

Parental Decision-Making for a Child with a Life-Limiting Condition

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Thesis Abstract

Purpose: To explore the decision-making experiences of and the supports provided to the parents of children with life-limiting conditions.

Qualitative Study: A qualitative interpretive description study guided by the Ottawa Decision Support Framework was conducted. Interviews with parents and healthcare professionals revealed that parents made difficult healthcare decisions for their child and were prone to experiencing decisional conflict. Participants described a need for interprofessional support, guided decision support, and a preference for formal and informal support networks.

Scoping Review: A scoping review was conducted. The three eligible studies revealed that parents require early and timely decision support provided by an interprofessional team of healthcare professionals and aided by a structured decision support intervention.

Conclusions: Decisions made by parents of children with life-limiting conditions are complex. Healthcare professionals are required to facilitate appropriate decision support interventions for parents including a parent based support network.

Keywords: palliative care, decision-making, decision support, pediatric nursing, parents

Preface

Several authors have contributed to this thesis and their contributions are summarized below. Nahal Yazdani (NY) was the thesis candidate and primary author of this thesis. She conceived and designed the thesis, including the literature review, qualitative study, and scoping review with feedback and support from co-authors. NY drafted the thesis proposal, ethics applications, and request for a data sharing agreement between the University of Ottawa and CHEO. NY conducted the scoping review and interviews. She transcribed the interviews and coded transcriptions. NY drafted and edited all chapters of the thesis.

Dr. Julie Chartrand, RN, PhD (JC) was the thesis supervisor and engaged in all stages of thesis development. JC was involved in conception and design of the study, thesis proposal development and approval, and ethics application formulation. JC co-conducted qualitative data analysis including interview transcript coding and themes. JC guided and approved all chapters of this thesis, and oversaw final approval of this thesis.

Dr. Dawn Stacey, RN, PhD (DS) and Lynn Grandmaison Dumond, RN(EC) (LGD) were thesis committee members. Both DS and LGD contributed to the conception and design of the study and approved the thesis proposal. DS provided insight into the literature review and integrated discussion, in addition to sharing feedback on drafted thesis chapters. LGD supported the application for ethics approval from CHEO, provided a pediatric palliative care lens, and reviewed the drafted thesis. While all thesis committee members provided feedback after reviewing both individual chapters and then the full thesis, final approval was provided by JC and NY.

Summary of Contributions of Co-Authors

	NY	JC	DS	LGD
Conception and design	X	X	X	X
Approval of proposal	X	X	X	X
Data collection and transcription	X			
Data analysis and interpretation	X	X		
Review and provision of feedback for drafted thesis	X	X	X	X
Final approval of thesis	X	X		
Responsibility for all content	X			

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“I can no other answer make but thanks, and thanks, and ever thanks.”

- William Shakespeare

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List of Abbreviations

Abbreviation

CHPCA Canadian Hospice Palliative Care Association

HCP Healthcare Professional

Chapter One – Introduction

Advances in medical therapy and technology have increased the likelihood of children surviving poor prognoses early on in life, and given rise to the prevalence of children living with chronic, complex, and life-limiting conditions (Allen, 2014; Mitchell et al., 2019; Quiroga et al., 2018). Life-limiting conditions refer to those for which there is no reasonable hope for a cure and which likely result in children living shortened lives as a result of premature death (Verberne et al., 2019). Such conditions may include progressive metabolic, neurological, or chromosomal conditions; congenital anomalies, high-risk oncologic diagnoses, and neuromuscular conditions (Siden & Steele, 2015; Verberne et al., 2019). While it is difficult to determine exactly how many children have life-limiting conditions, due to the progressive nature of many conditions, in 2015, estimates suggested that approximately 50% of annual childhood non-traumatic deaths in Canada occurred as a result of such conditions (Siden & Steele, 2015; Statistics Canada, 2013).

Pediatric palliative care allows for the provision of both acute and palliative treatments (Canadian Hospice Palliative Care Association [CHPCA], 2006). Acute treatments, also referred to as curative treatments, are those intended to modify disease whereas palliative treatments in pediatric care aim to relieve suffering and/or improve quality of life (CHPCA, 2006; Spicer et al., 2014). Pediatric palliative care is an active and total approach to care that considers biopsychosocial-spiritual elements in order to meet desired outcomes, while offering comfort and care simultaneously (Spicer et al., 2014). The mix of concurrent treatments will vary for each child and family as a result of factors such as their goals of care, treatment priorities, values, preferences, and needs (CHPCA, 2006).

Healthcare related decision-making is necessary throughout the entire trajectory of a child's life and often, early decision-making processes and experiences form the basis for future decisions (Toebbe et al., 2013). These decisions, required of parents to manage their child's care,

may be challenging and result in parents experiencing psychosocial sequelae (Knapp et al., 2010; Miller et al., 2012; Streuli et al., 2019). For example, parents are required to routinely make healthcare decisions for their child regarding acute and palliative options while taking note of benefits, risks, and both short and long term outcomes along the trajectory of their child's life (Knapp et al., 2009). Such healthcare decisions, and in particular those made by parents on behalf of their child in cases where their child cannot participate in the decision, are value-sensitive, often with no clear *best choice*, and routinely require support (Jackson et al., 2008; Stacey et al., 2008). However, little is known about the decision making needs that parents' of children with life-limiting conditions may have or the ways in which healthcare professionals (HCPs) can support them with decisions that shift between acute and palliative care options.

Appreciation of the experience by which parents make these difficult decisions is integral to safeguarding against parents' experience of psychological distress, decreased physical health, and decreased quality of life (Allen, 2014). Engaging with parents of children with life-limiting conditions is instrumental in creating an understanding of their realities and experiences as they pertain to both their decisional needs and perceived decision quality (Gabe et al., 2004).

The purpose of this thesis is to explore the decision-making experiences of and the supports provided to the parents of children with life-limiting conditions. The thesis was guided by the Ottawa Decision Support Framework and the Palliative Care during Illness and Bereavement Model.

Conceptual Frameworks

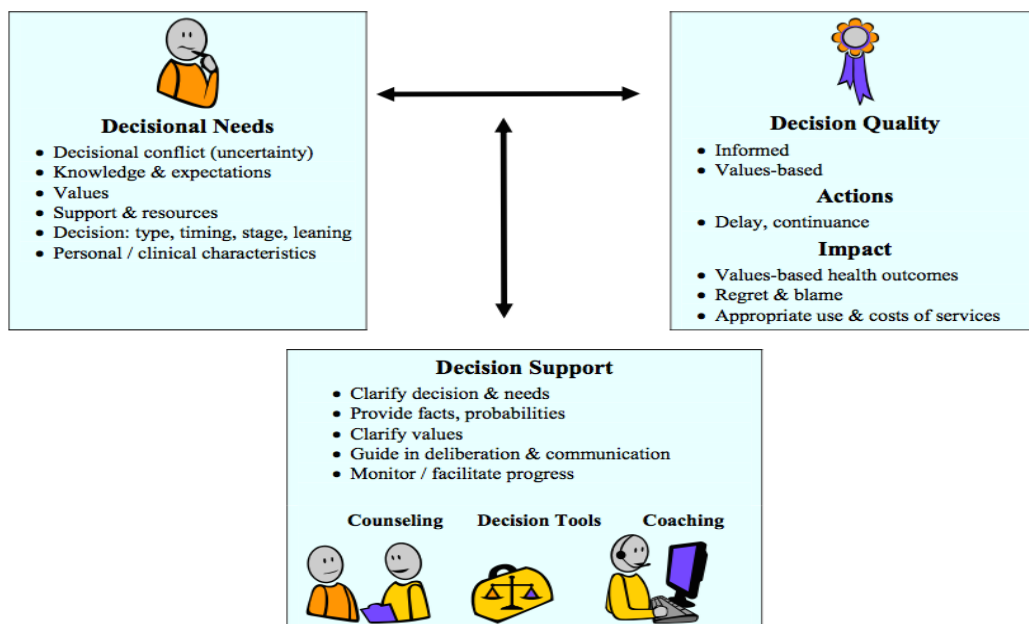
Ottawa Decision Support Framework

The Ottawa Decision Support Framework (ODSF) was used throughout this thesis to structure the assessment of decisional needs in order to better understand parents' decision-

making experiences. The ODSF is an evidence-based, practical, mid-range theory that draws on a variety of existing concepts and theories (see Figure 1.1) (O'Connor et al., 1998; Stacey et al., 2009). The framework was designed specifically for healthcare decisions that are related to new circumstances or transitions, requiring careful deliberation as a result of value-sensitive elements, and resulting in greater effort during the deliberation phase when compared to the decision implementation phase (O'Connor et al., 1998).

Figure 1.1

Ottawa Decision Support Framework (Stacey et al., 2009)



The ODSF highlights the notion that a participant's decisional needs impact their decision quality, the actions or behaviours that are associated with the decision, health outcomes, appropriate use of health resources, and emotional burden (regret and blame) (O'Connor et al., 1998; Stacey et al., 2009). Decision support, when provided through decision aids, coaching, and clinical counseling, can support decisional needs, and improve decision quality. The ODSF

describes effective decision support as interventions that aim to clarify decisional needs, provide information, clarify values, and facilitate the necessary deliberation and communication.

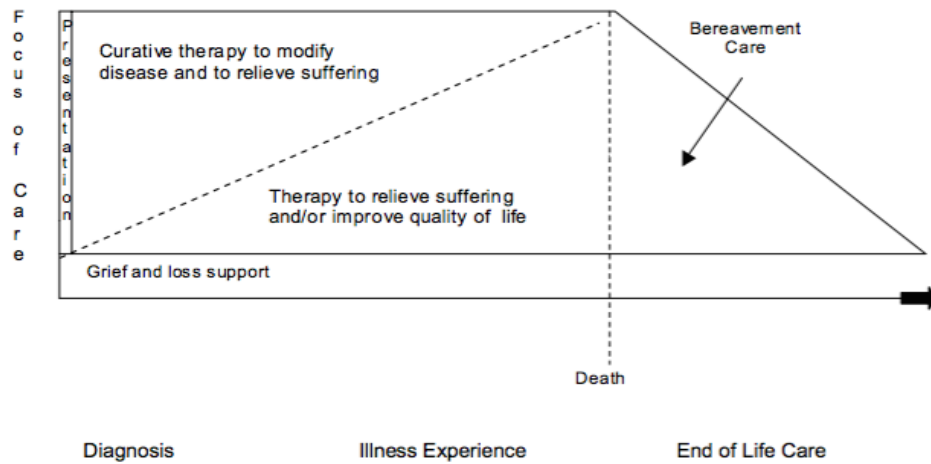
The linear process described by the ODSF notes that the selection of interventions based on known decisional needs and the addressing of sub-optimal modifiable determinants, allows for improved decisional quality (O'Connor et al., 1998). Consequently, decision outcome and quality may be unfavorably affected by unaddressed decisional needs (Stacey et al., 2009). These determinants are essential to the individual's decision-making. 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.

Palliative Care during Illness and Bereavement Model

The integrated Palliative Care during Illness and Bereavement Model originally conceptualized by Ferris et al., (2002) (see Figure 1.2) and adapted by the CHPCA in their *Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice* (CHPCA, 2006), was used to describe pediatric palliative care. The model describes pediatric palliative care as an active and total approach to care provided to children with life-limiting conditions and their families as a continuum, from presentation/diagnosis to death and into bereavement (CHPCA, 2006; Ferris et al., 2002; Spicer et al., 2014). While comfort and patient/family desired outcomes are the focus of pediatric palliative care, the delivery of acute therapies seeking to modify disease may occur simultaneously with palliative therapies that focus on relieving suffering and/or improving quality of life (Ferris et al., 2002; Spicer et al., 2014).

Figure 1.2

Integrated Palliative Care during Illness and Bereavement (Ferris et al., 2002)



Additionally, pediatric palliative care is delivered by an interprofessional team that considers the wholeness of the person (Liben et al., 2014). Given that the anticipation of loss and associated grief may begin as early as at the time of diagnosis, psychosocial supports are provided by the interprofessional team throughout the course of the life-limiting condition. This provision of support builds a foundational relationship that facilitates family-HCP relationships at the time of death and into the bereavement period (Ferris et al., 2002; Spicer et al., 2014).

Literature Review

According to the ODSF, decision support that targets the varying decisional needs of individuals facing value-sensitive decisions may enhance the overall decision quality and outcomes (O'Connor et al., 1998). For parents of children with life-limiting conditions, value-sensitive decisions are demonstrated in the recurrent choice between acute and palliative therapies. As such, it is prudent to better understand parents' decisional needs while considering options managing the challenge of balancing acute and palliative therapies.

A literature review was conducted in September 2017 and updated in May 2020 using CINAHL, PubMed, and ProQuest. The search strategy focused on parental decisional conflict, factors influencing parents' role in decision-making, and factors that impact parents' decision-making and their related experience. A combination of keywords and/or MeSH 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. Additionally, grey literature including that of Canadian pediatric palliative care organizations were hand-searched. English, peer-reviewed publications were included regardless of the year of publication, methodology, and clinical context in which the study took place.

Decisional Needs

According to the ODSF, common decisional needs are unclear values, lack of supports/resources, inadequate knowledge, unrealistic expectations, and decisional conflict (Edwards et al., 2018; O'Connor et al., 1998). The needs of parents making decisions on behalf of their child may vary along the trajectory of the child's life-limiting condition (Allen, 2014). These needs are also influenced by the type and timing of the decision as well as the characteristics of the parent and child (e.g., age, sex, culture, religion). An assessment of decision-making needs is necessary prior to the selection and implementation of interventions.

A systematic review of parents' decision support needs completed by Jackson et al., (2008) identified 149 studies across a variety of child related healthcare decisions, settings, and study designs. The study identified parents' three key decisional needs when making decisions on behalf of their child. These decisional needs were: information (with consideration of the content, delivery, and source), discussions with others including professionals and other potentially pressuring external sources, and a sense of control over the process (Jackson et al.,

2008). While the systematic review included studies regarding life support and intensive care decisions, it did not specifically include parents facing decisions for a child with a life-limiting condition.

A literature review of studies describing parents' perspectives regarding decision-making along the trajectory of their child's cancer treatment identified 17 studies (Markward et al., 2013). The studies sampled parents of children at varying stages of cancer treatment and reported that parents needed support, communication with HCPs, enhanced knowledge, and accurate information about their child's health. Johnston et al. (2008) conducted a mixed methods study by interviewing eight Canadian parents of children between 1 and 5 years of age in order to describe their decision-making needs related to cochlear implantation for their child. While the children of participants had either already received a cochlear implant or were awaiting surgery, results demonstrated that when making decisions, parents' were influenced by their preferences, desire for information, and a better understanding of other families' experiences. Both studies reported on parents' decision-making needs but did not sample parents faced with reoccurring decisions requiring choices between acute and palliative therapies for children with life-limiting conditions.

Decisional Conflict

The decisions parents face while managing the care of their child living with a life-limiting condition are complex, emotional, and leave parents susceptible to decisional conflict. Decisional conflict is a state of uncertainty regarding which course of action to select among competing actions that require the consideration of risk, loss, regret, and reconciliation with personal values, and if unmet, a decisional need (Garvelink et al., 2019; North American Nursing Diagnosis Association, 1992; O'Connor & Légaré, 2009). When experiencing decisional

conflict, parents may verbalize feelings of uncertainty, worry about undesired outcomes, delay decision-making, and/or display physical signs of stress (Garvelink et al., 2019).

A descriptive survey study conducted at a Canadian pediatric tertiary care hospital explored parents' perceived decision-making involvement and its association with experiences of decisional conflict (Boland et al., 2017). Four hundred and eighty parents, who self-identified that a decision about their child's health had been discussed in an ambulatory clinic encounter with a HCP, participated in the study. Among other findings, parental decisional conflict was noted to have a positive association with experiencing decision regret. In another descriptive study, 40% ($n = 50$) of interviewed mothers opting for the insertion of a gastrostomy tube for their child described experiencing uncertainty precipitated by feelings of inadequate support and/or information from HCPs (Guerriere et al., 2003). While experiences were described, no patient or family outcomes were reported in this study. The multilayered uncertainty experienced by mothers was influenced by a combination of medical, social, and personal uncertainties such as uncertainty regarding their child's complex condition, the fear of social stigma put on their child, and parental proxy uncertainty (Kerr & Haas, 2014). In the study of parents making decisions regarding cochlear implants for their child, parents described decisional conflict related to outcome uncertainty (Johnston et al., 2008). This uncertainty was primarily rooted in the lack of information pertaining to their choices (cochlear implant, hearing aid, or sign language). While parents were required to make decisions between alternative options, the decision was not between acute or palliative therapies and was conducted in a centre with a self-identified strong emphasis on auditory-verbal therapy possibly influencing parents' decision-making experience.

Decision-Making Involvement

Parental involvement in the decision-making process may fluctuate and be influenced by a series of factors. The ODSF notes that decision characteristics contribute to decisional needs and subsequent involvement in decision-making. The type of decision being made (to screen, test, treat, or palliate), the urgency with which a decision needs to be made, and the stage of decision-making (ranging from not thinking about options to close to selecting an option) contribute to parents' decisional needs (O'Connor et al., 1998). A qualitative descriptive study provided insights into the perceptions of bereaved parents who have experienced end-of-life care decision-making for children with life-limiting conditions in a pediatric intensive care unit (Mitchell et al., 2019). The study reported that parents found engaging in end-of-life care decision-making to be emotionally overwhelming. Despite having significant knowledge and experience that influenced their decision-making, parents relied on trusted relationships with HCPs in order to make decisions. The findings of this study may be limited as it specifically sampled parents making end-of-life care decisions for their child within a pediatric intensive care unit. The experiences of these parents may have been markedly different from that of a parent making reoccurring decisions along the trajectory of their child's life-limiting condition.

The characteristics of parents, including age, sex, education, and culture, may influence parents' decision-making involvement (O'Connor et al., 1998). These characteristics have also been found to influence parents' communication patterns and degree of involvement with physicians (Légaré et al., 2006).

Preferred Level of Involvement

The systematic review completed by Jackson et al. (2008) identified parents' desire to be in control of their level of involvement in the decision-making process. Particularly in the case of

long-term illness, parents noted a preference for ongoing discussions regarding their role in decision-making, enabling parents to routinely review their preferred level of involvement. A qualitative ethnographic study was conducted at two sites in Northern California describing parents' preferences regarding their role in decision-making for their child facing cardiac transplantation (Higgins, 2001). The study sampled 24 parents of 15 children who had been given the treatment option of cardiac transplantation, and noted that parents' desired level of involvement in decision-making varied. Different levels of preferred involvement for this specific decision included doing so independently/autonomously, in a shared manner with or as directed by a HCP.

A qualitative descriptive study interviewing 15 parents of children admitted to a hematology-oncology inpatient unit in Turkey explored their information-seeking behaviours and decision-making experiences (Kilicarslan-Toruner & Akgun-Citak, 2013). The findings indicated that parents preferred to be passively involved in decision-making and their preference appeared to be related to their responses to illness. Parent participants described believing that there was no choice to make when presented with major treatment options. The study went on to describe this response as being possibly affected by cultural norms that perceived physicians as authoritative figures.

A mixed methods study recruiting 36 parents of children less than 13 years of age and diagnosed with cancer, from a university-affiliated pediatric oncology facility in Midwestern Canada, was conducted to determine the factors that parents identified as influencing their role in treatment decision-making (Pyke-Grimm et al., 2006). The findings suggested that the parent-physician relationship influenced parents' involvement in treatment decision-making and their opinion of the quality of trust and satisfaction with the relationship.

A qualitative descriptive study conducted interviews with 12 parents of children admitted to a pediatric ward in a Norwegian hospital (Aarthun et al., 2018). Healthcare professionals' sensitivity and concern for their relationship with parents influenced parents' perceived degree of involvement in decision-making. This involvement in decision-making was reported to also be affected by parents' confidence in HCPs and contributed to their ability to cope with their role in decision-making and the hospitalization of their child. Of note, parents were included in the study if their child had been admitted to the hospital's pediatric ward during the three-month period prior to the study. Consequently, it was not limited to the parents of children living with life-limiting conditions.

Healthcare Professionals' Role in Parent Involvement

The role of HCPs in involving parents in decision-making was noted in a descriptive survey study conducted at a Canadian tertiary pediatric hospital (Boland et al., 2017). The study sampled parents who self-identified as having recently discussed their child's health in a clinical encounter with a HCP. Results noted that parents rated HCPs' efforts to involve them in decision-making favourably with 97% positive ratings ($n = 412$).

A case report conducted in the United States explored the role palliative care had in the quality of life of a 9-month-old girl with progressive microcephaly and intractable epilepsy (Brown & Clark, 2015). Results of this study, albeit based on a single family's experience, highlighted that parents, as key stakeholders, were involved in decision-making because of collaborative communication with HCPs.

Interventions to Support Decision-Making

The ODSF asserts that targeted decision support in the form of counseling, decision aids and decision coaching can improve decision quality by addressing unresolved and modifiable

decisional needs (O'Connor et al., 1998). Counseling, often referred to as shared decision-making, is an evidence-based approach that encourages collaboration between HCPs, patients, and family members by exchanging information (options, risks, and benefits) and preferences and values (Légaré et al., 2011). The integration of shared decision-making may promote parent involvement in decision-making and improve patient level outcomes such as the satisfaction experienced by parents with the decision-making process (Boland et al., 2019). Boland et al., (2019) conducted a systematic review of 79 studies, predominantly descriptive in nature and variable in methodological approach (qualitative, quantitative, and mixed). The systematic review synthesized the barriers and facilitators for shared decision-making in pediatric practice from the perspectives of both HCPs and parents. Shared decision-making was found to be frequently facilitated by quality information and low-stake decisions and impeded by insufficient time and decision-making skill.

A systematic review of 33 studies that used the Observing Patient Involvement in Decision Making Instrument was completed to assess the extent to which HCPs contributed to involving patients in shared decision-making (Couët et al., 2015). The review reported that HCPs mistakenly thought that they could identify patient's preferred level of involvement without asking. Furthermore, without interventions such as counseling, most HCPs did not demonstrate an attempt to consistently facilitate patient involvement in shared decision-making. While the review described HCPs' role in fostering shared decision-making, all of the included studies pertained to adult patients and did not include parents making decisions on behalf of their child.

Patient decision aids are evidence-based tools designed to prepare people to participate in decision-making (O'Connor et al., 1998). A Cochrane review including 105 randomized controlled trials evaluating decision aids for people facing health treatment or screening

decisions found the use of decision aids, compared to usual care, significantly improved patient knowledge, risk perceptions, and congruency between informed values and care choices (Stacey et al., 2017). Furthermore, decision aids significantly reduced the proportion of participants that were undecided and had a positive effect on patient-HCP communication. The review included studies regarding parents making decisions such as those related to vaccinations for their child, but none specifically focused on the use of decision aids for children with life-limiting illnesses.

A scoping review identifying and assessing the quality of decision aids available to help parents make end-of-life decisions for their child identified 11 decision aids in total (Medeiros et al., 2020). The review found that while the majority of decision aids focused on decisions related to preterm infants or those in neonatal intensive care, participants found them to be user-friendly, understandable, acceptable, and informative. Decision aid use was associated with reduced decisional conflict and increased knowledge and understanding regarding the decision. The study noted that it was unclear whether any of the decision aids identified were routinely used.

Decision coaching is provided to patients preparing to make healthcare decisions by a HCP trained to be non-directive, supportive, and to provide evidence rather than advice to support patient involvement in decision-making and achieve quality decisions (Jull et al., 2019; O'Connor et al., 1998; Stacey et al., 2008). A systematic review of decision coaching used within trials of patient decision aids for healthcare decisions identified 10 trials (Stacey et al., 2012). While the study did not capture the pediatric population, the findings indicated that decision coaching (when compared to usual care, a patient decision aid alone, or in conjunction with a decision aid) significantly improved patient knowledge, increased patient perception of participation in decision-making, and increased consistency of values-choice agreement without

reports of dissatisfaction. A Cochrane Review of decision coaching for people making healthcare decisions is currently underway (Jull et al., 2019).

A systematic review exploring the characteristics and effectiveness of interventions supporting the decision-making needs of children considering healthcare decisions included five intervention studies conducted in the United States (three randomized control trials, one controlled before-after study, and one non-randomized control trial) (Feenstra et al., 2014). Decision support interventions included decision coaching or educational workshops accompanied by computer programs, workbook exercises, telephone follow-ups, and information packages. Findings regarding the effectiveness of decision coaching alone versus no intervention indicated improved value-congruence between child and parent, and increased satisfaction with the decision-making process (Feenstra et al., 2014). However, the included studies involved children who themselves participated in decision-making and none of the trials were conducted with the parents of children with life-limiting conditions making decisions related to acute and palliative treatments.

A field testing study with a pre-/post-test design evaluated the feasibility and acceptability of decision coaching using the Ottawa Family Decision Guide with children and parents considering insulin delivery options for type 1 diabetes (Feenstra et al., 2015). The Ottawa Family Decision Guide is a standardized protocol designed to facilitate the provision of decision coaching (Stacey et al., 2008). The study conducted with seven participating families in Canada, found that the intervention was feasible and acceptable, particularly in cases where parents and children were looking for information, while highlighting the significant value of offering the support in a timely manner. The same study was used to evaluate the decision coaching provided by HCPs to participating youth and parents experiencing decisional conflict

(Lawson et al., 2020). After receiving decision coaching, youth and parent decisional conflict was found to decrease, youth-parent dyad agreement about the preferred insulin delivery option improved, and participants expressed satisfaction with the decision support intervention.

Summary of Literature

A review of the literature indicates that no studies have been done to explore the experiences of Canadian parents making decisions between acute and palliative therapies for their 0-18 year old child living with a life-limiting condition. Published studies describe decisions near the end-of-life, such as the withdrawal of life-sustaining treatment and decisions related to a cancer diagnosis where child participation in decision-making is possible and a focus on acute treatment. None of the studies specifically sampled parents of children living with life-limiting conditions and consequently did not capture their unique experience of routinely making value-sensitive decisions in the context of a life-limiting condition.

Thesis Objective

The purpose of this thesis is to explore the decision-making experiences and the supports provided to the parents of children with life-limiting conditions. The specific objectives are: 1) to explore the experiences of parents making decisions between acute and palliative therapies along the trajectory of their child's life-limiting condition and, 2) to examine interventions used to support parents' needs when making healthcare decisions for their child along the trajectory of their child's life-limiting condition. For the purposes of this thesis, the term *parents* is used to identify primary/decision-making caregivers.

Thesis Outline

This thesis is structured as a series of two papers followed by an integrated discussion. Chapter 2 is the first paper, entitled "Parental decision-making for a child with a life-limiting

condition.” It addresses the first objective by reporting on a qualitative study that explored parents’ decision-making experiences. Chapter 3 is the second paper, entitled “Interventions supporting the decision-making needs of parents in pediatric palliative care: A scoping review.” This chapter addresses the second objective by reviewing published interventions used to support the decision-making needs of parents specifically in the context of pediatric palliative care. Chapter 4 is an integrated discussion of the findings from chapters 2 and 3 and outlines their implications for clinical practice, education, and further research.

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Chapter Two

Exploring Parental Decision-Making for a Child with a Life-Limiting Condition: An Interpretive Description Study

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Abstract

The purpose of this study was to explore the experiences of parents making decisions between acute and palliative therapies along the trajectory of their child's life-limiting condition. An interpretive description qualitative study using thematic analysis was conducted. Semi-structured interviews were completed with six parents and six healthcare professionals. The Ottawa Decision Support Framework guided interview development and the coding of transcripts. Qualitative thematic analysis was used to identify, analyze, and report five themes: (i) "Going by your heart and gut": The process of making a unique decision, (ii) "Not black and white": Experiencing decisional conflict when making difficult decisions, (iii) "Widening the circle of care": Various sources of decision-making support, (iv) "Trying to support": Conversations to gauge where parents are in the decision-making process, and (v) "Always a worry": Concerns regarding parents' decision quality and outcomes.

Parents described experiencing decisional conflict when making healthcare decisions for their child with a life-limiting condition. Decision support provided by healthcare professionals in an interprofessional manner was preferred and supplemented by a parent based support network. Reassurance regarding their good parenting from healthcare professionals was described as supportive throughout the decision-making experience.

Keywords: palliative care, decision-making, decision support, pediatric nursing, parents

Background

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 (Allen, 2014; Mitchell et al., 2019; Quiroga et al., 2018). Parents of children living with life-limiting conditions are required to routinely make decisions between acute and palliative therapies, both intended to relieve suffering, along the trajectory of their child's life (Allen, 2014; Ferris et al., 2002; Mitchell et al., 2019). These decisions require parents to consider benefits, risks, and both short and long term outcomes (Boland et al., 2017). Given that their children are often cognitively unable to participate in making decisions for themselves, parents face difficult healthcare decisions that require support throughout the decision-making process (Jackson et al., 2008).

The reoccurring decisions requiring trade-offs between acute and palliative therapy options often lack an obvious best choice and are value-sensitive (i.e. dependent on individual and/or family values, beliefs, and goals). As a result, parents may be susceptible to a significant amount of uncertainty about the best course of action, resulting in decisional conflict (Jackson et al., 2008). Decisional conflict can be described as a state of uncertainty arising from decision-making that navigates two or more options involving risk, loss, potential for future regret, and/or challenges personal values and preferences (Garvelink et al., 2019; North American Nursing Diagnosis Association, 1992). The management of such decisional conflict may be challenging for parents and, if unaddressed, may lead to a long-term psychosocial burden, decision regret, and blame (Boland et al., 2017; Charlebois & Cyr, 2015; Streuli et al., 2019). In one qualitative descriptive study, 40% ($n = 50$) of mothers opting for the insertion of a gastrostomy tube for their child, described experiencing uncertainty and decisional conflict precipitated by feelings of

inadequate support and/or information from healthcare professionals (HCPs) (Guerriere et al., 2003).

The Ottawa Decision Support Framework (ODSF) describes the relationship between individuals' decisional needs, decision support interventions, and decision outcomes (O'Connor et al., 1998). According to the ODSF, 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. The ODSF describes decision quality as the extent to which these decisional needs are addressed. Decision support interventions can improve decision quality by clarifying an individual's values and needs; providing information and probabilities; guiding deliberation and communication; and minimizing feelings of regret, blame, and psychosocial burden. Decision outcomes may consist of the quality of the decision, including the congruence between values and the decision, and the impact of the decision on the appropriate use of resources.

A systematic review of parents' decision support needs when making healthcare decisions on behalf of their child identified 149 studies, the majority of which were from North America, the United Kingdom, and Australia/New Zealand (Jackson et al., 2008). Participants were recruited having made various healthcare decisions and from settings including primary and tertiary care centres; and the community (including schools, churches, and workplaces). Parents' decisional needs were information (with consideration of the content, delivery, and source); discussions with HCPs and other potentially pressuring sources such as family, friends, society, and the healthcare 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 identified 17 studies (Markward et al., 2013). The review reported that parents needed support, communication with HCPs, enhanced knowledge, and accurate information about their child's health. While both reviews included studies regarding life support and intensive care decisions, neither included parents facing reoccurring decisions between acute and palliative therapies for a child living with a life-limiting condition.

An integrative review describing factors that affect parental decision-making for medically complex children identified 31 studies conducted in several countries in addition to those in North America, such as Turkey, France, and Netherlands (Allen, 2014). Diagnoses of children included extreme prematurity, genetic anomalies, and neurological injury. The review reported that the majority of 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.

Although parents of children living with life-limiting conditions are required to make value-sensitive decisions routinely and over the entire course of their child's life, little is known about their decisional needs and tailored supports. Therefore, the purpose of this study was to explore the experiences of parents making decisions between acute and palliative therapies along the trajectory of their child's life-limiting condition.

Methods

Research Design

An interpretive description study rooted in constructivism was conducted in order to capture themes and patterns within a subjective interpretation and by generating descriptions for the purposes of enhancing and informing the existing clinical understanding and experience (Guba & Lincoln, 1994; Thorne, 2016; Thorne et al., 2004). The study received approval from

the research ethics board of the participating children's hospital (17/176X) and the affiliated university (H11-17-217) along with a data-sharing agreement between both organizations (see Appendix A).

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 progressive, life-limiting conditions as well as their families, on a referral basis. This support includes access to the affiliated eight-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, at different stages of their life-limiting condition, with varying needs, and accessing various programs.

Participants

Participants were eligible if they met inclusion criteria and if they were in one of two stakeholder groups: parents or HCPs. Parents were eligible if they: (a) had a child that was 18 years of age or younger, diagnosed with a life-limiting condition, and cognitively unable to contribute to decision-making; (b) were able to communicate in English; and (c) were followed by the hospital's palliative care team. Purposefully, an attempt was made to recruit parents such that a variation in child's age, diagnosis, and illness trajectory were represented. Eligible parents were approached by a member of their circle of care garnering their interest in discussing participation with the principal investigator. Upon expressing interest, the principal investigator

provided parents with the information and consent form which were to be reviewed and signed prior to participation.

Healthcare professionals were eligible if they were: (a) hospital or affiliated hospice employees who worked with families followed by the palliative care team and had been in a family's circle of care as they made healthcare decisions on behalf of their child; (b) physicians, social workers, registered nurses, or registered practical nurses; and (c) able to communicate in English. 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 (see Appendix B). Healthcare professional participants also reviewed and signed an information and consent form prior to participation (see Appendix C).

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 semi-structured interviews began with a brief explanation of the study and a review of the obtained written informed consent. Interview guides based on the ODSF and its Population Needs Assessment guide were developed separately for parents and HCPs (Jacobsen et al., 2013; O'Connor et al., 1998). The interview guides helped facilitate the sessions, stimulate discussion, and address the research objective with open-ended questions (see Appendix D). The iterative nature of the data collection process prompted ongoing reflections on the interviews and allowed for the evaluation, amending, and restructuring of questions (Thorne, 2016). Questions included "Please tell me about your experience with a healthcare decision made for your child"; and "What made this decision challenging for you?" Probes were used to elicit more information and further explore areas of interest. Basic socio-demographic information such as personal and

clinical characteristics were collected at the end of the interview for descriptive purposes given that such characteristics may contribute to decision-making needs (O'Connor et al., 1998). The interview guides were piloted with an experienced pediatric palliative care nurse and a parent in order to review flow and sensitivity. Each interview was digitally recorded and transcribed verbatim for analysis. The sample size was determined by attempting to obtain maximal variation in themes as a result of concurrent data collection, reflection, and analysis (Sandelowski, 1995; Thorne, 2016; Thorne et al., 2004).

Analysis

Consistent with interpretive description methodologies, data analysis was conducted to explore the meanings and patterns of participants' described constructed realities (Thorne, 2000; Thorne et al., 2004). Qualitative thematic analysis occurred in order to identify, analyze, and report themes while comparing and contrasting themes throughout the analysis process (Vaismoradi et al., 2013). Codes were identified by means of an inductive approach and then classified according to the ODSF (Braun & Clarke, 2006; O'Connor et al., 1998; Vaismoradi et al., 2013).

The analysis process consisted of five steps for each interview: 1) The audio recording was transcribed verbatim and read once in entirety prior to proceeding 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 by classifying according to the ODSF; 4) Categories were colour coded to form groups rather than prematurely being labeled; and 5) The colour coded groups were

carefully reviewed in order to identify constructed themes. These themes were compiled to interpret the data, describe participants' experiences, and capture exemplar quotes from the data (Braun & Clarke, 2006; Thorne, 2016). The interviews were independently coded and categorized by both the principal investigator and a senior member of the team who, together, resolved coding discrepancies by discussion in order to reach consensus.

Rigour

To ensure the rigour of this study, trustworthiness and its criteria of credibility, transferability, dependability, and confirmability, were considered (Guba & Lincoln, 1994; Korstjens et al., 2018). To enhance credibility, data triangulation was used by engaging both parents and HCPs as multiple data sources. Additionally, investigator triangulation with two researchers contributing to coding and data analysis occurred. Transferability was enhanced by providing detailed descriptions of the context including study setting and sample. To promote dependability and confirmability, documentation of the research design process, post-interview field notes, and thematic analysis were maintained. Additionally, journaling, to reflexively examine the principal investigator's conceptual lens and preconceptions throughout the data collection process, was completed.

Findings

Participant Characteristics

Ten eligible parents were approached by members of their circle of care to participate and six parents consented to participate. Parents who did not agree to participate reported that this was the case because of a personal/family reason to not take part in the study or the deterioration of their child's health status during the interview period. Of the six parents who participated, five were mothers and one a father, none of which were parenting the same child. Parents' age ranged

from 24 to 49 years old (Mdn = 35). One parent completed graduate studies, three had completed undergraduate studies, and two completed high school. Their children ranged in age from 1 to 11 years old (Mdn = 5.5 years old). Half of the children ($n = 3$) were diagnosed with genetic anomalies, one was extremely premature, one had spastic quadriplegic cerebral palsy, and one had a neurodegenerative condition.

Of the six HCP participants, four were nurses and two were social workers. One HCP had between 5-10 years, three had 10-15 years, and two had greater than 15 years of experience working with children and families followed by the palliative care team.

Themes

Five major themes were identified: (i) “Going by your heart and gut”: The process of making a unique decision, (ii) “Not black and white”: Experiencing decisional conflict when making difficult decisions, (iii) “Widening the circle of care”: Various sources of decision-making support, (iv) “Trying to support”: Conversations to gauge where parents are in the decision-making process, and (v) “Always a worry”: Concerns regarding parents’ decision quality and outcomes. Each of these themes are presented below.

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

Both parent and HCP participants described the process by which parents make healthcare decisions for their child with a life-limiting condition. Given the unique nature of their decisions, parents were described as relying on what felt right to them when making decisions. One parent participant 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 participant 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 life-limiting conditions routinely face were unique, with serious outcomes, and had varying degrees of risk. One parent participant described having to make a decision that involved feeling analogous to “pulling out his breathing tube and letting him suffocate [and die].” The seriousness and gravity of making a decision on behalf of another person, particularly in the case of a child unable to communicate personal preference, was articulated by one parent “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 HCP participant used the example of an elective spinal fusion surgery to highlight 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 parent participant echoed the stress associated with the decisions themselves and shared that it often felt “so intrusive, so un-normal, and unnatural.”

A Range in Parents' Preferred Role in Decision-Making. Within the overarching theme, a subtheme described parents' role in the decision-making process. The role of parents in decision-making was 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. to. When describing a preference for independent decision-making, one parent participant 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 healthcare decisions for their child, one parent participant stated that it “came down to my [spouse] and me.”

Descriptions of shared decision-making primarily involved HCPs. A parent participant 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 both choices.” The facilitation of a shared decision-making approach by HCPs, in response to parent’s preference, was described by a HCP participant: “depending on what medical teams are involved [in child’s care] (...) I’ve involved them in [supporting parents’] decision-making.” In another instance, a parent participant described sharing the decision regarding exploratory diagnostic testing with family members rather than a team of HCPs “that was the first decision, family decision, we made.”

Alternatively, a parent participant described a preference to defer to the HCP 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].” Given the range in preferred decision-making involvement, a HCP stated: “[HCPs] have to gauge parents, some parents don’t want to make those [difficult healthcare] decisions, and others have to approve everything. You kind of have to know the parents [and] really listen to them.”

“Not Black and White”: Experiencing Decisional Conflict when Making Difficult Decisions

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

Concerns regarding undesired outcomes, resulting from the decision and related distress, contributed to decisional conflict. One parent participant 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 participant 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 behavioural manifestation of uncertainty described by parents was the experience of wavering between choices. One parent participant stated that “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 that “my [spouse] and I have been back and forth, back and forth”. As a result of the best choice not being clear, a parent participant 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 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 Healthcare Support. A HCP participant described that parents may want “to meet with the people who are involved [in the decision], together, either if it is the palliative care doctors, the complex care doctors, maybe the surgeon, and the anesthesiologist [when considering options].” Parent participants 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 to parents making healthcare decisions for their child was described by a parent participant “the nurse held our hand through a little bit of it because we were very hesitant and nervous (...) the nurse reassured us several times.” A HCP participant 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 life-limiting condition].” Another HCP participant noted that it was critical to “make sure that you’re telling [parents of children with life-limiting conditions] that they’re doing the right thing. [Parents] need reassurance because there could be a lot of guilt associated with [making the decision].”

Both parent and HCP participants described the role of HCPs in supporting parents’ information needs related to decision-making. A participating 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 described by another 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.”

Both parents and HCPs noted that healthcare decisions for children with a life-limiting condition often required the consideration of both the financial and practical implications of options. One parent participant 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 healthcare decisions made for their child:

I had to consider how [child] would go to school with [decision to insert gastrostomy tube]. I 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. Parent participants repeatedly described a network of parents as being instrumental form of decision support. One parent shared “find[ing] the pockets of people that [they] needed when [attempting to make a decision].” This was also described by a HCP participant who 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].” A parent participant described the support experienced as a result of connecting with other parents:

I remember vividly having conversations with other families saying “I struggled for months or even years 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].

Parent participants considered their informal parent network as a decision support resource superior to HCPs. One parent participant 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 as opposed to [their] next appointment [with a HCP].”

Healthcare professionals noted that parents benefited from identifying and leaning into a support network external to the HCP team when making decisions. HCP participants 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.”

“Trying to Support”: Conversations to Gauge Where Parents are in the Decision-Making Process

HCP participants described varying roles or cited different means by which they provided parents with decision support. One HCP participant recalled experiences of accompanying parents to appointments with specialists, upon their request, in order to provide an added layer of support when parents posed questions regarding potential healthcare decisions. Participating nurses, in particular, noted that they felt their role in providing decision support to parents was to identify parents who were uncertain about the best choice and to “reinforce what the team [had] been saying [regarding the decision being made] and relay the same information. [HCPs] don’t want conflicting information, because that really confuses and makes [parents’ decision-making experience] so much worse when you’re just trying to support them.” All HCP participants described conveying information to parents as being their key contribution when providing decision support to parents. One HCP described their provision of information as a means to “empower parents making difficult decisions.” The HCP went on to say that this empowerment could only be realized as a result of “the [decision-related] information that parents are given”.

Both parent and HCP participants described supportive conversations conducted by HCPs to supplement the provision of information. One parent described these supportive conversations as an opportunity to “talk and work through [the decision] as helpful.” A HCP participant reflected:

It’s my job to be supportive, not judge, be a sounding board for families but at the same time discussing what it is they need to figure out. Maybe that means there’s a gap for me

to fill [during the decision-making process] or they just need to talk it out to figure out what [options] they truly want or prefer.

Another HCP participant stated: “parents just need a conversation...maybe many but these decisions [for their child with a life-limiting condition] need to be a conversation.”

“Always a Worry”: Concerns Regarding Parents’ Decision Quality and Outcomes

The uncertainty described by parents during the decision-making process was noted even after making a decision. One parent participant shared:

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.

A HCP participant noted that this outcome is often anticipated by HCPs and, as a result, there is “always a worry that parents feel guilty if things don't work out as expected [after the decision is implemented].” This HCP went on to describe parents feeling “guilt, sadness, and despair” as a result of the healthcare decision they made for their child with a life-limiting condition. Another HCP participant 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].” The difficulty and stress associated with uncertain outcomes significantly impacted parents’ decision-making experience and was 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 a HCP participant who described that “parents have some anxiety and worry about [outcomes] and try to do everything they can to avoid it”.

Discussion

This study improves our understanding of parents' decision-making experiences as it relates to their child living with a life-limiting condition and the means by which they are supported when making healthcare decisions. While this study sought to explore the experiences of parents making decisions for their child, between acute and palliative therapies, parents did not describe healthcare decisions in this manner. Parent participants 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 life-limiting condition. These decisions were not labeled as either acute or palliative in nature. Instead, they were likely the most recent challenging or unique healthcare decision recalled.

The findings of this study align with a previously completed systematic review describing the key needs of parents making healthcare decisions on behalf of their child (Jackson et al., 2008). 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 parent and HCP participants in this study.

Manifestations of Decisional Conflict

Parent participants experienced several manifestations of decisional conflict when faced with these difficult and unique decisions regarding their child's healthcare (O'Connor et al., 1998). 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 life-limiting conditions and palliative care for children (Garvelink et al., 2019). The review

concluded that decisional conflict was highest prior to making the decision and decreased after exposure to decision support interventions. One of the most common manifestations of decisional conflict described by participants was parents' fear of undesired outcomes, which has also been reported in other studies of parents' experience of decision uncertainty (Guerriere et al., 2003). This uncertainty regarding decision related outcomes and wavering between choices was described by parent and HCP participants, in addition to the need for decision support, in order to manage decisional conflict.

Providing Parents with Reassurance

Parent participants discussed the need to be reassured that their decisions made on behalf of their child with a life-limiting condition. This finding is in keeping with a previous study describing parents' beliefs regarding healthcare decision-making for their child and engagement with a pediatric palliative care team and the desire to be a *good parent* (Feudtner et al., 2015). Feudtner et al., (2015) 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 parent participants faced when prioritizing goals for their child with a life-limiting condition, participants identified their role in making informed medical care decisions on behalf of their child to be ranked in the top three attributes important to being a good parent, along with making sure their child felt loved and focusing on their child's health (Mooney-Doyle et al., 2018). Interactions with HCPs are deemed effective in supporting decision-making by parents when they are reassured of their good-parenting (Davies et al., 2017). The HCP's role in providing parents with reassurance as a form of emotional support was noted in this study by both parent and HCP participants. Despite the understanding that parental decision-making is inherent in managing the care of medically complex children, it may be perceived by parents as a double-

edged sword that occurs within the context of a relationship built on an innate power imbalance between the parent(s) and HCP(s) (Rafferty & Sullivan, 2017). Consequently, it is critical for HCPs to respond to parents' decision-making needs, facilitate their decision supports, provide opportunities for parent participation in decision-making, and to reassure them of their fulfillment of the good parent role (Feudtner et al., 2015; Mooney-Doyle et al., 2017).

Valuing a Parent Based Support Network

All parent participants identified a parent based support network as beneficial when making decisions. Parent participants conveyed a sense of being supported when making difficult healthcare decisions on behalf of their child. Much of this support was felt to be the result of a parent based 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 by Jackson et al. (2008) that described parents' preference for talking with other parents in similar situations through either formal or informal networks. 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 the opportunity to garner how other parents made decisions (Pieters et al., 2016). Parent participants accessed a single pediatric hospice, which has routinely made available both facilitated and self-directed parent support groups. The provision of support groups may have contributed to the establishment of the informal social network described to be supportive throughout the decision-making process by parent participants.

Strengths and Limitations

This study should be considered within the context of both strengths and limitations. Both the perspectives of parents and HCPs were captured in this study, informed the interpretation of

the findings, and allowed for a broader understanding of parent's experience with decision-making. The ODSF was used as a framework to guide and inform the data collection and analysis. This framework has previously been used in studies that have effectively evaluated decision support interventions in the context of pediatric care (Feenstra et al., 2015; Lawson et al., 2020). Parent participants 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 participation in research given, such as the number of other medical appointments scheduled, may have been factors (Kars et al., 2016). Although data saturation was achieved, the needs and experiences of these families may be under-represented here due to these recruitment challenges.

Conclusion

Parents and HCPs contributed to better understanding parents' decision-making experiences for children with life-limiting conditions. The experience of participating in decision-making and decisional conflict was discussed by parents. This decisional conflict was further described to manifest as concerns regarding consequential undesired outcomes, wavering between choices, and uncertainty regarding what is the best course of action. Both parent and HCP participants described parents' reliance on support that extended beyond a group of HCPs to also include a parent based support network. HCPs were described as providing parents decision support by engaging in supportive conversations and reassurance in regards to their good parenting. Further research is required to better identify resources such as guides, tools,

and/or aids to be used by HCPs to support the decision-making needs of parents with children living with life-limiting conditions.

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Chapter Three

Interventions supporting the decision-making needs of parents in pediatric palliative care:

A scoping review

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Abstract

Parents of children with life-limiting conditions are required to make difficult healthcare decisions throughout their child's life. The purpose of this scoping review was to examine interventions used to support parents' decisional needs when making healthcare decisions for their child along the trajectory of their child's life-limiting condition.

A scoping review, as described by Arksey and O'Malley's five-stage methodological framework, was conducted and followed by a narrative descriptive analysis of findings. A search of five databases was conducted in November 2018 and updated October 2019, along with a secondary hand-search of the reference lists of relevant articles.

Of 546 identified citations, three met pre-determined inclusion criteria. The interventions described included two decision-making tools and the completion of an inpatient pediatric palliative care consultation with families. All included studies reported positive patient/family outcomes such as parents' enhanced understanding of benefits and harms, increased engagement in decision-making, and increased congruence between care provided by HCPs and parents' goals. When healthcare professionals utilized structured therapeutic conversation guides, they provided parents with supportive decision coaching. Few studies have evaluated decision support interventions for parents making decisions for their child with a life-limiting condition. Research to identify supportive decision-making interventions is recommended.

Keywords: palliative care, decision making, decision support, pediatric, scoping review, parents

Background

The prevalence of children living with chronically complex and life-limiting conditions is rising (Brown & Clark, 2015). For children with such conditions, healthcare is primarily focused on managing symptoms, improving quality of life, and supporting the entire family (Siden & Steele, 2015). Given that their child has a life-limiting condition, parents often face healthcare decisions that are challenging, stress-inducing, and value-sensitive. As a result, parents may experience decisional conflict and a state of uncertainty related to choosing the best treatment option (Boland et al., 2017). Parents experiencing decisional conflict are at risk of undesired outcomes including decision regret (Boland et al., 2017). As such, parents may need support when considering options, benefits, risks, and short and long term outcomes. Given that many families perceive such decision-making as profoundly burdensome, healthcare professionals (HCPs) may be challenged to provide the necessary support (Canadian Hospice Palliative Care Association, 2006). For these value-sensitive decisions, family-centred care is optimized when the decision-making process is reflective of patient and family preferences and addresses their decision support needs (Boland et al., 2017; Jackson et al., 2008). A systematic review of the decision-making needs of parents concluded that parents require timely, consistent, and evidence-based information; support from others; and a sense of control over the decision-making process (Jackson et al., 2008).

According to the Ottawa Decision Support Framework, targeted decision support such as decision aids and decision coaching can improve decision quality and precipitating outcomes (O'Connor et al., 1998). A Cochrane review evaluated the effects of using decision aids with adults facing treatment or screening decisions for themselves or a child across 105 randomized controlled trials (Stacey et al., 2017). The review reported that decision aid use, compared to

usual care, significantly improved patient knowledge and the accuracy of risk perceptions. Furthermore, it decreased indecision about personal values and the tendency to be passive in decision-making. While the review included studies regarding parents making decisions for their child related to vaccinations, for example, none specifically focused on decisions for the child with a life-limiting condition. A systematic review exploring the characteristics and effectiveness of interventions designed to support the decision-making needs of children making healthcare decisions identified five studies (Feenstra et al., 2014). These studies included randomized control trials, a controlled before after study, and a nonrandomized control trial all conducted in the United States. Interventions included decision coaching or education workshops supplemented by activities such as workbook exercises and telephone follow-ups. The review reported increased satisfaction and value-congruence between child and parent decision-making with the use of decision coaching versus no intervention. However, the included studies involved children who themselves participated in decision-making and none of the trials were conducted with the parents of children with life-limiting conditions.

The purpose of this scoping review was to examine interventions used to support parents' decision-making needs when making healthcare decisions for their child along the trajectory of their child's life-limiting condition. The following research questions guided this scoping review:

- a) What are the characteristics of the decision support interventions?
- b) What were the experiences of patients with these decision support interventions?
- c) What are the outcomes of these decision support interventions?

Methods

A scoping review, as described by Arksey and O'Malley's (2005) five-stage methodological framework, was conducted. The five stages include: 1) identification of a

research question, 2) identification of relevant studies, 3) study selection, 4) charting the data, and 5) collating, summarizing, and reporting of results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used (Moher et al., 2009).

1. Identifying Research Question

Research questions were identified in advance of developing the search strategy. Questions were generated in response to lived clinical experience and identification of gaps in the literature. Research questions were linked to the study's purpose.

2. Identifying Relevant Studies

As described in Table 3.1, inclusion/exclusion criteria were determined *a priori* in order to ensure that selected articles fulfilled the review's aim. Studies focusing on parents making healthcare decisions for children 18 years of age or younger with life-limiting conditions and with all patient and system level outcomes were included. Primary studies that were peer-reviewed and published in English were included. Commentaries, narrative literature reviews, conference abstracts, and publications in other languages were excluded. Studies describing the child's participation in decision-making were excluded, as the review focused on interventions that are designed to support parents making decisions. In an effort to focus on decisions made throughout the child's life-limiting condition when acute versus palliative decisions reoccur, decisions related to advanced care planning, resuscitation, immunization, and study participation were excluded. No limitations were set to the publication year of included studies.

A search strategy was designed to answer the research questions, drawing on research team members' expertise in library sciences, decision-making, pediatrics, and palliative care. A search was conducted in the following electronic databases: Medline (Ovid), CINAHL,

PsycINFO, Scopus, and the Joanna Briggs Institute in October 2018 and updated in October 2019.

Table 3.1

Study Inclusion and Exclusion Criteria

Category	Inclusion	Exclusion
Population	Parents of children under 19 years of age Making healthcare decisions for their child along the trajectory of their child's life-limiting condition	Decisions related to advanced care planning/care directives/DNRs/resuscitation/ immunization/ study participation Children's participation in decision-making
Intervention	Interventions to support parents' healthcare decision-making needs	Interventions that do not support parents' healthcare decision-making needs during the decision-making process
Outcome	All patient-level and system-level outcomes	Articles that do not report parents' perspective or experience with the decision-making interventions
Language	English	Other Languages
Study methods	Primary studies	Commentaries Narrative literature reviews
Publication status	Published Peer-reviewed	Unpublished studies Non peer-reviewed Conference abstracts
Year of publication	All	

See Table 3.2 for the search strategy used in Medline (Ovid) and adapted for each subsequent database. A secondary hand-search of the reference lists of relevant articles was also conducted.

The PICO search strategy included subject headings and keywords related to: the population (e.g., parents), intervention (e.g., decision support), comparison (e.g., any comparison), and outcome (e.g., quality of communication between parents and HCPs) (Arksey & O'Malley, 2005; Schardt, Adams, Owens, Keitz, & Fontelo, 2007).

3. Study Selection

Retrieved citations were entered into a web-based tool designed to facilitate screening. The screening process was conducted in two steps: review of title and abstract followed by full-

Table 3.2

<i>Search Strategy Used for Medline (Ovid)</i>	
Group	Search Terms
1	exp Parents/ OR Caregivers/ OR exp Legal Guardians/ OR (Parent* OR Mother* OR Father*)ti,ab,kf
2	(Palliative Care/ OR Terminal Care/) Limit to: “all child (0 to 18 years)”
3	Decision Making/ OR Uncertainty/ OR (Decision* adj3(Making OR Support OR Need* OR Share OR Taken or Taking)).ti,ab,kf
4	Limit to: English

text review. Two reviewers independently screened citations, marking them as either *include* or *exclude*. If review of title and abstract resulted in uncertainty, citations were marked as *include*.

All citations marked with *include* by at least one reviewer were advanced to the second step. Full texts were obtained and independently reviewed by two research team members for final inclusion. Discrepancies regarding inclusion after full text review were resolved by seeking involvement and consensus from a third reviewer.

4. Charting the Data

To facilitate consistent and transparent data charting, a standardized form based on templates used by systematic reviews of decision support interventions was used (Arksey & O'Malley, 2005; Feenstra et al., 2014). The data charting form included: a) author, country, and year, b) study design, c) participants and setting, d) methods, e) intervention characteristics, f) main findings, and (g) reported limitations. Additionally, the sources of funding for included individual studies were reviewed.

5. Collating, Summarizing, and Reporting the Results

Findings were presented using the following domains: study selection, characteristics of studies and participants, quality appraisal, intervention characteristics, elements of decision support interventions, and outcomes. The 12 elements of decision support interventions reported on were identified by and used in previous studies to evaluate decision support interventions (Feenstra et al., 2014; Stacey et al., 2012) and the Ottawa Decision Support Framework (O'Connor et al., 1998). A narrative descriptive analysis of the findings was completed to identify and analyze reported patterns across the extracted literature (Braun & Clarke, 2006).

Quality Appraisal

Quality appraisal of included studies was completed to assess the methodological quality of each study and to determine the extent to which the possibility of bias was minimized. Critical appraisal tools from the Joanna Briggs Institute for cross sectional and qualitative studies were used (Joanna Briggs, 2017a, 2017b). Appraisal was conducted independently by two reviewers. As per each tool's checklist, the answers, *yes*, *no*, *unclear*, or *not applicable* were selected.

Findings

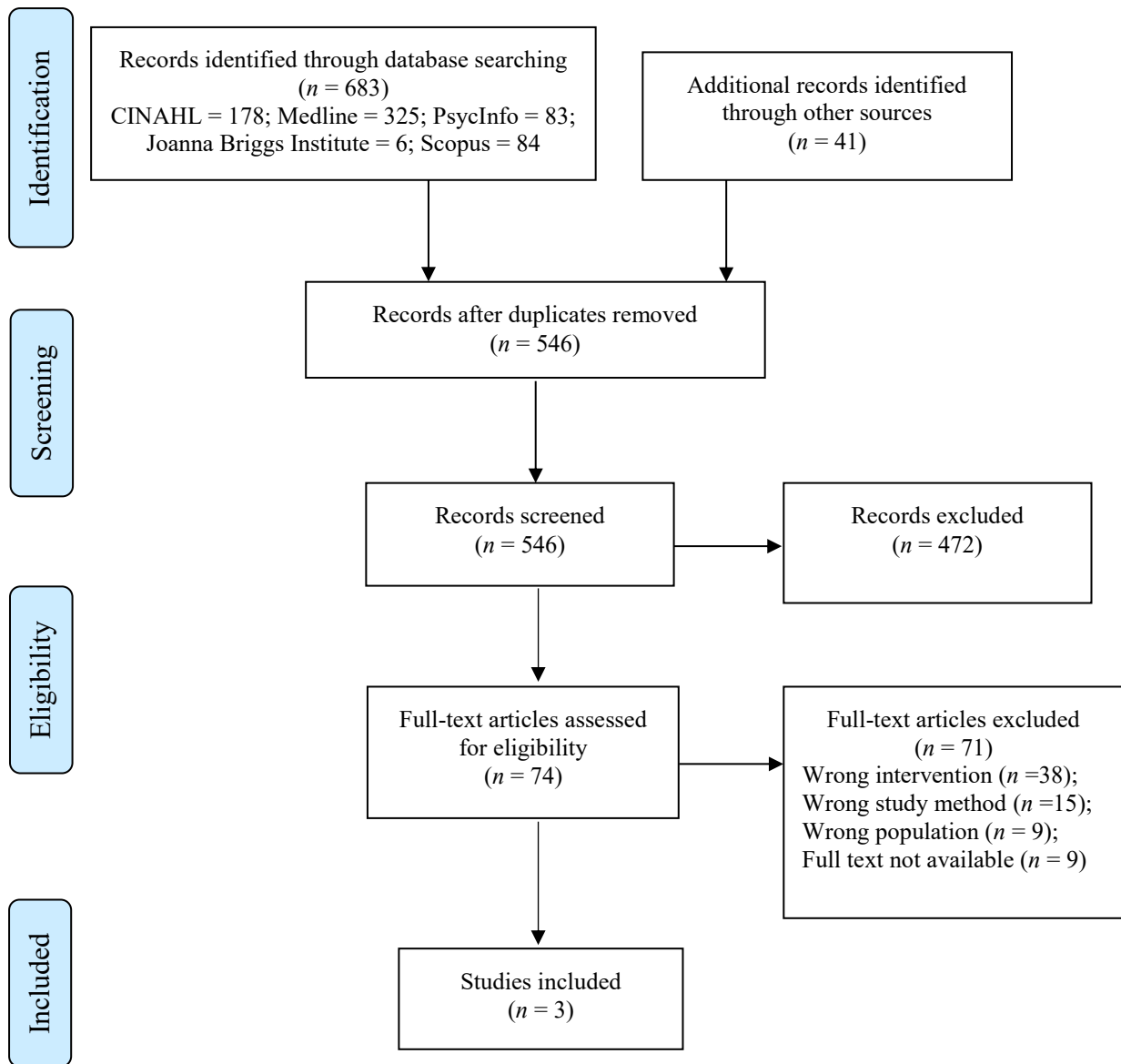
Study Selection

A total of 683 articles from databases plus 41 articles identified based on title and abstract by reviewing the reference lists of key articles found through the databases were retrieved (see Figure 3.1). After removing duplicates, the titles and abstracts of 546 articles were screened. Of the 74 full-texts reviewed, 71 were excluded due to wrong intervention (did not include an intervention supporting parents' decision-making needs), wrong study methods (literature reviews and commentaries), wrong outcomes (did not report on parents' experience with the decision-making intervention), wrong patient population (included adult populations),

and/or lack of full-text availability. Three articles were included as a result of meeting the inclusion criteria.

Figure 3.1

PRISMA Flow Diagram



Characteristics of Studies and Participants

All three studies were conducted in the United States and either in 2011 or 2012 (Byrne et al., 2011; Kline et al., 2012; Sheetz & Bowman, 2012). See Table 3.3 for study design among other characteristics. In one study, participants included the parents of children with life-limiting conditions and multiple comorbidities; ranging from neonates to late adolescence; and receiving the consultative services of a palliative care team in a pediatric tertiary care hospital (Byrne et al., 2011). Another study recruited parents of high-risk pediatric hematology-oncology patients with a mean age of 9.7 years approaching a significant change in treatment such as stem cell transplantation (Kline et al., 2012). The third study recruited bereaved parents whose children with life-limiting conditions had died in the past 7-36 months (Sheetz & Bowman, 2012).

Quality Appraisal of Studies

The descriptive analysis by Byrne et al. (2011) met all criteria for methodological quality and the addressing of potential biases (see Table 3.4). The Sheetz and Bowman (2012) study lacked clearly defined inclusion criteria, setting details, and method of measurement of exposure. Both Sheetz and Bowman (2012) and Kline et al., (2012) provided a limited description of outcome measures. No mention of funding sources was made by Kline et al., (2012), while the other two studies stated no financial support for their research or authorship.

Intervention Characteristics

Characteristics of the decision support interventions are described in Table 3.5. A decision-making tool (DMT) was described by two studies (Byrne et al., 2011; Kline et al., 2012) and the completion of an inpatient consultation with families as an intervention by another (Sheetz & Bowman, 2012). The interventions were administered exclusively by either the palliative care physician (Byrne et al., 2011) or nurse (Kline et al., 2012), or by any member of

the palliative care team (Sheetz & Bowman, 2012). Interventions were delivered at the time of inpatient consultation with the pediatric palliative care team (Byrne et al., 2011; Sheetz & Bowman 2012) or at any point at which an important treatment decision was necessary (Kline et al., 2012). Of the 12 reviewed elements of decision support interventions, one study addressed eight elements (Kline et al., 2012), one addressed seven elements (Byrne et al., 2011), and one addressed three elements (Sheetz & Bowman, 2012) (see Table 3.6). None of the studies explicitly described the support intervention elements of defining the problem and assessing/discussing parents' decision-making needs.

The purpose and administration of the two described DMTs differed (Byrne et al., 2011; Kline et al., 2012). Byrne et al., (2011), describe the DMT as a guide used exclusively by palliative care physicians facilitating their initial discussion with families only after receiving a consult request from referring physicians such as pediatric intensivists or oncologists. The DMT provided structure to frankly explore the risks, benefits, alternative therapies, and contextual issues related to a decision. Kline et al. (2012), described the DMT as a written synopsis provided to families by the palliative care team's nurse coordinator after a "supportive conference" that identified parents' goals and a plan of care related to their child's healthcare. The DMT synopsis was formatted for parent's review using the following structure: (i) medical indicators, (ii) patient/family preferences, (iii) quality-of-life factors, and (iv) contextual issues.

The third study described the palliative care teams' completion of an inpatient consultation with families as a decision support intervention in itself and consequently as requiring a consult request from the healthcare team (Sheetz & Bowman, 2012). Sheetz and Bowman (2012) describe that members of the palliative care team (physicians, nurses, social workers, and chaplains) were frequently consulted to provide medical decision-making support

Table 3.3*Characteristics of Included Studies (n = 3)*

Author, Country, and Year	Study design, Participants (n) and Setting	Intervention	Main Findings & Reported Limitations
Byrne et al., USA, 2011	Descriptive analysis of completed consult reports 43 families of children with life-threatening illness ranging from prenatal to late adolescence; 32 referring physicians in a pediatric hospital	Palliative care team consultation Decision-making tool to guide conversation	Parent preference for truth when uncertain, balancing urgency to decide against a need to wait, moving from negative emotions to mutual understandings with HCPs, utilizing a multilevel communication network, fearing abandonment, and with the reality of the life-threatening diagnoses. Reported limitations: convenience sample of a single service with data collected from written summaries and
Kline et al., USA, 2012	Mixed methods 29 parents of hematology-oncology patients (mean age of patient: 9.7 years) (20 completed survey and 9 completed interview) in a pediatric hospital	Decision-making consultation	Felt to have improved quality of life for child, (N = 20, n = 14) 70% Improved communication between the family and treatment team, (N = 20, n = 18) 90% Improved understanding of treatment options by parents (N = 20, n = 17) 85% Care provided by HCPs was reflective of parents' identified goals (N = 20, n = 16) 80% (N = 20, n = 17) 85% found the treatment team to be
Sheetz & Bowman, USA, 2012	Cross-sectional quantitative 12 question survey with 4 open-ended questions 65 parents of children with life-threatening conditions bereaved in the past 7-36 months in a pediatric hospital	Palliative care team consultation	Understanding child's condition and explanation of information and options. (N = 65, n = 49) 75% noted improved communication between the family and treatment team. (N = 63, n = 49) 78% agreed that the care provided by health care professional was reflective of parents' identified goals. (N = 64, n = 61) 95% found the treatment team to be supportive and engaged in shared decision-making. Reported limitations: may not be generalized as a single program. unknown reliability and validity of the instrument

HCP = Healthcare

Table 3.4*Quality Appraisal of Included Studies (N = 3)*

Appraisal Checklist	Byrne et al., (2011)	Kline et al., (2012)	Sheetz & Bowman, (2012)
JBICritical Appraisal Checklist for Analytical Cross Sectional Studies	-		
Were the criteria for inclusion in the sample clearly defined?	-	Yes	No
Were the study subjects and the setting described in detail?	-	Yes	No
Was the exposure measured in a valid and reliable way?	-	Unclear	No
Were objective, standard criteria used for measurement of the condition?	-	N/A	N/A
Were confounding factors identified?	-	N/A	N/A
Were strategies to deal with confounding factors stated?	-	N/A	N/A
Were the outcomes measured in a valid and reliable way?	-	No	No
Was appropriate statistical analysis used?	-	Unclear	Unclear
JBICritical Appraisal Checklist for Qualitative Research			
Is there congruity between the stated philosophical perspective and the research methodology?	Yes	No	-
Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	-
Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	-
Is there congruity between the research methodology and the representation and analysis of data?	Yes	Unclear	-
Is there congruity between the research methodology and the interpretation of results?	Yes	Yes	-
Is there a statement locating the researcher culturally or theoretically?	Yes	No	-
Is the influence of the researcher on the research, and vice-versa, addressed?	Yes	No	-
Are participants, and their voices, adequately represented?	Yes	Yes	-
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Yes	Yes	-
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes		-

JBIC = Joanna Briggs Institute; N/A = Not Applicable

Table 3.5

Characteristics of Decision Support Interventions Targeting Parents (N = 3)

	Byrne et al., (2011)	Kline et al., (2012)	Sheetz & Bowman, (2012)
Decision support	Consultation with PC team with Decision-Making Tool guiding conversation	Decision-Making Tool to summarize decision-making conversation	Consultation with PC team
Administered by	PC physician	PC nurse	PC team member: physician, nurse practitioner, nurse manager, social worker, and chaplain
Timing	During initial consult unless family/clinical situation does not permit, then during follow-up	When important treatment decisions are necessary	Inpatient consultation for: medical decision-making and supportive /PC

PC = Palliative Care

and assist parents set goals of care by means of a supportive environment and communication strategies.

Parents' Experiences with the Intervention and Intervention Outcomes

All three studies reported that the decision-making interventions improved families' experiences of communicating with the treatment team and enhanced parents' understanding of benefits and harms (Byrne et al., 2011; Kline et al., 2012; Sheetz & Bowman, 2012). While no study reported the statistical significance of an improvement, two of the studies noted increased engagement in decision-making support on the part of HCPs (Kline et al., 2012; Sheetz & Bowman, 2012). In both cases, this was identified as contributing to increased congruence between the provision of care by HCPs and parents' identified goals. Other positive effects included parents' perception of an improvement in their child's quality of life, HCP awareness of parents' variable decision-making readiness, and parents' deliberate weighing of intervention related benefits versus harms.

Table 3.6*Elements of Decision Support in Interventions (n = 3)*

	Byrne et al., (2011)	Kline et al., (2012)	Sheetz & Bowman, (2012)
Problem defined/explained			
Assess/discuss parents' decision-making needs			
Options (including alternatives) presented	✓	✓	
Benefits of options discussed	✓	✓	
Risks of options discussed	✓	✓	
Understanding assessed/clarified	✓		
Values/preferences discussed	✓	✓	✓
Builds skills in deliberation, communication, and accessing support		✓	✓
Ability/self-efficacy to enact plan discussed		✓	
Decision made or explicitly deferred		✓	
Facilitate progress in decision-making	✓	✓	✓
Follow-up arranged	✓		
Total number of elements	7	8	3

✓ = decision support element present

In one study, parents described perceiving the interprofessional approach to decision support provided as either helpful or very helpful to guiding their healthcare decisions (Kline et al., 2012). Another study reported that the interprofessional approach to decision support was considered by parents to be responsive to their many unique needs related to their child's life-limiting condition (Sheetz & Bowman, 2012).

No health system related outcomes were reported in the three studies. It is unclear to what extent the interventions supported decisional needs as none of the studies reported intervention outcomes. Analysis or metasynthesis were not possible as only a single study reported quantitative results.

Discussion

This scoping review included three studies regarding interventions used to support parents' decisional needs when making healthcare decisions for their child along the trajectory of their child's life-limiting condition. The number of identified studies highlights the lack of reported decision support interventions for parents making healthcare decisions for their child living with a life-limiting condition. While this should not be interpreted as an indication that such supports do not exist or are not provided by HCPs, it should rather encourage the reporting of such supports as they might be under-evaluated. Factors contributing to this scarcity may include the limited number of patients and parents available to participate in such studies and some HCPs' apprehension and fear of involving palliative children and their families in research (Weaver et al., 2019). The described interventions predominantly highlight the combining of pediatric palliative and supportive care teams rather than individually delivered and replicable interventions such as guides, tools, and/or aids.

Timely Decision Support

Families facing multiple difficult healthcare decisions over time, require timely access to decision support within the process of care, rather than waiting for a delayed consultation with a specialist palliative care team. In two of the studies, decision support was delayed until families had access to a palliative care team (Byrne et al., 2011; Sheetz & Bowman, 2012). Furthermore, bereaved parents described a desire to have been referred to a palliative care team at an earlier

point in their child's life-limiting condition (Sheetz & Bowman, 2012). In the other study, the palliative care team was embedded in the hematology-oncology team forming a "Supportive Care Team" (Kline et al., 2012). This study stated that it was necessary for this team to be accessible to families because medical issues arise routinely. Woolf et al., (2005) reviewed the advantages and disadvantages of the provision of decision support by both clinicians from within the healthcare team and HCPs beyond the healthcare team. It was reported that decision support provided by a HCP outside of the healthcare team may improve the consistency, quality, and efficiency of decision support. This is despite the fact that the clinician was described as possibly unfamiliar with pertinent healthcare information and whose involvement may lead to confusion if not well coordinated with the healthcare team. Alternatively, decision support provided from within the healthcare team was described as occurring in an integrated manner and from within the context of the trusted patient-HCP relationship.

A review of the impact of specialized pediatric palliative care programs on decision-making reports an improvement in decision-related communication between parents and HCPs (Streuli et al., 2019). Given that pediatric palliative care support is preferably offered early in the illness trajectory, consultation should be sought by healthcare teams in a timely manner to facilitate decision-making support, rather than waiting for an impending decision (Canadian Hospice Palliative Care Association, 2006).

Decision Support Using Structured Communication Guides

HCPs require structured therapeutic conversation guides in order to provide these parents with decision support. In two studies, when a DMT was used to guide the palliative care teams' conversation with parents, parents noted improved communication that explored decision related risks, benefits, alternatives, and contextual issues (Byrne et al., 2011; Kline et al., 2012). In these

studies, the tools used were guides designed to facilitate and document a decision-support conversation.

A systematic review of decision coaching in randomized controlled trials of patient decision aids identified 10 studies (Stacey et al., 2012). In these studies, decision coaching was described using terms such as counseling, consultation, preference-elicitation interview, and planning talk. A trained decision coach facilitates the decision-making process by assessing decision-making needs, supporting patients' review of options, clarifying beliefs and values, and screening for patients' needs related to decision implementation (Stacey & Légaré, 2015). The review reports that participants were more satisfied with decision-making when exposed to supportive decision coaching in one trial while no difference was noted in the other trial measuring patient satisfaction.

Decision coaching conversations related to goal setting and decision-making in palliative care may be difficult for HCPs to initiate as a result of barriers such as lack of training or comfort (Whitehead & Carter, 2017). This may factor into a healthcare team's decision to request a consultation from the palliative care team. In pediatric palliative care, efforts to enhance communication with parents and facilitate their engagement may support the decision-making process (Davies et al., 2017; Mooney-Doyle et al., 2017). A guide or checklist to structure conversation may minimize HCP anxiety and increase the occurrence of such supportive conversations in an effort to provide effective decision coaching (Lally et al., 2019).

Interprofessional Approach to Decision Support

An interprofessional approach to decision support is required for families making multiple value-sensitive decisions for their child with a life-limiting condition. All three of the included studies discussed the use of an interprofessional approach to supporting decision-

making. This approach was described by parents as being comprehensive in nature and designed to address the physical, psychosocial, and spiritual needs of parents. The Interprofessional Shared Decision-Making Model (IP-SDM) describes how HCPs from different disciplines, the patient, and family can engage in an integrated and iterative approach to decision-making that strives to reach an agreed-upon decision considering patient/family goals (Légaré et al., 2011). These interprofessional collaborations are critical to establishing both shared understandings and efforts to align decisions with available options and parents' preferences (Dogba et al., 2019). Pediatric palliative care norms of practice state that care is to be provided collaboratively with patients and families by an interprofessional team (Canadian Hospice Palliative Care Association, 2006). A commitment to an interprofessional approach may honour and respond to the multiplicity of needs identified by a family in the context of a life-limiting condition by responding to both emotional and decision-making needs (Sheetz & Bowman, 2012). A published editorial by the parents of a 4-year-old with a craniopharyngioma noted that their most challenging decisions all required a supportive interprofessional approach to decision-making given the variable option-related benefits and harms (Nemergut & Townsend, 2015).

Limitations

The individual studies used non-rigorous evaluation methods and had variable quality. Additionally, the individual studies focused on convenience samples drawn from single programs or service centres and were retrospective in nature, reflecting the experiences of only a discrete number of parents. The details of the DMTs presented in the studies were not described and therefore it was impossible to further examine elements of the supportive conversation and their contributions to improved outcomes.

At the review level, limitations included restricting included articles to English though it is unclear the extent to which studies were missed. Given the focus on decision-making along the trajectory of a child's life-limiting condition when acute and palliative therapies are possible, interventions supporting decisions that solely focused on end-of-life matters were excluded from this study.

Conclusion

Few studies have evaluated interventions designed to support the decision-making needs of parents making healthcare decisions on behalf of their child living with a life-limiting condition. The three identified studies describe the positive effects decision-making support has on elements such as parents' decision-making readiness, congruence between provided care and parents' goals, and the child's quality of life. The description of utilized interventions lacked a significant amount of detail, limiting replicability. Further research to identify supportive decision-making interventions including quantitative studies, with before and after designs to assess their efficacy, is recommended.

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Chapter Four – Integrated Discussion and Conclusion

Thesis Summary

Introduction

The purpose of this thesis was to explore the decision-making experiences and supports provided to parents of children living with life-limiting conditions. The specific objectives were two-fold: 1) to explore the experiences of parents making decisions between acute and palliative therapies along the trajectory of their child's life-limiting condition and, 2) to examine interventions used to support parents' needs when making healthcare decisions for their child along the trajectory of their child's life-limiting condition. A literature review (Chapter 1), a qualitative interpretive description study (Chapter 2), and a scoping review (Chapter 3) were conducted. This chapter will summarize the findings of this work, present an integrated discussion, and highlight implications for clinical practice, education, and future research.

Summary of Findings

A review of the literature (Chapter 1) indicated that parents of children with life-limiting conditions often face decisions regarding both acute and palliative therapies for their child. (Allen, 2014; Toebbe et al., 2013). The decisions made by parents on behalf of their children, particularly in cases where their child cannot participate in the decision, are value-sensitive with, often, no clear best choice (Jackson et al., 2008; Stacey et al., 2006). As a result, parents may remain uncertain and in a state of decisional conflict, which, if unmanaged, may contribute to long-term psychosocial burden and decision regret (Boland et al., 2017; Charlebois & Cyr, 2015; Streuli et al., 2019). Decision support that targets parents' decision-making needs may improve the quality of decision-making and mitigate negative sequela experienced by parents (Stacey et al., 2012; Stacey & Légaré, 2015). An integrative review of factors that affect parental decision-making for children with life-limiting conditions and medical complexity noted that the majority

of 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 (Allen, 2014). In summary, little is known about the decision-making experiences and needs of parents making decisions regarding the healthcare of their child living with a life-limiting condition.

Next, a qualitative interpretive description study was conducted to explore experiences of parents and healthcare professionals (HCPs) with decision-making regarding acute and palliative therapies along the trajectory of their child's life-limiting condition (Chapter 2). Guided by the Ottawa Decision Support Framework (ODSF), semi-structured interviews with six parents supported by the interprofessional palliative care team of a regional children's hospital in Canada and with six HCPs were analyzed inductively. The five major themes identified were: (i) "Going by your heart and gut": The process of making a unique decision, (ii) "Not black and white": Experiencing decisional conflict when making difficult decisions, (iii) "Widening the circle of care": Various sources of decision-making support, (iv) "Trying to support": Conversations to gauge where parents are in the decision-making process, and (v) "Always a worry": Concerns regarding parents' decision quality and outcomes. In summary, parents and HCPs confirmed that parents of children with life-limiting conditions routinely make difficult decision requiring support from HCPs and parent peers. Interestingly, HCPs delivered support by using conversations and participants did not identify resources such as guides, tools, and/or aids to use as adjuncts to decision support conversations. This contributed to the need to search for available and evaluated interventions designed to support parents' decision-making.

A scoping review, examining the characteristics and outcomes of interventions used to support the decision-making needs of parents making decisions throughout their child's life-limiting condition, along with their experiences, was conducted using a five-stage

methodological framework (Chapter 3) (Arksey & O'Malley, 2005). Of the 546 articles retrieved from searching databases and hand searching reference lists of included articles, three articles fulfilled the inclusion criteria. All three studies captured the perspectives of parents with children diagnosed with life-limiting conditions and multiple comorbidities either actively receiving care or who were recently bereaved. The findings revealed that the timing of a palliative care consultation, along with the use of structured communication guides when receiving decision coaching from HCPs, were integral to mitigating parents' stress during the decision-making process. Additionally, an approach to decision support that was interprofessional in nature was perceived to be supportive and designed to address parents' psychosocial needs. Although the qualitative study and scoping review discuss their own findings, the following is a broader integrated discussion.

Integrated Discussion

Together, the qualitative interpretive description study and the scoping review highlighted three important considerations: (i) the use of decision guides, tools and/or aids were underreported, (ii) a role for non-HCP delivered decision support was identified, and (iii) the need for consultation with a palliative care team early in the decision-making process.

The Use of Decision Guides, Tools, and/or Aids were Underreported

Although specific guides, tools, and/or aids may be highly valuable adjuncts to decision support conversations (Delany et al., 2017), their identification and use were underreported in both the descriptions of decision support from parent and HCP participants in the qualitative study (Chapter 2) and the scoping review of interventions designed to support parents' decision-making (Chapter 3). Furthermore, HCP participants described the importance of providing decision support to parents, especially in an attempt to prevent negative outcomes, yet did not

identify resources or tools to facilitate such support (Chapter 2). This is in line with previous studies of decision support practices that also noted that HCPs focused on the provision of information, potentially biased with their own preferred option, rather than implementing tools such as patient decision aids to further support parents during the decision-making process (Boland et al., 2019). In contrast, Cochrane reviews regarding decision aids and decision coaching for people facing healthcare decisions highlight the rising prevalence of these interventions (Jull et al., 2019; Stacey et al., 2017). The apparent lack of interventions specifically for use with parents of children with life-limiting conditions, may stem from the limited population size available to involve in the design, testing, and general study of a unique intervention.

A more generalized decision support tool, such as the Ottawa Family Decision Guide, a generic decision aid designed to provide decision coaching to those making difficult healthcare decisions, may be appropriate (Feenstra et al., 2015; Lawson et al., 2020). The feasibility and acceptability of the Ottawa Family Decision Guide was evaluated with parents and children considering insulin delivery options for type 1 diabetes management where a larger population may have been available (Feenstra et al., 2015). The general nature of the Ottawa Family Decision Guide may allow it to be a suitable decision guide offered as a means of support by HCPs for parents of children with life-limiting conditions.

A Role for Non-Healthcare Professional Delivered Decision Support was Identified

Decision support provided to parents by non-HCPs, and in particular, other parents of children with life-limiting conditions, may serve as a meaningful intervention to enhance decision quality and outcomes. Parent participants described the perceived value in receiving such decision support (Chapter 2). The non-HCP delivered decision support may also provide

parents with an additional source for reassurance (Chapter 2) and promote the timely delivery of decision support (Chapter 3).

While the ODSF identifies counselling, decision tools, and coaching delivered by HCPs as possible decision support interventions, non-HCP delivered interventions such as an informal parent support network and/or parent support groups are not described (O'Connor et al., 1998). The recently published 20th anniversary ODSF retained the same identified decision support interventions and described counselling as that which was provided by HCPs with disciplinary competence, legal authority, and accountability (Stacey et al., 2020). Furthermore, a role for trained peer patients in providing decision support was described specifically in response to inadequate information about others' experiences or in cases where option features are difficult to value. By recognizing non-HCP delivered interventions as a reasonable approach to actively providing parents with decision support, HCPs may better contribute to facilitating the establishment of parent support networks. The proactive integration of this form of decision support early in the course of the child's life-limiting condition may also allow for timely availability and ongoing decision support.

The Need for Consultation with a Palliative Care Team Early in the Decision-Making Process

Access to a palliative care team early in the course of a child's life-limiting condition may enhance the decision support provided to parents. Earlier consultation may ensure that decision support is accessible to parents in a timely manner (Chapter 3) and provided with the support of an interprofessional team (Chapter 2 & 3). Furthermore, this early consultation may allow for parents to engage with HCPs experienced in having decision support conversations with parents (Chapter 2).

When the palliative care team was integrated into the healthcare team and did not require a formal referral, decision support was more likely to occur early in the decision-making process (Chapter 3). A study interviewing 103 parents of children who died of cancer, revealed that parents understood prognosis nearly 100 days after physician recognition and this disparity hindered their understanding of the condition and their decision-making (Wolfe et al., 2000). Consequently, parents may require decision-making support prior to their own realization of an impending decision warranting earlier consultation by the care team for palliative care support.

A preference for decision support from an interprofessional healthcare team was noted in the literature and articulated by both parent and HCP participants (Canadian Hospice Palliative Care Association, 2006; Dogba et al., 2019; Kline et al., 2012; Sheetz & Bowman, 2012). The interprofessional nature of pediatric palliative care teams allows for the provided decision support to potentially meet several aspects of parents' decisional needs (Chapter 2 & 3). This may include emotional support and the provision of practical information. The early consultation with a palliative care team may encourage the establishment of therapeutic relationships with various members of the interprofessional team in order to offer this support and information.

However, the initiation of a pediatric palliative care team consult is often challenging for HCPs because of barriers such as uncertain prognosis, time limitations, and a lack of continuity of care (Verberne et al., 2018). Despite the fact that providing decision support is one of the key goals in consulting the palliative care team, HCPs continue to have reservations regarding the early involvement of palliative care (Feudtner et al., 2011). Bereaved parents have shared their desire to have been referred to a palliative care team earlier in the trajectory of their child's life-limiting condition, particularly in the context of receiving decision support (Sheetz & Bowman, 2012).

Implications for Nursing

Clinical Practice

The findings of this research have implications for nursing clinical practice among other domains as outlined in the role of the Advanced Practice Nurse (Canadian Nurses Association, 2008). The absence yet need for a resource available to assist HCPs with initiating supportive conversations early in the decision-making process was clear. For example, nurses could use a guide such as the Ottawa Family Decision Support Guide to facilitate their supportive conversations with parents however would also likely need training and support to use it (Lawson et al., 2020). Training that goes beyond lecture/didactic formats and considers demonstrations, discussions, and practice may be conducive to a wider range of adult learning styles and needs (Registered Nurses' Association of Ontario, 2005). These guides and educational workshops would also be relevant to other professions, highlighting, among others, the role of nurses, social workers, and recreation therapists in providing decision support to parents alongside their physician colleagues in the interprofessional manner preferred by parents. Additionally, purposeful training of a variety of members of the healthcare team may allow for more timely provision of decision support early in the decision-making process as described to be preferred by parents.

Parent participants described feeling supported by a parent based support network in the form of structured groups and an informal network. Clinical practice that reflects organizational efforts to provide parent support groups would be responsive to decision support needs described by parents. Opportunities for parents to engage with peers in groups facilitated by trained HCPs such as nurses and social workers may allow for the natural development of the informal support network described by parents. The systematic availability of such support may allow HCPs to

integrate the recommendation that parents consider engaging in such supports during their clinical encounters with parents.

While parent participants placed significant emphasis on peer-based and emotional support, acquiring information and the need to consider various sources and types of decision support was noted. Additionally, HCPs also articulated their role in providing parents with decision related information throughout the decision-making process in a way that ensured consistent messaging on behalf of the HCP team. The availability of basic and standardized information pertaining to healthcare decisions known to be difficult for parents and in various modes, such as video, infographics, and pamphlets, may allow for the desired consistency.

Education

In addition to the training necessary to integrate a guide such as the Ottawa Family Decision Guide into the practice of supporting parents' decision-making needs, the findings also have implications for nursing education (Lawson et al., 2020). Given the pivotal role nurses have in supporting parents and their routine interactions with families, these findings (Chapters 2 and 3) indicate a clear need to enhance nursing education regarding parents' decision-making. Robust education both during the pre-licensure/undergraduate phase and afterwards as ongoing professional development opportunities, should provide nurses with opportunities to learn about how better to actively support parents' decision-making. In particular, this education should include the assessment and identification of parents' decision-making needs, the provision of targeted decision support by nurses, and the evaluation of decision quality and outcomes.

Future Research

While the studies in this thesis expand on the current body of research pertaining to parent decision-making in pediatric palliative care, more research is required specific to

developing and testing effective interventions to better support them. Interestingly, none of the parent or HCP participants discussed parents' reoccurring decision-making along the trajectory of a child's illness. Given the retrospective nature of the study, participants likely focused on the most recent decision(s) they were involved in. Future research conducted in a longitudinal manner to prospectively monitor decision-making over time is required to better appreciate the cumulative impact of making many decisions on behalf of a child living with a life-limiting condition. This is particularly true given the understanding that the needs of parents making decisions on behalf of their child may vary along the trajectory of their child's life-limiting condition (Allen, 2014).

Studies designed to better understand the role of the parent support network are required. Exploration of the role of HCPs in facilitating and enhancing such a support network may better inform the provision of clinical care. Furthermore, this enhanced understanding may support the organizational integration of such supports in the development of pediatric palliative care programs.

Conclusion

Parents making healthcare decisions for their child with a life-limiting condition experience decisional conflict. The decisions they make are both complex and unique while their decisional needs are variable. The present interpretive description study confirmed that parents make difficult decisions and often fear their consequences. Decision support from both HCPs and a parent based support network were noted. Supportive conversations were the primary means by which HCPs described supporting parents as they made healthcare decisions for their child. HCPs concurred with parents' description of therapeutic conversations as the primary means of providing support. The scoping review highlighted the value of timely access to

decision support and the provision of decision support using structured communication guides by an interprofessional team. Nurses are well positioned to support parents facing complex decisions by responding to their decisional needs and facilitating appropriate evidence-informed support.

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Appendices

Appendix A

Ethics Documents

CHEO Research Ethics Approval



RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

CHEO Research Ethics Board Approval - Delegated Review

Principal Investigator: Ms. Lynn Grandmaison-Dumont
 REB Protocol No: 17/176X
 Romeo File No: 20170510
 Project Title: CHEOREB# 17/176X - Parental Decision Making for a Child with a Life-Limiting Condition
 Primary Affiliation: Clinical Research/Palliative Care
 Protocol Status: Active
 Approval Date*: November 17, 2017
 Valid Until**: November 15, 2018
 Annual Renewal Submission Deadline: 15 October 2017

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Protocol	Parental Decision Making_Protocol_V1_November 2017_Clean	2017/11/06
Consent Form	Parental Decision Making_HCP Consent_V1_November 2017_Clean	2017/11/06
Recruitment Materials	Parental Decision Making_HCP Poster_V1_November 2017_Clean	2017/11/06
Questionnaire/Survey	Parental Decision Making_Interview Guide_V1_November 2017_Clean	2017/11/06
Consent Form	Parental Decision Making_Parent Consent_V1_November 2017_Clean	2017/11/06
Recruitment Materials	Parental Decision Making_Parent Poster_V1_November 2017_Clean	2017/11/06

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed under the delegated review stream, which is reserved for projects that involve no more than minimal risk to human subjects.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.
2. The investigator is responsible for complying with all applicable guidelines and regulations regarding human research ethics conduct, as applicable to the research project.
3. Approval for studies that include an investigational device(s) is contingent upon the investigator securing an Investigational Testing Authorization notice from Health Canada.
4. Investigators must submit an annual renewal report to the REB 30 days prior to the expiration date stated above.
5. The investigator must not implement any deviation from, or changes to, the protocol, consents or assents without the approval of the REB.
6. The investigator must, prior to use, submit to the Board changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.

7. Investigators must provide the Board with French versions of the consent form, unless a waiver has been granted. An interpreter should be offered to participants as required or at the request of the participant throughout the course of research.
8. The investigator must promptly report to the REB all unexpected and untoward occurrences (including the loss or theft of study data and other such privacy breaches).
9. Investigators must notify the REB of any study closures (closed to accrual, temporary, premature or permanent).
10. Investigators must submit a final report at the conclusion of the study.

Should you have any questions or concerns, please do not hesitate to contact the Research Ethics Board Office at 613-737-7600 ext. 3350 or 2128.

Regards,

Richard Carpentier, PhD
Chair, Research Ethics Board
Président, Comité d'éthique de la recherche

* The final approval date for initial delegated study applications approved with or without modifications will be the date the REB has determined that the conditions of approval have been satisfied.

** The expiry date of REB approval for initial study applications that required no modifications will be as follows:

- If the date of review and approval was **on or before** the 15th of the month, the expiry date will be the 15th of the month prior to the date of review and approval by the Chair and/or delegate *in the following year*.
- If the date of review and approval was **after** the 15th the expiry date will be the 15th of the month in which the date of review and approval by the REB *in the following year*.

*** The expiry date of REB approval for initial study applications that require modifications will be as follows:

- If the date of review and approval was **on or before** the 15th of the month, the expiry date will be the 15th of the month prior to the date of review and approval by the Chair and/or delegate *in the following year*.
- If the date of review and approval was **after** the 15th of the month, the expiry date will be the 15th of the month of review and approval by the Chair and/or delegate *in the following year*.

University of Ottawa Ethics Approval


Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

LETTRE D'APPROBATION ADMINISTRATIVE | LETTER OF ADMINISTRATIVE APPROVAL

Numéro de dossier / Ethics File Number	H11-17-217
Titre du projet / Project Title	Parental Decision Making for a Child with a Life-Limiting Condition
Type de projet / Project Type	Thèse de maîtrise / MA Thesis
CÉR primaire / Primary REB	CHEO REB
Statut du projet / Project Status	Approbation administrative / Administrative Approval
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	04/12/2017
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	15/11/2018

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Rôle
Nahal Stoppels	School of Nursing / École des sciences infirmières	Chercheur principal / Principal Investigator
Julie Chartrand	School of Nursing / École des sciences infirmières	Superviseure / Supervisor
Dawn Stacey	School of Nursing / École des sciences infirmières	Collaboratrice / Collaborator
Lynn Grandmaison Dumond	CHEO	Primary Site PI (CHEO)

Conditions spéciales ou commentaires / Special conditions or comments:
CHEO REB # 17/176X

L'Université d'Ottawa a signé une Entente, conforme aux exigences de la plus récente version de l'EPTC et tout autre règlement ou législation applicable, permettant au CÉR ci-haut nommé d'être désigné comme CÉR primaire pour les projets de recherche où

- 1) les activités principales de recherche sont menées sous l'autorité ou sous les auspices de l'établissement lié au CÉR primaire et
- 2) Une partie du projet est également réalisé sous l'autorité ou sous les auspices de l'Université d'Ottawa.

Cette lettre confirme que l'Université d'Ottawa a autorisé que le CÉR primaire soit le CÉR officiel pour l'évaluation et la supervision de ce projet de recherche. Ceci n'est pas une approbation éthique.

Afin de nous aider à garder votre dossier à jour, veuillez soumettre une copie de toutes demandes de modification, renouvellement d'approbation éthique etc. soumis à et approuvé par le CÉR primaire dès qu'elles sont disponibles.

Cette approbation administrative est valide pour la durée indiquée ci-haut et est sujette aux conditions énumérées dans la section intitulée « Conditions spéciales ou commentaires ».

The University of Ottawa has signed an Agreement, compliant with current TCPS guidelines and any other applicable guidelines or legislation regarding multisite review, allowing the REB named above to serve as Board of Record (BoR) for research projects where

- 1) the main research activities are conducted within the auspices or jurisdiction of the BoR's institution and
- 2) parts of the project are also conducted under the jurisdiction or auspices of the University of Ottawa.

This letter confirms that the University of Ottawa has authorized the REB named above to serve as Board of Record for the review and oversight of this research project. This is not an REB approval.

In order to help us keep your file up to date, please submit a copy of all amendment requests, project renewals or any other changes submitted to and approved by the BoR, as they become available.

Administrative approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special conditions or comments".

Catherine Paquet
Directrice/Director

Data Sharing Agreement

**Data Sharing Agreement ("Agreement")
Transfer of Data for Research Use**

BETWEEN:	AND
Children’s Hospital of Eastern Ontario Research Institute Inc. ("CHEO RI") 401 Smyth Road Ottawa, Ontario, Canada, K1H 8L1	University of Ottawa ("Recipient Institution") 3042-800 King Edward Ave. Ottawa, ON, K1N 6N5
CHEO RI Investigator: Lynn Grandmaison-Dumond (together with CHEO RI: "PROVIDER")	Recipient Investigator: Dr. Julie Chartrand (together with Recipient Institution: "RECIPIENT")

Name of Study ("Study"): Parental Decision Making for a Child with a Life-Limiting Condition

CHEO RI REB Number: 17/176X

RECIPIENT REB: H11-17-217

Data to be provided: De-identified data per the REB approved Study Protocol, incorporated herein by reference ("Data").

This Agreement, effective as of the last date of signature below, is entered into between the parties to govern the transfer of the Data from PROVIDER to RECIPIENT for use in the Study, in compliance with applicable laws. PROVIDER retains the right to refuse transfer of the Data requested.

CHEO RI Investigator will prepare and furnish to RECIPIENT the Data in accordance with Ontario's *Personal Health Information Protection Act*. Transfer of the Data by PROVIDER to RECIPIENT will be in compliance with REB approved subject informed consent forms ("ICFs") or terms of an REB Waiver of Consent ("REB Waiver"), as applicable (incorporated herein by reference). The parties shall use a secure method of provision of the Data by PROVIDER to RECIPIENT. Data will not be transferred until each party's REB provides written approval for the Study, to the extent required by their respective REBs. RECIPIENT will not use Data until RECIPIENT receives a copy of the PROVIDER's REB approved ICF or REB Waiver, as applicable.

RECIPIENT shall use the Data in compliance with all applicable laws; and shall specifically only use or disclose the Data for the conduct of the Study in accordance with the permitted uses of the Data specified in the applicable ICFs or REB Waiver, or otherwise as required by law. All Data is owned by CHEO RI. No right, title or interest in and to the Data is granted or implied to any other party hereunder.

RECIPIENT and PROVIDER shall have the right to use (1) the analyzed, de-identified data derived from the use of the Data, and (2) de-identified results arising out of analysis of the Data, as part of a publication or presentation of the results of the Study. No personally identifying information shall be included in any publication or presentation of Study results. PROVIDER and RECIPIENT shall coordinate publication of the results of the Study and appropriate authorship of any such publication shall be in accordance with International Committee of Medical Journal Editors (ICMJE) guidelines.

RECIPIENT shall use appropriate safeguards to prevent any unauthorized use or disclosure of the Data and shall immediately report to the PROVIDER any unauthorized use or disclosure of which RECIPIENT becomes aware, or of any breach of this Agreement. RECIPIENT shall not use the Data to identify or contact the individuals from whom such Data was collected. RECIPIENT shall securely destroy the Data as required by the Protocol or the PROVIDER and shall provide a written confirmation of the manner of destruction in a form acceptable to PROVIDER. PROVIDER may conduct audits of the RECIPIENT concerning the maintenance of appropriate security safeguards to ensure compliance with this Agreement.

Appendix B

Consent Forms

Parent Information and Consent Form



Protocol Title: Parental Decision-Making for a Child with a Life-Limiting Condition

Investigator: Nahal Yazdani, RN, CHPCN(C)

Contact:

Primary Investigator: Lynn Grandmaison Dumond, RN(EC)

Contact:

For more simplicity, the word “you”, when used in this form, means “yourself” or “your child”

You are being invited to join in a research study about the decision-making experiences of parents with a child diagnosed with a life-limiting condition. You are being invited to join this study to share your personal experience with decision-making and the support you receive. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to participate or not in this study will not affect the care you receive at CHEO or Roger Neilson House. You are free to withdraw from the study at any time and there will be no penalty to you or your child.

Why is this study being done?

This study is being done to better understand the healthcare decision-making needs of parents who have children with life-limiting conditions. We hope to better understand parents' decision-making experiences and needs in order to inform healthcare professionals and enhance supportive care programs to optimize decision making outcomes.

How many people will participate?

At CHEO, we expect to have approximately 13-18 parents participate in addition to 13-18 healthcare professionals.

What will I have to do?

If you decide to participate in this study, you will be asked to:
Answer brief socio-demographic questions:

- Year of birth
- Sex
- Marital status
- Highest level of completed education
- Child's age

- Child's diagnosis
- Length of time involved with the CHEO Palliative Care Team (in years)

Participate in an approximately 30 to 45 minute interview that will be audio recorded discussing: Your experience with making a healthcare decision and related details.

Are there any risks to participating?

You may feel uncomfortable with some of the questions being asked. If you feel uncomfortable, you may choose not to answer a question.

Are there any benefits to participating?

If you decide to participate, you may or may not benefit from participating in this study; however, we hope to enhance clinical practice.

Will I be paid to participate?

You will not be paid to take part in this study.

Can I withdraw?

You can withdraw from the study at any time without any impact to your current or future care at CHEO or Roger Neilson House. Please discuss with the investigator if you would like to withdraw. If you withdraw your consent, the investigator will no longer collect, and disclose your health information for the purpose of this study. Information that was already collected will be discarded.

What about confidentiality and privacy?

Your personal information will be kept strictly confidential except as required or permitted by law. For the purposes of this study, we will be collecting, sex, year of birth, marital status, and highest level of education from parents' and participant's child's age, diagnosis, and length of time involved with the Palliative Care Team. Representatives from the CHEO Research Ethics Board and a member of the CHEO RI Quality Assurance and Risk Program may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

The data from this study including socio-demographic information, audio recordings, and their transcription will be kept in a locked cabinet in Dr. Julie Chartrand's locked office at the School of Nursing at the University of Ottawa. An electronic version of transcripts will be saved on a password protected computer and files will not be emailed. These pieces of data will all be de-identified and a code will be used. Only the investigator and three thesis committee members will have access to data. Following completion of the study, all data will be preserved as such for seven years.

You will not be identified in any publication or presentation of this study. A copy of the signed consent form will be provided to you.

Is the research team benefiting from the study?

The investigator will benefit by fulfilling a requirement for a University of Ottawa Master's in Science of Nursing.

What if I have questions?

If you have any questions concerning participation in this study, please contact:

Investigator - Nahal Yazdani -

CHEO Site Investigator –

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the

hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3273), although this person cannot provide any health-related information about the study.

Consent Form Signatures

By signing this consent form I agree that:

I am voluntarily agreeing to participate in this research study;

I understand the information within this consent form;

All of the risks and benefits of participation have been explained to me;

All of my questions have been answered;

I do not give up my legal rights by signing this form

A copy of the signed consent form will be provided to me.

Signatures

Printed Name Participant

Signature of Participant

Date

Printed Name of Person Obtaining
Informed Consent

Signature of Person Obtaining
Informed Consent

Date

Healthcare Professional Information and Consent Form

Protocol Title: Parental Decision Making for a Child with a Life-Limiting Condition

Investigator: Nahal Yazdani, RN, CHPCN(C)

Contact:

Primary Investigator: Lynn Grandmaison Dumond, RN(EC)

Contact:

For more simplicity, the word “you”, when used in this form, means “yourself” or “your child”

You are being invited to join in a research study about the decision-making experiences of parents with a child diagnosed with a life-limiting condition. You are being invited to join this study to share your personal experience with parents’ decision-making and provided support. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to participate or not in this study will not affect your employment at CHEO and/or Roger Neilson House. You are free to withdraw from the study at any time and there will be no penalty to you.

Why is this study being done?

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At CHEO, we expect to have approximately 13-18 parents participate in addition to 13-18 healthcare professionals.

What will I have to do?

If you decide to participate in this study, you will be asked to:

Answer brief socio-demographic questions:

- Year of birth
- Sex
- Highest level of completed education
- Health occupation
- Length of time involved with the CHEO Palliative Care Team (in years)

Participate in an approximately 30 to 45 minute interview that will be audio recorded discussing: Your experience with a parent’s making of a healthcare decision, related details, and provided support.

Are there any risks to participating?

You may feel uncomfortable with some of the questions being asked. If you feel uncomfortable, you may choose not to answer a question.

Are there any benefits to participating?

If you decide to participate, you may or may not benefit from participating in this study; however, we hope to enhance clinical practice.

Will I be paid to participate?

You will not be paid to take part in this study.

Can I withdraw?

You can withdraw from the study at any time without any impact to your current or future care or employment at CHEO. Please discuss with the investigator if you would like to withdraw. If you withdraw your consent, the investigator will no longer collect, and disclose your health information for the purpose of this study. Information that was already collected will be discarded.

What about confidentiality and privacy?

Your personal information will be kept strictly confidential except as required or permitted by law. For the purposes of this study, we will be collecting year of birth, sex, highest level of education, health occupation, and length of time involved in pediatric palliative care. Representatives from the CHEO Research Ethics Board and a member of the CHEO RI Quality Assurance and Risk Program may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

The data from this study including socio-demographic information, audio recordings, and their transcription will be kept in a locked cabinet in Dr. Julie Chartrand's locked office at the School of Nursing at the University of Ottawa. An electronic version of transcripts will be saved on a password protected computer and files will not be emailed. These pieces of data will all be de-identified and a code will be used. Only the investigator and three thesis committee members will have access to data. Following completion of the study, all data will be preserved as such for 7 years.

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Investigator -

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Consent Form Signatures

By signing this consent form I agree that:

I am voluntarily agreeing to participate in this research study;

I understand the information within this consent form;

All of the risks and benefits of participation have been explained to me;

All of my questions have been answered;

I do not give up my legal rights by signing this form

A copy of the signed consent form will be provided to me.

Signatures

Printed Name Participant

Signature of Participant

Date

Printed Name of Person Obtaining
Informed Consent

Signature of Person Obtaining
Informed Consent

Date

Appendix C

Recruitment Materials

Parent Recruitment Poster



Parental Decision Making for a Child with a Life-Limiting Condition

What is the study about?

Exploring parents' healthcare decision making experiences and needs as they relate to their child with a life-limiting condition

Who can participate?

Custodial parents of children up to 18 years of age, diagnosed with a life-limiting condition, cognitively unable to contribute to decision making, and involved with the CHEO Palliative Care Team. Participants must be able to communicate in English.

What is involved?

Participation would involve an audio recorded interview of approximately 30-45 minutes.

Where will the study take place?

If you decide to participate, the interview will take place in person and at a convenient location for you. The interview may also be done by telephone, or Skype/FaceTime.

Contact information:

If you are interested in participating in this research study, please contact:

Nahal Yazdani, RN, CHPCN(C) - Investigator

Healthcare Professional Recruitment Poster

Parental Decision Making for a Child with a Life-Limiting Condition

What is the study about?

Exploring parents' healthcare decision making experiences and needs as they relate to their child with a life-limiting condition

Who can participate?

English speaking physicians, social workers, registered nurses, and registered practical nurses, personal support workers, and allied health professionals at CHEO and/or Roger Neilson House, who work with palliative care families and have been in a family's circle of care as they are faced with decisions.

What is involved?

Participation would involve an audio-recorded interview of approximately 30-45 minutes.

Where will the study take place?

If you decide to participate, the interview will take place in person and at a convenient location for you. The interview may also be done by telephone, or Skype/FaceTime.

Contact information:

If you are interested in participating in this research study, please contact:

Nahal Yazdani, RN, CHPCN(C) - Investigator

Healthcare Professional Recruitment Email

Hello,

Please find attached a poster describing a study being conducted currently seeking healthcare professionals as participants. Your consideration in participating is greatly appreciated. Contact information for the study investigator can be found at the bottom of the poster for further inquiries.

Thank you.

Appendix D

Interview Guides

Parent Interview Guide

Good morning/afternoon/evening. My name is Nahal Yazdani and I am conducting interviews with parents in order to learn more about parents' needs when decisions are made about their child who is living with a life-limiting condition. We plan to use this information to be better able to meet the needs of parents'.

During this interview, you will be asked questions about your experience with a health care decision made for your child, where there was more than 1 option.

All of the information collected will be kept confidential including the recording. If there are any questions you would wish to pass on, please feel free to say so. Finally, your participation is voluntary and as such, you are free to withdraw any time throughout the interview.

Question 1

Please tell me about your experience with a healthcare decision made for your child.

Prompts:

- Health related?
- How was it presented?
- What was the process?

Question 2

Who was involved in making the decision?

Prompts:

- Self
- Spouse/partner
- Family
- Palliative Care Team
- Healthcare Professionals
- Other?

Question 3

How were they involved?

Prompts:

- Made decision for you
- Shared decision with you
- Supported your decision making
- Other?

Question 4

How did you feel as this decision was being made?

Prompts:

- Confident

- Unsure of how to make decision
- Stressed
- Upset
- Focused
- Physically impacted
- Delaying decision
- Wavering

Question 5

What made this decision challenging?

Prompts:

- Lack of information about options
- Lack of information about pros and cons (benefits and harms)
- Unclear of what was most important to you
- Lack of support
- Sense of pressure
- Lack of readiness

Question 6

What helped you make this decision? (if parents involved)

Prompts:

- Resources (other parents, support groups, provided by clinicians, online)
- Someone helping you think about the decision (decision coaching, shared decision making)

Question 7

What else could have been done or done differently to better support your involvement in the making of the decision?

Year of birth: ____

Sex: M____ F____

Marital status: Single____ Married/Common Law____ Divorced____

Highest level of education completed: High school____ College____ University undergraduate____
University graduate

Child's age (years): _____

Child's diagnosis: _____

Length of time involved with CHEO Palliative Care Team (years): _____

Healthcare Professional Interview Guide

Good morning/afternoon/evening. My name is Nahal Yazdani and I am conducting interviews with healthcare professionals in order to learn more about parents' decisional needs and experiences as it relates to their child living with a life-limiting diagnosis. The hope is that this information will allow us to better meet parents' needs.

During this interview, you will be asked questions in regards to your experience with parents who are making decisions for their child that may involve decisional conflict and are value-sensitive in nature.

All of the information collected will be kept confidential including the recording. If there are any questions you would wish to pass on, please feel free to say so. Finally, your participation is voluntary and as such, you are free to withdraw any time throughout the interview.

Question 1

Tell me about a healthcare decision made with a parent for their child that you were involved in.

Prompts:

- Treatment options
- A specific intervention

Question 2

What do you think may have made such a decision difficult for a parent?

Prompts:

- Lack of information about options
- Lack of information about pros and cons (benefits and harms)
- Unclear of what was most important to you
- Lack of support
- Sense of pressure
- Lack of readiness

Question 3

Can you please describe for me your role as it relates to parents making decisions for their children that are sensitive to their values?

Prompts:

- Made decision for parent
- Shared decision with parent
- Supported parent with decision making
- Other?

Question 4

Who else is often involved in making such decisions?

Prompts:

- Spouse/partner
- Family
- Palliative Care Team

- Healthcare Professionals
- Other?

Question 5

What helps parents make such decisions?

Question 6

Is there anything else that would help ensure parents were better supported with decision making?

Year of birth: _____

Sex: M ___ F ___

Highest level of education completed: High school ___ College ___ University undergraduate ___
University graduate

Length of time involved with CHEO Palliative Care Team (years): _____

Health occupation: MD ___ RN ___ RPN ___ PSW ___ RSW ___ Recreation
Therapist ___ Other _____