Parent' and health professionals' decision-making about medical care for children with life-limiting and life-threatening conditions: a qualitative constructivist case study

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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Thesis abstract

Background

Parents and healthcare professionals caring for children with life-limiting and life-threatening conditions are required to make a continuous number of interconnected decisions about medical care during a child’s life continuum. Reaching decisional agreement through collaboration has been identified as good practice but is poorly implemented and understood. In the Czech Republic, little is known about decision-making in paediatric care.

Aim

To explore how parents and healthcare professionals make decisions about medical care for children with life-limiting and life-threatening conditions in the Czech Republic.

Methods

A qualitative multiple case study design, underpinned by constructivism was adopted. Each case was defined by a child and consisted of a parent and healthcare professional. Data were collected by interviews and documentary analysis within a single hospital setting in the Czech Republic. Narrative analysis guided the within-case and cross-case analysis.

Findings

The study comprised ten cases with 21 participants (n=10 parents, n=11 healthcare professionals). Six categories were identified; five categories of factors which influence medical decision-making (Information and Knowledge, Child, Parents, Family, and Environment), with a sixth category of the Decision-Making Approach (comprising, parent-guided, physician-driven, or shared). A conceptual model of medical decision-making was developed to depict the interrelationships between the categories.

Discussion and Conclusion

Decision-making for children with life-limiting and life-threatening conditions, takes place in a complex landscape, with the decision-makers individually influenced by multiple external, personal and relational factors. Shared decision-making is seen as desirable but is challenging to implement, due to power imbalances, communication challenges (exacerbated by time restrictions) and parental uncertainty about their role.

Achieving shared decision-making requires respectful relationships, access to information, taking account of the factors which influence parents and their capacity to participate in decision-making, and achieving aligned perspectives on the child's best interests, all of which are enabled by the involvement of paediatric palliative care teams.

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Chapter 1. Introduction and background

1.1 Introduction

The focus of interest of this qualitative case study is decision-making about medical care for children with life-limiting and life-threatening conditions, from the perspective of parents and healthcare professionals.

In this study, the topic of decision-making is addressed by a qualitative case study approach to elicit perspectives of parents and healthcare professionals. A qualitative case study design enables the researcher to explore decision-making in real-life contexts, and to identify how decisions about medical care are made. Narrative analysis guided the analytical process of data collected through interviews, and by a review of electronic medical records.

The aspiration of this research is to generate new knowledge in the field of medical decision-making for children with life-limiting and life-threatening conditions and to provide insights into the dynamics of medical decision-making in a paediatric context.

The introductory chapter starts with discussion on the population of children with life-limiting and life-threatening conditions, paediatric palliative care, and the key concepts of decision-making within this population. This is followed by discussion of decision-making in paediatrics. The involvement of parents and healthcare professionals is presented together with different approaches to decision-making. The cultural specifics of the Czech Republic, where this study is set, are presented in detail in the next section of the chapter, focusing on healthcare and palliative care provision. To better understand my motivations for pursing this research topic, my background as a researcher and my personal story are also included in this chapter. Finally, the chapter concludes with a description of the thesis structure.

1.2 Children living with life-limiting and life-threatening conditions

Globally, an estimated 21 million children live with life-limiting and life-threatening conditions (Connor et al., 2017). Over 370 diagnoses from the International Classification of Diseases (ICD 10) have been identified as life-limiting or life-threatening in children population (Hain et al., 2013) and the prevalence is showing an upward trend (Bowers et al., 2020; Fraser et al., 2021). Among the life-limiting and life-threatening conditions - neurological, neuromuscular, congenital, or perinatal are the most common (Fraser et al., 2020; Hardelid et al., 2014).

Conditions classified as life-limiting and life-threatening are categorised into four categories based on the course of the illness and the expected outcome (ACT, 2009). The categories are the following: (category 1) life-threatening conditions with possible cure which can fail, such as cancer; (category 2) conditions with inevitable premature death where intensive treatment prolonging life is available, such as cystic fibrosis; (category 3) progressive conditions without curative treatment options, where treatment is exclusively palliative, e.g. Batten disease; and (category 4) irreversible but non-progressive conditions causing severe disability and the likelihood of premature death such as cerebral palsy (ACT, 2009). Category one includes conditions classified as life-threatening, while categories two, three and four include life-limiting conditions (Chambers, 2018). This categorisation was recently expanded by adding a fifth category, including unborn children and neonates who may benefit from perinatal palliative care (Benini et al., 2022). A description of the five categories of life-limiting and life-threatening conditions is presented in Table 1.

This widely used classification encompasses a heterogeneous group of diagnoses, but does not include all serious illnesses that children may endure (Fraser et al., 2020). The nomenclature is also open to criticism as life-limiting may refer to the limitation of abilities and not limitations to the expected length of life of the child, and the term *life-threatening* is often used interchangeably with *life-limiting*, which may be a source of confusion (Noyes et al., 2013).

Children living with conditions classified as life-limiting or life-threatening benefit from paediatric palliative care and therefore should have access to adequate palliative care provision (Benini et al., 2022). Paediatric palliative care is introduced in the following section.

Table 1 Categories of life-limiting and life-threatening conditions

(Adapted from Benini et al., 2022, p. e533)

Category	Description
Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Patients may have complex needs which may benefit from palliative care services. After achieving remission or following successful treatment, palliative care provision can be ceased (e.g., cancer, irreversible organ failures of heart, liver, kidney).
Category 2	Conditions through which premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities (e.g., cystic fibrosis, Duchenne muscular dystrophy).
Category 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (e.g., Batten disease, mucopolysaccharidoses).
Category 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the likelihood of premature death (e.g., severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury).
Additional category	
Category 5	Unborn children with major health issues who may not live through birth, neonates with limited life expectancy or with birth anomalies that may threaten vital functions, and neonates requiring intensive care.

1.2.1 Paediatric palliative care

Paediatric palliative care was defined by the World Health Organisation as following: *"Palliative care for children is the active total care of the child's body, mind and spirit,* *and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress"* (IMPaCTT, 2007, p. 2).

The primary goal of paediatric palliative care is to improve the quality of life of the ill child and its family (Bergstraesser, 2013). This is achieved through pain and other symptoms management, by providing goal concordant care, respecting family wishes and including parents in care and decision-making (IMPaCTT, 2007). Paediatric palliative care is child and family-orientated, and family has an active role in the care management (Chelazzi et al., 2023). Open, respectful communication together with emotional support were identified by parents as important components of paediatric palliative care (Crozier & Hancock, 2012).

The child and its family can benefit from paediatric palliative care the most, when the care provision starts early, ideally at the time of receiving the diagnosis (Benini et al., 2022). Early integration of paediatric palliative care into standard care has the potential to improve symptom burden, improve the child's quality of life, and affect the choice of place of death (Mack & Wolfe, 2006; S. Mitchell et al., 2017). Additionally, it can reduce the use of intensive treatment and promote advance care planning during the end-of-life stage (Taylor et al., 2020).

Advance care planning and shared decision-making are core components of paediatric palliative care (Marcus et al., 2020; S. Mitchell et al., 2017). Types of decisions which are common in paediatric palliative care are explored next.

1.2.2 Types of decisions made for children with life-limiting and life-threatening conditions

The conditions classified as life-limiting and life-threatening represent a wide range of diagnoses, as presented above, and the majority of them are characterised by uncertain prognosis and the need to make several difficult decisions about medical care during the child's life (Popejoy et al., 2017; Zaal-Schuller, de Vos, et al., 2016).

The decision-making starts at diagnosis and continues during the child's life (Allen, 2014). For some children, the decision-making begins prior to birth, when parents are informed about the diagnosis prenatally and are required to make decisions about the unborn child, including continuing or terminating the pregnancy (Luz et al., 2017; Toebbe et al., 2013).

Throughout the child's life, parents and healthcare professionals make diverse decisions for the child (Carroll et al., 2012). The decisions which may need to be made include on such conditions a tracheostomy and assisted ventilation, placement of gastrostomy and artificial feeding, and end-of-life care decisions (Jonas et al., 2022). Decisions about surgical interventions are also common (Ellis et al., 2024; Traynor et al., 2021).

An overview of the types of decisions parents and healthcare professionals may encounter during the care of the ill children is presented in Table 2.

Table 2 Types of medical decision for children with life-limiting and life-threatening conditions

(Adapted from: Beecham et al., 2017; Ellis et al., 2024; Jonas et al., 2022)

Category	Type of decision
Ventilation	Tracheostomy Ventilator placement Long-term mechanical ventilation
Nutrition	Gastrostomy tube placement Nasogastric tube placement Artificial nutrition and hydration (enteral, parenteral)
Surgical interventions	Central venous access, endoscopy, biopsy, bone marrow aspirate, injections, lumbar puncture, catheterisation, anaesthesia and others
Advance care planning/ end-of-life care	Place of care Place of death Limitation of treatment - Aggressive and invasive treatment Use of antibiotics Nutrition Admission to paediatric intensive care unit Intubation and assisted breathing Resuscitation and its extent

End-of-life care decisions are addressed through advance care planning and range from choices about place of care, and place of death, to decisions about limiting treatment and nutrition, withdrawal of treatment and resuscitation status (Carr et al., 2021; Jonas et al., 2022; Tsai, 2008). Decisions about intensive treatment during the end-of-life stage present a complex balance of potential benefit and harm. In the paediatric setting, it is common for intensive care to be provided up until the death of the child (Johnston et al., 2017; Kassam et al., 2017; Widger et al., 2023). While intensive interventions may offer a chance of survival or prolonged life, and maintain hope, intensive treatment can also lead to prolonged suffering, reduced quality of life, and increased psychological burden (Blume et al., 2014; Wolfe et al., 2000). Additionally, the provision of intensive treatment can delay or complicate transitions to palliative care and hinder advance care planning (Deming et al., 2022). Healthcare professionals often struggle to balance curative intent with palliative goals, especially in acute healthcare settings (McLorie et al., 2025).

Parental perspectives on intensive treatment at the end of life vary. For some, intensive interventions represent a chance of survival and an expression of hope, while for others they are seen as prolonging suffering and diminishing quality of life (Blume et al., 2014; Hirata & Kobayashi, 2023; Mekelenkamp et al., 2020). These views are dynamic and may change over time, influenced by parental prognostic awareness. However, there is evidence that parents have a limited understanding of prognosis and are reluctant to accept the severity of their child´s condition, which may in turn affect willingness to agree with treatment being limited or withdrawn (Durall et al., 2012).

In addition to medical decisions, parents of children with life-limiting and life-threatening conditions are frequently confronted with many other decisions, as discussed earlier (Miller et al., 2009). These include choices around everyday care routines, such as managing mobility, feeding, and hygiene needs (Lazzarin et al., 2018). Decisions about education also need to be made (Lindsay et al., 2016). Parents face ongoing choices about how to support siblings, manage family dynamics, and maintain marital relationships (Mitchell et al., 2021; Wang & Barnard, 2004), such as the use of respite care to help to maintain family functioning (Eaton, 2008; Edelstein et al., 2017). These non-medical care decisions, while less visible in clinical discussions, exert an impact on the choices parents make about medical care and affect parental wellbeing (Hatzmann et al., 2008). Moreover, the accumulation of non-medical decisions and parents' repeated exposure to caregiving challenges has been found to affect parents' decision-making style over time (Ray, 2002). Some parents adopt task-oriented approach characterised by active problem-solving and information-seeking, while others adopt a more cautious and deliberative style considering the long-term implications (Buchanan et al., 2022). Repeated exposure to uncertainty can increase parental reliance on professional guidance, while others become advocates for their children, particularly when encountering barriers to access to care or feeling their expertise is undervalued (Bogetz et al., 2022; Jonas et al., 2022).

1.3 Decision-making in paediatrics

In paediatric healthcare, decisions about medical care are usually made by parents and healthcare professionals on behalf of the children (Meert et al., 2013; RCPCH, 2004). The key participants in the decision-making process are parents and healthcare professionals, although children are also included (Larcher et al., 2015). Participation of children in decision-making is influenced by their developmental stage, communication skills, age, mental maturity, and health condition (Benini et al., 2022; Chelazzi et al., 2023; Coughlin, 2018). The level of their involvement should be aligned with their preferences (Lipstein et al., 2015). Children aged 16 and older are perceived as mentally capable of participating in the decision-making and their opinion should be considered (Larcher et al., 2015). Nevertheless, the involvement of children is often limited, and their participation is controlled by parents and healthcare professionals (Coyne et al., 2014; Wyatt et al., 2015).

The involvement of parents and healthcare professionals in decision-making is discussed next, followed by the exploration of the different approaches to decision-making.

1.3.1 Involvement of parents and healthcare professionals in decision-making

The decision-making process represents a sensitive interplay between parents and healthcare professionals. Parents, being the primary caregivers, function as surrogate decision-makers, and have the moral and legal prerogative to make choices for their children (Fraser et al., 2020; Wellesley & Jenkins, 2009). Legally, parents are able to give consent with the proposed treatments and speak on behalf of their child (Ross et al., 2012). Nevertheless, parental authority to make decision for their children is not without limits, and is surpassed by the interests of the ill child (Harrison, 2004; Nelson & Nelson, 1992). In situations when parental preferences are not aligned with the child’s best interest, their preferences may be medically futile or could even cause harm to the child, their permission may not be required (Paul et al., 2017).

While parents have the legal right to make decisions for their children, a discrepancy between this right and their actual involvement exists. The power balance in the decision-making process is not equal, but rather to the contrary - healthcare professionals have a dominant role in the process and can influence parental level of engagement based on their authority and medical knowledge (Aarthun & Akerjordet, 2014; Richards et al., 2018). Especially when making complex medical decisions, such as withholding or withdrawing treatment, healthcare professionals have a tendency to make those decisions based on their medical expertise or their perception of the child's best interest without including parents or asking their opinion (Orfali, 2004; Richards et al., 2018; Vos et al., 2011). Additionally, healthcare professionals use various strategies during communication with parents with the aim to influence parental involvement in the process, such as presenting selective options or putting emphasis on their preferred option (Popejoy et al., 2022; Richards et al., 2018).

The dominancy in the decision-making owned by healthcare professionals is reflected in parental experience of their participation in the decision-making which often does not match their preferred level (Aarthun & Akerjordet, 2014). Parents rely on the support of healthcare professionals and their invitation to participate in the decision-making process (Allen, 2014; Birchley et al., 2017; Markward et al., 2013; Popejoy et al., 2017; Richards et al., 2018).

The involvement of parents is further influenced by attitudes of healthcare professionals towards the decision-making process. Parental involvement can be minimal, and the decisions are done by the healthcare professionals, which is reflected in the paternalistic approach, or, on the other end of the spectrum, there is an autonomous approach which is led by the parents, or the patient (Streuli et al., 2021). In between, is the shared decision-making approach, which according to current evidence is a preferred approach among parents and healthcare professionals alike (Elwyn et al., 2012; Higgins, 2001; Jordan et al., 2020; Postier et al., 2018).

The theories of decision-making are discussed next.

1.4 Theoretical frameworks of decision-making in medical practice

In this section various theories of decision-making will be explored with the aim of presenting an overview of the theoretical frameworks used to navigate medical decision-making.

The most common theoretical frameworks within medical decision-making are based on evidence-based medicine, cognitive psychology and medical education research (McDermott, 2008; Sackett et al., 1996). Decision-making in medicine is not purely rational and cognitive but is also influenced by emotions (Kozlowski et al., 2017). This ambivalence is reflected in the dual-process theory of decision-making, which emphasises that decisions are made through two systems; one system is heuristic and intuitive, while the second is based on analytical and deliberative reasoning (Gerrard et al., 2008). The dual-process framework explains how healthcare professionals utilize both rapid thinking based on patterns recognition and emotions for routine cases and slower, deliberative reasoning for complex decision-making (Djulbegovic et al., 2012).

Evidence-based medicine provides a theoretical framework which highlights the use of available evidence in medical practice (Sackett et al., 1996). Since its introduction, the concept of evidence-based medicine has evolved to include the preferences and clinical state of the patient and the clinical expertise of the individual healthcare professionals (Haynes, 2002).

These theories can help explain how healthcare professionals make decisions by combining intuition and analytical thinking, however they are primarily focused on the healthcare professionals' perspective and limit the involvement of patients. Currently, there is a tendency to move away from paternalistic models of decision-making, where doctors decide for patients, toward shared decision-making, which aims to include patients' values and preferences alongside clinical evidence (Elwyn et al., 2012). The paternalistic approach and shared decision-making option are presented in the sections which follow.

1.4.1 Paternalistic approach to decision-making

The paternalistic approach towards decision-making emphasises the authority of healthcare professionals who make the decisions on behalf of their patients and minimises their autonomy (Charles et al., 1997; Ross et al., 2012). This approach is common in countries with paternalistic cultural and societal settings (Atout et al., 2017; El Halal et al., 2013; Kilicarslan-Toruner & Akgun-Citak, 2013). In the paediatric setting, the argument for the use of a paternalist approach highlights the medical knowledge of healthcare professionals and their superior understanding of the child's specific medical condition and interests (Birchley, 2014). An argument for the paternalistic approach - particularly when making end-of-life decisions - is that parental preferences may not be aligned with the child's best interest (Paul et al., 2017). Additionally, the paternalist approach enables parents to pass the responsibility for the medical decisions onto healthcare professionals (Clark, 2012).

1.4.2 Shared decision-making approach

Shared decision-making represents a collaborative approach between healthcare professionals, patients and - in the case of paediatric medicine - also parents (Coughlin, 2018; Stiggelbout et al., 2012). It is characterised by partnership, mutuality, equitability and equality between all involved parties, together with reciprocal respect (Jordan et al., 2020; Park & Cho, 2018).

In paediatric healthcare, shared decision-making is perceived as an appropriate approach towards decision-making as it acknowledges the role of parents and their authority as experts on the child, their social circumstances, values and preferences, as well as the medical expertise, experience and guidance of healthcare professionals (Coughlin, 2018; Fiks & Jimenez, 2010; Park & Cho, 2018). The decisions are made jointly by parents and healthcare professionals who work together as partners, and the final decision represents a compromise reached through discussion based on open and honest information sharing (Fiks & Jimenez, 2010; Park & Cho, 2018; Wellesley & Jenkins, 2009).

While shared decision-making is presented as the optimal approach towards decision-making, its implementation in practice is challenging. Healthcare professionals often have limited knowledge as to how they might proceed with shared decision-making, while parents lack effective support to be able to participate (Boland et al., 2016). The implementation of the shared decision-making approach is culturally determined, and with its origin in Western medicine, it is a less common in non-Western countries (Obeidat et al., 2013).

1.5 The socio-cultural context of the study setting - the Czech Republic

The Czech Republic is located in central Europe, covering an area of 78, 870 square kilometres (Figure 1). The population of the Czech Republic is reaching 10,9 million people with a life expectancy at birth being 76.9 years for men and 82.8 years for women.

The country went through a turbulent geopolitical time during the 20th century. Previously a part of the Czechoslovak Socialist Republic, it remained under the communist regime for more than four decades. This era came to an end in November 1989 with the Velvet Revolution, which marked the collapse of the regime. The fall of communism was followed by a separation of the two countries and the formation of the democratic state of the Czech Republic in 1993. Since then, the Czech Republic has become a part of the European Union and is a member of other international organisations.

Figure 1 Location of the Czech Republic

(Havel Václav Library, 2018)

1.5.1 Healthcare system in the Czech Republic

The current healthcare system in the Czech Republic was built after the collapse of the communist regime. Similar to other central and eastern European countries which were under the Soviet influence, the reforms moved from centrally planned socialist healthcare systems toward market oriented healthcare models (Romaniuk & Szromek, 2016). The healthcare administrations in post-communist nations underwent comprehensive transformations focused on financing mechanisms, organisational frameworks, and healthcare service delivery models (Rechel & McKee, 2009). The reforms in healthcare systems did not bring similar results for all post-communist countries; countries which started with the reforms early, such as Czech Republic and Poland, achieved better health system outcomes compared to countries with delayed reforms (Romaniuk & Szromek, 2016). However, the performance of the healthcare systems in the Czech Republic, Slovakia, Poland and Hungary, which together form the Visegrad Four Countries, does not reach the level of other European countries (Vitéz-Durgula et al., 2023). In the Czech Republic healthcare is provided through the principle of solidarity which means that access to services is equal and available to everyone regardless of their economic and social status. Funding is secured through a statutory health insurance system for which participation is mandatory and wage-based (Alexa et al., 2015). This covers around 80 % of all medical expenditure; with the remainder paid through a patient contribution (Kinkorová & Topolčan, 2012). Slovakia also has a solidarity healthcare funding, approach with mandatory healthcare insurance and some medical procedures being covered directly by the patients (Kapalla et al., 2010). In Poland, healthcare is mainly covered by health insurance and the state budget and is facing the lack of healthcare personnel and financial difficulties (Smarżewska et al., 2022).

In the Czech Republic, healthcare is provided at three levels: primary, secondary and tertiary. In paediatrics, primary care is delivered by doctors specialising in paediatrics in the outpatient setting and is available to all children from birth up to 18 years when they get transitioned into the care of general practitioners. Secondary and tertiary care settings include hospitals and highly specialised care centres, including the provision of paediatric palliative care.

1.5.2 Provision of paediatric palliative care in the Czech Republic

The Czech Republic´s trajectory in developing paediatric palliative care mirrors the experience in several of the other Central and Eastern European countries, with palliative care services for children continuing to be developed (Wager et al., 2022). As has been seen in many other European settings, the initial development of provision of paediatric palliative care emerged through paediatric services with the support of non-governmental organisations, rather than through integrated healthcare systems (Arias-Casais et al., 2020). This meant that paediatric palliative care was limited until recently, and only accessible only through the services of mobile hospices, with the focus on end-of-life care and was provided at the children’s home. As such, paediatric palliative care is provided by many hospices operating in the country, but it is not available in all regions of the Czech Republic (Pecánková & Žáčková, 2024). Access to inpatient hospice care was non-existent until mid-2024, when the first hospice for children was opened and started to provide inpatient care.

The development of paediatric palliative care in a hospital setting started in 2017 as part of a national pilot project focused on the development of in-hospital palliative care. The project enabled the establishment of the first paediatric palliative care team in the country (The Paediatric Supportive Care Team at University Hospital Motol in Prague). Originally, palliative care was provided only to children with oncological diagnoses, but subsequently the service became available to all paediatric patients with life-limiting and life-threatening conditions who were treated at the hospital, together with their families (Hrdličková et al., 2023). Nowadays, paediatric palliative care is accessible in several hospitals across the country (Hrdličková et al., 2024).

The ongoing development of paediatric palliative care is further supported by various professional bodies, non-governmental organisations, and foundations. Current activities are focused on the integration of paediatric palliative care into standard healthcare, on getting the care covered through the national insurance and on education of healthcare professionals working with children and their families.

1.5.3 Decision-making in Czech healthcare

In the Czech Republic, the paternalistic approach is embedded within the healthcare system, and participation of patients in the decision-making process is still not a part of standard practice (Daly et al., 2024; Dobiášová et al., 2021; Krizova & Simek, 2007). Patients and their families have limited involvement in decision-making and treatment decisions are primarily made by the physicians (Tietzova et al., 2024). The attitudes of patients and physicians towards their involvement in decision-making are not aligned, and the role of family relatives is underestimated by healthcare professionals (Houska et al., 2021). Nevertheless, patients and their families strive for involvement in decision-making and greater autonomy (Houska et al., 2021; Hrdlickova et al., 2023).

1.6 Study aim

Research focused on decision-making in paediatric healthcare in the Czech Republic is limited, and preferences of parents and healthcare professionals are not well understood. Therefore, this present PhD study aims to fill this gap and generate new knowledge in the field of medical decision-making for children with life-limiting and life-threatening conditions.

The research question is as follows: How are decisions about the medical care of children with life-limiting and life-threatening conditions experienced and constructed by parents and healthcare professionals?

1.7 My background as a researcher

My personal interest in paediatric palliative has been a driver for this study. Firstly, this began in the early days of my nursing career working at the cardiological intensive care unit for children where I was struck by the limited presence and involvement of the parents of the children in the unit. The term palliative care was more or less unknown at this time, and intensive medical care was provided up until the death of the child. Parents had minimal involvement in their child's care; and they were only allowed brief visits to see their child.

Twenty years later, I found myself at the very same hospital with my seriously ill and eventually dying child. My second son, Daniel, was born with a rare genetic condition which seriously affected his health. He spent most of his 26-month-long life in the hospital as he required intensive medical care and frequent hospitalisations. While staying with him in the hospital, I battled a lack of support from the healthcare professionals, and a lack of communication. I was offered limited involvement in his care, including in the decision-making process. Often, I had to stand my ground and fight for what I thought was the right choice for my son and my family. At this time, palliative care in hospitals was still non-existent, and hospices providing palliative care for children were not available. I felt very lost and alone most of the time I was taking care of my son. As his death was approaching, I felt isolated and lonely as nobody talked openly with me about what was happening and what I might expect.

After his death, I returned to university to finish my master's degree in healthcare management. I felt that I wanted to be the voice of other parents whom I met in the hospital and who went through an experience which was similar to mine. For this reason, in my master's thesis, I focused on exploring the needs of parents caring for a terminally-ill child during the illness, at the time of dying, and after the death of the child. While working on my thesis, I became passionate about research. I decided to pursue it further by getting a work position as a researcher in an organisation focused on the development of palliative care in the Czech Republic and by applying for a PhD in palliative care. Over the years, while working on my PhD and building a career as a palliative care researcher, I realised that I could improve the care provision for seriously ill children and their families through research, and I have participated in several projects focused on the development of palliative care provision in the country.

When I started to think about the research topic for my PhD thesis, I wanted to focus not only on the parents but also on the healthcare professionals. The relationship between parents and healthcare professionals was striking, given its importance during the care of the ill child and its impact on the whole experience of caring for a seriously ill child. This led to my decision to undertake a study involving both parents and healthcare professionals. Reflecting on my own lived experience with the care of my seriously ill child, I wanted to focus on the decision-making process, which I perceived as challenging or even non-existent during that time. Although my own experience and expectations could potentially influence the study, I believe it also gave me a unique insight into the studied phenomenon which I could effectively utilise while conducting the study.

Acknowledging my own lived experience and its possible influence on the study rigour was therefore important while conducting the study. The approaches undertaken to ensure study rigour are further explained in the chapter titled Methodology and Methods.

Even though doing a study so closely related to my experience was somehow challenging or even traumatic at times, I felt it was important to conduct this research. I hope its findings will improve the care provided to the children and their families who may find themselves in a similar situation as I did ten years ago.

1.8 Thesis structure

This thesis comprises five chapters.

Chapter 1: Introduction and Background; which focuses on presenting the background to the study, the need for the research, the study context, and my motivation for conducting this research.

In **Chapter 2: Literature review** the methods and findings of systematic review using a narrative synthesis approach are presented. The review focus was to explore how parents experienced their involvement in the medical decision-making for their child with life-limiting or life-threatening conditions.

The methodological framework guiding this study is presented in **Chapter 3**: **Methodology and Methods**. A qualitative multiple case study approach of Merriam (1998) set within the constructivist paradigm was used as the study design. The methods used for data collection, sampling, and recruitment, are also presented. The narrative approach to data analysis is discussed in detail.

Chapter 4: Findings present the findings of the empirical research. The chapter opens with presentation of the ten cases which are firstly introduced individually, followed by the presentation of the cross-case findings. The six categories identified in the analysis are then presented, five categories are the factors which influence decision making, and the sixth is the decision-making approaches identified. The interrelationships between these categories are depicted in a conceptual model of factors influencing medical decision-making of parents and healthcare professionals.

The conceptual model of factors influencing medical decision-making is considered within the context of global literature in the field of paediatric healthcare in **Chapter 5: Discussion.** The discussion is built around the individual components of the conceptual model, including the identified influencing factors, the relationship between the decision-makers, and the decision-making approaches. The strengths and limitations of the study are presented. The chapter concludes with recommendations for further research and implications for practice and policy.

1.9 Conclusion

In this chapter, the background to the research into decision-making for children with life-limiting and life-threatening conditions from the perspectives of parents and healthcare professionals has been outlined.

Decision-making for children with life-limiting and life-threatening conditions is a complex process requiring the integration of medical expertise, parental perspectives, and, when possible, the child's views. Shared decision-making is widely recognised as an ideal framework, fostering collaboration between families and healthcare professionals. However, decision-making practices are often shaped by traditional paternalistic approaches, with healthcare professionals playing a dominant role.
Children with life-limiting and life-threatening conditions represent a diverse group, often requiring complex medical care. Conditions can be classified into four main categories based on their trajectory and prognosis, with paediatric palliative care being essential to improving the quality of life for these children and their families.

In the Czech Republic, where this study is set, the decision-making in healthcare remains shaped by a paternalistic approach, where healthcare professionals hold the dominant role in medical decisions, and is not well understood how the decisions are reached.

The next chapter will present the findings of a systematic literature review focused on the parental experience with medical decision-making, providing a foundation for the empirical investigation that follows.

Chapter 2. Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A Systematic Review with Narrative Synthesis

This systematic review was published in the Journal of Palliative Medicine as Polakova et al. (2024); Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A systematic review with narrative synthesis. Palliative Medicine. 2024;38(1):7-24. doi:10.1177/0269216323121441, (Appendix 1).

2.1 Introduction

The aim of this systematic review was to identify and synthesise available literature exploring how parents experience their participation in the process of decision-making about treatment and future care for their children with life-limiting and life-threatening conditions. The involvement of parents in the medical decision-making process is seen as a standard practice in modern paediatric medicine (ACT, 2009; IMPaCTT, 2007). Nevertheless, the knowledge how parents experience their participation in decision-making is limited. Existing systematic reviews have tended to focus on exploring factors affecting the decision-making process and parents' perception of their role or the level of their involvement (Allen, 2014; Bennett & LeBaron, 2019; Eden & Callister, 2010; Markward et al., 2013; Popejoy et al., 2017; Zaal-Schuller, de Vos, et al., 2016), or their experience with end-of-life care (Barrett et al., 2023; Hirata & Kobayashi, 2023; Tan et al., 2021; Xafis et al., 2015).

In addition, despite evidence of similarities in the parental experience irrespective of the type of life-limiting or life-threatening condition (Wood et al., 2010), reviews into the area tend to distinguish between the conditions (Allen, 2014; Markward et al., 2013; Popejoy et al., 2017; Zaal-Schuller, de Vos, et al., 2016).

This review seeks to address the gap in knowledge by answering the review question What are the parental experiences of the decision-making process for children with life-limiting and life-threatening conditions?

2.2 Method

Given the variety of types of evidence, both qualitative and quantitative, this review has adopted a narrative synthesis (Popay et al., 2006), which permits different forms of data to be collated and similarities and differences to be identified (Dixon-Woods et al., 2005; Lucas et al., 2007).The review is framed by the PRISMA guidelines (Page et al., 2021). The review was registered at PROSPERO (registration number CRD42021215863).

2.2.1 Literature search strategy and study selection

The literature search was conducted in five databases - Medline, EMBASE, SCOPUS, CINAHL and PsycINFO in December 2020, and subsequently updated in June 2023. The search terms were developed together with a university librarian. MeSH terms were used to enhance the search strategy. Hand searching of the key journals was used in The Journal of Pediatrics, Journal of Pediatric Nursing, Journal of Hospice and Palliative

Nursing, Palliative Medicine, and MDPI Children. All included papers were checked for citation tracking. Details of the search strategy are presented in Appendix 3.

All identified papers were processed by the management tool EndNoteX9. Duplicates were removed electronically and manually. Titles and abstracts were screened independently by two reviewers against the inclusion criteria (Table 3). Studies which met the inclusion criteria were read in full text.

Table 3 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Parents/legal guardians, including bereaved parents of children 0—19 years old, diagnosed with a life-limiting condition.	Studies including parents/legal guardians of children with life-limiting conditions older than 19 years at the time of the study.
	Studies focused on parental decisions made prior to the birth of a child diagnosed with a life-limiting condition before birth.
	Studies focused on the experience of parents of prematurely born babies and parents with newborn babies <28 days old.
Reports on primary experience of parents/legal guardians involved in the decision-making process about the care of their child.	Studies that do not report on the parental experience from the parents’ perspective and accounts of parental experience obtained from other participants involved in the decision-making process (such as doctors and nurses).
Studies reporting on parental experience with decision-making about healthcare for their child.	Studies reporting on experience with phenomena other than decision-making in healthcare, including care experience, the experience of siblings, experience with providing care at home, care transition, decisions regarding fertility options for cancer patients, and organ donation.
English or Czech language.	Other languages.
Reports on primary findings of qualitative, quantitative, or mixed methods research. Published in peer-reviewed journal.	Commentaries, editorials, opinion papers, secondary data analysis, review articles, conference abstracts, and case studies including just/only one case. Any study published in non-peer-reviewed journals.
Published between 2000 and 2023.	Studies published before 2000.

2.2.2 Data synthesis

Data from the included studies were extracted using NVivo software, Excel spreadsheet and Word template. From mixed-method studies, qualitative data were extracted, including interviews and written responses to open ended questions from surveys.

The data synthesis process was guided by the four stages of narrative synthesis (Popay et al., 2006). The first stage of a narrative synthesis is focused on the development of a theoretical model which informs the process of synthesis. According to Popay (2006), this stage is not a mandatory requirement and can be omitted. For this narrative review, the shared decision-making approach was considered, but a theoretical model was not developed.

The second stage, developing a preliminary synthesis, enables findings from the included studies to be organised and searching for patterns across the studies (Popay et al., 2006). During this stage, each study was analysed separately using inductive coding. Data from the mixed-method studies were treated as qualitative data.

A textual description of parental experience for each study was developed and direct citations from parents describing their experience with decision-making together with parental experience, presented by the study authors, were extracted. This stage also included the categorisation of the studies based on the condition of the children, either as oncological diagnosis or as a life-limiting condition. Additionally, the setting of intensive care unit was recorded. This approach enabled the search for patterns in the data. An example of the data extraction is presented in Appendix 4.

The third stage of narrative synthesis is focused on exploring relationships in the data. In this review, identified inductive codes were collated together based on their similarities, and preliminary themes were developed. The coding process included merging codes together, re-coding, and developing new themes and subthemes. The codes, subthemes and themes developed through data synthesis are presented in Appendix 5. The relationship between the data was further explored by using visual maps in NVivo and the textual description of parental experience.

The last stage, assessing the robustness of the synthesis, is described in detail in the following section (2.2.3. Data evaluation).

2.2.3 Data evaluation

The quality of the included studies was evaluated using a quality assessment tool developed for critical appraisal of studies with different phenomenological backgrounds (Hawker et al., 2002). This tool was previously used to assess the quality of studies included in other systematic reviews in palliative care settings (Dakessian Sailian et al., 2021; Firn et al., 2016).

The Hawker et al. (2002) tool evaluates nine components: Abstract and Title, Introduction and Aim, Method and Data, Sampling, Ethics and Bias, Finding/Results, Transferability/Generalizability and Implication and Usefulness. Each component is marked as “good”, “fair”, “poor” or “very poor” and scored between 1 to 4 respectively. The overall minimum score is 9, the maximum is 36. To assess the overall quality of the included studies, the following grade definitions were used: good quality, 30–36 points; medium quality, 24–29 points; low quality, 9–23 points.

The quality assessment was completed by two reviewers. Final scores were appointed after comparing individual scores and through discussion of possible differences. All eligible studies had scores between 26 and 36, with a median score of 32, which was considered as being of medium or good quality.

2.3 Results

2.3.1 Search outcome and PRISMA diagram

After deduplication, 1,591 studies were screened for eligibility using titles and abstracts, and 85 papers were read in full, with 25 meeting the inclusion criteria. Three additional studies were identified through citation tracking, resulting in 28 papers being included in this systematic review (Figure 2).

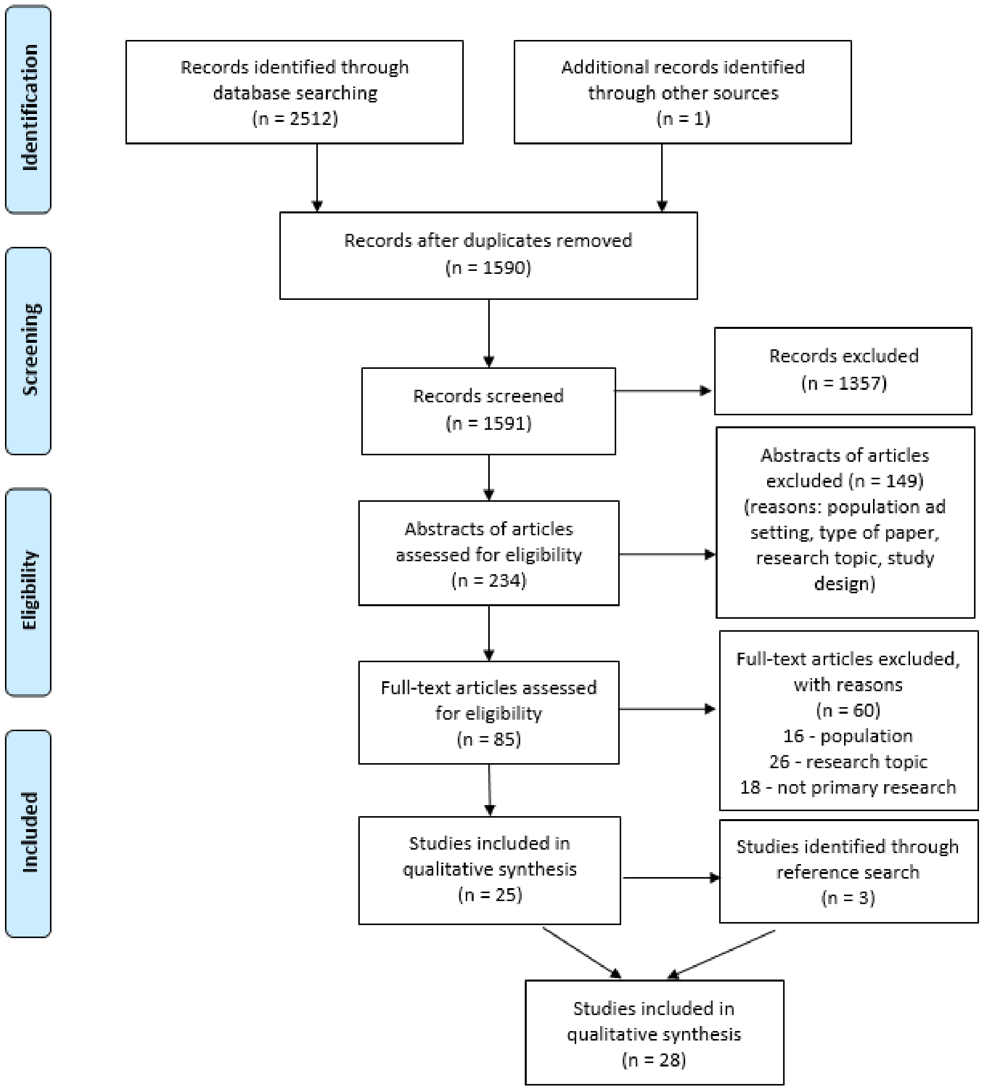


Figure 2 PRISMA flow diagram
(adapted from Moher et al., 2009)

The included papers originated from fifteen different countries and presented data from 923 parents (including 294 bereaved parents) of 757 children. The study characteristics are presented in Table 4

Table 4 Overview of the included studies

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Atout et al. (2017) Jordan	To understand the experiences of mothers of children with palliative care needs about their involvement in decision-making.	Qualitative study Participant observation and semi-structured interviews	15 mothers 12 physicians 20 nurses	Life-limiting conditions Treatment and care (not closely specified)	When making decisions, mothers relied on doctor's expertise. They were experiencing a lack of confidence to make their decisions. Mothers were worried they would feel guilty in the future if making the decision for their children.	32 (good)
Badarau et al. (2016) Switzerland Romania	To examine the perspectives of parents of children with cancer and their physicians on the experiences with decision-making.	Qualitative study Interviews	37 parents (29 mothers, 5 fathers, 3 grandmothers) 26 physicians	Oncology Starting treatment Trial treatment Fertility treatment Treatment and care (not closely specified)	Participants in both countries described decision-making similarly. Parents could only participate in less important decisions.	32 (good)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Bandinelli, Goldim (2016) Brazil	To get an understanding of the decision-making from the perspectives of parents.	Mixed-method study Semi-structured interviews and questionnaires	10 parents (9 mothers, 1 father)	Oncology Starting treatment Catheter insertion	Parents felt like they did not have a real choice. They experienced a lack of time and felt anxiety and fear. It was difficult to grasp the reality of the diagnosis and act on it.	32 (good)
Beecham et al. (2016) United Kingdom	To understand how parents approach and experience advanced care planning.	Qualitative study In-depth interviews	18 parents (9 bereaved), (16 mothers, 2 fathers)	Life-limiting conditions Place of care Place of death Limitation of treatment	Parents wanted to keep options open and to be able to change their minds. It was difficult to foresee the possible consequences of treatment limitation. Making decisions about future treatment was difficult as parents perceived it as hypothetical.	32 (good)
Bergviken, Nilsson (2019) Sweden	To explore how parents of children with cancer choose type of central access device.	Qualitative study Interviews	17 parents (11 mothers, 6 fathers)	Oncology Central access device	Parents were making decisions in a limited timeframe and in stressful situation. They were not sure which type of the device was the right one and had difficulty to foresee the future.	32 (good)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Bogetz et al. (2022) USA	To explore the parental experience with decision-making for children with severe neurological impairment.	Qualitative study Semi-structured interviews	25 parents (19 mothers, 6 fathers)	Life-limiting conditions Intensive care unit Treatment and care (not closely specified)	Parents acted as advocates for their children and felt responsible for the outcome. Parents felt they were not listened to by the medical team.	26 (medium)
Carlisle et al. (2022) USA	To get an understanding of parental preferences when deciding on surgery for solid tumours.	Qualitative study Semi-structured interviews	10 parents (gender not specified)	Oncology Aggressive treatment Tumour resection	Parents preferred to be involved in the decision-making, but some did not have enough information and were not adequately engaged. Parents acted as advocates for their children. Participation in decision-making was overwhelming and frustrating if they felt they were not included. Asking questions was difficult as parents did not know what to ask.	27 (medium)

Author, year, country	**Objective/aim of the study**	**Study design/ Data collection**	**Participants**	**Condition/ Type of decision**	**Key findings**	**Quality score**
Carnevale et al. (2007) Canada France	To examine whether physicians or parents assumed responsibility for treatment decisions and how this related to the parental experience.	Qualitative study Semi-structured interviews	31 parents (19 mothers, 12 fathers) 9 physicians 13 nurses	Life-limiting conditions Oncology Intensive care unit Life support Surgical interventions	Parents described their experience as very hard. They felt like they were abandoning their child if they agreed to stop treatment. Parents found it difficult to concentrate as they were in a state of shock.	32 (good)
Carnevale et al. (2011) Italy	To explore how life-sustaining treatment decisions were made for critically ill children and experienced by clinicians and parents.	Qualitative study Focus groups Interviews	9 parents (6 bereaved), (7 mothers, 2 fathers) 16 physicians 26 nurses	Life-limiting conditions Intensive care unit Life-sustaining treatment (not closely specified)	Parents found it difficult to make decisions, and they relied on the physician’s advice. They had difficulty processing information due to their emotional state.	26 (medium)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
De Clerq et al. (2022) Switzerland	To get an understanding of how parents experienced decision-making about initiating oncological treatment for their children.	Qualitative study Semi-structured interviews	25 bereaved parents (14 mothers, 11 fathers)	Oncology Starting cancer treatment, radiotherapy, chemotherapy	Parents felt there were no viable options. Parents knew the condition was terminal but hoped for a miracle. Parents focused on the child's quality of life. Parents felt at peace with their decisions. Some found support in faith.	30 (good)
Edwards et al. (2020) USA	To explore the parental experience of decision-making to initiate long-term ventilation.	Qualitative study Semi-structured interviews	44 parents (34 mothers, 10 fathers)	Life-limiting conditions Initiation of long-term ventilation	Parental experience was described as extremely difficult. They felt like they did not have a real choice and questioned the quality of the child's life. They could not comprehend what long-term ventilation meant for everyday life.	31 (good)
Graetz et. al. (2022) Guatemala	To explore the decision-making preferences and experiences of parents of children with cancer.	Mixed-methods study Semi-structured interviews Cross-sectional survey	118 parents (89 mothers, 29 fathers) 1 grandparent 1 sibling	Oncology Treatment and care (not closely specified)	Parents preferred the healthcare providers would make treatment decisions; they trusted their medical opinion. Most parents (64%) did not regret their decisions. Parents (24%) sought advice from religious leaders.	29 (medium)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Gurková et al. (2015) Slovakia	To analyse the experience of parents of children with failed cancer treatment.	Qualitative study Semi-structured in-depth interview	5 bereaved parents (4 mothers, 1 father)	Oncology Starting/ limitation of treatment Trial treatment Aggressive treatment Bone-marrow transplant	Parents felt forced into a decision and in conflict with the doctors. They lacked support and understanding from them and acted as advocates for their children.	29 (medium)
Huang et. al. (2022) Taiwan	To explore the lived experience of parents of children with brain tumours.	Qualitative phenomenological study In-depth interviews	10 parents (7 mothers, 3 fathers)	Oncology Treatment and care (not closely specified)	Parents needed time to adjust to the new situation to be able to participate in decision-making. Parents felt unable to participate in the discussion when English terms were used.	33 (good)
Janvier et al. (2019) USA Canada UK other	To investigate how parents of children with Trisomy 13 and 18 experienced their interactions with clinicians.	Mixed-methods study Questionnaire with open questions	332 parents (187 bereaved), (257 mothers, 74 fathers)	Life-limiting conditions Limitation of treatment Treatment and care (not closely specified)	Parents felt forced into decisions by healthcare professionals. They acted as advocates for their children. Parents valued support from healthcare professionals. Parent didn’t want to decide about their child’s death.	30 (good)

Author, year, country	**Objective/aim of the study**	**Study design/ Data collection**	**Participants**	**Condition/ Type of decision**	**Key findings**	**Quality score**
Kelly, Ganong (2011) USA	To explore how divorced parents make treatment decisions for their children with cancer.	Qualitative study In-depth interviews	15 parents (8 mothers, 7 fathers	Oncology Starting treatment Trial treatment Aggressive treatment Bone-marrow transplant	Parents prioritised the child's best interest over the relationship with the ex-spouse. Parents valued support from their new partners. Single parents lacked support from the other parent.	33 (good)
Liu et al. (2014) Taiwan	To explore the parental experience of making decisions about resuscitation for their child.	Qualitative study In-depth interviews	16 parents (including bereaved parents, 9 mothers, 7 fathers)	Life-limiting conditions Oncology Intensive care unit Attempting resuscitation Do Not Resuscitate status	The decision about resuscitation was difficult. It made parents feel responsible for the death of their child. Parents felt pressured by healthcare professionals to sign the Do Not Resuscitate form. Parents found helpful their faith in God and believed in reincarnation.	28 (medium)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Mitchell et al. (2019) United Kingdom	To provide an insight into the experiences and perceptions of parents who had made end-of-life care decisions for their children.	Qualitative study In-depth interviews	17 parents (11 mothers, 6 fathers)	Life-limiting conditions Intensive care unit Limitation of treatment End-of-life decisions Advance care planning	Parents described their experience as difficult; they experienced conflicting emotions. While some parents wanted advance care planning and to have information about the end-of-life, others did not. Maintaining hope was important.	36 (good)
Parker et al. (2021) USA	To investigate the decision-making of parents deciding about clinical trial enrolment.	Qualitative study Semi-structured interviews	20 parents (17 mothers, 3 fathers)	Oncology Enrolment in clinical trials	Deciding between standard and trial treatment was difficult and overwhelming. Parents were worried their decision would affect their child's future health, and they would feel guilty if the outcome were negative.	26 (medium)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Popejoy (2015) United Kingdom	To get an understanding of the lived experience of parents who made end-of-life care decisions for their child.	Qualitative study Semi-structured interviews	3 bereaved parents (mothers only)	Life-limiting conditions End-of-life decisions (place of care, place of death, limitation of treatment)	Parents valued cooperation with the medical team and passed the responsibility onto the physicians. The end-of-life decision was perceived as difficult or impossible as it led to the child's death. Parents acknowledged the need to have a plan and not to make decisions in the time of crisis.	33 (good)
Rapoport et al. (2013) USA	To explore parental perceptions about their experience and their child's quality of death after choosing forgoing artificial nutrition and hydration.	Qualitative study In-depth interviews	11 bereaved parents (6 mothers, 6 fathers)	Life-limiting conditions Forgoing artificial nutrition and hydration	Parents needed support from healthcare professionals and the medical team to be aligned. The decision was difficult, but parents felt at peace with it as it improved their child's quality of life. Some parents felt judged for their decision.	34 (good)

Author, year, country	**Objective/aim of the study**	**Study design/ Data collection**	**Participants**	**Condition/ Type of decision**	**Key findings**	**Quality score**
Robertson et al. (2019) Australia	To explore parents' and adolescents' views on the treatment decision-making in oncology.	Qualitative study Semi-structured interviews	25 parents (23 mothers, 2 fathers) 5 children	Oncology Clinical trial Central venous access insertion/ removal Start of treatment Fertility preservation Radiotherapy	Parents experienced information overload, which made difficult to analyse all the information and make decisions. They trusted their oncologist to make treatment decision. Parents lacked medical expertise and felt pressured to decide without having enough information. Involvement of children in minor decision was desirable.	33 (good)
Sharman et al. (2005) USA	To identify and describe factors important to parents during decision-making.	Qualitative study Semi-structured In-depth interviews	14 parents (9 mothers, 5 fathers)	Life- limiting conditions Oncology Limitation of treatment Withdrawal of life support	Parents appreciated support and expertise of healthcare professionals. Parents experienced lack of time and felt pressured into a decision. Quality of life of the child and the child's will to live was acknowledged. If possible, parents included the child in the decision-making. Parents relied on their faith.	29 (medium)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Stewart et al. (2012) USA	To describe the process of parents making treatment decisions for their children with cancer.	Qualitative study Semi-structured interviews	15 parents (9 mothers, 6 fathers)	Oncology Clinical trial Bone marrow transplant	Parents wanted to make the right decision for their children. They valued support from the healthcare professionals. Making decisions was difficult and overwhelming. Parents relied on their spirituality and faith in God.	32 (good)
Sullivan et al. (2020) Australia	To examine bereaved parents' views and experiences of decision-making for their ill child.	Qualitative study Semi-structured interviews	25 bereaved parents (gender not specified)	Life- limiting conditions Oncology End-of-life decision Limitation of treatment	Decisions were experienced as difficult. Parents were doing the best for their child, including terminating the life support or withdrawing treatment. Parents who participated in the decision-making were more likely to feel they made the right decision compared to parents who did not participate.	34 (good)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Woodgate et al. (2010) Canada	To get understanding of parents' participation in decision-making about clinical trials enrolment.	Qualitative study Interviews	31 parents (20 mothers, 11 fathers)	Oncology Enrolment in clinical trials	The decision-making was difficult and overwhelming, and the decision seemed to be impossible to make. Parents relied on the support of healthcare professionals and their relationship. Some parents felt obliged to agree with the trial to avoid upsetting their healthcare professionals. The future implications of the trial on the child's health were considered.	31 (good)
Yazdani et. al. (2022) Canada	To explore the experience of parents making decisions for their children with life-limiting condition.	Qualitative study Semi-structured interviews	6 parents (5 mothers, 1 father)	Life- limiting conditions Treatment and care (not closely specified)	Parents experienced decisional conflict; it was difficult to foresee the outcome of their decisions. They acted as advocates for their children and wanted to be involved in the process or make the decisions independently. Parents valued support from healthcare professionals.	30 (good)

Author, year, country	Objective/aim of the study	Study design/ Data collection	Participants	Condition/ Type of decision	Key findings	Quality score
Zaal-Shuller, Willems, et al. (2016) Netherlands	To compare the experiences of parents and physicians who were involved in the end-of-life decision-making process.	Qualitative study Semi-structured interviews	17 parents (including bereaved parents, 14 mothers, 3 fathers) 11 physicians	Life- limiting conditions End-of-life decision Limitation of treatment Do Not Resuscitate Artificial nutrition and hydration Invasive treatment	Parents felt they were the experts on their child's health and their opinion should be taken seriously. Parents appreciated advice and support from the healthcare professionals; some felt they lacked the medical expertise. Some decisions were made under time pressure. Parents relied on their faith.	31 (good)

2.4 Themes

Following the narrative synthesis, six themes and 21 subthemes were identified and are shown in Table 5. Each theme and its subthemes are presented in the following chapters.

Table 5 Themes

Theme	**Subthemes**
Temporal aspects affecting the experience with decision-making	*Lack of time while making the decision* *Difficulty to foresee the future*
Losing control of the situation	*Not having a real choice* *Being forced into the decision* *Difficulty grasping the reality*
Transferring the power to decide to the doctors	*Reluctance to make a decision* *Transferring the responsibility to doctors* *Relying on the doctor's expertise* *Lack of confidence and medical expertise*
To be a "good" parent and protect the child	*Child in the centre: what is best for the child* *Advocating for the child* *Trying everything possible*
The emotional state of parents	*Overall experience* *Range of emotions* *Guilt* *Feelings after*
Sources of support to alleviate the parental experience	*Behaviour of doctors* *Including parents in decision-making* *Having enough information* *Being supported by loved ones* *Faith*

2.5 Temporal aspect affecting the experience with decision-making

Time played an important role for parents, both in the lack of time to make decisions and their sense of frustration about the inability to foresee the future.

2.5.1 Lack of time while making the decision

Parental experiences during the decision-making process were affected by the timeframe of the decision (Bandinelli, 2017; Bergviken & Nilsson, 2019; Edwards et al., 2020; Liu et al., 2014; Rapoport et al., 2013; Sharman et al., 2005; Woodgate & Yanofsky, 2010; Zaal-Schuller, Willems, et al., 2016). Parents were often required to make decisions under time pressure and with urgency (Bandinelli, 2017; Bergviken & Nilsson, 2019; Liu et al., 2014; Zaal-Schuller, Willems, et al., 2016). Lack of time meant that parents felt like they did not have enough information to make an informed decision, and they would have preferred to have more time (Bandinelli, 2017; Bergviken & Nilsson, 2019; Robertson et al., 2019; Sharman et al., 2005).

The time pressure caused anxiety and fear in parents and was associated with disagreements and conflicts with healthcare professionals (Liu et al., 2014; Sharman et al., 2005; Zaal-Schuller, Willems, et al., 2016) which interlinks with the subtheme *Being forced into the decision.* In contrast, parents who were given what they saw as sufficient time to come to a decision - which varied between a few hours to a week - talked about their experience peacefully (Edwards et al., 2020; Rapoport et al., 2013; Woodgate & Yanofsky, 2010).

2.5.2 Difficulty to foresee the future

Parents made decisions which could have a long-lasting impact on their child’s quality of life, but at the same time, they struggled to comprehend the future in its complexity (Beecham et al., 2017; Bergviken & Nilsson, 2019; Bogetz et al., 2022; Edwards et al., 2020; S. Mitchell et al., 2019; Stewart et al., 2012; Woodgate & Yanofsky, 2010; Yazdani et al., 2022). Even parents of children with pre-existing life-limiting conditions found it difficult to plan for the future and to make advance care planning decisions as these situations were hypothetical for them and filled with uncertainty (Beecham et al., 2017; Bogetz et al., 2022; S. Mitchell et al., 2019; Yazdani et al., 2022).

Additionally, parents did not know how their decisions would impact their everyday lives at home (Bergviken & Nilsson, 2019; Edwards et al., 2020; Yazdani et al., 2022).

2.6 Losing control of the situation

This theme refers to the parental perception of lacking agency and control around the decision-making process.

2.6.1 Not having a real choice

Most parents felt like they did not have a real choice about the decisions made (Atout et al., 2017; Badarau et al., 2017; Bandinelli, 2017; Beecham et al., 2017; Carlisle et al., 2022; Carnevale et al., 2007; De Clercq et al., 2022; Edwards et al., 2020; Graetz et al., 2022; Robertson et al., 2019; Stewart et al., 2012; Woodgate & Yanofsky, 2010). Often this was associated with a lack of alternative choices; the other option meant they would agree with letting the child die, or the procedure was undertaken without asking them, and they were not given a choice in the matter (Atout et al., 2017; Beecham et al., 2017; Carnevale et al., 2007; De Clercq et al., 2022; Edwards et al., 2020; Graetz et al., 2022). Parents of children with cancer were expected to follow a treatment protocol (Badarau et al., 2017; Stewart et al., 2012).

2.6.2 Being forced into the decision

In some studies, parents felt that the final decision was not their own, but they were manipulated or even coerced into it by the healthcare professionals (Bergviken & Nilsson, 2019; Carnevale et al., 2007; Gurková et al., 2015) or family members (Carlisle et al., 2022). Parents felt like they did not have enough information about all available options, lacked support for a different option, or were worried about disappointing the clinician if they disagreed with the proposed treatment (Bergviken & Nilsson, 2019; Woodgate & Yanofsky, 2010).

Parents who thought they were coerced felt anger, bitterness and distress, and they described their experience as horrific and painful (Bergviken & Nilsson, 2019; Robertson et al., 2019; Sullivan et al., 2020; Woodgate & Yanofsky, 2010).

2.6.3 Difficulty grasping the reality

When making decisions, parents struggled with the reality of the situation. Often, decisions had to be made shortly after receiving new information about their child's health or during an unexpected change in the child's health (Bandinelli, 2017; Bergviken & Nilsson, 2019; Carnevale et al., 2007; Edwards et al., 2020; Robertson et al., 2019). Parents were required to make decisions while not knowing what the outcome would be and whether their treatment decision would help their child or not (Bogetz et al., 2022; Stewart et al., 2012; Woodgate & Yanofsky, 2010; Yazdani et al., 2022). This is linked with the subtheme *Difficulty to foresee the future.*

With some decisions, such as long-term ventilation and end-of-life decisions, parents found it difficult to accept the seriousness of the situation and were in denial about the possibility their child might die (Edwards et al., 2020; Liu et al., 2014; S. Mitchell et al., 2019). The challenging circumstances led some parents to unintentionally passing the responsibility for the decision-making onto the healthcare professionals (Robertson et al., 2019; Stewart et al., 2012; Woodgate & Yanofsky, 2010).

2.7 Transferring the power to decide to the doctors

While the previous theme, *Losing control of the situation,* highlighted the experience of parents not being in control of the decision-making process, this theme shows that for some parents, being in control is challenging, and they felt ill equipped or unable to make a decision.

2.7.1 Reluctance to make a decision

Some parents found it difficult to accept the responsibility for medical decisions (Atout et al., 2017; Carnevale et al., 2007; Edwards et al., 2020; Janvier et al., 2020; Popejoy, 2015; Rapoport et al., 2013; Robertson et al., 2019; Sharman et al., 2005; Stewart et al., 2012). The decision-making process was deemed impossible and offensive as parents did not know what the right decision was (Edwards et al., 2020; Sharman et al., 2005; Yazdani et al., 2022). Other parents' reluctance to be included in decision-making was because it engendered a sense of complicity in the death of their child or concerns about future burdens if the outcomes were unfavourable (Atout et al., 2017; Janvier et al., 2020).

2.7.2 Transferring the responsibility to doctors

There was evidence that some parents preferred to transfer the responsibility of decision-making onto doctors entirely, particularly with children with life-limiting conditions other than cancer (Atout et al., 2017; Carnevale et al., 2007; Graetz et al., 2022; Huang et al., 2021; Janvier et al., 2020; Popejoy, 2015; Rapoport et al., 2013; Robertson et al., 2019; Stewart et al., 2012; Yazdani et al., 2022). By passing this responsibility parents could relieve themselves of feelings of future guilt (Carnevale et al., 2007; Huang et al., 2021). Alternatively, some parents transferred responsibility because they found it difficult to verbalise their preferences or felt too much pressure to make the right decision (Popejoy, 2015; Robertson et al., 2019). Although this transfer was done willingly, there was some evidence of parental regret and questioning of the treatment decisions (Carnevale et al., 2007).

2.7.3 Relying on the doctors' expertise

Parents relied on the expertise of the healthcare professionals who they believed were doing the best for their children (Badarau et al., 2017; Carlisle et al., 2022; Graetz et al., 2022; Huang et al., 2021; Liu et al., 2014; S. Mitchell et al., 2019; Robertson et al., 2019; Sharman et al., 2005; Stewart et al., 2012). Healthcare professionals working together as a team and with consistency was seen as important by parents (Carlisle et al., 2022; Carnevale et al., 2007; Rapoport et al., 2013). There was a preference for familiar healthcare professionals to be involved in the process (Carnevale et al., 2007; Zaal-Schuller, Willems, et al., 2016). Additionally, trust was important as a mediator in relieving parental distress (Carnevale et al., 2011; Graetz et al., 2022; Robertson et al., 2019; Stewart et al., 2012).

2.7.4 Lack of confidence and medical expertise

A lack of medical knowledge made it difficult for parents to make medical decisions. They were concerned that their decision could negatively impact their child's health, and they lacked confidence (Atout et al., 2017; Beecham et al., 2017; Liu et al., 2014; Robertson et al., 2019; Stewart et al., 2012; Zaal-Schuller, Willems, et al., 2016). Emotional exhaustion further compounded the lack of confidence (Stewart et al., 2012). Parents, therefore, relied on the clinician's expertise and advice even when they were aware that the healthcare professionals might not be right (Atout et al., 2017; Beecham et al., 2017; Robertson et al., 2019).

2.8 To be a "good" parent and protect the child

During decision-making, parents needed to act as a "good" parent of their child. Being a good parent involved focusing on the child's best interests, acting as their advocate, and exploring all available medical options.

2.8.1 Child in the centre - what is best for the child

Parents made decisions based on what they believed was best for their child and in their best interest (Beecham et al., 2017; De Clercq et al., 2022; Edwards et al., 2020; Huang et al., 2021; Kelly & Ganong, 2011; Liu et al., 2014; S. Mitchell et al., 2019; Popejoy, 2015; Rapoport et al., 2013; Stewart et al., 2012; Sullivan et al., 2020; Woodgate & Yanofsky, 2010; Zaal-Schuller, Willems, et al., 2016). At times, this meant going against what parents wished for.

The process of balancing the child’s best interests and parental wishes and uncertainties made the experience difficult (Carnevale et al., 2007; Gurková et al., 2015; Lin et al., 2020; Liu et al., 2014; Popejoy, 2015; Sharman et al., 2005; Woodgate & Yanofsky, 2010). The conflict of wanting their child to live as long as possible whilst wanting to avoid additional suffering for their child was particularly challenging (Beecham et al., 2017; De Clercq et al., 2022; Huang et al., 2021; Liu et al., 2014; S. Mitchell et al., 2019; Popejoy, 2015; Rapoport et al., 2013; Sharman et al., 2005; Sullivan et al., 2020). Additionally, keeping hope for a positive outcome was important for parents even in most adverse situations (Carnevale et al., 2011; De Clercq et al., 2022; Edwards et al., 2020; Liu et al., 2014; Mitchell et al., 2019).

2.8.2 Advocating for the child

In several studies, parents took on the role of advocates (Bogetz et al., 2022; Carlisle et al., 2022; Edwards et al., 2020; Gurková et al., 2015; Janvier et al., 2020; Sharman et al., 2005; Stewart et al., 2012; Yazdani et al., 2022; Zaal-Schuller, Willems, et al., 2016). This meant being responsible for the decisions (Carnevale et al., 2007; Edwards et al., 2020; Gurková et al., 2015; Popejoy, 2015; Sullivan et al., 2020; Woodgate & Yanofsky, 2010).

Parents saw themselves as experts on their children, and they had a strong need to protect them (Bogetz et al., 2022; Gurková et al., 2015; Janvier et al., 2020; Sharman et al., 2005; Stewart et al., 2012; Zaal-Schuller, Willems, et al., 2016). Parents of nonverbal children saw themselves as the voice of their children; making decisions on their behalf (Bogetz et al., 2022; Yazdani et al., 2022; Zaal-Schuller, Willems, et al., 2016). Parents of children with developmental delays perceived that healthcare professionals did not always treat their child with dignity and respect because of the mental impairment and felt they had to fight for appropriate care and treatment (Janvier et al., 2020; Sharman et al., 2005; Zaal-Schuller, Willems, et al., 2016).

Children participated in decision-making through verbal expression of their wishes or nonverbal signs that indicated their desire to live (Liu et al., 2014; Robertson et al., 2019; Sharman et al., 2005; Stewart et al., 2012; Woodgate & Yanofsky, 2010).

2.8.3 Trying everything possible

When making decisions, parents seek to try all options of treatment available or to look for treatment elsewhere, including alternative therapies and seeking a second opinion (Atout et al., 2017; Badarau et al., 2017; Carlisle et al., 2022; De Clercq et al., 2022; Edwards et al., 2020; Graetz et al., 2022; Gurková et al., 2015; Huang et al., 2021;

Janvier et al., 2020; Liu et al., 2014; Mitchell et al., 2019; Woodgate & Yanofsky, 2010). This was particularly evident when making decisions about withdrawing treatment; parents needed to be sure no other options were remaining and be reassured that that they could change their decision depending on the child's health (Atout et al., 2017; Badarau et al., 2017; Beecham et al., 2017; Gurková et al., 2015; Janvier et al., 2020; Liu et al., 2014; S. Mitchell et al., 2019; Popejoy, 2015; Woodgate & Yanofsky, 2010).

Even when the condition was uncurable and clearly terminal, some parents wanted to try all possible options (De Clercq et al., 2022).

2.9 The emotional state of parents

Parents experienced a wide range of emotions when they were making decisions for their ill children. This theme is interlinked with all the other themes.

2.9.1 Overall experience

The overall experience was described by many parents as overwhelming, scary, heavy, horrible, painful, gut-wrenching, horrific, and emotionally exhausting (Carlisle et al., 2022; Edwards et al., 2020; S. Mitchell et al., 2019; Parker et al., 2021; Stewart et al., 2012; Sullivan et al., 2020; Yazdani et al., 2022).

Some parents experienced inner conflict and cognitive dissonance, which affected their ability to make decisions (Edwards et al., 2020; S. Mitchell et al., 2019; Stewart et al., 2012; Yazdani et al., 2022). For others, the decision-making process was a frustrating experience, especially when the decision did not lead to the expected outcome or when parents felt they were not involved in the process (Liu et al., 2014; Robertson et al., 2019).

2.9.2 Range of emotions

During the decision-making process, parents experienced a wide range of negative emotions, including anxiety, depression, sadness, fear, nervousness, a sense of helplessness, stress and anger (Bandinelli, 2017; Bergviken & Nilsson, 2019; Bogetz et al., 2022; Edwards et al., 2020; Huang et al., 2021; S. Mitchell et al., 2019; Robertson et al., 2019; Stewart et al., 2012; Yazdani et al., 2022). Anger and frustration were associated with the feeling of not being listened to or being manipulated into a decision (Bergviken & Nilsson, 2019; Bogetz et al., 2022). Parents experienced exhaustion and information overload which precluded decision-making as they felt unable to focus (Carlisle et al., 2022; S. Mitchell et al., 2019; Stewart et al., 2012).

2.9.3 Guilt

Making medical decisions was connected with the feeling of guilt (Atout et al., 2017; Carnevale et al., 2007; Gurková et al., 2015; Liu et al., 2014; Parker et al., 2021; Popejoy, 2015; Rapoport et al., 2013; Sharman et al., 2005; Woodgate & Yanofsky, 2010; Yazdani et al., 2022). The reasons for guilt included not being active enough in the decision-making process; letting the doctors decide the outcome; making decisions which could cause the death of their child; giving up on the child; and undermining their child's will to live (Atout et al., 2017; Carnevale et al., 2007; Kelly &

Ganong, 2011; Liu et al., 2014; Popejoy, 2015; Rapoport et al., 2013; Sharman et al., 2005).

Additionally, parents were anxious that their current decisions would make them feel guilty in the future (Atout et al., 2017; Parker et al., 2021; Yazdani et al., 2022).

2.9.4 Feelings after

After the decision-making process, parents experienced feelings of disappointment, helplessness, or relief (Gurková et al., 2015; Liu et al., 2014; Robertson et al., 2019; Sharman et al., 2005). Some parents experienced regret and had difficulties in accepting their decision (Carnevale et al., 2007; Gurková et al., 2015; Liu et al., 2014; Robertson et al., 2019; Sharman et al., 2005; Sullivan et al., 2020; Woodgate & Yanofsky, 2010).

Having doubts about their decision was enhanced by feelings of uncertainty about the child's condition and the selected treatment approach (Carlisle et al., 2022; Rapoport et al., 2013; Stewart et al., 2012). Nevertheless, some parents were at peace with their decision (De Clercq et al., 2022; Graetz et al., 2022).

2.10 Sources of support to alleviate the parental experience

Parental experience with decision-making was positively influenced by having access to support, which they sought from a variety of sources.

2.10.1 Behaviour of doctors

Parents appreciated supportive behaviour from clinicians, which included giving hope, respecting parents' choices, being personal, and being non-judgmental (Carlisle et al., 2022; Huang et al., 2021; Janvier et al., 2020; S. Mitchell et al., 2019; Parker et al., 2021; Rapoport et al., 2013; Stewart et al., 2012; Woodgate & Yanofsky, 2010; Yazdani et al., 2022).

Doctors who were empathic, compassionate, respectful, honest, truthful, and upfront, who spent time explaining the situation and gave parents time to ask questions, and those who offered options to choose from were much appreciated (Carlisle et al., 2022; Janvier et al., 2020; Liu et al., 2014; Parker et al., 2021; Robertson et al., 2019; Sharman et al., 2005; Stewart et al., 2012).

In contrast, parents who felt they did not have enough support from healthcare professionals experienced stress and felt like they had to defend their decisions (Bergviken & Nilsson, 2019; Edwards et al., 2020; Janvier et al., 2020).

2.10.2 Including parents in decision-making

Parents valued being part of the decision-making process, particularly being acknowledged and listened to by physicians and enabled to make decisions together with them (Badarau et al., 2017; Bogetz et al., 2022; Carlisle et al., 2022; Edwards et al., 2020; Janvier et al., 2020; S. Mitchell et al., 2019; Robertson et al., 2019; Sharman et al., 2005; Stewart et al., 2012; Yazdani et al., 2022; Zaal-Schuller, Willems, et al., 2016).

The experience of decision-making was less stressful if parents were engaged and supported in the process, given professional guidance and treated with respect (Carlisle et al., 2022; Janvier et al., 2020; S. Mitchell et al., 2019; Robertson et al., 2019; Sharman et al., 2005; Yazdani et al., 2022; Zaal-Schuller, Willems, et al., 2016).

2.10.3 Having enough information

Having sufficient information was emphasised as an important aspect of active participation in the decision-making process (Carlisle et al., 2022; Carnevale et al., 2011; Edwards et al., 2020; Huang et al., 2021; S. Mitchell et al., 2019; Parker et al., 2021; Robertson et al., 2019; Sharman et al., 2005; Yazdani et al., 2022).

Having information enabled parents to know about the options available and to trust their feelings and instincts during the process (Carnevale et al., 2007; Edwards et al., 2020; Janvier et al., 2020; Yazdani et al., 2022). Lack of information, as well as having too much information, had a negative impact on parental ability to participate (Edwards et al., 2020; Parker et al., 2021; Robertson et al., 2019; Sharman et al., 2005). Parents used other sources of information, including other parents and the internet (Carlisle et al., 2022; S. Mitchell et al., 2019; Parker et al., 2021; Sharman et al., 2005; Yazdani et al., 2022).

2.10.4 Being supported by loved ones

When making decisions, parents valued the support of their spouse, wider family and friends (Carlisle et al., 2022; Edwards et al., 2020; Graetz et al., 2022; Kelly & Ganong, 2011; Parker et al., 2021; Popejoy, 2015; Rapoport et al., 2013; Sharman et al., 2005; Stewart et al., 2012; Yazdani et al., 2022).

Support between spouses was experienced as crucial; single or divorced parents described the decision-making as hard and were full of doubt given they had no spouse to discuss their decision with (Kelly & Ganong, 2011; Rapoport et al., 2013; Sharman et al., 2005).

2.10.5 Faith

Religiosity and faith had an impact on the experience with decision-making (Carlisle et al., 2022; De Clercq et al., 2022; Edwards et al., 2020; Graetz et al., 2022; Janvier et al., 2020; Liu et al., 2014; Sharman et al., 2005; Stewart et al., 2012; Zaal-Schuller, Willems, et al., 2016).

Religious parents trusted in God’s guidance to make the right decision, or they put the responsibility in God’s hands (Edwards et al., 2020; Janvier et al., 2020; Liu et al., 2014; Sharman et al., 2005; Stewart et al., 2012). Praying and believing in God gave parents the strength to deal with their situation and a sense of comfort and peace (Edwards et al., 2020; Sharman et al., 2005; Stewart et al., 2012). Some parents believed they would meet their child in the afterlife (De Clercq et al., 2022).

2.11 Discussion

The purpose of this systematic review was to explore how parents experience the process of decision-making about medical care for their children with life-limiting and life-threatening conditions. The review identified that participation in decision-making is emotionally challenging. The wide range of negative emotions experienced by parents compounds the experience by affecting their ability to make decisions and to be in control of the process. Perhaps unsurprisingly, there were no positive emotions experienced by parents, reflecting the lack of positive emotions described in a wider body of literature in this field (Jackson et al., 2008; Lipstein et al., 2012).

This review extends the knowledge of decision-making in the medical environment by providing evidence that decision-making is experienced similarly by parents, irrespective of the child’s diagnosis. This supports the findings of previous research on decision-making undertaken in a general paediatrics setting (Bennett & LeBaron, 2019; Boland et al., 2019; Jackson et al., 2008; Lipstein et al., 2012).

Guilt, including anticipatory guilt, was identified as an emotion frequently experienced by parents while making decisions. This is a new perspective on guilt, which is more frequently connected with loss and bereavement (Li et al., 2014; Miles & Demi, 1992) or with the sense of responsibility for the child’s condition and suffering (Steele & Davies, 1998; Tan et al., 2021). Guilt in connection to decision-making has been identified in research into parents of preterm infants or children with disabilities (Eden & Callister, 2010; Zaal-Schuller et al., 2016). Anticipatory guilt is more commonly found in situations when parents imagined their life after the death of the child (Steele & Davies, 1998).

This review shows that parents are required to make decisions in challenging circumstances. This impacts on their ability to make decisions and can lead to a reliance on doctors to make decisions instead. Experiencing pressure and coercion from healthcare professionals during decision-making was connected with negative emotions. The use of persuasive strategies by healthcare professionals was identified in a recent study by Popejoy et al. (2022). The present review extends this knowledge by adding evidence that persuasive strategies can have a negative impact on the emotional state of the parents.

The review findings indicate that parents need to have enough time to process information provided by the healthcare professionals. Lack of time is stressful for parents and can cause conflicts. This is a consistent finding in this field; time has been identified as the main environmental barrier to shared decision-making and to directly affect ability of parents to participate in the decision-making and their perception of being pushed into the decision (Boland et al., 2019; Jackson et al., 2008; Lin et al., 2020; Xafis et al., 2015).

This review identified that parents need to keep their parental role, be a "good parent", and advocate for their child during the decision-making. Being a "good parent" is a known concept connected to parental desire to be a good parent to their ill child which is subsequently influencing their perspective on what is best for their child and their decision-making (Weaver et al., 2020). This attitude thus puts parents in a difficult position as they try to balance their wishes and uncertainties with the need to be a "good parent" when making decisions for their child.

Parents used their subjective perception of their child's will to live to guide their decisions. This was described in a previous study, where the child's will to survive affected parental decision-making (Zaal-Schuller, de Vos, et al., 2016).

The parental experience with decision-making was further affected by a lack of confidence caused by limited medical knowledge, emotional exhaustion, and insecurities. While this finding is consistent with previous studies (Boland et al., 2019; Lipstein et al., 2012; Xafis et al., 2015), this review shows that this lack of confidence may cause parents to follow the decisions made by healthcare professionals even when they do not necessarily agree with them.

Participation in decision-making is stressful for parents, but this review has found that it is possible to mitigate their negative experiences. The support provided by a spouse, family, or friends can positively impact the experience with decision-making, and is consistent with previous research (Tan et al., 2021). Single parents experienced additional challenges as they did not have support from the other parent and were required to make decisions independently.

Faith in God and praying represented supportive strategies, consistent with other research which has identified the importance of faith in decision-making (Hexem et al., 2011; Lipstein et al., 2012; Tan et al., 2021; Xafis et al., 2015). In this review, trust in God's guidance and belief in the afterlife helped parents find comfort, hope, and peace. Unlike other research which identified churches and religious communities as sources of support, these were not identified within this review (Hexem et al., 2011).

In this review the attitude of healthcare professionals was found to affect the whole experience of decision-making. Actively inviting parents to participate in the decision-making, respecting their role as parents and giving them enough information while keeping their hope made the experience less traumatic.

Available research shows that active participation can be difficult for parents, and they need to be invited by healthcare professionals to contribute, as the power distribution in the medical setting is not well balanced (Boland et al., 2019; Joseph-Williams et al., 2014; Richards et al., 2018). This review has identified that active participation in the decision-making process is further affected by access to information, a finding which aligns with other research (Boland et al., 2019; Hoang et al., 2020; Pyke-Grimm et al., 2006; Sullivan et al., 2014). Parents also valued honest communication and being listened to, as highlighted in previous research (Hirata & Kobayashi, 2023; Pyke-Grimm et al., 2006; Tan et al., 2021).

2.12 Strengths and limitations

This review has several limitations. The inclusion criteria were not limited to a specific diagnosis; therefore, a larger number of studies were included in the review, thus possibly affecting the robustness of the synthesis. The data extraction and analysis were conducted by one reviewer, which could lead to a personal bias in the data interpretation.

Although the studies were assessed for quality, the used tool has its limitations. The Hawker's tool provides an aggregated score for nine components without distinguishing how each component is affecting the quality of the given study. The use of structured approaches for assessing qualitative evidence can lead to bias and inconsistency in the judgment of the reviewers (Dixon-Woods et al., 2007).

The participants in the included studies were predominantly mothers. Whilst the fathers' experiences were included, there is a paucity of research about the paternal experience.

Included studies were retrospective in nature, and some included bereaved parents, which could have affected parents' recollections of their experience. Additionally, only studies which were written in English and Czech were eligible for the review.

Notwithstanding the limitations listed above, this review has several strengths. To our knowledge, this is the first review focused solely on parental experiences of decision-making for their children with life-limiting and life-threatening conditions. This review provides a robust synthesis of available evidence of the studied phenomenon. Wider inclusion criteria made it possible to include studies focused on different types of diagnoses of the children and various types of decisions. This approach made it possible to get an understanding of the experience from a wider perspective.

Although the data extraction and analysis were done by one reviewer, the whole process was overseen by the supervisors and the quality assessment was done by two reviewers.

2.13 Conclusion

This review highlights that parental experiences with decision-making are complex and multifactorial. Parents' ability to effectively participate in the process is limited, as they are not empowered to do so, the circumstances in which the decision-making takes place are challenging, and their participation is dependent on the healthcare professional. Given the review findings about these limitations to even participating in decision-making the focus of empirical study shifted from exploring shared decision-making to exploring the decision-making process more broadly. This adjustment allowed the study of medical decision-making without the assumption that it is necessarily shared. It also enabled an exploration of how medical decisions are made within the cultural context of the study setting. This refinement of the theoretical underpinnings and the research question are congruent with the selected case study approach (Merriam, 1998) adopted for the empirical research. The theoretical considerations are discussed along with working methods in the next chapter.

Chapter 3. Methodology and methods

3.1 Introduction

In the previous chapters, the background of this study was presented, followed by the methods and findings of the systematic review, which is focused on the parental experience with decision-making. This chapter will first describe the philosophical underpinnings which guided the study, and the study design used to respond to the research question. Second, the methods used in the empirical part of this research are presented in detail, with attention given to both the ethical considerations and the measures utilised to ensure an ethically sound study. The chapter concludes with a discussion of approaches undertaken to maintain study rigour throughout the research endeavour.

3.2 Research question and study aim

The aim of this study is to explore medical decision-making from the perspectives of parents of children with life-limiting and life-threatening conditions and healthcare professionals. By focusing on the perspectives of both parents and healthcare professionals, the aim is to get a better understanding of the whole process and how the decisions are experienced and constructed by both participating parties.

Research question: How are decisions about the medical care of children with life-limiting and life-threatening conditions experienced and constructed by parents and healthcare professionals?

3.3 Research paradigm

A research paradigm is a framework that philosophically underpins the choices made when conceptualising and conducting research (Bunniss & Kelly, 2010; Weaver & Olson, 2006). Selecting a research paradigm includes critically examining its key concepts, ontology, and epistemology (Denzin & Lincoln, 2000; Guba & Lincoln, 1994). The choices made within this PhD study are now presented and discussed.

Ontology relates to the nature of reality and what we can know about it (Guba & Lincoln, 1994). This study adopts a relativist ontology, which assumes that the studied reality is multiple, subjective and socially constructed (Guba & Lincoln, 1994; Kivunja & Kuyini, 2017). Applying a relativist ontology lens to research focused on the decision-making process enables an in-depth exploration of individual experiences and of the subjective realities of different participants (Broom & Willis, 2007). This PhD study explores the phenomenon of medical decision-making from two distinct perspectives of parents and healthcare professionals who may construct their experiences and realities differently. Within the relativist ontology, realities are constructed by the individual interacting with the outside world (Scotland, 2012) and are diversly interpreted depending on the experiences of the involved participants (Bunniss & Kelly, 2010).

Epistemology is the second key concept of the research paradigm and refers to the relationship between the researcher and the studied subject; identifying the nature of knowledge and how it is acquired (Guba & Lincoln, 1994; Phoenix et al., 2013). The epistemological stance applied to this research is constructivism. A constructivist epistemology enables the exploration of individual interpretations of the studied experience and how the meaning of the studied phenomenon is constructed by the participants (Merriam & Tisdell, 2016). This exploration uses the emic perspectives of the participants, in the case of this research, the perspectives of the parents and healthcare professionals (Tavakol & Zeinaloo, 2004). The meaning of knowledge is developed socially and is influenced by the individual's surroundings and interactions with others (Phoenix et al., 2013). This is relevant for the decision-making research, as medical decision-making is affected by the social and cultural context (Santoro & Bennett, 2018).

This PhD study adopts a constructivist paradigm, which is aligned with the study's aim and my philosophical position. Research conducted within the constructivist paradigm emphasises the studied individuals and their interpretation of the external world while focusing on how social reality shapes their experiences (Crossan, 2003; Kivunja & Kuyini, 2017; Phoenix et al., 2013). The decision-making process is influenced by the interactions between patients and healthcare professionals, and using the constructivist stance to explore this phenomenon will enable a deeper understanding of the individual perspectives (Wilson, 2000). It further allows exploration of the studied phenomenon from the perspective of two distinct types of participants whose realities are different, whilst recognising the influence of cognitive, contextual and cultural factors, which are likely to be influential in decision-making (Pope & Mays, 1995; Tetley et al., 2009; Weber & Morris, 2010).

The choices of a relativist ontology, a constructivist epistemology and a constructivist paradigm guided the decisions about an appropriate research design and methods for data collection and analysis, which are discussed below.

3.4 Research design

Within the constructivist paradigm, several contender research designs were explored: grounded theory, phenomenology, and case study research. A constructivist grounded theory design was considered as it is congruent with the relativist ontology (Burns et al., 2022; Charmaz, 2017). The main focus of grounded theory is to develop theory of the studied phenomenon rooted in the data collected from the study participants (Renjith et al., 2021). The 'blank slate' aspiration within grounded theory, though arguably conceptual, did not align well with my own lived experiences in paediatric palliative care. Moreover, while grounded theory is a powerful inductive method of developing codes and eventually a theory, the focus is generally associated with a single broad perspective or populations. From this the researcher may seek later to explore the developing theory with other groups (Chapman et al., 2015). This study seeks to understand decision-making from two perspectives, which would be difficult to achieve through grounded theory research (Elliott & Lazenbatt, 2005).

Phenomenology is focused on exploring the lived experience of the participating individuals in-depth (Burns et al., 2022). The meaning of the studied experience is explored from the perspective of the study participants who have experienced the studied phenomenon similarly (Renjith et al., 2021). A phenomenological research design seeks homogeneity in the sample, which is not congruent with the anticipated sample of this study, which combines two distinct types of participants (Creswell, 2007). Furthermore, the focus of the study is on how the decisions are constructed by the participants, rather than in-depth exploration of their experience of the decision-making process.

The third research design considered for this PhD study was a case study approach. Case study research enables the exploration of the studied phenomenon in depth from different perspectives; in this study, understanding how decisions are constructed by parents and healthcare professional (Miller & Brewer, 2015). As case study research yields an understanding of the structures and process affecting the studied phenomenon, it aligns with the recognition in this research that decision making is located within a context which also needs to be taken into account (Brogan et al., 2019). As such a qualitative case study design (located in constructivism) was selected, and is discussed below, along with an overview of the development and strands of case study design.

3.4.1 Case study design

Viewed as an approach or research strategy rather than a methodology (Tight, 2010; Verschuren, 2003; Walshe et al., 2004), case study design is particularly suitable for exploring complex issues in-depth as it enables the creation of a holistic picture of the studied phenomenon and yields a better understanding of events happening in their real-life context (Brogan et al., 2019; Cope, 2015; Crowe et al., 2011; Miller & Brewer, 2015). Case study approaches enable the exploration of a studied phenomenon from different perspectives (Miller & Brewer, 2015); build understanding of the structures and process which affect the studied phenomenon (Brogan et al., 2019); and permit insights into characteristics of larger groups (Gerring, 2004).

The exploration of case study design as a research strategy has been undertaken by three primary methodologists: Yin, Stake and Merriam (Brown, 2008). Although each adopted a different philosophical stance and approach towards case study research, they align and enhance each other (Yazan, 2015). All three approaches towards case study research were carefully considered for this PhD study.

Robert K. Yin, does not specify his epistemological position, but his work suggests that he inclines towards the positivist paradigm (Brown, 2008; Yazan, 2015). The approach of Yin is based on pre-defined theoretical propositions that serve as hypotheses and guide data collection and analysis (R. K. Yin, 2018). While acknowledging the strengths of Yin's case study design, the positivist paradigm is not aligned with the constructivist paradigm guiding this PhD study. Therefore, Yin's approach was not perceived as congruent.

The second approach explored was that of Robert E. Stake, who positioned himself within the constructivist paradigm and highlighted the role of the researcher, who is the interpreter of the studied reality (Stake, 1995). The researcher has a key role when generating knowledge and interpreting the meaning of data while actively interacting with the study participants (Harrison et al., 2017; Yazan, 2015). Close interaction and development of the relationship between researcher and the studied phenomenon is central to Stake's position and would be difficult to achieve while conducting this study (Boblin et al., 2013).

The third approach considered for this study was the qualitative case study of Sharan B. Merriam set within the constructivist paradigm (Brown, 2008; Merriam, 1998). The qualitative case study approach assumes that reality is constructed intersubjectively through meanings, while understanding is developed socially and experientially (Merriam & Tisdell, 2016).

3.4.2 Qualitative case study approach

The qualitative case study presented by Sharan B. Merriam was selected as the most congruent with the study's aim and my philosophical position. Studies using a qualitative case study design strive to get an understanding of the individual experiences and their meaning (Brown, 2008; Yazan, 2015).

Merriam (1998) identified three key characteristics of qualitative case study research - particularistic, descriptive, and heuristic - all of which align with research into medical decision-making. The particularistic aspect enables the study to be focused on particular events, such as the situations where decisions were made. The descriptive characteristic of case study reflects the focus on providing a rich description of the studied phenomenon. This includes the personal perspectives of the participants and any factors which affect the explored events. The heuristic attribute enables a deeper understanding of the studied phenomenon by explaining the background of the events, what happened and why (Merriam, 1998).

Qualitative case study research is defined by the object of study, the case, which represents an example of the studied phenomenon occurring in a bounded context (Merriam & Tisdell, 2016; Milles et al., 2014). The case is characterised by well-defined boundaries and is selected based on the research aim and question, and what it could reveal about the phenomenon of interest (Crowe et al., 2011). Seeing the case as a single entity helps to explore the phenomenon in depth and to uncover new characteristics (Merriam, 1998; Yazan, 2015). Merriam's understanding of the case is the following: *"the case is a thing, a single entity, a unit around which there are boundaries"* (Merriam, 1998, p. 27).

Qualitative case study can include a single case or multiple cases. A multiple case study consists of several cases which enables comparison across the cases and exploration of multiple realities (Merriam & Tisdell, 2016). Exploration of the decision-making phenomenon from perspectives of different participants was aligned with the multiple case study approach and was therefore utilised in this study.

Merriam (1998) recommends starting the research endeavour with a literature review and the development of a theoretical framework which will guide the research process and frame the study. The theoretical framework is based on the researcher's perspectives and existing theories and helps to select appropriate methods for data collection and analysis (Ebneyamini & Sadeghi Moghadam, 2018). The systematic review which shaped the research question in this PhD study was presented in the previous chapter and the research methods are presented in following sections.

In a qualitative case study, data can be collected using both qualitative and quantitative methods, including interviews, observations and document analysis (Harrison et al., 2017). Sampling is done on two levels; the case under study is first selected followed by within-case sampling of the study participants (Merriam, 1998). Sampling is undertaken using purposive strategies with the aim of selecting appropriate cases which will provide rich information about the studied phenomenon.

Data analysis takes place simultaneously with data collection (Merriam & Tisdell, 2016). Analysis is a complex process involving data consolidation, reduction, and interpretation with the aim to make sense of the collected data (Merriam, 1998). Emphasis is on the overall process of analysis and data management rather than adopting a specific analytical approach (Harrison et al., 2017; Merriam, 1998). In multiple case studies data analysis is conducted in two stages; first within-case analysis and second cross-case analysis (Merriam, 1998). The analytic approach comprises coding patterns and insights in the data (individually within each case and then across cases) which are subsequently merged into categories. These evolve during the analytical process and can be presented in the form of a model to depict the interrelationship between the categories (Merriam & Tisdell, 2016). For this study a narrative analysis approach was adopted as it aligns with the qualitative case study design and constructivist paradigm.

3.4.3 Narrative analysis

A narrative analysis uses personal stories to gain an understanding of human experience within the cultural and social context of the story-teller (Polkinghorne, 1995). It is suitable for studies of challenging life situations, including exploration of experiences with chronic illnesses and hospitalisation, and as such is congruent with research focused on exploring personal experience with decision-making in healthcare settings (Bailey & Tilley, 2002; Olofsson & Norberg, 2001; Riessman, 1990, 2000). Narrative analysis is also suitable for exploring perspectives of different types of participants, represented in this PhD study by parents and healthcare professionals (Olofsson & Norberg, 2001).

The strategy used in this study draws on the structural approach to narratives of personal experience developed by Labov and Waletzky (Labov, 1972; Labov & Waletzky, 1967), which is useful for comparison of narratives across multiple cases (Riessman & Quinney, 2005). Labov's analytical model is based on the identification of clauses, each clause having a specific function within the narrative of personal experience. The complete narrative of personal experience consists of six elements: the abstract, orientation, complicated action, evaluation, resolution, and coda (Table 6) (Labov, 1972).

Labov's structural approach is focused on events described by the narrator (Andrews et al., 2013; Emden, 1998). As argued by others, this approach can lead to the dismissal of partial stories that do not have all six elements of a complete narrative, and meanings can be lost by taking the narrative out of its context and analysing selected clauses without reflecting the whole narrative (Andrews et al., 2013; Polanyi, 1981; Riessman, 2005).

Table 6 Six elements of complete narrative of personal experience
(adapted from Labov, 1972; Wiles et al., 2005)

Element	Description
Abstract	Framing of the story, what the story is about. Abstract summarises and frames the story and draws the attention of the listener.
Orientation	Background information about the narrative - the setting, time, and characters. Explains when, who, what and where. Orientation consists of free clauses which help the listener to orient himself within the person, place, time and situation of the story. Orientation may not be present in every narrative.
Complicated Action	Turning point of the story and presentation of specific events such as crisis or problem or series of these: “then what happens”. It is the main body of the narrative and consists of a series of events describing what happened in the narrative.
Evaluation	Comments and interpretation of the story by the narrator. It is the main point or “soul” of the narrative. Evaluation is usually placed between elements of complicated action and resolution.
Resolution	The result or outcome of the plot. Resolution can be presented as a standalone element, or it can be part of the evaluation and indicate the ending of the story.
Coda	The end of the narrative. The coda returns the audience back to the presence. The coda closes the story and may not be present in each narrative.

A combination of different strategies for narrative analysis was proven to be an effective strategy to address those limitations (Bailey & Tilley, 2002; Emden, 1998; Riessman, 1993; Wiles et al., 2005).

The structural approach by Labov and Waletzky used for the analysis within this study was therefore enforced by identification of partial stories and by applying rhetorical aspects of the narratives to the transcripts to ensure that the active elements of speech are not lost. The analytical approach is described in detail in Chapter 3.5, Research methods.

3.4.4 Reflexivity

In a qualitative study, the interpretation of the studied reality can be influenced by the researcher; therefore, to ensure the study's rigour, it is necessary to address one's subjectivity and assumptions (Bradbury-Jones, 2007; Milles et al., 2014; Peshkin, 1988). This is possible by using reflexivity, an approach used to identify factors which can influence data interpretation, such as previous experiences, cultural background, values, personal preconceptions and expectations (Bryman, 2016; Creswell & Creswell, 2014; Fischer, 2009; Flick, 2014).

Reflexivity helps to achieve integrity in qualitative case study research (Merriam & Tisdell, 2016). Addressing this issue was seen as paramount in this study due to my background, which was explained earlier in the thesis. To limit the impact of my lived experience on the study, I used several precautions during the whole process. I informed my supervisors about my experience so they could identify any possible personal influence during data collection, analysis, and interpretation. During the data collection, I kept a reflexive journal where I noted my feelings and assumptions after each interview. To limit any bias during data collection, participants were unaware of my experience. During data analysis, I used the reflexive diary as it was important to keep personal experience and my conclusions aside.

It is possible that even when applying various ways in how to address reflexivity, I was not fully objective and my experience indeed affected the findings of the study (Lynch, 2000). Nevertheless, it should be noted that subjectivity does not have to be seen only as a disadvantage but can enhance the understanding and sensitivity towards the studied phenomenon (Jootun et al., 2009).

3.5 Research methods

This section outlines how the qualitative case study research design was applied to this particular study with the aim of exploring decision-making about medical care for children with life-limiting and life-threatening conditions, and how these are experienced and constructed by parents and healthcare professionals.

This study was conducted in a single setting, a university paediatric hospital in the Czech Republic, which provides a tertiary level of medical care for children. The hospital has a well-established paediatric palliative care team.

3.5.1 Participant selection

The process of sampling in case study research has two levels. The first level is selecting the studied cases, and the second level is identifying the study sample within the case (Merriam & Tisdell, 2016). The selection of the cases is outlined below and is followed by a description of the recruitment of study participants.

3.5.1.1 Identification of a case

The identification of a case follows the approach of Merriam (1998), who defines each case as a single entity with boundaries, as discussed in the previous section (3.4.2). The choice of the case boundaries was driven by the study aim and the research question. The case was defined by a child with the diagnosis of a life-limiting or life-threatening condition (see Chapter 1.2 for an overview of the conditions). The case consisted of the child's parents and healthcare professionals involved in the child's care. In line with a constructivist case study, the identification of each case was made at the start of the case study research and before the sampling process began (Merriam & Tisdell, 2016). This study consists of multiple cases.

3.5.1.2 Sampling of the cases

Sampling of cases started with the selection of the eligible children. This step was conducted with the help of the collaborating doctor from the paediatric palliative care team, who had access to the children's medical records and knew their medical history. Selected children were screened against the inclusion and exclusion criteria

(Table 7). A purposive approach was adopted to achieve variation regarding the medical diagnoses of the children based on the four categories of life-limiting and life-threatening conditions.

Table 7 Inclusion and exclusion criteria for the children

Inclusion criteria
Living child.
Age range: 0-18 years.
The child was diagnosed with a life-limiting or life-threatening condition.
The child was under the care of the paediatric palliative care team within the last 12 months.
Decisions about medical care were made within 12 months before case selection.
Decision/s about medical care on behalf of the child were done in any of the following areas: - Significant treatment decisions (discontinuation of treatment, postponement of treatment, change in the type of treatment, invasive interventions beyond the standard treatment procedure, etc.). - Decisions leading to the limitation of care (do-not-resuscitate/intubate, limitation of antibiotic treatment, limitation of nutrition). - Decisions related to invasive procedures that may pose a significant risk to the child during the procedure and/or reduce the quality of life (e.g. surgery, tracheostomy, tube feeding). - Decisions related to end-of-life care (limitation of care, preferences for end-of-life care, hospice care, place of death).
Exclusion criteria
Deceased child or death of the child prior to an interview with the parents.
Decisions about medical care were made more than 12 months before the data colection.

3.5.1.3 Within-case sampling of study participants

After the identification and sampling of the eligible children, the second level of sampling was conducted. Each case consisted of two types of participants: parents and healthcare professionals, who were invited to participate in the study based on the following set of inclusion and exclusion criteria (Table 8).

Table 8 Inclusion and exclusion criteria for parents and healthcare professionals

Inclusion criteria	Exclusion criteria
Parents	
Biological parents or legal guardians of the eligible child.	Bereaved parents.
Able to speak in Czech.	
Adults aged 18 years and above.	
Healthcare professionals	
Healthcare professionals of various specialisations (doctors, nurses, social workers, psychologists) involved in the decision-making process regarding the care of the eligible child.	
Identified by parents or the collaborating doctor as a healthcare professional involved in the medical care and in the decision-making process.	

3.5.2 Recruitment

The recruitment of the study participants, parents and healthcare professionals followed a strategy depicted in Figure 3. Detailed description of the recruitment process for each type of participants is provided in the next two sections.

The recruitment of participants was a lengthy process, spanning from July 2021 to March 2023. It was impacted by the COVID-19 pandemic and other factors.

Parents were often difficult to reach, with long pauses between each contact, and multiple attempts were sometimes necessary to arrange an interview. This was caused by the demanding care required by their children and the unpredictable changes in the children's health.

Similarly, recruiting healthcare professionals proved challenging due to their heavy workloads, irregular schedules, and, in some cases, difficulties in reaching them.

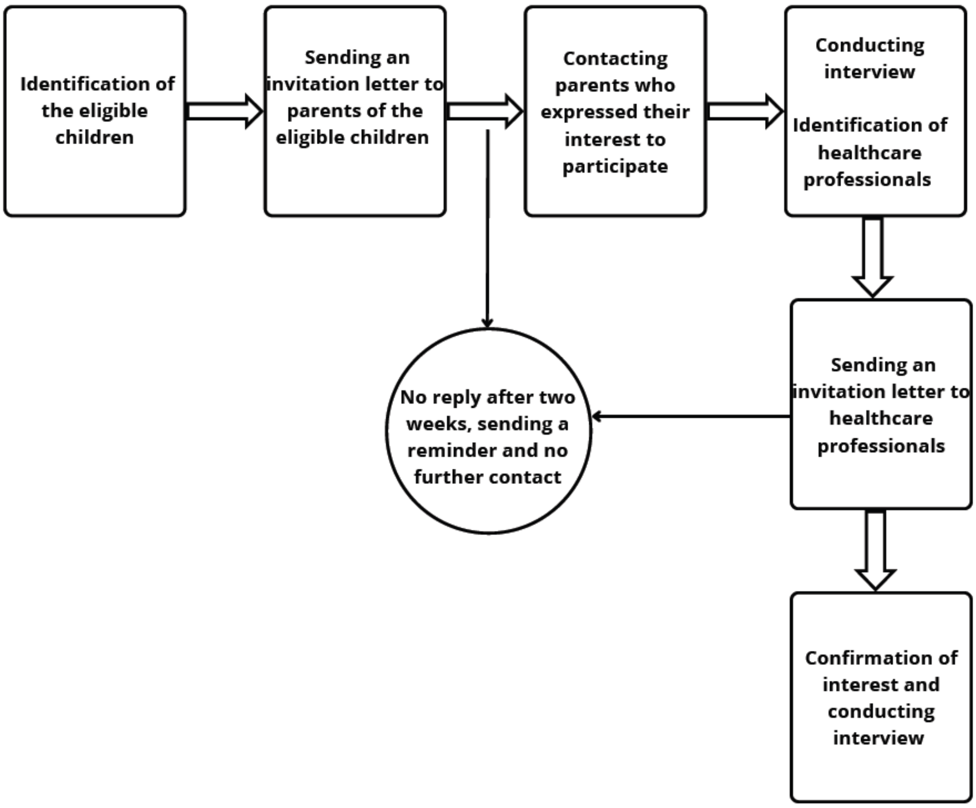


Figure 3 Recruitment of study participants

3.5.2.1 Parents

The recruitment of parents was undertaken together with the collaborating doctor who sent parents of the eligible children a letter of invitation. This strategy was employed as the doctor had access to children's medical records and could contact parents directly. Only biological parents (mothers and fathers) or legal guardians of the eligible child were invited to the study. Parents interested in participating in the study replied to the researcher via email. This approach allowed parents to decide about their participation without feeling overwhelmed if approached directly (Tomlinson et al., 2007).

Parents who agreed to participate were sent an informational pack about the study, including a cover letter, a participant information sheet and a consent form (Appendix 6, 7). Subsequently, a date and place for the interview were arranged based on the participants' preferences.

3.5.2.2 Healthcare professionals

Healthcare professionals were identified by parents at the end of their interview. This approach empowered parents to make recommendations regarding the next participants being invited to the study (Robinson, 2014). Recruitment of healthcare professionals was a crucial part of this study, therefore, personalised and relationship-based strategies were used to enhance their engagement in the study (Bruneau et al., 2021). Letting parents identify healthcare professionals who would be invited to participate in the study also enabled a personalised aspect to be added into the recruitment strategy, as healthcare professionals were asked to talk about a specific child in the invitation letter.

This approach also empowered parents to take an active role in the research process which seemed to increase the likelihood of healthcare professionals' participation. At the same time, there was awareness that the request to identify a healthcare professional could provoke discomfort in the parents, as previous research indicates that parents may be reluctant to use personal networks for recruitment or have concerns over privacy and role boundaries (Kim et al., 2023). Additionally, there is a risk that this approach may place undue pressure on healthcare professionals to participate, owing to the pre-existing therapeutic relationship (Bruneau et al., 2021). To limit those ethical challenges, parents were invited to identify a healthcare professional but in cases where they declined to do so, the collaborating doctor could also provide the nomination.

The identified healthcare professionals were approached via email with an adapted version of the information pack about the study (Appendix 7, 8). Interviews with healthcare professionals were arranged to reflect their preferences regarding the form and place.

Both parents and healthcare professionals were sent a reminder after two weeks if they did not reply to the first invitation email. No further contact was initiated if they did not respond to the reminder.

3.5.3 Data collection

Data in this study were collected using two different techniques – interviews and document analysis.

In congruence with Merriam's approach (1998), the main source of data were in-depth interviews with parents and healthcare professionals. Using interviews to collect data empowered parents and healthcare professionals to talk about their experience with decision-making from their perspective and to create their reality of the events (Riessman, 1990). An additional source of data was a document analysis of medical records. Analysis of documents represents another strategy for data collection in qualitative case study research (Yazan, 2015).

3.5.3.1 Interviews

In line with qualitative case study design, the data were collected through individual in-depth interviews with parents and healthcare professionals.

An interview topic guide was used to navigate the interviews. Two version were created, one version for parents and the other for healthcare professionals (Appendix 9). The interview topic guide was based on the findings of the literature review, carried out as part of this thesis, and reflected the aim of the study (Bryman, 2016). The topic guide used open-ended questions and probes to identify the events of decision-making, and to explore the experience of the participants. Following Merriam's (1998) recommendation for a flexible approach during interviews, this study used the interview guide to navigate the conversations while allowing participants to share their experiences at their own pace without strict adherence to the guide’s structure. Both versions of the interview guide were piloted with a parent and healthcare professional to ensure the clarity of the questions in gathering relevant information.

All interviews were conducted in Czech language and audio recorded. The interviews took place face-to-face, by phone or as an online meeting (Teams) based on participants’ preferences and the current epidemiological situation. The interview started after verifying their consent with participation. At the start of each interview, participants’ demographic data, such as age, marital status, faith, education, number of children in the family and length of medical practice, were collected. All participants were asked to identify decisions about medical care which they perceived as important and to talk about their experience.

Field notes and memos were taken during and after each interview to record the emotions of the participants and the situation in which the interview took place. The field notes from the interviews with parents were used during the interviews with healthcare professionals to remember the context of the interviews with the parents. Additionally, a reflexive account was written after each interview to capture the experience and my feelings from the interview while bracketing my own experience with the studied phenomenon.

3.5.3.2 Documentary data

For each case, documentary data were collected. The electronic hospital database was used to access the medical records of the children. Access to the medical records was approved by the hospital governance, and additional permission was obtained from the parents.

Due to security clearance, my access was limited to the reports submitted by the paediatric palliative care team. Medical reports from other hospital departments were not therefore available. Limited access was compensated by robust medical reports from the paediatric palliative care team, as they use an innovative approach to document the medical consultations and their outcomes. This approach requires parental authorisation of the written report, which gives parents control over the interpretation of the consultations (Hrdlickova et al., 2023).

The collected documentary data were authored by healthcare professionals working within the paediatric palliative care team, although some records were reviewed and endorsed by parents prior to submission to electronic hospital database as explained above. The documentary data also included e-mails written by parents to healthcare professionals. The record of the first consultation with the palliative care team provided a detailed overview of the child´s personality, family context and health condition. While the documentary data mainly reflect healthcare professionals´ perspectives, they provide an insight into parental experience and offer a broader context for each case and understanding of the family´s dynamics.

3.5.4 Data analysis

This study utilised a structural narrative approach supported by the identification of partial stories and by the application of rhetorical aspects of speech to the transcripts.

The data analysis in this study was conducted in two stages (within-case and cross-case), with five steps to the analytic process. The documentary analysis followed the five steps of data analysis. The analytical process was concluded with the development of categories and of the conceptual model.

All collected data were analysed in Czech. The recordings, transcripts and documents were uploaded to ATLAS.ti 23 software for analysis and further management.
The process of the data analysis is described in detailed below.

Stage one: within-case analysis.

All data collected within one case were analysed separately using a three-step process; familiarisation with all collected data in each case; identification of stories in the collected data in each case; and searching for relations in the data matrix within each case. Each case was analysed in turn before moving on to the next case. Following completion for all cases, cross-case analysis was conducted.

- <u>Step 1 – Familiarisation with data (within-case)</u>

The analysis started with familiarisation with the collected data within each case individually. In each case, collected interviews were repeatedly listened to and transcribed verbatim. Identifiers were removed from all transcripts, and children were given aliases to ensure their anonymity. Transcripts were read while listening to the recordings, with the aim of immersing myself in the data and reliving the experience of each interview. The medical records were read in full. During this process, emerging narratives related to the studied phenomenon were marked for further analysis.

- Step 2 – Identification of stories (within-case)

Within each case, the narratives describing the stories of experience with decision-making were identified in the interview transcripts. The narratives were identified as structural narrative of personal experience if they consisted of the six elements of a narrative. Narratives which did not include all six elements were also identified and marked as partial stories. The identified stories were extracted from the transcripts and structural stories were presented in lines following the rhythm of active speech. An example of analysis is presented in Appendix 10.

This process was concluded by a written description of each story. The number of stories identified for each participant was recorded in an Excel spreadsheet, together with the types of decisions participants were talking about (Appendix 11, 12).

The medical records within each case were searched for narratives relating to the stories of decision-making described by the participants. All narratives identified in the medical records were extracted and marked as partial stories. The selected narratives provided further information regarding the events parents and healthcare professionals talked about during the interviews. A written summary of each identified story was developed. The extracted excerpts were subsequently coded. Data driven codes were developed during the coding process. The coding process was focused on identifying the key aspects related to decision-making. The identified set of codes was used for parents and healthcare professionals alike.

The analysis of medical records supported the findings from the interviews with the study participants. An example of a documentary data analysis is presented in Appendix 10.

- Step 3 – Searching for relations in the data matrix (within-case)

After the identification of stories in an individual case, the within-case analysis focused on exploring relations in the data matrix which was extracted in each individual case. The aim of this step was to identify connections and patterns in the data. Initial data coding was conducted, followed by the creation of a mind map for each participant to visually organise the codes and identify emerging categories (Appendix 13). A written interpretation was then developed for each case, synthesising the findings and describing the experience with the decision-making.

The findings of within-case analysis were translated into a short summary which is presented in form of individual vignettes for each case in the following chapter (4.3.)

Stage 2: Cross-case Analysis

Following completion of within-case analysis for all cases, step 4 (cross-case analysis) and step 5 (development of the categories) was conducted.

- Step 4 – Cross-case analysis

Using the written synthesis of the findings, the findings for each case were compared and contrasted against each other to look for patterns, using the mind maps developed during within-case analysis. To ensure that the meaning of the original stories was not lost or misinterpreted, the cross-case analysis process was backtracked to the original transcripts. The initial codes and categories developed during within-case analysis were revised, and new codes and categories were added. Subsequently, codes were aggregated thematically together, and tentative categories were identified.

- Step 5 – Development of the categories

The data analysis was concluded with the identification of tentative categories and subcategories, and their re-organisation into final presentation. This process required thorough interaction with the original data, including revisiting the transcripts to ensure that the interpretation was accurate and the categories captured any underlying meanings.

The final categories were derived from the collected data; initially using an intuitive process which became more deductive as analysis progressed. It was important for the final set of the categories to be solid and supported by the data (Merriam & Tisdell, 2016). The final developed categories were subsequently used to develop a conceptual model of the findings. The findings of the analysis are presented in Chapter 4.

3.5.5 Development of the conceptual model of decision-making

The conceptual model was developed based on the cross-case analysis process described above and based on the final categories. Mind maps and visual aids were used to capture the findings in the form of a conceptual model which depicts the complex experience of decision-making.

The cross-case analysis showed that the identified factors have different level of influence on parent and healthcare professionals. Additionally, the analysis also showed that the decision-makers influenced each other in varying intensity.

To explore the intensity of these influences further, each identified factor was examined to assess its relative intensity of influence on the decision-makers. The perceived importance of the factors for parents and healthcare professionals guided this process. Subsequently, three types of influence were identified, and are presented as strong, medium, and weak influence. A strong influence is exerted by key factors which are dominant in shaping decision-making; a medium influence related to factors which support decision-making, and a weak influence reflects factors which are considered but do not directly shape decisions.

The conceptual model is presented in detail at the end of the following chapter.

3.6 Research ethics and governance approval

Ethics approval was obtained from the Lancaster University Faculty of Health & Medicine Research Ethics Committee (FHMREC) (Appendix 14) and by the Ethics Committee for Multi-Centric Clinical Trials of the University Hospital of Motol (Appendix 15).

3.6.1 Informed consent

All participants were required to give informed consent to participate in the study. Consent was obtained before the interviews and their recording started. Written consent was collected for in-person interviews, while verbal consent was used for interviews conducted by phone or online. Parents had to provide additional consent to access their children's medical records.

All participants were informed that their involvement in the study was voluntary, and they could end the interview at any time. They were assured that all information shared during the interviews are confidential and that raw data would not be disclosed to medical personnel. Additionally, parents were informed that their participation would not influence their child's treatment. All participants were given two weeks after the interview to withdraw their consent. Permission was required to use direct quotations from the interviews.

3.6.2 Distress and protection of participants

Conducting research with parents of severely ill children represents an ethically challenging situation due to the vulnerability of the participants (Tomlinson et al., 2007). Inviting parents to research can put an additional burden on them by opening sensitive and unresolved topics, and parents can feel obligated to participate in the study when approached by healthcare professionals (Tomlinson et al., 2007). Therefore, the following measures were employed in this study.

Participants were required to actively consent to participate, and only one reminder was sent if they did not reply to the initial email. Although requiring active consent can lead to lower participation rates (Stenhammar et al., 2011), it was considered more respectful of participants’ autonomy. Sending a detailed information letter about the study before the first direct contact with the researcher gave parents time to consider their participation (Hynson et al., 2006; Steinhauser et al., 2006). Parents were encouraged to respond to the invitation letter directly to me rather than to the healthcare professionals, which could put pressure on them.

Parents and healthcare professionals could choose the form and the location of the interview. During interviews, it was important to minimise the distress parents may experience by being compassionate, empathetic and understanding (Dyregrov, 2004; Hynson et al., 2006). To address the psychological distress experienced by participants during the interviews when talking about emotionally difficult experiences, a distress protocol was designed specifically for this study and followed when necessary (Appendix 16).

Additionally, parents could influence the length of the interview and were not rushed. Before commencing the interview, parents were advised they could stop the interview at any time, either just for a break or all together if necessary. After the interview, participants were given the opportunity to ask additional questions and to reflect on their participation (Dyregrov, 2004).

3.6.3 Data anonymisation

The rare diagnoses of the children, the single hospital setting and the narrow study population represented a risk of participant identification. Therefore, maximum effort was put into data anonymisation. The children were given alias names, and their diagnoses were not fully disclosed. The age, specialisations and length of practice of healthcare professionals were removed to prevent their identification. The age of parents was also removed to protect their identity. Raw data were available only to the researcher. Additionally, participants were asked to give their consent for using direct quotations from their interviews.

3.6.4 Data management

Data management in this study complied with the EU General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. All collected data were stored at the Lancaster University One Drive. The audio data were transferred after recording on the encrypted and password-protected data laptop and deleted from the recording device afterwards. Audio data will be deleted after the PhD thesis is submitted and defended. The personal data of the participants were stored separately from the collected data.

Transcribed data will be stored for ten years. After this period, the transcribed data and any other collected data will be deleted by personnel appointed by Lancaster University.

3.6.5 Harm to the researcher

Paediatric palliative care research can be emotionally disturbing for the researcher, and a role conflict can occur when the participant asks for advice or is expecting support beyond the interview (Weaver et al., 2019). Therefore, precautions were taken as the research had the potential to be emotionally disturbing and included the researcher's alone work.

To address the emotionally challenging topic, I kept a reflexive journal during the research process to process the emotions experienced during the interviews.
To minimise risks during fieldwork, the guidance on the safety of fieldwork issued by the University was followed while setting up the interviews (Mallows et al., 2005).

3.7 Study rigour

Addressing study rigour to ensure adequate quality is an integral part of any research inquiry, including case study research. Case study design was previously questioned for its ability to maintain study rigour (Harrison et al., 2017; Verschuren, 2003). A frequently raised concern regarding case study rigour is the limited generalisability related to the small number of cases in a study (Crowe et al., 2011; Verschuren, 2003).

The criteria used to assure the study rigour are dependent on the study paradigm (Kivunja & Kuyini, 2017). In qualitative inquiries, the criterion of trustworthiness presented by Guba and Lincon is commonly used to enhance a study's rigour (Morse, 2015). The aspects of trustworthiness include credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Although Merriam (1998) uses positivist terms of internal validity, reliability, and external validity in her work, she refers to the terms as defined by Guba and Lincon (1994). The following strategies proposed by Merriam were applied throughout this study.

To ensure the rigour of internal validity of the study, Merriam (1998) recommends several strategies. Triangulation includes using multiple sources of data, methods or investigators to confirm the findings; and peer examination to refine emerging findings. Also recommended is engagement in data collection, disclosure of researchers' bias and reflexivity to disclose assumptions, expectations, and personal experiences with the phenomenon (Merriam, 1998). In this study, triangulation was achieved through the use of multiple data sources, including interviews and medical records, to confirm the findings. Peer examination was facilitated by regularly discussing emerging results with supervisors during data analysis. Data collection was concluded upon reaching saturation and was designed to include variation by recruiting ten diverse cases. Reflexivity was maintained by presenting the researcher's prior experience with the studied phenomenon and consistently keeping a reflexive diary, complemented by supervisory discussions to address potential biases.

Reliability, or dependability, focuses on whether the research can be replicated with consistent findings and is closely tied to maintaining an audit trail (Merriam, 1998; Merriam & Tisdell, 2016). This involves documenting how the study was conducted, including data collection and analysis processes, and recording reflections and decisions through research journals and memos. Additionally, the investigator's assumptions and position, including the social context of the collected data, should be clarified (Merriam, 1998). In this study, an audit trail was created through detailed documentation of data collection and analysis, with field notes and memos being kept throughout. Data analysis was performed using the Atlas.ti 23 software, enabling backtracking of the analytical steps. The researcher's position and experiences were outlined at the start of the study and revisited throughout the process.

Transferability, or external validity, relates to how the study's findings can be applied to other contexts (Merriam, 1998). Recommendations include providing rich, thick descriptions of the study's setting, participants, and findings, supported by direct quotes and detailed case accounts (Merriam & Tisdell, 2016). Maximum variation, achieved by including diverse sites, cases, and situations, further enhances transferability. In this study, rich descriptions of the study setting including the socio-cultural background of each case was described in detail in the form of vignettes. Direct quotes from interviews were used to support the findings. Maximum variation within the sample was achieved by using a multiple-case design and purposeful sampling to achieve diversity in the sample.

An overview of the strategies used to ensure a study's rigour are presented in Appendix 17.

3.8 Conclusion

This chapter has provided a comprehensive overview of the philosophical foundations that informed this study, alignment with the constructivist paradigm and a justification for the selection of a qualitative case study method, and narrative analysis.

The qualitative case study design set within the constructivist paradigm, enabled to explore the studied phenomenon from various realities and get a better understanding how parents and healthcare professional make medical decisions for children with life-limiting and life-threatening conditions. In line with case study design, data were collected by individual in-depth interviews and supported by medical records.

The narrative approach to data analysis is based on the structural approach of Labov (1972) and supported by using additional strategies to strengthen the analytical process, including identification of partial stories and using rhetorical discourse towards narratives.

The chapter is concluded with the presentation of the ethical issues connected the study with the focus on the protection of participant and of the measures taken to ensure methodological rigour of the study.

Chapter 4. Findings

4.1 Introduction

In this chapter the findings of the research into the decision-making process from the perspectives of parents of children with life-limiting and life-threatening conditions and healthcare professionals are presented. First, individual vignettes of each case are introduced together with the findings from the within-case analysis. This is followed by the presentation of findings from the cross-case analysis in the form of six categories.

The chapter is concluded with the presentation of a conceptual model of medical decision-making develop based on the findings from the cross-case analysis.

4.2 Presentation of the cases and study participants demographics

The study consists of ten cases, each case was developed around the child and consisted of two types of participants – parents, and healthcare professionals.

The children had various types of conditions. Most common (N=4) were conditions classified as life-threatening for which curative treatment may be feasible but can fail (category 1). The other three categories included two children each: category 2, which covers conditions where premature death is unavoidable; category 3, encompassing progressive conditions; and category 4, which involves irreversible but non-progressive conditions.

The age of the children varied, with the youngest child being 2 years old and the oldest 16 years old. Three of the children passed away during the study.

The ten cases consisted of 21 participants, ten of the participants were parents, one in each case. All participating parents were biological parents – mothers and fathers, of the eligible children. The group of parents included mothers (N=7), and fathers (N= 3). Eight participating parents were married; two parents were divorced. The average age of parents was 37 years (range 31-42). The interviews had an average length of 60 minutes (range 38-89 minutes). Half of the interviews with parents were conducted in person; the other half was done by phone or online.

The study includes 11 healthcare professionals: doctors (N=8), nurses (N=2) and a psychologist (N=1). Two of the healthcare professionals were participants in three cases and five of the cases included two healthcare professionals. The average length of their professional practice was 26 years (range 5-46). The participating doctors had various specialisation including nephrology, oncology, neurology, intensive care, palliative medicine, cardiology and paediatrics. Some of them had more than one specialisation. The average age of healthcare professionals was 50 years (range 30-70). The interviews had average length of 27 minutes (range 15-51 minutes). Interviews took place either at the hospital, online or over the phone. The demographics of the children and the study participants are presented in Table 9.

Table 9 Demographics of the children and case study participants

Case number and alias	Demographics of the children		Demographics s of the study participants	
	Age in years/ status	Diagnosis /category	Parents	Healthcare professionals
Case 1 - Jacob	12 / living	genetic/3	mother/married	doctor/male
Case 2 - John	2/ living	cancer/1	father/ married	psychologist/female
				doctor/male
Case 3 - Elisa	6/ deceased	cancer/1	father/ married	doctor/female
Case 4 - Thomas	13 / living	organ failure/1	father/ divorced	doctor/female
Case 5 - Anna	16 / living	neurological/4	mother /married	doctor/female
Case 6 - Julia	4/ living	genetic/2	mother/married	paediatric nurse/female
				doctor/male
Case 7 - Samuel	2/ living	genetic/3	mother/married	paediatric nurse/female
				doctor/female
Case 8 - Lucas	8/ living	genetic/2	mother/married	doctor/female
				doctor/male
Case 9 - Marty	2/ deceased	neurological/4	mother/married	doctor/female
				doctor/female
Case 10 - David	11/ deceased	cancer/1	mother/divorced	doctor/female

4.3 Vignettes of the cases

In this chapter, all cases are presented in the form of a vignette (Stake, 1995). The vignettes are based on the data collected through interviews and medical records and provide a deeper insight into the individual cases. The vignettes follow similar format: first, the contextual background of the case is presented, including an introduction of the child, their age, diagnosis, relevant medical history, and family structure. The case's background is not presented in full detail to minimise the risk of identification of the families due to the rare conditions of their children. This is followed by an overview of decisions made for the child and which were discussed during the interviews with the study participants. The vignettes are closed by a summary of the findings from the within-case analysis, focusing on the experience with decision-making.

4.3.1 Case one – Jacob

Jacob is a 12-year-old boy with a genetic condition who lives with his parents and two siblings. The mother takes care of the children while the father goes to work. Jacob has been ill since birth, but he did not receive his diagnosis until he was five years old. The genetic syndrome causes developmental delay, and progressive damage to the kidneys, but his parents did not wish to proceed with haemodialysis or kidney transplantation.

Decisions made for Jacob included decisions regarding advance care planning, limitation of care, commencing haemodialysis, kidney transplantation, and involvement of the palliative care team.

During the decision-making, the mother and the doctor appeared to share similar opinions and outlook on the care for Jacob. The focus was on the child's quality of life and limitation of suffering, with invasive procedures perceived as unacceptable. The mother felt that her perspectives were acknowledged during the decision-making. The mother described that she valued the support provided by healthcare professionals. The impact of the decisions on the whole family was also taken into consideration by the mother and participating doctor alike. Both the mother and the healthcare professional described the involvement of the paediatric palliative care team as supportive.

4.3.2 Case two – John

John is two years old and lives with his parents and an older brother. He was diagnosed with cancer shortly after being born and was treated at the oncology department. He spent his first months of life in hospital undergoing chemotherapy. The father questioned the need for the proposed treatment, its benefits and the impact of the treatment and hospitalisation on such a small baby.

Decisions made for John about his medical care included continuation of chemotherapy, surgery and undergoing magnetic resonance imaging.

The decision-making was described by the father as challenging. The father and the healthcare professionals experienced difficulties in reaching an agreement and third parties, including a lawyer and the palliative care team, were involved during conversations to prevent a conflict escalation. The father felt responsible for the decisions and their outcome. He believed that his choices were guided by the perception of suffering and John's quality of life. Communication with the parents was perceived by healthcare professionals as difficult.

4.3.3 Case three – Elisa

Elisa was six years old, and she lived with her father and grandmother and had a younger brother. She was born healthy, but before her 6th birthday, she was diagnosed with cancer with a fatal prognosis. Elisa underwent a cycle of radiotherapy, after which she went with her family on a holiday trip. When they returned home, her health started to deteriorate, and her parents decided not to proceed with further treatment. Elisa died during the study.

Decisions made for Elisa included whether to repeat cycles of radiotherapy, a do-not-resuscitate order, care at home, involvement of hospice and palliative care team, place of end-of-life care, and comfort care.

The decision-making process of the father was influenced by the terminal prognosis and by the close relationship the father had with her. He reported a sense of responsibility for his daughter and the need to protect her from suffering. It was important for him to ensure that she had a good life until the end. The father described valuing the support and advice he received from his family and from healthcare professionals who supported him and respected his preferences. In this case, both the father and the doctor felt that Elisa's preferences and opinions were acknowledged and valued. The support provided by the paediatric palliative care team during end-of-life care was seen by the participating doctor as crucial to ensure the father's preferences were met.

The father requested that his data not be used in the quotes, and as such, they are omitted, although the data contributed to the findings.

4.3.4 Case four – Thomas

Thomas is a 13-year-old boy. His parents are divorced, and he and his sister live with their father. Thomas was born as a healthy baby. He started to show the first symptoms of his illness when he was in kindergarten. Thomas was diagnosed at the age of nine with progressive heart and lung failure, and he requires oxygen therapy at home. Taking care of both children while working full time to provide for the family - including a seriously ill son - was stressful for the father, who developed severe depression.

Decisions made for Thomas included cardiac surgery, adjusting the dosage of medication, and future heart and lung transplantation.

According to the healthcare professional, the decision-making for Thomas was guided by the treatment which were available. At the same time, the father expressed feeling responsible for decisions. For the doctor, it was important to maintain a trusting relationship with the father and to come to the decision together. He expressed his desire not to force the father into a decision. As such, the father and the doctor had several discussions before reaching an agreement. However, some decisions were based on medical evidence, and the father was not included in these. The involvement of the paediatric palliative care team was experienced was experienced by the participating father and doctor as helpful during communication and enabled the situation to be seen from different perspectives. The father experienced the support provided by his family as crucial.

4.3.5 Case five – Anna

Anna is 16 years old and an only child who lives with her parents. Anna has been seriously ill since birth and has a severe mental and physical impairment. She was diagnosed later in her life with genetically caused epilepsy and started to develop more serious health problems requiring prolonged hospitalisation after she celebrated her 10th birthday. Due to her health issues, she is enterally fed through gastrostomy. Her respiratory problems raised the question of tracheostomy, which was subsequently refused by parents and healthcare professionals alike.

Decisions made for Anna about her medical care over her life included tracheostomy, percutaneous endoscopic gastrostomy and jejunostomy, limitation of treatment and care including do-not-resuscitate status, do-not-intubate status, and extent of care.

The decision-making process of the mother and the healthcare professional was focused on Anna’s quality of life; the mother reported that ensuring Anna would have a good, normal life was paramount to her and Anna’s father. Both the healthcare professional and parent considered any available interventions through the lens of Anna’s disability and what benefits they would give to her. They both perceived interventions which would worsen Anna’s quality of life, although they could extend her life, as not acceptable. The participating doctor felt that she valued the opinion of Anna’s parents and saw them as key participants. The mother felt responsible for the decisions and worried about making the right choices for her daughter. It was important for her to make decisions together with her husband.

4.3.6 Case six – Julia

Julia is four years old and living with her parents and two brothers. Her parents were aware of the potential for serious health problems from pregnancy and Julia needed intensive medical care after birth for several months. Julia is severely delayed in her development and requires continuous care, which is demanding for her parents.

Decisions made for Julia about her medical care included cardiological surgery, tracheostomy, jejunostomy, limitation of treatment including a do-not-resuscitate status, and use of artificial life support.

The mother's experience with decision-making was influenced by limited knowledge about the outcomes such decisions would mean for Julia. The mother believed that her ability to make decisions was affected by her own health and she felt exhausted from long hospital admissions. The mother expressed a need for information to be able to understand what was happening with her daughter. She trusted the doctors and let them make the decisions, although she also wanted Julia to be included in the decision-making and sought out non-verbal signs of Julia's will to live. The participating healthcare professional felt like they acknowledged parental preferences and listened to their opinions regarding treatment choices. The support of the paediatric palliative care team was experienced as valuable by parents and healthcare professionals alike.

4.3.7 Case seven – Samuel

Samuel is a two-year-old boy. He lives with his parents and brother. His parents were aware of the possibility that their baby would be ill during the pregnancy. Samuel was born prematurely and consequently diagnosed with a genetic syndrome. The health condition of Samuel was very fragile, requiring several hospitalisations. His health improved after he had surgery for a tracheostomy and gastrostomy.

Decisions made for Samuel about his medical care included tracheostomy, gastrostomy, cochlear implant and type of diet.

During the decision-making process, the participating mother believed that she was dependent on healthcare professionals and their medical expertise to make the right decisions for her son, and she followed their advice. In order to participate in the decision-making, she needed to have information and open communication, and to be heard and respected. The mother felt that she made the decisions together with her husband. The decision-making process was reported by the participating mother and healthcare professionals to be prone to conflicts. The involvement of the paediatric palliative care team was experienced by the mother and healthcare professionals as useful to navigate communication and mitigate disagreements. The doctor perceived the communication with the parents as challenging, as the father requested individualised care for his son and did not want to follow the hospital rules. The doctor tried to include the parents in all care decisions, including giving them the information they needed and acknowledging their preferences, but felt responsible for the child and the outcomes of the decisions. Similarly, the participating nurse reflected that the parents wanted to be actively involved in the decision-making and were asking many questions which was often perceived by the hospital staff as annoying and resulted in conflicts. Her decisions were guided by the ill child and his comfort.

4.3.8 Case eight – Lucas

Lucas is an eight-year-old boy who lives with his parents and a younger sibling. The mother is at home, caring for the children, while the father works. Lucas was born as a healthy boy, and his health started deteriorating when he was two years old. He was diagnosed with a genetic syndrome affecting growth and kidney function. He went into renal failure within a year and now requires peritoneal dialysis. His condition caused him epileptic seizures and uncontrollable headaches.

Decisions made for Lucas about his medical care included type of dialysis, treatment of headaches with opioids, involvement of hospice care, bone marrow transplant and advance care planning.

From the perspective of the mother, decisions about Lucas' care were made together with her husband and healthcare professionals. She felt that the goal of care for Lucas was to have a good quality of life; to be at home and live a normal life. The mother reported that both she and Lucas' father considered how the decisions would impact the whole family. She expressed that she fully trusted Lucas's doctor and followed their recommendations, and felt that their well-established relationship made her experience with decision-making easier. The participating doctor described making decisions based on information gathered from various sources due to the rarity of the condition. She would then discuss these with others. For the healthcare professional some decisions were made based on the availability of treatment options.

4.3.9 Case nine – Marty

Marty was a two-year-old boy living with his parents and three siblings. He had a traumatic birth and underwent a prolonged resuscitation, which resulted in severe brain damage. He required several life-saving surgeries during his first weeks of life. He had drug-resistant epilepsy and was experiencing serious epileptic seizures. Marty's health and development were severely impacted by his condition. He died during the study.

Decisions made for Marty about his medical care included decisions about various surgeries, establishing do-not-resuscitate status and do-not-intubate status, the involvement of home care and hospice care and advance care planning. Other decisions were focused on the use of antibiotics, application of intravenous hydration and the commencement of a keto diet to control his epilepsy.

Marty's mother reported that decisions were made together with her husband, but she found the decision-making process to be challenging. The mother felt judged and questioned by healthcare professionals and reported that she did not feel respected, although she valued those professionals who she felt supported her in her parental role. She described finding communication with healthcare professional as distressing and she felt that she did not have enough information.

The participating healthcare professional perceived that their relationship with the parents was impaired by the lack of trust of the mother. They described the importance of knowing the parents' preferences and their goals of care. The involvement of the paediatric palliative care team was experienced as helpful by both the parent and doctor in facilitating communication and care planning.

4.3.10 Case ten – David

David was a ten-year-old boy; an only child who lived with his mother. They had a very close and loving relationship. Prior to his illness, David was a healthy boy. He was diagnosed with cancer with a terminal prognosis at the age of nine. He underwent radiotherapy, and his mother was trying alternative therapies. He died during the study.

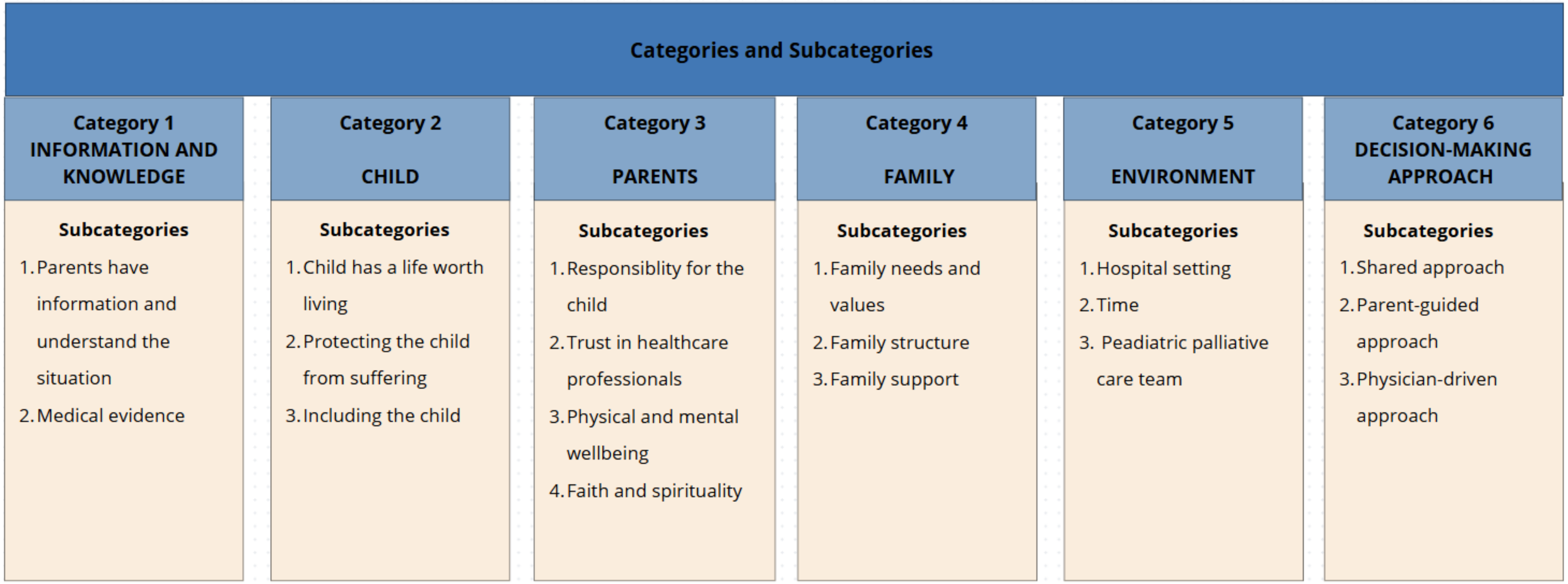
Decisions made for David about his medical care included radiotherapy, alternative therapies, involvement of hospice care and end-of-life care.

The mother expressed feeling responsible for all decisions and said she included David in the process. As a single parent, she described being familiar with making decisions for her son on her own. During decision-making she relied on healthcare professionals and valued their expertise and opinions. The mother wanted the best for David, and she felt it was impossible for her to accept his terminal prognosis. This attitude was experienced as challenging by the participating doctor as it made it difficult to plan for end-of-life care. Maintaining a good relationship with the mother was perceived as important by the doctor and she wanted to avoid pressuring her into accepting the terminal prognosis of her son.

4.4 Categories

Guided by the narrative approach of Labov (1972), each case was firstly analysed individually, followed by cross-case analysis of narratives from both parents and healthcare professionals. The process of within and cross-case analysis was described in detail in the previous chapter. The identified categories integrate the perspectives and experiences of the participating parents and healthcare professionals. While some categories reflected shared understanding, others were more strongly based on the narratives of one group. In these categories the parental narratives dominated, reflecting the detailed and child-centred focus of their experiences when making decisions. In contrast, healthcare professionals often described decision-making that occurred across multiple patients and clinical contexts, offering a broader but less individualised perspective. In line with the constructivist positioning of this research the aim when analysing the data from the two sets of participants is that the categories represent different constructions and interpretations of the studied reality driven by the emic perspectives of the study participants.

The within and cross-case analysis coded patterns and insights in the data. These were thematically merged into eighteen subcategories and six categories: Information and Knowledge, Child, Parents, Family, Environment, and Decision-making approach (Figure 4). The categories are considered below followed by a depiction of their relationship in the conceptual model of decision making.



Categories and Subcategories					
Category 1 **INFORMATION AND KNOWLEDGE**	**Category 2** **CHILD**	**Category 3** **PARENTS**	**Category 4** **FAMILY**	**Category 5** **ENVIRONMENT**	**Category 6** **DECISION-MAKING APPROACH**
Subcategories 1. Parents have information and understand the situation 2. Medical evidence	**Subcategories** 1. Child has a life worth living 2. Protecting the child from suffering 3. Including the child	**Subcategories** 1. Responsiblity for the child 2. Trust in healthcare professionals 3. Physical and mental wellbeing 4. Faith and spirituality	**Subcategories** 1. Family needs and values 2. Family structure 3. Family support	**Subcategories** 1. Hospital setting 2. Time 3. Peadiatric palliative care team	**Subcategories** 1. Shared approach 2. Parent-guided approach 3. Physician-driven approach

Figure 4 Categories and subcategories of the decision-making of parents and healthcare professionals

4.5 Category 1: Information and knowledge

Access to information was identified as fundamentally important during decision-making for parents and healthcare professionals alike. Different forms of information were used by parents and healthcare professionals. Parents used various sources of information to get an understanding of what is happening with their child. Healthcare professionals relied on medical evidence and their expertise. This category consists of two subcategories: Parents have Information and Understand the Situation; and Medical Evidence.

4.5.1 Parents have information and understand the situation

During decision-making, parents required to have information related to the medical condition of their child, the treatment and care. The main source of information were healthcare professionals. Parents required to have information delivered from healthcare professionals repeatedly, to have conversations with them and be able to ask questions. Lack of information from healthcare professionals made parents become proactive and search for information independently. They used other sources, such as the internet, patients' groups, and friends.

> *"We could ask (questions), we asked repeatedly. My husband needs to have a lot of information. So, they really explained it to us and were totally cool with it. It didn't bother them at all that they were saying it for the tenth time. So, they just explained it to us until we got it." (C5 mother)*

The need for access to information was influenced by parental perception of their limited medical knowledge regarding their child's health condition. Gathering of information enabled them to build their knowledge about the child's condition which helped them to actively participate in the decision-making and control their emotions.

> *"Well, I'm a lay person, so for me, I've had to study to understand. After all, my experiences and education were focused completely differently. This is just something that I've had to fill in, and I just wanted to know and study it all so that I would have some awareness of it and not be so emotional." (C6 mother)*

Parents had a better understanding of the situation when they had a previous experience with a similar situation. They were better prepared for what to expect and foresee how their decision would impact the child. Previous experiences also made parents less worried.

Previous experiences with similar situations helped parents to make decisions for their children. In some cases, based on their previous experience, parents decided not to proceed with proposed intervention or treatment. In other cases, previous experience provided reassurance to agree with the intervention.

> *"(The procedure was) for the second time, because actually the first tube was something completely new. A new type of feeding style, completely new stuff and now it actually looks the same, they just put a second tube in there." (C5 mother)*

Gaining understanding of the situation allowed parents to agree with the proposed interventions, although it did not necessarily lead to acceptance of the situation.

4.5.2 Medical evidence

Healthcare professionals made decisions based on available medical evidence. They often consulted the decisions with other specialists or within a multidisciplinary team. Decisions based on medical evidence were done solely by healthcare professionals, parents were not included but were subsequently informed about the outcome. In existence of a treatment protocol, healthcare professionals followed its guidance.

> *"The crucial decision was at the beginning whether to operate or not. Unfortunately, the parameters were such that we couldn't, but that's not a decision that we can pick and choose. It was based on the parameters which were there." (C4 doctor)*

The decisions of healthcare professionals were driven by the children's medical condition, their overall health state and expected prognosis. Decisions perceived as medically futile were not acceptable.

> *"Decision about the limitation of care in the sense of not intubating and not resuscitating. He really was a very ill child, where medically it made absolutely no sense to intubate and resuscitate. We made a medical decision not to proceed with resuscitation based on his overall health and unfavourable prognosis." (C9, doctor)*

Healthcare professions also used their previous experiences, but in some cases, they had limited experience due to the rarity of the medical conditions. Therefore, they used other sources of information, including other specialists, literature and consultation with foreign colleagues.

4.6 Category 2: Child

Consideration of the child was equally important for parents and healthcare professionals. Decisions were done with the aim to ensure that the child would have a good life to live and would be protected from additional suffering. Preferences of children were also considered. This category comprised three subcategories: Child has a Life Worth Living; Protecting the Child from Suffering; and Including the Child.

4.6.1 Child has a life worth living

Parents needed to ensure that their children lived a good and normal life despite their medical conditions, and their perception of what a good and normal life meant guided their decision-making. Being at home with the family, doing everyday activities, going for walks and social outings, going to school, and limiting hospital admissions were identified as attributes of a good life.

> *"We don't sit at home with the oxygen; we are trying (to live). We bought an electric scooter he uses to move around. We went on a trip to a castle. He is happy. He's going into his teenage years, and I don't want him to sit at home. He needs to make some social contacts." (C4 parent)*

Parents and healthcare professionals harboured a desire to ensure that children could lead a life perceived as normal and of a good quality. This desire influenced their decision-making. In some instances, it led to the refusal of further treatments, especially when such interventions were anticipated to negatively affect the child's wellbeing or result in prolonged hospitalisations.

> *"We got to the stage that we decided that it is not a priority for us to treat at any cost, we decided to do what would be best for John at his current state of being a baby. And that means he is at home with us, living normally, communicating with his brother and not on a drip alone in a room somewhere. So, it was an easy decision." (C2, parent)*

Healthcare professionals involved in the care of the children understood the importance of them living a normal life and tried to manage the treatment so the children could be discharged home to be with their families.

> *"The goal was comfort care and to potentially get her home; that was one of the things that her parents mentioned very often because she had only been in a hospital. She had never been home, and her parents wished she could be discharged home one day." (C6 doctor)*

Ensuring the child had a good life was connected with the desire to do what is best for the child. While healthcare professionals understood the importance of children living a normal life, the perception of what is best for the child was not always shared by parents and healthcare professionals. This discordance in their opinions resulted in disagreements and conflicts in some cases. In contrast, some healthcare professionals acknowledged they have different opinions regarding quality of life to the parents.

> *"The primary effort is basically addressing not what that parents want but what we think is good for that child. We're convinced of that, but of course, in the end that may not be true because we know less about that family's*

> *value system than the parents do. We're just trying to act in the best interest of the patient, but at the same time, it's not a dogma." (C6 doctor)*

To maintain a normal life and to be at home was also important during end-of-life care. The support of healthcare professionals was necessary to enable the wish of parents. Healthcare professionals provided highly individual care to the families, often going beyond what could be considered standard care.

> *"What we perceived from their (parents') side was that Elisa didn't want to go to hospital. We did not contradict this, but on the contrary, we supported his (father's) decision. But it certainly put a lot of extra strain on all the clinicians. But on the other hand, we saw that that the father managed the care at his end and that everything was just as Elisa wanted it to be." (C3 doctor)*

During end-of-life care, healthcare professionals valued support from the palliative care team, and this type of support is presented in the latter category.

4.6.2 Protecting the child from suffering

For parents and healthcare professionals it was paramount to protect children from suffering. Parents did not want to make the children's state worse and were reluctant to agree with treatment which would have a negative impact on their life. Parents also used experiences they had with medical care for their children in similar events when deciding about treatment. Parents were reluctant to agree with treatment which they perceived that previously caused suffering to the children. Similarly healthcare professionals made decisions with the intention to ensure that the outcome of the decision would not lead to a worsening of the children's health state.

> *"… we discussed that the tracheostomy would be for the mother an unacceptable deterioration of the quality of life (of Anna). She would have reached the tracheostomy in a state where she would have been even worse, I think, and there wasn't much hope that she would be better, that she would at least be as she is now." (C5 doctor)*

The quality of life was more important than the length for both parents and healthcare professionals alike. Prolonging life of the children while causing additional suffering or extending suffering was perceived as unacceptable. Ethical aspects of decisions to prolong children's lives, particularly when such actions might cause additional suffering, were considered by healthcare professionals.

> *"I think Anna was through enough, and we couldn't handle watching her to be on the machines. It is hard, but we'd rather let her go away in some good way of living. I'd rather have her to have a good two or three years than to have her on machines for ten years in hospital. We don't want this." (C5 parent)*

The perception of what is unacceptable suffering was individual, based on the overall state of the child, their prognosis and family lifestyle. In case two, the side effects of the treatment, including nausea, vomiting, sleep disturbance and mood changes, were perceived as unacceptable by the father.

> *“We felt like there was a worsening tendency of the reaction to the chemotherapy, and we just knew that if we kept doing it, it was wrong. It was very clear because he wasn’t sleeping, he wasn’t eating, he was vomiting.” (C2 parent)*

Parents used their own judgment to assess if the child was suffering or not, but, when possible, they relied on the children to guide their decisions. The involvement of children in the decision-making represents the next subcategory.

4.6.3 Including the child

It was important for parents to acknowledge what their children wanted and to include them in the decision-making. How the children participated varied, depending on their health, mental ability, and age. Parents were aware of the children’s dependency on adults and their inability to express their feelings and preferences accurately because of their young age or mental impairment. Parents of non-verbal or severely disabled children used non-verbal signs their children were showing to assess their will to live. They relied on the close relationships they had with their children which helped them to navigate through the decision-making and to make decisions on their behalf.

> *“I just wanted Julia to make that decision herself, to show that it made sense. I kind of wanted to see it (that she wants to live), rather than me deciding it or the doctors deciding it, that I was like, well, if she wants to, then let her have that chance.” (C6 mother)*

Parents of older and mentally mature children wanted to be honest with them and disclose the truth about their diagnosis and prognosis, but this was often challenging. Some parents needed months or even years before they were able to have an open conversation with their child. The parental need to have enough time was presented in the first category.

> *"In January this year, we told him. He has a cool personality; yeah, he's so phlegmatic and can mentally handle his situation. I took it worse than he did. He knows now, and I'm so much more relaxed that I'm telling him the truth, and there are no secrets". (C4 father)*

Including children in the decision-making was also seen as important by healthcare professionals, especially during the end-of-life stage. Preferences of the children at this stage were considered by healthcare professionals and the treatment was planned accordingly.

> *"I think the comfort of the child and her mood is very important in it, because no child wants to be in a hospital, and everybody wants to be at home and be in peace. And in this case, when we're talking about the last few weeks and months of her life, I think that even such a young child can express her preference in that." (C3 doctor)*

The Child category presented how children influenced the decision-making of parents and healthcare professionals, the next category is focused on parents.

4.7 Category 3: Parents

Parents felt responsible for their children and the choices they made. Parents relied on their trust in healthcare professionals, lack of trust made the experience challenging. Parents struggled with physical exhaustion and emotional stress. Some parents found comfort in their spiritual beliefs. The close relationship between the parent and child, from the perspective of the parent participants, was a strong theme in their accounts and is reflected in this category and its four subcategories: Responsibility for the Child; Trust in Healthcare Professionals; Physical and Mental Wellbeing; and Faith and Spirituality.

4.7.1 Responsibility for the child

Parents felt responsible for their children and the decisions. Sense of responsibility was perceived by parents as an integral part of the parental role. They felt responsible not only for the decisions but also for the consequences of those decisions.

> *"Of course, it was a difficult decision because we also realised that maybe our decision might not be the right one. But this is the responsibility of us as parents." (C2 father)*

Not all parents felt confident to be responsible for the decisions. For some parents, the sense of responsibility was challenging and they experienced intensive emotions of a worry, burden and regret.

> *"I felt a terrible responsibility, and I still feel it to this day, just a big responsibility. For that decision and for my daughter, too. Just a terrible*

> *weight of making the decision and having to face the consequences." (C6 mother)*

Responsibility for the ill child was experienced as more demanding compared to the sense of responsibility parents had for their healthy children.

4.7.2 Trust in healthcare professionals

Trust between parents and healthcare professionals represented an important aspect of decision-making. Trust influenced the relationship between parents and healthcare professionals. Parents build their trust in healthcare professionals over time. Knowing the healthcare professionals for a long time and an established relationship supported the parental sense of trust. Trust was strengthened further by positive perception of medical expertise and experience of the healthcare professionals. A trusting relationship enabled the avoidance of conflicts and to reach agreement even when the preferences of parents and healthcare professionals were not aligned.

> *"Yeah, I have confidence in them; we've been going there for years. I don't need to interfere with something I don't even, like, understand. I don't think so. What would I tell them? What to do, how to treat him? Surely not." (C8, mother)*

The ability of parents to build trust was hindered by previous negative experiences within the healthcare setting. Parental lack of trust in healthcare professionals negatively affected their communication and decision-making. Healthcare professionals experienced difficulties to form a relationship with parents when they did not trust them.

> *"I didn't feel like she had complete trust in us because maybe her trust in doctors in general, was already terribly broken from those previous experiences." (C9, doctor)*

4.7.3 Physical and mental wellbeing

Parents' physical and mental health influenced their ability to make decisions. Parents felt exhausted and overwhelmed by the care they had to provide to their ill child while managing other responsibilities. Parents had to deal with other life events which required their attention, such as illness or death in the family, managing a family business, facing financial difficulties or being a sole parent. This made them question if the choices are the right ones for the child and the family.

> *"The treatment or the care after the chemotherapy was extremely demanding. I was taking care of my older son, driving him every day (to nursery), driving my wife with our son to the hospital every day. It was insane. I just couldn't handle it. So, we said that the treatment is not for us." (C2 father)*

Parents were required to take care of their children and make decisions regardless of their own health problems, including making decisions immediately after giving birth. Health conditions would affect parental ability to make decisions for the child.

> *"I was in a very emotionally challenging situation, just after giving birth, the decision-making is not completely cool-headed, my condition interferes with it. They can't be separated from each other and the decision-making must be necessarily influenced by it." (C6 mother)*

Being a parents of seriously ill child had an adverse impact on parental mental health. Parents felt depressed, upset, irritated, and overwhelmed. The experience was described as devastating and crushing. Unexpected situations, such as getting diagnosed after birth or a sudden worsening of health, resulted in parents feeling shocked and stressed. Decisions about limitation of care or a do-not-resuscitate order were especially difficult for parents to make. The disturbance of mental health experienced by parents impacted their ability to take care of the children and make informed decisions. Some parents therefore reached out for psychological help.

> *"I was so deeply depressed that I just couldn't even look after the kids anymore. I was standing helplessly in the room, not knowing what I should do. I was terrified of the carpet, that it was swaying, yeah. It just completely blew my mind. Well, she (psychologist) just got me back functional within a year." (C4 father)*

Emotionally challenging were situations when the parents had to make decisions alone, without their spouse. Such situations were caused by hospital visiting regulations or the Covid-19 pandemic. Situations were also stressful when they had to make decisions quickly and under time pressure. The need of parents to have enough time to make decisions and discuss their choices with someone close to them was presented in the first category.

> *"I was stressed out, crying while on the phone with my husband because he was not there because of covid, they didn't let us in much. So, I made one of the worst decisions of my life, and again, I got criticised." (C9, mother)*

The emotional state of parents was further affected by the behaviour of healthcare professionals. Interactions with healthcare professionals perceived by parents as unpleasant made them feel angry, upset, exhausted, anxious and stressed. Parents wanted to be taken seriously and be treated with respect. Criticism and rudeness from healthcare professionals made parents feel insecure and question their own decisions.

4.7.4 Faith and spirituality

The wellbeing of parents was strengthened by their faith and spirituality. Faith gave parents a sense of support and guidance in their life. Religious parents felt empowered by faith. It helped them to face difficult situations experienced with their children and to accept their illness. Faith in God helped parent to make choices for the children. Parents put their trust in God and let the divine to make the decision for the child.

> *"It (faith) helps me a lot in the decision-making, and it's important. When I really don't know, when I'm not able to make a decision, I really just put it in his (God's) hands". (C7 mother)*

The sense of connection with something greater than themselves helped parents to make choices and not to lose hope.

4.8 Category 4: Family

The Family category reflects the influence the family (including extended family) of the ill child has on decision-making for both parents and healthcare professionals. For parents, it denoted the interplay between the focus on their ill child and external realities, influences and demands of family life. Support provided by wider family was especially important for parents. For healthcare professionals understanding family needs and values and aligning medical care with these shaped how decisions were made. This category comprised three subcategories: Family Needs and Values; Family Structure; and Family Support.

4.8.1 Family needs and values

The needs of other family members and the family as whole together with the value system uphold by the family were considered by parents and healthcare professionals. The knowledge healthcare professionals had about family needs and values was limited. Exploring family needs and values was necessary to provide value laden medical care.

> *"We tried to include the ideas of parents in the care planning. What is best for their child, what is their value system, and what is the quality of life for them. Because we know very little about the family's value system compared to the parents, therefore it is necessary to involve them in that. (C6 doctor)*

Caring for an ill child represented a challenge for parents, who had to manage the needs and care for other family members, including healthy siblings. Parents were worried how they will manage the care for the ill child together with the care required by their other children. To be able to satisfy different needs of all family members, some parents split the care of their children between themselves, but this approach was not acceptable for all families. Parents and healthcare professionals therefore thought of how the outcomes of the decisions would affect their life at home and whether they would be able to maintain their desired lifestyle. Parents were also concerned that the decisions would cause changes to which they would have to get used to.

> *"We are a bigger family after all. We don't have just one kid, and it would be so limiting for me and the whole family. The idea of it, that he's hooked up somewhere for a long time where I can't be, I can't imagine that." (C1 mother)*

Practical aspects of the necessary care were also considered. Parents and healthcare professionals reflected that interventions which would lead to a prolonged or frequent hospitalisations were not acceptable for them as it would impact the life of the whole family. Another practical aspect was the distance the family lived from the hospital, which was affecting their ability to travel for the required treatment

> *"Well, what type of dialysis? It was based on the fact that they live where they live, where they are from (the countryside). And also, it is such a long-term thing; therefore, the idea that they would drive somewhere was illusory." (C8 doctor)*

For parents, to have a realistic perception of how the decision will impact the whole family and their everyday life was difficult as they struggled to get a full understanding of the procedures, and the care required. They lacked this type of information from healthcare professionals and reached to other sources, as identified in the first category.

> *"It was challenging because I couldn't imagine it. I needed to hear it from more people or know someone with the feeding tube. I did not know anyone till then. I needed them to explain to me what life looks like with it (feeding tube) from other parents." (C5 mother)*

Family needs and values affected how the decisions were made. Exploration of the needs and values was identified as necessary in order to make decisions reflecting parental preferences.

4.8.2 Family structure

The structure of the child's family affected parents during care provision and decision-making. Two-parent families relied on reciprocal support when taking care of the ill child. Married parents reflected on the importance to include the other parent in the decision-making and make decisions together. Situations, which required fast decisions, and where the other parent was not present, were experienced as stressful.

> *"Most of the time, we always discuss important decisions together, but we mostly have the same opinion, we do not disagree that he wants something*

> *else, I want something else. We always do what is best for Lucas." (C8 mother)*

Single parents had to make decisions on their own, without the other parent. This caused an additional stress for them. They were overwhelmed with the intensity of the care they had to provide to their child and were exhausted as they did not have time for their own physical and mental regeneration. The total dependency of the child on them, and the reality that nobody could replace them in the care provision worried them.

> *"I found out that it can't work without me. If anything were to happen to me, nobody could take care of this boy. Well, of course, the doctors, so he would be in the hospital, but without me, he wouldn't make it there. He's not well now, so he's quite dependent on me, I would say." (C10 mother)*

Single parents faced other challenges connected with being the sole provider for the family. Balancing care for the child with paid employment and securing the family financially was particularly demanding when the child has sudden onset of the disease. The support from other family members was important for them.

4.8.3 Family support

The wider family represented an important source of support for parents. Parents valued mental support provided by their own parents or siblings. This form of support was especially important for single parents, who lacked the support of a spouse.

> *"I was there (in hospital) with my sister, she really wanted to support me. She wanted to hear it from them, and we were putting our thoughts together because Thomas's mum didn't go once to the hospital. I was glad that my sister could see the doctors, and we discussed it all. And this helped me to reach the decision to agree with the treatment." (C4 father)*

Parents relied on the family for support with everyday tasks, domestic chores and transport to the hospital.

> *"I get support from my mum; she comes here and helps me. My father drives us to the doctors, and he does shopping for us, so we have some groceries here." (C10 mother)*

Help from family lessened the intensity of the care parents had to provide. Lack of support from family members was a source of frustration and anger.

4.9 Category 5: Environment

This category relates to the environment. The impact of the hospital setting was dominant in the parental narratives, who were affected particularly by the visitation policy and access to facilities. Time was impacted both participants indifferent ways, it was identified as an important influence on parental involvement and as an environmental constraint for healthcare professionals. The decision-making was supported by the involvement of the paediatric palliative care team. This category consists of three subcategories: Hospital setting; Time; and Paediatric Palliative Care Team.

4.9.1 Hospital setting

Hospital setting was identified to impact parental wellbeing. Hospital facilities were experienced by parents as uncomfortable and insufficient to cover their basic needs. Due to uncomfortable sleeping conditions provided by the hospital, parents were not able to get enough sleep during the night and felt exhausted or experienced health problems, such as migraines. Tiredness and lack of sleep made it difficult for them to make decisions and care for their children.

Access to refreshments represented another barrier related to the hospital environment. Parents did not have access to meals at the ward, therefore they had to leave the child's bedside to eat. Leaving the child alone without their supervision was experienced by parents as stressful. The reluctance to leave the child unattended affected parental decision-making.

> *"It's crazy in the hospital, you're lying there, but we (parents) have to go downstairs to get food. It's ridiculous; every day I go there, and every day I get lost. For me, it was so stressful to leave the boy alone in the room for a long time. I need to be with him all the time, so I know what's going on." (C10 mother)*

Although parents wanted to accompany their child and stay in the hospital, it was not always allowed. The hospital utilised a restricted visiting policy which represented a barrier for parental participation in decision-making. When parents were not physically present at the hospital, they were informed about the child's health over the phone. They had to make decisions based on the information they received from healthcare professionals without fully understanding the consequences.

> *“They (doctors) called; I wasn’t there with her. I left. I wasn’t allowed to be in the intensive care unit overnight. And when I called to see how she was doing, they said she was in a critical condition. We had to make a decision. At that point we wanted them to do everything for her. Only after the doctors explained what it would look like if they did everything possible, like resuscitation or intubation, but at that point I didn’t know anything.”(C5 mother)*

Limited presence of parents during hospitalisation of their child thus affected their access to information, which was earlier identified as prerequisite for their involvement in decision-making.

4.9.2 Time

Decision-making was affected by the time parents and healthcare professionals had available. Parents lacked time when they had to make urgent decision and were not able to gather all the information they required to make informed decisions. Time pressure affected the ability of parents to discuss the decision with other family members or friends and reach an outcome together, which was perceived as crucial by some parents when making decisions on behalf of the children.

> *“I’m not able to make decisions that quickly, I just can't. I have to let it go through my head. Well, there was that problem again. Like, we're procrastinating because we can't make up our minds right away. But I don't think you can make a decision in an hour. We needed to absorb the*

> *information, to discuss it with somebody, to have an explanation of what they expect from it". (C2, father)*

Healthcare professionals needed time to gather medical evidence and consult the decisions with their colleagues. Including parents in the decision-making was time consuming, as healthcare professionals needed to spend additional time with the families. For some, finding the time to include parents was difficult because of their heavy workload. In some cases, the healthcare professionals perceived the time invested into the communication as worthy of the outcomes.

> *"Yeah, well, it was a few meetings with the family. It was about three hour-long conversations. But it was worth it. Yeah, it was beneficial because, over a period, we were able to figure out what to do with him (the child)." (C1, doctor)*

The amount of time required to make a decision was viewed differently by parents and healthcare professionals. This discrepancy impacted communication between them, and lead to conflicts and disappointments.

4.9.3 Paediatric palliative care team

The involvement of the paediatric palliative care team supported the decision-making by facilitating communication between parents and healthcare professionals. This was done by providing a safe and supportive environment, offering frequent consultations and providing opportunity to ask questions. This approach enabled repeated discussions, which gave parents additional time to think about their decisions and encouraged them to share their care preferences and discuss different care options. The communication between parents and healthcare professionals was facilitated also by bringing together specialists from various departments. Involvement of the paediatric palliative care team enabled them to look at the whole situation from a different perspective and to think about topics parents and healthcare professionals did not think about or tried to avoid.

> *"It [the palliative care team] placed me somewhere else a bit; I sort of turned myself in a different direction. Personally, I think it helped me a lot. Because they talked about things about which people would not think about or would push them away. We sort of dealt with it gradually during the consultations because there were more consultations. And there was space in between to think about it." (C1 mother)*

Facilitation of communication was especially important when events of disagreement or conflict between parents and healthcare professionals arose. In these situations, the paediatric palliative care team acted as a mediator and mitigated the conflict. The neutral role of the paediatric palliative care team, together with the supportive approach helped to reach an agreement and avoid further escalation of conflict.

> *"Well, without them (the palliative care team), we wouldn't be able to agree together. Communication with the palliative team was crucial for us, and there was a wider team of people. It was obvious that they were supporting us, so this was good." (C2 father)*

Having an opportunity to talk about their own preferences and have an honest, open and respectful communication empowered parents to participate in decision-making. Because of the involvement of paediatric palliative care team parents felt more confident in their parental role. As a result, parents expressed their care preferences and opinions during consultations and had the strength to insist on them.

> *"I feel a big support in you are strong, you are strong, and we support you in that, and we just know that you can do it. They didn't try to direct us differently but understood that we were functioning well. The service is very important." (C7 mother)*

For healthcare professionals the paediatric palliative care team was a valuable source of support during difficult conversations with parents and care management. Input of the palliative care team was especially welcomed during conversations about limitation of care or advance care planning. By inviting the paediatric palliative care team to participate in the medical care, healthcare professionals could share the responsibilities and have support from other specialists.

> *"I was a little bit relieved. I felt that I was carrying the weight of all that care, and I can't sort it all out because I'm not an expert on all of it. So, I was slightly relieved that the burden of the responsibility for the child was shared with the other specialists and that the child had more complex care." (C1 doctor)*

Support from the paediatric palliative care was important also during end-of-life care, and it helped to align care provision with the parental preferences and the preferences of the ill child.

4.9 Category 6: Decision-making approach

Parents and healthcare professionals used different approaches during decision-making. Shared approach enabled to reach decisions together through communication and discussion. Parent-guided approach highlights the role of parents and their ability to influence the outcome. The physician-driven approach reflects the position of healthcare professionals and their power to influence how parents make decisions. This category consists of three subcategories: Shared Approach; Parent-Guided Approach; and Physician-Driven Approach.

4.9.3 Shared approach

Reaching a mutually shared agreement during decision-making was perceived as important by parents and healthcare professionals. Healthcare professionals preferred consensus, as it helped to maintain a positive and collaborative relationship with the parents and keep their trust. The shared decision-making approach was supported by an established trusting relationship, open communication and discussions about treatment options. Aligned opinions of parents and healthcare professionals regarding treatment also enabled them to reach mutually shared decisions.

> *"I really felt like the mother had an insight and that we actually sort of talked it all through during the consultation. I told the mother what was possible and what was sensible from my point of view. And she commented on that as well, and from this, we reached the consensus between us." (C5 doctor)*

During shared decision-making, parents relied on advice and recommendations from healthcare professionals, which helped them to be actively involved in the decision-making and make the decisions together. Access to information was another prerequisite for their active involvement (Category 1).

> *"We definitely let them give us advice, like half and half, but still I wanted to be able to say what I think, together with my husband." (C5, mother)*

Respecting parents and their preferences while giving them opportunity to voice their opinions were identified as an enabler to gain consensus and avoid conflicts. Supporting parents was an integral part of shared decision-making.

> *"We were trying to do shared decision-making. We were looking at how parents approached the situation so that we could reach the goal of care. We were trying to incorporate parents' ideas into it and what they think is best for their child, their perception and value system. We were leaning towards the fact that the procedure would be unacceptable for them." (C6, doctor)*

Different opinions and the inability to have open communication and discussion, made the process of reaching a shared agreement challenging or even impossible and could result in conflict. Involvement of the paediatric palliative care team was identified as beneficial in a situation when reaching consensus between parents and healthcare professionals was difficult.

4.9.4 Parent-guided approach

Parents wanted to participate in the decision-making and influence the outcomes. They were able to guide the decision-making by expressing their opinions and preferences regarding medical care and treatment for their children. Opportunities when they could share their opinions regarding treatment were valued by them. It was important that healthcare professionals considered their suggestions seriously. Although parents wanted to guide the decision-making, they also valued advice and guidance by healthcare professionals.

> *"Yeah, we had the opportunity to interfere; we could specify what we want and what kind of journey we want. And the doctor actually accommodated the care to our preferences. Like, to us. We wanted to have our say, my husband and me." (C5 mother)*

Parents wanted to be able to guide the decision-making without being judged or questioned. Situations in which parents felt disrespected and not being listened to were difficult to manage and resulted in unpleasant interactions between parents and healthcare professionals.

> *"I didn't want to take blood samples in the morning or in the evening, but I want them to do it in the afternoon. I arranged it with the doctor, and*

> *then the nurse comes and takes him from me in the evening. And I say, you’re not going anywhere, and she starts yelling at me that I don’t have a say in it.” (C7 mother)*

Challenging were also situations when parents had different opinions regarding medical care or treatment than healthcare professionals. When different opinions of parents were not taken seriously, parents experienced insecurity in their parental role and felt like they had to defend their choices. This could potentially result in parents losing control over what was happening. In case two, the father reached for external support to help him defend the choices he made for his son.

> *“So, we knew we didn’t want to continue (with the treatment), and the doctor didn’t want to hear anything about it. So, based on that, we contacted a lawyer”. (C2 father)*

Involvement of the paediatric palliative care team or a lawyer was identified to support parental ability to guide the decision-making. Their involvement helped parents to maintain their preferences and to reach consensus between parents and healthcare professionals. The court intervention was not seen by healthcare professionals as a desirable approach to be used during decision-making.

4.9.5 Physician-driven approach

Healthcare professionals were identified to have a control of the decision-making process, and of the parents. During communication with parents, healthcare professionals used various strategies to make parents agree with their recommendations or even to change their opinion. They influenced parental decisions by presenting the preferred option to parents as more favourable while suppressing other possible options. By using this technique, parents' attention was focused on the preferred option.

> *"We can point it (decision-making) in the direction we need a little bit, can't we? Of course, if you pick up one intervention, you can suppress the other and so on." (C8, doctor)*

Another strategy included the use of pressure and criticism during communication which made parents self-doubt their ability to make decisions, and they started to question if they made the right choices. This insecurity often resulted in parents agreeing with the medical care preferred by healthcare professionals even when they initially refused it. Parents would agree with healthcare professionals because they wanted to avoid further escalation of the distressing event, or to remove themselves from the situation.

> *"Well, she (doctor) came to me and said: What am I doing? Why am I refusing transfusion? So, I said, that's our decision. So again, she is so unpleasant to us, so I said you know what, just give it to him. So, this is what happened to my decision." (C9 mother)*

Healthcare professionals also controlled parental access to information, which was described in Category 1. Additionally, some decisions were done by the healthcare professionals only; parents were not participating in them or were not invited to do so. This was typically for decisions based on medical evidence, such as proceeding with surgery or resuscitation.

> *"The decision is done at the indication seminar, where all the department head doctors meet; surgeons are there, and they just go over it. All those findings of that patient, including ultrasounds, how the heart is functioning, and those parameters measured during that catheterisation. And from that, some conclusion is made." (C4 doctor)*

The three approaches to medical decision-making present in the decision-making category (shared, parent-guided, and physician-driven) demonstrated varying levels of power distribution and participation between parents and healthcare professionals.

In the following section the categories and their relationship with each other are presented in a conceptual model of medical decision-making.

4.10 Conceptual model of medical decision-making

The conceptual model depicts the tripartite structure of decision-making encompassing influencing factors, decision-makers, and decision-making approaches (Figure 5). The final presented category (Decision-making approach) is influenced by the other five categories (Information and Knowledge, Child, Parents, Family, and Environment). Information and knowledge are conceptualised as Cognitive factors, followed by Child-related factors (health status, preferences of the child, and quality of life considerations); Parental factors (responsibility towards the child, trust, parental wellbeing, and their faith); Family factors (family needs and values, family structures, and support systems); and Environmental factors (hospital setting, time, and access to palliative care team).

As presented in the model, the five influencing factors do not exist in isolation but interact with each other, creating a dynamic web of influences. The intensity of this influence on parents and healthcare professionals varies, with factors having a strong, medium or weak impact on decision-making. Factors with strong impact directly influence decision-making; factors with medium impact play a supporting role in decision-making, and weak factors have little impact but are considered.

There is variation in whether a factor has a strong, medium or weak influence depending on the decision maker (parent or healthcare professional). Cognitive and child factors have a strong influence for both parents and healthcare professionals. Parental and family factors have a medium influence for parents and weak influence for healthcare professionals. Environmental factors have medium influence on both decision-makers. In addition, the interactions between parents and healthcare professionals also influence decision-making; with healthcare professionals having a strong influence of decision-making for parents, and parents having a medium influence for healthcare professionals.

The interplay of the influencing factors with each other and the intensity of influence they exert on parents and healthcare professionals (and the influence these groups also exert on each other) determine the approach to medical decision-making; parent-guided, physician-driven, or shared. The parent-guided approach emphasises parental autonomy, while the physician-driven approach highlights the role of healthcare professionals in decision-making. The shared approach shows the collaboration between the decision-makers.

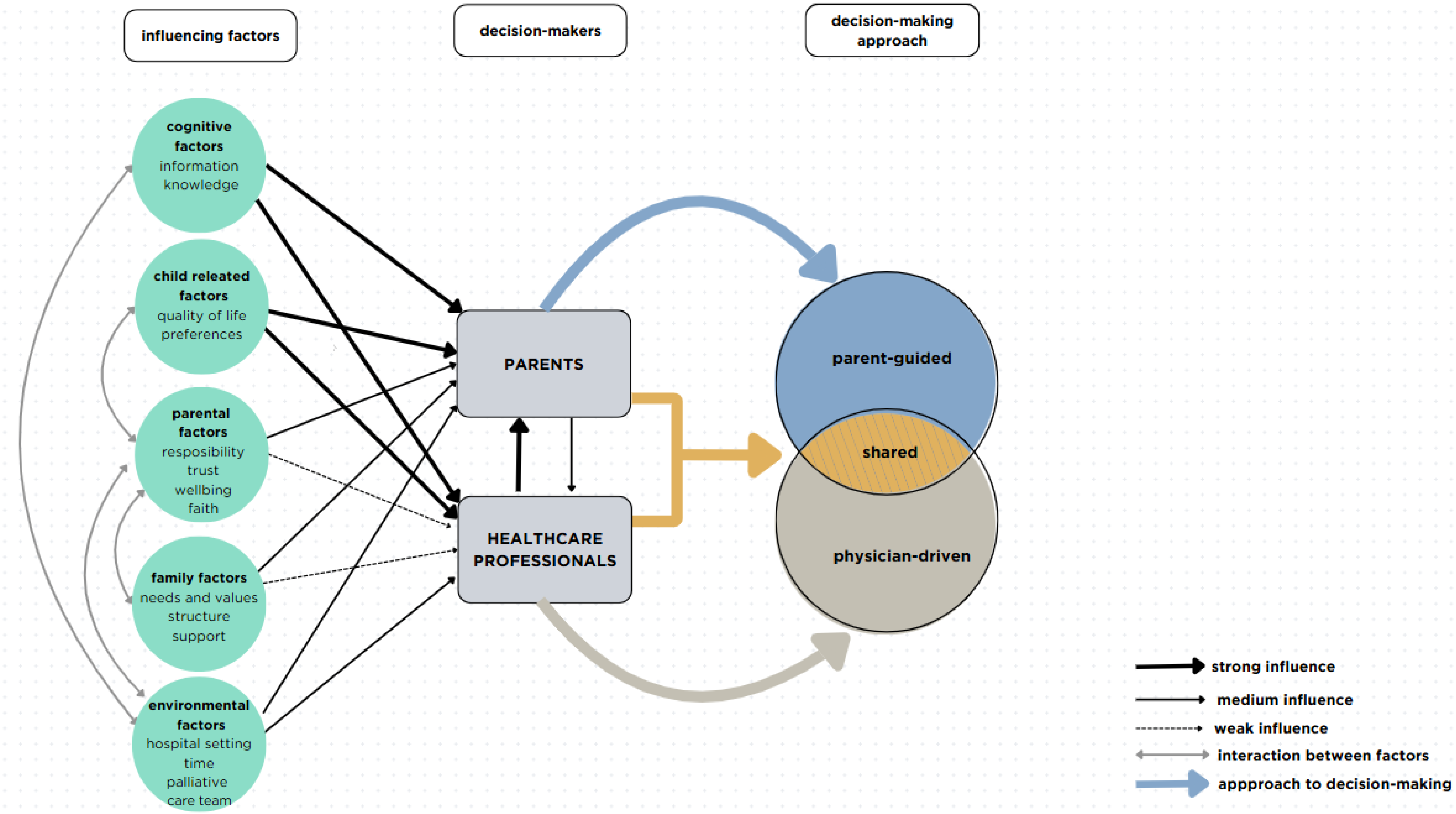


Figure 5 Conceptual model of factors influencing medical decision-making

4.10 Conclusion

In this chapter, the six categories identified through the within-case and cross-case analysis were described. Five of the categories (Information and Knowledge, Child, Parents, Family, and Environment) capture the factors influencing parents and healthcare professionals. These were conceptualised in the theoretical model as Cognitive factors, Child-related factors; Parental factors; Family factors; and Environmental factors. The sixth category reflects the approaches of decision-making employed by parents and healthcare professionals.

The interplay between the influencing factors, the decision-makers, including the intensity of influence of these factors, and the association between the decision-making approaches were depicted in a conceptual model.

The conceptual model of factors influencing medical decision-making captures the complex dynamics of medical decision-making in paediatric healthcare. It presents decision-making as a spectrum ranging from parent-guided through shared decision making, to a physician-driven approach. The type of medical decision-making approach adopted is influenced by the factors, which exert different intensities of influence.

The study findings and the conceptual model are discussed in the context of wider literature in the next chapter.

Chapter 5. Discussion

5.1 Introduction

The previous chapter presented the findings of this qualitative multiple case study, focused on medical decision-making for children with life-limiting and life-threatening conditions. Six categories were identified; five as categories which influence decision making (Information and knowledge, Child, Parents, Family, and Environment); the sixth category being decision-making approaches. The interplay between the influencing-type categories on decision-making approaches was depicted in a conceptual model of medical decision-making.

In this chapter the model is explored through context of existing literature, including the literature review undertaken as part of this thesis. First, the model is presented, followed by discussion of the five categories of influencing factors (cognitive, child-related, parental, family, environmental factors) and of decision-making approaches. Next the implications for policy, practice and research are explored, followed by the strengths and limitations of the study, a section on reflexivity, and the conclusion.

5.2 Conceptual model of factors influencing medical decision-making

The conceptual model (Figure 5) presents five factors which influence medical decision-making (represented on the left side of the model). These influencing factors exert influence at two levels. First, some factors exert an influence on other influencing factors; environmental factors on parental and cognitive factors; family factors on parental factors; and child factors on parental factors. This influence is reciprocal rather than unidirectional.

Second, all the influencing factors exert an influence on the decision-makers (parents and healthcare professionals, represented in the centre of the model). The amount of influence these exert varies between factors and decision-maker; either strong, medium or weak influence and is in detail discussed below.

Cognitive factors in the model are shown to have strong influence on both parents and healthcare professionals. For parents, access to information is a necessary for their participation in decision-making. They also relied on their experiences which shaped their medical decision-making. For healthcare professionals, cognitive factors encompass clinical judgement, medical knowledge, and evidence application. In practice, knowledge often functions as a tool of professional authority rather than a shared resource (Joseph-Williams et al., 2014). The model suggests that access to information is a prerequisite for shared decision-making, but it does not fully capture the tensions around access to and ownership of knowledge.

Child-related factors also exert strong influence for both decision-makers, reflecting a growing emphasis on including children in decision making (Cai et al., 2023). Parents frequently act as interpreters of their child’s preferences, which validates the child’s perspective but can limit their direct involvement (Bennett & LeBaron, 2019).

Decisions are guided by the desire to preserve quality of life and minimize the suffering of the child, yet parents and professionals may conceptualize suffering differently (de Weerd et al., 2015; Salter, 2020). The model, however, does not fully reflect the underlying tension between protecting the child and supporting autonomy.

Parental and family factors have medium influence on parents and weak influence on professionals. These factors shape parents' engagement in decision-making in complex and sometimes contradictory ways: a strong sense of responsibility can enhance involvement but also induce stress. Trust, prior experiences, wellbeing, and family support affect parental participation in decision-making. These interrelated dynamics illustrate the variability and fragility of parental engagement.

Environmental factors exert medium influence for both parents and healthcare professionals and contextualize decision-making. Hospital restrictions, limited facilities, and time pressures can impede meaningful engagement, while paediatric palliative care team facilitates communication and support. The environmental factors underscore that decision-making is socially situated, with environmental conditions shaping the decisions (Dudley & Carr, 2004).

The model also shows the relationship between parents and healthcare professionals. Interactions between decision-makers are mutual but uneven: healthcare professionals have strong influence over parents, while parents exert medium influence on professionals. This mirrors findings in the literature, which emphasise power imbalances in healthcare settings (Boland et al., 2019; Joseph-Williams et al., 2014). The uneven influence presented in the conceptual model questions the idea of shared decision-making, shifting the balance towards physician-driven decisions despite the appearance of collaboration. Respect and open communication are essential for reducing these imbalances but challenging to achieve in practice.

The relative influence of factors on decision-makers leads to three types of decision; parent-guided, shared or physician-driven; all depicted to the right of the model.
The parent-guided approach reflects the parental desire for autonomy, supported by access to information and prior experience. Physician-driven decisions highlight professional authority justified by clinical expertise and the child’s best interest, but can marginalise parental input and reinforce hierarchical power imbalances. In the Czech context, this reflects a persistent paternalistic culture in paediatric healthcare (Daly et al., 2024; Dobiášová et al., 2021; Krizova & Simek, 2007). Shared decision-making represents a collaborative approach which balances individual influences and where parents and professionals negotiate treatment options together, grounded in mutual respect and trust (Jordan et al., 2020).

The conceptual model of factors influencing decision making effectively demonstrates the interplay of influencing factors and decision-making outcomes, but inevitably simplifies a complex, context-dependent process. Each identified factor—cognitive, child-related, parental, family, and environmental—is shaped by communication practices, cultural norms, systemic constraints, and power dynamics that the model cannot fully capture. Similarly, categorising outcomes as parent-guided, shared, or physician-driven is a practical heuristic, but in reality, decision-making is fluid, negotiated, and often shifts between or falls between these categories.

In the following sections the five influencing factors will be explored drawing on relevant literature, followed by discussion of decision-making approaches.

5.3 Cognitive factors: Information and knowledge

Information and knowledge are foundations for informed decision-making in paediatric healthcare. This study identified that access to information empowered parents to actively engage in the decision-making process and to make choices based on knowledge rather than emotions. This finding is consistent with the available literature on decision-making in paediatric medicine, which indicates that access to information is a prerequisite for parents to make informed decisions on behalf of their children (Allen, 2014; Boland et al., 2019; Hirata & Kobayashi, 2023). Having information also helps parents to manage their anxiety and forms a foundation for discussions about the medical care with the healthcare professionals (Balling & McCubbin, 2001).

Having access to information and making informed decisions enabled parents to get a better understanding of the outcomes of their decisions. The systematic review presented in this thesis identified that parents struggle to foresee the consequences of their decisions (Polakova et al., 2024). This present study extends that evidence by adding that parents also have difficulty envisioning the extent of care their child will require at home and how their everyday life will be affected by the decision. This is discussed further in section 5.6 below – Family factors

5.3.1 Sources of information

Parents obtain information from a variety of sources; the main source being healthcare professionals. This aligns with the wider literature which found that parents caring for children with life-threatening conditions relied on healthcare professionals to provide information (Kilicarslan-Toruner & Akgun-Citak, 2013; Knapp et al., 2011). Interestingly, although other research has found that parents seek a second opinion with other healthcare professionals (Allen, 2014; Mordechai et al., 2015; Polakova et al., 2024), this was not a source of information in this study.

Although healthcare professionals in this study were aware that parents relied on them for information, the information provided by them was perceived as insufficient by parents, who sought information from other sources, such as the internet, other parents, patient's groups or their family and friends. The use of the internet and other sources of information by parents has been found in previous research (Kilicarslan-Toruner & Akgun-Citak, 2013; Knapp et al., 2011; Zaal-Schuller, de Vos, et al., 2016). Another information source is other parents with similar experience as they can help develop an understanding of the potential implications of decisions. Existing research supports this, showing that contact with other parents helps parents to obtain required knowledge and ease their distress (Iversen et al., 2009; Zaal-Schuller, Willems, et al., 2016).

In this study, previous parental experiences with similar medical encounters were used to navigate their decisions and shaped how parents interpreted clinical information, anticipated possible outcomes, and weighted treatment options. Relying on previous encounters with illness or death was identified to be beneficial during decision-making in existing literature (Jonas et al., 2022). However, whilst other studies have identified the use of previous experiences with death in decision-making (Sharman et al., 2005), this was not found here. Previous experiences with similar healthcare situations can affect how parents assess and react to medical emergencies (Gross & Howard, 2001).

This study finding brings new evidence that accumulated experiences with a child's specific condition creates a knowledge base that parents draw upon for future medical decisions. Additionally, previous experiences acquired within the healthcare setting were identified in this study to affect parental trust in the system and healthcare professionals. Negatively experienced encounters with healthcare professionals can have a longstanding impact on their therapeutic relationship. This is discussed further in section 5.5.2.

5.3.2 Parental lack of medical knowledge

Parents lack medical expertise which hinders their ability to make decisions for their children. This results in parents not trusting their own judgement as a lay person and negatively affects their participation in discussions with healthcare professionals. Other studies in similar settings have also found that parents and patients tend to perceive their own medical knowledge as insufficient while healthcare professionals are seen as medical experts with education, expertise and knowledge, and thus have the power to make the decisions on their behalf (Joseph-Williams et al., 2014; Polakova et al., 2024).

Despite limited medical knowledge, parents perceive themselves as experts on their children and believe they know them better then healthcare professionals. In line with previous research (Balling & McCubbin, 2001), parents in this study were empowered by this perception and it led to an expectation of having more control over the provision of medical care.

Previous research has shown that parents with low health literacy are more likely to defer decisions to healthcare professionals and are not perceived as partners in their child's care (H. S. Yin et al., 2012). Parental health literacy was identified previously to impact on the child´s health outcomes (Lee et al., 2020; Zaidman et al., 2023). This study finding adds to the evidence that health literacy enables parents to engage in decision-making, but they are limited by their own perception of lacking medical knowledge. However, this study shows, that parents use experiential knowledge of their child as an important dimension of health literacy. Even when parents perceive their medical knowledge as limited, their lived expertise enables them to negotiate their role, assert authority, and actively participate in decision-making.

5.3.3 Clinical judgment and evidence

While parents depend on access to information provided by healthcare professionals, healthcare professionals make decisions grounded in their medical knowledge, expertise and evidence. Basing decisions on best available medical evidence, expertise and possible treatment options is a standard part of the decision-making process (Rennke et al., 2017).

In this study, healthcare professionals actively searched for information when they lacked experience and expertise. The lack of experience was similarly described in previous research with clinicians caring for children with medical complexities (McLorie et al., 2023).

Decisions were often made with colleagues, with the intention of identifying a suitable evidence-based treatment. Making decisions in collaboration with other specialists was previously identified as an effective strategy which promotes information-sharing and increases understanding of the patient's medical condition (Radcliffe et al., 2019). Involvement of the multidisciplinary team in the decision-making process can improve patient care and outcomes and reduce hospitalisation (Lanceley et al., 2008).

In this study, any decisions made using medical evidence were made by the healthcare professionals alone, and parents were not involved, only informed about the outcome. This behaviour represents the physician-driven approach identified in this study and aligns with previous literature on medical decision-making for children being made without including parents (Vemuri et al., 2022).

5.4 Child related factors: quality of life and inclusion

The wellbeing of the children and involving them in decisions are essential components in decision-making. This section will first examine wellbeing and how parents and healthcare professionals conceptualise quality of life and suffering in the context of care decisions. Next, involvement of the child in decision-making will be discussed.

5.4.1 Wellbeing of the children and its impact on the decision-making

The decision-making process is driven by the desire to ensure the best possible quality of life for the child. This is conceptualised in relation to the mundane and every day; with normal life seen as the child being at home with the family, participating in everyday activities, attending school, having social interactions, and limiting hospital admissions. This finding echoes the conclusions of a study exploring parental perspectives of quality of life of their children in paediatric palliative care which identified similar components of parental perception of what a good quality of life means (Gaab, 2015).

Parents also want their child to have a normal life during end-of-life care. This aligns with previous end-of-life care research where the parental need to ensure some level of normalcy in the child’s life influenced the decision-making process (Carroll et al., 2012). Having an opportunity to reclaim their child from the healthcare system and take care of the child in the home environment gives parents a chance to resume their parental autonomy and strengthens their parental role (Barrett et al., 2023). However, even in the home setting, parents are dependent on healthcare professionals to be able to care for the child and to maintaining normalcy in their child's life during the end-of-life stage.

Good quality of life is determined by the presence or absence of suffering, and both parents and healthcare professionals make decisions with the aim of limiting the child's suffering. Parents perceive suffering as the presence of distressing physical symptoms including pain, nausea, vomiting, restlessness, or seizures. This finding is in agreement with previous literature which described the presence of physical symptoms as influencing the perception of suffering (de Weerd et al., 2015; Gaab, 2015; Marcus et al., 2022). In line with the de Weerd et al. study (2015), this study found that the parents and healthcare professional have different perceptions of which symptoms are connected to suffering, with symptoms such as nausea or vomiting seen as treatment side effects by healthcare professionals but as indicating suffering by parents. This divergent conceptualisation aligns with previous findings that healthcare professionals and parents interpret children's suffering in different ways (de Weerd et al., 2015; Salter, 2020). This present study adds to the evidence whereby these different perceptions of suffering represent a potential source of misunderstanding and can lead to conflicts between parents and healthcare professionals during decision-making.

Consistent with de Weerd et al.'s (2015) findings, not only did both groups consider immediate suffering in their decision-making but also anticipated future suffering. Neither considered it acceptable to pursue life-extending treatments that would impose additional suffering on the child.

Notably, parents' desire to protect their child from suffering took precedence over their wish to maximise the child's life span. This internal conflict of wanting the child to live as long as possible, but not to impose additional suffering is consistent with previous research in the field of paediatric decision-making (Polakova et al., 2024).

5.4.2 Involvement of children in decision-making

Both parents and healthcare professionals consider it essential to include children in the decision-making, regardless of their developmental stage or cognitive impairment. The extent of children's involvement was influenced by the quality of the parent-child relationship, supporting previous findings by Madrigal et al. (2016) about the importance of the parent-child relationship in decision-making. The bond between parents and children enables parents to better understand and interpret their child's preferences and make decision on their behalf. This aligns with previous research indicating that parents view themselves as experts on their children, possessing deeper insight into their children's needs than any other party (Bennett & LeBaron, 2019; Zaal-Schuller, de Vos, et al., 2016).

Healthcare professionals also recognise the importance of acknowledging children's preferences, especially during the end-of-life phase. This finding is aligned with previous research focused on the involvement of children in medical decision-making (Badarau et al., 2017; Cai et al., 2023; Vaknin & Zisk-Rony, 2011). The importance of children being giving opportunity to express their preferences before their health deteriorates was also highlighted in a recent study conducted among healthcare professionals caring for dying children (McLorie et al., 2025).

The level of involvement depends on the age of the child, their developmental state or any cognitive impairment, which is similar to previous research (Coyne et al., 2014). Parents of children with intact mental capacity want to inform them about their condition and prognosis, hear their treatment preferences, and choose a place of care. Parents of non-verbal children use their body language and non-verbal signals to identify children's preferences and will to live, which is a recognised phenomenon among the parents of seriously ill children (Marcus et al., 2022; Sharman et al., 2005).

The participation of children in decision-making can be challenging due to concerns about protecting them and maintaining their hope, as well as the belief that they may not fully understand or cope with the information provided (Hirata & Kobayashi, 2023). Nevertheless, including children in decision-making supports their sense of being heard and valued by their caregivers (Coyne & Gallagher, 2011; Miller, 2009). This study adds to the evidence that participation of children in decision-making is important for caregivers in the cultural context of the Czech Republic. This is finding thus brings new evidence, that, despite the power imbalances and paternalism, Czech parents and healthcare professionals have desire to include children in decision-making.

5.5 Parental factors

For parents, decision-making is shaped by factors which relate directly to their personality and parental role; namely a sense of responsibility for the child, trust in healthcare professionals, and parents' overall wellbeing. These factors play a vital role in how parents' approach and participate in medical decisions for their children.

5.5.1 Sense of responsibility for the child

In this study, the parental commitment to their child was reflected in their perception of themselves as the stakeholder who is responsible for the decisions. Given, the paternalistic cultural setting of this study (Krizova & Simek, 2007), this is an important finding which highlights the universal perception of parents as the responsible parties for their children. As previous research has found, parental responsibility for medical decisions represents a key aspect of the parental role when taking care of child with life-limiting or life-threatening conditions (Barrett et al., 2023; Bennett & LeBaron, 2019; Hirata & Kobayashi, 2023).

For parents in this study being responsible for decisions also means being accountable for the potential consequences, which is a stressful experience. This is supported by previous research conducted with Jordanian mothers of children with palliative care needs where lack of confidence and fear of future guilt limited their ability to make independent decisions (Atout et al., 2017). Similar to the study by Carnevale (2007), this research found that being responsible for the decision is connected with the feeling of regret.

The sense of parental responsibility is further heightened by the urgency of the decision, and in emergency situations parents prefer the healthcare professionals to make the decisions. This is aligned with the findings of previous systematic reviews (Barrett et al., 2023; Polakova et al., 2024), where transferring responsibility to doctors represented an effective strategy used by parents to bypass responsibility and let the healthcare professionals be in control.

5.5.2 Parental trust in healthcare professionals during decision-making

Trust is an important issue in decision-making. The importance of trust in paediatric settings is not new; other research has found that higher levels of parental trust in healthcare professionals is associated with greater inclination of parents to participate in decision-making (Boland et al., 2019; Madrigal et al., 2022), while lack of trust can lead to conflicts (Forbat et al., 2015).

In this study, trust in healthcare professionals helped parents to perceive them as medical experts, follow their advice and avoid conflicts. This is consistent with the literature, which identifies that the perception of healthcare professionals as medical experts facilitates the development of trust among parents (Janvier et al., 2020).

In this study, the development of trust was further encouraged by the caring and empathetic attitude of healthcare professionals towards the child and the family, and by parental belief that healthcare professionals were doing what is best for the child. Showing interest and concern for the child and the family was previously reported to support parental trust in healthcare professionals (Hsiao et al., 2007; Janvier et al., 2020).

Aligned with the findings of previous research exploring trust in healthcare setting (Coyne & Gallagher, 2011; Gómez-Zúñiga et al., 2019), the sense of trust was connected to the length of the relationship between healthcare professionals and parents. Knowing healthcare professionals for an extended period helps parents to trust them and follow their advice.

Parental trust is impacted by previous interactions with healthcare professionals. Negatively perceived experiences within the healthcare setting have a longstanding impact and affect future relationships with other healthcare providers. This is an important finding as the long-term impact of challenging encounters within the healthcare setting on trust is not well understood (Madrigal et al., 2022), even though negative interactions with healthcare professionals are common among parents of children with life-limiting or life-threatening conditions (Janvier et al., 2020; Zaal-Schuller, Willems, et al., 2016). This finding thus expands current understanding of trust within healthcare setting (Dewan et al., 2024) by adding influence of previous negative experiences as an element which hinders parental trust in healthcare professionals. In paediatric medicine, parental trust in healthcare professionals is extremely fragile and can be easily hindered by approaching parents with lack of respect, dishonest communication and dismissal of parents being experts on their child (Barrett et al., 2023).

For healthcare professionals trust is also important, specifically maintaining a trusting relationship and not losing parental trust. This was demonstrated through their acceptance of parental preferences, or giving parents more time if needed, as long as these did not cause harm to the child. The trust healthcare professionals have in their patients is an understudied phenomenon in general medicine, and needs further research (Grob et al., 2019).

5.5.3 Physical, mental and spiritual wellbeing of parents and its impact on their ability to participate in decision-making

When taking care of an ill child, parents experience psychological distress which affects their ability to provide care for their child and to make decisions. This finding aligns with the study by Collins et al. (2020), which found that parenting children with life-limiting and life-threatening conditions has a severe impact on mental health and is associated with higher levels of stress, anxiety and depression. Similar to previous research conducted among parents of children with special needs (Caicedo, 2014), parents in this study reported experiencing intense emotional distress, including feelings of sadness, frustration, irritability and depression, and physical exhaustion when providing care to their child. The demanding nature of care left parents feeling physically and emotionally drained and overwhelmed by the responsibilities associated with care. Previous research supports this whereby caring for a child with complex medical conditions or a disability is associated with physical and emotional burden (Murphy et al., 2007) and leads to lower health-related quality of life for parents (Hatzmann et al., 2008).

This present study also revealed that making decisions shortly after giving birth was perceived as challenging, primarily due to the emotional vulnerability experienced by mothers after labour. This is consistent with previous research where disclosing information about the child's diagnosis immediately after birth had a negative effect on the parents' ability to participate in the decision-making process (Luz et al., 2017) and their involvement in the child's care (Pizur-Barnekow, 2010). Abdin et al. (2022) found that healthcare professionals are aware of the potential impact of decisions on parental psychological well-being but this was not identified in this research.

Decision-making for seriously ill newborns can be particularly difficult for parents because they are often processing intense emotions—such as shock, grief, anger or hope—while trying to absorb complex medical information (Luz et al., 2017; Piette et al., 2022). Limited medical knowledge, uncertainty about prognosis, and being overwhelmed with information can further hinder parental understanding and engagement in decision-making in the postpartum period (Piette et al., 2022). To provide a better support for parents in these moments, healthcare professionals should use clear, jargon-free language, break information into smaller portion, have repeated discussions, and provide parents visual or written materials (Beltran & Hamel, 2021). Parents can be further supported by having the conversations in a calm, private environment and by having enough time to process obtained information (Beltran & Hamel, 2021; Piette et al., 2022).

The ability of parents to engage in decision-making is affected by events in their personal lives, including illness or death of other family members. The need to care for other family members, such as parents or other children imposes additional stress on parents, and requires them to prioritise whom they will care for. This finding is particularly relevant in light of the sandwich generation phenomenon (Steiner & Fletcher, 2017), which requires parents to concurrently care for the child and their older parents, although this is not well understood within the context of parenting children with life-limiting or life-threatening conditions.

Spirituality and religious faith emerged as important factors shaping how parents approach medical decision-making for their children. Parents use faith and spirituality as a source of support, strength and guidance during decision-making and spirituality helps them to accept their child’s illness. The use of faith as both a guidance mechanism and a way to delegate decision-making responsibility to a higher power, is seen in other research which has documented the role of faith in medical decision-making (Allen, 2014; Boss et al., 2008; Jonas et al., 2022; Lipstein et al., 2012). Passing the authority to make a decision about the ill child to the divine is a common strategy among religious parents (Allen, 2014; Polakova et al., 2024). Additionally, this study identified that in adverse situations parents relied on their own spirituality and outlook on life.

The prominence of faith in parental decision-making emerged as a particularly noteworthy finding given the secularised cultural context of the study setting (Vido et al., 2016). This finding provides new evidence that Czech parents draw on faith even when they are not actively practicing religion, highlighting the need for spiritual support. This study finding supports the conclusion from previous research focused on death and dying in the same cultural setting which identified that religion was used as a coping mechanism in challenging life situations including illness or death of a loved one (Furstova et al., 2021).

5.6 Family factors

During the decision-making, both parents and healthcare professionals are influenced by factors related to the child’s family. Consideration of the needs of the broader family, the impact of treatment, and family values during decision-making enables value-laden care to be provided. For parents, support from a spouse or other family member eases the burden of decision-making.

5.6.1 Influence of family on decision-making: family needs and values

When treatment decisions are made for the ill child, parents and healthcare professionals consider how the decision and its consequences will affect the entire family. Other research has identified this as important in decision-making, as children with life-limiting and life-limiting conditions require intensive and time-consuming care (Caicedo, 2014; Lazzarin et al., 2018).

This study found that, although the impact of a decision on the family was a consideration for parents, they rarely had sufficient knowledge of what the impact on life at home would be. As identified in the systematic review parents struggle to make decisions which would have long-lasting impact on their life as they find it difficult to imagine the consequences (Polakova et al., 2024). Making decisions about invasive procedures such as tracheostomy or enteral feeding fills parents with uncertainty and a sense of limited understanding of the consequences. Similar uncertainties were described in a study exploring decision-making about initiating home mechanical ventilation by Rahman et al. (2021).

When making decisions, parents consider the practical aspects connected with the care, such as the frequency of hospital visits, the need for hospitalisations, the distance of their home from the hospital, and how to coordinate the needs of all their children. This reflects the conclusion of a recent systematic review, which highlighted the complex impact of chronically-ill children on siblings and the importance considering their needs (Tan et al., 2024). There was some evidence that in families with a single ill child, parents adjust their lifestyle to meet the child's needs, although this needs further exploration as there were only two single-child families in this study.

In contrast to previous research (Sharman et al., 2005), the financial impact of medical care was not identified as a consideration in this study. This could be influenced by the free medical care available in the Czech Republic (Kinkorová & Topolčan, 2012). Financial difficulties relating to the child's illness, such as caring responsibilities at home and during frequent hospitalisations, were described by single parents in this study. This aligns with existing knowledge about the financial burden that caring for ill child imposes on families, and that single parents are at a higher risk of experiencing financial difficulties (Callery, 1997; Granek et al., 2014; Klassen et al., 2012; Lin et al., 2024).

The current research found that both parents and healthcare professionals incorporate family needs and values into their decision-making. This finding aligns with Lipstein et al.' s (2012) research, which identified the influence of family values on parental decision-making. The recognition and integration of family values has been consistently identified as a crucial component and facilitator of shared decision-making in healthcare contexts (Gravel et al., 2006; Hirata & Kobayashi, 2023; Meert et al., 2013).

In this study, healthcare professionals were found to possess limited knowledge of the family values system, highlighting the need to explicitly ask parents about their values rather than making assumptions. This finding resonates with previous research by Boland et al. (2019) and Richards et al. (2018), which established that integrating family values into decision-making can be challenging, particularly when the stakeholders have divergent value systems that influence their decision-making approach (Kon, 2006).

In the current research healthcare professionals emphasised the importance of actively engaging with parents and thoroughly exploring their value systems to ensure that medical decisions aligned appropriately with families' preferences and lifestyle considerations. This is important finding within the cultural context of the study setting, as it shows, that Czech healthcare professionals include parents in the medical care and decision-making. This finding supports research by Hrdlickova et al. (2023) which found that healthcare professionals in paediatric settings tend to include parents in decision-making and respect their wishes. This evidence thus suggests that there is a change in the attitude of healthcare professionals towards decision-making as they are becoming less paternalistic and are valuing parental involvement in the decision-making. This study thus shows an actual shifts in clinical practice from a paternalistic decision-making, which has been prevalent in the Czech cultural setting (Daly et al., 2024; Dobiášová et al., 2021; Krizova & Simek, 2007).The finding

Nevertheless, it also indicates a discrepancy between the perspectives of healthcare professionals and the experiences of parents, who previously reported limited involvement in decision-making (Ratislavová et al., 2016; Sikorova & Kucova, 2012). This imbalance in experiences is also reflected in the relative influence of decision makers on each other identified in the model; with healthcare professionals exerting a strong influence over parents, while parents exert medium influence on professionals.

5.6.2 Support from family and family structure

Family represents an important source of support for parents. Similar to the findings by Lindeblad et al. (2007), this research also found that lack of support from family members is associated with negative emotions and frustration.

The structure of the family impacts how parents make decisions. For married couples, having a spouse to rely on and share responsibilities helps to alleviate the stress of making decisions. Previous research found similar patterns of spouses depending on each other during decision-making (Sharman et al., 2005; Yazdani et al., 2022). While Madrigal et al. (2016) found that support from a spouse was ranked by parents as less important than other types of support, the current research suggests otherwise. Reciprocal support between spouses enhances their decision-making capabilities, whereas lack of such support can create challenges for parents.

The research reveals unique challenges encountered by single parents caring for seriously ill children. This aligns with Granek et al.'s (2014) research showing that single parents of children with cancer experience cumulative stress arising from previous negative experiences within the former family.

Single parents have to make decisions, manage the care for the child and the household and secure employment without support from the former partner. These challenges mirror the stressors documented by Kelly and Ganog (2011) in their study of single parents caring for children with cancer. Single parents of ill children in the Czech Republic seek support from other family members when making decisions. The experience of single parents caring for seriously ill child in the Czech Republic is not well studied. This study thus offers a new insight into their experience and highlights the need for greater support of single parents’ households.

5.7 Environmental factors

Environmental factors have an important influence on the decision-making ability of parents and healthcare professionals. For parents, visiting hours restrictions, access to facilities, and time pressures are all barriers to decision-making. Time influences both parents and healthcare professionals, although perspectives about this vary. Finally, the role of the paediatric palliative care team and its ability to enhance communication and prevent conflicts is discussed in this section.

5.7.1 Hospital setting

Parents’ ability to make decisions is negatively affected by the hospital environment, especially by restricted visitation hours and insufficient access to hospital facilities. These findings are supported by previous research which identified the hospital setting as a major stressor for parents (Coyne, 1995; Dudley & Carr, 2004; Lam et al., 2006; Piette et al., 2022; Ygge & Arnetz, 2004). The finding about insufficient access to hospital facilities adds to the knowledge about the perceived impact of inadequate provision to satisfy basic needs such as sleeping, eating, and personal hygiene. This not only reduces the time parents can spend with their hospitalised children and makes them feel unwelcome in the hospital (Coyne, 1995; Lam et al., 2006; Shields et al., 2004), but also impacts their ability to make decisions for the child.

Parents in this study emphasised the effect of restricted visitation hours on their ability to make decisions. Not being allowed to stay with their child caused parents to see themselves as visitors who must adhere to the visitation hours rather than as a parent with an unlimited access to the own child. This echoes the findings of a previous study conducted in the Czech Republic, where mothers of hospitalised newborns reported not being able to be with their baby and feeling unwelcomed by the healthcare professionals (Sikorova & Kucova, 2012). This is disturbing, since the presence of parents during the hospitalisations of their children has long been established as a basic need for children and a right for parents (Platt, 1959; Shields et al., 2004; Thornes, 1983). Previous research has found that unrestricted visiting hours have a positive effect on parental overall satisfaction with provided care and can lower psychological distress experienced by parents (Garrouste-Orgeas et al., 2008).

This finding brings new evidence about how limited visiting hours negatively affect Czech parents and impacts their decision-making ability. The issue with restricted visitation hours in the Czech hospitals is frequently discussed topic within the Czech media space, and this study finding can support those discussions by bringing evidence about how parental ability to participate in decision-making is affected by their limited access to their child.

Sleeping and eating facilities for parents in the hospital are seen as important. Previous research has highlighted that inadequate facilities represent a source of stress for parents and can cause their mental and physical exhaustion (Coyne, 1995; Lam et al., 2006; Shields et al., 2004). In this study parents were reluctant to leave their child to attend to their own needs and felt exhausted, which supports Lam et al.'s (2006) finding that parents do not want to leave their child's bedside to care for their own personal needs.

Additionally, this study found that parents need sufficient sleep to be able to actively care for their children and make informed decisions during hospitalisation. The parental need to have a good quality sleep during hospitalisation was reported previously in study by Hagvall et al. (2016), whilst Meltzer et al. (2012) identified poor facilities as a sleep disruptor which affected parents during hospitalisation of their child. In the present study, parents' sleep was affected by uncomfortable sleeping provisions in the hospital, which was identified previously as one of the sleep disruptors affecting parents during their stay in the hospital (Meltzer et al., 2012).

5.7.2 Influence of time on decision-making

Time is a barrier to informed decision-making, for both patents and healthcare professionals, which is consistent with current literature (Boland et al., 2019; Gravel et al., 2006).

Parents need ‘enough’ time to gather information and gain understanding in order to make informed decisions. The importance of having ample time to process and accept the information obtained from healthcare professionals is supported by the findings of a systematic review into the informational needs of parents making end-of-life decisions for their children (Xafis et al., 2015). Consistent with the present study’s findings, Xafis et al. (2015), reported that temporal factors influence the ability of parents to gather, process, and utilise information for informed decision-making.

In this study, time constraints created pressure which served as a barrier for parents to engage in decision-making. This finding is in agreement with previous literature, where time pressure was reported as stressful and overwhelming for parents (Polakova et al., 2024; Zaal-Schuller, de Vos, et al., 2016). Additionally, time pressures can lead to disagreement and conflict between parents and healthcare professionals, which is a phenomenon reported in other research within a similar population (Zaal-Schuller, Willems, et al., 2016).

Time-related factors also influence healthcare professionals; gathering of information and including parents in decision-making are seen as time-demanding. This was compounded by the hospital setting where intensive workloads and lack of personnel restricted long consultations with parents. The latter reinforces the work of Légaré et al. (2008), who identified that heavy workload and limited human resources in healthcare settings can inhibit the engagement of patients in decision-making. Nevertheless, this study found that healthcare professionals consider the time invested in the effort to include parents as being worthy of the outcome.

Parents and healthcare professionals have divergent perspectives about what constitutes sufficient time to make a decision. Existing research indicated that while parents express a desire to have more time to make decisions (Rapoport et al., 2013; Xafis et al., 2015), decisions are often made and implemented within a short period of time (Oberender & Tibballs, 2011; Zawistowski & DeVita, 2004).

5.7.3 Paediatric palliative care team and its role during decision-making

The paediatric palliative care team is an important environmental factor which influences both parents and healthcare professionals during decision-making. Their involvement positively influences communication between parents and healthcare professionals and provides external support. This finding reflects existing literature, which concluded that the participation of palliative care teams enhances communication and improves parental satisfaction with care provision (Hays et al., 2006; Koch & Jones, 2018; Streuli et al., 2019).

Communication is further strengthened by bringing parents and various specialists together. This enables exploration of different perspectives and enhances the decision-making process. Within the cultural context of the study this is an important finding, as the involvement of patients and the family in the decision-making is limited and often does not reflect their preferences (Daly et al., 2024; Dobiášová et al., 2021; Krizova & Simek, 2007). It also supports the conclusion in a study by Hrdlickova et al. (2023), done in the same setting, which found that parents appreciate the presence of multiple specialists during consultations.

Involving the palliative care team was identified as providing support to parents and empowering them during communication with healthcare professionals. This support gave parents the opportunity to express their priorities and preferences without feeling judged or questioned.

As identified in existing research (Hrdlickova et al., 2023; Streuli et al., 2019), the consultation with the paediatric palliative care team was seen to provide an opportunity for parents to discuss a variety of topics with healthcare professionals and to share their concerns and preferences. The frequency of consultations with the palliative care team gave parents additional time to think about the information they received and to ask questions. Similar attributes have been reported as supporting parental engagement in communication, in a recent study conducted in the same setting (Hrdlickova et al., 2023). These finding also support previous research, which reported that access to the paediatric palliative care team gives parents a sense of security and support, and facilitates an effective communication in healthcare setting (Hsiao et al., 2007).

The findings of this PhD study show that the support provided by the paediatric palliative care team during the decision-making process is also valued by healthcare professionals. Paediatric palliative care teams are able to offer support during difficult conversations with parents, including discussions about advance care planning, limitation of care, end-of-life care or setting goals of care. The helpfulness of involving a palliative care team in those types of consultations was similarly reported in a study conducted among paediatric cardiologists (Balkin et al., 2017).

Involving the paediatric palliative care team allowed healthcare professionals to share medical responsibility for their patients and deliver more complex care to children. This finding aligns with previous research by Brandon et al. (2014), which showed that paediatric palliative care team involvement can reduce moral distress experienced by healthcare professionals when caring for paediatric patients.

In this present study, access to the paediatric palliative care team was controlled by healthcare professionals, who acted as gatekeepers, as similarly reported by Hrdlickova et al. (2023). The need for additional support during difficult consultations with parents was frequently identified as a motivating factor to involve the palliative care team. This aligns with Twamley et al.'s (2014) study, which reported that the most common reason for healthcare professionals for palliative care referral were challenging discussions about end-of-life preferences, including place of death.

Previous research has identified that paediatric healthcare settings are prone to disagreement and conflicts (Linney et al., 2019; Studdert et al., 2003). This present study similarly identified presence of conflicts during decision-making and brought new evidence about the important role of the paediatric palliative care team in their management and prevention. Through open communication and an empathetic approach towards parents, the palliative care team is seen to mediate relationships between parents and healthcare professionals. This supports previous research findings about the potential of palliative care teams to improve communication and decision-making (Streuli et al., 2019). The involvement of the team prevented conflict escalation and facilitated agreement between parents and healthcare professionals. Similarly, Chiarchiaro et al. (2016) found that the communicational approaches used by palliative care specialists helped to avoid conflicts with patients and their families.

5.8 Decision-making approaches utilised by parents and healthcare professionals

Available evidence suggests that parents of children with life-limiting conditions want to actively participate in decision-making (Allen, 2014; Zaal-Schuller et al., 2016). This present study indicates that the level of involvement in decision-making must be individually considered, as parental preferences may differ, and adopting a universal approach would not be suitable for all. For some parents, participation in decision-making was challenging and burdensome, and they preferred the healthcare professionals to be in charge of the decisions. In contrast to this finding, for other parents, it was important to be in control of decision-making which was perceived as an integral aspect of their parental role. This finding is aligned with previous research which identified that active participation empowers parents in their parental role and helps them to keep their parental identity (Barrett et al., 2023; Sullivan et al., 2020).

However, this study finding suggests that active participation of parents can be challenging to implement by healthcare professionals in everyday practice due to the time constraints, heavy workload and limited resources.

Additionally, parental decision-making when caring for a seriously ill child changes over the course of the illness (Fiks et al., 2012; Lipstein & Britto, 2015). Parental involvement is influenced by their emotional coping, prognostic understanding, and relationship dynamics with healthcare professionals (Park & Cho, 2018; Zaal-Schuller, Willems, et al., 2016). Initially, parental involvement in decision-making is limited by their emotional state after receiving diagnosis, limited knowledge and time urgency (Pyke-Grimm et al., 2006). Over time, parents become more confident and competent and their involvement increases (Gibson, 1995; Stewart et al., 2005). Parents in this present study reported a similar evolution in their decision-making. From an initial passive approach to decision-making and letting healthcare professionals be in control, they progressed into more active involvement and a greater desire to participate in decision-making.

Near the end-of-life, parents' decision-making shifts from focusing on medical interventions and treatment to prioritising quality of life and comfort care, while balancing hope with medical uncertainty (Barrett et al., 2023; Hirata & Kobayashi, 2023). Similar aspects of end-of-life decision-making were identified in this present study, where parents wanted to maintain hope and spend intimate time with their child, preferably at home. Available evidence suggests that the parental perception of how the decisions for their dying child were conducted has a long lasting impact on bereaved parents (Sullivan et al., 2020), but this aspect was not explored in this PhD study.

This present study shows, that the influencing factors (cognitive, child-related, parental, family, and environmental) exert a weak, medium or strong influence on the decision-makers, as discussed above. The relative influence of the factors on the decision-makers leads to three types of approach to decision making; parent-guided, shared or physician-driven.

The parent-guided approach highlights the ability of parents to navigate and influence the decision-making process. The physician-driven approach emphasises the authority and power owned by healthcare professionals. The third approach, shared decision-making, reflects the partnership, respect and collaboration between parents and healthcare professionals, and acknowledges the input of the ill children.

The three decision-making approaches identified in this PhD study will be explored below. First, however, consideration will be given to how the two types of decision-makers exert influence on each other through their relationships. As depicted in the model (Figure 5) healthcare professionals have a strong influence on parents, and parents have a medium influence on healthcare professionals.

5.8.1 Relationships between parents and healthcare professionals

Healthcare professionals influence parents and their engagement in decision-making. The impact of healthcare professionals on parental involvement in decision-making is a constant finding in the literature (Boland et al., 2019; Sullivan et al., 2014).

In this study, healthcare professionals empowered parents by acknowledging their parental expertise, giving them information and by establishing trusting relationships. Having trust in healthcare professionals, their medical expertise and belief in their good intentions enables parents to follow their advice and agree with the decisions. The importance of trust in healthcare professionals and their expertise was similarly identified in several studies included in the systematic review focused on parental decision-making experience (Polakova et al., 2024). Healthcare professionals influence parents during decision-making by giving them information. Aligned with existing research (Kilicarslan-Toruner & Akgun-Citak, 2013; Knapp et al., 2011) healthcare professionals represent the main source of information for parents. Gaining knowledge and understanding of the child’s condition empowers parents to actively engage in the decision-making process, a finding that has been reported in previous research on shared decision-making in paediatric healthcare (Cai et al., 2023; Park & Cho, 2018).

The interactions between parents and healthcare professionals are further influenced by the communication style used. Respectful communication is identified as important in decision-making. Healthcare professionals use persuasive communication strategies to influence the decision-making process, such as presenting their preferred option as more favourable and minimising other options, together with using repetition and pressure. Similar persuasive strategies have been previously reported in literature focused on decision-making (Birchley et al., 2017; October et al., 2020; Popejoy et al., 2022; Richards et al., 2018). In addition, the findings of this study identified that criticism was also used as a strategy to influence parental decision.

This finding highlights the need for adequate communication training for healthcare professionals, however available evidence shows that the training received by healthcare professionals is insufficient, despite recognising its importance in clinical practice (Hrdlickova et al., 2021). Healthcare professionals are often not prepared to have serious conversations with parents, including conversations about advanced care planning and end-of-life discussions (Snaman et al., 2016).

Discrepancies in communication and differing opinions about treatment approaches cause conflict between healthcare professionals and parents. Different perceptions of what is best for the child, lack of trust and time pressure are identified as the foundations for conflicts, supporting evidence in the literature about conflict in paediatric settings being commonly associated with poor communication and disagreement (Forbat et al., 2015; Linney et al., 2019; Studdert et al., 2003). For parents, the experience of conflict is stressful, as they feel they have to defend their parental role and find it difficult to be in disagreement with the healthcare professionals.

For both parents and healthcare professionals the paediatric palliative care team represented an effective mediator in conflicts, as previously discussed. Some parents used a lawyer as the third party, who empowered parents to insist on their preferences. Previous research has similarly reported the positive impact legal representation may have on situations when it is difficult to reach an agreement (Abdin et al., 2022; Larcher et al., 2015).

Healthcare professionals in this study felt they supported parents and treated them with respect. The study by Hrdlickova et al. (2023) similarly found that healthcare professionals emphasised their respectful approach towards parents. This is somewhat unexpected given the paternalistic context of the study setting (Krizova & Simek, 2007). It may indicate a willingness to include parents as partners in decision-making, however the divergent perceptions of the decision-making experienced by the participants, and the lack of respect parents described, are arguably at odds with this position. Additionally, parents were not involved in every decision made for the child and their preferences were not always acknowledged by healthcare professionals. This limited input was similarly reported in research in paediatric oncology (Badarau et al., 2017).

This finding suggests that healthcare professionals experience parental participation in decision-making differently than parents actually perceived their own involvement. Similar findings were reported in study by Vemuri et al. (2022), which reported that while healthcare professional perceived they had utilised a shared decision-making approach, their actions were more aligned with a physician-led approach. In this study, although the healthcare professionals believed they supported parents in active participation, this did not align with the parents' accounts.

A possible explanation of this finding is that healthcare professionals are not fully aware of how parents experience their own participation and how to empower parents in their participation, or of how to enable parents to act as equal partners in the decision-making, while respecting their individual preferences.

This finding brings new knowledge about why parents and healthcare professionals misunderstand each other and the impact of unequal power in relationships in the context of the Czech Republic.

5.8.2 Parent-guided approach in decision-making

The parent-guided approach, as identified in this study, represents the desire of parents to be in control of the decision-making process and be able to influence the outcomes. This finding aligns with previous research in the same cultural context (Houska et al., 2021; Hrdlickova et al., 2023), which showed that patients and families in the Czech Republic seek more autonomy in healthcare decisions. This study brings new evidence that Czech parents want to actively participate in decision-making and be autonomous in their parental role. This finding offers a new understanding how parents perceive their role in decision-making and it questions the paternalistic approach commonly practiced within the Czech healthcare system (Daly et al., 2024; Tietzova et al., 2024)

The parent-guided approach is one where parents are able to express their opinions about treatment and they are seriously considered by healthcare professionals, even when these opinions differ from the medical recommendation. Utilising the parent-guided approach enables parents to feel they are partners in decision-making, and to be more in control of the process. This finding shows that parents need support from healthcare professionals to be empowered to actively participate in decision- making and to be in control of the process. This is an important finding, as active involvement has a positive impact on parents, and was previously reported to make the experience of decision-making less stressful (Polakova et al., 2024), and to have a positive impact on post bereavement experience of parents (Sullivan et al., 2020).

This present study found that the parent-guided approach is dependent on parental access to information. The parental need for information is a consistent finding within decision-making research (Allen, 2014; Boland et al., 2019; Hirata & Kobayashi, 2023) and is in discussed in detail as an influencing factor above.

An important finding of this study is that parents use their previous experiences to navigate their medical decision-making. Previous experiences with similar situations helped them to get a better understanding of what is happening and how their decision will impact their child and the whole family. This finding supports existing research which found that previous encounters with similar medical decisions supported active parental engagement in decision-making, (Jonas et al., 2022). This current study additionally found that parents also consider how their child reacted to the treatments and interventions in previous instances and make their decisions based on that, with the aim to protect their child from additional suffering. This finding brings a new insight into parental approaches towards decision-making within the Czech cultural context.

Similar to previous research with parents of children with life-limiting conditions (Balling & McCubbin, 2001; McNeilly et al., 2017; Zaal-Schuller, Willems, et al., 2016) parents in this PhD study see themselves as experts on their child and feel responsible for the decisions. This perception empowers them to make decisions on the children's behalf and to guide the decision-making process.

This study adds evidence, that the parent-guided approach does not diminish the role of healthcare professionals; parents continued to value their medical expertise and appreciate their professional advice and guidance. Trust and established relationships between parents and healthcare providers enhances parental acceptances of their recommendations. This finding is aligned with other studies, which described the importance of trust and parental dependence on healthcare professionals (Madrigal et al., 2022; S. Mitchell et al., 2019; Pinto Taylor & Doolittle, 2020).

5.8.3 Physician-driven approach

This study has identified that healthcare professionals are often in control of the decision-making process; the physician-driven approach. Healthcare professionals have the power to make decisions without parents and to influence them. Previous research has described that the power is not equally distributed between decision-makers, with healthcare professionals occupying a stronger position than parents (Aarthun & Akerjordet, 2014; Boland et al., 2019; Joseph-Williams et al., 2014; Richards et al., 2018; Vemuri et al., 2022). Within the study setting of the Czech Republic, this finding suggests that the paternalistic approach towards decision-making is still present and practiced in paediatric medicine. Nevertheless, the study findings also show that paternalism is not as strongly utilised as could have been expected given the findings from previous research about how strongly embedded paternalism is within the Czech healthcare system (Daly et al., 2024; Dobiášová et al., 2021; Krizova & Simek, 2007). This study brings evidence that for some parents the physician-driven approach was acceptable or even preferred. This finding shows that Czech parents have varying preferences regarding their level of involvement in decision-making, and an individual approach is necessary to ascertain their preferences and respond to their needs.

This present study has brought evidence, that healthcare professionals use different strategies to control the decision-making process. The strategies spanned from guiding parents, across influencing parents, to making the decisions for them. Existing research has described similar approaches used during decision-making (Vemuri et al., 2022). Healthcare professionals perceived themselves as experts on medical care and could better judge the best option for the child and the family. Previous research has identified that healthcare professionals believe they are morally and ethically entitled to make medical decisions (Popejoy et al., 2022; Vemuri et al., 2022). In this study the choices reflected the aim of doing what is best for the child and protecting the child from suffering, which are similar sources of motivation when making decisions for paediatric patients found elsewhere (Birchley et al., 2017; Popejoy et al., 2022; Richards et al., 2018).

While healthcare professionals felt justified in their use of a physician-driven approach it was challenging for some parents. It influenced their ability to participate in the decision-making process and made parents more likely to defer to the healthcare professionals' judgement. Parents found it challenging to defend and assert their preferences for care. This finding supports the conclusions of the systematic review which identified that parents can be coerced or manipulated into a decision and pass the decisional authority onto healthcare professionals (Polakova et al., 2024).

The identification of physician-driven approach highlights the strong position healthcare professionals have in decision-making within the Czech cultural context. The finding that certain types of decisions are made without parents being involved shows that parents are not invited to all decision-making events. This tendency of Czech healthcare professionals to make decisions on behalf of the patients without asking their preferences were similarly identified in a study conducted in adult healthcare setting (Tietzova et al., 2024). Within the Czech paediatric setting, this in a novel finding.

While this study shows that paternalism is still present in the medical practice, the findings indicate a shift in actual practice as healthcare professionals included parents in decision-making and parents were identified as exerting an influence on healthcare professionals when decisions were made. Especially during end-of-life care, parents were able to express their wishes and preferences regarding medical care and were included in the decision-making process.

5.8.4 Shared decision-making approach

The shared decision-making approach is characterised by a collaborative process in which parents and healthcare professionals make decisions together in a respectful manner. Individual preferences and needs are considered. This finding is aligned with other research exploring shared decision-making, which identified similar characteristics (Jordan et al., 2020; Park & Cho, 2018).

This present study shows that respectful communication and a trusting relationship supported the use of a shared decision-making approach. Open discussion about the child's condition and available treatment options was an integral part of this. Other studies have similarly highlighted the need for open and honest communication in shared decision-making (Fiks & Jimenez, 2010; Park & Cho, 2018; Wellesley & Jenkins, 2009). Aligned treatment preferences and mutually shared perspectives of what was best for the chid enabled a consensus to be reached. This idea of a common goal has previously been identified as a key attribute of shared decision-making in paediatric healthcare (Park & Cho, 2018).

This present study found that parents need support and guidance from healthcare professionals to be able to participate in shared decision-making. This echoes other findings about lack of support being a barrier for shared decision-making in paediatric healthcare (Boland et al., 2016), and parents needing guidance during shared decision-making about their child with cancer, and welcomed being navigated by healthcare professionals (Huang et al., 2021). The present study further adds to understanding about support for parents by including reassurance from healthcare professionals, that parents made the right choice for their child, as a form of support.

This present study identified that the involvement of children was perceived as important, and children were included in a way which reflected their preferences and abilities. Whilst the notion that including the ill child in decisions about themselves is not new (Larcher et al., 2015), it is a novel finding within the cultural context of the study setting as it brings new insight into how the shared decision-making approach is being used in the Czech Republic. Research in other settings has found that parents and healthcare professionals believe that children should be involved in decisions as much as possible (Cai et al., 2023). The level of involvement of each child was not explored in this study; however the healthcare professionals emphasised their involvement at the end-of-life stage and wanted to honour their preferences regarding place of death. This increase in involvement during the later stage of the illness has been similarly described in research into children with cancer (Badarau et al., 2017). Within the Czech cultural context, the involvement of children during end-of-life stage were not yet studied, nor the position of parents and healthcare professionals towards their involvement. Therefore, this study offers a unique insight into how Czech parents and healthcare professionals think about children being involved in end-of-life decision-making.

For parents, including children in the shared approach was challenging as they had to disclose the truth about the condition and prognosis to the child. This supports the conclusion of previous research that parents want their children to collaborate in the decision-making, but face insecurities how to inform the child about what is happening (Huang et al., 2021).

5.9 Implications for practice

This thesis highlights the role parents have in the decision-making. Within healthcare practice, healthcare professionals should recognise and respect the parental preferred level of involvement and aligned decisions with the family’s preferences. Individualised approach which would reflect the family’s value system can lead to greater parental satisfaction with the care provision. Parents should be regarded as partners in their child’s care and be empowered to participate in the decision-making.

Since parents may not always fully understand the consequences of the decisions, healthcare professionals need to ensure that parents understand the implications not only for the child, but also for the family. Providing clear, realistic information can help parents to better understand the consequences.

The role of children in decision-making has shown to be acknowledged by both parents and healthcare professionals. Children should therefore be included in the conversations and parents should be supported in their involvement. Healthcare professionals should recognise parents as experts on their children and work closely with them to explore the child’s perspectives and preferences.

Healthcare professionals should be aware that parental ability to make decisions is affected also by their mental and physical wellbeing and their wider family. Parents should be able to have access to psychological and social support. Single parents represent a particularly vulnerable group and would benefit from additional support to address their unique needs.

This study has highlighted that hospital facilities affect parents’ ability to make decisions and care for their children. Hospital administrators need to be aware of this impact and take action to improve conditions, as parents are an integral part of the care dynamic. Hospital administrators need to provide adequate sleeping and eating facilities to ensure that parents can get sufficient rest, attend to their personal hygiene needs, and have access to meals.

5.10 Implications for policy

The study identified several areas within the healthcare provision that could benefit from policy-level improvements to support both parents and healthcare professionals.

The policymakers should focus on improvement of communication between parents and healthcare professionals. Adequate training is necessary to improve communication skills of healthcare professionals (Feraco et al., 2016). Training in communication should become a mandatory component of the pre-gradual and post-gradual study curriculum. Hospital governance should provide additional training in communication with parents and advance care planning.

Another important implication for policy is to ensure that parents have unlimited access to their children during hospitalisation. The presence of parents is crucial and has a direct impact on decision-making and, consequently on the medical care and health of the child. Although current policy measures in the Czech Republic stipulate that parents have the right to be with their children in hospital, this study reveals that this basic right is not always upheld.

The paediatric palliative care team represents an important stakeholder which has a positive impact on both parents and healthcare professionals. Further development of palliative care teams should be supported at the national level. Development of national standards about paediatric palliative care provision would help to ensure the service is provided at an adequate quality level.

5.11 Implications for research

This study identified a conceptual model of the decision-making, but several aspects of the model need further exploration to get a better understanding of medical decision-making of parents and healthcare professionals.

The study findings suggest that the intensity of influence differs among the factors, and parents and healthcare professionals are influenced by different factors. Further research is needed to examine in-depth the intensity of the influence of individual factors on each group and how this influence evolves throughout the child's illness.

Further research is needed to explore how the child's quality of life is conceptualised by parents and healthcare professionals. This would help to gain a better understanding of what aspects of the child's life parents and healthcare professionals consider when they make medical decisions.

The study identified that children influence the decision-making process. More research is needed to explore how children experience their participation and focus on non-verbal children and how are they included.

Parental factors represent a topic which should be explored further. Research should focus on exploring how negative experiences within medical settings affect parental trust and relationships with healthcare providers.

Further studies should also focus on exploring the impact of psychological distress and physical demand of the care, and how this affects parents' ability to participate in decision-making.

The conceptual model suggests that decision-making is influenced by family structure. Given the diversity of modern families, more research is needed to understand how parents make medical decisions across various family types, including multi-child families, single-child families, and single-parent households. Exploration of how the needs of other family members and the family values influence decision-making, with the focus on how healthcare professionals identified what the family values are and how they incorporate them into the decisions would be beneficial.

Within the family context, further research should also explore how parents balance their various caregiving roles, and how responsibilities for other family members affect their ability to make decisions for their children.

The findings related to the influence of the environment would also benefit from further investigations. Specifically, research should examine how paediatric palliative care teams impact decision-making to get a more comprehensive understanding of their role. Further research should explore what motivates healthcare professionals to invite the paediatric palliative care team into the patient's care and how a collaboration between medical teams and palliative care team is established.

Additionally, this study explored the perspectives of parents of living children with life-limiting and life-threatening conditions. The experience of bereaved parents with focus on end-of-life decision-making for their children would benefit from further research.

This is the first study which is focused on decision-making in paediatric healthcare in the Czech Republic, therefore these findings provide a foundation for future research to build upon and expand the understanding of paediatric healthcare decision-making in this cultural context, but can be applied to other cultural settings.

5.12 Study strengths and limitations

This research offers a unique perspective on decision-making by examining the views of both parents and healthcare professionals in the Czech Republic. It is the first study to focus on decision-making in paediatric healthcare within this cultural context. The study also enabled an exploration of the service provided by the paediatric palliative care team, recently established in the hospital setting. It is a new type of service which has not been well studied within the local cultural system, therefore this study provides a unique insight into its role.

The study employed a multiple case study design, which allowed for data collection from various sources and their triangulation. This approach facilitated a detailed examination of each participant's perspective while also capturing the interactions among the stakeholders. The study included various professionals, which were identified as being important during decision-making by the participating parents.

All participants were involved in the decision-making, which ensured that that they could recall the events from their own experience. Data from interviews were supported by data obtained from medical records, to enable a more robust database.

A few limitations of this study are noteworthy. The study was done in one setting; however, parents were from different regions within the Czech Republic. The original intention was to include multiple hospital sites. Two additional hospitals were approached and invited to participate. Although both institutions initially agreed and several meetings were held, these collaborations did not result in any participants recruitment. Consequently, the study was carried out at a single hospital setting.

Healthcare professionals were all based in the hospital and predominantly doctors participated in the study. The perspective of other healthcare professionals is not represented strongly in the study. The study was focused solely on parents and healthcare professionals, data were not collected from the children, therefore their perspective was missing.

The experience of bereaved parents was not explored within this study. Therefore, the study did not explore decision-making in the context of end-of-life care, or how parents reflect on their experience after the death of their child. There may be additional influencing factors about these sorts of decisions.

The recruitment strategy used for this study represents another limitation. The study participants were recruited through the collaborating doctor from the palliative care team operating within the hospital. By using the hospital based palliative care team as an access point to the study cases the experiences of parents whose children were not in the care of the palliative care team were not explored. Therefore, some aspects of their experience with decision-making could be missing.

Additionally, letting parents identify healthcare professionals could lead to gatekeeper bias. The perspectives of other healthcare professional which were involved in the medical care of the child but were not identified by parents were not explored.

The data were collected from two sources, interviews and medical records. The shorter length of some interviews, particularly those with healthcare professionals, could represent a limitation in the data collection process and may have meant that some details about decisions were not identified by the participants. A narrow scope of inquiry was adopted whereby healthcare professionals were asked to talk about their experiences with a specific child rather than about their overall experience with medical decision-making. However, while parents tended to be involved in and recall all decisions about their child, healthcare professionals were not involved in every medical decision concerning the ill child. Additionally, the interviews were conducted during working hours, and for some participants, time constraints may have posed a barrier to engaging in longer interviews.

Medical records were obtained only from one source. The intention was to get medical records from different departments, which was not possible. Only one type of record, from the paediatric palliative care team, was available, which could lead to some bias in interpretation.

The study did not use observation for data collection, which would enable the observation of interactions between parents and healthcare in real time. This approach to data collection was not possible given the epidemiological situation.

The study explored mainly decisions which had already happened. It did not study how the decisions developed over time. A longitudinal study would explore this aspect and could provide a valuable insight into how the approach of parents and healthcare professionals changes during the course of the child's illness.

5.13 Personal reflexivity and reflections

In this chapter, I would like to look back on my experience of conducting the PhD study. Becoming a PhD student has been a long-term dream of mine, which I did not expect to ever turn into reality. Little did I know that the events of my life, which I introduced at the start of this thesis, would navigate my journey towards a PhD study in palliative care.

Doing my study as a part time student, while working full time and being a single parent to a child with special needs has proven to be very challenging. Other unexpected life events which occurred during this time put further strain on me, and during many occasions I felt too overwhelmed and stressed to continue. Yet, the sense of responsibility to the parents and healthcare professionals who agreed to participate in my research pushed me forward.

When I started with the research, I was worried it would be difficult to recruit healthcare professionals and convince them to speak about their experiences and opinions. To my surprise they were very welcoming. They talked about their experiences openly and honestly and I could see they valued the opportunity to express their feelings. I also value the openness of parents who were willing to give me their time and share their experience, even though it was often very emotional for them.

Interviews with parents and healthcare professionals brought back many memories I had from my own time I spend in the hospital, either as a nurse or as a parent. I have tried to keep the boundary and not let my own experiences interfere, but after some interviews I was very emotional. Similarly, visiting the hospital and being back at the hospital ward where I have been before with my own son was emotionally disturbing. On the other side, seeing other parents in similar situations as I was before gave me the strength and resilience to finish my research.

I believe that the time I spent on my studies and research has helped me to grow both as a person and as a professional, and strengthen my enthusiasm for research in palliative care.

5.14 Conclusion

This thesis into medical decision-making for children with life-limiting and life-threatening conditions found that parents and healthcare professionals are influenced by five types of factors: Information and Knowledge, Child, Parents, Family, and Environment. The relative influence of these factors, along with the influence physicians and parents have on each other (healthcare professionals exert strong influence on parents, while parents have comparatively low impact on healthcare professionals), determine which of the three decision-making approaches will be employed: shared, parent-guided or physician-driven.

Shared decision-making is characterised by a respectful relationship between parents and healthcare professionals. Access to information, knowledge, and aligned perspectives on the child's best interest are prerequisite for effective shared decision-making to take place. The involvement of a paediatric palliative care team can enhance this approach by facilitating communication and providing support to all decision-makers.

A parent-guided approach reflects parental desire for control; enabling them to influence decisions and supporting their autonomy. This approach is dependent on parents having access to information and being empowered to make decisions for their children. Parents also rely on their previous experiences with similar medical situations.

The strong influence of healthcare professionals is encompassed in the physician-driven approach. In this healthcare professionals occupy the central role in decision-making and influence both parents and outcomes. Medical evidence, the child's condition and healthcare professionals' perception of what is best for the child empowers healthcare professionals to direct and control the decision-making process.

While the shared decision-making approach represents an ideal outcome, its application into standard practice remains challenging. Parents often lack awareness that they can be equal partners in the medical decision-making and are dependent on healthcare professionals inviting and including them. Conversely, healthcare professionals often are aware that shared decision-making is desirable but struggle to present the available options without influencing parents, even unintentionally, particularly when a decision is time constrained.

This study brings evidence that parents in the Czech Republic - a country with a traditionally strong paternalist approach to healthcare - want to be actively involved in decision-making for their children. The position of parents and healthcare professionals in this context remains unequal; parental involvement in decision-making is largely dependent on healthcare professionals. Moreover, their authority and medical expertise further enables them to control the decision-making. Whilst this study was focused on the Czech Republic, the findings are likely to be of relevance to other countries, especially those with a of paternalistic approaches.

The results from this research emphasise that shared decision-making requires healthcare providers to recognise and take account of the factors which influence parents and their capacity to participate in decision-making. This includes acknowledging parental wellbeing, and respecting family needs and values. Enhancing facilities so they meet parents' needs is an important factor in parental wellbeing. The behaviour and communication styles of healthcare professional toward parents were identified as key in establishing a trusting relationship, and attention should be paid to the development of effective and sensitive communication skills in healthcare providers. The paediatric palliative care team is an important facilitator in these relationships, and in shared decision-making in general, and involving them in decision-making should be actively supported.

References

Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: an integrative review. *Journal of Nursing Management*, *22*(2), 177–191. https://doi.org/10.1111/j.1365-2834.2012.01457.x

Abdin, S., Heath, G., Neilson, S., Byron-Daniel, J., & Hooper, N. (2022). Decision-making experiences of health professionals in withdrawing treatment for children and young people: A qualitative study. *Child: Care, Health and Development*, *48*(4), 531–543. https://doi.org/10.1111/cch.12956

ACT. (2009). *A Guide to the Development of Children's Palliative Care Services*. Association for Children's Palliative Care.

Alexa, J., Recka, L., Votapkova, J., van Ginneken, E., Spranger, A., & Wittenbecher, F. (2015). Czech Republic: health system review. *Health Systems in Transition*, *17*(1), 1–165.

Allen, K. A. (2014). Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*, *51*(9), 1289–1304. https://doi.org/10.1016/j.ijnurstu.2014.02.003

Atout, M., Hemingway, P., & Seymour, J. (2017). The Experience of Decision Making in the Care of Children with Palliative Care Needs: The Experiences of Jordanian Mothers. *Comprehensive Child and Adolescent Nursing*, *40*(4), 240–256. https://doi.org/10.1080/24694193.2017.1330371

Badarau, D. O., Ruhe, K., Kühne, T., De Clercq, E., Colita, A., Elger, B. S., & Wangmo, T.

(2017). Decision making in pediatric oncology: Views of parents and physicians in two European countries. *AJOB Empirical Bioethics*, *8*(1), 21–31. https://doi.org/10.1080/23294515.2016.1234519

Bailey, P. H., & Tilley, S. (2002). Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing*, *38*(6), 574–583. https://doi.org/10.1046/j.1365-2648.2000.02224.x

Balkin, E. M., Kirkpatrick, J. N., Kaufman, B., Swetz, K. M., Sleeper, L. A., Wolfe, J., & Blume, E. D. (2017). Pediatric Cardiology Provider Attitudes About Palliative Care: A Multicenter Survey Study. *Pediatric Cardiology*, *38*(7), 1324–1331. https://doi.org/10.1007/s00246-017-1663-0

Balling, K., & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing*, *16*(2), 110–119. https://doi.org/10.1053/jpdn.2001.23157

Bandinelli, L. (2017). Evaluation of Parents’ Decision-Making in Oncologic Pediatric Treatment. *Psicologia Em Estudo*, *21*(4), 603–615. https://doi.org/10.4025/psicolestud.v21i4.31716

Barrett, L., Fraser, L., Noyes, J., Taylor, J., & Hackett, J. (2023). Understanding parent experiences of end-of-life care for children: A systematic review and qualitative evidence synthesis. *Palliative Medicine*, *37*(2), 178–202. https://doi.org/10.1177/02692163221144084

Beecham, E., Oostendorp, L., Crocker, J., Kelly, P., Dinsdale, A., Hemsley, J., Russell, J., Jones, L., & Bluebond-Langner, M. (2017). Keeping all options open: Parents’ approaches to advance care planning. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, *20*(4), 675–684. https://doi.org/10.1111/hex.12500

Beltran, S. J., & Hamel, M. N. (2021). Caring for Dying Infants: A Systematic Review of Healthcare Providers’ Perspectives of Neonatal Palliative Care. *American Journal of Hospice and Palliative Medicine®*, *38*(8), 1013–1027. https://doi.org/10.1177/1049909120965949

Benini, F., Papadatou, D., Bernadá, M., Craig, F., De Zen, L., Downing, J., Drake, R., Friedrichsdorf, S., Garros, D., Giacomelli, L., Lacerda, A., Lazzarin, P., Marceglia, S., Marston, J., Muckaden, M. A., Papa, S., Parravicini, E., Pellegatta, F., & Wolfe, J. (2022). International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *Journal of Pain and Symptom Management*, *63*(5), e529–e543. https://doi.org/10.1016/j.jpainsymman.2021.12.031

Bennett, R. A., & LeBaron, V. T. (2019). Parental Perspectives on Roles in End-of-Life Decision Making in the Pediatric Intensive Care Unit: An Integrative Review. *Journal of Pediatric Nursing*, *46*, 18–25. https://doi.org/10.1016/j.pedn.2019.02.029

Bergstraesser, E. (2013). Pediatric palliative care - When quality of life becomes the main focus of treatment. *European Journal of Pediatrics*, *172*(2), 139–150. https://doi.org/10.1007/s00431-012-1710-z

Bergviken, H., & Nilsson, S. (2019). Focusing on the hospital stay or everyday life with cancer: Parents’ experiences of choosing a central access device for their child with cancer. *Journal for Specialists in Pediatric Nursing : JSPN*, *24*(3), e12261. https://doi.org/10.1111/jspn.12261

Birchley, G. (2014). Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care. *Health Care Anal*, *22*, 203–222. https://doi.org/10.1007/s10728-013-0267-y

Birchley, G., Gooberman-Hill, R., Deans, Z., Fraser, J., & Huxtable, R. (2017). "Best interests" in paediatric intensive care: an empirical ethics study. *Archives of Disease in Childhood*, *102*(10), 930–935. https://doi.org/10.1136/archdischild-2016-312076

Blume, E. D., Balkin, E. M., Aiyagari, R., Ziniel, S., Beke, D. M., Thiagarajan, R., Taylor, L., Kulik, T., Pituch, K., & Wolfe, J. (2014). Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease. *Pediatric Critical Care Medicine*, *15*(4), 336–342. https://doi.org/10.1097/PCC.0000000000000072

Boblin, S. L., Ireland, S., Kirkpatrick, H., & Robertson, K. (2013). Using Stake's Qualitative Case Study Approach to Explore Implementation of Evidence-Based Practice. *Qualitative Health Research*, *23*(9), 1267–1275. https://doi.org/10.1177/1049732313502128

Bogetz, J. F., Trowbridge, A., Lewis, H., Shipman, K. J., Jonas, D., Hauer, J., & Rosenberg, A. R. (2022). Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children with Severe Neurological Impairment During Decision-Making. *Journal of Pain and Symptom Management*, *62*(6), 1117–1125.

https://doi.org/10.1016/j.jpainsymman.2021.06.011.

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. *Implementation Science*, *14*(1). https://doi.org/10.1186/s13012-018-0851-5

Boland, L., McIsaac, D. I., & Lawson, M. L. (2016). Barriers to and facilitators of implementing shared decision making and decision support in a paediatric hospital: A descriptive study. *Paediatrics and Child Health (Canada)*, *21*(3), e17–e21. https://doi.org/10.1093/pch/21.3.e17

Boss, R. D., Hutton, N., Sulpar, L. J., West, A. M., & Donohue, P. K. (2008). Values Parents Apply to Decision-Making Regarding Delivery Room Resuscitation for High-Risk Newborns. *Pediatrics*, *122*(3), 583–589. https://doi.org/10.1542/peds.2007-1972

Bowers, A. P., Chan, R. J., Herbert, A., & Yates, P. (2020). Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0-21 years using health administration data. *Australian Health Review*, *44*(4), 630–636. https://doi.org/10.1071/AH19170

Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: Exploring subjectivity through Peshkin’s I’s. *Journal of Advanced Nursing*, *59*(3), 290–298. https://doi.org/10.1111/j.1365-2648.2007.04306.x

Brogan, P., Hasson, F., & McIlfatrick, S. (2019). Lessons learnt: examining the use of case study methodology for nursing research in the context of palliative care.

Journal of Research in Nursing, *24*(6), 446–459. https://doi.org/10.1177/1744987119867737

Broom, A., & Willis, E. (2007). Competing paradigms and health research. In M. Saks & J. Allsop (Eds.), *Researching health : Qualitative, quantitative and mixed methods* (pp. 16–28). SAGE.

Brown, P. A. (2008). A Review of the Literature on Case Study Research. *Canadian Journal for New Scholars in Education*, *1*(1), 1–13.

Bruneau, J., Moralejo, D., Donovan, C., & Parsons, K. (2021). Recruitment of Healthcare Providers into Research Studies. *Canadian Journal of Nursing Research*, *53*(4), 426–432. https://doi.org/10.1177/0844562120974911

Bryman, A. (2016). *Social Research Methods* (5th ed.). Oxford University Press.

Buchanan, F., Lai, C., Cohen, E., Milo-Manson, G., & Shachak, A. (2022). Decision-making for Parents of Children With Medical Complexities: Activity Theory Analysis. *Journal of Participatory Medicine*, *14*(1), e31699. https://doi.org/10.2196/31699

Bunniss, S., & Kelly, D. R. (2010). Research paradigms in medical education research. *Medical Education*, *44*(4), 358–366. https://doi.org/10.1111/j.1365-2923.2009.03611.x

Burns, M., Bally, J., Burles, M., Holtslander, L., & Peacock, S. (2022). Constructivist Grounded Theory or Interpretive Phenomenology? Methodological Choices Within Specific Study Contexts. *International Journal of Qualitative Methods*, *21*, 1–13. https://doi.org/10.1177/16094069221077758

Cai, S., Cheng, L., Wang, R., Zhou, X., & Peng, X. (2023). A shared decision-making model in pediatric palliative care: a qualitative study of healthcare providers. *BMC Palliative Care*, *22*(1), 190. https://doi.org/10.1186/s12904-023-01307-0

Caicedo, C. (2014). Families With Special Needs Children: Family Health, Functioning, and Care Burden. *Journal of the American Psychiatric Nurses Association*, *20*(6), 398–407. https://doi.org/10.1177/1078390314561326

Callery, P. (1997). Paying to participate: financial, social and personal costs to parents of involvement in their children's care in hospital. *Journal of Advanced Nursing*, *25*(4), 746–752. https://doi.org/10.1046/j.1365-2648.1997.t01-1-1997025746.x

Carlisle, E. M., Shinkunas, L. A., Lieberman, M. T., Hoffman, R. M., & Schacht, H. (2022). Empowering parents of pediatric surgical oncology patients through collaborative engagement with surgeons. *Journal of Pediatric Surgery*, 6–13. https://doi.org/10.1016/j.jpedsurg.2022.12.029

Carnevale, F. A., Benedetti, M., Bonaldi, A., Bravi, E., Trabucco, G., & Biban, P. (2011). Understanding the private worlds of physicians, nurses, and parents. *Journal of Child Health Care*, *15*(4), 334–349. https://doi.org/10.1177/1367493511420183

Carnevale, F. A., Canoui, P., Cremer, R., Farrell, C., Doussau, A., Seguin, M.-J., Hubert, P., Leclerc, F., & Lacroix, J. (2007). Parental involvement in treatment decisions regarding their critically ill child: A comparative study of France and Quebec. *Pediatric Critical Care Medicine*, *PAP*(4), 337–342. https://doi.org/10.1097/01.PCC.0000269399.47060.6D

Carr, K., Hasson, F., McIlfatrick, S., & Downing, J. (2021). Factors associated with health professionals decision to initiate paediatric advance care planning: A systematic integrative review. *Palliative Medicine*, *35*(3), 503–528. https://doi.org/10.1177/0269216320983197

Carroll, K. W., Mollen, C. J., Aldridge, S., Hexem, K. R., & Feudtner, C. (2012). Influences on Decision Making Identified by Parents of Children Receiving Pediatric Palliative Care. *AJOB Primary Research*, *3*(1), 1–7. https://doi.org/10.1080/21507716.2011.638019

Chambers, L. (2018). *A Guide to Children' s Palliative Care* (A. Goldman (ed.); 4th ed.). Together for Short Lives.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least to to tango). *Social Science and Medicine*, *44*(5), 681–692. https://doi.org/10.1016/s0277-9536(96)00221-3

Charmaz, K. (2017). Constructivist grounded theory. *Journal of Positive Psychology*, *12*(3), 299–300. https://doi.org/10.1080/17439760.2016.1262612

Chelazzi, C., Villa, G., Lanini, I., Romagnoli, S., & Latronico, N. (2023). The adult and pediatric palliative care: differences and shared issues. *Journal of Anesthesia, Analgesia and Critical Care*, *3*(1), 1–8. https://doi.org/10.1186/s44158-023-00085-8

Chiarchiaro, J., White, D. B., Ernecoff, N. C., Buddadhumaruk, P., Schuster, R. A., & Arnold, R. M. (2016). Conflict management strategies in the ICU differ between palliative care specialists and intensivists. *Critical Care Medicine*, *44*(5), 934–942. https://doi.org/10.1097/CCM.0000000000001583

Clark, J. D. (2012). Balancing the Tension: Parental Authority and the Fear of Paternalism in End-of-Life Care. *Archives of Pediatrics & Adolescent Medicine*, *166*(7). https://doi.org/10.1001/archpediatrics.2012.556

Collins, A., Burchell, J., Remedios, C., & Thomas, K. (2020). Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: A cross-sectional study of caregiver-reported outcomes. *Palliative Medicine*, *34*(3), 358–366. https://doi.org/10.1177/0269216319892825

Connor, S. R., Downing, J., & Marston, J. (2017). Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis. *Journal of Pain and Symptom Management*, *53*(2), 171–177. https://doi.org/10.1016/j.jpainsymman.2016.08.020

Cope, D. G. (2015). Case study research methodology in nursing research. *Oncology Nursing Forum*, *42*(6), 681–682. https://doi.org/10.1188/15.ONF.681-682

Coughlin, K. W. (2018). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics and Child Health*, *23*(2), 138–146. https://doi.org/10.1093/pch/pxx127

Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*, *18*(3), 273–280. https://doi.org/10.1016/j.ejon.2014.01.006

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, *20*(15–16), 2334–2343. https://doi.org/10.1111/j.1365-2702.2010.03582.x

Coyne, I. T. (1995). Partnership in care: parents' views of participation in their hospitalized child's care. *Journal of Clinical Nursing*, *4*(2), 71–79. https://doi.org/10.1111/j.1365-2702.1995.tb00014.x

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). Sage Publications.

Creswell, J. W., & Creswell, D. J. (2014). *Research design: qualitative, quantitative, and mixed methods approaches* (4th ed.). SAGE Publications, Inc. https://doi.org/10.4135/9781849208956

Crossan, F. (2003). Research philosophy:towards an understanding. *Nurse Researcher*, *11*(1), 46–55.

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology*, *11*(1), 100. https://doi.org/10.1186/1471-2288-11-100

Crozier, F., & Hancock, L. E. (2012). Pediatric palliative care: beyond the end of life. *Pediatric Nursing*, *38*(4), 198–203, 227; quiz 204. http://www.ncbi.nlm.nih.gov/pubmed/22970486

Dakessian Sailian, S., Salifu, Y., Saad, R., & Preston, N. (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliative Care*, *20*(1), 112. https://doi.org/10.1186/s12904-021-00791-6

Daly, D., Sedlicka, N., Švanderlíková, K., Kovařčíková, P. A., Wilhelmová, R., & Begley, C. (2024). An online survey of women's views of respectful and disrespectful pregnancy and early labour care in the Czech Republic. *BMC Pregnancy and Childbirth*, *24*(1), 370. https://doi.org/10.1186/s12884-024-06448-5

De Clercq, E., Grotzer, M., Landolt, M. A., von Helversen, B., Flury, M., Rössler, J., Kurzo, A., & Streuli, J. (2022). No wrong decisions in an all-wrong situation. A qualitative study on the lived experiences of families of children with diffuse intrinsic pontine glioma. *Pediatric Blood & Cancer*, *69*(9), 1–12. https://doi.org/10.1002/pbc.29792

de Weerd, W., van Tol, D., Albers, M., Sauer, P., & Verkerk, M. (2015). Suffering in children: opinions from parents and health-care professionals. *European Journal of Pediatrics*, *174*(5), 589–595. https://doi.org/10.1007/s00431-014-2440-1

Deming, R. S., Mazzola, E., MacDonald, J., Manning, S., Beight, L., Currie, E. R., Wojcik, M. H., & Wolfe, J. (2022). Care Intensity and Palliative Care in Chronically Critically Ill Infants. *Journal of Pain and Symptom Management*, *64*(5), 486–494. https://doi.org/10.1016/j.jpainsymman.2022.07.002

Denzin, N. K., & Lincoln, Y. S. (2000). Handbook of Qualitative Reasearch. In N. K. Denzin & Y. S. Lincoln (Eds.), *SAGE Publications* (2nd ed.). SAGE Publications Inc. http://link.springer.com/10.1007/s11229-017-1319-x

Dewan, T., Whiteley, A., MacKay, L. J., Martens, R., Noel, M., Barnard, C., Jordan, I., Janvier, A., & Thorne, S. (2024). Trust of inpatient physicians among parents of children with medical complexity: a qualitative study. *Frontiers in Pediatrics*, *12*.

https://doi.org/10.3389/fped.2024.1443869

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising Qualitative and Quantitative Evidence : A Review of Possible. *Journal of Health Services Research and Policy*, *10*(1), 45–53. https://doi.org/10.1258/1355819052801804

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A., & Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, *12*(1), 42–47. https://doi.org/10.1258/135581907779497486

Djulbegovic, B., Hozo, I., Beckstead, J., Tsalatsanis, A., & Pauker, S. G. (2012). Dual processing model of medical decision-making. *BMC Medical Informatics and Decision Making*, *12*(1), 94. https://doi.org/10.1186/1472-6947-12-94

Dobiášová, K., Kotherová, Z., & Numerato, D. (2021). Institutional reforms to strengthen patient and public involvement in the Czech Republic since 2014. *Health Policy*, *125*(5), 582–586. https://doi.org/10.1016/j.healthpol.2021.03.011

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing Distress Protocols for Research on Sensitive Topics. *Archives of Psychiatric Nursing*, *23*(5), 343–350. https://doi.org/10.1016/j.apnu.2008.10.008

Dudley, S. K., & Carr, J. M. (2004). Vigilance: The experience of parents staying at the bedside of hospitalized children. *Journal of Pediatric Nursing*, *19*(4), 267–275. https://doi.org/10.1016/j.pedn.2004.05.008

Durall, A., Zurakowski, D., & Wolfe, J. (2012). Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics*, *129*(4). https://doi.org/10.1542/peds.2011-2695

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science and Medicine*, *58*(2), 391–400. https://doi.org/10.1016/S0277-9536(03)00205-3

Eaton, N. (2008). "I don't know how we coped before": A study of respite care for children in the home and hospice. *Journal of Clinical Nursing*, *17*(23), 3196–3204. https://doi.org/10.1111/j.1365-2702.2008.02630.x

Ebneyamini, S., & Sadeghi Moghadam, M. R. (2018). Toward Developing a Framework for Conducting Case Study Research. *International Journal of Qualitative Methods*, *17*(1). https://doi.org/10.1177/1609406918817954

Edelstein, H., Schippke, J., Sheffe, S., & Kingsnorth, S. (2017). Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child: Care, Health and Development*, *43*(3), 323–333. https://doi.org/10.1111/cch.12430

Eden, L. M., & Callister, L. C. (2010). Parent Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review. *Journal of Perinatal Education*, *19*(1), 29–39. https://doi.org/10.1624/105812410x481546

Edwards, J. D., Panitch, H. B., Nelson, J. E., Miller, R. L., & Morris, M. C. (2020). Decisions for Long-Term Ventilation for Children. Perspectives of Family

Members. *Annals of the American Thoracic Society*, *17*(1), 72–80. https://doi.org/10.1513/AnnalsATS.201903-271OC

El Halal, G., Piva, J. P., Lago, P. M., El Halal, M. G., Cabral, F. C., Nilson, C., & Garcia, P. C. (2013). Parents' perspectives on the deaths of their children in two Brazilian paediatric intensive care units. *International Journal of Palliative Nursing*, *19*(10), 495–502. https://doi.org/10.12968/ijpn.2013.19.10.495

Elliott, N., & Lazenbatt, A. (2005). HOW TO RECOGNISE A 'QUALITY' GROUNDED THEORY RESEARCH STUDY. *Australian Journal of Advanced Nursing*, *22*(3), 48–52. https://doi.org/10.37464/2005.223.1975

Ellis, D. I., Chen, L., Gordon Wexler, S., Avery, M., Kim, T. D., Kaplan, A. J., Mazzola, E., Kelleher, C., & Wolfe, J. (2024). Goals of Surgical Interventions in Youths Receiving Palliative Care. *JAMA Network Open*, *7*(11), e2444072. https://doi.org/10.1001/jamanetworkopen.2024.44072

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Feraco, A. M., Brand, S. R., Mack, J. W., Kesselheim, J. C., Block, S. D., & Wolfe, J. (2016). Communication Skills Training in Pediatric Oncology: Moving Beyond Role Modeling. *Pediatric Blood & Cancer*, *63*(6), 966–972. https://doi.org/10.1002/pbc.25918

Fiks, A. G., & Jimenez, M. E. (2010). The promise of shared decision-making in paediatrics. *Acta Paediatrica*, *99*, 1464–1466. https://doi.org/10.1111/j.1651-2227.2010.01978.x

Fiks, A. G., Mayne, S., Localio, A. R., Feudtner, C., Alessandrini, E. A., & Guevara, J. P. (2012). Shared decision making and behavioral impairment: a national study among children with special health care needs. *BMC Pediatrics*, *12*(1), 153. https://doi.org/10.1186/1471-2431-12-153

Firn, J., Preston, N., & Walshe, C. (2016). What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliative Medicine*, *30*(3), 240–256. https://doi.org/10.1177/0269216315615483

Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research*, *19*(4–5), 583–590. https://doi.org/10.1080/10503300902798375

Flick, U. (2014). *The SAGE Handbook of Qualitative Data Analysis*. SAGE Publications, Inc. https://doi.org/10.4135/9781446282243

Forbat, L., Teuten, B., & Barclay, S. (2015). Conflict escalation in paediatric services: Findings from a qualitative study. *Archives of Disease in Childhood*, *100*(8), 769–773. https://doi.org/10.1136/archdischild-2014-307780

Fraser, L. K., Bluebond-Langner, M., & Ling, J. (2020). Advances and Challenges in European Paediatric Palliative Care. *Medical Sciences*, *8*(20). https://doi.org/10.3390/medsci8020020

Fraser, L. K., Gibson-Smith, D., Jarvis, S., Norman, P., & Parslow, R. (2020). *"Make Every Child Count" Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*.

Fraser, L. K., Gibson-Smith, D., Jarvis, S., Norman, P., & Parslow, R. C. (2021). Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliative Medicine*, *35*(9), 1641–1651. https://doi.org/10.1177/0269216320975308

Furstova, J., Malinakova, K., Sigmundova, D., & Tavel, P. (2021). Czech Out the Atheists: A Representative Study of Religiosity in the Czech Republic. *The International Journal for the Psychology of Religion*, *31*(4), 288–306. https://doi.org/10.1080/10508619.2020.1844967

Gaab, E. M. (2015). Families' perspectives of quality of life in pediatric palliative care patients. *Children*, *2*(1), 131–145. https://doi.org/10.3390/children2010131

Garrouste-Orgeas, M., Philippart, F., Timsit, J. F., Diaw, F., Willems, V., Tabah, A., Bretteville, G., Verdavainne, A., Misset, B., & Carlet, J. (2008). Perceptions of a 24-hour visiting policy in the intensive care unit. *Critical Care Medicine*, *36*(1), 30–35. https://doi.org/10.1097/01.CCM.0000295310.29099.F8

Gerrard, M., Gibbons, F. X., Houlihan, A. E., Stock, M. L., & Pomery, E. A. (2008). A dual-process approach to health risk decision making: The prototype willingness model. *Developmental Review*, *28*(1), 29–61. https://doi.org/10.1016/j.dr.2007.10.001

Gerring, J. (2004). What is a case study and what is it good for? *American Political*

Science Review, *98*(2), 341–354. https://doi.org/10.1017/S0003055404001182

Gibson, C. H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, *21*(6), 1201–1210. https://doi.org/10.1046/j.1365-2648.1995.21061201.x

Gómez-Zúñiga, B., Pulido Moyano, R., Pousada Fernández, M., García Oliva, A., & Armayones Ruiz, M. (2019). The experience of parents of children with rare diseases when communicating with healthcare professionals: Towards an integrative theory of trust. *Orphanet Journal of Rare Diseases*, *14*(1), 1–14. https://doi.org/10.1186/s13023-019-1134-1

Graetz, D. E., Rivas, S., Wang, H., Vedaraju, Y., Ferrara, G., Antillon-, F., Fuentes, L., Cáceres-, A., Devidas, M., Metzger, M., Rodriguez-, C., & Mack, J. W. (2022). Cancer treatment decision-making among parents of paediatric oncology patients in Guatemala: a mixed-methods study. *BMJ Open*, *12*(e057350), 1–8. https://doi.org/10.1136/bmjopen-2021-057350

Granek, L., Rosenberg-Yunger, Z. R. S., Dix, D., Klaassen, R. J., Sung, L., Cairney, J., & Klassen, A. F. (2014). Caregiving, single parents and cumulative stresses when caring for a child with cancer. *Child: Care, Health and Development*, *40*(2), 184–194. https://doi.org/10.1111/cch.12008

Gravel, K., Légaré, F., & Graham, I. D. (2006). Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implementation Science*, *1*(1), 16. https://doi.org/10.1186/1748-5908-1-16

Grob, R., Darien, G., & Meyers, D. (2019). Why Physicians Should Trust in Patients. *JAMA*, *321*(14), 1347. https://doi.org/10.1001/jama.2019.1500

Gross, G. J., & Howard, M. (2001). Mothers' Decision-Making Processes Regarding Health Care for Their Children. *Public Health Nursing*, *18*(3), 157–168. https://doi.org/10.1046/j.1525-1446.2001.00157.x

Guba, E. G., & Lincoln, Y. S. (1994). Competing Paradigms in Qualitative Research. In N. K. Denzin & S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage.

Gurková, E., Andraščíková, I., & Čáp, J. (2015). Parents' experience with a dying child with cancer in palliative care. *Central European Journal of Nursing and Midwifery*, *6*(1), 201–208. https://doi.org/10.15452/CEJNM.2015.06.0004

Hagvall, M., Ehnfors, M., & Anderzén-Carlsson, A. (2016). Experiences of parenting a child with medical complexity in need of acute hospital care. *Journal of Child Health Care*, *20*(1), 68–76. https://doi.org/10.1177/1367493514551308

Haigh, C. & Witham, G. (2015). Distress Protocol for qualitative data collection. *Manchester Metropolitan University*, *31*(1), 1–4. https://www2.mmu.ac.uk/media/mmuacuk/content/documents/rke/Advisory-Distress-Protocol.pdf

Hain, R., Devins, M., Hastings, R., & Noyes, J. (2013). *Paediatric palliative care : development and pilot study of a ' Directory ' of life-limiting conditions*.

Hardelid, P., Dattani, N., Gilbert, R., Macfarlane, A., Saxena, S., Muller-Pebody, B., Knowles, R., Parslow, R., Stiller, C., Shah, A., Sidebotham, P., & Davey, J. (2014).

Estimating the prevalence of chronic conditions in children who die in England, Scotland and Wales: a data linkage cohort study. *BMJ Open*, *4*(8), e005331–e005331. https://doi.org/10.1136/bmjopen-2014-005331

Harrison, C. (2004). Treatment decisions regarding infants, children and adolescents. *Paediatrics & Child Health*, *9*(2), 99–103. https://doi.org/10.1093/pch/9.2.99

Harrison, H., Birks, M., Franklin, R., & Mills, J. (2017). Case study research: Foundations and methodological orientations. *Forum Qualitative Social Rsearch*, *18*(1).

Hatzmann, J., Heymans, H. S. A., Ferrer-i-Carbonell, A., van Praag, B. M. S., & Grootenhuis, M. A. (2008). Hidden Consequences of Success in Pediatrics: Parental Health-Related Quality of Life—Results From the Care Project. *Pediatrics*, *122*(5), e1030–e1038. https://doi.org/10.1542/peds.2008-0582

Havel Václav Library. (2018). *The Vaclav Havel European Dialogues*. https://www.vaclavhavel.cz/cs/dialog/praha-2018

Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: Reviewing disparate data systematically. *Qualitative Health Research*, *12*(9), 1284–1299. https://doi.org/10.1177/1049732302238251

Haynes, R. B. (2002). Clinical expertise in the era of evidence-based medicine and patient choice. *Evidence-Based Medicine*, *7*(2), 36–38. https://doi.org/10.1136/ebm.7.2.36

Hays, R. M., Valentine, J., Haynes, G., Geyer, J. R., Villareale, N., Mckinstry, B., Varni, J. W., & Churchill, S. S. (2006). The Seattle pediatric palliative care project:

Effects on family satisfaction and health-related quality of life. *Journal of Palliative Medicine*, *9*(3), 716–728. https://doi.org/10.1089/jpm.2006.9.716

Hexem, K. R., Mollen, C. J., Carroll, K., Lanctot, D. A., & Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Medicine*, *14*(1), 39–44. https://doi.org/10.1089/jpm.2010.0256

Higgins, S. S. (2001). Parental Role in Decision Making About Pediatric Cardiac Transplantation : Familial and Ethical Considerations. *Journal of Pediatric Nursing*, *16*(5), 332–337. https://doi.org/10.1053/jpdn.2001.27209

Hirata, M., & Kobayashi, K. (2023). Experiences with the end-of-life decision-making process in children with cancer, their parents, and healthcare professionals: A systematic review and meta-ethnography. *Journal of Pediatric Nursing*, *69*, e45–e64. https://doi.org/10.1016/j.pedn.2022.12.004

Hoang, K., Halpern-Felsher, B., Brooks, M., & Blankenburg, R. (2020). Shared Decision-making With Parents of Hospitalized Children: A Qualitative Analysis of Parents’ and Providers’ Perspectives. *Hospital Pediatrics*, *10*(11), 977–985. https://doi.org/10.1542/hpeds.2020-0075

Houska, A., Tučková, A., Vlčková, K., Poláková, K., & Loučka, M. (2021). Optimal participation in decision-making in advanced chronic disease: perspectives of patients, relatives and physicians. *Annals of Palliative Medicine*, *10*(4), 3951–3959. https://doi.org/10.21037/apm-20-2368

Hrdličková, L., Houska, A., & Kopecký, O. (2024). Dětská paliativní péče poskytovaná v nemocničních prostředí v České republice. *Paliativní Medicína*, *5*(3 SE-), 1–8. https://www.palmed.cz/pm/article/view/218

Hrdličková, L., Kokešová Kleinová, G., Nováková, L., Makešová, D., Doušová, T., Taberyová, M., & Snítilová, D. (2023). Five years of experience in providing paediatric palliative care in hospital setting. *Česko-Slovenská Pediatrie*, *78*(1), 44–47. https://doi.org/10.55095/CSPediatrie2023/008

Hrdlickova, L., Polakova, K., & Loucka, M. (2021). Important Aspects Influencing Delivery of Serious News in Pediatric Oncology: A Scoping Review. *Children*, *8*(2), 166. https://doi.org/10.3390/children8020166

Hrdlickova, L., Polakova, K., & Loucka, M. (2023). Innovative communication approaches for initializing pediatric palliative care: perspectives of family caregivers and treating specialists. *BMC Palliative Care*, *22*(1), 1–9. https://doi.org/10.1186/s12904-023-01269-3

Hsiao, J. L., Evan, E. E., & Zeltzer, L. K. (2007). Parent and child perspectives on physician communication in pediatric palliative care. *Palliative & Supportive Care*, *5*(4), 355–365. https://doi.org/10.1017/S1478951507000557

Huang, T.-Y., Mu, P.-F., & Chen, Y.-W. (2021). The Lived Experiences of Parents Having a Child With a Brain Tumor During the Shared Decision-Making Process of Treatment. *Cancer Nursing*, *45*(3), 201–210. https://doi.org/10.1097/NCC.0000000000000979

Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine*, *20*(8), 805–811.

https://doi.org/10.1177/0269216306072349

IMPaCTT. (2007). IMPaCCT: standards for paediatric palliative care in Europe. *European Journal of Palliative Care*, *14*(3), 109–116.

Iversen, A. S., Graue, M., & Clare, J. (2009). Parents' Perspectives of Surgery for a Child Who Has Cerebral Palsy. *Journal of Pediatric Health Care*, *23*(3), 165–172. https://doi.org/10.1016/j.pedhc.2008.04.006

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, *11*(3), 232–251. https://doi.org/10.1111/j.1369-7625.2008.00496.x

Janvier, A., Farlow, B., Barrington, K. J., Bourque, C. J., Brazg, T., & Wilfond, B. (2020). Building trust and improving communication with parents of children with Trisomy 13 and 18: A mixed-methods study. *Palliative Medicine*, *34*(3), 262–271. https://doi.org/10.1177/0269216319860662

Johnston, E. E., Alvarez, E., Saynina, O., Sanders, L., Bhatia, S., & Chamberlain, L. J. (2017). Disparities in the Intensity of End-of-Life Care for Children With Cancer. *Pediatrics*, *140*(4). https://doi.org/10.1542/peds.2017-0671

Jonas, D., Scanlon, C., & Bogetz, J. F. (2022). Parental Decision-Making for Children With Medical Complexity: An Integrated Literature Review. *Journal of Pain and Symptom Management*, *63*(1), e111–e123. https://doi.org/10.1016/j.jpainsymman.2021.07.029

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, *23*(23), 42–46.

https://doi.org/10.7748/ns2009.02.23.23.42.c6800

Jordan, Z., Tremblay, C., Lipstein, E., Jordan, I., & Boland, L. (2020). Is sharing really caring? Viewpoints on shared decision-making in paediatrics. *Journal of Paediatrics and Child Health*, *56*, 672–674. https://doi.org/10.1111/jpc.14806

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031

Kassam, A., Sutradhar, R., Widger, K., Rapoport, A., Pole, J. D., Nelson, K., Wolfe, J., Earle, C. C., & Gupta, S. (2017). Predictors of and Trends in High-Intensity End-of-Life Care Among Children With Cancer: A Population-Based Study Using Health Services Data. *Journal of Clinical Oncology*, *35*(2), 236–242. https://doi.org/10.1200/JCO.2016.68.8283

Kelly, K. P., & Ganong, L. (2011). Moving to place: childhood cancer treatment decision making in single-parent and repartnered family structures. *Qualitative Health Research*, *21*(3), 349–364. https://doi.org/10.1177/1049732310385823

Kilicarslan-Toruner, E., & Akgun-Citak, E. (2013). Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*, *17*(2), 176–183. https://doi.org/10.1016/j.ejon.2012.03.001

Kim, L., Costello, C., Golding, M. A., Janse van Rensburg, C., Protudjer, J. L. P., & Wittmeier, K. (2023). Determining the benefits and drawbacks of parents using personal connections and social networks for recruitment in research projects: a qualitative study. *Research Involvement and Engagement*, *9*(1), 58. https://doi.org/10.1186/s40900-023-00470-1

Kinkorová, J., & Topolčan, O. (2012). Overview of healthcare system in the Czech Republic. *EPMA Journal*, *3*(1), 1–8. https://doi.org/10.1007/s13167-012-0139-9

Kivunja, C., & Kuyini, A. B. (2017). Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, *6*(5), 26. https://doi.org/10.5430/ijhe.v6n5p26

Klassen, A. F., Dix, D., Papsdorf, M., Klaassen, R. J., Yanofsky, R., & Sung, L. (2012). Impact of caring for a child with cancer on single parents compared with parents from two-parent families. *Pediatric Blood & Cancer*, *58*(1), 74–79. https://doi.org/10.1002/pbc.22952

Knapp, C., Madden, V., Marcu, M., Wang, H., Curtis, C., Sloyer, P., & Shenkman, E. (2011). Information seeking behaviors of parents whose children have life-threatening illnesses. *Pediatric Blood & Cancer*, *56*(5), 805–811. https://doi.org/10.1002/pbc.22674

Koch, K. D., & Jones, B. L. (2018). Supporting parent caregivers of children with life-limiting illness. *Children*, *5*(7). https://doi.org/10.3390/children5070085

Kon, A. A. (2006). Answering the Question: “Doctor, if This Were Your Child, What Would You Do?” *Pediatrics*, *118*(1), 393–397. https://doi.org/10.1542/peds.2005-2655

Kozlowski, D., Hutchinson, M., Hurley, J., Rowley, J., & Sutherland, J. (2017). The role of emotion in clinical decision making: an integrative literature review. *BMC*

Medical Education, *17*(1), 255. https://doi.org/10.1186/s12909-017-1089-7

Krizova, E., & Simek, J. (2007). Theory and practice of informed consent in the Czech Republic. *Journal of Medical Ethics*, *33*(5), 273–277. https://doi.org/10.1136/jme.2005.015164

Labov, W. (1972). *Language in the Inner City: Studies in the Black English Vernacular*. University of Pennsylvania Press.

Labov, W., & Waletzky, J. (1967). Narrative analysis: oral versions of personal experience. In H. June (Ed.), *Essays on the Verbal and Visual Arts* (pp. 12–44). University of Washington Press.

Lam, L. W., Chang, A. M., & Morrissey, J. (2006). Parents' experiences of participation in the care of hospitalised children: A qualitative study. *International Journal of Nursing Studies*, *43*(5), 535–545. https://doi.org/10.1016/j.ijnurstu.2005.07.009

Lanceley, A., Savage, J., Menon, U., & Jacobs, I. (2008). Influences on multidisciplinary team decision-making. *International Journal of Gynecologic Cancer*, *18*(2), 215–222. https://doi.org/10.1111/j.1525-1438.2007.00991.x

Larcher, V., Craig, F., Bhogal, K., Wilkinson, D., & Brierley, J. (2015). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Arch Dis Child*, *100*(Suppl 2), s1–s23. https://doi.org/10.1136/archdischild-2014-306666

Lazzarin, P., Schiavon, B., Brugnaro, L., & Benini, F. (2018). Parents spend an average of nine hours a day providing palliative care for children at home and need to maintain an average of five life-saving devices. *Acta Paediatrica, International*

Journal of Paediatrics, *107*(2), 289–293. https://doi.org/10.1111/apa.14098

Lee, H. Y., Zhou, A. Q., Lee, R. M., & Dillon, A. L. (2020). Parents' functional health literacy is associated with children's health outcomes: Implications for health practice, policy, and research. *Children and Youth Services Review*, *110*, 104801. https://doi.org/10.1016/j.childyouth.2020.104801

Légaré, F., Ratté, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling*, *73*(3), 526–535. https://doi.org/10.1016/j.pec.2008.07.018

Li, J., Stroebe, M., Chan, C. L. W., & Chow, A. Y. M. (2014). Guilt in Bereavement: A Review and Conceptual Framework. *Death Studies*, *38*(3), 165–171. https://doi.org/10.1080/07481187.2012.738770

Lin, J. J., Evans, E. M., Praxedes, K., Agrawal, A. K., & Winestone, L. E. (2024). Financial assistance and other financial coping strategies after a pediatric cancer diagnosis. *Pediatric Blood & Cancer*, *71*(4), e30890. https://doi.org/10.1002/pbc.30890

Lin, J. L., Clark, C. L., Halpern-Felsher, B., Bennett, P. N., Assis-Hassid, S., Amir, O., Nunez, Y. C., Cleary, N. M., Gehrmann, S., Grosz, B. J., & Sanders, L. M. (2020). Parent Perspectives in Shared Decision-Making for Children With Medical Complexity. *Academic Pediatrics*, *20*(8), 1101–1108. https://doi.org/10.1016/j.acap.2020.06.008

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. SAGE Publications.

https://books.google.cz/books?id=2oA9aWlNeooC

Lindsay, G., Ricketts, J., Peacey, L. V., Dockrell, J. E., & Charman, T. (2016). Meeting the educational and social needs of children with language impairment or autism spectrum disorder: the parents' perspectives. *International Journal of Language & Communication Disorders*, *51*(5), 495–507. https://doi.org/10.1111/1460-6984.12226

Linney, M., Hain, R. D. W., Wilkinson, D., Fortune, P. M., Barclay, S., Larcher, V., Fitzgerald, J., & Arkell, E. (2019). Achieving consensus advice for paediatricians and other health professionals: On prevention, recognition and management of conflict in paediatric practice. *Archives of Disease in Childhood*, *104*(5), 413–416. https://doi.org/10.1136/archdischild-2018-316485

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, *32*(2), 246–258. https://doi.org/10.1177/0272989X11421528

Lipstein, E. A., Brinkman, W. B., Fiks, A. G., Hendrix, K. S., Kryworuchko, J., Miller, V. A., Prosser, L. A., Ungar, W. J., & Fox, D. (2015). An Emerging Field of Research: challenges in pediatric decision making. *Medical Decision Making*, *35*(3), 403–408. https://doi.org/10.1177/0272989X14546901

Lipstein, E. A., & Britto, M. T. (2015). Evolution of Pediatric Chronic Disease Treatment Decisions. *Medical Decision Making*, *35*(6), 703–713. https://doi.org/10.1177/0272989X15581805

Liu, S.-M., Lin, H.-R., Lu, F. L., & Lee, T.-Y. (2014). Taiwanese parents' experience of making a “do not resuscitate” decision for their child in pediatric intensive care unit. *Asian Nursing Research*, *8*(1), 29–35. https://doi.org/10.1016/j.anr.2013.12.002

Lucas, P. J., Baird, J., Arai, L., Law, C., & Roberts, H. M. (2007). Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology*, *7*, 1–7. https://doi.org/10.1186/1471-2288-7-4

Luz, R., George, A., Spitz, E., & Vieux, R. (2017). Breaking bad news in prenatal medicine: a literature review. *Journal of Reproductive and Infant Psychology*, *35*(1), 14–31. https://doi.org/10.1080/02646838.2016.1253052

Lynch, M. (2000). Against Reflexivity as an Academic Virtue and Source of Privileged Knowledge. *Theory, Culture & Society*, *17*(3), 26–54. papers://19c883a6-3c99-49f6-afbc-194c85f8c172/Paper/p677

Mack, J. W., & Wolfe, J. (2006). Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. *Current Opinion in Pediatrics*, *18*, 10–14. https://doi.org/10.1097/01.mop.0000193266.86129.47

Madrigal, V. N., Carroll, K. W., Faerber, J. A., Walter, J. K., Morrison, W. E., & Feudtner, C. (2016). Parental Sources of Support and Guidance When Making Difficult Decisions in the Pediatric Intensive Care Unit. *The Journal of Pediatrics*, *169*, 221-226.e4. https://doi.org/10.1016/j.jpeds.2015.10.061

Madrigal, V. N., Hill, D. L., Shults, J., & Feudtner, C. (2022). Trust in Physicians, Anxiety and Depression, and Decision-Making Preferences among Parents of

Children with Serious Illness. *Journal of Palliative Medicine*, *25*(3), 428–436. https://doi.org/10.1089/jpm.2021.0063

Mallows, B., Henderson, K., Wigham, T., & Veale, D. (2005). *Guidance on safety in fieldwork*. The University Safety and Health Association, Universities and Colleges Employers Association. https://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf

Marcus, K. L., Kao, P.-C., Ma, C., Wolfe, J., & DeCourcey, D. D. (2022). Symptoms and Suffering at End of Life for Children With Complex Chronic Conditions. *Journal of Pain and Symptom Management*, *63*(1), 88–97. https://doi.org/10.1016/j.jpainsymman.2021.07.010

Marcus, K. L., Santos, G., Bilodeau, M., Wolfe, J., Dussel, V., Aires, B., Aires, B., & Care, P. (2020). Impact of Specialized Pediatric Palliative Care: A Systematic Review. *Journal of Pain and Symptom Management*, *59*(2), 339–364. https://doi.org/10.1016/j.jpainsymman.2019.08.005.Impact

Markward, M. J., Benner, K., & Freese, R. (2013). Perspectives of parents on making decisions about the care and treatment of a child with cancer: A review of literature. *Families, Systems, & Health*, *31*(4), 406–413. https://doi.org/10.1037/a0034440

McDermott, R. (2008). Medical decision making: Lessons from psychology. *Urologic Oncology: Seminars and Original Investigations*, *26*(6), 665–668. https://doi.org/10.1016/j.urolonc.2007.12.006

McLorie, E. V., Fraser, L., & Hackett, J. (2023). Provision of care for children with medical complexity in tertiary hospitals in England: qualitative interviews with health professionals. *BMJ Paediatrics Open*, *7*(1), e001932. https://doi.org/10.1136/bmjpo-2023-001932

McLorie, E. V., Hackett, J., Barrett, L., Peat, G., Weatherly, H., Hinde, S., Walker, G., Noyes, J., Oddie, S., Vasudevan, C., Feltbower, R. G., Phillips, B., Hewitt, C., Hain, R., Subramanian, G., Haynes, A., Papworth, A., Fraser, L. K., & Murtagh, F. E. M. (2025). Healthcare professionals' perspectives of providing end-of-life care for infants, children and young people in acute settings: A multi-site qualitative study. *Palliative Medicine*. https://doi.org/10.1177/02692163251320204

McNeilly, P., Macdonald, G., & Kelly, B. (2017). The participation of parents of disabled children and young people in health and social care decisions. *Child: Care, Health and Development*, *43*(6), 839–846. https://doi.org/10.1111/cch.12487

Meert, K. L., Clark, J., & Eggly, S. (2013). Family-Centred Care in Pediatric Intensive Care Unit. *Pediatric Clinics of North America*, *60*(3), 761–772. https://doi.org/10.1016/j.pcl.2013.02.011.Family-Centered

Mekelenkamp, H., Lankester, A. C., Bierings, M. B., Smiers, F. J. W., de Vries, M. C., & Kars, M. C. (2020). Parental experiences in end-of-life decision-making in allogeneic pediatric stem cell transplantation. *Pediatric Blood & Cancer*, *67*(5). https://doi.org/10.1002/pbc.28229

Meltzer, L. J., Davis, K. F., & Mindell, J. A. (2012). Patient and parent sleep in a children's hospital. *Pediatric Nursing*, *38*(2), 64–71; quiz 72.

http://www.ncbi.nlm.nih.gov/pubmed/22685865

Merriam, S. B. (1998). *Qualitative research and case study applications in education* (2nd ed.). Jossey-Bass.

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: a guide to design and implementation* (4th ed.). Jossey-Bass. http://acc.aacnjournals.org/cgi/doi/10.1097/NCI.0b013e3181edd9b1

Miles, M. S., & Demi, A. S. (1992). A Comparison of Guilt in Bereaved Parents whose Children Died by Suicide, Accident, or Chronic Disease. *OMEGA - Journal of Death and Dying*, *24*(3), 203–215. https://doi.org/10.2190/G41E-RKTF-P0XD-LJLK

Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Services Research*, *9*(1), 242. https://doi.org/10.1186/1472-6963-9-242

Miller, R., & Brewer, J. (2015). Case Study Research. *The A-Z of Social Research*, *29*(41), 36–40. https://doi.org/10.4135/9781412986281.n32

Miller, V. A. (2009). Parent–child collaborative decision making for the management of chronic illness: A qualitative analysis. *Families, Systems, & Health*, *27*(3), 249–266. https://doi.org/10.1037/a0017308

Milles, M., Huberman, M., & Saldana, J. (2014). *Qualitative data analysis* (3rd ed.). SAGE.

Mitchell, A. E., Morawska, A., Vickers-Jones, R., & Bruce, K. (2021). A Systematic

Review of Parenting Interventions to Support Siblings of Children with a Chronic Health Condition. *Clinical Child and Family Psychology Review*, *24*(3), 651–667. https://doi.org/10.1007/s10567-021-00357-1

Mitchell, S., Morris, A., Bennett, K., Sajid, L., & Dale, J. (2017). Specialist paediatric palliative care services: What are the benefits? *Archives of Disease in Childhood*, *102*(10), 923–929. https://doi.org/10.1136/archdischild-2016-312026

Mitchell, S., Spry, J. L., Hill, E., Coad, J., Dale, J., & Plunkett, A. (2019). Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. *BMJ Open*, *9*(5), e028548. https://doi.org/10.1136/bmjopen-2018-028548

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, *7*(6). https://doi.org/10.1371/journal.pmed.1000097

Mordechai, O., Tamir, S., & Weyl-Ben-Arush, M. (2015). Seeking a Second Opinion in Pediatric Oncology. *Pediatric Hematology and Oncology*, *32*(4), 284–289. https://doi.org/10.3109/08880018.2014.987938

Morse, J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research*, *25*(9), 1212–1222. https://doi.org/10.1177/1049732315588501

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-

2214.2006.00644.x

Nelson, L. J., & Nelson, R. M. (1992). Ethics and the provision of futile, harmful, or burdensome treatment to children. *Critical Care Medicine*, *20*(3), 427–433. https://doi.org/10.1097/00003246-199203000-00022

Noyes, J., Edwards, R. T., Hastings, R. P., Hain, R., Totsika, V., Bennett, V., Hobson, L., Davies, G. R., Humphreys, C., Devins, M., Spencer, L. H., & Lewis, M. (2013). Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. *BMC Palliative Care*, *12*(18), 1–17. https://doi.org/doi.org/10.1186/1472-684X-12-18

Obeidat, R. F., Homish, G. G., & Lally, R. M. (2013). Shared Decision Making Among Individuals With Cancer in Non-Western Cultures: A Literature Review. *Oncology Nursing Forum*, *40*(5), 454–463. https://doi.org/10.1188/13.ONF.454-463

Oberender, F., & Tibballs, J. (2011). Withdrawal of life-support in paediatric intensive care - a study of time intervals between discussion, decision and death. *BMC Pediatrics*, *11*, 2–7. https://doi.org/10.1186/1471-2431-11-39

October, T. W., Jones, A. H., Greenlick Michals, H., Hebert, L. M., Jiang, J., & Wang, J. (2020). Parental Conflict, Regret, and Short-term Impact on Quality of Life in Tracheostomy Decision-Making. *Pediatric Critical Care Medicine*, *21*(2), 136–142. https://doi.org/10.1097/PCC.0000000000002109

Olofsson, B., & Norberg, A. (2001). Experiences of coercion in psychiatric care as narrated by patients, nurses and physicians. *Journal of Advanced Nursing*, *33*(1), 89–97. https://doi.org/10.1046/j.1365-2648.2001.01641.x

Orfali, K. (2004). Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science & Medicine*, *58*(10), 2009–2022. https://doi.org/10.1016/S0277-9536(03)00406-4

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, n71. https://doi.org/10.1136/bmj.n71

Park, E. S., & Cho, Y. I. (2018). Shared decision-making in the paediatric field: a literature review and concept analysis. *Scandinavian Journal of Caring Sciences*, *32*, 478–489. https://doi.org/10.1111/scs.12496

Parker, K., Cottrell, E., Stork, L., & Lindemulder, S. (2021). Parental decision making regarding consent to randomization on Children's Oncology Group AALL0932. *Pediatric Blood Cancer*, *68*(e28907). https://doi.org/10.1002/pbc.28907

Paul, T. K., Vercler, C. J., & Laventhal, N. (2017). A Dose of Paternalism: How Eliciting Values, Not Amplifying Parental Permission, Can Promote the Interest of Children and Families. *The American Journal of Bioethics*, *17*(11), 24–26. https://doi.org/10.1080/15265161.2017.1378767

Pecánková, M., & Žáčková, L. (2024). *Rozvoj dostupnosti mobilní specializované paliativní péče mezi roky 2018 a 2021 a 2022*. https://www.mobilnihospice.cz/omobilnich-hospicich#odborne-dokumenty

Peshkin, A. (1988). In Search of Subjectivity — One ’ s Own. *Educational Research*, *17*(7), 17–21.

Phoenix, C., Osborne, N. J., Redshaw, C., Moran, R., Stahl-Timmins, W., Depledge, M. H., Fleming, L. E., & Wheeler, B. W. (2013). Paradigmatic approaches to studying environment and human health: (Forgotten) implications for interdisciplinary research. *Environmental Science and Policy*, *25*, 218–228. https://doi.org/10.1016/j.envsci.2012.10.015

Piette, V., Dombrecht, L., Deliens, L., Cools, F., Chambaere, K., Goossens, L., Naulaers, G., Laroche, S., Cornette, L., Bekaert, E., Decoster, P., Beernaert, K., & Cohen, J. (2022). Barriers and facilitators for parents in end-of-life decision-making for neonates at the Neonatal Intensive Care Unit: A qualitative study. *Palliative Medicine*, *36*(4), 730–741. https://doi.org/10.1177/02692163221076365

Pinto Taylor, E., & Doolittle, B. (2020). Caregiver Decision-Making for Terminally Ill Children: A Qualitative Study. *Journal of Palliative Care*, *35*(3), 161–166. https://doi.org/10.1177/0825859719885947

Pizur-Barnekow, K. (2010). Maternal Health After the Birth of a Medically Complex Infant: Setting the Context for Evaluation of Co-Occupational Performance. *The American Journal of Occupational Therapy*, *64*(4), 642–649. https://doi.org/10.5014/ajot.2010.08160

Platt, H. (1959). The Welfare of Children in Hospital. In *British Medical Journal* (Vol. 1, Issue 5115).

Polakova, K., Ahmed, F., Vlckova, K., & Brearley, S. G. (2024). Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A systematic review with narrative synthesis. *Palliative Medicine*, *38*(1), 7–24. https://doi.org/10.1177/02692163231214414

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, *8*(1), 5–23. https://doi.org/10.1080/0951839950080103

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. *ESRC Methods Programme*, *2006*, 93. https://doi.org/10.13140/2.1.1018.4643

Pope, C., & Mays, N. (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*, *311*(6996), 42–45. https://doi.org/10.1136/bmj.311.6996.42

Popejoy, E. (2015). Parents' experiences of care decisions about children with life-limiting illnesses. *Nursing Children and Young People*, *27*(8), 20–24. https://doi.org/10.7748/ncyp.27.8.20.s23

Popejoy, E., Almack, K., Manning, J. C., Johnston, B., & Pollock, K. (2022). Communication strategies and persuasion as core components of shared decision-making for children with life-limiting conditions: A multiple case study. *Palliative Medicine*, *36*(3), 519–528. https://doi.org/10.1177/02692163211068997

Popejoy, E., Pollock, K., Almack, K., Manning, J. C., & Johnston, B. (2017). Decision-making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child: Care, Health and Development*, *43*(5), 627–644. https://doi.org/10.1111/cch.12461

Postier, A., Catrine, K., & Remke, S. (2018). Interdisciplinary Pediatric Palliative Care Team Involvement in Compassionate Extubation at Home: From Shared Decision-Making to Bereavement. *Children*, *5*(3), 37. https://doi.org/10.3390/children5030037

Pyke-Grimm, K. A., Stewart, J. L., Kelly, K. P., & Degner, L. F. (2006). Parents of Children With Cancer: Factors Influencing Their Treatment Decision Making Roles. *Journal of Pediatric Nursing*, *21*(5), 350–361. https://doi.org/10.1016/j.pedn.2006.02.005

Radcliffe, K., Lyson, H. C., Barr-Walker, J., & Sarkar, U. (2019). Collective intelligence in medical decision-making: a systematic scoping review. *BMC Medical Informatics and Decision Making*, *19*(1), 158. https://doi.org/10.1186/s12911-019-0882-0

Rahman, M., Jeffreys, J., & Massie, J. (2021). A narrative review of the experience and decision-making for children on home mechanical ventilation. *Journal of Paediatrics and Child Health*, *57*(6), 791–796. https://doi.org/10.1111/jpc.15506

Rapoport, A., Shaheed, J., Newman, C., Rugg, M., & Steele, R. (2013). Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care. *Pediatrics*, *131*(5), 861–869. https://doi.org/10.1542/peds.2012-1916

Ratislavová, K., Beran, J., & Lorenzová, E. (2016). Decision-making of Czech mothers about contact with their baby after perinatal loss. *Kontakt*, *18*(1), e30–e35. https://doi.org/10.1016/j.kontakt.2016.02.003

Ray, L. D. (2002). Parenting and Childhood Chronicity: Making visible the invisible work. *Journal of Pediatric Nursing*, *17*(6), 424–438. https://doi.org/10.1053/jpdn.2002.127172

RCPCH. (2004). *Witholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*. Royal College of Paediatrics and Child Health.

Rechel, B., & McKee, M. (2009). Health reform in central and eastern Europe and the former Soviet Union. *The Lancet*, *374*(9696), 1186–1195. https://doi.org/10.1016/S0140-6736(09)61334-9

Renjith, V., Yesodharan, R., Noronha, J., Ladd, E., & George, A. (2021). Qualitative methods in health care research. *International Journal of Preventive Medicine*, *12*(1), 20. https://doi.org/10.4103/ijpvm.IJPVM_321_19

Rennke, S., Yuan, P., Monash, B., Blankenburg, R., Chua, I., Harman, S., Sakai, D. S., Khan, A., Hilton, J. F., Shieh, L., & Satterfield, J. (2017). The SDM 3 circle model: A literature synthesis and adaptation for shared decision making in the hospital. *Journal of Hospital Medicine*, *12*(12), 1001–1008. https://doi.org/10.12788/jhm.2865

Richards, C. A., Starks, H., O'Connor, M. R., Bourget, E., Hays, R. M., & Doorenbos, A. Z. (2018). Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care. *American Journal of Hospice and Palliative Medicine*, *35*(4), 669–676. https://doi.org/10.1177/1049909117734843

Riessman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine*, *30*(11), 1195–1200. https://doi.org/10.1016/0277-9536(90)90259-U

Riessman, C. K. (2000). Analysis of personal narratives. In *The SAGE Handbook of Interview Research: The Complexity of the Craft* (Issue January 2001). https://doi.org/10.4135/9781452218403.n26

Riessman, C. K., & Quinney, L. (2005). Narrative in Social Work:A Critical Review. *Qualitative Social Work*, *4*(4), 391–412. https://doi.org/10.1177/1473325005058643

Robertson, E. G., Wakefield, C. E., Shaw, J., Darlington, A.-S., McGill, B. C., Cohn, R. J., & Fardell, J. E. (2019). Decision-making in childhood cancer: parents' and adolescents' views and perceptions. *Supportive Care in Cancer*, *27*(11), 4331–4340. https://doi.org/10.1007/s00520-019-04728-x

Robinson, O. C. (2014). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, *11*(1), 25–41. https://doi.org/10.1080/14780887.2013.801543

Romaniuk, P., & Szromek, A. R. (2016). The evolution of the health system outcomes in Central and Eastern Europe and their association with social, economic and political factors: An analysis of 25 years of transition. *BMC Health Services Research*, *16*(1), 1–12. https://doi.org/10.1186/s12913-016-1344-3

Ross, J. R., Capozzi, J. D., & Matava, M. J. (2012). Discussing Treatment Options with a

Minor: The Conflicts Related to Autonomy, Beneficence, and Paternalism. *Journal of Bone and Joint Surgery*, *94*(1), e3. https://doi.org/10.2106/JBJS.J.02007

Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: what it is and what it isn't. *BMJ*, *312*(7023), 71–72. https://doi.org/10.1136/bmj.312.7023.71

Salter, E. K. (2020). The new futility? The rhetoric and role of "suffering" in pediatric decision-making. *Nursing Ethics*, *27*(1), 16–27. https://doi.org/10.1177/0969733019840745

Santoro, J. D., & Bennett, M. (2018). Ethics of end of life decisions in pediatrics: A narrative review of the roles of caregivers, shared decision-making, and patient centered values. *Behavioral Sciences*, *8*(5). https://doi.org/10.3390/bs8050042

Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching*, *5*(9), 9–16. https://doi.org/10.5539/elt.v5n9p9

Sharman, M., Meert, K. L., & Sarnaik, A. P. (2005). What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine*, *6*(5), 513–518. https://doi.org/10.1097/01.PCC.0000170616.28175.D9

Shields, L., Hunter, J., & Hall, J. (2004). Parents' and staff's perceptions of parental needs during a child's admission to hospital: An English perspective. *Journal of Child Health Care*, *8*(1), 9–33. https://doi.org/10.1177/1367493504041851

Sikorova, L., & Kucova, J. (2012). The needs of mothers to newborns hospitalised in intensive care units. *Biomedical Papers*, *156*(4), 330–336. https://doi.org/10.5507/bp.2011.046

Snaman, J. M., Torres, C., Duffy, B., Levine, D. R., Gibson, D. V, & Baker, J. N. (2016). Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution. *Journal of Palliative Medicine*, *19*(3), 326–332. https://doi.org/10.1089/jpm.2015.0253

Stake, R. E. (1995). *The Art of Case Study Research*. SAGE Publications Inc.

Steele, R., & Davies, B. (1998). Impact on parents when a child has a progressive, life-threatening illness. *International Journal of Palliative Nursing*, *12*(12), 576–585. https://doi.org/https://doi.org/10.12968/ijpn.2006.12.12.22544

Steiner, A. M., & Fletcher, P. C. (2017). Sandwich Generation Caregiving: A Complex and Dynamic Role. *Journal of Adult Development*, *24*(2), 133–143. https://doi.org/10.1007/s10804-016-9252-7

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Lindquist, J. H., & Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine*, *20*(8), 745–754. https://doi.org/10.1177/0269216306073112

Stenhammar, C., Bokström, P., Edlund, B., & Sarkadi, A. (2011). Using different approaches to conducting postal questionnaires affected response rates and cost-efficiency. *Journal of Clinical Epidemiology*, *64*(10), 1137–1143. https://doi.org/10.1016/j.jclinepi.2011.01.006

Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2005). Parental Treatment Decision Making in Pediatric Oncology. *Seminars in Oncology Nursing*, *21*(2), 89–97. https://doi.org/10.1016/j.soncn.2004.12.003

Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2012). Making the right decision for my child with cancer: the parental imperative. *Cancer Nursing*, *35*(6), 419–428. https://doi.org/10.1097/NCC.0b013e3182431071

Stiggelbout, A. M., Weijden, T. V. d., Wit, M. P. T. D., Frosch, D., Legare, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: really putting patients at the centre of healthcare. *BMJ*, *344*(jan27 1), e256–e256. https://doi.org/10.1136/bmj.e256

Streuli, J. C., Anderson, J., Alef-Defoe, S., Bergsträsser, E., Jucker, J., Meyer, S., Chaksad-Weiland, S., & Vayena, E. (2021). Combining the best interest standard with shared decision-making in paediatrics—introducing the shared optimum approach based on a qualitative study. *European Journal of Pediatrics*, *180*(3), 759–766. https://doi.org/10.1007/s00431-020-03756-8

Streuli, J. C., Widger, K., Medeiros, C., Zuniga-Villanueva, G., & Trenholm, M. (2019). Impact of specialized pediatric palliative care programs on communication and decision-making. *Patient Education and Counseling*, *102*(8), 1404–1412. https://doi.org/10.1016/j.pec.2019.02.011

Studdert, D. M., Burns, J. P., Mello, M. M., Puopolo, A. L., Truog, R. D., & Brennan, T. A. (2003). Nature of conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics*, *112*(3 I), 553–558.

https://doi.org/10.1542/peds.112.3.553

Sullivan, J., Gillam, L. H., & Monagle, P. T. (2020). After an end-of-life decision: Parents' reflections on living with an end-of-life decision for their child. *Journal of Paediatrics and Child Health*, *56*(7), 1060–1065. https://doi.org/10.1111/jpc.14816

Sullivan, J., Monagle, P., & Gillam, L. (2014). What parents want from doctors in end-of-life decision-making for children. *Archives of Disease in Childhood*, *99*(3), 216–220. https://doi.org/10.1136/archdischild-2013-304249

Tan, A., Tiew, L., & Shorey, S. (2021). Experiences and needs of parents of palliative paediatric oncology patients : A meta-synthesis. *European Journal of Cancer Care*, *November 2020*, 1–20. https://doi.org/10.1111/ecc.13388

Tan, R. B., Chan, P. Y., & Shorey, S. (2024). Experiences of siblings of children with chronic pediatric conditions: a qualitative systematic review. *European Journal of Pediatrics*, *184*(1), 44. https://doi.org/10.1007/s00431-024-05826-7

Tavakol, M., & Zeinaloo, A. A. (2004). Medical research paradigms: positivistic inquiry paradigm versus naturalistic inquiry paradigm. *Journal of Medical Education*, *5*(2), 75–80.

Taylor, J., Booth, A., Beresford, B., Phillips, B., Wright, K., & Fraser, L. (2020). Specialist paediatric palliative care for children and young people with cancer: A mixed-methods systematic review. *Palliative Medicine*, *34*(6), 731–775. https://doi.org/10.1177/0269216320908490

Tetley, J., Grant, G., & Davies, S. (2009). Using narratives to understand older people's decision-making processes. *Qualitative Health Research*, *19*(9), 1273–1283. https://doi.org/10.1177/1049732309344175

Thornes, R. (1983). Parental access and family facilities in children's wards in England. *British Medical Journal (Clinical Research Ed.)*, *287*(6386), 190–192. https://doi.org/10.1136/bmj.287.6386.190

Tietzova, I., Buzgova, R., & Kopecky, O. (2024). Decision-making and ethical dilemmas experienced by hospital physicians during the COVID-19 pandemic in the Czech Republic. *BMC Medical Ethics*, *25*(1), 144. https://doi.org/10.1186/s12910-024-01133-w

Tight, M. (2010). The curious case of case study: A viewpoint. *International Journal of Social Research Methodology*, *13*(4), 329–339. https://doi.org/10.1080/13645570903187181

Toebbe, S., Yehle, K., Kirkpatrick, J., & Coddington, J. (2013). Hypoplastic Left Heart Syndrome: Parent Support for Early Decision Making. *Journal of Pediatric Nursing*, *28*(4), 383–392. https://doi.org/10.1016/j.pedn.2012.11.005

Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., Wrathall, G., & Sung, L. (2007). Challenges to participation in paediatric palliative care research: a review of the literature. *Palliative Medicine*, *21*(5), 435–440. https://doi.org/10.1177/0269216307077173

Traynor, M. D., Antiel, R. M., Camazine, M. N., Blinman, T. A., Nance, M. L., Eghtesady, P., Lam, S. K., Hall, M., & Feudtner, C. (2021). Surgical Interventions During End-of-Life Hospitalizations in Children's Hospitals. *Pediatrics*, *148*(6).

https://doi.org/10.1542/peds.2020-047464

Tsai, E. (2008). Advance care planning for paediatric patients. *Paediatrics and Child Health*, *13*(9), 791–796. https://doi.org/10.1093/pch/13.9.791

Twamley, K., Craig, F., Kelly, P., Hollowell, D. R., Mendoza, P., & Bluebond-Langner, M. (2014). Underlying barriers to referral to paediatric palliative care services. *Journal of Child Health Care*, *18*(1), 19–30. https://doi.org/10.1177/1367493512468363

Vaknin, O., & Zisk-Rony, R. Y. (2011). Including children in medical decisions and treatments: perceptions and practices of healthcare providers. *Child: Care, Health and Development*, *37*(4), 533–539. https://doi.org/10.1111/j.1365-2214.2010.01153.x

Vemuri, S., Hynson, J., Williams, K., & Gillam, L. (2022). Decision-making approaches for children with life-limiting conditions: results from a qualitative phenomenological study. *BMC Medical Ethics*, *23*(1), 52. https://doi.org/10.1186/s12910-022-00788-7

Verschuren, P. J. M. (2003). Case study as a research strategy: Some ambiguities and opportunities. *International Journal of Social Research Methodology: Theory and Practice*, *6*(2), 121–139. https://doi.org/10.1080/13645570110106154

Vido, R., Václavík, D., & Paleček, A. (2016). Czech Republic: The Promised Land for Atheists? In *Annual Review of the Sociology of Religion* (pp. 201–232). BRILL. https://doi.org/10.1163/9789004319301_012

Vitéz-Durgula, J., Dunay, A., Thalmeiner, G., Vajai, B., & Pataki, L. (2023). Financial

Analysis and Survival Research of the Visegrad Countries' Health Industries. *Sustainability*, *15*(16), 12360. https://doi.org/10.3390/su151612360

Vos, M. A. De, Heide, A. Van Der, Maurice-stam, H., Brouwer, O. F., Meeteren, S., Willems, D. L., Heymans, H. S. A., & Bos, A. P. (2011). *The Process of End-of-Life Decision-Making in Pediatrics: A National Survey in the Netherlands*. https://doi.org/10.1542/peds

Walshe, C. E., Caress, A. L., Chew-Graham, C., & Todd, C. J. (2004). Case studies: A research strategy appropriate for palliative care? *Palliative Medicine*, *18*(8), 677–684. https://doi.org/10.1191/0269216304pm962ra

Wang, K. W. K., & Barnard, A. (2004). Technology-dependent children and their families: A review. *Journal of Advanced Nursing*, *45*(1), 36–46. https://doi.org/10.1046/j.1365-2648.2003.02858.x

Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, *53*(4), 459–469. https://doi.org/10.1111/j.1365-2648.2006.03740.x

Weaver, M. S., Mooney-Doyle, K., Kelly, K. P., Montgomery, K., Newman, A. R., Fortney, C. A., Bell, C. J., Spruit, J. L., Kurtz Uveges, M., Wiener, L., Schmidt, C. M., Madrigal, V. N., & Hinds, P. S. (2019). The Benefits and Burdens of Pediatric Palliative Care and End-of-Life Research: A Systematic Review. *Journal of Palliative Medicine*, *22*(8), 915–926. https://doi.org/10.1089/jpm.2018.0483

Weaver, M. S., October, T., Feudtner, C., & Hinds, P. S. (2020). "Good-Parent Beliefs": Research, Concept, and Clinical Practice. *Pediatrics*, *145*(6), e20194018.

https://doi.org/10.1542/peds.2019-4018

Weber, E. U., & Morris, M. W. (2010). Culture and Judgment and Decision Making. *Perspectives on Psychological Science*, *5*(4), 410–419. https://doi.org/10.1177/1745691610375556

Wellesley, H., & Jenkins, I. A. (2009). Withholding and withdrawing life-sustaining treatment in children. *Pediatric Anesthesia*, *19*(5), 972–978. https://doi.org/10.1111/j.1460-9592.2009.03027.x

Widger, K., Brennenstuhl, S., Nelson, K. E., Seow, H., Rapoport, A., Siden, H., Vadeboncoeur, C., Gupta, S., & Tanuseputro, P. (2023). Intensity of end-of-life care among children with life-threatening conditions: a national population-based observational study. *BMC Pediatrics*, *23*(1), 375. https://doi.org/10.1186/s12887-023-04186-9

Wiles, J. L., Rosenberg, M. W., & Kearns, R. a. (2005). Narrative analysis as a strategy for understanding interview talk in geographic research. *Area*, *37*(1), 89–99. https://doi.org/10.1111/j.1475-4762.2005.00608.x

Wilson, H. J. (2000). The myth of objectivity: is medicine moving towards a social constructivist medical paradigm? *Family Practice*, *17*(2), 203–209. https://doi.org/10.1093/fampra/17.2.203

Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., Emanuel, E. J., & Weeks, J. C. (2000). Symptoms and Suffering at the End of Life in Children with Cancer. *New England Journal of Medicine*, *342*(5), 326–333. https://doi.org/10.1056/NEJM200002033420506

Wood, F., Simpson, S., Barnes, E., & Hain, R. (2010). Disease trajectories and ACT/RCPCH categories in paediatric palliative care. *Palliative Medicine*, *24*(8), 796–806. https://doi.org/10.1177/0269216310376555

Woodgate, R. L., & Yanofsky, R. A. (2010). Parents’ experiences in decision making with childhood cancer clinical trials. *Cancer Nursing*, *33*(1), 11–18. https://doi.org/10.1097/NCC.0b013e3181b43389

Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P., Wang, Z., Domecq Garces, J. P., Montori, V. M., & LeBlanc, A. (2015). Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. *Academic Pediatrics*, *15*(6), 573–583. https://doi.org/10.1016/j.acap.2015.03.011

Xafis, V., Wilkinson, D., & Sullivan, J. (2015). What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliative Care*, *14*, 19. https://doi.org/10.1186/s12904-015-0024-0

Yazan, B. (2015). Three Approaches to Case Study Methods in Education: Yin, Merriam, and Stake. *The Qualitative Report*, *20*(2), 134–152. https://doi.org/10.1007/BF00243003

Yazdani, N., Chartrand, J., & Stacey, D. (2022). Exploring Parental Decision Making for a Child with a Life-Limiting Condition: An Interpretive Description Study. *Journal of Hospice and Palliative Nursing*, *24*(2), 140–146. https://doi.org/10.1097/NJH.0000000000000839

Ygge, B. M., & Arnetz, J. E. (2004). A study of parental involvement in pediatric hospital care: Implications for clinical practice. *Journal of Pediatric Nursing*, *19*(3), 217–223. https://doi.org/10.1016/j.pedn.2004.02.005

Yin, H. S., Dreyer, B. P., Vivar, K. L., MacFarland, S., van Schaick, L., & Mendelsohn, A. L. (2012). Perceived Barriers to Care and Attitudes Towards Shared Decision-making Among Low Socioeconomic Status Parents: Role of Health Literacy. *Academic Pediatrics*, *12*(2), 117–124. https://doi.org/10.1016/j.acap.2012.01.001

Yin, R. K. (2018). *Case study research and applications: Design and methods* (Vol. 53, Issue 6). SAGE Publications Inc. https://doi.org/10.1177/109634809702100108

Zaal-Schuller, I. H., de Vos, M. A., Ewals, F. V. P. M., van Goudoever, J. B., & Willems, D. L. (2016). End-of-life decision-making for children with severe developmental disabilities: The parental perspective. *Research in Developmental Disabilities*, *49–50*, 235–246. https://doi.org/10.1016/j.ridd.2015.12.006

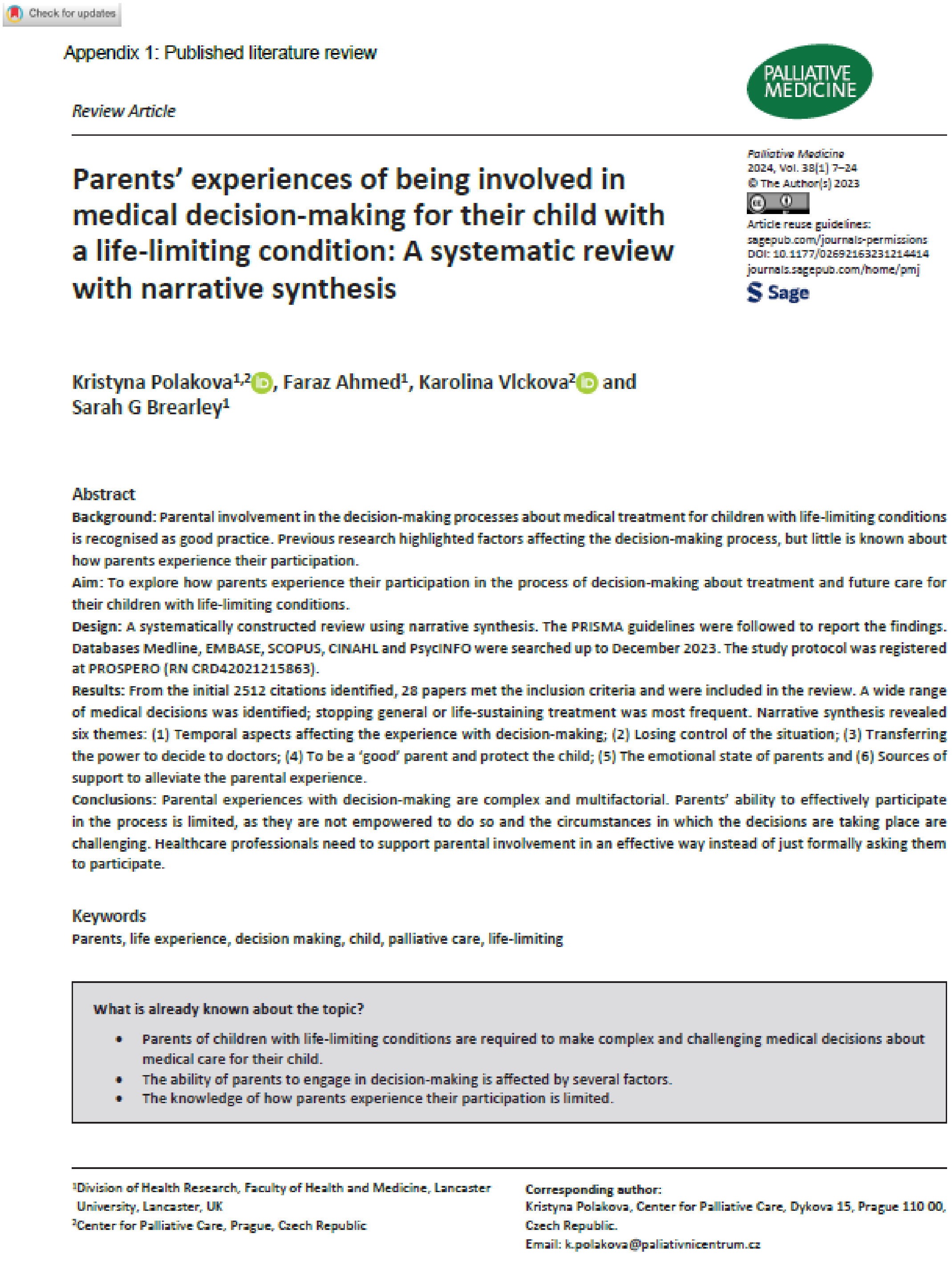
Zaal-Schuller, I. H., Willems, D. L., Ewals, F. V. P. M., van Goudoever, J. B., & de Vos, M. A. (2016). How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, *59*, 283–293. https://doi.org/10.1016/j.ridd.2016.09.012

Zaidman, E. A., Scott, K. M., Hahn, D., Bennett, P., & Caldwell, P. H. (2023). Impact of parental health literacy on the health outcomes of children with chronic disease globally: A systematic review. *Journal of Paediatrics and Child Health*, *59*(1), 12–31. https://doi.org/10.1111/jpc.16297

Zawistowski, C. A., & DeVita, M. A. (2004). A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life-sustaining treatment. *Pediatric Critical Care Medicine*, *5*(3), 216–223. https://doi.org/10.1097/01.PCC.0000123547.28099.44

Appendices

Appendix 1: Published literature review



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Appendix 1: Published literature review

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Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A systematic review with narrative synthesis

Kristyna Polakova[1,2], Faraz Ahmed[1], Karolina Vlckova[2] and Sarah G Brearley[1]

Abstract

Background: Parental involvement in the decision-making processes about medical treatment for children with life-limiting conditions is recognised as good practice. Previous research highlighted factors affecting the decision-making process, but little is known about how parents experience their participation.
Aim: To explore how parents experience their participation in the process of decision-making about treatment and future care for their children with life-limiting conditions.
Design: A systematically constructed review using narrative synthesis. The PRISMA guidelines were followed to report the findings. Databases Medline, EMBASE, SCOPUS, CINAHL and PsycINFO were searched up to December 2023. The study protocol was registered at PROSPERO (RN CRD42021215863).
Results: From the initial 2512 citations identified, 28 papers met the inclusion criteria and were included in the review. A wide range of medical decisions was identified; stopping general or life-sustaining treatment was most frequent. Narrative synthesis revealed six themes: (1) Temporal aspects affecting the experience with decision-making; (2) Losing control of the situation; (3) Transferring the power to decide to doctors; (4) To be a 'good' parent and protect the child; (5) The emotional state of parents and (6) Sources of support to alleviate the parental experience.
Conclusions: Parental experiences with decision-making are complex and multifactorial. Parents' ability to effectively participate in the process is limited, as they are not empowered to do so and the circumstances in which the decisions are taking place are challenging. Healthcare professionals need to support parental involvement in an effective way instead of just formally asking them to participate.

Keywords

Parents, life experience, decision making, child, palliative care, life-limiting

What is already known about the topic?

- Parents of children with life-limiting conditions are required to make complex and challenging medical decisions about medical care for their child.
- The ability of parents to engage in decision-making is affected by several factors.
- The knowledge of how parents experience their participation is limited.

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What this paper adds?

- Participation in the decision-making process is an emotionally challenging situation and parents experience a wide range of negative emotions.
- Parents' ability to make decisions for their child is affected by their emotional state and their perceived lack of confidence to act on behalf of their child caused by limited medical knowledge, emotional exhaustion and insecurities.
- Making difficult decisions in challenging circumstances can result in difficulties in maintaining the parental role and in losing the ability to make decisions for their child.

Implications for practice, theory or policy

- Parental negative experience can be mitigated by a sensitive attitude of the clinicians, providing parents with adequate support and preparing them for decision-making.
- Parents should be actively invited and encouraged to participate in the decision-making by clinicians, but it is necessary to tailor the level of participation individually for each parent and enable them to engage at their preferred level.
- Further research should focus on the experience of fathers and single parents, as this population is understudied.

Background

The involvement of parents in the medical decision-making process is seen as a standard practice in modern paediatric medicine.[1,2] Individual needs and preferences of each parent should be acknowledged as the level at which parents want to be included may differ.[3,4] This also applies to parents of children with life-limiting or life-threatening conditions.

Conditions which can be classified as life-limiting or life-threatening represent a diverse group of often rare diagnoses, but together they affect a large population of children, with a worldwide estimation of around 21 million children.[5] Life-limiting and life-threatening conditions can be divided into four categories, based on the course of the illness and the expected outcome: (I) life-threatening conditions with possible cure which can fail, such as cancer; (II) conditions with inevitable premature death where intensive treatment prolonging life is available, such as cystic fibrosis; (III) progressive conditions without curative treatment options, where treatment is exclusively palliative, for example Batten disease and (IV) irreversible but non-progressive conditions causing severe disability and likelihood of premature death like cerebral palsy.[2] Although conditions which fall within the life-threatening category can be possibly curable, they can also be fatal and result in premature death of the ill child[6]; therefore, for this review, the term life-limiting conditions will be used for all four categories. All conditions which fall within the categories presented above are characterised by uncertain prognoses and unpredictable changes in a child's health.[7,8] Therefore parents have to make complex and often challenging decisions about medical care during the child's life.[9,10]

Within the population of parents of children with life-limiting conditions, the available evidence suggests a strong preference for active parental participation in decision-making.[8,10] The ability of parents to engage in decision-making for their child is affected by several aspects. The most highlighted aspect is concerning the child's quality of life,[7,11,12] followed by having a sufficient amount of information and sensitive communication with healthcare professionals.[10,12–14] Additionally, parents need adequate support from clinicians, who act as gatekeepers in the decision-making process[15,16] to be able to actively participate.[7,10,12] During the decision-making process, healthcare professionals and parents should work together as partners and reach the decision through discussion.[17,18] To give parents adequate support during this process, it is important to understand how parents experience their participation, but this knowledge is limited. Available systematic reviews in this area have focussed on exploring factors affecting the decision-making process, parents' perception of their role or the level of their involvement,[7,8,10,12,19–21] or their experience with end-of-life care.[22–25] Furthermore, the available studies tend to distinguish between the four categories of life-limiting conditions, either focussing on parents of children with cancer[12,23,25] or children with complex healthcare needs and disabilities,[7,8] despite evidence that parental experiences of caring for of their child are similar irrespective of the child's condition.[26] Distinguishing among the four categories of life-limiting conditions can hinder the identification of possible similarities in the experience of making decisions about medical care and thus limit our understanding of this phenomenon.[7,10] By bringing together studies exploring parental experience with decision-making for children regardless of their condition, it is possible to fill the gap in the available literature and to gain a better understanding of the decision-making process. The need for research focussed on communication between healthcare professionals and parents, including care-related decision-making, was identified among research priorities within the population of children with life-limiting conditions.[27]

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Parents/legal guardians, including bereaved parents of children 0–19 years old diagnosed with a life-limiting condition	Studies including parents/legal guardians of children with life-limiting conditions older than 19 years at the time of the study
	Studies focussed on parental decisions made before the birth of a child diagnosed with a life-limiting condition before birth
	Studies focussed on the experience of parents of prematurely born babies and parents with newborn babies <28 days old
Reports on primary experience of parents/legal guardians involved in the decision-making process about the care of their child	Studies that do not report on the parental experience from the parents' perspective and accounts of parental experience obtained from other participants involved in the decision-making process (such as doctors and nurses)
Studies reporting on parental experience with decision-making about healthcare for their child	Studies reporting on experience with phenomena other than decision-making in healthcare, including care experience, the experience of siblings, experience with providing care at home, care transition, decisions regarding fertility options for cancer patients and organ donation
English or Czech language	Other languages
Reports on primary findings of qualitative, quantitative or mixed methods research. Published in peer-reviewed journal	Commentaries, editorials, opinion papers, secondary data analysis, review articles, conference abstracts and case studies including just/only one case. Any study published in non-peer-reviewed journals.
Published between 2000 and 2023	Studies published before 2000

Therefore, the purpose of this systematic review was to identify and synthesise available literature exploring how parents experience their participation in the process of decision-making about treatment and future care for their children with life-limiting conditions.

Aim

A systematic review of the literature to explore how parents experience their participation in the process of decision-making about treatment and future care for their children with life-limiting conditions. The review question is: what are the parental experiences of the decision-making process for children with life-limiting conditions?

Methods

The presented systematic review utilised the guidance for narrative synthesis by Popay et al.[28] Narrative synthesis enables the integration of different types of evidence, including qualitative and quantitative data,[29] permitting data from different types of studies to be collated into a homogenous group, while also identifying any differences in the studies and gaps in the literature.[30]

The review was reported by using the Preferred Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines[31] (Supplemental Appendix 1) and registered at PROSPERO on 12 February 2021 (registration number: CRD42021215863).

Inclusion criteria

Following inclusion and exclusion criteria were applied to each study (see Table 1).

Information sources and search strategy

The literature search was conducted in Medline, EMBASE, SCOPUS, CINAHL and PsycINFO in December 2020. The search terms were developed together with a subject librarian, and MeSH terms were used to enhance the search strategy. Details of the search strategy used in Medline database are presented in Table 2. Hand searching of the key journals was used in The Journal of Pediatrics, Journal of Pediatric Nursing, Journal of Hospice and Palliative Nursing, Palliative Medicine and MDPI Children. To identify any potentially relevant studies, included papers were checked for citation tracking. The searching process was documented by using the PRISMA 2020 statement: an updated guideline for reporting systematic reviews.[31]

Study selection

All identified papers were processed by the management tool EndNoteX9. Duplicates were removed electronically and manually. Titles and abstracts were screened independently against the inclusion criteria, and studies which met the inclusion criteria were read in full text by KP and KV. Any disagreement was resolved with SB and FA.

Table 2. Search concepts for MEDLINE database.

Concept number	SPIDER	Pearl growing	MeSH	Search query
Concept #1	Parent Guardian	Caregiver	Parents Mothers Fathers	Parent* OR mother* OR father* OR guardian OR caregiver
Concept #2	Decision	Decision support	Decision making	decision OR decision making OR decision support
Concept #3	Experience	Perception View Feeling Attitude Belief	Life experience	experience OR view OR feeling OR perception OR attitude OR belief*
Concept #4	Child	Infant	Children Paediatric	child* OR infant OR paediatric
Concept #5	Life-limiting Life-threatening	Medically complex	Disabled Severely disabled Cancer Oncology Neoplasm Tumour Intensive care Long term care Terminal care	'life-limiting' OR 'medically complex' OR disabled OR 'severely disabled' OR 'terminal care' OR 'long term care' OR 'intensive care' OR cancer* OR oncolog* OR tumour* OR tumour* neoplasm OR malignan*

Data collection and synthesis

Data from the included studies were extracted using NVivo software. Additional data were extracted in Excel and Word. The narrative synthesis was conducted by KP and subsequently reviewed by SB and FA. During the first stage of the narrative synthesis,[28] each included study was analysed separately, and a textual description of the parental experience was developed. From each study, the direct citations from parents describing their experience with decision-making were extracted using NVivo. The description of parental experience presented by the study authors was also included in the synthesis. The data synthesis process included categorising the studies based on their setting (oncology and life-limiting) and participants (mothers and fathers) to allow comparison of the experiences with decision-making. This process was followed by data analysis using an open coding approach. Inductive codes identifying parental experience with the studied phenomenon were developed and subsequently collated together based on their similarities, thus developing preliminary themes used as a matrix during the analysis. The coding process included merging codes together, re-coding and developing new themes and subthemes. The data extraction and analysis were done by KP, identified themes were developed in consultation with SB and FA. Six themes were developed and are presented in the Results section.

Data evaluation

With the aim to include only studies of a sufficient methodological rigour all of the included studies were evaluated using a quality assessment tool developed for critical appraisal of studies with different phenomenological backgrounds.[32] This tool was previously used to assess the quality of systematic reviews in palliative care settings.[33,34] The Hawker et at. tool[32] evaluates nine components the score for each component ranges between 1 and 4; the overall minimum score is 9, the maximum is 36, which denotes high quality of the study. To assess the overall quality of the included studies the following grades definitions were used: high quality, 30–36 points; medium quality, 24–29 points and low quality, 9–24 points. In previous systematic review which used the Hawker et al. tool the minimum score for including studies was set at score of 20.[33]

Quality assessment was completed independently (by KP and KV), final scores were appointed after comparing individual scores and through discussion of possible differences. The assessed studies had scores between 26 and 36, with a median score of 32, which was considered as medium or high quality. Therefore, all eligible studies were included in the final synthesis.

Results

After deduplication, 1591 studies were screened for eligibility using titles and abstracts. A total of 85 papers were read in full, with 25 meeting the inclusion criteria. Three additional studies were identified through citation tracking, resulting in 28 papers being included in this systematic review (see details in Figure 1).

Overview of the studies

The methodological design of the included studies was mainly qualitative ($n = 25$), with three mixed methods

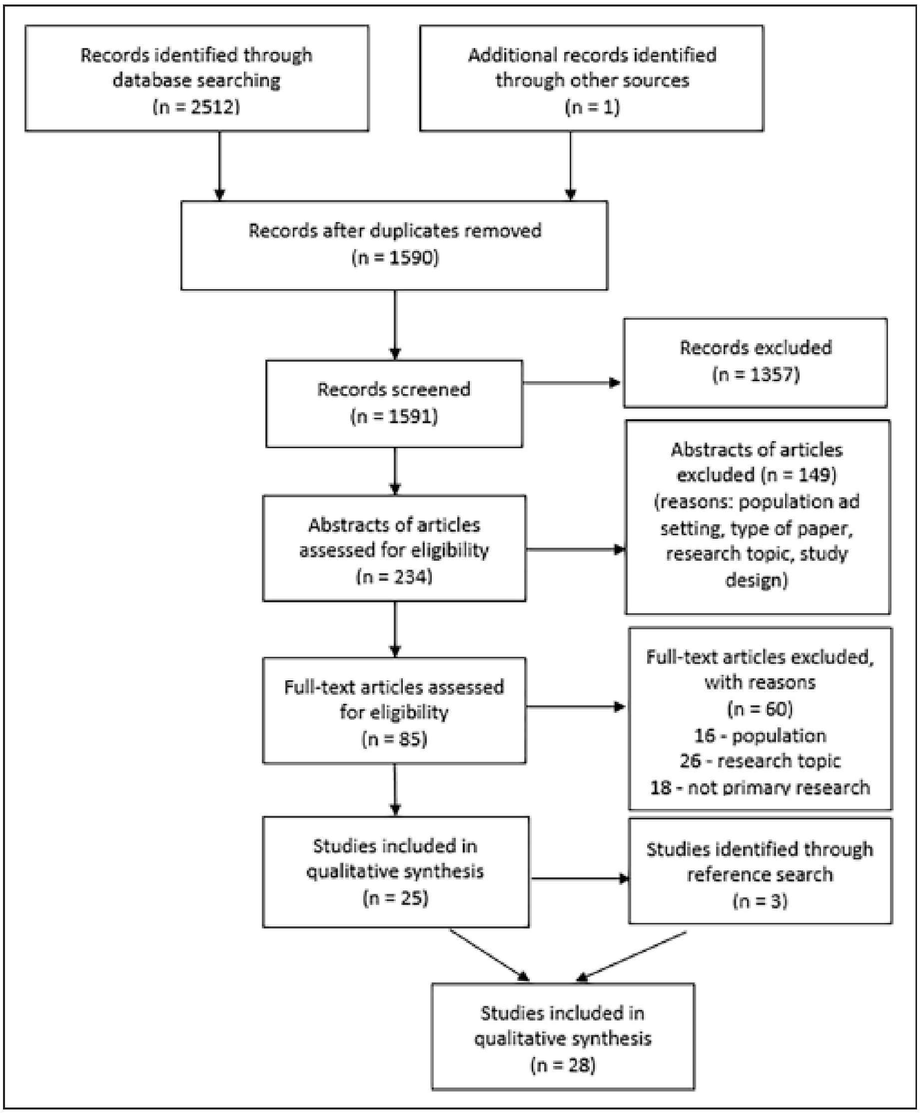

Figure 1. PRISMA flow diagram.[22]

studies.[35–37] The included papers originated from 15 countries (see Table 3) and were mostly published between 2010 and 2023 (*n* = 26); two studies were published in 2005 and 2007.[38,39] A total of 13 studies were set exclusively at oncology setting,[35,37,40–50] 12 studies explored the decision-making of parents with children with life-limiting conditions[36,38,51–60] and 3 had a population with mixed diagnoses.[39,61,62] Six studies were set in intensive care units.[38,39,53,55,57,61]

The included studies present data from 923 parents (including 294 bereaved parents) of 757 children. The majority of parents were mothers (*n* = 665), but most studies (*n* = 24) included fathers in the sample. Included studies explored various types of decisions. The most frequent decisions were about limitation of treatment and life-sustaining treatment (see Table 3 for an overview of types of decisions).

Synthesis

Following a narrative synthesis, 6 themes and 21 subthemes were identified. The identified themes represent the main domains of parents' experiences with the decision-making process (Table 4). Codes for each theme are presented in Supplemental Appendix 2.

Temporal aspect affecting the experience with decision-making. The first theme includes two subthemes connected to the aspect of time, which is influencing parents while making decisions.

Lack of time while making the decision. Parental experiences during the decision-making process were affected by the timeframe of the decision.[35,38,44,49,56,59,60,61] Parents were often required to make decisions under time pressure and with a sense of urgency.[35,44,60,61] Decisions made under time pressure included the Do Not Resuscitate status, an agreement to start an oncology treatment, a placement of a central access device and end-of-life decisions.[35,44,60,61] The lack of time meant that, in some studies, parents felt like they did not have enough information to make an informed decision and they would have preferred to have more time.[35,38,44,63] The time pressure caused anxiety and fear and was associated with disagreements and conflicts with healthcare professionals.[38,60,61] This subtheme was interlinked with the *Being forced into the decision* subtheme.[36,38,45,48,49,61,63] Those parents who had been given enough time to come to a decision talked about their experience peacefully.[49,56,59] The timeframe deemed sufficient to make sound decisions varied between a few hours to a week.[49,59]

Difficulty to foresee the future. Parents had to make decisions which could have a long-lasting impact on their child's quality of life, but at the same time, they struggled to comprehend the future in its complexity.[44,48,49,52–54,56,57] Even parents of children with pre-existing life-limiting conditions found it difficult to plan for the future and to make decisions about advanced care planning as these situations were hypothetical for them, filled with uncertainty and it was difficult to imagine them happening.[52–54,57] Additionally, some parents were worried about how their decisions will impact the child.[52,53]

The location in which decisions were made further compounded these challenges, as parents experienced difficulties in anticipating the impact of their decisions on everyday life at home when the decision was made when the child was still in the hospital environment.[44,52,56]

Losing control of the situation. The losing control of the situation theme refers to the parental perception of not being in charge of the decision-making process.

Not having a real choice. Most parents felt like they did not have a real choice.[35,37,39,41,43,48–51,54,56,63] This was because they were not given any alternative choices to the proposed option, and the other option meant they would agree with letting the child die, or the procedure was undertaken without asking them, and they were not given a choice in the matter.[37,39,41,51,54,56] For parents of children with cancer, the expectation was that they would follow a treatment protocol.[43,48]

Being forced into the decision. Some parents felt that the final decision was not their own or that they had been manipulated or even coerced into it by the clinicians[39,44,45] or family members.[50] Parents felt like they did not have enough information about all options available or were not involved as they wished. When making a treatment choice which did not align with the clinician's, a minority of parents felt they lacked support or worried about disappointing the clinician.[44,49] Parents who thought they were coerced into decision-making felt anger, bitterness and distress and they described their experience as horrific and painful.[44,49,62,63]

Difficulty grasping the reality. Parents struggled with the reality of the situation when they were making decisions. Often decisions were required when parents were still dealing with challenging new information about their child's health, such as a new diagnosis, an unexpected change in the child's health or a sudden health decline.[35,39,44,56,63] In several studies parents were required to make decisions while not knowing what the outcome would be and whether their treatment decision would help their child or not.[48,49,52,53] This is closely linked with the subtheme *Difficulty to foresee the future*. With some decisions, including long-term ventilation and end-of-life decisions, parents found it difficult to accept the seriousness of the situation and were in denial about the possibility their child might die in the near future.[56,57,61] In some cases, this led to parents unintentionally passing the responsibility for the decision-making onto the healthcare professionals.[48,49,63]

Transferring the power to decide to the doctors. While the previous theme *Losing control of the situation* highlighted the experience of parents not being in control of the decision-making process, this theme shows that for some parents being in control is challenging and they may prefer the doctors to be in charge. Four subthemes were identified in this theme, all related to the parental experience of letting the doctors make the decision for several reasons, as presented below.

Table 3. Overview of the included studies.

Author, year, country	Method/data collection	Objective/aim of the study	Setting	Quality score	Participants	Type of decision	Key findings
Atout et al. (2017), Jordan	Qualitative study Participant observation and semi-structured interviews	To understand the experiences of mothers of children with palliative care needs about their involvement in decision-making.	Life-limiting conditions	32	15 mothers 12 physicians 20 nurses	Treatment and care (not closely specified)	When making decisions, mothers relied on doctor's expertise. They were experiencing a lack of confidence to make their decisions. Mothers were worried they would feel guilty in the future if making the decision for their children.
Badarau et al. (2017), Switzerland Romania	Qualitative study Interviews	To examine the perspectives of parents of children with cancer and their physicians on the experiences with participation in decision-making.	Oncology	32	37 parents (29 mothers, 5 fathers and 3 grandmothers) 26 physicians	Starting treatment Trial treatment Fertility treatment Treatment and care (not closely specified)	Participants in both countries described decision-making processes in similar ways. Parents could only participate in less important decisions.
Bandinelli, Goldim (2016), Brazil	Mixed-method study Semi-structured interviews and questionnaires	To get an understanding of the decision-making phenomenon from the perspectives of parents.	Oncology	32	10 parents (9 mothers and 1 father)	Starting treatment Catheter insertion	Parents felt like they did not have a real choice. They experienced a lack of time to make the decision and felt anxiety and fear. Parents found it difficult to grasp the reality of the diagnosis and act on it.
Beecham et al. (2016), UK	Qualitative study In-depth interviews	To increase the understanding of how parents approach and experience advanced care planning for their children.	Life-limiting conditions	32	18 parents (including 9 bereaved parents, 16 mothers and 2 fathers)	Place of care Place of death Limitation of treatment	Parents wanted to keep options open and to be able to change their minds. It was difficult for parents to foresee the possible consequences of treatment limitation. Making decisions about future treatment options was difficult as parents perceived the options as hypothetical.
Bergviken, Nilsson (2019), Sweden	Qualitative study Interviews	To explore how parents of children with cancer choose which type of central access device to use.	Oncology	32	17 parents (11 mothers and 6 fathers)	Central access device	Parents were making difficult decisions in a limited amount of time and in stressful situation. They were not sure which type of central access device was the right one and had difficulty to foresee the future.
Bogetz et al. (2022), USA	Qualitative study Semi-structured interviews	To explore the parental experience with decision-making for children with severe neurological impairment.	Life-limiting conditions Intensive care unit	26	25 parents (19 mothers and 6 fathers)	Treatment and care (not closely specified)	Parents acted as advocates for their children to ensure they would get the treatment they needed; parents felt they were not listened to by the medical team. When making decisions, parents felt responsible for the outcome while uncertain if the treatment would benefit the child.
Carlisle et al. (2022), USA	Qualitative study Semi-structured interviews	To get an understanding of parental preferences for surgical counselling when deciding on surgery for solid tumours.	Oncology	27	10 parents (gender not specified)	Aggressive treatment Tumour resection	Parents preferred to be involved in the decision-making process, but in some cases, parents did not have enough information and were not adequately engaged. Parents acted as advocates for their children. Participation in decision-making was experienced as overwhelming and frustrating if they felt not included. Parents found it difficult to ask the surgeons questions as they did not know what to ask.
Carnevale et al. (2007), Canada, France	Qualitative study Semi-structured interviews	To examine whether physicians or parents assumed responsibility for treatment decisions and how this related to the parental experience.	Life-limiting conditions Oncology Intensive care unit	32	31 parents (19 mothers and 12 fathers) 9 physicians 13 nurses	Life support Surgical interventions	Parents described their experience as very hard. They felt like they were abandoning their child if they agreed to stop treatment. Parents found it difficult to concentrate as they were in a state of shock.

(Continued)

Table 3. (Continued)

Author, year, country	Method/data collection	Objective/aim of the study	Setting	Quality score	Participants	Type of decision	Key findings
Carnevale et al. (2011), Italy	Qualitative study Focus groups and interviews	To explore how life-sustaining treatment decisions were made for critically ill children in Italy and how were these decisional processes experienced by physicians, nurses and parents.	Life-limiting conditions Intensive care unit	26	9 parents (including 6 bereaved parents, 7 mothers and 2 fathers) 16 physicians 26 nurses	Life-sustaining treatment (not closely specified)	Parents found it difficult to make decisions, and they relied on the physician's advice. They had difficulty processing all the information due to their emotional state.
De Clerq et al. (2022), Switzerland	Qualitative study Semi-structured interviews	To get an understanding of how parents experienced decision-making about initiating treatment for their deceased children diagnosed with diffuse intrinsic pontine glioma.	Oncology	30	25 bereaved parents (14 mothers and 11 fathers)	Starting cancer treatment, including radiotherapy and chemotherapy	Parents felt there were no viable options due to the lack of treatment protocols. Parents knew the condition was terminal, but they hoped for a miracle. At the same time, they focussed on the child's quality of life. Some parents decided to pursue the treatment to get additional time with the child, while others tried alternative therapies. Parents felt at peace with their decisions. Some found support in faith.
Edwards et al. (2020), USA	Qualitative study Semi-structured interviews	To explore the parental experience of decision-making to initiate long-term ventilation.	Life-limiting conditions	31	44 parents (34 mothers and 10 fathers)	Initiation of long-term ventilation	Parental experience with making decisions for the initiation of long-term ventilation was described as extremely difficult. They felt like they did not have a real choice and questioned the quality of the child's life. They could not comprehend what long-term ventilation meant for everyday life.
Graetz et. al. (2022), Guatemala	Mixed-methods study Semi-structured interviews and cross-sectional survey	To explore the decision-making preferences and experiences of parents of children with cancer.	Oncology	29	118 parents (89 mothers and 29 fathers) 1 grandparent 1 sibling	Treatment and care (not closely specified)	Parents preferred the healthcare providers would make decisions about treatment as they trusted their medical opinion. Most parents (64%) did not regret their decisions. About 24% of parents asked for advice from religious or spiritual leaders.
Gurková et al. (2015), Slovakia	Qualitative study Semi-structured in-depth interview	To illuminate and analyse the experience of parents of children with failed cancer treatment and the death of their child.	Oncology	29	5 bereaved parents (4 mothers and 1 father)	Starting treatment Limitation of treatment Trial treatment Aggressive treatment Bone-marrow transplant	Parents felt like being forced into a decision or being in conflict with the doctors. They lacked support and understanding from healthcare professionals and acted as advocates for their children.
Huang et. al. (2022), Taiwan	Qualitative phenomenological study In-depth interviews	To explore the lived experience of parents of children with brain tumour during decision-making.	Oncology	33	10 parents (7 mothers and 3 fathers)	Treatment and care (not closely specified)	Parents needed time to adjust to the new situation to be able to participate in decision-making. If doctors were using English terms to talk about the children's conditions, parents felt unable to participate in the discussion.
Janvier et al. (2019), USA, Canada, UK other	Mixed-methods study Questionnaire with open questions	To investigate how parents of children with Trisomy 13 and 18 experienced their interactions with clinicians.	Life-limiting conditions	30	332 parents (including 187 bereaved parents, 257 mothers and 74 fathers)	Limitation of treatment Treatment and care (not closely specified)	Parents felt as forced into decisions by healthcare professionals. They acted as advocates for their children. Parents who had a good relationship with healthcare professionals wanted their support and involvement in the decision-making so they wouldn't have to decide about their child's death.

(Continued)

Table 3. (Continued)

Author, year, country	Method/data collection	Objective/aim of the study	Setting	Quality score	Participants	Type of decision	Key findings
Kelly, Ganong (2011), USA	Qualitative study In-depth interviews	To explore how divorced parents make treatment decisions for their children with cancer.	Oncology	33	15 parents (8 mothers and 7 fathers	Starting treatment Trial treatment Aggressive treatment Bone-marrow transplant	Divorced parents prioritised the child's best interest over the relationship with the ex-husband/wife. Parents valued support from their new partners. Single parents lacked support from the second parent. Parents excluded stepparents from decision-making to avoid future blame for negative outcomes.
Liu et al. (2014), Taiwan	Qualitative study In-depth interviews	To explore the parental experience of making a Do Not Resuscitate decision for their child.	Life-limiting conditions Oncology Intensive care unit		16 parents (including bereaved parents, 9 mothers and 7 fathers)	Attempting resuscitation Do Not Resuscitate status	The decision about the Do Not Resuscitate status was difficult. It made parents feel responsible for the death of their child. Parents felt pressured by healthcare professionals to sign the Do Not Resuscitate form. Parents found helpful their faith in God and believed in the reincarnation of the child.
Mitchell et al. (2019), UK	Qualitative study In-depth interviews	To provide an in-depth insight into the experiences and perceptions of parents who had made end-of-life care decisions for their children.	Life-limiting conditions Intensive care unit	36	17 parents (11 mothers and 6 fathers)	Limitation of treatment End-of-life decisions Advanced care planning	Parents described their experience as difficult, as they were having conflicting emotions. While some parents wanted advanced care planning and to have information about the end-of-life, others did not want this, keeping a hope that the child would recover.
Parker et al. (2021), USA	Qualitative study Semi-structured interviews	To investigate the decision-making process of parents deciding about the enrolment of their ill child in a clinical trial.	Oncology	26	20 parents (17 mothers and 3 fathers)	Enrolment in clinical trials	Deciding whether to continue with standard or trial treatment was difficult and overwhelming for parents. Parents were worried their decision would affect their child's future health, and they would feel guilty if the outcome were negative.
Popejoy (2015), UK	Qualitative study Semi-structured interviews	To get an understanding of the lived experience of parents throughout the process of making and revising end-of-life care decisions for their child.	Life-limiting conditions	33	3 bereaved parents (mothers only)	End-of-life decisions (place of care, place of death, limitation of treatment)	Parents valued cooperation with the medical team and passed the responsibility for the decision-making onto the physicians. The end-of-life decision was perceived as difficult or impossible as it led to the child's death. Parents acknowledged the need to have a plan and not to make decisions in the time of crisis. Plans can be changed based on the current health condition of the child.
Rapoport et al. (2013), USA	Qualitative study In-depth interviews	To explore parental perceptions about the experience and their child's quality of death after choosing forgoing artificial nutrition and hydration in children at the end-of-life.	Life-limiting conditions	34	11 bereaved parents (6 mothers and 6 fathers)	Forgoing artificial nutrition and hydration	Parents needed support from healthcare professionals and the medical team to have the same opinion and not contradict themselves. Forgoing artificial nutrition and hydration was a difficult decision, but parents felt at peace with it as it improved the quality of life of their child. Some parents felt judged by healthcare professionals or their family/friends for their decision.

(Continued)

Table 3. (Continued)

Author, year, country	Method/data collection	Objective/aim of the study	Setting	Quality score	Participants	Type of decision	Key findings
Robertson et al. (2019), Australia	Qualitative study Semi-structured interviews	To explore parents' and adolescents' views and perceptions of the treatment decision-making process in paediatric oncology.	Oncology	33	25 parents (23 mothers and 2 fathers) 5 children	Clinical trial Central venous access insertion/removal Start of treatment Fertility preservation Radiotherapy	Parents experienced information overload, which made them unable to analyse all the information and make decisions. They trusted their oncologist to make the best treatment decision. They felt like they lacked the medical expertise to make the decisions by themselves and felt pressured to make decisions while not having enough information to do so. Parents believed the child should be involved in minor decisions.
Sharman et al. (2005), USA	Qualitative study Semi-structured In-depth interviews	To identify and describe factors important to parents during the decision-making process.	Life-limiting conditions Oncology	29	14 parents (9 mothers and 5 fathers)	Limitation of treatment Withdrawal of life support	Parents appreciated support from healthcare professionals while making the decision. They relied on the healthcare professionals' expertise. They sometimes did not have enough time and felt pressured into a decision by healthcare professionals. Parents acknowledged the quality of life of the child and the child's will to live/die and leaned their faith while making the decision. If possible, parents were including the child in the decision-making.
Stewart et al. (2012), USA	Qualitative study Semi-structured interviews	To describe the process of parents making major treatment decisions for their children with cancer.	Oncology	32	15 parents (9 mothers and 6 fathers)	Clinical trial Bone marrow transplant	Parents were determined to make the right decision for their children. They valued support from the healthcare professionals. The decisions they had to make were difficult and overwhelming. Parents experienced various emotions such as anxiety, fear, depression, stress and anger. Parents felt exhausted and had a high level of uncertainty while making the decisions. Parents relied on their personal faith in God and on spirituality.
Sullivan et al. (2020), Australia	Qualitative study Semi-structured interviews	To examine bereaved parents' views and experiences of decision-making for their child and how they reflect and live with their decision.	Life-limiting conditions Oncology	34	25 bereaved parents (gender not specified)	End-of-life decision Limitation of treatment	End-of-life decisions were experienced as difficult. Parents were doing the best for their child, which included terminating the life support or withdrawing treatment. Parents who participated in the decision-making process were more likely to feel they made the right decision. Parents who did not participate felt regrets and were more emotionally distressed.

(Continued)

Table 3. (Continued)

Author, year, country	Method/data collection	Objective/aim of the study	Setting	Quality score	Participants	Type of decision	Key findings
Woodgate et al. (2010), Canada	Qualitative study Interviews	To get a detailed, in-depth understanding of parents' participation in decision-making about childhood cancer clinical trials.	Oncology	31	31 parents (20 mothers and 11 fathers)	Enrolment in clinical trials	The decision-making was difficult and overwhelming. The decision seemed to be impossible to make. Parents relied on the support of healthcare professionals. Their relationship with them was crucial while making the decision. Some parents felt obliged to agree with the trial so they would not upset their healthcare professionals. Parents also thought about the child's future and the possible implications of the trial for his/her health.
Yazdani et.al. (2022), Canada	Qualitative study Semi-structured interviews	To explore parents' and healthcare professionals' perceptions of the experience of parents making decisions for their children with life-limiting condition.	Life-limiting conditions	30	6 parents (5 mothers and 1 father)	Treatment and care (not closely specified)	Parents experienced decisional conflict; It was difficult to foresee the outcome of their decisions. Parents acted as advocates for their children and preferred to make the decisions independently or be involved in the process. Making decisions for their children was experienced as difficult, stressful and filled with uncertainty. Parents valued support from healthcare professionals and other parents.
Zaal-Shuller et al. (2016), Netherlands	Qualitative study Semi-structured interviews	To compare the experiences of parents and physicians who were involved in the end-of-life decision-making process.	Life-limiting conditions	31	17 parents (including bereaved parents, 14 mothers and 3 fathers) 11 physicians	End-of-life decision Limitation of treatment Attempting resuscitation Do Not Resuscitate status Artificial nutrition and hydration Invasive treatment	Parents felt they were the experts on their child's health and their opinion should be taken seriously. Parents appreciated the medical advice and support from the healthcare professionals, and some felt they lacked the medical expertise needed to make the decision. Some decisions were made under time pressure, and this was perceived as disturbing. Parents also relied on their faith.

Table 4. Framework of the themes.

Theme	Subthemes
1. Temporal aspects affecting the experience with decision-making	*Lack of time while making the decision* *Difficulty to foresee the future*
2. Losing control of the situation	*Not having a real choice* *Being forced into the decision* *Difficulty grasping the reality*
3. Transferring the power to decide to the doctors	*Reluctance to make decision* *Transferring the responsibility to doctors* *Relying on the doctor's expertise* *Lack of confidence and medical expertise*
4. To be a 'good' parent and protect the child	*Child in the centre: what is best for the child* *Advocacy for the child* *Trying everything possible*
5. The emotional state of parents	*Overall experience* *Range of emotions* *Guilt* *Feelings after*
6. Sources of support to alleviate the parental experience	*Behaviour of doctors* *Including parents in decision-making* *Having enough information* *Being supported by loved ones* *Faith*

Reluctance to make a decision. Some parents found it difficult to accept the responsibility for making medical decisions themselves.[36,38,39,48,51,56,58,59,63] When decisions were made, the process was deemed impossible and offensive as parents did not know what the right decision was. A minority of parents avoided making the decisions entirely,[38,56] or did not want to be included in the decision-making process as it engendered feelings of complicity in the death of their child or concerns about being burdened with the negative outcome.[36,51] For other parents, it was difficult to make the decisions due to the feelings of uncertainty they experienced.[52]

Transferring the responsibility to doctors. In several studies, parents preferred to transfer the responsibility of decision-making onto doctors entirely, particularly parents of children with life-limiting conditions other than cancer.[36,37,39,42,48,51,52,58,59,63] By passing the responsibility onto clinicians, some parents were able to relieve themselves of future guilt feelings.[39,42] Although this transfer was done willingly, some felt regret afterwards for letting the physician decide and questioned whether the treatment decision done by the physician was right.[39] Two studies brought evidence that parents found it difficult to verbalise their decision and were grateful when the physician did it for them, while others felt too much pressure to make the right decision and welcomed the option to pass the responsibility onto the physicians.[58,63]

Relying on the doctors' expertise. Several parents relied on the expertise of doctors and the medical team as they believed they were doing the best for their children.[37,38,42,43,48,50,57,61,63] It was seen as important for healthcare professionals to work together as a team and to be consistent in their approach during the decision-making process.[39,50,59] The preference was for a familiar clinician to be involved in the process.[39,60] Additionally, trust was important as a mediator in relieving parental distress.[37,48,55,63]

Lack of confidence and medical expertise. A lack of medical knowledge made it difficult for parents to make decisions related to medical care; they were concerned that their decision could negatively impact their child's health, and they lacked the confidence to make the decision.[48,51,54,60,61,63] When combined with parents' perceptions of their limitations, they found it difficult to contradict the clinicians' opinion or to question the decision made by clinicians. Emotional exhaustion further compounded parental lack of confidence in decision-making.[48] Instead, parents relied on the clinician's expertise and advice even when they were aware that the clinicians might not be right.[51,54,63]

To be a 'good' parent and protect the child. This theme includes three subthemes highlighting the parental need to act as a parent of their child and to protect their child.

Child in the centre – what is best for the child. In majority of the included studies, parents stated they had the child's best interest in mind when making the decisions, and the decisions were based on what they believed was best for their child.[41,42,46,48,49,54,56–59,60–62] At times, this meant going against what parents wished for. The process of balancing the child's best interests and the parents' wishes and uncertainties about the right decision made the experience difficult.[38,39,45,49,58,61,64] The conflict of wanting their child to live as long as possible whilst wanting to avoid additional suffering for their child was particularly challenging.[38,41,42,54,57–59,61,62] Additionally, parents kept hope for a positive outcome even in most adverse situations.[41,55–57,61]

Advocating for the child. Parents often take on the role of advocates when it comes to making critical decisions.[36,38,45,48,50,52,53,56,60] Parents firmly believe in their responsibility to make decisions which include choices related to treatment and life support.[39,45,49,56,58,62] There was also evidence of child involvement, either through verbal expression of their wishes or nonverbal signs that indicate their desire to continue living.[38,48,49,61,63]

Parents saw themselves as experts on their children and, in situations in which they felt like they were not getting enough support from doctors, they had a strong need to protect the child.[36,38,45,48,53,60] Parents of nonverbal children expressed their role of being a voice for their children and the need to make the decision on the children's behalf.[52,53,60] In some cases, parents of children with developmental delays perceived that physicians did not always treat their child with dignity and respect because of the mental impairment and felt they had to fight for appropriate care and treatment.[36,38,60]

Trying everything possible. When making decisions, parents wanted to try all options of treatment available or to look for treatment elsewhere, including alternative therapies and seeking a second opinion.[36,37,41–43,45,49–51,56,57,61] This was particularly evident when making decisions about withdrawing treatment; parents needed to be sure there were no other options remaining and that they could change their decision depending on the health state of their child.[36,43,45,49,51,54,57,58,61] Even when the condition was uncurable and clearly terminal, some parents wanted to try all possible options.[41]

The emotional state of parents. The emotions experienced during the decision-making process are presented in this theme. There are not stand-alone emotions, but they are closely linked to the other themes presented in this review.

Overall experience. The overall experience was described by many parents as overwhelming, scary, heavy, horrible, painful, gut-wrenching, horrific and emotionally exhausting.[40,48,50,52,56,57,62] Some parents experienced inner conflict and cognitive dissonance, which then affected their ability to make decisions.[48,52,56,57] For others, the decision-making process was a frustrating experience, especially when the decision did not lead to the expected outcome or when parents felt they were not involved in the process.[61,63]

Range of emotions. During the decision-making process, many parents experienced a wide range of negative emotions, including anxiety, depression, sadness, fear, nervousness, a sense of helplessness, stress and anger .[35,42,44,48,52,53,56,57,63] Parents felt exhausted and unable to make decisions as they were experiencing informational overload and were not able to focus their minds.[48,50,57] In some cases, anger and frustration were associated with the feeling of not being listened to or being manipulated into a decision by professionals.[44,53]

Guilt. Being a parent of a child with a life-limiting condition and making decisions about their healthcare was connected with the feeling of guilt.[38,39,40,45,49,51,52,58–59,61] Parents felt guilty for multiple reasons, including not being active in the decision-making process; letting the doctor decide; making decisions which could cause the death of their child; giving up on the child and undermining their child's will to live. Additionally, parents were anxious that their decisions would make them feel guilty in the future, and this made it more difficult for them to participate in the decision-making process.[40,51,52]

Feelings after. After the decision-making process, parents experienced feelings of disappointment, helplessness and relief. Some parents experienced regret and had difficulty accepting the decision they had made.[37,38,39,45,49,50,61,62,63] Having doubts about their decision was enhanced by feelings of uncertainty about the child's condition, and the selected treatment approach.[48,50,59] Nevertheless, some parents were at peace with their decision and were not experiencing regret.[37,41]

Sources of support to alleviate the parental experience. The last theme identifies various sources of support which can mitigate the complexity of the decision-making process and have a positive impact on the parental experience.

Behaviour of doctors. Parents appreciated supportive behaviour from clinicians, which included giving hope; respecting parents' choices; being personal; and being non-judgmental.[36,40,42,48–50,52,57,59] Doctors who were empathic, compassionate, respectful, honest, truthful and upfront, who spent time explaining the situation and gave parents time to ask questions, and those who offered options to choose from were appreciated.[36,38,40,48,50,61,63] In contrast, parents who felt like they did not have enough support from the healthcare professionals experienced stress and felt like they had to defend their decisions.[36,44,56]

Including parents in decision-making. In several studies parents valued being part of the decision-making process, particularly being acknowledged and listened to by physicians and enabled to make decisions together with them.[36,38,43,48,50,52,53,56,57,60,63] The experience of decision-making was less stressful if parents were engaged in the process, given professional guidance, treated with respect and received support from clinicians.[36,38,50,52,57,60,63]

Having enough information. Having sufficient information was particularly emphasised as important in the active participation in the decision-making process.[38,40,42,50,52,55–57,63] This enabled parents to know about the options available and to trust their feelings and instincts during the process.[36,39,52,56] The lack of information had a negative impact on parental ability to participate in the process, but finding the right amount of information was challenging as being overwhelmed with information led to similar outcomes.[38,40,56,63] In some studies parents used other sources of information, including other parents in a similar situation and the internet.[38,40,50,52,57]

Being supported by loved ones. When making decisions, parents valued the support of their partner, wider family and friends.[37,38,40,46,48,50,52,56,58,59] Support between spouses was experienced as crucial; single or divorced parents described the decision-making process as a hard task which was full of doubt given they had no spouse to discuss their decision with.[38,46,59]

Faith. Religiosity and faith in God had an impact on the experience with decision-making.[36,37,38,41,48,50,56,60,61] Religious parents trusted in God's guidance to make the right decision, and in some cases, they put the responsibility in God's hands.[36,38,48,56,61] Some parents believed they would meet their child in the afterlife.[41] Praying and believing in God gave parents the strength to deal with the situation and some sense of comfort and peace.[38,48,56]

Discussion

The purpose of this systematic review was to explore how parents experience the process of making decisions about medical care for their children with life-limiting conditions.

The review identified that participation in the decision-making process is emotionally challenging. The wide range of negative emotions experienced by parents compounds the experience by affecting their ability to make decisions and to be in control of the process. This presented review extends the knowledge of decision-making in the medical environment by providing evidence that decision-making is experienced similarly by parents, irrespective of the child's diagnosis. This supports findings of previous research on decision-making done in a general paediatrics setting.[19,20,65,66] It is not surprising that positive emotions were not mentioned in studies included in this review, given the lack of positive emotions described in a wider body of literature in this field.[20,65] Interestingly, this review identified guilt, including anticipatory guilt, as an emotion frequently experienced by parents while making decisions. This finding offers a new view on guilt as the concept of guilt is usually connected with loss and bereavement[67,68] or with the sense of responsibility for the child's condition and suffering.[25,69] Guilt in connection to decision-making was mentioned in previous studies with parents of preterm infants or children with disabilities[8,21] while anticipatory guilt was described in situations when parents imagined their life after the death of the child.[69]

This review shows that parents are required to make difficult decisions in challenging circumstances, which can impact their ability to make decisions. Parents may rely on doctors to make decisions instead.

Experiencing pressure and coercion from healthcare professionals during the decision-making process was connected with negative emotions. The use of persuasive strategies by healthcare professionals when making decisions for children with life-limiting conditions was identified in a recent study by Popejoy et al.,[70] which shows that healthcare professionals use persuasion based on their moral work done during decision-making. This presented review extends this knowledge by adding evidence that persuasive strategies can have negative impact on the emotional state of the parents. Persuasive techniques used by healthcare professionals include presenting preferred options in a more positive light while not presenting other options as viable by healthcare professionals.[15,70]

Being required to make decisions in a limited period of time was experienced as stressful and, in some cases, led to conflicts with healthcare professionals. In previous research, time was identified as the main environmental barrier to shared decision-making.[24,65,66,71] The timeframe in which the decision took place was found to directly affect the parental ability to participate in the decision-making and their perception of being pushed into the decision.[24,65,66,71] The findings of this review shows that parents needed to have enough time to process information provided by the physicians in order to make informed decisions, a finding congruent with previous research.[24]

This review identified that parents need to keep their parental role, to be a 'good parent', and to act as an advocate for their child during the decision-making process. The need to act as a 'good parent' represents an interesting concept explored in previous research[72] and is characterised by making informed decisions based on the child's best interest, being responsible for the decisions, advocating for the child and protecting the child from suffering.[19,73,74] The findings from this review bring new insight by collating available evidence that this attitude puts parents in a difficult position as they try to balance their own wishes and uncertainties with the need to be a 'good parent' when making decisions for their child. This conflict between their own desires and what is best for the child can put additional strain on parents and negatively affect their communication about medical care with healthcare professionals.[22] To guide their decisions, parents used their subjective perception of the child's will to live. This was described in a previous study, where the child's will to survive affected parental decision-making.[8]

This systematic review identified that limited medical knowledge, other parental insecurities and emotional exhaustion led to a lack of confidence in parents about their ability to act on behalf of their children. While this finding is consistent with previous studies, which found that parental belief about their deficit in medical knowledge had a negative impact on their involvement in the decision-making process,[20,24,66] this review shows that parents may follow the decisions made by healthcare professional even when they do not agree with them. Parental ability to make decisions is further affected by the situation and circumstances in which the decision-making took place and by the emotional state of parents, including the feeling of being stressed, overwhelmed or in shock.[22,75]

Participation in decision-making is extremely stressful for parents, but this review has found that it is possible to mitigate their negative experience.

The support provided by a spouse, family or friends can positively impact the experience with decision-making. This finding is consistent with a previous systematic review set in paediatric palliative care, in which friends and family were identified as an important source of support during end-of-life care, easing parental feelings of guilt and doubt.[25] This presented review highlights that single parents who lacked support from a spouse experienced additional challenges as they were required to make decisions on their own. This is a poorly explored area and future research should focus on this population.

Another strategy parents used during decision-making was their faith in God and praying, which is consistent with findings about /related to the importance of faith in decision-making identified in previous research in paediatric medicine.[20,24,25,76] In this review, trust in God's guidance and parents' belief that they will meet their child in afterlife helped parents to find a sense of comfort, hope and peace. Similarly, Hexem and Tan[25,76] identified the benefits of using religion and faith by parents during decision-making. The potential of Church and religious communities as sources of support for parents, reported in the study by Hexem et al.,[76] was not identified in this review.

The experience was greatly affected by the behaviour of healthcare professionals. Enabling parents to keep their hope and respecting their parental role made the experience less traumatic. Parents value honest communication and being listened to, as highlighted in previous research.[23,25,75] The role of clinicians was found to affect the ability of parents to participate in the decision-making process, which is consistent with findings of how the behaviour of clinicians can influence parental involvement in decision-making.[4,66] Parents perceived their experience as less stressful when/if they were able to actively engage in the decision-making. To do so, they needed to be invited by the healthcare professionals, as the power distribution in the medical setting is not balanced, and it can be difficult for parents to engage in the decision-making process.[15,66,77]

Having adequate information was identified in this review as a prerequisite for parents' active participation, which is consistent with findings of previous research focussed on the parental need to have enough information to be able to engage in the decision-making process.[4,66,75,78]

The findings of this review suggest that healthcare professionals involved in care of children with life-limiting conditions can make the experience of parents with decision-making less traumatic by actively inviting parents to participate in the decision-making, respecting their role as parents and giving them enough information.

Strengths and limitations

This review has several limitations. The use of narrative approach enabled the authors of this review to include methodologically heterogeneous studies, which was challenging for the subsequent synthesis. The inclusion criteria were not limited to a specific diagnosis; therefore, a larger number of studies were included in the review, thus possibly affecting the robustness of the synthesis. The data extraction and analysis were conducted by one reviewer, which could lead to a personal bias in the data interpretation. Due to limited resources, only studies written in English and Czech were eligible for the review. Although the included studies originated from several countries, the impact of different cultures was not explored in this review as it was not the focus of the review. Future research in this field should explore the impact of cultural settings on decision-making in paediatrics. The participants in the studies included in this review were predominantly mothers. Whilst the fathers' experiences were included, there is a paucity of research about the paternal experience. Additionally, the studies were retrospective in nature, and some included bereaved parents, which could have affected parents' recollection of their experience.

Notwithstanding the limitations listed above, this review has several strengths. To our knowledge, this is the first review focussed solely on parental experiences of decision-making for their children with life-limiting and life-threatening conditions. This review provides a robust synthesis of available evidence of the studied phenomenon. Wider inclusion criteria made it possible to include studies focussed on different types of diagnoses of the children and on various types of decisions. This approach made it possible to get an understanding of the experience from a wide perspective. By using a narrative approach, it was possible to synthesise the data without delineating between different types of decisions and diagnoses. Although the data extraction and analysis were done by one reviewer, the whole process was supervised by the other authors, including the screening of eligible studies, the development of preliminary and final themes and discussion of the findings. Each of the included studies was assessed for its quality by two reviewers, although studies were not excluded based on the score achieved.

Conclusion

This study brings evidence that parental experience with decision-making represents a complex phenomenon. The experience with decision-making was not affected by the conditions of the child, which suggests that this is a universal experience framed by the parental role. Clinicians need to be aware of how parents experience their participation in the process and provide them with adequate support. Parents should be actively invited and encouraged to participate in the decision-making by clinicians. Considering the long-lasting impact this experience has on parents, it is necessary to tailor the level of participation individually for each parent and enable them to engage at their preferred level. Further research should focus on the experience of fathers and single parents, as this population is understudied and on exploring decision-making in various cultural contexts.

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Author contributions

KP, SB and FA contributed to the study design, study selection, data analysis and interpretation of data. KP and KV performed the literature search, study selection and performed the quality assessment. KP drafted the manuscript and SB and FA reviewed it. All authors have reviewed and approved the final manuscript.

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Supplemental material

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References

1. IMPaCTT. IMPaCCT: standards for paediatric palliative care in Europe. *Eur J Palliat CareJ Palliat Care [Internet]* 2007; 14(3): 109–116.
2. ACT. *A guide to the development of children's palliative care services*, 3rd edition. Bristol, England: Association for Children's Palliative Care, 2009.
3. Higgins SS. Parental role in decision making about pediatric cardiac transplantation : familial and ethical considerations. *J Pediatr Nurs* 2001; 16(5): 332–337.
4. Sullivan J, Monagle P and Gillam L. What parents want from doctors in end-of-life decision-making for children. *Arch Dis Child [Internet]* 2014; 99(3): 216–220.
5. Connor SR, Downing J and Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. *J Pain Symptom Manage [Internet]* 2017; 53(2): 171–177.
6. Benini F, Papadatou D, Bernadá M, et al. International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *J Pain Symptom Manage* 2022; 63(5): e529–e543.
7. Popejoy E, Pollock K, Almack K, et al. Decision-making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child Care Health Dev* 2017; 43(5): 627–644.
8. Zaal-Schuller IH, de Vos MA, Ewals FVPM, et al. End-of-life decision-making for children with severe developmental disabilities: the parental perspective. *Res Dev Disabil [Internet]* 2016; 49–50: 235–246.
9. Hill DL, Miller V, Walter JK, et al. Regoaling: a conceptual model of how parents of children with serious illness change medical care goals. *BMC Palliat Care* 2014; 13(1): 1–8.
10. Allen KA. Parental decision-making for medically complex infants and children: an integrated literature review. *Int J Nurs Stud* 2014; 51(9): 1289–1304.
11. Carroll KW, Mollen CJ, Aldridge S, et al. Influences on decision making identified by parents of children receiving pediatric palliative care. *AJOB Prim Res [Internet]* 2012; 3(1): 1–7.
12. Markward MJ, Benner K and Freese R. Perspectives of parents on making decisions about the care and treatment of a child with cancer : a review of literature. *Fam Syst Heal* 2013; 31(4): 406–413.

13. Harrison C. Treatment decisions regarding infants, children and adolescents. *Paediatrics & Child Health* 2004; 9(2): 1–7. https://doi.org/10.1093/pch/9.2.99
14. Stevenson M, Achille M and Lugasi T. Pediatric palliative care in Canada and the United States: a qualitative meta-summary of the needs of patients and families. *J Palliat Med [Internet]* 2013; 16(5): 566–577.
15. Richards CA, Starks H, O'Connor MR, et al. Physicians perceptions of shared decision-making in neonatal and pediatric critical care. *Am J Hosp Palliat Care [Internet]* 2018; 35(4): 669–676.
16. Birchley G, Gooberman-Hill R, Deans Z, et al. "Best interests" in paediatric intensive care: an empirical ethics study. *Arch Dis Child [Internet]* 2017; 102(10): 930–935.
17. Fiks AG and Jimenez ME. The promise of shared decision-making in paediatrics. *Acta Paediatr* 2010; 99: 1464–1466.
18. Wellesley H and Jenkins IA. Withholding and withdrawing life-sustaining treatment in children. *Pediatr Anesth* 2009; 19(5): 972–978.
19. Bennett RA and LeBaron VT. Parental perspectives on roles in end-of-life decision making in the pediatric intensive care unit: an integrative review. *J Pediatr Nurs [Internet]* 2019; 46: 18–25.
20. Lipstein EA, Brinkman WB and Britto MT. What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Med Decis Mak* 2012; 32(2): 246–258.
21. Eden LM and Callister LC. Parent involvement in end-of-life care and decision making in the newborn intensive care unit: an integrative review. *J Perinat Educ* 2010; 19(1): 29–39.
22. Barrett L, Fraser L, Noyes J, et al. Understanding parent experiences of end-of-life care for children: a systematic review and qualitative evidence synthesis. *Palliat Med* 2023; 37(2): 178–202.
23. Hirata M and Kobayashi K. Experiences with the end-of-life decision-making process in children with cancer, their parents, and healthcare professionals: a systematic review and meta-ethnography. *J Pediatr Nurs [Internet]* 2023; 69: E45–E64.
24. Xafis V, Wilkinson D and Sullivan J. What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliat Care [Internet]* 2015; 14: 19.
25. Tan A, Tiew L and Shorey S. Experiences and needs of parents of palliative paediatric oncology patients : a meta-synthesis. *Eur J Cancer Care (Engl)* 2021; 30(3): e13388.
26. Wood F, Simpson S, Barnes E, et al. Disease trajectories and ACT/RCPCH categories in paediatric palliative care. *Palliat Med* 2010; 24(8): 796–806.
27. Booth A, Maddison J, Wright K, et al. Research prioritisation exercises related to the care of children and young people with life-limiting conditions, their parents and all those who care for them: a systematic scoping review. *Palliat Med* 2018; 32(10): 1552–1566.
28. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews. *ESRC Methods Program [Internet]* 2006; 2006: 93.
29. Dixon-Woods M, Agarwal S, Jones D, et al. Synthesising qualitative and quantitative evidence : a review of possible. *J Heal Serv Res Policy* 2005; 10(1): 45–53.
30. Lucas PJ, Baird J, Arai L, et al. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol* 2007; 7: 1–7.
31. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ [Internet]* 2021; 372: n71.
32. Hawker S, Payne S, Kerr C, et al. Appraising the evidence: reviewing disparate data systematically. *Qual Health Res* 2002; 12(9): 1284–1299.
33. Firn J, Preston N and Walshe C. What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliat Med* 2016; 30(3): 240–256.
34. Dakessian Sailian S, Salifu Y, Saad R, et al. Dignity of patients with palliative needs in the middle east: an integrative review. *BMC Palliat Care [Internet]* 2021; 20(1): 112.
35. Bandinelli L. Evaluation of parents' decision-making in oncologic pediatric treatment. *Psicol em Estud* 2017; 21(4): 603–615.
36. Janvier A, Farlow B, Barrington KJ, et al. Building trust and improving communication with parents of children with Trisomy 13 and 18: a mixed-methods study. *Palliat Med* 2020; 34(3): 262–271.
37. Graetz DE, Rivas S, Wang H, et al. Cancer treatment decision-making among parents of paediatric oncology patients in Guatemala: a mixed-methods study. *BMJ Open* 2022; 12(e057350): 1–8.
38. Sharman M, Meert KL and Sarnaik AP. What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med [Internet]* 2005; 6(5): 513–518.
39. Carnevale FA, Canoui P, Cremer R, et al. Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatr Crit Care Med [Internet]* 2007; 8(4): 337–342.
40. Parker K, Cottrell E, Stork L, et al. Parental decision making regarding consent to randomization on Children's Oncology Group AALL0932. *Pediatr Blood Cancer* 2021; 68(4): e28907.
41. De Clercq E, Flury M, Grotzer M, et al. No wrong decisions in an all-wrong situation. a qualitative study on the lived experiences of families of children with diffuse intrinsic pontine glioma. *Pediatr Blood Cancer* 2022; 69(e29792): 1–12.
42. Huang T-Y, Mu P-F and Chen Y-W. The lived experiences of parents having a child with a brain tumor during the shared decision-making process of treatment. *Cancer Nurs* 2021; 45(3): 201–210.
43. Badarau DO, Ruhe K, Kühne T, et al. Decision making in pediatric oncology: views of parents and physicians in two European countries. *AJOB Empir Bioeth [Internet]* 2017; 8(1): 21–31.
44. Bergviken H and Nilsson S. Focusing on the hospital stay or everyday life with cancer: parents' experiences of choosing a central access device for their child with cancer. *J Spec Pediatr Nurs [Internet]* 2019; 24(3): e12261.
45. Gurková E, Andraščíková I and Čáp J. Parents' experience with a dying child with cancer in palliative care. *Cent Eur J Nurs Midwifery* 2015; 6(1): 201–208.

46. Kelly KP and Ganong L. Moving to place: childhood cancer treatment decision making in single-parent and repartnered family structures. *Qual Health Res [Internet]* 2011; 21(3): 349–364.
47. Robertson EG, Mitchell R, Wakefield CE, et al. Enrolment in paediatric oncology early-phase clinical trials: the health-care professionals' perspective. *J Paediatr Child Health [Internet]* 2019; 55(5): 561–566.
48. Stewart JL, Pyke-Grimm KA and Kelly KP. Making the right decision for my child with cancer: the parental imperative. *Cancer Nurs [Internet]* 2012; 35(6): 419–428.
49. Woodgate RL and Yanofsky RA. Parents' experiences in decision making with childhood cancer clinical trials. *Cancer Nurs [Internet]* 2010; 33(1): 11–18.
50. Carlisle EM, Shinkunas LA, Lieberman MT, et al. Empowering parents of pediatric surgical oncology patients through collaborative engagement with surgeons. *J Pediatr Surg [Internet]* 2023; 58(9): P1736–P1743.
51. Atout M, Hemingway P and Seymour J. The experience of decision making in the care of children with palliative care needs: the experiences of jordanian mothers. *Compr Child Adolesc Nurs [Internet]* 2017; 40(4): 240–256.
52. Yazdani N, Chartrand J and Stacey D. Exploring parental decision making for a child with a life-limiting condition: an interpretive description study. *J Hosp Palliat Nurs* 2022; 24(2): 140–146.
53. Bogetz JF, Trowbridge A, Lewis H, et al. Parents are the experts: a qualitative study of the experiences of parents of children with severe neurological impairment during decision-making. *J Pain Symptom Manag* 2022; 62(6): 1117–1125.
54. Beecham E, Oostendorp L, Crocker J, et al. Keeping all options open: parents' approaches to advance care planning. *Heal Expect* 2017; 20(4): 675–684.
55. Carnevale FA, Benedetti M, Bonaldi A, et al. Understanding the private worlds of physicians, nurses, and parents: a study of life-sustaining treatment decisions in Italian paediatric critical care. *J Child Health Care [Internet]* 2011; 15(4): 334–349.
56. Edwards JD, Panitch HB, Nelson JE, et al. Decisions for long-term ventilation for children. Perspectives of family members. *Ann Am Thorac Soc [Internet]* 2020; 17(1): 72–80.
57. Mitchell S, Spry JL, Hill E, et al. Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. *BMJ Open [Internet]* 2019; 9(5): e028548.
58. Popejoy E. Parents' experiences of care decisions about children with life-limiting illnesses. *Nurs Child Young People* 2015; 27(8): 20–24.
59. Rapoport A, Shaheed J, Newman C, et al. Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care. *Pediatrics* 2013; 131(5): 861–869.
60. Zaal-Schuller IH, Willems DL, Ewals FVPM, et al. How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Res Dev Disabil* 2016; 59: 283–293.
61. Liu S-M, Lin H-R, Lu FL, et al. Taiwanese parents' experience of making a "do not resuscitate" decision for their child in pediatric intensive care unit. *Asian Nurs Res (Korean Soc Nurs Sci) [Internet]* 2014; 8(1): 29–35.
62. Sullivan JE, Gillam LH and Monagle PT. After an end-of-life decision: parents' reflections on living with an end-of-life decision for their child. *J Paediatr Child Health* 2020; 56(7): 1060–1065.
63. Robertson EG, Wakefield CE, Shaw J, et al. Decision-making in childhood cancer: parents' and adolescents' views and perceptions. *Support Care Cancer* 2019; 27(11): 4331–4340.
64. Lin B, Gutman T, Hanson CS, et al. Communication during childhood cancer: systematic review of patient perspectives. *Cancer [Internet]* 2020; 126(4): 701–716.
65. Jackson C, Cheater FM and Reid I. A systematic review of decision support needs of parents making child health decisions. *Heal Expect [Internet]* 2008; 11(3): 232–251.
66. Boland L, Graham ID, Légaré F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci* 2019; 14(1): 7.
67. Li J, Stroebe M, Chan CLW, et al. Guilt in bereavement: a review and conceptual framework. *Death Stud [Internet]* 2014; 38(3): 165–171.
68. Miles MS and Demi AS. A comparison of guilt in bereaved parents whose children died by suicide, accident, or chronic disease. *OMEGA – J Death Dying [Internet]* 1992; 24(3): 203–215.
69. Steele R and Davies B. Impact on parents when a child has a progressive, life-threatening illness. *Int J Palliat Nurs* 1998; 12(12): 576–585.
70. Popejoy E, Almack K, Manning JC, et al. Communication strategies and persuasion as core components of shared decision-making for children with life-limiting conditions: a multiple case study. *Palliat Med* 2022; 36(3): 519–528.
71. Lin JL, Clark CL, Halpern-Felsher B, et al. Parent perspectives in shared decision-making for children with medical complexity. *Acad Pediatr [Internet]* 2020; 20(8): 1101–1108.
72. Weaver MS, October T, Feudtner C, et al. "Good-parent beliefs": Research, concept, and clinical practice. *Pediatrics* 2020; 145(6): e20194018.
73. Feudtner C, Walter JK, Faerber JA, et al. Good-parent beliefs of parents of seriously ill children. *JAMA Pediatr [Internet]* 2015; 169(1): 39.
74. Hinds PS, Oakes LL, Hicks J, et al. "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *J Clin Oncol* 2009; 27(35): 5979–5985.
75. Pyke-Grimm KA, Stewart JL, Kelly KP, et al. Parents of children with cancer: factors influencing their treatment decision making roles. *J Pediatr Nurs* 2006; 21(5): 350–361.
76. Hexem KR, Mollen CJ, Carroll K, et al. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *J Palliat Med* 2011; 14(1): 39–44.
77. Joseph-Williams N, Elwyn G and Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns [Internet]* 2014; 94(3): 291–309.
78. Hoang K, Halpern-Felsher B, Brooks M, et al. Shared decision-making with parents of hospitalized children: a qualitative analysis of parents' and providers' perspectives. *Hosp Pediatr* 2020; 10(11): 977–985.

Appendix 2: Presentation at the EAPC Congress

EAPC
VZW

12th World Research Congress of the European Association for Palliative Care

Interactive Online Sessions
18 - 20 May 2022

RESEARCH

CERTIFICATE OF PARTICIPATION

We hereby confirm that

Kristyna Polakova

Presented an oral abstract:

Parents' experiences of being involved in medical decision making for their child with a life-limiting condition: a narrative review

at the

12th World Research Congress online of the European Association for Palliative Care
18-20th May 2022

Christoph Ostgathe
President of EAPC

Camilla Zimmermann
Chair of the Scientific Committee

Pending

Title

The role of paediatric palliative care team during the decision-making process in paediatric healthcare - a qualitative case study

Presenters

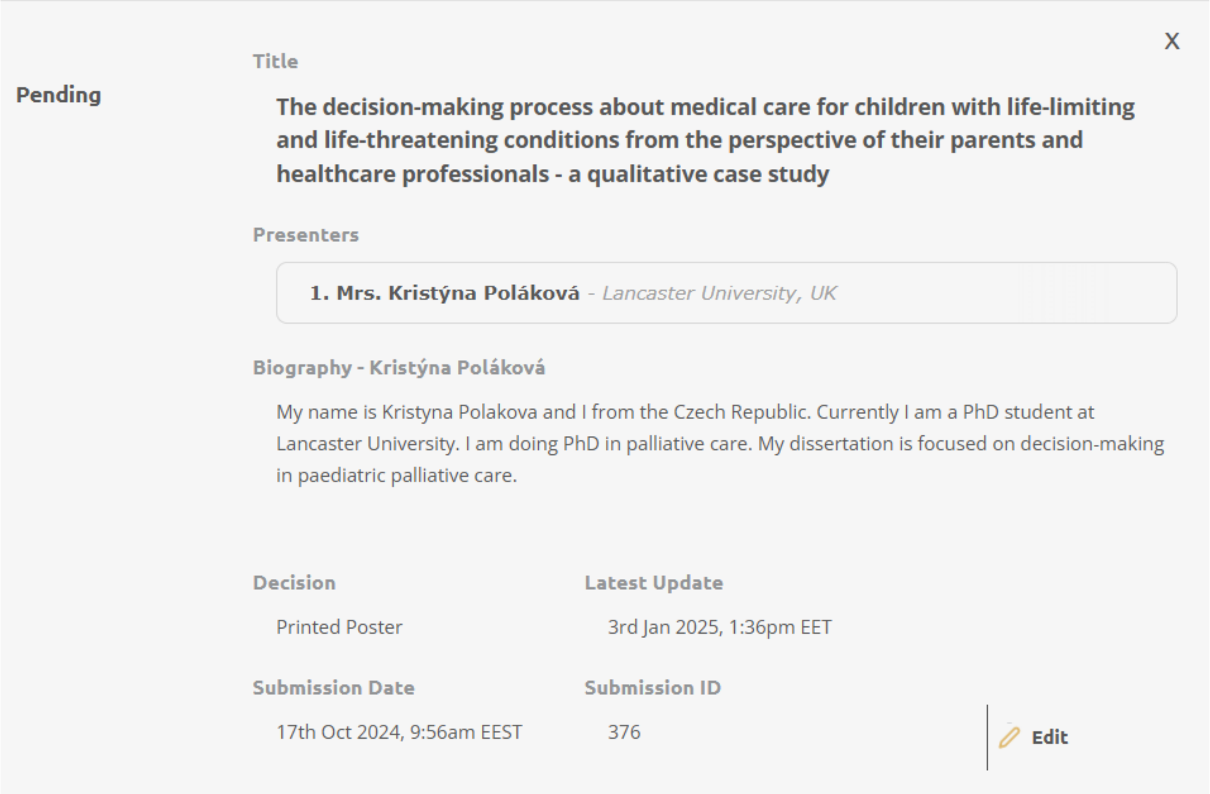
1. **Mrs. Kristýna Poláková** - *Lancaster University, UK*

Biography - Kristýna Poláková

My name is Kristyna Polakova and I from the Czech Republic. Currently I am a PhD student at Lancaster University. I am doing PhD in palliative care. My dissertation is focused on decision-making in paediatric palliative care.

Decision	Latest Update
Oral Abstract Session	3rd Jan 2025, 1:36pm EET

Submission Date	Submission ID
17th Oct 2024, 10:11am EEST	377



Pending

Title

The decision-making process about medical care for children with life-limiting and life-threatening conditions from the perspective of their parents and healthcare professionals - a qualitative case study

Presenters

1. **Mrs. Kristýna Poláková** - *Lancaster University, UK*

Biography - Kristýna Poláková

My name is Kristyna Polakova and I from the Czech Republic. Currently I am a PhD student at Lancaster University. I am doing PhD in palliative care. My dissertation is focused on decision-making in paediatric palliative care.

Decision	Latest Update
Printed Poster	3rd Jan 2025, 1:36pm EET

Submission Date	Submission ID
17th Oct 2024, 9:56am EEST	376

Appendix 3: Search concepts for MEDLINE database

	SPIDER	**Pearl growing**	**MeSH**	**Search query**
Concept #1	Parent Guardian	Caregiver	Parents Mothers Fathers	Parent* OR mother* OR father* OR guardian OR caregiver
Concept #2	Decision	Decision support	Decision making	decision OR decision making OR decision support
Concept #3	Experience	Perception View Feeling Attitude Belief	Life experience	experience OR view OR feeling OR perception OR attitude OR belief*
Concept #4	Child	Infant	Children Paediatric	child* OR infant OR paediatric
Concept #5	Life-limiting Life-threatening	Medically complex	Disabled Severely disabled Cancer Oncology Neoplasm Tumour Intensive care Long term care Terminal care	"life-limiting" OR "medically complex" OR disabled OR "severely disabled" OR "terminal care" OR "long term care" OR "intensive care" OR cancer* OR oncolog* OR tumor* OR tumour* neoplasm OR malignan*

Appendix 4: Data extraction sheet and quality assessment

Code	05_Ber_M
Author	Bergviken, Hanna, Nilsson S.
Study title	Focusing on the hospital stay or everyday life with cancer: Parents' experiences of choosing a central access device for their child with cancer
Year	2019
Journal	Journal of Specialist Pediatric Nursing
Country of origin	Sweden
INCLUDED	

Design of the study	
Methodology	Qualitative
Method of data collection	Interviews
Setting	Pediatric cancer center
Sample (size, population)	17 parents • 11 mothers • 6 fathers
Data analysis	Inductive qualitative content analysis
Aim of the study	To explore how parents of children with cancer deal with making decision about a type of central access device. Their mental and emotional process of making this decision.
Context	Oncology
Medical decision	Choosing central access device- decision between central venous catheter and subcutaneous venous port
Quality assessment (Hawker)	

Findings
Experience of parents (direct citations, page)

parents felt in the healthcare setting tended to affect their ability to imagine the future and prevented them from deciding what was best for their child in the long run. Time was a crucial factor in the parents' struggle to make an informed decision. The feeling of urgency precluded them from thinking over every aspect to gain an understanding of the whole treatment period that lay ahead of them. (4)

The parents perceived the healthcare professionals' influence as helpful, but in many cases, they felt overwhelmed by what they perceived as the healthcare professionals' personal attitudes. They felt that the decision ultimately taken was not really their own (4)

The initial shock surrounding the onset of the disease was highly stressful for the parents, and the situation could be perceived as overwhelming

In the initially baffling hospital environment, the parents found it hard to look to the future. This, in turn, caused them to make decisions based on hospital conditions rather than considering the
families' future everyday life. (5)

most of them said that they had no previous experience that could help them in the decision-making process.:
I don't think you get it because I, I didn't get what these
things were or anything; so, it sort of just went the way it
went ...
(Mother 8) (5)

Deciding quickly under pressure…. Parents reflected on how they did not have enough time to make an informed decision. They talked about how the stressful conditions and the sense of urgency had caused them to take decisions based on what they believed to be limited information.
... and what it was all about I couldn't really grasp. I didn't
think about it that much: why it was all that desperately

urgent, why it had to be decided so quickly ... *(Father 1) (6)* The parents felt that the healthcare professionals provided biased information and that they tried to force them to choose one option over the other… The parents explained that, when the healthcare professionals tried to “sell” an option to them, they could feel that their choice was being manipulated. The parents also thought that they did not receive sufficient information about the advantages and disadvantages of each option, and they felt cheated. Also, the parents felt they had not received the support they wanted from the healthcare professionals in cases where their decision was the opposite one to that favoured by the healthcare professionals. *... I know I wept at some point because I felt I couldn’t defend my decision or our decision. [...] Support! It’s important; it’s really hard to need to defend your decision when you aren’t all that sure it’s the right one ...* *(Mother 11) (6)* The parents in the present study stressed that this chaotic situation affected their ability to make decisions…many of them felt that they had not had enough time to think things over and that the decision was made in haste. … The parents in this study said that they experienced anger and bitterness towards the healthcare professionals when they felt that they had been coerced or manipulated in the decision-making process. They commented that the information they had been given was biased (07)	
Words use to describe the experience	Struggle to make an informed decision Feeling of urgency

	Decision was not their own Not having enough time Stressful Overwhelming hard to look to the future no previous experience feeling forced by HCP being manipulated cheated lack of support if having different opinion then HCP not being sure what is a right decision chaos anger and bitterness biased information
Type of medical decision parents experienced	Medical device

Implication for the systematic review	Parents are making difficult decision in limited amount of time. They are under lot of stress, don’t have enough information to make the decision or they are given biased information. They are not sure, which decision is the right one, and have difficulty to foresee the future. They are deciding around the time of diagnosis being made. They have no previous experience to rely on. They experience lack of support from HCP, feeling of being manipulated into decisions by HCP.

Inclusion/exclusion criteria

Inclusion criteria		**Exclusion criteria**	
Parents/legal guardians including bereaved parents of children between the age of 0 and 19 years old diagnosed with life-limiting condition	x	Studies including parents/legal guardians of children with life-limiting condition older than 19 years at the time of the study.	
		Studies including parents/legal guardians of children with life-limiting condition older than 19 years at the time of the study.	
		Studies focused on parental decisions made before the birth of a child who was diagnosed with life-limiting condition prior to the birth.	
		Studies reporting on the experience of parents of prematurely born babies and of parents with newborn babies > 28 days old.	
Reports primary experience of parents/legal guardians involved in decision-making process about the care of child	x	Studies which do not report on the parental experience from their own perspective and the accounts of parental experience were obtained from other participants involved in the decision-making process (such us doctors, nurses).	
Studies reporting on experience with decision-making about health care	x	Studies reporting on experience with other phenomenon than decision-making in health care. This includes care experience, experience of siblings, experience with providing care at home, care transition, decision	

		regarding fertility options for cancer patients, organ donation	
English or Czech language	x		
Published in peer-reviewed journal	x		
Reports primary findings of qualitative, quantitative, or mixed methods research	x	Commentaries, editorials, opinion papers, secondary data analysis, review articles, conference abstracts, case studies with including just one case	
Published between 2000 and 2020	x	Studies published before 2000	
Included	**x**	**Excluded**	

Quality assessment form (Hawker, 2002)

	Good (4)	**Fair (3)**	**Poor (2)**	**Very Poor (1)**	**Comment**
1. Abstract and title	**x**				
2. Introduction and aims			**x**		
3. Method and data		**x**			
4. Sampling	**x**				
5. Data analysis		**x**			
6. Ethics and bias	**x**				
7. Findings/results	**x**				
8. Transferability/generalizability	**x**				
9. Implications and usefulness		**x**			
Total	**31**				

Appendix 5: Themes, subthemes and codes for literature review

Theme	**Subthemes**	**Codes**
Temporal aspects affecting the experience with decision-making	Lack of time while making the decision Difficulty to foresee the future	Lack of time Difficult to plan for the future
Losing control of the situation	Not having real choice Being forced into the decision Difficulty grasping the reality	Being forced into decision Difficulty to grasp reality Feeling not making the decision by themselves Being judged Conflict with doctors Information overload Not respecting parents Not having real choice
Transferring the power to decide to the doctors	Reluctance to make decision Transferring the responsibility to doctors Relying on the doctor’s expertise Lack of confidence and medical expertise	Don’t want to make the decision Lack of confidence No medical expertise Previous experience Transferring the responsibility to HCP Doctor’s expertise

To be a “good” parent and protect the child	Child in the centre-what is best for the child Advocacy for the child Trying everything possible	Taking responsibility for the decision Advocacy Including the child Keeping hope Keeping all options open What is best for the child Making the right decision Trying all options of treatment Outcome of the child Quality of life Keeping ole of a parents Abandoning the child Protecting the child Asking second opinion Trying all options of treatment Making difficult decisions
The emotional state of parents	Overall experience Range of emotions Guilt Feelings after	Being exhausted Difficult decision Frustration Guilt feeling Regret about the decision Emotions after Having doubts Overwhelming Conflicts Anger Information overload

Sources of support to alleviate the parental experience	Behaviour of doctors Including parents in decision-making Having enough information Being supported by loved ones Faith	Faith and praying Having enough information Cooperation with parents Lack of support Respecting/not respecting parents Support from doctors Trust Specialist work as team Support from family Enough information Respecting parents' choices even if different Communication Telling truth

Appendix 6: Cover letter for parents

Dear (name of the parent),
on behalf of the Child support and palliative care team of the Motol University Hospital we would like to invite you to take part in a study undertaken at the hospital. The main purpose of this study is to explore how parents of children with life-limiting illness and health-care professionals make decision about future medical care. We would like to find out, how these decisions are made, what is your experience of making such decisions and how are the decisions changed over time.
The findings of the study will help to get a better understanding of how decisions about care are made and how to provide a better support for the parents who are making such decisions.

This study project is a part of a doctoral thesis of Mgr. Kristýny Polákové conducted as a part of PhD studies of palliative care at Lancaster University, Great Britain and is supported by the head doctor of the team MUDr. Lucií Hrdličkovou.

The study will be conducted in several ways. We will ask you to participate in a interview with the researcher. The interview is expected to last around 60 minutes and can be done in person or on-line. The interview can be done repeatedly during the research project. The interview will focus on your child and your experience with making decision for your child. We will also ask you to keep a written or recorded diary about your feelings and experience you would have during the consultation about the care for your child. Additionally, the researcher (Mgr. Kristýna Poláková) can be present during the consultations with your clinician which will be focused on future care planning for your child. You do not have to participate in all activities stated above except of the interview, which is necessary.
All information you will tell us during the interview will be anonymised and treated confidentially.
You can withdraw your consent at any time.

Your decision whether to participate in the study or now will not affect the care your child is getting at any way.
If you would consider to take a part in this proposed study please replay " I agree" at the following e-mail: k.polakova@paliativnicentrum.cz. Within few days you will be contacted by the researcher Mgr. Kristýna Poláková who will give you more information about the study and will answer any of your question. By this replay, you are not giving your consent to participate in the study.
If you don not agree to participate in the study and wish not to ne conctacted regarding this matter any further please reply "I do not agree" at the above e-mail address.

We are looking forward for your replay,
With kind regards,

Appendix 7: Information about the study and informed consent

INFORMACE PRO ÚČASTNÍKY VÝZKUMNÉHO PROJEKTU:

Sdílené rozhodování o péči u dětí s život limitujícím onemocněním z pohledu jejich rodičů a poskytovatelů zdravotní péče.

Vážená paní, vážený pane,

rádi bychom Vás požádali o pomoc při výzkumu, který provádíme ve Fakultní nemocnici Motol. Cílem našeho projektu je porozumět tomu, jakým způsobem se rodiče dětí, které mají závažné onemocnění, podílejí na rozhodovacím procesu o další léčbě a péči pro své dítě společně s lékařským i nelékařským personálem, který je do péče o dítě zapojený.

Výzkumný projekt je součástí disertační práce Mgr. Kristýny Polákové v rámci postgraduálního studia paliativní péče na Lancaster University ve Velké Británii. Vedoucím disertační práce je Dr Sarah Brearley (kontaktní e-mail: sarah.brearley@lancaster.ac.uk). Mgr. Kristýna Poláková se dlouhodobě věnuje výzkumu v oblasti dětské paliativní péče.

Projekt byl schválen Etickou komisí Fakultní nemocnice Motol dne 27.1.2021 a Etickou komisí Lancaster University dne 26.3.2021.

Vaše zapojení do projektu znamená následující:

- Absolvování **výzkumného rozhovoru**, o trvání cca **30–60 minut**. Rozhovor s Vámi bude nahráván na diktafon, tento záznam bude následně přepsán pro účely analýzy a zvukový záznam bude smazán. Rozhovor je možné během projektu vést opakovaně.
- Přítomnost výzkumné pracovnice (Mgr. Kristýna Poláková) na konzultaci s lékařem či dalším personálem během které budete mluvit o plánování další péče pro Vaše dítě.
- Vedení písemných nebo zvukových záznamů o Vašich pocitech během procesu plánování další péče.
- Povolení přístupu do zdravotnické dokumentace Vašeho dítěte.

Pro účast v projektu není nutné splnit vše výše uvedené, nezbytný je pouze rozhovor.

Všechna **data** získaná během rozhovoru, pozorování i v písemné formě jsou považována za **důvěrná**, přístup k nim bude mít pouze Mgr. Kristýna Poláková, případně vedoucí disertační práce (Dr Sarah Brearley). Veškerá data budou **anonymizována**. Souhrnné výsledky budou publikovány anonymně. Vzhledem k anonymizaci dat, je možné data s výzkumné souboru odstranit nejdéle do 14 dní od jejich sběru.

Řešitel výzkumného projektu, u něhož si můžete vyžádat další informace ke studii:

Mgr. Kristýna Poláková
e-mail: k.polakova@paliativnicentrum.cz
tel: 603 103 013

INFORMOVANÝ SOUHLAS S ÚČASTÍ VE VÝZKUMNÉM PROJEKTU:

Sdílené rozhodování o péči u dětí s život limitujícím onemocněním z pohledu jejich rodičů a poskytovatelů zdravotní péče.

Prohlášení: Já, níže podepsaný/á, jsem byl/a seznámen/a s Informacemi pro účastníky daného výzkumného projektu. Porozuměl/a jsem údajům v něm obsaženým. Všechny mé dotazy a připomínky byly zodpovězeny k mé spokojenosti. Jsem si vědom/a, že účast ve výzkumném projektu je zcela dobrovolná. Jsem si vědom/a, že svůj souhlas s účastí ve výzkumném projektu mohu stáhnout kdykoliv bez udání důvodu. Na základě poskytnutých informací a po vlastním zvážení souhlasím s účastí ve výzkumu, a s anonymním využitím dat ke zpracování a publikaci. Obdržel/a jsem vlastní výtisk Informací pro účastníky výzkumného projektu a Informovaného souhlasu s účastí ve výzkumném projektu.

Jméno a příjmení účastníka

……Kód:…………

Místo a datum

…………………………………………………………………………

…………………………………………………………………………   …………………………………………………………………………

Podpis účastníka   Celé jméno a podpis výzkumníka

FN MOTOL

Lancaster University

INFORMACE PRO ÚČASTNÍKY VÝZKUMNÉHO PROJEKTU:
Sdílené rozhodování o péči u dětí s život limitujícím onemocněním z pohledu jejich rodičů a poskytovatelů zdravotní péče.

Vážená paní, vážený pane,

rádi bychom Vás požádali o pomoc při výzkumu, který provádíme ve Vaší nemocnici. Cílem našeho projektu je porozumět tomu, jakým způsobem se rodiče dětí, které mají závažné onemocnění, podílejí na rozhodovacím procesu o další léčbě a péči pro své dítě společně s lékařským i nelékařským personálem, který je do péče o dítě zapojený.

Výzkumný projekt je součástí disertační práce Mgr. Kristýny Polákové v rámci doktorandského studia paliativní péče na Lancaster University ve Velké Británii. Vedoucím disertační práce je Dr Sarah Brearley (kontaktní e-mail: sarah.brearley@lancaster.ac.uk). Doktorandka Mgr. Kristýna Poláková se dlouhodobě věnuje výzkumu v oblasti dětské paliativní péče.

Projekt byl schválen Etickou komisí Fakultní nemocnice Motol dne 27.1.2021 a Etickou komisí Lancaster University dne 26.3.2021.

Vaše účast ve výzkumném projektu je dobrovolná. Z projektu můžete kdykoliv odstoupit bez udání důvodů.

Vaše zapojení do projektu znamená následující:

- absolvování **výzkumného rozhovoru**, o trvání cca **30-60 minut.** Rozhovor s Vámi bude nahráván na diktafon**,** tento záznam bude následně přepsán pro účely analýzy a zvukový záznam bude smazán. Rozhovor je možné během projektu vést opakovaně.
- Přítomnost výzkumné pracovnice (Mgr. Kristýna Poláková) na Vašich konzultacích s rodiči dětského pacienta, během kterých budete mluvit o plánování další péče. Pozorování je možné pouze za předpokladu, že s ním bude souhlasit i daný rodič.

Pro účast v projektu není nutné splnit vše výše uvedené, nezbytný je pouze rozhovor.

Všechna data získaná během rozhovoru a pozorování jsou považována za **důvěrná**, přístup k nim bude mít pouze Mgr. Kristýna Poláková, případně vedoucí disertační práce (Dr Sarah Brearley). Veškerá data budou **anonymizována**. Souhrnné výsledky budou publikovány anonymně. Vzhledem k anonymizaci dat, je možné data s výzkumné souboru odstranit nejdéle do 14 dní od jejich sběru.

Řešitel výzkumného projektu, u něhož si můžete vyžádat další informace ke studii:

Mgr. Kristýna Poláková
e-mail: k.polakova@paliativnicentrum.cz
tel: 603 103 013

FN MOTOL

Lancaster University

INFORMOVANÝ SOUHLAS S ÚČASTÍ VE VÝZKUMNÉM PROJEKTU:
Sdílené rozhodování o péči u dětí s život limitujícím onemocněním z pohledu jejich rodičů a poskytovatelů zdravotní péče.

<u>Prohlášení</u>: Já, níže podepsaný/á, jsem byl/a seznámen/a s Informacemi pro účastníky daného výzkumného projektu. Porozuměl/a jsem údajům v něm obsaženým. Všechny mé dotazy a připomínky byly zodpovězeny k mé spokojenosti. Jsem si vědom/a, že účast ve výzkumném projektu je zcela dobrovolná. Jsem si vědom/a, že svůj souhlas s účastí ve výzkumném projektu mohu stáhnout kdykoliv bez udání důvodu. Na základě poskytnutých informací a po vlastním zvážení souhlasím s účastí ve výzkumu, a s anonymním využitím ke zpracování a publikaci. Obdržel/a jsem vlastní výtisk Informace pro účastníky výzkumného projektu a Informovaného souhlasu s účastí ve výzkumném projektu.

Jméno a příjmení účastníka: .... Kód:...........

....
Místo a datum

....
Podpis účastníka Celé jméno a podpis výzkumníka

Appendix 8: Cover letter for healthcare professionals

Dear Doctor,

I am writing to you to ask for your cooperation in connection with a research project that is being conducted at Motol University Hospital and deals with shared decision-making about care for children with life-limiting illness from the perspective of their parents and healthcare providers. The project has been approved by the Deputy Minister for LPP, Dr. Martin Holcát, and the Ethics Committee of Motol University Hospital and is carried out in cooperation with Dr. Lucie Hrdličková.

The research project is a part of my dissertation work carried out as a part of postgraduate studies in palliative care at Lancaster University in the UK. At the same time, I am also working as a researcher at the Palliative Care Centre and collaborating with the Paediatric Supportive Care Team at Motol University Hospital.

The main aim of the project is to find out how parents are involved in decisions about further treatment and care for their sick child, together with the medical staff involved in their child's care. The results of the study should lead to a better understanding of how decisions about care occur and how this process is perceived by both parties involved.

The research is designed as a qualitative multiple case study. The main form of data collection is an interview focusing on the experience of making care decisions for a particular child.

Therefore, I would like to ask you for an interview that would focus on care decision making for your patient xxx. The length of the interview is approximately 30 to 45 minutes. All data collected during the study is considered confidential and will be anonymized. The interview may be conducted in person, by telephone, or online.

Attached please find further information on the project and informed consent.

If you have any questions I will be happy to answer them.

Thank you for considering my request,

Have a nice day, Best regards

Appendix 9: Interview topic guides

Interview topic guide for parents

Introduction - Consent with interview - Consent with recording - Introduction of the research focus Opening of the interview	I'd love to talk to you about your experience making medical decisions for your/your ....son/daughter....... Can you start by telling me about your experience with your/your... son/daughter...?
Decision-making Identifying the type of decision relevant for the study Feelings about decision	Can you tell me what kind of decisions about medical care did you have to make for ……..(*child)*……….? Did you consider some of those decisions more important the others? - Can we now talk about this decision? **OR** Can you think of a time when you participated in decision making about the medical care for ……*(child)*……..? - What was the decision about? *IF NOT recalling any decisions ask about the decisions listed above.* Can you tell me how did you feel while making the decisions? Prompts:

Process of decision-making	• Mental state while making the decision (anxiety, stress, fear, depression, frustration, overwhelmed) • Being able to make the decision (confidence, medical knowledge) • Acting as parents while making the decision (protecting the child, best-interest, advocating for the child) • Worries and fears regarding the decision • Being under pressure (HCP, time, circumstances) How did you come to the decision?
Reflection of the decision-making process	What helped or hindered your decision-making? Prompts: • Support (partner, family, friends, HCP, religion) • Talking about the decision with someone else. • Information (enough, lack, difficulty to understand) • Time (enough, lack, rushed into) • Approach of healthcare professional towards them (respect, listening or not) • Other aspects affecting the decision-making • Who made the final decision • Role of the parent during the process Can you tell me, in retrospect, what your feelings are about your decision-making experience?

	Prompts - Helpful aspects - Unhelpful aspect - Level of involvement in the process (less, more and how)
Other decision (if appropriate) *(Different experience)*	Can you remember a situation when you experienced the decision-making process in different way than we just talked about? Were all your experiences like this one or can you think of a time when it was different? Can we talk about this decision?
Closure Summarise Signalise ending of the interview Thanks for participation	Would you like to add something else about your experience with making decision for ………….*(child)*…….? Is there anything else you'd like to add?

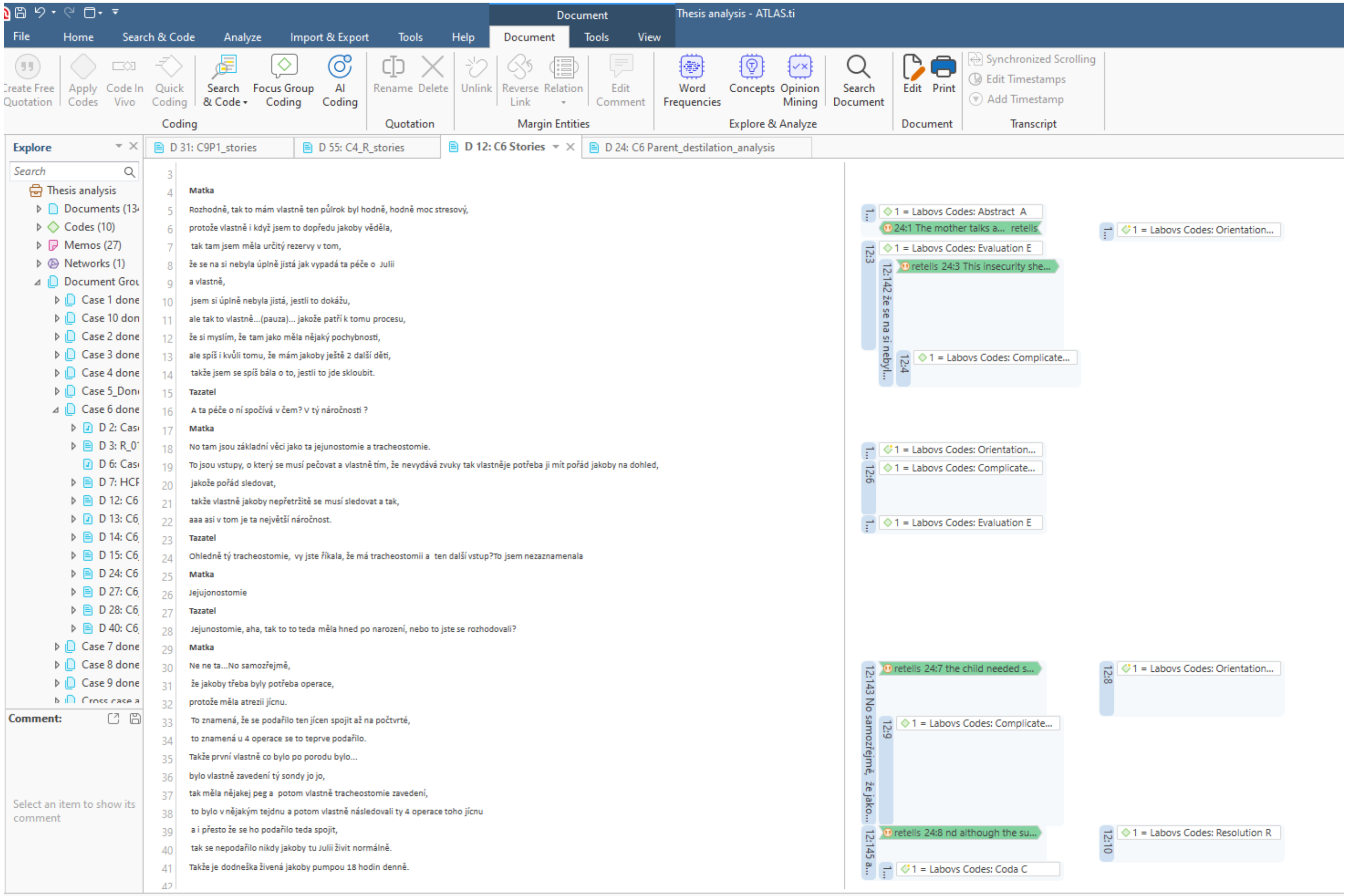
Interview topic guide for healthcare professionals

Introduction - Consent with interview - Consent with recording - Introduction of the research focus	I am interested in your experience of decision making about the medical care for ……….*(your patient)……….* Prompts:
To get information about the child and its family.	- Can you tell me about your patient? - Can you tell me about the medical history of this patient? - What is the child's diagnose? - How long is the child in your care?
Decision-making	Can you recall the process of making healthcare decisions for your patient?
Identifying the type of decision relevant for the study	Can you recall a situation where you had to make an important decision about medical care? Prompts: - Can you recall any decisions you made? - Do you remember any decisions particularly well? - On what basis did you make the decision? (What factors?) - Who was involved in the decision? - Do you think your parents may have been involved in the decision? - Do you think they had enough information?
Process of decision-making	Can you tell me how you arrived at the final decision? What helped or made the decision difficult for you?

Reflection of the decision-making process	Prompts: - Colleagues - Parents - Difficulty of the process - Time (enough, little, pressure) Can you tell me your feelings about your decision-making experience in retrospect? Prompts: - What was your role in the decision-making process? - Do you think parents were equally involved in the process? - How did you feel during the decision-making process? - How do you perceive the situation in retrospect? - Would you have done anything differently?
Other decision (if appropriate) *(Different experience)*	Were all your experiences of decision-making the same? Can you think of a situation where you had a different experience? Can we talk about that decision?
Closure Summarise Signalise ending of the interview Thanks for participation	Is there anything else you would like to add regarding your experience with care decisions for your patient...........?

Appendix 10: Examples of analysis in Atlas.ti 23

10.1. Structural narrative



Matka
Rozhodně, tak to mám vlastně ten půlrok byl hodně, hodně moc stresový,
protože vlastně i když jsem to dopředu jakoby věděla,
tak tam jsem měla určitý rezervy v tom,
že se na si nebyla úplně jistá jak vypadá ta péče o Julii
a vlastně,
jsem si úplně nebyla jistá, jestli to dokážu,
ale tak to vlastně...(pauza)... jakože patří k tomu procesu,
že si myslím, že tam jako měla nějaký pochybnosti,
ale spíš i kvůli tomu, že mám jakoby ještě 2 další děti,
takže jsem se spíš bála o to, jestli to jde skloubit.

Tazatel
A ta péče o ní spočívá v čem? V tý náročnosti ?

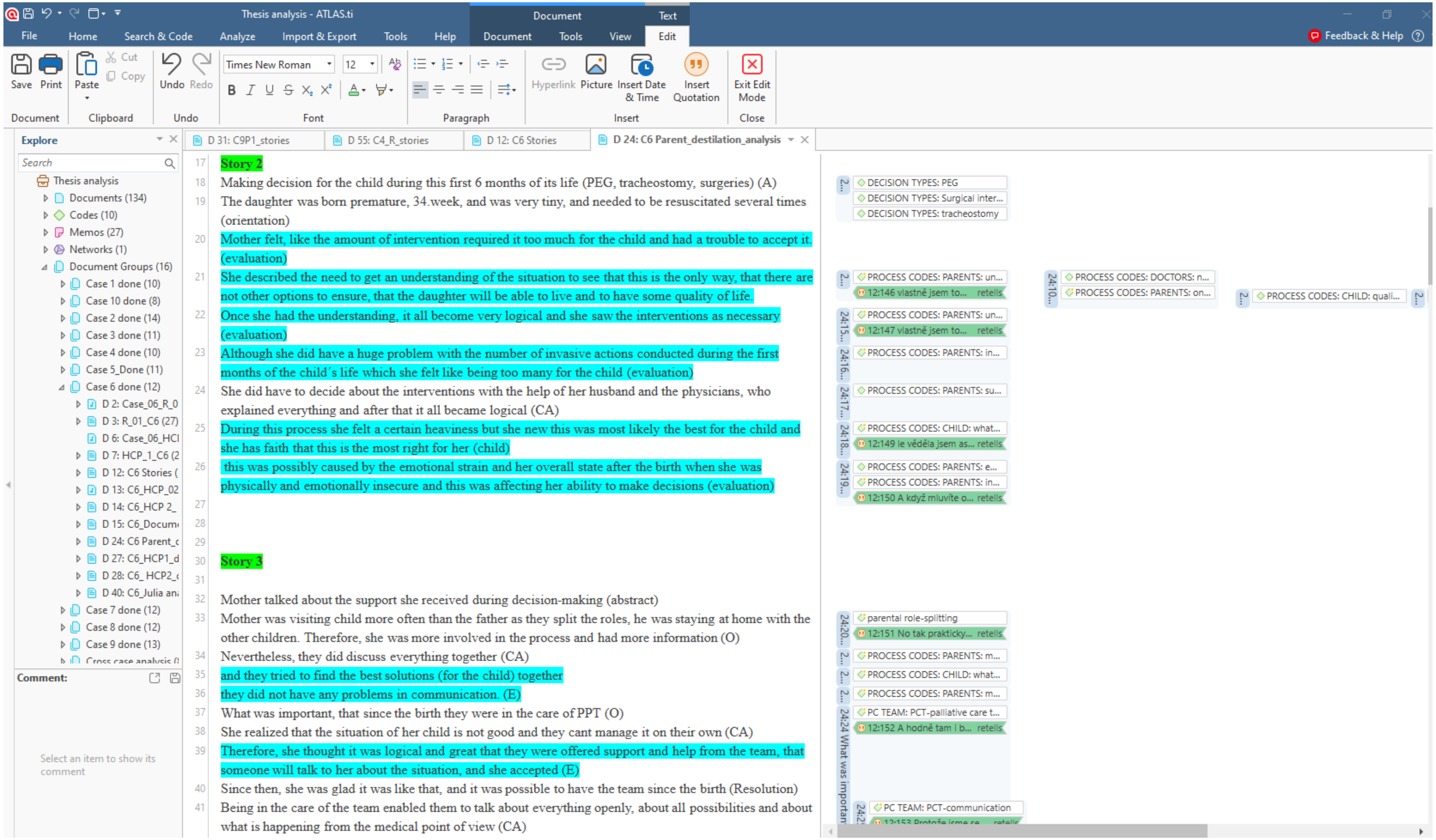
Matka
No tam jsou základní věci jako ta jejunostomie a tracheostomie.
To jsou vstupy, o který se musí pečovat a vlastně tím, že nevydává zvuky tak vlastněje potřeba ji mít pořád jakoby na dohled,
jakože pořád sledovat,
takže vlastně jakoby nepřetržitě se musí sledovat a tak,
aaa asi v tom je ta největší náročnost.

Tazatel
Ohledně tý tracheostomie, vy jste říkala, že má tracheostomii a ten další vstup?To jsem nezaznamenala

Matka
Jejujonostomie

Tazatel
Jejunostomie, aha, tak to to teda měla hned po narození, nebo to jste se rozhodovali?

Matka
Ne ne ta...No samozřejmě,
že jakoby třeba byly potřeba operace,
protože měla atrezii jícnu.
To znamená, že se podařilo ten jícen spojit až na počtvrté,
to znamená u 4 operace se to teprve podařilo.
Takže první vlastně co bylo po porodu bylo...
bylo vlastně zavedení tý sondy jo jo,
tak měla nějakej peg a potom vlastně tracheostomie zavedení,
to bylo v nějakým tejdnu a potom vlastně následovali ty 4 operace toho jícnu
a i přesto že se ho podařilo teda spojit,
tak se nepodařilo nikdy jakoby tu Julii živit normálně.
Takže je dodneška živená jakoby pumpou 18 hodin denně.



17 **Story 2**

18 Making decision for the child during this first 6 months of its life (PEG, tracheostomy, surgeries) (A)

19 The daughter was born premature, 34.week, and was very tiny, and needed to be resuscitated several times (orientation)

20 Mother felt, like the amount of intervention required it too much for the child and had a trouble to accept it. (evaluation)

21 She described the need to get an understanding of the situation to see that this is the only way, that there are not other options to ensure, that the daughter will be able to live and to have some quality of life.

22 Once she had the understanding, it all become very logical and she saw the interventions as necessary (evaluation)

23 Although she did have a huge problem with the number of invasive actions conducted during the first months of the child´s life which she felt like being too many for the child (evaluation)

24 She did have to decide about the interventions with the help of her husband and the physicians, who explained everything and after that it all became logical (CA)

25 During this process she felt a certain heaviness but she new this was most likely the best for the child and she has faith that this is the most right for her (child)

26 this was possibly caused by the emotional strain and her overall state after the birth when she was physically and emotionally insecure and this was affecting her ability to make decisions (evaluation)

30 **Story 3**

32 Mother talked about the support she received during decision-making (abstract)

33 Mother was visiting child more often than the father as they split the roles, he was staying at home with the other children. Therefore, she was more involved in the process and had more information (O)

34 Nevertheless, they did discuss everything together (CA)

35 and they tried to find the best solutions (for the child) together

36 they did not have any problems in communication. (E)

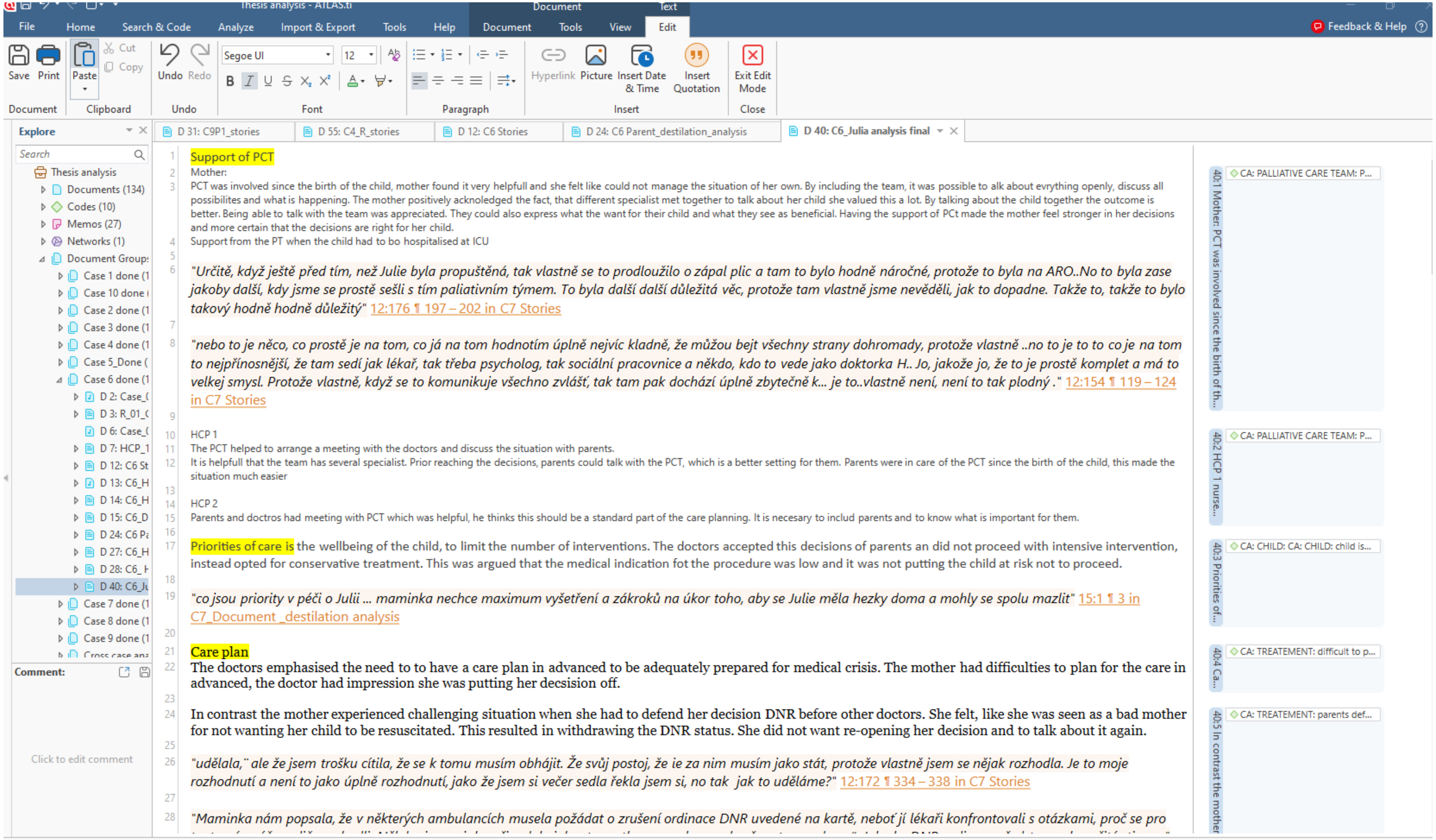
37 What was important, that since the birth they were in the care of PPT (O)

38 She realized that the situation of her child is not good and they cant manage it on their own (CA)

39 Therefore, she thought it was logical and great that they were offered support and help from the team, that someone will talk to her about the situation, and she accepted (E)

40 Since then, she was glad it was like that, and it was possible to have the team since the birth (Resolution)

41 Being in the care of the team enabled them to talk about everything openly, about all possibilities and about what is happening from the medical point of view (CA)



Support of PCT

Mother:

PCT was involved since the birth of the child, mother found it very helpfull and she felt like could not manage the situation of her own. By including the team, it was possible to alk about evrything openly, discuss all possibilites and what is happening. The mother positively acknoledged the fact, that different specialist met together to talk about her child she valued this a lot. By talking about the child together the outcome is better. Being able to talk with the team was appreciated. They could also express what the want for their child and what they see as beneficial. Having the support of PCt made the mother feel stronger in her decisions and more certain that the decisions are right for her child.

Support from the PT when the child had to bo hospitalised at ICU

"Určitě, když ještě před tím, než Julie byla propuštěná, tak vlastně se to prodloužilo o zápal plic a tam to bylo hodně náročné, protože to byla na ARO..No to byla zase jakoby další, kdy jsme se prostě sešli s tím paliativním týmem. To byla další další důležitá věc, protože tam vlastně jsme nevěděli, jak to dopadne. Takže to, takže to bylo takový hodně hodně důležitý" 12:176 ¶ 197 – 202 in C7 Stories

"nebo to je něco, co prostě je na tom, co já na tom hodnotím úplně nejvíc kladně, že můžou bejt všechny strany dohromady, protože vlastně ..no to je to to co je na tom to nejpřínosnější, že tam sedí jak lékař, tak třeba psycholog, tak sociální pracovnice a někdo, kdo to vede jako doktorka H.. Jo, jakože jo, že to je prostě komplet a má to velkej smysl. Protože vlastně, když se to komunikuje všechno zvlášť, tak tam pak dochází úplně zbytečně k... je to..vlastně není, není to tak plodný ." 12:154 ¶ 119 – 124 in C7 Stories

HCP 1

The PCT helped to arrange a meeting with the doctors and discuss the situation with parents.

It is helpfull that the team has several specialist. Prior reaching the decisions, parents could talk with the PCT, which is a better setting for them. Parents were in care of the PCT since the birth of the child, this made the situation much easier

HCP 2

Parents and doctros had meeting with PCT which was helpful, he thinks this should be a standard part of the care planning. It is necesary to includ parents and to know what is important for them.

Priorities of care is the wellbeing of the child, to limit the number of interventions. The doctors accepted this decisions of parents an did not proceed with intensive intervention, instead opted for conservative treatment. This was argued that the medical indication fot the procedure was low and it was not putting the child at risk not to proceed.

"co jsou priority v péči o Julii ... maminka nechce maximum vyšetření a zákroků na úkor toho, aby se Julie měla hezky doma a mohly se spolu mazlit" 15:1 ¶ 3 in C7_Document _destilation analysis

Care plan

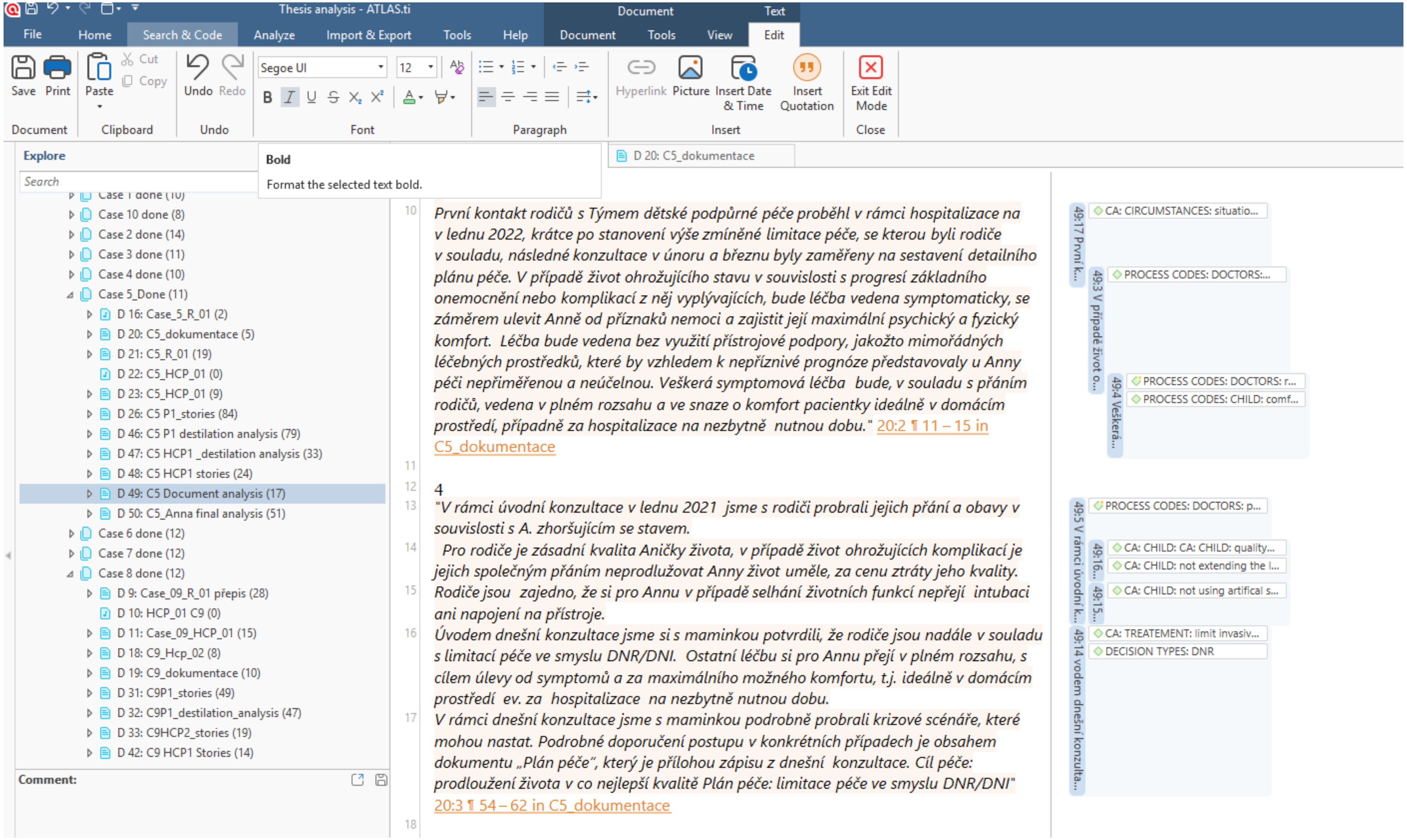
The doctors emphasised the need to to have a care plan in advanced to be adequately prepared for medical crisis. The mother had difficulties to plan for the care in advanced, the doctor had impression she was putting her decsision off.

In contrast the mother experienced challenging situation when she had to defend her decision DNR before other doctors. She felt, like she was seen as a bad mother for not wanting her child to be resuscitated. This resulted in withdrawing the DNR status. She did not want re-opening her decision and to talk about it again.

"udělala,¨ ale že jsem trošku cítila, že se k tomu musím obhájit. Že svůj postoj, že ie za nim musím jako stát, protože vlastně jsem se nějak rozhodla. Je to moje rozhodnutí a není to jako úplně rozhodnutí, jako že jsem si večer sedla řekla jsem si, no tak jak to uděláme?" 12:172 ¶ 334 – 338 in C7 Stories

"Maminka nám popsala, že v některých ambulancích musela požádat o zrušení ordinace DNR uvedené na kartě, neboť jí lékaři konfrontovali s otázkami, proč se pro

10.2. Medical records -documentary data



První kontakt rodičů s Týmem dětské podpůrné péče proběhl v rámci hospitalizace na v lednu 2022, krátce po stanovení výše zmíněné limitace péče, se kterou byli rodiče v souladu, následné konzultace v únoru a březnu byly zaměřeny na sestavení detailního plánu péče. V případě život ohrožujícího stavu v souvislosti s progresí základního onemocnění nebo komplikací z něj vyplývajících, bude léčba vedena symptomaticky, se záměrem ulevit Anně od příznaků nemoci a zajistit její maximální psychický a fyzický komfort. Léčba bude vedena bez využití přístrojové podpory, jakožto mimořádných léčebných prostředků, které by vzhledem k nepříznivé prognóze představovaly u Anny péči nepřiměřenou a neúčelnou. Veškerá symptomová léčba bude, v souladu s přáním rodičů, vedena v plném rozsahu a ve snaze o komfort pacientky ideálně v domácím prostředí, případně za hospitalizace na nezbytně nutnou dobu." 20:2 ¶ 11 – 15 in C5_dokumentace

4

"V rámci úvodní konzultace v lednu 2021 jsme s rodiči probrali jejich přání a obavy v souvislosti s A. zhoršujícím se stavem.

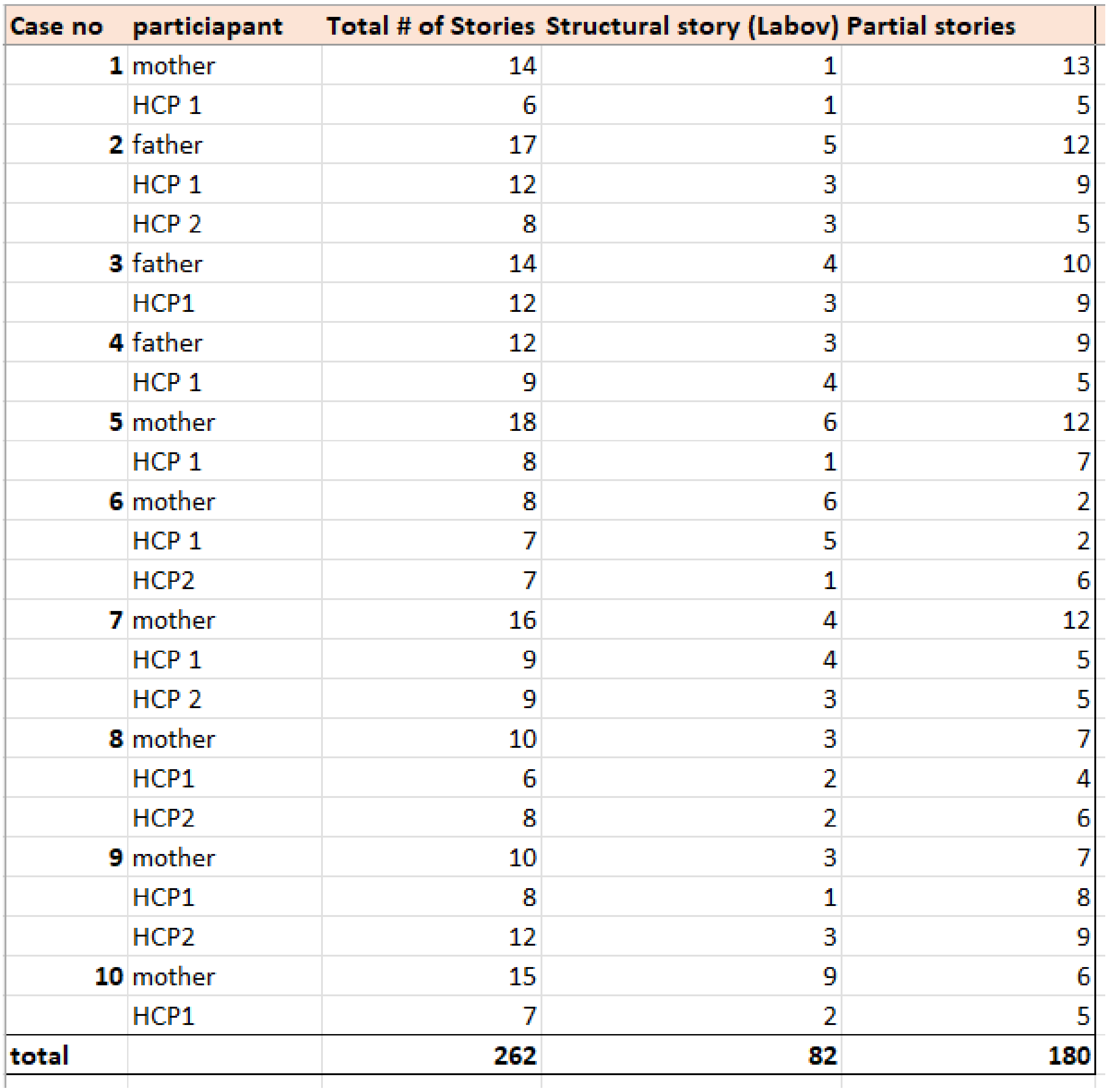
Pro rodiče je zásadní kvalita Aničky života, v případě život ohrožujících komplikací je jejich společným přáním neprodlužovat Anny život uměle, za cenu ztráty jeho kvality. Rodiče jsou zajedno, že si pro Annu v případě selhání životních funkcí nepřejí intubaci ani napojení na přístroje.

Úvodem dnešní konzultace jsme si s maminkou potvrdili, že rodiče jsou nadále v souladu s limitací péče ve smyslu DNR/DNI. Ostatní léčbu si pro Annu přejí v plném rozsahu, s cílem úlevy od symptomů a za maximálního možného komfortu, t.j. ideálně v domácím prostředí ev. za hospitalizace na nezbytně nutnou dobu.

V rámci dnešní konzultace jsme s maminkou podrobně probrali krizové scénáře, které mohou nastat. Podrobné doporučení postupu v konkrétních případech je obsahem dokumentu „Plán péče", který je přílohou zápisu z dnešní konzultace. Cíl péče: prodloužení života v co nejlepší kvalitě Plán péče: limitace péče ve smyslu DNR/DNI"

20:3 ¶ 54 – 62 in C5_dokumentace

Appendix 11: Number and type of the extracted stories

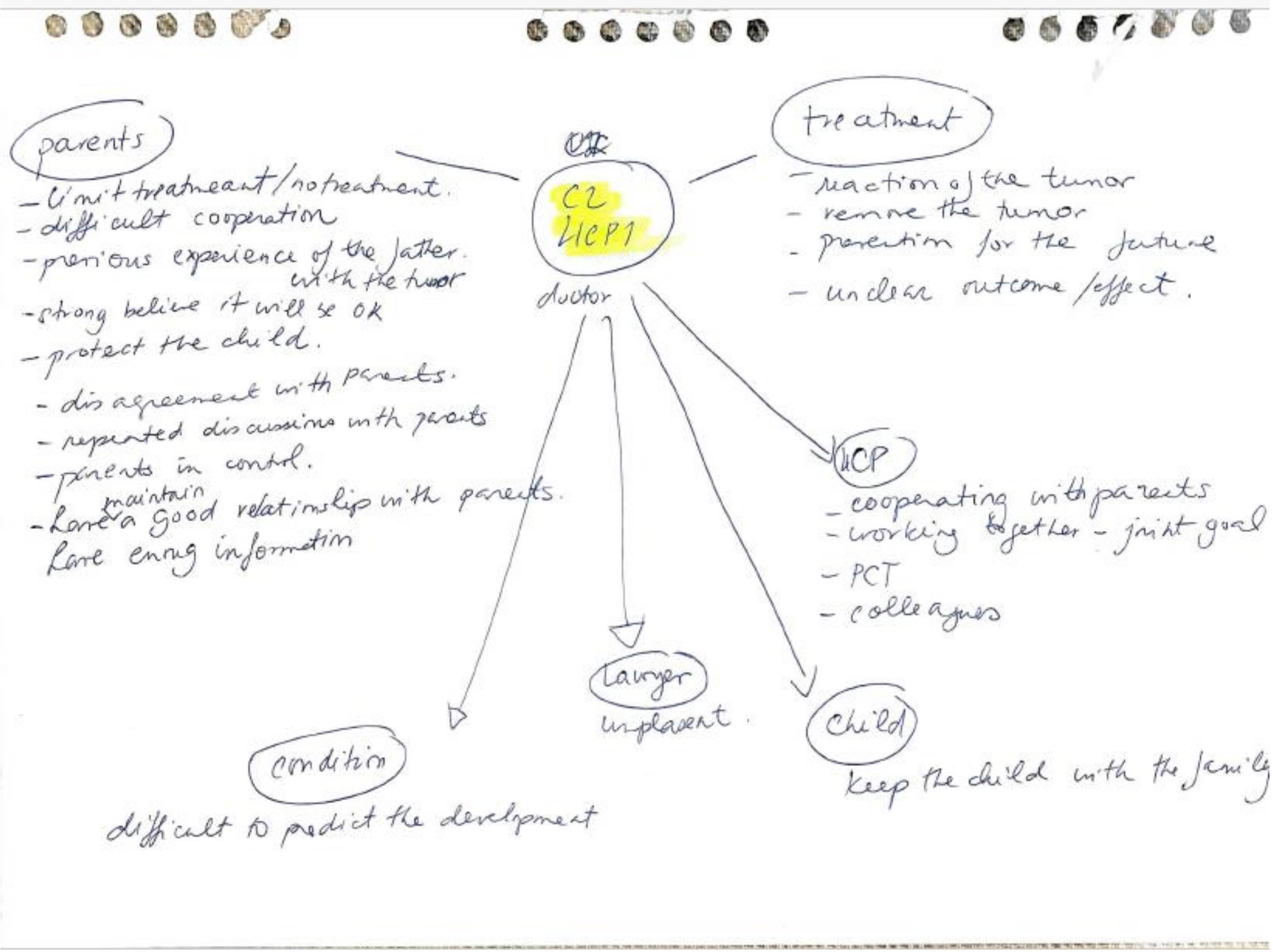


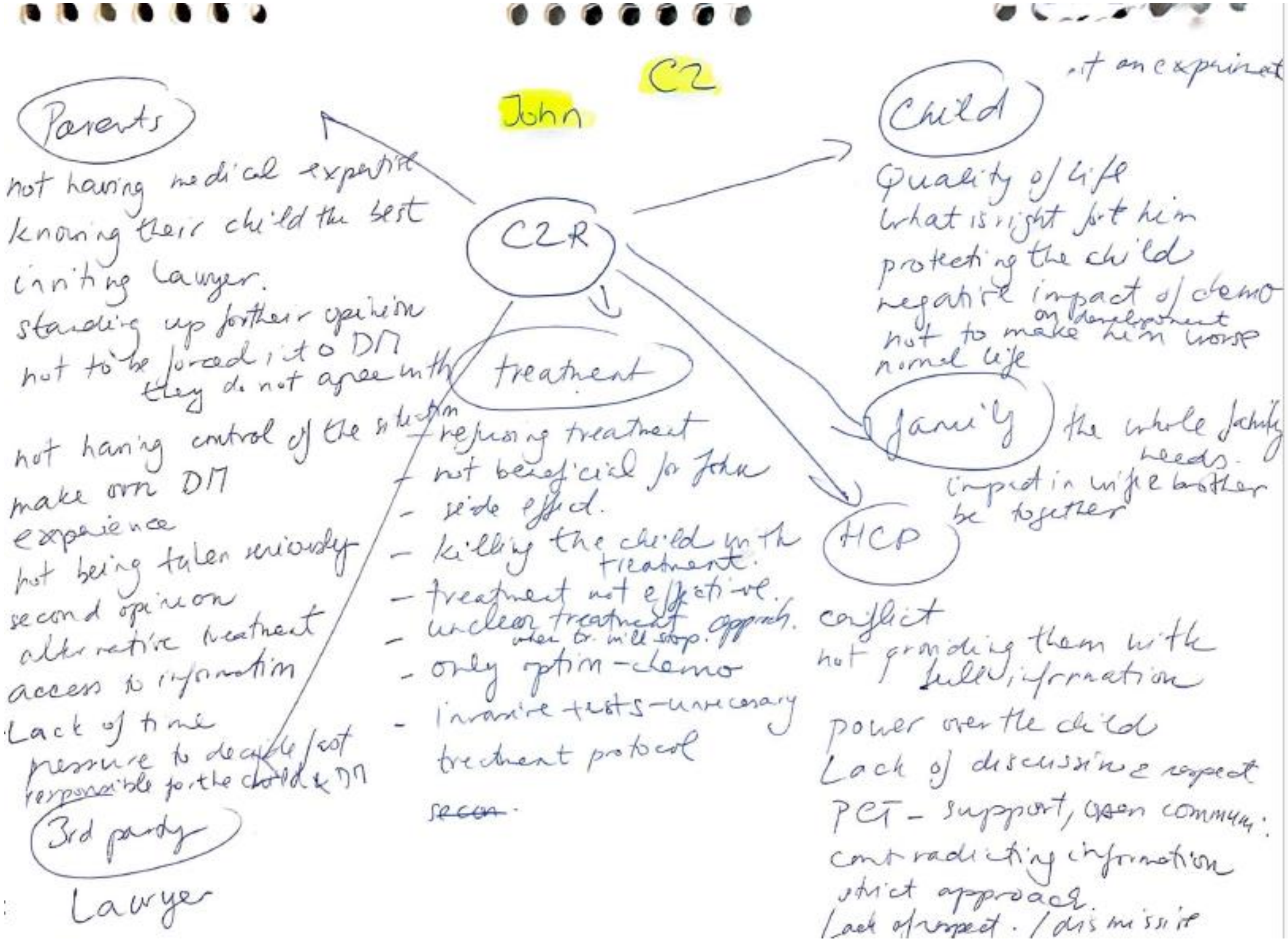
Case no	particiapant	Total # of Stories	Structural story (Labov)	Partial stories
1	mother	14	1	13
	HCP 1	6	1	5
2	father	17	5	12
	HCP 1	12	3	9
	HCP 2	8	3	5
3	father	14	4	10
	HCP1	12	3	9
4	father	12	3	9
	HCP 1	9	4	5
5	mother	18	6	12
	HCP 1	8	1	7
6	mother	8	6	2
	HCP 1	7	5	2
	HCP2	7	1	6
7	mother	16	4	12
	HCP 1	9	4	5
	HCP 2	9	3	5
8	mother	10	3	7
	HCP1	6	2	4
	HCP2	8	2	6
9	mother	10	3	7
	HCP1	8	1	8
	HCP2	12	3	9
10	mother	15	9	6
	HCP1	7	2	5
total		**262**	**82**	**180**

Appendix 12: Types of decisions in each case

Case no	participant	Types of decisions								
1	mother	advanced care planning	limitation of care	hospital transport	dialysis	kidney tx				
	HCP1	advanced care planning	limitation of care	PCT	dialysis	kidney tx				
2	father	stopping chemotherapy	surgery	MRI						
	HCP1	stopping chemotherapy								
	HCP 2	treatment								
3	father	anti-vomiting medication	radiotherapy	NG tube	trial treatment	advanced care planning	PCT			
	HCP1	radiotherapy	limitation of care	care at home	PCT	comfort care				
4	father	medication dose	transplant	PCT						
	HCP1	medication dose	surgery	transplant						
5	mother	tracheostomy	PEG/JPEG	DNRI	advanced care planning	PCT	extent of care	ICU	surgery- insertion of PEG, narcosis	waiver of DNR for surgery
	HCP 1	tracheostomy	DNRI	limitation of care						
6	mother	PEG	tracheostomy	surgeries	extent of care	ICU				
	HCP1	surgeries	extent of care	ICU						
	HCP2	DNR	extent of care							
7	mother	tracheostomy	gastrostomy	cochlear implant						
	HCP 1	tracheostomy	PEG							
	HCP 2	tracheostomy	gastrostomy	type of feeding						
8	mother	dialysis	Pain control	BMT						
	HCP1	dialysis	Pain control	BMT	PCT					
	HCP 2	Symptom control	Pain control	BMT						
9	mother	surgery	transfusion	ATB	ketogenic diet	CBD oil	tracheostomy	PEG		
	HCP 1	DNR/DNI	ketogenic diet	CBD oil						
	HCP 2	surgery	PEG	care plan						
10	mother	radiotherapy	alternative therapy							
	HCP 1	care plan	end-of- life care	alternative therpies	hospic					

Appendix 13: Mind map





John

C2

C2R

Parents

not having medical expertise

knowing their child the best

inviting Lawyer.

standing up for their opinion

not to be forced into DM
they do not agree with

not having control of the situation

make own DM

experience

not being taken seriously

second opinion

alternative treatment

access to information

Lack of time

pressure to decide / not
responsible for the child & DM

3rd party

Lawyer

treatment

- refusing treatment
- not beneficial for John
- side effect.
- killing the child with treatment.
- treatment not effective.
- unclear treatment approach. when tr. will stop.
- only option - chemo
- invasive tests - unnecessary

treatment protocol

~~secon~~.

Child

it an experiment

Quality of life

What is right for him

protecting the child

negative impact of chemo on development

not to make him worse

normal life

family

the whole family needs.

impact in wife brother

be together

HCP

conflict

not providing them with full, information

power over the child

Lack of discussion & respect

PCT - support, open commun:

contradicting information

strict approach.

Lack of respect. / dismissive

Appendix 14: Ethics approval FHMREC

Applicant: Kristyna Polakova
Supervisor: Sarah Brearley, Faraz Ahmed
Department: DHR
FHMREC Reference: FHMREC20116

26 March 2021

Re: FHMREC2020116 Approval to external Application
Title: The shared decision-making process about the care of children with life-limiting conditions from the perspective of parents and health care providers

Dear Kristyna,

Thank you for submitting your ethics application and Motol University Hospital's approval for the study mentioned above. Based on the information provided, I can confirm that the **Chair/Deputy Chair** of the Faculty of Health and Medicine Research Ethics Committee has granted approval for your part in this project.

As Principal Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

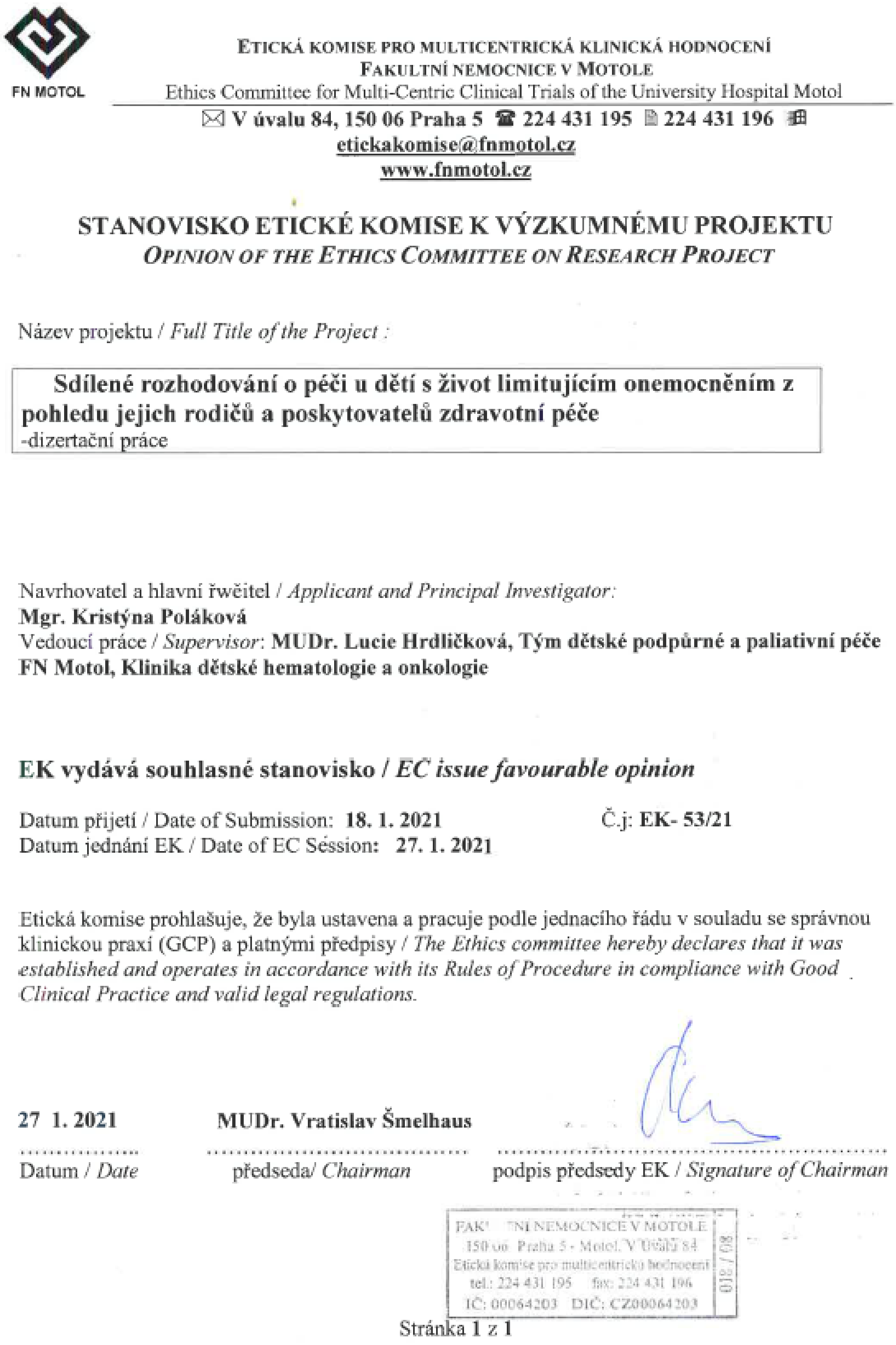
Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Dr. Elisabeth Suri-Payer
Research Ethics Officer, Secretary to FHMREC

Appendix 15: Ethics approval from the hospital



FN MOTOL

ETICKÁ KOMISE PRO MULTICENTRICKÁ KLINICKÁ HODNOCENÍ
FAKULTNÍ NEMOCNICE V MOTOLE
Ethics Committee for Multi-Centric Clinical Trials of the University Hospital Motol
✉ V úvalu 84, 150 06 Praha 5 ☎ 224 431 195 📠 224 431 196
etickakomise@fnmotol.cz
www.fnmotol.cz

STANOVISKO ETICKÉ KOMISE K VÝZKUMNÉMU PROJEKTU
OPINION OF THE ETHICS COMMITTEE ON RESEARCH PROJECT

Název projektu / *Full Title of the Project :*

Sdílené rozhodování o péči u dětí s život limitujícím onemocněním z pohledu jejich rodičů a poskytovatelů zdravotní péče -dizertační práce

Navrhovatel a hlavní řwěitel / *Applicant and Principal Investigator:*
Mgr. Kristýna Poláková
Vedoucí práce / *Supervisor*: **MUDr. Lucie Hrdličková, Tým dětské podpůrné a paliativní péče FN Motol, Klinika dětské hematologie a onkologie**

EK vydává souhlasné stanovisko / *EC issue favourable opinion*

Datum přijetí / Date of Submission: **18. 1. 2021** Č.j: **EK- 53/21**
Datum jednání EK / Date of EC Session: **27. 1. 2021**

Etická komise prohlašuje, že byla ustavena a pracuje podle jednacího řádu v souladu se správnou klinickou praxí (GCP) a platnými předpisy / *The Ethics committee hereby declares that it was established and operates in accordance with its Rules of Procedure in compliance with Good Clinical Practice and valid legal regulations.*

27 1. 2021 **MUDr. Vratislav Šmelhaus**
Datum / *Date* předseda/ *Chairman* podpis předsedy EK / *Signature of Chairman*

FAKULTNÍ NEMOCNICE V MOTOLE
150 06 Praha 5 - Motol, V Úvalu 84
Etická komise pro multicentrická hodnocení
tel.: 224 431 195 fax: 224 431 196
IČ: 00064203 DIČ: CZ00064203
018 / 08

Stránka 1 z 1

Appendix 16: Distress protocol

(Modified from Draucker, Martsolf, & Poole, 2009; Haigh, C. & Witham, 2015)

Indication of distress during interview	• Participant indicates they are experience a high level of stress or emotional distress OR • Exhibit behaviours suggestive that the interview is too stressful such as uncontrolled crying, incoherent speech, shaking etc.

Response 1	• Stop the interview. • Offer support and allow the participant time to regroup • Assess mental status: Tell me what are your thoughts? Tell me what are you feeling right now? Do you feel you are able to go on about your day? Do you feel safe?
Action	• If a participant's distress reflect an emotional response reflective of what would be expected in an interview about a sensitive topic, offer support and extend the opportunity to stop the interview, regroup and reflect • If participant feels able to carry on- resume interview • If participant is unable to carry on- Go to response 2

Response 2	• Discontinue the interview • With participant consent contact the mental health care professional from the healthcare team to provide support • Encourage the participant to contact their mental healthcare provider if they have one • Contact the healthcare team for further advice

Follow up	• Follow participant up with courtesy call (participant consent needed) • Encourage the participant to call if experiencing distress preserves

Appendix 17: Overview of the strategies the enhance study rigour

Validation of data	Case study tactics	Approach used in this PhD study
Internal validity (credibility) Refers to the congruency of the finding with the studied reality and if the findings capture the reality (Merriam, 1998).	**Triangulation of data-** use of multiple sources of data, methods or investigators to confirm the findings (Merriam, 1998). Comparing and cross-checking collected data (Merriam & Tisdell, 2016).	Multiple sources were used to collect data, including interviews and medical records.
	Peer examination- cooperation with other researchers during data analysis (Merriam, 1998).	During the data analysis, the emerging findings were repeatedly discussed with the supervisors.
	Adequate engagement in data collection- getting close to the participants' understanding of the studied phenomenon. Collecting enough data to reach saturation and ensuring variation in the studied cases (Merriam & Tisdell, 2016).	The data collection was stopped when data saturation was reached. The study consists of 10 cases. A certain level of variation was sought during the recruitment process.
	Disclosure of researcher bias and reflexivity- clarifying the researcher's assumptions, expectations, worldview and theoretical orientation (Merriam, 1998).	My previous experience with the studied phenomenon was presented at the start of the research. During the whole research process, I kept a reflexive diary and had discussions with my supervisors to address any raised issues.

Validation of data	Case study tactics	Approach used in this PhD study
Reliability (dependability/consistency) Addresses the extent to which the research can be replicated while obtaining the same findings. The results are consistent with the data collected (Merriam, 1998).	**Audit trail-** describing how the study was conducted, how data were collected, and how it was analysed. An audit trail is kept via research journals and memos, which record personal reflections and decisions made throughout the process (Merriam & Tisdell, 2016).	The data collection and analysis processes were recorded. Field notes and memos were kept during the data collection. Data analysis was done in the software Atlas.ti 23 which enables to backtrack the process.
	Explanation of the investigator's position- explaining their assumptions and positions, including the social context of the collected data (Merriam, 1998).	Explaining my position and experience as described above.
Transferability (external validity) Relates to how the study findings can be transferred and applied to other situations.	**Rich, thick description of collected data-** presenting a detailed description of the study setting and participants. Presentation of the study findings with evidence in the form of quotes from participant interviews, field notes, and documents (Merriam & Tisdell, 2016).	Providing a thick description of the findings for the reader. Using direct quotes from the interviews to illustrate findings. Providing a description of the study setting and of the socio-cultural context. Providing a detailed description of the cases.
	Maximum variation – using several sites, cases and situations to maximise diversity (Merriam & Tisdell, 2016).	Using multiple-case design to maximise the diversity of the studied phenomenon. Using purposeful sampling to achieve variation in the cases.