



## Exploring parent treatment decision-making in relapsed and refractory neuroblastoma: A qualitative study

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### ABSTRACT

Parents often become involved in making treatment decisions for their child with cancer when there is no standard treatment protocol, typically seen in poor-prognosis cancers. Advances in scientific medicine has led to more treatment options being available for children resulting in parents making repeated treatment decisions depending on their child's response to treatment. The emotional turmoil of their child's cancer diagnosis can be exacerbated when combined with making decisions that have uncertain outcomes. This study aimed to identify, describe, explore, and explain how parents made repeated treatment decisions and the role of emotion in decision-making when their child had relapsed or refractory neuroblastoma, a poor-prognosis cancer.

Data were collected using qualitative interviews between 2020 and 2022 with parents of children with relapsed or refractory neuroblastoma in the United Kingdom. Data were analysed using Reflexive Thematic Analysis.

Eighteen parents who made between one to six treatment decisions participated. Decision-making incorporated four themes which enabled, influenced, and informed how parents made treatment decisions: 1) time as a structure within decision-making; 2) uncertainty and its relationships with treatment risk, side effects and outcomes; 3) parent oscillation of their cognitive and emotional adjustment; 4) parent responsibility and involvement in decision-making. Time was the central organising concept which structured and organised parent decision-making. We adopted Orlikowski and Yates's (2002) temporal structures to characterise the experience of time and Stroebe and Schut's (1999) dual-processing theory to explore the oscillation of parent adjustment of their situation cognitively and emotionally. A conceptual framework showed the interrelationships of these themes.

### 1. Background

Neuroblastoma accounts for approximately 8% of childhood cancers overall. Typically, this disease is seen in children under five years of age (Shohet & Foster, 2017) and in the United Kingdom (UK), approximately 100 children are diagnosed with neuroblastoma each year (Public Health England, 2021). Of these, 50% of children have stage IV high-risk disease which has a cure rate of less than 50% (Morgenstern et al., 2016). Children with IV high-risk disease can experience a relapse or have refractory disease which significantly impacts their survival. Relapsed disease is seen in approximately 60% of children either during

front-line treatment or after treatment has completed (Basta et al., 2016) with survival being less than 8% (Basta et al., 2016). Refractory disease which has not responded adequately to induction chemotherapy during front-line treatment has a survival rate of less than 20% (Schrey et al., 2015). Overall, from the 50 children diagnosed each year with stage IV high-risk disease, 40 children will experience either relapsed or refractory disease associated with poor survival outcomes.

There is no standard treatment for relapsed and refractory neuroblastoma (Morgenstern et al., 2016; Schrey et al., 2015). Standard treatments are those shown to be the best available for a particular disease, proven through clinical trials (National Cancer Institute, 2021).

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When there is no standard treatment, parents become very involved in making treatment decisions for their child. This can result in children receiving multiple treatments over months or years depending on treatment response, associated toxicities, availability of treatments and the child's clinical condition. Parents can make repeated treatment decisions in the hope of their child's survival.

### 1.1. The parental journey

Parents experience a crisis in parenting when their child is diagnosed with cancer (Dixon-Woods et al., 2001) transitioning into a crisis period whereby their parental role is compromised due to uncertainty of their child's health and how they will tolerate and respond to treatment (Vance & Eiser, 2004). This is in parallel to the psychological adjustment of the diagnosis within the family unit (Vance & Eiser, 2004). Parents want to be involved in making treatment decisions for their child with cancer (Hinds et al., 1997; Mack et al., 2012). Seminal work by Hinds et al (2009) demonstrated parents spoke of being a 'good parent', making decisions which are in their child's best interests whilst protecting them from harm and suffering (Hinds et al., 2009), and deciding on treatments which provide the best possible outcome (Stewart et al., 2012). Parents take a more active role in decision-making if standard treatment fails and relapse strategies are required (Hinds et al., 1997), and there is more than one treatment option available (Elwyn et al., 2022).

In poor-prognosis cancer, parents want to have tried everything possible including participation in clinical trials even when there is unlikely to be any direct benefit (Wakefield et al., 2023; Woodgate & Yanofsky, 2010), in an attempt to cure their child or at the very least prolong their life. Clinical trials increase treatment options for parents; however in doing so they can increase decisional burden and potential for decisional regret (Woodgate & Yanofsky, 2010). For parents of children with relapsed and refractory neuroblastoma who are making repeated treatment decisions over time, this decision-making is complex with their child's survival severely compromised. This decision-making differs and is not equal to decision-making in paediatric contexts where parents are not making decisions for their child who has a life-threatening or life-limiting decisions for example in Autism disorders (Saez et al., 2022).

### 1.2. The importance of information in making decisions

The primary goal for parents in their treatment decision-making is to cure their child (Hinds et al., 1997; Mack et al., 2019). Parents require quality information including treatment options, risks, and benefits to make an informed decision which aligns with their values and preferences (Brown et al., 2021; Mack et al., 2007; Robertson et al., 2018). Research on parent information-seeking behaviours by Kiliarslan-Toruner and Akgun-Citak (2013) showed parents sought information from multiple sources including healthcare professionals, other parents, and the internet (Kiliarslan-Toruner & Akgun-Citak, 2013). However, parent involvement in treatment decision-making can lead to psychological distress, decisional conflict between treatment and quality of life, and decisional regret (Boland et al., 2017; Robertson et al., 2018; Woodgate & Yanofsky, 2010). Decisional conflict can arise when treatment options and information regarding risks and benefits are unclear or options conflict with a parent's values and preferences (Boland et al., 2017). This conflict may increase over time as parents make repeated treatment decisions where treatment options are decreasing, and the impact on their child's quality of life may increase due to toxicities and side effects from previous treatments received. Decisional regret in either not continuing with treatment or administering treatment that induces suffering and harm to their child can have a lasting impact on parents, particularly if their child dies (Hinds et al., 1997; Lichtenthal et al., 2020; Mack et al., 2019). Research by Mack et al (2019) showed forty-one percent of parents whose child had relapsed or had refractory neuroblastoma experienced decisional regret related to their most recent

treatment decision (Mack et al., 2019). This research focused on a single treatment decision and the impact of making repeated treatment decisions remains unexplored. Bereaved parents can experience conflicting views on decisional regret. Research showed some parents wanted to pursue further or more intensive treatments for their child whilst other parents wished they had focused less on treatment to improve their child's quality of life and reduce suffering (Lichtenthal et al., 2020). This suggests parents are continually conflicted during their decision-making, wanting to make treatment decisions which cure or prolong their child's life whilst maintaining a good quality of life. There is no research which has explored how parents make repeated treatment decisions over time in the context of poor-prognosis childhood cancer. Doing so may highlight aspects of this decision-making which change over time and help identify support needs required during this process to facilitate reducing psychological distress, decisional conflict, and future regret.

### 1.3. Decision-making theories and evidence

Theories have explored the process of decision-making providing explanations of how people make decisions. These can be grouped into three processes: rational (Newell et al., 2015); descriptive/psychological (Hammond et al., 1987; Kahneman & Tversky, 1979); and emotional (Lerner et al., 2015; Lerner & Keltner, 2010). Rational decision-making theories are mostly seen in economics and finance (McFall 2015) for example the Expected Utility Theory developed in the field of economics for decision-making involving risk (Newell et al.). Humans are the decision analysts in decision-making suggesting an element of psychology must be involved in these processes (Hunink et al., 2014) considering people's experience and intuition. Descriptive/psychological theory such as naturalistic decision-making, recognised the need for a knowledge-based approach incorporating experience, pattern recognition and expertise within decision-making (Klein, 2008). However, what rational and descriptive/psychological processes fail to acknowledge are emotions and how these can inform or influence decision-making. Emotions are the dominant driver in most meaningful life decisions (Frijda, 1988; Lerner & Keltner, 2010) suggesting these may influence how people make decisions in the context of healthcare where diagnosis and treatments can be life-threatening, life-limiting and uncertain.

Exploring decision-making processes in a more contextualised way, Hunink et al. (Hunink et al., 2014) evidenced the extent to which emotions are integral in healthcare decision-making. However, only recently has a theoretical model, the emotional-imbued choice model (Lerner et al., 2015) been suggested, which incorporates rational, descriptive/psychological and emotional decision-making processes. This model is better suited to explaining the potential complexities of decision-making acknowledging the competing or conflicting processes of rational, descriptive/psychological and emotion in decision-making and how these co-exist simultaneously. This is particularly important in healthcare where people can be making life changing decisions in emotionally charged circumstances. A literature review exploring parent treatment decision-making in poor-prognosis cancer showed the concept of emotion was lacking in the literature (Pearson et al., 2022) with only one study acknowledging that parents experience a range of emotions including shock, grief and sadness at relapse (Hinds et al., 1996a). This literature review incorporated a Patient and Public Involvement (PPI) consultation with bereaved parents who felt the literature was sanitised as a definitive way parents made decisions without acknowledging or exploring how emotions inform and influence their decision-making processes (Pearson et al., 2022). It is therefore helpful in the context of parental decision-making in relapsed and refractory neuroblastoma where parents are making repeated, complex decisions over time, that a decision-making model incorporates the technical information (rational), individual characteristics (psychological/descriptive) and the role emotion may have in informing and influencing parents' decisions.

#### 1.4. Situating this study

There is a gap in knowledge of how parents make repeated treatment decisions and how emotion informs and influences decision-making in poor-prognosis childhood cancer (Pearson et al., 2022). This study focuses on these two unexplored aspects. Given the lack of standard treatment for relapsed and refractory neuroblastoma, increasing availability of treatments and clinical trials for poor-prognosis childhood cancers and the psychological impact of decision-making on parents, this warrants further exploration of how parents make repeated treatment decisions over time. The knowledge generated from this study has the potential to inform decision support tools or interventions for parents and increase understanding of how emotion informs and influences parents in their decision-making. This would enable healthcare professionals and other actors to consider their approaches and support mechanisms for parents making these complex decisions. Understanding repeated decision-making also has the potential to be applied in other contexts with parents of children with other life-threatening and life-limiting conditions.

The aim of this qualitative study was to identify, describe, explore, and explain how parents make treatment decisions when their child has relapsed or refractory neuroblastoma. Findings will build on existing scholarship, contributing to the theoretical literature on decision-making and offering a novel perspective on the evolution of repeated decision-making over time.

## 2. Methodology

### 2.1. Methodological positioning of the study

The study took a relativist approach where social reality is dependent on individual interpretation and knowledge (Braun & Clarke, 2013) resulting in multiple realities existing (Braun & Clarke, 2013). Parents interpret scientific evidence and information which is influenced by their interactions with others and their own knowledge. This creates their reality shaping and informing their decision-making processes (Talja et al., 2004). Parents use cognitive processes to construct and make meaning of their social and psychological worlds, known as cognitive constructivism (Talja et al., 2004; Young & Collin, 2004), the epistemological viewpoint adopted in this study. This positioning supported a reflexive thematic analysis (Reflexive TA) approach (Braun, 2019).

## 3. Methods

### 3.1. Study design

This was a qualitative study using semi-structured interviews addressing three research questions: 1) How do parents make treatment decisions when their child has relapsed or refractory neuroblastoma?; 2) Does parent decision-making changes over time and if so, how?; 3) What is the role of emotion in parent treatment decision-making when their child has relapsed or refractory neuroblastoma? Parents were invited to participate via their child's Primary Treatment Centre in the UK if their child was receiving treatment for relapsed or refractory neuroblastoma and they had recently made a treatment decision. The definition of a treatment decision was the need for parents to decide on what cancer treatment to administer to their child. Both parents were invited to participate and could be re-interviewed if they made repeated treatment decisions whilst the study was open. Maximum variation sampling (Moule & Hek, 2011) was used to specifically recruit parents of children with relapsed or refractory neuroblastoma.

### 3.2. Study participants and recruitment strategy

Eligible parents were identified and contacted by the lead researcher

(HP) to discuss the study and if agreeable, a convenient time was organised for the interview. Interviews were virtual or by telephone due to the coronavirus pandemic.

Thirty-one parents were identified through Primary Treatment Centres. Seven parents declined due to feeling overwhelmed with the diagnosis and having a busy home life. One healthcare professional felt unable to approach a parent due to safeguarding concerns, and another forgot to provide the study information to the parent when they attended the hospital. Two parents agreed to participate but did not engage with arranging an interview. One child died before the parent could be approached. One parent agreed to participate, an interview was arranged but their child died unexpectedly the day before the interview was due to take place.

### 3.3. Ethical approval and consent

Ethics approval was obtained from the XXXXXXXXXXXX (study sponsor) and NHS Health Research Authority London Bloomsbury Research Ethics Committee (19/LO/1715). Consent was audio-recorded and uploaded onto the secure University server.

### 3.4. Data generation

Parent demographic information were collected at the beginning of the interview. Interview questions were devised based on clinical experience, a literature review (Pearson et al., 2022) and in partnership with the study's PPI group. This group consisted of four parents and one grandparent all of whom were bereaved having had a child treated for relapsed or refractory neuroblastoma. The integration of PPI within this study is published elsewhere (Pearson et al., 2024). Interviews were conducted between 2020 and 2022 by HP who had not been involved in the clinical care of any child. Interviews were audio-recorded and transcribed verbatim by an independent transcribing company. Identifiable information was removed from all transcripts which were stored electronically on a password secure University computer and uploaded onto NVivo Release 1.0 (Lumivero, 2020).

### 3.5. Data analysis

Interviews were analysed using reflexive TA following Braun and Clarke's 6-steps (Braun, 2019). Themes contained patterns of shared meaning united by a central organising concept (Braun, 2019; Braun & Clarke, 2013) interpreted to provide a conceptual narrative across the dataset (Braun & Clarke, 2022). The data consisted of multiple realities of parent decision-making supporting a relativist approach.

Each interview was analysed as a unit irrespective of whether it was a single or joint parent interview. In joint interviews, parents had co-constructed their story as a dyad (Van Parys et al., 2017), each had the potential to influence the responses of the other (O'Rourke & Germino, 2000). Therefore, parent realities of decision-making co-existed. Separating the dialogue risked losing meaning and the complexity involved (Smith, 2017) in decision-making.

Data were analysed by HP. An inductive approach was initially taken using open coding across the dataset of parents who had made one treatment decision. At this timepoint, data were analysed with relevance to research questions one and three. After initial coding, a sample of data were worked on by a second coder (FG) for inter-rater reliability, thereby improving coding validity. From decision two onwards, data were analysed both inductively and deductively and incorporated the second research question to explore whether decision-making changed over time.

Deductive coding was informed by coding and concepts from the previous decision timepoints which provided an interpretative lens to make meaning of the data (Braun & Clarke, 2022). Inductive coding explored the differences in how parents made treatment decisions over time. As new codes and concepts developed inductively through the

different decision points, data from previous decision points were reviewed. Preliminary analytical insights were shared with FG, MM and ASD at each stage of the analysis for in-depth discussion to support analysis development and exploration of relevant theory. A reflexive diary provided an audit trail of HP's approach to data analysis, documenting conscious decisions made towards the data and subjectivity. A reflexive diary was important as HP worked in clinical practice with this parent population. The diary documented assumptions and knowledge of the phenomenon allowing for subjectivity to be brought to the fore which could influence how the data were analysed. For example, not all parents wanted to be involved decision-making which did not align with the knowledge of this phenomenon in clinical practice. Data analysis required critical in-depth engagement to reduce the potential for preconceived and underdeveloped themes which did not acknowledge the multiple realities of decision-making in this context. Two parents from the PPI group supported data analysis by reviewing codes and data for sense-making and given the sensitivity of the research subject, supported identification of theme names.

#### 4. Findings

##### 4.1. Participants

A total of 18 parents participated across 15 interviews (Table 1). Interviews ranged between 30 and 78 min. Parents made between one and six treatment decisions with a combined total of 47 treatment decisions. Three parents (two mothers and one father) were interviewed twice at different treatment decision timepoints. Both parents were interviewed together in six of the interviews at their request. Fourteen interviews were conducted virtually and one via telephone based on parent preference. Sixteen parents were married or in a domestic partnership and two parents declined to answer.

Twelve mothers and six fathers participated who collectively represented the experiences of 13 children, nine children with relapsed disease and four children with refractory disease (Table 2). The findings include illustrative quotes from mothers and fathers from dyad and individual parent interviews.

##### 4.2. Themes

Findings are organised by themes as per Braun and Clarke's Reflexive TA (Braun & Clarke, 2013) and have been represented in an infographic: [https://youtu.be/kf1Tdhbfnqo?si=R1CvNe\\_CopvXO2NQ](https://youtu.be/kf1Tdhbfnqo?si=R1CvNe_CopvXO2NQ) (Fig. 1) Through data interpretation and engagement, four themes were generated relating to how parents made treatment decisions, how decision-making changed over time, and the role of emotion in

**Table 1**  
Participant characteristics.

Characteristics	Participants (Total = 18)
<b>Parents:</b>	
Mothers	12 (67%)
Fathers	6 (33%)
<b>Age range:</b>	
22–34	6 (33%)
35–44	9 (50%)
45–54	2 (11%)
55–65	1 (6%)
<b>Ethnicity:</b>	
British	13 (72%)
European	5 (28%)
<b>Education:</b>	
Secondary	2 (11%)
College	9 (50%)
University	7 (39%)
<b>Employed prior to child's diagnosis</b>	17 (94%)
<b>Employed at time of interview</b>	5 (28%)

**Table 2**  
Child characteristics and treatment decisions taken.

Family	Participants	Number of Treatment decisions at time of interview	Relapsed or refractory disease	Child sex	Child age range
1	Mother 001 Father 002	1	Refractory	Female	1–5 years
2	Mother 003	1	Relapsed	Male	6–10 years
3	Mother 004 <sup>a</sup>	5	Relapsed	Female	6–10 years
4	Mother 005 <sup>a</sup>	3	Relapsed	Female	6–10 years
5	Father 006 <sup>a</sup> Mother 007	4 1	Relapsed	Female	1–5 years
6	Mother 008 Father 009	2	Refractory	Male	6–10 years
7	Mother 010	1	Relapsed	Male	1–5 years
8	Mother 011	2	Relapsed	Female	1–5 years
9	Father 012 Mother 013	1	Refractory	Male	1–5 years
10	Mother 014 Father 015	1	Relapsed	Male	1–5 years
11	Mother 016	1	Relapsed	Female	6–10 years
12	Mother 017	3	Relapsed	Male	1–5 years
13	Father 018	3	Refractory	Female	1–5 years

<sup>a</sup> Indicates interviewed twice.

decision-making.

- 1) Time as a structure within decision-making (overarching theme)
- 2) Uncertainty and its relationship with treatment risks, side effects and outcomes (underpinning theme)
- 3) Parent oscillation of their cognitive and emotional adjustment
- 4) Parent responsibility and involvement in decision-making

#### 5. Time as a structure within decision-making

Time was the overarching theme which informed, influenced, and enabled parent decision-making either directly or indirectly across themes. Time related to prolonging their child's life, focusing on the present moment, or to plan for future treatments. Time enabled parents to adjust cognitively and emotionally in order to cope and manage their situation to make decisions. Finding information and researching treatment options required time and in doing so increased parent involvement and responsibility within decision-making. Parents were faced with navigating subjective time, which was socially constructed and flexible and in which they had agency and objective time which was regulated by structural restraints (e.g., clock time) with limited space for human agency. Decision-making was made with these temporal structures which was revisited and negotiated as parents made repeated treatment decisions.

##### 5.1. Time: prolonging child's life and time as "good" time

Parents grappled with time, and through decisions wanted to 'buy time' in the hope their child would survive, or at the very least, prolong their child's life to increase the time they had with their child. However, grappling with time led to potential trade-offs with their child's quality of life as treatment options decreased, and experimental therapies were considered. Conflict between treatment which might produce unwanted side effects, or a deterioration in the disease, due to administering treatment and maintaining their child's quality of life resulted in time



# EXPLORING PARENT TREATMENT DECISION-MAKING IN RELAPSED & REFRACTORY NEUROBLASTOMA



Fig. 1. Infographic of the findings from parent interviews. An infographic detailing the themes and sub-themes generated from the analysis of parent interviews.

potentially becoming compromised. This conflict resulted in time being considered either optimistically with a good quality of life or viewed negatively as a result of treatment tolerance and side effects which deteriorated the quality of time with their child.

“We probably will go ahead with it [treatment] but it’s difficult you think, how much good time have they got? It feels like a gamble, a risk; you’re gambling some time where [child] not going to feel great. You have to spend that time really carefully.” Mother 017, TD03, Relapsed

## 5.2. Time: focusing on the present as well as the future

After the first treatment decision was made, some parents focused on the present, not contemplating what may lie ahead for their child, whilst others explored future treatment options. Time enabled parents to process their situation and in doing so some parents developed contingency plans in the event treatment failed. Subjective characteristics such as parent beliefs, and values influenced the approach parents took to their decision-making.

“I am looking into things in the background and trying to inform myself about what else is out there not just in the UK but elsewhere. So, if things aren’t going to plan, we’ve got a plan B, plan C and plan D.” Mother 003, TD01, Relapsed

How parents contextualised time, and what time could provide, was specific to the individual and important for different reasons. This included lost time if treatment did not work, time for treatments to have an effect, time lost with members of their social networks if away from home, time for new treatments to become available and quality time with their child.

“When you are in that relapse, you’re trying to buy time, even if it’s just to keep it stable, for that next thing to open and try.” Father 006, TD03, Relapsed

## 5.3. Time: finding information and researching options

Time had objective meaning for parents in the form of requiring practical time to undertake tasks such as gathering information. Parents early in their decision-making needed time to search for information specific to their child’s disease situation, gather and explore information on treatment options and speak with other parents of children with the same disease. Having this information was essential for informing and developing plans for subsequent treatments should the current ones not work. Later in decision-making, through experience of making repeated decisions, parents accessed search engines and bibliographic databases such as Google Scholar and PubMed to undertake their own research. This had the potential to influence their thinking towards treatment options and, combined with their lived experiences, informed their decision-making.

“Looking through hundreds of PubMed papers [ . . . ] the whole day from the moment I wake up it is devoted to getting [child] better.” Father 018, TD03, Refractory

## 6. Uncertainty and its relationship with treatment risks, side effects and outcomes

Due to the poor-prognosis associated with the disease and lack of standard treatment uncertainty was consistently present for parents, underpinning their decision-making. Uncertainty influenced decisions parents made, being present throughout decision-making and appeared in parental narratives relating to a range of concepts including: their child’s prognosis, adjustment of being involved in decision-making, conflict between quality of life, treatment options and outcomes, and effect on parent cognitive and emotional adjustment.

### 6.1. Prognostic uncertainty

Uncertainty around their child’s prognosis and likely outcomes was explicitly and implicitly acknowledged. Not knowing which treatment may have a positive outcome caused uncertainty with the need for parents to justify decisions to feel they had made the right decision.

*“Something the doctor said ‘you’re going to live with the decision for the rest of your life’ so that made me really think [ .... ] because any one of those could be right or wrong. I wanted to give it a chance, even though it might put [child] through a lot.”* Mother 010, TD01, Relapsed

Parents recognised decision-making was complex and their willingness to accept treatment risks appeared dependent on their level of knowledge, understanding and experience of the disease, along with perception of risks versus benefits of treatment. In conjunction with parental lived experiences, parent knowledge and understanding of the disease increased with the amount of time they were embedded within the neuroblastoma setting which informed their decision-making. Knowledge and understanding were limited in parents who had not been exposed to the neuroblastoma setting for as long, potentially impacting their abilities to make informed decisions.

*“None of the treatments make sense to us [ .... ] even when it’s explained. We just want to see the end result. We couldn’t say we’ve made those decisions based on the evidence or knowledge we have.”* Father 002, TD01, Refractory

*“You kind of choose [treatment] that would be the most sensitive [ .... ] [child] got poor kidney function so that was taken into consideration, and the sickness.”* Mother 014, TD01, Relapsed

## 6.2. Uncertainty of involvement in decision-making

There were instances where parents were given treatment options without discussion with their child’s medical consultant on the role they wanted, if any, in making decisions. When this took place without consultation, some parents were left feeling isolated and uncertain with a lack of clarity on treatment options available and the associated risks and benefits.

*“It shouldn’t be left to parents [ .... ] professional opinions should be given. If the parent decided not to take it, that’s their wish.”* Mother 010, TD01, Relapsed

*“We put it to them [consultant] that this is not a decision we can make. We’re not the experts, we’re not consultants.”* Father 009, TD02, Refractory

## 6.3. Uncertainty and conflict between quality of life, treatment options and outcomes

In first treatment decisions, parents focused on maintaining their child’s quality of life, opting for treatments which were evidence based.

*“For us not putting [child] through really intense treatment from the get-go [ .... ] if something is working and it’s providing quality of life, we’re more than happy to continue.”* Mother 016, TD01, Relapsed

However, as treatment strategies failed and experimental therapies were considered, the centrality of quality of life was more often balanced with considerations such as continuing with treatment even if side effects and outcomes were unknown. Parents cognitively appraised the risks and benefits of treatments against their child’s quality of life and the need to continue with treatment.

*“The quality of life is first and foremost, but you have to balance that up [ .... ] does that mean you don’t try for something?”* Mother 005, TD03, Relapsed

As treatment choices diminished, parents were more willing to consider experimental early-phase clinical trials which had been dismissed previously due to parents’ uncertainty because of limited evidence. Throughout decision-making, parents rationalised their decisions based on information gathered and speaking with other parents in conjunction with their experience and knowledge which increased over

time.

*“When we chose [treatment] it was the only one I was considering. I wasn’t really considering what we’re doing now, and I didn’t consider it because I thought it’s only been tested in the lab [ .... ] as a clinical trial [child] would more or less be replacing a lab rat and that for me was no, no, no. Now it’s like these are the only options you have left and I’m like yes, let’s just do anything.”* Mother 011, TD02, Relapsed

Over time, when treatment limitations were recognised and parents acknowledged their child may not survive, the focus on quality of life increased. The time at which this was acknowledged differed between parents, based on their disease experience, but was typically seen in parents that had made three or more treatment decisions. However, parents did not discontinue treatment but refocused their decision-making opting for treatments which could enable more time with their child whilst accepting that cure was unlikely.

*“I would rather try something that’s not going to make [child] unwell if we haven’t done it before and there’s a likelihood it could work, but I’m not naïve in any shape of form [ .... ] If they [professionals] thought there was no hope they wouldn’t be offering us treatment, so we fight on. That’s our choice because dying would be a lot worse.”* Mother 004, TD05, Relapsed

Uncertainty and the effect on parents’ cognitive and emotional adjustment.

Uncertainty affected parents’ cognitive and emotional adjustment to their situation. Not knowing how their child would tolerate and respond to treatment and a lack of clarity regarding ongoing treatment plans, led to parents experiencing emotional turmoil.

*“It is a lot to take on emotionally, there’s multiple sides to it. It’s not just you can sit down and make a rational decision.”* Father 006, TD03, Relapsed

## 7. Parent oscillation of their cognitive and emotional adjustment

Parent cognitive and emotional adjustment was fuelled by uncertainty as parents struggled to comprehend how their child would tolerate and respond to treatment. Time enabled parents to adjust to their situation cognitively and emotionally. This adjustment fluctuated throughout decision-making relevant to the current situation parents faced, regardless of whether this related to managing treatment side effects, researching treatment options, seeing their child deteriorate or making subsequent treatment decisions. Parent involvement in decision-making was imperative to ensure they did everything possible to prevent their child from dying. This impacted their cognitive and emotional processing as the burden on decision-making increased over time. Parent’s cognition and emotions were affected by their child’s diagnosis, response to treatments and availability of treatments. The need to make decisions, their child’s quality of life, decisional conflict, anticipated future feelings and support networks were concepts which influenced parental cognition and emotions.

### 7.1. Adjustment to the initial diagnosis and the need to make decisions

Parents’ cognitive capacity was compromised at the first treatment decision due to overwhelming emotions upon being told their child had relapsed or refractory disease. During this time parents faced an uncertain reality that their child could die and having to live with the decisions they made.

*“When you’re told that your child is relapsing, it’s quite hard to hear. I think it needs to sink in first before you start drawing lines in the sand.”* Mother 017, TD03, Relapsed

As parents processed the initial shock of their child’s diagnosis, they

suppressed their emotions in order to prioritise making the best treatment decisions for their child. During interviews, when describing the difficult and emotional aspects to decision-making, some parents switched from speaking in the first-person tense to the third person. This may have been employed as a coping mechanism to temporarily detach from their own reality to recount their experiences of decision-making.

*“We were both in a position where we didn’t want to ask any questions that gave us answers that we didn’t want to hear. I got the distinct impression that [consultant] wanted to get [child] onto treatment as soon as possible and I didn’t really want to know why so I decided to go with that.”* Mother 003, TD01, Relapsed

## 7.2. Adjustment to treatment responses, availability of treatments and impact on quality of life

Parents experienced a rollercoaster of cognitive and emotional adjustments, oscillating between these two states relevant to the decisions which needed to be made, such as having statistical evidence of treatment effectiveness and the impact on treatment with their child’s quality of life. Parents spent considerable time contemplating decisions made or needing to be made which impacted their cognitive processing and emotional adjustment.

*“What are going to be the implications of treatment? There’s the kidney problem, well if both kidneys are damaged and [child] hasn’t got lots of life left, is that going to result in spending lots of time in hospital for a secondary problem that was caused by treatment?”* Mother 017, TD03, Relapsed

As treatment strategies failed, treatment decisions became increasingly difficult with increased burden of making the best decision. Parents were continuously adjusting at each treatment decision point to reframe their situation in order to continue making decisions.

*“We’d rather follow something that’s already been used rather than something brand new, initially, if that’s what we’ve got available [ ... ].”* Father 006, TD03, Relapsed

## 7.3. Adjustment in anticipation of future feelings

Parents anticipated their future feelings on the outcome of their decisions suggesting parents were fearful of having decisional regret, an emotional reaction, ‘second guessing’ their decision-making which exacerbated parent uncertainty.

*“You’re factoring in the data and everything and deciding whether it’s any good or not. You’ve then got to factor in how you feel, years down the line when you don’t go and do it.”* Mother 003, TD01, Relapsed

Parent emotion was high in response to decisional conflict between treatment and their child’s quality of life. Parents justified their reasons for continuing with treatment because not having treatment relinquished hope of their child’s survival. The continued cognitive appraisal of treatments resulted in parents becoming cognitively exhausted from the emotional burden of making repeated decisions.

*“It’s the last choice really to either do this because I feel like if I had gone for the first or second option where it’s just let [child] go, I wouldn’t regretted not trying this. Then this treatment, I feel like if that didn’t work, I would have regretted leaving [child] in that room for so long.”* Mother 011, TD02, Relapsed

## 7.4. Adjustment to the hindrance and help of support networks

During early treatment decision-making there was often a conscious decision to reduce contact with family, friends, and extended support networks. Parents reported needing to distance themselves to avoid

having to manage the emotions and anxieties of others.

*“I don’t find it easy to talk to them [family] about it. It’s not a conversation we need to be having because it tends to end up with them passing back their fear and anxiety and I can’t deal with that.”* Mother 003, TD01, Relapsed

Over time, when parents had absorbed the diagnosis, they often came to view their support networks differently and recognised the role they could play in assisting and facilitating their decision-making. Family and friends were important resources of practical and emotional support, in particular enabling parents to access treatment for their child away from home when there were siblings and wider family to consider.

*“It was quite a big decision because we’ve had to split the family up. [child] is staying at home and we have to weigh-up the cost-benefit from a family point of view. We are fortunate we’ve got family, friends at home who can support [child] and our pets, there is some consideration given to the pets!”* Father 006, TD04, Relapsed

## 8. Parent responsibility and involvement in decision-making

A lack of standard treatment and uncertainty about their child’s overall outcome saw parents recognising they had a responsibility to their child to be involved in decision-making. As repeated decisions were made, parents engaged with multiple people such as other parents, professionals, and technologies such as the internet. Parent responsibility was characterised by making decisions which maximised their child’s quality of life, sharing parental roles between mothers and fathers and moving away from paternalistic decision-making to being involved. Involvement saw parents discuss treatment with their child, seek support and information from the neuroblastoma parent community and professionals, entering into a collaborative decision-making partnership with their child’s medical consultant. Over time, parents advocated for their child and subsequently became independent in decision-making as experts by experience.

### 8.1. Responsibility to maximise their child’s quality of life

Parental responsibility was to make the best treatment decisions for their child to maximise their quality of life and opt for treatments which minimised suffering and harm. However, quality of life became conflicted as treatment options decreased and experimental therapies were considered.

*“I will always do what is in [child] best interests no matter what. I would never, ever let [child] suffer. All I do is try and find out as much information as I can, and then I have to make a decision and hope it’s the right one.”* Mother 004, TD06, Relapsed

### 8.2. Discussing treatment with their child but maintaining responsibility for decisions made

As children grew older, some parents discussed treatment plans with their child and considered their opinions, but they were not involved in the decision-making process. Discussion with their child acknowledged their cognitive development since initial diagnosis and the need to provide age-appropriate treatment information. This had the potential to facilitate their child’s engagement with treatment whilst providing them with some control and perceived involvement in decision-making. However, ownership of decision-making remained with parents.

*“This time round [child] was really devastated to get the diagnosis. [child] had quite a few more questions, but I think [child] is still young enough that [child] not really involved in making the decisions.”* Mother 003, TD01, Relapsed

### 8.3. Responsibilities between parents

By taking on different responsibilities regarding decision-making, mothers and fathers provided sources of support for each other. This included information gathering of treatment options, being the child's main carer or a combination of these depending on family dynamics.

*"I feel I'm more of the knowledge, she [mother] always asks 'what can we do to support [child]?' [ .... ] the knowledge that I'm try to get is other information to support the decisions we make."* Father 012, TD01, Refractory *"What I am after is, how can I support [child] because I'm always with [child] so what will be the affect, how can I support [child]? [father] and I work as a team."* Mother 013, TD01, Refractory

### 8.4. Involvement in the neuroblastoma parent community to inform decision-making

The wider neuroblastoma parent community provided support through sharing knowledge, information, and emotional support. Parents saw their responsibility as being knowledgeable and informed, gathering information from other parents, and not being dependent on information offered by healthcare professionals. Parents relied on support and knowledge from other parents early in their decision-making.

*"Sometimes it's not just about reading, but when you have people going through these feelings, they understand more."* Mother 016, TD01, Relapsed

However, the weighting of this support and information changed for some parents as they gained their own knowledge and experience through repeated decision-making. Parents began to recognise the limitations of engaging with other parents, filtering information due to disease complexity, the individual nature of their child's disease and personal biases towards certain treatments.

*"We are on groups for parents [ .... ] one thing we always keep in mind because we've been around and we've experienced our own is, we're careful to read things – not read too much into people's emotions. Everyone has a different understanding of the disease [ .... ] You have to try and be objective."* Father 006, TD04, Relapsed

### 8.5. Involvement in decision-making: the role of professionals and self-advocacy

Parents wanted support and guidance from healthcare professionals on treatment options to make informed decisions and acknowledgement of the difficult and emotional situation they faced. Parents described how they perceived a lack of empathy from healthcare professionals, impacting on an open and honest dialogue which could result in disengagement with healthcare professionals.

*"Sometimes from the professional level you have to come down to being a human being."* Mother 010, TD01, Relapsed

For some parents gathering or interpreting information was a challenge which influenced their understanding of treatment options and ability to make informed decisions. Interpretation of information may have been impacted by parent emotions, being able to understand information but not necessarily able to relate this in the context of their own child. Parents of children with relapsed disease had more experience and understanding of the disease relevant to how long their child had been receiving treatment and time since diagnosis.

*"We're more informed. We have the benefit of years of being in this community. It's evolved [ .... ] its experience. We're older [ .... ] these things, maybe not consciously when you're making the decision about treatment but they are there. They're subconsciously there."* Father 006, TD04, Relapsed

At the first treatment decision, parents of children with refractory disease would have been diagnosed three to four months previously, thereby limiting their knowledge and experience of neuroblastoma. This appeared to impact their understanding and interpretation of information and required guidance and support from professionals.

*"We're relying on the doctors to give us the answers because we don't understand [ .... ] there is a stage where they ask you to make the decision and we can't make that decision [ .... ] 'we're not experts, we're not consultants, we need you to help us here'."* Father 009, TD02, Refractory

For all parents the first treatment decisions were led by professionals due to parents' reduced cognitive and emotional capacity.

*"There were a couple of options. They didn't even mention that other one, they went for the [treatment] and said that it worked okay so they went with that."* Mother 016, TD01, Relapsed

Following the outcome of the first treatment decision where treatment had failed, all parents started to gather information on treatment options to support their decision-making. Information gathered was used to inform subsequent treatment discussions with professionals, creating a collaborative partnership in decision-making between parents and professionals.

*"I did ask [consultant] a lot of questions [ .... ] I did ask about the various trials that I had heard of and where they fitted into things. [consultant] said if I come up with anything that I want to know more about, that [consultant] will either tell me about it or look into it if [consultant] doesn't know what it is."* Mother 003, TD01, Relapsed

Over time the collaborative partnership between parents and professionals changed. Parent self-advocacy increased with experience and knowledge through repeated decision-making, and this gained momentum when there were no suitable treatment options in the UK. Parents became independent from their child's medical consultant in decision-making. Their perception was that consultants became disengaged from the decision-making process, possibly due to the lack of treatment availability in the UK and statistical evidence to support clinical trials in other countries.

*"I found [consultant] is very 'once they've relapsed, that's it'. [consultant] may have given up on [child] but I won't [ .... ] it's like they're numbers but that's my life. It's my heart and soul walking around."* Mother 004, TD05, Relapsed

Parents considered and pursued treatments that were not offered by their child's medical consultant. They contacted professionals directly to explore and facilitate their understanding of available treatment options.

*"I suppose if we're being really honest there is a definite feeling that remission will be off the cards and you're looking more at the palliative route. Whereas you're talking to other consultants [internationally] you hear about children who are six, seven relapses and they're still going."* Mother 005, TD03, Released

Having made multiple treatment decisions, parents became experts by experience. Ultimately, parents needed to assure themselves that they had done everything possible to save their child's life; this was critical to reduce the potential for regretting decisions made in the future.

## 9. Discussion

The focus of this research was to identify, describe and explain how parents make repeated treatment decisions and explore the role of emotion in decision-making when their child had relapsed or refractory neuroblastoma. Findings comprise four themes: 1) time as a structure within decision-making; 2) uncertainty and its relationship with treatment risks, side effects and outcomes; 3) parent oscillation of their



cognitive and emotional adjustment; 4) parent responsibility and involvement in decision-making. These themes informed, influenced, and enabled parents in their decision-making processes. Children diagnosed with cancer have additional care needs (Hinds et al., 2009). The parental role is extended by not only caring for their child with cancer, but also learning about the disease and its treatment (Eiser, 2004). This is further complicated when there is no standard treatment protocol requiring parents to become involved in making treatment decisions for their child often in situations where the prognosis is poor. Supporting parents in making decisions which are in their child's best interests whilst also providing the day-to-day care their child requires is essential. Concepts of parental decision-making such as uncertainty (Hinds et al., 1996b; Mullins et al., 2016), hope (Kamihara et al., 2015; Mack et al., 2007; Salmon et al., 2012) and coping (Patterson et al., 2003; Verberne et al., 2019) are well described in the literature. Involvement in decision-making can be emotionally challenging (Polakova et al., 2024) however the role of emotion in how it can influence and enable parent decision-making has not been fully explored. In this study, parents oscillated between cognitive and emotional adjustment throughout the decision-making process in order to manage their emotions related to their child's disease and responses to treatment whilst cognitively engaging in making the best decisions for their child. This was essential to manage the burden and conflict between treatment, quality of life, and the uncertainty of not knowing how their child would tolerate and respond to treatment and survive. The dual-processing theory (Stroebe & Schut, 1999) acknowledges oscillation between loss and restoration orientations. Although dual-processing theory is specific to bereavement and has not been explored in the context of parents or carers, it acknowledges the family aspect of bereavement (Stroebe & Schut, 2015) and different perceptions of bereavement, not necessarily related to the death of a person. Parents in this study grieved the loss of what could have been in relation to their child's quality of life, missed opportunities of a 'normal' childhood and the loss of a positive outcome at each treatment decision point, and the ongoing turmoil of an uncertain future. Through repeated decision-making, parents experienced cognitive exhaustion, and possibly cognitive decline (Elwyn et al., 2022; Lahey & Elwyn, 2020) inhibiting their ability to make informed decisions which were in the best interests of their child.

Decisional conflict in parent treatment decision-making within childhood cancer is widely recognised (Boland et al., 2017; Lichtenthal et al., 2020; Mack et al., 2019; Robertson et al., 2018; Ye et al., 2021). Conflict is defined as an individual's perception of uncertainty regarding which option to choose when all options have potential for risk, regret, or loss (Carpenito and Carpenito-Moyet, 2000). Parents were internally conflicted when considering experimental therapies where treatment side effects and outcomes were unknown. The subjective nature of time influenced parents' perception of uncertainty in the decisions they made resulting in conflict between their child's quality of life and pursuing treatment. This conflict increased over time as treatment options decreased. Parents spoke of the potential for regret in the decisions they made.

Concepts which are less well described in the literature relate to repeated treatment decision-making and how time influences, informs and enables parents in making decisions. In particular, how parent responsibility and involvement in decision-making changes over time and how emotion influences and impacts their decision-making.

Decision-making evolved over multiple encounters with a range of people and technologies as parents made repeated treatment decisions, characterised as distributed decision-making (Rapley, 2008). Distributed decision-making acknowledges decision-making is an ongoing event which does not happen in isolation and evolves through encounters with multiple agents<sup>60</sup>. These encounters included their child's healthcare team, utilising the neuroblastoma parent community, and accessing information through the internet and parent social media platforms, all of which informed and influenced their decision-making. The role of the internet in distributed decision-making supported

parents in initially sense-checking their decisions acting as a decision crutch and subsequently played a stimulating role being used to inform and influence their decision-making (Bussey & Sillence, 2019). Distributed decision-making reinforces the ontological relativist approach taken within this study, whereby parents created their reality through their interactions with others and knowledge gained which resulted in multiple realities existing of parent decision-making experiences.

Time was the central organising concept of how parents structured and organised their decision-making. The temporality of decision-making is not isolated to a discrete cognitive moment in time but built over time (Goodwin, 2014) shaped by many encounters as seen through distributed decision-making (Rapley, 2008). Temporal structures are processes used to characterise the experience of time developed through ongoing engagement with the world (Orlikowski & Yates, 2002). This provides a practice-based perspective of subjective time which is socially constructed, contextual and flexible (Glucksmann, 1998) and objective time which is quantifiable, linear, and shaped by structural conditions (Jaques, 1982). Parents' individual preferences in making decisions were characterised by subjective time which enabled a mechanism to make decisions which could prolong their child's life, try to facilitate a good quality of life, and exercise their agency.

Time was also practical, described in the literature as objective time (Starkey et al., 1989) which is independent of human action and compromised parental agency in decision-making. Parents required time to gather information and research treatment options which informed and influenced their decision-making, and involvement in the decision-making process. The time required to gather information and research options can be characterised as 'illness work' (Corbin & Strauss, 1985) where parents were considering treatment options and what is available which informed their decision-making. Illness work related to the diagnosis and management including symptoms of the illness alongside 'daily work' of chores and tasks required to manage a household, which until now has been a phenomenon investigated in the context of chronically ill adults and their spouses (Corbin & Strauss, 1985). Parent illness work could also be related to the burden of treatment theory (May et al., 2014) whereby patients, in this case parents balance the workload associated with managing their child's illness and treatment with their individual resources or capacity which are internal or external to enable them to perform the work of treatment. Time was required for both illness work and daily work to care for a sick child often resulting in parents ceasing employment or reducing paid work hours which had a financial impact on the family (Lewandowska, 2022).

Parent responsibility and involvement in decision-making changed over time. Parent's reduced cognitive capacity to absorb and retain information resulted in their child's medical consultant making the first treatment decision, viewed as paternalistic decision-making (Charles et al., 1997). This limited cognitive capacity mirrors the concept 'regulating shock' (Hinds et al., 1996b). With time, parents processed their emotions and adjusted cognitively which enabled them to become involved in making treatment decisions for their child. This involvement often created a collaborative partnership with their child's medical consultant fostering shared decision-making (Klick & Hauer, 2010) for the majority of parents. Parents wanted all treatment options to be presented to them enabling transparency in a collaborative approach to decision-making. Parents experienced a lack of clarity when treatment decisions were not discussed which had the potential for relationships with medical consultants to breakdown.

Decision-making is suggested to be intrinsically collaborative, distributed over time with no place for autonomy (Goodwin, 2014). However, in this context parents became independent in their decision-making, advocating for clinical trials with limited evidence, unpublished data or accessing treatments outside of the NHS. Pursuing or opting for treatments that their child's medical consultant did not agree with often led to the perception that their medical consultant disengaged from the decision-making process. Through repeated

decision-making, parents became experts by experience resulting in this partnership becoming compromised as parents became independent from their child’s medical consultant, supporting the evolution of decision-making over time.

Rational decision-making can be compromised by emotion and fear impacting capacity to make informed decisions (Hillen et al., 2017; Lahey & Elwyn, 2020). Some parents anticipated their future feelings related to decisions they were making and the impact this had on their decision-making processes. This contradicts previous research which found adults inadequately consider their future preferences and emotions on option outcomes (Wilson et al., 2003). Within this context, where parents were making decisions on behalf of their child, with a poor-prognosis cancer and no standard treatment, uncertainty and the potential for decisional regret which affected parent emotions was increased. The emotion-imbued choice model (Lerner et al., 2015) is the first to combine rational, descriptive/psychological and emotion in decision-making suggesting these are intrinsically linked. This model places emphasis on the expected outcomes from a decision including emotions and how they influence the decision-maker’s current emotions and decision-making processes. Emotions can be overlooked in decision-making and have been shown to be more influential than fact-based information within cancer care (Zikmund-Fisher et al., 2010). This highlights the need for an approach to decision-making which acknowledges and incorporates rational, descriptive, and emotional processes within decision-making particularly in healthcare and in contexts where there are poor outcomes associated with the disease, no standard treatment, or clear endpoints.

9.1. Conceptual framework

A conceptual framework (Fig. 2) shows how themes were inter-relational through uni and bi-directional arrows of how these relationships informed (green), influenced (blue), and enabled (orange) parents in making treatment decisions. Parent decision-making was informed through knowledge and information acquired. How parents developed their thoughts or behaviours within and towards decision-making was influenced by specific aspects. An enabler resulted in something becoming possible for parents which supported them in making treatment decisions for their child.

Time enabled parents to continually adjust to their situation which saw them become involved in making treatment decisions. This involvement influenced their cognitive and emotional adjustment, changing their participation in decision-making over time from paternalistic to independent. Over time, parents acknowledged the uncertain outcomes for their child which influenced them to be involved in decision-making. Involvement and responsibility in making decisions influenced parent uncertainty in whether they were making the right decisions for their child. Conflict between treatment options and the impact on their child’s quality of life increased over time resulting in uncertainty being continually influenced by the need to make repeated treatment decisions. There were concepts within themes which changed over time as parents made repeated treatment decisions. Parents engaged with temporal structuring to characterise their experience of time which changed how concepts informed, influenced, and enabled their decision-making processes.

This framework provides a baseline for researchers to empirically test in other contexts of treatment decision-making where parents are making repeated treatment decisions. This could be within the context of poor-prognosis childhood cancer or other paediatric life-threatening or life-limiting conditions.

9.2. Recommendations for clinical practice

Translations of the study findings into clinical practice can inform how healthcare professionals support parents making repeated complex treatment decisions. Mechanisms are required to facilitate discussions between healthcare professionals and parents to explore their emotions and how these influence their decision-making. Extending appointment times and including a member of the healthcare team that parents have built a trusting relationship with may facilitate these discussions. Healthcare professionals should regularly revisit the role parents want in decision-making to support collaborative working in the best interests of the child. Healthcare professionals need to provide guidance and support to parent on the use of social media in their decision-making. In doing so this may extend conversations providing more transparency of what informs and influences parents in their decision-making processes to facilitate discussions on treatment options.

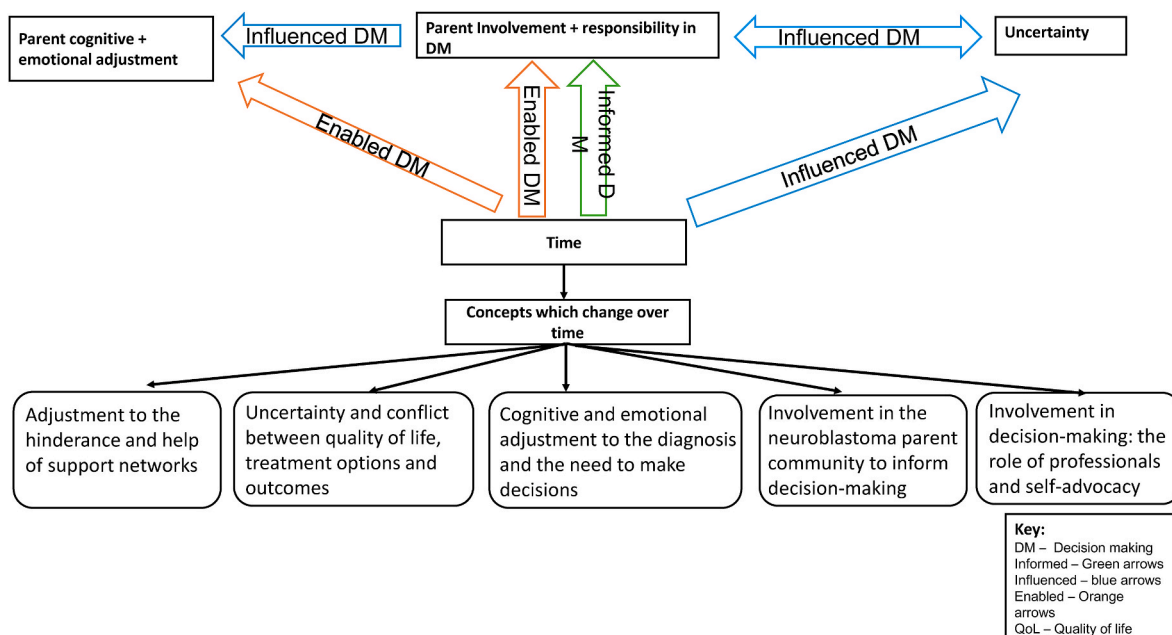


Fig. 2. Conceptual Framework

A conceptual framework developed to show the relationships between themes and specifically the components of decision-making which changed over time.

### 9.3. Recommendations for future research

Future research could explore the perspectives of healthcare professionals supporting parents in their treatment decision-making such as medical consultants, clinical nurse specialists and psychologists. Having knowledge of both perspectives (parents and healthcare professionals) could strengthen shared decision-making and continued partnership working through repeated decision-making making recommendations for clinical practice. Transferability of the study findings beyond neuroblastoma to other poor-prognosis childhood cancers or life-limiting/life-threatening illnesses could be researched using the conceptual framework developed in this study. This would provide a wider perspective of parent treatment decision-making in other paediatric illnesses where parents are making repeated treatment decisions for their child. The findings from this study could be translated into practical advice and information through an intervention such as decision support tools to support and empower parents in the decision-making process.

### 10. Limitations

Findings are limited to the experiences of parents who participated in this study. The willingness of parents to participate might have been an indicator that those recruited for this study are already more active and involved in treatment decision-making for their child. The parent sample did not include non-English speaking parents and could have missed the voice of parents who are seldom heard and may have different decision-making experiences. The majority of parents who participated had children with relapsed disease which is expected given the higher statistical percentage of relapsed compared with refractory disease. Although some differences in decision-making were identified, inclusion of more parents of refractory disease may have highlighted additional needs for this parent population.

Children's cancer Primary Treatment Centres identified potential participants with the need to reapproach parents if they had made a subsequent treatment decision whilst the study was open. This approach reduced the number of parents who could have been reinterviewed to explore treatment decision-making over time. Interviews were time and context dependent acknowledging parents may have spoken differently dependent on influencing factors such as how their child was tolerating treatment at the time of the interview, personal circumstances such as relationships, financial concerns, and impact of treatment and coping on family dynamics. Interviewing the same parent on a different day or time may have provided a different narrative of their experiences.

### 11. Conclusion

This research addressed a gap in knowledge of how parents make repeated treatment decisions when their child has a poor-prognosis cancer and the role of emotion within these decisions. The emotional investment in such decisions is difficult to articulate but we have for the first time shown how this can inform and influence parent treatment decision-making when their child has a poor-prognosis cancer. This is important given the increase of treatment options, specifically precision medicine, and experimental therapies, requiring parents to make repeated treatment decisions over time. Our roles as healthcare professionals are to support and facilitate this complex decision-making, working with parents in partnership in order for them to make the best possible decision at the time with the knowledge and information available. These findings can facilitate healthcare professionals to understand the competing processes for parents when making decisions which may facilitate open and honest treatment discussions supporting a partnership approach in decision-making.

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### Ethical approval

Ethics approval was obtained from the University of Southampton (study sponsor) and NHS Health Research Authority London Bloomsbury Research Ethics Committee (19/LO/1715). Local approvals at the twelve Paediatric Oncology Primary Treatment Centres who acted as Participant Identification Centres was also obtained.

### Consent to participate and publish

Informed consent was audio-recorded from each participant prior to any research activities taking place. Consent included anonymised data being included in publications.

### CRediT authorship contribution statement

**Helen Pearson:** Writing – review & editing, Writing – original draft, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Faith Gibson:** Writing – review & editing, Supervision, Methodology. **Michelle Myall:** Writing – review & editing, Supervision, Conceptualization. **Anne-Sophie Darlington:** Writing – review & editing, Supervision.

### Declaration of competing interest

The authors have no interests to declare.

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## Abbreviations

UK: United Kingdom

NIHR: National Institute for Health and Care Research

Reflexive TA: Reflexive Thematic Analysis