University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

Parents’ Experience of Advance Care Planning:

A Grounded Theory of Re-constructing Meaning Through Advance Care Planning.

by

Helen Elizabeth Bennett

ORCID ID 0000-0002-6811-4229

Thesis for the Degree of Doctor of Philosophy

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Abstract

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Children with life-limiting and life-threatening conditions are living longer due to medical advances and increasing options for health care intervention. This makes discussions about choices of care more complicated and engagement in the process of advance care planning ever more complex. A scoping review revealed that current understanding of parents’ experience of advance care planning is limited.

Through a constructivist grounded theory approach this study aimed to deepen our understanding of the contextual and relational complexities of advance care planning for parents of children with life-limiting or life-threatening conditions. Methods combined open ended, semi-structured interviews and examination of advance care plans. Thirteen parents were interviewed, nine who were parents of children receiving palliative care and four parents of children who had died. Transcripts of digitally recorded interviews and nine advance care plans were analysed through a constant comparative approach.

The study identified three conceptual components of realisation, reconciling multiple tensions and building confidence and asserting control, which revealed the experience of re-constructing meaning for parents as they engaged in the process of advance care planning. *Re-constructing meaning through advance care planning* enabled parents to re-adjust their thoughts, beliefs and expectations in response to ongoing changes in their child’s condition and a life anticipated without their child.

The study has generated deeper understanding of parents’ experience of advance care planning and that advance care planning conversations are essential in supporting parents to live with uncertainty and the growing possibility of their child’s death. The study challenges health care professionals to reframe their approach to advance care planning; from being a record of decisions about do-not-resuscitate and treatment options, to a continuous, relational conversation about choices of care that enables parents to re-construct meaning. By fostering an approach that recognises the re-adjustments made to their values and beliefs, health care professionals can improve the experience for parents and help them to reflect on and manage the complexity and contradictions embedded within the advance care planning process for their child.

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Declaration of Authorship

Helen Elizabeth Bennett

Parents’ Experience of Advance Care Planning: A Grounded Theory of Meaning-Making Through Advance Care Planning.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Parents understanding of advance care panning in the context of children’s palliative care.

I confirm that:

1. This work was done wholly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed:	Helen Bennett
Date:	17th July 2020

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To my parents, and to Emily and Christopher who were quietly assured that I would reach the end…

And finally to Tim, who has been my anchor – always believing that this was possible.

‘To run with perseverance the race that is set before us…’ Hebrews 12:1

Definitions and Abbreviations

Definitions

Palliative care for **children** and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond.

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. (Life-limiting is used throughout the thesis to encompass all children and young people with either life-limiting of life-threatening conditions)

Life-threatening conditions are those for which curative treatment may be feasible but can fail.

Life-sustaining treatments are those that have the potential to prolong life.

Advance care planning is making decisions about the care a person would want to receive if they become unable to speak for themselves – or in the case of a child the decisions a parent would make for them. These are individual decisions about care, based on personal values, preferences, and discussions with loved ones

For the purposes of this study, the term **child** encompasses all **children and young people** recognising the spectrum of age and developmental capacity. The child is defined as less than seventeen, recognising the child’s ability to consent at an earlier age (Gillick 1995) but parental responsibility to age 18.

Gillick competence is a term originating in England and is used in medical law to decide whether a child (16 years or younger) is able to consent to his or her own medical treatment, without the need for parental permission or knowledge.

Informed consent is the principle that a person gives permission to another for care, treatment or research. A person making consent should be informed, free from coercion and understand the consequences of their decision.

Assent is a term used to express willingness to participate by persons who are by **definition** too young to give informed **consent** but who are old enough to understand the proposed care, treatment or research, its expected risks and possible benefits.

Abbreviations

Advance care plan(ning)	ACP
Advanced decision to refuse treatment	ADRT
Community Children’s Nursing Team	CCNT
Do not attempt cardio-pulmonary resuscitation	DNACPR
Emergency Health Care Plan	EHCP
End-of-Life	EOL
Health Care Professional	HCP
High Dependency Unit	HDU
Life-limiting condition	LLC
Life-sustaining treatment	LST
Life-threatening condition	LTC
Paediatric Intensive Care Unit	PICU
Participant information sheet	PIS
Patient and Public Involvement	PPI
Together for Short Lives	TFSL

Chapter 1 Introduction to the study

> *'Our lives are a mosaic of shattered tiles, of broken pieces fashioned together into something more priceless and more beautiful* Rachel Wright (2015)

1.1 Introduction

In the last five years advance care planning for children has evolved as a central part of end-of-life care. It has attracted increasing attention in policy and practice, with an emphasis on timely conversations and completion of end-of-life documents. Moreover, it is identified as a core standard in the guidelines for end-of-life care for infants, children and young people (NICE 2017). However, there is much debate about what constitutes advance care planning for children. To date, the field of children's palliative care has relied heavily on the growing evidence base from adult palliative care research to inform and develop practice, and the development of frameworks and tools informed by findings from service evaluations and descriptive accounts of clinical practice. Advance care planning as a distinct approach to care is often hidden within published debate about making decisions at the end-of-life. Therefore, advance care planning for children remains largely unexplored through research, and there is little understanding of the experience and perspective of parents. Specifically, there is limited knowledge about the process of advance care planning, of when and how to talk to parents about end-of-life care for their child. In addition, medical advances and increasing options for health care interventions influence parents' expectations of what might be possible, making choices and advance care planning more complicated.

These concerns about advance care planning presented above are also informed by my experience in practice. As a senior nurse working in children's palliative care for over 25 years I have encountered advance care planning on a number of levels. I have been involved in clinical practice supporting families through conversations about end-of-life and in bringing together the completion of a document about their goals for care and wishes at time of death. On a strategic level, I have contributed to the development of advance care planning tools and this has included training and education for nurses and doctors. My observations of practice suggest that health care professionals (HCPs), despite striving to offer high quality care at the end-of-life, lack confidence in talking to parents about end-of-life goals for their child. In my experience, the practice of advance care planning is oversimplified. Conversations with families tend to be about seeking answers to predetermined questions to inform the completion of paperwork. These questions have a medical focus that emphasise treatment options and decisions around resuscitation status, meaning issues of comfort, spirituality and emotional care are of secondary importance. Thus, the practice of advance care planning can take a prescriptive and formulaic approach, directed and led by health care professionals, rather than parents. It is further complicated as parents engage in multiple conversations about advance care planning throughout their child's illness and across different settings. These experiences left me with a sense that advance care planning is far more complex than reported. Moreover, we have little understanding of what really matters to parents. It was this very knowledge that I wished to discover and informed the central focus of the study.

To set the context of the study and to centre the reader on the experience of parents, the next section offers a reflective case study from my personal experience in practice. This is offered to help orientate the reader to the experience of advance care planning.

> *Jenny was thirteen with severe cerebral palsy. She experienced multiple complex symptoms with frequent admissions to hospital. She was cared for day and night by Sarah, her mum, and although they had occasional respite support at the local hospice, Sarah never left her side. Sarah had an advance care plan for Jenny that stated she was for full resuscitation and all interventions to maintain her life.*
>
> *Over the last two years, Jenny had presented with complicated symptoms of her gut that were distressing for both her and Sarah. The escalation of her symptoms had resulted in two admissions to intensive care. The latest hospital admission and Jenny's deteriorating health prompted conversations of whether Sarah would like to talk about the advance care plan and consider alternative options for her care. In the first instance, Sarah believed the decisions outlined in the plan for acute intervention were the right ones for Jenny and that she still had a good quality of life. Her hope was that Jenny would survive this crisis.*
>
> *Jenny slowly recovered but remained frail and not so responsive. She spent just two weeks at home before another crisis and a further admission to intensive care. The inability to resolve Jenny's symptoms and her significant distress led to further conversations about ongoing care. The paediatrician and nurse sat with Sarah to talk. The emphasis was not about making any decisions but talking through all the options, all the 'what ifs', and looking at different priorities and pathways of care. Sarah recognised that Jenny was deteriorating and realised that if her heart stopped she would not want anyone to resuscitate, but she did want other care and interventions. The conversation enabled Sarah to recognise that perhaps she no longer wanted to care for Jenny in the intensive care setting and she agreed for this*

> *to be written in the plan. She decided that on her next admission to hospital she would go the children's ward for treatment and not intensive care. Sarah realised that this meant if Jenny became critically unwell, they would no longer intubate or offer respiratory support.*
>
> *In the following days, Jenny became weaker and sleepier and was no longer absorbing any of her feed (via naso gastric tube). At this point Sarah instigated a conversation with the doctors and nurses caring for Jenny. She wanted to discuss the different options of care and questioned whether they would both be happier at the local children's hospice. This meant further deliberations about intervention and priorities of care, to which Sarah decided not to have any further acute treatment for Jenny. Sarah sat with the doctor and nurse again to talk through and review the advance care plan. This conversation opened up the space to talk about Jenny dying and all that Sarah hoped for in the last few days of her life. Sarah was able to share that she did not want Jenny to suffer any more or to be in pain. She wanted time to be with Jenny away from the busy and noisy hospital. Subsequent plans were made for them to transfer to the hospice. Sarah and Jenny spent a week at the hospice making memories and being together before she died.*

This reflective example of my practice emphasises the complexity involved in advance care planning. I have come to understand advance care planning is connected to deeper psychosocial processes beyond simply determining future medical decision-making. These processes determine the importance of understanding advance care planning not as a single event, but as a continual adaptation of parental choices influenced by an unknown psychosocial context and the changes in their child's condition and health care needs.

1.2 The development of advance care planning in policy and practice

Advance care planning was initially developed in the United States in response to increasing advances in technology and the need to clarify a patient's wishes at the end-of-life. Originally referred to as a 'living will', it was proposed in 1969 and subsequently embedded in United States legislation. It included both instructions for treatment and the appointment of a Power of Attorney. Advance care planning was first adopted in the UK in the early 1990's and embedded in early policy emphasising the importance of choice and preferences for end-of-life care (DH 2003). These guiding principles were outlined in key cancer guidance to support best practice in both adult (NICE 2004) and children's cancer care (NICE 2005) and the end-of-life strategy (DH 2008a). In the last twenty years, advance care planning has become increasingly influential in policy, integrated in initiatives such as the Gold Standards Framework and Preferred Priorities of Care and within palliative care guidelines and standards for good practice. (NICE 2011; NPEOLCP 2015).

However, although there were a growing number of *wishes* documents, advance care planning for children was mostly focused on do-not-resuscitate orders to inform emergency decisions. As the scope of children's palliative care has expanded to respond to an increasing range of life-limiting conditions (See section 1.3), the aims of children's advance care planning have shifted, this has challenged the historical narrow focus of advance care planning of a single clinical decision. Consequently, advance care planning conversations in children's palliative care (DH 2008b) have focused on informing approaches to treatment and care, and goals for end-of-life. This has influenced the development of specific advance care planning documentation for children (CYPACP 2019). Thus, current forms include do-not-resuscitate orders alongside the wider aspects of supportive care. An example of the latest advance care planning tool for children and young people is provided in the appendix (Appendix A).

Moreover, initiatives such as 30 million stars project (ACT 2011) have further influenced the development of advance care planning for children through focused projects on end-of-life care (WMPPCN 2011; CYPACP 2019). This resulting knowledge of the importance and unique nature of advance care planning in children's palliative care has informed recent children's end-of-life policy (NICE 2016) and is a key standard in the Children's Palliative Care Core Pathway (TFSL 2018).

1.2.1 What constitutes advance care planning

Advance care planning is described both in policy (DH 2008a; NICE 2016) and professional guidance (NEOLP 2008; TFSL 2018) as a process of discussion between an individual, their care provider and those close to them. There is significant focus on discussions that may lead to decisions such as advance decisions to refuse treatment (ADRT), do-not-attempt-cardiopulmonary-resuscitation orders (DNACPR) and lasting Power of Attorney. There is a growing perception that the principles, which primarily centre on treatment decisions, in preparation for incapacity, have developed to include the wishes and needs of patients for their preferred care. The process of advance care planning promotes shared decision-making and is considered an integral part of best practice in end-of-life care (DH 2008a; NICE 2016).

In children’s palliative care there are contextual issues that make advance care planning unique. The complex medical conditions encountered in children’s palliative care has resulted in resuscitation discussions that not only include do-not-resuscitate orders, but also modifications to resuscitation (See appendix A), which are bound within the concept of limitations to life-sustaining teatments (Larcher et al. 2015). Thus, where the emphasis in adults has shifted towards determining goals of care (Morgan et al. 2018; Myers et al. 2018), in the case of children and parents, emphasis has shifted towards understanding parents choices for mulitple approaches to care (Beecham et al 2017) rather than pre-determining decisions in advance.

This shift in the focus for advance care planning and how parents approach decisions about their child’s end-of-life has raised questions about our understanding and knowledge of the process of advance care planning in children’s palliative care and warrants further investigation.

1.3 Defining children’s palliative care

Historically palliative care developed as an approach to care for people who had an incurable illness, to ensure their comfort through an holistic approach to care (WHO 2019). In contrast, palliative care for children has developed with reference to life-limiting and chronic illness and therefore has focused on care from diagnosis, supporting the child and family throughout the course of illness (TFSL 2018). Thus, palliative care is appropriate for children with a wide range of long-term conditions and typically stretches over many years. This differentiation between adult and children’s palliative care is contextually important, because rather than being associated with a discrete end-of-life phase, advance care planning is interwoven into care decisions throughout the course of the child’s illness. Advance care planning is therefore integral to the philosophy of children’s palliative care.

Defining children’s palliative care has prompted much discussion which has resulted in various interpretations of what constitutes children’s palliative care (Thompson 2015). The following fairly lengthy definition is provided by the World Health Organisation (2019) and offers a similar definition to Together For Short Lives (TFSL 2018) the UK national organisation for children’s palliative care.

> *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. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.* (WHO 2019 www.who.int)

Although this definition appears all encompassing, there are limitations in its scope, in that it does not refer to the complex childhood conditions that may be incorporated in the definition of palliative care. There are multiple conditions that come under the remit of children's palliative care services that are better understood by reference to life-limiting (LLC) (those for which there is no reasonable hope of cure and from which children or young people will die) and life-threatening conditions in childhood (LTC) (those for which curative treatment may be feasible but can fail). These include conditions requiring intensive long-term treatment aimed at maintaining quality of life and progressive conditions in which treatment is exclusively palliative (LLC), as well as advanced or progressive cancer where the intention is cure but may fail (LTC). It also includes severe non-progressive disability that causes extreme vulnerability. All children with these conditions can be supported by palliative care. In addition, there are a diverse range of treatments, interventions and care offered within the scope of children's palliative care.

Many childhood conditions have specific challenges, which make it increasingly difficult to determine when and how palliative care might be offered, for example the length of illness and complexity of condition. Furthermore, these make treatment decisions, whether life-sustaining treatments (LST) (those that have the potential to prolong life) or withdrawal, more complex and challenging. This makes it important to embed such treatment and care decisions for children with life-limiting or life-threatening illness in advance care planning. Yet, as discussed above, it means such decisions and, in turn advance care planning needs to extend across many months (and years). Thus, conversations about advance care planning may start at diagnosis, during the course of illness or towards the child's end-of-life. The concept and development of children's palliative care is also heavily influenced by the context of living with a child with a LLC (See section 1.5).

What constitutes palliative care for children and young people is therefore far reaching and does not solely include end-of life care. Because it stretches across the course of a child's illness it can include services such as respite, short breaks, symptom management and end-of-life care, all provided under the umbrella of palliative care. This expanding scope of children's palliative care is broad and complex and the acknowledged differences from adult palliative care, has led to the development of specialist children's palliative care as a distinct field of practice.

This study therefore recognises the multidimensional nature of children's palliative care encompassing all children and young people with life-limiting and life-threatening conditions, and that conversations with families about advance care planning may take place at any point during a child's illness.

1.4 Prevalence of children's palliative care

Children's palliative care is a relatively new field of practice dealing with a small population. There is little data to determine the numbers of children in the UK requiring palliative care. However, the most widely recognised survey in 2011 suggested there were 40 000 children and young people in the UK with a life-threatening or life-limiting condition (Fraser et al. 2011). More recent data suggests this was a significant underestimation (Fraser et al. 2014; Fraser et al. 2020). National prevalence of LLC in Children in England has increased over 17 years from 26.7 per 10000 in 2001/2 to 66.4 per 10000 in 2017/18 (Fraser et al. 2020). This is a marked increase, which has a major influence on children's palliative care both in planning services and improving care for children and their families

The increase is partly due to increasing survival and with advances in medical treatment children and young people are living longer and require more complex care (Fraser et al. (2020).This impacts not only on the complexity of decisions faced by parents but how these changing situations influence the choices they make.

1.5 The context of living with a child with a life-limiting illness

Children's palliative care is not exclusively about end-of-life and advance care planning but one where the milieu of living with a child with a life-limiting condition interweaves throughout the illness journey. Thus, where the previous section familiarised the reader with palliative care and advance care planning the next section will convey the experience of families living with a child with a life-limiting condition and the impact of this on their lives.

It is well reported that the care of children with complex and progressive illness is demanding and permeates across all dimensions of family life (Steele & Davies 2006; Rallison & Raffin-Bouchal 2013). Rallison & Raffin-Bouchal (2013) describe the relentlessness of families' experience and resulting exhaustion. Day-to-day life is focused on caring, and families do not look too far into the future. The physical and emotional demands this brings, become part of the context defined by parents of what it means to be a parent of a child with a life-limiting condition (Bluebond-Langner et al. 2007). It is clear that the illness journey is complex (Rallison & Raffin-Bouchal 2013) nevertheless, parents go to extraordinary efforts to create as 'normal' a life as possible for their child and their family (Carnevale et al. 2006; Carroll et al. 2012; Thompson 2015) and endeavour to maintain their personal and cultural values alongside the struggle of constant change. They do this by drawing on resilience and hope (Somanadhan & Larkin 2016), to protect themselves from suffering and overwhelming emotions in order to do what is to be done (Kars et al. 2010). Parents describe an inner resilience from surviving ongoing adversity and hardship, experienced in the number of times they cope with crisis events where their child pulls through (Menzes 2010).

Such coping strategies generate a changed perspective for parents involving a new capacity to see what is important (Collins et al. 2016). Parents describe this through expressions of hope. Feudtner (2009) identifies many different hopes voiced by parents; hopes for their child, their family and themselves. Moreover, hope in this context, of living with a child with a life-limiting illness is complex (Reder & Serwint 2009) where parents constantly adjust their hopes as the child's illness progresses (Hinds et al. 1997; Clayton et al. 2005; Reder & Serwint 2009; Rishel 2010). Hope is essential to be able to live with death in view, framed as hope for survival (Reder & Serwint 2009), hope provides an opportunity to create a vision of their child's future. Hope for cure is transformed to a hope for comfort (Rishel 2010). Thus, for parents, the context of living with life-limiting illness is one of dualisms, of living with the demands of daily life and the threat of death where, hope is then used as a compass for the choices made.

This context is influenced by the shifting landscape of health care, where parents are required to make choices about their child's care against a medical backdrop of increasing technologies, expectations of cure and children living longer, but with more complex needs. Moreover, these choices are socially contextualised by publicised ethical and moral debates about life-sustaining treatments (Channel 4 2018; Wallop 2018) and the ethics of treatment at all costs (Pearson 2018). The high profile cases of Charlie Gard and Alfie Evans have bought to the public attention the complexity of decisions around end-of-life care and the withdrawal of treatment, and parents' determination to explore every option for their child's survival.

Choices around care and treatment are increasingly more extensive and complicated and have influenced recent changes to local and national advance care planning documents

(ReSPECT 2018; CYPACP 2019). Yet, it can be argued that parents' experience of living with dying and their capacity to manage on a day-to-day basis, conflict with this increasingly medical and interventional focus of dying. They do not see themselves or their child within a clinical model of end-of-life. Their focus on managing normalcy and building memories does not fit with the growing attempts in health care to control dying through treatment decisions. Moreover, they do not define their child as 'end-of-life' or likely to die in the next two years, but frame their experience in terms of survival and hope. These contextual dimensions of living with a child with a life-limiting condition are important to consider when investigating how and when parents engage in the process of advance care planning.

1.6 Decision-making with children and families

The processes of family decision-making and the shared and often intimate relationships within families significantly influence advance care planning. Moreover, decision-making in families is contextualised by individual interpretation of family culture.

The legal and ethical framework for decision-making promotes autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress 2013) and within families, a crucial issue relates to the rights of the child and parents in the decision-making process. Children have a developing capacity and a recognised right to be involved in decision-making (UNCRC 1989; Gillick 1995) and parents legally hold parental responsibility (DH 1969) and the right to make decisions on behalf of their child until they are 18 years old. However, many children are young, or non-verbal and unable to voice their wishes, therefore, this role naturally falls to their parents.

Parental autonomy, set within the principle of best interests, assumes that parents will make the best decisions for their child. In the case of children with complex needs and disability, parents are also making clinical judgements for their child. In recent years', they have been considered the 'expert' in their child's care. This has arguably shifted the weight given to parental opinion in clinical decisions and a desire for parents to be decision-makers for their child (Sullivan et al. 2015).

Neverthless, the influence on decision-making extends to the significant involvement of health care professionals (Fraser et al. 2010) and increased the importance of shared decision-making between parents and the clinical experts involved in their child's care.

Thus, a family-centred model of shared decision-making, sensitive to these complex dynamics is essential. One that recognises the impact of emotions, relationship dynamics and practice contexts (Connor & Leonard 2013). This is of particular importance when families are making choices about palliative and end-of-life care (Noyes et al. 2013).

If, as observations of practice suggest, the process of advance care planning is complex, complicated by life-limiting illness and options for health care intervention, and of family decision-making, then there are many distinct factors that need to be considered that will affect how health care professionals operationalise the process of advance care planning.

1.7 Purpose and aims of the study

The main purpose of the study was to understand parents' experience of advance care planning for their child, specifically to investigate how and when parents wish to engage in advance care planning.

By being grounded in parent's experience of advance care planning, the study will provide a greater awareness of the impact and complexity of advance care planning for parents and inform policy and practice.

Thus, the following research question will be asked of the data: How and when do parents wish to engage in advance care planning for their child?

1.8 Introduction to the thesis

The study seeks to explain parents' experience of advance care planning and is positioned in a situated context for parents living with children with a life-limiting condition. The thesis consists of nine chapters and provides an overview of advance care planning to rationalise the purpose of the research.

Chapter 2 outlines the purpose of conducting a scoping review of the literature prior to undertaking a qualitative grounded theory research study. It illustrates current knowledge of the practice and process of advance care planning that provides a background to the study and explains why this study is important.

The theoretical framework of the study is presented in the following two chapters. Chapter three provides justification for using a constructivist grounded theory approach and describes the methodology and main methods selected to answer the key objectives of the study. Chapter four explains the iterative process of analysis that was applied to the study.

Chapters five to seven introduce the findings in detail and explain each of the three categories that emerged through the data, *realisation, reconciling multiple tensions* and *building confidence and asserting control*. These chapters integrate selected literature to enhance the analysis. Collectively these categories constitute an emergent theory of *re-constructing meaning through advance care planning* which is explained in chapter eight.

The theory is discussed in detail in chapter eight and its contribution to knowledge explicated. At the end of the thesis, ways of supporting health care professionals to improve parents' experience of advance care planning are explored and recommendations for practice are considered. An evaluation of the study is presented and personal reflections of learning shared.

Chapter 2 Current knowledge of advance care planning practice

This chapter seeks to understand what is currently known about advance care planning to identify gaps in knowledge and limitations in our understanding of current practice. The following scoping review offers a range of literature to highlight key features of advance care planning and provide a theoretical background to the study.

2.1 Scoping review

The role of an initial literature review in grounded theory has been widely debated (McGhee et al. 2007; Dunne 2011; Charmaz 2014) and although there are arguments for and against undertaking a literature review before developing the research methods, there is also an ethical obligation for researchers to establish evidence that already exists (Dunne 2011). Glaser (1992) strongly asserts there should be no engagement with the literature at the start of grounded theory, so as not to influence the researcher, or contaminate data collection or analysis, and to allow the categories to emerge naturally. Glaser (1992) also argues that given the nature of grounded theory and emerging concepts it is likely that the literature most relevant to the research is not known at the start. This principle informed the decision to undertake a focused literature search in relation to the emerging concepts as part of theoretical analysis. However, it is also important to recognise that researchers already come with previous experience and knowledge in the field (Strauss & Corbin 1990) that gives insight to the field of study (Clarke 2005) and will influence and shape data collection and analysis (Charmaz 2014). The fundamental point is therefore how to make proper use of this knowledge within the research process (Strübing 2007), how to be open to existing knowledge and mindful of how this affects interpretations of the study (Charmaz 2014). It was recognised that analysis of existing knowledge to inform the background to the study was valuable.

Thus, engagement with the literature occurred at two distinct points within the study. Initial scoping of the literature, conducted to contextually situate the study in the evidence base for advance care planning for children, and focused search and appraisal of literature undertaken as part of constant comparison and theoretical analysis (Glaser & Strauss 1967 p. 46). How the literature was used in the study is summarised in table 2.1. The approach taken acknowledged the original ethos of grounded theory (focused search and appraisal of literature planned at later stages of the study) and the need to engage with the literature and integrate existing knowledge at an early stage.

Table 2.1 How the literature was used in the study

Type of literature review	Purpose	Methods
Scoping review	• To map the literature to determine current knowledge and debate of advance care planning • To understand the fit between practice and policy in the UK with regard to the construct of advance care planning in practice • To guide the research design and justify topic • To contextualise the study in relation to children's palliative care and advance care planning with children and parents • To identify gaps in knowledge in relation to advance care planning in the context of children's palliative care	• Search strategy (1990 – 2019) to include electronic database of Medline, CINAHL & PyscINFO; Hand search and search of reference lists • Identify relevant studies for relevance to the research questions • Charting of data related to research questions • Summary of themes
Focused search, retrieval and appraisal of literature	• To locate the study in relation to aims and objectives and research questions • To analyse significant works to further define the conceptual categories • To extend the debate by assessing and critiquing the literature in relation to the emerging grounded theory especially convergence and divergence • To identify and discuss recognised theoretical concepts and earlier theories and locate these in relation to the emerging theory • To situate the emerging theory and how this contributes to gaps in knowledge • To position the study and its contribution to practice	• A number of focused searches related to the different concepts and categories • Inclusion of published peer review and grey literature • Assessment of retrieved titles/abstracts • Appraisal for relevance and quality using an appropriate framework

A scoping review design, rather than a systematic literature review, was congruent with the purpose of establishing and examining the published debate of advance care planning beyond research studies (Bennett et al. 2005) The aim was to examine the extent, range and nature of research and debate (Tricco et al. 2018) to provide an overall picture of advance care planning in policy and practice. Scoping reviews differ from systematic reviews in that their purpose is to assess and synthesise the range of research and debate informing a topic, rather than focusing on research evidence, which meets specified methodological criteria. Nevertheless, scoping reviews share similar processes to systematic reviews to ensure rigour, methodological standardisation and transparency to provide confidence in the utility and strength of evidence (Pham et al. 2014). In addition, the conduct (Peters et al. 2015) and reporting of scoping reviews (Tricco et al. 2018) is important within the process.

The selected methods for the scoping review were informed by the 5 stage framework for scoping reviews based on work by Arksey and O'Malley (2005) and followed the subsequent PRISMA extension for scoping reviews (PRISMA-ScR) developed by Tricco et al. (2018). These frameworks have been critically evaluated and widely used to inform research agendas and identify implications for practice. (Levac et al. 2010; Tricco et al. 2018).

2.1.1 The research topic and fit

The purpose of searching the literature at the start of the study was to understand the research which had already been undertaken in advance care planning for children (Arksey & O'Malley 2005; (Valaitis et al. 2012). The question guiding the scoping review was 'how is advance care planning conceived and constructed in clinical practice for children with long term conditions and life-threatening and life-limiting conditions'.

This was essential to determine how advance care planning is currently framed within policy and practice and the impact this has on process and practice. Levac et al. (2010) warn against a scoping review that is too broad and suggest a focused search strategy that is feasible to answer the review questions. Thus, the search enabled an examination of the breadth of evidence about advance care planning to contextualise the study and to identify any gaps in knowledge and research (Levac et al. 2010; Daudt et al. 2013).

2.1.2 Identify relevant studies

Criteria for the selection of papers were based on the scope of enquiry and focused on relevance rather than the methodological quality of studies (Arksey & O'Malley 2005; Levac et al. 2010; Valaitis et al. 2012; Dijkers 2015). Inclusion and exclusion criteria were therefore devised (See Table 2.2) to give direction and focus but to avoid a large volume of papers that would be overwhelming. The search was limited to papers published in English and the database search dated back to the first policy inception of advance care planning in 1990. I excluded papers that were irrelevant to the review question and those addressing end-of-life decisions in mental health, HIV or solely focused on do not resuscitate orders as they did not have a palliative care focus. It was important to gain the experience of all parents with a child with a life-limiting condition.

Table 2.2 Inclusion and exclusion criteria

Inclusion	• Papers that addressed the review focus • Papers that raised debate about advance care planning • Children and young people with life-limiting conditions • Bereaved and non-bereaved parents of children with life-limiting condition • Papers that addressed health care professionals' perspective of children's / parents advance care planning • English language • 1990 – December 2019
Exclusion	• HIV focus • Do not resuscitate focus • Non-palliative care specific (Children dying of trauma or suicide) • Adult population • Language other than English

2.1.3 Study selection

In the first instance, the electronic databases CINAHL, Medline and PyscINFO were used to identify available relevant studies. These databases provided good coverage of qualitative and research evidence from across disciplines and fields of practice (Wright et al. 2015) that related to the specific focus of the search.

The search combined MeSH and broad base terms of *advance care planning*, and *child, young adult, parents and palliative care* (see Table 2.3). Wright et al. (2015) argue that broad base terms effectively capture a good source of relevant studies. The search terms outlined in table 2.3. were identified and refined using a framework appropriate for scoping reviews, comprised of Population, Concept and Context (PCC) (Tricco et al. 2018).

Table 2.3 PCC framework to identify search terms

PCC	Term	Keywords	MeSH/Broad base term
Population	Children, young people or parents (combined with OR)	Child/children Young people/Adolescents Parents	Child* Young adult Parents
Concept	Advance care planning	Advance care planning Advance directives Advance Medical planning	Advance care planning
Context	Palliative care and end of life	Palliative care Terminal care End of life care	Palliative care

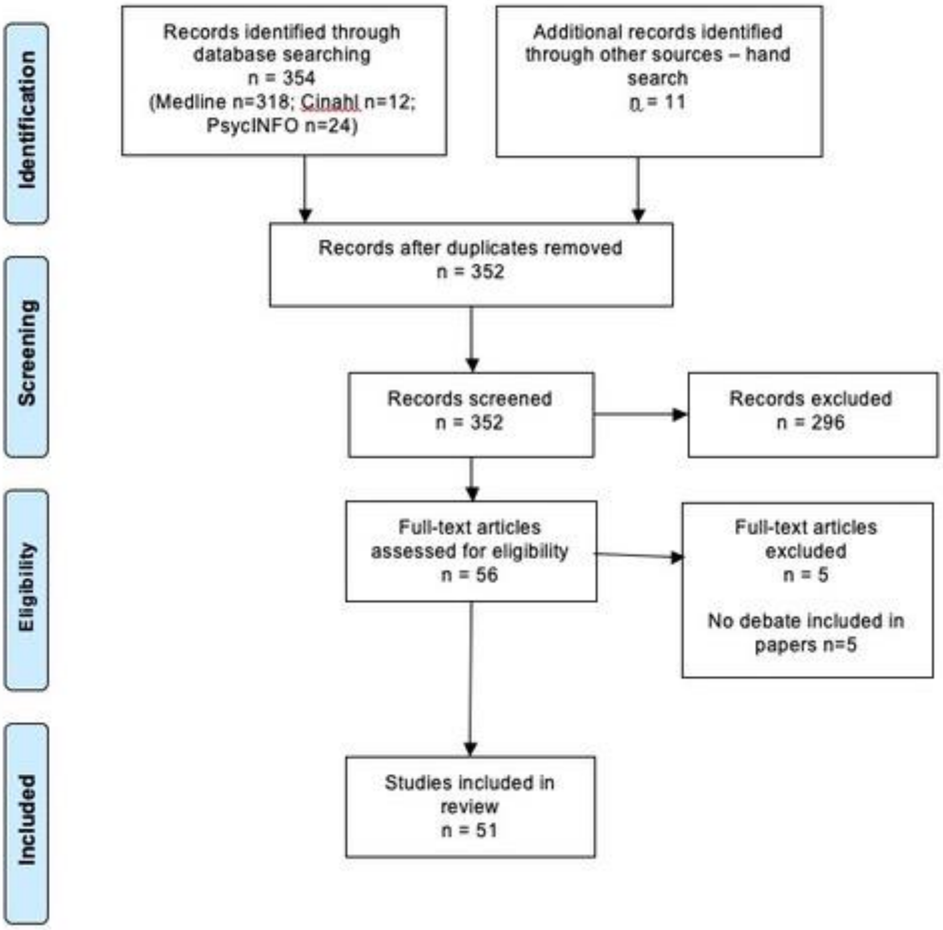
Reference lists were examined in papers retrieved for any sources not catalogued in search databases, and further papers selected. Having practised in the field for a number of years I also held a number of papers about advance care planning and these were checked for duplication to determine if any had not been identified by the review.

The data revealed 15 papers at the start of the study in 2013 that met the inclusion criteria however, as the scoping review is an iterative process (Arksey & O'Malley 2005) I continued to search for relevant literature as the study progressed. The importance of continued engagement with literature throughout the study enabled me to keep sight of the changes and developments of advance care planning in practice and the impact this has had for parents. With the development of advance care planning practice a further 36 papers were identified during the study, of which there were 20 published papers in the last two years. These were included to ensure contemporary discussion was incorporated.

I returned to literature searching on several occasions with a final literature search in December 2019. The outcomes of the search are outlined in Figure 2.1 using PRISMA ScR flow diagram.

354 papers were identified through database searching and a further 11 papers identified through reference lists, handsearch and networking. Following the removal of duplicates a total of 352 papers were screened. After title and abstract screening 56 papers were identified as relevant to the review question. As Arskey and O'Malley (2005) noted, abstracts cannot be assumed to be representative of the whole article, so each article was read to assess for the quality of debate to make the final decision about their inclusion. A further 5 papers were excluded as they offered no debate and therefore did not meet the inclusion criteria. 51 papers were included in the review.

Figure 2.1 Search results: PRISMA-ScR flow diagram



2.1.4 Data charting

The next stage was to chart the data to capture relevant information on key study characteristics. Arksey & O'Malley (2005) recommend collecting standard information across all papers for example, the design, methodology, population, aims, findings and key discussion, in this case in relation to the focus of advance care planning. Full details of data charting results are presented in appendix B. To address the review question, each paper was carefully assessed and judged for the quality debate presented, in order to determine the overall quality of debate underpinning conceptualisations and constructions of advance care planning for children. Thus, papers were reviewed in terms of whether the debate was informative, well-reasoned, logical and persuasive (Duke and Bennett 2010). The key themes were grouped along with the broad findings.

The search revealed a diverse range of articles focused on advance care planning, goals of care and end-of-life decisions for children, young people and parents. The papers included children and young people who had a range of life-limiting and life-threatening conditions from complex neurological conditions, Spinal Muscular Atrophy, Duchene's Muscular Dystrophy and Cancer. The retrieved papers represented a mix of qualitative studies, service development and evaluation, descriptions of the process of advance care planning and opinion papers (See Table 2.4).

Table 2.4 Classification of papers

Classification of papers	
Randomised control Trial	1
Systematic review	4
Qualitative studies; Thematic and content analysis	11
Survey	12
Audit	8
Mixed methods	4
Commentary	11
Total	51

Of the original research studies, 13 were conducted with parents, 6 with adolescents and young adults and 10 of health care professionals perspective of children's advance care planning. There were no original research studies with children as participants about advance care planning. The majority of papers were from the US or UK with only 4 from Europe and 4 Australia.

2.1.5 Collating and summarising

The final stage presents an overview of all the material reviewed. The purpose was to provide a thorough view of the debates about how advance care planning was conceptualised. Thus, key debates were extracted that focused on the process and complexity of advance care planning and how advance care panning is currently represented in practice. The qualitative content approach enabled the opportunity to understand potential issues relating to advance care planning as well as debates that frequently occurred across papers. Key debates were grouped and labelled into emerging themes. This was an iterative process with the final themes collated into a narrative account. The aim was to interpret and explain the current debate and to provide a comprehensive understanding of advance care planning across children’s palliative care. This analysis informed the background to the study, established gaps in knowledge and shaped the research design.

2.2 Current context of advance care planning

The scoping review provides insight into the current understanding of advance care planning in children’s palliative care. The analysis revealed several central themes surrounding the process and practice of advance care planning and a strong emphasis on the context in which advance care planning takes place. The majority of papers described the policy context in driving the completion of advance care planning alongside the increasing numbers of children with life-limiting conditions and increasing life expectancy. This context set a focused background in the literature for promoting the practice of advance care planning and the importance of end-of-life conversations with families. The scoping review revealed four overarching themes discussed below, communication, knowledge and decision-making, the process of advance care planning, and benefits and barriers of advance care planning.

2.2.1 Communication

The central tenant of advance care planning is one of good communication (Hughes et al. 2018) where timely conversations (Wolff et al. 2011) and ongoing discussions (Erby et al. 2006) offer the basis for a framework of best practice. The last few years have seen a significant shift in advance care planning practice towards an increasing emphasis on advance care planning as a process of conversation (Jack et al. 2018) rather than a single conversation. There is growing evidence that conversations about advance care planning are important (Basu & Swil 2018) and that good communication can achieve good outcomes at end-of-life (Lyon et al. 2013). Studies report that conversations are evidenced in health care records (Edwards et al. 2012; Martin & Beringer 2019) however, there is little to suggest what types of conversations are held with patients or how they are initiated (Jack et al. 2018).

There remains much debate of when and where to hold conversations (Durrall et al. 2012; Edwards et al. 2012; Jack et al. 2018). There is debate that conversations should start early, near to diagnosis (Erby et al. 2006; Edwards et al. 2012; Heckford & Beringer 2014; Mitchell & Dale 2015; Basu & Swil 2018; DeCourcey et al. 2018). However, reports suggest that conversations do not happen early enough (Hiscock & Barclay 2019) or that conversations occur too late (Sanderson et al. 2016; Basu & Swil 2018; Hiscock & Barclay 2019). There is mixed evidence as to who should, or may start a conversation with reports of parents being more likely to introduce the topic (Hammes et al. 2005; Erby et al. 2006) whilst health care professionals are more likely to avoid the conversation (Hiscock & Barclay 2019). In contrast, Beecham et al. (2016) suggest that parents do not always want to talk about advance care planning. Two qualitative studies provided a different perspective in that parents do want the opportunity to talk about advance care planning but not at moments of crisis (Jack et al. 2018; Hiscock & Barclay 2019).

Moreover, for parents of children with a life-limiting illness it is not just when to have these conversations, but how health care professionals might approach conversations with them (Beecham et al. 2016). How children and young people are involved in these discussions and understanding their wishes must also be considered (Taylor 2012; Wiener et al. 2012) yet there were limited accounts of young people’s views and no views from children. What is clear is that effective advance care planning conversations enable sharing of information (Lyon et al. 2013) which can have an impact on outcomes at end-of-life.

2.2.2 Knowledge and decision-making

Despite reports that parents do not know about the process of advance care planning (Erby et al. 2006) or knew about the concept (Heckford and Beringer 2014) they do have significant knowledge about their child (Mitchell et al. 2019) which is an important contribution to decision-making at end-of-life (Beernaert et al. 2019). Evidence suggests that several factors are influential to advance care planning including, previous knowledge and experience and relational and system factors (Popejoy 2017). However, evidence of the impact of these wider contextual elements of decision-making in advance care planning is less clear. There is some evidence from a small randomised controlled trial that explaining advance care planning enhances family involvement and end-of-life decision-making (Lyon et al. 2013). However, most of the sources reviewed focused on decisions related to location of care and death (Dussel et al. 2009; Beringer & Heckford 2012). For example, in a study which interviewed parents (n=18) about the conversations they had with health care professionals (Beecham et al 2016), parents reported discussions and making decisions relatively late in their child's illness about place of care and place of death for their child. This study emphasised the importance to parents' of keeping their options open, whereas the study by Lyon et al (2013) found that early involvement in advance care planning helped families to make decisions which limited end-of-life care decisions. However, whilst there is growing understanding of the content and outcome of advance care planning, what is of importance to parents within advance care planning is little understood.

There is emerging understanding that effective decision-making and engagement in advance care planning are dependent on trusting relationships between parents and health care professionals (Mitchell et al. 2019). In an interview study with parents (n=17) Mitchell and colleagues found continuity of care to be a key determining factor of such relationships. Others have reported that it is important to be able to discuss the difficult and emotional aspects of end-of-life care (Finlay et al. 2008) and to 'navigate the unspeakable' (Erby et al. 2006). However, there is much evidence to suggest discordance and lack of trust exist (Wharton et al. 1996; Hughes et al. 2018; Hiscock & Barclay 2019; Mitchell et al. 2019). Some report health care professionals have unrealistic expectations of parents, which can cause disagreements between health care professionals and parents (Durall et al. 2012) and claim the resulting lack of trusting relationships (Mitchell & Dale 2015) impacts on effective advance care planning. Parents are also cautious about doctors not sharing information effectively (Beerneart et al. 2019). The literature presents an unsettled picture about parental and health care professionals' expectations and realistic options of care.

2.2.3 The process of advance care planning

The process of advance care planning has afforded much discussion in the literature with emphasis placed on the practical elements of advance care planning (Horridge 2015). Published audits of retrospective case note reviews indicate the presence of advance care plans in practice and promotion of their use (Finlay et al. 2008; Beringer & Heckford 2012; Edwards et al. 2012; Fletcher et al. 2018; Hoell et al. 2018; Harmony et al. 2019; Martin & Beringer 2019). Findings from a number of surveys reported adaptations to, or the development of, models of advance care planning in practice (Finlay et al. 2008; Wiener et al. 2010; Wolff et al. 2011; Noyes et al. 2013; de Arruda-Colli et al. 2018; Hughes et al. 2018; Loeffen et al. 2018). However, although these studies have endorsed the uptake of advance care plans and offer recommendations of how to frame end-of-life discussions (Haynes et al. 2019), they have largely focused on health care professionals' approach to completing advance care plans (Sanderson et al. 2016; Basu & Swil 2018). Other studies emphasise choice for preferred location of death (Dussell et al. 2009) and whether goals for end-of-life care, were met (Edwards et al. 2012).

There is an emerging disparity over what should be discussed within the process of advance care planning and the literature reveals a lack of a unified approach. The commentary provides mixed opinion about who is responsible or best placed to have conversations about advance care planning with parents. Paediatricians are acknowledged to be experts in the child's condition (Basu & Swil 2018), whereas Harrop et al. (2018) suggest any professional with expertise can engage with parents about advance care planning decisions. Others emphasise that conversations are best tailored to individual need and the importance of trusting relationships rather than expertise (Hiscock & Barclay 2019). In addition, Mitchell et al. (2014) report a wide variation in the use of advance care plans with an inconsistency across the country. There is no single model presented. The introduction of ReSPECT (2018) and a unified form, is intended to standardise practice across the country, to minimise the variation in practice. Yet, it would be wrong to suggest that advance care planning is solely achieved through the completion of a standardised form (Lund et al. 2015) or that a standard form will achieve the best outcomes for all parents.

There is increasing consensus that the process of advance care planning is not a single treatment decision, but involves a relational and conversational approach (Mitchell et al. 2019; DeCourcey et al. 2019) consisting of an ongoing, stepped process (Fraser et al. 2010; Lotz et al. 2017; Jack et al. 2018) requiring repeated conversations. Such an approach is consistent with research illustrating that parents' views about end-of-life decisions change over time (Beecham et al. 2016) and the resulting complexity of advance care planning. However, there is a paucity of research exploring parents' perceptions about how best to implement such an approach. There is some indication that parents who have frequent contact with health care services are more likely to be interested in participating in advance care planning decisions at an early stage in their child's condition, compared to those with infrequent contact (Liberman et al. 2014).

Studies report the process and practice of advance care planning is heavily influenced by the skills and knowledge of professionals (Liberman et al. 2014; Mitchell & Dale 2015; Hughes et al. 2018) and health care professional's experienced in children's palliative care are more able to have advance care planning conversations (Sanderson et al. 2016).

2.2.4 Benefits and barriers of advance care planning

The literature highlights emerging evidence that advance care planning is of benefit (Mitchell & Dale 2015), can improve outcomes for parents (Heckford & Beringer 2014; Lotz et al. 2015; DeCourcey et al. 2019) and can positively affect health outcomes in terms of achieving preferences for care (Dussell et al. 2009). Conversely, the absence of advance care planning negatively influences these outcomes (Mitchell & Dale 2015). Where parents had been engaged in advance care planning, they felt more prepared and able to plan location of death (DeCourcey et al. 2019). Parents felt assured of best care (Hammes et al. 2005) and reported that advance care planning helped to understand diagnosis and prognosis and to make the 'best' decisions for their child (Mitchell et al. 2019).

Despite the reported positive benefits, several barriers hinder effective advance care planning discussions. Whilst the challenges reflect the difficult nature of advance care planning (Durrall 2012; Sanderson et al. 2016; Basu & Swil 2018) and the fear of upsetting parents (Heckford & Beringer 2014; Basu & Swil 2018) there is evidence to suggest more practical barriers that inhibit effective advance care planning. Health care professional's report a lack of communication skills (Durrall 2012; Mitchell & Dale 2015; Hughes et al. 2018) and lack of confidence in initiating conversations (Lotz et al. 2015; Hughes et al. 2018). In addition, workplace pressures and lack of time (Basu & Swil 2017), and difficulties due to prognostic uncertainty (Edwards et al. 2012; Liberman et al. 2014; Basu & Swil 2018; Fahner et al. 2019) create further obstacles.

These barriers appear to directly influence initial and ongoing conversations where there is a reluctance to talk and avoidance from both health care professional's (Beringer and Heckford 2012; Hiscock & Barclay 2019) and parents (Noyes et al. 2013; Hiscock & Barclay 2019). Overall there are significant barriers identified in the literature that suggest gaps in knowledge in how best to approach advance care planning conversations with parents.

2.3 Considerations following the scoping review

As a general critique, the research evidence in relation to advance care planning has until recently predominantly focused on care of adults (Martin & Beringer 2019). What constitutes advance care planning and how it should be approached for children with life-threatening or life-limiting conditions and their families is less developed. Of the studies reviewed, the evidence is dominated by debates arising from the views of health care professional's so the constructed analysis about the process of advance care planning and the benefits and barriers are mainly drawn from a professional perspective. The barriers identified by health care professional's provided rich debate, however, this does not provide a comprehensive picture of the process of advance care planning. Although some studies involved parents as participants (n=13), much of the knowledge presented was generated from surveys (n=12), with pre-determined focus on preferred location of care (Dussell et al. 2009) and the development of advance care planning documents (Weiner et al. 2010; Weiner et al. 2012; Mitchell et al. 2014). These debates have been well argued but do not extend to what parents may or may not have found helpful in the process. There is little reference to what is important to families.

In addition, a large number of papers were retrospective case note reviews (n=8) to determine the development of advance care planning tools (Finlay et al. 2008; Fletcher et al. 2018), reported advance care planning discussions and goals of care (Edwards et al. 2012; Heckford & Beringer 2014; Harmony et al. 2019), or to measure against standards of practice (Beringer & Heckford; Hoell et al. 2018). There is inadequate analysis of the content of discussions, of decisions made, or, of the outcomes and impact of advance care planning.

In other areas, the debate was largely constructed from practice knowledge with assumed interpretations of parent's involvement. There is inadequate knowledge about the benefits of advance care planning and whether the process is a positive one.

Overall, whilst the review raised factors such as timing and process of conversations in advance care planning in children's palliative care, the evidence fails to adequately explain the complexities from parents' perspective or how to manage these complexities with children and parents. There are limited studies that explore the impact of advance care planning on parents. Without this information we cannot fully take account of the distinct perspectives of the child or family and as a result may not have the knowledge to support them effectively. These limitations and observations of practice suggest there are key features of advance care planning worthy of further consideration.

2.3.1 The timing of the conversation

Inherent within the process of advance care planning for childen are decisions about when to have a timely conversation with parents, who should initiate this discussion, and when the plan should be reviewed. In adults, advance care planning is predominantly discussed with a patient who is thought to be in the last year of life. With children, discussions with parents take place over a number of months and years, with initial discussions that begin at diagnosis (ACT 2004). A protracted and unpredictable illness trajectory in childhood conditions further influences these decisions. It is suggested that conversations should be initiated following cues by parents that they are ready to talk (Mitchell et al. 2019), but it is unclear what these cues are, how they are interpreted and how they might be used. It means parents may have a range of encounters with several different professionals about advance care planning, who may interpret differently the best time to have a conversation.

Furthermore, it is not known whether discussions relating to end-of-life care for example, resuscitation, are helpful or detrimental early in an illness trajectory. As a consequence of the challenges associated with a long illness trajectory, a partial or stepped approach to advance care planning has been considered (Martin & Beringer 2019) and this requires multiple conversations. Fraser et al. (2010) suggest decisions and ongoing discussions around advance care planning need to fit alongside an illness trajectory of slow deterioration and crisis events, to reach a treatment and resuscitation decision at a sensitive appropriate time for the child and family. However, this is based on professional opinion and it is unclear whether parents share this view or whether it is helpful to frame conversations in this way when discussing end-of-life care. Furthermore, although conversations that have taken place are recorded in writing (Jack et al. 2018), the content of what is said is not recorded and we have little information of what was discussed or how this impacts on the family. The process of advance care planning in this context requires rigorous examination, including if, and how parents wish to talk about their child's end-of-life care.

2.3.2 Complexity of advance care planning

Advance care planning decisions for children are becoming increasingly challenging with innovations in complex treatment and options for supportive intervention that extend life expectancy. Additional factors inherent within children's palliative care complicate the process of advance care planning, including; decision-making with parents at the end-of-life (Carroll et al. 2012; Sullivan et al. 2015; Xafis et al. 2015a; Mitchell et al. 2019) and the frequency of advance care planning discussions (Lotz et al. 2015). Clincial complexity and whether a child has a palliative or complex neurological diagnosis (Brombley & Harrop 2016) adds further challenges.

This is compounded by the significant increase in the number of children and young people with complex symptoms or on long term ventilation (LTV) who are often cared for at the end-of-life in intensive care (Edwards et al. 2012; Mitchell & Dale 2015; Martin & Beringer 2019). Parents are no longer making simple do-not-resuscitate decisions but rather making complicated choices that involve modifications to resusciation and the limitation of treatment (Mitchell et al. 2019).

These complex moral and ethical debates involving the limitation of treatment or keeping all options open (Beecham et al. 2017) further complicate decision-making with parents.

There is an emerging asumption that advance care planning for children should be about the conversation regardless of the outcome of the decision (Tatterton 2018). These significant factors influence advance care planning and impact on decision-making.

Despite emerging discussion about complex end-of-life decisions for children with life-limiting conditions (Mitchell et al. 2019) there remains limited evidence about how to conduct advance care planning discussions and how parents are able to manage decisions with increasing options for treatment and intervention. In particular, how to address issues of complex care and life-sustaining treatments (LST) in relation to withholding or withdrawing such treatments. Such difficult decisions impact on decision-making for the family and health care professionals.

2.4 Limitations in knowledge

It is clear there are significant gaps in our knowledge about children's advance care planning (Lotz et al. 2017) that requires development. Specifically, there is disagreement about the benefits and value for parents of completing a document and when to initiate a conversation. It is reported that conversations should take place following cues from parents however, we do not know what these cues might be. There is an assumption that advance care planning is increasingly complex due to increasing life expectancy and options for treatment and care yet there is limited evidence to describe such complexity. Moreover, it is noted that advance care planning involves discussion related to medical decision-making and psychosocial and spiritual dimensions of care but we do not know what this means for parents. Research with parents and children to understand their views and experience is missing. The emerging findings of complexity, ongoing conversations and parents chioce to keep options open, challenges what constitues advance care planning in children's palliative care and how we should approach conversations with parents. The analysis of the literature suggests that the current understanding is inconsistent and not fully understood. It fails to recognise what is important to parents and how they would wish to engage in advance care planning conversations.

Therefore, the subject of advance care planning and understanding advance care planning practice from a parent's perspective, is an essential place to start. Knowledge gained will enable health care professionals understand how and when to have conversations with families and provide the effective support of parents whilst they are caring for their child at the end-of-life. This scoping review provides an essential first step towards developing the study reported in this thesis.

2.5 Understanding of advance care planning at the start of the study

By exploring the breadth of literature the scoping review enabled understanding of the current interpretation of advance care planning. Although recognised in both policy (DH 2008a) and practice (NEOLCP 2008, TFSL 2018, NICE 2016) there was no agreed definition (Lotz et al. 2013). Thus, the premise at the start of this thesis was that:

> *Advance care planning is a process of discussion involving timely and sensitive conversations, between an individual and their care providers about their needs and wishes in the context of deterioration of their condition. Advance care planning may therefore lead to decisions such as advance decisions to refuse treatment, Do Not Resuscitate orders and the appointment of a lasting Power of Attorney. It may involve advance statements about priorities for care and preferred place of care and death.*

Within children's palliative care advance care planning discussions take place with the child/young person if they have capacity, and their parents and care providers.

2.6 Chapter summary

In summary, the scoping review helped to identify the central themes within the field that support the background to the study (Coffey & Atkinson 1996) and ensured a similar study had not been done before, whilst recognising existing knowledge (Creswell 2013). It revealed that advance care planning is routinely used in children's palliative care. However, despite a growing evidence base, the initial scoping review identified a gap in knowledge about how advance care planning is used in the context of children's palliative care. Observations of practice suggest the process of advance care planning is complex and challenging yet little research exists to help understand what this means for parents' in their experience of advance care planning for their child. A study to understand parents' experience and perspective of advance care planning is clearly warranted.

Given the complexity of advance care planning and the dynamic interpretations of end-of-life conversations, a theoretical framework is required to explain what is occurring. The next chapter provides a rationale for why a grounded theory research approach was used to answer the research questions.

Chapter 3 Research method

This chapter provides a rationale for why a grounded theory methodology was appropriate to address gaps in research knowledge identified through the scoping review. It is the first of two chapters explaining the study's research methods and process of analysis. Considerable attention was given to ethical issues related to investigating parents' understanding of advance care planning to ensure an ethically sensitive approach was taken throughout the study.

3.1 Selection of methodology

Indications from the literature and observations from practice revealed that advance care planning discussions were co-constructed from conversations between professionals and parents. Thus, a methodology was needed which explained how and when this happened and which took account of the factors influencing the process. (Strauss & Corbin 1990).

This pointed to a situated and interpretative design. Interpretive designs including phenomenology, ethnography, narrative and grounded theory (Corbin & Strauss 2015) share the philosophical perspective that human action and experience can be understood through meaning, language and communication (Charmaz 2014) and that society, reality and self are constructed through interaction. However, each of these approaches are rooted in different philosophical traditions, and have different purposes.

To address the aims and purpose of the study grounded theory was considered appropriate because it enables the identification and description of phenomena and associated social psychological processes (Charmaz 2014) important for understanding the complexity of the advance care planning process. Moreover, grounded theory stresses the importance of the context in which people live, and this was considered crucial for understanding advance care planning in the context of parents' experience of caring for a child with a life-limiting illness.

In contrast, phenomenology would focus on the meanings ascribed to advance care planning by parents and how these meanings shape the experience of being a parent to a child with a life-threatening or life-limiting illness. An ethnographic approach would focus on the cultural meanings of advance care planning, and by determining these be concerned with explaining societal influence and purpose of advance care planning. A narrative approach would focus on social understandings of advance care planning, captured through the way in which parents constructed their experience (Creswell 2015).

Grounded theory has the advantage of examining the social processes that occur in advance care planning and how these influence parents' experience and how the advance care planning documents are used. Grounded theory, draws on multiple sources of data to develop understanding and an explanation of these dynamics. Thus, the goal was to develop an explanation of the social psychological processes of the study and to develop a theory.

Grounded theory was also congruent with my own truths and beliefs about 'being' and how knowledge is created and embedded in social life; in particular, how knowledge is constructed through situated contexts and interactions, and how experience and values influence my interpretation and understanding. Different approaches to grounded theory also emphasise the interaction between the researcher and participant as an inherent part of the research and includes what researchers and participants bring to it and do within it (Clarke 2005). This position was important given the in-depth encounters I had with parents throughout the study and how my interpretation of data influenced the findings.

Thus, a grounded theory approach provided congruence between the purpose, questions and methods of this study. It was chosen to generate new perspectives and explanations about parents' experience. Furthermore, while previous studies investigating advance care planning have used quantitative and qualitative approaches the scoping review revealed none had utilised a grounded theory design.

3.1.1 Philosophical basis of grounded theory

Grounded theory embraces a process of interaction between people and the way they understand their social world and is a method to study social psychological process. It attempts to discover the core process, in a given situation, from the perspective of participants. It supports an emergent theory grounded in data and can provide a substantive and formal theory (Glaser & Strauss 1967).

Glaser and Strauss (1967) developed grounded theory as a way to extend the boundaries of qualitative inquiry and developed a theoretical framework to provide abstract, conceptual understandings of the studied phenomenon. They aimed to make grounded theory more accessible to researchers and more meaningful to understanding practice.

The methodology is influenced by the philosophical position of both Glaser and Strauss and combines an in-depth interpretative analysis and principles of symbolic interactionism (Strauss) with a rigorous and robust research process (Glaser), and offers a theoretical framework to afford explanations of experience and social process. It provides researchers with a methodology to capture complexity and variation within the identified problem.

Despite their different philosophical backgrounds, grounded theory is arguably rooted in a sociological perspective of pragmatism and social behaviourism (Kenny & Fourie 2015), a philosophical position focused on social interaction and interpretation (Mead 1934). Mead described humans as innately social beings, interpreting their individual sense of the world and communicating it to others. He stated that individuals develop their own meaning of the social world based on others' behaviours, how they interpret these behaviours and then respond to them. Actions and responses can be planned, but also influenced by others' expectations and the social world around them. This concept of how the mind and self emerge from the social process of communication is fundamental to the theory of symbolic interactionism, coined by Blumer (1937).

Glaser and Strauss subsequently developed two divergent views in approach and methods which has led to numerous variations of method (Glaser 1978; Strauss & Corbin 1990; Clarke 2005; Charmaz 2006). Recent adaptations of grounded theory build on a classic grounded theory approach (Glaser and Strauss 1967) to achieve a feminist and social perspective (Clarke 2005), a greater depth of analysis (Schatzman 1991) and recognition of the experience and perspective of the participant (Charmaz 2006). Contemporary revisions therefore take a relativist epistemology and acknowledge the multiple standpoints of both the research participant and the researcher, to enable a strong reflexive stance of actions, situations and interpretation (Morse et al. 2009).

Critical debate in the literature considers the credibility of such methodological divergence (Morse 1995; Dey 1999; Amsteus 2014) and whether deviations in method and approach take the research process beyond the limits of classic grounded theory (Piantanida et al. 2004). However, Glaser and Strauss in their original work (1967) and in later developments of the grounded theory approach (Strauss & Corbin 1990; Glaser 1992) describe the importance of a methodological flexibility and an open-mindedness that embraces a continually evolving research process. Therefore, the credibility of grounded theory is less about following a classical approach, and more about providing a transparent research process that demonstrates inductive and deductive methods (Amsteus 2014; Charmaz 2014), and adopting research methods that fundamentally promote thinking about process and structure (Strauss and Corbin 1990). It is clear from the debate that grounded theory should not be a prescriptive step-by-step process, but more importantly, an approach that enables the researcher to make meaning of their data. The process should demonstrate a justification and commitment to understand the identified 'problem'. The value of grounded theory is therefore its fit and flexibility (Glaser 1978; Charmaz 2014) and practical applicability to understand human action. A grounded theory is more than a descriptive account it is a robust analytical product.

After considerable analysis of the different grounded theory approaches, by charting the different ontological, epistemological and methodological approaches (See Table Appendix C) Charmaz constructivist grounded theory (2006) was selected.

This epistemological and methodological approach provided flexibility and enabled a personally meaningful approach to explore parents' experience of advance care planning through their own words (Charmaz 2006) and to investigate the complexities of advance care planning practice. It was also congruent with the co constructed nature of advance care planning and my standpoint of the inherent interaction of the researcher-participant relationship. In particular, my belief that the researchers involvement influences the construction and interpretation of data. Another important consideration was its alignment to the nursing and my worldview to understand the subjective experience of patients. A constructivist grounded theory approach was adopted and followed throughout the rest of the study.

In addition, Clarke's (2005) situational analysis approach was used to strengthen the interpretative inquiry. Using Clarke's situational analysis alongside a constructive grounded theory approach, offered access to analysis of specific contexts and types of interaction, often hidden in difficult and unexplored areas of health care practice (Clarke 2005). It broadened the network analysis, important when investigating the variation within constructs (Carmichael & Cunningham 2017). Moreover, it enabled a deeper exploration of the differences and distinctions between people and the hierarchies of power (Clarke 2005) which were important to investigate in the process of advance care planning. The analytical advantage of using situational analysis is that Clarke explicitly emphasises the involvement and contribution of all salient social worlds drawing on internal and external concerns.

Furthermore, both Charmaz (2014) and Clarke (2005) emphasise the value of engaging in supplementary analysis to enrich the development of concepts. Clarke argues that situational analysis can be used to provoke analysis to explicitly focus on the social process and power constructs of a situation that otherwise may be missed. Charmaz and Clarke recognise that this approach goes beyond traditional versions of grounded theory but believe it accounts for deeper analysis concerning non-human factors, discourses and structural elements of the studied situation (Charmaz 2014 p.220). Furthermore, Charmaz emphasises the value of combining grounded theory methods to provide a robust frame for qualitative enquiry rather than accentuating different methods. She claims that all variants of grounded theory offer helpful strategies for collecting, managing and analysing data (Charmaz 2014 p.15).

Charmaz and Clarke also embrace a feminist standpoint underpinning their research methods, one that recognises the importance of relationship and connections. Understanding relationships and connections was crucial for the analysis to find a way to hear and represent complex layers of personal and political perspectives within the process of advance care planning.

In summary, the study is informed by a classic grounded theory and symbolic interactionism approach (Glaser & Strauss 1967) and draws on current adaptations that combine Charmaz (2006) constructivist approach and Clarke's situational analysis (Clarke 2005) to strengthen the interpretative inquiry and social perspective of the study. A constructivist approach (Charmaz 2006) is used to elucidate the key elements of process and structure within the practice of advance care planning and a supplemental situational analysis (Clarke 2005) is used to take account of the wider social circumstances that influence and impact on advance care planning. These recent advances in grounded theory made by Charmaz (2014) and Clarke (2005) enable the study to address situated analysis of complex advance care planning situations revealing meaningful constructions of reality (Charmaz 2006) within the context of children's palliative care. This process of interpretation and analysis has the capacity to generate a theory that can inform health care practice.

3.2 The method

The key principle of grounded theory is to generate theory by being grounded in data from the field alongside simultaneous involvement in data collection and analysis, the constant comparative method. The central method of grounded theory is constant comparative analysis for the development of categories and their properties. The fundamental features integral to grounded theory; constant comparison, coding, memoing, theoretical sampling, theoretical sensitivity and saturation, emphasise the importance of process and structure. By using inductive and deductive methods, grounded theory (Glaser and Strauss 1967) provides a systematic construction of theory that explains process, action and interaction, emphasising a greater understanding between concepts and experience. At the same time the methods and process remain open minded and flexible to the focus of the study (Morse et al. 2009; Charmaz 2014). The analytical process generates an emerging theory. Grounded theory is thus a process and a product that moves through phases of refining data collection, raising terms to concepts, asking more conceptual questions and making further discoveries and clarifying concepts (Charmaz 2014).

The subsequent section explains how the methodology was translated into a method for this study and how a constructivist grounded theory and situational analysis approach was used to meet the aims and objectives of the study. It addresses in detail the ethical issues raised by the study.

3.2.1 Patient and public involvement

Patient and public involvement (PPI) has received increasing attention in healthcare improvement and research (NIHR 2020), and emerging evidence highlights the benefits of public and patient engagement (Holmes et al. 2019). Active involvement of service users in research can lead to research of greater quality and relevance due to the unique perspective that users bring to the research (Brett et al. 2014). However, there is some concern about the impact of PPI in relation to the lack of evidence relating to patient reported outcomes in research (Haywood et al. 2015).

Given the lack of research about parents experience of advance care planning it was important to consult parents in the design of the study but to take into account that little is known about the impact of PPI on participants. Thus, this was carefully considered when approaching parents to ensure accurate information was given in relation to the purpose and outcome of their involvement. The focus was one of engagement with parents rather than PPI as an outcome in itself.

Parents were informed of the study through the local children’s palliative care network, which had a number of parent representatives who regularly supported network activity. Parents, who expressed an interest in the study, were invited to be part of the advisory group. Those who were part of the advisory group were not participants in the study.

Four parent advisors who had direct experience with advance care planning contributed to the design of the study. All the parents on the advisory group were mothers. Two parents were bereaved and two currently supporting their child with a life-limiting condition. The conditions of the children matched the sample population and included oncological, neurological and progressive conditions. All four parents had experience of community nursing and hospital care and two parents of hospice care. All four parents had engaged in advance care planning conversations and two had completed advance care plans.

The purpose of engagement with the PPI group was to support the design of the study by drawing on the unique experience of parents caring for children with life-limiting illness. Communication and valuing parents’ contribution was central. This was achieved by regular contact and informing the group of how I collated and used their feedback.

All four parents participated in the design of the study. They each contributed to the wording of the participation information sheets (PIS) and the interview questions to ensure that the study was relevant to their experience and sensitively managed. In response to parental feedback, the PIS were altered to ensure I differentiated between parents caring for children and bereaved parents, and to ensure the language was appropriate to their individual experience. The interview questions were revised to capture factors of advance care planning that the PPI group believed would be significant to know (See section 3.2.4), for example the involvement of siblings in advance care planning discussions. I shared the changes I made to the PIS and interview questions to ensure I had interpreted their comments accurately. This feedback and comments proved invaluable and provided robust evidence during ethical approval for the formulation of the research proposal, PIS and initial questions. One of the parents participated in a pilot interview (See section 3.2.4).

In addition, the parent advisory group strongly informed the sampling strategy and the population required to answer the aims of the study. They emphasised the many different stages of advance care planning throughout the child's illness and the importance of including both parents caring for a dying child and bereaved parents to offer unique and valuable insight to the experience of advance care planning.

Communication with the PPI group took place throughout the study via email predominantly in the early stages of the research design. Communication with parents offered a sense check in the initial direction of the study and that early findings resonated with their own experience. Although all members of the group participated in early stages of the study and were keen to contribute to outputs of the study in posters, presentations and publication, there was potential to use the advisory group in other areas of the study, for example, interpreting the data as suggested by Blackburn et al. (2018). Thus PPI involvement met indicators of good practice, (NIHR 2020) in relation to the study design phase and the clear benefits derived from this involvement was a strength of the study.

3.2.2 Sampling strategy

In planning the study considerable thought was given to how best to gain knowledge of advance care planning practice in children's palliative care and whether this should involve parents (bereaved and those caring for a child) and/or children with a life-limiting condition. Having recognised the limited knowledge available about advance care planning practice the logical place to start to inform an understanding of the complexities of practice lay with parents and they were selected to be the primary participants in this study. Parents were chosen as they are central to the decision-making and coordination of advance care planning for their child and offer a rich source of data to improve understanding and build practice knowledge of advance care planning.

Children were not participants in this study but they were the subjects of advance care planning and in some cases were directly involved in discussions. They were also part of the family system influencing the dynamics of advance care planning, so although the child was not a direct participant in this study they were actively involved in the advance care planning process and inherently connected to the systems and structures under investigation.

Sampling was purposeful, meaning that parents were selected because of their ‘fit for the purpose’ of answering the research questions about advance care planning. Purposeful sampling provided ‘information rich cases’ (Patton 2002) and was undertaken in this way to gain insight into the particular field of study (Carmichael & Cunningham 2017). Purposive sampling was employed to ensure there was a sample including mothers and fathers, bereaved, non-bereaved and with children with different conditions.

The study population were parents of children with a life-limiting or life-threatening condition. The sample was taken from England, as current practice of advance care planning is largely influenced by English policy, and from the caseload of a children’s community nursing team (CCNT), as they were primary health care professionals responsible for the care of children with a life-limiting or life-threatening condition and their families.

Inclusion and exclusion criteria (Table 3.1) were applied to ensure the sample met the aims and purpose of the study. All parents (mothers and fathers) from the CCNT caseload who met the inclusion criteria were invited to participate. This was inclusive of parents who were currently caring for a child with a life-limiting condition and bereaved parents. The inclusion of both parents caring for a child with a life-limiting illness and bereaved parents was considered valuable to understanding parents’ perspective. Parents caring for a child with a life-limiting illness share current experience of advance care planning whilst facing the death of their child and current influencing factors. Whereas bereaved parents, despite the bias of recall are able to reflect on their child’s end of life and the influence of advance care planning decisions. They are able to share what they wished had gone differently.

Parents could participate whether they had completed an advance care plan or not because many parents are engaged in advance care planning conversations but may not have a completed document.

Table 3.1 Inclusion and exclusion criteria

Inclusion

- Parents identified within the regional caseload of the CCNT
- Parents (mothers, fathers and partners) of children aged 0-17 years with a LLC or LTC
- Bereaved parents of a child aged 0-17 years who had a LLC or LTC

Exclusion

- English speaking is required as there are no funds available for an interpreter for non-English speakers.
- Parents accessing services in the region of the researchers practice
- Parents will not be approached whose child was too unwell as determined by the CCNT

The initial sample was recruited from the South Central region as this area had developed and implemented a unified advance care planning document for children and young people. At the start of the study, a site was identified where data demonstrated a significant population of children with a life-limiting or life-threatening condition (n=207) (Fraser et al. 2011). This was deemed feasible to meet the sampling criteria and gain access to participants who would be willing to participate in the study. Permission was gained from the relevant NHS Trust. The aim was to provide a reasonable sample to capture the experience for parents of engaging in advance care planning. Defining a specific area made the study manageable, in particular when dealing with multiple research governance arrangements. A subsequent site was included later in the study to support recruitment and access.

Sample size

There has been considerable discussion about sample size in qualitative research but with little definitive guidance as to what constitutes a sufficient sample (Mason 2010; Carmichael & Cunningham 2017). Grounded theorists have taken different positions on sample size and guidance varies from six participants to 35. Most authors offer the guiding principle of saturation (Mason 2010). Charmaz (2014) describes sample size in relation to saturation but also argues that a small sample can produce a study of lasting significance depending on the quality of the interviews and the depth of analysis. In grounded theory, factors such as, appropriately selected participants (Bryant 2002) and the effective use of theoretical sampling (Charmaz 2014) are influential in guiding sample size. However, despite this guidance, there is still a tension to quantify the sample to meet institutional research governance requirements. Thus, the exact number of participants required to answer the research question was not entirely predictable but estimated to be around 12 interviews.

Thirteen parents were recruited; their characteristics are shown in table 3.2. The table demonstrates where parents requested either use of a pseudonym or their child's own name in the study report (thesis) and publications, during the consent process (see 3.3.2/3.3.3). As recommended by the PPI advisory group the study population includes parents who were either caring for a child or whose child had died of a life-limiting or life-threatening condition. All parents were recruited through and therefore were known to the children's community nursing service. In addition, all had significant experience of hospital care. All but one of the parents also received care from a hospice service. This supported a greater understanding of parents' experience of advance care planning across settings. All parents had been engaged in some conversation about advance care planning and all but one had a completed advance care plan document.

Table 3.2 Sample demographics of participants and their child

<table>
<tr><th>Participant Identification No.</th><th>Sex</th><th>Relationship to child</th><th>Current / Bereaved</th><th>1.Own name 2.Pseudonym</th><th>Child's age</th><th>Child’s condition</th><th>Time of Diagnosis</th><th>Consent to share advance care planning</th><th>Resuscitation status</th><th>Length of time advance care plan held</th></tr>
<tr><td>1/250116/1c</td><td>F</td><td>Mother</td><td>C</td><td>Charlotte (2)</td><td>5yrs</td><td>Chromosone 18 (Genetic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>2 years</td></tr>
<tr><td colspan="11">Charlotte was the family’s eldest child and had a younger sister. She was born at 31 weeks gestation with multi complex symptoms and diagnosed with a genetic condition. She had been in and had multiple admissions to PICU. She was entirely dependent on her parents for her care and had a gastrostomy and enteral feeds. She had complicated seizures and frequent respiratory infections. The family accessed the local hospice for respite support. Her parents took a number of months to complete her ACP, which involved numerous conversations with her community nurse and the hospice team.</td></tr>
<tr><td>2/301115/1c</td><td>F</td><td>Mother</td><td>C</td><td>Lewis (1)</td><td>7yrs</td><td>Complex Cerebral Palsy</td><td>Birth</td><td>Yes</td><td>Full</td><td>18 months</td></tr>
<tr><td colspan="11">Lewis was the second child. His elder brother was nine. He was born with complex cerebral palsy due to premature brain injury. He had complex seizures and severe gut dysmotility. He was enterally fed and dependent on his parents for all his care. He had shown a gradual deterioration in his condition over the previous 6 months. His family accessed the local hospice for respite support. His parents had a completed ACP and had regular ongoing conversations with his paediatricians because of his changing condition.</td></tr>
<tr><td>3/070116/1c</td><td>M</td><td>Mother</td><td>C</td><td>George (2)</td><td>12yrs</td><td>Congenital Heart Defect</td><td>Birth</td><td>Yes</td><td>Full</td><td>4 years</td></tr>
<tr><td colspan="11">George was the eldest of two boys. He had a severe cardiac condition that meant his life was threatened by sudden death. He managed to attend school for some part of the day but became tired very quickly. He experienced many admissions to hospital and overcame numerous crisis events. He had recently been diagnosed with epilepsy, which had further complicated his condition. His parents had written an ACP with his consultant, to ensure that when George collapsed paramedics and HCP’s would do everything possible to resuscitate him.</td></tr>
</table>

<table>
<tr><th>Participant Identification No.</th><th>Sex</th><th>Relationship to child</th><th>Current / Bereaved</th><th>1.Own name 2.Pseudonym</th><th>Child's age</th><th>Child’s condition</th><th>Time of Diagnosis</th><th>Consent to share advance care planning</th><th>Resuscitation status</th><th>Length of time advance care plan held</th></tr>
<tr><td>5/220115/1c</td><td>F</td><td>Mother - Partner of 8</td><td>C</td><td>William (2)</td><td>8yrs</td><td>1p36 deletion (Genetic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
<tr><td colspan="11">William had an elder sister. He was born with a degenerative life-limiting condition and dependent on his family for all his care. He had multiple complex symptoms and suffers from seizures and recurrent chest infections. He had experienced many admissions to hospital. His family spent regular time at the local hospice. Although engaged in a number of conversations his parents found it difficult to complete the ACP form.</td></tr>
<tr><td>6/100516/1c</td><td>M</td><td>Father</td><td>C</td><td>Bethany (1)</td><td>12yrs</td><td>Chromosonal disorder</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
<tr><td colspan="11">Bethany was an only child. She had complex symptoms as a result of a chromosonal disorder. She was dependent on her parents for all her care. She was highly susceptible to infection which could cause a life threatening event. She had experienced multiple crisis events with admissions to PICU.
Her parents hoped the ACP would avoid the need to constantly repeat information and being asked questions at difficult times. Her parents were her sole carers and they did not like to leave Bethany in hospital or in respite care. They had completed an ACP to ensure rapid response to a crisis situation.</td></tr>
<tr><td>7/250416/1c</td><td>F</td><td>Mother</td><td>C</td><td>Finlay (1)</td><td>2yrs</td><td>Aicardi-Goutaieres Syndrome (Genetic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
<tr><td colspan="11">Finlay was the youngest of two boys. He was born with a severe genetic condition with multiple complex symptoms. He was not expected to live to his first birthday. His parents discussed and wrote an advance care plan in the first few weeks of his life.</td></tr>
<tr><td>8/100516/1c</td><td>M</td><td>Father Partner of 5</td><td>C</td><td>William (2)</td><td>8yrs</td><td>1p36deletion (Genetic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
</table>

<table>
<tr><th>Participant Identification No.</th><th>Sex</th><th>Relationship to child</th><th>Current / Bereaved</th><th>1.Own name 2.Pseudonym</th><th>Child's age</th><th>Child’s condition</th><th>Time of Diagnosis</th><th>Consent to share advance care planning</th><th>Resuscitation status</th><th>Length of time advance care plan held</th></tr>
<tr><td colspan="11">See 5/220115/1c</td></tr>
<tr><td>9/130317/1cj</td><td>F</td><td>Mother partner of 12</td><td>C</td><td>Beatrix (1)</td><td>7yrs 10mths</td><td>Wolf Hirschhorn Syndrome (Metabolic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
<tr><td colspan="11">Beatrix was the eldest of three. She experienced many complex symptoms related to her condition and was dependent on her parents for all her care. She suffered from complex seizures, was enterally fed and had spent long periods of time in hospital. She suffered from brittle bones which further complicated her condition. Her family occasionally accessed the local hospice for respite support, however her mum had used the counselling service for periods of time throughout her daughter’s life. Her parents had only recently been introduced to ACP to support decisions at time of crisis and admission to hospital.</td></tr>
<tr><td>10/230117/1b</td><td>F</td><td>Mother</td><td>B</td><td>Brooke (1)</td><td>11mths at death</td><td>SMA Type 1 (Neuromuscular)</td><td>I month</td><td>Yes</td><td>Modified</td><td>2 months</td></tr>
<tr><td colspan="11">Brooke was 11 months when she died. She was an only child. She suffered from a progressive condition that required acute intervention and visits to PICU. Her parents were engaged in discussions about end-of-life care and treatment options from diagnosis. They held an ACP which was reviewed on several occassions as her condition deteriorated.</td></tr>
<tr><td>11/100317/1b</td><td>F</td><td>Mother</td><td>B</td><td>Dylan (1)</td><td>13yrs at death</td><td>Tumours of the spine (Oncology)</td><td>11 years</td><td>No advance care plan</td><td>Full</td><td>n/a</td></tr>
<tr><td colspan="11">Dylan died aged 13 from cancer. He had been a healthy young boy reaching all stages of development until he presented with severe pain in his legs and back at age 11. Treatment was unsuccessful. At the time of his death, his parents did not have an ACP. They have subsequently</td></tr>
</table>

<table>
<tr><th>Participant Identification No.</th><th>Sex</th><th>Relationship to child</th><th>Current / Bereaved</th><th>1.Own name 2.Pseudonym</th><th>Child's age</th><th>Child’s condition</th><th>Time of Diagnosis</th><th>Consent to share advance care planning</th><th>Resuscitation status</th><th>Length of time advance care plan held</th></tr>
<tr><td colspan="11">spoken about the benefits they felt they would have gained from being able to talk about possible options and care. They wished they had been advised about the opportunity to have an ACP conversation.</td></tr>
<tr><td>12/130317/1cj</td><td>M</td><td>Father partner of 9</td><td>C</td><td>Beatrix (1)</td><td>7yrs 10mths</td><td>Wolf Hirschhorn Syndrome (Metabolic)</td><td>Birth</td><td>Yes</td><td>Full</td><td>1 year</td></tr>
<tr><td colspan="11">See 9/130317/1cj</td></tr>
<tr><td>13/150617/1bj</td><td>F</td><td>Mother partner of 14</td><td>B</td><td>Catherine (1)</td><td>14yrs 4mths at death</td><td>Cerebral Palsy</td><td>Birth</td><td>Yes</td><td>DNACPR</td><td>8 months</td></tr>
<tr><td colspan="11">Catherine had an older brother. She had died following a gradual deterioration in her condition and no longer being able to maintain her own airway and becoming increasingly susceptible to recurrent chest infections. She had been dependent on her family for all her care and regularly visited the local hospice for respite care. Her parents initially completed an ACP to ensure intervention during crisis episodes but later reviewed options of care as her condition deteriorated. They reviewed the ACP on several occasions moving from decisions for full resuscitation, to modified resuscitation and then a final decision of do not resuscitate.</td></tr>
<tr><td>14/150617/1bj</td><td>M</td><td>Father partner of 13</td><td>B</td><td>Catherine (1)</td><td>14yrs 4mths at death</td><td>Cerebral Palsy</td><td>Birth</td><td>Yes</td><td>DNACPR</td><td>8 months</td></tr>
<tr><td colspan="11">See 13/150617/1bj</td></tr>
</table>

3.2.3 Participant recruitment and access

Parents were identified and recruited through the children's community nursing team (CCNT). The study was introduced and progress discussed with the team at their weekly meeting. The CCNT assessed a potential participant against the inclusion and exclusion criteria and if participants met the inclusion criteria, they were given a detailed Participant Information Sheet (PIS) (Appendix D). There were two separate PIS - for parents currently caring for a child and bereaved parents. If parents wished to participate in the study, they completed and returned the tear off slip. I made the first telephone contact with parents to give a brief outline of the study and explain next steps regarding participation in the study and consent process. A meeting was organised to address any remaining questions, to complete the consent forms and conduct the interview. The CCNT were kept informed of a parent's decision to be involved in the study and this was recorded in the care files.

I wanted to ensure equity of access for research participation and hoped the CCNT would engage with all parents identified as eligible in the research protocol. However, despite ethical approval for the intended recruitment process, accessing participants was a significant challenge. Specifically, parents who met the study criteria, were not invited to participate when the community nurses felt it inappropriate for them to discuss advance care planning. To manage these difficulties, I increased the time I spent with the team so I could understand their concerns.

Reflective discussions with individuals and the team as a whole revealed several underlying reasons impacting on recruitment of parents. The overriding concern was one of confidence in talking about end-of-life decisions and therefore in introducing the study. The nurses were hesitant in handing out the PIS. This was captured in my research diary (Box 3.1) as I reflected on how initiating conversations about the study mirrored those in practice when nurses are talking about end-of-life with parents.

Box 3.1 Extract from research diary 1st April 2016

Correspondence with CCNT who are asking me to change the PIS and take out the end-of-life sentence so they feel more able to give out to parents. I explained this was not possible and why - but it also prompted questions about their anxiety in introducing the study and discussing advance care planning and end-of-life. It feels as if the very process of undertaking the study mirrors my fear of what is happening in practice in relation to nurses / professionals who are too frightened / lack confidence in talking to parents and are fearful of the parent's response. Thus, when the conversation does take place it is on the HCP's terms and agenda so they feel comfortable, but does this meet the needs of parents? This provides further evidence for needing to do the study to support HCPs to have conversations in practice.

Further reflections and observations suggested that parents were perceived as vulnerable (although not necessarily self-defined) and there was a tendency for children's community nurses to inadvertently influence parents not to take part (Wanat 2008) by emphasising they may find it hard. This required ongoing attention. Discussions necessitated constant encouragement in the knowledge that parents generally did want to be involved, and whilst they might express how hard it was to talk – this did not mean they did not want to.

A number of other reasons were voiced, impacting on access. The children's community nurses felt it was not an appropriate time; that the study might cause distress; that the child was unwell and that the social circumstances of the family meant it precluded them from participating in the study. In addition, changing organisational structures both internally and regionally, influenced the capacity of staff to support the study alongside the pressures of managing their caseload. The team were faced with a constant change of staff with three team leaders within a twelve-month period. This had an impact on my contact and ongoing communication and in particular seeking a champion for the study on a weekly basis. Furthermore, there were some practical challenges including, forgetting to take the PIS on visits.

I also needed to consider the challenges I faced in how I was perceived. I was credible as a clinician having worked in children's palliative care practice for a number of years. I came with a significant background in the field that offered a rich context of understanding, but it took time to be seen as a credible researcher (Kennedy-Macfoy 2013). These issues of working in the field were against a backdrop of a changing NHS and the demands of working within an environment of uncertainty and constant change. In summary, there was a need to rethink the routes and modes of access and ways of negotiating access (Wanat 2008) rather than assume the children's community nurses would hand out the PIS to anyone that met the inclusion criteria. Together we identified a number of actions. We met regularly and I invested in building relationships and empathising with their situation. I was open to dialogue to allay fears (Wanat 2008) and able to draw on a feminist ethical and collaborative approach, recognising that these relationships were unpredictable, and ever changing. We discussed how they were approaching conversations with parents (Crowhurst 2013) and how to support approaches that would initiate dialogue and guidance on what to say. We were able to identify a champion for the study, which helped the team to identify families that met the inclusion criteria and to ensure the PIS were distributed. On a practical note, we discussed always keeping copies of the PIS in their diaries so they were easily accessible.

Subsequent encounters revealed a change in the dynamics of the relationship, to one of greater trust where the nurses were interested in and voiced the value of the study. On reflection, there was a shift in my understanding about the research process, from using the nurses as a vehicle to access parents, to one where building empathetic relationships had a significant impact on the study. However, there remained an on-going culture of resistance to approaching parents to participate and the difficulties of gatekeeping provoked concern about adequate recruitment. This resulted in deciding to add a further site 12 months into the study in order to be confident of achieving sufficient participants.

3.2.4 Data collection

Two data collection tools were used to capture the breadth and depth of available data, an interview and a child's advance care planning document. The expectation was that the two techniques would complement each other and facilitate contextual understanding about how parents construct their experience of advance care planning and end-of-life care.

Intensive interviews are a way of generating rich data for qualitative research (Silverman 2007; Creswell 2013) as they create an open and interactional space for participants to relate their experience (Charmaz 2014). They were the primary data collection tool in this study as there were no other feasible ways of gathering the necessary and relevant data. There is, however, criticism of qualitative methods being saturated by interviews (Silverman 2007) and that interviews can be manufactured. It has been argued that interviews conducted under specific research conditions, can only give a retrospective narrative and critics warn that they cannot provide an authentic account of experience (Atkinson & Silverman 1997).

Despite this criticism, there was good reason to use interviews in this study rather than other qualitative methods, for example observation or case note review. Observation was not suitable as a method. Advance care planning discussions are frequently held at critical points when a child was unwell and conversations rarely planned ahead, making it difficult to access and observe these conversations as they occurred. Case note reviews would potentially provide some evidence where conversation had been recorded by professionals however, there are limitations to case note reviews in regards to bias and inaccurate or incomplete data (Chan et al. 2011). This method does not sufficiently allow for in-depth understanding of parent's experience. Furthermore, the scoping review revealed that previous studies which employed case note reviews failed to provide in-depth knowledge about advance care planning from parents' perspective. Crucially interviews were used to capture the voice and perspective of the parent, which is currently missing in the literature. Thus, a planned intensive interview enabled parents to share their experience in depth, at a time when they were not immersed in the critical care of their child.

Moreover, Charmaz (2014) acknowledges the criticisms raised about interviews as a data collection method and counters this criticism by emphasising the power of the interview to reveal meaningful experience. She claims that interviews can be a site of connection offering a depth not achieved in everyday life. Thus, using a constructivist grounded theory approach, interviews are a means to co- construct, and re-construct parents' experience and this provided a strong rationale for interviews as a method to talk with parents about the profound issues of their child's end-of-life care planning. In addition, they enable rich data about the context of advance care planning from parents' perspectives and of the social process and relationships associated with advance care planning. They enabled each parent to share their individual experience and interpretation of advance care planning (see interview design and conducting the interview). Interviews were conducted with all participants recruited to the study.

These key debates outlined were influential in planning the timing of interviews and when to ask parents to share their experience in relation to the illness trajectory. This informed discussion with my supervisors about the advantages and limitations of a prospective or retrospective approach. A prospective approach potentially would have advantage in capturing the detail of experience in a 'moment in time' whereas a retrospective approach was likely to capture experience after it had been processed and interpreted.

A prospective approach would have been time consuming and difficult to organise, given the unpredictability of changes in the child's condition and likely changes to parents decisions within the process of advance care planning. Therefore, the decision was made to interview parents wherever they were in the illness and bereavement journey. The interview would provide understanding about parents experience with advance care planning in relation to that particular time and how that was influenced by previous experience.

Collectively the interviews provided data of multiple encounters of advance care planning conversations that offered an interpretation of how and why parents changed their decisions and the subsequent outcomes within the advance care planning process.

Alongside interviews, advance care planning documents were used as a supplementary source of data and subjected to qualitative analysis. Documents provide a major form of data that can raise intriguing questions (Clarke 2005, Charmaz 2014). The children's advance care plans were a significant source to provide insight into the process of advance care planning as well as conducting interviews. They included co-constructed material shaped by parents and health care professionals and offered a representation of the conversational accounts of advance care planning discussions. They were considered within the study not just for their content but the process by which parents and professionals produced the document, what it was intended to accomplish and how they were viewed by parents. Thus, the documents were analysed for what they 'do' as part of the process of advance care planning. This was important to investigate given the assumed purpose and meaning of advance care planning documents to provide definitive decisions about end-of-life care.

Data collection was undertaken over a two-year period from April 2015 to March 2017. It was expected the number of interviews would yield sufficient data to inform the analysis and developing categories. However, due to the challenges identified with slow recruitment, the data collection period was extended for a further three months to June 2017.

Interviews

The aim of interviews was to seek parents' experience of engaging in conversation about advance care planning and to learn about parents own words and meanings. Being able to conduct intensive interviews with parents meant I was immersed in the context of advance care planning (Charmaz 2014) with parents and enabled in-depth exploration of the issues and situations of advance care planning. Moreover, interviews enabled me to explore areas of theoretical interest, to learn more about the process of advance care planning and to construct a theory (Charmaz 2014).

Interview design

The interview schedule was developed to offer shape and direction to the conversation and provide a structure and order. It was designed to be sensitive and reflexive recognising the nature of the topic and began with an open-ended question asking parents to share their experience of advance care planning. The aim was for parents to speak freely about any issues around advance care planning and to share their own personal stories.

The interview questions were informed by the gaps identified through the scoping review and shaped from feedback from the parent advisory group (See appendix H). The questions were designed to explore, not to force or interrogate, but to learn about parent's experience.

Following the initial question, I used prompts and supplementary questions to guide the conversation (See appendix G) and to cover areas of interest that would illuminate how and when parents were involved in advance care planning (Charmaz 2006). These prompts were used only when parent's dialogue ended and if these areas had not already been covered.

Prior to the first interview, a practice interview was undertaken with a parent from the parent PPI forum. The pilot enabled an evaluation of the proposed questions and format of the interview and subsequent changes were made, including how to frame the questions. It provided an opportunity to learn about interview style and increased my confidence in interviewing. This experience was invaluable in understanding the importance of the format, preparation, the need for clear explanations, and in conducting the interview itself and managing the recording. Furthermore, it increased understanding of the researcher- participant relationship and the power differentials present to ensure the participant was supported and felt in control. The practice interview was particularly helpful in gaining confidence to interview about a sensitive topic, to understand which terms and phrasing were acceptable to parents and to be able to ask supplementary and deeper questions to explore meaning. This was reflected in my researcher's diary (Box 3.2).

Box 3.2 Extract from research diary 22nd June 2015

Really good exercise to practise – it helped me to understand about using a leading question and to be confident in asking supplementary questions to gain a better sense of the parents' perspective and meaning of what they are saying.

But also how sensitive and aware I need to be of how I ask the questions given the nature of the subject about advance care planning and end-of-life.

The practice interview helped to create a better understanding of how to order questions and where to soften questions acknowledging the sensitivity of the conversation.

Interview preparation

Interview preparations were important, to establish and build relationships with parents. An initial phone call gave them a choice over when and where they would like the interview to take place. The interviews were planned within four weeks following the initial phone call. Two of the interviews were rescheduled as the child was unwell and the parents in hospital. These interviews were therefore undertaken within two months of the initial phone call. All parents chose to be interviewed at home. This was more comfortable for parents and supported the researcher-participant relationship. Furthermore, it proved the most convenient for parents whose children were at home from school or recently discharged from hospital.

The preparation time pre-interview enabled a greater confidence to develop between myself and the participant before the taped interview. Non-interview dialogue addressed issues such as personal introductions, an explanation of the study and the scope and format for the taped interview. In most cases, this time also focused on the children that were home to ensure parents were happy to continue with the interview with the child present or in an adjoining room. Other topics included any eventualities should the interview be interrupted or they wished to withdraw from the interview. Once initial information was shared and any questions had been answered, participants were asked to complete the consent form. This was then subsequently copied and put in the child's notes in the community children's nursing office.

Conducting the interview

All interviews were recorded to support accurate transcription and lasted from 45 minutes to 1 ½ hours. The interviews were framed through open-ended questions, intermediate and ending questions. The first three interviews were shaped by my knowledge and experience of interviewing and adopted a conservative and traditional approach. I acknowledged what the parents were saying, but dialogue was limited. The style was one of questioning but not intervening, drawing on the principle that the collection of data should be (as far as possible) uncontaminated by the researcher. This felt strained at times and reflections of the first few interviews prompted a change to the style of interviewing. Thus, the interviews were adapted and subsequent interviews took a more personal and conversational approach, to enable a more open and natural dialogue. I took an approach that reflected more a guided conversation (Conrad & Schober 2008) and one that recognised the inherent role of the researcher and the co-productive nature of the interview. Known as the ‘active interview’ (Holstein & Gubrium 1995), this approach offered a better fit with the underlying philosophy of symbolic interactionism, highlighting the inherent interpretative activity of interviewing (Holstein & Gubrium 1995). As I grew in confidence, I began to realise the value of this approach, captured in a reflection following an interview (Box 3.3).

Box 3.3 Extract from research diary 7th January 2016

I have been trying to adopt a more conversational approach to the interviews and so reflection of each interview has really helped to shape my learning, and understand the dynamics of the researcher-participant relationship. In this last interview, I initially questioned the explanation I gave to a question and was anxious that I had stepped outside of the interview remit (defaulting to my problem solving practitioner role). However, on reflection and reading the transcript, I believe it was this very information and engagement in a deeper understanding of advance care planning practice from me, (rather than just asking a series of questions) that created a space for deeper reflection and meaning from (the parent) I was speaking with. This enabled her to consider what the advance care planning process meant for her son as he got older. She stepped away from the past and present experience of advance care planning to allow herself the possible meaning of the advance care plan when he was a teenager – a time she had heard could prove complicated in regards to his condition. It gave her the opportunity to think and talk about something that she might not naturally have done as all other areas of the interview focus on the here and now.

Active interviewing had a significant impact on the shape of the study and enabled greater flexibility to go back to issues that participants had raised to gain a depth of understanding.

The interviews were also shaped by a constant reflexive approach. I was also able to draw on my nursing and palliative care experience and advanced communication skills to establish a rapport and enrich the conversation. As I reflected on the interviews in my diary (Box 3.4) I was able to recognise how I was using my knowledge and skills to support parents throughout the interview.

Box 3.4 Extract from research diary 7th January 2016

In this interview, I noticed that if I listened and was confident to leave pauses, mum would fill these gaps with more information which I would have cut off if I had asked another question. By really listening, I was able to sense that there was more she wanted to say and although I felt I was pushing the pauses and my lack of confidence made me feel uncomfortable, it was worth it and she spoke in more depth.

At the end of each interview, time was taken to talk through any further support the participants might need and what they should do if they felt they wanted to make any changes to the advance care plan. The community nurses were informed that a parent had taken part in an interview and were asked to make a follow up call.

Notes were taken immediately after the interview to record any non-verbal observations as an aid to the transcription. As the study progressed data collection became more focused and selective on particular subjects to explore developing themes and concepts.

Transcription

Transcription is the process of converting recorded data to text. I transcribed verbatim all the audio files to enhance my knowledge and meaning of the data. As a novice researcher this enabled reflections on the interview process, style and skills and immersion in the data (Holloway & Wheeler 2002). I tried to catch every detail including emotions, silences and interruptions, to ensure the transcription was accessible and meaningful. I used continuous memos in the process of transcription to support thoughts, reflections and early analysis as the transcription was taking place. Once the transcripts were finalised initial coding was carried out.

Advance care planning documents

The documents were analysed using Clarke’s situational analysis maps (Clarke 2005) and analysis of their content and process integrated into the wider theoretical analysis. This provided further insight into the relationship between the document and conversations, as well as clarifying the social and power constructs within the context of children’s palliative care. It enabled an understanding of the parents’ voice in the writing and implementation of the document, as they moved from space to space, passed between professionals and from one organisation to another.

Consent to receive a copy of the advance care plan was sought at the interview and subsequently requested from the CCN. All documents were received by post within 3 weeks of the interview. The document was analysed after the transcription and analysis of the interview.

Analysis of the documents were not an end-point but used for ‘opening up’ the data to interrogate in fresh ways. Thus, I considered the documents as an ‘analytical exercise’ to enhance the depth of the analysis in order to more adequately portray parents’ voice and their experience. Charmaz (2014) also urges consideration of what is not recorded, to inform and shape theoretical questions. Moreover, on discussion with my supervisors, I was concerned that if I had analysed the advance care plan prior to the interview, the interview would be influenced by the information gathered from the document. This could have potentially directed the conversation about its content and consequently become a discussion focused on problem solving. In contrast, I wanted parents to speak openly and freely about their experience.

Nevertheless, it was important to consider whether parents would want to consult their advance care plan document, if one was completed, in the interview, to provide detail or justify their decisions if they chose to do this. I decided this was appropriate as the document was part of their experience

All participants interviewed were asked for a copy of their child’s advance care plan for me to read. One parent did not have an advance care plan for their child and where I interviewed both parents of a child, there was one advance care plan, there were nine advance care plans used in the analysis.

Other data sources

In addition to interview and advance care plans, other sources of data and documents informed analysis. These included literature, biographies, personal communication and meeting discussions, my field notes and research diary. These texts and supplemental material provided further insights enhancing the context of advance care planning and served as an analytical purpose that enabled reflection and learning of the research process.

Field notes

Full systematic field notes were kept throughout the research process, which captured the descriptive and reflective information of being 'in the field'. This was different from the 'raw data' of the interviews and advance care plans (Coffey & Atkinson 1996). My field notes therefore incorporated observations, reflections and interpretations during interviews, when analysing the documents, and conversations with the children's community nursing team.

Research diary

There is much debate about whether a researcher's reflective diary can be used to inform the analysis, however, within an interpretive approach recognition of a researcher's interpretation is central to the research process and therefore an important dimension through which to inform the theoretical analysis. I used my reflective diary to generate knowledge while dealing with complex situations (Schon 1991), and this created a greater understanding of myself in the research process. As Schatzman and Strauss highlight it has been a 'vehicle for ordered creativity'(1973 p.105), using my reflective diary to capture the challenges of the research process, personal research development and limitations.

3.3 Ethics

Quality research is needed in children' palliative care practice to extend the knowledge base and provide evidence base care. Yet there are distinct challenges highlighted when conducting research in palliative care (Duke & Bennett 2010), with children and young people with life-limiting and life-threatening conditions (Crocker et al. 2014; Beecham et al. 2016). The ethical process inherent within children's palliative care research is reported as a significant barrier (Beecham et al. 2016). Thus, the ethical considerations of this study were rigorously examined to ensure ethical sensitivity throughout the research process. Attention was paid to public and patient involvement, choice of data collection tools and style of interview. My role as a researcher and with the CCNT was carefully considered alongside the sensitive nature of carrying out research with parents of children with life- limiting conditions and bereaved parents. Practical ethical considerations included, safeguarding, confidentiality, anonymity, data management and consent. Specific ethical challenges for the study are highlighted (Figure 3.1) together with an explanation of how they were addressed

Figure 3.1 Ethical considerations of the study

3.3.1 Parents of children with a life-limiting condition as participants

There is significant debate about the recruitment and participation of families to palliative care studies (Crocker et al. 2014; Beecham et al. 2016) of whether parents want to participate in research (Lotz et al. 2013), how to manage recruitment, and issues of gatekeeping (Crocker et al. 2014). There are voiced perceptions of the potential physical and psychological burden for families of participating (Beecham et al 2016) and reported concerns from professionals about inviting parents to discuss advance care planning as it may cause them distress (Crocker et al. 2014). Nevertheless, we know from practice and current studies that parent's want to talk about advance care planning (Lotz et al. 2013) and this was supported by the parents reference group and the team leader of the CCNT who championed the study. Engagement and communication with the CCNT were constantly monitored to assess participation and recruitment and it was evident that participating parents, welcomed the opportunity to engage in conversation about their child's advance care planning. However, it has not been possible to ascertain why parents chose not to accept the invitation to participate in the study. Understanding why parents do not engage in research is important for future research.

3.3.2 Informed Consent

Informed consent is a widely accepted legal and ethical requirement in research practice – an activity that presents information and supports decision-making for participants. Parents were asked for their initial consent (Appendix E) at the beginning of the first meeting to seek permission for the interview, recording, transcribing and using the data to inform the research study. Consent was then ongoing and renegotiated throughout the research study. Managing consent in this way enabled issues, not anticipated when informed consent was initially taken (Lawton 2001) to be discussed. Consent was also sought from parents to gain a copy of any advance care planning documents they had completed. The option for parents to consent to share an advance care plan remained open – thus, if at first, they had withheld consent, following the interview they could change their mind. All parents (13) consented to participate and consented for their interview to be recorded and transcribed. All parents (12) that had a completed advance care plan consented to sharing the document.

Integral to the consent process for this study were considerations of the family context, and although not direct participants, acknowledging the inherent involvement of the child. Specifically, the advance care plan was about the child and they may have been involved in related decisions and competent to make their own decisions. Thus, although the inclusion criteria were parents of children 0-17 years who held parental responsibility for their child, the consent process involved asking parents to talk with their child and gain assent as appropriate. If the child/young person did not wish for the advance care plan to be read it was not used. All but one of the advance care plans were for children with very limited capacity or children who had died, and parents were confident in their decision and consent to share their child’s advance care plan. The mother of George (who had capacity) explained that she was talking to a nurse about his ‘plan’.

A further consideration within the consent process was supporting both parents to participate in the study and managing the process of consent. Two of the interviews had been planned with mothers yet on arrival, their partners (fathers) who had not initially been invited to participate, were present. Both fathers stated that their partners would be participating in the interview however, they both contributed significantly to the conversation. I checked out during the interview that they were happy to proceed and verbal consent was gained, to continue the conversation with their input. This raised an interesting ethical dilemma that the interview proceeded with participation from individuals without written consent at the outset. Both fathers clearly wanted to participate as the interview progressed and both had significant information to share. They were clearly affected by the issues under consideration (Holstein & Gubrium 1995) and the care of their child inherently collaborative, so that together with their partners they were co-

constructing the responses to my questions (Taylor & de Voch 2011). The joint interviews revealed a different perspective and as Taylor & de Voch (2011) recognise, each partner's behaviour influenced the response and behaviour to produce a joint account of their experience. This was important to consider but also how I managed consent. There is little in the literature that offers guidance to this situation, however, my heightened awareness to ensure an ethically sensitive approach and drawing on a reflexive stance, I believed that to gain consent at the end of the interview would value their participation and meet the ethical requirements for consent. Following the interview both fathers were happy to give consent to use their contribution and written consent was gained. I had not set out with a preference for one-to-one or joint interviews, but as the study progressed, I was more aware of the potential for partners to want to interact and offer their views. Combining both approaches enabled a flexible approach to recruitment and required a responsive approach to the consent process.

3.3.3 Confidentiality and anonymity

Confidentiality and anonymity of participants was central to the ethics of the study and several safeguards were put in place to ensure data they provided could not be traced back to them. The data e.g. audio-recordings were held in a password protected computer folder and transcripts stored in a locked cupboard. Numerical coding of the data was used to ensure linked anonymity.

The consideration of anonymity in research is often concerned with not divulging identities which, Grinyer (2002) claims is a culturally embedded assumption. The debate recognises the importance of securing data and compliance with The Data Protection Act whilst challenging the traditional principle of anonymity as being central to the research design. There is a growing shift of anonymity as an accepted norm. Grinyer (2002) argues an underestimated preference for participants to be acknowledged in published research and for them to retain authorship and ownership of their stories.

In her seminal work, Grinyer (2002) offered parents the choice of using a pseudonym or their child's real name in the study report. Many parents chose for their child's real name to be used, considering it wrong to conceal their child's identity, through the practice of using a pseudonym. Moreover, there is an argument that this further reinforces the loss of parental identity experienced by bereaved parents (Grinyer 2002). Thus, the principle of giving parents a choice is now recognised as good practice. Thus, parents in this study were given the option to use a pseudonym or real name for their child. The consequences of both choices were explained in the consent process

Where parents requested the use of a real name or pseudonym for their child this was discussed on an individual basis. Of the 13 parents, four requested a pseudonym for their child's name and nine parents chose for their child's own name to be used in the writing up and dissemination of the findings. Not one parent chose complete anonymity. On reflection the question of anonymity could have been extended to the parent's themselves and would be an area of consideration before any of the work is published.

3.3.4 Researcher participant relationship

The relationship between the researcher and participant has a recurrent concern in the research literature regarding the imbalance of power and privilege (Raheim et al. 2016). Reflexivity was crucial in supporting the researcher-participant relationship, to mitigate as far as possible any power influences or over involvement that may impact on the consent process and subsequent interviews. It involved ongoing attention to ensure I managed and valued the narrative / stories shared by parents, both during the interview and in writing up, by taking care of both the interpretation of the interviews and in transcribing the recordings.

3.3.5 Safeguarding

An important ethical concern was the child present at the interview. Parents were asked for their child not to be present during the interview. However, given the unpredictability of the child's illness there was a strong likelihood for children to be at home. Not to continue would limit participation and have a significant impact on recruitment. If a child was present during the interview, I checked that participants were happy to proceed and this was continually monitored throughout the interview. Of the eleven interviews five children were present. Where children were present this was managed by careful and sensitive communication ensuring parents were aware of the content of the interview prior to consent and careful observation of the child's capacity to understand the discussion. The one child with capacity to understand the conversation was in a different room.

3.3.6 Parental distress

Distress and upset has been reported as a significant reason not to invite parents of children with life-limiting condition to participate in research (Crocker et al. 2014). Therefore, the support of parents and managing emotional wellbeing was a central concern during the interview. These elements of support were achieved by good communication and relationships with the CCNT. Avenues of follow up support were made clear, so that parents had someone to talk with following the interview if they should choose. In the first instance they were directed to the CCNT but many parents identified a family member who they would talk to. In closing the interview, I always asked what they were doing with the rest of the day. This enabled an opportunity to check out their emotional wellbeing and to guide them to further support as appropriate. The lead CCN was informed by letter that the interview had taken place (See Appendix F) so they could contact parents and address any follow up questions regarding the advance care plan.

A further consideration was recognised that any distress experienced by parents might impact on the interview and on the narrative being shared. In some circumstances this could limit their involvement. A sensitive balance was taken to ensure the validity of the study by including distressed parents' experience against the rationale for stopping the interview. Parents indeed became distressed but not to the degree where they were unable to continue with the interview or asked to stop. My observations were that the distress was the expression of a deep sorrow of their child's condition and thoughts of future loss, and parents did not see this as a reason not to engage in conversation.

3.3.7 Researcher / practitioner roles

One of the ethical issues identified in planning and designing the study involved the clarity between my clinical role and research role and being mindful of the distinction between each. An explanation of each role was given to parents at the beginning of the study and I endeavoured not to take on my nurse practitioner role with participants during the study. If parents made requests in relation to practice, I encouraged them to communicate these to a named professional supporting their child's care. I also needed to manage my passion as a clinician to 'fix a problem' - and maintain good conduct as a researcher to ensure the analysis was effectively used to inform the emerging theory and recommendations for practice. The interview was not a vehicle for completing or changing an advance care plan; however, it was acknowledged that the very nature of discussing advance care planning might stimulate thoughts for parents that could result in them wanting to make changes to the document. Parents did not want to change the advance care plan during the interview but did express the need to go back and review the document with an appropriate professional following our conversation.

3.3.8 Ethical approval

Ethical approval was sought from the University ethics committee (ERGO 12608) and the South Central Research Ethics committee (15/SC/0177: IRAS 167355), and the study was approved by ERGO (See Appendix I.1) and by NRES (Appendix I.2) with two conditions. These were: changes to the PIS to add a qualifier to the confidentiality section and clarification of the Data Protection Act and, to change the title of the study to make it parent specific. Approval for specific sites was gained from the relevant Research and

Development departments. Research Governance approvals were gained from each participating NHS sites (IRAS 167355).

3.4 Critique of the method

There were particular considerations regarding the appropriateness of recording interviews and authenticity of data. Whilst parents were initially aware of the tape recorder it did not appear to cause any anxiety and parents did not opt to refrain from using the recorder. The recording added accuracy to the data without losing intimacy. Moreover, I transcribed the interviews as soon as possible following the interview, so that I could account for observations and interpretations during the interview and not lose information critical to the narrative.

The method and analysis were also significantly influenced by single and joint interviews. The initial design involved conducting single interviews with individual parents. I had not anticipated that partners would be present. The ethics of this in regards to uninvited participants and consent are addressed elsewhere (See section 3.3.2). There were two unexpected joint interviews involving both parents, and this raised both analytical and methodological considerations.

A joint interview is qualitatively different from a single interview (Arksey 1996) in how knowledge is discursively co produced (Polak & Green 2016) and there are limitations with joint interviews. There are reported concerns that one partner may silence another (Polak & Green 2016) particularly when talking about sensitive topics, or that one partner may dominate another (Arksey 1996). I conducted two joint interviews and did not observe either of these issues and found that the joint interviews enhanced a joint dialogue. In addition, by offering a choice for parents to continue or not, enabled them to opt out if they had individual concerns. The fact that they chose to continue as a joint interview provided data of how partners shared decision-making about advance care planning and how it was important to them as a family. Moreover, it provided a sense of sharing the burden of managing their child’s illness (Corbin & Strauss 1988).

In addition, the joint interviews raised some practical considerations. There were unanticipated challenges in keeping a focus to the structure of the interview and this required skilful facilitation. Having recognised the unplanned nature of the two joint interviews nevertheless, there were advantages.

As I reflected on and analysed the joint interviews I was aware that there were opportunities to corroborate information and for each partner to fill in some missing gaps They enabled parents to justify and rationalise assumptions of each other that were left unknown in the single interviews. This was a valuable insight about how parents' co-constructed their knowledge and experience of advance care planning and provided understanding in how parents jointly made decisions for their child and family. It revealed a different knowledge that I would not have gained through a single interview and was a rich source of data. In particular, it offered insight into the nature of relationships within the process of advance care planning that might not have otherwise been heard. Thus, the joint interviews enabled not only analysis of an individual perspective but of their shared experience.

It is clear there are strengths and limitations of joint interviews. Nevertheless, they can add analytic value (Polak & Green 2016) by elucidating parent's shared perspective. In particular, it has been an appropriate approach for understanding the complex nature of shared values and goals in relation to advance care planning.

A further critique of the method was concerned with being flexible in order to adapt the interview style to one that involved active interviewing. This reshaped the study creating opportunities to engage in deeper and more meaningful conversation with parents as they shared their stories of advance care planning. Furthermore, I was better able to appreciate the social construction of interviews, through the actions taken to produce and interpret it (Holstein & Gubrium 1995). This enabled an understanding of what was not said and recognition of the significance of silences. These encounters with parents were actively formed and shaped, and knowledge co-constructed. Charmaz (2014) states that this is when meaning is created, not merely elicited by skilful questioning or truthful replies, but strategically constructed throughout the interview process (Holstein &Gubrium 1995). This was a significant benefit of face to face interviews.

However, face to face interviews are not free from limitations. They took resource and time. It took over an hour to travel to most of the parents homes. Despite this, overall, the strength of interviews was their flexibility, ability to seek clarity and depth and an opportunity to gather in depth data.

3.5 Achieving rigour

The rigour of the research design and ethics approval process sets a benchmark for the quality of the study. The trustworthiness of the research process was dependent on the consistency and accuracy of the research methods applied. This was achieved in a number of ways.

- A sensitive recruitment process, to maintain the inclusion, exclusion criteria.

- Sensitive interviewing whilst staying true to the methodology to answer the research questions.

- Careful scrutiny of data and adoption of the constant comparative approach to maintain a credible amount of data that addressed fully the research question.

- Rigorous theoretical analysis and attention to theoretical sensitivity to fully account for the developed and emergent theory.

- A continued reflexive approach to maintain an ethically sensitive research process, to ensure open interpretation of data and honour the parents' experience.

The study was assessed against the rigour of theory construction within grounded theory; theoretical plausibility, direction, centrality and adequacy (Charmaz 2014). Theoretical plausibility provided a way to understand the many encounters and situations, which once analysed provided theoretical direction to the study. As the direction of the study developed this offered a theoretical centrality to certain ideas and areas of inquiry, which ensured theoretical adequacy of categories and informed theoretical development of the grounded theory.

Further measures of rigour were how credible the findings were in reflecting the experiences of participants and of their transferability and trustworthiness in relation to a substantive theory. This is demonstrated throughout the findings chapters and discussed in detail in chapter nine.

3.6 Chapter summary

This chapter has provided an overview of the philosophical background and development of grounded theory. It has justified the use of constructivist grounded theory with supplemental situated analysis to support the investigation in to parents' experience of advance care planning. The chosen method provides direction to the research process. The following chapter presents the process of analysis through a series of worked examples.

Chapter 4 The process of analysis

This chapter provides a detailed account of the process of analysis adopted to develop a substantive theory depicting parents' experience of advance care planning. The analytical strategy was informed by constant comparison method. This method is central to theory construction in Grounded Theory. Analytical distinctions, variations, patterns and relationships are established by making comparisons between data at each level of analytical work (Charmaz, 2006:p 54). Thus, data were initially compared within and across transcripts to gain an in-depth understanding of parents' experience of advance care planning. As data collection and analysis progressed data were compared with data, data with category, category with category and category with conceptual themes (Charmaz 2006: p 187).

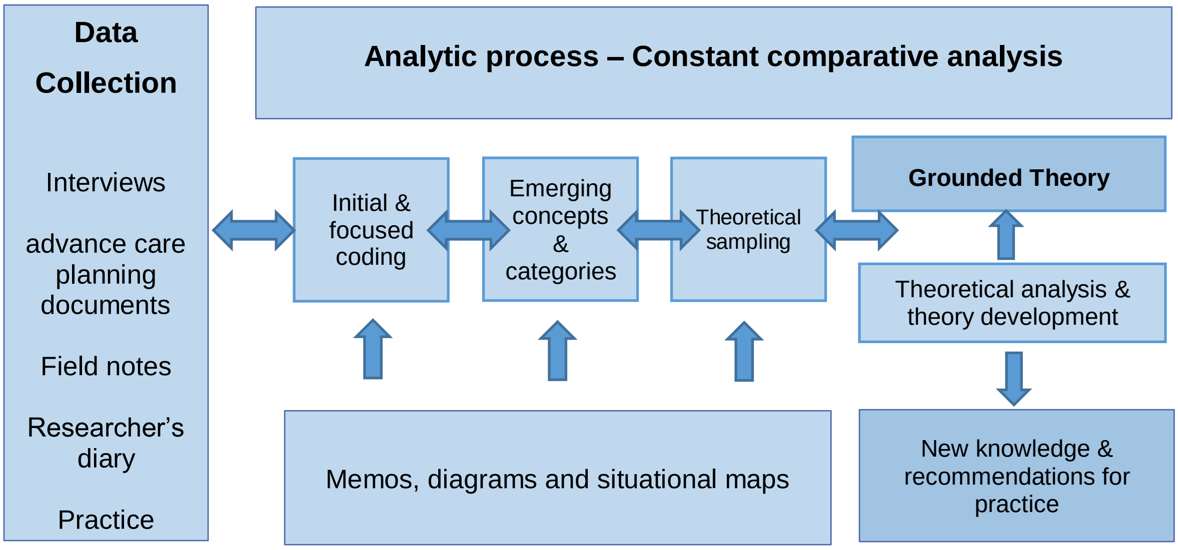
In constructivist grounded theory, analytic processes such as coding, memo writing and diagramming are used to facilitate interpretation and these combined with situational mapping (Clarke 2005) were used to incorporate the social and situational context within analysis (Charmaz 2014). This process and the concurrent engagement in data collection and theoretical sampling strengthened the quality of data collected and the depth of interpretation.

By following the analytical principle of a systematic approach inherent in the constant comparison method, data moved beyond description to a meaningful and theoretical explanation of parents' experience of advance care planning (Figure 4.1). I went backwards and forwards through the data, constantly writing memos and drawing diagrams to identify conceptual themes.

Theoretical coding and analysis were undertaken to identify the relationships between concepts and emerging categories, and theoretical sampling, as a key component of grounded theory, was used to support deductive analysis and produce theoretical verifications of the grounded theory. This transparent and robust process using inductive and deductive methods ensured credibility within the grounded theory approach.

Application of these methods and the iterative process of comparative analysis enabled conceptual interpretations and the generation of categories from the data. Most importantly, it enabled an exploration and interpretation of data gathered to understand meaning and the perspective of parents when engaged in advance care planning for their child.

Figure 4.1 An illustration of the analytic process of the study



4.1 Memos

Memo writing was a pivotal and integral analytical process throughout data collection and analysis; memos construct, record and track interpretive insights informed by these processes (Charmaz, 2006). Memos were written alongside data collection and analysis to capture insights, differences and incoherencies in data, analysis and interpretations. Successive memo writing kept me engaged with the data and were used to continuously integrate interpretation within the constant comparative process (Piantanida et al. 2004). It provided space to make comparisons and create meaning underpinning the emerging concepts. Memos supported a pathway of theory construction.

I started writing memos at the outset during the process of initial coding following transcription and immediately began to understand the fundamental importance of memos to develop my analysis and fully engage in data. They were written in a notebook and on sticky notes so as not to forget the hunches and thoughts at the moment they occurred. Memos were written, logged and dated and kept as part of the methodological research diary:

They helped me to ponder, explore, sort and revise data and concepts. Furthermore, they deepened the analysis and raised significant questions that shaped theoretical sampling (See.section 4.1.7). Thus, memos played a central role in the construction of categories and to spark ideas that shaped the development of conceptual components of the emergent theory (Charmaz 2006).

Early memos were invaluable in capturing initial ideas that I then built on. For example, a memo (Box 4.1) that first identified the multiple tensions faced by parents when making decisions about end-of-life care for their child, helped to shape the emerging concept of *reconciling multiple tensions*.

Box 4.1 Memo capturing initial ideas about tensions described in parents' stories

I am struck by the number of tensions coming through within parents' stories – recognising the need to discuss EOL but not wanting to – wanting acute intervention but not wanting their child to suffer – and preferences for preferred place of care being hospital and hospice depending on the intervention / care required. How do we work with families to reconcile these tensions to enable them to make decisions within an advance care plan?

It is not a single decision we are asking them to make but a complex dynamic process of multiple choices that needs to be captured in a document – recognising too that decisions and choices made will change. (29/02/16)

As the number of memos increased and the analysis progressed, I began to recognise the depth of analysis that each memo held, I did not want to lose these, so began to rewrite the memos on sticky notes in a different colour to the codes. Using this approach meant they stood out as memos but were integrated with the building of focused codes and concepts. The analysis became a vivid rainbow of colours with every developing category represented on an A3 sheet of paper with coloured codes and memos for each. This process as a principal activity within grounded theory, (Charmaz 2014) supported connections and described relationships between data and concepts and shaped the emerging categories.

Field notes and memos of the research process were also integrated into the analysis that helped to build emerging concepts. The methodological memos in my researcher's diary served as a way to write down questions and decisions made about the research process. This was significant in how I came to adapt my style of interviewing (see section 3.2.4).

Later in the process, I used memos to initiate discussion and to tell the story of a concept or category (See Box 4.2). This helped to discover and explore new interpretations and ideas.

Box 4.2 A memo telling the story of an emerging category

Parents realised that something had changed and they recognised they needed to talk. They drew on their previous knowledge to help them understand what this meant. There were a number of triggers and other indicators that acted as prompts or signified a change in their child's condition that further emphasised a sense of realisation.

Memos therefore opened up data and illuminated new lines of inquiry that I might have otherwise missed and helped me to give direction and purpose to the construction of the categories.

4.2 Initial and focused coding

Coding is a pivotal link between collecting data and developing the emergent theory. Coding generates the bones of analysis (Charmaz 2006). Whilst there is some discrepancy within the literature regarding the different types of coding and how they are used to sort and explain data (Strauss & Corbin 1990; Glaser 1992; Dey 1999; Kenney & Fourie 2005; Charmaz 2006), I used three levels of coding to enable progressive analysis. Initial coding, focused coding and theoretical coding (Charmaz 2006) were used to make connections between concepts and to identify patterns and properties to inform emerging categories. They helped to refine properties and moved the analysis from an iterative to conceptual interpretation of the data (Piantanida et al. 2004).

Initial coding is concerned with identifying words and statements in the data, which describe actions meanings and interpretations and describe situations or interactions (Charmaz 2006). Codes are constructed to identify and label sections of data and following the process described by Charmaz (2014) I coded word by word and line by line coding, paying attention to the language used in the texts and coding segments that I explicitly or instinctively sensed as important.

Coding consisted of underlining words or phrases and constructing an initial code to concisely describe the text segment, which was marked in a column by the side of the transcript (Table 4.1). This was a process of actively constructing labels, naming each word or phrase and defining what was seen as significant in the data (Charmaz 2006). Following this process, 285 initial codes were identified from the interviews (see appendix J).

Table 4.1 Extract from transcript to demonstrate initial coding

Extract from transcript illustrating word by word and line by line coding.	Initial codes written in the margins of the transcript
I think it feels quite final, it feels like um, it felt like making really big decisions which again is something - I really don't like making final decisions, um so anyway, I can't remember I think some months later, I think actually we were asked about it and one of the consultants said he had quite a lot of experience of doing them with parents and would we like to meet with him um, so we went through it all again, so quite a lot had changed, yes that's right it was off the back of um, a really long hospital admission (1/250116/1c)	*The impact of completing/signing the document (emotions/feelings) *Challenges in making decisions/The depth and importance of decisions made *Timing of the advance care planning *Skills of the professional *Changes to situation *Trigger to conversation – hospital admission

A significant learning point at this stage was the importance of gaining a balance in the amount and purpose of coding. For example, the data included descriptive accounts of respite care that were not directly relevant to the research question (although important in understanding the situated context in which parents were making decisions). A balance needed to be struck in sufficiently coding these descriptions to provide contextual understanding. Thus, it was important not to code in so much detail that contextual detail of respite care detracted from detail about parents' experience of advance care planning. Conversely, it was important not to code descriptions of respite too lightly as this risked a superficial analysis of the context in which decisions were formed and made. To strike this balance it was important to continually return to the research question and aims to ensure analysis and coding related to the purpose of the study.

Codes in grounded theory are provisional and can be changed, as analysis progresses. Once initial coding had occurred, *In vivo* codes (using parent's own words) were introduced as they were useful in preserving parents' meaning of their views and experience. These were later converted to Gerund codes. A gerund is an English verb which ends in an 'ing' but that primarily functions as a noun. Gerunds can be used in grounded theory as part of the coding process to assist with conceptualisation and enabled the analysis to portray actions and processes within the data. Gerunds supported an explanation of patterns and processes of behaviour that informed the basic social process and emerging theory.

I also refined the language used to construct codes to ensure they adequately described the data coded. For example, the code ‘what was helpful’ did not specify what was helpful, so was changed to ‘not feeling rushed (was helpful)’. This resulted in codes, which had closer fit to data. This process of refinement helped to articulate other concepts for analysis. For example, I identified that trusting relationships influenced what was helpful when engaging in advance care planning and this was raised as a significant theme to explore in more depth.

Once initial codes had been refined, they were reviewed again for their fit with data to ensure an accurate meaning of parents’ experience. For example, review of the initial codes revealed two very similarly expressed codes; ‘*fear of advance care planning’* and ‘*fear around advance care planning’*. I wondered whether these two codes should be grouped together but a review of their fit with the data revealed different meanings. The code ‘*fear of advance care planning’* expressed explicit anxiety about the form / document and the unknown, whereas the code ‘*fear around advance care planning’* represented the emotional fear of what engaging in advance care planning actually meant. This prompted further analysis to understand in more detail the distinction between the two codes and how they related. In this way, initial codes were developed, reviewed and refined and the iterative process of the grounded theory approach meant the process of coding, was flexible and responsive to the interpretive analysis (Charmaz 2006).

Once the initial codes were reviewed and refined they were translated on to sticky notes. This enabled movement of ideas and the development of themes to determine relationships and patterns. I also began to use memos in an integrative way, writing as I went along to capture all that was in my head as I was coding.

Focused coding is a process of sorting, synthesizing and organising codes to make the data more manageable and to determine emerging categories (Charmaz 2006). Focused coding was systematically managed through *Atlas ti* (a computer assisted software programme for qualitative analysis) by uploading the codes into the software. This produced a structured list of codes with the ability to determine emerging patterns and connections.

I endeavoured to use *Atlas ti* throughout the coding process and it was helpful in the systematic identification of codes. However, it was not a method that enabled the creative and sometimes chaotic analysis that is afforded by a grounded theory approach (Charmaz 2014). The use of ‘sticky notes’ better enabled me to engage more deeply in the constant comparative method to identify, review and refine codes that shaped and fit the emerging categories.

Initial codes, written as labels on sticky notes, were sorted by analysing potential relationships with each other and by grouping codes together on A3 paper. For example, there were a number of initial codes, which described triggers or prompts to having an advance care planning conversation (Table 4.3) and explained what these triggers meant for parents.

Table 4.2 Example of development of initial and focused coding

Descriptor	**Initial codes: triggers / prompts to conversation**	**Focused code**
So quite a lot had changed, yes that's right it was off the back of um, a really long hospital admission	Hospital admission / change in condition	Triggers/prompts to the conversation
He had been in hospital for 8 months um been quite poorly	Hospital admission	
But everything's started to shift and change over the last few years and everything's changed for him	Change in condition ,	
that showed that the brain had deteriorated even further (OK) and that's when they pulled us aside and said … he's not going to get better, he's going to deteriorate	Deteriorating condition / diagnosis	Realisation of the need to discuss advance care planning
unwell and in intensive care,	Admission to ITU,	
I was narrowly avoiding PICU, he ended up on airvent and everything else		
so, a lot more input from (the palliative care consultant)…	Increased conversations with professionals	Moments of realisation that something has changed
she's got older and got more complex, so and with her um staying in hospital quite a lot	More complex care / frequent hospital admissions	
and at one stage it was touch and go,	Crisis event	

Focused coding therefore changed the interpretation of data from being informed by my professional understanding of advance care planning, triggers which might indicate appropriate timing for advance care planning conversations, to an understanding of parents' experience and the significance of changes to their child's condition in relation to advance care planning. This resulted in focused codes of the *realisation of the need to discuss advance care planning.* Following constant comparison and theoretical analysis this focused code was refined to the concept of *defining moments and triggers* and later informed the emerging category of *realisation* (see worked example of the development of a category Appendix K).

In addition, focused coding further refined initial codes to explicitly express their meaning. For example, the initial code *Trigger to advance care planning conversation* did not specify the detail of the trigger. Focused coding renamed the initial code as *diagnosis as a trigger* and *deteriorating condition as a trigger.* This contributed to a deeper understanding of the many triggers / prompts or moments that are evident in practice or in the child's illness trajectory that may prompt a (advance care planning) conversation.

4.3 Maps and Diagrams

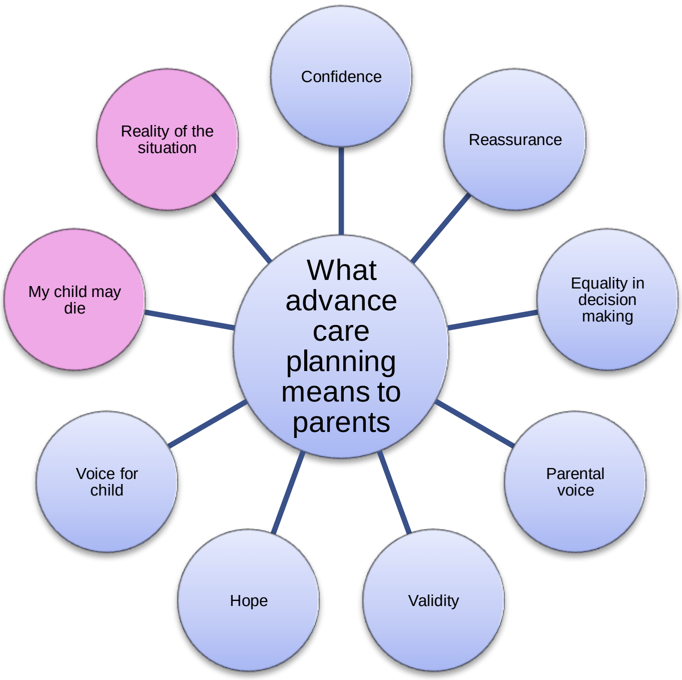
As the analysis took direction, the use of maps and diagrams helped to visually interpret the data. Diagrams were used to give direction to the developing categories and helped to make connections between codes and categories. In addition, maps were constructed to inform the wider contextual elements of the study by utilising situational mapping (Clarke 2005).

4.3.1 Diagrams

Diagrams were used to sort and organise the data and make sense of the overwhelming number of codes. They helped to put the data back together (Glaser 1978) and supported the explanation of the similarities and relationships between codes, moving the analysis towards the construction of categories.

An example of how diagramming enhanced analysis involved several codes related to the meaning of a completed advance care plan for parents. Most of the codes described a positive relationship with the advance care plan, for example, feeling in control and involved in the decision-making for their child. These codes were drawn from explicit descriptions by parents. However, when I returned to the data and started to examine these codes through diagramming, I identified less explicit descriptions but significantly important data, which exposed the emotive meaning associated with having an advance care plan. Parents expressed that an advance care plan made the reality of the situation '*more real'* and this made bare the realisation that their child might die. This led to two new codes. The diagram (see figure 4.2) helped to account for and integrate the codes, which described positive meanings explicitly expressed by parents (blue), and the more hidden emotive meanings associated with having an advance care plan for their child (pink). This led to two new codes, *the reality of the situation* and *my child may die.*

Figure 4.2 Early diagram supporting the developing analysis about what advance care planning means to parents



Diagramming helped to draw out variance and contradictions which were not explicit in the initial codes. By using diagrams to interrogate data and codes ensured a full explanation of the emerging concepts that may have otherwise been disregarded. This then helped to explain the developing categories (see 4.5.3) and the relationship between categories.

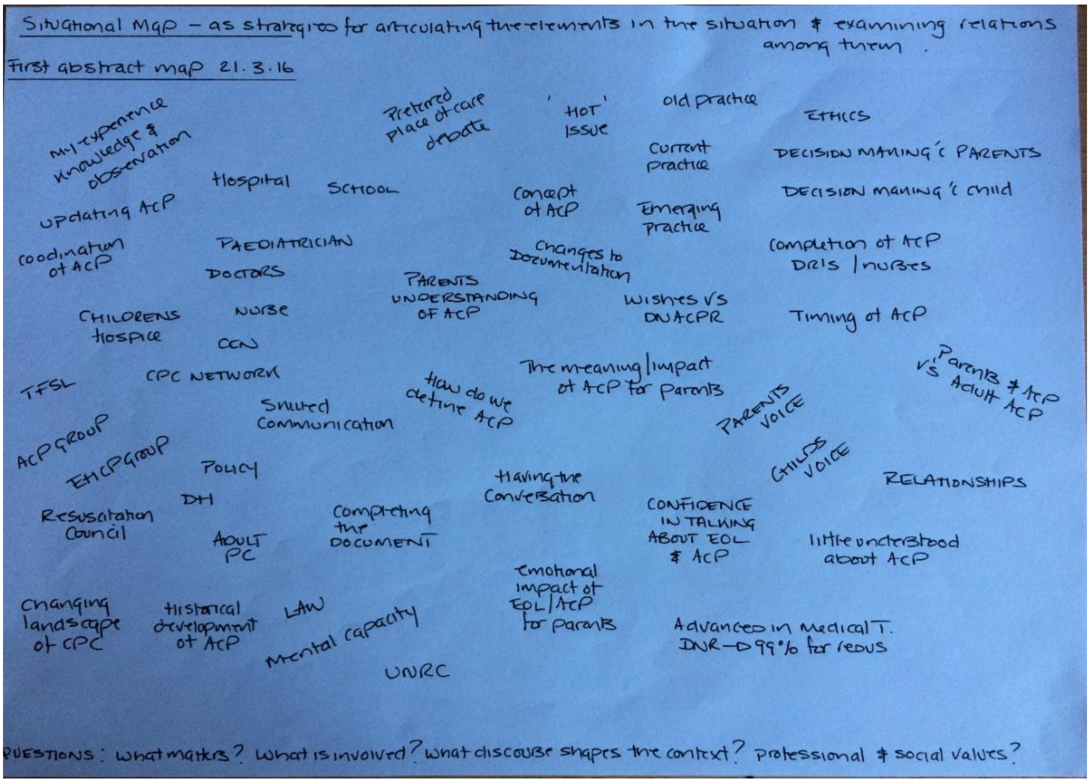
There is some similarity between diagramming and the clustering technique described by Charmaz (2014) used to understand and organise data. I found this technique helpful early on in the process of analysis, for example when sorting codes once on sticky labels onto A3 sheets of paper to construct focused codes and as described to account for divergent codes.

4.3.2 Situational maps

Situational maps, (abstract situational map, social and positional maps) were used in a more focused way compared to diagramming and asked more specific questions of data. The purpose was to elicit a greater analysis of the situation in relation to discourse, structure and conditions that characterised the situation of inquiry (Clarke 2005). Thus compared to clustering and diagramming, the situational maps provided greater depth and more focused inquiry to investigate the social and political complexity of advance care planning.

Initially, a situational map was constructed to identify and articulate the diverse elements associated with the practice of advance care planning. Clarke (2005) argues that we already know much about our research topics and that collecting data in this way helps to illuminate this knowledge. This initial map (see photograph 4.1) included the features described by Clarke (2005) as constituting situational maps, who and what are in the situation and what elements make a difference. This enabled an exploration about what mattered, what was involved and what shaped the context of advance care planning.

Photograph 4.1 Photograph of situational map analysis of the wider context of advance care planning

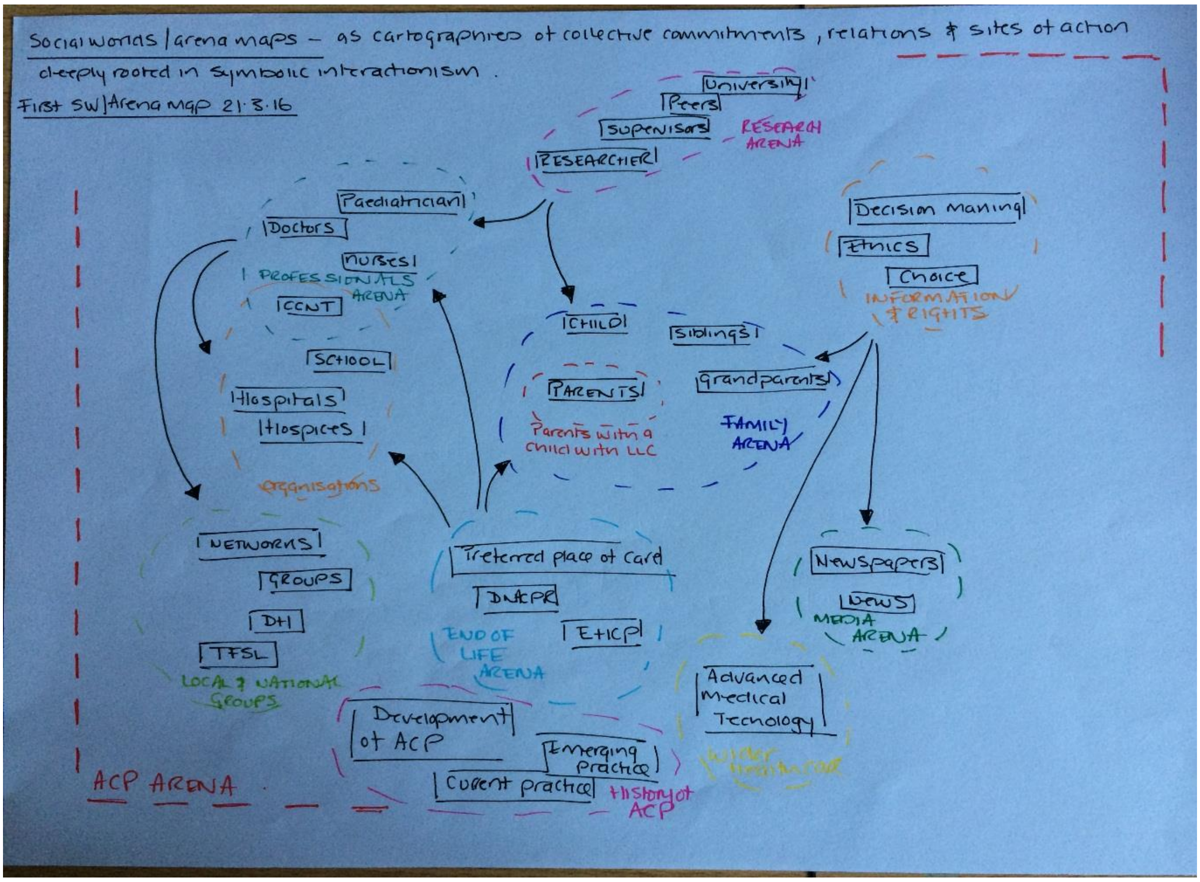


The questions about context and sites of action enabled connections to be made between the social worlds and arenas represented and moved the analysis from a micro to organisational level of analysis so providing a greater understanding of the social process of advance care planning.

This analysis led to the development of the social world map (see photograph 4.2). Social world maps enable depiction of collective commitment, relations and sites of action (Clarke, 2005:86). Thus, by realising the social processes that influenced advance care planning deepened my understanding of the many interlinking elements that may influence or impact on advance care planning and where discussions of advance care planning were acted out.

In particular, I asked, what arenas were present for advance care planning, what was the individual work of each arena and what were the overlaps, similarities and differences? For example, the work of the end-of-life policy arena in relation to advance care planning had a different focus to that from the family arena, but understanding the relationship between the two was essential for the practice of advance care planning. The maps depicted that the media and public arenas influence on end-of-life care were prominent during the study and enabled a link between this and the health care expectations of parents and health care professionals. This had a direct impact on advance care planning where parents explicitly expressed their thoughts and views of end-of-life media stories and how this shaped their own values and beliefs.

Photograph 4.2 Photograph of social world map beginning to make connections



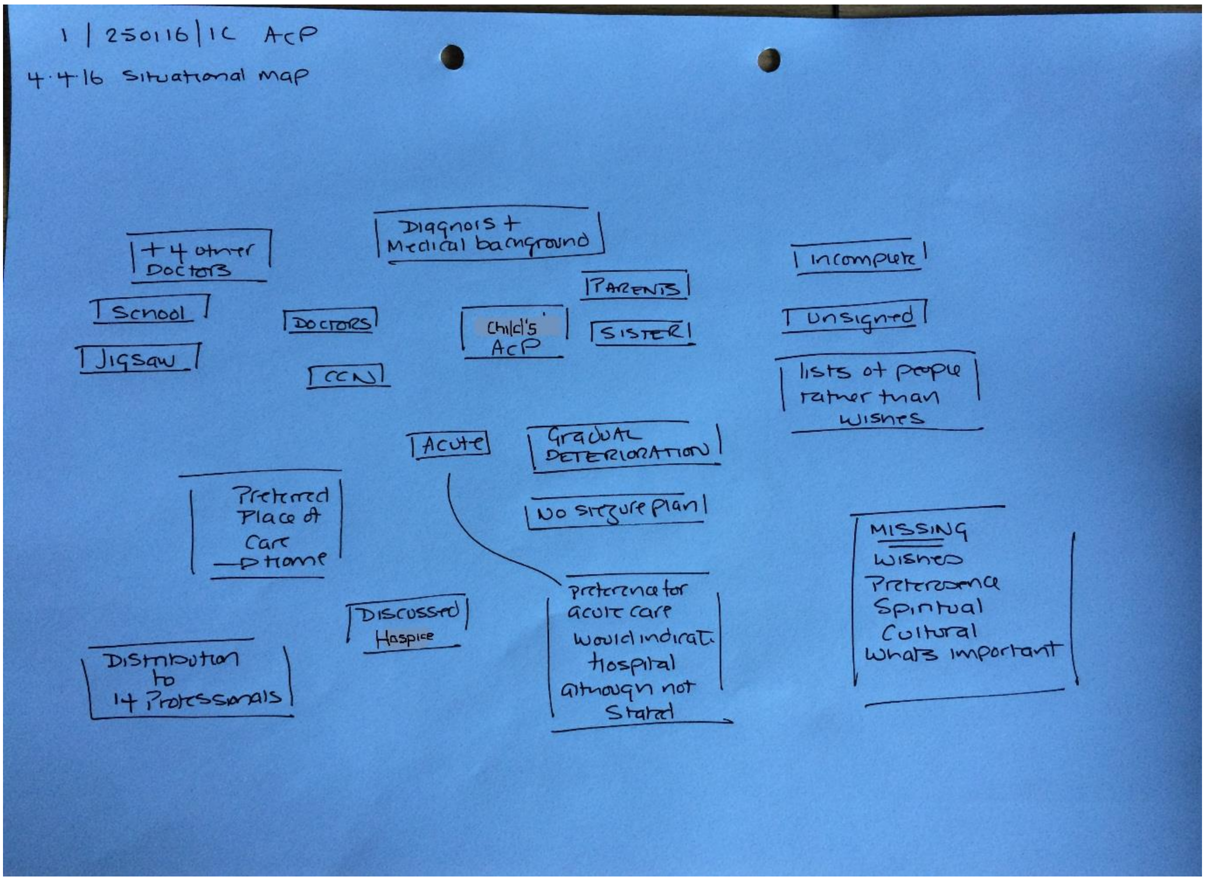
The analysis from the maps helped to strengthen initial interpretations of data. For example, where parents described the different settings and organisations involved in advance care planning the maps helped to articulate more explicitly all the arenas influencing advance care planning. Thus, maps were integral to the process of comparative analysis and enabled in depth analysis and new insights that revealed a greater understanding of the process of advance care planning.

4.4 Integrating the advance care planning documents into the analysis

Integrating the analysis from the advance care plans was central to the developing concepts and categories. This was achieved by constructing situational maps to analyse the nine individual advance care plans. Each map plotted all the important elements in the situation, (the advance care plan) and was analysed using questions of, who and what are in this situation? who and what matters in this situation? and what makes a difference?

Thus, each document was analysed and captured the structure and social elements, including its content, complete and incomplete questions, who had led on the document, who was involved and an immediate sense of what I thought was missing. An example of an individual (advance care plan) situational map is shown in Photograph 4.3.

Photograph 4.3 Photograph illustrating an individual advance care plan situational map analysis



Subsequently the mapped information from each of the documents was tabulated (see table 4.3). This included information regarding the lead reviewer, resuscitation status, distribution to professionals and key points about the breadth and depth of discussion represented in the sections of spirituality, wishes during life and choices and preferences following death.

Table 4.3 Mapped information from the advance care planning documents

ACP document	Lead reviewer	Resuscitation instruction	Acute deterioration treatment and intervention	PPC	Signed by parents	Distribution no. of professionals	Breadth of discussion	Comments
1c	CCN	Attempt resus with modifications Airway-yes Breathing-yes Circulation-yes	All options including intubation & PICU Review after 48 hrs parents would like to discuss future treatment if appropriate	Home Hospice discussed	Unsigned by parents	14 (including 5 doctors)	Spirituality, burial, cremation Limited record of discussion	Organ donation not discussed
2c	Doctor	For full resus *'parents are realistic about potential outcomes'*	Acute intervention for GI infection, Hickman line infection, RT infection, Seizures	EOL – Hospice Acute deterioration - Hospital	Signed by Doctor Signed by mum (not dad)	12 (including 5 doctors)	Limited/not complete	Diagnosis and medical summary recorded in detail
3c	CCN	Full resus with modifications	Detail of specific symptoms and treatment Management of infection and seizures Detailed description of life threatening event Yes to all options for intervention	Home if possible Hospital for cardiac event PICU	Named consultant No parents signature	8 (including 3 doctors)	Information on who is important to the child No other conversations recorded	Diagnosis and medical summary recorded in detail
5c and 8c	Doctor	Full resus	Seizures, infection Yes to all options for intervention	EOL – Hospice Acute deterioration - Hospital	Signed by doctor and both parents	6 (including 2 doctors)	Very limited discussion recorded	Diagnosis and medical summary recorded in detail Organ donation contact no.'s recorded but no record of discussion

6c	CCN	Full resus with modifications	Seizures, infection, Yes to all options for intervention	EOL – Home PICU – review after 48 hours	Signed by doctor and both parents	13 (including 4 doctors)	Whose important to the child Incomplete	Additional medical notes included Organ donation contact no.'s recorded but no record of discussion
7c	CCN	Full resus	All options for intervention	EOL – Hospice Acute deterioration - Hospital	Not signed by doctors or parents	15 (including 7 doctors)	Recorded discussion of spirituality and organ donation	Diagnosis and medical summary recorded in detail
9c and 12c	Doctor	Full resus	Management of seizures, infection All options for intervention	Hospital	Signed by doctor and father	9 (including 2 doctors)	Limited record No to organ donation	Incomplete
10b	Doctor	Full resus with modifications	No specific treatment plan	Not decided	Signed by doctor and both parents	7 (including 4 doctors)	Incomplete	A number of sections unrecorded
13b and 14b	Doctor	Full resus	Management of infection and seizures	Hospital	unsigned	7 (including 2 doctors)	Stated Roman Catholic	Incomplete

The analysis from the situational maps and comparative analysis with interviews, provided several insights that influenced the developing categories.

Firstly, the sections in the advance care plan relating to diagnosis, symptoms and DNACPR were completed in all of the advance care plans. Moreover, the section relating to DNACPR indicated the complexity of such a decision through the variations of resuscitation decisions recorded, full resuscitation, DNACPR and resuscitation with modifications.

Secondly, the completed sections strongly indicated a medical focus to advance care planning, reinforced by the sections, which were incomplete, typically those sections relating to the cultural and spiritual wishes of the child and family. This reflected analysis from the interviews where families described the document as overly medical. Moreover, it was clear from the interview data, the way in which advance care planning discussion with parents were recorded within the documents, did not represent their beliefs and values informing the decisions made; they did not represent the depth of discussion reported in the interviews.

Furthermore, the completed sections of the advance care plans provided understanding about how the document was produced and the degree to which the plans were co-constructed with parents. For example, the list of professionals included in each plan gave an impression about the intended audience (other professionals vs parents). As noted in a memo, the voice of parents and their child was limited compared to those of professionals (box 4.3).

Box 4.3 Memo raising questions about the purpose of advance care planning

I am immediately struck by the tiny part of the parents and child's voice – swamped/ overwhelmed by all the medical and practical issues/questions

The questions of diagnosis and resuscitation, and where to be cared for, overpowers the voice/ narrative/ wishes of the parent and any real sense of the spiritual element of advance care planning, which they articulate so clearly in the interviews.

It is a medical form…this raises so many more questions around the purpose of advance care planning. (21/03/16)

Thus, the analysis raised several questions, related to the social and power constructs within the process of advance care planning, and whether the purpose and meaning of advance care planning was different for parents and health care professionals? I was also struck but the medical emphasis of the document and whether this was a concern for parents within the process of advance care planning.

These questions were addressed by comparison across data; by integrating the analysis from the situational maps and associated memos, and with the clustering diagrams of coding on the A3 sheets of paper for each developing concept and emerging category, described above. This comparative analysis and discussions with my supervisors revealed that although the advance care planning documents were not a ‘valid’ record of advance care planning conversations, they supplemented parents’ understanding. Thus, both were important to parents’ experience and the combination of both the tool and the conversation constituted their experience. Moreover, the advance care planning document was valuable to parents as a tool to express their views about medical treatment for their child.

4.5 Developing concepts and categories

Following the process above constant comparison involved theoretical coding and theoretical sampling to inform developing concepts and categories.

4.5.1 Theoretical coding

Theoretical coding is a process that follows focused coding and is a way of conceptualising how the focused codes relate to each other. It is a process to move the analytic story in a theoretical direction (Charmaz 2014). These codes involved more abstract labels and supported the development of emerging concepts to discover new insights. They were used to help clarify and enhance the analysis. Theoretical codes were integrated in to a developing theory to explain parents’ experience of advance care planning.

4.5.2 Theoretical sampling

Theoretical sampling was the core strategy used to inform the continued process of data collection. In grounded theory, ‘sample’ not only refers to the population of participants but also to the purposeful generation of data to develop categories (Glaser 1978). Thus, theoretical sampling was used to simultaneously engage in data collection, and analysis. Theoretical sampling enhanced the development and refinement of the categories, to confirm relationships between categories (Dey 1990).

An example of theoretical sampling can be drawn from the development of interviews where initial coding and analysis informed changes to the prompts within the interview schedule and led to more focused questions, which were not anticipated at the start. For example, later interviews asked, how parents chose and managed the multiple choices presented and given the number of choices how this impacted on place of care. Furthermore, as the analysis began to reveal issues around confidence and control I was able to ask parents whether they felt in control of the choices they made. Thus, theoretical sampling was integral to category development demonstrated in the worked example (see Appendix K). Where there were questions raised of data or insufficient data to explain a category I was able to ask focused questions within the interview to further explain the developing category. Memos were pivotal to inform theoretical sampling and enabled me to follow leads and ideas.

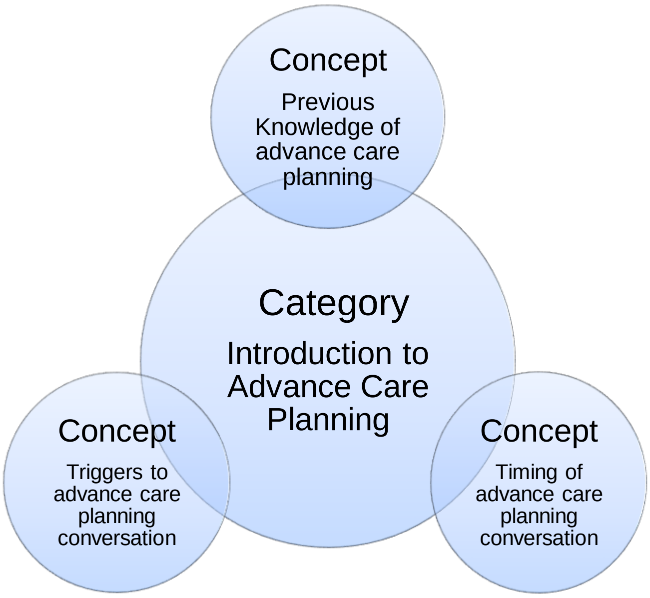
4.5.3 Development of categories

The categories were developed by drawing together the focused codes, memos, (written on sticky notes) situational maps and diagrams onto A3 paper. The sticky notes were organised and sorted so that each A3 sheet of paper contained coded data which appeared related and from which concepts were established. Using sticky notes enabled codes to be moved from one emerging concept to another until a best fit was achieved. Through this process, potential relationships between concepts and developing categories were identified. Explanations were given to initial ideas, events and processes, linking patterns in several codes (Charmaz 2014).

Initial category labels were reviewed regularly against codes and the raw data, to determine appropriate and adequate conceptual descriptions and their association with other categories. Charmaz (2014) warns against being too quick in determining conceptual categories because of the danger of making conceptual leaps to adopt theories before the necessary analytical work. I therefore tried to be open to interpretations of the data and to put aside preconceived ideas, to ensure the data built the concepts rather than fitting the data into assumed titles. The importance of this process is underlined by early analysis which identified an emerging category of the introduction to advance care planning (see figure 4.3). This was based on evidence in the data that parents were able to describe and identify when advance care planning was introduced and what led to the conversation.

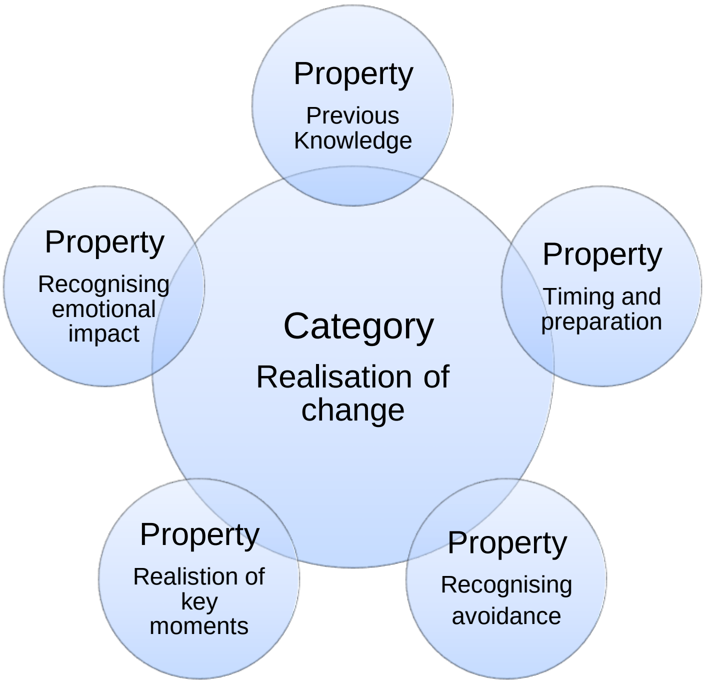
However, on reflection I realised that I was interpreting the data from a nursing perspective, of wanting to look for practical solutions to the problem, whereas it was important to remain open minded and to allow new ideas to emerge from the data and the process of coding and not to be fearful of abstract concepts. The process specifically required stepping away from a practical explanation of data and being open to theoretical possibilities (Charmaz 2014). This enabled ‘analytical momentum’ (Charmaz 2014 p.246) but importantly a leap of faith to let parents stories illuminate the journey.

Figure 4.3 An early illustration of an emerging category



Thus, I re-examined the data I had coded. It became apparent that the emerging category was not explicitly about the introduction of advance care planning, but more widely about other significant dimensions associated with the realisation of a change in condition of their child. Subsequent analysis and sorting of codes led to emerging concepts of delay and avoidance and how this impacted on initial conversations. This analysis refined the development of the category and its properties (see figure 4.4).

Figure 4.4 Later illustration of an emerging category and its properties



As theoretical analysis became embedded in a constant comparison approach further patterns and relationships were identified and I realised some concepts had a better fit in other categories. This process clarified and strengthened the properties of a category and developing theoretical framework.

Furthermore, by exploring the implications and variance within each concept made it feasible to fill in the gaps and condense each category. Thus, as the categories developed I was able to analyse the properties of the category, of how it operates, the conditions under which it changes and its relation to other category's (Charmaz 2014).

As this analytical process progressed, I became confident in the description of the category and its properties. Thus, emerging categories began to stand alone as a conceptual element of a possible theory (Glaser & Strauss 1967).

Three categories, *realisation, reconciling multiple tensions* and *building confidence and asserting control* were developed that enabled a greater understanding of parents' experience of advance care planning. The process as a whole was significant in building the theoretical direction of the study to inform theoretical centrality (Charmaz 2014).

4.6 Focused search of the literature

A focused search and appraisal of the literature was embedded in the process of theoretical analysis and central to the development of categories and the emerging theory.

It was undertaken at a point when developing categories stabilised (Locke 2001). The purpose was to locate the study, and to evaluate and defend the position taken (Holliday 2002) in relation to the emerging concepts and emerging theory. Thus, the research literature was woven into theoretical arguments throughout the analysis presented in the findings chapters.

A literature review of each concept, enabled a critique of earlier studies and theories (Charmaz 2014), to clarify ideas and strengthen developing arguments. It included different styles of literature from published peer review articles, to grey literature. For example, the sociological and bereavement literature on grief and loss highlighted a number of associated concepts, which helped to articulate the concept of the *shadows of loss and grief*. Furthermore, this process made it possible to link together other emerging themes including *confronting reality* and together explained the emotional impact expressed by parents, from which the concept ‘enduring the heartbreak’ emerged.

Thus, analysing each concept systematically, and making comparisons to existing literature created a robust meaning of the emerging concepts and how they explained the evolving category. Using the literature in this way helped to make comparisons as well as reveal gaps in extant knowledge that informed the category. It was an iterative process that helped to better understand the developing categories and the theoretical possibilities for elaborating the emerging theory (see section 4.8) This important analytic process moved the dialogue to a theoretical discussion and advanced understanding of advance care planning practice.

4.7 Saturation

In grounded theory (O’Reilly & Parker 2013) saturation does not refer to the point at which no new ideas emerge or the point at which no repetitions in observation appear (Charmaz 2006). Rather, the concern is that categories are fully accounted for, the variability between them explained and the relationships between them are theoretically tested and validated (O’Reilly & Parker 2013; Charmaz 2014). This involves careful use of the constant comparison approach at every stage of theory development (Charmaz 2014).

Thus, to determine saturation is complex and demonstrating saturation has come under much scrutiny for grounded theorists (Morse 1995). For example, Morse (1995) criticised the tendency of researchers to claim rather than demonstrate saturation, However, Dey (1999) points out saturation is not about demonstrating proof of analysis but about ensuring theoretical aedquacey and preventing premature foreclosure of analysis (Charmaz, 2006). Consequently, Dey (1999) suggests saturation is better understood as ensuring theoretical sufficiency (Dey, 1999).

Thus, to ensure theoretical sufficiency, I engaged in constant mapping of codes and the developing categories, going back to data as part of constant comparison. Each category and its related codes were reviewed to ensure their fit and adequacy against the data. For every focused code I went back to data to ensure the data was sufficient in explaining the code. I continued with this process until I was confident that theoretical sufficiency had been achieved.

4.8 Theory development and theoretical sensitivity

The process of theory development and ensuring theoretical sensitivity is an integral part of the grounded theory (Carmichael & Cunningham 2017). Concepts and categories connected to each other provide an explanation for a core category (Charmaz 2014). The core category should capture the essence of the study so that all the categories and concepts are integrated around it to form the theoretical explanation of why and how something occurs (Corbin & Strauss 2015). The core category holds and connects all the categories together.

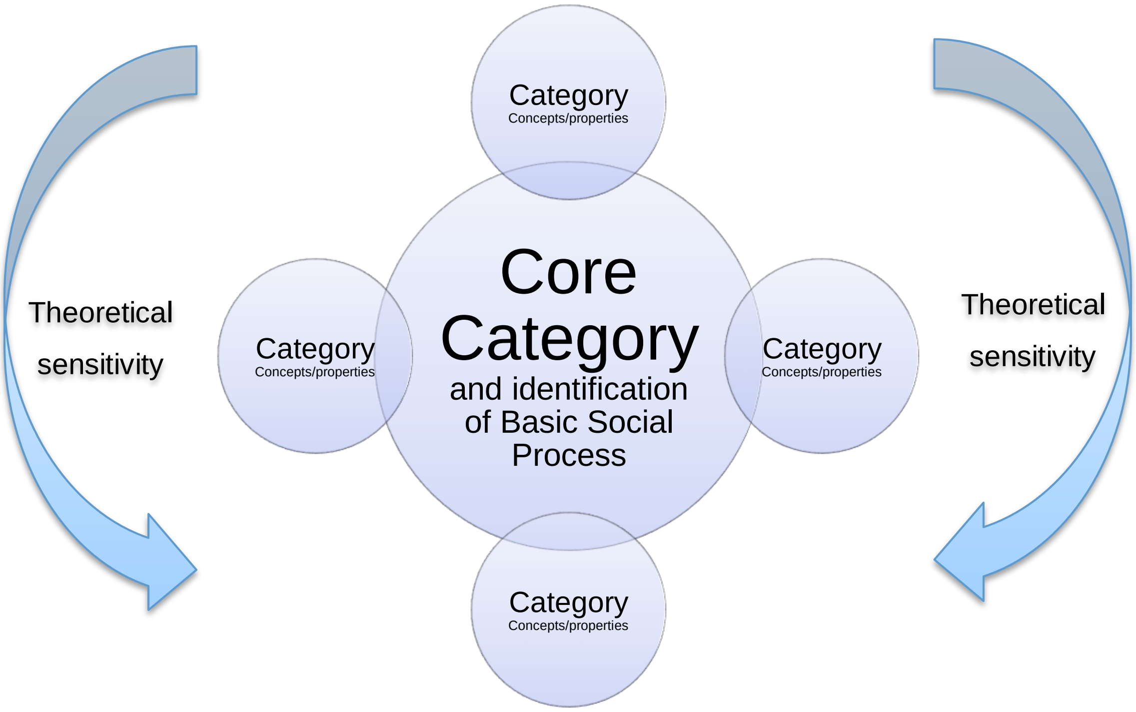
The core category may also illuminate an identifiable single basic process that unifies actions and processes that happen and change over time (Charmaz 2014). Glaser describes this as a basic social process (BSP) that occurs around a core category (1978) and argues that whilst a core category is always present in grounded theory a BSP may not be (Glaser 2005). Thus, grounded theory is not dependent on identifying a single basic process. Furthermore, Charmaz emphasises the challenges of identifying a single basic process when studies may reveal numerous processes or problems occurring in a situation (2014). She further highlights that when a single basic process is identified, it is not the only explanation derived from the data but the most plausible in explaining the research aims.

Thus, theory development aimed to identify the relationships between concepts and categories, to establish a core category that may illuminate a single basic process. This involved constructing an explanation of these connections, and to articulate the differences and distinctions within each category. Identifying a core category and single basic process allowed for a deeper understanding of the situated action and meaning of parents’ experience of advance care planning.

This process of defining and conceptualising relationships and experience provided direction to construct a substantive grounded theory as illustrated below (Figure 4.5) and explained in full in chapter 8.

Charmaz (2014) contends that this constructivist approach to theorising leads to a situated knowledge and substantive theory, ‘a theoretical interpretation or explanation of a delimited problem in a particular area (Charmaz 2014 p.334). Thus, a substantive theory, rather than a formal theory, is one grounded in the research on one particular substantive (empirical) area. Whereas, a formal theory addresses a more abstract, conceptual area of research and the comparison takes place with and between different substantive areas (Glaser 2005).

Figure 4.5 Diagram illustrating the relationship between categories, theoretical sensitivity and core category – the key elements of a substantive theory



The substantive theory is therefore a theoretical explanation of the identified problem, in this study, parents experience of advance care planning and is dependent on the identified categories, their concepts and properties, theoretical sensitivity and the core category and basic social process.

This process was enhanced by theoretical sensitivity, by drawing on previous knowledge, experience and knowledge of the literature to fully develop the emerging theory (Glaser and Strauss 1967). A key component of this process was understanding the developing theory's emergent fit (Wuest 2000) by explaining the concepts, categories and core category and their fit with pre-existing concepts or theories. Thus, previous knowledge and the literature were interwoven into theory development and the cumulative knowledge supported an explanation of the developed theory. This ensured that the emerging substantive theory was grounded and well integrated.

Theoretical sensitivity allowed me to move beyond description to see theoretical possibilities by establishing connections and asking questions (Charmaz 2014). The process enriched the development of abstract concepts grounded in data and ensured I rendered theoretically the substantive grounded theory.

The analytical process followed, explains theory development that was grounded in the social world of parents, in this case, parents living with a child with a life-limiting condition. The selected methods strengthened the research process to reveal meaningful constructions of parents' experience of advance care planning within the context of children's palliative care. Thus, the robust process of theory development demonstrated empirical fit and relevance (Charmaz 2014) and provided a substantive theory.

4.9 Chapter summary and introduction to findings chapters

This chapter has described in detail the process of analysis undertaken and demonstrated how the analytical process supported the development of categories to establish an emerging theory. The theory was constructed from the three categories, *realisation, reconciling multiple tensions* and *building confidence and asserting control*. These are explained in detail in chapters' five to seven.

Each chapter commences with a summary of the category represented by a diagram followed by an in-depth discussion of the associated concepts and properties. The concepts are described separately but in reality they are intrinsically intertwined and no one concept sits in isolation of the others. With each concept the properties are explained to provide an understanding of the meaning attributed to it and the conditions under which it occurs and how it relates to other categories.

Memos and parents' quotes are interlaced into each chapter to enhance the analysis. Where joint quotes are used each parents' voice is represented in different coloured font.

Consistent with a grounded theory approach, the methods of theoretical sampling and constant comparison were used alongside additional data to develop the findings. The purpose was to explain the experience of the parents, not merely to describe these experiences (Glaser 1992). Thus, selected literature associated with nursing and healthcare and the exploration of other, pertinent data are interwoven in the discussion findings.

Chapter 5 Realisation

'The fountains of the great deep open and our inner being is laid bare. Here in the silence and our aloneness we learn the ultimate truth for which there are no words'

Adapted from K O Schmidt (1946)

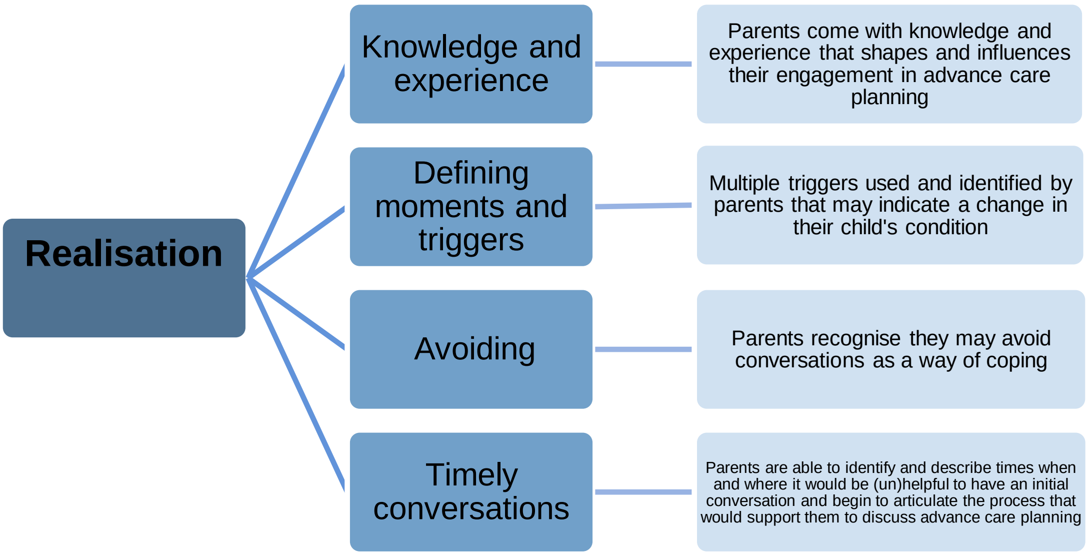
The findings in the next three chapters present the categories of the emergent theory in turn, their associated concepts and properties. The concept of *realisation* is one of three processes and explains parents' understanding that things have changed and their child's condition is or will deteriorate. This new perspective challenges their previous assumptions and beliefs and provokes need to talk.

5.1 Realisation as a category

The experience of *realisation* as part of the process of advance care planning signifies a turning point in parents' understanding of their child's situation, triggered by the perceived deterioration of their child's condition or a health crisis. Parents describe this experience occurring at various points within the child's illness trajectory that may be immediate or may take place over many months. Through the process of *realisation*, parents describe strategies to help them cope and the need to gather new knowledge to understand and make sense of the new situation.

The process of realisation is characterised by four concepts *knowledge and experience*, *defining moments and triggers*, *avoiding* and *timely conversations*. The conceptual themes and an explanation of the concepts are outlined in fig 5.1.

Figure 5.1 The Category: Realisation and its concepts



Parents come with knowledge and experience that shapes and influences their engagement in advance care planning

Multiple triggers used and identified by parents that may indicate a change in their child's condition

Parents recognise they may avoid conversations as a way of coping

Parents are able to identify and describe times when and where it would be (un)helpful to have an initial conversation and begin to articulate the process that would support them to discuss advance care planning

The concepts and properties (see table 5.1) are explained in detail below.

Table 5.1 The category: Realisation, its concepts and associated properties

Concept	Properties
Knowledge and experience	• Expert and intimate knowledge • Not knowing • Experience of clinical decisions • Encounter with ACP
Defining moment and triggers	• Clinical triggers • Number of triggers • Emotional impact of triggers
Avoiding	• Parental avoidance • Avoidance as a coping strategy • Avoidance by HCP's
Timely conversations	• When to talk about ACP • How to approach the conversation • Challenges to timing of conversation

5.2 Knowledge and experience

All parents, had an intimate knowledge of their child and were intensely knowledgeable about their child's diagnosis, treatment and care. Parents illustrated this expertise with authority and confidence. Described in the literature as a 'sense of knowing' (Rishel 2014), this in-depth knowledge of their child meant they understood the behaviours and responses of their child in detail and recognised the smallest of changes in their condition. Their knowledge and experience in the context of their child's condition was often greater than that of the clinicians.

Thus, at the point of *realisation* parents already had significant knowledge and experience about their child's condition and treatment, however they did not fully understand the term or process of 'advance care planning'. They did not know what advance care planning meant or what it meant for their child.

> *'No definitely hadn't heard of it, not in respect to children, I had in respect to end-of-life for older adults.'* (1c)
>
> *'I had heard of the term but didn't know anything about it. I thought it was mainly for children with, … like oncology patients.'* (2c)

Not knowing about the process of advance care planning (Erby et al. 2006; Mitchell et al. 2019) or understanding the concept (Liberman et al. 2014) has been reported by others. Nevertheless, despite not knowing what advance care planning was, parents had encountered conversations about diagnosis, treatment and palliative care.

> *'When he was born we were given his diagnosis and his condition with a range of outcomes …and our knowledge and thoughts have grown over time.'* (5c)
>
> *'We were asked those sort of questions like what we actually wanted done now because we didn't have to go down the medical intervention route*.' (1c)
>
> *'I didn't know about advance care planning but we kind of always had the questions in our head of what we would do if the worst thing happened… so we had those conversations before he was born.*' (7c)

Parents recalled engagement in conversations with professionals where they were asked to make a critical choice about their child's life. They identified that these conversations occurred at initial diagnosis, a crisis in their child's illness or when in hospital during serious illness or a crisis episode. It became apparent that although not directly related to an advance care planning conversation, the experience they gained from these previous conversations was informing their knowledge and understanding both of the condition of their child and the systems and structures of clinical decision-making, illustrated in the following memo (Box 5.1).

Box 5.1 Memo illustrating early understanding of the influence of previous knowledge and experience

Multiple stories are being shared in the first ten minutes of the interview as they try and make sense of the complexity of all the things they have experienced. Parents are constructing their stories and understanding of advance care planning based on clinical history, previous experience and then their current situation. This feels important to explore in more depth – how does their previous experience and knowledge impact on and shape the choices they make within advance care planning? (29/02/16)

It became evident that parents drew on this experience and knowledge to make sense of their child's illness and any changes in their child's condition. Parents used this knowledge to evaluate future communication and to construct an understanding of what an advance care planning conversation might hold.

> *'It's not a completely alien concept, when you have a child with complex needs from the moment they are born, from her time in neonates, we'd had to have those kind of conversations, I think on about day 3, we'd been asked what route do you want to go down, the palliative care route or the intervention route, so whether that prepared us or not, I'm not sure. Although when you've had a child that's been very poorly, in a sense, you do think about the circumstances you might like in this and this situation. So although it wasn't packaged in that sense, once you've been asked these questions they then stay with you and you go back to them in your head and kind of think them through.'* (1c)

For many parents their first introductions of advance care planning were from other parents. One mother explained how she first heard about advance care planning from a friend whose child had the same condition as her son.

> *'She talked to us about advance care planning and what a reassurance it was and how they were glad they had talked about it before hand. So that was kind of the first time I had heard of it.'* (5c).

In addition, their knowledge came through other parents' experience, observing in hospital or hospice, and learning from the community of families who had a child with a life-limiting condition. This meant that many parents had an understanding of advance care planning even before health care professionals used the term.

However, how parents accepted and responded to initial conversations about advance care planning was influenced by their experience of trusting relationships with health care professional's. This was important for how they gathered knowledge (See section 6.3.1) and interpreted the process of advance care planning which ultimately impacted on the choices they made.

Parents who shared experience of open and clear conversations and trusting relationships with health care professionals, where their knowledge was recognised and respected, tended to voice a positive experience in talking about advance care planning. Those with poor experience of breaking bad news, inappropriate and poorly timed questions and discussions, and where they felt their knowledge and experience was ignored, were more anxious when confronted with initial conversations. All but one parent expressed some negative experience with regards to professional conversations about their child which had an impact on how they approached advance care planning.

These associations between past experience and current situations influenced the knowledge parents held and the choices they made. The influence of knowledge and experience in parental decision-making is supported in the literature (Beernaert et al.

2019; Mitchell et al. 2019), in particular how parents draw on past experiences to inform decisions (Sharman et al. 2005). This includes experience of serious episodes of ill health (Mitchell et al. 2019) and previous experience of end-of-life decision-making of a loved one. This was evident when one mother shared the experience of her sister dying and how that influenced her choices with respect to her daughter.

> *'I said no to life support cause I'd gone through that with my sister, she was on life support for 3 weeks and we had to make the decision to turn her off and I said I'm not going through that again.'* (10b).

It was apparent that the more knowledge and experience parents had, the more they were able to anticipate the likely content of advance care planning discussions. Nevertheless, as they realised changes in their child's condition, their hopes and expectations changed and their confidence in the knowledge of their child was shaken. Parents experienced a new place of emotional vulnerability (see section 6.2.3).

Thus, parents sought guidance to validate and make sense of the information they had received (Rishel 2014). They looked for reassurance as they processed this new information in the context of their own experience and their child's condition. (Meyer et al. 2006; Bluebond-Langner et al. 2007; Janvier et al. 2014; Rishel 2014). This was crucial to inform their choices as they moved through the process of advance care planning and is discussed in detail in the following chapter.

5.3 Defining moments and triggers

Parents came to the *realisation* of change through defining moments and triggers that signified something was different about their child's condition. Parents articulated several moments, prompts or cues that acted as a 'trigger' representing change. Memos identified the volume and significance of these triggers (Box 5.2).

Box 5.2 Memo illustrating the growing importance of triggers

Within the first interview, I can immediately see there are a number of triggers experienced by parents that led to the first conversation. They are hinting at a change that is prompting a conversation. (16/01/16)

The meaning of moments that symbolise change are standing out in the data. (28/02/17)

Parents described triggers as nudges,

> ‘*I can’t remember when it was that various medics started nudging us*…’ (1c)

prompted by who was involved in their child’s care,

> ‘*We initially saw the gastric consultant but the following day the palliative care consultant came in behind him and it sort of dawned on us.’* (2c)

and by the increasing number of visits from doctors. They also mentioned triggers related to professional language and recognised statements from health care professionals such as ‘*there’s nothing more I can do’* or ‘*the next time he is admitted we won’t admit him to PICU’,* that suggested a change in the level of care.

Triggers indicated that something had changed. This was heightened by prompts from health care professionals to discuss the changing situation.

> *‘They tried increasing his medication, but they were basically saying that there’s nothing more we can do other than manage this and we don’t know what or why it’s happening. So when that started happening, then the conversation came up again and this time it was more, what’s the word? Not pushed - that’s not the right word - we had more support, I suppose somebody pushed, I don’t know if that’s the right word pushed, but somebody actually took ownership of it and managed it and encouraged us to do it.’* (5c)

The varied and diverse prompts and triggers (see table 5.2) were significant to parents experience of realising something had changed and this change was critical in building a picture of realisation for parents.

Table 5.2 Defining moments and triggers experienced by parents

• Hospital admission and increased length of stay • More frequent hospital admissions • Nudges from HCP’s • Increased consultations form doctors • Frequent admission to PICU • Increased chest infection • Escalation of intervention • Escalation from HDU to PICU • New symptoms • Referral to palliative care team / hospice	• Introduction to the palliative care Doctor • Changes to medication • Increased conversations with HCP’s • Key phrases used by HCP’s e.g. *there’s nothing more we can do* • A change in language and approach • Changes with the child (less smiley) • Things are different • Deteriorating condition Perceived threat to their child’s life

My initial analysis suggested that triggers were not a good thing. I had associated them with negative experiences described by parents where health care professionals had avoided engaging in advance care planning conversations (see section 5.4). However, I began to realise their importance and value when a parent revealed how the discussion about increasing hospital admissions helped her recognise the deterioration in her child's condition. I was able to reflect differently on the impact of triggers in recognising change and within the process of advance care planning (see Box 5.3)

Box 5.3 Memo highlighting the values of triggers

Triggers are not necessarily a bad thing – I have been able to identify triggers that indicate / lead to a conversation about advance care planning. In some instances, it has been a trigger with a positive outcome – the trigger has led to the realisation that something has changed.

Also that the trigger and realisation of change can be parents but also HCP's that then prompts a conversation or recognition of the need to talk. So triggers (if managed appropriately and timely) can be helpful in the first stages of the advance care planning process. (24/06/16)

Despite being potentially helpful, further analysis identified that they also found triggers difficult because they evoked a strong emotional response. Parents expressed emotions of; *not being ready,* and *too raw to contemplate*, that indicated a sense of vulnerability and uncertainty in the meaning behind the triggers associated with aspects of the child's condition they had not experienced in the same way before. Occasional visits to hospital increased to a number of admissions in only a few months, or escalation from the high dependency unit (HDU) to intensive care indicated a level of severity and deterioration which was a real threat to their child's life.

The way parents described the changes in their child's condition also highlighted the realisation of changing relationships with health care professional's. Moreover, conversations and new knowledge prompted a different understanding of their child's illness. One mother recalled the time she recognised things were different.

> *'We didn't know where we were going, everything started to shift and change over the last year, everything's changed for him, so it's meant everything, it became more….it made it much clearer what we wanted as a family and what was best for Lewis… it's hard…I mean the last couple of weeks have been hard cos he's going downhill and although he still smiles there's lots going on underneath that in a way you've forgotten, but now seeing and knowing the changes… It's hard.'* (2c)

Thus, triggers were important to the process of realisation because they signalled change and were the means by which parents evaluated and synthesised information and understanding of their child's condition. 'Triggers' are recognised in the literature, for example, deterioration despite treatments (Mitchell et al. 2019), loss of abilities, and repeated life threatening events (Menzes 2010). Meeker and Jezewski (2008) highlight 'cues' involving gathering information from health care professionals, family members and the patient themselves. However, the significance of triggers and cues to the process of parents realisation of their child's changing condition is not recognised in previous work.

Thus, there is little recognition in the literature of triggers as a prompt to open conversations of advance care planning. In contrast, most studies focus on effective communication (Kissane & Hooghe 2011) and approaches to decision-making without addressing the context and emotional impact of what led to this point.

The analysis also demonstrated that triggers were symbolic for parents in being able to adjust to and understand the meaning of the changes in their child's condition. This is an important part of the process of realisation, in helping parents re-construct a changing reality. However, although some parents were able to respond openly to the triggers, others recognised that they chose to avoid the signs of their child's changing condition.

5.4 Avoiding

Despite an intimate knowledge of their child's condition, and a growing awareness of the triggers and changes, parents also recognised that they could avoid conversations with family and health care professionals. Avoiding was used as a means of coping, however parents also described a sense that health care professionals' were avoiding facing the reality of the situation.

Avoiding the issue was clearly expressed by parents and they were conscious of what they were doing. One mother explained;

> *'I just don't want to do it... which is me sticking my head in the sand again*'. (5c)

Parents described the act of avoiding by themselves and HCP's.

> '*She came here, brought some leaflets and said when you're ready, call me and we'll arrange to meet to write the plan but, it was all just a bit woolly. I'm not very good with written things, I'm much more of a numbers person and it was just too easy to ignore it, and at that point there was nothing going on that made us think we needed it.*' (5c)

One approach was to delay the conversation for as long as possible - as one father revealed.

> *'So there was a hint of procrastination, a hint of fear so we just kept putting it on the back burner.'* (8c)

Parents used avoiding when they found it difficult to shift their thinking and accept their child was deteriorating and they needed to consider different palliative care goals, such as quality of life or a good death. Not confronting these changes was also about avoiding the loss of their child through death.

Thus, avoiding was used as a way of managing and coping with the distress associated with discussing advance care planning or end of life care, to withdraw from the grief and loss that they might otherwise have to confront. Parents explained that avoiding the issue gave relief from the changing reality of the situation.

Darlington et al. (2017) highlights the importance avoidance provides as a protective function offering respite from a situation that is emotionally overwhelming and becomes particularly important for parents as their child declines. Thus, avoiding was a coping strategy (Bluebond-Langner 1996; Clayton et al. 2005) or protective mechanism (Kars et al. 2010) that parents used to withdraw from the stressful situation (Darlington et al. 2017). It was part of process whereby parents managed the struggle between realisation of their child's changing condition and hope for survival (Kars et al. 2010).

The concept of avoidance is closely associated with the concept of denial regarded as a negative description of coping (Darlington et al. 2017). Thus, in clinical practice, parents are often *labelled* as being 'in denial' when they avoided conversations about their child's changing condition. This negative association of denial is challenged by some authors who argue the importance of understanding the meaning of why parents respond in this way (Bluebond-Langner 1996; Clayton et al. 2005). However it can also be an obstacle to end of life decisions (Rayson 2013) and as such may impact on the capacity for parents to engage with advance care planning conversations.

However, parents in this study did not describe themselves as 'in denial', refusing to face the reality of their child's deteriorating condition. Instead, avoiding was used when they needed to delay the implications of realisation of this change. Parents described how they pushed back signals of the approaching death by focusing on details. Kars et al. (2010) suggest this allows parents to avoid reading the signs, creating room for ambiguity.

A good example in this study is how parents concentrated on each symptom in detail with health care professionals rather than emotional or spiritual issues. The treatment sections of advance care planning documents were completed in full and there was significant detail provided about symptom management. In contrast, little detail was provided about spiritual wishes of care. This finding resonates with previous reports where there was a tendency for end-of-life plans to focus on acute events rather than emotional or spiritual issues (Finlay et al. 2008).

Thus, the focus on symptoms and how these could be managed within the advance care plan, served to obscure the underpinning meaning of the symptoms, Individual symptoms could be treated more easily whereas together they might have more significance. Thus, parents recognised that by attending to specific symptoms they were avoiding the realisation of their child's deterioration.

The concept of avoiding in this study is not isolated from other concepts and strategies that parents use in the process of advance care planning (see section 6.2.1 Negotiating complex choices) such as quality of life, preference in place of care and death and managing intervention and palliative care. These concepts are intertwined, and the degree of influence and factors that affect avoidance as a coping strategy, changes over time. Parents were aware they used avoiding in order to cope with the process of realisation involved in advance care planning and this helped to explain how and when they engaged in both the conversation and in writing the advance care plan document (see chapters 6 and 7). This reflects the growing understanding of how parents use different strategies to adjust to changing circumstances as an effective way to cope (Darlington et al. 2017).

Avoiding was also expressed by parents in relation to health care professionals. If health care professionals find it difficult to talk to parents about end-of-life care and are unable to meet the need for emotional support, parents may interpret their discomfort as avoidance (Aschenbrenner et al. 2012). Parents identified occasions when health care professionals were reluctant to talk about changes and prognosis or avoided addressing the real issue.

One mother and father reflected together on an aspect of their daughter's care in the last months of her life.

> *'She was finding it difficult to breathe, so we discussed ways of treating her and the least invasive was a nasopharyngeal airway, which she had. We were told at that point that it wasn't essential but would improve her quality of life, but you know with hindsight you can look back and think at that point, surely somebody should have said to us, this is the beginning of the end, but nobody actually said that, they just skirt around the issue. It was obvious she couldn't manage without it, she would really struggle to breathe without the tube, but still nobody actually talked about advance care planning.'* (13b).

A number of explanations are posed to explain why health care professional's do not initiate discussions about end-of-life or advance care planning, including, prognostic uncertainty (Basu & Swil 2015; Lotz et al. 2017), the fear of upsetting parents and causing emotional distress, and the fear of taking away hope (Mack & Joffe 2014; Lotz et al. 2015). Stayer & Lockhart (2016) refer to 'the elephant in the room' whereby clinicians talk about everything except what should be talked about; the child's failing condition and prognosis.

Others identify that health care professional's find it difficult to raise the issue and where there is any uncertainty about prognosis, are more likely to avoid discussing it (Mack & Joffe 2014). Furthermore, Wolfe et al. (2000) argue that clinicians have difficulty confronting the loss of a young patient since their intent is cure, which creates barriers to effective communication and decision-making. Langton-Gilks (2018) believes that when doctors are trained to save lives it becomes difficult to talk about death and they become more focused on 'fixing' the problem.

This is complicated for children with complex needs who present with multiple symptoms and problems that require 'fixing'. Parents reported in this study, that health care professionals were '*too quick'* to talk about interventions and procedures without discussing the impact of treatment on the child's quality of life. The recent Channel 4 documentary (2018) captured these challenges where each consultant focused on 'fixing' their (speciality) problem for the child that no one stopped to understand the whole picture. Each individual problem impacted on quality of life however, the burden of multiple treatments was avoided.

Parents felt that practitioners also used avoiding as a strategy because they assumed parents did not want to know what lay ahead, or were not ready for the information. But, as Langton Gilks (2018) explains, parents might not *want* to know, but might *need* to know to be involved in decision-making. Parents consider it important to talk even though distressing (Lotz et al. 2017). Thus, rather than avoiding such conversations, the emphasis should be on the importance of doctors being able to deal with parents' emotional response (Langton-Gilks 2018). If health care professionals avoid discussions of advance care planning, conflict and disagreement may result, and parents being unprepared for the death of their child. Langton-Gilks poignantly explains (See Box 5.4) her own reflections following the death of her child.

Box 5.4 Extract from Follow the Child

If you adopt the, *don't dare to talk to us about it, we'll take it as it comes, thank you*, the downside is avoidable crises. Children can become seriously ill seriously fast, and from a stable situation a panicked emergency call is a heartbeat away.

(Langton-Gilks 2018 p. 31)

Although there is much uncertainty and a constant risk of sudden and unpredictable deterioration, it is crucial to provide opportunity to discuss potential outcomes as part of advance care planning (Mack & Joffe 2014) before acute deterioration precipitates rushed and ill informed decisions (Siden 2016).

5.5 Timely conversations

The concept of *realisation* is intrinsically linked to timely conversations. Initiating conversations and preparing parents for what was to come is central to the process of advance care planning. *Timely conversations* are crucial to support parents discuss their choices and to have space and time to reflect and to be able to adjust their values and beliefs.

Parents were able to articulate when and how health care professionals could introduce them to the idea of advance care planning. For some parents in this study there was a frustration and anger at not being told earlier about advance care planning or about the future decisions they might have to make. If initiated early they could respond in a timely way to the growing awareness of change. It was not the level of detail that was important at this time, but being introduced to the concept of advance care planning. They found it overwhelming if introduced too late or at the wrong time and expressed a desire to know early on what it was, even if they were not ready to discuss it in detail. Thus, it was about identifying the right time and enabling families to prepare and to reflect on the wider issues that impacted on end-of-life discussions. To do this, they needed to know *who* they could talk to, when they were ready.

> *'I think maybe it's worth you knowing 6 months down the line, a year down the line, once families have got use to it – use to is not the right word um had a chance to digest what they've been told - to maybe approach… especially if they're life limiting children, to then broach with them and say actually in the future whether it be a year 2, 3 years down the line, it would be worth sitting down with someone, you know, to sit down and say actually what do you want to happen if something happens*'. (2c).

There is much debate in practice about the appropriate time to introduce conversations about advance care planning (Durrall 2012; Edwards et al. 2012; Jack et al. 2018). Different opinions are associated with medical prognosis and uncertainty and the unpredictability of the illness trajectory (Thompson et al. 2009).

Nevertheless, timing of conversations is an important issue and fundamental to the process of advance care planning (Zwakman et al. 2018; Mitchell et al. 2019). Studies report that parents explicitly prefer early introduction to end-of-life discussions (Erby et al. 2006; Hendricks-Ferguson 2007; Lotz et al. 2015; Mitchell & Dale 2015; Popejoy 2015; Basu & Swil 2018). Furthermore, they are more likely to introduce the topic than doctors (Hammes et al. 2005).

There is recognition that a child's condition can change fast and parents wish to be informed before their child deteriorates (Hendricks-Ferguson 2007). However, it is often reported that conversations happened too late (Durall 2012; Sanderson et al. 2016; Basu & Swil 2018; Hiscock & Barclay 2019). There are links here to the concept of *avoiding* (discussed above) but also to the challenge for professionals of when to initiate a conversation. In oncology there is a marked stage within the illness trajectory where cure is no longer possible (Bluebond-Langner et al. 2007). With children with a life-limiting condition, the focus throughout the entire illness trajectory is to manage the condition and support a better quality of life. There is also a growing trend to sustain life at all costs. There is no clear measure of when the direction of care and intervention changes from cure to palliative care and when is the right time to initiate conversations about advance care planning.

Nevertheless, parents were clear that they wanted to be prepared for what might come. One mother illustrated this as she reflected on the turning point of a critical intervention,

> *'I think there was probably a lack of communication between them (the doctors) because I do think that's when we should have started along that road and if they had eased us into it, we might have understood a bit more about what was going on. It was like we've put the tube in and now off you go home and it will be fine, and of course it was never going to be fine, but still we never had any conversations about end-of-life.'* (13bj)

The one parent in the study whose child did not have an advance care plan subsequently learnt through later conversations what it could have offered. She talked about the difference it might have made if she had known and discussed advance care planning prior to her son's death and how she might have been better prepared.

> *'I have thought, why weren't we warned about what we could do. I think when he started to deteriorate when he lost the use of his arms, I think it would have been nice if they had said obviously he's deteriorating, we still don't know how long he's got, cos no one knew, but I think it would have been nice to know should this happen or should he have difficulties, you would need to do this. I had heard it round the hospital (advance care planning) but no one had actually approached the subject with us. I don't think at the time we were told of his diagnosis we would have taken it in. But sometime in the future…We've not been told anything what so ever, and I know it could have been different.'* (11b)

For most parents this was *not at point of diagnosis* as there was too much other information to take on board. This is in contrast to reports gathered in the initial scoping review with studies emphasising a preference for conversations to begin at diagnosis (Erby et al. 2006, Basu & Swil 2018, Mitchell & Dale 2015; DeCourcey et al. 2019). Parents in this study acknowledged that shortly after diagnosis might be acceptable.

As one mother explained:

> *'I think you find yourself when it goes - they get very poorly very quickly - you're suddenly thrust… everyone's telling you what to do, what not to do and it's a minefield of information and you don't, can't process it. And I know how I felt when he had been poorly on the ward and just diagnosed, and they said we need to do this, this and this…you're like hang on a minute, back up, back up. Hang on, I need to process this. I think it would be good just to give families a chance to think about it and say actually I want to do that now, I'd like to do that in a years' time or, um I'll do it in 5 years, sort of thing. I think it's just giving that option, being made aware of it would help.' (2c)*

Other studies have recognised the benefits of introducing conversations about advance care planning, after diagnosis during a period of stability (Durrall 2012; Basu and Swil 2015) when parents are able to better adjust to changing circumstances and gather information and knowledge to make best decisions for their child.

A mother who was not aware of advance care planning until much later in her child's illness described how she felt it could have been introduced shortly after diagnosis.

> *'I think I would have welcomed it if it had been introduced slowly right from the start. I mean when he was born we were given his diagnosis and a range of outcomes, so he might be this end or this end, we were aware he was going to be medically a really complex little boy. …I don't feel anyone has ever been really frank with me about how they see his prognosis and I have to read it from implied things and I personally would have liked that conversation right at the beginning.*
>
> *For me, I would have liked someone to say it's a long way off, its 20 years off, its 30 years off, you know it might not even be in your lifetime but, so you are aware and along the lines of we have this conversation with everyone, so we are not talking to you because we think that your boy is at any particular risk, but this is part of the induction if you like, that we have this conversation about advance care planning and what that involves and whatever. And even if that had been an introduction at that point and even if someone a year later had come and said... do you remember when we talked about that…*
>
> *To be something that was introduced at the beginning and grown over time as our knowledge has grown as well and our thought.*' (5c)

Early conversations for advance care planning are still infrequent, despite evidence reported in the scoping review and parents expressed desire for conversations early in a child's treatment, following diagnosis. Moreover, the timing of conversations is crucial in enabling parents to reflect and process information. This has a significant impact and influence on their ability to make good decisions (Zaal-Schuller et al. 2016) (see section 6.3.2). Yet, there are numerous accounts from parents that present a different and less satisfactory picture, when conversations were initiated during a crisis event or on intensive care. This is a common occurrence in practice when the conversation is a '*bolt out of the blue'*, is difficult to manage and is emotionally overwhelming. One mum's account epitomises this struggle,

> *'We'd been faced with really inappropriate times and questions like ''what are your wishes for your child'' when she's in intensive care. It comes off the back of a period of illness and it's a very stressful time and we were tired, very, very worried about her and those are really difficult times to make good decisions.'* (1c).

Parents know that trying to talk about advance care planning at a crisis point, when in hospital and when their child is ill, is not a good time. At these challenging moments parents themselves stated that they were not in the best place to make good decisions. Furthermore, it creates tension and conflict and when under pressure there is more likely to be disagreement between parents and health care professional's (Zaal-Schuller et al. 2016). With increasing numbers of children with life limiting conditions being repeatedly admitted to (Fraser & Parslow 2017; Mitchell et al. 2019), and dying in intensive care (Pearson 2018; Mitchell et al. 2019) conversations about advance care planning should not wait until or start at this point.

Parents were clearly saying the introduction of advance care planning was not timely enough with missed opportunities early in the course of illness. Despite the difficulties and potential avoidance, they did want to talk and being able to plan, prepare and engage in timely conversations was crucial. The most appropriate time will depend on the child’s condition and degree of deterioration but early in the course of illness appeared to be a positive benchmark. Conversations were best held when things were stable as parents were better able to make what they perceived were good decisions. It enabled ongoing conversations and time to reflect on what advance care planning was and what it meant.

5.6 Chapter summary

For parents the deterioration of their child’s condition provokes a *realisation* that something has changed and the need to talk about advance care planning. Parents enter into a new world beyond understanding diagnosis and having a child with complex needs to one where decisions take on a different meaning. These new relationships and choices of care are less familiar and create a sense of vulnerability and uncertainty, where parents feel out of control. *Realisation* as part of the process of advance care planning marks a turning point when parents need to re-construct a new understanding of their child’s condition.

Realisation is influenced by previous knowledge and associated with the triggers that may prompt *realisation.* Parents and health care professional’s may encourage and embrace the opportunity to talk about advance care planning but they may also avoid conversations to manage the process of realisation of the child’s changing condition.

If managed sensitively, with opportunity to talk and timely conversations parents are better prepared for what is to come. Yet if poorly managed and at the wrong time it can have significant impact on how parents respond and approach advance care planning and on the decisions they make. To engage in early conversations will enable them to confront the numerous choices within the process of *reconciling multiple tensions*. This process as part of advance care planning is addressed in detail in the following chapter.

Chapter 6 Reconciling multiple tensions

> *'We shall not cease from exploration, and the end of all our exploring will be to arrive where we started and know the place for the first time'* TS Elliot (1960)

Following *realisation*, there are a number of difficult and conflicting choices faced by parents that they need to assimilate and make sense of, in order to understand the changes in their child's condition and participate in advance care planning. These choices are intensified by several influencing factors that impact on advance care planning, a process that may be complex and emotionally overwhelming. How parents navigate this process is collectively described as *reconciling multiple tensions*.

6.1 Reconciling multiple tensions as a category

Within the process of advance care planning, parents are confronted with complex and philosophical choices, which create multiple tensions influencing their values and beliefs. Although they navigate and reconcile choices throughout their child's illness journey, this process is significantly different, it is characterised by the specific and profound tensions that escalate following *realisation* and the unique and unimaginable decisions that follow and that are intrinsically linked to advance care planning.

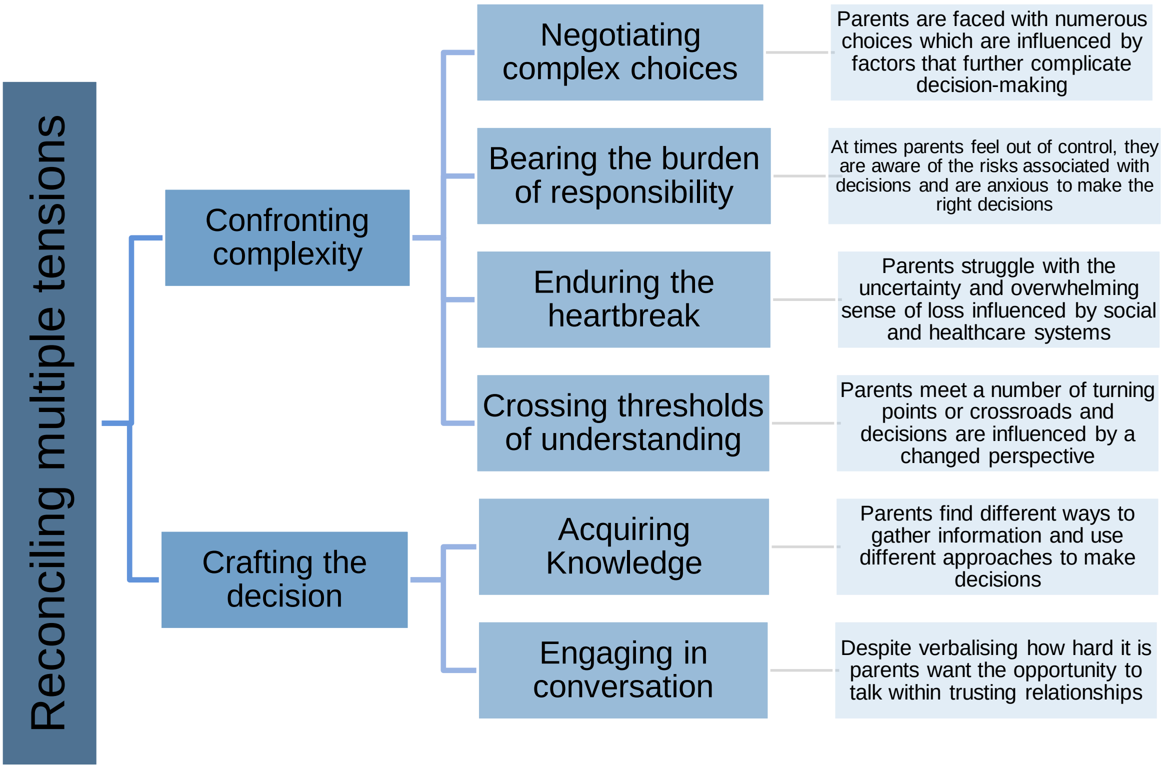
To participate in the process of advance care planning, parents need to voice their deepest beliefs and fears and make moral judgements about their child's care. The tension raised by these moral judgements cannot be reconciled without discussion but by working through this process and developing strategies to support their judgement parents begin to rebuild confidence in their knowledge of their child that was previously lost during the process of *realisation*.

Parents described the enormity of the choices they faced,

> *'But these are momentous, they're huge decisions.'* (13b)

Reconciling multiple tensions as a category is characterised by two sub categories of *Confronting complexity* and *Crafting the decision* (see fig 6.1). *Confronting complexity* includes the challenges inherent within advance care planning and tackles the sometimes implicit and intangible factors involved in the choices parents make. *Crafting the decision* describes how parents navigate their way through this process. The two sub categories are intrinsically linked and both essential *to reconciling multiple tensions*.

Figure 6.1 The category: Reconciling multiple tensions its sub categories and concepts



6.2 Confronting complexity

Confronting complexity is a disordered and emotional aspect of advance care planning, where parents are faced with conflicting treatment options and choices of care. It is explained by four conceptual themes, *negotiating complex choices, bearing the burden of responsibility, enduring the heartbreak* and *crossing thresholds of understanding* (See Table 6.1).

Table 6.1 The sub category: Confronting complexity, its concepts and associated properties

Concept	Properties
Negotiating complex choices	• Requesting acute intervention and palliative care • Perceived vulnerability and deterioration • Keeping all options open and choosing resuscitation • Balancing preference in place of care and place of death • Struggling with pain and suffering • Maintaining quality and quantity of life • Living with life and death • Seeking information about organ donation
Bearing the burden of responsibility	• Perceived risk • (Dis)empowerment • Being a good parent
Enduring the heartbreak	• Confronting reality • Challenging assumptions • Relinquishing certainty • Shadows of loss and grief
Crossing thresholds of understanding	• Facing plateaus and gateways • Thresholds of understanding

6.2.1 Negotiating complex choices

For many parents, advance care planning was difficult with multiple treatment options and choices of care that they found intensely complicated. It stood out as a key concept from initial analysis, as illustrated by early memos (Box 6.1).

Box 6.1 Memo illustrating early analysis of complexity

Parents are sharing multiple stories in the first ten minutes of the interview as they try and make sense of the complexity and emotional impact of decisions around advance care planning. There are a number of tensions in the same sentence, all with different weight and meaning. Decisions seem to be determined by clinical history, current experience, acute and / or gradual deterioration - and there is constant change and uncertainty. (29/02/16)

Parents tried to grasp and make sense of their child's current clinical condition and prognosis against an unrelenting uncertainty regarding their child's illness trajectory. They were aware of their child's vulnerability and likely deterioration but wanted to consider treatment interventions and resuscitation options where possible. Choices changed over time depending on the child's fluctuating condition. This is illustrated by the conversation Clara's mother shared describing the various aspects of her illness, from issues of gradual deterioration, acute illness, quality of life, admissions to PICU, uncertainty of prognosis, past illness and future care.

> *'If Clara becomes unwell because of her underlying condition we would get to a point where we would decide we didn't want to keep supporting that, but it's not quite that straightforward cos if she's got a cough or cold or something she struggles way more than a healthy child, but we would want to try and support her over that. However, I guess we are conscious of the fact that we certainly don't, if she ended up in intensive care every year on a ventilator. In terms of her quality of life we wouldn't feel that was fair on her, but the difficulty is she has periods of wellness in between, but if we felt the balance had tipped we'd probably revisit (our decision) based on the last year.'* (1c)

Complexity was expressed in relation to the number of options, around symptom management and intervention and withholding treatment. Parents tried to understand these options and their consequences in order to make choices for their child's care. Parents expressed the sheer number of options .

> *'There's a complete range of options.'* (1c)

> *'so let's predict this, these are the options and there's probably 5 or 6 things we need to deal with, so now let's make an informed choice.'* (9c)

This experience for parents resonates with the complexity of decision-making described (Kannampallil et al. 2011; Pask et al. 2018) and is inevitably influenced by the changing landscape of children's palliative care (Pask et al. 2018). Parents are faced with increasing treatment options due to advancing technology and this means children are living longer with greater health care needs.

The complications associated with choices of care and treatment options are implied in the literature and predominantly focus on choices at the end-of-life (Hinds et al. 1997; de Vos et al. 2011). The significance of the number of choices for parents of children with complex needs has not been well captured in research, yet this was clearly evident in the study.

Beatrix's mother explained all the different symptoms she experienced.

> *'Every single time is a different management of each situation. I think if you were going to do that you would need an advance care planning for every single ailment that she has got and Beatrix has got up to 24 different things.'* (9c)

She continued by trying to explain the complex symptoms including the complication of her brittle bones.

> *'So if she has a massive seizure then we are just focusing on her epilepsy, but are you going to write a care plan for each individual issue that Beatrix has got. Today people, it's respiratory, tomorrow it's epilepsy, no, now we've got a broken bone… and if she's got a respiratory problem we need to do this but if she's bust her leg then we need to do that.'* (9c)

The sheer number of options made choices complicated (Kannampallil et al. 2011) but the interaction between each made decision-making more complex. Each option or symptom was influenced by the presence, management and response of another. Furthermore, symptoms, treatment options and the condition of their child changed over time presenting a fluctuating and dynamic picture (Pask et al. 2018). Parents struggled with trying to make individual decisions for each symptom whilst understanding the interconnection of symptoms and making decisions based on the whole picture. This made advance care planning inherently more complex.

Difficult decision-making at end-of-life is identified by Hinds et al. (1997) and de Vos et al. (2011), complicated by complex symptom management and choices for intervention (Hinds et al. 1997) and whether to continue or cease treatment (Hinds et al. 1997; Kars et al. 2010; Aschenbrenner et al. 2012). Whilst these factors were identified in the study, a more intricate picture of the choices parents make within advance care planning emerged.

Parents needed to weigh up a range of issues, for example, the degree to which they were influenced by acute intervention and/or palliative care, the challenges of balancing pain and suffering and quality of life, and choices around resuscitation. Rarely spoken about in the palliative care literature is the question of organ donation (see section seeking information about organ donation), but parents sought information on this subject and wanted to make an informed choice. For many this was an important part of advance care planning.

Parents were trying to grasp both a clinical understanding of the situation and assimilate its meaning. Langton-Gilks (2018) has acknowledged that trying to process all these options is difficult, but understanding them is critical to the process. Moreover, Wilkinson and Savulescu (2019) argue that these decisions are complex because they are not solely about scientific evidence but are value laden, requiring sophisticated deployment of ethical concepts. There has been limited investigation to understand advance care planning for parents from these perspectives.

Requesting acute intervention and palliative care

The overriding tension experienced by parents for advance care planning was the choice between acute interventions and palliative care, of maintaining all options of treatment until such time it was evident they needed to consider palliative care.

> ‘*our goal is to try everything first if we can but if we have the consultants at the hospital saying look I am really sorry there’s not much more that we can do, then we know it’s time for us to go to the hospice now and he can go peacefully without hospital surroundings.*’ (7c)

Judgements about whether to choose intervention or palliative care were influenced by the child’s current clinical condition and prognosis, likely deterioration, the degree of pain and suffering and quality of life. This made any transition from curative to palliative care complicated. Supporting families to transition to palliative care is recognised as important (Gardiner et al. 2015) however, how health care professional’s can support this transition for parents is unclear. Liben et al. (2008) describe the difference between curative and palliative care, and the literature presents a process of transition from acute intervention to palliative care. However, parents argued in this study that they did not want to choose between curative and palliative care but wanted an approach that balanced both (Bluebond-Langner et al. 2007; Heinze & Nolan 2012). The challenge for children with complex needs is being able to predict an accurate prognosis and the outcome of treatment (Kars et al. 2011) in order to balance the options of both intervention and/or palliative care. In addition, talking about end-of-life and poor prognosis and conversations about advance care planning, has an emotional impact (section 6.2.3) and there is a need to consider the sharing of information at appropriate times with the potential cost of emotional burden for parents and the child (Mack & Joffe 2014; Sisk et al. 2016). The association with timely conversations is apparent (see section 5.5).

There is a growing body of evidence that demonstrates that transparent communication about prognosis has important benefits in end-of-life decisions. Such conversations can help parents to make more *realistic* treatment and end-of-life choices about their child's care (Wolfe et al. 2000; Mack & Joffe 2014). This is important for advance care planning conversations. Parents supported the idea of talking about their child's condition and prognosis but analysis of data suggested these conversations were not taking place early enough. Furthermore, the interpretation of what is *realistic* in regards to intervention and palliative care may be different for parents and health care professionals.

For parents realistic choices were dependent on having *enough* information about their child's condition and prognosis. However, predicting prognosis for this population of children with complex needs is uncertain, it is therefore difficult to make decisions based on prognosis alone. As parents talked through the process of advance care planning, it was apparent they were also making choices determined by the current condition of their child and clinical history, for example, how many times the child had already been admitted to PICU or how many chest infections they had had this winter. One mother described the past year for her son.

> '*He had been unwell and in intensive care, But this time I was narrowly avoiding PICU, he ended up on airvo and everything else.'* (3c)

These episodes of illness and being able to see the current clinical situation alongside clinical history were indicators of deterioration. Lewis' mother explained how she realised he was deteriorating.

> *'We didn't know where we were going, everything started to shift and change over the last year, everything's changed for him, so it's meant everything, it became more….it made it much clearer what we wanted as a family and what was best for Lewis… it's hard…I mean the last couple of weeks have been hard cos he's going downhill and although he still smiles there's lots going on underneath that in a way you've forgotten, but now seeing and knowing the changes… it's hard.'* (2c)

The majority of parents acknowledged that at some point they needed to choose an approach to care dependent on the illness trajectory of their child's condition. By engaging in the process of advance care planning parents began to voice a changed perspective, however, they found themselves in an unfamiliar place describing a different narrative of their child's condition.

The choice for intervention and/or palliative care was further complicated in that, a gradual deterioration provided a different picture from a crisis event where acute intervention was possible. This created significant tension for many parents regarding the setting where this care might take place. Their request for acute intervention most commonly required a hospital setting, but this was not the place of choice for palliative care (See section balancing preference in place of care and place of death). It was clear that place of care did not completely determine approach to care.

> *‘We would try everything in hospital with the hope that of getting him better or getting him in a stable enough condition where he can continue being at home basically, even if that meant more invasive breathing support or other things. If it ever came to a time where they said, he is not getting better then that’s the moment we would go to the hospice and spend the time we could there before the end.’* (7c)

Understanding the turning point from acute intervention to palliative care was extremely difficult as parents were describing a balance between different care options for different purposes. It was heavily influenced by the perceived vulnerability and deterioration of the child.

Perceived vulnerability and deterioration

For many parents their choices were informed by the perceived vulnerability of their child and nature of deterioration. They described the reason for deterioration being either a crisis event or due to their condition and these influenced treatment options, a crisis event necessitated acute intervention or resuscitation, whereas deterioration due to the underlying condition revealed other choices of hospice care or care at home. One mother tried to make sense of the difference for her son.

> ‘*We’ve pretty much said if it’s a 999 situation then we are in the doctor hands, they need to do what they need to do. If we are in a slower situation, then that’s different. We’ve said we don’t want him to be intubated, but again we’ve not been 100% about that because it would depend on the reasons. If they were saying to us, I mean, I’m not a doctor I don’t know all the possible outcomes, but if they came to us and said we need to intubate him while we give him this I don’t know, sometimes children are put into medical comas to break seizures and things aren’t they, so if that’s what they’re saying and we need to do this for 2 or 3 days then, OK maybe we try it - it would be worth it, but we don’t want to do it when there’s no hope because whose interest is that in?’* (5c)

The choice of interventions was intrinsically linked to the risk of treatment with regards to pain, suffering and survival, and therefore the likely outcome of treatment also contributed to the choices they made. Parents understood that the outcome was dependent on the child's vulnerability and their capacity to respond to the various treatments prescribed.

Challenges further arose, when the child was acutely deteriorating and clinicians tended to take greater responsibility giving less opportunity for parents to feel completely involved (de Vos et al. 2011). This was described by Catherine's mother when she deteriorated really quickly before they had made an advance care plan.

> '*Unfortunately she deteriorated really quickly, she actually did crash basically and he just stepped in, he did resuscitate her and she did get intubated, he was standing there and he was squeezing adrenalin in to her foot before we had made a decision.'* (13bj)

Many parents reported that they looked to doctors as the experts but they equally felt frustrated if they were uninformed of likely events. Beatrix mother explained her frustration in not being fully informed about the treatment options for her daughter.

> '*Professionals don't really go into that much detail or explaining that this, this or this could happen. For example; Bea had a really big episode when she had a really big crash what about 3 years ago now. They had her in and they said we can't get IV access we need to go for a head cannula. No one had ever really suggested that to us before, yet there we were with Beatrix who was quite vulnerable never having had that discussion. So we were like 'wow'… that was hard, because (her dad) wasn't around and she had gone from being a little bit unwell to being very unwell in the space of about 20 minutes. It wasn't until about 5 or 6 days later when actually community nurses came in and went – well she could have died in that 20 minutes - but no one had explained that before.' (9c)*

Parents were unhappy that knowledge was held by doctors and not shared. If a decision could have been anticipated and they could have contributed, they were angry if they were unable to participate. They felt there had been a missed opportunity for shared decision-making. Parents felt if they were better informed of likely treatments and potential outcomes, recognising the vulnerability of their child and capacity to respond, that they would be more prepared for the choices in front of them. Where they felt unprepared, these experiences directly led to their choosing full resuscitation as part of advance care planning.

Keeping all options open and choosing resuscitation

The fear and likelihood of potential sudden deterioration and the uncertainty surrounding prognosis meant parents considered it extremely important to choose full resuscitation for their child. They clearly articulated this choice stating reasons of hope that intervention would be taken, offering every chance for their child's survival. They were certain of their decision to resuscitate.

> '*It's full intervention until we say otherwise, until we reach that threshold. I mean I would never ever, ever go to a DNR, because I still want the option. It went without saying she was for full resus.'* (9c)

All nine advance care plans in this research had statements for full resuscitation despite the vulnerability of the child's condition. I initially found this hard to contemplate especially after parents had described their child's complex and deteriorating condition. It raised a deeper question of how parents interpreted full resuscitation (Box 6.2) and why parents made these resuscitation choices when their child was extremely vulnerable with a poor prognosis.

Box 6.2 Memo raising questions about resuscitation

For full resuscitation – what does this actually mean in an advance care plan and how does it relate to parents' interpretation of full resuscitation? (27/01/16)

Subsequent analysis revealed that parents chose full resuscitation to keep all options open in the immediate situation should their child suddenly collapse, and to prevent doctors making decisions and doing anything without discussing this with them first. They reached these decisions based on the rationale of giving their child every chance of survival. Beecham et al. (2017) note that parents reported it was difficult to visualise the consequences of treatment and therefore opted to keep all options open with the knowledge that they could change their mind.

> '*That was certainly the conversation we had that was very divided into if he's suddenly taken ill and we have to call an ambulance then let them do their thing and I think you would be very hard pushed to stop them doing their thing anyway, regardless of what it had in the plan because if he gets suddenly ill we don't know why he's ill and that might be something that can't be fixed but it could be something that's fixed and we're sorted. And I suspect in those circumstances things are going to happen so fast that by the time we stop and think – either, they won't have saved him or we are then moving on the more slower, having the time to think about decision-making.'* (1c)

Resuscitation decisions may also be influenced by understanding the erratic illness trajectory for children with complex needs and parents' experience of children surviving previous crisis events.

> *'He's not standard so don't necessarily follow the text book. He has come through before.'* (3c)

If parents had seen their child get better from previous life-threatening episodes, they were firm in their belief that they would do so again. Parents described these episodes as '*near misses*' or suggested that their child would '*bounce back'* as discovered by Noyes et al. (2013). Thus, the pattern of illness for children with complex needs presents a picture where children repeatedly survive crisis events where they might have died (Menzes 2010). Horridge (2015) claims that doctors should be mindful of improved survival opportunities for children with complex needs who may not follow predictable journeys. With the hope of survival, decisions were therefore made not just on a medical understanding of the condition, but based on the child and family narratives.

Further analysis identified a reason for full resuscitation not previously recognised. What emerged through theoretical sampling was that many parents chose resuscitation as a default position for intervention to give themselves time and space to consider what to do next. It provoked doctors to stop and talk with them. If their child survived initial resuscitation despite being gravely ill, parents found themselves more time and a sense of control. Notwithstanding the severity of the situation, parents believed that in reaching this crossroads they were more able to stand back and reflect. They believed this space enabled them to ask questions of how their child might respond and the likely outcomes of intervention. With more time, they felt they could consider their child's quality of life, which was less likely when making decisions at a moment of crisis.

Having been in crisis situations before, parents drew on this experience to interpret how they might make decisions regarding resuscitation. They considered that the severity of crisis their child had already undergone was similar to what they might experience with resuscitation. However, for most families, crisis events had been associated with respiratory deterioration and intervention is distinctly different to a cardiopulmonary arrest. It might be that if they had experienced cardiopulmonary resuscitation they might have a different perspective. One father voiced the distinction between respiratory deterioration and cardiopulmonary resuscitation.

> *'(He) finds it really difficult because he's worked in A &E and he says it is brutal when they throw the book at you and try everything.'* (4c)

Most parents voiced the importance of immediate resuscitation in moments of crisis. Constructing these choices in an acute situation was supported through the advance care plan where a section, unique to children's practice, allows for modifications to full resuscitation. This enabled parents to make additional choices should their child collapse; for example, alongside cardiopulmonary resuscitation they could choose admission to PICU and ventilatory support. However, it was not clear whether parents were aware of the impact of these interventions and the capacity of each hospital to manage such acute treatments, i.e. intensive respiratory support is only available in tertiary hospitals and to choose interventions of this nature would mean travelling to the appropriately resourced hospital. For some families this had significant implications in distance from home and disruption to family life. These important issues for families are not openly discussed as part of advance care planning and were not discussed as part of this study but raises important questions as part of advance care planning conversations.

Further confusion associated with choices of care arose when the option for acute intervention that was sometimes suggested by doctors, was in conflict with decisions stated in the advance care plan.

> *'She ended up on life support cos she struggled in* (the local) *hospital and obviously they're not an intensive care unit and I think the highest they had is Bipap. They had her on one of the highest ones and she still wasn't breathing on that and so they phoned up* (The tertiary hospital) *and the doctor came over with the ambulance and he said the only way we would get her over would be to put her on life support just to get her over there. And then we could see, cos she could have passed away in the ambulance and we didn't really want that. They would rather take her over there and see what they can do.'* (10b)

It is clear that in an acute situation, the advance care plan can guide conversations and highlights that parents choices can change dependent on multiple factors not always predicted. What parents are requesting from health care professionals is the knowledge that this may happen.

These situations are closely linked to the concept of perceived vulnerability and deterioration and whether parents perceived their child would be able to cope with such intensive intervention. If their child survived resuscitation but was critically unwell, parents were able to indicate how long they and their child would need in order to consider the alternative option of palliative care. They appeared to express the need for a window of reflection in order to consider ongoing intervention or transition to hospice and palliative / end-of-life care. However, this was different for each family and ranged from a few hours to two to three days.

> '*Our plan with Finlay, within his advance care plan, is that we would try everything for 24 hours and then we would review it. Cos past experience is that he is a child who can get very seriously ill but he does bounce back quite quickly, so we've said we would like to try everything possible, even if it was to have a trachy, we'd want to try it first before instantly dismissing it*.' (7c)

Resuscitation decisions were also influenced by the degree to which they believed their child might suffer and they strongly associated this with quality of life. Parents described how their child would '*tell them they had had enough'*. In Sharman's (2005) study of parents whose child was at the end-of-life, parents felt they were able to perceive their child's will to survive or not. These choices revealed a deeper understanding of the values parents held in their beliefs about dying. They all wanted a good and peaceful death for their child away from the bright lights of the hospital and they struggled with the balance between a medical focus and intervention, and the spiritual wishes of a good death and not wanting their child to suffer. It added another dimension to the complexity of advance care planning, of when to shift the focus of care and revealed a significant finding not previously identified. One mother admitted.

> *'I suppose I'd quite like to get to that point as opposed to being all clinical, resus room and bright lights and medical and all of that.'* (9c)

Decision-making at the end-of-life has predominantly focused on oncology, neonatal care and intensive care in PICU, and depicted decisions in terms of the continuation of, or withdrawal of treatment (Zaal-Schuller et al. 2016). There is limited evidence that illuminates the complex choices described by parents in this study that influence decisions about resuscitation. There is an assumption that certain conditions, for example neurological degenerative conditions would warrant DNACPR at some point in the illness trajectory, but there is no indication of when this might be. In addition, it is implicit in the literature that health care professionals would choose DNACPR earlier in the course of illness than parents (Horridge 2015). This study has revealed that decisions about resuscitation are not solely related to when, or, whether or not it is futile to attempt resuscitation, but are influenced by complex dynamics that involve parents wanting to have space and a voice to make the best decisions for their child. This is part of the complexity of decisions within advance care planning for parents impacting on options of care to a degree not understood before.

Balancing preference for place of care and place of death

The tensions parents face in issues of resuscitation, their child's current clinical condition, uncertain prognosis, vulnerability and deterioration all affect decision-making. Where these decisions can no longer be delayed, a further tension arises for parents, as they need to choose place of care and place of death. The majority of parents recognised that their preference for acute care in hospital was not appropriate for palliative or end-of-life care.

> *'I don't think the trauma of having the bright lights, resus kind of room, where we've been a few times now - I don't think I'd cope with that at the end and that being your lasting memory. Where at least if you were in a place where it's a bit calmer, maybe like the hospice, at least then you know it's less stressful.'* (9c)

Parents were confident that hospital was the most appropriate place of care to manage their child's symptoms and possible deterioration. It enabled an expression of hope that if something could be done, if there was a chance for intervention, then hospital was the best place to be. Survival as the priority of care was the driving decision factor.

Where a change in the illness trajectory was evident, parents faced choices related to preferences for place of death and there was a significant difference in their choice. Although there was an inevitable recognition that their child might die during a crisis event in hospital, all of them at the point of death, wished for their child to be at home or in a hospice.

> '*Well home, he loves his home, he loves his bed and the distractions of hospital would be wrong on every level.*' (3c)

Although many parents voiced the wish to be at home when their child died it was not the choice for all parents. One father was clear home was not appropriate for him.

> '*I think, well we don't know how we would be when it comes round to his advance care planning and where he should be, but there are other factors like some people want them to pass away in their own home but it's all very well, but a certain part of me doesn't fancy him passing away here. Cause there's a fair old chance that we might move anyway, but there's a fair chance we might not and if he passes away here in this house I think there's increasing probability that we would have to move, quite considerably, so I'm thinking about the implications of further on. So this is his room but what happens if he passes away in his room and it will be OK we just can't stay here um, so I think the hospice works out as a good option. I would rather he did not pass away in Hospital, but if that's the best place for him to be managed for his care, but we don't know what the future holds.'* (8c)

The extent to which parents believed it was possible to achieve their preference for care and place of death was apparent in the advance care plan. Eight parents stated acute intervention with all options of care open, but hospice or home for palliative and end-of-life care. They clearly demonstrated different views in relation to place of care and place of death. The choice for parents was not straightforward and influenced by multiple factors and priorities - as illustrated by one mother.

> *'That's interesting again really about place of care, because at that stage, obviously I don't envisage that stage, only because it's not healthy, but he'll either be, it'll be sudden or if it was a deterioration, I would still be under the impression of constant hope - that if he was in professional care could intervention be the right thing. If we were at home would that mean that he wasn't as safe as he could be. So, it would be circumstantial. I'd like to think that if like in movies they tell us a time and you know a no hope thing, then this would be the best place, but if that prevented interventions that might be possible in hospital of course because if he was struggling and the chances of intubating him and resuscitating him were all hopeful then of course the last place he would need to be is here (home). So I think again it's circumstances and I think because we don't know what those ends will be I suppose I can't really say. I suppose the preference if I was given that wonderful amount of time then obviously home.'* (3c)

Many parents felt unprepared when unexpected events occurred. These accounts revealed further insight into parents' preferences for care and place of death. Having received the information, parents needed the space and time to reflect and they were then more able to make decisions.

> *'We were at home and he called at 3 in the morning and said she's on the edge of a cliff and I need to know what you want me to do. The choice is I can call an ambulance and they can take her to (Hospital) or we can keep her here (Hospice) and make her comfortable and do what we can. I need you to make that decision for me. We talked about it and decided the worst thing to do for her would be to fetch her out of the hospice into the bright lights of the hospital with cannulas and so we decided for her to stay and said, can you make her comfortable and we'll come. We were able to talk about her care and our wishes and that was helpful.'* (13bj)

There is growing debate about preferences and priorities in place of care and death (Bluebond-Langner et al. 2013). The shift to understanding priorities of care has largely been influenced by increased medical intervention and survival well beyond possible treatments of the condition. Children are living longer with increasing expectations around the right to treatment where the priority of care and focus of treatment is about survival. This makes choices about place of care more complicated and articulating this in an advance care plan difficult. Increasingly children with complex needs require more intensive treatment to survive that would demand a hospital and often a PICU admission.

This study reveals that parents choose multiple places of care depending on different circumstances and thus, preferred place of care as a single option is not helpful, rather it needs to be understood in relation to approach to care and possible care in different settings.

Moreover, factors such as pain and suffering and quality of life are significant for parents in the choice of care and preference of place of care. Parents recognised that the hospice provided more quality time and they interpreted this environment as a place free from suffering. As their child deteriorated or they believed there was no further chance of intervention, balancing pain and suffering and quality of life came to the fore.

Struggling with pain and suffering

Pain and suffering were strongly associated with quality of life (see maintaining quality and quantity of life) and had a direct and immediate impact on the choices parents made. Emphasis on striving for all interventions was outweighed by not wanting their child to suffer. Parents' explicit expression of not wanting their child to suffer was a major factor in advance care planning.

> *'We know we don't want him to suffer*.' (5c)

Similarly, Sharman et al. (Sharman et al. 2005) and Hinds et al. (1997) recognised that pain and suffering were key influences in parental decision-making at the end-of-life. They noted that a child's pain caused parental suffering and that this significantly affected their choices. Catherine's parents, who were interviewed together explained:

> *'It wouldn't be fair to put her through that again and so we made the decision, we made it clear that we didn't want her to go through that again, no there's no way. We had seen her go through so much discomfort and pain and not to get back to anywhere near where she was before, you couldn't put her through that again, no she was already suffering so much, it would have caused her more suffering and we'd already seen that she hadn't benefited from that.' (*13bj/14bj)

Part of the process for parents was weighing up the risks of intervention against suffering and potential benefits.

> *'What was the point of putting her through the pain, of keep bringing her back to go through the same thing again. She obviously can't tell us she was in pain, like what was the point of putting someone through that.'* (10b)

The degree of pain and suffering was a significant factor closely linked to quality of life.

Maintaining quality and quantity of life

Intrinsic to the choices parents made was the balance between quality and quantity of life. Parents tried to make sense of maximising the amount of time they had left to spend with their child whilst ensuring quality of life. This directly influenced choices about quantity of life (Heinze & Nolan 2012) where parents described a shift when quality of life would become more important and for their child to be free from pain and suffering. As Langton-Gilks argues, quality of life takes over the time remaining (2018).

The question parents asked themselves was whether the quantity of life gained through treatment and intervention was worth it, given the cost of side effects and experience of pain. One father described this difficult balance.

> *'But then again you've got to think about, the, what's the word I'm looking for, um, the life that's she's going to lead, about her quality of life, - whether that's going to be affected or whether I thought she was going to be in any sort of distress or pain, that I couldn't bear for her to go through, then things might be different. But all the time that's she's here, then I'm going to fight for her and do whatever I can for her.'* (6c)

Quality and quantity of life remains a difficult tension to manage (Beecham et al. 2017) and there is considerable evidence that despite not wanting their child to suffer, parents still chose treatments that might extend the time they had with their child. de Vos et al. (2015) note in their study that despite health care professionals explaining their preference to withdraw or withhold treatment in nearly half of cases, parents requested to continue treatment. Janvier et al. (2014) suggests a better understanding of outcomes and associated risks of treatment to support parents in decision-making is needed. However, for each family the meaning and context of quality of life was different. For some it was important to continue treatment at all costs, for others if they felt they had tried everything they would then choose their remaining days or hours in a hospice. Lewis' mother tried to articulate this tension around quality of life.

> *'The way we've understood it in ourselves is that say he had a chest infection that turned to pneumonia and he was vented and they've said, you know these antibiotics and bits and pieces will help which is giving him a rest, then we'll fight on that side of things. But we know that, and having seen families go through it ourselves, close family friends, when they're just too tired and they're just, they're not enjoying their life any more or they're just lying there, there's no quality there any more, I think then that's how we'll know he's starting to make a decision. You know he's tired from everything and maybe then that's the time saying ok enough's enough, we'll let him go on his terms in his timescale. That would be that time, but*

> *if there's something medically we can do and we think he can fight it, then I think we will fight with him and I think we'll help you know, we'll do everything in our power to get him the medical help he needs. But if there's nothing more that medically can be done then we'll let him make the decision as such, in a way, that like I was saying, if he's not got quality, he's not happy and he's switching off, really then we'll let him on that scale, go.'* (2c)

What was similar for all parents was that the quality of life of the child and the remaining time they had together marked a turning point to a changed perspective on the survival of their child. The act of making decisions about quality and quantity of life, and discussing place of care and place of death, presented the ultimate question of choosing between life and death.

Living with life and death

There was a profound sense of knowing that every decision was about their child's survival and ultimately their death. One father described,

> *'There's no good way to do it, you can wrap that mail gauntlet, that spikey gauntlet up in velvet as much as you can but it's still there, it's a knockout blow however it comes and you have to deal with it every single day.'* (8c)

The dualism of life and death and the inherent tensions was apparent in parents' narrative, '*living with a life threatening condition but remaining positive', 'making end-of-life decisions but not wanting to', 'knowing the worst could happen but not wanting it to'* and *'living with death and dying but trying to live as much as possible'.* Kars et al (2010) describe these as internal struggles, the struggle between preservation, preventing the loss of their child and prolonging life, against letting go and recognising the inevitability of death.

Conversations about advance care planning brought these issues to the fore. Each choice created a different burden on the family (see 6.2.2) and for many parents it was not the case of choosing one or the other, but trying to manage both at the same time. Kars et al (2010) stated that parents very often adopted a letting go perspective in one respect whilst preserving life in another, managing the duality of choice. Furthermore, choosing different interventions did not necessarily indicate parents' expectations of cure (Bluebond-Langner et al. 2007), but a hope for survival and worth trying, in order to have more time.

Parents did not want to think about the possibility of death every day. Despite knowing that the end-of-life was near, they were intensely focused on their child's survival. Nevertheless, there were occasions when they sought information they hoped would make them more prepared for their child’s end-of-life. Understanding about organ donation was a key issue about which parents wanted further information.

Seeking information about organ donation

Organ donation as a factor in advance care planning was not initially identified as a theme as it did not directly influence decisions related to care. However, the more parents spoke, the more apparent it became that this was an important factor for them within advance care planning discussions. Seven parents interviewed raised the subject of organ donation and it was documented in five of the advance care plans. Initially it was coded as a miscellaneous theme as its fit was unclear. Further consideration showed that it contributed to the complexity of advance care planning as demonstrated by one mother.

> ‘*We hadn’t even considered things like organ donation and things like that and I didn’t quite understand the organ donation process, from what I’d seen on TV I thought it would be after he had passed away but from what I understand they like them to be, preferably the organs, to still be alive and things like that. It was good in a way cos we could make decisions that we thought would be best for Finlay and it gave us loads of information around that, of choices of where we could go and what we could have done, and it was kind of reassuring.*’ (7c)

Parents wanted more information about organ donation, including whether it was possible for their child to donate and how. Langton-Gilks (2018) described after her son had died, that she wished she had known more about how her son’s death might contribute to scientific research, even though he had been unable to donate organs. Many parents had several questions regarding organ donation, which were left unanswered, yet they were important as they influenced their choice regarding the place of care at the end-of-life. Moreover, raising questions about organ donation, enabled parents to have an open conversation, to question each other’s perspective and be able to jointly decide what they wanted. More importantly, the process of being able to discuss organ donation with each other contributed to the therapeutic dimension of the advance care planning process for parents, in being able to come to the same position and in building a legacy for their child (see Chapter 7).

Organ donation is rarely discussed in the literature for children with a life-limiting condition. There are a dearth of studies, meaning experiences of parents and their wishes regarding organ and tissue donation is little understood (Darlington et al. 2019). Of the limited evidence, it is reported that health care professional’s do not raise the topic of organ donation with parents, leaving them to make assumptions as to the reason why (Darlington et al. 2019). The findings reported by Darlington et al. (2019) resonate with a recurrent theme throughout this study that if parents are left uninformed about their child’s condition, prognosis or potential for organ donation they experienced frustration and feelings of disempowerment (see section 6.2.2). Parents expressed this anxiety of not knowing, as a significant burden within advance care planning.

6.2.2 Bearing the burden of responsibility

Making such profound advance care planning decisions can feel like a burden as parents struggle with feeling out of control. The risks associated with such complex decisions prompt further questions and contradictions. This intensifies parents' concerns about how others perceive them and their sense of disempowerment. They are left to make assumptions as to why and become distrustful of health care professionals to make the right decisions for their child. This has an impact on their own belief of whether they are making the right decisions so that they repeatedly question whether they are making 'good' decisions for their child, themselves and their family. *Bearing the burden of responsibility* is the second concept in the sub category confronting complexity. As a concept, it is intertwined with *enduring the heartbreak* (6.2.3) but it has distinct properties.

The burden of such difficult advance care planning decisions and the responsibility this brings, was strongly expressed by parents.

> *'Really big decisions which again I really don't like making such final decisions.'* (1c)

> *'It's a huge responsibility and I felt all the way through her life that you are completely responsible for making decisions for a child who can't voice their preference themselves. So we had to make small decisions and big decisions all the way through her life, but these (end-of-life decisions) are momentous, they're huge and you really are reliant on the medical experts to give you the information and guiding you.'* (13bj)

This was accentuated when they recognised a distinction in the responsibility they carried for their ill child compared to a healthy sibling and the different parameters of making decisions - illustrated by one mother,

> *'It's like all these things with the choking spells. Sam would choke 3 or 4 times a night and I still wouldn't call an ambulance but whereas a normal kid would choke once and you'd call an ambulance.'* (5c).

Parents felt a burden of needing to justify treatment for their ill child - so even though they were more vulnerable to coughs and colds it was still acceptable to treat them. They recognised that 'normal' for their ill child was different to their siblings and the parameters of care and risks were not the same.

Perceived risk

The perceived risks associated with advance care planning prompted further questions for parents as to whether requesting acute intervention was acceptable, or whether their child was likely to be strong enough to survive another episode of acute illness and treatments.

Parents recognised that there were risks.

> ‘*We know there are risk factors.’* (5c)

They acknowledged that they were constantly weighing up the risks associated with treatment, of the possible outcomes and potential for pain and suffering.

> *‘We know the options are temporary and they also come with risks.’* (3c)

Each perceived risk required a re-visioning of their choices (Wilson et al. 2011) which were complicated by the emotional impact, their values and beliefs. Risks were further affected as parents tried to manage the uncertainties associated with prognosis and the illness trajectory. Little is known about how parents balance the risks and options inherent with different choices at the end-of-life or how this informs advance care planning. The literature in children’s palliative and end-of-life care recognises the complexity of decisions but there is limited exploration of parents’ perception of risk in the decision-making process. The literature in adult palliative care suggests that a number of factors are involved in balancing risk (Wilson et al. 2011) including available resources, sufficient information and individual values. These themes are apparent in this study but it would appear that the perceived risks of advance care planning decision for parents are more complex given the vulnerability of the child and uncertainty of prognosis. At times parents found the burden of trying to balance the risks too great and frequently described a lack of confidence and feeling out of control. Their perception of the advance care planning process, of how they were perceived and the degree of their involvement led them at times, to feel disempowered.

(Dis)empowerment

The burden of responsibility was made worse by feelings of disempowerment. Whilst in part this was due to their experience of inadequate information and lack of involvement in shared decision-making, it was accentuated by how they felt they were perceived by health care professionals and the presence (or not) of trusted relationships with health care professionals. This sense of powerlessness was also influenced by not being able to control the death of their child.

> ‘*We felt we had no control and the worst was going to happen somewhere*.’ (7c)

Parents' sense of disempowerment was strongly influenced by their capacity to cope within the medical environment and their relationship with health care professionals. They struggled with the 'alien' language used, which they did not understand and found it difficult to articulate their meaning in a medical context. This was illustrated in the interviews where most parents had moments of not finding the right words to explain what they were thinking and feeling. They expressed how much more difficult it was to articulate their thoughts in the busyness of a medical environment and in when talking about future care for their child. They were also challenged by the hidden rules of decision-making and the significance of hierarchy; when information was shared or withheld, or when explanations were limited.

Nearly all parents identified poor experiences that highlighted barriers to shared decision-making that impacted on advance care planning. In particular, these experiences influenced how they felt they were perceived leading to feelings of not being trusted or respected.

> *'Other medical professionals, but mostly doctors of a certain age see a mum who's rolled up at A&E in the middle of the night with her hair everywhere and still in half her pyjamas and is overweight and they don't see me as the accountant or able to make decisions, they see me as the mess who needs to be patronised.'* (1c)

They were concerned that they were seen as over anxious and therefore not heard.

> *'I think I felt like I might have come across like the anxious mum.'* (7c)
>
> *'It's like someone thinks I'm a crazy person.'* (3c)

They did not feel they were able to share in decision-making or that there was an equal partnership between them and the health care professionals involved in their child's care. This created an imbalance of power (Edwards et al. 2012) and distrust. Those parents who did speak out, as Bethany's father illustrated were then anxious as how they came across.

> *'Now I'm the main carer, I'm not backwards in coming forward when I'm in hospital, I tend to push things, I mean my wife's quite quiet, whereas I'm more, I tend to open my mouth a little bit more, and maybe I say the wrong things sometimes but it's all in Bethany's best interest. And I think a lot of the time you've got to be a little bit more, I don't know if forceful is the write word, but a little bit more like um, outgoing, and to say what you want done with her.'* (6c)

They were then selective as to whom they spoke and if they felt judged, were less likely to reveal any information. Sam's mother was adamant, following a poor conversation, that she wouldn't talk about advance care planning again and left these conversations to her husband. However, most parents were able to identify a trusted individual and named a key professional who they were able to speak with about advance care planning, particularly at important times. Mitchell et al. (2019) reported this as a key component for effective decision-making.

There are similarities here with studies on the (patient) role in decision-making, of distrust and terminology being a barrier to shared decision-making (Joseph-Williams et al. 2013; Mitchell et al. 2019). In addition, patients (parents) are likely to undervalue their expertise, and believe that their own knowledge is superfluous and that the doctor knows best. Parents often stated that they felt disempowered and believed they only had a passive role. This was evident in certain settings where parents reported a dependence on doctors to make treatment decisions, which were not their choice. In moments of crisis, emergency and in PICU, parents felt they relied on being in the '*doctor's hands'* and stated they were not in control and felt disempowered. Joseph-Williams et al. (2014) identifies this as a 'covert contract' where decisions are characterised by passivity and compliance. In contrast, in other settings - for example, in their own home or in the hospice, parents expressed a sense of an equal relationship and space and time to make decisions within a shared partnership.

Not feeling listened to, nor being equally involved, was a barrier to advance care planning and had wider consequences. Poor experiences of decision-making and feeling disempowered had a direct influence on advance care planning - illustrated by Catherine's mother.

> *'The experience was so antagonistic, and once he'd gone we said we didn't like that, we are not happy about that at all and I think that almost might have swayed any decision I had to make for many months after.'* (13b)

Parents found it difficult to adjust to the changes in power bases in particular when professionals had seen them at their most vulnerable. They found it hard to adjust to an equal decision-making approach. Their own feelings of self-worth transferred to feeling their child was perceived as less valuable than a normal child. This made parents distrustful of health care professionals in making the right decision for their child and impacted on their perspective about discussions related to advance care planning.

Edwards et al. (2009) identify empowerment (or disempowerment) as an important element of shared decision-making. This particularly related to information exchange and the sharing of knowledge. Crucially in this study, parents felt empowered when they used the advance care plan as a vehicle for imparting knowledge of their child. They believed they then held decision-making responsibility and not the doctors. This was illustrated by Catherine's mother.

> *'We felt we needed to have our wishes documented because we can't be put on the spot in the middle of an emergency having to make decisions and we felt at the time we are just not going to be dictated to. So we chose full resuscitation on the form to say we want everything done, and don't ask us again just do it.'* (13bj)

Parents believed the advance care plan provided statements for pursuing treatment they felt doctors might not undertake. This may offer an explanation of the choice for full resuscitation where parents are giving their child a chance when others would give up.

Clinicians reaction to parents' decisions also enhanced or diminished parents' sense of competence and confidence. A breakdown in communication could erase a parent's sense of confidence (Meert et al. 2008) and create additional burdens within decision-making. Challenges in communication were most obvious where there was disagreement about treatment decisions (Sharman et al. 2005; de Vos et al. 2015) and several parents described a clash around life-sustaining treatment where they wanted treatment but doctors were suggesting otherwise. These disagreements had a direct impact on how parents felt about the choices they made and how they felt they were viewed, of whether they felt empowered to share in the advance care planning process.

This was further complicated where they perceived their child was viewed differently within a medical context, in contrast to their endeavours for their child to be seen as an individual. As Catherine's mother stated.

> *'He patted her head and said I've seen children like this before. I just thought – no you haven't, all children are so individual.'* (13b)

In these situations, parents found it difficult to hold on to their family values within the pressures of a medical environment and the structures of the healthcare system. Many parents felt they needed to re-construct their normal family lives to accommodate a focused medical context. This meant families found it challenging to maintain previous social contacts, their lives no longer synchronised with others as they managed appointments, hospitals and the uncertainty of death (Seale 1998).

Despite a move in health care towards shared decision-making (Joseph-Williams et al. 2013; Belanger et al. 2014) parents continued to describe numerous encounters where health care professionals took a paternalistic approach and where parents found it difficult to find an equal balance in the process. Trusting relationships with health care professionals has been seen as fragile (Mitchell et al. 2019). This is significant, in that shared decision-making depends on the sharing of information and an ability to influence the decision-making encounter (Joseph-Williams et al. 2013). If parents believe that trust is compromised by inadequate information and feel unable to equally contribute to the decision-making process, they will doubt whether they have made the right decisions for their child as part of advance care planning.

Being a good parent

Underpinning the burden of advance care planning decisions was the desire of parents to make the ‘right’ decisions and to be seen as a ‘good’ parent

> *‘We are reducing the levels of guilt in respect of doing the right thing at the right time for the right reason.*’ (8c)

This was especially important during points of critical decision-making (October et al. 2014) and making decisions in the best interests of their child (Hinds & Oakes 2009). Carroll et al. (2012) noted that parents grapple with the responsibility of decision-making and question whether they are doing enough, judging themselves about the decisions they confronted. Caroline’s father illustrated this.

> *‘It was totally the right decision because she had a good summer but it was definitely the right decision because if we had said no we would have regretted for ever and ever. That would have been huge, a huge thing to think that we had not given her a chance.’* He went on to revisit this later in the interview. *I’m so glad we made the right decision, it could have gone the other way and that would have been absolutely… I couldn’t have lived with that if we’d made the wrong decision.’* (14bj)

For some parents no decision was ever going to be right in the context of the death of their child.

> *'I suppose there's a little bit about self-preservation as well. If you are being honest, cos if you are making that decision and you make the wrong decision, and let's face it if she passed away It's going to be the wrong decision, do you know what I mean, no matter what you do maybe they worked on her too long etc and that was my fault, maybe I should have had a DNR at the beginning when her heart failed because of this. You're never going to appease yourself.'* (9c)

On the whole a decision felt right if both parents were happy and agreed with the decision made.

> *'It was helpful to know that my husband did feel differently and there were some things we went OK is that really important to you or is it less important and coming to a compromise that we were both happy with, which is difficult when you are being honest when you're being really honest with each other but it's really important you know if things were going to go wrong and ending up with Clara dying then these kind of decisions are really important for both parents to be happy with.'* (1c)

Parents constantly questioned the choices they made and looked for assurance that they had made the right (Heinze & Nolan 2012; O'Neill 2019) and good decisions (Lotz et al. 2017). They also frequently questioned the decision they made asking themselves what would have happened if they had decided differently (Kars et al. 2011). Wilkinson and Savulescu (2019) acknowledge that often there is no single option or right course of action. O'Neill (2019) describes poignantly, not that decisions are the 'right' ones, but that whatever decision *is made*, it will not be 'wrong'.

The ongoing nature of their child's illness impacted on their choices and parents were only too aware that things may change, however, they felt reassured that having made a decision and recorded it in the advance care plan, they were able to change their minds.

> *'There's no right or wrong, that it's really important to have an appreciation that you might not really know, but important to write it down and actually in the situation you might feel completely different to how you feel in theory, in an abstract conversation, and it was made clear that it is a baseline and you can change it and override it and it will depend on the situation you are in.'* (1c)

Evidence suggests there is a difference in opinion of what it means to be a good parent (Hinds & Oakes 2009). The key themes of fighting at all costs, not giving up and not letting one's child suffer are evident in this study. Furthermore, October et al. (2014) identified key factors of being a good parent during critical decisions that reflect the narrative from this study; focusing on the child's quality of life, advocating for the child, and making informed decisions. These themes were all evident during the process of discussion and writing the advance care plan. What is captured less well, is the constant questioning and struggle to do the right thing. Parents described an unrelenting doubt about the decisions they had made.

As parents strived to make good and right decisions for their child they looked for reassurance and support from professionals. O’Neill (2019) in her personal account of her daughter’s death, highlights the importance of support from health care professionals in reassuring parents of decisions they have made. She explains how critical it is for parents not to feel abandoned or left feeling that health care professionals disapproved of the decisions they made. Disapproval implies the wrong decision. The consequence of making good decisions was a huge burden and strongly linked to the emotional impact of advance care planning.

6.2.3 Enduring the heartbreak

The emotional impact of advance care planning and enduring the heartbreak of loss was evident in all the interviews, where parents described end-of-life and advance care planning conversations as *‘traumatic’, ‘hard’, ‘difficult’, ’emotive’,* and *‘shocking’.* Part of the process was being able to voice that their child was life limited, that this placed demands on the whole family, and that their child was going to die.

Parents described the emotional reality of the situation,

> *‘The difficult time is when you discuss it with the consultant and he’s very kind but honest and tells you like it is, that’s when it gets me and when I find it really emotional.’* (3c)

It was also about recognising the unimaginable space of what life would be like after their child’s death. Parents were faced with decisions that had an emotional and heart-breaking impact inherently tied to past, present and future experiences. The depth and rawness of emotion expressed was profound. Parents believed that health care professionals were not able to comprehend the depth of emotion or understand their decisions. No matter how skilled the professional or how supportive, parents stated, they could not take away the difficult and overwhelming heartbreak of their child’s death.

Confronting reality

The overriding theme for parents was that talking about their child dying was extremely difficult. Advance care planning meant they needed to confront the reality of death but talking about their child dying was the hardest thing to do.

> '*It's something you don't really want to discuss and it's the last thing on your mind that that's gonna happen.. it's not something you really want to be talking about, you can be as nice as you like but you're asking questions no one wants to hear.'* (6c)

Admitting they were going to die was exceptionally painful,

> *'It's profoundly hard and I'm living with the reality that I'm going to have to bury my little boy somewhere along the line and have a funeral.'* (8c)

and acknowledging the far reaching effects of the death of their child was overwhelming.

> '*You know it's there like a giant big oppression of a psychological experience that's already built up and then you are dealing with the guilt of how he actually goes and how you're going to deal with that and so that wears upon you, so from a logical point of view, we've got a great big lift there, that's rather obvious, that's going to be a massive reminder.*' (8c)

These conversations were compounded by other sociological factors that made talking about their child more difficult.

Challenging assumptions

Significantly, parents frequently portrayed that talking about their child dying and advance care planning, was 'not normal'. It felt *'alien'* and therefore more difficult to talk about. It challenged their assumptive worlds and their values and beliefs.

> '*It's not something that regular people discuss.*' (3c)

> *'Talking about end-of-life - we couldn't really get our heads round it, it was shocking as well.'* (10b)

> '*The one thing we can't possibly nail down is the funeral and I think to a large part that we are scared of discussing it, and we know it's the elephant in the room – it's the BIG GIANT elephant in the room.'* (8c)

Parents recognised it was not a conversation you would have with friends and that other people did not really understand the depth of what it meant.

> *'I think I did share with a few friends - I think I put something about it on Facebook that we were doing advance care planning. Some people were sympathetic but some people said yes I've just had to write a care plan for my child because they've got a nut allergy or something and I'm like oh just... so... um. Yeah. I don't think people get it.'* (5c)

They found they were struggling with society's understanding of the normal social processes of death and a conflict with society's construction of the 'natural order' (Seale 1998). Parents do not generally expect their children to die before them. As one father described, emphasising the community of families they were connected to.

> '*We had 4 elderly members of the family go, that's bad luck that happens, especially when they are in their 70's and 80's so OK, but when you have 4 children's funerals in one year and you're going I shouldn't really be attending more than a couple of these in my whole life*.' (8c)

Nevertheless, parents showed a degree of resilience and an emotional strength in that although they expressed it was hard, it was not as hard as they feared.

> '*I was prepared for what they were going to say because my wife knew quite a lot and it wasn't as daunting as I thought it was going to be, although it was still quite horrible.'* (6c)

The intensity of emotion shifted over time and was influenced by other factors. Parents voiced anger and despair if they had a negative experience with health care professionals. Being poorly informed and not listened to affected decisions and impacted on their confidence (Carroll et al. 2012). All parents reacted emotionally as they recalled their child's illness experience and the choices they needed to make, but it did not mean they were incapable of engaging in conversation (de Vos et al. 2011). There were several occasions in the interviews where parents expressed great sadness and shared experience of enduring heartbreak. There were moments of deep reflection and tears, but not one parent wanted to stop. The experience of grieving for their child did not prevent them from asking questions, gathering information and being able to express preferences regarding their child's care.

Health care professionals tend to worry that these decisions are emotionally burdensome (Gillam & Sullivan 2011). There is concern that parents are making an emotional decision rather than a rational one, but as Janvier et al. (2014) states, most major decisions in life are not purely rational and having knowledge and intelligence do not counter powerful emotions. Parents should not be prevented from participating in decisions because they are emotionally difficult (Gillam & Sullivan 2011). Furthermore, de Vos et al. (2011) emphasise that the capacity of parents to understand complex issues should not be underestimated despite their stress and grief.

Further caution around parental decision-making is that parents base decisions on risk and benefit for themselves, not for the child, that the anticipation of losing a child may impede decision-making (Janvier et al. 2014). This suggests a caution regrading parents advance care planning decisions. However, none of the parents that were interviewed, indicated they were incapable of making decisions on behalf of their child. Furthermore, health care professionals are involved in valued and emotive decisions and are not exempt from the emotional impact of decisions (Janvier et al. 2014). Moreover, Wilkinson and Savulescu (2019) emphasise that medical decisions are not based only on medical facts, but also on values. Each individual doctor will vary in the values they hold, and these will influence the decision-making process.

Relinquishing certainty

All parents described a persistent uncertainty about prognosis, of the unpredictability of their child's condition, and needing to make advance care planning decisions but not knowing the answers. At times they found this overwhelming, describing it as '*making decisions in the abstract*'.

Parents expressed feelings of '*it's impossible to know'* and uncertainty about their child's condition and the future. Harris (2011) identified four key fears related to uncertainty: pain and suffering, the unknown, loss of control and loss of self and others. All these elements were voiced by parents as they tried to grasp an understanding about their child's care at the end-of-life. Parents were able to make advance care planning decisions and managed the uncertainty through the knowledge that they could change their minds. They based their decisions on the current situation and should this change, there was always the option to make a different choice.

> *'There's a complete range of different opinions, they're all very possible, and there's no right and wrong – I think a lot of it felt like we'd write something down and we realised it was important to write something down but actually in the situation you might feel completely different to how you'd feel sort of in theory, in an abstract conversation and I think that was made quite clear to us and I can't remember if that was verbally or whether that's built in to the writing of it but I think my understanding is that you have this, but it's a baseline and you can change it and you can override it and it will depend on the situation that you are in.'* (1c)

Parents had to relinquish any sense of certainty, as they no longer remained in a constant or unchanging world. With such uncertainty, they made advance care planning decisions with the least risk of loss (Kars et al. 2011).

Shadows of loss and grief

Underpinning and weaving through all the stories that parents shared was the shadow of loss and anticipated death of their child. Parents expressed multiple losses, experienced throughout the child’s illness and there was no doubt that they carried the grief of not having a ‘normal’ child. This sense of grief and loss was heightened as parents engaged in advance care planning conversations. Parents were able to imagine how they might feel at the death of their child and they voiced their sense of loss in terms of loss of parenthood and the loss of seeing themselves in their chid. The bereaved parents who shared their experience expressed a deep and profound grief as they reflected on their child’s life and death. Harvey (2002) identified these multiple losses as layers of loss, encompassing loss in terms of what is now known and what is anticipated in the future.

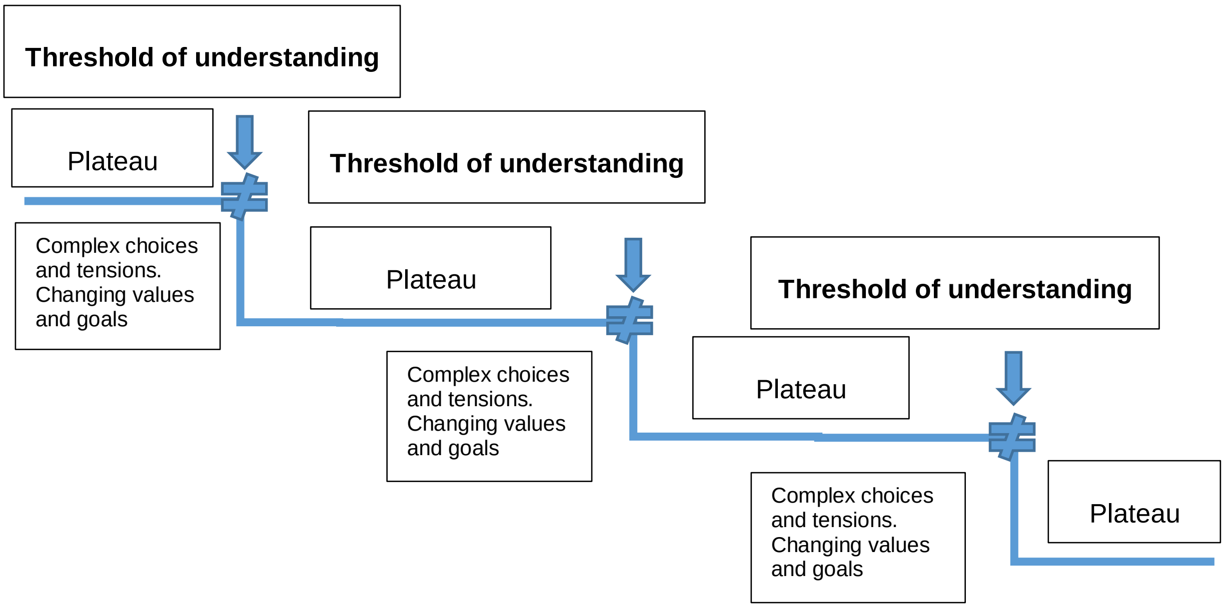
There is extensive literature on parental bereavement and loss following death, however, the emotion and loss that parents experience throughout a child’s life, prior to death has received much less attention. There is emerging evidence from psychologists and therapists (Harris 2011; Neimeyer 2014a; Roos 2018), that grieving and loss is not just reserved for those who experience physical death and that the experience of chronic sorrow (Olshanksy 1962; Roos 2018), nonfinite loss (Bruce & Schultz 2001) and ambiguous loss (Boss 2006) all impact on our view of the world. This loss experienced by parents has similar life-altering and never-ending impact (Roos 2018). Parents caring for children with life-limiting illness repeatedly make adjustments to loss. In this study, this appeared complicated by contradictions where feelings of joy and sorrow were intertwined and demonstrated so richly in stories shared by parents. They experienced profound sorrow, but joy of spending precious time with their child. Parents were managing the conflicting emotions of hope for survival and not wanting their child to die against the realisation of their child dying.

Parents’ stories reflected a sense of sorrow that intensified by the triggers and crisis events they experienced, knowing that death might follow. These experiences were accentuated through the process of advance care planning whereby the balance of hope and reality of grief shifted as they spoke about advance care planning. As parents navigated these complex and emotional choices, they began to reconstruct their understanding of their child and family, and the life to be.

6.2.4 Crossing thresholds of understanding

The final concept in confronting complexity is *crossing thresholds of understanding* and explains how parents move from one perspective to another within the course of the child’s illness journey. The concept is defined by a period of stability or plateau and subsequent deterioration or crisis event that leads to a gateway of new choices and changing values and goals. These choices mark a shift in direction, a turning point or crossroads that represents a threshold of understanding, where the situation changes and parents voice a different perspective of their child’s condition and future hopes. Parents’ experience-*crossing thresholds of understanding* on multiple occasions and it is a fundamental part of reconciling the tensions inherent in advance care planning (see Fig 6.2).

Figure 6.2 A representation of the concept: Crossing thresholds of understanding



Understanding this concept is closely associated with multiple other concepts recognising the inherent link between hope and survival, quality and quantity of life (See section 6.2.1), timely conversations (See section 5.5) and living with life and death (See section 6.2.1). It begins to illustrate the cyclical process of advance care planning and the multiple and complex experiences of advance care planning.

A mother and father who jointly shared their experience of their daughter's life and described the different understandings that episodes of wellness and crisis events presented, illustrate this concept.

The narrative captures the rollercoaster journey of illness for parents as their child deteriorated leading to end-of-life.

> *'By the time she was 2 ½ she was really quite poorly she had lots of chest infections caused by aspirating reflux, so she had surgery, she had a gastrostomy and fundoplication and she then started having periods of being well…*
>
> *As she got bigger, although she always had periods of being well she still had chest infections and things, and if she ever got a cold she always ended up in hospital on oxygen, it was always her lungs and digestion… and then when she*

> *was 12, she started making a noise, breathing noises and they told us that her airway was collapsing and that's really frightening. They discussed various ways of treating her and some, it was fairly extensive surgery that we didn't like the sound of, so the least invasive was to have a nasopharyngeal airway permanently in situ, which is what she had and she lived for another 2 years. They said this would enhance her life and perhaps it was like that in the beginning, but quite soon after having the tube probably about 6 months, it was obvious she couldn't manage without it. If we ever had a problem with it, it became dislodged or needed changing, she would really struggle to breathe without the tube in, so it was holding the airway open and there were lots of problems. She got pseudomonas and then she was on these wretched nebulisers which she hated and the level of care really stepped up and it was impossible for anyone else to really look after.*
>
> *In the end she had been a bit snuffly and chesty, but by that evening it was obvious that she had become quite unwell, so I took her up to the hospital and the consultant on call, who knew Catherine really well, said I am concerned that Catherine is going to suddenly go downhill over this weekend. Unfortunately, over the weekend she did deteriorate, she actually had a crash basically… her blood pressure was absolutely in her boots, we wanted her resuscitated. She was so strong and I think that's the thing about special needs children, they function at a level that no one else could cope with, and she did bounce back and we had the most amazing summer, she was smiling, happy… but come the autumn she had another chest infection, this time she was in high dependency and she was there pretty much in a coma for 2 weeks. We discussed her end-of-life plan and then over that weekend she woke up. She opened one eye and 2 and then she smiled and she was back again. We got to go home but again she became really unwell and I called an ambulance, and of course an ambulance won't take somebody to a hospice. So we got taken to a hospital and she was just so poorly, they managed to stabilise her in resus and they said this is it basically what do you want us to do? Do you want her intubated again and we said no, and she went up to the ward. She was going to be moved to the Hospice in the morning but she died before she was moved. She was just 14.'* (13b)

This powerful story of Catherine's life reflected many stories told by parents of their child's illness and the impact these experiences have on advance care planning. Identifying specific dimensions of the illness journey helped to strengthen the analysis giving depth to the concept of *crossing thresholds of understanding*.

Chapter 6

Facing plateaus and gateways

For many parents the illness trajectory was marked by periods of stability or ‘plateaus’, interspersed by a crisis event or gradual deterioration of their child’s condition. These crisis events opened ‘gateways’ where complex advance care planning conversations were needed.

Parents described plateaus as times when their child was fairly well or stable. They were able to live in the day-to-day within these spaces, striving to maintain the normalcy of family life. These were the times they expressed a desire to talk, and recognised they were the best time to talk about advance care planning. During these plateaus, parents were aware that the situation might change and anticipated a crisis event or declining health. Charmaz (1991) in her research of the experience of illness, described plateaus of managing illness until a crisis event, which shifts the direction of thinking. Rallison & Raffin-Bouchal (2013 p 197) describe these as *liminal* spaces, emphasising a transition from a situation that has passed away, while waiting for a new one to arrive.

As their child entered a period of declining health or crisis event, parents faced a gateway of different choices. These gateways, described by one parent as a ‘trapdoor’, represented a ‘drop’ from one plateau to another where their child’s condition had worsened. As one mother commented,

> ‘*He’s kind of stable and then drops a bit and then he’s kind of dropping again so we need to rethink.’* (2c)

The extent of the drop and the emotional burden this holds; the experience of ‘falling from one plateau to another’ (Steele 2000), was dependent on how ill their child was and the likelihood of death. Parents experienced these new plateaus as unfamiliar territory, which prompted a need to construct new understandings of the situation and changed priorities. Steele (2000 p 58) describes these crisis events as ‘*dropping off the plateau’*.

Whilst some parents described a clear trajectory of long plateaus followed by episodes of declining health, for others it was an erratic and unpredictable journey where repeated incidents of deterioration and crisis events occurred with only limited periods of stability in between. On occasions, these events could happen daily if not hourly and could result in multiple changes and review of the advance care plan. This chaotic journey of rapid deterioration and multiple crisis events marked a downward slope in their child’s illness journey. It was illustrated by stories of repeated admissions to hospital, to HDU or PICU, with long stays in hospital and only short periods at home before another admission. Each situation brought complex choices and tensions, which on occasion were barely resolved, if at all, before another change occurred. Some parents described two or three of these transitions, whereas some parents experienced multiple plateaus and gateways.

> *'We've had 2 or 3 moments in hospital where he's been close and come back but at the moment he's fairly well. But we know there will come a time where we're potentially leading to a situation where we will need to think about a DNR.' (*8c)

These narratives reflect the experience of living with chronic illness (Corbin & Strauss 1988; Charmaz 1991). As parents moved through plateaus and gateways the process became a measure of how ill their child was and a marker of deterioration. Each plateau and gateway represented moments where parents needed to rethink their deepest values and beliefs. How much they felt in control is expressed in Kars et al. (2010) study through the metaphor of changing levels of the river regulated by a chain of locks. Kars et al. (2010 p 31) describe parents who try to preserve the existing situation by keeping the gate closed (locked). When the water leakage becomes unstoppable they descend to the next basin and try to preserve the new situation. Hill et al. (2014) identify these gateways as critical points where parents may try and stay on the same path or move to a second path. This conceptual model suggests parents can disengage from one path and re-engage in new goals. They label this process *regoaling* (Hill et al. 2014).

These concepts and parents experience shed some light on the challenges for parents and health care professional's to find the right balance in advance care planning conversations when there are constant re-adjustments. However, whilst these models depict the unrelenting process of changing goals that are possible in advance care planning, they fail to explain how parents' make sense of these changes and what influences their capacity to adjust to such changes.

Thresholds of understanding

Thresholds of understanding marked a turning point for parents that was crucial in explaining how they made sense of the situation they faced and the change in their child's condition. Each threshold represented a different understanding with a changed perspective of their child's potential for survival and nearness to death. Consequently, the complexity of advance care planning decisions was intensified by the emotional significance of the situation as parents recognised they were moving towards another stage in their child's illness.

Parents described thresholds of understanding in multiple ways.

> '*He's just a little fighter so as long as you're willing to fight we'll give it 24 hours and at least that way we can sort of say enough's enough it's not helping him.*' (7c)

> *'We are for full intervention until we need to draw a line.'* (12c)

Thresholds were indicated by recognition that their child would not return to previous capabilities or that the pain and suffering now outweighed treatment and care.

> '*We are used to dealing with her being at 80% unwell but it would be different if she was at 95% unwell and close to 100%*.' (12c)

This resulted in a different understanding, a new meaning with a shift in expectation.

> *'It's kind of drawing that line when it's because of her condition and when it's because of everything else, and obviously there will come a point when you've got to make that decision … If you've seen her go through hell and back and they still can't save her, or they've put her on life support and you've spent the last 3 days, and she's had a series of operations they've done, and they've done this to her, actually I know that I'll come to a point when actually no more.*'(9c)

This process of transition, between plateaus and crossing thresholds of understanding is described as a place that lies, 'betwixt and between' or a liminal space, through which individuals cross (Turner 1988). These spaces initially described in a religious context are signified by rites of passage, (Van Gennep 1908; Translated Vizedom & Caffee 1960) markers of whatever we hold sacred (Turner 1988). Such sacred spaces have psychological and emotional significance (Turner 1988) and characterised by emotional and powerful spiritual experiences that shake the personality (Thomassen 2009). It is evident that passing through these liminal spaces are crucial in the process of end-of-life care. Lund et al. (2015) recognise advance care planning as extending beyond a personal and existential set of decisions to a process that is a rite of passage that defines a person's shifting identity. However, this understanding relates to adults making their own end-of-life decisions, the concept of crossing thresholds of understanding and liminal spaces for parents in this context is not fully understood. Bowman & Schwantes (2016 p 9) begin to describe an emerging picture of '*sacred*' or '*hinge places'* that may help to understand parents' experience of moving from one reality to another.

In this study, this process of change and crossing thresholds, signified a transition from life to death for most parents. It also revealed a number of other social and psychological changes that were more hidden. Some mothers questioned society's view as to whether they would be seen as a mother to two or three children, and where the child was an only child, parents questioned their role and identity as a mother or father. Moreover, many parents voiced a realisation that once their child died, their friendship groups might change, they would no longer be a part of the community of having a disabled or child with complex needs. These experiences created social and emotional disruption and the psychosocial transitions in this context challenged parents' assumptions of their world which resulted in it becoming an unsafe place with increased personal vulnerability (Parkes 1996).

If unaddressed, these tensions were difficult for parents to reconcile and unless they were articulated, they could become hidden or unvoiced experiences within the liminal spaces (Turner 1988). However, for many parents these were private thoughts and to make public their inner most thoughts and fears created additional burden (Thomassen 2009). This anxiety and fear impacted further on their confidence and required greater concentration to make sense of what had or what was likely to happen to their child.

Turner (1988) believes that to articulate these thoughts, alongside knowledge and experience, and to understand their connection, is essential to support the process of crossing such thresholds. To grasp such a deep understanding and recognise the powerful change within this process requires a skilled approach with careful and sensitive attention to the sacred meaning inherent within *crossing of thresholds of understanding*. Parents require the space and time to make sense of these changes to be able to voice their thoughts as part of advance care planning.

Such space and time was important, as having experienced the transition of crossing thresholds of understanding, parents were only too aware that a plateau in their child's condition would lead to another gateway and they would need to cross another threshold. Families were acutely aware that one of these moments would be the final one.

> *'The hard part is knowing that at some point we will lose him, we will have to make a decision of knowing it's the end, of accepting that that's the way it's going.'* (2c)

This process of *crossing thresholds of understanding* prompted different conversations with parents and provided opportunity to make or review decisions already taken. However, despite these marked changes resulting in a new perspective, the depth and context of such profound decisions were not reflected in the advance care plans, Documents were only changed in regards to the status of DNACPR and they did not capture these complex changes within the process.

In addition, although parents recognised changes in their understanding and wanted to talk, they also stated that opportunities to engage in conversation with health care professionals was not always available. This might explain the lack of changes to the advance care plan. Thus, where parents were less confident of the advance care planning process and had not discussed fully the alternatives with health care professionals, the advance care plan did not fully reflect their thinking.

In summary, confronting complexity was fundamental to the process of *reconciling multiple tensions*. It was defined by deep emotions and a burden of responsibility but also a desire by parents to understand the treatment options and choices of care available to them to make the right decisions for their child as part of the process of advance care planning. Parents were grappling with multiple tensions each dependent on and informing one another, of wanting all intervention but not wanting their child to suffer, knowing at some point they would need to draw a line, but not being able to define when this was until they were actually there. All these factors impacted on place of care. Understanding these choices was different from one moment in time to another where parents emphasised a changed perspective and different priorities. To achieve this transition and reconcile the tensions, parents used different strategies for *crafting the decision*.

6.3 Crafting the decision

The concept *crafting the decision* evolved at a later stage of the research. Having focused on the complexity of choices within the process of advance care planning questions arose about how parents reconciled the tensions they faced. Thus, the identified concepts and properties (see table 6.2) explain how parents gather and use information and draw on different approaches to engage in conversation as part of the process of advance care planning.

Table 6.2 The sub category: Crafting the decision, its concepts and associated properties

Concept	Properties
Acquiring Knowledge	• Gathering information • Decision-making approaches • Employing heuristics
Engaging in conversations	• The opportunity to talk • Collaborative conversations • Multivocality • Seeking compassion

6.3.1 Acquiring knowledge

Parents seek opportunities to gather information and use different approaches to inform advance care planning. The narrative suggests parents acquire knowledge alongside engaging in conversation and that these two concepts work together. Parents either acquire new knowledge that prompts a conversation or engage in conversation to gather information. It is not a linear process and the two concepts fit side by side although described separately.

Gathering information

Parents gathered information to gain a better understanding of the situation and sought information through various means: by conversations with health care professionals, partners and family members and with other families and parents.

> '*There's a network of mums on line and we share information and I actually go to appointments and say look in America they're trialing this or doing this and its great cause I feel like I'm listened to and respected.*' (7c)

Although information helped to guide advance care planning it was not a single exercise and parents required different information at different points throughout the illness journey and as they met new choices. It is clearly documented that families want and seek detailed information about symptoms (de Vos et al. 2015), prognosis (Heinze & Nolan 2012; Mack & Joffe 2014) and outcomes (Janvier et al. 2014). However, the degree to which parents felt they received adequate information from health care professionals was variable (Hinds et al. 1997; Aschenbrenner et al. 2012).

Parents shared stories where lack of information and limited time impacted on the ability to make good decisions and to engage fully in the process of advance care planning. Parents wanted to be informed and have knowledge in anticipation of crisis events and possible treatment options. This would also avoid having to make decisions in a moment of crisis. Lack of information impeded parents' ability to make decisions (Xafis et al. 2015b) and this was made worse by poor and insensitive communication.

Hendricks-Ferguson (2007) argued that parents need specific and continuous information and support, but how this information is shared is unclear. The level of importance of specific information was different for each parent (Langton-Gilks 2018) and how they interpreted and evaluated this information in the context of their own experience and their child's condition (Janvier et al. 2014).

Nevertheless, the process of acquiring knowledge provided an element of control (Pyke-Grimm et al. 1999) and helped parents build confidence.

> *'As time has gone on I've just become more experienced and I just think- I don't know really I've become more informed.'* (7c)

Acquiring further knowledge was supported by positive approaches to decision-making both from health care professionals and those that parents adopted themselves.

Decision-making approaches

When parents had gained a greater knowledge and understanding of the situation they were better able to make an assessment, realise the alternatives and make a decision. This meant using multiple strategies to manage and shape the decision-making process (Corbin & Strauss 1991).

Parents' immediate decision-making was influenced by a number of factors including past experience and current situation (Carroll et al. 2012). This is illustrated by Catherine's parents as they reflected on writing the second (revised) advance care plan and what had been different from one to the next. Catherine had been extremely unwell and ventilated on PICU, she had returned home for a few days when her parents were asked to review her advance care plan.

> *'We said no to intubation on the 2nd form. He (the paediatrician) did a lot of explaining about what's fair and what would not be fair to put her through again and so we made that decision. She wouldn't have survived the anaesthetic again let alone the intubation. It was obvious at that point, they were filling out the Glasgow Coma Scale and it was looking really bleak and that was when they decided we should have the discussion about end-of-life but she came round like nothing had happened - but by then we felt we needed to be more prepared.'* (13bj)

Parent's ability to assess and understand the situation was clearly influenced by clinical history, the child's ability to fight, and the opportunity to talk over a period of time, of being fully informed and being able to prepare for situations that might arise. All these factors were important in parental decision-making (Dietrich 2010) and critical for health care professionals to recognise in their approach to decision-making with families.

This was crucial in supporting parents to make decisions, which they found difficult when the approach was not effective. For example, it was problematic when a number of different doctors were involved in their child's care all of whom contributed to decisions. This was accentuated by the number of settings involved making communication and sharing information more challenging.

> *'When you've got a long list of professionals that deal with Bethany there's so many people that are involved with her I don't think it's an easy thing to let everyone know that she's got an advance care plan.'* (6c)

Although the literature gives an insight into parental decision-making at the end-of-life the majority of studies have been undertaken in neonates, PICU and oncology. Families in paediatric palliative care are grappling with several additional influences, as demonstrated above, that extend well beyond standard discussions around medical decisions (Carroll et al. 2012). This increased complexity was further complicated by the fact that parents were not making a single decision but attempting to balance opposing views.

Moreover, where parents were increasingly seen as experts in their child's care the question arose of who had the final authority? There is often confusion associated with parental knowledge and whether this means they 'have the final word' (Zaal-Schuller et al. 2016). Parents clearly expressed a need for health care professionals to respect their knowledge of their child and that they knew them best. Nevertheless, tensions often arise around decision-making responsibility. In this context, parents recognised that every child was different and resented doctors' assumption that they knew them well.

As one father illustrated

> '*I think it's about being mindful of other known facts about the child, to try to consider everything you can but don't assume you know everything, cos you don't.'* (8c)

Thus, parents were distressed if not listened to (Popejoy 2015) or if they were not involved in decisions. If they were excluded, they felt they were not respected and this had a direct impact on their confidence. Furthermore, many parents claimed that health care professionals rarely understood the emotional impact of decisions or responsibility that parents held, and parents wanted them to understand the magnitude of the task (Sullivan et al. 2014).

Nonetheless, parents wanted doctors to support them to make decisions for their child (Sullivan et al. 2014: O'Neill 2019) and looked for reassurance that doctors would respect and support their decisions (Lotz et al. 2015; O'Neill 2019). As Catherine's parents explained,

> *'He was experienced in guiding us, and he definitely guided us in one direction. He explained everything and made it clear, that it was our decision and he affirmed what we said.'* (13bj/14bj)

Parents desired a shared decision-making approach that created a balance between decisions made solely by parents, and paternalistic decision-making directed by professionals as the experts.

Each parent expressed the need for an individual approach for advance care planning and recognised it was not just a ‘text book form’ to complete or a single conversation. For some parents it was a request for upfront, comprehensive information (Meert et al. 2011). This included additional information like funeral support. Others needed bite size chunks of information over a period of time. Some parents preferred an initial discussion and others suggested *seeing* a blank advance care plan before filling it in, would be helpful.

Thus, the approach to decision-making was supported by the introduction of the advance care plan that helped to prompt and direct discussions. These documents were used in a variety of ways, with parents reporting different experiences of first seeing and reading the form.

> *‘We were given this blank advance care planning to fill in before the meeting. This was fine once we were in the meeting because we filled it in with the nurse and the doctor. But I think before the meeting I would have welcomed something a bit softer, something with less tick boxes and something more like - almost with big spaces that says, you know, in the event of your child becoming ill suddenly what do you want to happen? or if they have been ill chronically what do you want to happen? and if they pass away what do you want to happen? – you know something a bit more fluffy, it was fine because we turned our fluffiness into the form, but I felt I was trying to make my emotions fit into a job application form.’* (5c).

The question of when to introduce the advance care plan, either a blank document to read prior to the first discussion, or following a conversation when it had already been written by a health care professional revealed different perspectives. Some parents having received the information wanted to make a decision and complete the advance care plan straight away,

> *‘It was completely my choice, leading up to we would talk about it in bits over a few weeks but it was my choice I just wanted to do it, to do it in a day, I just wanted to get it done. It’s just the way I am, when I’ve made a decision about something I just want to get it done, I don’t want to sort of dwell on*.’ (7c)

others needed time to process the information over many months.

> ‘*So about a year ago we started to discuss it and we got the first draft 3 weeks ago.*’ (5c)

> *'I think it's important not to rush it cos in the heat of the moment you can make something or say something and then look back and wish I'd not done that.'* (7c)

Each parent expressed an individual view of what was helpful for them and how they wished to use the form as part of the process for discussion. They each gathered and processed information in different ways and they recognised the need for varying levels of information at different times (Noyes et al. 2015). Various models with written resources have been used to support advance care planning discussions (Fraser et al. 2010; Noyes et al. 2013; Xafis et al. 2015a) but it is apparent from the number of different preferences that an individual approach is essential.

Parents clearly wanted to be involved in the decision-making process and were able to draw on other strategies to help them make sense of the options and to make the right decisions for their child.

Employing heuristics

Parents employed metaphorical language and heuristic strategies derived from previous experience of similar problems that they used to support them in making complex decisions. They frequently used heuristics in different contexts to help them make decisions; to understand the deterioration of their child's condition and to inform advance care planning (Table 6.3).

Mitchell et al. (2019) reported families using medical jargon and slang that demonstrated their experience and knowledge of their child's condition. By using these strategies parents were able to make sense of situations, to engage in decision-making with health care professionals and to reduce the complexity of the clinical judgement (Renjilian et al. 2013).

Table 6.3 Examples of heuristic phrases used by parents to support decision-making within advance care planning and the context in which they used the phrase

Heuristic phrase	**Understanding deterioration of the child's condition**	**Choosing options of care**	**Understanding threshold for decision**
'To be guided by him'	√		
'To fight himself'	√		
'We will fight with him'	√		
'To do everything'		√	
'Enough's enough'			√
'nothing more that can be done'			√
'Switching off'	√		√
'I do not want my child to suffer'		√	
'to give them the best quality of life		√	√
'I want him to be happy'		√	
'he was in trouble'	√		
'he shows he wants to be here'		√	
'where there's hope'		√	√
'at any cost'		√	√

There was a substantial number of heuristics used by parents to support advance care planning decisions, for example, '*I do not want my child to suffer', 'we will continue to fight',* and *'any hope of survival'.* They were used to support complex decisions to help understand and focus the situation and as a compass to justify a choice. Renjillan et al. (2013) suggests parents use heuristics as decision-making aids or shortcuts, expressed verbally as a rule of thumb, maxim or mantra and intended to portray a compelling truth or guiding principle.

Parents specifically used heuristics to describe interpretations of their child's deterioration that they found difficult to express and that added value to the choice made.

> *'Enough is enough'* or *'we will be guided by him.'*

It was also apparent that parents used heuristics to give a reason for continuing treatment where they anticipated they may be challenged.

> *'He's unique and survived this before.'*
>
> *'He's a fighter.'*
>
> *'He wants to be here.'*

The heuristic phrases of *'a little fighter'* and '*enough's enough'* stood out in many of the interviews and were used across the narrative. Trying to understand what sat behind these phrases was important as it was clear they meant something different to each parent. *He's a fighter* was strongly linked to pain and suffering and quality of life, that they would fight until the suffering was too great.

Enough's enough was defined in context of time, of how long they would fight, given the circumstances surrounding the deterioration in their child's condition.

Using these heuristics in the contexts described enabled parents to manage and hold the uncertainty surrounding their child's condition and prognosis but provided a way for them to engage in conversation and to craft decisions.

6.3.2 Engaging in conversations

Although parents expressed a desire to talk this was not always easy and was influenced by different voices, responses and behaviours that impacted on advance care planning and end-of-life decisions. By finding the opportunity to talk parents found ways to connect and make meaning of the situation.

The opportunity to talk

The opportunity to talk was a striking theme with all parents stating the desire and need to talk. They were able to acknowledge how important it was to engage in conversation to open up issues between their partners and family and with health care professionals.

> *'Each question kind of raised a whole load more questions.'* (1c).

> *‘Yes, I mean I suppose in a way if you start thinking about it and start talking about it, then at least it’s out in the open and what you’ve thought about in the past - and you don’t want it, I mean I don’t think I’d ever have to discuss Bethany’s future and everything, but I think some things are best out in the open and talked about, and at least then you know it’s been discussed.’* (6c)

The challenge for many parents as described in the previous chapter was that conversations were often too late. Alternatively, there was an assumption by health care professionals that parents did not want to talk (Mack & Joffe 2014); however, as Langton-Gilks (2018) stated, parents might not have *wanted* to talk about their dying child as described above; it is difficult and not normal; but not *wanting* to is not the same as needing to. Langton-Gilks illustrates this as she writes following the death of her son.

> *No one wants to talk about end-of-life, and they usually mean their own or their parents’: it’s inconceivable it would be about your child. They are the most painful conversations I hope I ever have to have. I dreaded and detested them, but you will have to trust me when I say that, looking back, I understand I needed those conversations.* (Langton Gilks 2018 p.24)

Parents recognised the importance of advance care planning discussions even if they found them distressing (Lotz et al. 2017). Other studies have identified the contradictions and conflict associated with wanting to talk, where the challenges of realising the emotional impact have meant health care professionals keeping a distance (Hooghe & Rober 2012). These issues have been explored in the bereavement literature but not with families of children with a life-limiting condition.

Furthermore, parents often found that they were seeking opportunities to talk, but that health care professionals were either not engaging or parents felt communication was poor.

> *‘No one wants to talk.’*(4c)

> *‘I’ve always found that conversation really hard and I don’t think it’s necessarily been dealt with particularly well.’* (5c)

This feeling was supported from my field notes.

Box 6.3 Extract from field notes Sept 2013

Experience shared by a mum at the CPC network meeting about advance care planning *'I am not worried about the title of the document or the colour of the pages, I just wished someone had had the conversation and enabled us some thinking time and preparation time… I would have liked the opportunity to have regularly visited the subject, to review where we were and to talk further. Even mentioning the subject would have given us the choice to say no but come back to us at a later date – or even to have left behind a letter to read in our own time'*

The literature describes a lack of, and poor communication as contributing factors to poor experiences of end-of-life care and advance care planning (Detering et al. 2010), whereas parents who described a positive experience were able to share information and to make more realistic choices (Mack & Joffe 2014). It was a difficult balance to manage the emotional impact of such complex conversations, but with skilled and sensitive communication the opportunity to talk helped parents to reconcile the tensions and to redefine hope (Langton-Gilks 2018).

This study clearly suggests that parents do want the opportunity to talk, however this contrasts with some accounts in the literature. Beecham et al. (2016) are cautious about stating that all parents want to engage in end-of-life decisions when many find it difficult to visualise what they describe as hypothetical outcomes. In contrast, others have noted that families wanted information and the opportunity to engage in conversation so they were better prepared for anticipating and discussing treatment decisions (Hammes et al. 2005; Noyes et al. 2013; Lotz et al. 2015). These issues of timely conversations were identified in the scoping review and the findings from this study strengthen the emphasis on providing appropriate opportunities for parents to talk. What is clear is that when parents do want to talk, taking the right approach and when to engage in collaborative conversations is central to helping them engage in advance care planning.

Collaborative conversations

Parents talked about an initial nudge to start a conversation, closely linked to *realisation.*

> '*It's about things we wouldn't have talked about, so to get us to actually do it, we need a bit of impetus, like a very gentle cattle prod*.' (8c)

Harrop et al. (2018) suggest the first conversation may simply be a warning shot relaying information of the need to talk in more detail later. Parry et al. (2014) suggest conversations can be initiated in a variety of ways and to raise the issue gently, '*to knock* *on the door rather than push it open'* (p 339) may be the best approach. They were then able to prepare for subsequent conversations. Thus, a stepped approach is advocated, one that involves multiple conversations (Fraser et al. 2010, Harrop et al. 2017) and an ongoing process (Lotz et al. 2015, Lotz et al. 2017) that should be adapted to the individual preferences of the family. This reflects the experience of parents in the study who described the value of being able to talk on several occasions.

Moreover, the timing of conversations was important to provide crucial space and time to reflect.

> '*We'd thought about it more and we'd had time to reflect on it.'* (13bj)
>
> '*It's kind of good in a way because it kind of gives you time to process what's said.'* (7c)
>
> *'I think it's important that the process isn't done like in a couple of hours, or in a week, cos then it gives you the time to reflect and go over a couple of things.'* (7c)

Key factors for parents were not to feel pressured with the space and time to make decisions (Hammes et al. 2005; Xafis et al. 2015b; Beecham et al. 2017) alongside an understanding of what to be prepared for and likely outcomes (Xafis et al. 2015b). Thus, the pace and timing of conversations was an important factor in communication with parents and enabled families to comprehend and accept information that had been shared. (Meert et al. 2011; Xafis et al. 2015b). Moreover, parents valued shared decision-making and highlighted the importance of trusting relationships.

Parents were able to verbalise what helped the process to engage in conversation and the challenges they faced. Some of these factors are intertwined in concepts already discussed around avoiding, knowledge and gathering information and decision-making approaches. However, there were additional factors identified by parents that health care professionals should consider when engaging in conversation with parents about advance care planning

Multivocality

Parents used a number of strategies to navigate conversations and one key theme was the different roles they inhabited to support advance care planning decisions. This extended to the voice of the child as perceived by the parent and how they observed the voice of the professional within the conversation.

How parents constructed stories through different voices and relationships and the meanings they placed on this (Holstein & Gubrium 1995), impacted on advance care planning. Attending to these voices (Silverman 2016) and to parents' responses and behaviours supported a greater understanding of their experience.

Parents portrayed different perspectives when speaking about their role as 'mother' or 'father' to that of 'parents'. There was a difference between the individual voices and the collective parental voice, expressed as 'we'. Here there was a sense of a co-constructed narrative and joint decision-making. There was a clear emphasis from parents that it was important to agree together. They described this as being on '*the same page'*. Decisions were co-constructed through talking together and reaching a compromise.

When parents spoke in the 'I' they often took the position of 'father' or 'mother' and this was intensely more emotional.

> *'I suppose from a selfish point of view I want him any way I can have him, if a mother's going to be honest I would take him any way.'* (3c)

The child's voice also had significant impact within advance care planning where parents had a profound sense of 'knowing' their child, that their child 'would tell them what they wanted and if they had had enough'. This sense of knowing was as strong for those children with little communication and capacity as those able to express themselves verbally (Sharman et al. 2005).

> *'He's come back from beyond so it shows he wants to be here.'* (3c)
>
> *'She wants to be here.'* (1c)
>
> '*She was so ill she must have just not wanted to be here.'* (13bj)

Parents spoke of the child's voice guiding them, to help them make decisions. For the majority of parents, they found comfort in not solely taking the responsibility themselves. They often spoke in the 'we' suggesting their experiences were also co-constructed with their child.

> *'We've always felt and hoped that she will let us know when enough is enough and I think that has informed our, definitely informed what we want to encapsulate in the advance care planning, because you know I can't really imagine it until it happens but I hope that Clara will make it easy for us, I hope she will… it will become clear.'* (1c)
>
> *'We have both agreed that with Lewis we want to be guided by him. We want.. if he's suffering and he's not happy he's telling us, really then we'll go with him.'* (2c)

While for some families there was a collective family voice where they agreed together and parents spoke about the importance of the siblings' voice and being involved, on the whole there was little to suggest other family members played a significant role. Generally, parents made decisions on their own, a finding consistent with other studies (Meyer et al. 2006; Sharman et al. 2005).

What did stand out was the voice of professionals and parents' perception of their involvement in advance care planning. Parents spoke about professionals throughout the interview and their level of influence was dependent on a range of factors, specifically the strength of the relationship, the level of trust and past experiences, whether negative or positive. The professional voice was most heavily evident in the advance care planning documents in relation to clinical information, but also at critical times in the illness trajectory, at diagnosis, crisis events and end-of-life. Parents struggled with the power of the medical voice, often feeling their own accounts were unheard and that doctors failed to recognise the context in which they were living on a day-to-day basis.

It is clear that all these voices have a powerful and emotional impact on advance care planning and the study clearly suggests that parents construct their understanding of advance care planning through the different roles they inhabit. There is limited understanding of how parents co-construct decisions at their child's end of life and this warrants further research.

Seeking compassion

Parents emphasised the importance of a trusting relationship and sensitive communication. These necessitated professionals who were available, honest and open and who recognised the emotional impact of engaging in a conversation about advance care planning. It was about a compassionate approach and support for shared decision-making.

> *'It's more the delivery, having somebody that's very informed but also very compassionate and sympathetic, I think that's really important. … it's important to have someone whose got the time and the understanding.'* (7c)

It was crucial for parents to feel safe as they discussed end of life care for their child. According to Toller (2005), how safe parents felt and how sincere people were, ultimately determined how open or closed they would be and therefore directly influenced how much they would share. Thus, parents recognised that it was not merely about the document but how the process was conducted and the relational investment from others.

> *'It might not just be the tool but the way in which it's done.'* (1c)

> ‘*The most important thing - I don’t think it’s actually the form itself, because it covers all the bases, it’s more the delivery around it and understanding each bit. So talking about your options when they pass away, or organ donation and having somebody that’s very informed but also very compassionate and sympathetic, I think that’s really important.’* (7c).

> *‘I think it was helpful to have someone who is going to listen to what you are saying, listen to any discrepancies between parents and then be able to put that in a useful written form.’* (1c)

Parents recognised that advance care planning was not just a tick box or checklist, but about communication (Seymour et al. 2010). Previous studies have also demonstrated the importance of sensitive communication to empower parental decision-making (Lotz et al. 2017), a relational approach (Briggs 2004), and respect of individuals (Borgstrom 2015).

Beecham et al. (2017) reported that parents predominantly relied on positive and compassionate relationships to help with decision-making. For parents it was crucial that clinicians were able to understand the bigger picture. This reflected parents’ stories that dominated the interviews of needing health care professionals to understand the wider experience of living with a life limited child on a daily basis. In addition, understanding the treatment options and likely outcomes, alongside the space and time to consider decisions (Popejoy et al. 2017) was fundamental to parents throughout the study in managing a compassionate approach to advance care planning. One father summed this up.

> *‘Be respectful and as I say no matter how much velvet you wrap round that mail gauntlet you’ve still got to deliver it. So you want to deliver it preferably with time you have available in the kindest way you possibly can, don’t give false expectations and just try and be the best you can – I don’t think there’s any magical formula, it just comes down to respecting your fellow man and just going with the consultation with the family and relatives – I can’t think of any great magical phrase that would help…., be kind.’* (8c).

6.4 Chapter summary

Despite the uncertainty that parents face about their child’s condition and the daunting and emotional impact of advance care planning, parents nevertheless become accustomed to managing multiple and complex choices. Comprehending the process by which parents seek and make decisions for advance care planning is important in understanding the decisions they made. It is clear that the process of advance care planning is not a linear or a chronological one and there are multiple factors that influence the choices they make.

Parents have illustrated that advance care planning is not simply about resuscitation and limiting treatment but ongoing discussions about intervention and care options, of managing the balance of length of time with their child alongside an awareness of the degree of pain and suffering their child experiences. They do not stop searching for or asking for information to support their understanding of the options available, and they continue to employ strategies to enable them to cross thresholds of understanding and reconcile tensions.

The concept of *reconciling multiple tensions* for parents therefore means being informed and prepared so when they meet a critical threshold of new and complex choices they have space and time to reflect, and feel able to make the right decisions for their child. It also means keeping all options open knowing they can change their minds.

Reconciliation for parents is where the opposing forces within decision-making can sit side by side. With support and the right approach, it makes the emotional burden more bearable and helps to build a confidence in understanding their child’s illness. By doing so they are able to move towards *building confidence and asserting control* which is third process identified within parents’ experience of advance care planning and is discussed in detail in the following chapter.

Chapter 7 Building confidence and asserting control

> '*His hand opens in the air and lets something go, somewhat in the way in which we set a bird free. He is taking leave of all uncertainty, of all happiness still unrealised'* RM Rilke (1902)

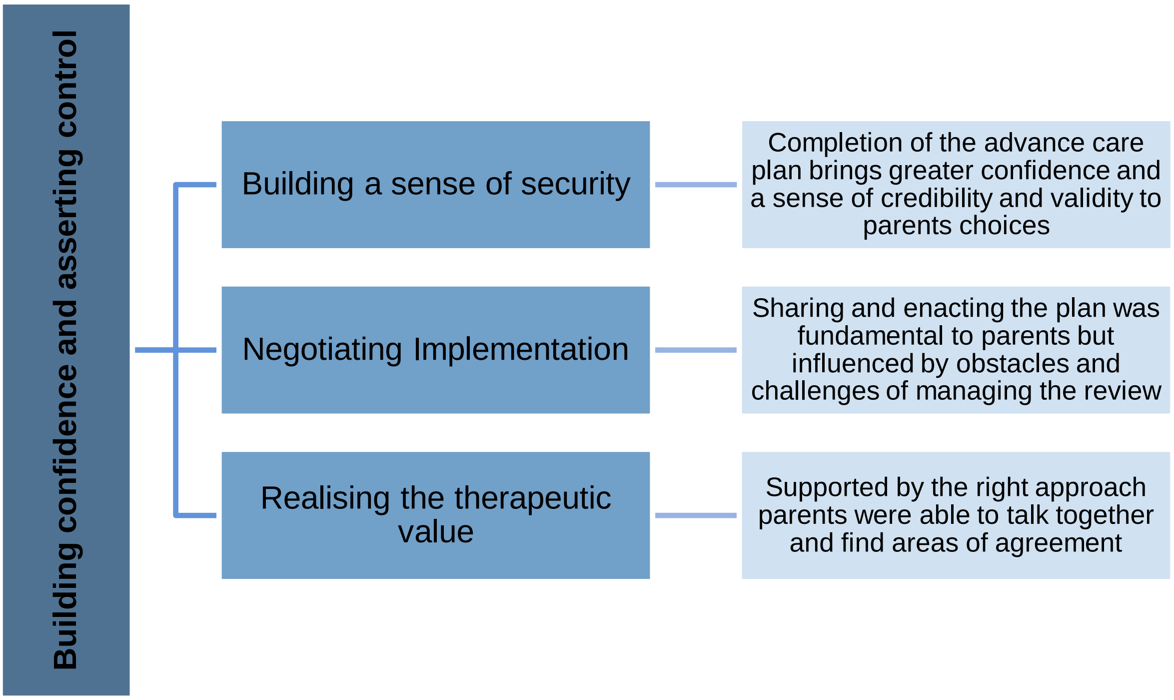
The process of *building confidence and asserting control* represents the third process of the emergent theory and explains how parents find a sense of security in a completed advance care plan. Although parents recognise various challenges to implementing the advance care plan, the process as a whole, reveals an unanticipated therapeutic benefit.

7.1 Building confidence and asserting control as a category

The process of *building confidence and asserting control* is marked by a greater understanding of the child's current condition with an increased knowledge of the options available for care at the end-of-life. Although parents might continue to experience critical thresholds of advance care planning decisions, the process of advance care planning as a continued conversation provided a growing confidence and sense of control. With the right approach parents were better able to participate in an equal partnership with health care professional's whilst making decisions to complete the advance care plan. While parents clearly experienced barriers in the operationalisation of the advance care plan, which caused frustration and discontent, they realised the value of the advance care plan. Through talking together and following completion of the document they were able to find space and time for memory making.

Building confidence and asserting control as a category is characterised by the concepts of *building a sense of security*, *negotiating implementation* and *realising the therapeutic benefit* (See fig 7.1). The concepts *building a sense of security* and *negotiating implementation* took shape early in the analytic process, as parents explicitly discussed the confidence they felt in the completed advance care plan and of sharing the document with professionals. The concept *realising the therapeutic value* developed much later during an ongoing, deeper analysis of the outcome and benefits of advance care planning for parents.

Figure 7.1 The category: Building confidence and asserting control and its concepts



The concepts and properties (see table 7.1) are explained in detail below.

Table 7.1 The category: Building confidence and asserting control, its concepts and associated properties

Concept	Properties
Building a sense of security	• Emerging confidence and control • The significance of the ACP
Negotiating implementation	• Knowing and sharing • Enacting the ACP • Barriers to implementation • Ongoing conversations • Managing reviews
Realising the therapeutic benefit	• Hidden benefits • Opportunity for memory making

7.2 Building a sense of security

Despite the emotional realisation their child might die, the process of completing the advance care plan enabled parents to make choices about their child's treatment and death, and provided reassurance in being able to take control, to some degree, of what was out of their control. This conceptual theme captures the emerging confidence experienced by parents as they undertake advance care planning and the value and meaning of having an advance care plan, which for parents provided a sense of security.

7.2.1 Emerging confidence and control

The onset of the study was characterised by a certain caution about the benefits of advance care planning for parents of children with a life-limiting condition, but the narrative that arose from the data was clear; from the outset parents spoke positively about the completed advance care plan and the value they placed on both the process and written document. They experienced a growing confidence in the process and felt the completed document gave more credibility and reassurance.

> *'I feel more confident now. Because we've been through the advance care planning process I feel more validated.*' (5c)

> *'It does give me a lot of reassurance having a plan in place.' (7c)*

This emerging confidence influenced care of their child and a growing trust in relationships with health care professional's which, parents identified as an important part of the process.

> *'I've really struggled in leaving her in hospice care because I haven't felt as confident as I would like and I haven't felt they have known us as well as they could, but doing the advance care planning that actually built bridges I suppose.'* (1c)

As parents engaged in conversation with professionals, their partners and families they found they were able to ask questions and open up areas of discussion not previously considered.

> *'So we talked about things we wouldn't have talked about - getting us round to talking about things we SHOULD talk about.'* (8c)

Conversations extended beyond clinical issues and covered subjects such as organ donation, funeral plans, religious and spiritual issues.

> '*I think the difficult things were probably talking about afterwards, like whether we wanted him cremated or buried, did we want to donate his organs? It's kind of hard because we had never thought… we'd thought a little bit beyond that point but I'd never actually made a decision and put it down in writing.'* (7c)

If the approach was well managed, it enabled and empowered parents to express their wishes and preferences.

> *'I think it's more to clarify everything from our point of view, that yes, we definitely want to do that. It's making it clear.'* (2c)

To voice preferences at end-of-life that included not only clinical decisions but values and beliefs, and spiritual and cultural issues, is recognised as an important part of end-of-life conversations (Lund et al. 2015). For parents being able to communicate their preferences and have them written down was essential to develop their confidence and provide a sense of control. In particular, having voiced their preferences, parents believed it would prevent any confusion regarding their wishes. Hammes et al. (2005) noted that advance care planning helped avoid conflict between parents and doctors, but also helped parents in not having to continuously re-explain their preferences to the many professionals they encountered. There was an understanding that once written they would not have to verbalise their choices unnecessarily, especially in a stressful situation.

> *'Obviously we will talk about it, but if it's all written down we shouldn't have to go through that all the time… when's she sick, I can concentrate on Bethany rather than having to go through the stress with doctors or whoever asks the questions.'* (6c)

> *'It's reassuring that everyone knows and that everyone's on board and I'm not gonna have someone quickly ask me a question at the time and have to try and make a decision on the spot.'* (7c)

Parents emphasised that although they had previously not felt listened to, the advance care plan then affirmed their choices. Alongside a growing element of trust with health care professionals, they strongly believed their wishes would not only be respected, but doctors would abide by and action their choices. Walsh-Kelly et al. (1999) and Lotz et al. (2015) reported this to be important in situations when a doctor did not know the child, or when parents were not present. This emphasised the necessity to ensure their preferences were communicated amongst all professionals and across settings.

As Clara's mum stated

> *'At its best it's a really useful document, it can be a tool to guide professionals that don't know Clara so well without us each time having to go through everything, particularly in a hospital situation, but I guess in emergency situations too.'* (1c)

The presence of an advance care plan in these situations reassured parents that everything possible would be done. As one mother illustrated,

> *'The plan from that point of view is marvellous cos the plan's basically telling them, don't do what you think, do what this says. Keep resuscitating even if you totally believe it's irrelevant until you see his known professionals – just keep going because he's come through huge periods of resuscitation before, and I believe he would again.'* (3c)

She went on to say

> '*So that gives you peace of mind doesn't it, that if we didn't have the advance care plan or weren't there and somebody arrived to care for him, there's a possibility that whatever I had said wouldn't necessarily be what they did. – so this just backs up your thing, that no honest, trust me, he can do It, so yeah it gives you peace of mind and they have to abide by it.*' (3c)

Parents were confident the document acted as a plan for best care and, as reported in other studies, that this offered the best quality of life (Hammes et al. 2005). Vickers & Carlisle (2000) stated if parents were reassured that everything possible had been done, they were better able to live with the decisions they had made. This was an important element of advance care planning for parents, it reinforced the concept of making good decisions for their child (see 6.2.2) and further supports the sense of security that parents felt on completion of the advance care plan. Eskola et al. (2017) reported that when parents felt secure, they coped better with situations around their child's deterioration and were more able to actively participate in decisions.

> *'Cos, I just felt like before, especially with previous hospital visits they didn't really know or understand Finlay and his condition. I kind of felt they were telling me what they were going to do and I didn't have much say or input into his care. But now we understand Finlay and obviously I do a lot more care for him at home than I did at the time and I'm sort of part of the decision team, rather than going along and following what people say.'* (7c)

Parents discovered, that having experienced the process of completing an advance care plan, they were more confident to engage in the process and this gave them a greater ability to assert some control.

> '*It's giving you the chance to have some control over what happens to your child.'* (2c)
>
> *'It was good in a way cos we could make decisions that we thought would be best for Finlay and it gave us loads of information of choices of where we could go and what we could have done, and it was kind of reassuring cos we kind of felt we had a little bit of control back around the situation whereas up to then we felt we had no control and the worst was going to happen somewhere, whereas at least now I feel although we have no idea of when and where, we've got our wishes written down in place and I kind of feel a bit more secure.'* (7c)

It helped to them to participate confidently and assert control in future decisions.

> *'In an emergency situation I would feel more confident saying what I want whereas I wouldn't have done before.'* (5c)

This sense of control in the process of advance care planning and being able to make future plans was important for parents as there were some things they had no control over. Lotz et al. (2017) reported that parents believed it gave them a sense of control in being able to prepare for what was to come (the death of their child). The process gave opportunity for parents to make choices about their child's death and despite the rawness of impending loss engaging in these choices gave them some sense of control. One mother talked about the choices they made for the time of their child's death.

> *'I don't know if the words accept it because we haven't accepted it now, but I think it's more we had the understanding that we had that control on some of it, cos we haven't got control on anything else. I think we had some control over this, between us and that was our decision.'* (2c)

In contrast, the one parent who did not have an advance care plan, who had not discussed options at the end-of-life, described a sense of helplessness and lack of confidence when making decisions at the end-of-life. Her story reflects a profound sense of regret, of not being in control to make good and right decisions.

> *‘His breathing changed and we were like what do we do? I didn’t know who to call. And my husband was going well ring the ward and it was like well what are they going to do? So when I rang 999 and they were like well what do you want? and I was like, I don’t know. So the police and paramedics came but when they arrived they said there was nothing they could do.*
>
> *Within an hour he had gone. They had taken him. Which we weren’t expecting that. We obviously thought he would be left here a while so we could all say our goodbyes. The police called the undertaker. The undertaker stood in that corner and didn’t say a word to us. He went to the hospital morgue - we know that. But I didn’t really want him going there, cos he hated that hospital, cos he’d been in there so long. We weren’t really given any options, it wasn’t until the next day someone rang and he was transferred to (the hospice.)’* (11b)

This mother spoke with anguish of her experience and stated that she knew things could have been different. When she subsequently learnt about advance care planning, she believed such a conversation and the time to think about choices would have helped her make better choices for her son and that she would have felt more in control. This sense of helplessness and lack of control that parents can experience when they are not given the opportunity to prepare for end-of-life is barely represented in the literature.

Deeper analysis revealed that many important choices within advance care planning were influenced by the context of the family. Parents expressed an optimistic feeling that the advance care plan gave them confidence to discuss and make decisions that were right for the child, siblings and the family as a whole.

> *‘It gives you the control to make decisions that are right for you and your family.’* (5c)
>
> *‘It’s kind of like our little family and what do we need to do and want to do.’* (7c)

Conversations provided increased opportunity for family communication and there was evidence that parents shared advance care planning discussions with siblings. There is a strong emphasis advocating the involvement of siblings (Giovanola 2005; Russell 2018) and family centred care at the end-of-life (Kissane 2016). For parents, it was crucial to make the right decisions and support the whole family with what was to come, drawing on their individual coping strategies and values. One father described how important it was to travel with the whole family together including their son with severe complex needs. He did not feel health care professionals entirely understood.

> ‘*We have a certain psychological premise that we’ve noticed of let’s just do it. So this will be the third year of taking him to the Isle of Wight festival, he’s been to the US once, he’s been to Ireland twice, he’s been to France four times, we go fully loaded up. We make sure we get all the reviews especially neuro reviews and respiratory reviews around the April - May time so we get to the holiday season and we say Yes we will get out there.’* (8c)

This was an important element of advance care planning, being able to express these wishes within the document. Planning ahead was not just about clinical decisions and resuscitation but what they wanted to achieve as a family. Working within the whole family context may be challenging and as Lotz et al. (2015) stated, parents were unsure that doctors would understand their individual choices, concerns, needs and ways of coping. Emerging research has explored the perspective of young people and advance care planning (Mitchell et al. 2017) but further research is needed to explore advance care planning within the family context.

All parents recognised the potential benefits of advance care planning. As one father described,

> *‘I know it sounds really daunting and it’s going to drag up a lot of emotions you might not want to go through, but for me personally, once we’d completed the process I found it so reassuring having a plan in place and I personally felt that once we’d completed it, I could put it aside and say, well I’ve had that discussion and it’s in writing, I don’t need to think about it all the time or worry about it all the time because everybody knows what our wishes are.’* (7c)

These positive statements demonstrated a confidence in their belief about the value of advance care planning. Hammes et al. (2005) reported that, for many parents, it gave peace of mind and provided clear direction, a sense of control and allowed for known preferences without confrontation, so that, even if circumstances meant their choices were not actioned, parents felt empowered having had the conversation and having an advance care plan.

Moreover, although parents struggled with uncertainty, as seen in *reconciling multiple tensions* and were fearful of what the future might hold, the process of advance care planning brought them to a different place with an emerging confidence and sense of control. It was evident that behind these decisions and the benefits expressed by parents there was a more significant meaning associated with the advance care planning.

7.2.2 **The significance of the advance care plan**

The advance care plan for parents represented a variety of different things and in early analysis it became clear that parents held a deeper relationship with the advance care plan than merely as a competed form. At the forefront of discussions was a significant focus on the choices of treatment and intervention that would prevent death and prolong their child's life, but advance care planning was also about limitation of treatment and making decisions about their child's death. This evoked deeper spiritual and emotional meaning and presented a different reality.

For parents, having a written copy of advance decisions represented the reality of having a child with a life-limiting condition.

> 'T*he advance care planning makes you think about your child dying'* (1c)
>
> '*I have got this boy who is life limited, he goes to a hospice for children who are life limited and he has an advance care plan.'* (5c)

They acknowledged it was emotional to talk about, but more profound was the impact of seeing it written down.

> *'It's quite different once you sort of see it in writing to just having a discussion.'* (7c)

Parents identified an important connection between decisions made and needing to put their choices down on paper, which made 'it real'.

> *'Having an advance care planning that's real.'* (3c)
>
> *'I think the difficult things were probably talking about afterwards, like whether we wanted him cremated or buried, did we want to donate his organs, it's kind of hard because we had never thought… we'd thought a little bit beyond that point but I'd never actually made a decision and put it down in writing.'* (7c)

Writing down their decisions had a profound impact in transforming thoughts into reality. Psychologists recognize that writing taps into a different level of consciousness that opens up 'seeing', opportunities that cannot simply be observed by just thinking about them (Butler & McManus 2014). Writing down their preferences appeared to be a stronger motivator for making decisions than just verbalising their choices. It may be as Butler & McManus (2014) suggest, that writing goals is more meaningful and provides greater clarity, with a greater belief that the choices parents had made would be enacted.

Despite the reality that their child would die, completing the advance care plan enabled parents to experience a feeling of hope and they expressed a sense of hope even as they spoke about the final hours of their child's life.

> '*So there's hope, there's so much hope, it'll be sudden his deterioration, but I would still be under the impression of constant hope.'* (3c)

Advance care planning as perceived by parents was not about giving up hope, but holding on to hope whilst recognizing the serious condition of their child (Lotz et al. 2017).

Thus, once completed the advance care plan represented something more than a collective summary of the decisions made. During the interview most parents needed to physically get hold of a copy of the advance care plan. It became a symbol that represented the reality of their situation and parents placed a real sense of importance on the hard copy they held. It provided both an element of control alongside a sense of hope.

The advance care plan was a voice for both their own and their child's wishes, and it was clear parents placed equal weight on the meaning and value of the conversation and the written document. This offers a different perspective from previous research with parents who ascribed more importance to verbal agreements than written documents (Lotz et al. 2017). However, a study with adults identified both conversation and written documentation as important elements of the process that should be included in a strategy for advance care planning (Sudore et al. 2017). The challenge is to capture and record conversations that help explain decisions within the advance care plan and reflect both clinical decisions and the values and spiritual issues parents share about the impending death of their child.

In summary, parents found a confidence through the advance care planning process to talk about the end-of-life care for their child and expressing their wishes and preferences gave a greater sense of control. Being able to prepare for and participate in decisions about what was to come gave them a sense of security. As one father explained,

> *'find someone you can talk to and who is supportive, just listen and give it a try because in my opinion it gave us a lot of confidence in what is going to happen and reassurance – so it was definitely worth doing it.'* (7c)

This emerging confidence helped parents to negotiate the challenges and barriers to implementation of the advance care planning.

7.3 Negotiating implementation

Having identified their preferences and navigated the process of advance care planning which provided a sense of security, parents were faced with trying to understand and help facilitate the operationalisation of the advance care plan. This involved practical aspects of ensuring the document was known about by professionals and different organisations. Furthermore, this knowledge and sharing of information was important to ensure their choices were enacted in an emergency situation. Implementation also accounted for parents changing their minds and the structures around a formal review. The deeper meaning of advance care planning and all that has been discussed was profoundly important but the operationalisation of advance care planning was also a key factor for parents. They were concerned about how the advance care plan was managed within the infrastructure of the healthcare system and what they could do themselves to support this.

7.3.1 Knowing and sharing

Following completion, parents believed that to distribute and share the advance care plan with all professionals, organisations and teams was important so that everyone understood the decisions made and the child received the agreed care. The distribution of the advance care plan to all relevant providers is a recognised principle of advance care planning (Lotz et al. 2015; Beecham et al. 2017; Harrop et al. 2017) and parents gave exhaustive lists of the professionals involved in their child's care who they believed held (or should have held) a copy of the document. For some families this meant up to 13 named professionals.

> *'I give a copy to the school and I guess they have a copy at the hospital. I always have a couple, one in the car and one in the house. So the (community nurse) obviously has a copy and there is a list on the back to say about all the professionals that are involved, who are going to be having one, or who have access to it. So all the relevant people.'* (3c)

However, the number of professionals needing copies of the document created concern for parents,

> *'Even though she's got the advance care planning it doesn't necessarily mean that people know that it's there unless they are actually told. I mean I was under the impression that it flashed up on a screen or something, or there was some sort of marker that said that she has got an advance care planning and that's what they should look at, but I don't know if that's the case or not.'* (6c).

Parents felt that to ensure the appropriate and relevant health care professionals had a copy or were able to access the advance care plan, they needed to facilitate the distribution themselves.

> *'That's one thing that I will make sure myself when I'm in there that whoever I speak to is aware that she has got one so they know exactly what's going on with her.'* (6c)

Seymour et al. (2010) found the storage and retrieval of advance care planning records was a significant issue within health care systems, when patients were seen by many professionals with multiple admissions to hospital. This is complicated for parents of children with a life-limiting condition where they attend different hospitals, hospice services, community respite and schools, all of whom need access to the advance care plan. Despite the goal of sharing the advance care plan to relevant providers, this was not accurately evidenced in the plans and it was unclear who held a copy. Parents were unsure of who had a copy of their child's advance care plan. In addition, although advance care planning coordinators are suggested as a way to distribute and update plans across a region (Harrop et al. 2017), not one of the parents was assured this was happening. Furthermore, parents raised the question of whether all settings would accept the plan. Harrop et al. (2017) identified that some settings, for example, schools, may have less access to health care professionals and be less able to make a decision in line with parental choice. Parents were clearly anxious about the knowledge and skills of staff in understanding and being able to manage the relevant clinical aspects of the advance care plan.

7.3.2 Enacting the advance care plan

One of the main concerns for parents with implementing the advance care plan was reassurance that professionals would act on the choices they had made, particularly, in an emergency situation. The focus of advance care planning at these times was about resuscitation and the survival of the child. It was important for parents to know how professionals, especially paramedics, would respond, so that if they or others called 999, they would follow the written instructions. Parents also believed that the advance care plan was a flag, which would mean paramedics would come more quickly.

> *'It brings attention to him, it's another flag on his name that probably speeds things up, I'm hoping it would speed things up. You know it's not like he is going to wait 30 minutes for an ambulance is it. I would like to believe that that would be the case.'* (3c)

Challenges of enacting the advance care plan outside of the hospital environment was a key question and whether instructions and choices in an advance care plan were possible to implement in every setting? Parents assumed that every professional who had contact with their child would be able to understand what the advance care plan was asking of them.

There are wider implications here of how advance care plans are written, the detail of the instruction, and the training of staff to enact on them. The advance care plans analysed were vague in their instructions, even in regards to resuscitation, and would not provide the detailed guidance for an inexperienced health care professional to enact the choices stated. Lotz et al. (2015) reported that professionals were anxious about enacting the advance care plan due to lack of confidence and were likely to call for emergency support. This was about confidence and skill and understanding the instructions in the advance care plan. For those parents who did not want their child readmitted to hospital this created a conflict. Parents believed professionals would respond to the advance care plan to deliver care but it is more likely they would call 999 (Lotz et al. 2015). This has consequences for preferred place of care. These concerns were compounded by parents' anxiety that not all health care professionals would understand and would therefore judge, the value decisions they had made.

Enacting the advance care plan was particularly relevant for parents who faced an end-of-life situation. Natalie's mother illustrated how the advance care plan helped at the end of her daughter's life.

> '*I think it was better cos at least we had a plan in place rather than it getting to that day and we wouldn't have known what to do cos it would have been a panic more than anything and it was still a panic, but they had the paperwork there to say you've said this, do you still want us to go ahead with this? So I think it's a good idea it's a hard idea but it's a good one cos at least you don't get to the end and you're like, what do we do? It's there for you.'* (10b).

Three bereaved parents who had used the advance care plan in an end-of-life situation felt that previous discussions and the advance care plan itself, had informed their final decisions. This reinforces reports by Hammes et al. (2005) that at the point of death, parents chose the preferences that had been discussed during advance care planning conversations. Even if parents diverted from the choices they had previously made and recorded, they stated that the conversations had enabled them to participate in advance care planning. Much of the literature is focused on achieving preference for place of care or death (Bluebond-Langner et al. 2013) and there is little to inform our understanding of the impact of advance care planning at the time of death.

7.3.3 Barriers to implementation

Alongside distributing the document amongst relevant professionals and ensuring the advance care plan was actioned, parents raised other barriers, specifically, lack of information and ineffective communication that caused them concern. They were unsure of whose responsibility it was to coordinate the distribution, updates and reviews. This had an impact on their sense of control and could result in their feeling less reassured that their child would receive the care they needed.

Parents felt there were better ways to share the plan and openly argued for a key worker to manage the process. They were hopeful that the implementation process would reduce tensions and aid communication of their wishes. Those who shared a positive experience of the process were able to name a key professional who supported the process throughout. Those who did not name an individual, reported poor communication and were less clear about how the advance care planning process worked, beyond the completion of the signed document.

Many of the barriers to advance care planning identified within the scoping review addressed challenges around initiating conversations. The findings in this study have identified that for parents, they were equally concerned about its implementation. There are a number of factors identified that inhibit implementation, including roles and responsibilities, the confidence of staff (Lund et al. 2015) and relationships with doctors (Simon et al. 2015). Lotz et al. (2013), following a systematic review of children’s advance care planning, ask whether it is achievable to manage both medical emergency decisions and value based decisions and that trying to manage both causes confusion. Despite the implementation of advance care planning embedded in policy (NICE 2017) current practice is fragmented (Lund et al. 2015) and studies that have identified barriers to advance care planning in children’s practice have not investigated the challenges beyond initial conversations and writing the plan.

Where there were barriers parents were frustrated and believed they were not in control. They suggested that many of these situations could be easily rectified with formal structures and better information. These frustrations created a complete contrast to the reassurance they felt the advance care plan offered, if the process and approach were well managed.

7.3.4 Ongoing conversations

The capacity for parents to change their mind influenced implementation processes. They recognised advance care planning as an ongoing process with continued negotiations and placed significant importance on being able to make alterations as their child's condition changed.

This involved the opportunity to reflect and to adapt the advance care plan as their thoughts and values changed over time. Parents acknowledged that initial conversations raised questions that 'sit in the back of their mind'. They needed to come back to and address these questions against changing circumstances, and recognised it might mean changing decisions already made.

> '*I guess once you've been asked these questions then they stay with you and for me I've, you know, gone back to them in my head and kind of thought them through.'* (1c).

At these times, parents looked for ongoing conversations with health care professionals and sought reassurance about decisions made. This was crucial if they were to develop confidence and take control.

Furthermore, they found reassurance in the fact that even though it was in writing, there was still opportunity to change their mind*.*

> *'We can update it or if there's something specific we want to do then we can change it and this gives us a bit of control.'* (2c)
>
> '*Although it's final I think I would still like to tinker with it.'* (1c)

Lotz et al. (2017) found the possibility to retract decisions was important for parents, built on a real sense of security (Lotz et al. 2015) and gave them 'peace of mind' (Hammes et al. 2005). This pattern suggests the implementation process needs to account for uncertainty, knowing that parent's will need to revisit issues, thus leaving questions open.

Moreover, parents were engaged in multiple informal conversations with different professionals that influenced and shaped their thinking.

> *'He spent a lot of time talking to me and I suppose you could class that as an advance care planning discussion, but it wasn't a formal review and he was really, really sensitive.'* (13b)

This was evident with bereaved parents where multiple conversations guided decisions over time from choosing full resuscitation to no intervention. Continued communication reinforced the reasons for decisions made, which Sullivan et al. (2014) argued reduced future uncertainty and misunderstanding to enhance final care at end-of-life.

> *'We talked with (him) lots of times, not just filling in the form but about her care and our wishes and it was really helpful.'* (13b)

The confidence parents felt to change their minds was not just about the deterioration of their child's condition, but was influenced by previous history, knowledge of available options, trusting relationships with doctors and nurses, and the opportunity to talk. The conceptual thread of space and time was fundamental to supporting these conversations. However, this crucial aspect of the implementation process is rarely acknowledged in models or frameworks for advance care planning. There is an evident focus on conversations to initiate an advance care plan (NICE 2017) but little that captures the continued negotiations following completion of the document.

7.3.5 Managing reviews

Parents clearly gained comfort from knowing they could change their minds however, they were anxious about keeping the plan updated. They needed reassurance that it accurately reflected their changing thoughts and they looked to the formal review to achieve this. The structure of review was an important part of implementation for parents. Continued conversations reinforced their trust in the choices made and provided greater confidence whilst participating in reviews. The purpose of the review date was initially open to question, but parents found it reassuring to know there was an opportunity for formal review.

> '*To me* (the review*) that's really important and helpful.'* (1c)

Others have reported managing change and review as an important element of the advance care planning process (Beringer & Heckford 2012; Liberman et al. 2014; Harrop et al. 2018). Sullivan et al. (2014) identified benefits of a review in providing ongoing support, respecting decisions made and enabling appropriate referral to other services.

However, although parents valued the review they found it difficult to understand the formal structure, how it worked and who was responsible.

> *'I've found it hard to keep it updated, they kind of do them but it's not revisited, which is fine it doesn't need a conversation every month but once a year. Some years unless there's a significant event you shouldn't really need to update it but there needs to be a protocol because with each individual illness we decide on the best course of action at the time. Our care plan says for full intervention, but that might not be the case.*' (9c)

Parents were anxious about liaising with so many professionals and fearful that something might be missed. They recognised they all needed to be involved and were unsure of the systems in place that would support this.

> *'Well because they're so many people involved with Bethany it would have to be quite a big meeting, so everyone can say what needs to be put in there, because we won't necessarily know. We've got a lot of the information but you still need to talk to all these other people so you don't miss anything out. Cos you don't want to be doing it and maybe 3 months down the line that this has happened and then you have to change it. So everyone's got to be involved when it's reviewed.'* (6c)

As indicated in other studies there was confusion around the timing of reviews and whose responsibility it was to oversee any changes (Beringer & Heckford 2012). Some parents felt a review should be instigated by a key professional but again, they were worried about who would do this and when it would be done. This was illustrated by Clara's mother.

> '*It felt like there wasn't one key designated person taking the lead.'* (1c)

The literature offers no definitive answer, stipulating the skills of the individual in regards to communication and knowing the child, rather than naming a lead.

Some parents clearly wanted a formal process for the review to allay their concerns.

> *'To have an annual meeting with a professional of your choice who knows about this and has experience in it where you can sit down and review it and go, do you feel like this still or is anything changed, do you want anything to change, cos having that formal time would probably suit me because I probably wouldn't get round to it myself.'* (1c)

For others just checking in, using an informal approach, to see how they were and whether anything had changed felt right. However, all parents recognised they needed space and time to assimilate and accommodate any changes. They also recognised that following a review the advance care plan required re-distribution which was difficult to achieve.

How frequently the advance care plan was reviewed depended on a number of circumstances including changes in the child's condition, their age and the number and type of services involved. Those visiting respite and palliative care services had the advance care plan reviewed more regularly. There were also more frequent changes made to the advance care plan as end-of-life approached.

Advance care planning is clearly not a one off event and parents wanted the space and time to engage in informal conversations and to manage regular formal reviews (Sudore et al. 2017). The implementation processes are not simple and parents' experience reinforced the recommendations that describe a gradual and sensitive approach that takes account of the whole family (Lotz et al. 2017). Thompson et al. (2009) emphasises a progressive, step by step approach with flexibility to change plans and reset priorities. To achieve this Lund et al. (2015), and Simon et al. (2015) argue for a better understanding of the dynamics of implementation processes and an improvement of the infrastructure in health care systems that support advance care planning.

7.4 Realising the therapeutic benefit

Despite the stated barriers and challenges to implementation parents found confidence in having the advance care plan and on deeper analysis it emerged that there were clear, if unforeseen benefits of undertaking advance care planning. With an intense focus on understanding such complex choices and how these decisions were implemented, the therapeutic value of the process initially remained hidden. However, the more that parents talked about their experience of advance care planning the more obvious was the inherent benefit. Furthermore, completing the advance care plan afforded precious space and time to build memories. If parents were not supported in the process there was more likely to be disagreement and if they were not on *'the same page'*, it was more difficult to engage in memory making.

7.4.1 Hidden benefits

The wider value of the process as an outcome of advance care planning emerged more slowly, but has been highly significant. The study has revealed strong evidence for health care professionals that, despite their reservations, the advance care planning process has meaningful and therapeutic benefits for parents. In particular, for parents to address difficult issues together was an important and previously unrecognised outcome of the process.

The therapeutic value of the process for parents is evident on a number of levels and Hammes et al. (2005) and Parry et al. (2014) identify the value for parents through developing the advance care plan and the psychological benefits of the conversation. The benefits gained from the process were influenced by a number of factors: the opportunity to talk, trusting relationships with health care professionals, the ability to facilitate space and time and using the advance care plan as a tool to encourage parents to talk together.

The opportunity to talk (see section 6.3.2) and the value in engaging in ongoing conversations (see section 7.3.4) was easily overlooked, as some parents clearly admitted they might not want to talk. However, they also acknowledged they *needed* to talk and realised the benefits of having had the conversation.

> '*It's really important and helpful to do because I think you might not want to and it's not normal in the general course of things but it's been helpful cos I think I feel; it's impossible to know what you will want in that end situation but it's still useful to have gone there in your head.'* (1c).
>
> *'I suppose in a way if you start thinking about it and start talking about it, then at least it's out in the open and what you've thought about in the past, - and you don't really want it, I mean, I don't think I'd ever have to discuss Bethany's future and everything, but I think some things are best out in the open and talked about, because then - it doesn't take the pressure off any more, I don't know if that's the right word, but at least then you know it's been discussed.'* (6c)

Studies have shown the importance of conversations about future illness and demonstrated that levels of hopelessness significantly decreased following a discussion (Parry et al. 2014). Parry et al. (2014) study suggested for adult patients, this change was about being able to express preferences of care and a doctor's ability to provide hopeful news. Parents in this study highlighted these elements as important for their confidence and sense of control, and equally spoke about hopefulness, even when facing the death of their child.

> *'It was quite a helpful way of getting to know the consultant at the hospice and that helped me feel that he knew us and Clara better.' (1c)*

This gave a benefit beyond having a conversation. It helped to build trust that enabled deeper and more honest communication. Parents valued these relationships and many parents could identify one key professional whom they trusted who had provided extra support. These relationships were important particularly at difficult times when they needed to make key decisions.

Where relationships, especially with doctors were compromised, this affected their experience of the advance care planning process. This happened when professionals made decisions without their involvement and, as previously discussed when parents felt ignored (see section 6.2.2).

The importance of sensitive communication, trusting relationships and understanding parents' needs were essential elements of advance care planning that supported a therapeutic benefit. The right approach provided time to process information, which was therapeutic for parents in being able to make 'good' and 'right' choices for their child (see section 6.2.2).

> *'It's kind of good in a way because it kind of gives you time to process what's happened.'* (7c)

Most importantly the right approach, and using the advance care plan as a tool to work together, assisted parents on getting to a place where they were '*on the same page'*. It enabled them to acknowledge difference and find points of agreement.

> *'Probably the most valuable bit was where we were supported to fill it in together, because it made us realise where our wishes came together and where they were slightly different, and did it matter that they were slightly different? So that side of it is good.'* (5c)

One mother described the benefits of being able to talk together to address issues they had not revealed before.

> *'My husband felt really strongly of what he wanted and I think I didn't and it seems like quite a small thing but there were a few things like that, that we hadn't ever talked about or really knew about.'* (1c)

Newton et al (2009) reported this as an important reason for undertaking ongoing conversations that the process enabled more questions to be raised and to uncover sensitive issues for partners not previously discussed. This is further illustrated in the bereavement literature. Hooghe and Rober (2012) suggest that parents spend time protecting one another and not talking about issues that would evoke painful and distressing emotions, therefore avoiding and missing opportunities to talk together. Nevertheless, there are times where parents are able to come together to discuss loss and difficult issues.

This study has shown that advance care planning conversations enabled parents to come together to talk about difficult, emotional and practical issues that they had not previously shared with each other. Advance care planning offered a framework for conversation that was structured and manageable. It offered an important balance to talk together about death, but to also keep a distance by concentrating on living. Parents were able to talk about the experience of living day-by-day and talk about the unimaginable, that their child would die. Hooghe and Rober describe this as 'cycling around the emotional core' (2012). This provided another example where opposing tensions of caring for their child and end-of-life planning co-existed side by side.

However, there were also times where parents experienced disagreement and this could cause significant pressure and distress.

> *'I think the other thing that raised for us was where we felt differently, and I felt that quite useful to know if my husband did feel differently and there was some things where we went OK is that really important to you or is it less important and coming to a compromise that we were both happy about, which I think is quite difficult when you're honest, when you're being really honest with each other., It's really, really important, cos just imagine this, if things were to go wrong and ending up with Clara dying, then these kind of decisions are really important and for both parents being happy with them.'* (1c)

This was most evident around conversations about organ donation and funeral planning with parents sometimes voicing opposing views. The conversation and process of advance care planning enabled parents to express their views and find some common ground. There was a positive sense that parents found avenues for agreement by using the process of advance care planning.

> *'I think it helped knowing that me and Paul were both on the same page, that we both wanted the same things. I think, cos the discussions are so hard to have between ourselves, cos I think neither one of us in a way have wanted to really face up to what was coming, I think that's what's been hard and I think this made us sit down and make a decision, and that we both knew that the other person had the same ideas. I think that kinda helped and that the support's there, knowing that it doesn't matter what we decide we were supported on those decisions and someone will be there for us.'* (2c)

The concept of '*being on the same page'* was an important part of advance care planning and this was evident throughout the interviews. Even where parents were interviewed separately, there was a real sense that they were looking out for their partners and that co-constructing their beliefs and plans was an essential element of advance care planning.

Using the advance care plan as a vehicle to discuss sensitive issues is addressed by Lotz et al. (2017), however the outcome of therapeutic benefit is not currently evidenced. This research contributes a new understanding about the benefits of advance care planning with parents. It provides further confirmation of the importance of the right approach and systems to support health care professionals whilst having conversations with parents, and how they can effectively use advance care planning.

7.4.2 Opportunity for memory making

Where parents found the opportunity to talk together and to find some common ground, they subsequently had time to concentrate on building memories. They expressed the importance of being able to focus on making memories as part of advance care planning and found they were better able to do this once they had discussed the advance care plan and were '*on the same page'*.

> *'Now we can make plans and we can do things, and we can make the most of the time we've go.t'* (7c)

Langton-Gilks (2018) recognised how advance care planning can support memory making in the remaining time left, but also prompts the recording of memories. This is captured by one mother from 'Follow the child' (Langton-Gilks 2018).

Box 7.1 Extract from Follow the Child

'Long story short, he made it through and we had another wonderful, precious 18 months with him. We had already made lots of memories with him throughout his illness. We started to photograph and video more and more…

We laughed lots and we worried lots, but the memories we made continue to be vital to our ongoing struggle with grief.' (Langton-Gilks 2018 p. 98)

Making memories supported the stories that parents built and helped with meaning-making. Having had the opportunity to build memories and to share their stories was clearly supportive following death. Catherine's mother reflected on the last six months of her life revealing the confidence they felt in the choices they had made. More profoundly she was able to reflect on the quality time they had together and the memories they had made.

> *'She was only 14 when she died, so the extra six months was quite a large chunk of her life and she had a last birthday and we had a lovely summer. She had a last Christmas with the family and we would have been denied all those important occasions if we had followed the advice.'* (13bj).

There is little in the literature that captures this important element of memory making as part of advance care planning. Papers describe the process of 'making wishes' (Fraser et al 2010) but the general focus has been on wishes and choices of treatment and place of care. Others describe memories in relation to bereavement or extending a child's life (Bosticco & Thompson 2005). Regardless of the time they have left, parents strive to build as many memories as possible whilst the child is alive, to draw on these memories in bereavement. Thus, memory making is intrinsically linked to advance care planning. If managed well, advance care planning offers a therapeutic benefit to parents by supporting them to talk, to voice the tensions and contradictions, to support partners being '*on the same page'* and to build precious memories.

7.5 Chapter summary

Building confidence and asserting control is a crucial part of the process of advance care planning and enables parents to engage in current and future advance care planning conversations. Both the process and written document have a deeper meaning for parents that extends beyond end-of-life decisions. However, for advance care planning to be effective, parents find they need to negotiate implementation processes and it is apparent that the approach which is meaningful for parents, is not fully understood in practice. Despite this, there are evident therapeutic benefits of the process, which have previously not been recognised.

A new understanding of parents' experience of advance care planning has been offered in the preceding chapters, explained by the three categories *realisation, reconciling multiple tensions* and *building confidence and asserting control*. The next chapter considers these categories how they relate to the core category and as conceptual components contributing to the emergent theory.

Chapter 8 Theory development and discussion

> *'Planning ahead doesn't mean giving up, you never give up, you always have hope, you never stop chasing rainbows...'* Kimberley (2014)

8.1 Introduction to the emergent theory

Preceding chapters explored, characterised, and explained parents' experience of advance care planning for their child through the interwoven processes of *realisation* (Chapter 5) *reconciling multiple tensions* (Chapter 6) and *building confidence and asserting control* (Chapter 7). Although considered separately in previous chapters, the relationship between the categories are intertwined and give rise to a core category and single basic process of *re-constructing meaning.*

Re-constructing meaning explains the continual and dynamic process experienced by parents where they re-adjusted their thoughts, beliefs and expectations in response to the ongoing changes in their child's condition and encounters with advance care planning. Provoked by advance care planning conversations, they re-constructed meaning for themselves, their family and anticipated life without their child.

Thus, the application of grounded theory methods facilitated the emergence of detailed categories and core category, which served as interpretative theoretical components of the substantive theory. The theory represents a process grounded in data that provides a new way of conceptualising parents' experience of advance care planning.

This chapter explains the core category and identified single basic social process (BSP) of *re-constructing meaning* which accounts for parents' experience of advance care planning. It sets out the substantive theory and explains contributions of the theory to knowledge.

8.2 Development of the core category and identified single basic process

My initial assumption about the process of advance care planning was one of a prescriptive tool to principally inform health care professionals and something not entirely meaningful for parents. From practice, I was frustrated by the formulaic and medical focus to advance care planning and left with a number of questions about the value and benefits for parents, whilst engaging with and completing an advance care plan. Moreover, it was clear from the literature there was little knowledge of parents' experience of advance care planning to inform practice. Thus, the aim of the study was to develop a greater understanding of parents' experience and perspective of advance care planning.

Initially, the re-construction of meaning for parents was not anticipated to be a key element of their experience of advance care planning. However, once the categories began to take shape it became clear that parents were not engaging solely in discussion to inform end-of-life decisions or complete a form, but through discussion adjusting to a changing reality.

From the moment of realisation, parents asked questions that suggested changing perspectives to their thinking and which challenged their previous held assumptions, values and beliefs. Through the process of constant comparison the theme of re-constructing meaning took momentum and was supported by memos (Box 8.1).

Box 8.1 Memo illustrating development of the concept of re-constructing meaning

I am struck by all that advance care planning entails, the variations for each parent in the pace and approach of the conversation, opportunity to talk, gathering information and chance to reflect on the now, to when they reach turning points of understanding and are able to articulate future possibilities. But as I read and analyse more, what holds all this together is how it is provoking constructions of meaning. Talking about advance care planning brings this to the fore, as they try and understand the complexity of the task. (12/10/17)

These memos prompted a return to data (Charmaz 2014), to early codes and each of the developing categories to understand further evidence of parents actions and processes that would suggest that *re-constructing meaning* was the core issue in explaining their experience of advance care planning.

Initial and focused codes, many of which were *in vivo* codes (parents' own words) and converted to gerund codes (active process codes) provided a greater understanding of the experience of re-constructing meaning. The codes emphasised the struggle parents experienced when attempting to assimilate new information and accommodate new situations provoked by their child's changing condition and advance care planning conversations. For example, '*meaning of decisions', 'needing time to absorb and reflect', time to process information', understanding reasons', 'opening up more questions', 'managing tension between decisions', 'the meaning of resuscitation',* and '*what the* *advance care plan means'.* These codes helped to build a meaningful picture that revealed parents' re-construction of meaning as they encountered advance care planning conversations. Data and emerging concepts provided other illustrations of *re-constructing meaning*, for example, how parents managed complex issues of hope and survival, pain and suffering, and life and death, that posed new questions to inform the core category.

The centrality and workability (Glaser 2005) of *re-constructing meaning* as a core category was strengthened by further memos (Box 8.2) and theoretical analysis of the categories.

Box 8.2 Memo illustrating insights gained from going back to data to inform the core category

Advance care planning is making parents think about the 'reality' of the situation, that something is altered, and that the future looks different. (17/11/17)

The process appears to be of paramount importance in finding meaning. (04/11/18)

The importance of *re-constructing meaning* was evident in *realisation* through the defining moments signifying something had changed, and a need to talk about advance care planning. This opened the doors to an awareness and conception that something was different. Within the process of *realisation* parents began to recognise the changes in their child's condition and advance care planning conversations brought to the fore the more likely possibility of death. Parents made determined efforts to understand and make meaning of their new situation amidst great uncertainty. This moment superseded past meanings and forced a new construction of meaning. *Realisation* was an intense emotional recognition that marked a turning point in time, whereby parents needed to interpret triggers and additional information to make sense of, and find meaning in the new situation. By drawing on their previous knowledge and experience parents began to re-construct meaning within their changing world. Where parents embraced *realisation* they were able to engage in conversations about advance care planning and begin to adjust their values and beliefs. Those that did not were more likely to avoid opportunities to talk and this made advance care planning complicated. Where professionals lacked skills to understand and manage these conversations effectively, or tried to discuss with parents when parents considered it to be the wrong time, made conversations problematic.

Following *realisation* parents were confronted with complex and conflicting choices. The process of *reconciling multiple tensions* was deeply emotional, as they needed to find ways to express their values and beliefs and make sense of the complexity and contradictions of advance care planning. *Reconciling multiple tensions* was not straightforward as parents attempted to make adjustments and understand contradictions that co-existed side by side, such as preferences for treatment that required hospital admission, but the fear of their child dying in acute circumstances. They were faced with a changing reality that was both personal and social. Having adapted their lives and slipped into an illness routine, parents found that advance care planning conversations challenged all that was familiar. Ways of coping became fragmented and there was a change in hope, from cure to free from suffering and, from quantity to quality of life. These advance care planning conversations pushed ‘normalcy’ to the limit and the realisation of death and dying emerged as a real possibility. Parents found that advance care planning conversations illuminated a world edged by sorrow where they needed to re-conceptualise the future.

As part of the process of *reconciling multiple tensions*, parents were constantly faced with not only their own competing values, but also the competing and differing values of professionals and of organisational systems and structures. Re-constructions of meaning were relentless and involved parents conquering their fears and dreads, and re-defining their hopes and dreams. There was an unfolding of possibilities related to treatment options and care, interwoven with a deep personal understanding of living, knowing their child would die.

Despite these contradictions and the enduring presence of loss and grief, the process of *building confidence and asserting control* enabled parents to plan care for their child and to re-construct meaning, which empowered them to participate in future decisions and find space and time to make memories. *Building confidence and asserting control* describes how parents were able to accommodate, make judgements and find a new way of being. Being able to adapt and adjust to a changing reality helped to build confidence and capacity, to engage in the process and complete the advance care plan. It promoted an ability to assert control even in the face of extreme difficulties and vulnerability. This new understanding provided an avenue and direction for future decisions knowing that further change could emerge at any time and this would result in the need to review the advance care plan. Most importantly, it enabled opportunity to make memories and embed new meaning for themselves and their family.

Thus, it became clear that advance care planning conversations provoked parents think not just about clinical decisions for their child but also the underpinning values and beliefs for themselves and their family that would influence future decisions. Parents were trying to make sense of advance care planning, of what it was and what it would do, and the significance of the advance care plan in what it meant for their child now and in the future. Parents were using advance care planning to create a new understanding of the situation and to make sense of a new reality.

Through the process of theory development categories were subjected to further analytical refinement to determine their theoretical reach and centrality (Charmaz 2014). These theoretical concepts were analysed for the connections and patterns between them and their ability to explain and define the core category.

The process of using ‘gerunds’ stimulated an interpretative understanding of parents’ experience and I began to use phrases and terms such as ‘adjusting’ and ‘navigating’ to explain the action and processes arising from theoretical analysis. However, these early abstract labels did not resonate fully with how parents described their experience. Further interpretative analysis mainly through diagramming, helped to conceptualise parents’ narrative and resulted in meaning –making as a way to account for parents’ experience. Following critical discussion with my supervisors and further theoretical analysis this concept was re-labelled as *re-constructing meaning* to provide a more accurate interpretation of parents experience of advance care planning.

By conceptualising what *re-constructing meaning* involves and how parents enacted it, the theoretical development of *re-constructing meaning* as a single basic process was illuminated (Charmaz 2014). This single basic process unified the actions and processes of *realisation, reconciling multiple tensions and building confidence and asserting contro*l. This analysis helped explain what parents did within the process of advance care planning and why they acted in these ways.

Re-constructing meaning as a process was purposeful and whether they voiced their values and beliefs or not, all parents were aware of the significance of *re-constructing meaning* within advance care planning. Analysis identified that *re-constructing meaning* was not a singular event and although experienced similarly by parents it presented a number of different and distinct variations. Such variations arose where parents encountered multiple re-constructions of meaning, depending on the nature and trajectory of their child’s illness, their family life and the number of encounters with advance care planning. For example, the number of complex symptoms, options and crisis events made the process of *re-constructing meaning* more problematic. They struggled with the conflicts that arose between making clinical decisions and their values and beliefs. Relationships with health care professionals and the approach to advance care planning were influential to encourage open and trusted conversations.

This variation was significant in that trusting relationships, which encouraged shared decision-making, supported re-constructions of meaning for parents, whereas those who felt disempowered struggled to assimilate and accommodate new situations within the process of advance care planning.

In addition, emotions associated with the anticipated death of their child were intensified when trying to make advance care planning decisions in a crisis or without comprehensive knowledge of the situation. Discussions were focused on clinical decisions without addressing their values and beliefs. At these times, parents expressed the fundamental need for patience, and time and space to reflect, to enable them to make sense of the new situation. This was a crucial time of *re-constructing meaning* for parents but one often overlooked by health care professionals.

Furthermore, for each parent, their child's life-limiting illness resulted in a unique experience of loss portrayed in various ways throughout the process of advance care planning. Experiences of grief and loss significantly impacted on their ability to make sense of each situation and there were times when the hopelessness, disbelief and grief broke through and their capacity to cope and engage in advance care planning conversations was stretched to the limit. Nevertheless, most parents spoke of a resilience and ability to re-construct meaning through the process, supported through relationships with family and friends, despite living with the constant presence of grief and loss.

Advance care planning conversations disrupted parents' constructs of their values and beliefs, of normalcy, their child's illness, family life and known reality. Furthermore, parents struggled to always express their values and beliefs when confronted with rigid healthcare systems and ideologies that meant on occasions they felt their voice was not heard. Nonetheless, the process of *re-constructing meaning* could clearly be a positive one. Parents used the process of advance care planning conversations both in a pragmatic and empirical way, to gather information and to understand the process. This enabled them to engage in future decisions and to re-construct their social world. These re-constructions of meaning took place in conversations with family, friends and health care professionals and were central to the process of advance care planning for parents. The process is not a linear one but involves an awareness and realisation, of managing options of care and readjustment of their values and beliefs to be able to making sense of a changing reality.

This process confirms the ways in which parents came to think about and take action as a consequence of advance care planning conversations and recognises the complexity and interactional processes of *re-constructing meaning. Re-constructing meaning* is a conscious strategy that helps parents to understand their own experience within the developing context of their child’s illness and to engage in advance care planning. Thus, the process becomes symbolic, both in maintaining attachment with their child and in recognising the threat it represents in the loss of their child.

This offers a greater purpose for parents when engaging in advance care planning that brings meaning and redefines their values and beliefs and where by the process of *re-constructing meaning* through advance care planning provides a therapeutic benefit.

Thus, the categories and analytical process give theoretical direction to *re-constructing meaning* as the core category and explains the single basic process for parents’ as they experience advance care planning. *Re-constructing meaning* is a cyclical process, which is central to how parents engage in advance care planning, re-adjust to ongoing changes and how they make sense of new experiences. Parents move between, through and around the concepts of *realisation, reconciling multiple tensions,* and *building confidence and asserting control* to find meaning as they work through advance care planning so that regardless of the conditional variations of individual experience, *re-constructing meaning* remained a core process of advance care planning for them all.

The categories, core category and single basic process serve as conceptual interpretations and offer an abstract understanding to explain the emerging substantive theory. As the substantive grounded theory developed, it was supported by existing literature to situate the theory and explain how the theory builds on current knowledge.

8.3 Situating the emerging theory with existing literature

The final stage of analysis was to situate the developing theory alongside existing literature. This process of theory development followed the principles outlined by Charmaz for a grounded theory embedded in data (2014). It involved contextualising the emerging theory against wider theoretical networks to substantiate the theory through inductive, deductive and abductive methods. This contrasts with generating a theory of emergent fit (Wuest 2000) which examines and integrates existing related concepts and theory to extend or produce a formal theory (Glaser 2005). Given the lack of understanding of parents’ experience of advance care planning identified in the scoping review the aim was to develop knowledge in a substantive area rather than engage in the development of a formal theory.

Thus, the process below examines the concept of meaning identified in the emerging grounded theory and explores the significance of decision-making theory and research to *re-constructing meaning*. The process aimed to refine the interpretation offered in the emerging theory *re-constructing meaning through advance care planning*.

Chapter 8

Meaning

The concept of meaning has attracted increasing interest as philosophers and psychotherapists try to interpret how people integrate meaning into their lives and make sense of their lives through their life stories. Meaning is understood whereby beliefs, goals and values (Park 2010), are constructed, made or realised (Tomer 2012), where meaning is the web of connections, understandings and interpretations that help individuals to comprehend experience and formulate plans (Steger 2012). Meaning is therefore relational and culturally and socially constructed and gives a sense of purpose and coherence to the world. Thus, each person is immersed in meaning-making, (Kegan 1980) constructing life stories that give meaning to the experience and situation (Gillies & Neimeyer 2006; Neimeyer 2014b). Whether or not people are aware of their own meanings in life, appears to powerfully influence individual thoughts, actions and emotional responses (Park 2010).

Meaning-making was first embraced by Victor Frankl (1959), who argued that meaning can be discovered under all circumstances even in the most difficult and tragic experiences. He believed that meaning could be found until the last day of life (Frankl 1959). Meaning is therefore a pivotal concept in understanding the complexity and predicaments of life (Wong 2012) and is of particular importance during critical transitions or stressful situations in life (Janoff-Bulman 1992; Gillies & Neimeyer 2006; Pakenham 2008; Park 2010). The concept has provoked interest within both bereavement and crisis literature (Keesee et al. 2008) and in more recent studies widening the concept of meaning- making to other life altering events (Park 2010; Schultz & Harris 2011; Roos 2018) and chronic illness (Charmaz 1991; Pakenham 2008). Therefore, meaning is significant to understanding parents' experience of advance care planning in relation to the meaning they place on the deterioration of their child's condition and consequent advance care planning conversations they have about their child's treatment and care.

The works of Charmaz (1991), Pakenham (2008) and Park (2013) refine understanding of constructions of meaning and its relevance to the emerging grounded theory. Charmaz (1991) described how constructions of meaning in chronic illness enabled people to live with hope whilst living with uncertainty and the possibility of death, of living with dying. Pakenham (2008) reported how patients re-appraise meaning throughout illness in a continuous cycle of sense making. Park (2013), in her work on cancer survivorship, outlined how meaning was particularly important during transitions, in particular, diagnosis, treatment options and whilst dealing with the immediate demands of illness.

The emerging conclusion from these studies is that life's meaning is questioned when there is a threat to life. The previously taken for granted meaning of our life stories

(Neimeyer 2014b), is shattered by events and life-altering transitions and this raises doubts and questions about life’s meaning as we try to negotiate and process the event and its implications on and in our lives (Pakenham 2008; Neimeyer 2014a).

Applied to this study advance care planning can be considered a life-altering event which provokes a re-construction of all that was previously known and anticipated as parents try to make sense of the past, present and future. Parents create stories of their child from diagnosis and integrate these stories with their child’s life story to shape ongoing meaning (Bailey-Pearce et al. 2018). Thus, advance care planning initiates re-constructions of meaning to reframe these stories, which take account of future meanings and the danger and threat imposed by the anticipated death of their child. The emerging grounded theory describes how parents navigate multiple thresholds or crisis events linked to the process of advance care planning which challenge both their individual and family beliefs and which require readjustment and adaptation. Moreover, it exemplifies how engagement in advance care planning amplifies the enormous emotional threat for parents of losing their child.

These events are compounded by the choices and actions parents take to make good and right decisions, moral components embedded in the concept of meaning (Sommer et al. 2012). These choices challenge parents personal and social reality, affect their hopes and dreams, and alters life’s meaning.

In addition, Park & Folkman (1997) emphasise the importance of situational meaning to the distress experienced by the discrepancy between global meanings and reappraised meaning, following a crisis event (Park 2010). These conceptual components of situational meaning are important in understanding parents’ distress during advance care planning, striving to make good and right decisions that challenges their values and provokes the process of *re-constructing meaning.*

Thus, parents’ first encounters with advance care planning prompted a *realisation* of discrepancies between their global meaning and changing situation of their child’s condition. This provoked distress and the need to re-construct meaning. In addition, in the process of *reconciling multiple tensions,* parents were faced with ongoing discrepancies in treatment options that urged further re-adjustments to their global meaning. Having restored a sense of meaning parents attempted to manage situational meaning through sharing of the advance care plan with professionals, to ensure they were aware of their choices. Knowing when the advance care plan was to be reviewed gave a sense of control in preparing for further impact of situational meaning.

More specifically, if parents were able to engage in the process of advance care planning and re-construct meaning, they were more likely to adjust to altered situational meanings.

If not, it was likely they would experience ongoing distress and unable to re-construct meaning.

Thus, the process of advance care planning directly confronted parents' global meaning and provoked the reappraisal of their values and beliefs on numerous occasions with the need to substitute alternative goals. Advance care planning has not been understood in this way before neither has it been conceptualised as a process of *re-constructing meaning* where parents need to confront their global meaning and re-construct meaning in relation to their child's changing condition. This has significant implications for how health care professionals might approach advance care planning conversations (See chapter 9).

To fully explain the emerging theory *re-constructing meaning* was analysed with recourse to the literature from the scoping review to determine how and if *re-constructing meaning* was articulated. Of the 51 papers, discussion pertaining to values and meaning were limited however, there were some key issues highlighted worthy of discussion.

Meaning is implied in relation to recognising (Popejoy et al. 2017) and balancing competing values (Erby et al. 2006), and inferred in relation to preferences and wishes but it is not explicit. Lotz et al. (2017) identifies the needs and concerns of the whole family and the facilitation of coping but it fails to shed light on the process of re-constructing meaning as part of coping in advance care planning. There is emerging understanding of the complex and multifaceted nature of advance care planning beyond that of clinical decisions (Mitchell et al. 2019), but this does not extend our knowledge or provide a full explanation for the purpose and outcome of advance care planning identified in this study.

Thus, *re-constructing meaning* is a process within advance care planning which enables parents to live in the present but also prepare for the future. When conceptualised as a process of *re-constructing meaning*, advance care planning can support parents to discuss and make sense of the now, of how to live with uncertainty, and how to find meaning in preparation for their child's death. It can assist parents to manage and find meaning in the paradoxes and contradictions that arise from making plans for their child's care and treatment.

In summary, the literature associated with life's meaning offers an understanding of how meaning is constructed and re-constructed over time, which has not previously been applied to advance care planning. Moreover, when applied to the emerging theory it illuminates the explanatory power of the theories conceptual components and the core category.

Decision-making

Throughout theoretical analysis, frequent reference was made between advance care planning and decision-making and this warranted further discussion to determine the contribution of theory and research about end-of-life decision-making processes to the emerging theory. Advance care planning decisions can be complex and overwhelming and therefore sensitive approaches to decision-making are central to support parents in understanding options of care. Moreover, many influencing factors are inherent in parents' experience of advance care planning and impact on the decisions they make. Thus, the following discussion presents a discursive review of decision-making theory and how this informs parents' experience of advance care planning, and a review of research depicting parental end-of-life decision-making.

Various models of decision-making can be found in the literature with a significant emphasis on rational decision-making theories (Turpin & Marais 2004). Rational decision-making theories assume decision-making follows a logical and deliberate process (Schwartz 2016) and there is a degree of certainty to the decision made. The process of rational decision-making comprises a number of steps, developing, analysing and assessing a course of action (Simon 1977). This model implies that all possible alternatives to a decision and the consequences of those decisions are known (Turpin & Marais 2004; Giacomoni 2019). Furthermore, the process is one of actions and strategies to solve problems with the ability to compare consequences to determine a preferred choice. Reasoning that arises from rational decision-making assumes the world is stable (Giacomoni 2019).

Rational decision-making models from business management (Simon 1977) are embedded in health care. Furthermore, my observations of practice and analysis following the scoping review, suggests advance care planning practice is considered a rational decision-making process, supported by tools and frameworks, which provide a defined course of action or definitive answers to question. (Zinner 2009; Fraser et al. 2010; Weiner et al. 2011; Noyes et al. 2013; Xafis et al. 2015). However, this conflicts with findings in this study of how parents made decisions alongside uncertainty and distress, when the consequences of treatment options or choices of care were not known.

However, there are other decision-making theories, which provide better explanations of parents' experience of advance care planning. For example, ethical decision-making theory argue key factors and variables such as, intuition and emotion influence decision-making (Schwartz 2016). Schwartz (2016) importantly raises the fundamental importance of the 'nature' of the issue and moral intensity of the decision. Thus, ethical decision-making takes account of the situational context of advance care planning by recognising the profound nature of decisions parents make. It emphasises the impact of decisions that involve judgements about benefit and harm on others and of the burden of responsibility. These conceptualisations of decision-making resonate with the intuition, heuristics, emotion and burden, inherent in parents' descriptions of advance care planning.

In addition, a dual process model of decision-making described by Reyna & Brainerd (2011) helps to explain the differing values parents place on different options and priorities of care. In Fuzzy Trace Theory, they describe how people make decisions when confronted with choices between different outcomes, where each outcome has a different value of worth when weighed up against the risk of the outcome (Reyna & Brainerd 2011). They describe how emotion and cognition are combined to manage outcomes that are ambiguous and vague. This helps to explain how parents choose preferences of treatment and care. However, the theory does not explain why parents make such choices, the meaning of these choices for themselves and their family, nor that parents are able to choose a number of different outcomes at once.

Turpin & Marias (2004) provide some explanation of why parents might choose to keep several options open rather than make a decision with a definitive outcome. In their phased approach to decision-making, they describe a divergent exploratory phase of gathering intelligence and a convergent phase where the focus is reducing the number of alternatives and coming to a conclusion. Importantly the convergent phase can be postponed to keep options open until the last moment, if the uncertainty related to not making a decision can be managed (Turpin & Marias 2004). Parents in this study gave numerous accounts of managing uncertainty by keeping options open. Specifically, parents' capacity to delay decisions and remain open to other possibilities, or to continually move between divergence and convergence is in direct contrast to a rational decision-making model, that seeks a definitive course of action. The incongruence between these two approaches to decision-making can be a significant source of conflict and challenge for health care professionals and parents.

Furthermore, there is an incongruence not just in the way health care professionals and parents make decisions about advance care planning, but in the way in which decision-making is understood. Reyna and Brainerd claim that intuition and emotion is part of a rational process, and that these key components are of no less value in the process of decision-making than the rational perspectives of design, choice and review (Turpin & Marais 2004). Indeed Reyna (2011) claims that intuition and emotion are advanced forms of reasoning.

However, in clinical practice emotional components of end-of-life decision-making are rarely considered part of a rational reasoning process. On the contrary, parents' decisions are often considered incoherent when they move backwards and forwards within the decision-making process and change their minds. To embrace intuition and meaning as a rational process and embed these components in advance care planning process requires a different perspective.

My analysis reveals that on the whole decision-making is framed as a rational process taking account of factors that assume logic and stability and that these reflect approaches currently used within advance care planning. Advance care planning is framed as a rational clinical decision-making model in pursuit of the resolution to specific questions about treatment and care. Rational decision-making approaches do not account for the complexity of decisions within advance care planning or for emotion, intuition and meaning, all essential components of reasoning and key elements of parents' experience. As Paton (2019) argues there is disconnect between theories of decision-making and contemporary clinical practice.

The findings from the study therefore provide strong evidence that we should question current approaches to advance care planning, to reframe and extend decision-making approaches to include the key components identified by parents in this study. Health care professionals must consider the multifaceted ways in which parents enact advance care planning.

To further situate the emerging theory, it was also important to understand how literature of parental decision-making at the end of life informed theoretical analysis.

Although there is a growing body of evidence on end-of-life decision-making, discussions about the process and factors important for decision-making (Hinds et al. 1997) tends to predominate. This literature recognises the importance of relationships (Popejoy et al. 2017), the challenges of withholding and withdrawing treatment (Harrop et al. 2018) and sets out barriers to end-of-life decisions (Hinds et al. 1997, 2005; Meert et al. 2000). Few studies consider parents experience or depict meaning as part of the decision-making process. However, four key papers contribute understanding of the emergent theory.

Rishel (2010) in her development of a conceptual framework for parental end of life decision-making recognised that parents rely on *something* in addition to clinical facts to make decisions. She identified parents' observations of pain and suffering and the burden of wanting what is best for their child. Rishel (2010) recognised the psychological adjustments parents need to make and the influence this may have on their ability to transition to end-of-life decisions. These findings reflect the complex dynamic process of transitioning to end-of-life care, evident in parents' experience of advance care planning and of the deeper elements that influence decisions. However, she does not fully identify what these value based factors might be, or how parents decisions are influenced by such factors.

Similarly, Carroll et al. (2012) recognised that parents grapple with several influences on decision-making. Their study revealed four interrelated themes that explained the decisions parents were making about their child. They described how parents orientate and seek direction, to establish the context of decisions and ponder what would be best for the child through defining what is good. In addition, the importance of relationships and communication were central to decision-making and how parents coped with their emotional responses and self-judgements. These concepts resonate with findings from this study and offer further insight about the factors that influence parents' decisions, most importantly that thoughts and feelings are as important as clinical factors. Nevertheless, despite recognising diverse influences and the benefits of using a psychological framework for decision-making, meaning as an interwoven concept is not explicitly considered.

More recent understanding of decision-making draws on psychosocial influences that have greater application to re-constructions of meaning. Hill et al. (2014) described a conceptual framework of *regoaling* and the factors that promote and inhibit parents' ability to disengage and reengage with new goals. The model implies a process similar to the process of meaning-making (Park 2010) yet there is little to determine what facilitates or inhibits goal reengagement. The proposed model is important because it emphasises that parents readjust their thoughts and feelings, however it is equally important to understand how parents make these transitions so we are better able to support them. This knowledge is currently missing from parental end-of-life and advance care planning literature.

A significant review by Popejoy et al. (2017) recognised the complex interplay of numerous factors on decision-making and future planning for children, including decisional, relational and family factors. They identified the influence of hope as an important element of meaning and for assisting families to cope. The study recognised the individualised nature of hope as a central thread through decision-making but there was no indication of beliefs and values or how parents adjust to changing situations.

These studies have raised important questions regarding the numerous factors involved in decision-making, however, whilst decision-making is undoubtedly relevant to advance care planning my analysis found limited evidence of meaning as a feature of parental decision-making at end-of-life or of theoretical frameworks of decision-making to underpin the analysis. This would benefit from further research to explore value based decisions for parents and to understand how these interconnect with *re-constructing meaning* as part of advance care planning.

Decision-making theories and end of life decision-making research does not fully account for parents' experience of advance care planning. There are currently no theories that fully illuminate and explain how parents make decisions within the process of advance care planning. So, although decision making theories shed some insight to how parents make decisions and the factors involved, it does not articulate the importance of re-constructing meaning. Thus, it fails to fully represent how parents construct and engage in decisions at the end-of-life. Further research is needed to explore emotion and meaning in the decision-making process and how this translates to the situational context of advance care planning. This has important implications for practice in how to support parents in conversations about advance care planning.

In summary, the process of theoretical analysis and theory development gives rise to the study's emergent theory that gives focus to *re-constructing meaning* as a core process for parents as they engage in advance care planning. *Re-constructing meaning* is conceptualised as a desirable feature of advance care planning and offers benefits to parents. Indeed, it provides opportunity for adjustment and sheds new and unique insights into the process of advance care planning.

8.4 Explanation of the theory: Re-constructing meaning through advance care planning

The robust approach to theory development involving inductive and deductive analysis explained the categories, the relationship between the categories and core category. The theory emerged from and is grounded in data and provides an interpretation of how parents re-construct meaning through their experience of advance care planning. The analysis resulted in the generation of an integrated and comprehensive substantive grounded theory that explains the process of *re-constructing meaning through advance care planning*.

The constructed substantive theory described by Charmaz (2014) is evidenced through its relevance and fit (Glaser 2005) such that the substantive theory describes the processes of *realisation, reconciling multiple tensions and building confidence and asserting control* and explains how these processes were enacted by parents in a cyclical and interconnected way to enable *re-constructing meaning through advance care planning*.

Re-constructing meaning through advance care planning achieves an intimate interpretation of parents' experience of advance care planning and provides an explanation obtained from the data. The theory was developed through a systematic application of methods (Charmaz 2014) and offers new insights not previously known and deepens our understanding of parents' social world. Furthermore, it fulfils the core principles outlined by Glaser (2005) of centrality, a process that reoccurs frequently, takes time to saturate, relates to other categories and is completely variable. It integrates the theory and renders the theory dense and saturated leading to theoretical completeness.

Re-constructing meaning through advance care planning explains the actions and processes of parents' experience and provides a purpose for advance care planning and therapeutic benefit. Parents adapt and adjust to the changing circumstances of advance care planning through this process. This is important in how we approach advance care planning conversations and implications for practice (see chapter 9).

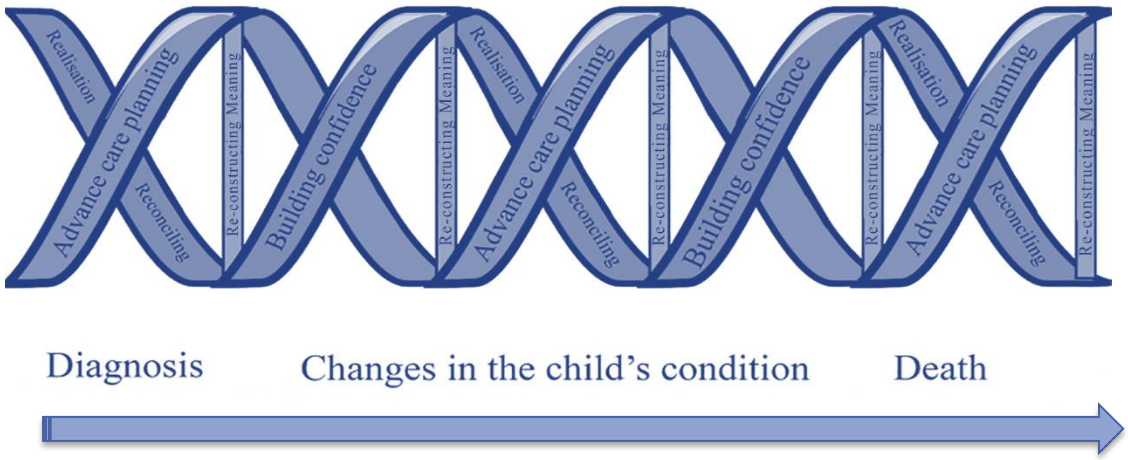
The substantive theory offers a unique interpretation of advance care planning for parents and illustrates how they continually re-construct meaning through the process of *realisation, reconciling multiple tensions* and *building confidence and asserting control,* where parents re-construct meaning alongside the growing possibility of their child's death and engagement in advance care planning.

Thus, in summary, there is much to be understood about *re-constructing meaning* for parents within the process of advance care planning. The findings and discussion outlined above provide strong evidence for the substantive theory, *re-constructing meaning through advance care planning* which is defined as:

> *Re-constructing meaning through advance care planning* is a substantive theory to explain the process undertaken by parents as they re-adjust to a changing reality through their encounters with advance care planning. *Re-constructing meaning through advance care planning* illuminates a realisation of change, reconciling multiple tensions and building confidence and asserting control. It enables parents to understand and make sense of the changes and deterioration in their child's health and of their anticipated death, to assimilate and adapt meaning as they engage in advance care planning. *Re-constructing meaning through advance care planning* in this context is multi layered and dynamic and involves intense emotional work.

The theory of *re-constructing meaning in advance care planning* is represented diagrammatically below (Figure 8.1). The *double helix* is used as a diagrammatic representation of complementary strands that bind together, demonstrating the interwoven conceptual components of the theory.

Figure 8.1 Diagram of the theory: Re-constructing meaning through advance care planning



Thus, the process and experience of advance care planning is explained by the interwoven theoretical components that reflect the temporal and recurring process of the constructed theory. It reveals the dynamic nature of *re-constructing meaning through advance care planning* that takes place over time at any point from diagnosis to death and influenced by the constant changes in their child's condition.

8.5 Discussion

The study has shown that the significance of *re-constructing meaning* is central to the process of advance care planning. The scoping review revealed there was minimal research and what there was, failed to provide a full explanation of the implications of advance care planning for parents. Furthermore, the individual experience for parents was not fully understood. Research has failed to consider the complexity of advance care planning or to hear parents' experience.

Current understanding of and approaches to advance care planning misrepresents parents' experience and expressed purpose of engaging in conversations. Previous studies focused on preferred place of care and wishes (Beecham et al. 2016; Fraser et al. 2010) whereas parents use the process to challenge health care professionals' assumptions and expectations about treatment and to re-construct meaning. In part, this can be explained by the promotion of advance care planning within end-of-life care and a drive to measure outcomes however for parents, a single outcome is not a measure of effective advance care planning. What is important is the opportunity to discuss all the options available with the ability to change their mind.

The social world of understanding end-of-life and survival has also shifted and this has made a difference to how parents and health care professionals' are using the process of advance care planning. Parents are using conversations to orientate their values and beliefs alongside making treatment decisions. In contrast, the literature implies health care professionals are using advance care planning conversations to avoid conflict of decisions at end-of-life and decisions that are deemed futile. This demonstrates a disconnect whereby rational decision-making approaches used by healthcare professionals, do not account for the complexity of advance care planning or include the key components of emotion and meaning that parents expressed were important to the process.

Furthermore, although timely conversations are important as identified in the scoping review (Fraser et al. 2010; Wolff et al. 2011; Durrall et al. 2012; Jack et al. 2018), the findings have demonstrated advance care planning as a continuous process. These continuous conversations are interwoven with the complex picture of how parents engage with advance care planning.This is not something achieved in one-step, nor a singular process or solely a medical one.

Advance care planning for parents involves multiple complex choices and raises issues and questions for parents that they would otherwise not have addressed. They use the process to address their worst fears and voice the reality of the death of their child. This takes space and time for parents to reflect and make adjustments to their global meaning. Thus, instead of articulating advance care planning as a process for clinical decision-making or preferences for care we need to adjust our approach to enable re-constructions of meaning for parents. This is barely recognised as a feature of advance care planning. Yet, shifting the approach will be complicated if, as the literature claims, it is easier for health care professionals to talk about clinical decision-making than to engage with families about their beliefs and values.

The grounded theory reveals that advance care planning is multifaceted, and this offers a different interpretation from the original concept outlined at the start. Advance care planning goes beyond the central tenets of resuscitation and preferences of care to a deeper encounter with reappraising and adjusting to beliefs and values of the world. Thus, the theory generated from the study builds on our learning of advance care planning and suggests the process and purpose of advance care planning for parents is far reaching and one that has not been fully explored in the literature to date.

It is clear that this process is not just a tool but relational, contextual and ongoing. Although there is some emerging debate about the relational context of advance care planning (Mitchell et al. 2018) the findings have shown that the process is influenced by constructs of family and society, which provokes deep personal questions of life's meaning. It illuminates a greater understanding of parents' values and beliefs, how these change, and what that means now and for the future.

It may be argued that the experience described are adjustments that parents make throughout the deterioration and ongoing changes in their child's condition. Indeed the consequences and characteristics of advance care planning are intertwined with the day-to-day adjustments parents make in living with a child with a life-threatening illness outlined in chapter 1. Nevertheless, parents' responses in this study were generated from questions associated with their experience about the process of advance care planning and what it felt like, to make decisions directly related to advance care planning. This provides strong evidence of the unique processes inherent within advance care planning that explain parents' experience.

The study demonstrates that advance care planning offers unique understanding where *re-constructing meaning* is magnified beyond daily considerations. Advance care planning therefore supports parents to re-construct meaning and to make the transitions from palliative to end of life care. Thus, *re-constructing meaning through advance care planning* is fundamental to support adaptation and adjustment to global meaning. Advance care planning has not been articulated in this way before.

Furthermore, advance care planning has not previously been seen as a process by which constructions of meaning can be achieved. If we can help parents to fit pieces together and make sense of the experience of advance care planning, it is likely to give them a sense of security and a greater ability to cope. The study has shown that parents are able through their own words to share their thoughts and feelings both of themselves and through the voice of their child. Advance care planning empowers parents to make future decisions and enables them to re-construct meaning that offers hope and resilience to face the future death of their child. In this sense advance care planning is helpful for parents and can be seen as a positive process if managed effectively.

The findings have transformed our understanding of advance care planning. The theory and its theoretical components offer vital knowledge about the experience of advance care planning for parents in the context of children's palliative care. Moreover, the study provides important insights that affect parents' experience. It will inform health care professionals who care for children with life limiting conditions to appreciate the significance of *re-constructing meaning* for parents and will enable professionals to reframe their approach to the process of advance care planning, to foster meaning. Furthermore, the study will inform the growing discussion about the significance of advance care planning for policy and practice and to give wider consideration to *re-constructing meaning* within the definition and process of such planning.

In summary, the process of advance care planning for parents offers new insights to knowledge but, it is the importance of *re-constructing meaning through advance care planning* that significantly emphasises the need to reframe the approach to advance care planning in children's palliative care. The current approach is focused on decisions related to life-threatening events and deterioration of their child's condition and its evidence measured by the completion of a form. A new approach should emphasise the importance of a continuous conversation and one that embraces re-constructions of meaning, measured by the ongoing record of conversations. The theory *re-constructing meaning through advance care planning* contributes to the growing discussion about the purpose, approach and outcome of advance care planning to which *re-constructing meaning* offers a new understanding. These issues contribute a wider understanding of advance care planning that has significant implications for practice. (See chapter 9)

8.6 Wider contribution of theory

It is possible that the concepts discussed and the substantive theory presented resonate with other phenomena where the concept of *re-constructing meaning* is central to the process and thus can inform other studies. More broadly, this substantive theory may extend beyond advance care planning and may be transferable to any crisis or life-altering transition that impacts on meaning.

Life events such as failed relationship, pregnancy, abortion or loss of job, may provoke a realisation of change and the need to reconcile multiple tensions whereby building confidence and asserting control, enables choice and control in future decisions.

8.7 Chapter summary

This chapter has explained the theory *re-constructing meaning through advance care planning*. It argues that, for parents with a child with a life-limiting illness, the process of advance care planning, gives past, present and the future, new and intensified meaning. Parents re-construct meaning through advance care planning conversations in the knowledge that their child will die. Time, changes in their child's condition and meaning of moments, all impact on their understanding. Death, dying and bereavement become part of their consciousness as they engage in deliberate and thought provoking advance care planning conversations. The magnitude of the loss and the uncertainty that surrounds their child makes the process more problematic. This cyclical and dynamic process requires parents to assimilate and adapt life’s meaning in order to tell their stories. The experience sheds light on new knowledge that enhances our understanding of advance care planning and the importance of a relational approach to foster re-constructions of meaning.

The final chapter will outline the learning from the study and how this translates to practice and will offer key recommendations. It will address methodological considerations and limitations of the study and offer personal reflections of learning.

Chapter 9 Implications, recommendations and conclusion

> *'We need to stop being so afraid of challenging the status quo. We have to be prepared to step outside of what we've always done to step into the solutions of the future'* Lucy Watts MBE (2018)

The previous chapter presented the theory*, re-constructing meaning through advance care planning* and explained the theory's contribution to knowledge. This new knowledge provides a better understanding of the complex choices parents face and will enable health care professionals to reframe the approach to advance care planning, to include greater emphasis on the adjustments parents make to their beliefs and values.

This final chapter will summarise the purpose and aims of the study and address implications for practice and key recommendations. It describes how learning from the study might translate to practice to support health care professionals' in their approach to advance care planning. There remain gaps in knowledge about advance care planning with parents and these are important to address through research to strengthen our understanding of this important activity in children's palliative care. Strengths and limitations are considered and reflections offered of my personal learning, before drawing together a final conclusion to the thesis.

9.1 How and when parents wish to engage in advance care planning

The initial scoping review revealed current knowledge of children's advance care planning is constructed from the perspective of health care professionals and little was known of what was important for parents. Thus, the study aimed to examine parents' experience of advance care planning specifically how and when they wished to engage in advance care planning.

The scoping review portrayed a mixed message about whether parents wanted to talk about advance care planning (Erby et al. 2006; Beecham et al. 2017; Lotz et al. 2017; DeCourcey et al. 2019). However, parents in this study wanted to be actively engaged in advance care planning. In addition, the scoping review revealed health care professionals find it difficult to talk with parents about advance care planning (Durrall et al. 2012; Basu & Swil 2018; Hiscock & Barclay 2019) for fear of causing them distress (Heckford & Beringer 2014). In this study, parents emphasised they do not want health care professionals to avoid talking to them even though such conversations can be difficult and distressing. Parents who were supported by a trusting relationship with health care professionals were better able to assimilate and accommodate new situations within the process of advance care planning.

The grounded theory explained that by embracing emotion and talking about their deepest fears, parents express the meaning embedded in the decisions they made. These meanings embrace family values, social circumstances and past, present and future meaning in relation to their child's deteriorating illness and death. Therefore engaging in advance care planning is important to parents because it provides them with an opportunity to contextualise treatment and care decisions with what is important to them as a family. Moreover, engaging in advance care planning provides parents with an opportunity to raise and discuss issues they might not otherwise have addressed with their partners.

Consequently, they co-constructed their choices and this helped them to find some common ground and to be 'on the same page'. Parents found a therapeutic benefit in sharing their thoughts and values. The importance and value of engaging in advance care planning described by parents, has not been reported before.

The scoping review revealed a growing awareness of the complexity of advance care planning for children (Horridge 2015; Popejoy 2017; Mitchell et al. 2019). Factors such as balancing hope and avoidance (Erby 2006), clinical uncertainty (Horridge 2015), unpredictable illness trajectory (Edwards et al. 2012), and the emotional burden of end of life decisions (Mitchell et al. 2019) influence advance care planning. The study contributes to this debate by revealing how parents' choices for treatment and care are interwoven with their hopes and dreams. Parents take account of practical, clinical and existential issues when navigating the complexities of advance care planning.

Furthermore, whereas health care professionals use advance care planning as a structured process focused on clinical decisions and limitations to treatment to determine specific answers to questions (Finlay et al. 2008; Harrop et al. 2018; Haynes et al. 2018), parents in this study, resisted definitive answers to questions and preferred to keep options open. This helped them to maintain a sense of control, continue to be engaged in decision-making with health care professionals, to mitigate the uncertainties of their child's condition and outcomes of treatment and manage the emotional and existential consequences of their child's deterioration. Thus, the study adds knowledge about how parents engage in advance care planning and explains how they navigate and manage the issues, which make this process complex.

The findings also depict a potential tension between how parents and health care professionals approach advance care planning. The scoping review identified that health care professionals considered it important to engage in timely conversations with parents (Fraser et al. 2010; Wolff et al. 2011; Durrall et al. 2012; Jack et al. 2018), but there was no consensus in when and where conversations should be initiated or continued and no evidence of whether conversations were helpful for parents. The study confirms that parents wish to have continuous advance care planning conversations and why this is important.

Parents' prefer to have early and continuous advance care planning conversations with health care professionals, which can start in the first few months following diagnosis. This approach enables discussions so they can anticipate crisis moments in their child's condition and be as prepared as they can be for the consequences of these moments.

Making decisions at moments of crisis risks limiting conversations to a narrow medical focus and missing wider issues of values and goals (Edwards et al 2012). The study confirms that parents do not want to make decisions at moments of crisis (Jack et al. 2018; Hiscock & Barclay 2019) or when they considered it to be the wrong time for them personally or as a family. However, parents know that such decisions need to be made at critical times. Parents emphasised that early introduction to the process of advance care planning, before a crisis event, prepared them to be involved in decision-making at critical times. This enabled them to think through potential options in advance, that accounted for their values and goals and prevented distress caused by needing to have conversations 'out of the blue'.

Parents know it is not possible to predict when critical times in their child's illness will occur and therefore appreciate setting specific times for advance care planning conversations is not always possible. What is crucial to parents is that they are involved in continuous conversations about their child's illness and treatment so they can be prepared to engage in advance care planning decisions as their child's condition deteriorates.

Early advance care planning conversations enabled parents to participate in shared decision-making and to guide critical decisions so that they were 'right' for them and their family. Ongoing discussion provided reflective opportunities to review the changing circumstances in their child's condition and provided a sense of control for future decision-making.

In summary, parents wish to engage in advance care planning and use advance care planning as a process by which they re-construct meaning of their child's illness and negotiate complexities of end-of-life care decisions. They prefer advance care planning to consist of ongoing conversations with health care professionals rather than conversations planned at determined points of time or at times of crisis. Moreover, in contrast to health care professionals conceptualisation of advance care planning as a rational process which determines specific treatment and care options, parents described a process more akin with Fuzzy Trace Theory (Reyna & Brainerd 2011) and a phased approach (Turpin & Marias 2004), which embodies beliefs and values and acknowledges uncertainty.

This new understanding of advance care planning provided by parents' experience and the grounded theory of re-constructing meaning transforms our knowledge of advance care planning and suggests significant changes are needed to current approaches to reframe the process of advance care planning. Moreover, the findings point to this being less about how and when advance care planning should be undertaken with parents and more about a continuous process of advance care planning conversations, which foster re-constructions of meaning. The following section addresses these issues and the importance of transforming knowledge to a practical application (Charmaz 2014) to guide health care professionals in practice.

9.2 Implications for practice – Re-framing advance care planning

Whereas health care professionals approach advance care planning as a structured rational decision-making process focused on definitive treatment options, parents consider it a continuous, relational process through which they strive to make the 'right' and 'good' decisions for their child, and prefer to keep their options open. The process of advance care planning helps parents to navigate the complexities of end-of-life care and to re-construct the meaning of their child's illness, in relation to their own values and those of their family. Thus, as Lund and colleagues (2015) argue, advance care planning is better understood as a rite of passage, an intrinsic part of a social transition which signals forthcoming death and bereavement, and which is consequently imbued with meaning.

First and foremost, what is critical to understand is that doing more of the same will not enhance the process of advance care planning for parents; our approach to advance care planning needs to significantly change to support the way in which parents engage in this process. Thus, as Lund and colleagues (2015) explain, best practice in advance care planning does not just depend on sensitive communication skills or regular reviews of advance care decisions. It requires an understanding of the emotional complexity involved in this process (Mitchell et al. 2019) and an appreciation that parents use advance care planning to navigate these complexities, not to resolve them.

Thus, advance care planning should be approached by health care professionals as series of conversations in which parents' values and goals for themselves and their family are explored. This will help parents to manage the uncertainties related to their child's illness, their family life and their future, and to re-orientate their values and goals as their child's condition deteriorates. In this way health care professionals can support parents in the process of *re-constructing meaning through advance care planning* and optimise the therapeutic benefits of advance care planning, to live with uncertainty and be able to make 'good' and 'right' decisions for their child.

The study confirms that parents wish to engage in advance care planning, therefore, health care professionals should not avoid talking to parents about end of life care and treatment, but encourage ongoing informal conversations. This should involve, early introductions to advance care planning so parents know that advance care planning exists and they can talk when they are ready. The benefits offer opportunity for parents to discuss together, issues that they might not otherwise have addressed and to find some common ground surrounding issues of conflict. Understanding of advance care planning and all that it entails is better once discussed. Thus, even though it may distressing, health care professionals should have confidence to persevere in talking with parents and sensitively continue with discussions.

Reframing advance care planning as a series of conversations will help parents to discuss their changing values and goals, beyond disease related topics. Knowing advance care planning is not solely about do not resuscitate or limitations to treatment, will enable parents to anticipate likely options and there outcomes, so they are as prepared as they can be. Continuous conversations will provide time and space for parents to adjust and find meaning in changed values and goals and to make 'good and right' decisions for themselves and their family.

Furthermore, parents do not give definitive answers to questions, are able to delay making decisions and can live with uncertainty. Health care professionals should support parents with their preferences for multiple options of treatment to enable them to keep their options open. At significant times when their child's condition deteriorates or at moments of crisis, the document is a starting point for a conversation and a good prompt for discussion.

Thus, the approach to advance care planning is a series of conversations that should embrace unplanned and spontaneous discussions. These conversations can support parents in managing the transition from palliative to end of life care knowing, that advance care planning is a turbulent but 'normal' process and can have a therapeutic benefit.

9.3 Key recommendations to inform practice

This study offers two key recommendations to inform practice.

- To reframe the approach to advance care planning to one that fosters a series of conversations and embraces *re-constructing meaning*.
- To openly acknowledge the complexities and contradictions of advance care planning for parents, that will enable them to re-adjust their values and goals as their child's condition deteriorates.

9.4 Further research

This study has identified the core issue of *re-constructing meaning through advance care planning* for parents and goes some way to inform knowledge of advance care planning practice. However, the study identified areas of practice where further knowledge will strengthen our understanding of advance care planning. In particular, it would be useful to know where and how advance care planning conversations currently take place and are recorded. Further examination of how parents cope with the tensions and contradictions would help us to better understand their experience of advance care planning. Moreover, better understanding of the ways by which parents construct meaning through their experiences of advance care planning holds great promise for appreciating the different ways parents adjust to the changes in their child's condition, including how they adjust to the increasing likelihood of their child's deaths

The study has revealed a gap in our knowledge of how advance care planning impacts on decisions at the time of death and in bereavement. There are further questions to consider in understanding if advance care planning is helpful at the end-of-life. Care should be taken to avoid placing a value on the advance care plan when its efficacy is uncertain or assume that every parent can complete one. Thus, a longitudinal study to understand how parents' goals and preferences change over time and impact of advance care planning conversations at the time of death and into bereavement would be of great value.

This study did not set out to explore the child's perspective but to explore parents' experience of advance care planning. However, it was recognised at the start of the study that hearing the child's voice is crucial if we are to fully understand their experience of advance care planning. If re-constructing meaning is of value to parents, how does this translate to the needs and experiences of children with life-limiting illness? It is known from recent research that the views of the child are different from their parents (Noyes et al. 2018) and their own sense of meaning will be uniquely personal. This is a significant area for future research.

9.5 Methodological considerations

This section will critique the grounded theory method used and analytical approach taken, to understand the impact this might have had on the findings. In particular, consideration is given to the choice of methods, placement of the literature review, recruitment and gatekeeping, theoretical sampling and saturation.

Whilst the study adopted a constructivist grounded theory approach (Charmaz 2006) it took some time to determine methods to answer the research question and to understand how the choice of methods might influence data analysis (Charmaz 2014). As my knowledge developed, I became more confident to embrace a flexible approach, using complementary methods that had a significant impact on the research process. This was more important than adhering to structured principles and enabled the introduction of Clarke’s supplementary approach of situational analysis (2005). By drawing on her approach of situational mapping and integrating this method throughout the analysis, I was better able to explore the socio-cultural context of advance care planning. Furthermore, being flexible and open to questions provided a platform for how I carried out the methods and not being frightened to adapt these as the study developed.

A further consideration was the issue of how and when to engage with literature. There are heated disputes (Dunne 2011; Charmaz 2014) about the placement of a literature review, which can create considerable confusion. I was initially influenced by the classic grounded theorists Glaser and Strauss (1967) who advocated delaying the literature review to the end of the study and believed this would avoid any bias or being swayed by other people’s ideas. What became clear was the importance of the literature review to provide rigour to the research process (McGhee et al. 2007; Dunne 2011; Charmaz 2014). The skill was one of reflexivity (McGhee et al. 2007) and of responding to this knowledge and its impact on, and in, the study.

The issue of recruitment, and gatekeeping provided an unanticipated challenge. In planning the study, I was prepared for a low number of participants given the field of practice and for slow recruitment, but I was not prepared for the challenges of understanding the dynamics of the relationships with the children’s community nurses. Having identified a sufficient sample, it was accessing parents that proved to be most difficult. The challenges of recruiting to palliative care studies - access, gatekeeping and co-operation have been reported by others (Crocker et al. 2014; Beecham et al. 2016) and it was no different in this study. It was not just about getting past gatekeepers as a metaphorical ‘entry gate’ (Crowhurst 2013) but of using a reflexive approach to consider the social relationships that informed encounters with gatekeepers in the field, which in turn affected the research process. The realisation that gatekeeping was not simply a practical consideration but a theoretical consideration shifted my understanding of gatekeeping within the research process (Crowhurst 2013). The ‘Gate’ ceased to be viewed as a mechanistic instrument but one of a discursive construction, giving meaning and making sense of the research encounters I experienced in the field (Crowhurst & Kennedy-Macfoy 2013). It became more of a dynamic process recognising the importance of the social and political relationships that were shaping the study. It was not possible to fully understand the situated context of children’s community nurses and therefore I was not able to control the relationships in the field (Campbell et al. 2006). However, this reflection and new knowledge prompted a different approach and transformed how I interacted and negotiated access with the nurses as the study progressed.

Thus, although data collected in this study were extensive, the sample was small. However, the design was intended to achieve depth and it could be argued that low numbers are less of a concern. In particular, as the scoping review highlighted a lack of existing research in the field, the study has revealed significant new understanding about advance care planning not previously identified.

A consideration not debated elsewhere was the presence of the child at interview. This could have further affected recruitment if interviews had not taken place due to the presence of a child. It required careful and sensitive adjustments to enable parents to continue to participate. This is an interesting and important ethical issue with potential for informing future research and ethics committees about research with families in the field of children’s palliative care.

Theoretical sampling in grounded theory is a further issue for consideration. To enhance analysis and inform the developing concepts and categories theoretical sampling is continually used to guide data collection and inform analysis. The true sense of theoretical sampling is to allow for creativity and flexibility to stimulate analysis (Corbin & Strauss 2015; Charmaz 2014) as the study transitions from an inductive to a deductive process. Thus, theoretical sampling as a process is guided by the emerging theory (Draucker et al. 2007). Researchers are often criticised for not describing this process in detail that would evidence an audit of their developing theory (Coyne 1997; Draucker et al. 2007). It was therefore important to monitor the process of theoretical sampling and how it impacted on the study. With the development of tentative categories theoretical sampling was used to refocus interview questions to gain specific information regarding an emerging concept. For example, I identified that parents’ experienced multiple tensions in the options they faced and wanted to deepen my understanding of this issue. Asking parents to tell me more about the choices they faced and how they managed these choices helped to inform the emerging category of reconciling multiple tensions. The questions and gaps that emerged were subsequently used as lines of enquiry and helped to fill out the categories.

A record of how the questions were revised demonstrated how this process increased the complexity of the analysis.

However, analysis of the initial interviews took eighteen months and it was not until the final interview, that the value of theoretical sampling became evident. Theoretical sampling at this point, served to test out emerging ideas and the developing theoretical framework. In particular, it was used to pursue difference and variation that enriched the research by engaging in data that addressed the complexities and contradictions of advance care planning. This process had an impact on the proposed method of undertaking second interviews. I had intended to undertake second interviews with parents following analysis of the advance care planning documents. The aim was to investigate whether the advance care plans represented parents' choices revealed in the interviews. However, by engaging with theoretical sampling and reflexivity, I realised that I held preconceived assumptions that the interview data would not match the advance care plan documents and this was guiding the purpose of the second interview. Analysis demonstrated that the process of advance care planning was far more than the completion of the document and that meaning as part of the process was not going to be illuminated in the plans. I realised that it was not about comparing each method but how they worked together. The process was about both the conversation and the document. Thus, using the second interview to 'challenge' the content of the document was not helpful and might undermine the rich information that parents had shared. I therefore chose to adapt the methods and not to engage in second interviews.

The final area of methodological consideration that required attention was saturation and being able to define and evidence that saturation had occurred. There is a growing expectation to meet the requirement of '*saturation*' and much debate in the literature that suggests this is often poorly understood and evidence unsatisfactory (O'Reilly & Parker 2013). The traditional concept of saturation states that data should continue to be collected until nothing new is generated (Green & Thorogood 2004). Evidence of saturation when applied in this way, is used as criteria to measure the quality of a study (O'Reilly & Parker 2013). Emphasis on the process of theoretical saturation in grounded theory is further defined by being able to fully account for and the patterns and relationship between the categories (Green and Thorogood 2004). I found this concept difficult to apply and by drawing on the philosophy of continually seeking something new in data (Charmaz 2014) found it impossible to determine whether I had reached saturation. What became easier was knowing the categories had been robustly assessed and the relationship and connections between them comprehensively addressed (O'Reilly & Parker 2013; Charmaz 2014). The stance I have taken is about sensitising concepts and ensuring a theoretically integrated analysis rather than the pursuit of fully saturated categories (Dey 1999; Clarke 2005). Thus, the decision to stop formal data collection was made following a comprehensive review of the content and properties of the conceptual themes informing the categories and when there was robust evidence shaping and directing the emerging theory.

9.6 Rigour of the study

Monitoring the rigour of the research process is a fundamental part of the research process. Researchers need to demonstrate the reliability and validity of their study (Seale & Silverman 1997; Corbin & Strauss 2015). A variety of methods to assess quality have been developed (Glaser 1978; Seale & Silverman 1997; Charmaz 2014; Corbin and Straus 2015) each outlining strategies and criteria for such evaluation. This study has demonstrated rigour on two levels; throughout the research process (Charmaz 2014) and by being able to justify the credibility and trustworthiness of the rendered theory, its fit and relevance (Glaser 1978).

The robust systematic application of methods has provided rigour and theoretical sensitivity and ensured a credible and trustworthy study and substantive theory. Furthermore, the research process was guided by the theoretical considerations of plausibility, direction, centrality and adequacy to robustly demonstrate theory development and theory construction (Charmaz 2014).

Charmaz (2014) argues that these four theoretical considerations affect theoretical thinking throughout a study from what data you collect and how you collect it (*theoretical plausibilty*); how you create and develop tentative categories which gives *theoretical direction* to the study; using the process of theoretical sampling to inform *theoretical centrality* and *theoretical adequacy* to determine that concepts and categories have been fully addressed.

These criteria were met through careful consideration of parents’ views and experiences, and being attentive to how I engaged with and responded to parents throughout the interviews. Patterns in the data gave direction to the developing categories and I was able to pursue these ideas to focus on key concepts until the categories and their properties were adequately explained. This evaluative process demonstrates theoretical sensitivity and how the rigour of the research process is also integral to the end product of constructing a substantive theory.

However, the rigour of a grounded theory study is not only dependent on a robust research process. Glaser (1978) and Charmaz (2014) also argue that the quality of the constructed theory and how it conveys what is meaningful from the data should provide evidence of rigour. To measure this, Charmaz (2014) builds on the criteria of Glaser (1978) to highlight four key criteria and I used these to evaluate the grounded theory.

Credibility - the study was embedded in the subject area and the interviews and advance care plans provided rich data to make comparisons and identify patterns and links between the categories. The complex analysis and subsequent discussion provided robust evidence to the theory.

Originality - The theory is uniquely original and offers new insights that have not previously been known. It captures an understanding of advance care planning observed in practice, but not evidenced or articulated to this extent

Resonance – The key recommendations align to observations of practice and will challenge health care professionals to reframe advance care planning to inform a change in practice.

Usefulness - The theory captures a new understanding that both adds to our knowledge and will support the experience of advance care planning for parents. It offers a platform for future research to explore further how parents engage in re-constructing meaning to understand the anticipated death of their child.

These criteria demonstrate validity, however, they do not emphasise the importance of reflexivity argued to be a significant contribution to the rigour of grounded theory (Hall & Callery 2001) and integral to how the endpoint is reached. Thus, it is included here to supplement the criteria of theoretical sensitivity described by Charmaz (2014). Reflexivity was a significant element of the grounded theory approach, of my involvement in the research process, my interpretation of the interviews and how I have reported the findings. It was also central to how I engaged with parents and to the conversations I had with colleagues and my supervisors. These encounters shaped my thinking, enhanced my analysis and gave direction to the emerging theory. Reflexivity was central to the essence of grounded theory (Charmaz 2014) and demonstrated a depth of understanding and knowledge of the approach and all its complexities in constructing a grounded theory.

9.7 Strengths and limitations of the study

One of the major strengths of this study was the use of a constructivist grounded theory approach providing significant insight of parents’ experience of advance care planning. The combination of Charmaz’s (2006) constructive approach and Clarke’s (2005) supplementary method of situational analysis enabled me to reveal complexities and contradictions that were not previously known. The use of these different methods helped to contribute to the theory that changed my understanding of the process of advance care planning.

The analysis, combining interviews and the advance care planning documents also provided an understanding of the process of advance care planning that would not have been achieved if either had been explored in isolation. The findings have demonstrated that both the conversation and the document are important for advance care planning and this provides vital knowledge for practice.

However, there are four notable limitations of the study. It is clear that not all parents who have a child with a life-limiting condition came forward to participate in the study. I have written extensively about the challenges of gatekeeping, but of those parents who were invited to participate, I do not know why they declined. It may be, that those parents that participated were better able to hear and understand the decisions about their child and engage in advance care planning and wanted to talk. The reasons are unknown but it is possible that I did not hear the full range of views of parents' experience of advance care planning.

A further limitation emphasises the need for a greater understanding of the individual perspectives of mothers and fathers and how they construct a joint narrative. Only four fathers participated in this study and it is unlikely I achieved a complete representation of fathers' views. The small number of fathers who participated meant it was not possible to investigate the similar or different perspective of mothers and fathers. Furthermore, whilst the two joint interviews revealed an emerging understanding that parents co-constructed meaning within the process of advance care planning, further joint interviews are needed to explore this in detail. These are important areas to consider to fully appreciate parents' experience of advance care planning.

I was aware that parents revealed issues not heard about in practice and may have used the study as a therapeutic way to talk. It is possible they used the research study as a means to talk about advance care planning that kept a slight distance from reality. Nothing was to be put in writing in regards to a formalised plan and this may have promoted some safety in being able to voice their views, which may be different in a practice environment. This requires some consideration of how to capture opportunities for parents to talk where they feel safe to express their views.

Lastly, the study has not revealed where parents struggled or were unable to make meaning and the impact of this at end-of-life and in to bereavement. I only interviewed four bereaved parents so understanding the impact of the advance care planning process and the outcome in bereavement is limited.

9.8 Personal reflections

This section will explore my personal thoughts regarding the study. The process has been a journey of continual exploration and learning, supported by multiple conversations, critical discussions and endless reading. It has provided considerable personal growth and development beyond my expectation. These encounters with new knowledge have shaped my worldview and deepened my understanding of relationships, of living with sorrow and of the contradictions and meaning in our lives.

At the start of the study, I came with my own ideas and expectations about advance care planning from the encounters I had had with parents and colleagues. I was nervous at the outset about the bias this held. However, I was reassured by Charmaz (2014) who recognises that we cannot ignore our past experiences, as it is these experiences that shape and bring us in search of new knowledge. Moreover, reflection and support from my supervisors has greatly helped me understand bias, and where I was not entirely reflecting the role of a researcher, to take a step back and rethink. At times, it has been difficult as a nurse, not to problem solve and I struggled in the beginning to think more imaginatively, relying on practical interpretations of my data. As I have gained confidence it has been illuminating to understand abstract and concepts that have enriched the emerging theory.

The greatest learning has been the development of my research knowledge. I came to the study with a basic understanding of research but the taught elements of the programme and the engagement in supervision has enabled me to gain confidence, particularly in grounded theory. As a novice researcher, it was difficult at the start to establish a confidence in the grounded theory approach when there were so many competing debates about different versions of grounded theory, their strategies and approach to methods (Morse et al. 2009). In the first instance although I had chosen to use Charmaz's (2006) constructivist grounded theory, I felt pressured to conform to set principles of coding, theoretical sampling and emergent categories and commenced the study using a much more formulaic approach consistent with Glaser's (1978) methods of grounded theory. This influenced when I conducted a focused search of the literature (as previously described). Having undertaken an initial scoping review, I had a sense of current thinking about advance care planning but I resisted exploring the literature in depth until the categories were nearly developed. As a result, I believe it generated a considerable amount of reading later on in the study and it took longer to locate the work within theoretical debates.

In addition, it was difficult to grasp the concept of analysis with simultaneous methods of data collection, coding and theoretical sampling. It was not until later in the study I developed greater knowledge of the methods and gained a confidence in the constant comparison approach. This was supported by the publication of the second edition of Charmaz's Constructing Grounded Theory (2014) which strongly influenced the direction and shape of the study as it provided comprehensive case studies of methods and approach. In essence, it enabled me to develop a greater understanding of the inductive and deductive approach being more open to the chaos of coding and abstract concepts.

Furthermore, I have developed a greater understanding of analytical development and how my thinking and critical stance is shaped through constructive discussion with critical friends. Discussions encountered at supervision acted as a catalyst to my thinking. The process of analysis was exciting, as Clarke described, I was '*constantly banging in to and bouncing off the interpretations of others'* (2005 p. 8). This unquestionably enriched the grounded theory.

The study has taken place during some significant high profile media cases of end-of-life care in children. These have undoubtedly shaped my understanding of the wider socio-political context of health care and of the needs and experiences of family's; of how we manage the tension where families and professionals do not always agree. This has been a key driver to complete the study and to contribute to health care professionals' knowledge of advance care planning.

My learning has enabled me to see advance care planning through a new lens, understanding that meaning in life is a balance of contradictions, where living and dying do not cancel each other out and where joy and sorrow co-exist side by side. This has shifted my focus in what advance care planning means to parents, and therefore my approach in practice. It has encouraged me to have conversations with parents to be present in their distress and to stick with it when I previously may have diverted the conversation. I have learnt through the research that to stay alongside parents, to go deeper with a conversation, enables them to share the rawness and helplessness of the situation and that they do want to talk. Kathryn Mannix (2017) identifies that so many times in practice we think in our own heads about whether we should ask a particular question, whether we have the courage to go there, but often the question is too raw and we are afraid we might touch on something fearful and too easily back off. The study has given me courage and confidence to ask the question, parents can choose not to answer, but more often, they are relieved to be able to voice their thoughts and fears.

Most importantly, I have learnt to challenge the dominant power constructs of practice recognising the wider situatedness of people's lives and the multiple interpretations of reality. This has helped me to believe that another way is not necessarily wrong, but that knowledge creates a different perspective. This new knowledge needs to be heard in order for us to consider change and take a new path.

9.9 Conclusion

The constructed substantive theory offered in this thesis asserts that *re-constructing meaning* is central to the process of advance care planning and that parents use the process of *re-constructing meaning through advance care planning* to re- adjust, and re-construct meaning for themselves their family and a future without their child. It has addressed the experience of advance care planning for parents establishing a process of *realisation, reconciling multiple tensions* and *building confidence and asserting control*. The grounded theory promotes a new way to think about advance care planning and encourages us to reframe the process for parents.

Whilst the findings challenge the current approach to advance care planning with parents, this substantive theory must be tested. How parents' experience *re-constructing meaning through advance care* requires further research. The learning though, highlights that advance care planning conversations are essential in supporting parents to live with the uncertainty and growing possibility of their child's death. By engaging in continuous conversations, health care professionals can improve the experience for parents of caring for their child and provide a more skilled palliative care service.

This means careful attention to the process of advance care planning in practice. It is the most challenging tightrope to walk, in recognising uncertainty, yet nevertheless to understand when it is right to support the 'enough' expressed by parents as a time to let go. It is about supporting parents to make the most difficult of decisions through continuous conversations. Thus, to implement meaningful conversations becomes a measure of how parents are able to talk about their values and beliefs associated with advance care planning for their child. The study has shown that advance care planning is a significant area of ethical practice and one that emphasises a relational, child and family focused approach. As health care professionals, we need to build confidence so we are able to work in this unique space with parents.

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Appendices

A. CYPACP form link
B. Data Charting Form
C. Charting the different ontological, epistemological and methodological grounded theory approaches
D. Participation information sheets
    D.1 Participation information sheet (current)
    D.2 Participation information sheet (Bereaved parents) (2)
E. Consent form
F. Letter to children’s community nursing team
G. Outline for interview questions
H. Feedback from parents about interview questions and changes made
I. Ethical approval
    I.1 Ergo
    I.2 NRES
J. Initial codes
K. The analytical process for the emerging category, Reconciling multiple tensions

Appendix A CYPACP Form

The link provides an example of an advance care plan used with parents to discuss future care for their child.

http://cypacp.uk/document-downloads/care-plan/advanced-care-plan-with-respect/

Appendix B Data charting form: Table of papers identified through the scoping review and their key characteristics

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Wharton et al	1996	US	Survey	Questionnaire	Parents	Special needs	Parents understanding of their child’s condition and future needs	Most parents understood their child’s condition; Doctors knowledge of child Discordance between parents and doctors leads to parents requesting written document
Walsh-Kelly et al	1999	US	Discussion				Challenges and implementation of advance decisions in ED	Complication if parents not present and challenges of resus in different settings Need for comprehensive discussion with parents. Jointly completed form
Hammes et al	2005	US	Qualitative	Interviews, content analysis	Parents	LLC	To understand the process and population of ACP	The process of ACP is helpful for parents, it assured best care & gave time to make decisions ACP gave peace of mind and sense of control

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Erby et al	2006	US	Qualitative	Interviews, thematic analysis	Parents	DMD	Parents attitudes and experience of ACP	Most parents not heard of ACP, not ready to discuss, challenges of effective communication Opportunity to talk, hope vs avoidance
Finlay et al	2008	UK	Audit	Case note review	Children	Neurological	Analysis of EOL plans to support development of framework to guide practice	EOL plans focused on acute interventions rather than emotional or spiritual themes To use a framework to help HCP's discuss EOL
Zinner	2009	US	Discussion				The engagement of children and young people in EOL decisions	Children and young people are involved in ACP discussions Encourage greater involvement
Dussell et al	2009	US	Survey	Questionnaire via interview	Bereaved parents	Cancer	To understand EOL planning & location of death	Being able to plan LOD has benefits and may improve QOL. Barriers identified, communication Further research to develop knowledge
Fraser et al	2010	UK	Discussion				ACP set against policy context	Difficulties in EOL planning, recommend the use of a tool

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
								Conversations should start at diagnosis, framework to assist HCP's
Wiener et al	2010	US	Survey	Document review	Adolescents, young adult	HIV, cancer	To review adult document for use in young adults	Young adults reported helpful to have documents for EOL planning Participants more interested in how they wanted to be treated and remembered
Wolff et al	2011	UK	Discussion				To explore the need for family held personal resus plan	Development of resus plan, family and MP approach, to address medical decisions and religious and cultural issues Challenges where there was disagreement, and with review and distribution
Beringer & Heckford	2012	UK	Audit	Case note review	Children	LLC	Review against standards	Reported conversations, joint planning, a written plan, review and emotional support No record of LOD, is it discussed? Lack of evidence that documents are used

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Wiener et al	2012	US	Survey	Review of pilot document	Adolescents, young adult	HIV, Cancer	To review new planning documents	AYA wanted their voices heard and to be involved in EOL planning Involvement of AYA enables them to reflect on their lives to make choices
Durrall et al	2012	US	Survey	Itemed questionnaire	Physicians, nurses	LLC	To identify barriers to ACP in CPC	Lack of parent readiness, communication skills, ethical considerations Professionals report parental issues as barrier to ACP
Edwards et al	2012	US	Review	Case note review	Children	Home ventilation	Review for documented discussions that explicitly address EOL goals	Discussions took place in PICU & wards, decisions made in regards to acute deterioration Earlier opportunities for discussions
Taylor	2012	UK	Discussion				To give children a voice	Parents do not know what to expect and want to help their child Positive and skilled communication for parents & child

Appendix B

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Noyes et al	2013	UK	Mixed methods	Interviews, questionnaires thematic analysis	Parents, young people, professionals	LLC	To develop, pilot & evaluate a tool	Mixed response from parents in using booklet & its purpose, Barriers reported from HCP's Importance of planning ahead
Lyon et al	2013	US	RCT	Intervention dyad, interview	Young adults	Cancer	To examine the efficacy of family centred ACP	Young adults better informed & greater congruence with intervention dyads ACP empowered YA to communicate their wishes & congruence with parents
Lotz et al	2013	US	Systematic review	13 papers reviewed	Children, young people, family members, HCP's	HIV, cancer, MD, complex needs	To assess current practice, effects & perspectives	Few ACP programs, lack of evidence from HCP's, ACP's supportive Evidence is insufficient to make definitive conclusions about children's ACP
Mitchell et al	2014	UK	Survey	Questionnaire	Lead clinicians	PICU	To identify & compare children's ACP documents in use in UK	Not all PICU use ACP & variation within document Variation in the use of ACP, Controversy and misunderstanding between ACP & DNR

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Liberman et al	2014	US	Survey	Questionnaire	Parents, caregivers	Chronic illness, hospital	To explore parents/carers experience, knowledge & preferences of ACP	Parents not heard of ACP Poor understanding of ACP, uncertainty around prognosis key barrier
Heckford & Beringer	2014	UK	Audit	Case note review	Children	LLC	To review ACP	25% no documented discussion Challenges of children's ACP
Horridge	2015	UK	Discussion				To outline elements of ACP	Multiple aspects to children's ACP Planning of EOL care needs to improve using a framework
Mitchell & Dale	2015	UK	Qualitative	Interviews, thematic analysis	Consultants, senior nurses	PICU	To explore experience of senior staff in PICU	Recognition of child's illness and the value of ACP, challenges and consequences of inadequate ACP Multiple potential benefits if done well
Lotz et al	2015	US	Qualitative	Interviews, content analysis	HCP's	Severely ill children	TO explore attitudes and needs of HCP's	HCP's perceived discomfort & uncertainty with EOL decisions Barriers to ACP

Appendix B

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Popejoy	2015	UK	Qualitative	Interviews, phenom analysis	Mothers (3)	LLC	To understand how parents make & revise decisions	Barriers & facilitators EOL decisions are complex
Xxafis et al	2015	Aus	Mixed methods	Development of handbook, pilot, thematic analysis	Professionals parents	LLC	Development of a written resource	Parents found the resource helpful but in different ways EOL resources helpful but difficult to ascertain when to initiate
Sanderson et al	2016	US	Survey	Itemed questionnaire	Doctors, nurses	LLC	To explore clinicians preparedness to participate in ACP discussions & approaches to practice	Those with less experience were less prepared, emotional impact on staff Barriers to ACP being uncertainty & differing expectations, difficult to discuss issues
Beecham et al	2017	UK	Qualitative	Interviews, grounded theory principles	Parents	LLC	How parents approach & experience ACP	Parents reported having discussions & making decision. Different times meant different decisions Views change over time

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Lotz et al	2017	US	Qualitative	Interviews, evaluation	Bereaved parents	LLC	Parents views & needs for ACP	Parents find it difficult to engage in ACP but consider it important Sensitive individual approach suggests principles to improve practice
Hiscock et al	2017	UK	Systematic review	3 papers reviewed	Parents	DMD, NMD	To investigate EOL conversations between HCP's & YA	No evidence of conversations or preferences for timing Limited literature, need for education & use of EOL plans
Popejoy et al	2017	UK	Systematic review	9 papers reviewed	Children, young people	LLC	To investigate decision-making & future planning	Four analytical themes, influential decision, family & relational factors, system factors Future planning is difficult, individualised, relational & contextual aspects of decision making need further research
Basu & Swil	2018	Aus	Survey	Questionnaire	Physicians	LLC	To investigate physicians experience	Encounters with ACP should be earlier, multi professional approach, barriers of prognostic uncertainty Improvements in training and timely conversations

Appendix B

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Harrop et al	2018	UK	Discussion				Why, when and how to do ACP	When done well ACP will have significant benefits ACP conversations may present difficulties for HCP's
Clayton & Aldridge	2018	UK	Discussion				ACP to address spirituality & wholeness	To encourage children's involvement in ACP
Tatterton	2018	UK	Discussion				ACP can be used to manage anticipated symptoms	ACP linked to symptom management, challenges & prescribing Nurses need access to training, good communication
Hughes et al	2018	UK	Systematic review	22 papers reviewed	Young people	LLC	To investigate engagement of YP in ACP	Families want their YP to be involved, however conflict can arise Barriers to effective ACP, good ACP can provide good outcomes
Jack et al	2018	UK	Qualitative	Interviews, thematic analysis	HCP's	LLC	How ACP conversations take place	The timing of planning conversations The value of ACP in stages & to avoid difficult conversations at time of crisis

Author	Date	Co	Design	Methodology /intervention	Study population	Condition / environment	Aims	Key discussion
De Arruda-Colli	2018	Aus/ Brazil	Qualitative	Interviews, evaluation tool	HCP's, young people	LLC, cancer	To investigate involvement of AYA & use of tool	Important to involve AYA, adaptation of tool to meet cultural context for ACP Culture is likely to have unique impact on ACP
Pao & Mahoney	2018	US	Discussion				Rationale & benefits of talking about ACP	Preparation, understanding of death, creating a plan Difficult, but important
Fletcher et al	2018	Aus	Audit	Case note reviews	Adolescents, young adults	Cancer	To inform future models of ACP discussions	Different preferences EOL preferences for AYA differ from adults
Hoell et al	2018	Eur	Audit	ACP document review	Children, young people	LLC	To investigate the number of medical orders for LST with TFSL categories	Different options for those in different categories Timely conversations
Loeffen et al	2018	Eur	Mixed method	Development of tool, pilot, evaluation	Children, young people	LLC	To develop & pilot an individualised plan	To include 5 domains Attention to ACP & anticipatory planning

Appendix B

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Martin & Beringer	2019	UK	Audit	Case note review	Children, young people	LLC	How has planning developed over 5 years	Prognostic discussion has risen ACP document consistently in use EOL conversations have increased, evidence of better quality ACP
DeCourcey et al	2019	US	Survey	Questionnaire	Bereaved parents	LLC	To evaluate parental preferences for ACP	All parents reported ACP important ACP associated with improved parent reported EOL outcomes
Mitchell et al	2019	UK	Qualitative	Interviews, thematic analysis	Bereaved parents	PICU	Experience & perceptions of bereaved parents	5 interconnected themes, parents have significant knowledge, trusting relationship, importance of effective communication, emotional impact EOL decision making is complex
Haynes et al	2019	UK	Discussion				What ACP should involve	Preparation & instruction, approach to ACP Discuss options and document
Hiscock & Barclay	2019	UK	Qualitative	Interviews, thematic analysis	HCP’s	NMD	To investigate the views of HCP’s concerning having	Environmental, organisational and personal barriers No consensus on when best to discuss

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
							conversations about ACP with teenagers	Skilled staff and importance of trusting relationship
Harmony et al	2019	US	Audit	Case note review	Children	LLC	To determine PPC involvement, ACP and circumstances od death	Patients with PPC involvement were more likely to have discussed ACP and to have goals of care documented Important benefits of involving PPC and importance of ACP as part of PC
Needle et al	2019	US	Mixed method	Case note review, conversation analysis	Adolescents, young adults	BMT	To explore & better understand influences on decision making for AYA about future care	Pain & suffering & the future of illness influential in decision making YP want to be involved in EOL planning, complexity of reasoning ‘what ifs’ to make decision beyond uncertainty
Faher et al	2019	Eur	Survey	Questionnaire	paediatrician	LLC	To assess experience of ACP with paediatricians	ACP discussed with parents, focused on medical issues Themes within conversations

Appendix B

Author	**Date**	**Co**	**Design**	**Methodology /intervention**	**Study population**	**Condition / environment**	**Aims**	**Key discussion**
Beernaert et al	2019	Eur	Survey	Questionnaire	Parents, bereaved parents	SMA	To assess experience & wishes of parents regarding information & decision making	Information about condition was inadequate to make decisions, lack of information about options Improvements needed in providing information

Appendix C Charting the different ontological, epistemological and methodological grounded theory approaches

Grounded theory approaches	**Classic methods defined by Glaser and Strauss (1967) *Discovery***	**Strauss (1987) *Straussian***	**Glaser (1992) *Glaserian***	**Charmaz (2006) *Constructivist***	**Clarke (2005) *Situational analysis***
Ontological and Epistemological view	Guided by a realist ontology, a single truth that can be discovered Correlates with a positivist stance objectivist view and external reality	Later views aligned more closely to pragmatism and symbolic interactionism Post positivist stance, maintained objective view but recognised that some aspects of the social world cannot be captured	Positivist stance Objectivist view	Constructivist Draws on a range of concepts and theories to use with symbolic interactionism Pragmatist approach and constructivist view	Post-structuralist Draws on a range of concepts and theories to use with symbolic interactionism Relativism Multiple realities
Data	Discovered by a neutral observer	Discovered by a neutral observer	Discovered by a neutral observer	Mutually constructed through interaction	Supplementary approaches to GT to analyse discourse, structure and conditions that characterise the situation of enquiry

Process of analysis	Constant comparative analysis (Theoretical sampling, memos) Search for a basic social process as an objective process and specifies variables	Constant comparative analysis (Theoretical sampling, memos) Specific formulaic coding process and structure / Conditional matrix and diagrams	Constant comparative analysis (Theoretical sampling, memos) Search for a basic social process	Constant comparative analysis (Theoretical sampling, memos and diagrams) Continuous reflexivity acknowledging subjectivities throughout analysis and specifies range of variation	Situational mapping. Emphasis on analysing varied positions and power and at a more meso /organisational level
Social world and arenas		Attention to social worlds and arenas			Integrated social worlds and arenas through situational mapping
Substantive theory	Discovered emergent theory	Emerging interpretative theory	Discovered	Constructed	Emphasis on analysis of BSP within the situation of enquiry
Recognition of participant, researcher perspective	Assumes an unbiased observer	To avoid preconceived prejudice and preconceptions	Assumes an unbiased observer, by attention to careful coding procedures	To engage fully in the participants world, making interpretations explicit	Assumes situated and interpretative knowledge

Appendix D Participant information sheets

D.1 Participant information sheet (1)

Study title: Parents understanding of advance care planning in the context of children's palliative care.

This information sheet invites you to take part in a research study. It outlines the reason for the research and what it involves. Please take time to read all the information and decide whether or not you wish to take part. You may find it helpful to talk with someone about whether you wish to participate. It is important you understand why the research is being done and what it will involve. Please ask if there is anything that is not clear or you have any further questions.

Who is organising and funding the research? - Helen Bennett is the researcher who will undertake this study. She has worked as a children's palliative care nurse for the past 25 years and has a special interest in supporting parents with conversations at the end-of-life. The study is part of a PhD and supported by the Faculty of Health Sciences at University of Southampton. Helen Bennett's contact details are at the end of the information sheet.

How does the study relate to me? - You have been chosen as you have a child with a condition that means they need supportive and palliative care and you have thought about or had a conversation about an advance care plan. You may have also discussed or thought about the wishes and preferences for your child's care at the end of their life.

Do I have to take part? - It is up to you to decide whether to take part of not. It is entirely voluntary. If you choose to participate you are still free to withdraw at any time during the research without giving an explanation. Any information you have already shared will not be used in the study without your permission. Your decision to take part or not, will not influence the care you or your child receive now or in the future.

What is involved? - If you agree to take part in the study Helen will contact you to organise a time to meet. This would be in your own home or a place you feel comfortable to talk. At the meeting Helen will explain more about the research and about the consent process for the study. You will be asked for your permission to inform your community nurse that you have participated in the study. You will then be asked to share your experiences of advance care planning for your child through an interview. The interview will be recorded and then transcribed in to a written copy. You will be asked to share a copy of your child's advance care plan if you have completed one. If you have a completed advance care planning you will be invited to take part in a 2nd interview. Your child will not be interviewed.

Are there any possible risks? - The conversation between you and the researcher involves no foreseeable risks. However the emotional impact of talking about advance care planning is acknowledged and the researcher will ensure that there are avenues of support in place with your children's community nurse if you should wish to talk to someone following the interview.

What if there is a problem?- If you wish to complain about any aspect of the research and the way you have been approached or treated, please contact the Research Governance Office at the University of Southampton. Email: rgoinfo@soton.ac.uk or Tel: 02380595058

Are there benefits to taking part? - The study will improve our understanding of parents experience about advance care planning. It will help health care professionals to be better able to support parents when discussing their wishes for their child’s care at towards the end-of-life. You will be offered a summary of the research on completion.

Will my taking part be kept confidential? - Your confidentiality will be fully protected unless there are any concerns which I would need to report to the relevant authority. The interview tapes and any written material will be locked in a draw. When the transcribing is complete the interview tape will be wiped clean. All study data will be coded so it will not be linked to any one individual. If you wish for your child’s name to be used or to use a pseudonym this will be supported within the consent process. All data will be kept for 10 years compliant with the Data Protection Act.

What will happen to the information I share? - The research findings will be written up as part of the final thesis and may be published in journal articles or presented at seminars or conference.

Who has reviewed the study?- The study has been reviewed by the NHS ethics committee.

What happens now? - If you would like to take part in this study or talk to Helen to find out more please complete the tear off slip at the bottom of the leaflet and return to Helen in the stamped addressed envelope provided.

Contact details for further Information

Please contact Helen Bennett

Tel:

Email:

PhD Supervisor

Dr Sue Duke, University of Southampton

Thank you, Helen

……………………………………………………………………………………………………

Please complete this section and return to Helen Bennett in the envelope provided

Name:

Address:

Tel No

I would like to hear more about the study and am happy for Helen to telephone me

SIGNED: **Date:**

D.2 Participant information sheet (2)

Study title: Parents understanding of advance care planning in the context of children's palliative care.

This information sheet invites you to take part in a research study. It outlines the reason for the research and what it involves. Please take time to read all the information and decide whether or not you wish to take part. You may find it helpful to talk with someone about whether you wish to participate. It is important you understand why the research is being done and what it will involve. Please ask if there is anything that is not clear or you have any further questions.

Who is organising and funding the research? - Helen Bennett is the researcher who will undertake this study. She has worked as a children's palliative care nurse for the past 25 years and has a special interest in supporting parents with conversations at the end-of-life. The study is part of a PhD and supported by the Faculty of Health Sciences at University of Southampton. Helen Bennett's contact details are at the end of the information sheet.

How does the study relate to me? - You have been chosen as your child received end-of-life care and you had a conversation about or completed an advance care plan for your child. You may have also discussed wishes and preferences for your child's care at the end of their life.

Do I have to take part? - It is up to you to decide whether to take part of not. It is entirely voluntary. If you choose to participate you are still free to withdraw at any time during the research without giving an explanation. Any information you have already shared will not be used in the study without your permission. Your decision to take part or not, will not influence the support you will continue to receive from professionals who cared for your child.

What is involved? - If you agree to take part in the study Helen will contact you to organise a time to meet. This would be in your own home or a place you feel comfortable to talk. At the meeting Helen will explain more about the research and about the consent process for the study. You will be asked for your permission to inform your community nurse that you have participated in the study. You will then be asked to share your experiences of advance care planning for your child through an interview. The interview will be recorded and then transcribed in to a written copy. You will be asked to share a copy of your child's advance care plan if you have completed one. If you have a completed advance care planning you will be invited to take part in a 2nd interview.

Are there any possible risks? - The conversation between you and the researcher involves no foreseeable risks. However the emotional impact of talking about advance care planning is acknowledged and the researcher will ensure that there are avenues of support in place with the children's community nurse if you should wish to talk to someone following the interview.

What if there is a problem?- If you wish to complain about any aspect of the research and the way you have been approached or treated, please contact the Research Governance Office at the University of Southampton. Email: **rgoinfo@soton.ac.uk** or Tel: 02380595058

Are there benefits to taking part? - The study will improve our understanding of parents experience about advance care planning. It will help health care professionals to be better able to support when discussing their wishes for their child's care at towards the end-of-life. You will be offered a summary of the research on completion.

Will my taking part be kept confidential? - Your confidentiality will be fully protected unless there are any concerns which I would need to report to the relevant authority. The interview tapes and any written material will be locked in a draw. When the transcribing is complete the interview tape will be wiped clean. All study data will be coded so it will not be linked to any one individual. If you wish for your child's name to be used or to use a pseudonym this will be supported within the consent process. All data will be kept for 10 years compliant with the Data Protection Act.

What will happen to the information I share? - The research findings will be written up as part of the final thesis and may be published in journal articles or presented at seminars or conference.

Who has reviewed the study?- The study has been reviewed by the NHS ethics committee.

What happens now? - If you would like to take part in this study or talk to Helen to find out more please complete the tear off slip at the bottom of the leaflet and return to Helen in the stamped addressed envelope provided.

Contact details for further Information

Please contact Helen Bennett

Tel:

Email:

PhD Supervisor

Dr Sue Duke

University of Southampton

Thank you

Helen

……………………………………………………………………………………………

Please complete this section and return to Helen Bennett in the envelope provided

Name:

Address:

Tel No

I would like to hear more about the study and am happy for Helen to telephone me

SIGNED: **Date:**

Appendix E Consent form

UNIVERSITY OF Southampton

Parents understanding of advance care planning in the context of children's palliative care.

Helen Bennett

Study Reference **Ethics Reference**

Please initial the box if you agree with the following statements:

I confirm that I have had the study explained to me by the researcher and have read and understood the information sheet and had the opportunity to ask questions about the study	☐
I understand that all my details will be kept confidential, that my data will only be used for the purpose of the study and my name will not appear on any reports or documents	☐
I agree to being interviewed and the interview being recorded and transcribed	☐
I agree to the researcher contacting my children's community nurse to inform them of my participation in the study	☐
I agree to the researcher having a copy of the advance care planning document	☐
I understand that my participation is voluntary and I may withdraw from the study at any time without having to give a reason and without the care I or my family receive being affected in any way.	☐
I would prefer my child's real name was used as part of the study I would prefer a pseudonym was used	☐ ☐
I agree to take part in this study	☐
Name of participant: **(Please print)** **Signature of participant:** **Date** **Name of Researcher:** **Signature of Researcher:** **Date:**	

Appendix F Letter to children's community nursing team

UNIVERSITY OF
Southampton

Re Research Study: Parents understanding of advance care planning in the context of children's palliative care.

Dear Children's Community Team

I am writing to inform you that the parent (name) of (child's name) has consented to participate in the above study and has taken part in a 1:1 face to face interview today.

They have given their permission for me to inform you of their involvement in the study and participation in the interview.

If you should have any questions please do not hesitate to contact me.

Yours sincerely

Helen Bennett

Tel:

Appendix G Outline of interview questions / prompts for discussion

The purpose of the interview is for you to share your experiences of advance care planning (advance care planning) or talking about end-of-life care for your child.

1. Please can you tell me about your experience of advance care planning
2. When were you approached to discuss advance care planning?
   (In relation to their child's condition / illness and / or changes to their condition)
3. Who has discussed advance care planning with you?
   (Which professionals – family/friends discussions)
4. How many times have you discussed advance care planning?
5. What form did it take?
6. Was your child involved in any of the discussions?
7. Were there things that were helpful?
8. What was difficult?
9. How did you feel about discussing advance care planning for your child?
10. Were there things you wanted to talk about or include in the advance care planning?
11. Do you have a completed advance care planning?
12. Would you be happy to share it as part of the research?
13. Have you had further thoughts/reflections since completing the advance care planning?
14. Do you have any other thoughts you would like to share?
15. Would you be happy to be interviewed again?
16. Follow up support

Appendix H Feedback from parents about the interview Questions and changes made

Question	Parents Comments	Changes
1. Please can you describe the experience you have had about ACP	P1: Please can you tell me about your experience of ACP – this could be an opening question with all the others as prompts. Will all participants know what an ACP is?	First Question for all parents Please can you tell me about your experience of ACP
2. When were you approached to discuss ACP? (In relation to their child's condition / illness journey and deterioration)	P1: Will parents be able to reliably remember when or how many times? P2: It might be helpful to ask was there a certain 'tipping point' – an obvious point or event that led to the appropriate moment for the discussion	All other questions as prompts. When were you approached and what influenced the timing of the discussion
3. Who has discussed ACP with you? (Which professionals and how many – family/friends discussions)	P1: You might like to ask whether the child was or will be involved in these discussions P3 and P4: It would be interesting to know if the child was involved P4: Were other children (siblings) involved in the ACP – were their thoughts and wishes considered? P4: Did you have a preference as to who discussed ACP?	Who has been involved in discussions about ACP? Has / will your child be involved?
4. What form did it take?		

5. What helped?	P4: How were you supported to have ACP discussions? P4: Were you given any preparation for the ACP process?	Using the prompt outlined but understanding underpinning issues to extend the conversation
6. What was difficult?	P4: Have you ever had any problems using ACP?	Being able to rephrase the questions so they are meaningful to individual participants
7. How did you feel about discussing ACP for your child?		
8. What did you feel was most important when discussing ACP for your child?	P1: Is this a repeat of Question 8?	Ordering of questions and question 8 removed
9. Were you able to talk about all the things that you felt you needed / wanted to discuss?	P1: Were there other things you wanted to talk about or include in the Advance Care Plan?	Rephrasing of question
10. How many times have you discussed ACP?	P4: Is the ACP reviewed / updated in a timely manner? Who is responsible for ensuring it is up to date?	To be mindful of review / updates and responsibility for ACP during interview
11. Do you have a completed ACP?	P4: Has the ACP been followed?	Further prompt associated with using the ACP

12. Would you be happy to share it as part of the research?		
13. Have you had further thoughts/reflections since completing the ACP?		
14. Do you have any other thoughts you would like to share		
Other comments.	P3: Will parents answer all the questions? P4: How is the ACP shared between professionals and organisations – is it sent to everyone you would wish? P4: Is the ACP used by professionals in an appropriate manner – and is it accessible at all times? P4: Will all settings respond appropriately to an ACP P4: Have you considered issues such as the stigma of an ACP, negative comments.	Parents will answer the first question and the others will be used as prompts A number of process questions that will hopefully be revealed during the interviews

Appendix I Ethical approval

I.1 ERGO Study approval

The Research Governance Office, University of Southampton

Submission / Reference Number 12608:

Submission Title Advance care planning in the context of children's palliative care:

The Research Governance Office has reviewed and approved your submission

Date 29th Jan 2015

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external ethics review (e.g. NRES).The following comments have been made:

I am writing to confirm that the University of Southampton is prepared to act as Research Sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005). We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/Researchgovernance/DH_4002112

If your study has been designated a Clinical Trial of an Investigational Medicinal Product, I would like to take this opportunity to remind you of your responsibilities under Medicines for Human Use Act regulations (2004/2006), The Human Medicines Regulations (2012) and EU Directive 2010/84/EU regarding pharmacovigilence If your study has been designated a 'Clinical Investigation of a Medical Device' you also need to be aware of the regulations regarding conduct of this work.

Further guidance can be found:http://www.mhra.gov.uk/

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

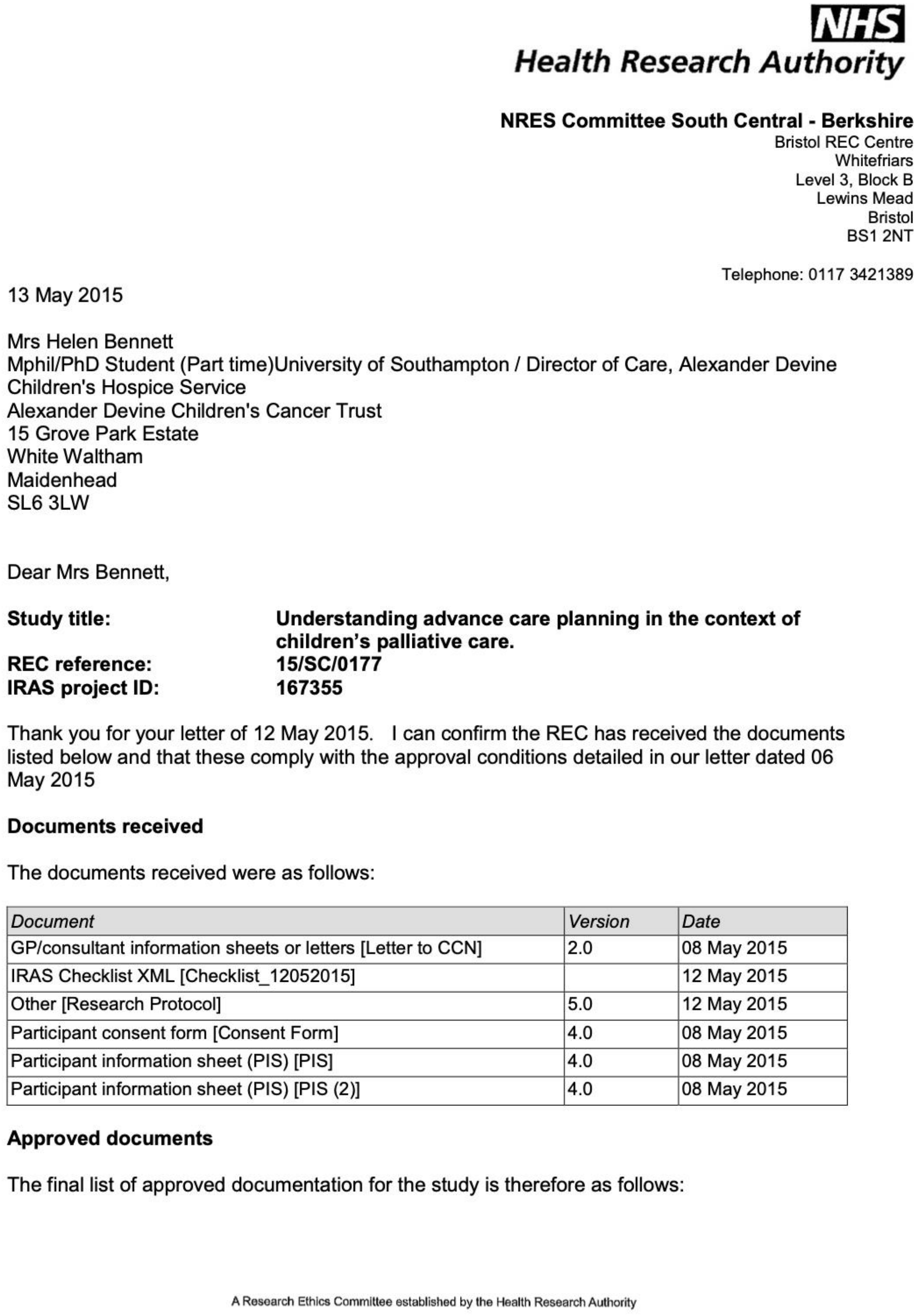
Please also familiarise yourself with the Terms and Conditions of Sponsorship on our website, including reporting requirements of any Adverse Events to the Research Governance Office and the hosting organisation.

If your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available. Please also be reminded that you may need a Research Passport to apply for an honorary research contract of employment from the hosting NHS Trust. Both our Terms and Conditions of Sponsorship and information about the Research Passport can be found on our website:http://www.soton.ac.uk/corporateservices/rgo

Failure to comply with our Terms may invalidate your ethics approval and therefore the insurance agreement, affect funding and/or Sponsorship of your study; your study may need to be suspended and disciplinary proceedings may ensue.

Please do not hesitate to contact this office should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

I.2 NRES Ethical approval Letter



NHS
Health Research Authority

NRES Committee South Central - Berkshire
Bristol REC Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421389

13 May 2015

Mrs Helen Bennett
Mphil/PhD Student (Part time)University of Southampton / Director of Care, Alexander Devine Children's Hospice Service
Alexander Devine Children's Cancer Trust
15 Grove Park Estate
White Waltham
Maidenhead
SL6 3LW

Dear Mrs Bennett,

Study title: **Understanding advance care planning in the context of children's palliative care.**
REC reference: **15/SC/0177**
IRAS project ID: **167355**

Thank you for your letter of 12 May 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 06 May 2015

Documents received

The documents received were as follows:

Document	*Version*	*Date*
GP/consultant information sheets or letters [Letter to CCN]	2.0	08 May 2015
IRAS Checklist XML [Checklist_12052015]		12 May 2015
Other [Research Protocol]	5.0	12 May 2015
Participant consent form [Consent Form]	4.0	08 May 2015
Participant information sheet (PIS) [PIS]	4.0	08 May 2015
Participant information sheet (PIS) [PIS (2)]	4.0	08 May 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter]		21 January 2015
GP/consultant information sheets or letters [Letter to CCN]	2.0	08 May 2015
Interview schedules or topic guides for participants [Outline of Interview Questions]	2.0	02 February 2015
IRAS Checklist XML [Checklist_12052015]		12 May 2015
Letter from sponsor [Sponsor approval]		29 January 2015
Other [Feedback from parents forum]	1.0	02 February 2015
Other [Alison Richardson CV 2nd Supervisor]	1.0	12 March 2015
Other [Research Protocol]	5.0	12 May 2015
Participant consent form [Consent Form]	4.0	08 May 2015
Participant information sheet (PIS) [PIS]	4.0	08 May 2015
Participant information sheet (PIS) [PIS (2)]	4.0	08 May 2015
REC Application Form [REC_Form_18032015]		18 March 2015
Referee's report or other scientific critique report [Peer Review Feedback]	1.0	01 December 2014
Summary CV for Chief Investigator (CI)		15 January 2015
Summary CV for supervisor (student research) [Sue Duke CV Lead Supervisor]	1.0	12 March 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/SC/0177	**Please quote this number on all correspondence**

Yours sincerely,

Rae Granville
REC Manager

E-mail: nrescommittee.southcentral-berkshire@nhs.net

Copy to: *Mrs Diana Gilpin*
Ms S Williams, SOLENT NHS TRUST

Appendix J Initial codes charted in Atlas ti before refining

1. A number of conversations before completing the plan
2. Ability to make decisions when clear about the child’s condition
3. Ability to transfer to palliative care from hospital
4. ACP acknowledges complexity of child’s condition
5. ACP as a guide
6. ACP captures wishes
7. ACP is woolly
8. ACP conversation with DR
9. ACP conversation with nurse
10. ACP gives confidence
11. ACP gives validity
12. ACP has enabled conversations that may not otherwise happen
13. ACP helpful in leading to DNR decision
14. ACP is a good framework
15. ACP is interwoven with all experience and demands of living with a child with LLC
16. ACP like signing a death certificate
17. ACP makes sense as a process
18. Admissions to ITU as a measure for EOL decisions
19. Agreement between parents
20. Agreement between parents and professionals
21. All experience impacts on ACP
22. All options are important
23. Anticipatory decisions
24. At any cost
25. Be the best you can
26. Being comfortable with the conversation
27. Being kind
28. Best time to have the conversations
29. Better to talk about it
30. Blank document to read first
31. Building confidence
32. Challenges of repeated paperwork
33. Changes to ACP on review
34. Character of the child impacting on decisions
35. Child’s ability to respond to acute deterioration
36. Child’s condition guiding decisions
37. Child’s current condition and clinical history
38. Clear and simple approach
39. Closed to future conversations because of bad experience
40. Communication between professionals could be improved
41. Complexity of ACP
42. Complexity of capturing all aspects of child’s condition
43. Concerns about knowledge of ACP in hospital
44. Confidence of decisions
45. Lack of confidence of decision
46. Confident in place of care
47. Conversation wasn’t scary
48. Daughter mother relationship
49. Decisions about quality of life
50. Decisions in ACP to match current clinical story
51. Decisions in best interest of the child
52. Decisions influenced by hope
53. Delaying/avoiding conversations and decisions
54. Demands of living with a LLC child
55. Depth and importance of decisions
56. Describing acceptance

57. Despite positive conversation still difficult to talk
58. Despite skilled conversation it still hurts
59. Deterioration and intervention
60. Deterioration impacts on decisions
61. Diagnosis as a trigger for ACP conversation
62. Difference between acute and gradual deterioration
63. Different circumstances affecting place of care
64. Different interpretations of children’s condition depending on setting
65. Different choices depending on circumstances
66. Different options
67. Difficult to accept EOL
68. Difficult to talk about
69. Difficult to do ACP when you’ve already been through so much
70. Difficult to start a conversation about ACP
71. Difficult to talk to people who don’t understand
72. Difficult to talk to wider family
73. Disagreement between parents and ACP decisions
74. Distribution of ACP
75. Don’t want child to suffer
76. Don’t think about it every day
77. Dying and illness balanced with living life as much as possible
78. Emergency situation to do your best
79. Emergency situation is different than a normal child
80. Emotional impact for extended family
81. Emotional impact for siblings
82. Emotional impact of ACP conversation
83. Emotional decisions are real
84. Environment important to ACP discussion
85. Every family is different
86. Expectations of condition
87. Experience of history shaping decisions
88. Expressing feelings
89. Family decision making
90. Family knowledge of ACP
91. Fast pace decisions when acutely unwell
92. Fear around ACP
93. Fear of ACP
94. Fed up of how treated by others
95. Feeling listened to
96. Fighting for best care
97. Fighting for survival
98. For full resus
99. For professionals to recognise emotional impact
100. Friends not helpful or supportive
101. Future possibility of life without child
102. Full explanation needed
103. Gathering information
104. Giving voice to the child
105. Giving every chance
106. Gradual deterioration giving time for decisions
107. Having a written document is important
108. Have conversations earlier
109. HCP’s influence decisions
110. HCP’s should not assume they know everything
111. Helpful to have the conversation
112. Helpful to talk at home
113. Helped to put things into perspective
114. Hiding feelings so as not to upset others
115. Hope
116. Hoping not now
117. Hope for survival
118. Hoping the ACP makes decisions at the time less stressful
119. Hospice offers safety

120. Hospital versus hospice or home
121. Hospital not the best place to make decisions
122. How and when to review
123. It hurts
124. Impact of quality of life
125. Impact and meaning of signing
126. Impact of other family losses
127. Importance of being fully informed
128. Importance of building relationships
129. Importance of hospice care at the EOL
130. Importance and impact of DNR decisions
131. Importance of legacy and memories
132. Important to understand reasons for deterioration and all possible outcomes
133. In control / not in control
134. Its individual
135. Information gained from other families with an ACP
136. Introducing the ACP
137. Issues around organ donation
138. It feels different in writing
139. It would be helpful to have an ACP coordinator
140. Its complex and emotive
141. Its not normal to talk about ACP for your child
142. Knowing your child is going to die and needing to make decisions about that
143. Knowing your child is unwell and may die
144. Knowing likely to die but hope
145. Lack of support
146. Length of explanation
147. Living with an ill child
148. Living with difficult decisions
149. Making choices that are reasonable and possible
150. Making decisions in the abstract / uncertainty
151. Making EOL decisions but not wanting to accept it
152. Making memories
153. Meaning of ACP
154. Medical advances impacting on decisions
155. Medical focus to ACP
156. Mindful of other issues
157. Missed opportunity to talk
158. More difficult to talk about death and funerals
159. Mother child relationship
160. Mother sibling relationship
161. Moving from clinical intervention to quality of life
162. Multiple stories
163. Multiple triggers to ACP conversations
164. Multiple choices
165. Multiple contradictions in one sentence
166. Needing time to absorb and understand what it all means
167. Needing time to process information
168. Never getting over the death of your child
169. Not able to plan
170. No previous knowledge of ACP
171. No right or wrong
172. Not believing your child will die
173. Not giving false hope
174. Not knowing how ACP works
175. Not knowing what ACP means
176. Not listened to
177. Not starting conversation when child is ill
178. Not the best decisions in a crisis
179. Not thinking it applies to you
180. Not just about the tool, it’s the way its done
181. Not making decisions when child is unwell
182. Not to rush the conversation

183. Not to be pressured into decisions
184. Not understanding the choices
185. Not wanting the child to suffer
186. Number of professionals involved
187. Opportunity to talk about wishes
188. Opportunity to ask questions
189. Other issues emerge of what’s important
190. Painful to acknowledge your child is going to die
191. Parent child relationship
192. Husband and wife decisions – the we voice
193. Parent professional decisions
194. Parental control
195. Parents influenced by society
196. Parents ask themselves about death and dying
197. Parents delaying the conversation
198. Parents feeling respected with their decisions
199. Parents feeling they are stupid
200. Parents feeling of not being tusted
201. Parents knowing their child best
202. Parents needing to be assertive
203. Parents not being included in conversations
204. Parents supporting siblings
205. Place if care
206. Poor communication skills of professionals
207. Poor information impacts on decisions
208. Previous knowledge of ACP
209. Previous conversation of ACP
210. Priority of care
211. Professional led conversation
212. Professional aware of ACP discussion
213. Professionals avoiding conversations
214. Questions stay with you
215. Raising issues not previously thought of
216. Reassurance in having the plan
217. Reality of the situation
218. Recognise he value of ACP
219. Reluctance to have the conversation
220. Repeatedly nudged
221. Pushed to complete ACP
222. Reactive decisions
223. Resus versus quality of life
224. Review of ACP
225. Risk factors that affect decisions
226. Seen as a mum not individual
227. Simple explanations are helpful
228. Skill in putting conversation in writing
229. Skills of professionals
230. Stamen s trigger to ACP
231. Stepped approach
232. Support for siblings
233. Support for wider family
234. Support from CCN’s
235. Support from family
236. Support from friends
237. Support from hospice
238. Talking about your child dying is hardest thing to do
239. Tension between acute intervention and palliative care
240. Tension between choice and rational decision (head and heart decisions)
241. Tension between normal and unwell
242. Tension of needing to discuss EOL and not wanting to
243. Tension between parents to treat and professionals choosing EOL
244. The child’s presence impacts on decisions (they are still here)
245. The child fighting

246. The child giving direction
247. The complexity behind the right thing
248. The context of LLC
249. The conversation is more important than the document
250. The impact of a child with complex needs
251. The importance of being able to talk about ACP with people who understand
252. The importance of the professional knowing the child
253. The importance for support at EOL
254. The importance of support for ACP decisions
255. The need to identify a key lead
256. The power of information
257. The process is important
258. The purpose of ACP is scary
259. Things can change
260. Things change dependent on child's condition
261. Things that helped
262. Thought ACP was for terminal care
263. Thoughts about the future and what this means
264. Thoughts and feelings change
265. Time to come to terms with decisions
266. Timing of ACP
267. Tired all the time
268. To have a conversation when the child is stable
269. Trigger nurses
270. Trigger hospital
271. Trigger ITU
272. Trigger frequent hospital admissions
273. Trigger increased conversations
274. Trigger statement
275. Trigger prompt to ACP
276. Trigger deterioration
277. Trigger diagnosis
278. Trigger changes to condition
279. Uncertainty of prognosis
280. Understanding ACP
281. Understanding reality of the situation
282. Understanding the wider context
283. Wanting to make right decisions
284. Weight and meaning of decisions
285. What others think of parents decisions

Appendix K The analytic process for the emerging category: Reconciling multiple tensions

The following section provides a worked example of the practical application of methods to support the development of a category.

Initial question

The initial question was developed through observations of practice, previous knowledge and following a systematic scoping review. The identified problem was to investigate parents' experience of advance care planning, specifically, how and when parents wish to engage in a conversation about advance care planning. Following initial purposive sampling, in depth interviews were undertaken with parents and examination of advance care plans. Coding the data and data analysis began after the first interview.

Initial coding

Extract from parents transcript	**Initial codes**	**Process**
So place of care is interesting because at this stage I would want him to die at home, he loves his home……but if its sudden and I'm under the impression there's hope, then intervention is the right thing and home isn't safe. *It would be circumstantial.* If there's *no hope then this would be the best place (home) but not if that prevented interventions that might be possible in hospital…..* *of course if he was struggling and the chances of intubating and resuscitation were hopeful then the last place he would want to be was here (home).* *We don't know what those ends will be.*	• Home as place of care • Choosing hospital and home as place of care • Hospital versus home depending on situation • Deterioration and intervention • Differences between acute and gradual deterioration • Chance of intervention • Different choices and options • All options are important	Initial coding took place immediately after each interview Word by word coding Line by line coding Coding for processes, actions and meaning Continual comparing data with data from subsequent interviews Initial codes loaded to Atlas ti

Appendix K

Concurrent collection and analysis of data supported by memos

Memos were used to actively interpret the data throughout the study. They were written immediately after each interview to capture reflections and ideas. The following memo was written after the third interview. It helped to illuminate the complex choices parents faced. More importantly it began to raise evidence of the tensions that parents experienced and of the opposing choices parents made within advance care planning.

> *I am struck by the number of tensions coming through within parents stories – recognising the need to discuss EOL but not wanting to – wanting acute intervention but not wanting their child to suffer – and preferences for preferred place of care being hospital and hospice depending on the intervention / care required. How do we work with families to reconcile these tensions to enable them to make decisions within an advance care plan?*
>
> *It is not a single decision we are asking them to make but a complex dynamic process of multiple choices that needs to be captured in a document – recognising too that decisions and choices made will change'*

Subsequent memos helped to inform emerging concepts and categories and how they inter-related. The following memo depicts how the tentative category *reconciling tensions* was refined following analysis and later constructed in to two sub-categories.

> *The significance of reconciling multiple tensions is important as part of the process of advance care planning, however it is not just about the decisions parents are making whether they are clinical, spiritual or value based, but also about how they make these choices, what influences their choices and what this means for them and their family.*

Initial codes raised to focused codes

Initial codes (selected example)	**Early focused codes (selected example)**	**Process**
▪ Resus versus quality of life ▪ Admissions to ITU as a measure for EOL decisions ▪ Ability to make decisions when clear about the child's condition ▪ Ability to transfer to palliative care from hospital ▪ Hospital versus hospice or home ▪ HCP's influence intervention ▪ Impact of quality of life ▪ Intervention until clearer clinical picture ▪ Giving every chance	Acute intervention versus palliative care	Synthesis of initial codes Identifying significant and frequent initial codes Refining of initial codes Data with data codes with data Determining adequacy and strength of initial codes
▪ Child's ability to respond to acute deterioration ▪ Deterioration and intervention ▪ Difference between acute and gradual deterioration ▪ Deterioration impacts on decisions	Deterioration versus intervention	
▪ Confident in knowing place of care ▪ Home as place of care ▪ Hospital then hospice as place of care ▪ If there is hope then hospital ▪ Chance of intervention affects place of care ▪ Priority of care affects place of care ▪ Different circumstances affecting place of care ▪ Different interpretations of child's condition depending on setting	Place of care	
286. Multiple contradictions in one sentence • Decisions depend on reason for deterioration and likely outcome • Options change depending on situation • Complexity of capturing all aspects of child's condition • Different options • Different choices depending on circumstances • All options are important	Different symptoms/ different options and choices	

Appendix K

Refining of codes

Focused codes	Refined codes	Process
Acute intervention versus palliative care	Requesting acute intervention and palliative care – renamed as requesting either intervention AND palliative care conceptualised the choice of parents in choosing both, rather than merely a single decision	Codes written on sticky notes Sorted and organised on to A3 paper Data to data / Data to codes Codes reworded to improve their fit with data and participants meaning and actions
Place of care	Balancing preference in place of care and place of death – renamed to capture the tension between parents balancing both place of care and place of death	

Emerging concepts

As the analysis progressed, coding identified actions and processes as well as the meaning experienced by parents within these processes.

Focused codes were grouped and themed and the strength of these codes and analytical process revealed the conceptual theme of *negotiating complex choices.*

Focused codes informing emerging themes

Focused codes (Selected examples)	Emerging theme/concept	Process
• Requesting acute intervention and palliative care • Perceived vulnerability • Keeping all options open • Balancing preference in place of care and place of death	Negotiating complex choices	Analysis of similarities and differences in actions and meaning Comparing codes with codes Integrating memos, field notes Integrating situational maps and diagrams Recognising patterns and relationships

Comparative analysis

Constant comparison was used throughout all stages of the analysis to identify similarities and differences and how these related to the emerging concepts, for example, balancing *preferences about place of care and death* are influenced by decisions parents made about active or palliative care. Collectively the interaction between these choices informed the concept of negotiating complex choice.

Analysis of the concepts and properties associated with the concept *negotiating complex choices* enabled further synthesis that recognised that all parents experienced a number of options and choices but the number of these made choices associated with advance care planning more complicated. In addition, the number of symptoms each child experienced made choices problematic. These interpretations of data informed and refined the analysis and developing category.

As the analysis progressed a wider understanding of the complexity of advance care planning was recognised, for example, decisions were not solely associated with intervention and treatment choices, but how parents felt about the decisions they made and what this meant for themselves, their child and their family. Parents expressed a deep responsibility for the choices they made and questioned whether they were making good and the right decisions.

Subsequent interviews and analysis of the advance care plans revealed further codes that reinforced emerging ideas and concepts and identified other factors that influenced and impacted on choices made within advance care planning.

For example. '*child's ability to respond to acute deterioration', 'wanting to make the right decisions' 'Talking about your child dying is the hardest thing to do' and 'Painful to acknowledge your child is going to die'.*

By analysing these codes and using the constant comparative approach an understanding of the emotional impact and burden of decision-making was revealed. Further sorting and synthesis identified patterns and relationships between the concepts to give strength to the emerging conceptual themes. For example, in order to make the right decisions parents needed to confront the reality of the situation as well as voice the grief and loss experienced in knowing their child was going to die. The burden of responsibility and enduring the heartbreak, as concepts are interwoven and help to explain confronting complexity as the emerging sub category.

Theoretical sampling and theoretical coding was used to further develop and refine properties within the developing category. Thus, the range of interview topics became more focused to gather specific data to develop these lines of inquiry and inform the emerging theory. For example, I began to seek out how parents made and what influenced their decisions, as well as the emotional impact of these choices. This helped to build and strengthen the concepts bearing the burden of responsibility and enduring the heartbreak and how they explained the sub category, confronting complexity.

Refining emerging concepts through theoretical sampling and theoretical coding

Emerging concept	**Example of theoretical sampling**	**Example of theoretical coding and theoretical sensitivity**
Bearing the burden of responsibility	I reshaped the interview questions to focus more specifically on the tensions parents described, to explore what strategies they used to understand or overcome them and to investigate the burden of responsibility in discussing advance care planning Subsequent interviews, further coding and analysis began to explain more fully how parents interpreted the risk associated with advance care decisions and of wanting to make good and right decisions. These understandings informed the emerging concept	Integration of previous knowledge and experience Integration of situational maps Focused search of the literature to inform and shape emerging concept The cumulative knowledge enabled a structured and more accurate explanation of concepts eg. Parents expressed being in and out of control but this was influenced by other factors associated with relationships and the health care system. Insights from the literature identified this as empowerment which had greater resonance to why parents felt in control (or not) of the choices they made, so the concept label was renamed *from feeling out of control* to *(dis)empowerment* providing a better fit with data and the emerging concept.

Category development

By grouping the codes into themes and building on emerging concepts, 4 tentative concepts of *negotiating complex choices, bearing the burden of responsibility, enduring the heartbreak and crossing thresholds of understanding* emerged to explain the sub category *confronting complexity.*

All data and codes were compared to the emerging concepts and the sub category to ensure their fit and explanation of parents' experience.

The constant comparison approach, returning to data, organising and sorting data helped to shape a greater understanding of complex decisions, of meaning and the fit of each concept within the sub category and category. This moved the developing category in a different direction.

As the analysis progressed, I began to identify how parents needed to reconcile these tensions in order to work within the process of advance care planning, but also the importance of associated processes intrinsically involved in the choices they made. An understanding of the deeper psychosocial processes of adjustment and meaning began to emerge from the data. There was a growing sense that advance care planning for parents was not solely about clinical end of life care choices and decisions but encompassed so much more in relation to changing and interpreting their values and beliefs.

The complexity of decisions and reconciling tensions began to stand out as a conceptual idea in relation to constant change, the risks and the emotional impact associated with the choices that parents were making within the process of advance care planning.

The development of the conceptual theme of *reconciling tensions* emerged to describe parents' experience of adjusting to continuous change, the tensions this created and how they coped with this experience.

The development of this category was refined following further interviews and the examination of advance care planning documents and data analysis.

The 4 concepts described the tentative category *reconciling multiple tensions*, however further memoing, diagramming and constant comparison facilitated a greater understanding of the properties of the category. Moreover, the integration of selected literature further situated the emerging theory within current knowledge and helped to strengthen the category.

Thus, the process of analytical thinking recognised that how parents crafted the decisions they made, was as important as understanding the many different choices identified within advance care planning. Two sub-categories were constructed to explain the interaction between the choices facing parents *confronting complexity* and how they crafted their advance care decisions, *crafting the decision*.

Saturation

The process of going back and forth between data, emerging concepts and interweaving literature strengthened the understanding of the emerging category. This process helped to determine saturation.

In addition to ensure saturation, I mapped all the focused codes from the category with the transcripts to ensure their fit with data and that parents' experience fully explained the identified concepts. This helped to demonstrate that each concept and the category was adequately sufficient.

Emerging core category

The systematic process of analysis as described above revealed the categories, *realisation, reconciling multiple tensions* and *building confidence and asserting control*.

Further refinement of the categories led to the emergence of a core category evidenced by the continual writing of memos.

Thus, the systematic application of the grounded theory methods and the process detailed, facilitated the emergence of a core category and substantive grounded theory, whereby the core category *re-constructing meaning* explained the major process at work for parents as they engaged in the process of advance care planning.

The interwoven processes of *realisation, reconciling multiple tensions* and *building confidence and asserting control* accounted for the actions and meaning for parents when engaging in advance care planning and provided a cyclical and interconnected understanding that determined the level of re-constructions of meaning for each parent.

The level of re-constructing meaning varied depending on each parents experience of their child's changing condition and of their differing values and beliefs. These constructed interpretations of re-constructing meaning had significant impact within the process of advance care planning.

Thus, the value of understanding re-constructing meaning in advance care planning is important for health care professional's in how they engage in advance care planning with parents.