



# Exploring Parental Decision Making for a Child With a Life-Limiting Condition

## *An Interpretive Description Study*

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The purpose of this study was to explore parents' and health care professionals' perception of parents' experiences in making decisions between acute and palliative therapies along the trajectory of their child's life-limiting condition. An interpretive description qualitative study was conducted. Semistructured interviews were completed with 6 parents and 6 health care professionals. Qualitative thematic analysis was used to identify, analyze, and report 4 themes: (1) "Going by your heart and gut": the process of making a unique decision; (2) "Not black and white": experiencing decisional conflict when making difficult decisions; (3) "Widening the circle of care": various sources of decision-making support; and (4) "Always a worry": concerns regarding parents' decision quality and outcomes. Parents described experiencing decisional conflict when making health care decisions for their child with a life-limiting condition. Decision support provided by health care professionals in an interprofessional manner was preferred and supplemented by a parent-based support network. Reassurance regarding their good parenting from health care professionals was described as supportive throughout the decision-making experience.

### KEY WORDS

decision making, decision support, palliative care, parents, pediatric nursing

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With advances in medical therapy and access to new technologies, there is an increased prevalence of children surviving poor prognoses and living with chronic, complex, and life-limiting conditions (LLCs).<sup>1-3</sup> Parents of children living with LLCs are required to routinely make decisions between acute and palliative therapies, both intended to relieve suffering, along the trajectory of their child's life.<sup>1,2</sup> These decisions require parents to consider benefits, risks, and both short- and long-term outcomes.<sup>4</sup> Given that their children are often developmentally and cognitively unable to participate in making decisions for themselves, parents face difficult health care decisions that require support throughout the decision-making process.<sup>5</sup>

Reoccurring decisions requiring trade-offs between acute and palliative therapy options often lack an obvious best choice and are value sensitive (ie, dependent on individual and/or family values, beliefs, and goals). As a result, parents may be susceptible to uncertainty about the best course of action, resulting in decisional conflict.<sup>5</sup> Decisional conflict can be described as a state of uncertainty arising from decision making that navigates 2 or more options involving risk, loss, and potential for future regret, and/or challenges personal values and preferences.<sup>6</sup> The management of such decisional conflict may be challenging for parents and, if unaddressed, may lead to long-term psychosocial burden, decision regret, and blame.<sup>4,7</sup>

The Ottawa Decision Support Framework describes the relationship between individuals' decisional needs, decision support interventions, and decision outcomes.<sup>8</sup> According to this framework, individuals' decisional needs may include inadequate knowledge and unrealistic expectations, unclear values, inadequate support and resources for both decision making and implementation, decision characteristics (type, timing, stage, or leaning), and decisional conflict. Decisional outcomes improve when these decisional needs are addressed. Decision support interventions can improve decisional outcomes by clarifying an individual's values and needs, providing information, and guiding communication. Decisional outcomes may consist of the quality of the decision, including the congruence between informed values and the



decision, and the impact of the decision on the appropriate use of resources.

### Summary of the Literature Review

A formal literature review was conducted in September 2017 and updated in May 2020 in CINAHL, PubMed, and ProQuest. A combination of keywords and/or Medical Subject Headings terms appropriate for each database were used based on the concepts of “decision-making,” “parent,” “child,” and “palliative care” along with related terms such as “consent,” “partnership,” “collaboration,” and “parent participation.” English, peer-reviewed publications were included regardless of the year of publication and clinical context. Priority was given to reviews.

A systematic review of parents' decision support needs when making health care decisions on behalf of their child identified 149 studies, most of which were from North America, the United Kingdom, and Australia/New Zealand.<sup>5</sup> Participants were recruited having made various health care decisions and from primary and tertiary care centers, and the community (including schools, churches, and workplaces). Parents' decisional needs were information (with consideration of the content, delivery, and source); discussions with health care professionals (HCPs) and other potentially pressuring sources such as family, friends, society, and the health care system; and the feeling of a sense of control over the process.

A literature review of studies describing parents' perspectives regarding decision making along the trajectory of their child's cancer treatment included 17 studies.<sup>9</sup> The review reported that parents needed support, communication with HCPs, enhanced knowledge, and accurate information about their child's health. Although the previous systematic review and this literature review included studies regarding life support and intensive care decisions, neither included parents facing reoccurring decisions between acute and palliative therapies for a child with an LLC.

An integrated literature review describing factors that affect parental decision making for medically complex children included 31 studies conducted in several countries, including North America, Turkey, France, and the Netherlands.<sup>1</sup> Diagnoses of children included major prematurity, genetic anomalies, and neurological injury. Most studies focused on critical decisions such as the continuation or termination of a high-risk pregnancy, withdrawal of life-sustaining therapies, and end-of-life care. Factors affecting parental decision making include the content (severity of illness and treatment options) and type (communication tools) of information provided to or sought by parents. The severity and extent of the child's illness, child's best interest, and emotional support also contribute to the parents' decision-making process.

In summary, parents need to gain knowledge about their child's illness or treatment options; to have conversations with HCPs, family members, and friends; and to

receive emotional support to make informed decisions about their child with an LLC. This review of the literature highlights the importance of attending to parents' needs because unmet needs may negatively affect decisions made for their child with an LLC. Parents of children with LLCs are required to make value-sensitive decisions routinely during the course of their child's life. However, little is known about their needs when making reoccurring decisions specifically between acute and palliative therapies for their child living with an LLC. Therefore, the purpose of this study was to explore parents' and HCPs' perceptions of the experience of parents in making decisions between acute and palliative therapies along the trajectory of their child's LLC.

## METHODS

### Research Design

An interpretive description study rooted in constructivism was conducted to capture themes and patterns within a subjective interpretation of a phenomenon (parents' experiences in decision making) and to generate descriptions for the purposes of enhancing and informing the existing clinical understanding and experience.<sup>10</sup> This research design was appropriate given the aim to develop clinically relevant knowledge to inform clinical practice. The study received approval from the research ethics board of the participating hospital (17/176X) and the affiliated university (H11-17-217).

### Setting

A regional children's hospital in Canada that serves an urban and rural population of 1.3 million provides the services of an interprofessional palliative care team. The palliative care team supports children with LLCs on a referral basis. This support includes access to the affiliated 8-bed pediatric hospice located on the grounds of the hospital. With the support of the palliative care team, the hospice offers a variety of programs including respite to families, perinatal hospice care, transition from hospital to home, symptom assessment admissions, end-of-life care, and grief and bereavement support. The hospice serves approximately 100 children at any given time and at different stages of their LLC.

### Participants

Participants were eligible if they were in 1 of 2 groups: parents or HCPs. English-speaking parents were eligible if they had a child who was 18 years or younger, given a diagnosis of an LLC, and cognitively unable to contribute to decision making, and they were followed by the hospital's palliative care team. Eligible parents were approached by a member of their circle of care discussing their interest in participating in the study.



English-speaking HCPs were eligible if they were (a) hospital or affiliated hospice employees who worked with families followed by the palliative care team and in a family's circle of care as they made health care decisions on behalf of their child or (b) physicians, social workers, registered nurses, or registered practical nurses. The hospital email listserv, a snowball recruitment approach, and posters displayed in the hospital and the affiliated hospice were used to invite eligible HCPs to participate. All participants reviewed and signed an information and consent form before participation. The sample size was determined by attempting to obtain maximal variation in themes as a result of concurrent data collection, reflection, and analysis.<sup>10</sup>

### Data Collection

In-person or phone interviews were conducted between January and November 2018 at a time and, if applicable, location that were convenient to the participant. The 30- to 60-minute semistructured interviews began with a brief explanation of the study and a review of the obtained written informed consent. Interviews were audio-recorded and transcribed.

Interview guides were developed separately for parents and HCPs with open questions to explore decisional needs of parents, among others, as described in the Ottawa Decision Support Framework.<sup>8</sup> The research team was composed of experts in decision making, pediatric palliative care, and parent engagement. Each perspective influenced the development and review of interview questions. Questions included "Please tell me about your experience with a healthcare decision made for your child", "Who was involved in making the decision and how were they involved?", "How did you feel when this decision was being made?", and "What made this decision challenging for you?" Personal and clinical characteristics were also collected for descriptive purposes given that such characteristics may contribute to decision-making needs.<sup>8</sup> The iterative nature of the data collection process prompted ongoing reflections on the interviews and allowed for amending and restructuring of questions.<sup>10</sup> The interview guides were piloted with an experienced pediatric palliative care nurse and a parent to review flow and sensitivity.

### Analysis

Consistent with interpretive description methodologies, data analysis was conducted to explore the meanings and patterns of participants' described constructed realities.<sup>10</sup> Qualitative thematic analysis occurred to identify, analyze, and report themes while comparing and contrasting themes throughout the analysis process.<sup>11</sup> Codes were identified by means of an inductive approach.<sup>11</sup>

The analysis process consisted of 5 steps: (1) An audio recording of the interview was transcribed verbatim and read in its entirety to encourage familiarization with the

data; (2) codes were generated for data relevant to the research questions by making notes in the margins, constantly comparing codes including those generated in previous transcriptions, and, together with associated data, collated in an Excel Spreadsheet after coding the entire transcription; (3) the codes that were related were sorted into subcategories and followed by categories; (4) categories were color coded to form groups rather than prematurely being labeled; and (5) the color-coded groups were carefully reviewed to identify constructed themes. N.Y. and J.C. compiled themes to interpret the data, describe participants' experiences, and capture exemplar quotes from the data, while accounting for their own knowledge and perspectives.<sup>10</sup> N.Y. and J.C. independently coded interviews and resolved coding discrepancies by discussion.

### Research Integrity

To ensure research integrity, evaluative criteria such as credibility, confirmability, meaning in context, saturation, and transferability were considered.<sup>10</sup> To enhance credibility, data triangulation was used by engaging both parents and HCPs as data sources. Investigator triangulation also occurred with N.Y. and J.C. contributing to data analysis. To promote confirmability, documentation of the research design process, postinterview field notes, and thematic analysis were maintained. The meaning-in-context criterion was met by having participants describe a specific example of when a decision was made about the health or treatment of a child with an LCC. Such details provided contextualization of the experience within a total situation. To reach saturation, dense and rich data were collected while redundancy of similar ideas also occurred. Transferability was enhanced by providing detailed descriptions of the context including study setting and sample.

## FINDINGS

### Participant Characteristics

Ten eligible parents were approached by members of their circle of care to participate, and 6 parents consented to participate. Parents who did not agree to participate reported that this was the case because of the deterioration of their child's health status during the interview period. Five mothers and 1 father participated, none of which was parenting the same child. Parents' age ranged from 24 to 49 years (median, 35). One parent completed graduate studies, 3 had completed undergraduate studies, and 2 completed high school. Their children ranged in age from 1 to 11 years (median, 5.5 years). Half of the children ( $n = 3$ ) were given a diagnosis of genetic anomalies: 1 was extremely premature, 1 had spastic quadriplegic cerebral palsy, and 1 had a neurodegenerative condition.

Of the 6 HCPs, 4 were nurses and 2 were social workers. One HCP had between 5 and 10 years, 3 had 10 to 15 years,



and 2 had greater than 15 years of experience working with children and families followed by the palliative care team.

## Themes

Four major themes were identified: (1) “Going by your heart and gut”: the process of making a unique decision; (2) “Not black and white”: experiencing decisional conflict when making difficult decisions; (3) “Widening the circle of care”: various sources of decision-making support; and (4) “Always a worry”: concerns regarding parents' decision quality and outcomes. Each of these themes is presented hereinafter.

### ***“Going by Your Heart and Gut”: The Process of Making a Unique Decision***

Given the unique nature of their decisions, parents were described as relying on what felt right to them when making decisions. One parent described that the types of decisions they made required them to “just nail down what [they] thought was going to be best for [their] daughter.” Another parent described a sense of self-efficacy when making decisions: “You can't always listen to doctors, you can't always go by what the tests say, or what the results are, you have to go by your heart and gut.”

The decisions that parents of children with LLCs routinely faced were unique, with serious outcomes, and had varying degrees of risk. One parent described having to make a decision that involved feeling analogous to “pulling out his breathing tube and letting him suffocate [and die].” One parent articulated the seriousness of making a decision on behalf of another person, particularly in the case of a child unable to communicate, “With a non-verbal child, it's guessing. I wish I could ask her about the G-tube. Tell me? Do you hate mommy because I did this? It's a little trickier because you're making a decision on behalf of a human.”

A parent expressed the stress associated with the decisions themselves and shared that it often felt “so intrusive, so un-normal, and unnatural,” whereas an HCP used the example of an elective spinal fusion surgery to echo the inherent risk associated with such decisions. The HCP stated, “I think [decision-making for parents] is difficult with very invasive procedures such as back surgery (...) it is a long procedure some children may not even be well enough from a respiratory or cardiovascular perspective to have this surgery.”

#### **A Range in Parents' Preferred Role in Decision Making**

A subtheme described parents' role in the decision-making process. The role of parents in decision making articulated by participants included making choices independently after considering options, a preference for sharing in the decision with others, and the HCP as the decision maker. When describing a preference for independent decision making, 1 parent stated that the decision, regarding nonpharmacological treatment options for their child's refractory epilepsy, was made “entirely [by] myself and < spouse>,”

there were no medical people involved in that decision-making.” When describing the process of making health care decisions for their child, 1 parent stated that it “came down to my [spouse] and me.”

Shared decision making primarily involved HCPs. A parent described that “the decision took place between myself, my [spouse], and the neurologist. He made us feel as if we were in control but gave us his opinion and presented choices.” In another instance, a parent described sharing the decision regarding exploratory diagnostic testing with family members rather than HCPs: “That was the first family decision we made.” The facilitation of a shared decision-making approach by HCPs, in response to parent's preference, was described by an HCP: “Depending on what medical teams are involved [in child's care] (...) I've involved them in [supporting parents'] decision-making.”

Alternatively, a parent described a preference to defer to the HCPs to make decisions: “Sometimes, [parents] have to trust the experts and that they're going to know what the right information is to give [the parents during the decision-making process].”

### ***“Not Black and White”: Experiencing Decisional Conflict When Making Difficult Decisions***

All parents described personal uncertainty resulting in decisional conflict. The experienced decisional conflict was expressed by a variety of behavioral manifestations including concerns regarding consequential undesired outcomes, wavering between choices, and uncertainty regarding what is the best course of action.

Undesired outcomes, resulting from the decision and related distress, contributed to decisional conflict. One parent recalled, “See[ing] things in a bigger picture and the consequences are (...) I'm sure this added to the stress [of decision-making]. It made the decision more difficult morally (...) the [option] was just more distressing because of the possible consequences.” Another parent shared that “not knowing exactly ahead of time, how the medication was going to have an effect on [child] made it a challenging decision.”

Another manifestation of uncertainty described by parents was the experience of wavering between choices. One parent stated, “I debated right up until the morning [of the selected intervention]. I was thinking, ‘gosh, I hate that she has to deal with this every day’ and ‘did I do the right thing?’” Another noted, “My [spouse] and I have been back and forth, back and forth.” As a result of the best choice not being clear, a parent explained, “You shake your head and think ‘how is this not black and white?’”

### ***“Widening the Circle of Care”: Various Sources of Decision-Making Support***

A widened external support network that included both an interprofessional team of HCPs and a parent-based support





network was described by participants. This support was described by parents as being reassuring, information rich, and preferably received early in the decision-making process. Both interprofessional HCP and parent-based decision support were identified as subthemes.

#### Interprofessional Health Care Support

Parents described the need for support from HCPs who are collaborating with one another throughout the decision-making process. This interprofessional HCP support was described by participants to be both emotional and informative in nature.

The emotional support provided by HCPs was described by a parent: "The nurse held our hand through a little bit of it because we were very hesitant and nervous (...) the nurse reassured us several times." On the other hand, an HCP shared that they routinely "talk[ed] to [parents] about their emotions (...) like anxiety and guilt when making these difficult [healthcare] decisions [for their child with a LLC]." Another HCP noted that it was critical to "make sure that you're telling [parents of children with LLCs] that they're doing the right thing. [Parents] need reassurance because there could be a lot of guilt associated with [making the decision]."

Parents and HCPs described the role of HCPs in supporting parents' information needs related to decision making. An HCP noted that "parents do usually seek the support of HCPs to get answers to the questions [related to decision-making]." This provision of information-based support was also described by a parent who shared that "[HCPs] educated us, gave us the pros and cons of switching medications and trying this new one. They told us as much as they could about what the side effects were going to be."

Parents noted that health care decisions for children with LLCs often required the consideration of the financial and practical implications of options. One parent described, "Be[ing] able to rely on [occupational therapist] to help [the parents] make decisions about the equipment to purchase and customize for <child> [as a result of their decision]." Another parent described the consideration of practical implications to health care decisions made for their child and that they "considered how [child] would go to school with [decision to insert gastrostomy tube], worried that this would make it harder. It was helpful to connect with her school nurse and [occupational therapist] to learn more about this."

#### Parent-Based Support Network

Parents repeatedly described a network of parents as being an instrumental form of decision support. One parent shared, "Find[ing] the pockets of people that [they] needed when [attempting to make a decision]." Another parent described the support experienced as a result of connecting with other parents sharing, "I remember vividly having conversations with other families saying 'I struggled with

this decision and I wish I could have gone back and made it sooner.' So that gave me a lot of comfort and confidence in making the decision [to insert a gastrostomy tube]."

Parents considered their informal parent network as a decision support resource to be superior to HCPs. One parent described the value in gathering information from other parents about their "day-to-day experience" with a decision and the subsequent outcomes. A parent noted that they "already knew quite a few families who had already [made the decision]" and that the "community of parents is probably [their] biggest source of influence about the decisions that [they] make."

Health care professionals noted that parents benefited from identifying and leaning into a support network external to the HCPs when making decisions. They explained that this external support network could either consist of "[parents'] own family members" or "another family who has been through a similar situation or procedure." In addition, another HCP articulated a need to be actively "widening the circle of care [to include other parents], just to ensure that families are prepared for whatever they're taking on [as a result of selected options]."

#### ***"Always a Worry": Concerns Regarding Parents' Decision Quality and Outcomes***

The uncertainty described by parents during the decision-making process was felt even after making a decision. One parent shared that "now I still at times second guess the decision I made because of some complications, not serious ones but discomfort is one that she has that is still sticking, and I hate to see her suffer and I think, 'was this really necessary?' (...) you carry guilt, you always wonder." The difficulty and stress associated with uncertain outcomes significantly impacted parents' decision-making experience and were described by another parent, "We knew that these [decisions] carried some risk and some discomfort to <child>, so that was really hard for us." This reality was noted by an HCP participant who described that "parents have some anxiety and worry about [outcomes] and try to do everything they can to avoid it." Another HCP noted that there is "always a worry that parents feel guilty if things don't work out as expected [after the decision is implemented]." This HCP described parents feeling "guilt, sadness, and despair" as a result of the health care decision they made for their child with an LLC. Another HCP shared that "it's not until after [the decision is made], when maybe, a month or so out, that [parents] really might start to relax a little bit [about the decision they made]."

## DISCUSSION

This study improves our understanding of parents' decision-making experiences as it relates to their child living with an LLC and the means by which they are supported when



making health care decisions. Although this study sought to explore the perception of parents and HCPs about parents making decisions for their child, between acute and palliative therapies, parents did not describe health care decisions in this manner. Parents cited examples of decisions made along the trajectory of their child's life such as the insertion of a gastrostomy tube and the need for careful deliberation in the context of their child's LLC. These decisions were not labeled as either acute or palliative in nature. Instead, they were likely the most recent challenging or unique health care decision recalled.

The findings of this study align with a previously completed systematic review describing the key needs of parents making health care decisions on behalf of their child.<sup>5</sup> Parents needed to receive information, discuss with others including HCPs and other potentially pressuring external sources, and feel a sense of control over the decision-making process. The control described by parents was related to access to information, the quality of relationships with the HCP, and parents' preferred level of participation in decision making. These decisional needs were described by parents and HCPs in this study.

### Manifestations of Decisional Conflict

Parents experienced several manifestations of decisional conflict when faced with these difficult and unique decisions regarding their child's health care.<sup>8</sup> A scoping review of decisional conflict, measured with the Decisional Conflict Scale across various clinical situations, included studies pertaining to treatment decisions for children with LLCs and palliative care for children.<sup>6</sup> Decisional conflict was highest before making the decision and decreased after exposure to decision support interventions. Associated uncertainty regarding decision-related outcomes and the need for decision support to manage decisional conflict were described by parents and HCPs.

### Providing Parents With Reassurance

Parents discussed their need to be reassured about their decisions made on behalf of their child with an LLC. This finding is in keeping with a previous study describing parents' beliefs regarding health care decision making for their child and engagement with a pediatric palliative care team and the desire to be a "good parent."<sup>12</sup> This study described being a good parent as making informed and selfless decisions on behalf of the child and in the best interest of the child. In a study describing the challenges parents faced when prioritizing goals for their child with an LLC, participants identified their role in making informed medical care to be ranked in the top 3 attributes important to being a good parent, along with making sure their child felt loved and focusing on their child's health.<sup>13</sup> Interactions with HCPs are deemed effective in supporting parental decision making when parents are reassured of their good

parenting.<sup>14</sup> The HCPs' role in providing parents with reassurance as a form of emotional support was noted in this study by both parents and HCPs.

### Valuing a Parent-Based Support Network

Parents identified a parent-based support network as beneficial when making decisions. They conveyed a sense of being supported by such a support network in the form of structured groups and an informal network, as opposed to by HCPs. This is consistent with the systematic review conducted that described parents' preference for talking to other parents in similar situations through either formal or informal networks.<sup>5</sup> Parents of children with chronic complex conditions have previously found it therapeutic to access peer support groups as they decrease feelings of isolation and vulnerability, allow for the exchange of complex factual and emotional information, and provide the opportunity to garner how other parents made decisions.<sup>15</sup> Parents accessed a single pediatric hospice, which may have facilitated parent support groups. These may have contributed to the establishment of the informal social network described by parents.

### Strengths and Limitations

Perspectives of parents and HCPs were captured in this study, informed the interpretation of the findings, and allowed for a broader understanding of parents' experiences with decision making. Parents were approached and recruited for participation in the study by the HCPs in their immediate circle of care. As is often the case in other palliative care studies, these HCPs acted as gatekeepers by making judgment that, despite being eligible, some parents should not be recruited for participation in research. Consideration of parents' vulnerability and the potential burden resulting from research participation, such as the number of appointments scheduled, may have been factors.<sup>16</sup> Although data saturation was achieved, the needs and experiences of these families may be underrepresented here because of these recruitment challenges.

### Implications for Nursing Practice

These findings may increase nurses' and HCPs' awareness about the parents' experiences when making health care decisions on behalf of their child living with an LLC. Nurses' and HCPs' role is critical in parental decision making. They respond to parents' decision-making needs, including information, conversations with HCPs, and emotional support, as well as facilitate parental decision supports and reassure parents of being good parents.<sup>12,13</sup>

## CONCLUSION

This study contributed to better understanding parents' decision-making experiences for children with LLCs. Parents



described decisional conflict to manifest as concerns regarding consequential undesired outcomes, wavering between choices, and uncertainty regarding what is the best course of action. Parents and HCPs described parents' reliance on a parent-based support network. Health care professionals were described as providing decision support by engaging in supportive conversations and reassurance in regard to good parenting. Further research is required to better identify resources to be used by HCPs to support the decision-making needs of parents with children living with LLCs.

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