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Parental Decision Making for Children With Cancer at the End of Life: A Meta-Ethnography

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Abstract

Parents of pediatric oncology patients are faced with difficult decisions when their child reaches the end of life. For health care providers to provide optimal care, they must understand parents' perspectives and preferences in end-of-life decision making. Therefore, this article provides a systematic review of the literature on the end-of-life decision making of parents of children with cancer as well as recommendations for practice and future research. Parents participated in surveys, focus groups, participant observation, and interviews to help researchers understand the expectations, hopes, fears, and values that guide their decision making. Common themes were patient-provider communication, extending time, and understanding prognosis.

Keywords

decision making; palliative care; parenting; neoplasm

Introduction

Very little is known about parental decision making at the end of life in children with cancer. In a groundbreaking study that was one of the first to address end-of-life decision making in parents of children with cancer, Hinds et al. (1997) revealed how complex and difficult decision making is for these families. Other researchers have documented that children suffer at the end of life (Wolfe, Holcombe, et al., 2000) and that the decisions parents make have an impact on both the comfort of the dying child (Kars et al., 2011) and the well-being of surviving family members (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004). Health care providers need to understand end-of-life decision making from the parents' point of view and support them in their role as decision makers (Edwards et al., 2008).

Over the past 30 years, 5-year survival in the pediatric oncology population has increased from 58.1% to 79.6% (National Cancer Institute, 2004). However, cancer remains the primary disease-related cause of death among children aged 1 to 14 years, with 1320 deaths expected in 2012 (American Cancer Society, 2012). Improving end-of-life care for

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children and adults is an initiative of the National Institutes of Health (NIH); the State of the Science conference in 2004 determined there are many barriers to conducting effective end-of-life research (NIH, 2004). Internal review boards are reticent to allow end-of-life research, particularly among children, where an end-of-life trial may be too great a burden to the child and family. Additionally, there are no psychometrically valid and developmentally appropriate instruments for children at the end of life (Hinds, 2004). Those studies that do exist are limited by small samples and homogeneity. In the clinical setting, training programs are available to provide evidence-based care and symptom management at the end of life, but they have not been standardized and uniformly implemented in the clinical setting (NIH, 2004).

Many professional organizations stress the importance of integrated palliative care programs. The American Academy of Pediatrics (AAP; 2007) statement on palliative care for children includes a call for the development of integrated palliative care and training in the communication skills necessary to navigate sensitive end-of-life issues. In their statement on the roles and responsibilities of registered nurses at the end of life, The American Nurses Association (ANA, 2010) states,

The nurse's fidelity to the patient requires the provision of comfort and includes expertise in the relief of suffering, whether physical, emotional, spiritual, or existential. Increasingly, this means the nurse's role includes discussions of end-of-life choices before a patient's death is imminent. (p. 1)

Despite widespread agreement on the importance of care at the end of life, the decision making of parents of children with cancer and the ways in which they can be supported remain poorly understood. Therefore, the purpose of this article is to examine current research on parental decision making at the end of life to elicit clinical implications and the need for future research.

Method

With the aid of a librarian, the terms *neoplasm, cancer, tumor, sarcoma, terminally ill, terminal illness, decision making, child, infant, adolescent, teen, and parent* were searched using MeSH terms. Databases included PubMed, CINAHL, PsychINFO, Cochrane Review, and Embase. The reference lists from all eligible studies and pertinent review articles were hand-searched. Studies were eligible if the sample included the parent(s) of a child who had died, or was expected to die from malignancy, if the study question was related to parental decision making, if the study was published in English, and if the study was published in a peer-reviewed journal between 2001 and 2011. This period of time was selected to obtain the most recent literature on this topic since the treatment and survival rates of children have changed significantly during the past decade. The titles and abstracts of all articles obtained from the search were examined, and full texts were reviewed for potentially eligible studies.

Meta-ethnography was used to synthesize the literature (Barnett-Paige & Thomas, 2009). This method is particularly useful when synthesizing qualitative findings across studies. Originally developed in the education research field, meta-ethnography has been useful to health care researchers to synthesize data across studies while maintaining the interpretive

properties of the primary data (Atkins et al., 2008). After articles were chosen using the selection criteria above, the authors read all articles to identify common themes using the 7 steps of metaethnography: getting started, deciding what is relevant, reading the studies, determining how the studies are related, translating studies into one another, synthesizing translations, and expressing the synthesis (Atkins et al., 2008). The authors made a list of themes, discussed how the studies differed or were related to one another, translated the studies into each other, and synthesized findings (see Table 1). Any disagreements regarding themes were discussed until agreement was reached.

Results

The initial search resulted in 47 articles; of these, 35 studies were excluded because they were not related to decision making, the study population did not include parents, or did not include parents of children with malignancies. Two studies were eliminated based on date of publication. The remaining 10 articles were analyzed for this review (see Table 2).

Characteristics of Included Studies

All studies were descriptive; 7 used qualitative methods and 3 used quantitative. Methods of data collection included semistructured interviews (6), surveys (3), participant observation (1), and focus group (1). Five studies were retrospective, 3 were prospective, and 2 were predominantly prospective but included a minority of retrospective interviews. Sample sizes ranged from 5 to 144; 2 studies had fewer than 10 participants, 1 study had between 10 and 50, 5 studies had 50 to 100, and 1 study had more than 100. Two studies reported the sample as “parents” of 5 and 34 children, respectively, but did not report an exact number of study participants. Three studies included responses from the child’s mother and father, but mothers’ perspectives were the majority (71% to 91%) in the remaining 5 studies. Half did not comment on the race of participating parents; articles that did report race reported predominantly Caucasian participants. Of the 5 retrospective studies, 2 studies did not report the time between the death of the patient and data collection; the remaining 3 studies reported 1 to 2 years (Hannon & Gibson, 2005), 4 to 6 years (Edwards et al., 2008), and 6 months to 14 years (Tomlinson et al., 2006) since death at the time of data collection. Four studies were conducted in the United States, 2 in the Netherlands, 1 in Germany, 1 in Canada, 1 in the United Kingdom, and 1 was collaborative between the United States and the United Kingdom. On 2 occasions (a total of 4 articles), the same data set was used to examine different questions. Methods used to guide qualitative data analysis included interpretive phenomenological analysis, grounded theory, semantic analysis, and constant comparison.

Themes

Three themes emerged from the literature: communication, extending time, and understanding prognosis.

Communication

Communication developed as a multifaceted concept involving provider–parent communication, intracouple communication, and parent’s desire for both information and empathy. Parents wanted direct and honest communication from their health care team (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007; Hinds et al., 2009; Kars et al., 2011; Tomlinson et al., 2006), and they equated clear and compassionate communication with excellent care (Edwards et al., 2008). Furthermore, parents valued the expertise of specialists (Hannon & Gibson, 2005) and wanted their health care providers to use experience to illustrate facts and expected outcomes of treatments; parents wanted providers to explain the expected positive and negative effects that may alter treatment decisions. One parent said when the physician explained MIBG treatment would require his child to be in complete isolation for 4 days and he “wouldn’t be able to hold his hand,” it made the decision clearer (Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010). Parents wanted facts that are concrete, clear, and reliable (Hinds et al., 2009; Kars et al., 2010, Kars et al., 2011). Hechler et al. (2008) found parents were significantly more likely to decide against resuscitation at the end of life if parents had a conversation with their health care team regarding end-of-life decisions prior to the time when it became necessary to make the decision.

In addition to factual information and clear communication, parents wanted emotional support from their health care providers. Parents expressed desires for comfort, emotion, sincerity, verbalizations of caring, and reassurance (Hinds et al., 2009; Mack, 2007; Maurer et al., 2010; Tomlinson et al., 2006). Additionally, parents wanted personal care; they expected health care providers to both observe and consider their family’s special circumstances including financial situation, religion, and patient and family quality of life (Hinds et al., 2009; Maurer et al., 2010; Tomlinson et al., 2006). Parents also stated they wanted the hospital staff’s reassurance that regardless of treatment decisions, their family would not be abandoned by the health care team (Maurer et al., 2010). Additionally, parents expressed how important it was for the staff to verbalize they were a “good parent” given their limited time remaining with their child (Hinds et al., 2009). Other communication preferences included a desire for staff to convey hope, ask about faith preferences, coordinate care, be pleasant, and use humor (Hinds et al., 2009).

Health care providers and parents did not always place importance on the same aspects of communication. In a survey of bereaved parents, and the oncologists who treated their children, Mack et al. (2005) found parents rated physician’s care higher when there was clear information on what to expect; communication with care and sensitivity; communication directly with the child when appropriate; and preparing parents for circumstances surrounding the child’s death. Parents’ reports of the child’s pain and suffering were not significantly correlated to ratings of care. However, when the oncologists were surveyed, parents’ reports of the child’s experience of pain and spending more than 10 days in hospital at the end of life were inversely associated to good care. Furthermore, the oncologists did not correlate parent-rated communication factors with high-quality care, meaning parents tended to place high value on relational care, whereas physician’s tended to rate care on biomedical factors (Mack et al., 2005).

Communication within couples also affected patients at the end of life. In a study of 38 bereaved couples, Edwards et al. (2008) found 42% of the couples agreed the primary goal of care in the last month of life is lessening suffering. Of these couples who agreed lessening suffering was the primary goal, 88% felt they achieved their goal. Conversely, when lessening suffering was not the primary goal of both persons in the couple, both persons reported increased patient suffering from cancer-directed treatment (Edwards et al., 2008).

Extending Time

The literature reviewed also revealed that parents' decisions are influenced by their desire to have more time with their child (Bluebond-Langner et al., 2007; Hannon & Gibson, 2005; Tomlinson et al., 2006). When choosing between cancer-directed versus symptom-directed care, having more time was a key feature of parents' approach (Bluebond-Langner et al., 2007; Tomlinson et al., 2006). Parents also considered gaining time with their child as a factor when deciding to administer palliative chemotherapy. In contrast, parents who chose symptom-directed care cited quality of life, patient wishes, and other family considerations as the basis for that decision (Maurer et al., 2010; Tomlinson et al., 2006). Bluebond-Langner et al. (2007) concluded that parents desired programs in which palliative care and cancer-directed therapy are not mutually exclusive.

Two studies in this review addressed the transition parents make in the end-of-life stage from "preserving" their child in his or her current state of health to "letting go," the realization that the patient is dying, and shifting the focus to meeting his or her needs (Kars et al., 2010; Kars et al., 2011). This transition from preservation to letting go was fluid, it ebbed and flowed as parents were presented with new information and responded to their child's needs (Kars et al., 2010; Kars et al., 2011). Hinds et al. (2009) described "good parents", regardless of treatment decisions, as those who make "informed, unselfish decisions in the child's best interest." However, Kars et al. (2011) argued that unless parents achieved the letting go stage, and saw their child's situation and needs realistically, it was difficult for parents to take the child's perspective, and therefore make decisions in the child's best interest. Kars et al. (2011) also made the distinction that letting go and having realistic expectations is not the same as "giving up." Parents also reported the importance of feeling that everything that could be done for their child was done (Hinds et al., 2009, Kars et al., 2010).

Two articles addressed how parents felt about their decisions to prolong time with their child in hindsight. Hechler et al. (2008) found 70% of parents would have decided against resuscitation in the end-of-life period. Additionally, 20% would have terminated medical care at the end of life in retrospect (Hechler et al., 2008). Kars et al. (2011) wrote, "In hindsight some parents felt they had (at times) lost sight of reality and therefore had inadequately assessed and managed their child's symptoms, suffering, or needs" (p. 32).

Understanding Prognosis

The third theme that emerged was parents' understanding of their child's diagnosis and prognosis. Correct understanding of diagnosis affected parents' treatment decisions (Kars

et al., 2011). Hechler et al. (2008) reported that at diagnosis, two thirds of the surveyed bereaved parents believed their child would survive. Edwards et al. (2008) found that 50% of bereaved mothers and 58% of bereaved fathers considered cure “very likely” at diagnosis. Mack et al. (2007) found at diagnosis, 61% of parents were more optimistic than their physicians that cure was possible for their child. Parents were much more likely to have the same views as their physician when the physician communicated certainty of the prognosis (Mack et al., 2007). Additionally, contradictions and uncertainty in communication lead to misunderstanding of prognosis (Hannon & Gibson, 2005; Tomlinson et al., 2006). One parent said, “[the oncologist] was telling us ... [our son] was going to die ... whereas the consultant in intensive care was saying ... he’s doing very well ... he’s not going to die” (Hannon & Gibson, 2005, p. 289).

Strengths and Limitations of the Literature

The qualitative approach used by the majority of the investigators in this review allowed for an in-depth exploration of parent decision making and revealed many concerns that parents have about caring for their children with cancer. This information provides important groundwork for the future. However, limitations in the studies reviewed include a lack of racial diversity among study participants and missing information on important participant characteristics such as age, race, education, and socioeconomic status. Seven of the 10 studies had a minority of responses from fathers, causing a potential bias toward mothers’ opinions. Among the retrospective studies, the time of death was reported 6 months to 14 years previous to data collection, which has the potential to introduce bias from opportunity to reflect over many years. Many studies in this review described disappointment in the limited and homogenous samples, but the sensitivity of the topic, small target population, and retrospective study designs made it difficult to obtain study participants (Hannon & Gibson, 2005; Hechler et al., 2008). Finally, 3 studies used surveys based on a survey developed by Wolfe, Holcombe, et al. (2000) but did not clearly state which questions were used or how the survey was modified for the purposes of their study.

Strengths and Limitations of the Review

Only studies from peer-reviewed journals were included to increase the likelihood of the inclusion of studies with a high level of academic rigor, but it is possible that studies in grey literature have relevant research that was not examined. Additionally, only articles published in English were included in this review; this may have caused the exclusion of applicable research published in other languages, which may have reflected a broader cultural perspective.

Discussion and Implications for Practice

In this review of parent decision making, the themes of communication, extending time, and understanding prognosis resonated with parents across studies. We found that parents valued accurate and reliable communication across the care continuum and valued specialists’ knowledge. Parents also reported that conflicting information compounded the difficulty of the decision-making process. Of concern is that this is one of the same issues reported in the 2004 State-of-the-Science report on end-of-life care. The report described, “[a] lack of flow of information across providers and settings” (NIH, 2004, p. 9). The NIH state of the

science report also called for more research into the transitions in care patients with serious illnesses face (ie, curative care to palliative care). One of the studies in this review found that parents' end-of-life decisions were different when they had discussed end-of-life care with their health care team before the decision was imminent. This review also showed that explaining not only possible health care decisions but also the expected outcomes of decisions was a factor in parent's decision-making process. Parents also reported that they did not wish to decide between curative care and palliative care, but desired programs that combine the two. Understanding the expected trajectory of illness, explaining treatment options and their outcomes, and guiding parents through end-of-life decisions will continue to be a key element of care in pediatric oncology.

The findings in this review that parents desired an accurate prognosis are consistent with other studies of parents of children with cancer. Wolfe, Klar, et al. (2000) found that physicians know a child's disease is incurable an average of 3 months before parents do. Parents in this review were very clear that they valued clinical expertise and direct communication. Supporting families through the end of life is an important role of the health care team. The AAP, ANA, and NIH, among others, have all emphasized the importance of training health care providers to assist families making end of life decisions (AAP, 2000; ANA, 2010; NIH, 2004). In addition to expertise in end-of-life care, the literature also shows that empathy, caring, and knowledge of each family's special circumstances are important to parents. Parents appreciated health care providers who considered their family's socioeconomic situation, values, belief system, and quality of life. The intense need for some parents to be assured that they were being a "good parent" offers important guidance to care providers of children with cancer and how they can be more supportive to these parents.

The Need for Future Research

Expanding racial, ethnic, socioeconomic, and geographic characteristics among qualitative, quantitative, and mixed methods studies may validate the findings reported here in a more diverse population. The involvement of samples that are more diverse is essential to understand the parent decision-making experience in a broader population. Advancing the science should include quantitative studies. The obstacles to obtain diverse samples will not change: The end of life will remain a sensitive topic and the size and accessibility of the target population is not anticipated to alter. However, improving research design is possible through a collaborative approach.

Developing interventional studies will be important to advancing the science of end-of-life care in children with cancer and their parents and other family members. Currently, all studies in parental decision making at the end of life in pediatric oncology patients have been descriptive. The articles in this review reveal many potential interventions such as improving parent-provider communication, planning goals of care, supporting parents in the "good parent" role, or helping parents transition from "preservation" to "letting go." Finally, increasing the use and development of theoretical models will provide a broader understanding of the experiences of parents.

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Biography

Katherine E. Heinze, BSN, RN, practiced pediatric oncology nursing for 7 years at the Johns Hopkins Hospital before she began to pursue her research interests as a PhD student.

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Table 1.

Summary of Themes

	Hannon and Gibson (2005)	Tomlinson et al. (2006)	Kars et al. (2011)	Kars et al. (2010)	Bluebond-Langner et al. (2007)	Maurer et al. (2010)	Hinds et al. (2009)	Hechler et al. (2008)	Edwards et al. (2008)	Mack et al. (2005)
Communication	X	X	X	X	X	X	X	X	X	X
Extending time	X	X	X	X	X	X				
Understanding prognosis	X	X	X					X	X	X

Summary of Articles

Table 2.

Title	First Author and Year	Sample	Research Question	Design	Measures	Outcome
Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed	Bluebond-Langner, 2007	Parents and health care providers of 34 pediatric patients in the United States (US) and the United Kingdom (UK)	How parents make decisions when standard therapy has failed, and whether parents' approaches differ in the US and the UK	Prospective ethnographic study using participant observation, open-ended semistructured interviews, and medical record reviews	Observation at home and hospital, semistructured interviews, and medical record review	1 Both US and UK parents seek cancer-directed care and effective symptom management. There was no difference in approach to care between US and UK parents.
Understanding of prognosis and goals of care among couples whose child died of cancer	Edwards, 2008	38 bereaved couples in the US	Do parents in couples differ by sex in understanding of prognosis and treatment goals? If there is discordance in couples, does it affect perceptions of end of life care?	Retrospective cross-sectional survey conducted individually on the phone or by mail	Survey about Caring for Children with Cancer, focusing on questions regarding parental perspectives of prognosis and treatment goals at diagnosis, during the child's end-of-life period, and in the last month of life	1 At diagnosis, fathers and mothers held a similar understanding of the child's prognosis. 2 During the end-of-life period, a majority of fathers and mothers reported lessening suffering as the primary goal. 3 When parents did not agree on the primary goal of lessening suffering, both parents were more likely to report that the child suffered significantly from cancer-directed treatment.
Advanced cancer in children: How parents decide on final place of care for their dying child	Hannon, 2005	Bereaved parents of 5 children in the UK	When deciding where to care for their child with advanced cancer, what factors and information do parents consider important, helpful, and unhelpful?	Semistructured interviews	Schedule guide constructed by the authors; data were interpreted using interpretive phenomenological analysis	Themes: 1 Valuing time left 2 Needing to feel safe and secure 3 We did not know what to expect 4 The difference between specialists and subspecialists
Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for	Hechler, 2008	Bereaved parents of 48 children in Germany	Bereaved parents' perspective on 5 areas: (a) symptoms and quality of life; (b) characteristics of the child's death; (c) anticipation of their child's death and care	Retrospective survey	A survey developed by Wolfe, Holcombe, et al. (2000) was translated into German and modified to fit the German health care system	1 Symptom prevalence was similar to reports from the US, Japan, Australia, and other European countries 2 Parents decided against resuscitation more frequently

Title	First Author and Year	Sample	Research Question	Design	Measures	Outcome
children dying from cancer			(d) end-of-life decisions; and (e) impact of the child's death on the parents and perceived social support by the health care team.			after discussion with the health care team
"Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children	Hinds, 2009	62 parents of 58 children in the US who had made a treatment decision for a seriously ill pediatric oncology patient in the previous 72 hours	What do parents believe is the definition of being a "good parent" to a child with incurable cancer? How can health care providers support parents in the "good parent" role?	Semistructured interviews	Parents were asked: (a) Please share with me your definition of being a good parent for your child at this point in your child's life. (b) Please describe for me the actions from staff that would help you in your efforts to be a good parent to your child now.	Most common "good parent" themes: <ol style="list-style-type: none"> 1 Doing right by my child 2 Being there for my child 3 Conveying love to my child
Factors influencing parental readiness to let their child with cancer die	Kars, 2010	44 parents (23 mothers and 21 fathers) of 23 children in the Netherlands	Identify, from a parental perspective, the main factors that influence parents' position between preservation and letting go.	Individual semistructured interviews (34 before death, 10 after)	Questions included parental care and goals, the parent-child relationship, parenting and loss, coping, professional care, and family life. A grounded theory approach was used to develop theory to interpret the data.	Most common helpful staff themes: <ol style="list-style-type: none"> 1 All that can be done is being done 2 Staff respect me and my decisions 3 Staff continue to comfort my child and me
Parental experience at the end-of-life in children with cancer: "preservation" and "letting go" in relation to loss	Kars, 2011	44 parents (23 mothers and 21 fathers) of 23 children in the Netherlands	Identify processes parents go through when cure is not obtainable, and to explore the influence of parental processes on the choices they make with respect to their child's treatment and care.	Individual semistructured interviews (34 before death, 10 after)	Questions included parental care and goals, the parent-child relationship, parenting and loss, coping, professional care, and family life. Interviews were tape-recorded and transcribed. The research team used Coding and Thinking Theoretically to analyze the data.	<ol style="list-style-type: none"> 1 Factors leading toward preservation: uncertainty, fragmentation, and anxiety. 2 Factors leading toward letting go: certainty, postponing grief, perception of suffering, the ability to disentangle needs or interests, and ability to parent meaningfully 3 Factors leading in both directions: hope, maintaining a peaceful parent-child relationship, and professionals (framing and guiding)
Parental experience at the end-of-life in children with cancer: "preservation" and "letting go" in relation to loss	Kars, 2011	44 parents (23 mothers and 21 fathers) of 23 children in the Netherlands	Identify processes parents go through when cure is not obtainable, and to explore the influence of parental processes on the choices they make with respect to their child's treatment and care.	Individual semistructured interviews (34 before death, 10 after)	Questions included parental care and goals, the parent-child relationship, parenting and loss, coping, professional care, and family life. Interviews were tape-recorded and transcribed. The research team used Coding and Thinking Theoretically to analyze the data.	<ol style="list-style-type: none"> 1 With respect to preservation the goal is "as long as possible, as well as possible" with an emphasis on long. 2 Letting go is demonstrated by parental willingness to subordinate their need to avoid loss to the child's well-being and comfort, which take

Title	First Author and Year	Sample	Research Question	Design	Measures	Outcome
Parent and physician perspectives on quality of care at the end of life in children with cancer	Mack, 2005	144 bereaved parents and 52 pediatric oncologists in the US	To ascertain parents' and physicians' assessments of quality of end-of-life care for children with cancer and to determine factors associated with high-quality care as perceived by parents and physicians.	Retrospective survey	Parents were asked to rate various aspects of care at the end-of-life, communication from the oncologist, and trust in the oncologist. Physicians were asked to rate how care went in the end-of-life period.	<p>precedence over prolonging life. The transition from "preservation" to "letting go" requires a switch in source of control. It is part of the parental dilemma.</p> <p>3 Professionals can support parents by providing encouragement and a justification for their transition to a "letting go" attitude.</p> <p>1 For parents of children who die of cancer, doctor-patient communication is the principal determinant of high-quality physician care.</p> <p>2 In contrast, physicians' care ratings depend on biomedical rather than relational aspects of care.</p>
Decision making by parents of children with incurable cancer who opt for enrollment on a phase I trial compared with choosing a do not resuscitate/terminal care option	Maurer, 2010	62 parents of 58 children in the US who had made a treatment decision for a seriously ill pediatric oncology patient in the previous 72 hours.	A comparison of the self-reported Semistructured rationale, good parent definition, interviews and desired staff behaviors of parents who had decided for phase I (PI) therapy with parents who chose a DNR or terminal care option.	Semistructured interviews	Parents were asked: <p>1 Please tell me the options that you considered when you made this treatment decision for your child.</p> <p>2 Please tell me your reasons for choosing the treatment decision you helped to make on behalf of your child.</p> <p>3 Please share with me your definition of being a good parent for your child at this point in your child's life.</p> <p>4 Please describe for me the actions from staff that would help you in your efforts to be a good parent to your child now.</p>	<p>1 Most PI group parents reported having felt compelled to continue cancer-directed therapy, whereas those who opted for DNR cited quality of life and patient wishes.</p> <p>2 Decision factors common to both groups were medical facts, doing right, and others' opinions. Both groups believed that a good parent did right, provided support and presence, and sacrificed for the child.</p> <p>3 The groups desired similar support from clinicians.</p>
Parental decision making in pediatric cancer end-of-life care: Using focus	Tomlinson, 2006	7 bereaved parents in Canada whose children died	What are parent's opinions about making the decision between palliative cytotoxic	Focus group	Parents were asked: <p>1 With regard to end-of-life care, what do you think about the options</p>	<p>1 Differing themes emerged among parents who choose palliative chemotherapy versus</p>

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group methodology as a prophase to seek participant design input		between 6 months and 14 years prior to data collection	chemotherapy and supportive care alone? What are the factors that parents regard as important when making this decision? Is there anything health care providers can do to help the decision-making process easier?		<p>of supportive care with palliative chemotherapy and supportive care alone? 2</p> <p>What are reasons do you think parents might choose chemotherapy? 2</p> <p>What are reasons do you think parents might choose supportive care alone? 3</p> <p>How do you think doctors, nurses and social workers might help a family having to make such a decision? 4</p>	<p>parents who choose supportive care alone.</p> <p>2 Among the themes that emerged as ways health care providers can help parents make decisions, 2 themes were honesty and awareness of the patient's unique situation.</p>