communication styles, some similarities and/or differences in communication could be extracted from the literature. We decided to include only English and Japanese studies in this review because of limitations regarding the researchers' language skills.

Historically, in Japan, the diagnosis of cancer was not actively disclosed even to adults (Chittem et al., 2013), but the nature of disclosure has changed because of a policy shift. Currently, the rate of HCPs who answered "always" or "occasionally" to whether they provided explanations of cancer diagnoses and prognoses to children with cancer in Japan was 61%, 84%, and 95% for children between 6 and 9, 10–15, and 16–18 years of age, respectively. Therefore, the diagnosis of cancer has come to be disclosed to children of all ages. However, as the condition progresses, the rate of disclosure of metastasis, recurrence, potential non-survival, and imminent death decreases sequentially. The rate of disclosure of imminent death is reportedly 2%, 11%, and 24% for children aged 6–9 years, 10–15 years, and 16–18 years, respectively (Yoshida et al., 2014).

Wiener et al. (2013) stated that the reluctance to discuss death can represent parents' pain and inability to accept the certainty of the end of their child's life. The decision to tell the truth to a child in the EOL context may be influenced by the parents' acceptance of death as inevitable, irrespective of culture. The parents' own experience may determine whether the child is involved in the EOL decision-making process.

The results of this review also demonstrate that the experiences of parents dealing with the inevitable distress of the child's death by avoiding confronting the eventuality of death pose significant communication difficulties during EOL decision-making. It is essential to support parents, which indirectly translates to care for the children, by implementing open and honest communication with children even during the EOL stage. Simultaneously, it is necessary for parents and HCPs to fully consider the kind of information that should be shared to provide the best EOL care for children. This is also an essential aspect of the EOL decision-making process.

Studies have reported that children seek truthful information (Henderson et al., 2017). However, a discrepancy exists between their preferences and the views of the parents and HCPs. On the other hand, children also want room for hope (Jalmsell et al., 2016), which suggests that information control can maintain hope.

Children and adolescents have reported that they trust their parents and HCPs to know the amount of information that they can handle and that their parents and HCPs will act with their best interests in mind (Kelly et al., 2017). Therefore, if there is a trusting relationship between the child, parent, and the HCP in the EOL context, making decisions with tacit understanding while leaving room for uncertainty could maintain the child's hopes. This review concluded that the core of social interaction in the EOL decision-making process is the mutual unspoken integration of values in children with cancer, their parents, and HCPs under situations of uncertainty. Maintaining control by avoiding confrontation with the child's death and having unrealistic expectations, providing information with carefully chosen words, and controlling information may not be inappropriate in the decision-making process.

Uncertainty and certainty co-exist in the EOL context. In addition, when HCPs share information with children and their parents, they attempt to channel uncertainty into certainty. However, this review demonstrated that there is a gap between understanding information and recognizing that information as something that will certainly happen to the children or their parents. When these gaps are identified, HCPs should not assume a lack of understanding of the information and should not repeatedly convey distressing information. Rather, parents should be viewed as individuals preparing to face their suffering and grief. Children and their parents should be guided to face this loss and find new hope at their own pace, rather than rushing them through this period of suffering and grief. This finding is an important aspect that should be examined in further research.

## Practice implications

This review found that parents fostered incompatible hope while witnessing the deterioration of their child's condition, before finally becoming aware of the inevitable reality, which renewed hope, albeit of a

different type. Kars et al. (2011) showed that certainty is a prerequisite for the transformation of hope. However, during the EOL decision-making process, children and parents may wish to remain uncertain for a particular period, rather than prolonging the survival time and ascertaining the duration of the child's survival. This study suggests the need to maintain unrealistic hope during a period of uncertainty. At the same time, rather than rushing to make choices when provided with information about treatment options, the study recommends that parents be supported such that they find new hope, based on the child's medical condition.

Hope and uncertainty are key elements of the EOL decision-making process. Although previous studies have shown that increasing uncertainty makes it less likely for a person to be hopeful (Mishel, 1983), the current review provides new and contradictory results. Hope gives the dying patient meaning in life and confers the strength to live. Therefore, hope that continues to exist during uncertainty could be, in certain situations, one of the crucial elements of the EOL decision-making process that could improve the QOL of dying children and their parents.

### Limitations and strengths

This review sought to provide new and in-depth knowledge about the EOL decision-making process in the pediatric oncology setting. However, some limitations exist regarding the generalizability of the findings. These limitations arise from the difficulty in recruiting participants for this sensitive area of research, problems with obtaining descriptive data from young children, a small sample size, and ethical considerations. Therefore, further research is needed that involves children with the utmost ethical considerations to understand the meaning of uncertainty and hope for children. Further research is required to explore the essence of hope for children with cancer and their parents during EOL, the manner of its advent, and the elements that transform hope via the parents' and children's inner mechanisms.

Further, while the review is unique as it incorporated studies conducted in both Asian and Western countries, it did not allow an in-depth analysis of cultural differences. Future research is warranted that focuses on the cultural differences at play during the EOL decision-making process.

### Conclusion

This review evinced new themes regarding the experiences of children, parents, and HCPs during the EOL decision-making process using meta-ethnography. It found a complex and characteristic three-way interaction among these three sets of individuals. It suggests that hope and uncertainty are key elements and that there is a need for future research that pursues how hope can be supported within the realm of uncertainty.

### Author contributions

M.H. designed the review. M.H. and K.K. examined the electronic search strategies, screened eligible studies, and assessed the quality of the included studies; M.H. and K.K. interpreted and synthesized the qualitative evidence. M.H. wrote the manuscript in consultation with K.K.

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