



Shaping confidence to advocate for my child:

The meaning of how 'significant others' can
support parents to make decisions when their
child has cancer

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DEDICATION

This thesis is dedicated to
Arthur William Frederick Jestico

8th October 2018

My star sailor

Abstract

Being told that a child has cancer is devastating for the whole family. As parents process this life-changing diagnosis they enter a world where they are faced with making many complex decisions including treatment and social decisions (such as school attendance and shielding). Whilst previous research has focused on how health care professionals may support parental decision-making, attention has not been given to how parents may turn to their social support networks for help.

This hermeneutic phenomenological study therefore explores what it means for parents to be supported by their 'significant others' with decision-making, and how this enhances our understanding of parents' experiences at an incredibly difficult time. During interviews, parents of children with cancer co-created ecomaps of their social support network and identified decisions that they had made. This prompted in-depth conversations about their experiences of being supported in decision-making by this network.

The findings of this study illuminate a loss of confidence that parents may experience when their child is diagnosed with cancer, and the critical role that 'significant others' may play in shaping parents' confidence. Looking at parents' stories through a philosophical lens promotes understanding that parents may need support to maintain and renew their identity as decision-makers, assert and release control of decision-making, and trust and challenge themselves and others in decision-making. Rather than depending on others to take over and make decisions on their behalf, parents feel supported when others offer 'solicitude' by empowering them to confidently advocate and make decisions for their own child.

Having a greater understanding of this is of critical importance, both for health care professionals who can help parents navigate social support, and for the general public who can learn to become attuned to the support needs of parents as they confront challenging decision-making.

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Overture

*Into the woods,
And who can tell
What's waiting on the journey?*

(Sondheim and Lapine, 1987:10)



Overture

This thesis tells the story of six parents of children with cancer and what it has meant for them to be supported by their 'significant others' with making decisions during an extremely difficult time. It tells the story of how, by engaging with the philosophy and methodology of hermeneutic phenomenology, I have come to understand these parents' stories through my own life context and how the philosophical ideas of Heidegger and Ricoeur have helped me to illuminate the meaning of their experiences. It is my hope that by sharing this journey of understanding, those who read or hear this work will form their own understanding and that this will inform their interactions with others who are living through similar stories. This thesis presents my interpretation of how 'significant others' can shape parents' confidence to make decisions when their child has cancer, and offer support by empowering parents to confidently advocate and make the decisions that they believe are best for their child.

Soundtrack: Blackbird, The Beatles (Lennon-McCartney), 1968

Blackbird singing in the dead of night
Take these broken wings and learn to fly
All your life

You were only waiting for this moment to arise...

This is a well-known song by the Beatles, a song that I have heard many times in my life, yet only recently have I learnt to really listen to the words. These resonate deeply with my journey through this research as I have had to learn to fly, and to see, in order to move from the dead of night towards the light of new understanding. More than this though, the lyrics resonate with the experiences of the parents who took part in this study. Like the blackbird's wings, their confidence in making decisions was shaken when their child was diagnosed with cancer. They needed to learn to fly again, and this thesis shows how the parents' social networks were able to support them to do this and fly from the dead of night to the light of day.

Scenery: Blackbird, Stephen Hill, 2023 (painting included with the permission of the artist, see [Appendix 1](#))

Stephen Hill's painting of the Blackbird is inspired by the Beatles' song. The monochromatic portrayal of the bird and the background, resonate with the darkness that the blackbird inhabits. The blackbird is turned away from the light of the moon and instead looks into the darkness of the night. Perched on a tree branch, the blackbird does not yet fly. I see an urgency created by the brush strokes of the sky, suggesting that something is unsettled. There is a story that needs to be understood.

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The Presentation of this thesis

The way that this thesis is structured is unusual and so warrants explanation before proceeding further. The usual scientific structure of Introduction, Literature Review, Methodology, Findings, Discussion and Conclusion just did not seem 'right' for this study, although the content that would be expected in this standard structure is still present. Hermeneutic phenomenology allows for creative approaches to presenting research (Crowther et al., 2017) and I felt I needed to find my own voice and way of presenting this study. As I pondered this, I realised that the whole of my research journey has been extremely iterative. My thinking throughout the study has moved backwards, forwards, and often around in circles as I have considered other narratives, conversations that I have had, and my engagement with philosophy. Similarly, the conversations that I had with the parents moved backwards and forwards between aspects of their stories, and even the writing of the thesis did not happen from start to finish but began in the middle and moved outwards. My reaction against the usual scientific structure was that I felt that this would present my work in a linear way and would not represent the iterative nature of the study. I had an idea to present my thesis as a film where the different strands of stories could come and go from the screen, but I recognised that neither did I have the skills to produce this, nor would this meet the required academic conventions. So, it struck me that instead, I could present the thesis as a play. The thesis is therefore structured in four acts, each consisting of a number of scenes. Whilst each scene has a particular focus that is played out on the stage, everything else continues in the wings. For example, Act 1 Scene 1 focuses on my own story – my pre-understandings. In subsequent scenes, my story is ongoing and always plays a role in other aspects. Then in Act 1 Scene 4, the spotlights shine on other relevant narratives and literature, but throughout Acts 2, 3 and 4, these move back to the edge of the stage to support what is happening centre-stage. Nothing in this research journey has happened in isolation and it is hoped that by presenting the thesis in this way, it will be possible to see how different aspects of the journey have been woven together to advance understanding about this topic.

As a research methodology, hermeneutic phenomenology is grounded in philosophy and this study draws particularly on the philosophical ideas of Martin Heidegger and Paul Ricoeur. Heidegger (1972) used the metaphor of our understanding following pathways through a forest where we are always searching for a clearing. Questions, Heidegger proposed, set us along pathways where we seek enlightenment. These pathways may take us through the dense forest, but in the clearing, there is a space that is free of trees and light can stream in. It is in this space where our understanding is illuminated, and we can see a phenomenon in a new way. Reflecting on this metaphor led me to consider Stephen Sondheim and James Lapine's

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musical “Into the Woods” (1987). This presents characters from a number of well-known fairy-tales (including Cinderella, Little Red Riding Hood, and Jack and the Beanstalk) who are each discontented with their everyday life and story. Independently they are called to make a journey ‘into the woods’. In the darkness of the woods, their stories collide with one another, and we learn to see each character in a new way. Ultimately, they each find their own clearing and leave the woods, quite transformed. This resonated for me with the transformation of understanding that I experienced during this research journey. The thesis is therefore loosely guided by Sondheim’s narrative. The journey starts in the everydayness of life at home, and then moves towards and into the woods to find a pathway towards the clearing. Finally, the journey moves out of the woods and back out into the everyday world but with a transformed understanding and motivation to enhance parents’ experiences of decision-making.

Every scene of this thesis starts with ‘stage directions’ consisting of the scenery and soundtrack. Paintings and music provide a series of metaphors to illuminate and evoke the prevailing stories of the thesis. The paintings are presented at the start of each scene, and then a short explanation is provided about the resonance that I felt between the painting, the selected piece of music, and the overarching narrative of the scene. Both Heidegger and Ricoeur believed that the arts could play a valuable role in helping us to reach new understanding. Heidegger felt that truth was fundamentally situated in the arts (particularly poetry and music) and that the arts could help to unfold truth that usually remains hidden (Dahlstrom, 2013); he believed that the arts could transport truth into the light of the clearing (Morrison, 2003). van Manen (2014) discussed Ricoeur’s proposition that whilst much of our understanding may come from written or verbal language, we should not consider this the only way to communicate, and that much understanding begins with our experience of art. The use of the arts in hermeneutic phenomenology has been advocated by others (Polkinghorne, 1983). Darbyshire and Oerther, for example, used poetry to explore the meaning of parenting, and they argued that the arts can shape our thinking in a different way from standard academic prose and help us to access a “meditative way of thinking” (2020:2). This allows us to engage with a phenomenon, or person’s experience, at a different level and therefore become more attuned to people’s unique stories and support needs.

The resonance of the arts is, of course, a unique and subjective experience. I discussed many of these paintings and musical works with others as I was writing the thesis, and these perspectives were enormously helpful. However, the final selection is mine and reflects a connection that I feel between the painting, music, and the emotions and message that I try to convey through words in each scene. As others read this work, they may not feel the same connection and may therefore choose to ignore the paintings and not listen to the music. The

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presentation of the arts is simply an invitation to my world and my personal journey through understanding. For me, the arts enhance this understanding and reflect that this is a thesis that is fundamentally about life as it is lived, about being a parent and the relationships between people.

It is worth briefly discussing the narrative language of this thesis. The thesis is written in the first person as is common in hermeneutic phenomenological studies (van Manen, 2014). Whilst the main characters in this study are the six parents, my role as narrator is not as an objective bystander, but as another player on the stage whose own story influences the pathway that the study takes. Writing in the first person reflects this role. Similarly the pronouns 'our' and 'we' are used at times during this thesis, with two intentions. In some places, this is to represent the shared journey through the narrative and understanding of the thesis, but in others this plural personal pronoun reflects the philosophical positions of Heidegger and Ricoeur, that the essence of our being is situated in a shared, social world – *our* world. The tense moves between the past and present tense (and at times the future tense). Act 1 focuses on the research journey and explains how and why the study was undertaken as it was, and also explores other narratives. It felt appropriate that most of this should be written in the past tense. However, Acts 2 and 3 focus on the parents' stories and my evolving understanding of these. I felt that these should be written in the present tense to indicate that the parents' stories are all ongoing and not something that has happened in the past. It also conveys that my own understanding is still evolving and I cannot say that this is something that is completed – my understanding is always happening, rather than having happened. Act 4 moves between the past tense, as I reflect on the study, the present tense, as I situate the findings within the sphere of current health care practice and how the findings may inform the general public, and the future tense, as I consider the implications of this study.

[An invitation into the hermeneutic circle](#)

Heidegger, Ricoeur and other philosophers in the field of hermeneutics and hermeneutic phenomenology (such as Gadamer) have conceptualised understanding as a hermeneutic *circle*. Our understanding moves around cyclically, always interpreting and re-interpreting, and linking parts of the picture to the whole picture as our understanding evolves (Chesterton and Jack, 2021).

This thesis presents a hermeneutic circle around the topic of what it means for parents to be supported by their 'significant others' with decision-making when their child has cancer. In fact, the thesis progresses along a journey of multiple circles within the overall circle – I entered a hermeneutic circle as I learnt about the principles of hermeneutic phenomenology; I entered

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another circle as I engaged with other narratives related to the topic, and finally, I entered a third circle as I grappled with the philosophies of Heidegger and Ricoeur. All of these became parts of the whole circle, and then together with the parents' stories, I was able to interpret the narratives, drawing these together with my reflections from my work as a children's cancer nurse and my personal life experiences. This allowed me to build the picture of understanding that is presented in this thesis.

As this Overture starts to build a picture of the thesis, some context should be given around what it is like to be a parent of a child with cancer in the United Kingdom (UK) and the first steps into the hermeneutic circle can be taken. In the UK, approximately 3,755 children and young people are diagnosed with cancer each year, including haematological malignancies and solid tumours (Public Health England, 2021). Whilst childhood cancer is rare, and survival rates have dramatically improved over the past 50 years, it remains the leading cause of death from illness in children aged 1 – 15 years (Cancer Research UK, 2021). Understandably then, a cancer diagnosis is life-changing for a family.

The diagnosis period can be lengthy, and some families experience repeated appointments with their General Practitioners (GPs) before tests suggest a potential cancer diagnosis. Other parents may take their child to a hospital's Accident and Emergency department if their child has become acutely unwell. Once a cancer diagnosis is suspected, the child will be referred to one of 21 Principal Treatment Centres for children's cancer in the UK. Here further diagnostic tests will be undertaken, and treatment initiated. Treatment varies greatly according to the type and stage of cancer and may include chemotherapy, radiotherapy, proton beam therapy, surgery, immunotherapy, and for some children a stem cell or bone marrow transplant. Much of this treatment will be delivered at the Principal Treatment Centre; some of the less intense treatment may be delivered at a hospital closer to the family's home (Paediatric Oncology Shared Care Units), and some treatment may be given in the child's home (such as oral chemotherapy, which the parents may administer themselves, or a low-dose intravenous bolus of chemotherapy, which would be administered by a specialist community nurse). In some cases, families may have to move to a more specialist centre even further from their home for the child's treatment (for example if their child requires a bone marrow transplant or proton beam therapy). With care being delivered across multiple hospitals, and in the home, parents may feel that they need to liaise between services and learn particular nursing skills such as changing central venous catheter dressings, administering medicines, and managing nasogastric tube feeds (Children's Cancer and Leukaemia Group (CCLG), 2023).

Within the context of this highly emotionally charged time, and the pressure to get to grips with this new way of life, parents are then faced with many complex decisions (Coyne et al.,

2014). These decisions may initially include treatment options, central venous catheter insertion, and fertility preservation, and as time goes on may include nutrition support, location of care, and symptom support. Parents have described this decision-making as feeling like a burden and generating stress, doubts, and uncertainties (Bandinelli and Goldim, 2017); some parents have suggested that it is more stressful to make decisions about their child's care than to make decisions about themselves (Gagnon and Recklitis, 2003). The prevailing model of care that guides children's nurses in the UK is 'family-centred care' (Boden, 2023). This proposes that the child is best cared for if support is given to the whole family rather than attention just being given to the ill child (Shields, 2015). It is therefore vital that children's nurses and other health care professionals have a good understanding of the support mechanisms that may help or hinder families when they are faced with making such challenging decisions.

Existing research has comprehensively explored the role of health care professionals supporting parental decision-making in the context of children's cancer care – this includes nurses' and allied health care professionals' roles, but predominantly focuses on doctors' roles (Pyke-Grimm et al., 2006; Coyne et al., 2014). However, I observed from my own clinical practice that parents may also turn to other people, outside of the hospital environment, to discuss decisions. I felt it was important to explore this further, in order to have a better understanding of parents' experiences of being supported through the stress of decision-making at such a challenging time and thus become more attuned to their support needs. I therefore constructed the following research question:

What does it mean for parents to be supported by their 'significant others' with making decisions when their child has cancer?

It is worth clarifying the meaning of 'significant others', as terms and concepts in the literature vary. Thoits (2011) defined 'significant others' as relationships within a 'primary group' consisting of people such as family members and close friends, as distinct from a 'secondary group' which is larger and may include work colleagues, neighbours and members of social organisations. This combination of primary and secondary groups could be conceptualised as a broader social network consisting of an inner circle of 'significant others' and an outer circle of looser relationships. However, it is important to acknowledge that these relationships are characterised by their fluidity and people may move between the inner and outer circles. I also recognise that individual perspectives and definitions of the meaning of 'significant others' will vary and allowing people to self-define these relationships is important.

Aims and Objectives

All research projects are done for a reason and purpose. As I set out on this journey my aims and objectives were as follows:

Aim:

To gain understanding of what it means for parents to be supported by 'significant others' when they are faced with making decisions about their child's cancer care; to promote conversations with health care professionals, and with the general public, regarding how parents' experiences of decision-making may be enhanced.

Objectives:

1. To undertake a systematic literature review in order to explore the current understanding of how parents are supported by 'significant others' when they make decisions about their child's cancer care.
2. To develop understanding of the decisions that parents face during their child's cancer journey and gain insight into their decision-making processes.
3. To explore who parents believe to be 'significant others' and whether these people change or evolve in their 'significance' during the child's cancer journey.
4. To use a hermeneutic phenomenological approach to interpret and develop new understanding about how 'significant others' may support parents when they are faced with making decisions.
5. To consider whether there may be changes to practice and culture that could be considered by health care professionals and the general public, in order to enhance the support from 'significant others', and thus improve parents' experiences of decision-making.

As I have travelled through my understanding of both the topic and the philosophical underpinnings of hermeneutic phenomenology, I have often questioned these aims and objectives. I have questioned my purpose in asking my research question and exploring this research topic, and wondered if new understanding will lead to changes in practice and help parents of children with cancer in the future. I hope that it will. Yet I acknowledge that these changes, and their impact, may be difficult to measure. Important as it is to be clear about the purpose of a study, it is also important to be clear about what is not the purpose. This study does not aim to, and will not, provide generalisable 'answers' to the question. It will present my interpretations of what it means, for the six parents in this study, to be supported by their

Overture

‘significant others’ with decision-making when their child has cancer. My hope is that this will enhance understanding of what parents may experience, and provoke conversations with both health care professionals and the general public so that they may become better attuned to parents’ support needs. One of the aims of hermeneutic phenomenological research studies is to evoke the ‘phenomenological nod’. These are the ‘aha’ moments when the reader or listener feels a resonance between what they are seeing or hearing, and their own experiences. These are moments when the reader or listener can see what they perhaps already knew but had not had the space to think about in this way, moments when they see that what is being said makes meaningful sense (van Manen, 1990; Dibley et al., 2020). Heidegger (1972) proposed that by moving to the clearing, not only does light stream in so that we can see more clearly, but also that an audible space for echo is opened, so that we can hear more clearly and feel this sense of resonance and understanding. My hope is that through art, music and the words of this thesis, this phenomenological nod will be achieved, and a place reached whereby understanding is enhanced, and through this, greater empathy and support may be offered to parents of children with cancer.

The structure of this thesis

This Overture has set the stage for the thesis. It has outlined why the thesis is presented as it is, and offered an invitation into the hermeneutic circle for the study by providing some context for the topic. This prompted the research question, aims and objectives of the study to be set out. With the purpose of the thesis established, the route of this thesis’ journey through the woods of understanding will be set out so that the journey can be started. As explained above, the main body of the thesis will be structured in four acts.

Act 1 describes the call to travel away from the everydayness of life and go “**into the woods**”. It starts by becoming immersed in the hermeneutic circle by laying out my pre-understandings as I “look into the mirror” in Scene 1. This allows me to address what led me to ask this research question and how my own experiences shape my interpretations throughout this study. Scene 2 provides the context of the philosophers whose work underpins this study – Martin Heidegger and Paul Ricoeur. “Navigating the research journey” is the focus of Scene 3 whereby the methodology and study’s methods will be described and justified. The final scene of this first act explores other narratives (which includes the formal literature review and looks beyond this to other sources of narrative). Each scene opens a window or doorway, where the woods can be seen ahead. By the end of this act, the first steps outside of the everyday home will have been taken, and the journey into the woods commenced.

Overture

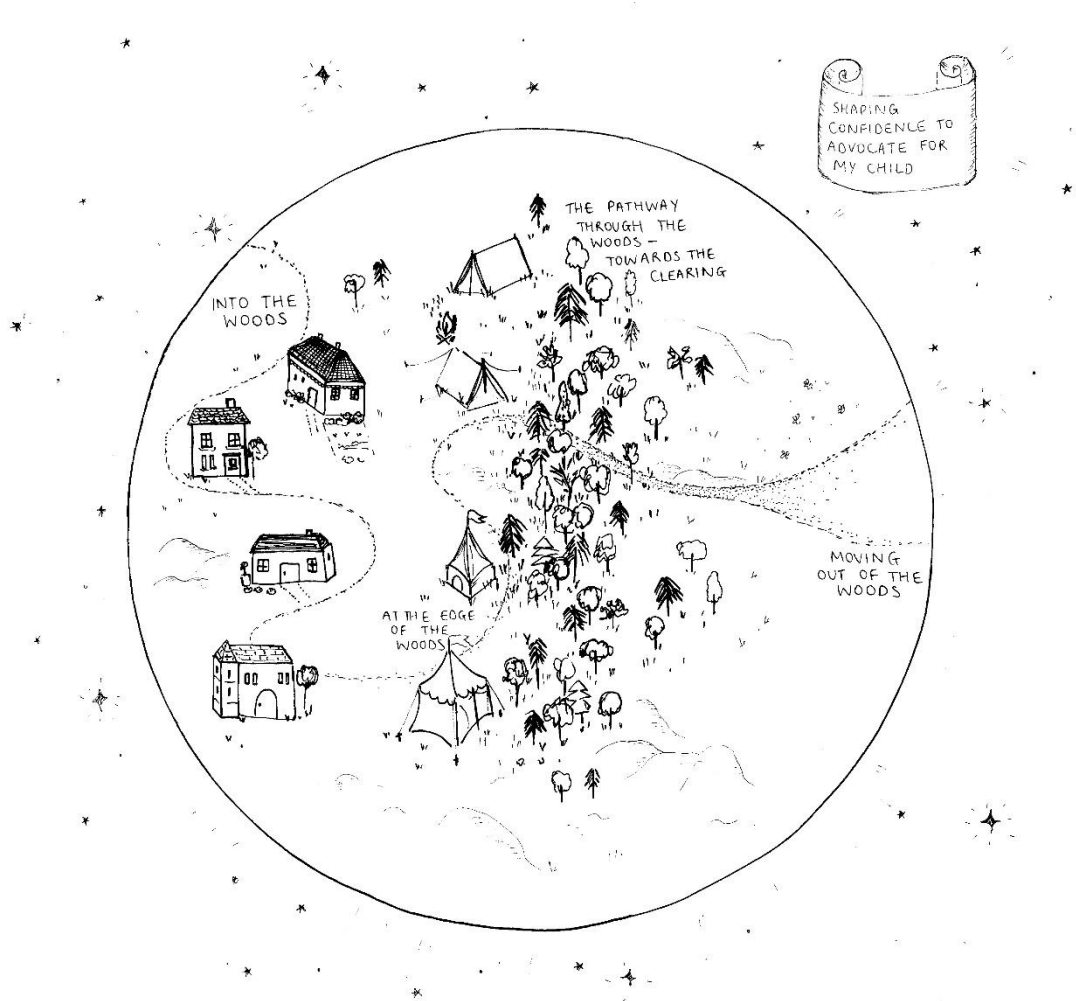
Act 2 is set “**at the edge of the woods**”. Here understanding is developed around the context of the parents who participated in the in-depth interviews with me; interwoven throughout these scenes is an exploration of some key Heideggerian notions. Scene 1 introduces these main characters and sets out their stories about their child being diagnosed with cancer. In Scene 2, the off-stage characters are discussed – the people that parents identified as ‘significant’ on the ecomaps that we created during the interviews. Finally, Scene 3 explores the decisions that parents described making whilst their child had cancer.

Having set the context of the parents, their ‘significant others’ and the decisions that parents have faced, the journey moves deep into the woods. **Act 3** travels along “**a pathway through the woods: towards the clearing**”. The first scene is set in the middle of a dark thicket and tells the story of how the parents felt a sense of losing confidence in themselves as parents when their child was diagnosed with cancer. Scenes 2, 3 and 4 then forge a pathway from the thicket to the clearing with an exploration of how ‘significant others’ may shape the parents’ confidence to make decisions and advocate for their child. Each scene focuses on a different aspect of this. Scene 2 considers how ‘significant others’ may shape a parent’s confidence to maintain and renew their identity as a parent, and their role as decision-maker; Scene 3 explores how ‘significant others’ may shape a parent’s confidence to assert and to release control of decision-making; Scene 4 finally discusses how ‘significant others’ may shape a parent’s confidence to trust and to challenge themselves and others in decision-making. As in Act 2, all of these scenes are explored with reference to Heideggerian philosophy, but in Act 3, the philosophy of Ricoeur is also discussed which develops and offers an alternative perspective to Heidegger’s philosophy. This exploration of philosophical ideas supports the journey to the clearing, where light shines on the phenomenon of confidence, and proposes that ‘significant others’ can shape confidence through offering ‘solicitude’.

Having reached the clearing, the focus of **Act 4** is on “**moving out of the woods**”. This looks back to the woods and draws on discussion from all previous scenes. The single scene in this final act considers how this understanding can help to travel onwards and shape future practice from the perspective of health care professionals, the general public, and me as a researcher, nurse educator and as a ‘significant other’ to people I know. Challenges encountered and lessons learnt from this study will be reflected on, and the transformative nature of hermeneutic phenomenology will be explored. This will lead to the **Finale** where the study will be summarised and concluded.

Overture

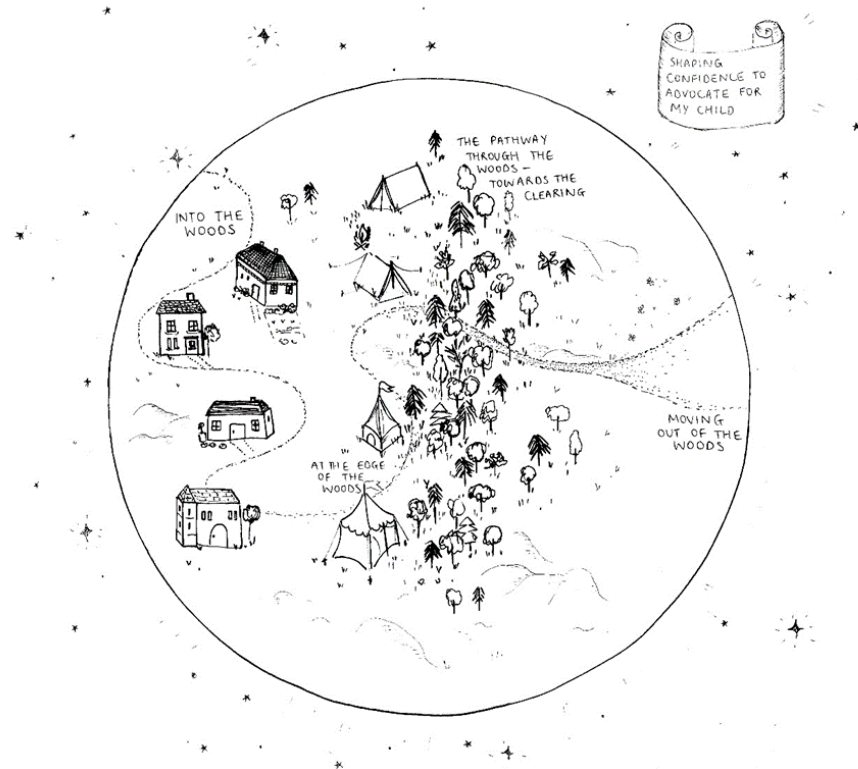
Figure 1: A map of this thesis' journey through the woods



Act One: Into the woods

*Into the woods,
It's time to go,
I hate to leave,
I have to, though.
Into the woods –
It's time, and so
I must begin my journey.*

(Sondheim and Lapine, 1987:9)



Act One: Into the woods

Introduction

The Overture has set the stage. This first act sets out the preparation for the journey into the woods. Scene 1 will open a window of the home to look out to the woods. By looking into the mirror, it will set out my pre-understandings around this study and start the iterative movement around the hermeneutic circle. Scene 2 will open a second window, this time presenting the context of the philosophers whose work guides this research. The journey will then be navigated by presenting the methodological principles that steer the research, with a full account of decisions that were made during the research journey. This will open the door to the woods and allow the first steps outside to be taken. Scene 4 explores these first steps towards the woods by exploring other narratives – both as a formal literature review, and also by engaging with other sources of literature. These scenes will pave the way for the whole study, and whilst the light shines on each of these aspects in each scene of the first act, they will remain to the side of the stage throughout. My pre-understandings, the underpinning philosophies, the methodological principles and other narratives will be integrated during all subsequent scenes. Yet now is the time to give them specific attention, and to demonstrate how they will prepare me to travel into the woods.

Act One: Into the woods

Scene One: Looking into the mirror



Act One: Into the woods

Scene One: Looking into the mirror

Soundtrack: Mother of God, Here I Stand, John Tavener, 2003

This piece of music has always had a huge impact on me. This is for no apparent academic reason, but it has a strong emotional resonance for me and so it seems an appropriate soundtrack for this scene where I lay out the perspectives from my own life that inform this study.

Whenever I hear it, I become utterly immersed in it and I cannot do anything else. Whilst there is always forward motion in this music, there is a sense of stillness and I physically experience this stillness as I listen to it. My body cannot move yet I feel my heartrate increase and tears fall down my face. I feel deeply vulnerable. Perhaps this comes from the title that suggests standing in front of a higher being where every thought and feeling is exposed, and like looking into a mirror, little can remain concealed.

Composed in four voice parts, there are sequences of suspensions between parts, where parts move to a note that clashes with another, and then resolve to a note that harmonises coherently. This tight harmony creates for me a tone that is introspective, full of anguish, yet always with a sense of peace and stillness. The musical directions at the top of the score simply state “Hushed, with infinite tenderness”.

Scenery: Mirror Lake, Franklin Carmichael, 1929

When I think about mirrors, I often think about the beautiful reflections that can be seen in a lake on a peaceful and still day. To me, a mirror lake conjures a balance between the introspective reflection of looking into a mirror, with an outward looking perspective of capturing the beauty of the world around. Carmichael’s reflection captures this balance with the detail of individual trees’ reflections, as well as the grand mountains behind. The beautiful array of colours in this painting, to me, represents how we can explore our own experiences and pre-understandings through different coloured lenses as I will do in this scene. Yet the reflection in this painting is not perfect. The island in the middle of the lake obscures the full reflection of the mountains. This seems to resonate with life – one particular experience may take up more space in the forefront of our reflections, whilst others may be partially concealed behind. And reflections evolve over time. This painting represents one perspective of this lake at a moment in time. It will change as the seasons change and the landscape evolves, just as our reflections on our own lives change over time.

Act One: Into the woods

The Curtain Rises

Every story must have its place to start. The journey of this thesis has been intensely iterative and understanding where and when it started has not been easy. The usual point of departure for a thesis is asking a research question. For me, the story of this thesis started many years before I asked the question. Moments and episodes of my life had planted thoughts in my mind which had largely remained dormant. However, as time went by, these moments of life started to collide with each other, and questions started to formulate. I realised that I wanted to understand more about parents' experiences of being supported with decision-making when their child has cancer, and I found myself focusing on this within the context of social support.

In the world of hermeneutic phenomenology, emphasis is placed on the researcher acknowledging their own position in the topic area (Crowther et al., 2017). Philosophers such as Heidegger and Gadamer suggested that these personal 'pre-understandings' or 'pre-suppositions' launch us into the hermeneutic circle (Crowther and Thomson, 2020). It is these previous experiences and understandings within which life is embedded, that therefore lead us to ask research questions and then form our understanding of the topic throughout the research journey. Heidegger (1927 / 1962:153) proposed that working out our pre-suppositions should be "the first, last and constant task" when attempting to understand an issue, although he acknowledged that we can never make our background completely explicit (Lavery, 2003).

Pre-understanding interviews and maintaining reflective diaries are strategies for engaging with one's pre-understandings that have been recommended by many hermeneutic phenomenologists (for example Crowther and Thomson, 2020, Dibley et al., 2020). Rather than undertake a formal, single pre-understandings interview, I have engaged in a constant process of reflexivity (as recommended by Dibley et al. (2020))¹. From the moment of enrolling on the PhD programme I have maintained a reflective diary, and similarly recorded my thoughts through voice notes whilst out walking (where much of my thinking about this project has happened). As I would be co-creating ecomaps with the participants as part of this study, I also spent time creating my own ecomap in the early stages of the study to understand who I considered significant to me. I then repeated this later on in the study which showed me how dynamic the significance of relationships may be. Finally, through regular meetings with supervisors, peer PhD students, and regular conversations with others interested in

¹ Reflexivity is defined by Sandelowski and Barroso (2002: 216) as the "ability and willingness of researchers to acknowledge and take account of the many ways they themselves influence research findings" and is an important feature of many qualitative research methodologies.

Act One: Into the woods

hermeneutic phenomenology, I have been able to engage in meaningful dialogue about my evolving understandings.

Having acknowledged that pre-understandings are the way into the hermeneutic circle (Crowther and Thomson, 2020; Grondin, 1994), and that reflexive engagement has underpinned this study, it makes sense to start the story of this thesis by looking into my mirror. I acknowledge that different moments and episodes of my life have led to the formulation of this question and have shaped my interpretations throughout. The mirror that I look into is like a kaleidoscope, with different lenses and different colours, each reflecting a different part of my life. And as the light shines through this rich and colourful mirror, the starting point of this interpretive journey is illuminated.

Looking through my lens as a nurse

I have worked as a children's nurse for seventeen years. I came to nursing unexpectedly having done a degree in Music and Education Studies. Soon after I graduated, I heard of the death of a childhood friend. This shocked me into action as I realised that the world is full of suffering, and I wanted to help in some way. For the first half of my career, I worked clinically, primarily caring for children with cancer. This was a role which I felt enormously privileged to hold. I was able to stand with families and metaphorically hold their hands as they lived through their darkest days.

A particular experience stands out to me from my years working as a children's cancer nurse. I was working a night shift, and my colleague was caring for a fifteen-year-old boy. He was due to have his next cycle of chemotherapy administered but as the nurse went to set this up, he ran away from the ward. He could not face any more treatment; he had had enough. I vividly remember the anguish of his Mum that night. This moment led me to start questioning myself about whether I had really appreciated the complexity of decision-making that families and young people were faced with, and how each decision created a ripple effect which could potentially impact on the whole family.

I truly loved the years that I spent working clinically, however I felt that there was more that I could do. I moved to education where I now work as a lecturer in children's nursing. Through this role I have been able to share the stories about things that I witnessed and what I learnt from the children and families, with students – the new generations of nurses. I teach the students about legal and ethical frameworks of children's nursing, which has a natural emphasis on decision-making. Every time I teach these sessions, my interest is further sparked, and more thoughts and questions are generated.

Act One: Into the woods

As I move into the research arena, I acknowledge the importance of helping families to share their stories. Over the course of my professional career, I have met so many families who have suffered so much yet have felt so alone. They have expressed difficulties in being able to articulate their experiences or finding a platform to share these stories. The same motivation that drove me initially to become a nurse, and to work as a nurse educator, drives me now. As a nurse researcher I can help families by shining a light on their stories and develop understanding about their experiences, thus promoting positive change to practice and culture, and enhancing future families' experiences.

Looking through my lens as a 'Significant Other'

Of course, life exists outside of the professional sphere, and this also impacts on our interpretive worlds. Each of us in the world is surrounded by other people, some of whom will be significant to us. Yet we also take on the role of 'significant other' to those around us. It is not uncommon to have conversations with those within our networks about decisions that somebody is facing. For me, there have been two particular instances where I have been a 'significant other' to friends, and this – without a doubt – has influenced the journey that led to me asking this research question.

Several years ago, whilst I was working part-time clinically, and part-time within my education role, I had a message from an old university friend. Her daughter had just been diagnosed with a brain tumour and was currently undergoing major surgery. The next day, desperate to help in some way, I went to visit them. Aside from offering emotional support and practical help, I became aware that my friend was overwhelmed in the new medicalised world that they had found themselves in, and I realised that I could help her by trying to explain all of this to her in a more accessible way. I saw how her wider family and other friends surrounded my friend and her daughter with so much love and support, and whilst at that time she never asked for support with making decisions, I realised how important social network support was for families going through experiences like this.

More recently, about two years before I started this project, another very close friend contacted me. This was not a situation related to childhood cancer, but she was faced with making a decision about whether her little boy should have a hernia repair or not. She asked me what I thought she should do. I felt an enormous responsibility at this moment, and this led me to reflect on decision-making further. Whilst I felt honoured that she had asked my advice, I also felt paralysed by not wanting to give bad advice. Again, the complexity of decision-making was apparent, and I reflected on how personal this process is – what might be right for me, might not be right for her. I responded to this situation by asking her questions to help her

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make a decision, rather than saying what I might do or giving advice. To this day, I do not know if this was helpful to her, and this uncertainty directly influenced my interest in the concept of 'significant others' supporting parental decision-making.

Looking through my lens as a decision-maker

There is a final lens through which I view this world, and that is as a person who has needed support with decision-making. In 2018 our son, Arthur, died. He was stillborn late in pregnancy. This was, and is, deeply traumatic and painful. Arthur's death was very sudden, there was no indication of any problems in the pregnancy, and as such we were not faced with any of the agonising decisions that other families may be faced with. However, in the days and weeks after his death, I found myself unable to make any decisions at all. A 'simple' decision like what flowers to have on Arthur's coffin felt impossible, and I started to lean on my family and friends for their advice with things like this.

So, whilst I have never experienced having a child with cancer, I have experienced the turmoil of being abruptly thrown into a world not of my choosing, and the devastation of losing a child. Arthur's life and death have had a profound impact on my life, and this influences all of my thoughts. It would be impossible to block this influence, but it is important to acknowledge the role that it plays and take care for this not to overshadow the stories that parents share with me about their experiences.

Looking through an evolving lens

Heidegger explained that acknowledging our pre-understandings enables us to enter the hermeneutic circle of understanding (Crowther and Thomson, 2020). However, life does not stop on entering the circle and the way that we see the world changes – perhaps partly due to developing understanding of the phenomenon of interest, but also because life continues to evolve. For me, this was never more evident than in the third year of this project, when my Mum died very unexpectedly. This changed my whole perspective of life and is really important to acknowledge here. My Mum had always been a huge support to me through all my life, particularly when Arthur died. However, I had also been a support to her during many challenges of her life. Therefore, I not only lost a major artery of support in my own life, but I lost being a support to her. As with Arthur, Mum's death was sudden and unexpected, and so there were no medical decisions to be made. From that perspective, in both cases, I had no control over the outcome. However, following the death of my Mum, I was faced with significant and complex decisions, initially about funeral arrangements, but later on about her financial affairs. The decisions that I was faced with would have far-reaching consequences, not just for me, but for other members of my family.

Act One: Into the woods

When Mum died, I was in the period of undertaking interviews for this study. I had completed the first two interviews, and then I completed the remaining interviews during the period that I was faced with making some of these significant decisions. I acknowledged that this experience would likely impact on the way that I interpreted the interviews but I was less prepared for it to happen in the opposite direction. As I processed the stress and grief of losing Mum, and making decisions in the aftermath, I noticed that the way I managed the situation was influenced by the interviews that I had done. Comments made by the participants about their approaches to decision-making were staying with me and this changed the way that I was approaching my own circumstances. This really brought alive the hermeneutic circle. My pre-understandings had certainly brought me into the circle and to my research question. However, as my understanding of the topic was deepening (through engaging with the literature and undertaking interviews with parents) my own approach to managing life in the present moment was evolving.

The Curtain Falls

Looking into this mirror has opened a window, a window where the woods lie ahead and the need to journey there and leave the world of everydayness is clear. Looking into this mirror has shown me that the events of my life, my relationships with others, and my professional and personal context, have shaped the way that I see the world around me. Shining a light on this as I enter the hermeneutic circle has allowed me to explore what led me to ask the question and into the topic of parents being supported by 'significant others' when faced with decision-making when their child has cancer. The next scene will open another window and provide context for the philosophers whose work underpins this thesis.

Act One: Into the woods

Scene Two: Understanding the philosophers



Act One: Into the woods

Scene Two: Understanding the philosophers

Soundtrack: So What, Miles Davis, 1959

Miles Davis was born in 1926, a year before the publication of Heidegger's *Being and Time* and died in 1991, the year after Ricoeur's publication of *Oneself as Another* (the two works that most fundamentally underpin this study). Davis was a jazz trumpeter who, like Heidegger and Ricoeur, was regarded as extremely innovative and influential.

The jazz musical movement grew out of existing musical traditions at the start of the twentieth century, but marked a significant shift in musical style and represented a new freedom and rebellion against tradition. Heidegger's philosophical ideas similarly mark a reaction to previous philosophical thinking and a new way to see the world and our existence.

"So What" showcases virtuosic, improvisatory solos performed by each member of the jazz band, with no sense of the pathway that they will each take, as is similarly felt in the writing of Heidegger. It also features the famous two "So What" chords that are heard throughout the eight minutes of music. These chords do seem to be audibly asking the question "So What?" and as they are repeated in different keys, the complexity of the question seems to intensify and the question never feels to be resolved. As will be demonstrated in this scene, Heidegger, in particular, is seen as a philosopher who asked bold questions, which are sometimes simply not possible to answer, with each question instead generating further questions.

Scenery: Portrait of a Philosopher, Lyubov Popova, 1915

As jazz marked a rebellion against traditional musical forms, cubism represented a similar revolution in art. Popova was a Russian artist and a Communist. She painted the Portrait of a Philosopher two years before the Russian revolution and this sense of disorder that was being experienced in Popova's world is seen in this painting. When I first looked at this picture it took me a long time to make sense of it and recognise the picture of the man – I needed time to adjust to this new form of imagery. Still there are aspects of the painting that I do not understand, such as some of the letters and numbers. My experience of reading the philosophies of Heidegger and Ricoeur was similar, it took me a while to adjust to their philosophical language and ideas, yet over time my understanding began to emerge, and I could see this philosophical world with new eyes.

Act One: Into the woods

The Curtain Rises

The last scene set out the context of my own personal and professional life and explored what led me to enter the hermeneutic circle of this topic. As explained in the Overture, this hermeneutic phenomenological study is supported by the work of two philosophers – Martin Heidegger and Paul Ricoeur. Their philosophical ideas not only underpin the methodological approach to the study (which will be discussed in the next scene), but also significantly inform my interpretations of the parents' stories. This scene will therefore provide some context for these philosophers' lives and works.

Dahlstrom (2013:1) cited Heidegger (1924:5) who, when speaking about Aristotle, said: "As for his personality, our only interest is that he was born at a certain time, that he worked, and that he died". I agree with Dahlstrom's (2013) and Davis's (2010) response to this comment, that the separation of the philosophy from the philosopher's life is inappropriate – particularly in the cases of Heidegger and Ricoeur. Davis (2010) questioned whether a philosopher's biography is significant in understanding their philosophy and concluded that, for Heideggerian reasons, this absolutely does warrant our attention. Heidegger's philosophy will be more fully explained further on in this thesis, however at this stage it is important to build on what was explained in the previous scene – that Heidegger proposed that our pre-suppositions should be "the first, last and constant task" when attempting to understand an issue (Heidegger, 1927 / 1962:153). As I have expressed my own pre-suppositions that shape this research, it therefore also seems important that the life contexts of the philosophers who inform this research are also laid out. At the heart of Heidegger's philosophy is the concept that we are who we are because of the world that we exist in (in terms of our historical situatedness, our geographical and cultural situatedness and our social situatedness). Therefore, whilst it is not possible to know who Heidegger and Ricoeur really were as people simply from biographical details (we cannot truly learn about their pre-suppositions), it nevertheless is important to know something about them. This scene will therefore lay out biographical information about Martin Heidegger and Paul Ricoeur and set the context in which they wrote their two works which most fundamentally influence my research: *Being and Time* (Heidegger, 1927) and *Oneself as Another* (Ricoeur, 1990).

Martin Heidegger

Martin Heidegger was born in Germany in 1889 and died in 1976, aged 86 (Blattner, 2006). He was raised in a small conservative town in Germany and initially studied theology with the intention of entering the priesthood (Davis, 2010). He changed direction, left the church, and studied mathematics, physics, and chemistry before finally devoting his studies to philosophy

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(Dahlstrom, 2013). Heidegger was 37 years old when his book *Being and Time* was published in 1927. This work is now considered to be his masterpiece (Dahlstrom, 2013), and even at the time it was recognised as groundbreaking, with reviewers comparing it to a lightning strike (Schmidt, 2010). The publication of *Being and Time* had a transformational impact on his career. He was already known in German academic life as a charismatic lecturer, but this publication led to his appointment to the Chair of Philosophy at Freiburg University (succeeding his teacher Edmund Husserl) and gave him international significance (Mulhall, 2005).

These short biographical details illuminate the context in which Heidegger developed his philosophy. He was German, lived through both the First and Second World Wars, and also experienced life in the aftermath of these wars. He also lived in an age of extensive technological advancement and a rapidly changing world (Davis, 2010). There are two specific areas relating to Heidegger's work and life that require further attention: his philosophical position as one of the twentieth century's most influential philosophers; and his political position as a member of the National Socialist (Nazi) party.

Sheehan (1988:38) claimed that Heidegger's influence as a philosopher is "incontestable". Gadamer, Sartre, Derrida, Ricoeur and many others were deeply influenced by Heidegger's thinking, and his influence has extended far beyond philosophy, with many other fields being shaped by his work: sociology, psychology, education, health care, the arts and humanities. Whilst his work has such wide influence, it has also been referred to as a "source of frustration" as well as fascination (Davis, 2010:1). This source of frustration arises from the complexity of his work both in terms of the concepts that he was exploring, but also in the way that he expressed these concepts. Inwood (1997) proposed that Heidegger did not give philosophical answers to questions posed by other philosophers but instead asked new questions, which he believed to be fundamental to our being and existence but cannot necessarily be answered. In fact, as Inwood (1999) suggested, every complex question that Heidegger asks raises further questions. His thinking and writing seem to be always "on the way" (Inwood, 1999:1) rather than having arrived. As he writes he works through the problems, finding his way as he goes, without planning his philosophical journey in advance. Heidegger's work is also difficult to understand because of the language he uses. He coins new words and phrases but also revives old words in order to express new ideas whilst recapturing earlier understandings of being (Inwood, 1999). He wrote in German, and whilst English translations have been produced, some of the German words that he uses are not easily translatable (such as '*Dasein*', a concept that will be explored later in this thesis). Indeed, different translators have used different

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English words in their translations, which can create further confusion by the different nuances the translated words convey.²

As Heidegger's writing takes itself on a journey, so too has my understanding of his work. My initial reading of *Being and Time* felt like standing in a thick fog – it felt utterly incomprehensible. Reassured by other hermeneutic phenomenologists who expressed similar initial feelings (Smythe and Spence, 2020), I persevered without attempting to understand every word and trust that my own pathway of understanding would unfold. My copies of *Being and Time* still have many question marks pencilled in throughout. As I continued reading, I also looked beyond the text. I talked about his work with others, I would go for long walks whilst listening to podcasts about his work, and I found that as I immersed myself further into this world, understanding was emerging. I found myself articulating thoughts on voice recordings whilst walking, and talking about Heidegger to people who had never heard of him - all of this helped my understanding. Then, as I continued to read Heidegger's texts, I found myself having "aha" moments. These "glimmers of insight" that Smythe and Spence (2020:5) referred to, were helping me understand the stories that parents had shared with me (such as Heidegger's notion of 'solicitude'), but beyond this, I found that they were helping me to understand my life in general. Aware that understanding **all** of Heidegger would not be possible during the span of this project, or likely during my remaining life, I have nevertheless been left with a thirst to understand more, to read and re-read his work, and to engage with philosophy further.

Despite my fascination with Heidegger's work, I do acknowledge and feel uncomfortable about his political associations with the National Socialist party, and it would feel remiss not to explore this. In the same way that Heidegger's influence as a philosopher is regarded to be "incontestable", so is the fact that Heidegger was a Nazi (Sheehan, 1988:38). It is well known that Heidegger was a member of the National Socialist party in the 1930s. Through virtue of this political allegiance, he was elected Rector of the University of Freiburg in 1933, although he soon became disaffected with the party and resigned from this post in 1934 (Dahlstrom, 2013). Commentators of Heidegger cast their attention on two key questions associated with this: firstly, how seriously was Heidegger associated with the political ideals of National Socialism, and secondly did his political position affect his philosophical thinking, and should that impact on how we use his philosophy?

² In this thesis I refer to two different translations: Macquarrie and Robinson (1962) and Stambaugh (2010) as I found my understanding of Heidegger enhanced by an awareness of both versions.

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It is clear that Heidegger's disaffection with the Nazi party happened before the outbreak of the Second World War. Inwood (1997) observed that what we now know about the Nazi party, was in 1933, still in the future. There were certainly strong suggestions of antisemitism but Hitler's plan to exterminate Jews was not known about at this stage. Nazism promised the German people much during a period of suppression following the First World War such as better opportunities for the unemployed and a return to the traditional values that had previously been held in Germany. Inwood (1997:130) therefore claimed that Heidegger saw Nazism "in terms of its possibilities, not its actuality". However, the counter-perspective to this sees Heidegger as a man, who through his role at Freiburg University, enacted strong anti-Semitic policies denying economic aid to any Jewish or Marxist students (Sheehan, 1988). Furthermore, whilst Inwood defended Heidegger for his political associations on the basis that the extremities of Nazi policy were still in the future, others have noted that Heidegger never apologised for his association with the party and remained largely silent about this period of his political life (Babich, 1992; Dahlstrom, 2013). This does feel deeply troubling, and Babich (1992) proposed that this silence about his involvement with the Nazi party is not only a failure to condemn fascism but is also a denial of the reprehensibility of the fascist parties' actions.

There is significant debate about whether Heidegger's philosophy is connected to his political position. Of course, his major work *Being and Time*, was published in 1927, before he formally became associated with the Nazi party. Nevertheless Sheehan (1988) and Blattner (2006) have suggested that there are some connections between his philosophical ideas and Nazism, even in this early work. This has led some researchers to reject the use of Heidegger's philosophy in their work. Randall and Richardson (2021), for example, argued that nurses should not dismiss the political influences within Heidegger's philosophy as they are incompatible with the values of nursing. They have controversially proceeded to suggest that, for this reason, nurse researchers should not use interpretivist phenomenology at all. Whilst Randall and Richardson's paper can be critiqued on the basis of a superficial presentation of Heidegger's philosophy, and a lack of evidence that they have provided for the political influence in this philosophy, the paper nevertheless draws attention to contemporary debate about using Heideggerian philosophy in health care research. Interesting questions are posed by Randall and Richardson (2021:3) such as "can 'bad' people have 'good' ideas; how bad does a person need to be before their ideas are deemed unsuitable for nurses to use; how good do the ideas need to be to make some bad behaviours of the originator acceptable?". I have reflected extensively on this and added my own questions: "can one separate a person from their work; the artist from the painting or the composer from the music?" We know, for example, that Wagner held antisemitic views, yet today people rarely refuse to listen to his music because of

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this. It does seem more complex though to separate the philosopher from their philosophy, which is such a reflection of their own thinking and being.

My thoughts about all of this have led me to a place where I feel strongly that it would be wrong to try to excuse or condone Heidegger's political associations on the basis that he lived in a different time and context from me. My maternal grandparents both lived on the island of Guernsey during the time of the Nazi occupation, and my life growing up there was framed by this, and first-hand stories of these experiences. It feels too easy to accept Heidegger's politics by using the argument of us not understanding or experiencing his historical or social context, when actually this context was lived through in my family's living memory. Yet despite this, I also recognise the vast influence of his philosophical work, that he is considered to be the founder of hermeneutic phenomenology, and that there is something in his work that fascinates me and resonates with the way that I see the world. I do not feel, therefore, that I can simply reject all of his work. My conclusion from these reflections is that Heidegger's philosophy is of value to my research, yet I must keep "a wary eye on his politics" (Blattner, 2006:7). I believe that, although I feel deeply uncomfortable about Heidegger as a person, his philosophy can give me a platform for furthering understanding about an important topic that will bring positive outcomes to families of children with cancer in the future. Despite Heidegger's political position, it is my belief that his philosophy can bring good to the world through research like this.

Paul Ricoeur

Whilst, to an extent, I found a way to reconcile the use of Heidegger's philosophy in my research, I also felt that to base my work exclusively on his ideas may prevent my openness both to the potential pervasiveness of politics in Heidegger's work, but also to the significance of influence that Heidegger had on subsequent philosophy. Throughout my years of study, alongside reading Heidegger, I also read about other philosophers. Early on I became aware of the work of Paul Ricoeur. I put this aside for a while, but as I worked through my interpretations of the parents' stories, I found myself being drawn back to his work (another example of the iterative nature of this study).

Ricoeur was born in France in 1913 and died in 2005. He became interested in philosophy towards the end of his school years and during the late 1930s was appointed to a number of teaching posts and started publishing his work about socialism and pacifism. However, in 1940 he was called up for military service (Simms, 2003). He was captured and spent five years in a prisoner of war camp in eastern Germany (van Manen, 2014), where he was instrumental in setting up an unofficial 'university of the prison camp' where prisoners worked together to

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research and to teach each other (Simms, 2003). During this time Ricoeur read the work of Edmund Husserl and translated one of Husserl's books (*Ideas of a Pure Phenomenology*) from German to French (van Manen, 2014). In the 1960s Ricoeur became the best-known philosopher in France, and it is said that his classes were so oversubscribed that loudspeakers were set up outside so that those who could not squeeze into the room could still hear him teach (Simms, 2003).

Despite his eminence as a philosopher and teacher, it also seems important to acknowledge that Ricoeur lived with much sadness in his life. By the age of three, both of his parents had died, so he and his sister were brought up initially by his grandparents and then by his aunt. He was very close to his sister, but she then also died during childhood. Later in his life, in the 1980s, Ricoeur's son tragically committed suicide (van Manen, 2014). It was shortly after this, in 1990, that Ricoeur published one of his most important works: *Oneself as Another*.

Understanding that Ricoeur had experienced the loss of his child is perhaps why I felt that his work resonated with the stories of the parents in my study, and indeed with my own experience. Where I had found Heidegger's work challenging, yet transfixing to read; I found Ricoeur's work far more accessible, yet equally transfixing. As I progressed through reading *Oneself as Another*, I felt his deep appreciation and empathy towards grief and suffering, and I saw this appreciation in his perspective of 'solicitude' that I had not seen through Heidegger's work. The tone of Ricoeur's work also felt to me to be very different from that of Heidegger's. Where Heidegger rejected previous philosophers' ideas in order to present his own innovative ideas, Ricoeur built on previous philosophical traditions to develop his creative philosophy. Simms (2003) suggested that this is reflective of Ricoeur's intentions throughout his life, that academics should work co-operatively and ethically rather than in opposition to each other.

Ricoeur's philosophy builds on Heidegger's work and there are clear similarities between the philosophies that will be explored in subsequent acts of this thesis. Rather than criticise or reject Heidegger's philosophy, Ricoeur adds a further dimension and perspective to this philosophy. Ricoeur's life and political perspective were profoundly different from Heidegger's though, and this does lead Ricoeur's philosophy to have what I would suggest is a more empathetic and compassionate foundation. There are certainly aspects of both philosophers' work that help me to illuminate understanding about the parents' stories in this study. Combining the work of both philosophers allows me to develop a balanced and nuanced interpretation.

Act One: Into the woods

The Curtain Falls

This scene has opened a second window to the woods. It has presented the context of the two philosophers whose work underpins this study's methodology and interpretations. It has also set out my reflections about my relationship with their work, the conflict that I have encountered with Heidegger's political life, and the resonance that I feel with Ricoeur's life and work. This scene started by asking the musical question "So What?" with the observation that philosophers ask complex questions that are not easily answered but rather often generate further questions. This "So What" question will remain to the side of the stage throughout the thesis. Further questions will be asked during the remainder of this act, and throughout Act 2. As answers to these questions, and indeed to the overall research question, begin to be formulated in Act 3, it is in Act 4 that we will return to the "So What" question to consider how the philosophical ideas of Heidegger and Ricoeur can shape understanding and practice back in the everyday world.

As the vision of the woods comes further into view, with both mine and the philosophers' contexts being established, the next scene will discuss the methodological decisions that were made throughout this study. It will set out the navigation of the journey into and through the woods.

Act One: Into the woods

Scene Three: Navigating the research journey



Act One: Into the woods

Scene Three: Navigating the research journey

Soundtrack: I am a poor wayfaring stranger, Traditional: arranged by Leon / Scholl, 2001

This is an arrangement of a traditional American folk song, and the words really resonate with the journey that I have experienced during this project. As I set out, I knew that there would be challenging times and that my way would be “rough and steep”. I also knew though, that if I could trust in the process and in myself, that this study would allow a transformation. It would allow me to see the world in a new way and that I would be able to share this transformation with others.

The specific arrangement of this song presents a fusion of musical styles. The American folk song tradition itself is performed by a German countertenor singing in a style usually associated with European Renaissance and Baroque music. He is accompanied by a string orchestra whose harmonisations provide a hint of Asian influence. This fusion echoes the fusion of philosophies, stories and interpretations that guided my research journey.

Scenery: ‘Hiker in the Swiss Alps’, Oswald Achenbach, date unknown

This painting echoes the sense of the journey heard in the soundtrack - hiking along a mountain path, knowing that my journey through the research would be “rough and steep”. Ahead on this path is the darkness of a tunnel. I knew that to gain new understanding and transformation I must accept a period of darkness on this journey when I would not be able to see the way ahead. Yet I also knew that I must trust that by travelling through this darkness, I would find new light.

Act One: Into the woods

The Curtain Rises

The call to a journey towards understanding this topic was set out in the first scene of this act, and the second scene provided the context of the philosophers whose work guides the research process and findings of this study. This scene provides an account of how the journey has been navigated. It will start with a methodological discussion about hermeneutic phenomenology, as my philosophical understanding of this orientated me to the research journey and shaped all research decisions as I travelled. Polkinghorne (1983) made clear that hermeneutic phenomenology should be seen as a methodology that guides an approach to research which can be responsive to the particular topic that is being explored. Other methodologies may have associated methodical processes that are guided by rules and steps, but hermeneutic phenomenology simply requires being open and attuned to the underpinning philosophy and beyond this permits creativity and freedom of method (Crowther et al., 2017). It is therefore important to start this scene with an orientation to hermeneutic phenomenology as a philosophy that has come to be used as a research methodology. The next section of the scene will discuss the ethical and quality considerations that also guided research decision-making throughout this study, and will also set out the early preparations that were made before commencing the research. This will all inform the final section of the scene, where the research journey itself is presented, with a discussion of how the parents' stories were gathered and then interpreted.

Orientating to the journey

Phenomenology

It is important to start any discussion about phenomenology with an explanation that neither phenomenology nor hermeneutic phenomenology were originally conceptualised as research methodologies. Rather these were significant philosophical movements that were later applied to research methodologies due to a quest for understanding about the complexity of life experiences that could not be addressed using traditional, empirical research methodologies (Lavery, 2003). Appreciating the philosophical roots of these movements is therefore critical in appropriately undertaking phenomenological research.

In the first part of *Being and Time*, Heidegger undertook an analysis of the word *phenomenology*. He drew attention to the two components of the word: *phenomenon* which derives from a Greek expression meaning “to show itself”, or “to bring into daylight” and *logos* which he explained is derived from a Greek word that means “discourse” (Heidegger, 1927 / 2010). This led Heidegger to explore the meaning of this and he concluded that a definition of

Act One: Into the woods

discourse is that which “makes manifest what it is talking about and thus makes it accessible to another” (Heidegger 1927 / 2010:32). At its heart, phenomenology therefore has the aim of illumination. By bringing things to light and articulating what shows itself, we come to understand these things better.

Husserl (1859 – 1938) is generally considered to be the founder of phenomenology as a philosophical movement and his prevailing goals were epistemological; he wanted to understand the nature of knowledge and how we come to know about things (Bradbury-Jones, Sambrook and Irvine, 2009). To do this, Husserl claimed, we needed to return ‘to the things themselves’ (Dibley et al., 2020). He placed an emphasis on knowledge being situated in our lived experience. This was in contrast to the prevailing epistemological attitude of his time, whereby knowledge was considered to be gained through examining phenomena and considering them as external and separate from our experience (Moules et al., 2015). Husserl’s novel approach to epistemology has led to a proposition that phenomenology was a rejection of positivism – an objective position in which knowledge is generalisable, testable and value-free (Bryman, 2012). However, there are positivistic elements of Husserl’s phenomenology in this objective and highly rigorous approach that he used to understand human experiences (Rolfe, 2006). Husserl’s phenomenology involved peeling through layers of appearances in order to uncover the true essence of phenomena and describe the essential qualities and characteristics of objects that make a thing itself (Moules et al., 2015). To be able to do this, Husserl proposed that we needed to bracket, or set aside, our own thoughts and interpretations about phenomena, in order to see them for what they truly, objectively, are. Translating Husserl’s philosophy to research, the aim of this descriptive phenomenological approach is to “describe the essential structures of phenomena in a manner that is free of interpretation” (Bradbury-Jones, Sambrook and Irvine, 2009:664).

[Hermeneutic Phenomenology](#)

Heidegger took great interest in phenomenology and similarly saw the value of its illuminating aim. However, he saw its purpose as something different from Husserl’s epistemological goals. This is because Heidegger’s philosophical focus was ontological – he wanted to understand what it means to *be*, and how we could understand reality in terms of our existence (Laverty, 2003). He saw phenomenology as the way of accessing ontological insight and wrote:

Ontology is possible only as phenomenology... Phenomenology is the science of the being of beings (Heidegger 1927 / 2010:35 – 37).

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Heidegger therefore proposed that to understand what it means to *be*, requires us to experience our being and articulate what is manifested through this experience. By doing this we can shine a light on our being and our understanding is advanced. But if we are trying to understand our own being, our own existence, how can we bracket out our thoughts and interpretations and study this in an objective way, as these are deeply subjective questions? Heidegger argued that Husserl's approach to a phenomenology free from interpretation was neither possible nor desirable.

Not only did Heidegger object to Husserl's objective approach to phenomenology, but he proposed that interpretation should be at the heart of phenomenology, and within the first few pages of *Being and Time*, he adopted the term *hermeneutics* alongside phenomenology:

The methodological meaning of phenomenological description is interpretation... Phenomenology of Dasein³ is **hermeneutics** in the original signification of that word, which designates the work of interpretation (Heidegger, 1927 / 2010:37).

Heidegger drew on the work of the nineteenth century philosophers Schleiermacher and Dilthey, who had advanced discussions around hermeneutics as studies of interpretation. Dilthey, in particular, saw hermeneutics as an alternative way to advance understanding about the humanities and social sciences as opposed to applying the objectively focused natural sciences to these areas (Chang and Horrocks, 2008). Heidegger claimed that phenomenology must involve interpretation, both as people describe a phenomenon that they have experienced, and in the way that people listening to the description make sense of it (Fochtman, 2008) because to be human is to be interpretive (Bradbury-Jones, Sambrook and Irvine, 2009). It is simply not possible to suspend, or bracket, what we know about something, we are always connected through our pre-understandings and unique context, and therefore we are always interpreting (Chang and Horrocks, 2008). From a Heideggerian perspective, hermeneutics and phenomenology belong together.

This emphasis on hermeneutics, on interpretation and searching for meaning, led Heidegger's phenomenology in quite a different direction from Husserl's descriptive phenomenological philosophy. Whilst both may have been concerned with human experiences and illuminating phenomena that may often be hidden and taken for granted, the way of exploring this experience differed, and this is reflected in how phenomenology as research has evolved (Laverty, 2003). Husserl had focused on epistemological questions about the relationships

³ Heidegger's concept of '*Dasein*' will be explored in further depth in Act 2 Scene 1, but this broadly relates to the human mode of existence, where we exist as *being-in-the-world*.

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between humans as 'knowers' and the objects of the study. Translated to research, descriptive phenomenology focuses on seeking the essence of experiential structures (Laverty, 2003) and there is an assumption that these essences are universal and independent of personal or cultural contexts (Lopez and Willis, 2004). Heidegger was opposed to this objective position, in which he felt that the ontological being, or life itself, was being neglected by Husserl:

I should let myself be carried along by the stream of life, 'joining in lived experience' rather than withdrawing from it in the *Epoche*⁴, we must 'understand' life from within. (Heidegger, 1919-20 cited by Inwood, 1999:119)

To understand life from within means embracing subjectivity and our own life's positionality. Translated to research this means that the researcher should not attempt to bracket their own thoughts and reflections about a phenomenon, but rather these should be embedded in the interpretive process. Heidegger's proposal that every person inhabits a world that is shaped by a cultural and temporal context, means that pre-understandings about a phenomenon will be unique and therefore the way that we make sense and interpret other experiences will also be unique. This similarly applies to participants in research, whose experiences are contextually dependent. This means that there cannot be universal, generalisable essences of experiences as Husserl had suggested (Lopez and Willis, 2004). The context of our world is ever evolving and by the time that experiences are being recalled and narrated, this is happening within a changed and changing context. What a participant discloses in a research setting, and how they disclose it, cannot be assumed to be exactly as the experience happened, and if discussed at another time, the conversation may likely lead to a different disclosure. The same applies to the way that the researcher interprets participants' stories. Chang and Horrocks (2008:389) articulated what happens when these two interpretive processes are combined:

The understanding of people is therefore kaleidoscopic in nature and constantly undergoes metamorphosis because they are constantly interpreting and reinterpreting their experiences in the light of subsequent experiences.

Rather than attempt to generalise about people's experiences, potentially leading to prescriptive interventions, the emphasis of this context-dependent interpretive approach to phenomenology is to enhance understanding of the potential diversity of experience. Being explicit about the context of these experiences in order to illuminate this understanding holds

⁴ 'Epoche' is the term that Husserl used to mean bracketing (or suspending) our pre-understandings, or pre-existing knowledge, in order to be open to new knowledge being made manifest. This is a concept that is an important part of descriptive phenomenological research, but was rejected by Heidegger and is incongruent with the principles of hermeneutic phenomenology (Chang and Horrocks, 2008).

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great potential to generate thinking and conversation and therefore support an orientation to becoming more attuned and empathetic to each person's specific support needs.

As explored in Scene 2, Ricoeur was influenced by both Husserl and Heidegger. Through his studies of Husserl, Ricoeur had demonstrated a similar perspective to Heidegger - that all phenomenology is compromised by interpretation as we are always interpreting (van Manen, 2014). He saw hermeneutics as the system to gain deep insight and significance (Kakkori, 2009). Yet despite his particular focus on philosophical hermeneutics, Ricoeur maintained his commitment to phenomenology (van Manen, 2014), thus continuing the philosophical stream of hermeneutic phenomenology that Heidegger had initiated:

Man learns about himself only through his acts, through the exteriorization of his life and through the effects it produces on others. He comes to know himself only by the detour of understanding, which is, as always, an interpretation (Ricoeur, 1991:60 cited by Rolfe, 2015:144).

If hermeneutic phenomenology is to be adopted as a research methodology, then this discussion of the philosophical foundations is fundamental to the premise of how to approach a research project. The following principles that are derived from the philosophy must underpin the research study.

1. The purpose of hermeneutic phenomenology is to illuminate the meaning of experience, allowing reflection and understanding (Green, Solomon and Spence, 2021), and to generate deep conversation about this (Darbyshire, Diekelmann and Diekelmann, 1999). The purpose is not to create generalisable universal statements or answers that can become the basis for developing theory (Crist and Tanner, 2003). Neither is the purpose to explain experiences in order to confirm a hypothesis (Morrison, 2003). This means, according to Darbyshire and Oerther (2020), that applying a theoretical or conceptual framework to a hermeneutic phenomenological study is inappropriate and misaligned with Heideggerian philosophy.
2. As discussed, Heidegger's focus was ontological rather than epistemological and he saw hermeneutic phenomenology as the way to access ontological insight. From a research perspective therefore, the focus should be about gaining philosophical, ontological understanding about phenomena. Using philosophy to guide interpretations is therefore a feature of this methodology (Lavery, 2003).
3. Interpretation is at the heart of hermeneutic phenomenology. The premise that humans are interpretive beings and that we bring our interpretations to every experience has particular implications for approaching a research study. As discussed

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in the Overture, the hermeneutic circle is a guiding principle of hermeneutic phenomenology (Cammell, 2014; livari, 2018; Burns and Peacock, 2019). This refers to a constant process of furthering understanding by moving between the parts and the whole, and that our pre-understandings shape our overall understanding. This circular movement inevitably means that as a methodology, hermeneutic phenomenology is an iterative, rather than linear, process. It also means that articulating pre-understandings and embedding reflections throughout about how these inform the evolving interpretations is a critical part of hermeneutic phenomenological research (Barrett-Rodger, Goldspink and Engward, 2022). The focus on interpretation rather than pure description means that researchers do not aim to describe just the words that people say, but look to reveal what lies beyond the words of people's stories (Crowther et al., 2017).

[Why Hermeneutic Phenomenology](#)

Having explored what hermeneutic phenomenology means as a philosophy, and the implications of this for adopting it as a research methodology, it is important to explore why this approach is appropriate for this study. The application of this philosophy to research has become a popular methodology in nursing and health care studies (Burns and Peacock, 2019). Whilst traditional hierarchies of evidence place quantitative methodologies over qualitative (Daly et al., 2007), there is a growing consensus that qualitative methods serve a very different purpose from quantitative, and that arguably it is not helpful to compare the approaches to each other. Where research aims to understand life, then a qualitative approach should be adopted, because after all, we live our lives in a qualitative way. Koch (1998) strongly emphasised the importance of health care professionals listening to stories in order to improve future practice, and Rolfe (2015) suggested that this qualitative approach is fundamental to health care and in particular to nursing. He proposed that nursing should be concerned above all with what it means to be a person, and that rather than attempt to generalise or theorise, which may lead to making assumptions about people, the practice of nursing should be an interaction between unique individuals. Of course, there are many aspects of nursing that do require an objective and generalisable position such as those that are concerned with nursing safety interventions. However, I do share Rolfe's perspective that there are also significant features of health care that should focus on these unique interactions between people, and this study is an example of the importance of this. This perspective closely mirrors the philosophical position of hermeneutic phenomenology, and if nursing practice itself mirrors this, then it seems highly appropriate for nursing research to also adopt this position.

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Chesterton and Jack (2021) concurred that nursing research should adopt a person-centred perspective to mirror person-centred nursing practice. A person-centred researcher, they suggested, should be able to explore a person's unique experiences within their own personal contextual world, whilst always maintaining their own self-awareness. This led Chesterton and Jack to propose that hermeneutic phenomenology is absolutely conducive to this ideal of person-centred research with its focus on interpretation and recognising individuals as unique and inhabiting their cultural, social, and temporal world. As a children's nurse I am committed to the philosophy of family-centred and child-centred care that underpins children's nursing practice (Boden, 2023). If hermeneutic phenomenology is conducive to person-centred care as Chesterton and Jack (2021) have proposed, then this is certainly also the case for family-centred care. In addition to their justification of this it is worth noting that the philosophical views of both Heidegger and Ricoeur have significant focus on relationships between people, and so this resonates deeply with the essence of how we, as children's nurses, care for the whole family and recognise the importance of these family relationships. This is particularly relevant for my study, where relationships between the immediate family, and wider family, friends, and acquaintances are being considered.

The first scene of this act laid out my pre-understandings around the topic through different lenses, one of these was my professional lens as a children's cancer nurse. When I think back to the years when I cared for children with cancer, the moments that emotionally affected me the most were when I was with a family as they were given the cancer diagnosis. The shock of this diagnosis seemed palpable and overwhelming for so many families. In that moment they had been jolted away from normality, where a natural life order had been assumed and death was so far removed from their life that it played no part. Whilst it was the child who 'had' the cancer, the whole family now lived with the life-threatening cancer diagnosis. The family faced the possibility that their child may die, and natural order was disrupted. The whole family now turned towards death, and this moment of diagnosis became a deeply existential moment. Against this backdrop, families needed to start making complex decisions, and so decision-making seemed to become intertwined with this existential thinking.

As I reflected on this, I realised that a descriptive study would not be able to reach the heart of these experiences. To reflect the existential shift that parents were experiencing, it seemed that this needed to be explored from a philosophical perspective. I saw that hermeneutic phenomenology could provide me with a way of accessing this perspective as well as being well suited to considering the unique social worlds of each parent.

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From a personal perspective, having experienced my own deeply existential moment, I valued the premise that hermeneutic phenomenology would generate understanding and conversation rather than trying to provide prescriptive solutions and answers. I could see that to try to apply or generate theory from people's experiences could devalue their unique stories (a perspective shared by Koch, 1998) but that the value of developing greater understanding could help to enhance empathy to people's specific support needs. I felt strongly that my story was mine alone, and nobody else would experience life in exactly the same way. If I felt like this, I could imagine that other families living through such difficult times may feel the same. I needed a methodology that could value each parent's individual story, allow my reflections to be visible and play a role in the interpretations, and that could develop understanding through a philosophical perspective. Hermeneutic phenomenology would allow me to do all of this. It would be well aligned to the topic, to my professional position, and to my personal perspective of the world, and so this methodology was adopted and orientated the study's journey.

Guiding the journey

As explained at the start of this scene, hermeneutic phenomenology is considered to be a methodology rather than method (Crowther et al., 2017). It is an approach guided by principles rather than a prescribed set of steps (Regan, 2012). In line with this, as I embarked on this study, I did not commit to a particular method from beginning to end. I read widely around different approaches to hermeneutic phenomenology, and the precise steps of the study were informed by this reading, conversations with colleagues also adopting this methodology, and continuous engagement with the philosophical concepts outlined above.

With the absence of a prescriptive process to guide my path, I felt that it was important for my decisions to be guided by appropriate quality and ethical approaches in addition to the philosophical principles described above. Therefore, with every decision that I faced in designing and conducting this study, I asked myself whether this would be in line with the philosophical, quality and ethical principles that I had committed to. This next section will outline these quality and ethical considerations. It will also outline the early stages of the study, and how these helped me to plan the route of my study.

Quality considerations

It is accepted that all research conducted should be of good quality, and the term rigour is generally used in association with this. Cypress (2017) proposed that rigour should be built into a study from the outset, rather than evaluate this at the end of the study. Similarly, Koch (1998) argued against rigour being considered as a set of steps or methods that inform how data is

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gathered and analysed, but rather suggested that a rigorous approach should guide the entire process. She proposed that conceptualisations of rigour should therefore be expanded to include “moral, political and ideological value-commitments” throughout the research process (page 1188). Quality considerations should therefore be closely linked to ethical considerations as well as the philosophical commitments that underpin the study.

Traditionally language around rigour is aligned to the positivist paradigm and includes criteria such as reliability, replication and validity (Bryman, 2012). The purpose of rigour within this context is to reduce bias (Bowling, 2014) in order to justify the generalisability of research findings. However, as earlier established, the purpose of hermeneutic phenomenology is not to seek theoretical generalisability, and rather than attempt to eliminate bias, there is a focus on making bias explicit. Qualitative researchers have acknowledged that it is not possible to evaluate quality using these quantitative criteria, but that this does not mean that qualitative research cannot be seen as rigorous. Alternative qualitative criteria have therefore been proposed, such as Lincoln and Guba’s (1986) development of the criterion of trustworthiness, with credibility, transferability, dependability, and confirmability as aspects of this.

Crowther and Thomson (2020) proposed that Lincoln and Guba’s (1986) criteria can be applied to a hermeneutic phenomenological study. They suggested that strategies including reflexivity, use of rich and varied participant quotes, providing explicit detail about the analytical process, and reporting of participants’ sociodemographic details and study context, all align to the criteria. Yet they also acknowledged the importance of philosophical congruence throughout the study, which does not align to Lincoln and Guba’s criteria; above all they argued that quality extends beyond these criteria of rigour, and that the quality of research should be judged according to whether it resonates with the readers and listeners of the work.

Other writers have argued that applying Lincoln and Guba’s (1986) criteria to hermeneutic phenomenological research is problematic (Koch and Harrington, 1998; Rolfe, 2006; Cypress, 2017). This is on the basis that these criteria have been developed in parallel with the quantitative criteria, which Cypress (2017) argued diminishes the value of qualitative research. Rolfe (2006) extended this argument further by proposing that the umbrella of qualitative research encompasses diverse methodologies which have varying epistemological and ontological paradigms – there is not an overarching qualitative paradigm, and therefore there should not be an overarching set of criteria that is applied to all qualitative research. Even applying the same set of criteria to a phenomenological study and a hermeneutic phenomenological study would be inappropriate as the aims, principles and underpinning

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philosophies are so contrasting. This led Rolfe (2006) to argue that each research methodology should be appraised in a way appropriate for that particular paradigm.

This led me to explore an alternative approach to appraising quality for my study. Mindful of Crowther and Thomson's (2020) acknowledgement of the importance of philosophical congruence, and resonance with the audience, Koch and Harrington's (1998) emphasis on reflexivity, and McCaffery et al.'s (2022) focus on interpretive analysis rather than data being descriptively organised, I looked for an approach that would encompass these aspects. In 2006, de Witt and Ploeg published a new framework for rigour, which not only relates to interpretive phenomenological research but also specifically focuses on interpretive phenomenology in nursing. They acknowledged that the purpose of interpretive phenomenology is to enhance understanding of multiple interpretations of people's experiences as opposed to seeking a single truth from an epistemological objective perspective. They also argued that hermeneutic phenomenology can, and should be, systematic and rigorous, but that this can be achieved in a different way from the scientific paradigm. Their framework consists of five expressions that should be used to appraise quality in hermeneutic phenomenology: balanced integration, openness, concreteness, resonance, and actualisation. The first two of these expressions relate to the research process, and the remaining expressions relate to the research outcome.

De Witt and Ploeg (2006) identified that a common weakness of interpretive phenomenological nursing research is the misrepresentation of philosophy. Balanced integration therefore seeks to address this, and they identify three characteristics of this: articulation of the philosophical theme and its appropriateness for the researcher and research topic; in-depth intertwining of philosophical concepts throughout the study methods and findings; and seeking a balance between the voices of the participants and the philosophical interpretations. In Act 1, Scene 2, I provided the context and rationale for focusing on the two philosophers whose works influence the philosophical methodology and interpretations of this study. As we travel through the woods, Act 2 will integrate the parents' context, social networks, and decision-making with key Heideggerian philosophical concepts. This discussion will facilitate deeper philosophical interpretations that will be intertwined with each parent's story in Act 3.

Openness relates to the "orientation and attunement toward the phenomenon of inquiry" (de Witt and Ploeg, 2006:225). This can be demonstrated through accounting for all decisions made during the research process. Openness can be seen throughout this work, from the justification for structuring the thesis as it is, to the orientation to the research topic and philosophers in the first two scenes of this act. This scene in particular provides an account of

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the decision-making around the methodology and specific methods around gathering and interpreting parents' stories. Subsequent scenes will draw on the decisions made as the study's findings are explored.

The final three expressions will be appraised in more detail towards the end of this study as they relate to the research outcome. De Witt and Ploeg (2006) explained that concreteness is evident when the findings are written in a way that examples situate the reader in the context of the phenomenon and link to their own experiences. Resonance refers to what the reader feels as they read the study – moments where the reader's understanding of the study collides with their self-understanding allowing them to make sense of the whole picture; actualisation is the acknowledgement that the interpretation is never complete but that both the writer and audience must be open to future interpretations (although de Witt and Ploeg acknowledged that there is no currently accepted mechanism for recording this).

These five expressions of quality do represent the principles of hermeneutic phenomenology in a more focused way than Lincoln and Guba's (1986) standard qualitative criteria. However, de Witt and Ploeg (2006) do not discuss the role of the researcher's own position or reflexivity in their framework and this is problematic as it is central to Heideggerian philosophy. I consider that reflexivity could be seen as part of both balanced integration and openness, and that as well as seeking a balance between the participants' voices and philosophical interpretations, the voice of the researcher should also be balanced with this. In Acts 2 and 3 I will present my own reflections about how parents' experiences resonated with mine, and how this informed the direction of my interpretations.

The final omission from de Witt and Ploeg's framework (and indeed also from Lincoln and Guba's (1986) criteria) is reference to ethical considerations. Arguably, for a study to be considered high quality it must be conducted ethically. Taylor and de Vocht (2011) proposed that a concern for the wellbeing of participants aligns to Heideggerian philosophy as we exist alongside others and that a fundamental characteristic of being human is to show concern towards others. The next section will therefore explore how I adopted an ethical approach throughout this study.

[Ethical considerations](#)

There were two overarching aspects of ethical considerations in this study: how could I maintain an ethical approach towards participants during the study, and what ethics approval processes would I need to navigate in order to commence the study. Concern for participants' wellbeing was paramount to me from the outset of this study and this position was very much

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influenced through the same lenses in which I set out my pre-understandings. As a children's nurse with a clinical background in children's cancer care, I felt that I had some insight into the challenges that parents were facing and I was mindful that I did not want to create any additional burden for them. In addition to considering the emotional burden, I was aware that parents may have limited time to talk to me and so I was keen to minimise the practical burden as well. From my perspective as a person who had experienced significant adversity, I was strongly conscious of the emotional burden of talking about this experience, yet I had also found it cathartic to talk to others in certain contexts. As I reflected on these potential burdens and benefits, I found myself aligning my thoughts to Beauchamp and Childress's (2009) biomedical ethical principles: autonomy, beneficence, non-maleficence and justice. As these principles are fundamental to ethical health care practice (including research) this exploration of ethical considerations will therefore be framed by these principles and will be referred to later in this scene as the methods of this study are discussed in more detail.

Respecting people's autonomy is central to my practice as a nurse (Nursing and Midwifery Council, 2018) and is also well attuned to a hermeneutic phenomenological study. This methodology facilitates autonomy to be seen beyond the standard informed consent processes that would be part of all research studies. As discussed earlier in this scene, this methodology is aligned to a person-centred research approach, and so as well as parents being free to make their own decisions about participating without any coercion, parents also had autonomy within the interview itself and were able to guide much of the discussion. This will be discussed in more detail later in this scene.

The balance between beneficence and non-maleficence was at the forefront of all research decision-making, as is expected in all research (NHS Health Research Authority, 2023). Knowing that inviting parents to participate would generate some burden (whether from an emotional or practical perspective) it was crucial that there would be sufficient benefit to the study. From my own experience, I recognised that there may be some cathartic benefit for individual parents in sharing their story, however I could not assume that this would be the case. It was also important to undertake the study in order to bring wider benefit to parents of children with cancer. This closely links to de Witt and Ploeg's (2006) expressions that relate to the outcome of the study, and this will be further discussed in Act 4. However, from the start of the study I was committed to disseminating the findings of my work in order to enhance understanding of this topic.

Holding on to this strong motivation that my study would have the potential to bring future benefit to parents, it was also important that I consider non-maleficence to take account of

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potential sources of harm and mitigate against these. The main potential harms of this study were the possibility of causing distress to the parents, and a risk of compromising their privacy. As I designed the study, I considered how to offer support to parents if they were to become distressed during the interview. I trusted that as an experienced nurse I would be sensitive to this and offer to terminate the interview and refer the parent to sources of support. This situation did not happen in any of the interviews. As the study progressed, I realised that it was not sufficient to consider distress in this narrow context, I needed to be aware of the distress that I could cause through misrepresenting the parents' stories, and take into account which aspects of the study I should send to the parents on completion of the study.

In line with legal obligations (Data Protection Act, 2018) it was important to promote the parents' confidentiality throughout this study. Whilst there were standard steps that I could take to preserve confidentiality as much as possible, such as changing all names to pseudonyms and carefully protecting identifiable data, it was not possible to guarantee absolute anonymity due to the small number of parents involved in the study. I recognised that as their stories were all unique, there would be a possibility that their identities could be worked out from details that I included in publications or conference presentations. For this reason, I made the decision not to gather details such as demographic information which might further compromise their identity. I also talked to each parent before the start of the interview to explain the potential limitation of confidentiality. They all understood this and agreed to proceed with the interview.

I needed to consider justice in terms of equity of access to the study. This related in part to the inclusion and exclusion criteria that I set for participation and was perhaps one of the most challenging parts of the ethical considerations. This will be discussed further later as I outline the inclusion and exclusion criteria, as it warranted significant thought.

The ethics approval process was complex, but also really helped the evolution of the study design. I initially applied to the Faculty Research Ethics Committee for approval and then proceeded to apply for approval from the National Health Service (NHS) Health Research Authority Research Ethics Committee. One of the three NHS sites at which I would be recruiting also required me to apply to, and attend a discussion with, their Clinical Research Adoptions Committee. Letters of approval from each of these committees can be found in [Appendix 2](#). There were a number of other processes that I needed to comply with in order to access participants through particular NHS sites. Feedback and discussions with each of these committees led to refinement of my study. For example, I reflected on the prompt questions in my interview schedule and refined these so that they were more aligned to hermeneutic

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phenomenology, I considered how I would encompass patient and public involvement in the dissemination of study findings, and I considered the potential impact of the study on my own wellbeing.

Shortly after I had made the original ethics submissions, the COVID-19 pandemic started. It soon became clear that my original plan to interview parents in person would not be possible. I therefore applied for amendments through the ethics committees so that the study could continue with interviews conducted online, and to extend the recruitment strategy to include social media rather than solely through the three NHS sites. There were several challenges in moving to online interviews, but there were also benefits. From an ethical perspective, my main concern was that if a parent were to become upset during an online interview, they would not be able to access immediate support, as they would if I interviewed them on a hospital site. This heightened my sensitivity towards them during the interviews and I recognised that if I were to become concerned for their emotional wellbeing, I may need to follow up afterwards to ensure that they were able to access appropriate support. The ethical advantage of online interviews and broadening the recruitment strategy was that I was also no longer limited by which hospitals I could travel to. This meant that participation was opened to the whole of the United Kingdom. This had two advantages: it became easier to promote confidentiality as the pool of potential participants was much wider, and equity to participate in the project was improved, as geography within the country was no longer a barrier to participation. Further practical challenges and benefits of the move to online interviews will be discussed in Act 4.

As I have demonstrated, there were many quality and ethical considerations that I needed to take into account as I designed and carried out this study, and these will be drawn on throughout the remaining sections of this scene and returned to in Act 4. There were a few other aspects that I needed to consider before I started to recruit and talk to parents about their experiences.

[Planning a route](#)

The first scene of this act laid out my pre-understandings and what led me to the study. I was mindful though, that while my motivation for exploring this topic was very important, I also needed to explore whether others would consider it a worthwhile area to research. I therefore spent time discussing the research idea with colleagues from practice and academia, and with people from outside the sphere of practice. Their interest in the topic and agreement with the literature outlining the stress and burden of decision-making on parents of children with cancer (Bandinelli and Goldim 2017) reassured me that it was a topic worth exploring. A little later in

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the study I again made contact with a number of people from outside of practice or academia and asked them to read the participant-facing documents to check that they were understandable from a lay perspective.

I also wanted to gather insight into what was already known about the topic, whilst acknowledging that even if similar studies had been conducted, the context for parents would be different and my interpretations would be shaped by my own context. Nevertheless, it felt important to understand wider research and literature, and I needed to summarise this in the ethics applications.

There is controversy about the timing and role of literature reviews in hermeneutic phenomenology (Smythe and Spence, 2012; Dibley et al., 2020). Returning to the philosophical principles to ensure coherence throughout the study (in line with de Witt and Ploeg (2006)), I concluded that it was appropriate to conduct the formal literature review in advance of the interviews. Whilst in a descriptive phenomenological study it would arguably be problematic to conduct a literature review in advance of the study, as it would add more complexity to the bracketing process, in a hermeneutic phenomenological study the aim was not to suspend understanding from the literature (Lopez and Willis, 2004). Inevitably my understanding would already be shaped by engagement with the literature for ethics applications, and so completing a full literature review would just complement my understanding with a more detailed picture of the topic. This literature review will be presented in the next scene, with additional discussion about how it shaped my understanding as I moved into the interview phase of the journey. The other advantage of undertaking the literature review at this stage was that it allowed me to further consider and justify my research design. For example, at an ethics committee meeting I was asked why I was planning to approach the topic with a broad, rather than focused, approach to the types of decisions that parents were facing, and also to the types of 'significant others' that parents would be talking about. My response was that I felt that it was really important for parents to be able to talk about the decisions that were important to them rather than be limited by my agenda, and that they should be able to self-identify who was 'significant' to them in their social support network. I had learnt from the literature review that most other studies had been driven by the researchers' agendas, both in terms of types of decision, and types of social support. This troubled me and therefore reinforced to me that it was important to let the participants identify and reveal what, and who, was important to them. I felt that this was more aligned to participant autonomy and the person-centred nature of the methodological and philosophical principles underpinning this study. Ricoeur, in particular, emphasised that certain experiences are more important to a

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person's life story than others (Flaming, 2005) and it should therefore not be assumed by others which experiences are important to that person.

The final aspect that I considered before I started to recruit and talk to parents, was my own proficiency as a researcher. I had completed a research project in the past, but I recognised that I was still a novice researcher, and this was my first hermeneutic phenomenological study. It was important that all of the interviews that I conducted with parents would be of good quality so as not to waste their time, and so to enhance my confidence and competence, I undertook a number of pilot interviews with friends and peer PhD students. This allowed me to practise using the online platform so that this would not cause any disruption in the real interviews, and also allowed me to gain feedback about my interview technique. I also spent time at this stage, discussing my project with other researchers who were immersed in hermeneutic phenomenology, which really helped me to keep focused on the philosophy underpinning my project.

All of these early stages helped me to approach the interviews in a prepared and considered way. Whilst this had all taken time, I now felt prepared to make the journey. The next section will provide a detailed account of how I gathered and interpreted the stories.

[Making the journey](#)

[Gathering the stories](#)

Recruitment

With ethics and site approvals granted, and my own confidence in interviewing developed, it was time to recruit parents for the study. Initially the plan was to recruit only through three NHS sites. In the early stages of the project, I had made connections at each site with oncology research nurses or advanced nurse practitioners who had expressed interest in supporting my study. I sent each of these contacts recruitment packs (by email and by post) which included study posters, invitation letters, participant information sheets, privacy notices and a form to indicate consent that parents' details could be shared with me if they wanted to participate ([Appendices 3, 4, 5, 6, 7](#)). I asked for these to be given out to any parent who met the inclusion criteria (Table 1) and for posters to be displayed on the children's cancer wards and clinics. If a parent decided that they would like to participate they could either contact me directly or they could consent to their details being passed on to me. The posters included my contact details and a QR code which directed interested parents to my study website where they could complete a form indicating their interest in participating. As discussed above, this strategy needed to be reviewed due to the challenges associated with the COVID-19 pandemic. I made

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contact with the Children's Cancer and Leukaemia Group (CCLG) who advertised my study on their closed Facebook group and in their patient facing 'Contact' magazine ([Appendix 8](#)), and I also posted about the study on Twitter ([Appendix 9](#)).

Table 1: Participant Inclusion and Exclusion Criteria

INCLUSION	EXCLUSION	RATIONALE
Parents of children who are currently receiving care for cancer (including those receiving end of life care if they choose to participate) or parents of children with non-cancerous brain tumours.		One of my ethical concerns was around parents being able to access support easily if the interview were to trigger any negative feelings. Including parents of children who were currently receiving care would mean that they would still be in the health system and having regular contact with professionals. Whilst they could seek support from outside of the NHS site (via charity support), ensuring that regular contact was available with professionals was also important.
The child must have been receiving care for cancer for at least one month.		This was to ensure that parents had been receiving care for enough time to have made some decisions.

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INCLUSION	EXCLUSION	RATIONALE
Parents of children with cancer who are aged between 0 – 11 years old.		This was for two reasons: firstly, one of the NHS recruiting sites cared for children up to the age of 12 years old so this criterion ensured consistency across sites. Secondly, it was acknowledged that as children become older, they are likely to become more involved in the decision-making conversations and this could change the nature of the study. Whilst this is a gradual process and cannot be attributed to a particular age, it was decided to limit the age to primary school aged children.
Parents able to converse easily in the English language (although not necessary for English to be their first language).		This criterion generated considerable thought. Whilst I was concerned about excluding people who could not communicate in English, I recognised that the interpretive and responsive nature of interviewing with this methodology could be hindered with an interpreter present. I did not want to undertake any interviews where I would not be attuned to the words of the participant and could not bring the best out of the conversation.
Parents must be over the age of 18 years.		This was included so that parents could legally consent to participate in the interview without the involvement of anybody else.

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INCLUSION	EXCLUSION	RATIONALE
Parents who are considered to have Parental Responsibility under the 1989 Children Act.	Cases where the Local Authority holds parental responsibility for Looked After Children.	It was important that this criterion was included as only those with legal Parental Responsibility are able to make certain decisions for their child.

Participants

Predetermining how many parents I should recruit was challenging. Ethics submissions required me to state a number, yet to be true to the principles of hermeneutic phenomenology research would mean being responsive to the study as it progressed rather than committing to a fixed number from the start. To manage this dilemma, I stated that I would recruit “up to 25 parents” in the ethics submissions which allowed flexibility to stop recruitment much sooner if that were to become appropriate.

Dibley et al. (2020) discussed sample size and concluded that there can be no fixed or prescribed sample size in hermeneutic phenomenological research but that several factors (such as study design and size of population) need to be considered. Ultimately though, sample size should be guided by the purpose of the research (Dibley et al., 2020; Koch, 1998). As hermeneutic phenomenological research seeks to illuminate the meaning of experiences and promote deep conversation rather than creating generalisable answers or confirming hypotheses, it is not necessary to recruit large numbers of participants. Other types of qualitative research use data saturation as a guide to decision-making about sample size, but Saunders et al. (2018) cautioned against using this without careful consideration as it is not necessarily aligned to all qualitative paradigms. Certainly, for a hermeneutic phenomenological study where the guiding philosophy focuses on the uniqueness of individuals and their contexts, the concept of data saturation in which the researcher assumes that participants will share similar insights, cannot be philosophically attuned.

Rather than be guided by data saturation, others have suggested that in this type of study, the researcher should be guided by their own sense of when the number of participants recruited, and interviews undertaken provides “an overwhelming sense of ‘enough’” (Smythe and Spence, 2020:2). Crowther, Smythe and Spence (2014:22) suggested that sample size should be guided by knowing that interpretations are “comprehensive, explicit and visible”. It takes

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confidence to start recruitment with this lack of certainty, but I was content to trust the process as Smythe (2011) has advised. After the first two interviews, which had both been long and full of rich conversation, I realised that 25 participants would be far too many. After the sixth interview, I felt a sense that this would be enough. I paused recruitment whilst I transcribed and reflected on all of the interviews, and then felt confident that this was indeed enough. I was concerned that if I continued and recruited more parents, I would be unable to give each parent a strong enough voice in my interpretations, and it was important for me to honour each parent with the space to present their stories and my interpretations in sufficient depth.

The six parents were from a range of geographical locations within the UK. Three were mothers and three were fathers. Whilst there is no need in hermeneutic phenomenology to include diversity of participants in terms of gender or other demographics as the purpose is not to compare differences (Taylor, 2017; Crowther, Smythe and Spence, 2015), I was really pleased to recruit a balance between mothers and fathers. Much qualitative research around children's cancer has presented a prevailing narrative of mothers' experiences (Robertson et al., 2019), so I wanted to be able to share the voices of fathers as well as mothers in this study.

Interviews

Whilst there are alternative strategies to gathering stories in hermeneutic phenomenology (Bradbury-Jones, Sambrook and Irvine, 2009), in-depth interviewing is perhaps the most commonly used strategy (Dibley et al., 2020). Interviews allow a Gadamerian fusion of horizons (Taylor and de Vocht, 2011) between the researcher and participant, and when viewed through Kvale's (2007) lens of an 'inter-view' are well aligned with Heideggerian philosophy around humans being interpretive beings existing in a world of others (Heidegger, 1927 / 2010).

There were decisions that needed to be considered in relation to the interviews. The first was whether parents should have the choice of being interviewed alone or as a couple. This was a complex decision. I recognised that the nature of the interaction would be quite different if it was me talking to one parent, or me talking to two parents. Taylor and de Vocht (2011) debated this issue with reference to Heideggerian philosophy. Whilst de Vocht justified her reasons for interviewing couples together well, I agree with Taylor's perspective that with two participants, the presence of one will inevitably impact the behaviour and words of the other. From a Heideggerian perspective, our own unique position may become absorbed by the

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other⁵ and therefore alter the unique stories that people want to share. I also felt that there was an ethical risk to participants if I interviewed them as a couple. Their reflections on who in their social network had been supportive or not, may well differ from each other. I was concerned that if people were to discuss this in the interview, it may generate tension between them, and this would be an unnecessary potential harm.

I also needed to consider whether I would do a single interview with each parent or multiple interviews. Again, there were ethical and philosophical reasons for my ultimate decision to do a single interview. As identified in the ethical considerations, I was keen to minimise burden for the parents. I was aware how precious their time was and thought that it would be more efficient to find a time to do one longer interview than several shorter interviews. If I were to do multiple interviews, I would need to have a strongly justified reason to do this, and McConnell-Henry, Chapman and Francis (2011) argued that acquiring more data through multiple interviews does not necessarily result in gathering richer data. A single, good quality interview is preferable if there are no specific reasons to do otherwise. Furthermore, from a philosophical perspective, Heidegger argued that our understanding is shaped not just by our social contexts, but also by our temporal context. A parent's story may be narrated differently, with different aspects focused on, if told on another day. So, to revisit a parent's story on a subsequent day may present challenges as they may vary their account or recall events differently.

As explained, all interviews were conducted online, at times that were convenient to each parent. Each interview started with obtaining informed consent, which was recorded on video and documented by me on a consent form ([Appendix 10](#)), as the parents responded to each question. I kept the paper documents securely in a locked cabinet, and the online consent recordings were also stored in the university's Google drive. Once the consent process was completed, I stopped the online recording and started a new recording in order to keep interview recordings separate from the consent.

I had prepared an interview guide ([Appendix 11](#)), but in line with a hermeneutic phenomenological approach, the interviews were treated as unique events, and the interview guide was used flexibly and in response to the conversation that evolved during each interview. Broadly speaking there were three stages of each interview, but this was very iterative and each conversation moved freely between these stages.

⁵ This relates to the Heideggerian concepts of 'authenticity and inauthenticity' and our relationship with '*Das Man*' ('*the They*'). This will be explained in depth, in Act 2, Scene 2.

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I started each interview by asking the parent to tell me a little about their story, what events had led to their child's diagnosis and what had happened since then. This open question allowed the parent to be comfortable in talking about a story that they knew well and had likely shared with others previously. It also allowed us to build a relationship as I could demonstrate compassion and sensitivity in my responses, and my genuine interest in listening to their story.

After this, I asked the parents if they could list some of the decisions that they felt that they had made so far. As they did this, I noted them in the chat function of the communication platform used so that we could refer back to these later. In some cases, parents told me the story around each decision, in other cases they simply listed them.

The next stage was for me to gain insight into who the parents believed to be 'significant' to them. I had made the decision to use ecomaps to support this process because, as acknowledged in the Overture, I recognised that perspectives of who may be considered 'significant' to a parent would vary and so I wanted to allow the parents to self-define these relationships. Ecomaps are tools that are used in children's nursing practice to assess and understand a family's social support system (Hemphill and Dearmun, 2010). They provide a visual representation of how the family interacts with its self-identified community and help to identify sources of support, and also potential sources of stress in relationships that may affect the family (McCormick et al., 2008). In recent years ecomaps have also been recognised as useful research tools, including in hermeneutic research (Moules et al., 2015). A paper that I published during my study (Jestico et al., 2023a) is included in [Appendix 12](#). This reflects on the congruence between the use of ecomaps and the Heideggerian philosophical foundations of hermeneutic phenomenology. Using the whiteboard function of the online communication platform, we co-created ecomaps. Each parent explained to me who their 'significant others' were and what those relationships were like, and I drew this on their ecomap (an example of an ecomap can be seen in Figure 2). Whilst in essence the ecomap that I designed was based on a traditional ecomap (Hemphill and Dearmun, 2010), the appearance looks different due to the functionality of the online whiteboard (for example a traditional ecomap would represent the strength of relationship with the thickness of the line, but this was not possible on the whiteboard and so I used 'heart' stamps to represent this strength of support). I did though make one significant change to the ecomap design. From my clinical practice I had observed that new relationships were sometimes forged between parents of children with cancer following a diagnosis, and so I felt it important to represent that relationships may change over time. I therefore used different colours to represent relationships that had existed before the cancer diagnosis, and new relationships that were forged after the child's diagnosis.

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Constructing these ecomaps took some time but generated important and rich conversation. As the interviews progressed, we often returned to the ecomaps and lists of decisions to add further details. The decisions that the parents identified, and ecomaps that they created, will be discussed in depth in Act 2.

During the third stage of the interview, I asked each parent if they could tell me about one of the decisions that they had identified, and whether anybody on the ecomap had been involved in any way (I left the whiteboard with the ecomap on screen so that they could refer to this as needed). The parents told me the story of a particular decision, and I asked prompt questions as necessary, such as “can you tell me a bit more about what happened at that point?”; “was anybody with you at this moment or were you on your own?”. At times, I asked if I could clarify what they had said to check that I was understanding, so I would paraphrase their story. When I felt that the story around this decision had been adequately discussed, I asked if we could talk about another decision. Ensuring that parents could choose what decision to focus our conversation on heightened their autonomy in the interview. However, whilst in some cases parents chose something else that they would like to talk about, in other cases they said that I should choose what to talk about next. In these cases, I tended to ask if we could talk about something that had jumped out as a complex decision, or a different type of decision from the first (for example if the first decision had been focused on a medical issue, we then focused on a social decision). Some of these stories were extensive and so two decisions felt enough; in other interviews we discussed a third (and on occasions a fourth) decision. In all cases, as our conversations progressed, I was aware that the stories were rich, and I could sense that my interpretations were already underway. At times people strayed from talking about the experience itself, to reflecting on their thoughts about this, thus moving between a phenomenological account and a hermeneutic account. Whilst hermeneutic phenomenology interviews tend to stay focused on the participant’s experience, with the researcher taking on the role of interpreter, I acknowledged that according to Heidegger, we are all, always interpreting (Heidegger, 1927 / 2010) so there was some inevitability that parents may start to interpret their experience. I came to see that it was difficult for parents to talk about examples of decision-making in a purely descriptive way, as decisions did not happen as a defined moment, but rather decisions evolved and became part of a wider context of who each parent was. These conversations therefore became bigger than the moment of actually making the decision, and therefore at times this led to a slightly more hermeneutic focus than a purely phenomenological one that focused on the story of the specific decision-making experience.

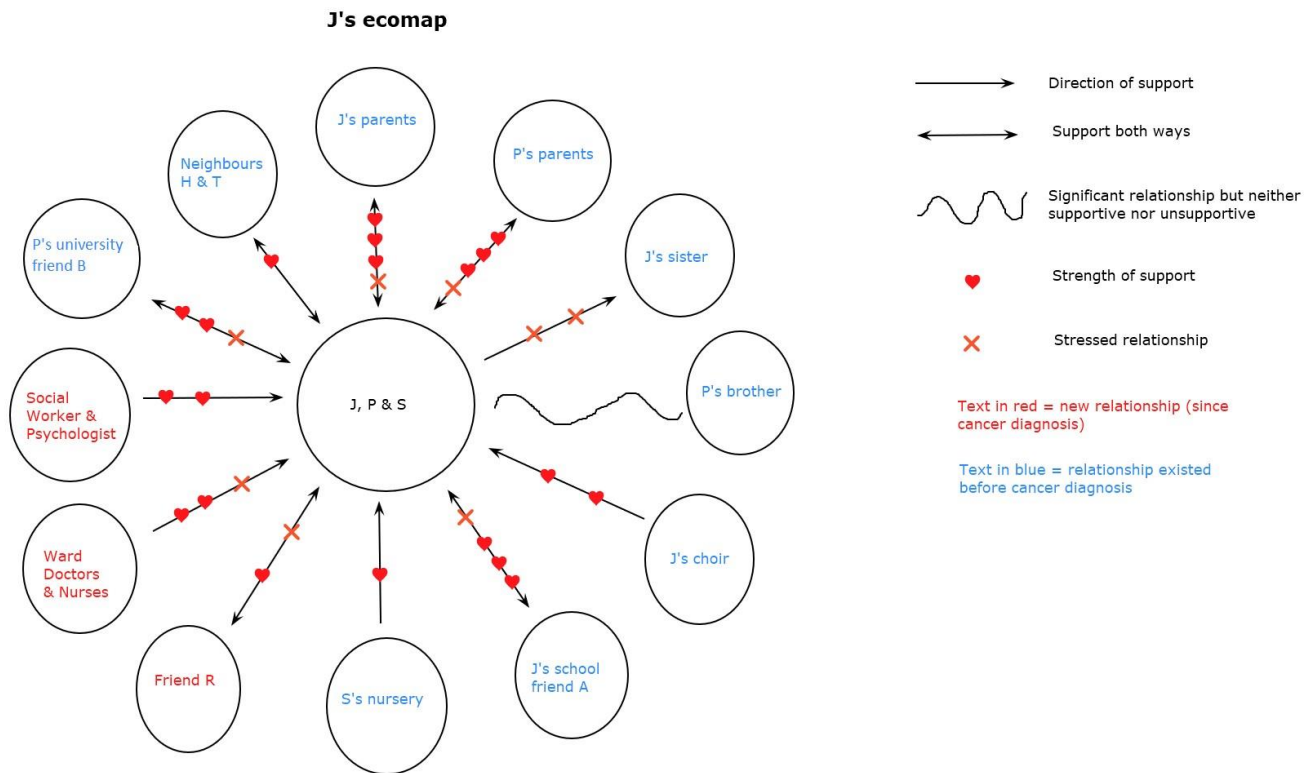
All of the interviews were long, ranging from one hour and 45 minutes, to just over three hours. In some cases, I felt that the conversation could continue further, but also recognised

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that the parents may become tired, and that my own capacity to deeply listen would be compromised if the interviews continued longer. As this time approached, I asked closing questions along the lines of “Is there anything that you would like to talk about in relation to this?”. This often generated further conversation but then led to a natural conclusion.

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Figure 2: An example of an ecomap



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Interpreting the stories

The term “analysis” does not feel to be appropriate for a hermeneutic phenomenological study. Analysis suggests that something is being broken down in order to understand its features, but in hermeneutic phenomenology the purpose is not to break the phenomenon down, but to understand the whole, and the heart, of the phenomenon’s being. For this reason, van Manen (2017) argued that phenomenology should absolutely not be seeking to code, sort, or search for frequencies, this would prevent the full phenomenon from showing itself. For this reason, I use the word “interpretations” to present the parents’ stories and how I learnt to understand these through engaging with philosophy and my own reflections. Having a separate section here to explain how my interpretations unfolded perhaps seems contrived – there was no start or end to this process, my interpretations started before the first interview and are still ongoing (in acknowledgement of de Witt and Ploeg’s (2006) criteria of actualisation). Yet this interpretive journey has shaped the whole of this study and so unpicking how this happened is important. Sloan (2002:129) referred to “moments of interpretation”, so this section will illuminate my moments.

Many researchers have provided a guide for how to work with data in hermeneutic phenomenological studies. In trying to establish what would work best for my study, I placed an emphasis on searching for a way that was grounded in philosophy (in order to remain aligned to de Witt and Ploeg’s (2006) framework). I was wary of following a guide that was process driven or that had poorly justified stages, and instead wanted to find something that would allow flexibility and creativity in order to respond to the parents’ stories rather than organise them according to a prescribed process. Crowther and Thomson’s (2020) approach to interpreting hermeneutic phenomenological research offers this flexibility and an acknowledgement of the iterative nature of interpretations, and has an emphasis on reflexivity and engaging with philosophical notions, and so I have used their approach in this study.

Crowther and Thomson (2020:6) included three levels in their approach but made it clear that this should be allowed to evolve iteratively and that different researchers may spend more or less time in each level. Level 1 involves crafting stories which allows participants’ words to be used to highlight the phenomenon of interest. Inevitably, the process of crafting stories involves some degree of interpretation, and so the interpretive process has begun. Level 2 moves to deeper interpretation by considering what is going on beneath the surface of the words, and then Level 3 makes the “interpretive leap” by engaging with philosophical texts and exploring how philosophical notions may further illuminate understanding.

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Whilst I certainly moved between all of these stages, I did feel that my interpretations started before the stage of crafting stories. It is also important to stress that most of my interpretive moments happened when I least expected them. They did not happen whilst I was working on the study, but often happened whilst I was out walking, singing, or talking with friends. My interpretations grew throughout the study, and keeping a diary of my thoughts helped to recognise and document that this was happening. Moments particularly happened during the interviews themselves. As parents spoke to me, I was making sense of what they were saying, and often my follow-up questions responded to these thoughts. Immediately after each interview I wrote a short account in my diary of my initial thoughts, what each parent had said that had particularly resonated with me, and how I felt at the end of each interview (examples of these reflections can be found in [Appendix 13](#)).

I transcribed each interview, and again I found that this triggered further thoughts, so I wrote these on each transcript. My supervisors also read each transcript at this stage and documented their thoughts (separately from mine). There then followed a period where I simply pondered what the parents had told me and dwelt with their stories. As well as re-reading the transcripts, I would often watch or listen to the recordings, sometimes whilst out walking. I constantly asked the question: “What is going on here?”. I started to craft stories, and this helped me to become more engaged with the transcripts. Over time I identified that my interpretations were drawing me to the phenomenon of “shaping confidence”. One Sunday, having spent the morning singing, I had an illuminating moment and mapped out my pathway to the clearing. I saw that shaping confidence could manifest itself through maintaining and renewing identity, and asserting and releasing control. This led to shaping parents’ confidence to ultimately trust themselves to advocate for their child.

Having moved tentatively from Crowther and Thomson’s (2020) Level 1 to Level 2 of interpretation, I moved back to Level 1. I began to craft stories again, but this time, with a clearer vision of the phenomenon that I was now focusing on. Again, this required close engagement with the transcripts. As I read and re-read the transcripts, and listened to the recordings, I asked myself “What does this tell me about confidence? What does this tell me about identity, control, and trust?” Crafting stories is a well-recognised methodical approach in hermeneutic phenomenology (Crowther et al., 2017). They allow the researcher to use the participant’s words to bring the whole story to life, rather than breaking down into short verbatim quotes. They have the potential to compel the reader or listener’s attention, and may therefore evoke the phenomenological nod (Smythe, 2011), a concept explained in the Overture which is aligned with de Witt and Ploeg’s (2006) criteria of concreteness and resonance.

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Act 3 will present the six crafted stories. I recognised that each transcript could be crafted into a number of different stories, but the final stories that I crafted represented to me specific aspects of the phenomenon particularly well. I felt it important that each parent should have their voice shared on the centre of the stage. However, whilst each of Scenes 2, 3, and 4 in Act 3 present two of the parents' stories, they all had something to say about identity, control and trust, so there are additional quotes throughout these scenes to contribute further dialogue with the crafted stories.

Having crafted the stories, I felt that there was something missing. Whilst the crafted stories helped to illuminate how the parents' confidence had been shaped by 'significant others', it seemed that there was also a story of losing confidence around the time of their child's diagnosis. As I repeatedly read the transcripts, I started to write down poignant phrases that parents had said. From these phrases, I found myself combining the phrases and words that the parents had used and could see that a poem was forming. Green, Solomon and Spence (2021) have promoted the use of crafted poetry in hermeneutic phenomenological research, proposing that poetry has the capacity to create a space of thinking and feeling in a unique way, and thus can bring to light the participants' experiences. This choral poem (as named by Green, Solomon and Spence (2021)) is presented in Act 3 Scene 1 and allowed me to bring together all six of the parents' voices and illuminate a particularly difficult time that the parents had lived through.

During the period that I was transcribing, crafting stories and writing reflective thoughts, I was also reading philosophical texts. Again, there were moments of epiphany as I read – for example, as I was reading *Being and Time* (Heidegger, 1927 / 2010) one evening, I read about the notion of 'solicitude'⁶, and this resonated very strongly with what I was seeing in the parents' stories around confidence. These moments constituted part of my interpretive leap. However much of this was an evolving thought process, and my understanding of what was going on very much grew as I wrote draft scenes or discussed my research through presentations. The final way that my interpretations were shaped was through the arts. I would listen to music as I wrote, and this seemed to help me to see the stories at a different depth. Similarly, I would visit art galleries, or look through art books, and a particular painting would stand out and make me think about the phenomenon in a new way. I felt that I was coming to

⁶ The notion of solicitude will be explained in Act 3 Scene 1 and forms the basis of significant discussion throughout this third act. Briefly, it relates to Heidegger's proposal that the basic structure of human existence is care, or concern, with others. When discussed in relation to our concern with other humans, the word 'solicitude' is used to describe the way in which other people matter to us (Heidegger 1927 / 1962).

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the clearing and that the combination of parents' stories, my own reflections, and the philosophy were leading me to a place of new understanding. I acknowledge though that the pathway that I will present in Act 3 is a possible pathway, not **the** only, or definitive pathway. I recognise that my interpretations will be ongoing and that there are many alternative ways in which the parents' stories may have been interpreted.

The Curtain Falls

The first two scenes of this act opened windows. From the everydayness of the home, the woods came into view by looking into a mirror of my own pre-understandings, and exploring the context of the guiding philosophers. This scene has now opened the door. The underpinning philosophy and methodology of hermeneutic phenomenology has been discussed and explored within the context of this study. Considerations that provided a guiding steer to my research journey have been presented, including quality and ethical considerations, and then a detailed account of how the research journey was navigated has been provided. The woods are now in full view, and it is time to step outside the comfort of home. The final scene of this act will take these first steps towards the woods by engaging with other narratives and moving further around the circle of understanding.

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Scene Four: Exploring other narratives



Act One: Into the woods

Scene Four: Exploring other narratives

Soundtrack: The Watermill, Ronald Binge, 1958

This scene demonstrates the iterative nature of hermeneutic phenomenology, and how engaging with the literature shaped my interpretations during and after the interviews, and how the conversations that I had with parents then shaped my further engagement with literature. This iteration can be heard in this beautiful piece of music. Just like a watermill, the accompaniment to the oboe solo circles around. The oboist though, provides an overarching melody that takes us forward. Even though we are hearing circular movement, there is still direction. As I engaged with other narratives, my understanding was always moving forwards.

The first time that I heard this music was as a child. It was used as the theme music for a television adaptation of *The Secret Garden*. Watching this as a child, I believed the story to be utterly magical, and the music played a significant role in how I saw the magic unfold. As an adult, I still see, and hear this magic. Now I see though that the story is not about supernatural magic. Rather, the magic and beauty come from being able to rediscover and see the world through new eyes.

Engaging with other narratives was a significant step in shaping my understanding of this study, allowing a transformation of how I would see the world through new eyes.

Scenery: 'The Philosopher in Meditation', Rembrandt van Rijn, 1632

This painting struck me as I looked at the man sitting at the table. Books are on the table, and although it could be assumed that he is studying, he is not looking at the pages but instead looks down. Reminiscent of my engagement with the literature in this study – whilst I needed to read the pages of research publications and other sources of literature, I often found myself deeply immersed in my thoughts during this time. I felt my thoughts moving between the different sources of literature, my anticipation and later reflections about the study interviews, and my own pre-understandings. I was moving around the hermeneutic circle and my understanding was constantly evolving. The spiral staircase next to the philosopher aligns with this metaphorical hermeneutic circle and the movement between the darkness and light of understanding.

The light in this painting creates a powerful sense of needing to look outwards – out of the home to follow the stream of light. As light started to shine on my research through engaging with other narratives, I became inspired to search for more light, to travel further into the study to look for more depth and better illuminate the phenomenon.

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The Curtain Rises

In Scenes 1 and 2, looking into the mirror of my pre-understandings and understanding the philosophers opened windows that looked into the woods. Scene 3 opened the door by navigating the research journey, and the woods came into full view. It is now time to take a step outside, and to start moving towards the woods. This scene will explore other narratives around what it means for parents to be supported with making decisions when their child has cancer. A formal review of relevant research literature will be presented, and this will then be supported with discussion about wider literature and how this has informed my thoughts and ideas about this topic area.

Approaching the narratives

As acknowledged in Scene 3, whilst there is controversy around the timing and role of literature reviews in hermeneutic phenomenology (Smythe and Spence, 2012; Dibley et al., 2020), there is justification for undertaking the literature review at an early stage in the study. Whilst the purpose of literature reviews is usually to synthesise and report what is currently known about a topic (Aveyard, Payne and Preston, 2016), in the context of a hermeneutic phenomenological study the purpose of the literature review is to incite thought (Smythe and Spence, 2012). This engagement with the literature therefore facilitates a journey further into the hermeneutic circle and our understanding travels forward.

I explored other narratives in two ways. In the early stages of the study, I undertook a formal literature review that focused on relevant research papers. This was an integrative review, aligned with Whittemore and Knafl's (2005) approach, and was written for publication (the full publication – Jestico et al., 2023b, can be found in [Appendix 14](#)). I also though wanted to explore narratives beyond the formal literature review. This involved keeping up to date with academic publications after my initial review had been completed, and also looking outside of academic publications and being open to thinking and learning about the topic from a variety of sources (such as publications aimed at families of children with cancer, and fictional narratives). This scene will present the formal integrative review's methods and findings, and will explore some of the alternative narratives. However, discussion of these narratives will also be integrated throughout Acts 2, 3 and 4.

Early scoping of the literature revealed that no previous research had addressed my specific research question. Rather than focusing on the *meaning* of how parents are supported to make decisions, I therefore looked more broadly at relevant literature and asked the question **“How do ‘significant others’ support parents with decision-making about their child’s cancer care?”**

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Integrative reviews provide a broad approach to reviewing and synthesising literature, enabling the development of new understanding (Whittemore and Knafl, 2005). In the context of this topic, this approach therefore enabled the inclusion of research using diverse methodologies. From the initial scoping of the literature, I was aware that relevant research included mainly qualitative, but also quantitative and mixed methods approaches. I did not want to exclude any potential sources of understanding because of a publication's research methodology, and therefore felt that an integrative approach would be a good way to review the literature.

The predominant search strategy for the integrative review involved using four computerised databases (The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO and the British Nursing Database (BND)) using the search terms presented in Table 2. Following lengthy consideration, I decided not to include the term of 'significant others' as a search term on the basis that this is a concept that is self-defined by individual families. I was concerned that if I included synonyms for this term, the search would become restricted by my subjective definitions of this concept, and I might therefore miss relevant studies. In addition to database searching and retrieval, I also consulted reference lists of retrieved papers to search for further relevant studies. Finally, I talked to experts in the field and sometimes these discussions highlighted other potentially relevant research. In addition to published research, relevant dissertations and theses were retrieved from these searches.

Table 2: Database search terms

1.	caregiver OR mother* OR father* OR parent* OR guardian* OR carer*
	AND
2.	decision* OR decide* OR consent*
	AND
3.	neoplasm* OR cancer OR oncolog*
	AND
4.	influence* OR support* OR help* OR advice* OR advis*
	AND
5.	child* OR pediatric* OR paediatric* OR adoles* OR youth* OR teen* OR infan*

I developed and applied inclusion and exclusion criteria (Table 3) in order to ensure that irrelevant studies were excluded. The search was limited to studies published in English. No research was excluded according to the date of publication as there was no clear rationale to do this and I wanted to capture all research about this topic. All types of primary research were included. Screening titles and abstracts according to the criteria reduced the number of papers

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significantly. I then read the full texts of the remaining papers to decide whether the inclusion criteria were met. Twenty-six studies met the inclusion criteria and were included in the analysis of this review.

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Table 3: Inclusion and Exclusion Criteria applied to literature

Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
Population involved in making decisions			
Parents of children with cancer	Children / adolescents / young adults with cancer	The focus of the study is on parents' support needs for decision-making, not children's support needs for decision-making.	10
	Parents of adolescents / young adults with cancer	In this study, the focus is on parents of children, as opposed to adolescents or young adults. The relationship and responsibility for decision-making between parent and child changes as the child becomes older, and the focus of this project is on a child who has limited capacity to make their own decisions. Therefore, if the research focused exclusively on parents of adolescents / young adults with cancer, it was excluded. However, a significant amount of the research did not differentiate between the ages of children, so in some cases literature was included that covered a broader age range.	0
	Adult patients with cancer who have children	Several of the retrieved studies related to adults with cancer who were parents, and the impact of this on their children, as opposed to the child having cancer.	10
	Parents of children with other conditions	The focus of this review is specific to children with cancer and only these studies could be included.	32

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Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
Context of Decision-Making			
Any decision that parents make about their child's cancer care, when their child has a cancer diagnosis	Decisions related to cancer screening	The focus of this project is on parents whose child has cancer and the decisions related to their care.	18
	Decisions related to cancer prevention (for example HPV vaccination)		
Source of Support or Influence			
Support from self-identified 'significant other' or social network member (even if this is not the	No reference to who the 'significant others' are	A few research studies referred to an unidentified person or group of people, as being involved in the decision-making process. These papers were excluded as one of the aims of this review is to understand how relationships may affect experiences of support. It is therefore necessary to identify the type of relationship between parent and 'significant other'.	4

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Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
primary focus of the study)			
	Support from health care professionals	The focus of this review is on the support from the parents' 'significant others'. It is possible that parents will identify the child's team of health care professionals as an emerging part of their network. However, the health care professional's role in supporting the parents' decisions is complex as their primary role is to advocate for, and promote the best interests of the child, rather than the parents. The abundance of existing research about the health care professional's role in supporting decision-making and the complexity of this role places this source of support beyond the remit of this review.	19
	No reference to decision-making being supported	When the full texts were screened it became apparent that a significant number of studies focused on parental decision-making processes and there was no focus on the parents receiving support from others with this process.	55
Type of Literature			
Primary research including all types of methodology (quantitative,	Secondary research (literature reviews) Opinion-based literature	The intention was to exclude literature reviews, however no relevant literature reviews were retrieved in the search. One non-research paper was relevant to this review (Massimo, Wiley and Casari, 2004). However, the opinions expressed in this paper did not add any original insight to the findings of this review.	4

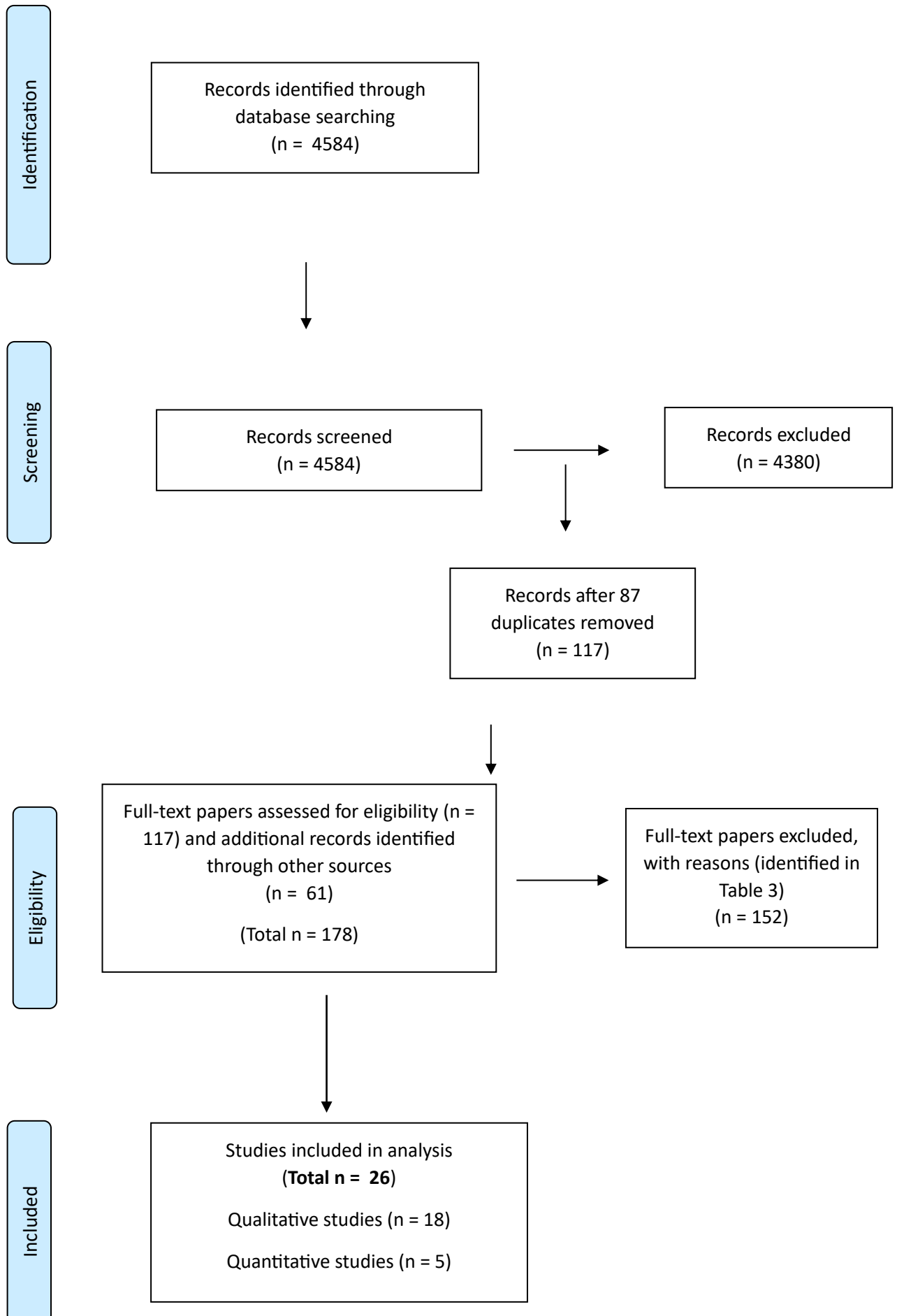
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Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
qualitative and mixed methods)			
		Total excluded at full text level of screening	152

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Figure 3: Flow diagram of screening process (adapted from PRISMA) flow diagram

(Moher *et al.*, 2009)



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I used the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) to appraise all of the research papers as this tool allows for the appraisal of quantitative, qualitative and mixed method studies. In line with Whitemore and Knafl's (2005) approach, this process did not result in the exclusion of studies, but the key limitations identified through this process are indicated in Table 4. This table also presents the studies included in the review with key details about the design and findings of each study.

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Table 4: Data extraction from the literature review

Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Alam & Kumar, 2019 India	To investigate the impact of an extensive financial, social support, and group counselling programme on treatment refusal and abandonment from 1995 to 2017 in North India.	Quantitative: Retrospective Cohort Study with three phases of support interventions. Data collected from the cancer registry. Children who abandoned / refused treatment were identified, and their parents were asked to complete a questionnaire about the reasons for abandonment.	Children recorded on the cancer registry from 1995 – 2017 (n = 1041) Parents of children with acute lymphoblastic leukaemia aged less than 18 years who completed the questionnaire relating to reasons for treatment abandonment (n = 196)	Engagement with parent support groups appeared to influence parents' decision to continue treatment for their child.	- Longitudinal nature of the study makes it impossible to eliminate other factors that may not be directly linked to the interventions. - Limited depth around the reported findings (possibly due to journal word limit) so not possible to unpick what element of the intervention impacted on decisions.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Blakeley, Riberiro & Crocker, 2000 Canada	To evaluate if parents were satisfied with the education and support provided to them in relation to making decisions about their child's central venous access device (CVAD).	Quantitative: 83 item questionnaire survey.	Parents of children with cancer who had a central venous access device inserted (n=44, return rate of 88%). 86% of respondents were mothers.	Some parents reported that their decision was made jointly with another family member.	- Questionnaire was not formally validated although it had been piloted. - Authors acknowledge that generalisability is problematic.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Cohen, Wakefield, Tapsell, Walton & Cohn, 2017 Australia	To compare views among parents, patients and health-care workers on the positive and negative aspects of Enteral Tube Feeding (ETF), the ways in which information was provided, and how the decision-making process was conducted.	Qualitative: Semi-structured interviews. Data analysed using content analysis.	Two groups of participants: (i) children with cancer aged less than 18 years (n = 10) or their parent if the child was aged less than 12 years (n = 20: 18 mothers, 2 fathers); (ii) health-care professionals (n = 18).	Parents seek information from other families on the ward. They watch other families' experiences, and this seems to influence their decision.	- Single site study - Authors acknowledge that recall bias may be problematic

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Eder, Yamokoski, Wittmann & Kodish, 2007 USA	To report suggestions that parents made about improving the informed consent process.	Qualitative: Interviews and Focus Groups. Parents were interviewed twice (at the time of informed consent and again 6 – 8 months later. Focus groups including all parents who had participated in the interviews. Finally, a parent advisory group on informed consent (PAGIC) was convened. Data analysed using an approach based on grounded theory.	Parents of children with leukaemia (across 6 hospitals). Initial interview (n = 132); Follow-up interview (n = 110); Focus groups (n = 72); PAGIC meeting (n = 9).	Parents suggested that they wanted to talk to their family and friends, and also other parents of children with cancer, before making a decision, they also suggested that allowing another person to attend the consultation with them would be helpful.	

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Gage, 2013 USA	To examine how network ties among parents of paediatric cancer patients shape parents' perceptions of the health care experience.	Mixed Methods: In-depth interviews and standardised survey questionnaire. Thematic analysis was conducted.	Parents of children with cancer (n = 76: 49 mothers, 27 fathers).	Other parents of children with cancer support parents and this may affect decision-making.	- Concept of 'similar' versus 'significant' others are imposed by the researcher on participants rather than self-defined.
Gage-Bouchard, 2017 USA	To explore how social support helps people to navigate the health care system.	Qualitative: In-depth interviews were undertaken and observations of clinical interactions between the oncologist and the parents were conducted. The parents who were interviewed were not the same parents who were observed.	Two groups of participants were interviewed: (i) parents of children with cancer (n = 80: 51 mothers, 29 fathers) (ii) paediatric oncologists (n = 8). Observations of clinical interactions between families and physicians (n = 73)	Social networks can offer informational support which may inform decision-making. The provision of practical support from social networks allows parents to be more present at the hospital and therefore more involved in decision-making.	- Unclear why the decision was made to interview a different group of parents to those being observed.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Hamama-Raz, Rot & Buchbinder, 2012 Israel	To investigate the coping experience of parents of a child with retinoblastoma.	Qualitative: Phenomenological interviews. Content analysis was undertaken.	Parents of children with retinoblastoma (n = 12 sets of parents, although one interviewee had been widowed and so was interviewed alone).	Other parents of children with retinoblastoma are considered a source of emotional support, and this links to the parents feeling that they can make decisions.	- Some of the participants had received their child's diagnosis 12 years previously which may have been considered too long a period of time for the participants to reflect back on their experiences.
Holm, Patterson & Gurney, 2003 USA	To explore parents' descriptions of their participation in medical care for their children with cancer.	Qualitative: Focus groups. Content analysis was undertaken.	Parents of children who had completed cancer treatment at least one year prior to the focus group (n = 45: 26 mothers, 19 fathers).	Parents sought informational support from other parents of children with cancer, and from family members and friends with medical expertise. This informed their decisions.	- Data collected between 1990 – 1998 and therefore may not be representative of people's experiences today. - Authors acknowledge that the data drawn upon for this study is used to answer a question that was not the original focus of the research project. Further questioning and exploration in relation to this topic may have elicited different responses. - Possible recall bias as participants were reflecting on events that happened up to nine years previously.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Huang, Mu & Chiou, 2008 Taiwan	To explore family experiences in terms of family resources and how these assist a single parent caring for a child with cancer.	Qualitative: Phenomenological interviews. Transcripts were analysed based on Colaizzi's (1978) principles of phenomenology.	Single parents of children aged less than 18 years receiving treatment for cancer (n=9: 5 mothers, 4 fathers).	Single parents may receive emotional, informational and practical support from relatives and friends, and also seek information from other parents of children with cancer. However, parents feel that the decision must be made alone.	- The authors identify that the results may not be representative as a limitation of their study; this is misaligned with the concept of phenomenology as the purpose of this research is not to present people's experiences as representative of others.
H-Yazdi & Meadows, 2021 UK	To explore how parents of children treated with Proton Beam Therapy (PBT) view the treatment and the sources of information surrounding the treatment.	Qualitative: Interviews. Transcripts were analysed thematically.	Parents of children who had been treated with Proton Beam Therapy (n = 27: 19 mothers, 8 fathers).	Parents seek information from family, friends and from other families of children who have undergone PBT.	- Authors acknowledge that a limitation is that parents were recruited to this study via online support groups which may have meant that the participants were more engaged with online support than other families may have been.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Israëls, Chirambo, Caron, de Kraker, Molyneux & Reis, 2008 Malawi	To gain insight into the guardians' perspective on cancer treatment, especially concerning factors which could influence abandonment of treatment.	Qualitative: Interviews and focus groups. A sequence of semi-structured interviews were undertaken at various points during the child's treatment trajectory. Focus groups were also held. Analysis was influenced by a grounded theory approach.	Guardians of children with Burkitt lymphoma or Wilms tumour (n = 32: 31 mothers, 1 father)	Some guardians asked their relatives for advice about decision-making.	- Lack of detail reported about the methods and analysis. - No quotes are used to illustrate themes. - Authors acknowledge that one of the interviewers was a physician on the ward where the child was being cared for and that this may introduce bias.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Jong, Boers, van Wietmarschen, Busch, Naafs, Kaspers & Tissing, 2020 Sweden / Netherlands	To develop an evidence-based decision aid for parents of children with cancer and to help guide them in the use of complementary and alternative medicine (CAM) for cancer care.	Mixed Methods: 23-item, validated questionnaire survey; and focus group (analysed using a directive content analysis). The survey and focus group were the first phase of the development of the decision aid (there were 4 phases in total) and is relevant to this review as it related to how people made decisions.	Parents of children with cancer (survey n = 70: 93% mothers; focus group n = 7)	Some parents sought informational support from family and friends.	- Unclear whether the survey findings influenced the design of focus groups

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Kelly & Ganong, 2011 USA	To explore how parents who no longer live together make treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. Analysis followed the grounded theory process.	Custodial (n = 7: 6 custodial mothers, 1 custodial father); Non-residential (n = 5: 1 mother, 4 fathers); and Stepparents (n = 3: 1 stepmother, 2 stepfathers) who had previously made a major treatment decision for their child with cancer (total n = 15).	The responsibility around the decision-making in diverse family structures is complex. Step-parents offered significant emotional support, and often informational support. However, the parent also needed space to make decisions. Different types of decisions required different types of support.	- Single site study
Kilicarslan-Toruner & Akgun-Citak, 2013 Turkey	To explore the information-seeking behaviours, perceptions, and decision-making experiences of parents of children with cancer.	Qualitative: Interviews. Inductive content analysis was undertaken.	Parents of children with cancer (n = 15: 13 mothers, 2 fathers).	Parents are supported with finding information from friends, and from other parents of children with cancer.	- Authors acknowledge that the findings are not intended to be generalisable. - Authors suggest that the study could have been strengthened by interviewing the other parent in the family.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Levi, Marsick, Drotar & Kodish, 2000 USA	To learn about, and to describe retrospective perceptions of parents of the circumstances of their child's cancer diagnosis and of the informed consent process.	Qualitative: Focus groups. Cross-case analysis was used.	Parents of children with cancer who had been eligible for a clinical trial research protocol (n = 22: 16 mothers, 6 fathers).	Some parents sought emotional and informational support from family, friends, and other parents of children with cancer. This helped them to make decisions.	- Although described as a qualitative study, the data analysis is treated in a quantitative way. - Authors suggest that it is not possible to generalise as the sample size is small, but this is not in line with a qualitative perspective.
Liang, 2002 Taiwan	To discover the cultural care practices of caregivers when promoting the health and well-being of children with cancer.	Qualitative: Ethnonursing interviews. Analysis underpinned by principles of ethnonursing.	Two groups of participants: (i) caregivers of children with cancer (n = 34: 23 mothers, 8 fathers, 1 grandmother, 2 aunts) (ii) nurses (n = 6).	Extended family members significantly influenced parents' decision-making about treatment. Parents worried that they might offend their family and health care professionals if they rejected their advice.	- Single site study

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
McKenna, Collier, Hewitt & Blake, 2010 UK	To identify parental perceptions of both their own involvement and that of others in the decision to enrol their child on to a specific cancer treatment protocol, and their satisfaction with this decision.	Quantitative: Questionnaires and interviews. Parents completed two validated questionnaires within an interview context with four additional questions also asked at the interview. Data analysed using the Statistical Package for the Social Sciences.	Parents of children with cancer (n = 66).	Some parents sought advice from relatives. When other people were involved with making a decision, they reported more difficulties with the decision-making process, however parents reported that they felt more satisfied with their decision if they had received the right amount of support.	- Nature of the methodology prevents depth in the exploration of parents' experiences. - Limited potential to establish cause versus effect, for example whether parents find it more difficult to make a decision when relatives are involved because of that involvement, or whether this is because they asked for support because it was a difficult decision to make. This is acknowledged by the authors.
Mostert, Njuguna, Langat, Slot, Skiles, Sitaresmi, van de Ven, Musimbi, Vreeman & Kaspers, 2014 Kenya	To explore parents' experiences with hospital retention policies and the impact of attitudes of family and friends on parents' decisions about continuing cancer treatment for their child.	Quantitative: Questionnaire via interview. Most questions framed on two-point, three-point, or four-point rating scale. There was one open-ended question. The responses were statistically analysed.	Parents of children with cancer who had abandoned cancer treatment (n = 46).	In many cases, extended family and other members of the community advised parents to abandon conventional treatment. Other parents of children with cancer also influenced the parents' decisions.	- An open question in the interview is alluded to but there is no reported analysis of responses.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
O'Neil, 1996 USA	To explore the experiences of parents as they made decisions when their child had a recurrence of cancer.	Qualitative: Phenomenological interviews. (<i>Doctoral Thesis</i>) Analysis underpinned by the philosophy of Heidegger.	Parents of children with relapsed cancer (n = 6 family units).	Support from family and friends was helpful if it was non-judgemental, emotionally reassuring and provided practical / financial help. However sometimes the help offered was misdirected and detrimental.	
Papadatou, Yfantopoulos & Kosmidis 1996 Greece	To investigate the experiences of Greek mothers who cared for a child dying of cancer at home or in the hospital, and to highlight some of their major needs during the terminal period.	Mixed Methods: Three methods of data collection were used: semi-structured interviews, patient medical records, and a validated questionnaire – the Grief Experience Inventory.	Mothers of children who had died of cancer (n = 15).	The findings suggest that having practical and emotional support available from extended family influenced the mother's decision to care for her child at home.	- Small sample size for a mixed methods study, and therefore statistical analysis is limited. - Emphasis in the paper is therefore on qualitative analysis. - No identification of how the information from medical records was integrated into the analysis.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Renner & McGill, 2016 Ghana	To explore factors influencing parental decision-making for children with cancer with regard to health seeking and retention in treatment.	Qualitative: Interviews and focus groups. Thematic content analysis was undertaken.	Parents of children with cancer (interviews n = 12, focus groups n = 7. Of this total of 19 participants, 13 were mothers and 6 were fathers).	Parents sought information from relatives, friends and other members of the community. Some parents made decisions to use native / herbal medicine because of influence of these people. Financial support from these groups also influenced their decision-making.	- Authors suggest that a limitation is that the findings aren't representative of the general population, but this is misaligned with a qualitative perspective.
Robertson, Wakefield, Shaw, Darlington, McGill, Cohn & Fardell, 2019 Australia	To explore parents' and adolescents' views and perceptions of making medical decisions in paediatric oncology.	Qualitative: Semi-structured interviews. Demographic data statistically analysed. Interview data thematically analysed.	Two groups of participants: (i) parents of children with cancer (n = 25: 23 mothers, 2 fathers); (ii) adolescents with cancer (n = 5).	Parents sought informational support from online parent forums and from other families on ward.	- Authors acknowledge that only one site was accessed and there was limited diversity of participants.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Sitairesmi, Mostert, Schook, Sutaryo & Veerman, 2010 Indonesia	To analyse parents' reasons for treatment abandonment and to ascertain the consequences of children who abandoned treatment.	Quantitative: Semi-structured questionnaires / interviews and observations of social / home circumstances were made. Statistical analysis applied.	Families of children with acute lymphoblastic leukaemia (n = 37).	Other people in their community, and other families of children with cancer, influenced the parents' decisions. Financial support from other people was also a factor that influenced their decisions.	- No information reported about how the questions were developed or piloted.
Stewart, Pyke-Grimm & Kelly 2012 USA	To describe the process of parents making major treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. The interview guide was revised throughout the study in line with the constant comparative analytic technique of grounded theory.	Parents of children with cancer (n = 15: 9 mothers, 6 fathers).	Findings suggest that parents do not want involvement of their social network when they make major treatment decisions.	- Authors acknowledge that there was a lack of cultural diversity within their group of participants.

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Author, Year and Country	Aim of Study	Research Design and Method	Participants	Key Findings in relation to this literature review	Study Limitations
Woodgate & Yanofsky, 2010 Canada	To understand Canadian parents' participation in decisions about childhood cancer trials.	Qualitative: Interviews. Constant comparative method was used to analyse the data.	Parents of children with cancer (n = 31: 20 mothers, 11 fathers).	This suggests that advice from "expert" family / friends is supportive.	- Authors acknowledge the retrospective nature of the study but also that the opportunity to reflect on decision-making is a strength. - There is a lack of diversity represented in the group of participants.
Yeh, Lin, Tsai, Lai & Ku, 1999 Taiwan	To document the determinants of parental decisions to "drop out" from cancer treatment for their child.	Qualitative: Interviews. Content analysis was undertaken.	Parents of children with cancer who had dropped out of cancer treatment (n = 19: 14 mothers, 5 fathers).	Decision to abandon treatment was significantly influenced by other parents of children with cancer. Some parents were also influenced by religious beliefs.	- Authors suggest that the study is limited by its small sample and that the sample is not representative, however neither of these limitations are in line with a qualitative perspective.

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Understanding research narratives

There were two stages of analysis for the research included in this integrative review. The first stage (represented in Table 5) involved extracting detail about the types of decisions that parents faced in each study, and the source of support (in relation to 'significant others'). It is important to recognise that most studies did not focus on support from 'significant others' and therefore the parents had not identified these people as significant to them. It should be noted that Gage's (2013) study in particular, specifically explored the role of 'experientially similar others', and drew a distinction between 'significant others' (parents' pre-existing social network of family members and close friends) and 'similar others' which in this context related to a new network of people who were living through a similar experience. It could be argued though that this concept of 'significant' versus 'similar' others was imposed on participants by the researcher rather than defined by participants.

Table 5: Types of Decision and Sources of Support identified in the literature review

Author and Year	Type of Decision	Source of Support ('Significant Other')
Alam and Kumar, 2019	Treatment abandonment	Other parents of children with cancer
Blakeley, Ribeiro and Crocker, 2000	Choice of central venous access device	Family member
Cohen et al., 2017	Nutrition (enteral tube feeding)	Other parents of children with cancer
Eder et al., 2007	Enrolment in research trial	Family / friends / other parents of children with cancer
Gage, 2013	Not specified - any decision relating to child's cancer care	Other parents of children with cancer
Gage-Bouchard, 2017	Not specified but focus is on "navigating the health care system"	Not specified but refers to "personal networks" and suggests that this includes relatives and friends. There is specific reference to members of networks who are health care professionals
Hamama-Raz, Rot and Buchbinder, 2012	Surgical treatment (removal of eye as treatment for retinoblastoma)	Other parents of children with cancer
Holm, Patterson and Gurney, 2003	General decisions about cancer care	Family / friends with medical expertise and other parents of children with cancer

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Author and Year	Type of Decision	Source of Support ('Significant Other')
Huang, Mu and Chiou, 2008	Various decisions; the focus of this research is not on decision-making but there is discussion about general decisions, place of care, education, and other lifestyle choices, all of which relate to the child's cancer care in a broad context	Family / friends and other parents of children with cancer
H-Yazdi and Meadows, 2021	Proton Beam therapy	Family / friends with specialist expertise; other parents of children with cancer and online support groups
Israëls et al., 2008	Treatment adherence / abandonment	Relatives, mainly grandparents
Jong et al., 2020	Complementary and alternative medicine	Family / friends
Kelly and Ganong, 2011	Major treatment decisions and daily decisions	Step-parents
Kilicarslan-Toruner and Akgun-Citak, 2013	General decisions and information e.g. mouth care, diet, and bigger treatment decisions	Relatives / friends / other parents of children with cancer
Levi et al., 2000	Treatment / research decisions	Friends / family / other parents of children with cancer
Liang, 2002	General care decisions including diet, alternative medicines (e.g. Chinese medicine / herbal medicine)	Friends / community (elders) / religious community / grandparents / other parents of children with cancer
McKenna et al., 2010	General treatment decisions	Grandparents and other relatives / family members
Mostert et al., 2014	Treatment abandonment	Grandparents and other relatives / friends / community / religious community / other parents of children with cancer
O'Neil, 1996	Relapse treatment decisions	Family / friends / neighbours / religious communities / employer - NOT other parents of children with cancer

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Author and Year	Type of Decision	Source of Support ('Significant Other')
Papadatou, Yfantopoulos and Kosmidis, 1996	Place of death of child with cancer	Relatives / grandparents / other parents of children with cancer / religious community
Renner and McGill, 2016	General treatment decisions	Friends / relatives / religious communities / herbalists / other parents of children with cancer / grandparents
Robertson et al., 2019	General but emphasis on treatment decisions, also acknowledges minor decisions.	Online parent forums / other parents of children with cancer
Sitairesmi et al., 2010	Treatment abandonment	Relatives / people on whom they are financially dependent/ religious communities / other families of children with cancer
Stewart, Pyke-Grimm and Kelly, 2012	Major treatment decisions	Family / friends / religious figures
Woodgate and Yanofsky, 2010	Research trial enrolment	Family / friends with expertise
Yeh et al., 1999	Treatment abandonment	Grandparents / parents of other children with cancer/ religious communities and figures

The second stage of analysis involved using the Constant Comparative Analysis method as recommended by Whittemore and Knafl (2005). I read each study multiple times and recorded direct quotations of relevant extracts, and made initial notes about codes and themes. This was an inductive and iterative process. As I read each study, my ideas about themes evolved and I reviewed notes about previous studies. Once I had read all the studies several times and the compared the notes from each study with each other, I constructed the two main themes with associated sub-themes.

I identified two overall themes: “Dimensions of Decision-Making Support” and “Expectations of Decision-Making Support”. The first theme (Dimensions of Decision-Making Support) included three sub-themes – informational support, emotional support, and instrumental support. The second theme (Expectations of Decision-Making Support) included two sub-themes – parental expectations of their role, and parental expectations of the role of ‘significant others’.

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Theme 1: Dimensions of Decision-Making Support

Parents experienced support, and a lack of support, in three key dimensions – informational, emotional and instrumental. These three dimensions were labelled according to House and Kahn's (1985) functions of support in order to explore if, and how, the mechanisms of social support could be aligned to decision-making support.

Theme 1 Sub-theme 1: Informational Support

Managing information

The literature indicated that parents received informational support in two distinct ways. The most direct way was when other people provided them with information or researched information on their behalf. This helped parents to gather and manage the information that they felt that they needed to make their decision.

Some parents used their 'significant others' to gather and assimilate information simply so that they could gain sufficient knowledge to make an informed decision (Yeh et al., 1999; Levi et al., 2000; Holm, Patterson and Gurney, 2003; Kilcarslan-Toruner and Akgun-Citak, 2013). Often, this information came from other parents of children with cancer. In addition, Holm, Patterson and Gurney (2003) found that some parents would seek this support specifically from family members and friends who had medical expertise, and Levi et al. (2000) noted that one family asked friends to conduct research, which supported their decision-making process.

Some authors were able to provide a more nuanced understanding of how information gathering could help parents. Gage (2013), Gage-Bouchard (2017) and Robertson et al. (2019) found that parents spoke about using their network to translate specialist knowledge to aid their understanding. Again, the source of this support varied. Like Holm, Patterson and Gurney (2003), Gage-Bouchard (2017) found that parents would seek informational support from particular people within their network who had specialist expertise. For example, one mother identified that there were two registered nurses within the family who were able to translate specialist medical information into more understandable language. These findings suggest that this type of support aided parents' understanding, which helped them to communicate more easily with clinicians. This may have subsequently eased the process of making decisions, but this is not explicit.

Gage (2013) found that other parents of children with cancer carried out this translation of specialist knowledge. This was particularly noticeable when families with more experience supported the families with a new diagnosis to understand the hospital structure, cancer treatment, and medical jargon. Parents reported that this information felt more accessible and

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easier to understand which allowed them to use this information to consider alternative options. Interestingly the parents in Gage's study expressed that they placed more credibility on the information that came from other parents than the information from health care professionals. The parents in Robertson et al.'s (2019) study acknowledged that the information given by health care professionals could feel overwhelming, but that seeking further information from their 'significant others' made it feel more understandable. This translation of information helped parents to compile a list of questions for their treating team, which enabled them to clarify information.

Whilst the studies reviewed highlighted that parents asked their network of 'significant others' to seek information on their behalf, a contrast was presented by Stewart, Pyke-Grimm and Kelly (2012). In this study, whilst a few parents sought information from their network, the majority deliberately did not seek this and only wanted input from medical professionals. This demonstrates that different parents, in varying contexts, have a range of perspectives about what is helpful and supportive.

Learning from people's stories and experiences

Informational support extended beyond this direct method of information provision, and parents learnt from other people's experiences and stories. This became a way for them to absorb less formal, experiential information but that had the potential to strongly influence their decisions.

In many of the studies this support stemmed from other families of children with cancer (Yeh et al., 1999; Huang, Mu and Chiou, 2008; Sitaresmi et al., 2010; Gage, 2013; Mostert et al., 2014; Renner and McGill, 2016; Cohen et al., 2017; Alam and Kumar, 2019; H-Yazdi and Meadows, 2021). However, this was not exclusively the case and some parents also sought information from family and friends who had related experience (Sitaresmi et al., 2010; H-Yazdi and Meadows, 2021; Jong et al., 2020). Whilst this type of experiential informational support was acknowledged in several studies, some did not explore this aspect in sufficient depth to provide understanding of how learning from others' experiences supported parents' decision-making, nor were they explicit that this actually impacted on decision-making (Huang, Mu and Chiou, 2008; Cohen et al., 2017; Alam and Kumar, 2019).

However more detail about this process was given by H-Yazdi and Meadows (2021) who found that parents focused on the importance of learning from real-life stories. In this study parents whose children had received proton-beam therapy felt it important to listen to the experiences (often through virtual contact) of other families whose child had received the same treatment.

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The participants explained that these sources of information were preferable to information sheets, medical reports and expertise from doctors, which they felt to be removed from reality. This sense of credibility in learning from others' real-life experiences is echoed by Yeh et al. (1999) and aligns to Gage's (2013) findings that direct information provided from other parents held greater credibility than that received from health care professionals.

Gage (2013:48) found that, by observing and listening to each other, parents appraised their own experiences with reference to the experiences of other families and referred to this as a process of "social comparison". These stories and observations influenced their attitudes towards their own child's care. Although it is not explicit that this informed their decision-making, parents did feel that this empowered them to advocate for their child, which suggests that this social comparison process could be helpful.

A number of studies focused on factors affecting parents' decisions about treatment continuation versus abandonment and here, the negative impact of the social comparison process had direct consequences on parents' decision-making (Yeh et al., 1999; Sitaresmi et al., 2010; Mostert et al., 2014; Renner and McGill, 2016). The studies by Sitaresmi *et al.* (2010) and Renner and McGill (2016) expressed parents' sense of fear of cancer treatment as they heard the stories and watched other families' experiences. Yeh et al. (1999) found that watching the negative experiences of other families influenced parents' decisions to abandon treatment, as they watched other children suffer treatment side effects or die despite treatment. This is echoed by Mostert et al. (2014:704) who noted that parents hearing and seeing what was happening to other parents of children with cancer significantly influenced their decision-making. These findings demonstrate that by observing the experiences of others, misinformation was being circulated ("surgery spreads cancer"; "cancer is not curable") which influenced parents' decisions to abandon treatment. This is particularly evident in research from Taiwan, Indonesia, Kenya, and Ghana and is not noted in research findings from Australia, or European and North American countries.

The potential negative impact of learning from others' experiences was found by O'Neil (1996) to be a reason why parents deliberately avoided this type of informational support. Parents expressed that they did not seek support from other parents of children with cancer, as it was too frightening to observe other families travelling their own journeys of relapsed cancer. This is in contrast to many other studies cited in this review where parents did look to other families for support (Yeh et al., 1999; Levi et al., 2000; Holm, Patterson and Gurney, 2003; Eder et al., 2007; Huang, Mu and Chiou, 2008; Sitaresmi et al., 2010; Gage, 2013; Kilicarslan-Toruner and

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Akgun-Citak, 2013; Mostert et al., 2014; Renner and McGill, 2016; Cohen et al., 2017; Alam and Kumar, 2019; Robertson et al., 2019; H-Yazdi and Meadows, 2021).

This is perhaps due to the focus of O'Neil's study which is on children with relapsed cancer (who are likely to have a poorer prognosis), whereas the majority of other studies focus on decision-making through the child's first diagnosis.

Theme 1 Sub-theme 2: Emotional Support

Emotional support was perhaps less tangible than informational support in the reviewed literature, but it was nevertheless viewed by parents as important and similarly it came from different parts of parents' networks. Hamama-Raz, Rot and Buchbinder (2012:30) described parents need for "emotional containment" in order to be able to make decisions. O'Neil (1996) found that parents felt that having an emotionally supportive network gave them the time and space to make decisions.

Often emotional support stemmed from parents' relatives and friends. Papadatou, Yfantopoulos and Kosmidis (1996:229) framed this as "being present", although it is not explicit that this emotional presence led to mothers feeling supported specifically with decision-making. This sense of parents feeling a "supportive presence" from their 'significant others' was also found by Stewart, Pyke-Grimm and Kelly (2012:424) and whilst it is suggested that this did support treatment decision-making, it is acknowledged that this was only discussed by very few parents in the study.

The manifestation of emotional support was more actively demonstrated in other studies. The parents in O'Neil's (1996) study looked to their wider community for emotional reassurance. A similar sentiment is expressed by Gage (2013), who found that parents needed people to understand how they felt. The parents interviewed in this study did not feel that they could get this sense of understanding from their pre-existing network of family and friends and so they turned to other parents of children with cancer. Whilst this extract of Gage's (2013) study does not link explicitly to decision-making, Gage does suggest that this emotional support reduced parental stress, which may then have helped them feel better placed to make decisions. The parents in Eder et al.'s (2007:854) study also looked to other parents of children with cancer as they felt that these people were at a similar "emotional level", and similarly Huang, Mu and Chiou (2008:2744) described this emotional support from other parents as a contribution to parents' strength and "courage to carry on".

However, there appeared to be a risk that parents seeking this emotional understanding and reassurance could inadvertently put themselves in the position of feeling judged for their

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decision-making. This had the potential to be emotionally unsupportive and damaging. This concern was particularly noted by the parents in O'Neil's (1996) phenomenological study who felt that some members of the community had negatively judged their decision, which parents had found difficult to manage.

Theme 1 Sub-theme 3: Instrumental Support

The literature demonstrated that instrumental support was offered to parents in two distinct ways, practical and financial support.

Practical Support

Several studies discussed practical support being offered to parents (O'Neil, 1996, Papadatou, Yfantopoulos and Kosmidis, 1996; Huang, Mu and Chiou, 2008; Stewart, Pyke-Grimm and Kelly, 2012; Mostert et al., 2014). This took the form of cooking (O'Neil, 1996; Papadatou, Yfantopoulos and Kosmidis, 1996), shopping (Papadatou, Yfantopoulos and Kosmidis, 1996) and providing childcare for parents' other children (O'Neil, 1996, Mostert et al., 2014). None of these authors explicitly state that this practical support affected parents' decision-making. However, there is an implicit thread in O'Neil's (1996) work that suggests that the support gave the parents the time and space to consider the decisions they were making. Similarly, Papadatou, Yfantopoulos and Kosmidis (1996) suggested that having this practical support provided by family and friends, reassured mothers that they could choose for their child to die at home rather than in the hospital, as the support would be in place. It should be noted though that in both cases, these inferences come from the authors' interpretations rather than the direct words of the parents.

Financial Support

Financial support was significant for many of the parents in the studies – particularly in research from African and Asian countries (O'Neil, 1996, Huang, Mu and Chiou, 2008; Israëls et al., 2008; Sitaresmi et al., 2010; Mostert et al., 2014; Renner and McGill, 2016). This financial support was useful for different reasons. A parent in O'Neil's USA (1996) study talked about how a friend had started fundraising on the family's behalf, this was specifically because the family were struggling to cover the cost of travelling to and from the hospital so regularly. For the families in Mostert et al.'s (2014) and Renner and McGill's (2016) studies, this financial support was provided by the parents' relatives, friends and wider communities, and was extremely significant as it enabled the families to pay for the medical bills and drugs that their child needed. The focus of both of these African studies was around treatment retention versus

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abandonment, and as one of the factors for abandonment was linked to financial pressure, this support likely contributed to the parents' decision to continue cancer treatment for their child.

An opposing perspective is shared by Israëls et al. (2008) and Sitaresmi et al. (2010). The parents in both of these studies acknowledged that they consulted with people on whom they were financially dependent (such as their relatives). These people had a strong influence on the decision-making process, and in Sitaresmi et al.'s (2010) study parents' financial dependency on others influenced their decision to abandon treatment.

Another aspect of financial support related to parents' employment. Sitaresmi et al. (2010) found in their Indonesian study, that 54% of fathers lost their job because of having to accompany their child to hospital. Huang, Mu and Chiou (2008) discussed how, in Taiwan, the combination of financial assistance and practical support that relatives provided allowed the parent to leave their child temporarily so that they could keep their job. However, it is not clear if, or how, that affected making decisions. However, Gage-Bouchard (2017) reported that parents felt excluded from health care decisions because they were working and therefore not at the hospital with their child. The parents in this American study felt that if they could have received sufficient financial support to be able to take leave from work, they would then have been able to be more involved with making decisions.

Theme 2: Expectations of Decision-Making Support

Parents' experiences of support were influenced by their expectations of their own role (sub-theme 1), and other people's roles (sub-theme 2) in decision-making. Their expectations and roles were affected by their relationships with other people and these relationships could have both a positive and negative impact on parents' feelings of being supported.

Theme 2 Sub-theme 1: Parental expectations of their role

The parents in several studies strongly believed that as an advocate for their child, it was their responsibility to make decisions about their child's care, and nobody else's (O'Neil, 1996; Papadatou, Yfantopoulos and Kosmidis, 1996; Huang, Mu and Chiou, 2008; Kelly and Ganong, 2011). For the parents in Kelly and Ganong's (2011) study, this responsibility was an extension of their parental role, and similarly Papadatou, Yfantopoulos and Kosmidis (1996) expressed that this responsibility was enmeshed with the culture of Greek family functioning, where parents take an active and protective role in decision-making. Further explanation about this responsibility was highlighted by a parent interviewed by Kelly and Ganong (2011) who explained that taking full responsibility to make the decision avoided the risk of blaming others if the outcome was negative, suggesting that this process would protect both the 'significant others' and also protect the parents from this feeling. Interestingly Huang, Mu and Chiou

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(2008) uncovered a different perspective. They found that parents would rely only on themselves, suggesting a lack of trust in others. It should be noted that the focus of Huang, Mu and Chiou's (2008) study was on parental experiences in single-parent families, and Kelly and Ganong (2011) focused on single-parent and re-partnered family structures, so perhaps this sense of responsibility lying solely with the parent stemmed from a history of potentially complex relationships. Indeed, Kelly and Ganong (2011) acknowledged the difficulty of making decisions in families with pre-existing conflict as some parents felt very mistrustful.

However, this sense of responsibility and self-expectation that their role, as a parent, was to make difficult decisions about their child's care could come to feel burdensome. This was particularly the case for single-parent families (Kelly and Ganong, 2011) where a mother talked about feeling alone, and struggled with not being able to share this decision-making burden with anybody else. Parents in Woodgate and Yanofsky's (2010:14) study also talked about the immense difficulty of trying to meet the expectations of being a "good parent" by making the "right" decision for their child. This burden and emotionally charged context could lead parents to lose confidence in their ability to make decisions (Stewart, Pyke-Grimm and Kelly, 2012) and thus their confidence in performing their role as the child's advocate. This could then lead, in some cases, to parents looking to their 'significant others' to play a role in supporting the decision-making process.

Theme 2 Sub-theme 2: Parental expectations of the role of 'significant others'

Parents had varied expectations of the role that 'significant others' should play when decisions needed to be made. For the parents who felt strongly that nobody else should be involved in decision-making (as acknowledged above by O'Neil, 1996; Papadatou, Yfantopoulos and Kosmidis., 1996; Huang, Mu and Chiou, 2008; Kelly and Ganong, 2011), the expectation was that other people should give them the time and space to make this decision. Whilst parents acknowledged that other people may provide support during this time (such as the informational, emotional or instrumental dimensions of support explored in Theme 1), they were not expected to take a role in actually making, or influencing, the decision. Kelly and Ganong (2011:355) described this process in terms of step-parents being expected to "step back". However, in other cases, parents needed their 'significant others' to become more involved with directly supporting decision-making.

In these situations, when parents turned to others to discuss the decision that they were facing, they needed to talk through their thoughts and essentially needed 'significant others' to listen and to act as a sounding board (Blakeley, Ribeiro and Crocker, 2000; Eder et al., 2007; Huang, Mu and Chiou, 2008). A parent in O'Neil's study (1996:210) described this as "being

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able to hear your own voice". In some cases, this role of being a sounding board evolved to 'significant others' providing advice to parents (Israëls et al., 2008; McKenna et al., 2010; Woodgate and Yanofsky, 2010; Kelly and Ganong, 2011). Parents acknowledged that it could be helpful to hear other people's perspectives about the decision that they were making (Eder et al., 2007). Woodgate and Yanofsky (2010) found that parents would seek out key family members or friends who had specific knowledge, and that they would ask these people for advice. This is consistent with the informational dimension of support where it was also acknowledged that parents would seek information from members of their network who had specific knowledge. However, Woodgate and Yanofsky (2010) suggest that by specifically asking for advice from these people, parents could cope better with the stress and guilt that they were experiencing about making decisions. This was though, dependent on relationships, as Stewart, Pyke-Grimm and Kelly (2012) noted that some parents limited the involvement of their social network in decision-making because of pre-existing conflict. Interestingly, McKenna et al. (2010) found that where parents sought advice from other people (such as family members) they reported that their decision was more difficult to make. However, the authors acknowledge that it cannot be assumed that this meant that seeking advice made the decision-making harder, as it is also possible that parents who were already finding the process difficult sought the advice.

The literature reviewed demonstrated that there was a fine line between 'significant others' offering supportive advice to parents, and this being perceived by parents as interference. The step-parents interviewed by Kelly and Ganong (2011:357) referred to this as needing to "tread lightly", as whilst they could offer opinions it was important that they recognised that it was not their place to make the decision. The crossing of the boundary from support to interference was particularly noted in Liang's study from Taiwan (2002:213) where parents sometimes felt pressurised to listen to suggestions from elder family members, citing an example of a parent who said "I have to listen to my mother-in-law's suggestions to give my child herbs sometimes". A similar story from Ghana is cited by Renner and McGill (2016) where the child's grandmother would not allow the parents to make the decision to access hospital treatment, and instead insisted that the child should be treated with native medicine. Yeh et al. (1999), who similarly conducted their research in Taiwan, also found that in a small number of cases (3 out of 19), the decision to abandon treatment was made by the grandparents, rather than the parents. In all three of these studies, it is unclear how this involvement of grandparents in the decision-making process affected the parents' experiences. However, O'Neil (1996) found that interference from others felt to parents like an assault on their

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advocacy for their child, suggesting that the arguably self-appointed role of others was in direct conflict with the role identity of the parents.

[Summary of these narratives](#)

Current research suggests that 'significant others' can support parents in three dimensions: informational, emotional, and instrumental support. However, parents' perspectives of their own, and others', roles in decision-making also influences how support may be provided and received. Sources of social support range from parents' family members and friends to other parents of children with cancer.

It is clear throughout these themes and sub-themes that there is a fine line between supportive and unsupportive behaviours. This suggests that parents' support needs vary, which is unsurprising as every family's experience is situated in a different personal, social and cultural context. The extent to which 'significant others' behaviours directly affected parents' decision-making is not consistently clear from the research reviewed. There is also a lack of depth about how or why this behaviour was supportive or unsupportive and what this means to parents.

Jackson, Cheater and Reid (2008) define decisional support as anything that helps people to gather information and clarify their values. Whilst the findings of this literature review support the importance of informational support, it also demonstrates that supporting decision-making extends beyond Jackson, Cheater and Reid's definition and is placed within a complex personal, social and cultural context. In addition to informational support, emotional and instrumental support can also play a role in parental decision-making, and expectations of support are strongly influenced by people's perceptions of decision-making roles and relationships with 'significant others'.

This literature review demonstrates that there is more to be understood about this topic, justifying this study. As the findings suggest that support needs vary according to each parent's unique personal, social and cultural context, it is of value to explore this topic using a methodology that respects this uniqueness of context. Heideggerian philosophy and the methodology of hermeneutic phenomenology is therefore further justified as an appropriate methodological approach as the journey goes further into the woods.

[Moving beyond these narratives](#)

Following this formal literature review, I felt that it was important to keep abreast of new research in this area. I set up alerts from the same databases that I had used in the integrative review and therefore had weekly notifications about newly published academic articles. In

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addition, I received email alerts from the International Society of Paediatric Oncology (SIOP) community about new publications in the field. During this period, I read four new articles that were of relevance to my topic, and that added new understanding to my initial literature review.

A descriptive phenomenological study exploring parents' experiences of having a child with a brain tumour during shared decision-making processes (Huang, Mu and Chen, 2022) supported my findings that parents may seek informational support from relatives, friends and also other parents of children with brain tumours. They clarified that this helped parents to take control of the decision-making process. Miller, Maurer and Felker (2022) administered a survey to caregivers of children with cancer to explore how they were affected by social media. Their findings similarly supported the point that parents may seek information from others to support their decision-making. However, their study demonstrated that parents may look to others for support via social media, rather than draw on existing relationships. This made me question the role of 'virtual' relationships which may be more anonymous than relationships with specific known people. This is something that was a feature for some of the parents in my study and will be discussed in subsequent parts of this thesis.

Graetz et al. (2022), in their mixed-methods study exploring decision-making among parents of children with cancer in Guatemala, echoed the findings of the second theme from my review, that parents felt that overall, they needed to make the decisions alone, as a couple. Whilst they may seek others' opinions, ultimately, they felt that it was their role to make the final decision. Pearson et al.'s (2022) literature review also though, showed that 'significant others' may play a role in influencing parental decisions by sharing their opinions. Pearson et al. raised another very interesting point. Drawing on other literature, they proposed that parents are not involved in treatment decision-making if their child can be treated on a standard care protocol and only become involved with decision-making if there is no such protocol available. This paper was published during the period that I was interviewing parents and resonated with some of my findings. Again, this will be discussed further later in this thesis.

In addition to learning from relevant research studies, I wanted to explore alternative types of literature. During the years of the study, I engaged with narratives from fiction, and also public facing publications. Whilst everything that I read during this period informed my thinking in some way, two works of fiction in particular, influenced my understanding: Ian McEwan's *The Children Act* (2014) and Jodi Picoult's *My Sister's Keeper* (2004). Both of these address decision-making when children have cancer. In *The Children Act* decision-making is considered from the perspective of a High Court judge when a seventeen-year-old boy is refusing treatment for

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cancer. The boy's parents play a very limited role in this story, so in some ways this is tangential to my study. However, it casts a really interesting perspective about the limits of agency, or control, in decision-making. It helped me to question, as Pearson et al.'s (2022) study had, the extent to which children, young people, or indeed parents, are able to make decisions within the context of the UK's legal system. *My Sister's Keeper* presents multiple perspectives of decision-making when a child has leukaemia. Perspectives are presented of the child's sister and brother, the child's parents, and a lawyer who becomes enmeshed in the family's situation. Above all from this book, I could see the complexity of decision-making and how decisions may impact on the whole family. Finally, I watched a documentary film called *A Lion in the House* (Bognar and Reichert, 2006). This is a documentary that followed the lives of a number of families whose child had cancer. Set in America, I was struck by how the difference in health care system may impact on the types of decisions that families may face in different countries, and how the gravity of this decision-making affects the child and parents. Neither these books nor the film consider how social networks may support decision-making, but they did further my understanding about the wider context of decision-making and will inform the discussions in subsequent scenes.

Contact magazine is created by the Children's Cancer and Leukaemia Group in the UK and is a public-facing publication aimed at parents of children with cancer and health care professionals supporting these families. The focus of the spring 2021 issue of *Contact* was decision-making and choices. Two articles in this edition particularly struck me. Emily Marshall (p5) wrote about her experiences as a parent making decisions. She reflected on the decision about whether or not to enrol her daughter onto the treatment trial; a decision around insertion of a port-a-cath, and a number of decisions about life outside of hospital such as diet and activity. These decisions about life outside of the hospital were not captured in the literature review that I undertook so were of interest to me. Interestingly these types of decision did become a significant source of discussion in my study's interviews, showing that the decisions framed as significant by researchers may not always be the same as parents' perspectives. Vikki Langford (p6), a clinical psychologist, acknowledged how challenging it can be for parents to make decisions about their child's cancer care and suggested that it can be helpful to seek the advice of others such as friends or people who have relevant experiences to draw on. This echoes the findings of my literature review but also further inspired me to explore this in more depth.

The Curtain Falls

This scene has presented other narratives that relate to this study. The formal integrative literature review was undertaken in the early stages of the study and as such, formed another

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part of my pre-understandings as I embarked on the interviews. All that I had considered as part of this informed my subsequent interpretations in, and after, the interviews. Reading of other narratives that I engaged with after the interviews was shaped by the conversations with the parents, and I found myself interpreting these narratives through the lenses of these conversations. This iterative movement between the literature, interview transcripts and interpretations was illustrative of being in the hermeneutic circle, and I could feel my understanding constantly evolving.

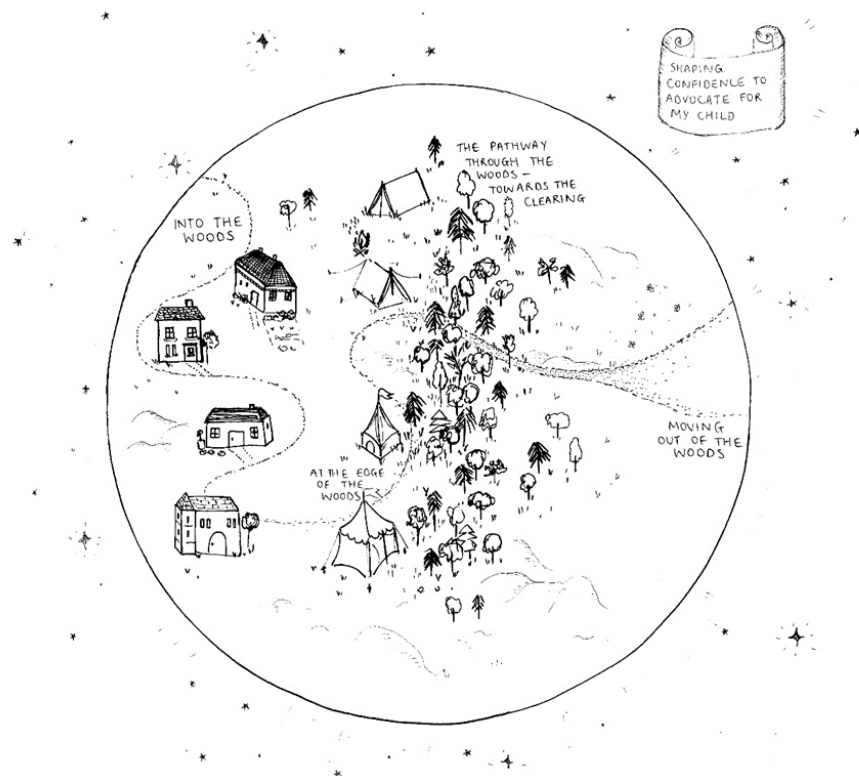
This opening act has established my need to journey into the woods. By looking in the mirror I opened a window and traced what was calling me to this journey, I explored how my own experiences might shape the path that I would take. Understanding the philosophers opened a second window to the woods through which I could start to set the context for the philosophical underpinnings of the journey. Navigating the research journey presented the principles that would steer the journey and opened the doorway. This scene has led me outside of the everyday home. I have explored the narratives and thus become more immersed in the hermeneutic circle. It is time to move further forwards, towards the woods and further around the hermeneutic circle. The main characters – the six parents – need to now be introduced, and discussion about who they identified as their ‘significant others’ and the decisions that they faced should be explored. Act 2 now takes us to the edge of the woods.

End of Act One

Act Two: At the edge of the woods

*Into the woods
Without regret,
The choice is made,
The task is set.
Into the woods,
But not forget-
ting why I'm on the journey.*

(Sondheim and Lapine, 1987:20)



Act Two: At the edge of the woods

Introduction

Act 1 started the journey within the hermeneutic circle and set the scenes for the journey into the woods. I presented my own, evolving, pre-understandings of this topic, and I also gave some context to the philosophers whose work will underpin this thesis. My journey through this research project was discussed, and other narratives were explored. Through the rest of this thesis, these scenes, whilst not necessarily always in clear sight, will remain in mind and underpin the writing of this work.

Act 2 travels further. This act is set at the edge of the woods and starts to ponder the direction of the path into the woods. Scene 1 introduces the main characters and tells a little about their stories when their child was diagnosed with cancer. This sets the context for what is to come in their stories about decision-making. To develop greater understanding of the characters, the Heideggerian concepts of '*Dasein*' ('being-in-the-world') and 'temporality' will be discussed.

Scene 2 will introduce the 'off-stage characters' in an acknowledgement that the main characters in every story are situated and influenced by others who may not always feature in the narrative. Understanding who these others are is important in order to better understand the experiences of the main characters, and particularly within this topic, it is important to explore the parents' social support networks. The ecomaps that I created with each parent will be presented and these will be accompanied by a discussion to further develop understanding. This discussion will be framed by two further Heideggerian concepts: 'being-with' others, and 'authenticity' / 'inauthenticity'.

Finally, Scene 3 will present the decisions that each character identified that they had been faced with whilst their child has had cancer. The final Heideggerian concept of the act will be discussed: 'thrownness'. This will contribute to the discussion and understanding about the decisions that parents faced in this new world of childhood cancer.

This act will prepare the ground to travel deep into the woods to seek a clearing, where a light will be shone on parents' experiences of being supported by others when they are faced with making decisions.

Act Two: At the edge of the woods

Scene One: Meeting the characters



Act Two: At the edge of the woods

Scene One: Meeting the characters

Soundtrack: Peer Gynt Suite No. 1 (Opus 46): Aase's Death, Edvard Grieg, 1875

This haunting orchestral work sets the tone for this topic as this scene introduces the parents and their very difficult and sad stories.

It is composed in a homophonic style; the instruments present a melody with underlying harmony. Each instrument plays its notes of the chord at the same time, which to me represents the unity of stories that we read in this scene, before we move on to understand the divergence and uniqueness of each story. During the first half of the music, the majority of phrases end with rising notes, rather than the traditional falling of a final cadence. This gives a sense of something new and the phrases sound like they are asking questions, which is echoed in the discussion that this scene will present. During the second half of music, the phrases are inverted, representing how these parents' lives have been turned upside down.

Scenery: Landscape with the Rest on the Flight into Egypt, Rembrandt van Rijn, 1647

I was really drawn to this painting, with the darkness of the sinister woods occupying the majority of the painting. Yet, despite the darkness, my eyes are drawn to the light which shines on the family, who rather than look outwards at the darkness, focus on protecting their child. Their world, like the worlds of the parents in this study, has been turned upside down and the darkness around them means that they cannot see their path ahead at this time. Despite the darkness of the world of cancer into which the parents in this study have been thrown, the light must be shone on the people and families at the heart of these stories.

Act Two: At the edge of the woods

The Curtain Rises

In this scene, the six parents (characters) are introduced⁷. At the start of each conversation, I asked them to tell me about their family and the story around what had happened when their child was diagnosed with cancer. The parents are introduced in the order that I met them. Each conversation fed into my hermeneutic circle of understanding, and therefore acknowledging the order in which my understanding developed is significant. Following these introductions, I will explore how these short stories aid my understanding, and how two of Heidegger's fundamental concepts: '*Dasein*' ('being-in-the-world') and 'temporality' highlight what more we need to uncover.

The characters

Tom (interviewed December 2021)

Tom lives with his wife Jenny, and their only child, Noah. Noah is now 4 years old.

In December 2019, when he was 2 years old, Noah had an ear infection – this was the first time he had ever been ill. A few months after this the COVID-19 pandemic started and the country went into lockdown. Around this time, in June 2020, Noah had some mild symptoms – he was a bit wobbly, lost his appetite and had a few bruises. At this time, it was not possible to see a doctor in person, so Jenny spoke to their General Practitioner (GP) and was told to wait for a few days. Noah was still not right so Jenny phoned the GP again and this time was told to go in. The GP immediately told Jenny to take Noah to the hospital. Tom joined them there. Tests were done and the family were then told that Noah had Acute Lymphoblastic Leukaemia (ALL).

Noah is still receiving treatment for ALL but, despite some complications along the way, he is currently doing really well.

Saira (interviewed December 2021)

Saira is married to Ben and they have four children: Jasmine is 15 years old, Myra is 13 years old, Aria is 11 years old and Timmy is 5 years old.

In June 2019 Aria complained of back pain. Saira took her to see a friend who is a physiotherapist, who was reassuring but suggested that Aria see a GP. Within a few days Aria was struggling to walk without pain and so Saira decided to take her to the Accident and Emergency department. An X-ray and blood tests were done which were all normal, but the next day Aria had a Magnetic Resonance Imaging (MRI) scan which showed that there was a

⁷ As acknowledged in Act 1 Scene 3, all of the names used in this thesis are pseudonyms.

Act Two: At the edge of the woods

mass on her T3 vertebra. A few days later a biopsy was done to ascertain what the tumour was, and the diagnosis was then given as Langerhans' Cell Histiocytosis (LCH). At this stage there were no other tumours and the spinal tumour self-healed over time.

Then, in January 2020, Aria complained that there was a spot on her head that was hurting. An X-ray revealed a significant skull lesion. It was agreed that this should be treated with chemotherapy and so Aria was entered onto the LCH4 trial which would include a randomisation to either 6 months of chemotherapy or 12 months. Aria was randomised to 6 months, and at the end of this period the family were asked whether they would like to take Aria off the trial and give a further 6 months of chemotherapy. Saira and Ben decided that they would do this. This treatment finished in February 2021.

In October 2021 Aria developed another skull lesion. She has had neurosurgery to remove this. A decision now faces the oncology team and the family about whether or not Aria should have further chemotherapy.

Kerry (interviewed May 2022)

Kerry is married to Tony and they have two sons - Rory is the older of the boys, and Harry is 5 years old.

Around Christmas of 2018 Rory caught chicken pox during an outbreak at school. He passed it on to Harry but whilst Rory recovered quickly and was fine, Harry just did not seem to get better and he did not seem right. Kerry took Harry to see their GP in the middle of January and he referred them on to the Accident and Emergency department as he was concerned that Harry was displaying signs of sepsis. After various tests and consultations, Kerry was told that Harry had septic arthritis and that the orthopaedic team would need to operate on his knee. A difficult period of recovery followed this and after two weeks, when Harry was still unable to walk, Kerry took him back to the hospital where he was re-admitted. Further tests were done and at this stage Harry was diagnosed with Acute Lymphoblastic Leukaemia (ALL) and he was admitted to the haematology / oncology ward.

Harry has just had his final dose of chemotherapy. He is waiting to have his port-a-cath removed and final scans. From September he will be considered as no longer vulnerable and will have normal immunity levels. He will be closely monitored for the next five years.

Maggie (interviewed May 2022)

Maggie lives with her husband Simon, and their two daughters - Flora (8 years old) and Rosie (5 years old)

Act Two: At the edge of the woods

Rosie was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in October 2020 when she was four years old. She had always been a 'well' child but that October, Maggie just had a really strong sense that something was wrong - she noticed that Rosie was running in a different way and she mentioned that her arms and legs really hurt. She had had a virus so initially the GP thought that this was post-viral aching, however Maggie believed that something more was happening. Rosie was referred to the hospital where initially they believed that she had septic arthritis. However, following further tests, Rosie was diagnosed with ALL.

She had four weeks of standard induction chemotherapy but did not respond sufficiently to this treatment - she still had 10% blasts in her blood. She was moved to regimen C of the ALL protocol and had a further four weeks of treatment. By the end of this she still had 2% blasts and so at that stage it was clear that she would need to have a bone marrow transplant (BMT). In the spring of 2021 Rosie was transferred to a different hospital, in a different city, for her transplant. This went well and she was initially discharged from the BMT unit after 5 or 6 weeks. However, there were further complications when Rosie developed Graft Versus Host Disease (GVHD) of her liver, tummy and skin. She was readmitted and required Extracorporeal Photopheresis (ECP). This was a long treatment which required returning to the BMT unit for three days a week until October 2021.

Rosie is now doing well but is being carefully monitored with monthly blood tests, and 6 - 8 weekly bone marrow aspirates.

Martin (interviewed July 2022)

Martin lives with his wife Helen and their two sons - Toby (4 years old) and Max (6 years old). Martin also has a daughter, Chloe (who is from a previous relationship), she is now 22 years old and has moved away from home.

In May 2022 there was a period of about three weeks when Toby was notably pale, feverish, lacked energy and wasn't sleeping well. Martin and Helen took Toby to the GP on numerous occasions - on the first visit he was diagnosed with an ear infection and prescribed antibiotics. After a week he was no better so they returned. He was then diagnosed with a throat infection and advised to continue with the antibiotics. Again, he did not get better so once again they returned to the GP. On the third occasion the GP suggested that they take him to their local hospital in order for Toby to have some blood tests done.

Blood tests were done and at this stage Martin and Helen were told that it was suspected that Toby may have leukaemia. Blood results showed that Toby had a dangerously low haemoglobin (Hb) level and so an urgent blood transfusion was administered. With a diagnosis of Acute

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Lymphoblastic Leukaemia (ALL) confirmed, Toby was then transferred by ambulance to a different city where the nearest Principal Treatment Centre for children's cancer was situated. They remained as an inpatient there for the first two weeks of induction treatment and were then discharged home. Treatment is now continuing through the outpatient process.

Rob (interviewed August 2022)

Rob and his wife Ella have two children - Sylvie is 5 years old, and Charlie is 3 years old.

In December 2021, when Charlie was 2 years old, Ella was changing his nappy and noticed a lump protruding from his side. She called Rob to have a look and they started to look up the possible causes. They decided to take Charlie to the GP who suspected that he may have a hernia and so referred him to the paediatric department at the hospital for further tests. Whilst they were waiting for this appointment, Charlie became increasingly distressed. Just after Christmas there was a night when he was in significant pain and had been crying, and tossing and turning, for hours. At this point Ella was really concerned so she phoned 111 (the NHS urgent advice helpline) who advised her to take Charlie to the Accident and Emergency department. On arrival there, they immediately did a scan which revealed that the lump was not a hernia. He was transferred to the ward for further tests and after numerous blood tests and scans, Rob and Ella were told that Charlie had a high risk, metastatic neuroblastoma.

Chemotherapy was commenced with the intention to give eight cycles of Rapid COJEC (the chemotherapy regimen for high-risk neuroblastoma). Charlie did not respond well to the chemotherapy and during this period had two admissions to paediatric intensive care. After the sixth cycle of chemotherapy and the second intensive care admission, the decision was made to stop the planned chemotherapy and try an alternative chemotherapy regimen. Charlie responded better to this.

After this initial chemotherapy treatment, Charlie was transferred to another specialist hospital where he had a stem cell harvest followed by high dose chemotherapy and then a stem cell rescue transplant.

The next step will be for Charlie to have surgery to remove the remaining tumour and his kidney. However, at the moment the focus is on managing Charlie's nutrition. He struggles to tolerate enteral feeds and so is currently receiving Total Parenteral Nutrition (TPN). Since his diagnosis eight months ago, Charlie has only been able to spend about two weeks at home.

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Understanding the characters

These short stories helped me to understand the context in which the six parents were situated, and how the story of having a child with cancer started for each of them. I learnt a descriptive account of what had happened, who the other family members were, and how the process of treatment was evolving. Heidegger would refer to this as an *ontic* account, a factual description of an entity (Dahlstrom, 2013) (in this case the parent's account of their story) that stands apart from interpretation or meaning.

However, Heidegger argued that to understand anything we need to start with the *ontic* account but then move to an *ontological* level, where we understand what it is to be (Davis, 2010). To **understand** being we need to see more than a description of an object, or a factual account. To understand what it is to be we need to explore an ontological perspective in which we interpret the meaning of being. To understand 'what it is to **be**' for Tom, Saira, Kerry, Maggie, Martin and Tom, it is important to understand the concept at the heart of Heidegger's philosophy: '*Dasein*'.

Heideggerian concept: '*Dasein*'

Central to Heidegger's philosophy is the fundamental question: "what is being?" (Inwood, 1997:9). Wrathall (2005:12) suggested that, in general, we consider what being is in terms of its physical, describable properties: "a lump of a dirt *is* a lump of dirt because of the physical properties it possesses". It is possible to extend this consideration of being to all objects, and even to people. However, Wrathall went on to explain that Heidegger believed that this physicality, or ontical description, is just one mode of being, one way of explaining being. Heidegger proposed that there are alternative modes of being that can better help us to understand objects and people.

Heidegger used the hammer as an example (1927 / 2010). Whilst its existence as a being in its own right can be explained through describing its appearance, its weight, the materials that constitute it, this is an *ontic* perspective, and it does little to help us understand its true being. Heidegger suggested that the hammer's existence should be understood not by seeing it as a self-sufficient entity, only reduced to its physical properties, but as a being that interacts with other beings. We understand the hammer through its interactions with other beings - with the carpenter, the nails, and the wood. These relationships and the purpose for which the hammer is used is what defines its meaning, and therefore its true being.

Heidegger then proposed that we, as humans, exist in a different mode. We cannot understand our way of being in the same way as a piece of equipment because we look for

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intelligibility in ourselves and in the world around us. Within the first few pages of *Being and Time*, Heidegger named this unique mode of being as '*Dasein*' (1927 / 2010:7) and this concept underpinned the entirety of this work.

Dasein is a being that does not simply occur among other beings. Rather it is ontically distinguished by the fact that in its being this being is concerned *about* its very being... Dasein understands itself in its being...Understanding of being is itself a determination of being of Dasein. The ontic distinction of Dasein lies in the fact that it *is* ontological (Heidegger, 1927 / 2010:12)

In other words, '*Dasein*' is unique, and can be described, from an ontic perspective, as being ontological. This is because '*Dasein*' has the capacity to understand and make sense of itself and the world around it in the way that no other animate or inanimate object can. We can describe the hammer from an ontic perspective, and understand its meaning in an ontological way. The hammer, though, cannot understand itself.

Some authors have translated '*Dasein*' to mean 'human being' (Conroy, 2003) but this neither correctly translates the German word, nor expresses the richness of the concept that Heidegger was intending to convey. Unlike many other words that Heidegger coined or created, the word '*Dasein*' is an established and common German word that is used to mean existence (Sembera, 2007). Inwood (1999) traced the word's historical use to the seventeenth century when it was used to mean 'presence', and then to the eighteenth century when it came to be used by philosophers to mean 'existence' or by poets to mean 'life'. Heidegger's use of the word means all of this and more. The word '*Dasein*' is a compound word constituting of '*da*' and '*sein*'. The German word '*da*' can mean 'here' or 'there', 'then' or 'since' (Inwood, 1999:42). The word '*sein*' means 'being' (Sembera, 2007). Many Heideggerian commentators therefore have translated '*Dasein*' to mean 'being-there' (Sembera, 2007, Inwood, 1999) or 'being-here' (Dahlstrom, 2013) whilst acknowledging that this belies the complexity of the concept. This complexity arises because Heidegger uses the term '*Dasein*' in an attempt to articulate a novel concept that addresses the enormity of life's fundamental question of being.

The '*da*' is not intended by Heidegger to mean 'here' or 'there' in a physical, spatial, sense (Dahlstrom, 2013). The here or there is a presence in a dynamic, living space that we inhabit in a world that is filled with evolving possibilities (this idea of presence is why Dahlstrom suggested that '*Dasein*' should be translated as 'being-**here**' rather than 'being-there').

"The essence of Dasein lies in its existence" (Heidegger 1927 / 2010:42) and this means that '*Dasein*' decides how to be (Inwood, 1999). We cannot describe '*Dasein*' as an *ontic* what, only

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as an *ontological* who, shaped by the decisions that each '*Dasein*' has made, and the unique contextual world that it inhabits (Inwood, 1999). '*Dasein*' is present in the world and interacts with the world – '*Dasein*' cannot exist outside of this world, nor can the world that we are constantly creating and influencing, exist without '*Dasein*' (Mulhall, 2005; Wrathall, 2005). Not only does '*Dasein*' exist in a world with other '*Dasein*' and other animate and inanimate entities (Taylor and de Vocht, 2011), but '*Dasein*' makes sense of and interprets the world that it interacts with. Heidegger therefore uses the phrase *in-der-welt-sein* (being-in-the world) to express '*Dasein*'s' holistic presence and interdependence in the world. '*Dasein*' is immersed in a world and has a regard for, and interprets, other '*Dasein*' and all things that it encounters. Returning to the example of the hammer, the hammer's meaning, and therefore its existence, is dependent on '*Dasein*'. A hammer would not be a hammer without the meaning that '*Dasein*' attributes to it. '*Dasein*' is therefore a concept that is irreducible and inseparable from the context of the world that it inhabits (Cammell, 2014).

The complexity of '*Dasein*' and the challenges of translating it are beautifully articulated by Smythe, Spence and Gray (2018:1):

Being is always an experience of being-there, in that moment, on that day, with one's own mood already infused into the emerging sense of unfolding. Being-there is an embodied experience; weary from the wait or energized by the dawn of a new day. Being-there is a peopled experience; the aloneness amidst the mass of strangers, the companionship of the whispered voice of a friend on the other side of the world, the at-homeness in sharing a sense of sacred worship. Being-there is everything that calls our attention, along with all that is passed by unnoticed. We are always being-there, always in an emerging situation, always remembering whilst at the same time we plan ahead; thinking, pondering, feeling, being.

'*Dasein*' means more than being human, it means more than physically existing. '*Dasein*' is so much more than a word, it is an articulation of the whole concept of being alive within the social, cultural, geographical and temporal world that we inhabit.

The concept of '*Dasein*' can help to understand the six characters. Tom, for example, does not exist as a self-sufficient entity. His *being*, he – as '*Dasein*' – exists in terms of the world that he is in. He is shaped by his relationships with his family, his wife Jenny and son Noah. The context of his world shapes who he *is*. Each of the parents is their own '*Dasein*' and each '*Dasein*' is unique. Whilst Tom, Kerry and Martin have in common that they have a son with Acute

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Lymphoblastic Leukaemia each of their contexts is unique, and their experience of having a son with ALL and what this means to them, is therefore unique.

The 'ontic what' of each parent can be explored by reading the short descriptions above. However, the 'ontological **who**' is yet to be uncovered. The subsequent journey through the woods will reveal more of *who* each parent is – how their '*Dasein*' inhabits a world shared with others and what the world that they find themselves in feels like. Crucially, journeying further into the woods will travel through the darkness of the thicket where it is difficult to understand what is going on, but then the clearing will be reached where a light will shine on how these other people and the world that each character lives in, shapes their decision-making.

Before travelling further though, it is important to understand the other fundamental Heideggerian concept that shapes our being – 'temporality'.

Heideggerian concept: '*Temporality*'

We, as '*Dasein*', exist in time. Existence is a temporal concept as all entities exist in a particular moment of time – no being can exist outside of time. As described above, the '*da*' of '*Dasein*' can, as well as meaning 'here' or 'there', mean 'then' or 'since' (Inwood, 1999:42) so it is evident that there is a temporal dimension inherent in the concept of '*Dasein*'. What sets '*Dasein*' apart from other entities (such as a hammer) is that '*Dasein*' can consider itself within a temporal context, it can consider its own past and future (from the moment of our birth and looking towards our own death), and indeed the past and future outside of its own individual existence (Inwood, 1997).

Heidegger proposed that there are three 'ecstases', or horizons of time – the past, present and future (Inwood, 1999) and these fundamentally shape '*Dasein*'. In his 1962 lecture *Time and Being*, he argued that: "Being and time reciprocally determine each other" (Heidegger, 1962 / 1970). The time (the past and present) that we find ourselves in shapes who we are, and through the decisions that we make during our life about how we want to exist in the world, we are led by our future time that we will live (Cammell, 2014). Rather than time happening in a sequence of linear events, '*Dasein*' therefore exists simultaneously and coherently in its past, ever-evolving present, and future.

Temporalizing does not signify that ecstases come in a 'succession'. The future is *not* later than having-been, and having-been is *not* earlier than the present. Temporality temporalizes itself as a future which makes present in a process of having-been. (Heidegger, 1927 / 1962:350)

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Heidegger argued, in his analysis of '*Dasein*', that one of its fundamental characteristics is that it can make sense of, and interpret, the world that it inhabits. *Being and Time* both starts (page 1) and ends (page 437) with the suggestion that it is time that gives us the "horizon of the understanding of being" (Heidegger, 1927 / 2010). We understand every phenomenon that we encounter, every being around us, and indeed our own being, with time as a reference. We are able to understand because of our 'temporality' (Davis, 2010). As '*Dasein*' is defined by its interpretations, and time gives us this horizon of understanding, '*Dasein's*' existence must therefore be defined in a temporal context.

Zahavi (2019:12) used the example of an alarm clock to illustrate this:

When first looking at the front of the alarm clock and then moving around to observe its back, the front might gradually disappear from sight, but not from mind. Our familiarity with the alarm clock increases because we are able to retain that which we have seen in the past.

This example helps us to understand the temporal nature in which we experience the world. However, it is perhaps an example that stays in the ontic realm as it focuses on describing the appearance of the clock. Translating this example to a Heideggerian perspective would be to consider, along with the appearance of the alarm clock, how our past experiences of alarm clocks change how we see this alarm clock in the present moment. We may think about how we feel when we have been woken up by an alarm clock in the past, and that may inform where we position this clock – will we be able to see the time when we wake up? Will we be able to turn the alarm off? Our past experience informs the meaning that we attribute to the present moment, and this, whilst acknowledging the unique context of each situation, informs how we plan for the future.

This fundamental concept of 'temporality' can develop our understanding of the parents' stories. When a child is diagnosed with cancer they will be placed on a treatment pathway, so the health care team, parents and children are managing the care in the present moment by looking to the future. The treatment pathways vary according to the type of cancer. The trajectory for a child with ALL is standardised across the UK according to the gender, age and white cell count on diagnosis of the child. Tom, Kerry and Martin will therefore have been faced with a very similar pathway for Noah, Harry and Toby at the point of diagnosis (with potential variations because of the development of treatment pathways between 2018 and 2022). The pathway for Rosie (Maggie's daughter) at the point of diagnosis will have appeared similar, however the treatment pathway for girls is shorter than for boys (26 months for girls rather

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than 38 months for boys) (CCLG, 2019). Rob and Saira's pathways will have looked very different as their children had different types of cancer. The trouble with considering 'temporality' in terms of these treatment pathways is that they belie the unpredictability of the future and the complexity of the past. From the small amount of information in these opening stories, it is evident – particularly for Maggie – that their treatment pathway has not progressed as expected and has significantly diverged from the pathway that Tom, Kerry and Martin are experiencing. Similarly, the initial mis-diagnosis of Kerry's son (Harry) demonstrates that the stories have all started from different points. Furthermore, the temporal context in which each character is situated extends far beyond the moment that their child is diagnosed with cancer. Their story was already in progress at that moment, running through their whole existence from their birth and looking ahead to their future. Every decision that they face in the present moment is informed by their whole temporal context. It is informed by their previous experiences, and by their hopes and aims for their future, and their child's future.

The Curtain Falls

This scene has introduced the six main characters. Reading their short stories helps to understand some of the context in which these six parents are situated. From hearing their stories, I learnt a little about the ontic "what" of the parents, about their immediate family, and a description of the world that they have been thrown into.

Considering Heidegger's concepts of '*Dasein*' and 'temporality' has highlighted the wider context that needs to be explored in order to truly understand the heart of the parents' experiences. This highlights that these short descriptions do little to advance understanding about the ontological "who" of each character and therefore I am left with more questions – like reading the cast list in the theatre programme, we may learn the characters' names but need to engage further with the play to learn how their stories will unfold. Whilst all six parents have in common that they are now inhabiting a world in which their child has cancer, it is not yet known how this world has impacted on their lives, or how they find meaning as '*Dasein*' within this new world. There is more to learn about each '*Dasein*', and how they approach decision-making. How does their temporal context influence decision-making, how does the wider world in terms of previous experiences and other people shape them as '*Dasein*'? How do they look to their future?

As I stand at the edge of the woods, I am faced with so many questions. The following scenes will explore who each character inhabits a world with – who they consider to be 'significant' in their lives at this time. The decisions that they have been faced with will then be explored.

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From that point I will travel along a pathway of understanding, and I will shine a light on how others may shape the way that parents make decisions.

As I travel further into the woods I acknowledge that I am my own '*Dasein*' and that the guiding philosophers – Heidegger and Ricoeur – are each their own '*Dasein*'. This journey will facilitate a synergy of the six parents' stories, whilst also firmly holding on to the uniqueness of each '*Dasein*'. It will allow an openness whereby my interpretations, as my own '*Dasein*', will connect with Heidegger's and Ricoeur's philosophical ideas, and the stories of Tom, Saira, Kerry, Maggie, Martin and Rob.

Act Two: At the edge of the woods

Scene Two: Introducing the off-stage characters



Act Two: At the edge of the woods

Scene Two: Introducing the off-Stage characters

Soundtrack: Spem in alium, Thomas Tallis, c. 1570

This Renaissance work is a famous choral motet, written in 40 parts and arranged in eight five-part choirs. The motet starts with two upper voices, each singing their own line but with a sense of unity. This reminded me that, with each parent I spoke to, there were core relationships at the centre of each ecomap. These two voices are soon joined by other parts each singing a distinct line. As more and more voices enter, the music becomes increasingly complex and whilst the original motif can still be heard bouncing between the choirs and voices, it can be difficult to pick out at times. The music moves between choirs, and there is a sense of freedom and uniqueness as each voice sings at points and falls silent at others. Despite every line being unique, there is also a feeling of unity and shared vision both in the words (“I have never put my hope in any other but Thee, God of Israel”) and the harmonic progression. Indeed, there are three moments in the 10 minutes of music, where all voices move away from singing polyphonically, to a homophonic motion. As will be discussed in this scene, Heidegger explained that each of us, as unique ‘*Dasein*’, inhabits a shared world with other ‘*Dasein*’ – with each ‘*Dasein*’ experiencing a unique context within that world. As I constructed the ecomaps in this study, this sense of a unique, polyphonic, independent story, existing within a social, shared world became apparent. However, there were also moments that parents felt that, despite the people identified on their ecomap, they were alone, and others fell silent.

Scenery: Deepened Impulse, Wassily Kandinsky, 1928

I was immediately drawn to this image as the pattern of circles reminded me of the ecomaps that are central to this scene’s discussion. In places the circles overlap, resonating with the interactions between different people and support shared between them. Most of the circles have multiple interactions and some circles have shared interactions with each other demonstrating the complexity of our shared world of relationships – as each family is the centre of its particular ecomap, there is an acknowledgement that everybody identified on this ecomap is in fact, at the centre of their own ecomap. Despite most of the circles being linked to each other, there are a few that are isolated, and this resonates with this sense that some parents talked about the people who were **not** present and supportive towards them during this time. The isolated circles represent this sense that this made the parents feel alone and isolated from those who had previously been ‘significant’ to them, and simultaneously represents how fluid the ecomaps are seen to be, with some circles drifting off on their own, whilst others join together and form stronger bonds.

Act Two: At the edge of the woods

The Curtain Rises

Act 2 Scene 1 introduced the six parents, the six main characters of this story who take centre stage. Every story has its main characters, but each of these characters are situated within the context of others – family, friends, colleagues – who even if not explicitly discussed, inform who the characters are and their stories. These relationships significantly shape who we are as individuals and play a critical role in Heidegger's philosophy. This scene will therefore move beyond the immediate context in which the parents' stories, and they (as '*Dasein*'), are situated. It will explore the wider social context in which each of the parents are placed. The ecomaps that I created with each parent during the interviews will be presented, discussed, and framed by Heideggerian concepts.

Heideggerian concept: 'Being-with' ('*Mitsein*')

The discussion about the concept of '*Dasein*' in Act 2 Scene 1 showed that Heidegger rejected the idea that the being of humans could be explained in terms of beings as self-sufficient entities. Instead, Heidegger expressed that '*Dasein*' is a concept that is irreducible and inseparable from the context of the world that it inhabits (Cammell, 2014). This led Heidegger to consider that this world that '*Dasein*' inhabits is a shared world ('*Mitwelt*'), a world that is inhabited by other beings like itself, other '*Dasein*'. Our way of being is therefore social (Mulhall, 2005). We exist with others, we are '*Mitsein*' ('being-with') (Heidegger, 1927 / 1962). This means that other people, other '*Dasein*', have a fundamental influence on who we are as '*Dasein*': "So far as *Dasein* is at all, it has being-with-one-another as its kind of being" (Heidegger, 1927 / 1962:125).

Heidegger proposed that this influence of others prevails, even when we are alone:

Being-with is an existential characteristic of *Dasein* even when factually no Other is present-at-hand or perceived. Even *Dasein*'s Being-alone is Being-with in the world.

(Heidegger, 1927 / 1962:120 – 121)

So even when not physically in the presence of others, Heidegger argued that the existence of other people in the world affects our own experiences of our world. Rather than experience ourselves isolated from others, we are immersed in the world with others (Blattner, 2006). Both Blattner (2006) and Mulhall (2005) explained that Heidegger made it clear that this concept of being-with others does not mean that we cannot be alone (physically or emotionally). Rather, that the concept of being physically alone, or emotionally isolated, is only a possibility because we are capable of 'being-with' others: "Aloneness is a deficient mode of *Dasein*'s being" (Mulhall, 2005:66).

Act Two: At the edge of the woods

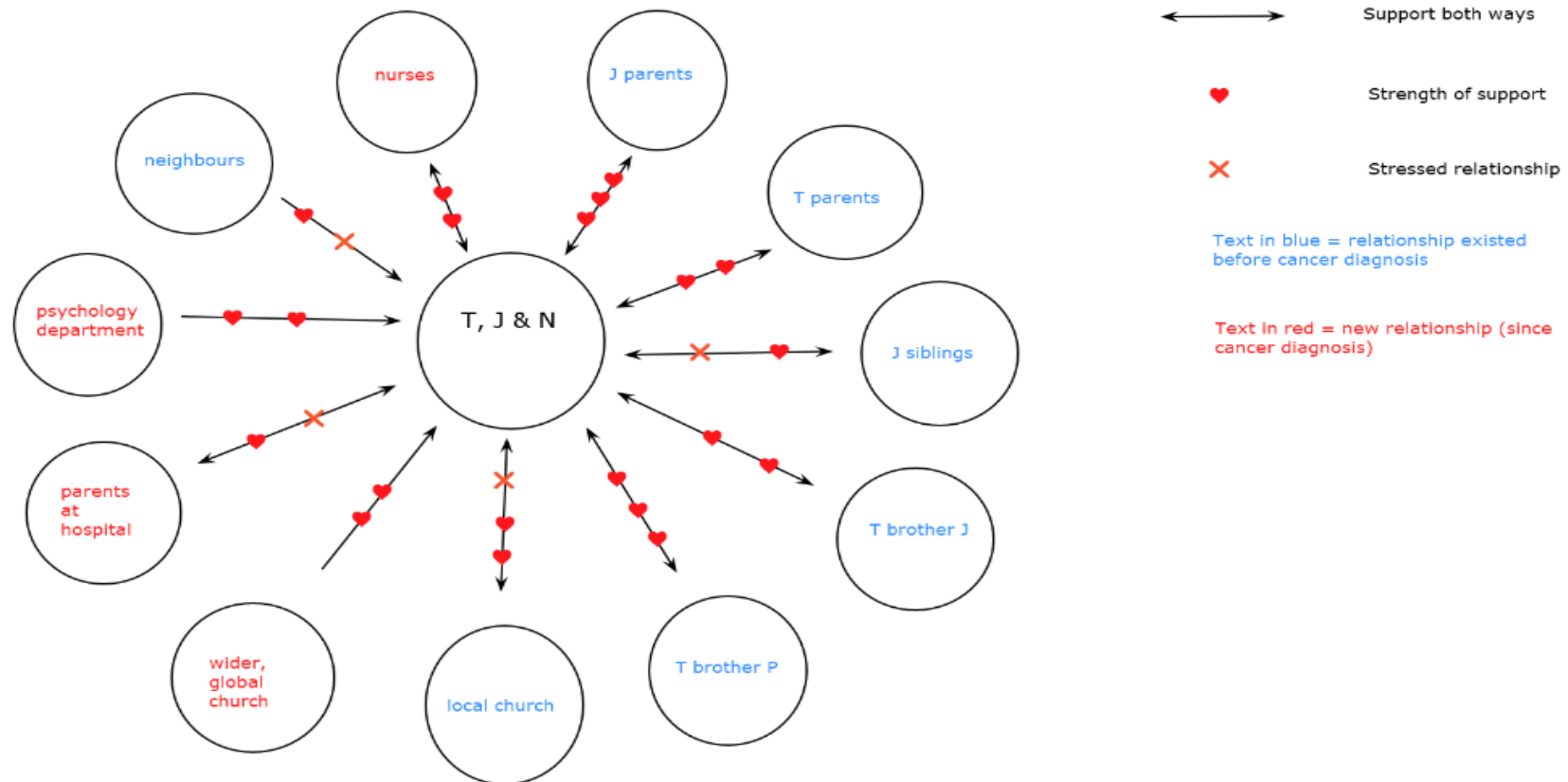
According to Heidegger, our relationships with others therefore fundamentally influence who we are, and even before we are aware of this influence, or have the ability to make decisions for ourselves, the people who inhabit our world with us are shaping the way that we live in it (Wrathall, 2005). Understanding who these people are, and how they influence our approach to decision-making is very important, and a fundamental aspect of this research. Co-creating ecomaps with the six parents became a way to understand who these people were – inhabiting an off-stage presence, but nevertheless with the potential to inform parents’ decision-making. The ecomaps could also allow me to shine a light on the nature of these relationships and present a springboard for further discussion (Jestico et al., 2023a).

Presentation of the ecomaps

The ecomaps are presented below. Again, they are presented in the order in which I met the parents as there was a strong temporal focus in the way that I interpreted these. Following the six ecomaps is a ‘collective ecomap’. I designed this to highlight the commonalities of the identified “off-stage characters” that parents spoke about. Designing a ‘collective ecomap’ allowed me to further my thinking and discussion about who was commonly appearing on the ecomaps, but also how each ecomap was unique from the others.

Act Two: "At the edge of the woods"

Tom's ecomap



Act Two: “At the edge of the woods”

Tom feels that they receive a huge amount of support from their family and friends. Jenny’s parents are a huge support, and they live in the same village. Jenny also has eight siblings, but Tom does not talk about them much during our conversation.

Tom’s parents and his two brothers are also very supportive. Tom works with his father and one of his brothers, so they are also significant in that way.

They are very active members of their local church and since Noah’s diagnosis, which also coincided with the pandemic, they have become connected to a wider, global church network. As Tom tells his stories about making decisions, this church community features significantly.

Tom also identifies the oncology health care professionals as part of his support network, in particular he talks about the psychology team and the ward nurses. Whilst it had not been my intention to focus on support from health care professionals in this study, Tom was clear that they play a big role and I therefore felt it important to include them on the ecomap. However, Tom also makes it clear that the role that the health care professionals play is different. Often during our conversation, he tells me that the doctors and nurses are great, but right at the end he says:

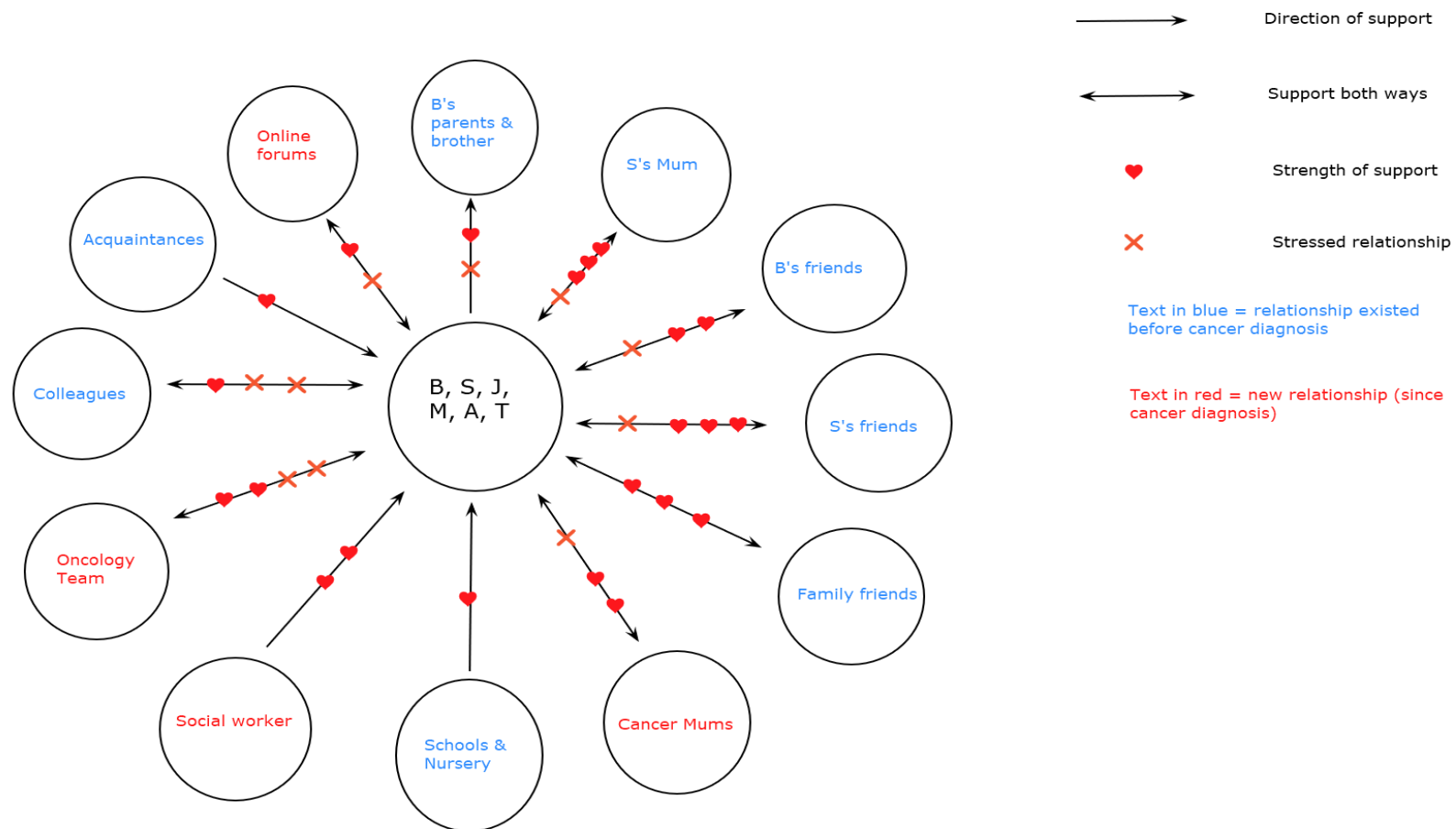
“You have to have some very, very strong people in the hospital to cope with what they see every day. They’ve got to have a kind and caring side, but they can’t go too far because they’re not the parents, they are still doing a job. So you need the support of other people to help you through it because the doctors and nurses can’t be that”

We go on to discuss that this is particularly relevant for children with ALL where the treatment pathway spans years, and for a lot of this time life will be lived outside of the hospital with limited contact with health care professionals.

Other people that Tom identifies as part of his network - parents who they have met at the hospital, and their neighbours, are not mentioned much in Tom’s stories. They are ‘present’ in their life, but do not play a significant role.

Act Two: "At the edge of the woods"

Saira's ecomap



Act Two: “At the edge of the woods”

Like Tom, Saira’s ecomap starts with the inclusion of family members, Ben’s parents, and Saira’s Mum. Saira talks warmly of their families and existing network of friends. However, as the conversation becomes focused on decision-making, these people are rarely mentioned. Instead, it is the people identified as ‘less’ supportive (fewer hearts noted) who have become more involved and supportive in this context. Saira has known some of these people for a while and they are grouped together under the label “acquaintances”. Saira speaks of other parents at the school gate who she chats to, and how this has led to wider networking. She also speaks about the group that she refers to as the “Cancer Mums”. This is a network that she has found herself part of following Aria’s diagnosis and had started with knowing the mother of another child who had leukaemia. Over time this group has grown, and whilst there are stressful aspects of communicating within this group, it plays a significant role in Saira’s support network. Finally, like Tom, Saira talks a lot about the health care professionals forming part of this network – there are particular doctors and nurses who she speaks of often. During our conversation Saira explains to me why these people have become so significant during the context of receiving cancer care during the COVID-19 pandemic:

“The only time we left the house was to go to the ward and have this really traumatic experience but also see the lovely doctors and nurses. For a good 10 or 12 weeks that’s the only kind of meaningful social contact I had outside of the house”.

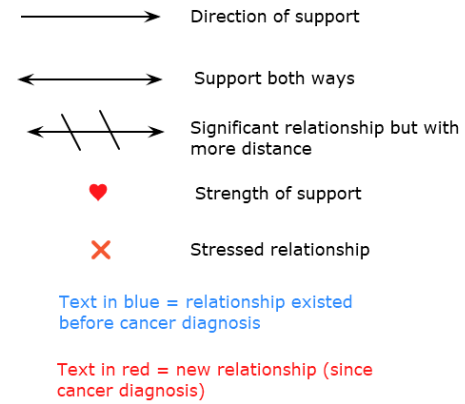
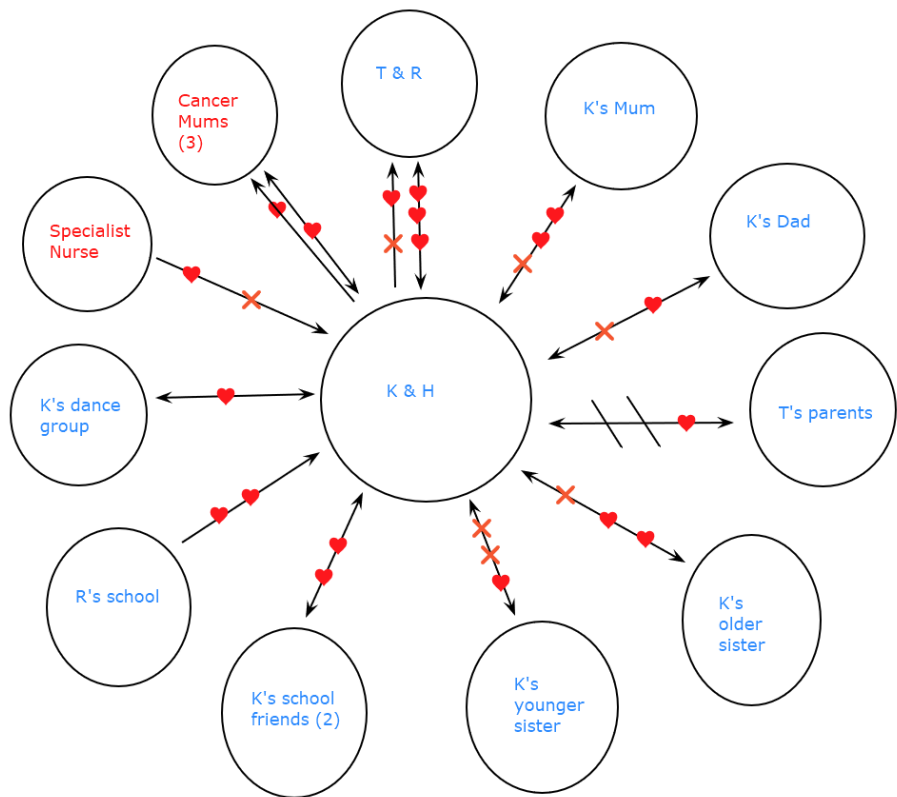
So perhaps for both Tom and Saira, the identification of health care professionals on their ecomaps is partly due to the context of being in lockdown and shielding during this period. These health care professionals have become the only face to face contact that they have, and these relationships have become a crucial source of support. Perhaps though, the health care professionals would have been identified as significant regardless of the pandemic. From my years of working as a nurse I remember the close relationships between the nursing team and families. Picoult similarly identified these relationships in *My Sister’s Keeper* (2004:227):

You get to know [the nurses] as they know you, because they take the place of friends you once had in a previous life, the one before diagnosis.

Whilst this feels to be an extreme perspective of nurses *replacing* friends, this quote does, to an extent, resonate with Saira’s comment.

Act Two: "At the edge of the woods"

Kerry's ecomap



Act Two: “At the edge of the woods”

Working with Kerry to create her ecomap is a fascinating process. For each parent, I had explained ecomaps in the same way (see [Appendix 11](#)). I showed the example of an ecomap (Figure 2) and my explanation started with:

“The idea is that in this middle bubble we usually put your immediate family, or the people who are in your household, and then we draw little circles around for anybody else who you feel is significant to you”.

As we start Kerry’s ecomap she says:

“Does it have to be like that? Because, based on what you said, I would put me and Harry in the middle. Rory and Tony are people who are coming out of our circle. I don’t know if this sounds harsh, but it has been me and Harry who have been through the journey... I always say to Tony that we’ve been on a different journey, you think we’re going from A to B, I’m going through rocky valleys, you’re going down the M6.”

This sense of feeling that she and Harry are alone in the centre of this story comes to be significant in her experiences of making decisions. This will become apparent in later scenes.

In terms of the people who feature on the ecomap, Kerry acknowledges similar groups of people to Tom and Saira: family, friends, school, other parents of children with cancer (like Saira, Kerry refers to this group as “the Cancer Mums”) and health care professionals.

Interestingly though the only health care professional who Kerry mentions is the specialist nurse. It is worth noting that Harry had been diagnosed with ALL in early 2019, and therefore the most intense parts of his treatment would have been delivered before the COVID-19 pandemic, perhaps this is why Kerry places less emphasis on health care professionals, as the relationship does not feel as intense as it does for Saira and Tom. Perhaps though this would have made little difference. As Kerry talks further about her experiences, it becomes apparent that she has a complex relationship with the doctors and nurses whom she has encountered during Harry’s hospital admissions. She speaks about the specialist nurse with more warmth, and more trust than any other health care professional and perhaps this is why she feels that this person should feature on her ecomap.

Whilst there may be commonalities with the people who feature on Kerry’s ecomap, there are clear visual differences. The process of creating this ecomap is very iterative. For example, Kerry separates out her Mum and her Dad as she feels that her relationships with them are quite different. Initially she gives her Mum one heart and one cross, but – having also given her Dad one heart and one cross, she asks if we can add an extra heart to her Mum to represent the difference. When it comes to Tony’s parents, Kerry feels that the symbols that I have shown

Act Two: “At the edge of the woods”

in my example do not reflect the nuance of her relationship. We therefore discuss how we could represent a relationship that was important (more than the wiggly line that I had shown in my example), but not physically or emotionally close. We resolve this by drawing two lines across the arrowed line. Similarly, when Kerry talks about her relationship with the Cancer Mums, she feels that there needs to be two separate lines - in some ways this is a two-way relationship and so having a two-way arrow is appropriate. However, Kerry feels that as time is moving on, she is providing more support to the other Mums, she refers to herself as a “veteran Cancer Mum” and therefore feels that there should be a separate line that indicates one way support from her to the other Mums.

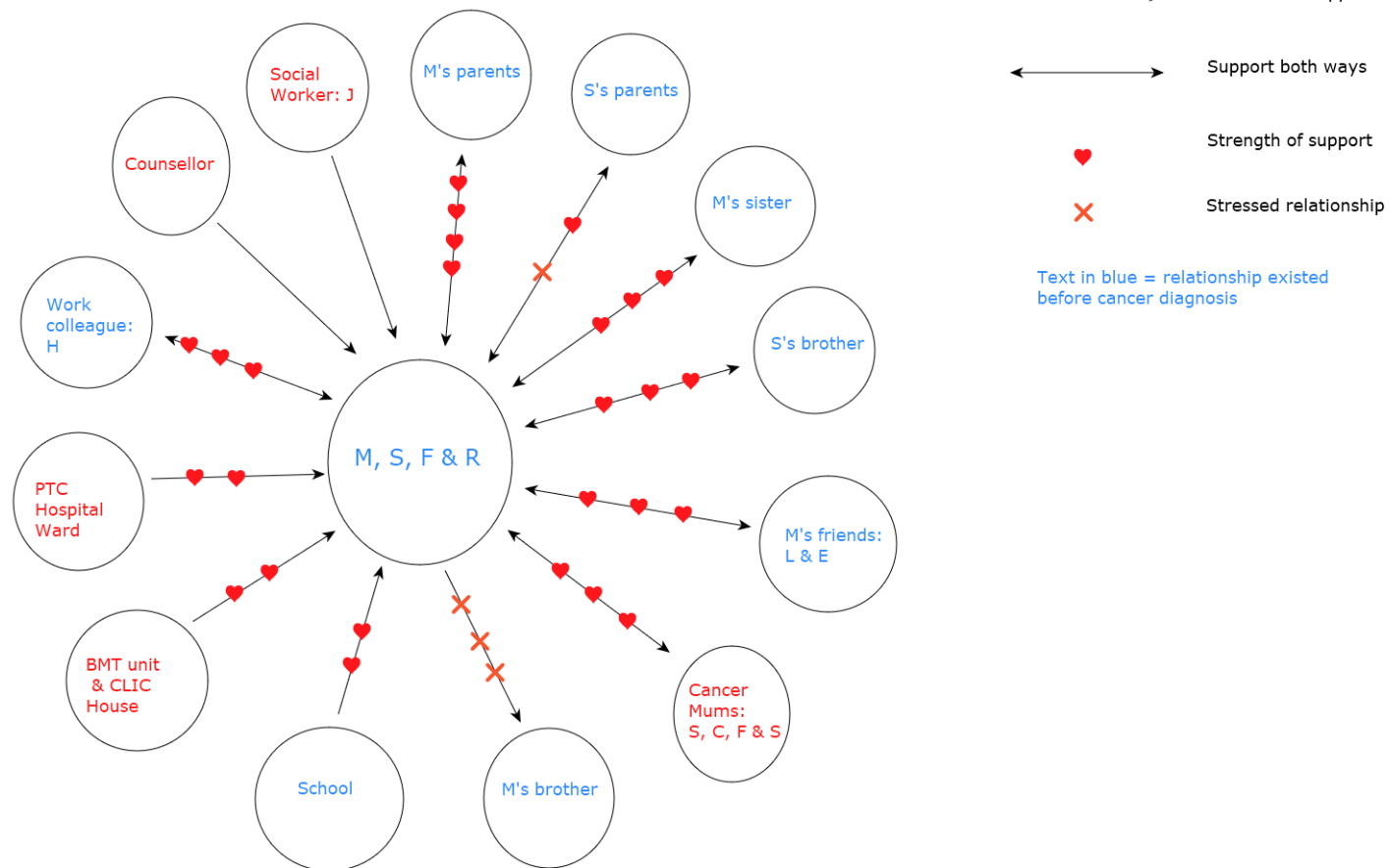
Finally, Kerry acknowledges towards the end of our conversation that there are people who, perhaps surprisingly, do not feature on her ecomap:

“I have felt over the years that a lot of people haven’t even acknowledged what Harry’s been through. Like people who I would have thought would have cared more – haven’t, and then people you think would never care – have.”

This led me to consider that the ecomap can only ever be a provisional representation of a person’s network. It shows who is significant at a point in time, and at different stages of life, even on different days, it may look very different.

Act Two: "At the edge of the woods"

Maggie's ecomap



Act Two: "At the edge of the woods"

Maggie also starts her ecomap with identifying her family. She speaks of many of her family members with a huge amount of warmth, in particular her Mum:

"My Mum has been ridiculously supportive... I can't put enough hearts on there".

Again, the groups of people that Maggie highlights are similar to the other parents. The complexity of Rosie's story is demonstrated in an increasingly complex ecomap. Where other parents identify the health care professionals on the ward where their child has been cared for, Maggie identifies that there are many more health care professionals involved in Rosie's care, one group at Rosie's Principal Treatment Centre hospital, and another at the Bone Marrow Transplant unit in a different city. Maggie feels that it is really important to acknowledge the support of these people:

"Because I was down at the BMT unit on my own with Rosie. So they were my support system when I was down there. And it was really stressful, especially when Simon went home. It was the same nurses that I would see, and the same doctors, every day. So when we were in all day, every day, I got to know them so well".

In a similar way to Saira, Maggie acknowledges that these health care professionals have become her social support network when she cannot see her friends and family. For Saira, this situation is due to the pandemic lockdown, for Maggie it is because she is so far from home. In both cases, Saira and Maggie, at an extremely intense moment in their lives have come to feel isolated, and the teams of health care professionals are playing a really significant role.

The Cancer Mums again are significant to Maggie. She explains to me that:

"It's just the little things that you just learn from other people. They tell you stuff at the hospital, but they don't tell you all that really important stuff".

Maggie explains that some of these things are practical ideas of what to take to the BMT unit. Other things that she learns from this group of people play a big role in the decisions that Maggie and Simon are facing. This will be discussed further in Act 3.

Maggie explains that the other Mums are more than this practical support though:

"It's a mutually supportive relationship. It does really help".

This sense of mutual support really struck me here, and Kerry had also alluded to this. I wondered if these two-way arrows on the ecomaps, signifying that the parents were **supporting** others, may be helping parents, as well as **being supported** by the 'significant others'.

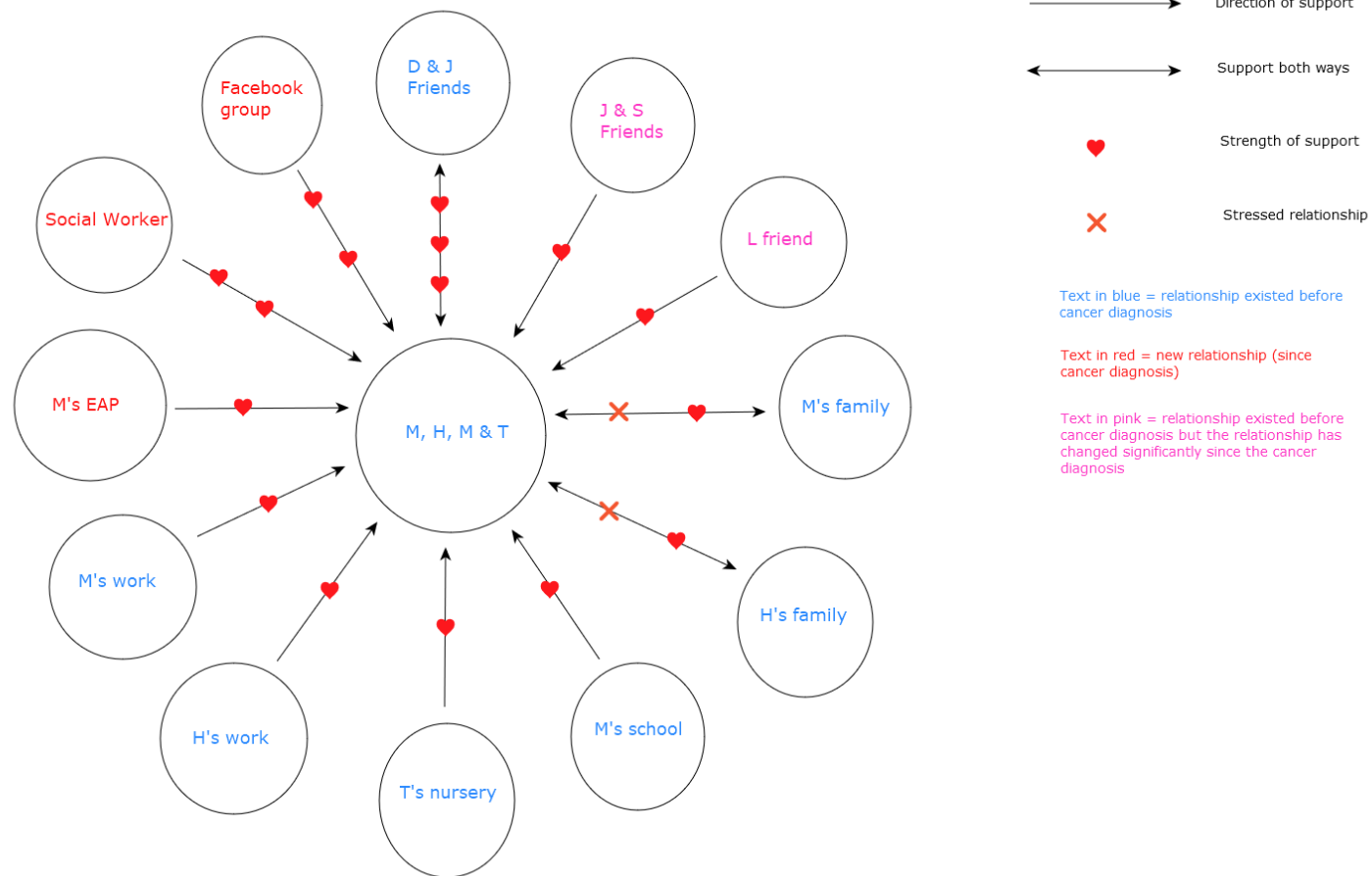
Act Two: "At the edge of the woods"

This really illuminates the ebb and flow of social support in a transactional relationship way as well as a temporal way as suggested by Kerry. Maggie also feels surprised that people she would have expected to be there for her during this time have not offered any support. She also acknowledges a subtle temporal ebb and flow that has changed throughout Rosie's treatment so far. As she reflects on whether the arrow connecting to her parents should be one-way or two-way she says:

"It is two-way now. At the time during when we were at the BMT unit, it was probably much more one-way, but actually now it's much more both ways".

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Martin's ecomap



Act Two: "At the edge of the woods"

Whilst Martin acknowledges similar groups of people on his ecomap to the other parents, it feels significant that he starts his ecomap with talking about his friends, and he does not mention his family until after these various friends. This contrasts with the other parents in this study and once again, highlights how unique everybody's network is. These friends are clearly significant to Martin and Helen, and he talks warmly about how much practical and emotional support they are providing. Martin tells me about three groups of friends: David and Jane; Joseph and Sarah; and Lucy. Whilst David and Jane have been close to Martin and Helen for a long time, Joseph, Sarah and Lucy were more distant friends until Toby's diagnosis but since then they have become a lot closer. This made me realise that having two colours to indicate existing relationships (blue) and new relationships since the cancer diagnosis (red) was too simplistic. I therefore added a new colour (pink) to represent this more subtle evolution of relationships.

Martin refers to Lucy as a Facebook friend who had been a colleague from a previous job. When Lucy heard that Toby had been diagnosed with ALL, she reached out to Helen and Martin as her daughter had been diagnosed with cancer five years earlier. This relationship has become really important to Martin and, as will be discussed later, has informed some of their decisions. Martin says:

"We've built a kinship because she's been sharing some of her experiences that we can then familiarise with."

Martin moves on to talk about family relationships. Whilst both his parents and Helen's parents are important to them, he explains that both of their parents live far away, and that this can place additional pressure on him as he has to update and reassure them frequently:

"We're close, but only at the end of the phone. They have been put in an awful situation where they can see me going through a difficult time, but not been able to support properly because of geography. That's actually caused a bit of stress on my side, because it's constant phone calls to update and let them know that things are OK".

Like other parents, Martin talks about how helpful schools, nurseries, and their workplaces are being in reducing as much pressure as possible on Helen and Martin in these respects. Martin adds an extra bubble here for the Employee Assistance Programme (EAP) from his workplace which has offered him significant support.

Martin's ecomap features only one health care professional, their social worker who is funded through the Young Lives Vs Cancer charity. He speaks of them very positively, however does

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not mention any other health care professionals. Perhaps this is because Toby has been diagnosed more recently than the other families in the study and Martin has not yet built these relationships. Perhaps this is because at the time that I speak with Martin, the country is no longer in full lockdown, so the relationships do not need to be as prevalent as for Tom and Saira. Or perhaps this is simply because Martin does not view these relationships as important to him at this point.

Finally, Martin tells me about a Facebook group that he has joined called ‘Mind the Chaps’. This is a group for Dads of children with cancer and from this he has joined a WhatsApp group. This peer support from other Dads is helpful:

“It’s been good to speak to peers, like-minded Dads in similar situations. So I have found that amazingly helpful. So this is a two-hearter”.

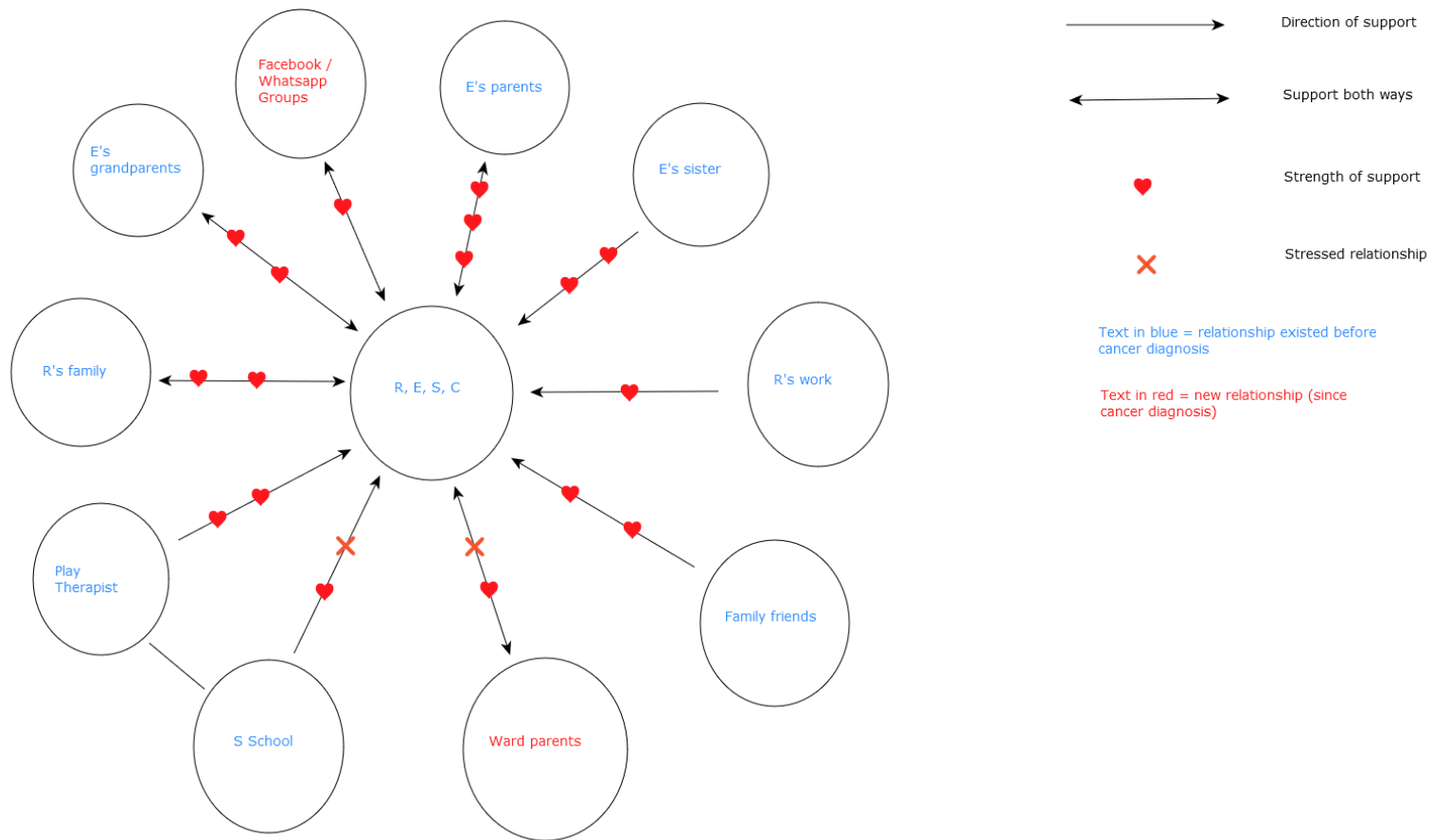
Finally, it is worth noting a concern that Martin raises during the process of creating his ecomap. As we add the arrows, hearts and crosses, he says:

“I’m just thinking, I mean I work in data, I’m an analyst. We’re going to end up with a lot of one-way arrows with hearts on there, and I don’t know if that’s going to tell you the story you want to hear, perhaps we need to review it”.

I explain to Martin that we can review the ecomap at any stage if he does not feel that it represents his network, but that he does not need to worry about what I “want to hear”, I just want to understand his unique world, and that this is not about drawing generalisable conclusions. As our conversation continues, there is a noticeable shift from Martin’s focus on being analytical, to a more reflective position.

Act Two: "At the edge of the woods"

Rob's ecomap



Act Two: "At the edge of the woods"

Finally, we come to Rob's ecomap. Of all the parents, Rob's ecomap takes the longest to complete. With most of the other ecomaps we had first identified the people in the circles, then added the lines and hearts / crosses. However, with Rob, we do this all at the same time. Each person that he adds generates significant conversation, and I find that we are starting to talk about decisions that he has faced as we work through the ecomap, so the process feels quite different.

Rob starts with adding Ella's parents. They live across the road and play a hugely significant role in the family's life. Rob speaks very warmly of them, and it is clear that he is very close to Ella's Dad, and that Ella and her Mum also have a close relationship. Interestingly Rob does not mention his own parents until much later. When he does speak about them, he is very positive about this relationship as well, however he explains that they live further away, and whilst they have offered significant support (particularly from an emotional and financial perspective), he settles on giving them two hearts:

"I'll put two hearts on theirs. I think the most support has come from Ella's parents, so I don't think anyone else is going to hit the three hearts".

Rob talks at length about his work colleagues. Work is clearly important to Rob and he is extremely grateful for the support that they have shown to him since Charlie's diagnosis. He justifies though why he feels that he can only give them one heart:

"The reason why I'm only sticking with one heart is because, to me, at the end of the day, it's work. I can't say that they've been two or three hearts like family has".

Rob goes on to talk about their large network of family friends, Sylvie's school, and the only health care professional that he mentions – the play therapist who is associated with the hospital but links with the school to support Sylvie. This raises a significant point in Rob's story – very early on in our conversation Rob tells me that one of his biggest concerns about the whole situation is the impact that this will have on Sylvie. A lot of his focus therefore is on her, and so support that friends, family, and professionals can offer in relation to Sylvie is really important to him.

Rob also talks about the ward parents, but acknowledges that this can be a source of stress as well as support. Finally, Rob tells me that, like Martin, he has joined the 'Mind the Chaps' Facebook and WhatsApp group. As will be discussed this group helps him with making decisions. However, he acknowledges the limit of this source of support:

"I'd say it's more of a one heart because there's not as much investment in each other".

Act Two: “At the edge of the woods”

I find this interesting as this resonates with how Saira has talked about the role of acquaintances and the online forum – these sources of support are perhaps more peripheral than others, but as will become clearer, they play a significant role in the stories of decision-making that are to unfold.

Towards the end of my conversation with Rob, he acknowledges that Ella’s ecomap would look very different to his:

“For mine it’s all support, there’s not really much stress. For her, there would be stress everywhere... I’m very relaxed and chilled, she stresses. So yeah, hers would look different. There probably would be more stress on hers”.

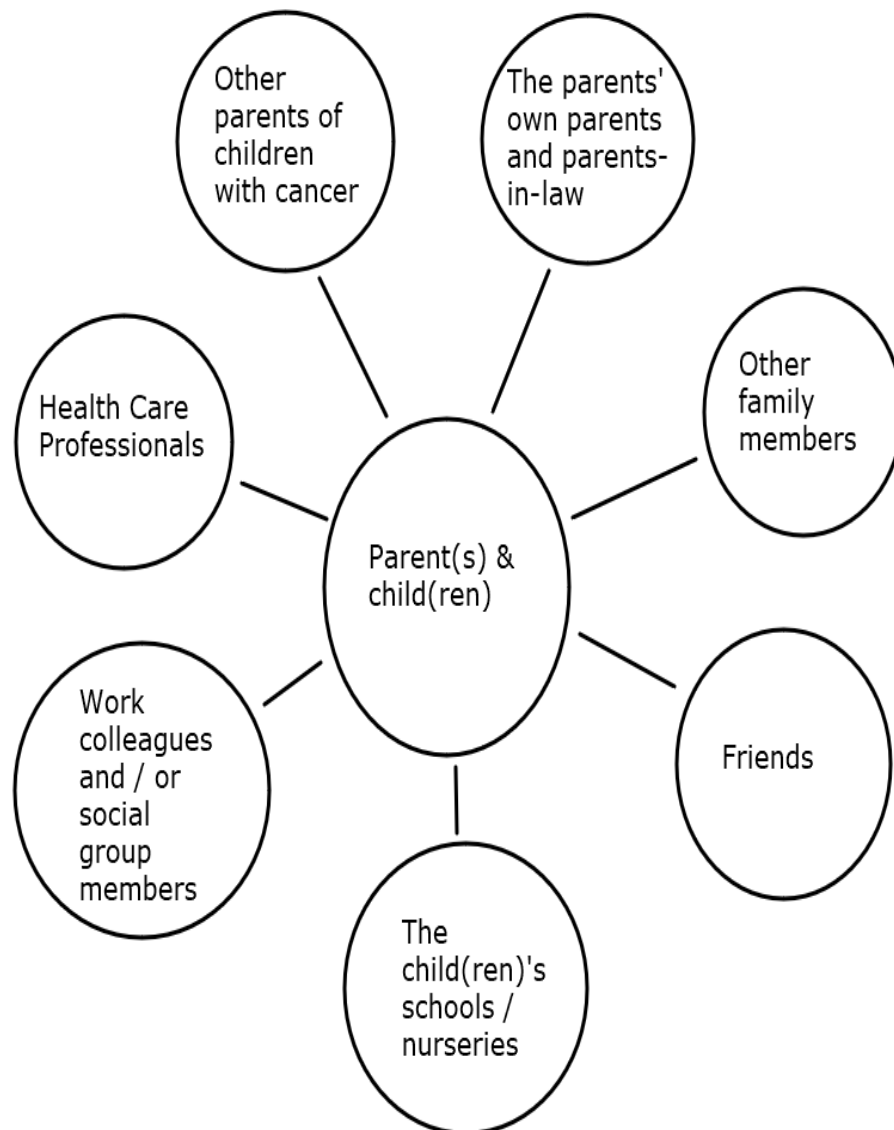
This demonstrates that each individual person’s perspective of their network is subjective. Even within a family, where the groups that each person are connected to may be the same, the nature of every relationship is unique.

Act Two: “At the edge of the woods”

Discussion

The process of co-constructing these ecomaps with each parent was fascinating. As I transcribed the interviews, read and re-read the transcripts, and reflected on the ecomaps, I saw that there were some similarities in the types of ‘significant other’ that parents were identifying. I therefore constructed a collective ecomap, a moment where the voices of each character join together.

Chorus: The collective ecomap



All of the parents talk about their own parents and parents-in-law, other family and friends. They all talk about their child’s school / nursery, or the schools of their other children, except for Tom. However, whilst Tom does not place the school on the ecomap (as Noah has not yet

Act Two: “At the edge of the woods”

started school) he does acknowledge that the school will play a role in the near future (another example of the temporal nature of ecomaps). They all speak about work colleagues or social groups that they are associated with. In some way, they all mention health care professionals, but as has been discussed, the nature and strength of these relationships varies. Finally, they all speak about building networks with other parents of children with cancer. Here the similarities end. The specific people mentioned, and the nature of every relationship is absolutely unique to each parent. Furthermore, as Rob acknowledges, this would be different even for the other parent in the relationship.

There are several points to consider in discussing the ecomaps. Firstly, it is important to recognise that the ecomaps represent who felt significant to the parents at that particular moment. As well as identifying these people, the parents will not have identified others. Heidegger (1927 / 1962) suggested that whenever we reveal something, we are also concealing something else. Whilst not necessarily a conscious decision, we all go through a process of revealing and concealing as we tell our stories (Davis, 2010). With the ecomaps the parents will not have included everybody in their lives, but they will have selected those that felt most significant at that moment. Saira provides an example of this after identifying her Mum:

“I think that’s probably it for family, I mean there’s the extended family, but they’re such a big group, and they’re not... I wouldn’t say they’re massively significant”.

Similarly, people who had perhaps not been previously considered significant, have taken on a more prominent role at this moment. For Saira, this is a group that we label “acquaintances” - people who she chats to at the school gate, or friends of friends who are linked to the world of children’s cancer. For Martin, this is a Facebook friend who has lived through a similar experience. He’d had little contact with her until now, but at this moment in life she has become more significant to him. In the Overture (and also in my published literature review (Jestico et al. 2023b)), I acknowledged the complexity of defining ‘significant others’. Drawing from Thoits’ (2011) definition of ‘significant others’ as relationships within a ‘primary group’ being distinct from ‘secondary groups’, I proposed that this combination of primary and secondary groups could be conceptualised as a broader social network consisting of an inner circle of ‘significant others’ and an outer circle of looser relationships with fluid movement between these circles. I proposed that individuals should be able to self-define these relationships. Constructing these ecomaps support this concept of fluidity, and reinforces that it is unhelpful to delineate between primary and secondary groups as the feeling of significance is unique to each person. The off-stage characters step in and out of the wings to take on more or less prominent roles as they are needed. And similarly, the main characters reach out to help

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these ‘significant others’ when needed. As highlighted by Maggie, there is a transactional ebb and flow in being **supported by** others and being **supportive to** others.

Another area of the ecomaps that interested me was the reference to other parents of children with cancer. I was not surprised that this group was mentioned, however I had expected these to be people that the parents had met on the ward that their child had been admitted to. This certainly is the case for Maggie and Rob, both of whom have spent significant periods of time with their child as an inpatient on the ward. For the other parents though, these relationships have emerged in different ways. Martin acknowledges that whilst he does occasionally chat to other parents on the ward, the conversations tend to be quite superficial, and he has not built up a relationship with them outside of the hospital. He acknowledges that the COVID-19 restrictions have limited the contact that parents have with each other on the ward. So for some parents, these relationships happen quite circumstantially – Martin’s friend Lucy becomes his link to another cancer parent; Tom talks about a second cousin whose child had received treatment for cancer several years previously, and also how he has made connections with other parents through the church community; and Saira talks about the Cancer Mums WhatsApp group – people who know of each other from the school network who have then connected with each other. Kerry, Martin and Rob have all been proactive about connecting with others through Facebook groups and have forged relationships in this way. One of the studies included in the literature review (Act 1 Scene 4) drew a distinction between ‘significant others’ (parents’ pre-existing social network of family members and close friends) and ‘similar others’ who were a new network of people living through a similar experience (Gage, 2013). I had been interested to see whether the parents in this study would identify other parents living through this experience as ‘significant others’. What I learnt was that not only did they consider them ‘significant others’ but that it could not be as clear cut as delineating between ‘significant’ and ‘similar’ others, because in some cases these groups overlapped. People already known to the family were living through, or had lived through, this similar experience and so parents fostered these relationships rather than necessarily forging new relationships. Again, an ebb and flow is demonstrated in these relationships, but here it is not only about a transactional fluidity, but also about a temporal fluidity. This is evident in all six ecomaps and indeed was very apparent when I constructed and compared my own eco-maps at different stages during this study. Relationships gain significance and lose significance over time. With reference to other parents of children with cancer, Saira talks about the changing relationships within the Cancer Mums WhatsApp group:

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"I think just time has changed, just you know, a couple of the kids have finished their treatment, a couple of us are still on it... you realise as well that everyone's got their own journey and that you have got an understanding that other people [outside the group] don't have, and so it's a place really, just, it is sometimes active it's sometimes not."

In Act 2 Scene 1, Heidegger's concept of 'temporality' was introduced. Not only is this concept evident when reflecting on these ecomaps but it is also clear that there is an interplay between his concepts of 'temporality' and 'being-with'. Our relationships with others exist in a temporal horizon. At particular moments in time, we may look back to past relationships and recognise that we may need to lean into these relationships again (either to receive or offer support), and we may also recognise that relationships existing in the present are functioning in a less significant way. Relationships do not necessarily evolve in a linear way as time moves forwards from the past to the future. Rather relationships become immersed in the combination of past, present, and future moments. Seeing time as a linear progression is one way to view time (Crowther, Smythe and Spence, 2015) and may be reflective of a child's treatment trajectory through different cycles of chemotherapy. However, Crowther, Smythe and Spence went on to propose that this is not the only way that we experience time, and that we also experience felt-time where moments or periods in life may **feel** longer or shorter than the metric time that passes in minutes, days and years. And like this, we may feel movement back and forth between the past, present and future as we draw on relationships and experiences from our past and contemplate our future. As Gillespie (1989:38) explained, Heidegger's concept of 'temporality' is "a stretching of our Being forward and backward out of the moment".

Aspects of this temporal ebb and flow are therefore (perhaps unconsciously) controlled by the person at the centre of the ecomap, drawing on relationships as needed in the moment. However, it is important to remember that each person that features on the ecomap (and indeed those who do not feature) are also their own '*Dasein*' and therefore they also have ownership of the relationship. This means that none of the relationships exhibited on the ecomaps are solely under one person's control. This is notable in the comments that Kerry and Maggie make about people who unexpectedly have not been more supportive, or when relationships have created additional stress. Moments like this, when relationships are less present than expected, can be unsettling. Kerry and Saira in particular talk about feeling alone in their story and this links back to Heidegger's concept of 'being-with', in which he asserted that whilst we are inevitably social beings and exist within a web of relationships, we may still feel alone. Taylor and de Vocht (2011) suggested that, if anything, others are felt more

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conspicuous by their absence – we feel more alone when people are absent, because we are used to their presence.

The process of constructing ecomaps focused on each parent identifying, specific, named or defined people who they felt were significant to them. Further exploration of Heidegger’s concept of ‘being-with’ demonstrates that this concept is not necessarily about being with other people who we know. We are part of a community and society and therefore we dwell alongside others who we do not know, unnamed people or anonymous group who Heidegger referred to as ‘*Das Man*’ (‘the They’) (1927 / 1962). The notion of ‘the They’ play an important role in Heidegger’s philosophy and underpin his concept of ‘authenticity’ / ‘inauthenticity’ which warrants further attention to understand the place that this unnamed group may take on the ecomaps, and how they may influence decision-making.

Heideggerian concept: ‘Authenticity’ (*Eigentlichkeit*) / ‘Inauthenticity’ (*Uneigentlichkeit*)

Heidegger proposed that ‘*Das Man*’ limits our potential possibilities to authentically live in the way that we would choose because this society, or group of others, impose social norms and ways of thinking on our existence (Wrathall, 2005). As a result, we generally live an ‘inauthentic’ existence (‘*uneigentlichkeit*’) (Davis, 2010) where ‘*Dasein*’ is absorbed, and lost to itself, in its concern towards others (Jestico et al 2023a).

Dasein, as everyday Being-with-one-another, stands in subjection to Others. It itself is not; its Being has been taken away by the Others. Dasein’s everyday possibilities of Being are for the Others to dispose of as they please.

(Heidegger, 1927 / 1962:126)

In this inauthentic mode, we feel compelled to laugh because “they” laugh, clap because “they” clap, we respond to the question “how are you?” with “fine, thank you”, even when we are not, because this cultural norm is what “they do” (Jestico et al 2023a). Inwood (1999:213) returned to Heidegger’s example of the hammer to explain this concept:

It is not I who decides what a hammer is. Nor does anyone in particular decide this. It is just what one, the One, thinks and does.

Heidegger offered an alternative to this mode of existence, one of ‘authenticity’ (*Eigentlichkeit*) (1927 / 1962). To transition to this way of being, a moment of disruption is needed that lifts ‘*Dasein*’ out of its normal way of being, Heidegger referred to this moment as ‘*angst*’ (Taylor and de Vocht, 2011). This moment provides an opportunity for ‘*Dasein*’ to look ahead to its own death and recognise that it can make its own choices independent of ‘the They’. It is important to acknowledge that Heidegger did not place a value on ‘authenticity’ or

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'inauthenticity', he did not consider that one mode of being is better or worse than the other (Mulhall, 2005), neither did he say that 'the They' is a good or bad thing. Rather than say that being authentic is 'good', he suggested that being authentic is about being questioning, whereas being inauthentic is to accept and conform to 'the They'. The point that Heidegger made is that it is possible to transition between these modes of being as we need to, and that an authentic existence requires us to embrace our 'temporality', by acknowledging both our past and our future, and understand that our life is always running ahead to its death, and that acknowledging our possibilities within the time that we have enables us to make our own choices.

Acknowledgement of this concept is important within this project. Assuming an authentic or inauthentic existence informs the ownership that we have over our decisions (in fact Blattner (2006) suggested that rather than translate '*Eigentlichkeit*' as 'authenticity' it should be translated as 'ownedness' suggesting that Heidegger was trying to capture the sense of owning our life). In an inauthentic existence, our choices will be governed by others. Therefore, within this project where the interplay between parents' decision-making and others in their life is the focus, questions are raised about this concept.

Firstly, all parents in the study are facing a moment of '*angst*', or disruption to their normal life. Whilst they are not overtly facing their own death, they are all faced with the reality that their child has a life-threatening disease. There is, then, genuine potential that facing the possibility of their child's death could lead to a transition to an authentic existence. Whether or not they do this remains to be seen and will be explored in subsequent scenes.

Secondly, there are questions around whether the 'significant others' who feature on the ecomap are classified as 'the They'. Heidegger was clear that 'the They' are not named, definite Others:

These Others, moreover, are not *definite* Others... The 'who' is not this one, not that one, not oneself, not some people, and not the sum of them all. The 'who' is the neuter, the 'they'.

(Heidegger, 1927 / 1962:126)

According to this then, the 'significant others' are not to be considered as 'the They'. Heidegger does not go on to explore the role that definite others do play in our transition between 'inauthentic' and 'authentic' existence. This is a source of critique of Heidegger's work, and Nancy (2008) argued that this is a shortfall of *Being and Time*. Further investigation is warranted to understand if the concept of 'the They' is in fact inherent in the ecomaps, or,

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whether the people featuring on the ecomaps assume a different role to ‘the They’ and in fact have the potential to facilitate the transition of the parent’s move between ‘inauthenticity’ and ‘authenticity’.

The Curtain Falls

This scene has presented the six characters’ ecomaps and introduced the ‘off-stage characters’, the people in each parent’s life who they felt was significant to them at this time. The process of constructing ecomaps reinforced that whilst there may be common categories of ‘significant others’ (highlighted in the collective ecomap), the nature of relationships for each parent was absolutely unique. Discussion of the ecomaps demonstrated that not only was each ecomap unique for that parent (and that it would look different from their partner’s perspective), but that it was also a provisional representation – unique to the parent at that moment in life. A transactional and temporal ebb and flow was evident in each ecomap.

Through exploring Heidegger’s concepts of ‘being-with’ (*‘Mitsein’*) and ‘authenticity’ (*‘Eigentlichkeit’*) / ‘inauthenticity’ (*‘Uneigentlichkeit’*) further depth has permitted greater understanding of the role that these people may take. However, as Act 2 Scene 1 concluded with raising questions, this scene has also identified issues that need to be further explored. Further travelling into the woods is required to unpick the role that named others (rather than the unnamed ‘they’) assume in the push and pull between ‘authenticity’ and ‘inauthenticity’.

The next scene will explore the Heideggerian concept of ‘thrownness’ and then describe the world of decisions that parents found themselves in. Understanding the possibilities that were available to the parents in this world, will help to establish the potential of transitioning between ‘inauthenticity’ and ‘authenticity’.

Act Two: “At the edge of the woods”

Scene Three: Exploring the decisions



Act Two: “At the edge of the woods”

Scene Three: Exploring the decisions

Soundtrack: American Tune, Paul Simon, 1973

Paul Simon based this song on J.S. Bach’s chorale: “O Sacred Head Sore Wounded”. This chorale (which is actually adapted from a hymn tune written in about 1600) features in Bach’s St Matthew Passion (1727) and is commonly referred to as the Passion Chorale. Paul Simon takes the melody of this chorale and applies meditative lyrics, reflecting on the struggles of everyday life, despite our hopes and dreams for the future. He refers to the pilgrims travelling to America (“we come on the ship they call the Mayflower”), and to space travel (“we come on the ship that sailed the moon”), but also about disillusionment with the American dream (“Still, when I think of the road we’re travelling on, I wonder what’s gone wrong”).

This song reflects the concepts that will be explored in this scene, that we are thrown into a world that is not of our choosing, and our experiences, and the choices that are available to us are heavily influenced by this world. Paul Simon’s use of Bach’s chorale draws together two worlds, acknowledging that our culture is influenced by our past. He also acknowledges that he has been thrown into a world founded on an American dream which has ‘gone wrong’. It is difficult to hear this song and not feel sadness, both at the lyrics but also at the music which in its original context is extremely poignant and moving. Paul Simon preserves this poignancy while adding a modern perspective. The sadness that I feel when listening to this song resonates with the sadness I felt when listening to the parents’ stories, and about how their hopes and dreams had been challenged.

Scenery: ‘Falls of the Anio, Tivoli’, Joseph Turner, date unknown

As we talked about the decisions that parents had faced, I became increasingly aware of the complexity of decision-making, and that one decision often led to another, cascading to further decisions. The image of a waterfall resonates with this sense of cascading and feeling out of control. Turner’s painting depicts the everydayness of life at the top of the hill – life before the diagnosis, but then the waterfall carries the observer’s eye to a new place, the forest, which is of stark contrast to the orderly town at the top of the hill. Like the families’ experience of being thrown into the world of childhood cancer, we do not know where the waterfall will end, we just know it will travel to a new place, not of its choosing or control. A solitary figure stands in the forest – able to see the town on the hill, but the ravine where the waterfall plunges separates the figure from everyday life. It seems difficult to see a path back to that world, and instead the figure stays, at least for the moment, in the new world.

Act Two: “At the edge of the woods”

The Curtain Rises

During the first two scenes of Act 2, standing at the edge of the woods, the six main characters have been introduced and an ontic description of their stories presented. The networks of off-stage characters have also been introduced. Discussions within these scenes have introduced the Heideggerian concepts of ‘*Dasein*’, ‘temporality’, ‘being-with’ and ‘authenticity’. These concepts have helped to develop understanding of each character’s world; however, each scene has generated further questions.

This scene will explore the decisions that each character identified that they have faced during this period when their child has had cancer. In order to further discussion about these decisions, this scene will start with a presentation of a further Heideggerian concept – ‘thrownness’.

Heideggerian concept: ‘Thrownness’ (*Geworfenheit*)

The last scene presented Heidegger’s concept of ‘authenticity’: whilst our everyday position is to be subsumed by ‘*Das Man*’ (‘the They’) and live in an inauthentic way where we follow social conventions, there is an alternative possibility where we can choose to live moments authentically and be free to make our own choices which are not dictated by others. This concept sits closely with another Heideggerian concept – ‘thrownness’. Heidegger suggested that we are not presented with infinite possibilities in which we can live authentically, rather we need to acknowledge that we have been **thrown** into a situation that presents us with a range of possibilities, but these are limited by our particular context (Gillespie, 1989). We are born into a historical world, within a particular generation and sociocultural group (Mulhall, 2005). This group essentially forms the “consensual hallucination” of ‘*Das Man*’ (‘the They’) (Mulhall 2005:67), and therefore shapes our inauthentic existence as ‘*Dasein*’. As acknowledged by Wrathall (2005), ‘*Dasein*’ means ‘being-there’, or ‘being-in-the-world’. To be there means to be in a particular place at a particular time, and this is the ‘there’ that ‘*Dasein*’ is thrown into. So, for example, the clothes that are considered appropriate by ‘the They’ are decided on the basis of our culture and the time that we live in. Even if we reject the views of ‘the They’ we are still limited in our possibilities by these factors. If I had been born 500 years ago, the possibilities of fabrics, colours and technology would not have been the same as today, therefore decisions about what to wear would have been limited. Similarly, whilst I have been presented with a very high number of career choices in my life, there are some career choices that are not open to me – as Mulhall (2005) observed, becoming a Samurai warrior is not a possibility for somebody living in London in the 21st century.

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However, 'thrownness' is not just about how our inauthentic existence is shaped. To live an authentic way is to acknowledge the finite possibilities that we are presented with, and to make choices on this basis. We are therefore living with a tension between believing that we have freedom to make our own choices, but also being subjected to a situation that we have been thrown into, and therefore have limited choice (Wrathall 2005), a situated freedom:

Dasein is placed in a particular situation that it did not choose to occupy, but from which it must nevertheless choose how to go on with its life.

(Mulhall 2005:140)

This concept feels very significant for the six parents. Each of them has been born into a particular time and culture. This, along with experiences during their life so far, influences who they are as '*Dasein*'. However, they have now been thrown into a new world, the world of cancer, and this 'thrownness' has presented them with a new range of decisions, and a new set of limitations on the choices that had previously been open to them. They have not chosen to enter this world, in the same way that I did not choose to be thrown into a 'bereaved world' at moments when members of my family died. However, with every moment of being thrown from one world to another, all of the parents (and I) have been faced with new decisions. For me, this meant making decisions about the path that my life would take whilst acknowledging that my new world had permanently blocked some paths. For the parents, rather than making everyday decisions about weekend or holiday plans, or which nursery or school to enrol their child in, they are now faced with making complex medical decisions and whether or not they should leave their home at weekends or go on holiday at all.

Understanding this concept of 'thrownness' is important as we move on to explore the decisions that parents are being faced with in this new and unfamiliar world.

Presentation of the decisions

After the parents have told me the story about how their child had been diagnosed with cancer, I ask them to tell me about any decisions that they had faced so far. As with the ecomaps, this is quite an iterative discussion. Often, they mention a few, but later in the conversation they remember other decisions that they have made. Table 6 presents the decisions that parents tell me about. These are grouped into decisions that they identify during the initial brainstorm, and decisions that they identify later in our conversation. Rather than present the parents in the order that I spoke with them, I have organised the table according to the child's diagnosis. Martin, Tom and Kerry all have a son with ALL and therefore it is helpful to see their decisions aligned to note commonalities and variations (I have ordered these according to the length of time their child has been receiving treatment). Maggie also has a

Act Two: “At the edge of the woods”

child with ALL but her treatment has taken a different pathway from the others. Finally, Saira and Rob have faced different types of decisions due to the different type of cancer that their child has.

After the initial brainstorm I ask each parent if they would like to choose a decision that feels significant to them and tell me about it in more detail. In some cases, the parent does choose this, in other cases they ask me to select this for them. After we have talked about one decision, I ask if we can talk about another decision, ideally one that feels like a different type of decision (for example if the first decision has been a medical type of decision, the second may be a social type of decision). Towards the end of our conversation, I ask if they would like to discuss anything else, and often this leads to a discussion about a third or fourth decision.

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Table 6: The decisions that parents faced

(Decisions underlined are those that formed the basis of further discussion during the interview)

Martin	Tom	Kerry	Maggie	Saira	Rob
ALL (diagnosed 2 months ago)	ALL (diagnosed 18 months ago)	ALL (diagnosed 3 years ago)	ALL (diagnosed 19 months ago)	LCH (diagnosed 2 and a half years ago)	Neuroblastoma (diagnosed 8 months ago)
Decisions identified in "brainstorm chat" towards the start of the conversation					
<u>Opting in or out of research trials</u>	<u>Decisions around isolation / shielding, particularly during height of COVID-19 pandemic</u>	Decision for Harry to be admitted to the cancer ward (Kerry was given the option to admit on the Saturday when the diagnosis was suspected, or wait until Monday when the cancer diagnosis would be confirmed)	Decision around whether Rosie should have a Hickman line or port-a-cath inserted	<u>Decision to initially take Aria to Accident and Emergency (A&E)</u>	<u>Decision to take Charlie to the GP</u>

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Martin	Tom	Kerry	Maggie	Saira	Rob
Central line (opted in to having a central line but no option regarding port-a-cath or Hickman line)	Decisions around household organisation e.g. renovation / redecorating	<u>Decision around whether Harry should have a nasogastric tube inserted</u>	Decisions around how to manage “life” – who will care for Flora and the pets at home	<u>Decision to take Aria off the research trial and give a further 6 months of chemotherapy</u>	Decision to take Charlie to A&E
<u>Decision around whether Toby should have a nasogastric tube inserted</u>	Decisions around what and how to communicate with Noah and how to reduce his anxiety about hospitals	Decision for Harry to have a port-a-cath inserted (initially Harry had a Hickman line – no choice was given about this, but 9 months later this was changed to a port-a-cath	Decisions around how much care at the hospital each parent would take on	<u>Upcoming decision around whether Aria should have chemotherapy for the latest tumour</u>	Consent to start treatment

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Martin	Tom	Kerry	Maggie	Saira	Rob
Decisions around nursery and school attendance for Toby (nursery) and for Max (school)	<u>Decision around whether Noah should have a nasogastric tube inserted</u>	Decision to shave Harry’s hair (this decision was made twice)	<u>Decision about whether Rosie should have a Bone Marrow Transplant or CAR-T</u>	Decisions to challenge medical opinions in general	Consent to alternative chemotherapy drugs
<u>Decisions around isolation / shielding</u>	Decision around whether Noah should have a stoma formed	Decisions around isolation / shielding	Decision around whether Flora should be tested to establish if she could be a donor	Decision around whether Aria should have a port-a-cath or Hickman line	General decisions to <i>agree</i> with medical decisions (as opposed to <i>making</i> the decisions)
		<u>Decisions around nursery attendance</u>	Decision of location of hospital for Bone Marrow Transplant	Decision to cut Aria’s hair	Decision for Charlie to have a nasogastric tube inserted
		Decision for Kerry to push to have the COVID-19 vaccine	Decision about where to live during the Bone Marrow Transplant	Decisions around whether medication should be administered as tablets or liquids	Decisions for Charlie to have a nasojejunal tube inserted

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Martin	Tom	Kerry	Maggie	Saira	Rob
		Decisions to challenge health care professionals when Harry was allocated to a bed in a bay versus a bed in a cubicle	<u>Decision about whether to take Flora to the Bone Marrow Transplant site or whether to leave her at home with Maggie’s Mum.</u>	Decisions around whether Aria should have a cannula inserted pre-anaesthetic or a gas induction	<u>Upcoming decisions around whether Charlie should have a gastrostomy</u>
		<u>Decisions around challenging care in general</u>	Decisions around work and finances	Decisions around what and how to communicate with Aria	Decisions around isolation / shielding
			<u>Managing decisions around treatment plans</u>	Decisions around what and how to communicate with other children	
			Decisions around general family arrangements	<u>Shielding / school attendance</u>	

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Decisions identified later in the conversation					
<u>Decision for Martin to accept help and support for himself</u>	Decision to consistently follow the advice of the medical team	Decision to open the envelope given to Kerry from the GP when she had been asked to pass this on to the team in A&E	Decision for Maggie to seek support for herself (this wasn't explicitly stated as a decision, but there was a lot of discussion around decision to access counselling and seeking support from family and friends)	Decision to take Aria to see physiotherapist (pre-diagnosis)	Childcare arrangements (for Charlie and Sylvie)
	Decision not to seek homeopathic remedies	Decisions around timing of nasogastric tube insertions	Decision around whether to offer support to others or not (this extends beyond the care of Rosie but still seemed relevant as it impacted heavily on Maggie)	Decision to challenge opinion when Aria had pain in her head	<u>Returning to work</u>

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	Decision around having the stoma reversed	<u>Treatment / research trial decisions</u>		Decision to join the LCH4 trial	Keeping family separated during chicken pox outbreak
	Forthcoming decisions around nursery / school attendance			Decisions around genome sequencing	Engaging with a play therapist for Sylvie
	Decision around whether to see an osteopath			<u>Decision to network with experts in other hospitals (linked to decision to take Aria off research trial)</u>	Insertion of a central line
				Decisions around what and how to communicate with wider family and friends	

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Discussion

This table demonstrates the complexity and variation of decision-making, both within each family and between families. A superficial glance at the table reveals that the list of decisions that Martin identifies is shorter than the other parents, this is not surprising as Martin’s family are much earlier in the process than any other family in this study. It is also evident that the decisions that parents speak about are not necessarily limited to their child’s cancer treatment, or even the care of their child. Several parents speak about decisions around care of siblings, and decisions relating to their own lives. My initial research question had been focused on “decisions about the child’s care”, but as I spoke to each parent, I realised that decision-making is more complex than this and in order to represent the parents’ experiences it needed to be conceptually broader than this. The following discussion will be grouped according to the types of decisions whilst acknowledging that these decisions are complex and that there may be overlap between the groups of decisions that were spoken about.

Before discussing these decisions in more depth, it is significant to note that when I ask the question around what decisions they have faced so far, the responses that I initially have are varied.

Tom’s immediate response is:

“Other than agree to what they’re offering, we really haven’t been given that many decisions to make. We just agreed with everything that they offered.”

and Saira, after talking about the decision to take Aria to A&E says:

“After that we didn’t really have any decisions to make. We were told what to do.”

However, when I ask Maggie the same question, she laughs and says:

“Well there’s loads”

and similarly Rob says:

“Oh yeah, there’s all sorts of stuff isn’t there”.

These initial responses have stood out to me strongly throughout this project. Having been thrown into this world of cancer where, to my mind, parents are faced with making so many decisions, I did not expect parents to respond by saying that they had not made any decisions. I have reflected on whether I asked the question in a clear way, and whether the word *decision* represented the same concept to me and to all of the parents. Noone (2002) undertook a concept analysis of decision-making. Her analysis identified that the antecedents for making decisions include awareness of choice, and evaluation of alternatives. Perhaps the parents here

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do not see that there is an alternative to treatment, and this is why they do not identify that they are making decisions. Noone also though, whilst reviewing research around decision-making cited several decision-making theories that have proposed that one approach to medical decision-making is a passive approach where people accept the medical advice without challenging it (citing for example, Janis and Mann, 1977; Petersen et al., 2000). It is difficult to apply Noone’s concept analysis and the theory included within her paper directly to this study as this all relates to people making decisions about their own health needs, as opposed to making decisions on behalf of another as the parents in this study are doing. It is possible though, that parents here are adopting this passive approach and deciding to follow medical advice, and this is what leads them to suggest that they are not making decisions themselves. This is perhaps therefore related to the agency (or lack of agency) that parents feel that they have in making decisions.

During the conversation with Tom, as I ask if there are any decisions that may not have been made in the hospital, he starts to reflect on more social decisions, and then returns to some medical decisions which he has felt that he has made. Similarly, as Saira and I travel further into our conversation she reflects back to her initial statement and says:

“You don’t really think about how you’re just constantly making decisions”.

Perhaps there is a disconnect in what I, as a health care professional with a clinical background of working in hospitals, consider to be a *significant* decision, and what feels significant to the parents. I had anticipated that they would focus on treatment and medical decisions, whereas it seems that sometimes parents feel that they have more agency, and therefore attach more significance to social decisions. This is a complex issue and warrants further discussion throughout this scene and on through the thesis – it will particularly become a key focus in Act 3 Scene 3. More immediately, it does emphasise the importance of allowing participants to identify what is important to them, rather than researchers making these assumptions.

Decisions relating to cancer treatment:

Interestingly both Saira and Rob talk at length about decisions to seek medical help before their child has been diagnosed with cancer. From the short stories shared in Act 2 Scene 1, we know that all of the parents have done this, but it is Saira and Rob who identify this as a significant decision. This leads me to question when decisions “start” for parents, and that being thrown into the world of cancer is not an abrupt moment in which a doctor tells the parent the diagnosis, rather it is a process of being thrown, an evolving moment during which life is changing from “normal” to “cancer”. This is a period where something is acknowledged by the

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parent and child as “not being right” without knowing what’s wrong, and reflecting on this, parents understood that their child **had** cancer before anybody formally knew this.

All of the parents do, at some stage during our conversations, highlight that there have been decisions that have been made about their child’s cancer treatment. Tom, Kerry and Rob all specifically acknowledge that they have signed the consent form to allow cancer treatment to be administered to their child. Particularly for Kerry, this decision is identified late in our conversation – almost as an aside:

“I don’t really remember... but if they had said to us ‘we think this is the best treatment plan based on the research’, we would have both agreed... The little things are where I was the one to make the decision. But the bigger picture, the cancer treatment plan, I would trust that it’s the right thing to do. The cancer part is the most straightforward part. I like facts and numbers, so if a researcher has said ‘that’s the facts, this is how it works’, I’d trust. I wouldn’t challenge the treatment plan.”

It seems that this type of decision is a “no-brainer”, and the choice is so clear to them that they barely consider it a decision at all, to the extent that there does not appear to be an alternative:

“You get the consent forms to say we’re about to give your child all this chemotherapy. You have to agree. I don’t know how anybody could make the decision not to, why would you not go ahead with this treatment? To us it was never a decision” (Rob)

This resonates with Coyne et al.’s (2014) work around decision-making when a child has cancer. They delineated decisions as major and minor, with the major decisions being referred to in the words of a health care professional:

There’s no real decision to be made, the decision is to treat or not to treat, of course they’re going to treat, because they want their child to live... that decision is out of their hands.

(Coyne, 2014:276)

This relates back to Noone’s (2002) concept analysis, the decision about whether to treat or not barely counts as a decision because of this lack of viable alternatives. Literature around this point shares varying perspectives. Like Coyne et al. (2014), Stewart, Pyke-Grimm and Kelly’s (2005) review of parental treatment decision-making in children’s cancer settings found that parents reported that they had no choice and relied on health care professionals to make these decisions. Similarly, Pentz et al. (2012:882) reported that one parent said: “You can call it a

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decision, but it wasn’t a decision”. Despite parents being required to sign consent forms in order for cancer treatment to be initiated, even health care professionals have stated that parents do not make treatment decisions if there is a standard treatment protocol available (Pearson et al., 2022). However, some parents in Pentz et al.’s (2012) study did acknowledge that technically a choice was available, but it was a choice between their child’s life and death, and O’Neil (1996) argued that parents should never feel that there is no decision to be made, proposing that there are always alternatives however undesirable or unacceptable these are. Perhaps it is this sense that the alternative to treatment is completely unthinkable and unacceptable that leads to this position of parents feeling that these decisions are “no-brainers”.

Saira, Martin and Kerry all specifically speak about decisions to opt in or out of research trials. For Martin and Kerry, like consenting to treatment, these seem to be fairly straightforward decisions:

“The consultants talked to us about the trial. They gave us a significant amount of paperwork to go through. So we sat down and went through it. We clarified with the consultants that none of this would be detrimental to Toby’s treatment, which they confirmed. So we were reassured by this. And at that point Helen and I decided that we wanted to try and give back as much as possible. If it can help somebody in the future, and it’s no detriment to Toby, then it’s an easy decision to opt in. Opting into these study trials was almost a non-decision.” (Martin)

For Saira, this is not a straightforward decision and a lack of medical evidence and established treatment protocols around Aria’s situation mean that there is no clear steer from the medical team about what is best to do. This decision really stands out for Saira and will be discussed further in subsequent scenes. The other parents do not mention research trials. This may have been because their child has not been eligible for a trial or may have been because they consider the research decision as synchronous with treatment decisions.

Maggie and Saira talk about further very specific decisions relating to medical treatment. For example, Maggie talks about the significant decision around whether Rosie should have a BMT or CAR-T as the next line of treatment, and Saira talks about whether or not Aria should be given further chemotherapy. For both parents, the emerging thrown moment is evident. One decision leads to another – for Maggie, deciding that Rosie should have a bone marrow transplant leads to decisions around testing Flora to see if she can be a donor, and then managing life around the BMT period. Similarly, this merging of thrown worlds is demonstrated in the types of decisions, or possibilities, available to them. Saira talks about genome

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sequencing as a new possibility, and the fact that Maggie is given the choice between the traditional BMT and new CAR-T treatment shows that the thrown world that they are inhabiting in terms of the time or moment of history, is co-existing with the thrown world in terms of living with cancer. These possibilities would not have been open to Maggie or Saira in preceding years.

Decisions relating to medical supportive care:

Where treatment decisions have been considered perhaps so ‘major’ that there is “no decision to be made” (Coyne et al., 2014:276) some parents talk more around what they consider to be more minor medical decisions. Tom, Kerry, Martin and Rob all talk about decisions in relation to nasogastric tubes, and Rob talks about how this decision has progressed to decisions around whether Charlie should have a nasojejunal tube and a percutaneous endoscopic gastrostomy (PEG). For Rob this cascade of decisions is mainly related to concerns around Charlie’s nutrition, however for Tom, Kerry and Martin the decision is focused around medication administration. Tom explains that, with hindsight, the decision about inserting a nasogastric tube was not particularly significant. However, at the time of making the decision it “*looms large*” because at the time “*you don’t know that they’re not so bad, it’s the fear of the unknown*”.

All of the parents, except for Tom, talk about decisions relating to central line access. In most cases the parents do not immediately identify this as a decision, and I ask them specifically if they have been asked to make a decision about this. I found this very interesting, as during my time working as a nurse on children’s cancer wards, this had seemed to me to be a very significant decision for parents to make – but it does not feel as though it is particularly significant for the parents in this study.

Tom talks about decisions that they have made in relation to Noah having a stoma formed, and later having this reversed – this is specific to Noah’s situation and demonstrates the unique context that each family is in. Similarly, Tom talks about considering complementary and alternative medicine (on the advice of a family member) which they have decided not to pursue. Saira identifies that there are lots of “little” decisions that have been made around medication administration and anaesthetic methods that Aria has been more involved with. Rob similarly talks about the importance of allowing Charlie to make choices around procedures where possible (such as choosing which arm he would like to have his blood pressure measured on).

Finally, Saira and Kerry speak more generally about challenging the medical team’s decisions. This is in relation to hospital processes, escalating concerns and bed allocation. Rather than

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discuss this aspect in terms of a particular decision, we frame this as a ‘decision to take a particular approach’ in managing life and interactions in this new world.

Decisions relating to managing life outside of the hospital:

The parents focus heavily on decisions outside of the hospital. These all relate to decisions that they perhaps feel more control over as are more in their usual domain, yet now that they are in this world of cancer, feel more complex than previously. Tom, Saira, Martin and Kerry all talk about decisions relating to communication in terms of what they should communicate not only to their child, but to wider family and friends. Tom and Maggie talk about household organisation, for Tom this is around projects with renovating the house to meet Noah’s needs. For Maggie this is significant and perhaps links to a role reversal whilst she is in hospital with Rosie, and her husband is managing practical things at home that he is not used to. Rob and Maggie also speak about decisions relating to support and childcare for their other child. This feels particularly significant for them because Charlie and Rosie have experienced very long inpatient stays, and this prompts concerns about how Sylvie and Flora are coping.

Tom, Saira, Kerry, Martin and Rob all identify that decisions have to be made around isolation or shielding. This is very interesting and demonstrates the multiple thrown worlds that parents are in. Not only are they in their existing thrown world (in terms of time and culture) and the world of childhood cancer, but they are also thrown into the world in the context of the global COVID-19 pandemic. With the pandemic has come perhaps a new recognition and language around the concept of immune vulnerability and the need for shielding. Before the pandemic, children with cancer had always been immuno-compromised and parents had needed to be careful around protection from illnesses, but the new emphasis of this that has come from the pandemic, if anything makes it easier for parents to articulate this. Maggie is not faced with a decision around this. The rigorous protections put in place for children undergoing bone marrow transplants means that Maggie is given no option – Rosie is automatically isolated during this period and the decision is out of Maggie’s hands.

Associated with decisions around isolation and shielding are decisions about whether their child should go to nursery or school. Tom, Kerry, Martin and Saira all talk about this, and the delicate balance that has to be found between protecting their child from infections, but not impeding their education or social development – a concern that is reflected in wider literature around childhood cancer (Pope and Jestico, 2021). Maggie and Rob do not talk about this issue, for them their child has spent so much time in hospital that this has not been presented as a possibility in their context.

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Only Saira and Kerry talk about the decision to cut or shave their child’s hair. Again, I had imagined that this would feel very significant to parents on the basis of what I had observed from practice. However, Saira is providing this as an example of a decision that Aria has been involved with and it does not feel that it is very significant to Saira. Similarly, Kerry comments that:

“Just shave it. He’s going to lose it anyway. It’s just hair at the end of the day. I’ve never really felt emotional about his hair. Of all the things he’s going through, his hair’s going to grow back.”

Finally, Maggie, Rob and Martin all talk about decisions around family finances and returning to work. This is of real significance for Rob and Martin, who express concern that they should return to work as soon as possible. For others, this seems less significant. Tom explains that he works with his Dad and brother so work feels like an extension of family life to him. Kerry is not currently working so this is not of significance to her, and Saira does not mention work at all during her conversation with me.

Decisions relating to the parent:

Maggie, Martin and Kerry speak to me about decisions that they have made that are more in relation to themselves. Kerry, for example, talks about her decision to ask to have the COVID-19 vaccine earlier than scheduled as she acknowledges that not only is she concerned about contracting the virus and passing it on to Harry, but she is also fearful about how her children will be cared for if she is to become unwell.

In Act 2 Scene 2 I discussed that offering support to others (particularly other parents of children with cancer) featured on some parents’ ecomaps. Maggie frames this as a decision and identifies that this is an evolving process – at times she has actively decided to look after other parents, but at other moments she needs to step back and protect herself from this.

This leads to the final point. Both Martin and Maggie tell me that they have decided to seek support for themselves. They both ask me if this “counts” as a decision. Martin says:

“I quickly realised that I had to reach out for some support because there was no way that personally I was going to cope with this. So whether that’s a decision or not, or just part of the learning curve, I’m not sure”.

We talk about it and conclude that this is a really significant decision as it is an acknowledgement that ensuring that they are being supported as a parent in this terrible situation, enables them to better support and care for their family.

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The Curtain Falls

Heidegger proposed that we are thrown into a particular world, where we are presented with a limited, finite, range of possibilities from which we choose our path. This scene has provided an insight into the decisions that parents have been faced with during the time that their child has had cancer. It seems important to acknowledge that we are potentially immersed in multiple ‘worlds’ or contexts, our ‘thrownness’ can be considered from multiple angles, and this thrown world is ever-changing and thus our possibilities are not static. The choices that we subsequently make are influenced by all of our thrown contexts and are incredibly complex. Heidegger’s philosophy emphasised that each individual ‘*Dasein*’ is situated within a world of anonymous others. He does not specifically address our relationships with named, definite others. When discussing decisions that are presented to us in our thrown world, again the focus is on authentic, or inauthentic, decision-making for us as individuals. In the context of this study, parents at times are making decisions for themselves, but they are also making decisions on behalf of their children. Further exploration is required to understand the extent to which we can make authentic decisions on behalf of others.

This scene has built on the stories that we initially learnt about the main characters and consideration of their social support networks. The decisions that the characters faced has now been explored upon a foundation of philosophy around ‘*Dasein*’, ‘temporality’, ‘being-with’ others, ‘authenticity’ and ‘thrownness’.

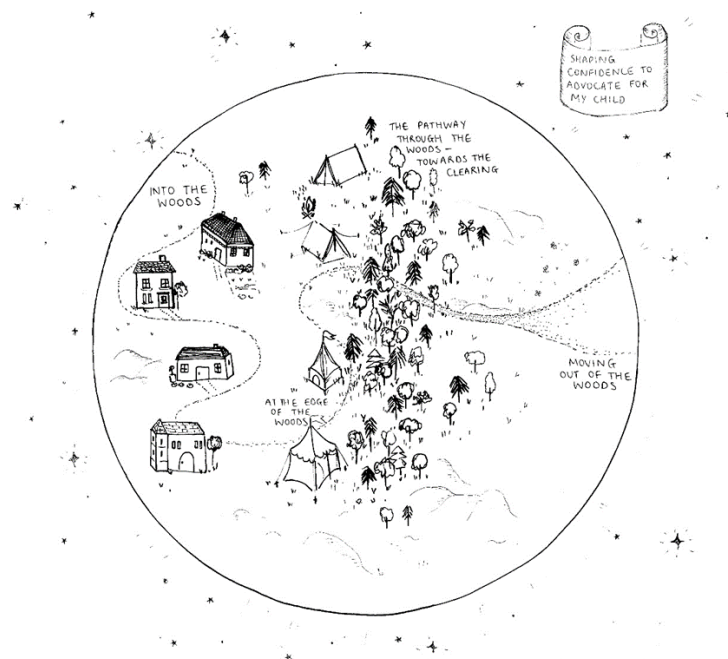
Having set this context, it is time to travel further into the depth of the woods in order to search for a clearing. By exploring and applying philosophical thinking to the stories in more depth, it will be possible to illuminate an understanding of how parents may be supported by their ‘significant others’ when they are faced with making such complex decisions.

End of Act Two

Act Three: The pathway through the woods – towards the clearing

*Though it's fearful,
Though it's deep, though it's dark
And though you may lose the path,
Though you may encounter wolves,
You can't just act,
You have to listen.
You can't just act,
You have to think.*

(Sondheim and Lapine, 1987:137)



Introduction

Act 2 ended at the edge of the woods, poised to travel further. Where Act 1 had set out the preparation for the journey by setting out my pre-understandings and introducing the philosophers, presenting other narratives and laying out the route for my research journey, Act 2 moved closer to the woods where the six main characters were introduced. As this context was set, Heidegger's concepts of '*Dasein*' and 'temporality' were explored with the need to truly understand the world of each character. Ecomaps then presented an opportunity to meet the "off stage characters" and explore Heidegger's concepts of 'being-with' and 'in/authenticity'. Finally, the decisions that parents had made was explored within the context of Heidegger's concept of 'thrownness'.

Act 3 will travel deep into the woods. As this act opens in Scene 1, a crafted poem will be presented which presents a heart-breaking story of the loss of confidence that parents experienced when their child was diagnosed with cancer, and the solitude that is felt within this. The Heideggerian concepts discussed in Act 2 will facilitate the introduction of Heidegger's notion of 'solicitude' that builds on these previous concepts, and this will direct towards a possible pathway towards finding light. A pathway will then be forged through the woods through Scenes 2, 3, and 4. This is one whole pathway, with each scene exploring particular twists and turns, but always travelling towards the same point – the clearing. Scene 2 will explore how 'significant others' may shape a parent's confidence to maintain and renew their identity as decision-makers. Scene 3 will explore how they may shape a parent's confidence to assert and release control in decision-making. Finally, Scene 4 will explore how 'significant others' may shape a parent's confidence to trust and challenge themselves and others when making decisions. Across Scenes 2, 3, and 4, parents' individual crafted stories will be presented to illuminate the pathway. Each scene will present two of the parents' stories.

Throughout this act, Heidegger's philosophy will continue to underpin the exploration of parents' experiences. From Scene 2 onwards, Ricoeur's philosophy will also be introduced. Act 2 left us with many questions about how Heidegger's philosophy could be applied to the context of this topic. As this act attempts to resolve these questions, Ricoeur's philosophy, which was strongly influenced by Heidegger, will cast a slightly different light. The synergy of both philosophers' work will allow the full light of the clearing to be found.

Act Three: The pathway through the woods – towards the clearing

Scene One: Losing confidence



Scene One: Losing confidence

Soundtrack: Opus 33a Four Sea Interludes (from Peter Grimes), Benjamin Britten, 1943

Britten's opera, Peter Grimes, tells the tragic story of a fisherman and the community of an isolated coastal village in Suffolk, on the shores of the bleak North Sea. The sea interludes were composed by Britten to cover the scene changes within the opera and four of these were later presented as a suite ("Dawn", "Sunday Morning", "Moonlight" and "Storm"). These four interludes each have a distinct tone that signify the different moods of the sea and the relationship between the unpredictable weather and response of the sea to this. Whilst beautiful compositions, I find these interludes uncomfortable to listen to. There is an unsettling mood to all four interludes. To me this really resonates with the parents' loss of confidence as they are told that their child has cancer.

There is a sense of isolation as "Dawn" opens that resounds with parents' feelings of being lost and alone expressed in this opening scene of Act 3. This contrasts with the rhythmic, almost jovial yet conflicted theme of "Sunday Morning". As "Moonlight" quietly creeps in, the strings are tentative as the theme starts to evolve, repeatedly interrupted by the woodwind and percussion who are perhaps signifying rain drops... the storm is brewing like the storm ahead that parents face as they stand looking ahead fearfully to their child's cancer pathway. Finally, "Storm" presents the height of the conflict (from an operatic perspective representing Grimes' inner turmoil and eventual demise). For the parents in this scene, this represents the overwhelming whirlwind where they find themselves "lost at sea".

Scenery: Wanderer above the Sea of Fog, Caspar David Friedrich, 1818

This painting had a strong impact on me when I first saw it and it immediately resonated with the poem that is presented in this scene. Whilst the soundtrack for this scene presents a metaphor of isolation and being "lost at sea", the painting portrays a solitary person, standing alone on a rocky crevice. The fog obscures the land below and so the view ahead is 'lost in a sea of fog'. This resonates with the parents' sense of feeling lost in where they are as parents, and lost in what is ahead in their life – with fog swirling around like the whirlwind of information they find themselves immersed in.

The Curtain Rises

As I engaged in the conversations with each parent, and later listened to the recordings and read the transcripts, I became aware that all of the parents had experienced – to varying extents – a loss of their own confidence. As the curtains rise on Act 3, this first scene is set deep in the thicket of the woods. The trees are dense and there is little light – like the feeling of being lost at sea expressed by the parents, here we are lost in the thicket of the woods, unable to see the path ahead. This scene will initially express that feeling of lost confidence experienced by the parents by presenting a crafted poem. The words in this poem are each drawn from the transcripts and are all words that the parents directly used. As I wrote this poem and read it back to myself, I also became aware that every single word resonated with my own experience of grief, where I also now see that I suffered a deep loss of personal confidence. Whilst the focus of this thesis is on parents whose child has cancer, I have also become aware that this phenomenon may be more broadly experienced by any parent who is facing adversity.

The poem will be followed by an exploration of specific examples where parents battled with fear for their child, and their loss of self-confidence. In those moments of fear, questions are raised about how others may help. Heidegger's concept of 'caring-for', or 'solicitude', will therefore be explored at the end of this scene as a gateway into the next scenes.

This presentation of lost confidence lays the foundation for the subsequent scenes in this act, where a pathway through the woods will search for a clearing where the phenomenon of how 'significant others' may "shape the confidence" of parents will be illuminated.

Act Three: The pathway through the woods – towards the clearing

Chorus: A crafted poem

The clock is ticking. It deafens me.
They are saying that our child has cancer,
Oh my God, my child has cancer...
The clock ticks, but time has stopped, everything has stopped.

We are lost at sea...
... Dropped in the deep end.

I am a terrible parent.
How did I not notice that something was so terribly wrong?

I am a terrible parent.
I should have spotted this sooner.
I am lost at sea...
... Dropped in the deep end.

We don't know what we are facing,
We fear what we don't know.
We can only imagine what is coming.
We are scared to death.
We are lost at sea...
... Dropped in the deep end.

I stand in a whirlwind of information,
Yet still I do not know enough.
How can I know what is right?
Is this my decision to make, or is it theirs?
I am lost at sea...
... Dropped in the deep end.

The decisions loom large,
We are overwhelmed.
We doubt ourselves...
We stand alone.
We are lost at sea...
... Dropped in the deep end.

Interpretations

These heart-rending words that parents spoke during our conversations are a stark reminder of how life-changing a child's cancer diagnosis is for the family. Whilst health care professionals working in the field of children's cancer may view this as their 'everyday' world, and those in the world who have no experience of children's cancer have no need to think of it, it is so important that we all keep hold of the devastation that a cancer diagnosis brings, and how this may impact on parents.

A cancer diagnosis changes everything for a family. The ontic, factual context of the cancer diagnosis challenges the parent's ontological perspective of their being-as-a-parent. As identified in Act 2 Scene 3, it is a time of being thrown from one's 'normal' world to a new, unknown, horrific world where everything seems different. As our relationships with others change (as identified in Act 2 Scene 2), it seems that how a parent sees themselves may also change as their self-confidence is altered.

As the parents talked to me more about this sense of losing confidence, I identified that there were three core examples of this which will now be explored in more detail: the lead up to and shock of diagnosis, taking on new parenting roles such as managing medication, and absorbing complex medical information.

The parents all tell me about the story of their child's diagnosis at the start of our conversation (presented in Act 2 Scene 1). As I reflect on these stories, I come to realise that all six parents have experienced complexity at this diagnostic stage. Tom, Maggie, Martin and Kerry all talk about having to be persistent as they know something is wrong and can see that initial advice or treatment from their medical team is not working.

"I just felt like there was something more... So I made them refer me to the hospital"
(Martin)

It strikes me that it must take great confidence to be persistent and challenge the medical team. However, this may also take a toll and Martin demonstrates that this really affects how he is feeling:

"The emotional journey was awful... seeing my son ill and just not getting better with the care that I had access to, that was horrible." (Martin)

Saira's decisions around taking Aria to A&E are directly related to her confidence and this story really demonstrates the importance of understanding the wider context:

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“The joke in my family is that I never take anyone to A&E, and if I do then there’s something definitely wrong with them... Myra [Saira’s other daughter] had hurt her ankle a few months earlier, and we’d said ‘you’re fine’, and she was fine... But it was still causing her pain and eventually we took her for an X-ray and it turned out she’d had a slight fracture. So with Aria, there was an element of actually maybe doubting ourselves.” (Saira)

So even before the diagnosis the parents are experiencing challenges where they have to exhibit confidence and challenge medical teams, but they may, like Saira, be coming from a place where their confidence has already been compromised. Again, understanding ‘temporality’ is important here as it helps us to understand this time of diagnosis within this context of past experiences.

Rob’s story around the diagnostic process really exemplifies this shift in confidence. He and Ella deliberate over the lump that they have noticed in Charlie’s side, trying to balance the acknowledgement that something is not right, with not wanting to worry over something that might be nothing. They are clearly concerned though and appropriately seek medical help. As the situation unfolds, he articulates:

“We wondered if we were being overly sensitive... but then when we were told, one of the first feelings is ‘Oh my God, I’m a terrible parent, how have I not spotted this sooner, I know my child, how can I not spot when something so bad is happening’”
(Rob)

This moment of diagnosis, of facing the reality that their child has cancer, whilst most clearly articulated by Rob, is clearly felt by all parents. Darbyshire and Oerther (2020) articulated that it must feel terrifying to be a parent of an ill child. Heidegger (1927 / 2010: 142) discussed how we may fear for others who are important to us:

Fearing for, is, after all, being afraid oneself. What is “feared” here is the being-with the other who could be snatched away from us.

As discussed in Act 2 Scene 2, Taylor and de Vocht (2011) proposed that we become used to the presence of others around us as we are always ‘being-with’, and therefore they may feel more conspicuous if they are absent or lost to us. We fear for ourselves because of the threat of losing the other.

At what is therefore an existentially terrifying moment, Darbyshire and Oerther (2020) have proposed that whilst parenthood is often framed as a set of effective / ineffective strategies, times like this demonstrate that parenthood cannot be reduced to a rulebook. What may have

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worked in the relationship between parent and child when the child was well may no longer be 'effective'. Parents are presented with a new set of skills that they must adopt within their role, such as administering medicines. The responsibility of undertaking this, combined with the understandable terror that they are experiencing, must redefine their sense of parenthood. It is not surprising that this is experienced as a lack of confidence.

Tom expresses this change in his parenting role and the difficulties that he and Jenny experience with administering medicines to Noah:

"We were struggling to get the medicines in... This was a kid that had been so well, he'd had basically one dose of Calpol probably every six months... So to suddenly be given all these medicines to try to give him. We had to pin him down to the floor and try and put them in his mouth with a syringe and it was an absolute nightmare because it got spat out. He didn't understand, he was two and a half. He thought that we were punishing him." (Tom)

Kerry also tells me about her experience of administering medicines to Harry:

"It was horrible... it was traumatic... We wrapped our little baby Harry up in a towel so that he couldn't punch out... one of us would do the medicine, the other one would hold him... When I look back, I think that was horrible, I feel bad that I did that to him"
(Kerry)

Both Kerry and Tom experience this shift in relationship with their child, where they now feel this sense of trauma as they are forcing their child to take medication. Their desire to talk about this and reflect on it with me suggests their feelings of discomfort and Kerry in particular reflects back to that time and regrets how this was managed. Moments like this undermine the parent's confidence in their ability to be a parent. Something that sounds so simple (administering several oral medications) is not at all simple when the child does not want to take them (particularly as they become aware that many of these taste horrible). However, the risk of their child not taking these medicines is significant. These medicines may be an integral part of their child's life-saving treatment, or they may be protecting them from severe side effects of chemotherapy. The pressure that parents may feel is enormous as they must find ways to persevere.

If not enough to have faced the devastation of their child's life-threatening diagnosis and then have to adapt their parenting to learn new skills and strategies, parents are also placed in a position where they have to absorb complex medical information and then be involved in decision-making around this. Martin articulates the difficulty of this:

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“The early days were an absolute whirlwind of information, we had to upskill very quickly in an area of biology that I didn’t actually know very much about.” (Martin)

And Tom expresses this sense of feeling dropped in the deep end because even if you have known other people who have had cancer *“when it hits your actual family you don’t know much about it”*.

The ‘whirlwind’ that Martin articulates is experienced by all parents. All acknowledge the speed with which they find themselves thrown into this situation, and that they are in a world where they have to learn the science and language of cancer very quickly, alongside processing the emotional trauma of the diagnosis. Their confidence in their knowledge may be low, their confidence in their parental instinct may be low, their confidence in their parenting strategies may be low. Combined with the enormous emotional trauma and fear that their child may die, they experience a loss of confidence in their being-as-a-parent.

The parents who I speak to are not alone in this feeling. My literature review (Jestico et al., 2023b and Act 1 Scene 4) identified that the burden and emotionally charged context of being a parent of a child with cancer could lead parents to lose confidence in their ability to make decisions. Stewart, Pyke-Grimm and Kelly (2012) particularly identified that the life-threatening nature of cancer, and the speed with which decisions had to be made and treatment instigated, could undermine the parents’ confidence in their competence to make the right decision. In a study of parents’ experiences when their child has a brain tumour, Barraza (2014) similarly found that parents described having their confidence stripped and that their ability to function had become so compromised that they could not process information adequately to make decisions. As discussed in Act 2 Scene 3, the parents in this study also face the challenge that they feel a loss of agency to make the ‘major’ decisions, again potentially compromising their sense of parenthood, further lowering their confidence to make decisions.

This of course, raises the very important question: how may others support parents through this? To gain insight into this, it is helpful to explore a further Heideggerian concept ‘caring-for’ / ‘solicitude’. This draws on the Heideggerian concepts discussed in Act 2 (‘Dasein’, ‘temporality’, ‘being-with’, ‘authenticity’, and ‘thrownness’).

Heideggerian concept: ‘Caring-for’ / ‘Solicitude’ (‘Fürsorge’)

The fundamental question running through Heidegger’s *Being and Time* (1927) is “what is being?” (Inwood, 1997:9). As discussed in Act 2 Scene 1, Heidegger proposed the concept of ‘Dasein’ – the unique mode in which humans exist. As Heidegger continued his analysis of ‘Dasein’ he argued that the basic structure of human existence, of ‘Dasein’, is ‘care’ (‘Sorge’) (1927 / 1962). This has the potential to create linguistic confusion as the word ‘care’ in English

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can mean a number of things. Often as health care professionals we would likely consider ‘care’ to mean, as Blattner (2006:37) described, “emotional phenomena of worry and devotion” (so, for example, when I say that as a nurse I ‘care’ for children and families, I mean that I look after them and do what I can to ease their suffering). Heidegger though intended ‘*Sorge*’ to mean that as humans, we are interested in, and question, our being (Spier, 2019).

From this overarching concept of ‘*Sorge*’, Heidegger distinguished how we take care of objects and affairs which he referred to as ‘*Besorgen*’ (‘concern’), and how we care for other people – ‘*Fürsorge*’, which is often translated as ‘solicitude’⁸. It is this notion of ‘*Fürsorge*’ – ‘solicitude’, or ‘caring-for-others’ that is particularly relevant to this thesis. As ‘care’ is not intended by Heidegger to describe an emotional state, ‘solicitude’ similarly is considered a term for the way that others matter to us (whether in a positive or in an indifferent way) (Blattner, 2006), and this care for, and interest in others is inevitable on the basis that Heidegger argued that ‘*Dasein*’ is always ‘being-with’ others (‘*mitsein*’).

Having articulated that ‘solicitude’ can present as a deficient mode (where we may be aware of others but do not pay much attention to them) as well as a positive mode (where others do matter to us), Heidegger then offered further analysis of this positive mode of ‘solicitude’ (Spier, 2019). He proposed that there are two extreme possibilities of this: ‘**leaping-in**’ and ‘**leaping-ahead**’.

Solicitude can take away ‘care’ from the Other and put itself in his position in concern: it can **leap in** for him... The Other is thus thrown out of his own position; he steps back... In such solicitude the Other can become one who is dominated and dependent. (Heidegger, 1927 / 1962:122)

In other words, by ‘leaping-in’ people try to help by taking over and act on behalf of the person in need. The person is disempowered to act for themselves and is therefore prevented from acting authentically. This then becomes considered an *inauthentic* way of ‘caring-for-others’.

The alternative, Heidegger suggested, is ‘leaping-ahead’:

In contrast to this, there is also the possibility of a kind of solicitude which does not so much leap in for the Other as **leap ahead** of him... not in order to take away his ‘care’

⁸ There is discrepancy in the translation of these words which may further add to confusion around these concepts. Sembera (2007) translated *Sorge* as “concern”, *Besorgen* as “concernedness” and *Fürsorge* as “concernedfulness” which perhaps helps to highlight the nuances between these words. Stambaugh (2010) translated *Sorge* as “care”, *Besorgen* as “taking care” and *Fürsorge* as “concern”. However, the Macquarrie and Robinson (1962) translations of “care”, “concern” and “solicitude” are more commonly referred to and I am therefore using these translations.

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but rather to give it back to him authentically...This kind of solicitude pertains
essentially to authentic care.

(Heidegger, 1927 / 1962:122)

So here, the person is empowered to freely act in an *authentic* way. Rather than ‘leap in’ to help a person in the current moment, ‘leaping-ahead’ recognises that the person needs to be empowered to take responsibility for themselves and look authentically to their future. Heidegger (1927 / 1962:122) further proposed how the difference between ‘leaping-in’ and ‘leaping-ahead’ may impact on us:

Everyday being-with-one-another maintains itself between the two extremes of positive solicitude - that which leaps in and dominates, and that which leaps forth and liberates.

Spier (2019) argued that Heidegger’s proposal is simply offering a binary alternative between inauthentic ‘leaping-in’ and authentic ‘leaping-ahead’. Heidegger did propose though that these are extreme ends of a spectrum of ‘solicitude’ (but acknowledged that within *Being and Time* he would not elaborate on this). This is perhaps more clearly translated in Stambaugh’s edition:

Between the two extremes of positive concern [‘solicitude’ if adopting Macquarrie and Robinson’s translation of ‘Fürsorge’] – the one which does someone’s job for him and dominates him, and the one which is in advance of him and frees him – everyday being-with-one-another maintains itself and shows many mixed forms whose description and classification lie outside of the limits of this investigation.

(Heidegger, 1927 / 2010:122)

In addressing the question: “how may others support parents to make decisions when they have experienced the loss of self-confidence portrayed in this scene?”, it seems that this Heideggerian concept of ‘solicitude’ with its possibilities of ‘leaping-in’ versus ‘leaping-ahead’ may help. Yet there is still much more to uncover. Is it necessarily true that ‘leaping-ahead’ is always the best way to approach supporting others as Heidegger proposes? Is this what the parents need or want? We understand that the parents have been abruptly thrown into this new world, do they want to be empowered to make all decisions at this moment, or is this an evolving process where others need to initially ‘leap in’ and later move to ‘leap ahead’? Do they perhaps want this mixed synergy between the two extremes that Heidegger suggests is also possible? Nancy (2008) critiqued Heidegger’s concept of ‘solicitude’ by arguing that whilst Heidegger proposed that ‘leaping-ahead’ may support others to live in an authentic way,

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Heidegger did not elaborate by explaining **how** we can 'leap ahead'. Arguably, Heidegger's intention though was never to tell us how to live or how to be, his intention was to enhance understanding about life and being, so perhaps Nancy's critique is misplaced. This question though is of relevance to this study, and further travelling towards the clearing will shine a light on how 'leaping-in' and 'leaping-ahead' may be made manifest in this context.

The Curtain Falls

The first scene of this act has been set deep in the thicket, the darkest part of the woods. The crafted poem portrayed the darkness for the parents as they experienced those early days around their child's diagnosis which was, to varying extents, accompanied by a loss of self-confidence. As discussion around Heidegger's concept of 'solicitude' has developed though, a glimmer of light can be seen. More attention needs to be given to the characters' stories, and different parts of the pathway through the interpretation of these stories will cast further light on whether this Heideggerian concept, or other philosophical concepts can help to further understanding about how 'significant others' may help parents to make decisions when their child has cancer.

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Scene Two: Shaping confidence to maintain and to renew identity



Scene Two: Shaping confidence to maintain and to renew identity

Soundtrack: Five Variants of “Dives and Lazarus”, Ralph Vaughan Williams, 1939

This is one of my favourite pieces of music. Vaughan Williams was an English composer who was well known for his interest in English folk song and Tudor music. “Dives and Lazarus” is an English folk song that is referenced in 16th century writings, but may well have been in performance circulation earlier than this. Vaughan Williams encountered the folk song and initially arranged this as a hymn tune (Kingsfold). He then transformed the tune into these wonderful variants, composed for string orchestra and harp.

Following the opening harpist’s chords, the Dives and Lazarus theme emerges and is played strongly by the strings. There is a sense of dialogue as the theme moves seamlessly between each of the four parts of the string orchestra. This theme is ever present throughout the 12-minute work, but Vaughan Williams uses techniques such as moving from common to triple time, and adding counter themes, so that we start to hear the theme in a different way. For example, about halfway through, there is a beautiful duet between a solo violin and harp, with the rest of the orchestra accompanying. Dives and Lazarus is explicitly still there, but it has evolved. This then moves into a canon with more aggressive, syncopated rhythms, again bringing new life to the theme. This builds to the climax in the final 2 minutes where the theme is heard strongly, with luxurious harmonies. We almost hear the theme as we did at the start, but we have experienced a journey, and it is impossible to now hear it in quite the same way. The music ends with a sense of quietness and calm – with space to reflect and take in the past 12 minutes of musical intensity.

What strikes me when I listen to this is the strength and profoundness of the central theme which is always present, despite the evolution that it takes. This reflects the central Ricoeurian point of this scene, that there is a core, unchanging aspect of our identity, yet there is also a continuity and evolution of identity that we experience through our relationships with others. We are always the same, and also always different as time evolves.

Scenery: Fir Forest, Gustav Klimt, 1901

This painting by Gustav Klimt represents this feeling of sameness in difference that is heard in the soundtrack. The painting of the fir forest is unmistakably a wood, something that we have always known – yet Klimt’s use of colour shows that each tree is unique and we see the individual trees, and the collection that make up a wood, in a different way. This painting also represents this place in the journey through the woods - whilst the trees are still dense, glimmers of light appear and a pathway through the trees can be seen to emerge.

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The Curtain Rises

Scene 1 of this act was placed in the dark thicket of the woods. The loss of confidence that parents experienced around the time of their child's diagnosis was expressed. These next three scenes will forge a pathway through the woods, from this thicket of lost confidence to the clearing, where understanding will be developed that 'significant others' may shape the confidence of parents as they navigate through decision-making when their child has cancer.

The pathway starts in this scene, with an exploration of how others may shape parents' confidence to maintain and to renew their identity. There are many psychological theorists who propose that our confidence relates to how we see and feel about ourselves (our self-esteem and self-efficacy) (for example Maslow, 1943 and Bandura, 1997). However, this is also a topic that is addressed by philosophers. As one of the principles of hermeneutic phenomenology is to seek ontological insight rather than apply psychological theories (Flaming, 2005), it is Ricoeur's philosophy that, in conjunction with Heidegger's, will be a guide along this pathway. This scene will therefore start with a discussion about Ricoeur's concept of identity and as the pathway progresses throughout the next three scenes, it will become clear that identity and confidence are philosophically linked. Two crafted stories will be presented that highlight this issue of identity, and how being supported to maintain one's original identity, but also being able to renew identity following a child's diagnosis of cancer, is important. This will be followed by further illustrations from other parents, along with my interpretations. Drawing this discussion together with Heideggerian and Ricoeurian philosophy will then cast further light on the parents' stories.

During the interviews something of each of the parents' identities shone out to me. As this scene progresses, these characteristics will become clearer. However, there seemed to be two commonalities between all six parents. Firstly, they all appeared to have a strength and resilience of character, and secondly, they all used this strength to advocate for their child. They saw their role, their identity as a parent, to be an advocate for their child. Having the confidence and self-belief that they were able to do this was therefore critical as they faced decisions.

Ricoeurian Concept: Identity

At the start of Act 2 Heidegger's concept of '*Dasein*' was introduced – a notion to represent our existence as 'being-in-the-world'. Ricoeur absolutely did not dismiss Heidegger's analysis of 'being-in-the-world' but rather, drew from Heidegger and from other philosophers, to propose how we can understand our identity as we exist in the world, and how this informs our actions and decisions (Simms, 2003; van Manen, 2014).

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In *Oneself As Another*, Ricoeur (1990 / 1992) drew upon his previous work around how we form intentions to act in a certain way. He proposed that any decision involves a 'what' (a description of the action), a 'why' (the motive of why the action is decided upon), and the 'who' (how our identity and character inform this decision), so in the context of this study, having confidence in 'who' we are is significant in our confidence to make decisions. Ricoeur's analysis of identity revolved around the dialectic between two Latin words that can both be translated to mean identity: '*idem*' – where identity is considered as *sameness*, and '*ipse*' – where identity is considered as *selfhood*. In answering the question of 'who' (the agent of our actions), we need to tell the story of a life experienced across time. This provides us with a narrative identity, and it is the concept of '*ipse*' that constitutes this narrative identity (Simms, 2003) and helps us make sense of who we are (Flaming, 2005).

Critical to these concepts of '*idem*' and '*ipse*' is the question of the extent to which our identity is *permanent* or *changeable* over time (therefore Heidegger's proposal of the 'temporality' of '*Dasein*' is important here). As we get older, we change physically, and we also change inside as we become more mature, more experienced, and more knowledgeable (van Manen, 2014). However, there is also an unchanging core of our identity that remains constant.

Ricoeur suggested that mediating between '*idem*' and '*ipse*' are the poles of **character** (where '*idem*' and '*ipse*' are closest to each other), and **self-maintenance**, or **self-constancy** "*where selfhood frees itself from sameness*" (Ricoeur, 1990 / 1992:119). Where '*idem*' and '*ipse*' both therefore have a permanence in time that is reflected in our character, '*ipse*' also has the freedom to change over time (a continuity of self) (van Manen, 2014). As Simms (2003:102) explained:

I am the 'same' person I was twenty years ago, even though I am so much different, and it is this sameness-in-difference that is my '*ipse*', my narrative identity.

This sameness-in-difference is really important to us. Flaming (2005) explained that '*idem*' (our stable, unchanging sense of identity) allows us to feel grounded in who we are, so being able to maintain this is significant. However, changes within our identity are inevitable and we also need to be open to renewal. Our '*ipse*' allows us to accept that stability and change, the maintaining and renewing of our identity, are not mutually exclusive, and that we can allow our identity to evolve without the threat of losing our core character.

Ricoeur acknowledged in *Oneself as Another* (1990 / 1992) that his ideas around character had evolved since his earlier writings. He argued in this new work that "Character designates the set of lasting dispositions by which a person is recognised" (page 121). These dispositions are

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habit and **acquired identifications**. Habits are formed and acquired and are temporally stable, Ricoeur proposed. Acquired identifications are where we identify ourselves with reference to the “values, norms, ideals, models and heroes” (page 121) of the community in which we reside. This very much resonates with Heidegger’s concept of ‘*Das Man*’ (‘the They’) and the associated ‘inauthenticity’ of ‘being-with’ others. However, whilst Ricoeur similarly framed this as community values (like the faceless Heideggerian ‘They’), there are also hints here of reference to associating with **direct, named** others (“heroes”). Again though, there is temporal stability with these acquired identifications, and if our behaviour does not correspond with these dispositions (of habit and acquired identifications) it may be noted that we are ‘acting out of character’ (Ricoeur, 1990 / 1992). This temporal stability, or permanence in time, is therefore what defines our sameness.

Our character is therefore, to an extent, informed by others as we identify with the values and norms of those around us. Our **self-constancy** (the pole where ‘*idem*’ and ‘*ipse*’ drift apart to allow diversity of identity over time), is also significantly informed by others. Self-constancy refers to our ethical accountability towards other people. As Heidegger suggested that we are always *mitsein* (‘being-with’ others), Ricoeur similarly proposed that our individual lives are always entangled with others’ lives (Simms, 2003). Our identity is therefore informed by our relationships and interactions with others. As each individual’s narrative, or life-story, evolves over time, our individual identity must also evolve. Where Heidegger’s analysis of ‘being-with’ is related to ‘authenticity’ / ‘inauthenticity’ towards ourselves, Ricoeur proposed that our relationships carry this ethical responsibility towards others so that they can rely on us (Ricoeur, 1990 / 1992). This is significant here as, for the parents in this study, it was difficult to apply Heidegger’s concept of authentic decision-making, when making decisions on behalf of a child. However, Ricoeur’s concept of self-constancy carries a possibility that a parent’s identity is (at least partly) situated in this sense of taking responsibility for another.

Ricoeur’s concept of identity, and in particular this notion of ‘sameness-in-difference’ can help to understand the importance of being supported to **maintain** yet also **renew** our identity, and how our identity is informed by our relationships with others. It is therefore of interest to consider the parents’ stories now and explore whether these Ricoeurian or Heideggerian concepts may further our understanding.

Martin’s Crafted Story

I can tell our story in a very matter of fact way, the details of what happened and when. But the truth is, there’s a whole emotional journey too, which has been awful. During those early weeks I am an emotional mess, a wreck.

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After loads of GP appointments and tests, Toby is diagnosed at our local hospital and we are transferred to a specialist hospital in another city. Helen has COVID so she can't come with us. All that Toby wants is his Mum, but all that he has is me. I have to stand and watch my son be so ill, he isn't getting better, and I can't help him. It is very hard, a trauma, an emotional journey.

We are in an absolute whirlwind of information; we have to upskill in an area of biology that I don't know much about. It is very intense. Lots of people are speaking to us about different things. And then they ask us to make a decision about opting in to a clinical trial. We have some big learning curves and some deep conversations. But we want to give back as much as we possibly can to help any other parents in the future, so we decide to opt in. This is a logical decision, an easy decision. I want to do as much as I can to help anyone in the future. Making logical decisions is easy for me. I have a professional skill set which means that I am always looking and analysing what is going on and looking ahead. That is my inherent mentality. My wife is not analytical. She has strengths in social skills, in dealing with people. So our social and professional influences help us with these decisions. But the actual decision is just between Helen and I, we are in the space at that moment and it's all happening so quickly.

We are faced with so many decisions that extend beyond Toby's treatment. I have to make decisions about returning to work. I find this very stressful. I am the main breadwinner and I need to support the household. Is it acceptable to take time off work now that I'm the father of a son with cancer? I chat about this on the 'Mind the Chaps' WhatsApp group. This is extremely supportive. All of the Dads on this group have different stories, but we're all Dads of children with cancer. We understand the journey that we're all going through... I feel that I can say to them "I'm having a bit of a shit day" and they all understand. When I ask what I should do about work they give me lots of feedback and this is amazingly helpful. This leads me to reach out to my employee assistance program at work and I start to access support for myself. By accepting that I need to seek support myself I feel stronger to look after Toby, and Helen and Max.

There are decisions ahead of me as well. Through all of this journey over the past weeks and months, I have questioned what is important in life. Two months ago, for me it was all about career and work, supporting my family and providing a roof over their head. What has happened has taught me that things like work don't matter. And I am questioning what value I am adding to this world. What's the value in my career, or my life? So I am exploring options about changing this, a new career, where I can add more value. I haven't made that

decision... yet, but I keep questioning what is important in life. And there is one thing I know for certain; family comes first now.

Tom's Crafted Story

Noah is our only kid, and he's always been so well. Everything is fine... until the ear infection. And then he seems a bit wobbly, he has a few bruises, he's off his food...

They come into the hospital room and they say "he's got leukaemia". We are dropped in the deep end. Everything has changed, we don't know anything about this. We know friends who have had cancer, but now this is my family and it's all just different.

But we are so lucky, we've got loads of support from friends in our church groups. We get messages from around the world from members of our church who have been through similar experiences. And our family is such a great support – it's not by chance that we live in the same village as Jenny's parents, if you believe in God, you know why he placed us here.

I wouldn't say that we make many decisions really, we just agree with everything that the doctors offer, because we don't know what else to do. We are just laymen, we don't know things and we don't know what's going on, but they – they are the experts and so we do what they say and agree with what they offer. What else can we do, if you really love your kid, why would you go against the advice of a consultant?

I suppose we did have to make a choice about whether Noah should have an NG tube... We'd been at home for a few days after he'd been diagnosed. We were really struggling to get the medicines into him. The thing was, this was a kid who had been so well, he'd basically had one dose of Calpol every six months. And all of a sudden, we were having to give him all these medicines. It was a nightmare. We had to pin him down on the floor and try to put them in his mouth with a syringe but then he'd spit it out. It was so stressful. And Jenny was so anxious that he wasn't getting the exact amount – we didn't know how much he was getting and how much he was spitting out. It was an absolute nightmare. And then the doctors and nurses talked about NG tubes. And we made the decision right then, at the hospital, because we trusted their advice. And it was miracle advice. Actually just a few weeks ago there was another little boy at the hospital and his parents were struggling and struggling to get his medicines into him. They decided to have an NG tube and we reassured them that it was a good decision. It felt really good to be able to share our experience with them, to give them encouragement and confidence in what they were doing. That link between all of us parents on the ward is really quite unique.

Sometimes other people in our life like friends and family think that they know more, they make suggestions to us, but they don't really know. The more people you involve, the more opinions you hear – and it's just not helpful. Some people have a different view to us – they think it's better to take chances and go against the advice of the doctors. But it's not a decision for them to make, it's our decision. It is for us to stand on our own two feet and make it.

The church is different. People there are more aligned with our way of thinking. All our lives we've been part of the church, we were born into it. I know that our leaders would always tell us to follow the best medical advice. They would never encourage us to paddle our own canoe and just try our own thing. And now that we are able to link in with the global church, we have people from all over the world – from Copenhagen, New Zealand – backing us up and supporting us. And this makes me feel that we are making the right decisions. They are all praying for us and sending us so much love and support. They give us strength to carry on and make the decisions that we are making. We are so fortunate. There must be thousands and thousands of parents who don't have support like us, we are so lucky... in that way.

The thing is, all of the decisions that we have had to make, and that we continue to make – they all have one thing in common. They are decisions for him. We know that if we trust ourselves to put him first, everything else will fall into place. No matter what the decision is, we are his parents, and we will make the decision that is best for him.

Interpretations

Within Ricoeur's analysis of identity, he suggested that there are key dialectics: that between '*idem*' and '*ipse*'; between *sameness* and *difference*, and that between *oneself* and *the other* (Ricoeur 1990 / 1992). As I reflect on Martin and Tom's stories, and indeed the transcripts from the other parents, I see another dialectic which aligns to Heidegger's *ontic* and *ontological*. This is an ontic identity – characterised by a label, or defined role that is recognisable and acknowledged by others (*what* we are); and a deeper, internal ontological identity that is formed of the character, dispositions and personality of the individual (*who* we intrinsically are) – this ontological identity informs the way that we function in the roles that we hold. Both aspects have the capacity for the sameness and difference that Ricoeur speaks of, and both influence, and are influenced by, our relationships with others.

If a person is asked "tell me a little about you, who are you?" – they would most likely start with these ontic descriptors. They may say their name, their job title, their role within a family, or perhaps membership of particular social groups. It would be less likely for them to start by

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talking about key aspects of their character, that they are compassionate, brave or generous – these qualities though would likely become evident in further conversation. On this basis, the following interpretations will be initially structured according to the configuration of ontic labels or roles, but, throughout, the intrinsic, ontological aspects of identity will be focused on.

Identity as a parent

Tom, Martin, Saira, Kerry, Maggie and Rob are all parents. This is a fundamental part of their life and their identity. Being a parent infuses every part of their life, this responsibility for a child informs every decision and every action. In Heideggerian terms their ‘being-in-the-world’ (*‘Dasein’*) is enormously shaped by their relationship, or their ‘being-with’ their child / children. As Darbyshire and Oerther (2020) proposed, the moment of becoming a parent shapes one’s identity and holds huge ontological significance. This reflects Ricoeur’s concept of continuity of self (1990 / 1992), whilst core aspects of identity can be maintained, becoming a parent changes the way that we see ourselves and shapes our future actions. Something of us changes and our narrative identity continues in a different way, it is renewed whilst maintaining its sameness. Bax (2017:390) cited Levinas’s claim that “it is only in the responsibility for another person that I truly come into my own”. This seems particularly relevant here, where identity is consolidated through parenthood.

As a parent’s ‘being-with’ is shaped by their relationship with their child they become attuned to their child’s needs. There are examples of this in all of the parents’ stories, but this quote from Maggie, reflecting on the pre-diagnosis period, really highlights this attunement as a parent:

“I kind of thought there was something a little bit wrong with her, it must be this Mum’s instinct thing. I just knew there was something wrong with her.”

As I reflected on all of the conversations that I have had with these six parents, I realised that for each of them, being a parent is not sufficient in terms of who they were, or who they want to be. They are all concerned with being a **good parent**. Darbyshire and Oerther (2020) alluded to societal rules and expectations around being a good parent and this is certainly evident in parents’ experiences from the literature. In a study about becoming a new mother, Kay et al. (2017:9) described the pressure that one mother felt to fit the profile of being the “perfect mother”. As I read and re-read the transcripts, particularly focusing on the period leading up to diagnosis, it seemed to me that being a good parent is certainly about being attuned and trusting a parental instinct as highlighted by Maggie. But above all, being a good parent is about this motive of advocacy at the heart of every story, that (in Tom’s words):

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"We are his parents, and we will make the decision that is best for him".

This sentiment of advocacy and promoting the child's interests as being a key role of the good parent is supported in the literature (Pyke-Grimm et al., 2006; Young et al., 2010) and so being a parent and advocate is evidently a critical component of identity. What parenting means and feels like significantly changes at the moment a child is diagnosed with cancer.

Identity as a parent of a child with cancer

Tom, Martin, Saira, Kerry, Maggie and Rob are no longer 'just' parents. They are now parents of children with cancer. Everything changes and their identity of being a 'normal' parent is shaken. Their world crashes down, and with that comes a loss of confidence in being a parent that was illustrated in the last scene and echoed in Martin and Tom's stories. They have lost confidence in being a parent, particularly in being a **good** parent. The early days in Martin's story really illustrate this:

"he isn't getting better and I can't help him"

It seems that Martin is almost paralysed by his helplessness. He sees that his role as a parent is to protect and care for his child, and at this moment he feels unable to fulfil this role.

Tom's account of trying to administer medicines to Noah shows that the world they find themselves in is new. Not only have parents lost confidence in being a normal parent, but they have no experience in this new world and therefore have little confidence in how to be a parent of a child with cancer. This experience can feel like a *"nightmare"*.

This new world is also seen in Saira's experience, where she moves from being an 'outsider' of the children's cancer world, to an 'insider'. Saira explains to me that her friend's daughter had been diagnosed with leukaemia several years before Aria's diagnosis. She acknowledges to her friend that she had been an outsider at that time, and only now could she understand what her friend had lived through. She tells me that being an insider is very isolating, everybody else on the ecomap (except the group of Cancer Mum friends) are outsiders and she feels increasingly disconnected from them. This resonates with Picoult's (2004) quote from *My Sister's Keeper* noted in Act 2 Scene 2 about parents feeling isolated from former relationships and replacing these with new relationships with nurses, and similarly Gage (2013) who observed that parents may feel that pre-existing friends and family lack a full understanding of what they are going through. As Saira tells me about this, it almost feels like the people on the ecomap have changed from direct, named people, to a more general, quasi-anonymous group and are now seen more as the Heideggerian 'They'. This disconnection means that these 'significant others' struggle to offer support or advice, simply because they do not fully understand. The 'They'

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have less influence on Saira's decisions now and she has almost no choice but to become more authentic. Saira says that this move from an identity as an outsider to insider is permanent:

"When you get that initial diagnosis, it is like looking into the abyss, and you can never unsee that. It sits in the back of your head and affects how you view everything."

During my conversation with Kerry, she reflects on how particular decisions are influenced by this new identity. One of the first decisions that Kerry faces is on the Saturday when she is told that it is suspected that Harry has leukaemia. She is asked if she would like Harry to be admitted to the oncology ward on this day, or wait until the Monday when diagnostic tests will likely confirm the diagnosis of ALL. Kerry said:

"Making that decision to go to the cancer ward is like 'you're a cancer kid now, you're not a question mark, you're a cancer kid now'".

Once that label is assigned, it must feel that there is no turning back. Everything in life, and every relationship, will change and so it seems unsurprising that such a significant shift in life is accompanied by a loss of confidence.

This identity is reinforced a few weeks later when Kerry is faced with the decision about whether Harry should have a nasogastric tube inserted and she acknowledges that if they decide to do this, he will look different:

"It's that image of a cancer kid. You always see the cancer kids, and now you have to accept that this is your kid 'my kid's got cancer'. But if he looks like a cancer kid, that's because he is – and, at the end of the day, it will be better for Harry and less stressful for him if he has it".

As Harry's visual identity changes, Kerry's identity as a parent of a child with cancer evolves. She perhaps considers what other people will think, and certainly here this seems to be within the context of anonymous, societal reactions – what will the 'They' think? Yet in this difference, and evolving identity, Kerry is maintaining that she must confidently and authentically advocate and do what is best for her son. So by allowing her identity to be renewed, she actually maintains the sameness of her identity as being a good parent, perhaps in spite of others' potential responses.

For all parents then, their identity has changed from being a parent, to being a parent of a child with cancer. But this sense of needing to be a good parent is maintained. They now emulate being a 'good parent of a child with cancer'. Hinds et al.'s (2009) research explored parental decision-making when a child has non-curative cancer. They explored this concept of parents needing to make decisions as a 'good parent' and identified that key aspects of being this good

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parent included making decisions that were informed, unselfish, in their child's best interests, and advocating for their child. A later study by Weaver et al. (2020) suggested that the concept of being a good parent may start before the child's birth but is influenced by a child's health needs. Therefore, being an advocate and making decisions that are best for their child, or children, is still central to their parenting, but as a parent of a child with cancer, this feels – according to Weaver et al. (2020) – more complex and requires greater skills in communication and advocacy. This then raises the question about what others can do to support this confidence in advocacy and this is something that comes through strongly in both Tom and Martin's stories.

Identity within a social group

A fundamental part of Tom's identity is his faith (he talks about this often during our conversation). His faith draws him to being part of the church community which features on his ecomap. This is absolutely constant for him (his faith has been a core part of him for his whole life and is his 'sameness'). So whilst his labelled identity has changed from being a parent, to being a parent of a child with cancer, he still has his faith and church community. His church community enables him to maintain this aspect of his identity which helps him to maintain his sense of being a good parent. However, due to the connections that he builds within this community he is also able to renew his identity as a parent of a child with cancer. On his ecomap, Tom differentiates between the local church and the wider church, and here they play slightly different roles in supporting him. The wider, global church means that Tom can connect to other people who have had similar experiences. In particular he tells me about a father in New Zealand whose son also had ALL. Tom explains that this gives him reassurance as they discuss the various decisions and situations that they are faced with, and Tom finds that he is being given confidence that he and Jenny are making the right decisions. This father from New Zealand is affirming to Tom that he is a 'good parent', which is significant in shaping Tom's confidence in being a parent of a child with cancer. Within the local church, whilst there may not be anybody else who has lived through the experience of having a child with cancer, he is surrounded by people who are *"aligned with our way of thinking"*. The church leaders reinforce the messages of the church, that Tom and Jenny should follow the medical professionals' advice rather than *"paddle their own canoe"*. Both the local and wider church allow Tom to connect with people who are on the same wavelength. This gives him confidence and strength.

This is an example of what Ricoeur (1990 / 1992:121) would refer to as 'acquired identifications' described earlier in this scene:

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We recognise ourselves by identifying with other people, 'values, norms, ideals, models and heroes' of communities of which we feel ourselves to be a part.

So, by connecting with people within the church community, Tom recognises that they are aligned to his way of thinking and therefore recognises himself and how he should respond to the decisions that he is faced with. When I first reflected on my conversation with Tom, I wondered if this was an example of Heideggerian 'inauthenticity', on the basis of Tom's position regarding decision-making:

"I wouldn't say that we make any decisions really, we just agree with everything that the doctors offer... we do what they say."

However, the more I read and re-read this transcript I increasingly see that Tom is being true to his identity in terms of his faith – religious faith which then informs faith in medical experts. So I now see that it is possible to be 'authentically inauthentic'. Choosing **not** to make a decision is in itself a decision.

Tom's faith is a strong part of his character, and this is temporally constant. When other people in his life make suggestions that are at odds with Tom's perspective (such as going against the advice of the doctors) he is clear that it is not helpful. However, the church community who share Tom's values, reinforce his confidence in his core character, and that then informs the way that he approaches decision-making.

Whilst Tom mainly talks about his church community, he also talks about belonging to a new group and highlights this on his ecomap - the other parents on the ward. He does not talk about this group much but does explain that this is a *"link which is unique"*. Martin similarly talks about this link with other parents and the need to draw on this shared experience. For him, rather than other parents on the ward, he focuses on the Facebook and WhatsApp groups that he has joined, and how the WhatsApp group in particular, has helped him make decisions about his work. Within our conversation, Martin tells me that he is very stressed about knowing how long was acceptable to take off work as he was the main breadwinner. It seems that his identity as the "breadwinner" had been compromised but turning to the WhatsApp group – specifically consisting of other fathers of children with cancer, helps him renew his identity as a legitimate part of this new group. Again, Martin is identifying with a "community with which he feels himself to be part" (Ricoeur, 1990 / 1992:121), but this is an example of a new community which therefore facilitates *continuity*, or difference in self – rather than sameness. Whilst Ricoeur proposed that this acquired identification forms our character which is constant in time, Martin's situation suggests that the communities which we feel part of are

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actually dynamic and therefore there may be moments when our character shifts over time, particularly at moments of crisis where we question who we are.

Identity as an advocate for my child

The role that social groups play has its boundaries, and it feels important that the parents could identify that crossing these boundaries is the difference between feeling supported by others, and feeling unsupported. This is particularly evident in Tom's story, where he identifies that some people try to give unsolicited advice:

"Sometimes other people in our life like friends and family think that they know more, they make suggestions to us... it's not helpful."

He goes on to explain that this feels like they are trying to take over Tom and Jenny's role as decision-makers.

"But it's not a decision for them to make, it's our decision. It is for us to stand on our own two feet and make it."

During my conversation with Martin, he said something similar:

"It was very much between Helen and I to make the decisions."

This very much echoes the findings of my literature review (Jestico et al., 2023b) where several authors noted that parents felt strongly that nobody else should be involved in decision-making (for example Kelly & Ganong, 2011; Papadatou, Yfantopoulos and Kosmidis, 1996). Here again, it seemed that the parents represented in the literature acknowledged this fine boundary between support and interference. O'Neil's (1996) research found that parents perceived interference from others as an assault on their advocacy for their child and I proposed in the literature review that others attempting to take over the decision-making role was in conflict with the parents' identity as decision-maker.

Heidegger's philosophy relating to 'solicitude' feels very relevant here. It seems that for Tom, like the parents' narratives in the literature review, when others try to give unsolicited advice they are trying to 'leap in' and take over. This pushes Tom away from being able to authentically decide for himself and undermines his confidence as an advocate and decision-maker. From a Ricoeurian perspective, the people who are trying to 'leap in' are not those from the community within which he feels himself to be a part, they are not aligned to his way of thinking in the same way as the church community. So not only does this feel like an assault on his externally labelled role as 'a parent', which Tom feels strongly should mean that he is an advocate for his child, but actually this also feels like an assault on his intrinsic character.

Identity as oneself

At the start of these interpretations, I proposed that there may be a dialectic between identity characterised by our roles, and identity characterised by the intrinsic self. I explained that my interpretations would be initially structured according to the ontic roles and labels. I therefore started with a discussion around identity as a parent, as a parent of a child with cancer, and as a member of particular social groups. Throughout, it has become evident that inherent within these roles are key aspects of the ontological self, and in particular a desire to be a ‘good’ parent. This led to discussion around identity as an advocate for a child, which is arguably an intrinsic aspect of the extrinsic parenting role. This leads us to consider each parent’s identity as a self, which rather than only being defined by labels, means that they can establish their identity from their inner character and personality.

Tom, Saira, Kerry, Maggie, Martin and Rob were each a person with a selfhood before they became a parent, and certainly before they became a parent of a child with cancer. They are still their own person, and they will continue to be as time moves forward. Aspects of each of them shone to me through the interviews – Tom’s faith, Saira’s independence, Kerry’s courage, Maggie’s empathy, Martin’s logic, and Rob’s openness. I wondered if these same aspects of their character would have shone in the same way if I had spoken to them several years earlier – were these aspects representing the sameness of character, or the difference of self-constancy? How had other people in their social networks influenced these aspects? And how might this be informing their decision-making?

Martin’s story casts some light on all of this, particularly in relation to his experience of making a decision about opting Toby in to research trials:

“We want to give back as much as we possibly can to help any other parents in the future, so we decide to opt in. This is a logical decision, an easy decision. I want to do as much as I can to help anyone in the future.”

This decision has been presented to Martin and Helen within days of Toby’s diagnosis, so they are likely drawing on aspects of their character that were formed before the diagnosis. There seem to be two aspects of this decision, firstly that Martin and Helen want to “give back”, and secondly that making logical decisions is important - both seem inherent characteristics. As we talk further, Martin gives some further context:

“I have a professional skill set which means that I am always looking and analysing what is going on and looking ahead. That is my inherent mentality. My wife is not analytical. She has strengths in social skills, in dealing with people.”

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Martin's quote raises two significant points – firstly, that Martin does not see that he is making the decisions alone, he is very much making them **with** Helen, and their individual selves, or characters, are meeting to arrive at a synchronous decision. Tom, Rob and Maggie also predominantly talked about decisions being made as a couple – so this synergistic character of the couple was important. However, this does not feel the same for all of the parents – Kerry and Saira in particular talk more about the decision-making feeling like it is largely their responsibility alone.

The other significant part of this quote is the reference to their careers. Martin works as a data analyst and Helen works in a school, so there is a suggestion that this professional aspect of their identity is helping them with this decision.

Returning to the point made at the start of these interpretations: "If a person is asked "tell me a little about you, who are you?... they may say their job title". I would certainly include my response that "I am a children's nurse" – this is important to me, and beyond seeing this as a job title, this feels like an inherent part of my ontological self. It is clear from Martin's quote above that professional identity plays a role in decision-making. It is not clear whether our professional identity forms because of our inherent character (do we choose our profession according to who we are?), or if our character evolves because of our profession (do we become who we are because of our professional influences?) – perhaps this happens in both ways. However, professional identity plays a role in other parents' stories and the socialisation that contributes to formation of this identity feels important. Rob talks to me a lot about his work, and this is clearly a significant part of who he feels he is. He tells me that prior to Charlie's diagnosis he feels like he was his manager's "*right hand man*". Taking time off work due to Charlie's diagnosis feels very difficult and decisions about returning to work are significant to him. Maggie is a nurse, and although she does not tell me about this until the end of our conversation, her approach to decision-making does seem to be information focused and evidence based, yet always full of compassion and empathy. She tells me that she needs to know the full plan, she does not want information to be given in bite size pieces, she needs to know everything so that she can fully understand the whole picture, yet despite this being what she needs, she also acknowledges that her husband cannot process this in the same way and she has to be sensitive to that. I wonder if this professional identity is important to these parents because they place a degree of self-confidence in this aspect of their identity. Drawing on their professional skills within which they have a degree of confidence, allows them to find confidence in themselves in this new world of children's cancer. Even though their work colleagues are perhaps regarded as an anonymous 'They', these people are in fact still playing a role in shaping the parents' confidence.

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Martin's story is fascinating. He has identified that his professional skill set has influenced the decision-making process (so Martin is who he is (at least partially) because of his professional identity and socialisation). However, he goes on to express that becoming a parent of a child with cancer is now also influencing his professional perspective:

"There are decisions ahead of me as well. Through all of this journey over the past weeks and months, I have questioned what is important in life. Two months ago for me, it was all about career and work, supporting my family and providing a roof over their head. What has happened has taught me that things like work don't matter. And I am questioning what value I am adding to this world. What's the value in my career, or my life? So I am exploring options about changing this, a new career, where I can add more value. I haven't made that decision... yet, but I keep questioning what is important in life. And there is one thing I know for certain, family comes first now."

So, his evolving identity is now shaping his professional aspirations (he is considering changing his profession because of who he now is). It strikes me that if Martin did choose to change career, the work network identified on his ecomap would consist of different people and they may therefore become a new community with which he associated. This may further inform his identity and consequently his decision-making – so this again exemplifies the iterative dance that plays out as our life's path evolves.

I perhaps had not anticipated that the parents' professional identities would be discussed in so much depth. However, for some parents this clearly feels very important and does inform their approach to decision-making. Particularly for Martin, whose logic shines when I talk to him, and also for Maggie, whose empathy is so evident – their work social environment and expectations of their work role influence their identity. This in turn influences their approach to decision-making and provides them with a way of processing decisions so that they can have the confidence to effectively advocate for their child.

At the heart of every parent's identity, therefore, is this need to make decisions that are best for their child. This is beautifully articulated by Tom:

The thing is, all of the decisions that we have had to make, and that we continue to make – they all have one thing in common. They are decisions for him. We know that if we trust ourselves to put him first, everything else will fall into place. No matter what the decision is, we are his parents, and we will make the decision that is best for him.

As a parent, as a parent of a child with cancer, as a member of a social group, and as a person, there is always this aspiration to be a good parent.

Reflections

So much of this scene has resonated with me. Before I was pregnant, I felt like I knew who I was and felt quite stable in my identity. But then everything changed as through pregnancy I became a parent. Just as Darbyshire & Oerther (2020) wrote, I felt this ontological shift. And then Arthur died. I didn't know if I could identify as a parent anymore and this shook all foundations and confidence of who I was. Like Saira, I had looked into the abyss, in fact, I felt like I had travelled into the abyss. And as much as life has continued, I can never unsee, or reverse that journey. Being a parent, and becoming a bereaved parent has changed me forever, and acknowledgement of that from my friends and families does help to validate my experience. However, I have also needed to keep hold of the person that I was before this happened, and it has felt that friends and family who knew me before, have really helped me to regrow the confidence that I still am who I am. I am the same, and I am different. Learning from these conversations with parents, and understanding Ricoeur's concept of identity has helped me to understand my own experience, as well as make sense of the parents' experiences.

The Curtain Falls

Travelling along this part of the pathway of "maintaining and renewing identity" has illuminated my understanding significantly. Making decisions and advocating for their child is seen by the parents as fundamental to their ontic roles of parenting. Yet their core unchanging and evolving ontological identity as a parent influences the decisions they are making. Understanding Ricoeur's philosophy around this has helped me to understand that other people in our lives can shape our identity, and I have seen here how others can shape parents' confidence in maintaining their core identity, and also acknowledge that their identity has evolved. Whilst they are the same person, they will now always be different from the person they were before becoming a parent of a child with cancer.

In January 2023 I wrote a note in my diary about the study:

*It's not **cancer** that is the story of this thesis, the story is about the families. The cancer plays a big role in the story, but it's not the only thing, nor is it necessarily the central thing. Other things in life are also happening or have happened, and they all affect the decision-making so much. At the heart of this story is people, and who these people are shapes everything.*

Shortly after writing this, I read Mukherjee's "The Emperor of All Maladies" (2011:1), in which, on the first page, he quotes June Goodfield: "Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact". As health care

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professionals it is easy to see past the fundamental importance of not only the child's identity, but the parents' identities, and all members of the family. Articulating Tom's and Martin's stories in this scene has returned who they ontologically are as '*Dasein*' to the understanding of decision-making.

As the next scenes unfold and further crafted stories are presented, it will be important to keep the identities of the people, the parents, at the heart of each story. As we travel along different pathways, the impact of Saira's independence, Kerry's courage, Maggie's empathy, and Rob's openness will be further illuminated, and it will remain clear how this informed their approaches to decision-making. The next scene will explore how others may shape the parents' confidence to assert and release control of decision-making, and that by empowering parents to do this, they are able to advocate for their child.

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Scene Three: Shaping confidence to assert and to release control



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Scene Three: Shaping confidence to assert and to release control

Soundtrack: Fantasia & Fugue in C minor, orchestrated by Edward Elgar (originally by Johann Sebastian Bach), 1921

J.S. Bach originally composed his Fantasia and Fugue in C minor for organ sometime between 1723 and 1750. Bach is well known for his mastery of the fugal style, particularly in his compositions for keyboard instruments. A fugue is composed according to very strict rules: a 'subject' (primary motif) is introduced and then this is followed by an answer which is an almost exact replica of the subject but played in a different key. Whilst the answer is played in a different voice, the original voice presents a new melody – the countersubject. Bach's talent lay in mastering the strict rules of the fugue whilst still creating beauty and magic within the music. Keyboard instrumentalists performing Bach's fugues must similarly master the technical control needed to accurately play the fugue, yet also the musicality to represent the genius and beauty of the music.

Two hundred years after Bach composed the Fantasia and Fugue in C minor, Elgar undertook a project to orchestrate this work, from the original keyboard composition to a version for full, modern symphony orchestra. The result is quite extraordinary. The musical rules are still present, both in the fantasia (the oboe plays an opening theme which is then transported to the strings), and even more so in the fugue, where the composition rules are absolutely followed. However, Elgar's orchestration introduces a sense of freedom; it feels like the rules are being relaxed and the control is released. From the glissandi of the harps (instruments that would not have been included in an orchestra in Bach's time), to the clamouring percussion and frenzied flute scales, the music rolls in waves between asserting tight control and releasing it. Bach's music is transfigured, and – no more and no less beautiful than Bach's original composition - Elgar creates something that has strength, power, and wonder. We hear the music with new ears and see the world with new eyes.

Scenery: The Doctor, Luke Fildes, 1891

This painting represents this shift in control that I heard in the parents' stories. The light shines on the doctor and child in the forefront of the painting. Behind, in the dim light is the father and I sense that he is standing hesitantly, not sure what to do. Should he let the doctor make the decision, or should he step in? Torn between wanting to protect his child and his wife, he stands between the two, looking at his child but with a hand on his wife's shoulder who is barely visible. Her head rests on the table in the darkness, resigned to the loss of control.

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The Curtain Rises

In the last scene, it was seen that having the confidence to advocate for their child was at the heart of Tom and Martin's stories. The focus of that scene was around how 'significant others' could shape confidence by helping parents to maintain and renew their identity. The pathway in this scene turns a corner and focuses on how 'significant others' may shape parents' confidence in terms of asserting and releasing control. This will draw on the discussion from Act 2 Scene 3 around the lack of agency that parents felt they had in decision-making and will present understanding of this through the lenses of Heidegger's 'thrownness', and Ricoeur's concept of the 'voluntary and involuntary will'. This will lead to further discussion around the Heideggerian concept of 'solicitude' and how 'leaping-in' and 'leaping-ahead' may shape a parent's confidence to release and assert control of decision-making. It will become clear though that the parents' identity is still a critical component of this assertion and release of control. This is not a new pathway, we follow the same pathway throughout as the focus twists, turns and meanders towards the clearing.

Maggie's Crafted Story

There have been loads of decisions to make, loads. Well... there's been loads of decisions all the way through that we've been involved in, but not really. They tell you the treatment plans and we have an opinion, but we have to completely put all of our trust in the specialist because this isn't something that we know how to deal with. So, we're involved, but not involved because it's all completely out of our control. We're not actually making any decisions. They tell you what the best treatment plan is, and you just go for it. And these decisions are happening all the time, but I actually feel good if I'm the one making a decision, because normally now I'm not. It's just all out of my control.

There is a time though that we are given a decision to make, and it is quite stressful. The plan is that Rosie will be having a Bone Marrow Transplant, and she has just started the immunotherapy, we're about ten minutes into it. We think that the BMT is the only option which is why the immunotherapy has been started. And it just happens that this same morning, the MDT meeting is happening – this is a national meeting, and our oncologist brings up Rosie's case and it's suggested in the meeting that CAR-T may be an alternative to the BMT. Ten minutes into treatment, our consultant comes into our room and tells us that the MDT have said that CAR-T is an option – it's quite an experimental treatment, but it is an option. She tells us that we have to decide quickly, as if the immunotherapy continues then the CAR-T won't be able to be given. So she gives us ten minutes to discuss it. We don't really have any information on which to base our decision, I need to do some research, but I

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don't have time. If I could have longer to decide then I could talk to the CAR-T team, and we could talk it through with my Mum and my sister – they are always my sounding boards for things like this. But we can't do any of that. Simon is overwhelmed and just says "what the hell, how can we make a decision like that". We stick with the BMT option in the end as we know more about that option. But this decision impacts on so much of what is to come.

When it comes to the time of Rosie needing to have the Bone Marrow Transplant, we have to make another big decision about whether Flora should move with us or stay at home with my Mum. We really don't want to split the family and we know it will be so stressful for her to be away from us. But Flora has ADHD, so routines and being in school are really good things. And Flora is very close to my Mum so she will be fine with her – but it's such a big ask for my Mum to care for Flora for all this time. A few weeks before the transplant we visit the unit for Rosie's appointment. We meet another dad there whose daughter is right in the midst of her transplant. He says to us: "It's literally hell on legs, you do not want your other child here because then you're going to have to worry about your other kid and you just want to focus on the one". That honesty really helps us to be more realistic about what we are facing, and we realise that it won't be right for Flora, or for us, to bring her with us. We decide to leave her at home with my Mum. But I feel completely torn between my children, it is terrible.

As we live through all of this day to day, we just learn to ride the wave, and go with the ups and downs. We are rarely involved in decisions – the decision about the CAR-T is very unusual as we're not used to having to actually decide something. Obviously, they need your consent often, but there's no way that you're not going to do it. So it's not a two-way conversation about a decision. That's difficult as a parent, to feel like nothing is actually in your control. As a parent you're so used to making decisions and making the right ones for your children – with this you don't have that opportunity.

Saira's Crafted Story

I am standing in the Accident and Emergency Department. The doctor is telling me that Aria's back pain is just muscular – nothing to worry about. I stand against him, and I say: "I've got four kids, I don't take them to A&E, there's something going on here, and you need to tell me what it is".

In those early days it is difficult, I don't understand any of it and I feel lost at sea. We don't have any decisions to make, and we are told what to do. I don't know how to check or challenge what is happening. But then a friend says to me "you're not stupid, so you will

understand everything and if you don't understand something it's because either they haven't explained it properly, or because it doesn't make sense, so don't be afraid to challenge stuff". Now my husband jokes that I'm the second most expert LCH person in the city – I have become that because I have taken responsibility to learn and find out the information from anybody I can. Now I understand what's happening and I feel I can have those conversations with people.

I realise that I have to be strong. When Aria starts to complain of a pain in her head it takes us a while, it takes me a while to convince everyone that there is something to worry about. I take responsibility for speaking out, and I take responsibility for the relationships with the MDT. I have to - during COVID only one parent is allowed to attend the hospital, so these are all my relationships now. The MDT is interesting. It runs our life and makes all of these big decisions, but I don't know how that is happening – who are they, and how do they reach these decisions? The decisions they make affect our whole family. At least in the early days when I feel so lost, I am reassured that they can confidently make the decisions. But then things start to change, the tone changes... our consultants aren't so sure anymore. At first, they knew what to do and they told us what to do. As things have progressed, they are less confident in the answers. Now they ask me, and the decision is more ours, the responsibility to consider everything is mine.

After the six months of chemo, we are asked whether we want to take Aria off the trial and continue chemo for an extra 6 months or stop. It is so hard to know what to do. Our consultant is off sick, so I feel that nobody is advocating for us. The MDT leave the decision to us, they say that it is up to us, and they will support us either way. But I really need advice. Fortunately, through our acquaintances we're only ever a couple of degrees of separation away from an expert who I can contact. I chat to somebody at the school gate who knows a leading expert in LCH. So I just decide to go beyond the MDT at our hospital and I email this person.

Connecting with experts helps me to understand the world that we're now in and helps me to access information. And that gives me more confidence. I have learnt that I must never make a decision without questioning. When the MDT say "Oh, we think it's this", I say "Why do you think this, why?"

As we look to the decision ahead about whether Aria will need further chemo, I see that the consultants are not sure what to do. There is no evidence now, no protocol. I have a great responsibility now to make sure that we are considering everything. We are dealing with judgements – educated guesses. It's hard to acknowledge that such a major decision is a guess. I need to spread the net wider and connect with people from other countries, I need

to have conversations with these experts. There are doctors in America who I think I need to reach out to now. But I do see now that it is my responsibility to do this.

Interpretations

As advocating for their child was at the heart of Martin's and Tom's stories, so it is for Maggie and Saira. There seems to be a delicate balancing act that both are making, between knowing when to stand up and advocate for their child and assert their control; but then also knowing that they need to release control in order to let the medical team act in their child's best interests. In a systematic review exploring parents making general health care decisions about their child, Jackson, Cheater and Reid (2008) concluded that parents want to be in control of decisions. Letting go of control is therefore not easy, as Maggie identifies. Making decisions is an inherent part of their role and identity as a parent, so to release control impacts on this identity. All that was discussed in the previous scene is therefore relevant now, and by shaping confidence to maintain and renew identity, 'significant others' are also shaping confidence to assert and release control.

The early days – asserting control

The need to assert control is evident for all parents as their story starts. Every parent, perhaps without realising it, has recognised that something is wrong with their child and taken control by accessing medical help. Often there have been delays with diagnosis leading parents to repeatedly return to their GP or hospital to voice their continued concerns. Saira's crafted story shows how she stands against the doctor in Accident and Emergency and fights to be listened to. Maggie similarly has to fight and take control so that her concerns about Rosie will be acted upon:

"She'd had a virus, so they thought maybe it was a post-viral aching, but I just felt like there was something more. I made them refer me to the hospital. I think the GPs thought that I was a massive pain."

The moment of diagnosis – releasing control

But then, at the moment of diagnosis, it feels that everything changes. In Act 2 Scene 3, I identified that parents feel a real lack of agency in relation to making decisions about their child's cancer treatment, and there is a sense of there being 'no decision to be made'. Words and phrases identified in that scene demonstrate this clearly. Tom said:

"We just agreed with everything that they offered."

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And later (in reference to the decision about the stoma, and the decision about the nasogastric tube):

"It was the only option."

For Tom here, particularly with the decision about the stoma, this would be a life-saving procedure, so he has no control over that – he sees this as the only option because the alternative (not consenting to this operation) would be too terrible to contemplate.

Both Maggie's and Saira's stories convey this lack of agency:

"We're not actually making any decisions. They tell you what the best treatment plan is, and you just go for it." (Maggie)

"We didn't have any decisions to make; we were told what to do." (Saira)

Rob similarly expresses this lack of control around major decisions but there is a hint of more control here:

"To us, there was never a decision, it was like 'he's having this done'. And he might not, if he remembers any of it, he might not forgive us for it, because they might have to remove his kidney which will affect him for the rest of his life. But we'd rather that over the alternative."

To me, this really emphasised the burden of making a decision on somebody else's behalf. Rob knows that consenting to treatment leads to unpredictable and potentially life-changing consequences, the alternative of not treating Charlie will, without doubt, result in Charlie's death. The only viable option therefore is to consent.

Martin uses similar language in reference to the decision about inserting a central line:

"It was a forced decision really, it had to happen. It was kind of black and white."

Through the decision to consent to treatment for their child's cancer, a cascade of other decisions is generated. For chemotherapy to be administered, the child must have a central line inserted so this decision then feels *"forced"*. In Tom's situation, the side effects of the chemotherapy lead to Noah requiring stoma surgery – this becomes their *"only option"*. Feudtner, Schall and Hill (2018) similarly recognised this, acknowledging that decisions are not made in isolation, one decision often leads to another which increases the complexity of the decision-making process.

These stories about loss of control correlate with the moment of being 'thrown' into the world of children's cancer, and so the Heideggerian notion of 'thrownness' feels very relevant.

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Ricoeur's thinking travelled along a similar path to that of 'thrownness'. He considered life as a dialectic, on one hand we are able to make choices about our actions (the 'voluntary'), but on the other hand we exist within a particular context and world where many things are beyond our control (the 'involuntary') (Simms, 2003). So, in simple terms, for each of the parents, they have 'voluntary' moments (for example, making the decision to repeatedly voice their concerns pre-diagnosis) but then when their child is diagnosed with cancer, they are placed in a world where decisions are beyond their control as parents – they have a stark encounter with the 'involuntary'. Specifically in relation to cancer treatment, parents feel that there is 'no decision to be made' because the 'thrownness' of the cancer diagnosis has changed the usual parenting 'voluntary' decisions to those that feel 'involuntary'. The parents certainly did not choose for this situation to happen to their child. They are now in a world where their identity has changed from being a normal parent, to a parent of a child with cancer, and with this comes a loss of confidence in their expertise (in terms of their knowledge of the disease and how to care for their child, and specific skills such as medicines administration that they need to master). Furthermore, they are not able to take control of decision-making, and so they also experience a loss of their autonomy and ability to make decisions on behalf of their child as they are used to. Not only have they therefore been placed in a world not of their choosing – they have also had to hand over decision-making responsibility to health care professionals who are 'leaping-in' to make life-saving decisions on behalf of the parents.

As Maggie says in her story:

"They tell you the treatment plans and we have an opinion, but we have to completely put all of our trust in the specialist because this isn't something that we know how to deal with... It's completely out of our control."

Picoult emotively expressed this sense of handing over control in *My Sister's Keeper* (2004:62):

We are told: 'Do not think; just give your child up to us, because otherwise she's going to die'.

Ricoeur proposed that this dialectic between 'voluntary' and 'involuntary' is always connected and Simms (2003:12) explained this in terms of the 'voluntary' decision to **consent**:

When I consent, I give myself over to something other than me over which I have no control, and that something is a form of necessity.

So when parents consent to treatment, whilst this in itself may be perceived or presented as a 'voluntary' decision, in consenting they are then handing over control to the health care

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professionals and from that moment a series of decisions feel “forced” (Martin), or that there is no other option (Tom), they are now ‘involuntary’.

van Manen (2014:135) further explained Ricoeur’s concept of consent: “consenting is understood through experienced necessity and refusal”. In other words, if we are placed in a situation where consent is required, we must either consent, or refuse to consent. Ricoeur proposed that it is through this process of consent that we experience freedom. Yet there is also this recognition of **necessity**. And it is this that seems to resonate with what the parents are experiencing – they are thrown into a world where they were asked to consent to treatment for their child. Faced with this binary alternative between consent and refusal, the parents really feel that consent is necessary to a point where there is no alternative:

*“Obviously you get the consent forms to say ‘we’re about to give your child these treatments, all this chemotherapy; you have to agree because we can’t just give it to him without that’ – we’re his guardians and it **needs** our consent” (Rob).*

So if consent is experienced as a necessity, I wonder if this essentially causes parents to experience a compromise of their autonomy, and this is what leads them to feel that they must release control. Interestingly, in *Oneself As Another*, Ricoeur (1990 / 1992:39) quoted Aristotle: “We deliberate about things that are in our power”. This strongly resonates with a quote from a participant in Pentz et al.’s (2012:884) study exploring shared decision-making within the context of paediatric bone marrow transplants:

The doctors are good at making you believe that you have a decision. I truly believe that you don’t have a decision... When he presented it to us, he presented it as options. There was no alternate in his mind.

What I hear from the parents in this study, and read from the literature, is that parents do not feel that it is in their power to refuse consent, and this puts into question whether the concept of consent does align with Ricoeur’s ‘voluntary will’ as Simms (2003) suggested, or whether this is actually another ‘involuntary’ situation. This explains the parents’ sense of there being ‘no decision to be made’ that was discussed in Act 2 Scene 3, and as Noone (2002) has proposed – if no alternative is available, can this even be considered a decision?

There seem to be two possibilities to consider in understanding this lack of power or control around consent: an external influence and an internal influence (which are intrinsically connected through the concept of ‘*Dasein*’). The external influence resides solidly within Heidegger’s concept of ‘thrownness’ that, as explained in Act 2 Scene 3, we are born into a historical world, within a particular generation and sociocultural group (Mulhall, 2005). All six

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parents are experiencing being a parent of a child with cancer in England, in the twenty-first century. Cancer treatment and its associated decisions are situated within this context where previous research has led to the current protocols.

However, the thrown world exists beyond the hospital walls and chemotherapy regimens. The parents also live in a world that is defined by its legal and social rules. From a legal perspective the Children Act (1989) expresses the concept of “Parental Responsibility” rather than “Parental Rights”. This emphasis presents a shift from parents having the right to make whatever decision they would like about their child, to parents having obligations aligned to their rights. This means that parents are expected to take responsibility to make decisions that are **in the child’s best interests**. If a parent is deemed to make a decision that is not in the child’s best interests, then the court could overrule this decision. Section 1 of the Children Act (1989) explicitly states that “the child’s welfare shall be the court’s paramount consideration” and this welfare will take precedence over the needs of the parents to make autonomous decisions if necessary. McEwan’s novel *The Children Act* (2014:38) presented the view of a High Court judge in a situation like this, where the judge concluded that:

Above all, the duty of the court was to enable the children to come to adulthood and make their own decisions about the sort of life they wanted to lead.

This perspective is echoed in the health care landscape and, whilst the philosophy of children’s nursing care tends to be family and child centred, if there are times when the family’s decisions conflict with the best interests of the child then the health care professionals have a responsibility to advocate for the child rather than the parents (Carter et al., 2014). Whilst it is a fundamental right for adults to make the decision to refuse medical treatment for themselves, parents do not have the same legal authority to make autonomous decisions on behalf of their children. This reinforces the point made in Act 2 Scene 3, that literature relating to adult decision-making is not necessarily applicable to this context. This lack of control that parents are expressing is very understandable. Consent is presented (by Ricoeur but also medico-legally) as a binary ‘consent or refuse’. Whilst the parents in this study technically could refuse consent, it is very likely that this would then be escalated to a court of law that may well overrule the decision and their child would receive treatment regardless of the parental decision (British Medical Association, 2021).

As well as the legal context, there is the social context. To an extent, my thrown context is similar to that of the parents; we live in the same country at the same time and our actions are informed by the same legal context as well as an acknowledgement of socially accepted norms. I have the additional thrown context of being a registered children’s nurse and having a

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professional understanding of children's cancer. It seems virtually unthinkable from my thrown context that a parent would refuse consent for their child to receive cancer treatment which would certainly lead to their child's death. The parents felt similarly, several of them tell me how shocked they are to think that somebody might refuse consent. Kerry articulates this strongly:

"I remember chatting to a nurse at the beginning... she said that some parents have challenged treatment based on religious beliefs or veganism. And that blows my mind, to me that is ridiculous. Why would you rather have your kid be dead than have an animal be tested on? Your kid could be treated and saved, but you're going to leave it to God's will? I can't... no! She did say there had been times when they would have to get social services in, because if you're making a decision that's going to potentially kill a child, we need to intervene."

Kerry's comment here is attuned to what feels socially acceptable and Lipstein, Brinkman and Britto (2012) acknowledged in their literature review regarding parental decisions about their child's medical treatments, that parents' decision making may be influenced by the social acceptability of the options. In our current social context, we (or the Heideggerian 'They') perhaps have a tendency to value and trust the advice of experts such as specialist doctors (although there are some high-profile cases that demonstrate that this position is not without exception). Whilst it is suggested that we, in our particular culture, have moved from a world of medical paternalism to a world where autonomy is valued more highly (Will, 2011), this does not seemingly apply to parental decision-making about life-saving treatment for children.

However, it is really important to acknowledge that all of this discussion is situated within our 'thrownness'. Opinions shared by Kerry and the other parents, as well as my own thoughts, are heavily influenced by the world we are in, and these opinions would likely not be shared by others in different social contexts. This is apparent in the literature. Mostert et al. (2014) researched decision-making about treatment abandonment in Kenya, and the findings of this paper suggest that it was absolutely socially acceptable for parents to abandon treatment, and actually social networks may discourage parents from accepting medical treatment. Similar findings were discussed by Renner and McGill (2016), Israëls et al. (2008), and Sitaesmi et al. (2010) in their research relating to childhood cancer in Ghana, Malawi, and Indonesia. Abandoning treatment would certainly lead to the child's death. So, whilst this would be neither legally nor socially acceptable in England, it is important to acknowledge that our context is not universal.

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In Act 2 Scene 3, 'thrownness' was discussed as a Heideggerian concept with the child's cancer used to exemplify the world that parents had been thrown in to. We see here that 'thrownness' extends far beyond this, and that other factors in the parents' worlds – legal and social positions – also impact on parents' experiences. The parents' lack of control around medical treatment decision-making is experienced. 'Thrownness' limits their possibilities, and from a Ricoeurian perspective leads them to feel that the decision to consent or refuse consent is 'involuntary'.

There is though the possibility that the parents could refuse to consent, so there is still some potential that the decision to consent is 'voluntary'. To do this they would need to fight the social rules (fight the 'They') and take on a complex legal battle. It would not be easy, but it would be their choice to do this. The reason that these parents do not to do this relates to their internal position. Of course, the whole point of Heidegger's concept of '*Dasein*' is that the internal cannot be separated from the external. The parents consent to treatment because they see their role as a parent (their identity) as being an advocate for their child. As the law sees the role of parents as taking a "responsibility to act in the child's best interests" (British Medical Association, 2021), the parents here also see that they must do what is best for their child. '*Dasein*', 'being-in-the-world', means here that they must acknowledge their thrown position and be that advocate. The parents therefore choose to hand over, to release, their control of decision-making to the health care professionals. They choose to allow health care professionals to 'leap in' and care for their child because at this moment in time they cannot 'fix' things themselves, they see that it is best for their child to release control of care to the health care professionals. They do this because their thrown world expects this, and they do this because this is who they are – their core identity is to advocate for their child as discussed in the last scene. Ricoeur expresses that the 'involuntary' consists of things that are beyond our control, and this is contributed to by our character – our character defies our will (Simms, 2003) and van Manen (2014:35) applied this to consent by saying that "consenting is restrained by character". Our character, our identity, '*Dasein*', therefore places us in a position where this decision becomes 'no decision to be made'. O'Neil concluded her thesis (1996:244) about parents making decisions in relation to their child's relapsed cancer, by arguing that "no parent should feel there are no decisions to be made". What I learnt from speaking to the parents in this study was that feeling that there are 'no decisions to be made' is almost inevitable in the context of cancer treatment decision-making, and this drives understanding forward from the discussion started in Act 2 Scene 3 about parents not identifying 'consenting to treatment' as a decision. It should certainly though be acknowledged by others (including health care professionals) that this is the inevitability of what is happening and that this may be difficult for

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parents to adapt to. Pearson et al. (2022) explicitly stated that parents are not involved in treatment decision-making if a best standard of care is available, yet from my experiences in practice and the stories that the parents shared with me, I do not believe that this lack of agency is openly acknowledged by medical professionals with parents during conversations around treatment planning and consent.

So far, this discussion has not referred to the role of 'significant others' (other than the broader social context of the 'They') when parents release control and step back as health care professionals 'leap in'. As I read and re-read the transcripts I kept asking myself 'what are these stories telling me about how parents are supported by their 'significant others'?' In relation to this aspect of releasing control and acknowledging the lack of agency in decision-making, I felt as though I was hitting a wall. Friends and family were not being discussed in reference to this, they just felt absent. As I reflected more deeply about this, I realised that this sense of absence (which felt very profound) was perhaps the point. Parents are not talking about other people here because they are not directly involved in this. 'Significant others' are absent in this aspect of the stories that parents have told me simply because they have not been present at the time. In this specific context, parents do not seem to see this as a problem, this silent acknowledgement from others that parents have handed over control and now lack agency is perhaps important but more than that is not needed or wanted. However, to understand the role of 'significant others', it is also helpful to return to the previous scene and the discussion around identity. There I discussed that social groups and individuals could shape the parents' confidence in maintaining their core identity, yet also acknowledge their evolving identity. And now in this scene we have explored that this release of control is part of who the parents are ('*Dasein*') and an important aspect of their identity or character. So in fact, 'significant others' are (unknowingly) supporting parents to release control by taking on a role in the background (and perhaps long before this release of control is necessary) through shaping their confidence to maintain and renew their identity.

There is a more direct way in which 'significant others' may support parents in relation to control, and this takes us to the point at which parents recognise that there are times, following the diagnosis, at which they need to re-assert control.

As time goes on – re-asserting control

Both Maggie and Saira experience moments when they feel that they have more control around treatment decision-making. This comes across in their stories in a way that is not heard in the other parents' stories. For Maggie, Rosie has not responded to the first line treatment for ALL and so they are no longer on the clear protocol that Kerry, Tom and Martin are

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experiencing with their child's treatment. And similarly for Saira – Aria's treatment is no longer following a clearly defined protocol and there is a lack of evidence around the next steps. It seems to be in these moments, where medical decision-making is shaped by the lack of clarity from an evidence-base, that Maggie and Saira find themselves re-asserting control and becoming more involved in the decision-making process. This change in agency is supported by Pearson et al.'s (2022) literature review which proposed that parents become more involved in decision-making at the point that treatment deviates from an evidence-based standard of care. From a legal and social perspective, perhaps this is because it is not known what is in the child's best interests and this frees the parents from *"agreeing with whatever is offered"*. Having more freedom enables the parents to take more control and in Saira's case, she does everything that she can to seek information (often through a process of networking with other people) so that her decision is as rooted in the evidence as possible, whilst acknowledging that ultimately the decisions are educated guesses. The circumstances of Maggie's decision between the BMT or CAR-T route, where Maggie is given a very short period of time to make a decision, mean that she is prevented from doing what she feels that she needs to. She needs to seek more information *"I'm the type of person that I would have liked to really research it"*, and she wants to talk to her Mum and sister. There is a suggestion therefore that in moments where parents do have the potential to assert control in relation to medical treatment decision-making, this can be facilitated by others in terms of information provision or being a 'sounding board'. This echoes the findings of my literature review, where parents did look to others for information (for example Cohen et al., 2017, H-Yazdi and Meadows, 2021) and similarly recognised that it was helpful to have a 'sounding board' (for example O'Neil, 1996; Blakeley, Ribeiro and Crocker, 2000; Huang, Mu and Chiou, 2008) as this could support a parent's confidence that they were making the best decision for their child.

The advice of Saira's friend gives her confidence that she can assert control and challenge plans when necessary:

"You're not stupid, so you will understand everything and if you don't understand something it's because either they haven't explained it properly, or because it doesn't make sense, so don't be afraid to challenge stuff".

This friend is empowering Saira to have confidence to take control and this is a really good example of 'leaping-ahead' that 'significant others' can offer in contrast to the 'leaping-in' of health care professionals. Saira experiences the 'leaping-in' of what she refers to as the *"slightly mythical concept"* of the multi-disciplinary team:

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“It runs your life and you don’t really know what it is, or what happens, or who it is or how those decisions are reached, but it decides everything. Initially it was reassuring, now it’s slightly frustrating”.

But, by networking with others and seeking information as discussed, Saira is able to make informed decisions about Aria’s care. The ‘leaping-ahead’ of this friend in the early days of Aria’s diagnosis significantly informs Saira’s approach to decision-making.

Whilst Maggie and Saira are the only parents who tell me about a time where they have felt able to assert control over decisions that specifically relate to their child’s cancer treatment, all the parents experience points where they are able to assert control in relation to other decisions. This often happens in relation to making social decisions as a family. Maggie’s story again demonstrates the complexity of decision-making; the decision around whether Rosie should have a BMT or CAR-T therapy leads on to a significant decision around whether Flora should move to the BMT city with them, or stay at home with Maggie’s Mum. This really exemplifies the balance that parents are having to strike between asserting and releasing control. An opportunity arises for Maggie to assert control (deciding between the BMT or CAR-T therapy) but her ability to actually assert control is limited by the situation in which that decision had to be made. This decision influences a sequence of further decisions that impact on the family. Maggie needs to have the confidence to assert control here as she considers the best interests of every member of the family, her Mum’s offer to look after Flora places Maggie in a position where she can take control of this decision as there is a viable alternative to Flora moving to the BMT city. However, in taking control of this decision, Maggie is also releasing a degree of parenting control to her Mum who will take responsibility for Flora’s care whilst Rosie is having the transplant.

Kerry’s story shows that she will absolutely consent to treatment and release control to the medical team in relation to Harry’s cancer treatment. However, in many other respects the need to assert control is very evident. In particular, this was the case in terms of life outside of the hospital:

“When Harry was diagnosed and they came in to do the whole chat, I remember saying at the time: ‘So basically if I could keep Harry isolated for three years he’d be fine?’”

She sees that the best way to protect Harry and prevent him from developing life-threatening infections is to isolate him from other people, thereby controlling the environment and keeping Harry safe:

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"I just didn't want Harry to leave the house. I just wanted to stay in, and everyone who came to the house – we hosed them down. I was saying to people: 'you're not coming into my house without washing your hands'".

As things turn out, the COVID-19 lockdowns fully enable this isolation. Whilst the lockdowns arguably removed people's control and ability to make certain decisions, for Kerry, this actually gives her the control that she wants:

"I got what I wanted... I loved lockdown, I was so happy... I didn't have to worry about anything."

This feeling of needing to control the family's environment resonates across a number of stories. Tom tells me that his wife Jenny is very concerned about infection and so rarely allows Noah to leave the house. Martin also explains how they have worked out a system of managing infection risk:

"So the hospital gave us the black and white facts and then we had to find our path about where we drew the line. We'd had some excellent support from our close friends – that first circle that we drew [on the ecomap] – David and Jane. We decided quite quickly that we should include them in our bubble. We couldn't exclude them. So we had an open discussion with them: 'we want to include you, but please be mindful that if you have any kind of illness, we won't be offended, stay away.' So they are definitely included. My family have been quite keen to visit and I've said: 'no, stay away, you're coming from a different geographical area, I don't know what you're going to bring'.

This sheds valuable light on this issue – David and Jane, and indeed all of the respective families and friends, need to respect the control that Martin, Kerry and Tom are now asserting. Respecting the rules around infection risk gives the parents confidence that they are able to protect their child in the best way that they can. By acknowledging and respecting this control, others are 'leaping-ahead' in their 'solicitude' towards the parents and empowering them to have the confidence to re-assert control following the 'leaping-in' of the health care professionals. Empowering parents to re-assert this control also facilitates a growth in confidence around maintaining and renewing their identity as advocate for their child.

Martin does though also acknowledge that he cannot fully control Toby's environment, as Toby's brother, Max, cannot avoid interacting with other children:

"Max has to go to school, and he's obviously coming back into our house, so you know that's something we can't control in terms of isolation."

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Again, the ‘thrownness’ of their context means that Toby has to attend school so this limits the control over the environment that Martin would like to take. This perhaps re-emphasises the importance of others respecting the rules and control that Martin can assert.

Rob articulates this importance of trusting his family to follow the ‘rules’:

“My family have been to visit when we’ve told them that they could. They’ve been really understanding and when we did allow them to come to visit, we were like: ‘right, if you’re unwell, if you’ve had a cough or anything, let us know because you’re not coming in the house’. And they were like ‘oh yeah that’s fine, we’d tell you if anything was up.’”

Asserting control over their social environment seems important to these four parents and Saira also speaks about this. Maggie speaks little about this, although she acknowledges that this is not something for them to control as once in the Bone Marrow Transplant Unit, the visiting rules are very strict, and even at their more local Principal Treatment Centre, the COVID-19 pandemic impacts heavily on visiting rules – for them there has been little time away from the hospitals.

Interestingly, Martin talks more about how they have “found a path” to find the balance around infection risk. He tells me about how his Facebook friend, Lucy, who he has identified on his ecomap, has helped him by sharing her experience:

“She took a very militant approach to this initially. She literally did build a brick wall around her and her daughter’s life to protect her. And then, as time went on, she sort of relaxed that, probably more in line with Tilly regaining strength, or maybe improved immune system. And that almost kind of reinforced... we’d been given the scare story by the facts from the doctor. And then her experience, about the fact that she had sort of mirrored that at home, built this wall of complete isolation to start off with, kind of reinforced that for a real-world example. And it was then that Helen and I decided to do similar, but with an exception for our close friends.”

Learning from another’s experience was noted as influential in decision-making in the published literature review (Jestico et al., 2023b). In Martin’s context, he certainly values hearing about Lucy’s experience, but this seems to be more than a process of learning for him. This is about reinforcing what he already seems to know and gives him confidence that he is right to keep control of the infection risk and manage the social environment as he plans to do.

Parents are, to an extent, able to assert their control because others are ‘leaping-ahead’ and giving them confidence to do this. There are times where health care professionals are ‘leaping-

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in' (often in terms of medical care) and their 'solicitude' in doing this is both for the parents and the child ('leaping-in' to take over the decision-making role of parents, and also 'leaping-in' to take over the care of the child). When others 'leap ahead' of parents, they are able to reclaim control of their decision-making role – a crucial aspect of their identity, but parents are then also able to 'leap *back* in' to care for their child, and thus reclaim their parenting role as carer and advocate for their child.

Reflections

This discussion around control has led me to consider my own experiences. I have thought about the days when I worked on the children's cancer wards, and I now see more clearly how hard it must have been for the families to have experienced the loss of control. I remember being taught as a student nurse that the parent knows best and is always the expert in their child, and that family-centred care should be at the heart of what we do. Through this process of understanding parents' stories, I see now that there are times when health care professionals do 'leap in' and take over the caring role towards the child, and that the best interests of the child may take precedence over the parents' usual autonomy. Parents acknowledge that they do not always know best, and when the child is newly diagnosed with cancer it is the haematology / oncology professionals who are expert in how to care for the child. Yet in many ways, the parents do know their child better than anybody else and it is important to empower them to make decisions and continue to advocate for their child as much as possible. I had not considered this in such depth when I worked in practice, and I now understand that this is why parents go through waves of releasing and asserting control and the conflict that they may feel with this. I now have a stronger appreciation of how others such as family and friends (often outside the view of life in hospital) may influence this empowerment.

I have also thought about my own experience of parenting. I have experienced very little control in my life as a parent. My pregnancy was as a result of in vitro fertilisation treatment, and so other than the initial decision that we made to embark on that process, we found ourselves on a pathway where we were controlled by the injections, scans and procedures, but we had very little control of that pathway or of the outcome. I found myself trying to assert some control once I was pregnant. Terrified that the pregnancy would go wrong I did all I could to protect the baby – I followed every bit of advice, never deviating from what I was 'allowed' to eat, drink, or do. For all that I had tried to control my environment and protect our child though, the control was utterly removed from me when Arthur died. There were no decisions that I could make in an attempt to save him and so from that moment we were faced with decisions about how to carry on living, and that is all that we have been able to control. At the

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start of this project, I would have firmly said that I had no decisions to make and that I had never been able to assert control. Engaging with the parents' stories here and delving into philosophy has shown me that I have been making decisions – whilst there was not a decision around Arthur's life, I did make decisions before his stillbirth, and I have learnt, with the support of my family and friends, to take control of my life since then.

The Curtain Falls

Ricoeur (1966:342) wrote: "A decision is never more than an islet of clarity in an obscure, moving sea of unknown potentialities" (cited by van Manen, 2014:135). This resonates so closely to my understanding of the stories discussed in this scene. The parents have found themselves in a thrown world in which decisions are being made often, but they need to navigate the balance of which decisions they are in control of, and which they need to rescind to health care professionals' control. Ricoeur's concept of the 'voluntary' and 'involuntary' illuminated that the parents' feelings of lack of agency may stem from the thrown situation that they are in (including the cancer diagnosis but also the legal and social context of their world), but also this lack of agency stems from the parents' characters and their inherent motivation to be a good parent and advocate for their child. In other words, each parent, as '*Dasein*', is immersed in their 'being-in-the-world' and this whole context of their character and world shapes their confidence to release control, allowing health care professionals to 'leap in'.

Whilst releasing control is in their child's best interests, it is acknowledged that this is not easy. There are times when parents can assert control, and this helps them to see more clearly that they are advocating for and protecting their child. 'Significant others' need to both quietly acknowledge that parents are having to release control and allow health care professionals to 'leap in', and also 'leap ahead' by respecting the control that parents can reclaim, thus empowering their confidence to make decisions that are best for their child.

With every twist and turn of the pathway, the light is becoming brighter as the clearing is approached. The next scene will build on the discussion around maintaining and renewing identity, and releasing and asserting control. This final section of the pathway will show how 'significant others' may shape parents' confidence to trust and challenge themselves and others in decision-making.

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Scene Four: Shaping confidence to trust and to challenge



Scene Four: Shaping confidence to trust and to challenge

Soundtrack: Ave Maria a 8, Tomas Luis de Victoria, 1572

This is a beautiful setting of Ave Maria composed by the Spanish Renaissance composer, Victoria. It is composed in an antiphonal style – two choirs (each comprising of Soprano, Alto, Tenor and Bass) interact by singing alternative musical phrases.

The piece starts with Choir 1 singing the opening theme, Choir 2 imitate this. For the first section of the music this continues with Choir 2 echoing Choir 1 – Choir 2 are trusting Choir 1 and following their lead. However, over time this changes. Choir 2 start to take the lead and Choir 1 imitate them. Choir 2 have become empowered to take the lead and have their own voice. There are moments though when the antiphonal style is paused, and instead both choirs sing together, creating resonant and full harmonies. There is also a notable change of style with the words “ora pro nobis peccatoribus” – here Victoria moves from writing in compound time (4 beats in a bar) to triple time (3 beats in a bar).

This balance between the choirs sounds like a manifestation of what is to be discussed in this scene – finding a balance between knowing when to trust and challenge others, and when to trust oneself. Like Choir 2, the parents need to be empowered to find, and trust, in their own voice. Balance is also required in parents’ relationships with others. Ricoeur proposes that ‘solicitude’ is found when friendship is mutual and equal – each person giving and receiving care. Victoria’s music offers this sharing of beautiful singing between the choirs. Both choirs have equal importance, and by achieving balance and unity, a transcendental openness is experienced, a musical clearing.

Scenery: Moses Viewing the Promised Land, Frederick Edwin Church, 1845

This painting mirrors the painting at the start of Act 3 – Friedrich’s ‘Wanderer above the sea of fog’. Here, the sun has burnt through the fog, the land below and ahead can now be seen. A dark cloud still lingers above the solitary person on the rock – all is not completely well, and some darkness remains - life will never be as it was tomorrow. As acknowledged by Saira in Act 1 Scene 2, “*I have looked into the abyss and I will never unsee that*”. However, this scene takes us to the clearing, where light shines on how others’ ‘solicitude’ may support parents to trust themselves to confidently advocate for their child.

The Curtain Rises

The pathway through the woods has forged an exploration of how ‘significant others’ may support a parent to make decisions by shaping their confidence to maintain and renew their identity, and assert and release control. The pathway now turns another corner and reaches the final stretch. Framed by the concept of ‘solicitude’, from the work of both Heidegger and Ricoeur, this scene will demonstrate that shaping a parent’s confidence, in the context of identity and control, can empower parents to trust and to challenge themselves and others. If parents are to allow health care professionals to ‘leap in’, as discussed in the last scene, they need to have confidence to trust that they, and the other people in their lives, have their child’s best interests at heart. They also need to have confidence to be able to challenge others when necessary. Ultimately though, they need to have confidence to trust themselves as parents. If parents can have confidence in their identity as a good parent and negotiate control so that decisions are made in their child’s best interests, they can have confidence to trust that they are advocating for their child.

Ricoeurian Concept: ‘Solicitude’

In the first scene of this act (losing confidence), Heidegger’s concept of ‘solicitude’ was introduced as proposing that people can either ‘leap in’ or ‘leap ahead’ in their care towards us (Heidegger 1927 / 1962). The relevance of this could be seen in the subsequent scenes within the phenomenon of ‘shaping confidence’ (in terms of maintaining and renewing identity, and releasing and asserting control). Alongside this, the Ricoeurian concepts of ‘identity’, and the ‘voluntary / involuntary will’ were discussed. Building on these concepts, Ricoeur discussed his interpretation of what ‘solicitude’ means, and this will be briefly explored in order to further understand the parents’ stories.

Ricoeur traced out a meaning trajectory in what he proposed we should consider the “ethical aim”:

Aiming at the good life with and for others in just institutions

(Ricoeur 1990 / 1992:172)

He broke this down into three components (aiming at the good life; with and for others; in just institutions) which he explained in depth, and argued that our self-esteem (or self-confidence) can only be fulfilled if we follow this ethical aim across all three.

“Aiming at the good life” very much draws on what has been discussed earlier. Our character (and therefore ‘identity’) informs what we believe to be “good”, and this informs our ‘voluntary and involuntary’ decisions and actions. We know from the preceding themes that parents

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aspire to be ‘good parents’ (and that by being a ‘good parent’ they are advocating for their child). This aspiration lies at the heart of the decisions that they make.

“In just institutions” relates to the fairness of the institutions that we inhabit. Ricoeur explained his use of the word “institution” as:

The structure of living together, as this belongs to a historical community – people, nation, region, and so forth... What fundamentally characterises the idea of institution is the bond of common mores [customs and conventions of a society or community] and not that of constraining rules.

(Ricoeur 1990 / 1992:194)

So, this very much relates to Heidegger’s concepts of ‘thrownness’ (where we find ourselves living in a particular time, culture and community) and ‘being-with’ (where we are always with others, inhabiting a shared world).

It is with the second component of the ethical aim (“with and for others”), that Ricoeur presented his concept of ‘solicitude’, and it is perhaps this concept that draws together the three components. ‘Solicitude’, according to Ricoeur, is based on the concept of friendship (Ricoeur 1990 / 1992). This draws on the philosophy of Aristotle which proposed that friendship serves as a transition between the solitary virtue of aiming for the “good life”, and the virtue of justice which is situated in human plurality (in the sense of justice within and between communities). Aristotle thus presented friendship as a virtue and a choice that we each make. Ricoeur progressed this thinking and distinguished three types of friendship: “for the sake of the ‘good’, of ‘utility’ or of ‘pleasure’” (Ricoeur, 1990 / 1992:183). He then suggested that friendship should be considered as a mutual relationship. This means that each should love the other as they are and for their own sake. This mutuality cannot be the case in a friendship based on utility or pleasure, where each loves the other for the sake of benefit. Ricoeur thereby suggested that true friendship is therefore only *for the sake of the good* which builds on Aristotle’s perspective of friendship as a virtue. ‘Solicitude’ therefore is built on this foundation – friendship is mutual and corresponds with the ethical aim of “goodness”.

With self-esteem corresponding to the overall aim of the good life (Ricoeur essentially argued that “the ethical aim” was synonymous with “self-esteem”), Ricoeur therefore proceeded to propose that ‘solicitude’ and self-esteem are intricately related:

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Solicitude is not something added on to self-esteem from outside but it unfolds the dialogic dimension of self-esteem... Self-esteem and solicitude cannot be experienced or reflected upon one without the other.

(Ricoeur 1990 / 1992:180)

This quote illuminates so much of the stories that the parents have shared with me. Good friendship ('solicitude') and self-esteem (or confidence) are so deeply connected that it makes sense that other people support parents going through this terrible time, by shaping their confidence.

This illumination is further brightened by Ricoeur's progression of thinking. He discussed the relationship between 'solicitude' and suffering. Rather than define suffering just in terms of physical or mental pain, he suggested that suffering happens when our capacity to act, or being-able-to-act, is reduced or even destroyed. In the context of this study therefore, the suffering associated with having a child diagnosed with cancer reduces a parent's confidence in their ability to make decisions. It is at times like this, Ricoeur suggested, that a friend may give their sympathy and compassion. Through this benevolence (where a friend is giving sympathy or compassion) the power balance between the friends initially becomes unequal – what is usually a mutual relationship, pivoting on a balance point, tips over into an unequal reciprocity. The person suffering receives the sympathy but cannot give back in the same way. Rather, Ricoeur suggested that they learn to give back by authentically sharing their vulnerability and fragility with their friend – this tips the balance back and reestablishes an equal and mutual relationship. For Ricoeur, it is at times like this where 'solicitude' can truly be seen:

This is perhaps the supreme test of solicitude, when unequal power finds compensation in an authentic reciprocity in exchange, which, in the hour of agony, finds refuge in the shared whisper of voices or the feeble embrace of clasped hands.

(Ricoeur 1990 / 1992:191)

If we are fulfilling our need for self-esteem through the ethical aim, the first component ("aiming for the good life") considers this according to our self (our identity, and our decisions / actions); the third component ("within just institutions") considers this according to our place within a community, society, and culture – a 'faceless' other; but it is with this second component, that we can see that we need friends, and through 'solicitude' our self-esteem is enhanced by recognising our value within a relationship of friendship.

Heidegger's work around 'being-with' and 'the They' ('*Das Man*') similarly suggested that we, '*Dasein*', are as we are (and arguably therefore our sense of self-esteem is as it is) through our

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relationships with others. Heidegger also proposed that ‘solicitude’ (‘caring-for’ other ‘*Dasein*’) is fundamental to us, and that this can be manifested by ‘leaping-in’ or ‘leaping-ahead’, and through ‘leaping-ahead’ we empower and build self-esteem. But for Heidegger the others always remain faceless. Ricoeur’s analysis of ‘solicitude’ “provides to the self another who is a face” (Ricoeur 1990 / 1992:202). Heidegger’s concept of ‘solicitude’ seems one-sided, and focuses on how ‘solicitude’ is offered to another. Ricoeur’s concept of ‘solicitude’ though is much more grounded in this notion of reciprocity – true ‘solicitude’ is always a two-sided, reciprocal relationship in which we both receive and offer support to each other. This feels relevant in this study where, in previous scenes, we have seen many ‘two-way arrows’ on the ecomaps, and parents have suggested that giving support to others plays a significant role in relationships.

By considering both Heidegger’s and Ricoeur’s concepts of ‘solicitude’ the following interpretations will develop an understanding of parents’ experiences of being supported with decision-making, by the direct, named others that each parent identified on their ecomap (those who do have a ‘face’).

Rob’s Crafted Story

It all starts when my wife notices a lump protruding out of Charlie’s side when she’s changing his nappy. Obviously the first things that go through our heads are all the worst options. We need to decide what to do – we are panicking a bit. “What is this? This wasn’t here when we changed his nappy earlier? Or is this nothing? Are we seeing things? Maybe this was always here?”. We both stand there for about an hour, just hawk eye, watching him, trying to see if this is actually something. We call Ella’s parents. They try to de-escalate and tell us not to panic, perhaps it’s nothing, maybe it’s a hernia? We all agree that it is best to get it checked out – people always tell you “if you notice anything that’s out of the ordinary, talk to your doctor”. So this is what we do – whilst they have tried to keep us calm, Ella’s parents have confirmed to us that we should go to the doctor and that we’re not being overly sensitive – there is something there. We go to the doctor, and they say the same “we suspect it’s a hernia but we’ll refer you on to the paediatrician for an emergency appointment – they will confirm what it is”. A couple of weeks later we are still waiting for the appointment. One night, Charlie is really unsettled, he is crying in pain. My wife phones 111 and they tell us to take him to the hospital immediately. They do a scan and say, “that’s not a hernia”. They do more tests and then they give us the devastating news that it is a tumour. “What!” – out of the blue, just like that, our son has cancer - high risk metastatic neuroblastoma. This is the worst possible outcome of a lump on his side.

Our first thoughts are “Oh my God, we are terrible parents, how have we not spotted this or tested for this sooner; We know our child, how could we not spot when something so bad is happening”. They say to my wife that she has done amazingly for spotting this so soon, we have caught it early.

After those early decisions about getting help there aren’t many to make for a while. We have to agree with the treatment plans and sign the consent forms. The consultant keeps us well informed and runs everything past us, but these aren’t our choices. We agree with the medical decisions because we’re not doctors, and obviously they’re not going to advise us, we’d hope, on anything that’s not in Charlie’s best interests.

We do have to make some decisions about nutrition. First, we decide to try an NG tube, but this doesn’t go too well, he just vomits every time it’s used. So a nurse suggests trying an NJ tube but this doesn’t work either. So now we are wondering about trying a PEG. Ella has done some reading and I’m asking about this on the ‘Mind the Chaps’ WhatsApp group. A few of the guys there tell me that their kid has a PEG and that it is so much better than an NG tube. This is really putting my mind at ease. So now we have suggested this to the doctors and we hope that this will happen when he has his next surgery. But it is hard to think about the future. The poor boy will have so many scars and marks on his body – this will really affect his quality of life. So to have another tube inserted is a big decision, we need to do the right thing. The support from the WhatsApp group helps me, all of the responses are positive in favour of having this done. I just need to know that this is a good decision to make, the right decision.

Kerry’s Crafted Story

Harry’s knee hasn’t healed well since his surgery for septic arthritis. We go back to hospital and the orthopaedic surgeon has a feel of his knee. I can tell by her face that something is bad. She tells us to go into town to buy food and toiletries because we will be readmitted. I know that something is bad – why are we back here? Why isn’t Harry walking? The next day the head nurse calls me into a quiet room and this top haematology consultant is there: “We are suspicious of leukaemia” she says. She explains that although they will have to do a bone marrow aspirate to confirm, they are sure that he has leukaemia. All I hear is the clock ticking really loud, in my mind everything has stopped.

We find ourselves making decisions immediately. On that first day they ask us if we want to go to the cancer ward now, or stay on the ward we’re on and move on the Monday – two

days later. To go to the cancer ward is accepting that he's a cancer kid now. We wait until the Monday.

Then soon after we are faced with a decision about inserting an NG tube. He keeps spitting his medicines out and he has to have so many medicines that this is all really stressful for him. Once he has a tube in, he will look like a cancer kid. But I have to accept this. If he looks like a cancer kid, it's because he is. A nurse suggests it will be much easier with the tube in. My Mum is with me and she understands what the nurse is saying – this nurse is lovely, we both really like her and we trust that she is looking out for Harry. I know it will be stressful for him to have the tube put in, but for the sake of 5 minutes stress, it will save stress for the rest of the day. It is really stressful – he is screaming and then he pulls it out immediately and they have to do it again. But it does take out so much stress in the end and I'm glad that we have made this decision.

I decide that Harry will not go to nursery. Kids are always full of snot bugs and sick bugs, and now with COVID on top of that... He's not going to go. I'm not asking anybody else about this, I'm not asking them if they think I should or not. I know what's best for him. My older sister works in a nursery, and this helps because I know that she can do assessments with him and make sure he's not falling behind.

In terms of treatment decision-making, we agree with all of the treatment plans. That is the most straightforward part, the easy decisions. I trust the facts and the research. I would never challenge science.

But sometimes I do have to challenge other decisions that are being made at the hospital. For example, sometimes they allocate him a bed in the bay, and I have to fight for him to be moved into a cubicle. He is immunocompromised and I won't risk him being around other kids. I am not nasty to anyone, but at the end of the day I don't care what they think of me, I am not here to make friends. I am here to speak up for Harry. But they don't listen to me, and it is so frustrating – why can't anyone just listen to me? It is stressful enough that my kid has cancer, why, on top of that, do I have to put up a fight in order for my son to be protected in the hospital?

Another time we are in the hospital and Harry's temperature is 35.7 and I tell the nurse that I'm worried. She says it's fine and it's within the normal bracket. But I've sat by Harry's bed for the past three years and watched his temperature. I know that if he's in the 36s I'm happy, but if he's low, or 37.4, then something is brewing, and I need someone to listen to me. I understand that they're saying it's normal – it's normal on a chart, but it's not normal for Harry. They need to listen to me and understand what I am saying.

I have had to learn to challenge things like this. A few years ago – when Rory was 2 and Harry wasn't born yet, I was made redundant under unfair circumstances. I'd worked there for 12 years, and I had loved my job, so I was really scared to challenge them, but I did it. I got legal advice and ended up getting a pay-out for unfair dismissal – that gave me the reassurance that I was right to challenge. I know this doesn't seem relevant, but the point is that I'm willing to speak up because I've done it before, and I will do it again when I've got a point. Others may see me as a troublemaker but I will do what I think is right. I know they don't agree with me when I complain at the hospital, and I know that they won't back me up, they think I should be grateful for the NHS. So I don't give them a chance to stop me and I speak up in that moment and tell them after I've done it.

I've learnt to be like this from my parents. My Dad always taught me "accept nothing, challenge everything". But he doesn't live that out as much as I do. And my Mum, she's got the gift of the gab. She's kind of lost it a bit as she's got older, but I remember when I was little, and she'd tell everybody what to do and they would do it. She used to be very assertive and people respected her. She would always speak up, she was never scared of anything. So I've learnt from both of them, but I've evolved and become me. My hubby and his parents – they hate conflict, so I seem quite extreme compared to them. But every time I challenge things at the hospital, I know that I am right to speak up so I don't feel guilty, whatever they say to me.

I have learnt to always trust my mother's instinct. I call myself Mrs Jumbo. I always say that she was never a mad elephant. They disrespected her kid and she lost it. And I'm like that and I say "I'm not a psycho, I'm sticking up for my kid. If you make fun of my kid's ears, I'm coming for you". I'm a Mrs Jumbo.

Interpretations

Trusting and challenging health care professionals

These final two crafted stories present two quite different experiences around decision-making. Rob demonstrates a need to have trust in himself to make the right decisions, and his story shows his growing confidence and strategies to achieve this trust. From the outset, Kerry seems to be the most confident of all six parents, and this confidence is often manifested through challenging the care and status quo of hospital processes. As her story develops, the context of this confidence becomes clearer.

What Rob and Kerry have in common though, and this is also seen in the stories of Tom, Martin, Maggie and Saira, is that there is a period where they have to place what might be

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described as almost blind trust in the health care professionals. This very much aligns to the need to release control that was discussed in the last scene – parents release, or relinquish, control because they trust the health care professionals to do what is best for their child. Robertson et al. (2019) suggested that whilst parents may have the responsibility to consent to their child's treatment, there are times where they may wish, or feel that they need to let medical teams take the lead in the decision. This is seen here, and as Rob says:

We agree with the medical decisions because we're not doctors, and obviously they're not going to advise us, we'd hope, on anything that's not in Charlie's best interests.

I really did not get the sense from my conversation with Rob that he feels any resentment about his lack of control with this decision-making. If anything, he is keen to defend the medical team and explains that they always keep him and Ella well informed, but ultimately, in that context, the medical team know how to look after Charlie in a way that they cannot. There seems to be a positive relationship between Rob and Ella, and the medical team, that is built on trust. Lown, Clark and Hanson (2019) argued in their study about shared decision making, that this is most effective when it occurs within exactly this type of relationship. With regards to cancer treatment decision-making, Rob does not want the health care professionals to 'leap ahead' and empower him and Ella to make decisions, they actually want them to 'leap in' and make the decisions for them. In this moment, their advocacy for Charlie is about trusting others to make decisions that are in his best interests.

This really resonates with a quote from Tom's crafted story in Act 3 Scene 2:

"We are just laymen, we don't know things and we don't know what's going on, but they – they are the experts and so we do what they say and agree with what they offer. What else can we do, if you really love your kid, why would you go against the advice of a consultant?"

Tom evidently believes the health care professionals to be credible and considers them "experts". We saw earlier that for Tom, the church played a role in this belief of credibility, and this was a real part of his identity. So here we can see that the previous sections of this pathway, around how 'significant others' shape confidence in our identity and degree of control, lead to this place of having confidence to trust the health care professionals.

Whilst much of Kerry's story revolves around challenging decisions, she is very clear that she would always trust the health care professionals in terms of cancer treatment plans:

"I trust the facts and the research. I would never challenge science."

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Whilst Tom and Rob place their trust in the experts, Kerry tends to place her trust in the evidence. Trust in evidence is also seen in the stories of Saira, Maggie and Martin (although Maggie does also speak of the importance of trusting the medical team as people). There does seem to be a difference between the two, trust in a person and trust in research output (even if it is the same person who has undertaken the research). Perhaps this is because trust in a person indicates a relationship, and as relationships are fragile, trust in a person can be broken – whereas trust in science and numbers feels more secure.

This is evident in Maggie's experience. As Maggie talks to me more about the day when she has to decide between Rosie having a Bone Marrow Transplant or CAR-T she says:

"We didn't really know that much about CAR-T to be honest. It's still quite a new development so we just relied on what the consultant said. And the thing is, we knew her quite well by then, and I did trust her opinion, but obviously I would have, in hindsight, liked a little bit longer to decide."

Relationships are really important to Maggie – she goes on to say that:

"I've always tried to be really honest with the health care teams and they've always been very honest with me, and I think if you don't have that relationship I don't know how you could let them make decisions about your child – you wouldn't trust them."

So, in this moment of the CAR-T decision, her valued relationship with the consultant comes under strain. She really trusts the consultant, but also places her trust in evidence, something that is likely formed from her professional identity as discussed in Act 3 Scene 2. When the evidence is unavailable due to the lack of time to research the options and the experimental nature of CAR-T, she has to place all of her trust in this relationship which is not easy. This leads Maggie to reflect on this experience in great depth later on.

Tom's story casts a slightly different perspective on this. The first part of Tom's story shows Tom deciding to agree with all of the medical advice. As time goes on, I can see that Tom is starting to challenge practice a little more. He focuses for a while on the decision that Noah should have stoma surgery. As the side effects of the chemotherapy take hold of Noah, Tom becomes aware that all of the nurses are using different creams which he thinks is wrong as he believes that it would be more sensible to use one cream for a few days and let it have an effect before trying something else. However, despite efforts to counterbalance the side effects, the surgeons advise that Noah should urgently have surgery to have a stoma created. Tom does not know much about this and only afterwards comes to understand how major this surgery has been, but he says:

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"Sometimes it's better to go into it a bit blind. Do what the health care professional suggests."

Perhaps, for Tom, this sense of blind trust is really important as too much information is terrifying. His experience also shows though, that even though trust and following the advice of the experts is very important as advocated by his 'significant others' of the church community, this does not prevent him having the ability to challenge practice when needed.

These experiences show that trust in health care professionals is not unconditional. As parents become more familiar in the world of children's cancer, their confidence to assert more control grows (as demonstrated in the last scene), and with this is an associated confidence to challenge decision-making of health care professionals.

The last scene revealed the 'leaping-ahead' of Saira's friend with their advice:

"You're not stupid, so you will understand everything and if you don't understand something it's because either they haven't explained it properly, or because it doesn't make sense, so don't be afraid to challenge stuff".

This leads Saira to assert more control, and to challenge the health care professionals.

This ability to challenge is also evident in Kerry's story. This story is complex, and it really seems that from the outset Kerry needs to challenge some of the hospital's decisions in order to best advocate for Harry. The opening stages of Kerry's story show that Harry is initially misdiagnosed with septic arthritis. It is not until a few weeks later, when the surgical site in his knee has not healed, that he is correctly diagnosed with ALL. Her trust in the medical team is potentially already compromised. Whilst she does then trust the haematology / oncology team in terms of cancer treatment, this trust is situated in the evidence and does not extend to all medical decision-making:

"I suppose it's like head versus heart. I let the doctors make the head decisions, but I'm going to make the heart decisions."

Like Saira, who sees her role as unique as she needs to consider Aria's care from a holistic perspective, Kerry sees that she can, and needs to, advocate for Harry in a unique way. Whilst she won't challenge the treatment decisions, she is prepared to challenge decisions around Harry's allocation to a bed in a bay rather than a cubicle. In another example Kerry tells me that she challenges the prioritisation of the lumbar puncture list⁹. Kerry challenges why Harry is

⁹ Children with ALL need to have regular lumbar punctures: these are usually done under a general anaesthetic, which requires children to be nil by mouth for a period of time in advance.

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toward the end of the list as he is extremely hungry and older children, who from her perspective can cope with being hungry for longer, are being seen first. Kerry also talks about challenging nurses in reference to interpretation of Harry's observations (such as his temperature). As her confidence in her identity as a mother of a child with cancer grows, she draws on her expertise to challenge the way that things are done in the hospital. She has learnt to understand the charts, but she also has become an expert in Harry's physiological responses. She has become an 'expert parent', a concept that has been explored in previous research (Ringnér, Jansson and Graneheim, 2011), and this allows her to assert control and challenge the medical decision making:

"I call myself a veteran Cancer Mum, because I've learned the ways to deal with stuff."

Saira's story conveyed a sense of being alone in asserting control of decisions. A similar sense is felt in Kerry's story, but for her – rather than just feeling alone – she feels that she is making decisions in opposition to her family. She tells me what happens when she tells her family about how she has challenged decisions at the hospital:

"I see their disapproving faces. And I know they don't agree with me, they wouldn't have backed me up, which is kind of all the more reason why I speak up in the moment because I know if I went home, that people would fly off and say "oh well, you should be grateful for the NHS" and they would try to talk me out of speaking up. So I'm more inclined now to say it in the moment, because I think then that it's real and I haven't had anyone try and make me feel guilty about speaking up."

Kerry does not want to give her family a chance to 'leap in' and take control, yet neither are they 'leaping-ahead'. She needs to be allowed to make the decision for herself. It seems clear that Kerry feels judged for her decision to challenge hospital staff, yet for her this is secondary to the importance for standing up and protecting Harry. Similarly, no 'solicitude' is evident in a Ricoeurian sense, relationships in this moment are not equal – no sympathy is offered from Kerry's network in this context, and she therefore feels that she cannot share how she is authentically feeling. With 'solicitude' lacking from both a Heideggerian and Ricoeurian conceptualisation, Kerry is left feeling alone – without the 'face' of another. Yet despite this lack of 'solicitude', Kerry is acting in an authentic way. In Act 2, I had questioned if it was possible to make authentic or inauthentic decisions if the decisions are made on behalf of somebody else. Kerry's decision to challenge practice in order to advocate for Harry do demonstrate that she is prepared to stand against the socially accepted behaviour in the hospital. She will not blindly accept what the 'They' say, or trust that all decisions in the

hospital are being made in Harry's best interests, just because that's what everybody else believes.

I wonder if the being-towards-death that she is facing with Harry's life-threatening illness has propelled her into this 'authenticity'. As Kerry gives me further context to her life though, I understand that there is a deeper temporal perspective. Kerry has experience of challenging the system in her work life. Learning that she has the ability to successfully challenge the establishment has given her reassurance that she can do this if she believes that something is worth fighting for. Kerry goes on to say that she has learnt how to "*accept nothing, challenge everything*" from her parents. So it seems that she has had this confidence to be authentic for a long time, and it is not necessarily the sense of being-towards-death that has enabled this, as Heidegger suggests. This really highlights to me that, as discussed in Act 2 Scene 1, decision-making does not happen in a moment, our decisions are situated within, and informed by, our whole life.

So for Kerry, whilst in this moment there is a lack of 'solicitude' and support from her social support network, her 'significant others' have shaped her confidence to challenge decision-making through previous life experiences. This has contributed to Kerry's confidence to advocate for Harry.

Trusting and challenging 'Significant Others'

My published literature review (Jestico et al. 2023b) demonstrated that sometimes people placed credibility and trust in their 'significant others' rather than in the health care professionals. When I spoke to most of the parents, I did not get the sense that they placed more credibility in other people than the medical team. Saira is perhaps the exception; over time she places credibility in her "expert acquaintances". Kerry does not place credibility in anybody other than the health care professionals and herself. For the other parents it is not that they are **not** placing credibility in their 'significant others', rather that they are not placing **more** credibility in 'significant others' than in the health care professionals. Having confidence to trust and challenge their 'significant others' is still an important part of finding a way to advocate for their child, but there is a careful balance between doing this whilst also maintaining trust in health care professionals and ultimately moving to a place of being able to trust themselves.

In Act 3 Scene 3, we learnt how Maggie listens to the advice of a father at the BMT unit. This leads to Maggie making the decision to leave Flora back home with her Mum whilst Rosie has her transplant. Maggie's trust in her Mum to care for Flora allows her to release control of Flora's care for a while, thus facilitating the decision. Here, she is actually allowing, or even

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wanting, her Mum to ‘leap in’ and take over care of Flora on her behalf. It seems that at this immensely vulnerable moment in Maggie’s life when she is facing a complex decision, having somebody to ‘leap in’ is helpful. Maggie says in relation to this decision:

“It made us rely on people.”

Maggie also talks about the balance in her relationships. She talks about how support would have been much more one sided (towards her) if I had spoken with her whilst Rosie was having her transplant, but now things feel more balanced. This moment where her Mum has ‘leapt in’ has perhaps led to this feeling of inequality in their relationship as she is having to rely on another. This situation, in that particular moment, does not achieve Ricoeur’s complete test of ‘solicitude’. It is not until later, when the balance is restored and Maggie no longer needs her Mum to ‘leap in’, that full ‘solicitude’ is achieved.

The conversation with the other father at the BMT unit is really interesting. It does link to the concept of ‘learning from others’ experiences’ discussed in my literature review; in particular it links to H-Yazdi and Meadows’ (2021) finding that parents emphasised the need to have access to real-life stories. In terms of ‘leaping-in’ versus ‘leaping-ahead’ I wonder if this may occupy the ‘middle ground’ that is hinted at in Stambaugh’s translation of *Being and Time*:

Between the two extremes of positive concern... everyday being-with-one-another maintains itself and shows many mixed forms.

(Heidegger, 1927 / 2010:122)

The other father is not telling Maggie what to do, but she really values his honesty and that helps her to trust his advice.

Martin places his trust in his Facebook friend when he works out how to minimise risk and control Toby’s environment. He is also ‘learning from others’ experiences’ so that he can understand a *“real world perspective”* and again there is this sense of the middle ground between ‘leaping-in’ and ‘leaping-ahead’.

Tom trusts his church community – a group of ‘significant others’ that are attuned to his deep religious faith. The church’s advice is to follow the advice of the medical teams, so Tom’s trust in the church reinforces his trust in health care professionals. Tom also talks about a member of the church in New Zealand whose daughter has lived through cancer treatment. Tom talks to this person a few times and finds that they are reassuring of Tom’s approach to trust the medical teams. There is an element of ‘leaping-ahead’ here, in that they are reassuring Tom and empowering him to continue to follow the path that feels right.

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On the other hand, as Tom tells me about his second cousin whose child has had cancer, there is a very different feel. Tom's second cousin advises Tom to seek homeopathic medication for Noah and he absolutely does not want to follow this advice. Here a line has been crossed with what Tom perceives as interference and a potential assault on his role as advocate for Noah. I propose that the second cousin here has 'leapt in', and that in this context this is unwanted and unhelpful. As Smythe (2003:201) wrote: "It takes skilled judgement to know when to leap in and when to leap ahead."

Where Maggie's Mum has got this judgment call right and 'leapt in' appropriately, Tom's second cousin is not attuned to whether Tom wants or needs this 'leaping-in'. Tom does not agree with his second cousin's approach to decision-making and this leads him to challenge this advice in this moment. Although Tom places significant trust in health care professionals, his trust in other people is not universal and he challenges when he needs to.

Rob also talks warmly of his trust in health care professionals, but again his trust in others is not absolute. He tells me about a difficult situation with Sylvie's school. Rob explains that in the early days following Charlie's diagnosis, conversations are had with Sylvie's school about the importance of monitoring infections within the school (in particular chicken pox) and communicating with Rob and Ella if there are any concerns. Rob explains that they need to place significant trust in the teachers that they will do this, as if Sylvie contracts an infection and passes it on to Charlie, this could be fatal. Unfortunately, a few months later there is a chicken pox outbreak in the school, and this leads Rob's trust to waver:

"They didn't tell us immediately which we weren't too happy about, but at the end of the day, it's not something they always think about – chicken pox in children, it happens everywhere, all the time... I don't think the school quite understood how serious it was... it's hard for them to know."

Whilst he understands the difficulties that the school face, there is frustration about this situation. He explains that because they haven't been told about the outbreak, Sylvie visits Charlie in hospital – a few days later chicken pox spots appear on her, and they realise that Charlie has been exposed to the virus. To an extent, this situation compromises Rob's trust in others, and I wonder if this impacts on his self-confidence as he questions whether he was right to trust others so freely.

Trusting oneself as a parent

I know that because I'm a parent I'm supposed to have all the answers, but I don't. I wonder every single day if I'm doing the right thing... There are times I think I know

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what I am doing is right, and there are other times I second-guess myself every step of the way.

Picoult (2004:388 – 389)

Learning to trust in oneself lies at the heart of all of the parents' stories. However, it is for Rob that this shines most brightly. Rob's story starts with him and Ella noticing the lump on Charlie's side. Rob tells me that they are panicking, but also doubting themselves. On the one hand they are terrified that the lump could be something really terrible, but on the other, they are worried that they are being over-sensitive and that there is nothing actually there. They turn to Ella's parents, who they clearly have a close relationship with. Ella's parents respond to this by simultaneously de-escalating Rob and Ella's worst fears *"They tell us not to panic, perhaps it's nothing, maybe it's a hernia"*, whilst also reassuring Rob and Ella that they are absolutely right to seek medical help; they acknowledge that there is a lump there, and therefore they are assuaging their worries of being over-sensitive. Rob and Ella are almost inviting her parents to 'leap in' and tell them what to do, but actually they 'leap ahead' by assuring Rob and Ella that their instincts are right, and this empowers their sense of confidence in their parenting skills. Ricoeur's concept of 'solicitude' also shines through here – Ella's parents recognise the anxiety and fear that Rob and Ella are experiencing and they are "there" for them in that moment – allowing Rob and Ella to authentically share their feelings of fear, whilst also offering reassurance and confidence that they should trust their instincts.

When, a few weeks later Charlie is formally diagnosed with a high-risk metastatic neuroblastoma, their confidence crashes again:

"Oh my God, we are terrible parents, how have we not spotted this or tested for this sooner; We know our child, how could we not spot when something so bad is happening?"

This time it is the health care professionals who attempt to reassure Rob and Ella – they tell them that they have done really well to spot it so soon and explain that the lump was very subtle and many people would not have spotted it this early. Whilst reassuring words can likely do little to make them feel better at such an awful time, they perhaps do go some way to helping Rob and Ella have confidence and trust in themselves.

A few months later it seems that Rob has more confidence to trust himself with decisions. He and Ella are making a decision about whether Charlie should have a PEG inserted. Interestingly, Rob and Ella suggest the idea of the PEG to the medical team rather than the other way round. Ella has been doing a lot of research about this and Rob feels that he wants to contribute to the

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decision-making process by checking with people who have experienced this. He sends a message out on the 'Mind the Chaps' WhatsApp group and the responses he gets reassures him that they are making the decision that is best for Charlie both in the present moment and for the future. Again, these messages tell him that he can trust himself, and that leads Rob and Ella to conclude: *"Right, yeah, let's get this done"*. This suggests that 'learning from other's experiences' is not just about placing credibility in those who have lived through something, as has previously been discussed, but it is also about using that learning to build trust in oneself. I ask Rob if he discusses this PEG decision with anybody else and he tells me that they have mentioned it to Ella's parents. The way he explains this to me is fascinating:

"We tell them and they say "that makes sense, this should be better for him", so it's less of an asking, more of a telling".

This really shows the shift between those very early days where they actively sought advice from Ella's parents, to now where they are keeping them informed but they do not need anything further. 'Leaping-ahead' in the early days has empowered Rob and Ella to trust themselves and they are now making authentic decisions that they believe are the best for Charlie.

Shaping confidence: a reciprocal process

It is important at this stage to consider the concept of reciprocity that has arisen on a few occasions during Acts 2 and 3. This is relevant to this notion of confidence and trust as it relates to Ricoeur's concept of 'solicitude' and further illuminates the confidence that is being shaped for each parent.

All of the parents speak about their relationships with other parents of children with cancer. The depth of these relationships really varies, and the strength of direction that support flows (although not possible to easily indicate this on the ecomaps) also varies. Martin and Rob specifically talk about the 'Mind the Chaps' WhatsApp group, which they have both joined relatively recently. For them, at this point in time, the direction of support seems to be mainly towards them.

However, some of the other parents tell me that they are offering support to these other parents. Tom tells me that a while after Noah has his NG tube, they meet another family on the ward who are trying to decide whether their child should have an NG tube. Tom tells them about Noah's experience and says to them *"It's a good decision"*, he goes on to tell me that he is pleased that he can do something positive and give another family some encouragement. It

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really seems that his trust in himself to make good decisions is manifesting itself through his confidence to support other families.

Kerry similarly tells me about how she has become connected with a network of Cancer Mums. She explains that she is not particularly close to any of them, but they do communicate a lot via social media. This is a group of people who can talk freely with each other, and Kerry uses her experience as a “*veteran Cancer Mum*” to offer advice to them about challenging care decisions, and gives them permission to articulate their frustrations:

“I can tell when people post, there’s a hesitation to tell the truth. They say “we’re really grateful for the care we’re getting but...” And I say that you don’t have to do that preface of “I’m really grateful”, you can just say “Today’s bullshit, I’ve had enough”.

Finally, Maggie talks at length about the support that she has given to other Mums with children who have cancer. She talks about this mutually supportive network and how much it helps her to be able to help others. However, she later tells me that:

“I took on a lot of people’s... I was supporting people almost a little bit too much... I’d taken on everybody else’s stress. It’s difficult when you’re that type of person, to give support but not go too far with it”.

It strikes me that this reciprocity relates to Ricoeur’s discussion of ‘solicitude’ being found in mutual relationships, and that giving support helps to keep the relationship balanced. However, the relationship balances on a narrow edge, and navigating how not to tip over the edge and feel like you are giving too much of yourself is a risk, as Maggie experiences.

This reciprocity extends beyond other parents of children with cancer, and as I review the ecomaps, it does seem that there are many two-way arrows for many of the parents. This contradicts Thoits’ (2011) theory that in times of adversity, social support ceases to be reciprocal. Many of the parents in this study do experience reciprocity and they tell me that this is because they acknowledge that the news of their child’s cancer is difficult for their extended family and friends as well. They realise that they all need to support each other. Again, Ricoeur’s ‘solicitude’ shines through here, with this mutual “good” friendship seen in caring for each other. However, again, this balances on a narrow edge. Saira tells me that there are times where she needs to offer so much reassurance to the people around her that this actually diminishes for her how serious her situation is. By saying “it’s all going to be fine” to others, she is not able to authentically reveal how she is feeling. The lack of ‘solicitude’ here makes her feel alone, she remains in solitude.

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Reflections

As the end of this pathway through the woods is reached, I have much to reflect on. When Arthur died, I lost all confidence to trust myself. I actively wanted people to ‘leap in’ and make decisions for me. I was exhausted and did not trust myself to make decisions for myself anymore. People who could help me like this understood that this was what I needed in that moment. Whether physically present, or emotionally present, I was surrounded with people who poured out their love to me and I knew that they felt devastated for us. I was able to talk to them and share my vulnerability. ‘Solicitude’ shone to me at that time.

Three and a half years later, when my Mum died, things felt different. As I faced decisions then, I needed people to ‘leap ahead’ and trust me that I would make the right decisions. If people could trust me, then I could trust myself. If people were to ‘leap in’ I would find myself losing confidence in myself and the relationships came to feel unequal. As Heideggerian ‘solicitude’ was being demonstrated through ‘leaping-in’, Ricoeurian ‘solicitude’ was not achieved. However, during this period, I was deeply engaged in this study. I was reading philosophy and hearing what participants were saying. I recognised that I needed people to ‘leap ahead’, and I recognised that there were people in my support network who could do that. I learnt that if I could surround myself with these people then I would be able to rebuild my confidence to trust myself to do the right thing.

This leads me to reflect on how I have supported others. I think that, with hindsight, when my friend asked me for advice about her son’s hernia repair, I was effectively ‘leaping-ahead’ but I do not know if this was what she needed in that moment. I wonder about the families who I have known from my days working on cancer wards – did I strike the balance between ‘leaping-in’ and ‘leaping-ahead’ with them, and what were they experiencing from their networks?

From solitude to solicitude

The opening scene of this act was set deep in the thicket of the woods where it was seen that the parents in this study experienced a deep lack of confidence when their child was diagnosed with cancer. The crafted poem illuminated this sense of being “lost at sea” and feeling of the family “standing alone”. A pathway has been navigated from that thicket to find the clearing. Along this pathway, crafted stories have been presented with my interpretations of the meaning of the experiences shown in these stories. Accompanying this has been a journey through Heideggerian and Ricoeurian philosophical ideas. Heidegger’s interconnected concepts of ‘*Dasein*’, ‘temporality’, ‘being-with’, ‘authenticity’ and ‘thrownness’ had been explored in Act 2. These became the foundation for the exploration of the key concept for this thesis –

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‘solicitude’. Alongside this, Ricoeur’s concepts of ‘identity’ and the ‘involuntary and voluntary of the will’ took us to an understanding of his concept of ‘solicitude’.

Each parent is ‘*Dasein*’ according to Heidegger. This means that Tom, Saira, Kerry, Maggie, Martin, and Rob are all ‘beings-in-the-world’. They experience life as being in the world around them. This world exists in time, so their ‘being-in-the-world’ is temporal. Their existence is experienced through their past, present and future. Their world is a world that they have been thrown into and includes the environment and culture that they live in and the relationships that they have with others (‘being-with’). These others (the ‘They’) inform the way that each parent decides to live their lives. They can conform with the way that the ‘They’ expects and make decisions in line with this (they can live inauthentically), or they can reject the social norms of the ‘They’ and live an authentic existence.

According to Heidegger, a fundamental feature of ‘*Dasein*’ is its care, or interest, in other beings. ‘*Dasein*’ takes interest in all beings, it is concerned with inanimate and non-human life, and it shows ‘solicitude’ towards other ‘*Dasein*’. ‘Solicitude’ can manifest itself as ‘leaping-in’ or ‘leaping-ahead’, and it is through this second manifestation (‘leaping-ahead’) that others can support us to move towards making authentic decisions about our life.

Throughout this act the ontological character of each ‘*Dasein*’ has been made manifest, and the way in which each parent experiences being supported by others with making decisions has been illuminated. Their stories have shown greater insight than the brief contexts set out in Act 2. Ricoeur’s concept of ‘identity’ has emphasised the importance of the “who” (the ‘*Dasein*’) in all decisions and actions. If our identity informs our decisions, then understanding how others may support our identity is a good place to start on the pathway of understanding. Ricoeur’s discussion of ‘*idem*’ and ‘*ipse*’ has enabled the stories to be enlightened with an understanding that within our identity we have sameness and difference. Our core character (which is stable in time) and our self-constancy which diversifies over time, are shaped by the world that we live in, and by the people around us (akin to Heidegger’s ‘being-with’). Our lives are always entangled with others, and as others shape our lives, we shape others’ lives. This sameness-in-difference of identity has been important to understand as we have seen that ‘significant others’ can shape parents’ confidence to maintain and renew their identity as decision-maker for their child. Throughout this act we have learnt about the parents’ identities and how others may have shaped confidence. We have seen how the church has supported Tom to maintain his core faith and identity, and how the ‘Mind the Chaps’ WhatsApp group has allowed Martin to connect with other dads of children with cancer and renew his identity. We have seen how Kerry’s identity has been shaped temporally through learning from her parents, and experiencing adversity at work, which has led her to both maintain her identity as being

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able to challenge others, and do this with renewed energy as she challenges others in order to protect her son. Above all, we have seen that the parents are concerned with wanting to be a 'good parent' as they adapt to being a parent of a child with cancer. To be a good parent is to make decisions that are best for one's child. If others 'leap in' and tell a parent what to do, this may feel like an assault on their identity as a good parent, and has the potential to therefore undermine their confidence.

'Significant others' can shape a parent's confidence to maintain and renew their identity as a 'good parent', and in turn this can shape a parent's confidence to advocate for their child.

Despite holding onto this identity as a good parent, and a good decision-maker, parents have to acknowledge that they are now a parent of a child with cancer. This means that they do not have the same capacity to make decisions as before, and they have to release control to the medical team, and trust that they will care for their child and make decisions in their child's best interests. Accepting the 'thrownness' of their situation and that there are some things that are within their control ('voluntary') but others that are not ('involuntary'), is important. It is not always clear which decisions parents do have control over and which they don't, and the consequences of one decision can lead to another decision, which then feels 'forced'. In releasing control of some decisions, parents are essentially allowing others to 'leap in' and make those decisions for them at particular moments in time. Others cannot do much to support parents at this time, but they can quietly acknowledge that this is what the parents are needing to do. As time goes on parents may need to re-assert control and their social support network can 'leap ahead' by empowering and respecting them to make these decisions.

Although it may feel counter-intuitive, releasing control of decision-making is as significant a part of advocating for a child's best interest as is asserting control, so the role of 'significant others' in shaping confidence in this also leads to shaping a parent's confidence to advocate for their child.

This final scene has explored parents' confidence to trust and challenge themselves and others in decision-making. The Heideggerian concept of 'solicitude' has continued to be explored, and supporting parents in navigating between trusting and challenging requires others to be attuned to whether those parents require them to 'leap in' or 'leap ahead'. Here it seems that there are times where the "middle ground" between 'leaping-in' and 'leaping-ahead' has been occupied. The Ricoeurian concept of 'solicitude' has run alongside this discussion. This rests on the bedrock of good friendship, which is mutual and reciprocal. At moments, parents seem to experience neither Heideggerian 'solicitude', nor Ricoeurian 'solicitude'. Instead, others demonstrate indifference, and the parents experience solitude.

Act Three: The pathway through the woods – towards the clearing

However there also seem to be times where ‘significant others’ do not explicitly ‘leap in’, ‘leap ahead’, nor occupy the middle ground. Yet neither are they indifferent. They are doing something more subtle than this which I propose is understood through Ricoeur’s concept of ‘solicitude’. They become the “other who is a face” (Ricoeur 1990 / 1992:202) by ‘being-with’ the parent, quietly acknowledging the suffering and being compassionate, and in turn allowing the parent to give to them by sharing their vulnerability and pain. I propose that by offering ‘solicitude’ in this way, the other is also offering Heideggerian ‘solicitude’ as they are becoming attuned to whether parents need, or want, them to ‘leap in’ or ‘leap ahead’, occupy the middle ground, or perhaps stand back and simply acknowledge the parents’ situations. By ‘being-with’ them, allowing reciprocity of support, and becoming attuned to the parent’s needs in their darkest moments, the other offers ‘solicitude’. And by doing this, they are shaping the parent’s confidence to trust that they are a good parent, and can authentically advocate to do what is best for their child.

The Curtain Falls

We have reached the end of this pathway. We have travelled through the woods from the solitude in the darkness of the thicket to find ‘solicitude’ in the openness of the clearing. This scene opened with an explanation of Ricoeur’s concept of ‘solicitude’. The final two crafted stories were then presented and discussed in relation to parents needing to navigate between trusting and challenging others, and ultimately growing confidence to trust themselves. Applying Heidegger and Ricoeur’s concepts of ‘solicitude’ to these interpretations revealed a clearing where it could be seen that others can support parents to make decisions through ‘solicitude’. By being good friends and acknowledging their suffering, and by being compassionate and allowing reciprocity of friendship, ‘significant others’ can become attuned to whether parents need them to ‘leap in’, ‘leap ahead’, or simply gently acknowledge the situation that parents are in. Through offering this ‘solicitude’, ‘significant others’ can shape a parent’s confidence to advocate for their child.

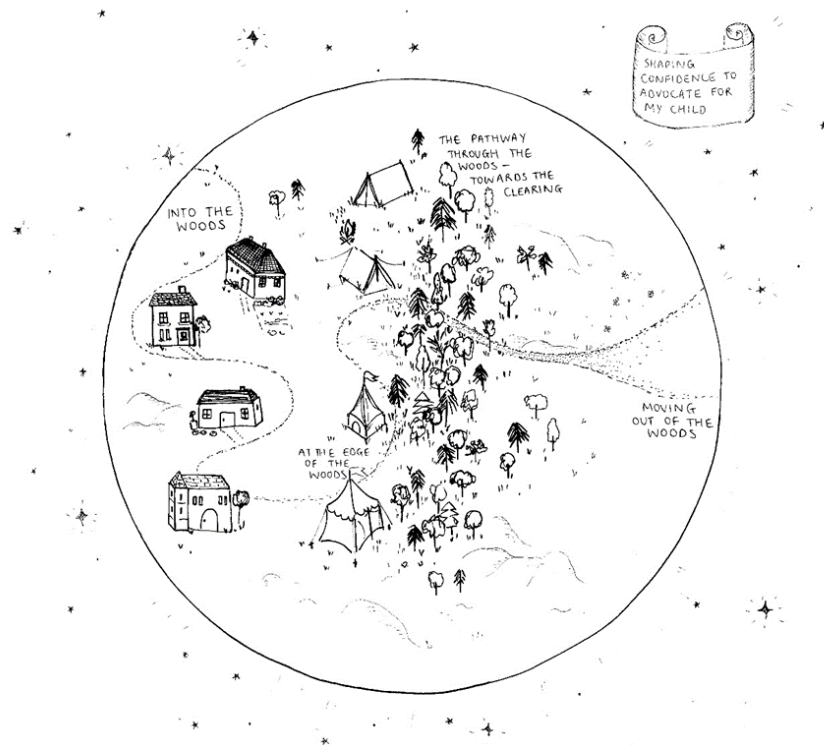
As this journey nears its end, it is time to move to the final act. There, the pathway leaves the woods and moves back into the everyday world, where through exploring conclusions and implications for the future, I will consider how life continues following this journey.

End of Act Three

Act Four: Moving out of the woods

*It takes care,
It takes patience and fear and despair
To change...
You've changed.
You're thriving.
There's something about the woods.
Not just
Surviving,
You're blossoming in the woods.*

(Sondheim and Lapine, 1987:54-55)



Act Four: Moving out of the woods

Introduction

This thesis has travelled from the everyday world, where the need was recognised to journey into the woods in order to address the research question (Act 1), to the edge of the woods where the characters were introduced, and their social networks and the decisions that they had faced were discussed (Act 2). Act 3 travelled to the heart of the narrative, deep into the darkness of the woods where it was seen that the parents lost confidence in themselves when their child was diagnosed. A pathway was then forged that twisted and turned showing that 'significant others' may shape a parent's confidence to maintain and renew their identity; assert and release control; and trust and challenge themselves and others to make decisions. Shaping confidence to advocate for their child is thus the phenomenon at the heart of this study. The philosophies of Heidegger and Ricoeur illuminated this phenomenon, and by following the pathway of these philosophical ideas, the clearing was reached whereby I proposed that ultimately 'significant others' may show 'solicitude' to parents and that this is how parents' confidence can be shaped.

This final act leads out of the woods and back into the everyday world. There is just one scene in this act which aims to look back to the woods and travel onwards. There is iterative movement between looking back to draw together learning from the parents' stories in Acts 2 and 3 and the other narratives that were introduced in Act 1; and looking forwards to consider how this learning may influence future practice from the perspectives of health care professionals, future support from the perspectives of 'significant others', and my own future thinking and pathway. Finally, reflections on the journey will facilitate consideration of the challenges encountered and lessons learned.

Act Four: Moving out of the woods

Scene One: Looking back to the woods and travelling onwards



Scene One: Looking back to the woods and travelling onwards

Soundtrack: Sure On This Shining Night, Morten Lauridsen, 2005

Both the words and the music of this contemporary composition resonate with the place that this thesis has reached. The words emphasise the contrast between being alone (the solitude articulated by some of the parents) and kindness (a Ricoeurian 'solicitude'), and through this 'solicitude' the clearing is found – a shining in the night. The music sets a balance between male and female voices, unusually for this genre of music, the tune is always heard first in the male voices before being echoed by the female voices. This beautiful balance between voices sits well with the balance between the voices of mothers and fathers that have been represented in this study. The combination of all voices, along with the piano creates a musical sense of space that also, to me, evokes the sound of the clearing.

Scenery: Starry Night Over the Rhone, Vincent van Gogh, 1888

This famous van Gogh work, similarly, depicts the shining of the stars in the night. The light of the stars shines down upon the world below and falls particularly on the two people walking by the river, who significantly are together, 'being-with' one another, rather than in solitude. The light of the stars is then reflected in the river, and this adds further illumination. I laid out my pre-understandings in Act 1 Scene 1 and I have drawn upon these throughout this work and will return to them again in this final act. As the light of the stars is combined with the reflection of the starlight in this beautiful painting, the synergy of parents' stories with my own reflections has allowed understanding of this topic to be brightly illuminated.

Act Four: Moving out of the woods

The Curtain Rises

This scene will start by drawing together the learning from this study. The Overture presented the acknowledgement that making decisions when their child has cancer can feel very stressful for parents (Bandinelli and Goldim, 2017; Gagnon and Recklitis, 2003) and that it is therefore important to understand parents' experiences of being supported with this. Act 1 Scene 4 explored other narratives and presented a literature review of previous research in this area. It led to the formulation of questions and gaps which had not been addressed in depth. As such it presented some potential pathways through the woods, but the lack of depth of previous research prevented the clearing from being reached. Through the conversations that I had with the six parents in this study and engagement with the philosophies of Heidegger and Ricoeur I have proposed an alternative pathway which does reach a clearing. In the clearing the light shines and allows us to see the phenomenon in full radiance - that confidence to advocate for their child is at the heart of parents' decision-making, and that 'significant others' can shape this confidence through 'solicitude'. This first part of the scene will therefore look back to the woods and to the clearing, and explore what has been learnt from the combined engagement with other narratives, conversations with the parents, and with the philosophical works that have underpinned this study.

The second part of the scene will change the direction of sight – from looking back to the woods, to looking ahead and travelling onwards. Here I will return to the musical question posed in Act 1 Scene 2: "So What?". This question leads to a consideration of what this all means back in the everyday world, what the implications are for health care professionals caring for families of children with cancer, what the implications are for the general public assuming the role of 'significant other' to those going through such difficult times, and finally what the implications are for me. As Act 1 Scene 1 looked into my mirror through these three lenses, this scene will present a kaleidoscopic view through these same lenses as I look forwards.

Finally, the scene will draw on key reflections from this study. This will focus, in particular, on the challenges that I have encountered during this study, including the difficulties that hermeneutic phenomenologists face when presenting provisional and contextual findings to an academic world which prioritises generalisable and intervention-based studies. Yet despite the challenges that were encountered, this scene will also demonstrate the transformative impact that this study has had.

[Looking back to the woods](#)

As I look back to the woods, my gaze flickers between Act 1, where I set the scene and discussed established narratives about the topic, and Acts 2 and 3 where I engaged with conversations with the six parents and explored my interpretations of these stories. The following discussion will be structured in the same way as my journey through the woods. This will start with consideration of the 'off-stage characters', which will lead to an exploration of the decisions that parents faced. Finally, dialogue will be presented between the literature review and my interpretations around the support that 'significant others' may offer to parents as they make decisions.

The Off-Stage Characters

The 26 papers reviewed in the literature review (Jestico et al., 2023b) encompassed a range of 'significant others' that parents turned to for support. These included friends, family members, religious communities, online support forums, employers, and other parents of children with cancer. Very few of these papers' prime focus was support from 'significant others', rather the focus of the papers tended to be about decision-making, while support from the identified 'significant others' formed part of the findings. Of those papers that did have a focus on support from others, the authors had directed their research aims to a particular group of 'significant others'. For example, Gage (2013) explored other parents of children with cancer as a source of support with an emphasis on delineating support between 'similar' and 'significant' others; Kelly and Ganong (2011) focused specifically on the role of step-parents supporting decision-making; and Mostert et al. (2014) considered a wider pool of family and friends.

It was important in this study to allow the parents the autonomy to identify who they considered to be a 'significant other' and the ecomap proved to be a valuable tool to facilitate this discussion. In general, the types of people that the parents included were similar to those identified in the literature review: friends, families, work colleagues / social group members, and other parents of children with cancer. The parents in this study also often identified a network from their child's nursery or school, and included health care professionals on their ecomaps (although it should be noted that I had excluded health care professionals from discussion in my literature review as this was not my focus). They did not delineate between 'significant' or 'similar' others, and regarded everybody on their ecomap as playing a significant role in some way. The ecomaps showed that there was fluidity in these relationships and people changed in their level of significance to the parents over time. It was also evident that support was often reciprocal and it became clear that there was a strong transactional and temporal ebb and flow in the relationships identified on the ecomaps. Looking at the ecomaps

through a Heideggerian lens (Jestico et al., 2023a) allowed a view of the relationships with ‘significant others’ in a much more nuanced way than had been possible from engaging with previous research about decision-making.

The decisions that parents faced

The majority of the papers included in the literature review focused on specific types of decision. Only eight papers focused on decision-making in general (Liang, 2002; Holm, Patterson and Gurney, 2003; Huang, Mu and Chiou, 2008; Kelly and Ganong, 2011; Gage, 2013; Kilicarslan-Toruner and Akgun-Citak, 2013; Gage-Bouchard, 2017; Robertson et al., 2019), where the researchers facilitated the parents to self-define which decisions were important to them, as I did in this study.

Enabling the parents to do this precipitated deep conversation and thinking about the reality of how much agency parents have in decision-making when their child has cancer and how complex decision-making can feel, which is associated with a potential loss of confidence in the parents’ ability to make decisions. Despite much of the research that was identified in the literature review focusing on treatment decision-making, for the parents in this study this was not their main focus, and more of their conversation was about making social decisions (such as shielding or school attendance) and medically supportive care decisions (such as nasogastric tube insertion). Interestingly, similar types of decisions were identified as important to Emily in the 2021 issue of *Contact* (CCLG) which echoes this difference of perspective around decision-making between parents and researchers or health care professionals. Of all the six parents in this study, Saira and Maggie focused most on treatment decision-making; both of them had faced making challenging decisions when their child had not responded as hoped to standard treatment and were now deviating from standard evidence-based treatment protocols. Pearson et al. (2022) have similarly suggested that parents become more involved with decision-making if no standard of care is available for their child, and that if a standard of care is available then parents are not involved in decision-making. This resonates with the work of Coyne et al. (2014:276) who found that parents felt that “there was no decision to make” in terms of ‘major’ treatment decision-making and that it is the ‘minor’ decisions where they have more agency to become involved. This is a complex issue that is reflected further in this study’s interpretations around parents needing confidence to assert and release control, and there are significant implications around this that will be discussed later in this scene.

What it means for parents to be supported by ‘significant others’ when making decisions

It was not possible to answer the research question from engaging with literature alone.

Whilst, to a limited extent, previous research had explored **how** ‘significant others’ may offer

Act Four: Moving out of the woods

support to parents faced with making decisions, there was insufficient depth in any of this previous research to explore what this support meant to parents. The literature review presented two themes: Dimensions of Decision-Making Support included the sub-themes of informational support, emotional support and instrumental support. Expectations of Decision-Making Support encompassed parents' expectations of their own role, and the role of others in decision-making.

The three sub-themes within Dimensions of Decision-Making Support can all be seen within the findings of this study. Parents did turn to 'significant others' for informational support: Saira talked about connecting with experts in the field through her network, and Tom, Maggie, Martin, and Rob all talked about seeking and receiving information from other parents of children with cancer. Kerry did not talk about turning to others for information. Previous research had shown that parents did turn to people in their network with specialist expertise, but also that they placed significant credibility in information provided from other parents of children with cancer. Whilst the parents in this study did place credibility in other parents of children with cancer, viewing parents' experiences through the ontological lens of confidence illuminated more deeply what this support meant to parents. Maggie and Rob both interacted with other parents who shared their experiences (in Maggie's case this related to the experience of bone marrow transplants, and for Rob this was about the benefits and disadvantages of gastrostomies). These interactions gave Maggie and Rob the confidence to trust themselves to make the decisions that would be right for their child and family. The other parents did not attempt to 'leap in' and tell Maggie or Rob what to do, neither did they specifically 'leap ahead'. They occupied a middle ground by simply 'being-there' and having a shared understanding of the world of children's cancer that they had all been thrown into. Tom and Martin were in a slightly different position and found themselves engaging with other parents of children with cancer who offered them reassurance and confidence that they were making the right decisions. There was more of a sense of 'leaping-ahead' here through sharing stories and empowering Tom and Martin that they were advocating for their child and should have confidence to continue to do this. Tom had experienced a relative attempting to 'leap in' and it was clear that Tom reacted strongly against this as he seemed to feel that this was an assault on his role as an advocate for Noah. This had the potential to undermine his confidence in his identity as a parent and so this informational support had, as the literature review articulated, crossed the fine line into interference. Saira's story showed a slightly different perspective and by seeking information from specialist experts she was able to have the confidence to assert control in the decision-making about Aria's treatment.

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Whilst informational support played a prominent role in the literature review – more than any other dimension, emotional support was present in the literature review but was less tangible in terms of its impact, or influence, on decision-making. For the parents in this study, the presence or absence of emotional support was felt to be really important. This shone through as we talked about the ecomaps, and as we delved deeper into decision-making, emotional support was threaded through all stories, and across the whole narrative around shaping confidence. Understanding of this was very much illuminated by Ricoeur's (1990 / 1992) concept of 'solicitude'. Heidegger's (1927 / 1962) version of 'solicitude' ('leaping-in' and 'leaping-ahead') focused on how others' care for us may lead us to make inauthentic or authentic decisions about our existence. Ricoeur placed a greater emphasis on mutual relationships. He acknowledged that suffering can impact on our capacity to act but through 'solicitude', in which friendship offers compassion and the sharing of vulnerability, self-esteem can be restored. The literature review acknowledged Papadatou, Yfantopoulos and Kosmidis's (1996:229) study that framed emotional support as "being present" but it was not explicit from their study that this presence led to mothers feeling supported with decision-making. However, considering this from a Ricoeurian perspective in this study demonstrates that emotional support offered as sympathy, compassion and being present may be a key element of parents regaining confidence to make decisions. Where this emotional support and 'solicitude' was not present, some parents (particularly Kerry and Saira) were left to feel that they were in solitude. This was particularly the case for Kerry who felt that not only was emotional support absent, but that others were emotionally unsupportive towards her. This led to her feeling that she was being judged and her confidence was undermined, and whilst this echoes findings from the literature, this study gives a greater understanding by considering this within the context of confidence.

The final dimension of decision-making support identified in the literature review was instrumental support. This was identified as a type of support by several parents in this study (Rob talked about his father offering financial support, Martin talked about friends helping with childcare), but it was only for Maggie that this instrumental support impacted on decision-making. This was in the context of her Mum offering to care for Flora whilst Maggie, Simon and Rosie moved to the Bone Marrow Transplant unit location. It was evident in this situation that this offer of support, and Maggie's trust in her Mum, equipped Maggie with confidence that this was a good decision to make.

The second theme of the literature review – expectations of decision-making support – cast a more ontological perspective on decision-making support in comparison to the first theme. Here the findings of the literature review can be seen to be more aligned to the findings of this

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study. This second theme was less prominent than the first theme and there was a lack of depth. However, it was identified here that parents felt strongly that their role was to be an advocate for their child (O'Neil, 1996; Papadatou, Yfantopoulos and Kosmidis, 1996; Huang, Mu and Chiou, 2008; Kelly and Ganong, 2011), but that they could lack confidence to fulfil this role (Stewart, Pyke-Grimm and Kelly, 2012) and therefore sometimes turned to others. This notion of having confidence to be an advocate for their child was at the heart of the parents' stories in this study and a pathway was forged where it was illuminated that 'significant others' could shape this confidence.

This pathway twisted and turned and started with interpretations about how 'significant others' may shape parents' confidence to maintain and renew their identity. As parents moved from being 'parents' to 'parents of children with cancer' they needed to renew their identity, and others could help them with this transition, but they also needed to maintain who they were. Ricoeur's philosophy around the sameness-in-difference of identity illuminated the importance of this. Accompanying the change from being a 'parent' to a 'parent of a child with cancer' was the constancy of their need to believe that they were being a 'good parent'. This concept of wanting to be a 'good parent' was identified in the literature review (Woodgate and Yanofsky, 2010), and Act 3 Scene 2 identified literature beyond the integrative review that similarly focused on the importance of being a good parent and decision-maker (Hinds et al., 2009; Darbyshire and Oerther, 2020; Weaver et al., 2020). It seemed important for the parents in this study, and the parents represented in the literature, that parents needed to maintain this role as decision-maker and advocate, and that if others attempted to take over this role parents may perceive this as interference which may undermine their confidence. 'Significant others' could therefore support parents by building parents' confidence to continue to identify as an advocate for their child.

The pathway through the woods then turned a corner and explored how 'significant others' may shape parents' confidence to assert and to release control. This notion of control was not present in the literature included in the review. Yet it was really significant to the parents in this study and links closely to the discussion regarding decisions that parents faced. There were decisions where parents felt that they needed to assert control, but other decisions – relating to medical treatment – where parents felt that they must release control and let health care professionals 'leap in' and make those decisions. 'Significant others' could do little to support parents when they needed to release control other than acknowledge that this was happening. They could, though, support parents when parents needed to assert control about other decisions (including for example decisions around shielding). Here 'significant others' could

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‘leap ahead’ by respecting this control that parents needed to take, thus empowering them to confidently make decisions.

The final part of the pathway arrived at the clearing where an exploration was developed around how ‘significant others’ may shape parents’ confidence to trust and challenge themselves and others. Here it was shown that to support parents to ultimately trust themselves, others must navigate between ‘leaping-in’ and ‘leaping-ahead’. Becoming attuned to this Heideggerian concept of ‘solicitude’ was seen to be challenging for others to do. Alongside the discussion of Heideggerian ‘solicitude’ was an exploration of Ricoeurian ‘solicitude’. By ‘being-with’ the parent and acknowledging the incredibly difficult time that each parent was experiencing, ‘significant others’ were able to offer compassion and then seemed to become more attuned to whether parents wanted them to ‘leap in’ or ‘leap ahead’. The literature review concluded by acknowledging that there was a fine line between support and interference. It is difficult for ‘significant others’ to know where that line is and what is needed by parents. Looking at parents’ stories through a philosophical lens has provided an interpretation whereby offering ‘solicitude’ and being prepared to ‘leap ahead’, rather than blindly ‘leaping-in’, may be the best way for ‘significant others’ to offer support, and allow parents to find their authentic way of navigating decision-making on behalf of their child. ‘Solicitude’ – both from a Heideggerian and Ricoeurian perspective – facilitates ‘significant others’ to shape parents’ confidence to be an advocate for their child.

Travelling onwards

In Act 1 Scene 2, the soundtrack posed the musical question “So What?” Since then, having travelled through the woods and now looking to how the journey should continue, it is important to return to this question and consider how the findings of this study may guide support of parents as they navigate the challenges of decision-making in the future. Whilst it is acknowledged that the pathway through the woods was one interpretation of just six parents’ stories, it nevertheless raises significant implications for a future way of being and thinking. This next section will therefore explore these implications through the same lenses as I explored my pre-understandings in Act 1 Scene 1.

Before looking through these kaleidoscopic lenses, it is important to rearticulate the purpose of this study. The aim of this study was stated in the Overture: “To gain understanding of what it means for parents to be supported by ‘significant others’ when they are faced with making decisions about their child’s cancer care; to promote conversations with health care professionals, and with the general public, regarding how parents’ experiences of decision-making may be enhanced”.

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Here I also pondered whether this study could lead to changes in practice and help parents of children with cancer. I do believe that this new understanding could lead to meaningful change, but I also acknowledge that the purpose of this study was not to provide a generalisable answer or solution, and therefore the implications for health care professionals, and for us all as ‘significant others’, will reflect this position. As Sloan (2002:120) proposed, hermeneutic phenomenology poses “unanswerable questions but that nonetheless deserve thoughtful attention”. On the basis that a hermeneutic phenomenological study cannot provide generalisable solutions, prescriptive interventions should not be mandated, and the impact of change may therefore be difficult to measure. Yet this does not mean that impactful change is not possible. Listening to people’s stories and travelling to the heart of interpretations about these stories has the potential to provoke powerful conversations and lead to meaningful changes in individual practice and approaches to life at an ontological level.

Implications for health care professionals

Health care professionals have a responsibility to listen to the stories of children and families’ experiences – for example, the Nursing and Midwifery Council Code (2018:7) states that nurses must “listen to people”. The more that health care professionals can understand these experiences, the better placed they are to offer support. The most important implication for health care professionals from this study is to invite families to tell their stories. Koch (1998) identifies some of the benefits of health care professionals listening to stories which includes the therapeutic benefits of people being able to tell their stories, showing a willingness to listen shows that their unique experiences are valued. Several of the parents who I spoke to told me that it had really helped them to be able to talk about their experiences with me: Kerry said that she had enjoyed talking to me because I was “*specifically asking [her] to talk about the stuff that no-one wants to listen to*” and Martin explained: “*It’s actually been quite helpful for me to play back the events in a factual storytelling way. I’m still processing so this has actually been quite supportive*” and it seemed clear that during the interview itself he was beginning to process the situation in a more reflective way. Being able to take the time to listen to a parent’s full story may really shape the relationships and help health care professionals to become attuned to their needs such as how they are feeling in terms of confidence as articulated in this study. Understanding parents’ stories will help health care professionals to learn about who parents are as individuals and respect their unique identity.

Taking time to create an ecomap during each interview was a helpful way to understand the context of the parents’ stories. Whilst ecomaps are used in some areas of health care practice, I have not previously encountered their use in the children’s cancer setting. The second implication for health care professionals is therefore a consideration of creating ecomaps with

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families when their child is diagnosed with cancer. Understanding the support that a family has outside of the hospital world could really help health care professionals to signpost to the family's existing support network and consider what additional support they may need beyond this. It is also helpful for health care professionals to acknowledge that they may play a role as a 'significant other' for some families – particularly in situations where the family may be far from home or isolated from their usual network.

The complexity of decision-making became apparent from the parents' stories. In terms of the major treatment decisions, it seems that parents may feel that these are not their decisions to make. This is a challenging issue to consider as a health care professional. On one hand there is a desire to promote autonomy, yet on the other there is a duty to promote the child's best interests. The conflict between family-centred and child-centred care is clear and further research is certainly warranted in relation to this. Arguably, health care professionals should be more explicit about this challenge in their early conversations with families and explain that there are some decisions that will be for the parents to make, but others that will be led by the medical team. Health care professionals should acknowledge that parents are, at least temporarily, releasing control of decision-making to them, and that this may feel very difficult for a parent. It should also be recognised that the decisions that parents face when their child has cancer extend far beyond these treatment decisions. A cancer diagnosis impacts on the whole family's life and parents therefore face decisions in all aspects of life that will impact on all members of the family, not just the child with cancer. Sensitivity to this is important, and recognition that if a family has released control around treatment decision-making, they may need further support to gain confidence in re-asserting control around other types of decision-making.

The stories that have been shared in this study have illuminated that parents may encounter a loss of confidence in themselves as parents following their child's cancer diagnosis. Parents may feel very alone at this time. Health care professionals may be able to support parents at this time by acknowledging the existing social networks that parents have and signposting to these people, but also considering if the parents may benefit from connecting with other parents of children with cancer (through in-person contact or virtual contact). Whilst health care professionals may inevitably have to 'leap in' and take the lead on treatment decision-making, it should be acknowledged that this may further impact on parents' lack of confidence. Where possible therefore, health care professionals should try to 'leap ahead' and empower parents to make decisions.

Aldiss et al. (2023) (on behalf of the Children's Cancer Priority Setting Partnership Steering Group) recently published the top ten research priorities for children's cancer, which were

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agreed in partnership with health care professionals, parents, and children with cancer. One of these priorities focuses on informed decision-making, so this study both adds to the body of knowledge around this and also reinforces the need for further research in this area. Most of the other priorities focus on medical research (for example relating to diagnosis and treatment), yet there are a number that relate to the psychosocial impact of cancer on children and families. Much of the focus of children's cancer research to date (or indeed research with children who have other serious illnesses) is within the hospital setting and considers how medical and psychosocial care may be improved within the hospital environment. This is clearly important and is likely to yield specific changes to health care professional practice. However, it is also important to explore the impact on life outside of the hospital and this study has been able to take this outward facing perspective and consider wider influences on parents' experiences. As discussed, this does have implications for health care professionals, but it also critically has important implications for the general public.

Implications for 'significant others'

In September 2023 I wrote a note in my reflective diary:

"As we go through our own lives, and we live our own stories, we don't always know what part we are playing in other people's stories. We don't know who may be seeing us as their 'significant other', or how we may be influencing their pathway. We know that we are the characters in our own story, and we know the other characters in our story, but we don't always know when we may be the 'off-stage' characters for other people."

All of us have people that are important to us ('significant others') and we are important to others. It is highly likely that there will be times in our lives when we will be a 'significant other' to somebody who is suffering adversity in some way, and possible that we may need to support people facing challenging decisions. We can never predict what form that adversity may take or if we will ever be a 'significant other' to a parent whose child has cancer. Yet, as discussed in Act 3 Scene 1, the findings of this study may be transferrable to parents suffering adversity other than their child having cancer, therefore it is important to disseminate this work to the general public who may support parents as their 'significant others'.

As is the case for health care professionals, it is important for 'significant others' to acknowledge and listen to the stories of parents who are going through such challenging times. It is crucial to understand that everybody's story is unique and that there is no 'right' way to be, or 'right' thing to say. 'Significant others' can support parents by becoming attuned to their unique story and individual needs (further research around the challenges of this attunement

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would be of value to this topic area). It is, though, helpful to understand that during a period of adversity parents may lose confidence in themselves. When this happens, 'significant others' may play an important role in shaping parents' confidence.

The findings of this study highlighted that 'significant others' may shape parents' confidence to maintain and renew their identity. Established friends or family members may be able to play a valuable role in helping parents to maintain their identity as they are likely to have a good understanding of the parents' core character. However, it is also important to acknowledge that something of the parents' identity may have changed due to the cancer diagnosis, and potentially facilitating links with other parents who are experiencing, or have experienced, a similar situation may help parents to renew their identity. Parents may need reassurance that they can identify as being a 'good parent' and that they can have the confidence to advocate appropriately for their child.

'Significant others' may also shape parents' confidence to assert and to release control. When parents feel that they need to release control and let health care professionals take over decision-making, there is little that 'significant others' can do other than acknowledge that this is happening and understand that this is difficult. They can though, support parents to re-assert control and respect parents' need to do this.

Above all, 'significant others' can shape parents' confidence to trust and to challenge, and in particular shape parents' confidence to trust themselves as parents. On the basis of the conversations that I had with parents, and the philosophies through which I interpreted these, I propose that 'significant others' can help to shape confidence through 'being-with' parents during difficult times, offering compassion, and being attuned to whether parents need people around them to 'leap in' and directly influence parents' decisions, or 'leap ahead' by empowering parents to make the decisions for themselves.

Implications for me

Having outlined the implications for health care professionals and for the general public, it is now important to consider my next steps. In order for the conversation around this topic to be engaged with and these implications be known, it will be important to effectively disseminate the findings of this study. In terms of disseminating these research findings to health care professionals, I will write academic papers for publication, present at conferences, and arrange to present at individual hospital study days. I also plan to arrange public engagement events in order to disseminate the findings to the general public, and I have been asked to write a summary of the study for the CCLG Contact magazine.

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Inspired by this study, I plan to take forward some further research that is justified by the findings of this study. Firstly, a project around the experiences of being a 'significant other' to a parent of a child with cancer with a focus on what it means from a 'significant other's' perspective to become attuned to the parents' support needs. Secondly, further research around the agency of decision-making is required in the context of treatment decisions to explore health care professionals' perspectives as well as parents', and consider how a better understanding of this may shape policy, and enhance practice and co-operative decision making.

As I consider my next steps in terms of dissemination and future research, it is also important to acknowledge my pre-understandings once again – as acknowledged in Act 1 Scene 1; working out these pre-understandings should be "the first, last and constant task" (Heidegger 1927 / 1962:153). I acknowledge that I embark on steps beyond the woods as a different person from who I was at the start of this journey. This has been a deeply immersive study and my absorption in the stories of the six parents, engaging with the philosophical ideas of Heidegger and Ricoeur, and connectedness with the arts has felt quite transformational. An entry in my reflective diary from August 2023 is included in [Appendix 15](#) to give some insight into the transformation that I have experienced. In Act 1 Scene 1, I wrote that the interviews that I was undertaking were changing my response as a person to making decisions in the face of adversity. Since then, I have changed my practice as a nurse educator and allowed this study to inform my teaching. Perhaps most importantly though, I have found myself changing as a 'significant other' to friends and family members, allowing my philosophical understanding of 'solicitude' to shape the way that I respond when they need my support by striving to be attuned to their needs.

Reflections on the journey

Reflecting on my journey through this study, it is important to acknowledge that I have encountered, and learnt from, many challenges. This final section of Act 4 will therefore discuss these challenges along the journey that has, at times, been 'rough and steep' as predicted when I set out in Act 1 Scene 3. Yet every challenge has helped me to learn and given me greater understanding about hermeneutic phenomenology and will guide me in future research.

Chronologically, the first challenge that I encountered was related to recruitment. Ethics approvals were all secured in 2021 and at this stage the world was still immersed in the COVID-19 pandemic, which was placing significant pressure on NHS services. My original recruitment strategy whereby nurses in practice would distribute recruitment packs to parents was not

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effective and I only recruited two parents via this method. I therefore changed my strategy to recruit using social media; this was more effective, and I quickly recruited another four parents at which point I was satisfied that I had enough participants to explore the topic in considerable depth. In future studies I would certainly consider recruiting via social media as a strategy. I acknowledge that there were voices of parents that I did not hear, for example from single parents (all of the parents I spoke to were part of a couple). I was very pleased though that I recruited a balance of mothers and fathers as often in psycho-oncology research the voice of fathers is under-represented (Robertson et al., 2019).

The second challenge was also created by the COVID-19 pandemic and related to the move to online interviews. I was very apprehensive about this as I worried that the parents might feel unsupported if they were alone at home rather than able to access support from professionals in the hospital setting. I was also concerned that there would be problems with technology and that parents may not want to participate in online interviews. I responded to my own anxieties about technology by rehearsing the interview with peers, and I practised constructing the adapted ecomap many times. There were no technological problems during any of the interviews and the parents seemed to find the interview process cathartic rather than upsetting (as discussed above). There may have been parents who chose not to participate due to the online medium, and the nature of the interviews may have felt different in person with additional body language cues. However, it is also possible that parents felt more comfortable to talk openly from their own home and that they were able to spend longer talking to me about their experiences as they had no concerns about managing childcare in the hospital, a perspective shared by Oliffe et al. (2021). The major benefit of moving to online interviews was that it was much easier to connect with people from a wider geographical area. I would certainly complete interviews online again in future studies if appropriate for the study topic. The disadvantage of online interviews perhaps only related to the emotional impact on me which leads to the next point of reflection.

Undertaking this study has, as I have acknowledged, been deeply transformational. It was a real privilege to talk to the parents, and engage with philosophy and the arts to further my understanding about a topic that I feel so passionate about. Yet this has also come with challenges. I found myself immersed in the conversations that I had with parents, but I did find that doing these online, from my own home, was emotionally challenging. I found that I would sit with their stories and that it was difficult to stop thinking about them. If I were to do online interviews again, I would try to be in a different environment so that I would be able to have some distance between the participant stories and my own life. As I moved to the transcription process and then on to crafting stories and writing my interpretations, I found this increasingly

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challenging – the more that I reflected on the parents' stories, the more I reflected on my own experiences. I was deeply immersed in the hermeneutic circle, and my understanding was developing significantly, but this did come at some emotional cost.

The final challenge relates to the issue of rigour that was discussed in Act 1 Scene 3. It was acknowledged in this scene that hermeneutic phenomenology does not seek to generalise about experiences or seek to present prescriptive answers or solutions – the findings of hermeneutic phenomenology are always contextual and provisional. Yet I acknowledge that I work in a professional and academic inter-disciplinary world where generalisability, interventions and impact are research priorities (Cruz Rivera et al., 2017). As I move back into this world, with the aim of disseminating the findings of this study, I recognise that persuading others of the importance of this type of research may be an ongoing challenge. Whilst the impact of this study may not be 'measurable' *per se*, I do believe that this is potentially an extremely impactful study and so targeted, wide dissemination is crucial. Returning to de Witt and Ploeg's (2006) criteria for rigour in a hermeneutic phenomenological study, the criteria of concreteness (where examples can situate the reader in the context of the phenomenon and link to their own experiences), resonance (the effect on the reader as they read the study), and actualisation (being open to future interpretations) are significant here. These all relate to the need to evoke the phenomenological nod (van Manen, 1990; Dibley et al., 2020). During the course of this study, I have presented aspects of the research to a number of different fora (see [Appendix 16](#)) which has enabled me to assess whether the findings do evoke the phenomenological nod. I have received feedback from these events such as:

- *"When I was a child, my sister had cancer, and everything you have just said makes so much sense."* (June 2023)
- *"Using paintings really helped me to see this in a different way."* (November 2023)
- *"When you talk about this, I feel like you're in my head."* (November 2023)
- *"I just wanted to say thank you for such a wonderful, powerful presentation – it was so moving, and thought-provoking. The music and art were a perfect end, really enhancing each parent's voice. Your poem was a powerful introduction to what must be one of a parent's worst nightmares."* (January 2024)
- *"Incredibly moving presentation – beautifully delivered, poignant and respectful."* (January 2024)
- *"As a mother of a child who had cancer, I just need to say that you've absolutely captured what it was like – thank you."* (January 2024)

This has all really encouraged me, and I do believe that my study achieves de Witt and Ploeg's (2006) criteria and that it is starting to generate conversations about the topic. In Act 1 Scene

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3, I justified the appropriateness of using hermeneutic phenomenology for this topic. Having reached the end of the journey, I am confident that using hermeneutic phenomenology, and thus adopting creative ways of presenting my interpretations, has allowed me to deeply understand what it means for parents to be supported by 'significant others' with making decisions when their child has cancer.

The Curtain Falls

This final act has moved out of the woods, beyond the clearing. Looking back to the woods has consolidated understanding from the parents' stories and the literature. This has allowed a view at what lies ahead by exploring how the understanding of this topic may shape health care professionals' future practice, how 'significant others' may be able to respond to people they know experiencing adversity such as this, and how I will take forward this new understanding. Finally, I have reflected on the journey and considered the challenges that I have encountered along the way. As this study draws to a close, the Finale will summarise the journey.

End of Act Four

Finale

*Into the woods you go again,
You have to every now and then.
Into the woods, no telling when,
Be ready for the journey.*

(Sondheim and Lapine, 1987:137)



Soundtrack: Blackbird, Hiromi Uehara, 2019

The opening song on the soundtrack of this thesis was The Beatles' 'Blackbird'. Here we hear an arrangement of the same song by the jazz pianist, Hiromi. We have moved around the hermeneutic circle and end almost as we started, yet, like Hiromi's arrangement, we are transformed. The simplicity of the original tune is still present but with an added complexity, and like in "American Tune" heard in Act 2 Scene 3, we hear references to Bach's music – this time "Jesu Joy of Man's Desiring" is subtly inserted. The style of jazz performance links to Act 1 Scene 2 (the scene about the philosophers) and provides a metaphor of how philosophers have changed the way that we hear the tune.

We have journeyed through the woods, and the Blackbird has learnt to fly...

Scenery: Birds, Franz Marc, 1914

From the solitary bird sitting on a branch with no colour, that we saw in the Overture, we now see a group of birds. No longer monochromatic, we now see them in many colours, the kaleidoscopic effect of looking at an image through different lenses has transformed their image.

And, as we hear in the soundtrack, we see here also that the birds have learnt to fly.

This study set out to understand what it means for parents to be supported by their ‘significant others’ when faced with making decisions about their child’s cancer, and has explored the phenomenon of “*shaping confidence to advocate for my child*”, as my interpretation of the meaning of this support. Opening with the Overture, the stage was set and explanation given around the iterative nature of this study’s hermeneutic phenomenological approach. The Overture also laid out the overarching metaphor of the thesis structure – a journey “into the woods”. Context was then provided to give some insight into children’s cancer services in the UK and an acknowledgement of the stress that parents may feel around decision-making (thus indicating why it is important to understand parents’ experiences of being supported with this). The call to go “into the woods” was established in Act 1 Scene 1, where I laid out my pre-understandings through different lenses of my life. This helped to establish what had drawn me into the hermeneutic circle, and how my own life experiences may shape my interpretations. Scene 2 shared some context about Martin Heidegger and Paul Ricoeur whose work underpins this study, and understanding something of their lives and works demonstrated why their philosophical ideas would be significant for my study. A philosophically focused methodological explanation of hermeneutic phenomenology was provided in Scene 3 with a justification of its appropriateness for this study, before proceeding to provide a detailed account of how the research journey was navigated, with methods framed by quality and ethical considerations. The final scene of Act 1 (Scene 4) explored other narratives, including a formal integrative review and a discussion of narratives beyond the usual academic discourse.

Act 2 was placed “at the edge of the woods” which aimed to set the context for the six parents of children with cancer who participated in this research. Interwoven with Heideggerian concepts, each scene took us a little further into each parent’s worlds. Scene 1 introduced the six parents and told a brief account about the story of their child being diagnosed with cancer. An explanation of Heidegger’s concepts of ‘*Dasein*’ and ‘temporality’ demonstrated that these brief, ontic, accounts would do little to further understanding about who the parents truly were or how they experienced life but that deeper ontological understanding would be needed. Scene 2 therefore provided further context about the ‘significant others’ in each parent’s world. The concepts of ‘being-with’ and ‘authenticity / inauthenticity’ were discussed and added to understanding that other people in our social world (or the ‘They’) influence who we are as individuals and the decisions that we make. Finally, Scene 3, explored the decisions that parents had faced alongside Heidegger’s concept of ‘thrownness’. The complexity of decision-making became really evident here and a professional conflict between parental autonomy and child beneficence was seen around the agency in treatment decision-making.

Act 3 travelled deep into the heart of the woods. The crafted poem in Scene 1 showed how parents experienced a loss of confidence in themselves as parents and decision-makers at the time of their child's diagnosis. This was an incredibly dark time in their lives, and the metaphor of being in the thicket of the woods felt really aligned to the parent's phrases of feeling "*lost at sea*" and "*dropped in the deep end*". Ricoeur's philosophical concepts started to be introduced in Scene 2 and, combined with Heideggerian philosophy, helped to forge a pathway through the woods. The pathway from the thicket to the clearing started with an exploration of how 'significant others' may shape parents' confidence to maintain and renew their identity as advocate for their child. Building on Heidegger's concept of '*Dasein*', Ricoeur's concept of 'sameness-in-difference of identity' illuminated that parents were moving from being a 'parent' to a 'parent of a child with cancer', and that whilst life was significantly different, they needed to maintain their sense of being an advocate for their child. Parents' 'significant others' could shape their confidence to maintain and renew this identity. The pathway twisted and turned towards Scene 3 where it was seen that 'significant others' may shape parents' confidence to assert and release control. Heidegger's concept of 'thrownness' was aligned with Ricoeur's concepts of the 'involuntary and voluntary'. Understanding was gained about this significant conflict around agency in decision-making and the parents' need to be acknowledged that they had to, at times, allow health care professionals to 'leap in' to make decisions about their child, but then at other times 'significant others' could facilitate parents to reassert control by respecting the parents' rules and boundaries. The final turn on the pathway took us to the heart of the phenomenon where it was identified that parents needed confidence to trust and challenge other people, but most importantly they needed to have confidence to trust themselves as parents and advocates for their child. Here, the key philosophical concept of 'solicitude' brought us to the clearing. It was seen that 'significant others' could shape parents' confidence by becoming attuned to whether parents needed them to 'leap in' or 'leap ahead' (thereby offering 'solicitude' from a Heideggerian perspective). However, in order to become attuned, they needed to offer 'solicitude' from a Ricoeurian perspective by 'being-with' the parent and offering compassion. This could then open up a reciprocal relationship whereby parents could share their vulnerability and allowed 'significant others' to become more attuned to the parents' needs, and thus could shape parents' confidence that they could advocate and make decisions that were best for their child.

Finally Act 4 moved out of the woods. A view back to the woods was taken and new understanding articulated that had grown from engaging with the stories of these six parents along with philosophy, and existing narratives. This then precipitated a consideration of what happens beyond the woods, in the everyday world, and how this study may influence health

Finale

care professionals, the general public, and me. This final act closed with reflections on the challenges encountered during this study and how this has impacted on my learning.

Whilst this part of the journey now ends, the hermeneutic circle has no end, and the journey of understanding will always be on-going. Hermeneutic phenomenology requires an acknowledgement that a final conclusion to understanding is never possible. This thesis has presented my interpretations of the stories that I heard from the six parents who I had conversations with. I recognise that another researcher, with different pre-understandings and life experiences, may have interpreted the stories differently and found an alternative pathway through the woods. I also recognise that my understanding will continue to evolve over time and that if I had undertaken this study at a different time in my life, my interpretations may have been different. The final expression of hermeneutic phenomenological quality proposed by de Witt and Ploeg (2006) is actualisation, an acknowledgement that interpretations are never complete; and the writer and audience must always remain open to future interpretations. Caputo (1987:294) (cited by Green, Solomon and Spence, 2021) wrote: “We do not aim at a conclusion but an opening. We do not seek a closure but an opening up”. I hope that the stories of these six parents, combined with interpretations influenced by reflections from my own life, and the philosophies of Heidegger and Ricoeur, facilitates an opening of conversations around this topic. I hope that those who read or hear about this work will also find themselves in their own hermeneutic circle of understanding and that this will inform their interactions with others living through similar stories.

THE END

Curtain Call

There is no better place to start with this 'curtain call' of acknowledgements than with the six parents: Tom, Saira, Kerry, Maggie, Martin, and Tom, who took part in this study. I am so grateful that you gave up your precious time to share your experiences so generously with me. It was an absolute privilege for me to talk with you and learn about your families and all that you were going through. Talking with you was truly inspirational and I will never forget our conversations.

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Mum and Dad, I am so sad that you did not live to see me get to this point in my life. Dad, I know that you would have been so proud to see this, and Mum – you told me at my MSc graduation that I should try and get "one of those lovely hats" – I'm not sure you realized how much work it would be to try to get one! I'm so grateful that you were able to read my published literature review before you died so that you knew what this was all about.

This thesis started with a dedication to our beautiful son, Arthur, and so it seems fitting that it ends with an acknowledgement of the impact that his very short life has had on this work. As we said goodbye to you at the hospital the day after your birth, Henry said to you: "I promise that we will make you proud of us". I hope that this goes some way towards that.

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Credits

Soundtrack

The Beatles (Lennon, J. and McCartney, P.) (1968) *Blackbird*.

Binge, R. (1958) *The Watermill*.

Britten, B. (1943) *Four Sea Interludes from Peter Grimes (Opus 33a)*.

Davis, M. (1959) *So What*

Elgar, E. (originally composed by Bach, J. S.) (1921) *Fantasia & Fugue in C minor*.

Grieg, E. (1875) *Peer Gynt Suite No. 1 (Opus 46): Aase's Death*.

Lauridsen, M. (2005) *Sure On This Shining Night*.

Simon, P. (1973) *American Tune*.

Tallis, T. (c. 1570) *Spem in alium*.

Tavener, J. (2003) *Mother of God, Here I Stand*.

Traditional: arranged by Leon, C. and Scholl, A. (2001) *I am a poor wayfaring stranger*.

Vaughan Williams, R. (1939) *Five Variants of "Dives and Lazarus"*.

Uehara, H. (2019) *Blackbird*.

Victoria, T. L. (1572) *Ave Maria a 8*.

Scenery

Achenbach, O. (date unknown) *Hiker in the Swiss Alps*.

Carmichael, F. (1929) *Mirror Lake*.

Church, F. E. (1845) *Moses Viewing the Promised Land*.

Fildes, L. (1891) *The Doctor*.

Friedrich, C. D. (1818) *Wanderer above the Sea of Fog*.

Hill, S. (2022) *Blackbird*.

Kandinsky, W. (1928) *Deepened Impulse*.

Klimt, G. (1901) *Fir Forest*.

Credits

Marc, F. (1914) *Birds*.

Popova, L. (1915) *Portrait of a Philosopher*.

Turner, J. (date unknown) *Falls of the Anio, Tivoli*.

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Van Rijn, R. (1632) *The Philosopher in Meditation*.

Van Rijn, R. (1647) *Landscape With The Rest On The Flight Into Egypt*.

Appendices

List of appendices included

1. Permission from Stephen Hill (artist)
2. Ethical approval letters
3. Study Poster
4. Invitation letter
5. Participant Information Sheet
6. Privacy notice
7. Consent to share parents' details
8. Contact magazine advert
9. Social media adverts
10. Consent form to participate in study
11. Interview Guide
12. Ecomap publication (Jestico et al. 2023a)
13. Examples of reflections after interviews
14. Literature Review publication (Jestico et al. 2023b)
15. Reflections from the library: my transformation
16. List of presentations delivered during the project

Appendices

[Appendix 1: Permission from Stephen Hill \(artist\)](#)

28/12/2023, 13:54

Google@Brookes Mail - Re: Blackbird illustration

OXFORD
BROOKES
UNIVERSITY

Liz Jestico

Re: Blackbird illustration

1 message

Stephen Hill <stephenjoehill@gmail.com>

26 October 2023 at 18:11

To: Elizabeth Jestico <ejestico@brookes.ac.uk>

Good evening,

Thank you so much. Yes of course you can use my illustration.

Let me know how I can help.

All the best, Steve

On Thu, 26 Oct 2023 at 12:50, Elizabeth Jestico <ejestico@brookes.ac.uk> wrote:

Dear Stephen,

I hope that you don't mind me emailing very out of the blue.

I am a PhD student at Oxford Brookes University - my thesis is exploring what it means for parents to be supported by their social networks with making decisions when their child has cancer.

The approach that I'm using for my research allows creativity, and the stories that I've gathered from parents about their experiences are unsurprisingly very emotive, so I'm integrating art and music throughout my thesis to illuminate and evoke this emotional journey that parents live through when their child has cancer.

When I was in Guernsey over the summer (where I spend quite a lot of time as I grew up there), I came across your Blackbird illustration in the Candie gallery. It's such a perfect fit for my opening thesis chapter as the music for that chapter is the Beatles song.

Initially my thesis will just be shared with my examiners, but once I have passed the PhD, it will be made available online.

I am therefore contacting you as the rights holder to ask if you would be able to give me permission to include the illustration in the online version of my PhD thesis.

The thesis will be made available online via the Oxford Brookes University institutional repository RADAR (<https://radar.brookes.ac.uk/radar/home.do>) and the British Library online service for UK theses, EThOS (<http://ethos.bl.uk/>). These services are non-commercial and openly available to all.

I would be so grateful if you could let me know your thoughts about this, and I'm really happy to discuss this with you further or give more context about the study.

Many thanks,

Liz

Liz Jestico

Senior Lecturer in Children's Nursing

Placement Lead for Children's Nursing

Faculty of Health and Life Sciences

Oxford Brookes University

[Jack Straws Lane](#)

[Marston](#)

[Oxford](#)

[OX3 0FL](#)

[Appendix 2: Ethical approval letters](#)

2a: Approval from Oxford Brookes University Faculty of Health and Life Sciences Research Ethics Committee

Liz Jestico

Oxford Brookes University

Marston Road Campus

Jack Straws Lane

OX3 0FL

26 June 2020

Dear Liz,

Re. What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care? A phenomenological study

Thank you for submitting your response to FREC on the 17/6/20. I can confirm that you have addressed the points of clarification and amendment. I am pleased to approve the research by Chair's Action on the condition you forward gatekeeper approvals when you have them and you adhere to the Faculty COVID-19 policies and procedures for research, these will be published shortly. I wish you all the with the study.

Yours sincerely



Kellie Tune

Chair, Faculty of Health and Life Sciences Research Ethics Committee

Cc –Ruzena Zemanova

Oxford Brookes University

Faculty of Health and Life Sciences

Decision on application for ethics approval

The Departmental Research Ethics Officer (DREO) / Faculty Research Ethics Committee (FREC) has considered the application for ethics approval for the following project:

Project Title: What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care? A phenomenological study

FREC Study Number: F.03.2019.22

Name of Applicant: Liz Jestico

Please tick one box

1. The Faculty Research Ethics Committee gives ethical approval for the research project. √ ☐

Please note that the research protocol as laid down in the application and hereby approved must not be changed without the approval of the DREO / FREC

2. The Departmental Research Ethics Officer / Faculty Research Ethics Committee gives ethical approval for the research project, subject to the following: ☐

3. The Departmental Research Officer / Faculty Research Ethics Committee cannot give ethical approval for the research project. The reasons for this and the action required are as follows: ☐

Signed: ...Kellie Tune ... Approval Date: 26 June 2020.....

Designation: Departmental Research Ethics Officer

(Signed on behalf of the Faculty Research Ethics Committee)

Date when application reviewed (*office use only*): 31 March 2020.....

H&LS/FRec/E3 August 2011

2b: Approval from Clinical Research Adoptions Committee, Great Ormond Street Hospital



10/09/2020

PI: Rochelle Lowe

R&D number: 20CB26

Title: What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care? A phenomenological study

Dear Elizabeth, Sue and Rochelle,

Thank you for your application to the Clinical Research Adoptions Committee (CRAC) and to Elizabeth and Sue for attending the meeting on Tuesday 8th September 2020. We were pleased to review your application and we recognise the importance of your project, and were glad to see Sue on the Zoom call in particular giving supervisory support.

The committee have no major objections to the conduct of this project at GOSH although they suggest that the research team consider the following points carefully:

1. Whilst Liz was clear in her responses to the committee, the consensus view was that the project was rather broad in approach, and that a clearer focus would be beneficial. "Social networks" are broad (and may not be widely understood) and could encompass a number of different aspects. Too broad a question will lead to such diverse responses that the data becomes unmanageable. An in- depth literature review around decision making may help refine the project.
2. Please provide more detailed methodology regarding the data sampling, with use of a sampling framework, to ensure diversity and balance of responses.
3. Please include parents / families more actively in your research. They should be involved in questionnaire design, and in particular in results dissemination: e.g. helping writing lay summaries of your project, above and beyond formal academic publication / presentation.
4. Please revise the consent forms. For example, point 5 regarding "anonymity cannot be guaranteed" is inappropriate: anonymity should be guaranteed in order to take part in the project. Is there a specific reason why this project is different to any others in this respect?
5. Inclusion / exclusion criteria: please consider including those who do not have English as a first language, or the recruitment bias in your sampling if you apply this exclusion criteria. This exclusion could be considered unethical by the Ethics committee.
6. We recognize that some parents would find participating in the study distressing, but suggest that formal psychological support is in place if this comes up.

UCL Institute of Child Health, 30 Guilford Street
London WC1N 1EH



7. Several members of the committee were surprised that you did not feel it necessary to identify yourself as a Nurse on the patient information sheets. Whilst this may be deliberate and considered at this stage, the committee felt that it was important that families understood the people that they are approaching and we would expect and encourage clarity from the outset.
8. Please consider the effects of recruitment / project failure. If this comprises a significant portion of your PhD, be careful not to put all your eggs in one basket. A clear back-up plan is needed to ensure that the requirements of a full PhD are met.
9. Allowing for coronavirus, face to face meetings may now need to be done online via Zoom or other creative platforms.

Decision: Conditional Approval

Please respond by letter to the CRAC committee outlining the amendments made to your study, and your point by point responses to the comments above. You do not need to resubmit your application, and you should proceed with Ethics submission in parallel.

You will shortly be contacted by R&D Governance who will support you through the process of obtaining the necessary approvals before your project can begin. You must not commence your project before receiving R&D approval.

Good luck with your study!

Regards,

A handwritten signature in black ink, reading 'Owen J. Arthurs'.

Dr Owen Arthurs
Chair, Clinical Research Adoption Committee

Joint Research and Development Office
Division of Research and Innovation
UCL Institute of Child Health, 30 Guilford Street
London WC1N 1EH

Tel: 020 7905 2700
gosh.nhs.uk

2c: Approval from Health Research Authority



Mrs Elizabeth Jestico

MPhil / PhD student

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Oxford Brookes University

Jack Straw's Lane

Oxford

OX3 0FL

06 April 2021

Dear Mrs Jestico

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care? A phenomenological study
IRAS project ID:	276970
Protocol number:	F.03.2019.22
REC reference:	21/LO/0121
Sponsor	Oxford Brookes University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

Appendices

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document “[After Ethical Review – guidance for sponsors and investigators](#)”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **276970**. Please quote this on all correspondence.

Yours sincerely,
Kathryn Davies

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Ms Kellie Tune

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Oxford Brookes Faculty Ethics Approval Letter]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Oxford Brookes Faculty Ethics Decision Letter]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Oxford Brookes Research Sponsor Governance Checklist]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Letter of conditional access Oxford University Hospitals]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Letter of conditional access Great Ormond Street Hospital]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Letter of conditional access Birmingham Children's Hospital]		
Covering letter on headed paper [Covering Letter]		16 December 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Oxford Brookes University Liability Evidence]		13 November 2020
Interview schedules or topic guides for participants [EJ Interview Guide November 2020]	1.1	21 February 2021
Interview schedules or topic guides for participants [EJ Interview Guide November 2020]	1.0	22 September 2020
IRAS Application Form [IRAS_Form_12012021]		12 January 2021
Letter from sponsor [Oxford Brookes University Sponsor Letter September 2020]		23 September 2020
Letters of invitation to participant [EJ Invitation Letter November 2020]	1.1	21 February 2021
Organisation Information Document [Organisation Information Document OUH]	1.0	18 January 2021
Organisation Information Document [Organisation Information Document Birmingham]	1.0	18 January 2021
Organisation Information Document [Organisation Information Document GOSH]	1.0	18 January 2021
Other [EJ REC response]	0.1	09 March 2021
Participant consent form [EJ Consent Form November 2020]	1.1	27 February 2021
Participant information sheet (PIS) [EJ Participant Information Sheet December 2020]	1.1	27 February 2021
Participant information sheet (PIS) [EJ Privacy Notice November 2020 (to supplement PIS)]	1.1	21 February 2021
Research protocol or project proposal [EJ Research Protocol December 2020]	1.1	21 February 2021
Schedule of Events or SoECAT [EJ Schedule of Events Birmingham December 2020]	1.0	16 December 2020

Appendices

Schedule of Events or SoECAT [EJ Schedule of Events Oxford December 2020]	1.0	16 December 2020
Summary CV for Chief Investigator (CI) [Liz Jestico CV December 2020 (Chief Investigator)]		09 December 2020
Summary CV for supervisor (student research) [JA CV December 2020]		11 December 2020
Summary CV for supervisor (student research) [TF CV December 2020]		10 December 2020
Summary CV for supervisor (student research) [SS CV December 2020]		15 December 2020

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
All sites will perform the same research activities therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites as per the Organisational Information Document.	A Local Collaborator should be appointed at study sites	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to hold Letters of Access if focus groups/interviews were held in clinical areas. Letters of Access would not be expected if they were held in non-clinical/administrative buildings.

Other information to aid study set-up and delivery

<i>This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.</i>
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

MAKING DECISIONS ABOUT YOUR CHILD'S CANCER CARE?

Are you a parent of a child aged 0-11 years old who has cancer or a non-cancerous brain tumour, and living in the UK?

Have you experienced support from your extended family and friends with making these decisions?

OR

Have you not received this sort of support but think it may have helped you?

If so I would love to talk to you about your experiences for my PhD study.

Interviews will take 1-2 hours via video call.

For further information please click [HERE](#) / scan QR code:

or contact: **Liz Jestico Email: 19001672@brookes.ac.uk**

Text/Phone: 07553 773728



REC Reference: 21/LO/0121



IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee

FREC Study Reference: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee

REC Reference 21/LO/0121

**TITLE OF STUDY: What are parents' experiences of being supported by
"significant others" when faced with making decisions about their child's cancer
care?**

Hello, my name is Liz Jestico, and I am a Children's Nurse and PhD student at Oxford Brookes University. I am researching parents' experiences of being supported when they are faced with making decisions about their child's cancer care, with a particular focus on looking at the support from parents' social networks, or "significant others".

In order to research this, I would like to interview some parents of children with cancer or noncancerous brain tumours, who have faced making decisions about their child's care. I have asked the oncology research nurse / advanced nurse practitioner from your unit to pass on this invitation letter to parents who have been in this situation.

I would therefore like to invite you to take part in this study. Alongside this invitation letter you will also have been given an information sheet which provides more detailed information about the study. You can also scan the QR code on this letter which will take you to a website about the study.

There is absolutely no obligation to take part in this study. If, once you have read the information sheet, you would like to be interviewed for this study, please either contact me directly by phone or email (details below). There is also an online form within the website which you can complete if you would like to contact me. Alternatively, you can sign the consent form in this pack which will allow the nurse to pass on your contact details to me and I will then be in contact with you. We will then arrange a suitable date and time to meet for the interview.

Thank you very much for taking the time to read this letter.

Yours sincerely,

Elizabeth Jestico (PhD Student)

Email: 19001672@brookes.ac.uk

Telephone: 07553 773728





IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee

Study Reference: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee

REC Reference 21/LO/0121

Study title

What are parents' experiences of being supported by "significant others" when faced with making decisions about their child's cancer care?

Invitation paragraph

You are being invited to take part in a research study that is being undertaken by a Children's Nurse, for a PhD study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully

What is the purpose of the study?

Parents are faced with making many decisions about their child's cancer care. Previous research has explored how parents make decisions in the context of relationships with Health Care Professionals (particularly doctors) and also how their children may be involved in these decisions. Research has not yet explored how relationships with significant others / social networks (for example, other family members and friends) may (or may not) be supportive and helpful with making decisions. By gaining a better understanding of what parents believe to be supportive, it is hoped that Health Care Professionals can improve how they help parents make decisions in future.

Why have I been invited to participate?

You have been invited to participate because your child is aged 0 – 11 years old, is currently receiving care for cancer or a non-cancerous brain tumour and it is likely you will have been faced with making a range of decisions about their care. It is anticipated that up to 25 parents will be interviewed for this study. If more people volunteer than is possible to interview, the first people who have volunteered will be interviewed.

Do I have to take part?

It is up to you to decide whether or not to take part in this research study; participation is entirely voluntary. If you do decide to take part you will be given this information sheet along with a privacy notice that will explain how your data will be collected and used, and you will be asked to sign a consent form. If you decide to take part, you are free to withdraw at any time without giving a reason. If possible, any data already supplied would be withdrawn from the

study. If the data analysis has already taken place this may not be possible but in this situation the researcher would not use your direct quotes in the thesis or any publications.

What will happen to me if I take part?

If you decide to take part, you will be invited to take part in an interview. The researcher would contact you to arrange a suitable date and time to do the interview. This will most likely be an online interview (using Zoom). However if your child is being treated at Great Ormond Street Hospital, Birmingham Children's Hospital, or the John Radcliffe Hospital it may be possible to meet within the hospital where your child is receiving care if you prefer and if Covid restrictions allow this. The interview would take about an hour (no longer than two hours) and would involve the researcher asking you questions about the types of decision that you have faced in relation to your child's cancer care; the people that you believe constitute your social support network; and your experiences of how these people may have supported you with making decisions. The interview would be video-recorded if meeting online, or audio-recorded if meeting in person.

What are the possible disadvantages and risks of taking part?

The main disadvantage of taking part in this study would be the cost of your time. It is also possible that the interview could provoke negative feelings about your experience. If at any time you were to find the interview is causing distress you would have the opportunity to terminate the interview and the researcher would be able to refer you to sources of support such as the Patient Advice Liaison Service and the team of healthcare professionals who care for you at the hospital.

You could also contact a charity for support such as Kids Cancer Charity (01792 480500) or Macmillan Cancer Support (0808 239 1492).

What are the possible benefits of taking part?

It is not possible to guarantee that you would directly benefit from taking part in this study and there will be no impact on you or your child's care.

However it is hoped that by taking part in this study you would be helping us to understand how significant others / social networks may support parents with making decisions about their child's cancer care. This understanding may influence practice and improve parents' experiences in the future. You may also find it helpful to talk about your experiences and share your opinions about this topic.

Will what I say in this study be kept confidential?

We will need to use information from you for this research project. This information will include your name, contact details, interview data and information about your support system. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead (this means that we would use a different name when referring to you, and we would not use your real name) as stated in point 6 of the consent form. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your information private and confidential unless we are concerned about your safety or the safety of others, in which case we may need to break this confidentiality. If we were to identify concerns, we would try to discuss this with you first and we would share information with others, such as your clinical team, where appropriate to maintain your wellbeing and the wellbeing of your child. We may be required to share information if it is subpoenaed or under freedom of information request.

Certain direct quotations from the interview may be included in the study but these would be associated with the pseudonym and would not be accompanied by any details that would directly identify you. However, you should be aware that as this study has a small sample size you may be able to recognise your own words from the direct quotations.

The information collected will be stored securely. Online interviews will be video recorded via Zoom (using secure, institutional access) and deleted as soon as they have been transcribed. Face to face interviews will be audio recorded and these recordings will be stored on an encrypted recording device and deleted as soon as they have been transcribed. Transcripts will then be stored in Google Drive, for which the University has a security agreement. Consent forms (which would contain your name) will be stored separately from the interview data. Hard copies from in person interviews will be kept in a locked filing cabinet at Oxford Brookes University.

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity and will therefore be retained for a period of ten years after the completion of the research project.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/ and if you have any concerns you can contact Oxford Brookes University's Information Security team (info.sec@brookes.ac.uk) or the Data Protection Officer (BrookesDPO@brookes.ac.uk).

What should I do if I want to take part?

If you would like to take part in this study, please contact the researcher:

Elizabeth Jestico

Email: 19001672@brookes.ac.uk

Telephone: 07553 773728

Or complete the online form on the [study website](#).

If you prefer, you can complete the attached consent form and ask the nurse who has given you this pack to share your contact details with the researcher.

What will happen to the results of the research study?

The results of the study will be written up for a PhD thesis. The results will also be published in academic journals and presented at conferences. A summary of the completed study would be available for you to read if you would like to (you will be able to contact the researcher by email to request this and the researcher will let you know at the time of the interview, roughly

when this will be available). A copy of the thesis will be stored in the University library and will also be available electronically.

Who is organising and funding the research?

The researcher is conducting the research as a student at Oxford Brookes University within the Faculty of Health and Life Sciences.

Who has reviewed the study?

The research has been reviewed, and given a favourable opinion, by the Faculty Research Ethics Committee at Oxford Brookes University and the London-Stanmore Research Ethics Committee (NHS Research Ethics Service).

Contact for Further Information

For further information please contact Elizabeth Jestico (PhD Student):

19001672@brookes.ac.uk or Jane Appleton (Director of Studies): jvappleton@brookes.ac.uk

If you have any concerns about the way in which the study has been undertaken please contact Kellie Tune (Faculty of Health and Life Sciences Research Ethics Officer): frec@brookes.ac.uk

Thank you very much for taking the time to read this information sheet.

Privacy Notice for research participants (for non-anonymised data)

IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee

Study Reference: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee

REC Reference 21/LO/0121

Full title of Project:

What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care?

This privacy notice provides information on how Oxford Brookes University collects and uses your personal information when you take part in any of our research projects. Please refer to the participant information sheet for further details about the study and what information will be collected about you and how it will be used.

Oxford Brookes University (OBU) will usually be the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it properly and will make decisions on how your data is used and for what reasons. You can contact the University's Information Management Team on 01865 485420 or email info.sec@brookes.ac.uk.

Why do we need your data?

Data will only be used for research purposes.

The purpose of this research is to better understand parents' support networks when they are faced with making decisions about their child's cancer care in order to enhance future practice

OBU's legal basis for collecting this data is:

- You are consenting to providing it to us; and / or,
- Processing is necessary for the performance of a task in the public interest such as research

What type of data will Oxford Brookes University use?

If you consent to be part of this study, you will be interviewed by the researcher. This interview will be audio or video-recorded and transcribed (audio-recordings will be stored on an encrypted recording device, video-recordings will be stored on zoom and the recording will be deleted once the interview has been transcribed). Transcriptions will then be analysed by the researcher.

Who will OBU share your data with?

Data will be recorded via Zoom. The transcription of your interview will be stored on Google drive for which the University has a security agreement.

The researcher will share the data with the supervisory team.

It is likely that findings from your interview (and other parents' interviews) will be shared through journal publications and at conferences. Certain quotations that arise during the interview may be included verbatim in the study, but these would be associated with a pseudonym rather than your name and would not be accompanied by any details that would directly identify you. However, you should be aware that as this study has a small sample size this may have implications for the identification of participants.

Will OBU transfer my data outside of the UK?

No

What rights do I have regarding my data that OBU holds?

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- You have the right to be informed about what data will be collected and how this will be used
- You have the right of access to your data
- You have the right to correct data if it is wrong
- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold about you
- You have the right to data portability
- You have the right to object to the university using your data
- You have rights in relation to using your data automated decision making and profiling.

Where did OBU source my data from?

You may have been approached for this research study because you have been identified by the hospital (where your child receives some of their care) as a parent who may wish to participate in the study. The hospital will only have shared your data directly with us if you gave them consent to do that. Otherwise, we will not have any information about you unless you choose to contact the researcher and share your contact information with us. You may also have seen a poster in the hospital or post on social media about this study and decide to contact the researcher and share your contact information.

If you do contact us, you will then be asked to sign a consent form before you share any information about your experience during the interview.

Are there any consequences of not providing the requested data?

There are no legal consequences of not providing data for this research. It is purely voluntary.

Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation."

How long will OBU keep your data?

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity and would therefore be retained for a period of ten years after the completion of the research project.

Who can I contact if I have concerns?

You can contact the Information Management team.

Postal Address: Information Management Team, IT Services, Room 2.12, Gibbs Building, Headington Campus, Gipsy Lane, Oxford, OX3 0BP

Email: info.sec@brookes.ac.uk

Tel: 01865 485420 in UK
+44 1865 485420 outside the UK.

CONSENT TO SHARE CONTACT DETAILS

IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee; REC

Reference 21/LO/0121

Full title of Project:

What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care?

Name, position and contact details of Researcher:

Elizabeth Jestico, MPhil / PhD student,

Email: 19001672@brookes.ac.uk, Telephone: 07553 773728

		Please initial box	
1.	I confirm that I give consent for the nurse who has given me this information pack to pass on my contact details to the researcher (Elizabeth Jestico)		
		Yes	No
2.	I consent for my email address to be shared with the researcher (Elizabeth Jestico)		
3.	I consent for my telephone number to be shared with the researcher (Elizabeth Jestico)		

Name of Participant

Date

Signature

Name of Nurse issuing information

Date

Signature

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[Appendix 8: Contact magazine advert](#)

Children's Cancer and Leukaemia Group, Contact, Summer 2022, Issue 95 (p4)

PARENTS OF CHILDREN WITH CANCER NEEDED FOR RESEARCH

Liz Jestico, Senior Lecturer in Children's Nursing at Oxford Brookes University, is exploring parents' experiences of being supported by their network of family and friends when faced with making decisions about their child's cancer care. If you are a parent of a child aged 0-11 who has cancer or a non-cancerous brain tumour and living in the UK, and would like to speak to Liz about your experiences, please email 19001672@brookes.ac.uk or text/phone 07553 773728.

Appendix 9: Social media adverts

TWITTER POST

I'm looking to interview parents of children with cancer for my PhD research, so if you meet the criteria below and would be willing to take part in an online interview, please click here <https://bit.ly/3r3wNYX> for more info or contact me via the details below. RTs would be really appreciated.



FACEBOOK POST (for CCLG closed Facebook group)

Hello, I'm hoping to interview parents of children with cancer for my PhD research. I'm interested in how your friends / family may support you with making decisions about your child's care (including medical decisions like treatment plans, choice of central line; and also social decisions like shielding during the pandemic, nursery / school attendance etc).

If you meet the criteria below and would be willing to take part in an online interview, please click here <https://bit.ly/3r3wNYX> for more info, or contact me by email (19001672@brookes.ac.uk) or text / phone (07553 773728)

Thank you so much!

Liz



CONSENT FORM

IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee; REC

Reference 21/LO/0121

Full title of Project:

What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care?

Name, position and contact details of Researcher:

Elizabeth Jestico, MPhil / PhD student,

Email: 19001672@brookes.ac.uk, Telephone: 07553 773728

		Please initial box	
1.	I confirm that I have read and understand the information sheet (dated 27 th February 2021) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.		
3.	I understand that the interview will be audio-recorded if in person, or video-recorded if online.		
4.	I agree to take part in the above study.		
5.	I understand that confidentiality can only be maintained within the limits of the law and that if concerns are raised within the interview confidentiality may need to be broken.		
6.	I understand that my personal data will be kept until the end of the PhD study and that research data generated by the study will be kept for a period of ten years.		
		Yes	No
7.	I agree to the use of pseudonymised quotes in publications.		

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

IRAS Project ID: 276970

Faculty of Health and Life Sciences Research Ethics Committee

Study Reference: F.03.2019.22

NHS REC Name: London – Stanmore Research Ethics Committee

REC Reference 21/LO/0121

TITLE OF STUDY: What are parents' experiences of being supported by significant others when faced with making decisions about their child's cancer care?

INTERVIEW GUIDE

DATE

TIME

PARTICIPANT NUMBER / PSEUDONYM

Start by thanking participant for taking part in the study and introduce myself.

CHECK UNDERSTANDING OF PARTICIPANT INFORMATION SHEET:

You will have been given a Participant Information Sheet.

To reiterate this, this study is all about exploring what your experiences have been of being supported by people in your social network / significant others, when you've had to make decisions about your child's cancer care. We're going to talk about the types of decisions that you've had to make so far, who you consider to be part of your social network, and then how these people have supported, or not supported, your decision-making, and what that's felt like for you.

Do you have any questions about this or anything else that you've read in the Participant Information Sheet?

Before we can start the interview you will need to give consent to take part in the study so we're going to do that now

- COMPLETE CONSENT FORM (if on zoom read each question out and share screen, document on hard copy).

If on zoom, stop recording once consent complete, and start new recording.

Part One:

Would you like to start off by telling me a little bit about the story of your child's cancer journey so far? When was your child diagnosed and how old were they?

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In order to explore your experiences of decision-making we're going to make a list of the various decisions that you may have been faced with during the course of your child's cancer treatment so far *(Use whiteboard on zoom / Write these down on paper as will use as prompt later)*. *If not sure where to start prompt with decisions such as: consent to treatment, consent to research, insertion of central line (were you offered a choice of lines?), place of care, fertility preservation, symptom support, nutritional support (NG tube / TPN at any stage), attendance at school.*

The next step is to create something called an ecomap - this a diagram that we can draw together to highlight all of the various social networks that may be around you.

SHOW EXAMPLE OF ECOMAP (share screen with electronic version prepared on another tab).

The ecomap has you and your immediate family in the middle of the diagram and then everybody that you consider to be part of your network in circles around you. This may include your extended family, friends, members of clubs / groups that you are part of, other parents from your child's nursery / school, virtual support groups. We can also use the ecomap to indicate how supportive these people are to you – it may be that they are very supportive, or it may be that they are unsupportive – it may also be that you provide support to them as well as them supporting you. These different symbols (on the example ecomap) show how we can indicate this.

It would be really good if we could capture how this picture of social networks may have changed over the course of your child's treatment – so we can use different colours to do this – (ie one colour for relationships that have been there from beginning, one colour for relationships that have emerged, one colour for relationships that have diminished).

If stuck with who should be on this talk about extended family members, friends, other parents from nursery / school, other parents on ward may become a new network, virtual support groups (eg Mumsnet and then cancer specific groups, facebook etc)

Draw this on large piece of paper / whiteboard on zoom – use different stamps / strengths of line to demonstrate sources of support / sources of conflict, arrows for direction of support.

NB – need to very clear about names on this – use pseudonyms / codes rather than real names

Part Two:

This section will emerge from the ecomap and list of decisions but broadly speaking the conversation will be prompted by questions such as:

Could you talk me through your experience of making one of these decisions? How did it feel to make that decision – was it easy or difficult and how did you come to make your decision? How did you feel about being in a position where you had to make these decisions? Did you feel that you needed support with this and why? Did any people on the ecomap help you with this? Did anybody hinder your decision-making? What was it that they did that supported you or made it more difficult to make the decisions and what did this feel like for you?

Did you want others to challenge your decisions and consider other ideas? Or did you want people to support your decisions? Did you ever change your mind as a result of this and how did that make you feel?

Was this consistent with other decisions? Some people say that the decisions range in children's cancer care from "big" decisions to "small" decisions. Did you feel like this? Were

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people that you regarded as “significant others” / part of your social networks, able to support you in different ways according to the magnitude or significance of the decision?

Over time, have your past experiences led you to change your approach to seeking support with decision-making?

If you could give advice to friends or family of other parents faced with making decisions about their child’s cancer care – what would you say?

How do you think nurses, doctors, and other health care professionals could help parents manage support from social networks around decision-making and how could they help parents in general with their decision-making?

Themes to consider throughout:

Influential Relationships with others and how this impacts on feeling supported (positive and negative eg judgement of others)

Experience of Roles of “parenting” and Responsibilities of being the “decision-maker”

How do people provide support and what does it feel like to receive this support or not:

- Emotional support
- Practical support
- Information seeking – if others seek information, do they potentially filter information?
- Sharing opinions

Closing question:

Is there anything else that you would like to discuss in relation to this?

Is there anything that you expected me to ask you that I haven’t?

If the participant needs support after the interview, ensure that they can seek this from ward staff, and that they have the contact details for PALS:

OUHFT: Email: PALS@ouh.nhs.uk Telephone: 01865 221473

Birmingham W&C: Email: bwc.pals@nhs.net Telephone: 0121 333 8403 / 0121 333 8505

GOSH: Email: pals@gosh.nhs.uk Telephone: 020 7829 7862

And charity support lines:

Kids Cancer Charity (01792 480500)

Macmillan Cancer Support (0808 239 1492).

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Appendix 12: Ecomap publication (Jestico et al. 2023a)

The contents of a published article have been removed due to copyright restrictions. Jestico,E., Taylor,B., Finlay,T., & Schutz,S. The ecomap: a tool for extending understanding in hermeneutic phenomenological research. *Nurse Researcher*, doi:10.7748/nr.2023.e1890.

[Appendix 13: Examples of reflections after interviews](#)

INTERVIEW 1 (Tom): 15.12.21

This was my first interview. Before I started I was terrified and excited! I had no idea what was going to be said and was worried that I wouldn't know how to respond or prompt – what if they don't say anything?

It did start off slowly – my heart sank when I asked what decisions had been made and he said “none”. But with a bit of prompting we got some and this definitely grew as we went through the discussion.

This definitely felt like a conversation as we got settled in – it felt very informal and I was so genuinely interested to hear the stories.

Things that stand out to me at the moment:

Definitely a sense that different decisions require different support. The “medical” decisions happened too fast and it was about them standing together as a couple to make these. Often it felt that there wasn't a decision to make. This all resonated with my reading.

The social decisions were a little different – still it was their decision and they very much owned this, but they needed practical support to enable their decision (again resonates with literature).

There were definite variations – sometimes helpful to talk to other people who'd experienced this, sometimes definitely not. Felt important to acknowledge that each situation was unique so nobody knew all the answers

The stoma decision was really significant. And the lack of ability to make a decision was troubling.

What stands out the most is this sense of faith, and that having a community praying every day and thinking about you, gives you the strength (and ??? confidence???) to stand strong, and stand on your own two feet to make the decisions that are for your child.

Keeping the child at the heart of everything, and trusting that by doing that you will do the right thing and not regret anything.

A lot of trust is placed in HCPs but also an acknowledgement that whilst everything they do is for your child, they are not just HCPs and to an extent this is their job and they have a life outside. So you can't only rely on them for support – you need other people around you as well.

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Impact of Covid is interesting – adds a dimension of decision-making that wasn't there, both in terms of the types of decisions (e.g. shielding) but also the complexity – one parent rule means that it's difficult to be together and make decisions in the same place.

Didn't want lots of people getting involved – really strong sense that the decisions needed to be owned by the parents, and that their job was to advocate for their child's best interests.

Also a sense of looking forward to future decisions – about school etc, and acknowledgement that this would change the support network.

Also – for another study – it came out that being handed the responsibility of doing fundamental care was sometimes really overwhelming – particularly with only one parent allowed to be there at a time...

17/12/21: I've been thinking about this over the past couple of days and the thing that is standing out the most is this sense of other people praying and sending love, that gives him the strength and confidence to make decisions. This sense of community support isn't about individual decisions – it gives an overarching strength that transcends over all decision-making.

INTERVIEW 2 (Saira): 31.12.21

This felt more comfortable than the first interview – I consciously stopped myself from talking as much and found that I didn't need to say much – again though it did feel more like a conversation.

A lot of this REALLY resonated with my own experiences – the idea that nobody else can understand – staring into the abyss – loss of innocence. A feeling of being quite self-sufficient, and that other people's experiences can be as much a source of stress as support – because it's your own journey and this is unique. And people want to help – unspent energy – so they try to do practical things, but actually nothing can really help.

I feel like this sense of confidence and strength really stood out strongly to me again. But it was different this time – this was more a sense of confidence DESPITE the people around, rather than because of the social support. A real sense of responsibility to advocate holistically and shut out the noise of family / friends and to an extent HCPs.

Information was critical to gain the confidence and that's where the support was useful – this came from acquaintances who therefore became more significant than they would be usually – the network definitely changed over time.

The confidence to challenge... and actually this came from a friend's advice (I should have gone back to this)

Also what came across was the importance of the HCP team – almost because of COVID they replaced the usual social network – because they were the only physical contact that the family had. This manifested itself therefore more as a “normal” – 2 way / hearts and crosses – type of relationship than it might otherwise have been.

And finally the thing that stands out is the “legitimacy” of needing support, the “hierarchy” of cancer / situations, and that the chemo justified the need for support and made it easier to conceptualise that this was a bad situation. This almost led to the family having to support the network rather than the other way around, because the group needed reassurance. This actually had the negative impact of not allowing the family to validate their feelings or legitimising their position. And this affected decision-making because they felt that their groups needed protecting, this made decision-making harder and their advocacy for their child had to be done almost in defiance to those around them.

INTERVIEW 3 (Kerry): 02/05/22

Interesting – very strong Mum who at the heart of everything feels that it is her responsibility to advocate for her son.

Things that instantly come out to me are:

- She has felt really alone. Support is there but nobody else understands and can't get that this has been her life for the past 3 years – every minute of every day and every night. And it doesn't end as treatment finishes – this goes on.
- She strongly believed that her husband and other son did not go in the same circle as she and her younger son. This was their journey alone.
- Massive amount of strength and confidence to challenge – where does this come from? After digging, it comes from her family, and learning from them.
- Real concerns about being judged – so often turns away from support network rather than turning towards.
- Nobody helped with individual decisions – but the overall support made decision-making easier.
- Covid didn't affect in the same way (as well established in treatment by the time it started) – and interestingly fewer HCPs mentioned in discussion (or on ecomap.)
- She found the “big” decisions (eg treatment) were easy to make – they were factual and evidence-based. It was the “little” decisions (challenging care / social decisions)

that were hard and actually felt more stressful and bigger – the heart decisions rather than the logical decisions.

I did find aspects of this interview hard, this was the first interview since Mum died, and then she spoke about her experiences of having miscarriages which was very triggering. I also found it hard because I'm so immersed in my transfer report. Confidence shone out so brightly in this interview as well, but I need to return to the transcripts because I may have been missing things.

There was definitely something about "thrownness" here – thrown into the cancer world, but also her thrownness into the situations where she had learnt how to be assertive and challenge behaviour.

Many similar aspects to Interview 2 – but what all three have in common is this sense of "every decision I make I do for my child" and "trust your instincts as a parent".

Following supervision discussion:

It's really struck me that taking the time to listen to her story I could understand why she challenged care decisions in the same way – her redundancy / miscarriages / lack of family support – this meant that she would do anything for her son and HAD to stand strong and always speak out for him. I feel really sad that she was so "grateful" to me for listening to her and that she had felt so alone for 3 years. A lot of this is about the relationships with nurses / HCPs – what more can we do to build these relationships and find time to be there and listen – had more of that happened they wouldn't have thought of her as being "difficult" and the conflict wouldn't have been necessary. This is a "nurse sensitive outcome" – nurses can make a real difference here. Whilst it's great that my research gave her the opportunity to share her story – this shouldn't have been necessary.

Perhaps the role of the ecomap needs to go back into practice – I've found it such a good way of "opening the hermeneutic circle" and understanding people's support. If we did that in practice then we would find out so much about the families and learn who they have around them and crucially who they don't. And it would make things make a lot more sense if we could understand that about people, and understand why they may be making the decisions that they are.

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REVIEW

Journal of
Clinical Nursing WILEY

How 'significant others' may support parents with decision-making about their child's cancer care: An integrative literature review

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supported by Oxford Brookes University.

Abstract

Aim: To synthesise what is known from current international evidence about how parents are supported by significant others when they are faced with making decisions about their child's cancer care.

Background: Parents are faced with making challenging decisions when their child has cancer and may benefit from support. Whilst previous research has comprehensively explored how healthcare professionals can offer support, little attention has been given to how support may be informally provided from a parent's network of significant others.

Method: An integrative literature review was undertaken and reported following the ENTREQ framework. Literature was identified from comprehensive database searching across four relevant databases (CINAHL, PubMed, PsychINFO and British Nursing Database) and hand-searching reference lists of retrieved studies. Studies that met the inclusion criteria were critically appraised and then analysed using the Constant Comparative Analysis method.

Results: Twenty-six articles were included in the review. Two overarching themes were identified. Theme 1—Dimensions of Decision-Making support—included three sub-themes: informational, emotional and instrumental mechanisms of support. Theme 2—Expectations of Decision-Making support—identified that parents' expectations of their own role, and the role of their significant others, affected how decision-making was supported.

Conclusions: Parents may seek and receive support from various significant members of their network, but there is a fine line between supportive and unsupportive behaviours.

Relevance to clinical practice: Each family's unique personal, social and cultural context strongly impacts on their support needs, and nurses and other healthcare professionals should be mindful of how parents may access support from their significant others. Further in-depth research around this area would contribute important knowledge around parents' support needs.

KEYWORDS

cancer, child, decision-making, neoplasms, parents, review literature, social networks

1 | BACKGROUND AND AIM

When parents are told that their child has cancer, they are faced with having to make many challenging decisions about their child's care (Coyne et al., 2014). These decisions may initially include treatment options, central line insertion and fertility preservation, and as time goes on may include nutrition support, location of care and symptom support.

Contemporary debate about healthcare ethics emphasises the importance of a person's right to make autonomous decisions (Beauchamp & Childress, 2019). However, where a child is too young to make an autonomous decision for themselves, this responsibility is usually deferred to the parents on the basis that the parents should make decisions in line with the child's best interests (Griffith & Tegenah, 2017). The rights and responsibilities of parents around decision-making are supported by legal frameworks both internationally, such as the United Nations Convention on the Rights of the Child (1989), and nationally (e.g. in England, this is expressed in the 1989 Children Act).

However, these rights and responsibilities may be accompanied by a sense of burden (Brinchmann et al., 2002). For parents of children with cancer, whose world has been turned upside down by a life-changing diagnosis, this burden has been described as generating stress, doubts and uncertainties (Bandinelli & Goldim, 2017). It is therefore vital that nurses and other healthcare professionals have a good understanding of the support mechanisms that may help or hinder families when they are in these situations.

Existing research has comprehensively explored the role of healthcare professionals supporting parental decision-making in the context of children's cancer care—this includes nurses' and allied healthcare professionals' roles but predominantly focuses on doctors' roles (Coyne et al., 2014; Pyke-Grimm et al., 2006). Providing this support is a fundamental part of healthcare professionals' roles but it is also important to recognise that other people may informally support parents as they make these decisions. Whilst this has been explored within the context of adult care, it cannot be assumed that the same findings would apply to a parent making a decision on behalf of their child (Gagnon & Recklitis, 2003; Lipstein et al., 2012). This review therefore aims to synthesise what is currently known from an international perspective about how parents' significant others may support them with decision-making in this context.

It is worth clarifying the meaning of significant others, as terms and concepts in the literature vary. Thoits (2011) defines significant others as relationships within a 'primary group' consisting of people such as family members and close friends, which is distinct from 'secondary groups' which are larger and may include work colleagues, neighbours and members of social organisations. This combination of primary and secondary groups could be conceptualised

as a broader social network consisting of an inner circle of significant others and an outer circle of looser relationships. However, it is important to acknowledge that these relationships are characterised by their fluidity and people may contextually move between the inner and outer circles. It is also important to recognise that individual perspectives and definitions of the meaning of significant others will vary and allowing people to self-define these relationships should be valued.

2 | METHOD

An integrative literature review was undertaken, aligned with Whittemore and Knafl's (2005) approach. Integrative reviews provide a broad approach to reviewing and synthesising literature, enabling the development of new understanding (Whittemore & Knafl, 2005). In the context of this topic, this approach therefore enabled the inclusion of diverse research methodologies. This was deemed necessary following initial scoping of the literature when it was noted that relevant research included mainly qualitative, but also quantitative and mixed methods approaches. The results are reported here using the framework of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) (Supplementary File 1). Currently, there is not a reporting guideline designed specifically for integrative reviews and so a framework was selected to align with the nature of the literature included within this study. The ENTREQ framework was used because the included studies are mainly qualitative, and the synthesis is presented in a narrative fashion. It was therefore appropriate to adopt this qualitative framework rather than a framework used primarily for quantitative systematic reviews.

2.1 | Identification of literature

Whittemore and Knafl (2005) emphasised the importance of comprehensive searching for relevant literature. The predominant search strategy in this review involved using four computerised databases (The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO and the British Nursing Database (BND)) using the search terms presented in Table 1. These search terms were initially constructed by the first author but then reviewed by all authors and discussed with university librarians. Subject headings were also explored for each database.

The terms 'caregiver' and 'carer' were used as alternatives to 'parent / guardian / mother / father', and the retrieved studies did use a range of terms. Whilst it is not always the case that a parent will be the main caregiver and make decisions on behalf of the child,

TABLE 1 Search terms

1.	caregiver OR mother* OR father* OR parent* OR guardian* OR carer*
AND	
2.	decision* OR decide* OR consent*
AND	
3.	neoplasm* OR cancer OR oncolog*
AND	
4.	influence* OR support* OR help* OR advice* OR advis*
AND	
5.	child* OR pediatric* OR paediatric* OR adoles* OR youth* OR teen* OR infant*

It was implicit within the context of all included studies in this review that the parents were the child's caregivers and consequently made decisions. After lengthy consideration, it was decided to exclude the concept 'significant others' as this is self-defined by individual families. There was a risk that by including synonyms, the search would become restricted to the researchers' subjective definitions of the concept and therefore miss relevant studies.

In addition to database searching and retrieval, reference lists of retrieved papers were also consulted to search for further relevant studies. Finally, a process of networking with experts in the field took place whereby discussions highlighted other potentially relevant research. In addition to published research, relevant dissertations and theses were retrieved from the database searches.

Inclusion and exclusion criteria were developed and applied (Table 2) in order to ensure that irrelevant studies were excluded. The search was limited to studies published in English. No research was excluded according to the date of publication as there was no clear rationale to do this and it was important to capture all research about this topic. However, the publication date was considered during the critical appraisal process to assess the relevance of the findings, and the studies spanned publication dates between 1996 and 2021. All types of primary research were included. Screening of titles and abstracts according to the criteria reduced the number of papers significantly. The full texts of these remaining papers were then read by the first author to decide whether the inclusion criteria were met.

Figure 1 presents a PRISMA flow chart demonstrating the number of papers identified, included and excluded throughout this process. 26 studies met the inclusion criteria and were included in the analysis of this review.

2.2 | Critical appraisal

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to appraise all of the research papers as this tool allowed for the appraisal of quantitative, qualitative and mixed method studies. This tool was initially completed by the first author, but for rigour a selection of four studies was read by the other authors who

reviewed the information represented in Table 3. Discussion about the identified limitations drawn from the appraisal tool led to a refinement of the data presented in Table 3. In line with Whittemore and Knaff's (2005) approach, this process did not result in the exclusion of studies; the key limitations identified through this process are indicated in Table 3.

2.3 | Data extraction

Table 3 presents the studies selected for the review with key details about the design and findings of each study.

2.4 | Data analysis

There were two stages of analysis. The first stage (represented in Table 4) involved extracting detail about the types of decisions that parents faced in each study and the source of support (in relation to significant other). It is important to recognise that most studies did not focus on support from significant others, and therefore, the parents had not identified these people as significant to them. It was therefore not possible to further categorise these sources of support into the primary and secondary groups defined by Thoits (2011). It should be noted that Gage's (2013) study specifically explored the role of 'experientially similar others' and drew a distinction between 'significant others' (parents' pre-existing social network of family members and close friends) and 'similar others' which in this context related to a new network of people who were living through a similar experience. It could be argued though that this concept of significant versus similar others was imposed on participants by the researcher rather than defined by participants.

Future research could explore which groups of people parents identify as 'significant' to them within this context. However, in the absence of this, the label of 'significant other' was assigned according to the interpretations of the researchers.

The second stage of analysis involved using the Constant Comparative Analysis method as recommended by Whittemore and Knaff (2005). Each study was read multiple times by the first author. Direct quotations of relevant extracts from all studies were recorded, and initial notes were made about codes and themes. This was an inductive and iterative process. As each study was read, ideas about themes evolved and notes about previous studies were reviewed and added to. Once all the studies had been read several times, the notes from each study were compared with each other. The research team met monthly throughout this project where findings of the studies were extensively discussed. These discussions led to the construction of the two main themes, and feedback from the team on the first author's early draft writing, refined the labelling of themes and identification of sub-themes. The other authors supported this process by reading four of the studies confirming that they had been appropriately represented within the analysis. All studies were analysed in a narrative, qualitative way regardless of

TABLE 2 Inclusion and exclusion criteria

Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
Population involved in making decisions			
Parents of children with cancer	Children / adolescents / young adults with cancer	The focus of the study is on parents' support needs for decision-making, not children's support needs for decision-making.	10
	Parents of adolescents / young adults with cancer	In this study, the focus is on parents of children, as opposed to adolescents or young adults. The relationship and responsibility for decision-making between parent and child changes as the child becomes older, and the focus of this project is on a child who has limited capacity to make their own decisions. Therefore, if the research focused exclusively on parents of adolescents / young adults with cancer, it was excluded. However, a significant amount of the research did not differentiate between the ages of children, so in some cases literature was included that covered a broader age range.	0
	Adult patients with cancer who have children	Several of the retrieved studies related to adults with cancer who were parents, and the impact of this on their children, as opposed to the child having cancer.	10
	Parents of children with other conditions	The focus of this review is specific to children with cancer, and only these studies could be included.	32
Context of Decision-Making			
Any decision that parents make about their child's cancer care, when their child has a cancer diagnosis	Decisions related to cancer screening	The focus of this project is on parents whose child has cancer and the decisions related to their care.	18
	Decisions related to cancer prevention (e.g. HPV vaccination)		
Source of Support or Influence			
Support from self-identified 'significant other' or social network member (even if this is not the primary focus of the study)	No reference to who the significant others are	A few research studies referred to an unidentified person or group of people, as being involved in the decision-making process. These papers were excluded as one of the aims of this review is to understand how relationships may affect experiences of support. It is therefore necessary to identify the type of relationship between parent and 'significant other'.	4
	Support from healthcare professionals	The focus of this review is on the support from the parents' significant others. It is possible that parents will identify the child's team of healthcare professionals as an emerging part of their network. However, the healthcare professional's role in supporting the parents' decisions is complex as their primary role is to advocate for, and promote the best interests of the child, rather than the parents. Healthcare professionals do play a significant role in supporting decision-making; however, the abundance of existing research about the healthcare professional's role in supporting decision-making and the complexity of this role places this source of support beyond the remit of this review.	19

TABLE 2 (Continued)

Inclusion	Exclusion	Rationale	Number of studies excluded (at full text level of screening)
	No reference to decision-making being supported	When the full texts were screened, it became apparent that a significant number of studies focused on parental decision-making processes, and there was no focus on the parents receiving support from others with this process.	55
Type of Literature			
Primary research including all types of methodology (quantitative, qualitative and mixed methods)	Secondary research (literature reviews) Opinion-based literature	The intention was to exclude literature reviews; however, no relevant literature reviews were retrieved in the search. One non-research paper was relevant to this review (Massimo et al., 2004). However, the opinions expressed in this paper did not add any original insight to the findings of this review.	4
Total excluded at full text level of screening			152

the study's methodological approach. The decision to do this was made because, as identified above, most studies did not focus specifically on support from significant others. This prevented meaningful, relevant conclusions being drawn from the quantitative data, and so, qualitative supporting data were extracted from the quantitative and mixed methods studies.

Computer software was not used for the analysis of this review.

3 | FINDINGS

Two overall themes were identified: 'Dimensions of Decision-Making Support' and 'Expectations of Decision-Making Support'. The first theme (Dimensions of Decision-Making Support) included three sub-themes—informational support, emotional support and instrumental support. The second theme (Expectations of Decision-Making Support) included two sub-themes—parental expectations of their role and parental expectations of the role of significant others.

3.1 | Dimensions of decision-making support

Parents experienced support, and a lack of support, in three key dimensions—informational, emotional and instrumental. These three dimensions were labelled according to House and Kahn's (1985) functions of support in order to explore whether, and how, the mechanisms of social support could be aligned to decision-making support.

3.1.1 | Informational support

Managing information

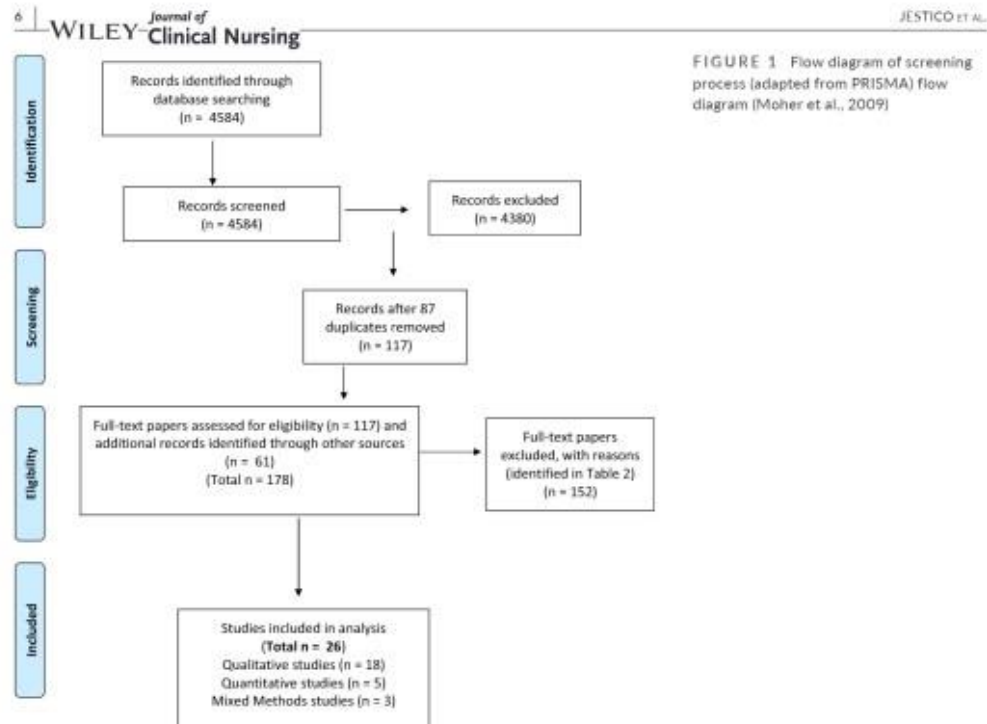
Parents received informational support in two distinct ways. The most direct way was when other people provided them with information or researched information on their behalf. This helped

parents to gather and manage the information that they felt that they needed to make their decision.

Some parents used their significant others to gather and assimilate information simply so that they could gain sufficient knowledge to make an informed decision (Holm et al., 2003; Kilicarslan-Toruner & Akgun-Citak, 2013; Levi et al., 2000; Yeh et al., 1999). Often, this information came from other parents of children with cancer. In addition, Holm et al. (2003) found that some parents would seek this support specifically from family members and friends who had medical expertise, and Levi et al. (2000) noted that one family asked friends to conduct research, which supported their decision-making process.

Some authors were able to provide a more nuanced understanding of how information gathering could help parents. Gage (2013), Gage-Bouchard (2017) and Robertson et al. (2019) found that parents spoke about using their network to 'translate' specialist knowledge to aid their understanding. Again, the source of this support varied. Like Holm et al. (2003), Gage-Bouchard (2017) found that parents would seek informational support from particular people within their network who had specialist expertise. For example, one mother identified that there were two registered nurses within the family who were able to translate specialist medical information into more understandable language. These findings suggest that this type of support aided parents' understanding, which helped them to communicate more easily with clinicians. This may have subsequently eased the process of making decisions, but this is not explicit.

Gage (2013) found that other parents of children with cancer carried out this translation of specialist knowledge. This was particularly noticeable when families with more experience supported the families with a new diagnosis to understand the hospital structure, cancer treatment and medical jargon. Parents reported that this information felt more accessible and easier to understand which allowed them to use this information to consider alternative options. Interestingly, the parents in Gage's study expressed that they placed more credibility on the information that came from other parents than the information from healthcare professionals. The parents in Robertson et al.'s (2019) study acknowledged that the information



given by healthcare professionals could feel overwhelming, but that seeking further information from their significant others made it feel more understandable. This translation of information helped parents to compile a list of questions for their treating team, which enabled them to clarify information.

Whilst the studies reviewed highlighted that parents asked their network of significant others to seek information on their behalf, a contrast is presented by Stewart et al. (2012). In this study, whilst a few parents sought information from their network, the majority deliberately did not seek this and only wanted input from medical professionals. This demonstrates that different parents, in varying contexts, may have a range of perspectives about what is helpful and supportive.

Learning from people's stories and experiences

Informational support extended beyond this direct method of information provision, and parents learnt from other people's experiences and stories. This became a way for them to absorb less formal, experiential information but that had the potential to strongly influence their decisions.

In many of the studies, this support stemmed from other families of children with cancer (Alam & Kumar, 2019; Cohen et al., 2017; Gage, 2013; Huang et al., 2008; H-Yazdi & Meadows, 2021; Mostert et al., 2014; Renner & McGill, 2016; Sitaresmi et al., 2010; Yeh et al., 1999). However, this was not exclusively the case and some parents

also sought information from family and friends who had related experience (H-Yazdi & Meadows, 2021; Jong et al., 2020; Sitaresmi et al., 2010).

Whilst this type of experiential informational support was acknowledged in several studies, some did not explore this aspect in sufficient depth to provide understanding of how learning from others' experiences supported parents' decision-making, nor were they explicit that this actually impacted on decision-making (Alam & Kumar, 2019; Cohen et al., 2017; Huang et al., 2008).

However, more detail about this process was given by H-Yazdi and Meadows (2021) who found that parents focused on the importance of learning from real-life stories. In this study, parents whose children had received proton-beam therapy felt it important to listen to the experiences (often through virtual contact) of other families whose child had received the same treatment. The participants explained that these sources of information were preferable to information sheets, medical reports and expertise from doctors, which they felt to be removed from reality. This sense of credibility in learning from others' real-life experiences is echoed by Yeh et al. (1999) and aligns to Gage's (2013) findings that direct information provided from other parents held greater credibility than that received from healthcare professionals.

Gage (2013:48) found that, by observing and listening to each other, parents appraised their own experiences with reference to the experiences of other families and referred to this as a process of

'social comparison'. These stories and observations influenced their attitudes towards their own child's care. Although it was not explicit that this informed their decision-making, parents did feel that this empowered them to advocate for their child, which suggests that this social comparison process could be helpful.

A number of studies focused on factors affecting parents' decisions about treatment continuation versus abandonment, and here, the negative impact of the social comparison process had direct consequences on parents' decision-making (Mostert et al., 2014; Renner & McGill, 2016; Sitaresmi et al., 2010; Yeh et al., 1999). The studies by Sitaresmi et al. (2010) and Renner and McGill (2016) expressed parents' fear of cancer treatment as they heard the stories and watched other families' experiences. Yeh et al. (1999) articulated that watching the negative experiences of other families influenced parents' decisions to abandon treatment, as they watched other children suffer treatment side effects or die despite treatment. This is echoed by Mostert et al. (2014) who noted that parents hearing and seeing what was happening to other parents of children with cancer significantly influenced their decision-making. These findings demonstrate that by observing the experiences of others, misinformation was being circulated ('surgery spreads cancer'; 'cancer is not curable') which influenced parents' decisions to abandon treatment. This was particularly evident in research from Taiwan, Indonesia, Kenya and Ghana and not noted in research findings from Australia, or European and North American countries.

The potential negative impact of learning from others' experiences was found by O'Neil (1996) to be a reason why parents deliberately avoided this type of informational support. Parents expressed that they did not seek support from other parents of children with cancer, as it was too frightening to observe other families travelling their own journeys of relapsed cancer. This is in contrast to many other studies cited in this review where parents did look to other families for support (Alam & Kumar, 2019; Cohen et al., 2017; Eder et al., 2007; Gage, 2013; Holm et al., 2003; Huang et al., 2008; H-Yazdi & Meadows, 2021; Kilicarslan-Toruner & Akgun-Citak, 2013; Levi et al., 2000; Mostert et al., 2014; Renner & McGill, 2016; Robertson et al., 2019; Sitaresmi et al., 2010; Yeh et al., 1999).

This is perhaps due to the focus of O'Neil's study which is on children with relapsed cancer (who are likely to have a poorer prognosis), whereas the majority of other studies focused on decision-making through the child's first diagnosis.

3.1.2 | Emotional support

Emotional support was perhaps less tangible than informational support, but it was nevertheless viewed by parents as important, and similarly, it came from different parts of parents' networks. Hamama-Raz et al. (2012:30) described parents need for 'emotional containment' in order to be able to make decisions. O'Neil (1996) found that parents felt that having an emotionally supportive network gave them the time and space to make decisions.

Often emotional support stemmed from parents' relatives and friends. Papadatou et al. (1996:229) framed this as 'being present', although it is not explicit that this emotional presence led to mothers feeling supported specifically with decision-making. This sense of parents feeling a 'supportive presence' from their significant others was also found by Stewart et al. (2012:424) and whilst it is suggested that this did support treatment decision-making, it is acknowledged that this was only discussed by very few parents in the study.

The manifestation of emotional support was more actively demonstrated in other studies. The parents in O'Neil's (1996) study looked to their wider community for emotional reassurance. A similar sentiment is expressed by Gage (2013), who found that parents needed people to understand how they felt. The parents interviewed in this study did not feel that they could get this sense of understanding from their pre-existing network of family and friends and so they turned to other parents of children with cancer. Whilst this extract of Gage's (2013) study does not link explicitly to decision-making, Gage did suggest that this emotional support reduced parental stress, which may then have helped them feel better placed to make decisions. The parents in Eder et al.'s (2007:854) study also looked to other parents of children with cancer as they felt that these people were at a similar 'emotional level', and similarly, Huang et al. (2008:2744) described this emotional support from other parents as a contribution to parents' strength and 'courage to carry on'.

However, there appeared to be a risk that parents seeking this emotional understanding and reassurance could inadvertently put themselves in the position of feeling judged for their decision-making. This had the potential to be emotionally unsupportive and damaging. This concern was particularly noted by the parents in O'Neil's (1996) small phenomenological study who felt that some members of the community had negatively judged their decision, which parents had found difficult to manage.

3.1.3 | Instrumental support

Instrumental support was offered to parents in two distinct ways, practical and financial support.

Practical support

Several studies discussed practical support being offered to parents (Huang et al., 2008; Mostert et al., 2014; O'Neil, 1996; Papadatou et al., 1996; Stewart et al., 2012). This took the form of cooking (O'Neil, 1996; Papadatou et al., 1996), shopping (Papadatou et al., 1996) and providing childcare for parents' other children (Mostert et al., 2014; O'Neil, 1996). None of these authors explicitly stated that this practical support affected parents' decision-making. However, there is an implicit thread in O'Neil's (1996) work that suggests that the support gave the parents the time and space to consider the decisions they were making. Similarly, Papadatou et al. (1996) suggested that having this practical support provided by family and friends, reassured mothers that they could choose for their child to die at home rather than in the hospital, as the support would

TABLE 3 Data extraction

Author, year and country	Aim of study	Research Design And Method
Alam and Kumar (2019) India	To investigate the impact of an extensive financial, social support and group counselling programme on treatment refusal and abandonment from 1995 to 2017 in North India.	Quantitative: Retrospective cohort study with three phases of support interventions. Data collected from the cancer registry. Children who abandoned / refused treatment were identified, and their parents were asked to complete a questionnaire about the reasons for abandonment.
Blakeley et al. (2000) Canada	To evaluate whether parents were satisfied with the education and support provided to them in relation to making decisions about their child's central venous access device (CVAD).	Quantitative: 83 item questionnaire survey.
Cohen et al. (2017) Australia	To compare views among parents, patients and healthcare workers on the positive and negative aspects of enteral tube feeding (ETF), the ways in which information was provided, and how the decision-making process was conducted.	Qualitative: Semi-structured interviews. Data analysed using content analysis.
Eder et al. (2007) USA	To report suggestions that parents made about improving the informed consent process.	Qualitative: Interviews and focus groups. Parents were interviewed twice (at the time of informed consent and again 6 – 8 months later. Focus groups including all parents who had participated in the interviews. Finally, a parent advisory group on informed consent (PAGIC) was convened. Data analysed using an approach based on grounded theory.
Gage (2013) USA	To examine how network ties among parents of paediatric cancer patients shape parents' perceptions of the healthcare experience.	Mixed Methods: In-depth interviews and standardised survey questionnaire. Thematic analysis was conducted.
Gage-Bouchard (2017) USA	To explore how social support helps people to navigate the healthcare system.	Qualitative: In-depth interviews were undertaken, and observations of clinical interactions between oncologist and the parents were conducted. The parents who were interviewed were not the same parents who were observed.
Hamama-Raz et al. (2012) Israel	To investigate the coping experience of parents of a child with retinoblastoma.	Qualitative: Phenomenological Interviews. Content analysis was undertaken.
Holm et al. (2003) USA	To explore parents' descriptions of their participation in medical care for their children with cancer.	Qualitative: Focus groups. Content analysis was undertaken.

Participants	Key findings in relation to this literature review	Study limitations
Children recorded on the cancer registry from 1995 to 2017 (n = 1041) Parents of children with acute lymphoblastic leukaemia aged less than 18 years who completed the questionnaire relating to reasons for treatment abandonment (n = 196)	Engagement with parent support groups appeared to influence parents' decision to continue treatment for their child.	- Longitudinal nature of the study makes it impossible to eliminate other factors that may not be directly linked to the interventions. - Limited depth around the reported findings (possibly due to journal word limit) so not possible to unpick what element of the intervention impacted on decisions.
Parents of children with cancer who had a central venous access device inserted (n = 44, return rate of 88%). 86% of respondents were mothers.	Some parents reported that their decision was made jointly with another family member.	- Questionnaire was not formally validated although it had been piloted. - Authors acknowledge that generalisability is problematic.
Two groups of participants: (i) children with cancer aged less than 18 years (n = 10) or their parent if the child was aged less than 12 years (n = 20); 18 mothers, 2 fathers; (ii) healthcare professionals (n = 18)	Parents seek information from other families on ward. They watch other families' experiences, and this seems to influence their decision.	- Single site study. - Authors acknowledge that recall bias may be problematic.
Parents of children with leukaemia (across 6 hospitals). Initial interview (n = 132); follow-up interview (n = 110); focus groups (n = 72); PAGIC meeting (n = 9)	Parents suggested that they wanted to talk to their family and friends, and also other parents of children with cancer, before making a decision, they also suggested that allowing another person to attend the consultation with them would be helpful.	
Parents of children with cancer (n = 76: 49 mothers, 27 fathers)	Other parents of children with cancer support parents and this may affect decision-making.	Concept of 'similar' versus 'significant' others are imposed by the researcher on participants rather than self-defined.
Two groups of participants were interviewed: (i) parents of children with cancer (n = 80: 51 mothers, 29 fathers) and (ii) paediatric oncologists (n = 8). Observations of clinical interactions between families and physicians (n = 73)	Social networks can offer informational support which may inform decision-making. The provision of practical support from social networks allows parents to be more present at the hospital and therefore more involved in decision-making.	Unclear why the decision was made to interview a different group of parents to those being observed.
Parents of children with retinoblastoma (n = 12 sets of parents, although one interviewee had been widowed and so was interviewed alone)	Other parents of children with retinoblastoma are considered a source of emotional support, and this links to the parents feeling that they can make decisions.	Some of the participants had received their child's diagnosis 12 years previously which may have been considered too long a period of time for the participants to reflect back on their experiences.
Parents of children who had completed cancer treatment at least one year prior to the focus group (n = 45: 26 mothers, 19 fathers)	Parents sought informational support from other parents of children with cancer, and from family members and friends with medical expertise. This informed their decision.	- Data collected between 1990 and 1998 and therefore may not be representative of people's experiences today. - Authors acknowledge that the data drawn upon for this study are used to answer a question that was not the original focus of the research project. Further questioning and exploration in relation to this topic may have elicited different responses. - Possible recall bias as participants were reflecting on events that happened up to nine years previously.

TABLE 3 (Continued)

Author, year and country	Aim of study	Research Design And Method
Huang et al. (2008) Taiwan	To explore family experiences in terms of family resources and how these assist a single-parent caring for a child with cancer.	Qualitative: Phenomenological interviews. Transcripts were analysed based on Colaizzi's (1978) principles of phenomenology.
H-Yazdi and Meadows (2021) UK	To explore how parents of children treated with proton beam therapy (PBT) view the treatment and the sources of information surrounding the treatment.	Qualitative: Interviews. Transcripts were analysed thematically.
Israels et al. (2008) Malawi	To gain insight into the guardians' perspective on cancer treatment, especially concerning factors which could influence abandonment of treatment.	Qualitative: Interviews and focus groups. A sequence of semi-structured interviews were undertaken at various points during the child's treatment trajectory. Focus groups were also held. Analysis was influenced by a grounded theory approach.
Jong et al. (2020) Sweden / Netherlands	To develop an evidence-based decision aid for parents of children with cancer and to help guide them in the use of complementary and alternative medicine (CAM) for cancer care.	Mixed Methods: 23-item, validated questionnaire survey; and focus group (analysed using a directive content analysis). The survey and focus group were the first phase of the development of the decision aid (there were 4 phases in total) and is relevant to this review as it related to how people made decisions.
Kelly and Ganong (2011) USA	To explore how parents who no longer live together make treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. Analysis followed the grounded theory process.
Kilicarslan-Toruner and Akgun-Citak (2013) Turkey	To explore the information-seeking behaviours, perceptions and decision-making experiences of parents of children with cancer.	Qualitative: Interviews. Inductive content analysis was undertaken.
Levi et al. (2000) USA	To learn about and to describe retrospective perceptions of parents of the circumstances of their child's cancer diagnosis and of the informed consent process.	Qualitative: Focus groups. Cross-case analysis was used.
Liang (2002) Taiwan	To discover the cultural care practices of caregivers when promoting the health and well-being of children with cancer.	Qualitative: Ethnonursing interviews. Analysis underpinned by principles of ethnonursing.
McKenna et al. (2010) UK	To identify parental perceptions of both their own involvement and that of others in the decision to enrol their child on to a specific cancer treatment protocol, and their satisfaction with this decision.	Quantitative: Questionnaires and Interviews. Parents completed two validated questionnaires within an interview context with four additional questions also asked at the interview. Data analysed using the Statistical Package for the Social Sciences.

Participants	Key findings in relation to this literature review	Study limitations
Single parents of children aged less than 18 years receiving treatment for cancer (n = 9; 5 mothers, 4 fathers).	Single parents may receive emotional, informational and practical support from relatives and friends, and also seek information from other parents of children with cancer. However, parents feel that the decision must be made alone.	The authors identify that the results may not be representative as a limitation of their study; this is misaligned with the concept of phenomenology as the purpose of this research is not to present people's experiences as representative of others.
Parents of children who had been treated with proton beam therapy (n = 27: 19 mothers, 8 fathers)	Parents seek information from family, friends and from other families of children who have undergone PBT.	Authors acknowledge that a limitation is that parents were recruited to this study via online support groups which may have meant that the participants were more engaged with online support than other families may have been.
Guardians of children with Burkitt lymphoma or Wilms tumour (n = 32: 31 mothers, 1 father)	Some guardians asked their relatives for advice about decision-making.	- Lack of detail reported about the methods and analysis. - No quotes are used to illustrate themes. - Authors acknowledge that one of the interviewers was a physician on the ward where the child was being cared for and that this may introduce bias.
Parents of children with cancer (survey n = 70: 93% mothers; focus group n = 7)	Some parents sought informational support from family and friends.	Unclear whether the survey findings influenced the design of focus groups.
Custodial (n = 7: 6 custodial mothers, 1 custodial father); non-residential (n = 5: 1 mother, 4 fathers); and step-parents (n = 3: 1 stepmother, 2 stepfathers) who had previously made a major treatment decision for their child with cancer (total n = 15)	The responsibility around the decision-making in diverse family structures is complex. Step-parents offered significant emotional support and often informational support. However, the parent also needed space to make decisions. Different types of decisions required different types of support.	Single site study.
Parents of children with cancer (n = 15: 13 mothers, 2 fathers)	Parents are supported with finding information from friends, and from other parents of children with cancer.	- Authors acknowledge that the findings are not intended to be generalisable. - Authors suggest that the study could have been strengthened by interviewing the other parent in the family.
Parents of children with cancer who had been eligible for a clinical trial research protocol (n = 22: 16 mothers, 6 fathers)	Some parents sought emotional and informational support from family, friends, and other parents of children with cancer. This helped them to make decisions.	- Although described as a qualitative study, the data analysis is treated in a quantitative way. - Authors suggest that it is not possible to generalise as the sample size is small, but this is not in line with a qualitative perspective.
Two groups of participants: (i) caregivers of children with cancer (n = 34: 23 mothers, 8 fathers, 1 grandmother, 2 aunts) and (ii) nurses (n = 6).	Extended family members significantly influenced parents' decision-making about treatment. Parents worried that they might offend their family and healthcare professionals if they rejected their advice.	Single site study.
Parents of children with cancer (n = 66)	Some parents sought advice from relatives. When other people were involved with making a decision, they reported more difficulties with the decision-making process; however, parents reported that they felt more satisfied with their decision if they had received the right amount of support.	- Nature of the methodology prevents depth in the exploration of parents' experiences. - Limited potential to establish cause versus effect, for example whether parents find it more difficult to make a decision when relatives are involved because of that involvement, or whether this is because they asked for support because it was a difficult decision to make. This is acknowledged by the authors.

(Continues)

TABLE 3 (Continued)

Author, year and country	Aim of study	Research Design And Method
Mostert et al. (2014) Kenya	To explore parents' experiences with hospital retention policies and the impact of attitudes of family and friends on parents' decisions about continuing cancer treatment for their child.	Quantitative: Questionnaire via interview. Most questions framed on two-point, three-point or four-point rating scale. There was one open-ended question. The responses were statistically analysed.
O'Neil (1996) USA	To explore the experiences of parents as they made decisions when their child had a recurrence of cancer.	Qualitative: Phenomenological interviews (Doctoral Thesis). Analysis underpinned by the philosophy of Heidegger.
Papadatou et al. (1996) Greece	To investigate the experiences of Greek mothers who cared for a child dying of cancer at home or in the hospital, and to highlight some of their major needs during the terminal period.	Mixed Methods: Three methods of data collection were used: semi-structured interviews, patient medical records and a validated questionnaire—the Grief Experience Inventory.
Renner and McGill (2016) Ghana	To explore factors influencing parental decision-making for children with cancer with regard to health seeking and retention in treatment.	Qualitative: Interviews and focus groups. Thematic content analysis was undertaken.
Robertson et al. (2019) Australia	To explore parents' and adolescents' views and perceptions of making medical decisions in paediatric oncology.	Qualitative: Semi-structured interviews. Demographic data statistically analysed. Interview data thematically analysed.
Sitaresmi et al. (2010) Indonesia	To analyse parents' reasons for treatment abandonment and to ascertain the consequences of children who abandoned treatment.	Quantitative: Semi-structured questionnaires / interviews and observations of social / home circumstances were made. Statistical analysis applied.
Stewart et al. (2012) USA	To describe the process of parents making major treatment decisions for their children with cancer.	Qualitative: Grounded theory interviews. The interview guide was revised throughout the study in line with the constant comparative analytic technique of grounded theory.
Woodgate and Yanofsky (2010) Canada	To understand Canadian parents' participation in decisions about childhood cancer trials.	Qualitative: Interviews. Constant comparative method was used to analyse the data.
Yeh et al. (1999) Taiwan	To document the determinants of parental decisions to 'drop out' from cancer treatment for their child.	Qualitative: Interviews. Content analysis was undertaken.

be in place. It should be noted though that in both cases, these inferences came from the authors' interpretations rather than the direct words of the parents.

Financial support

Financial support was significant for many of the parents in the studies—particularly in research from African and Asian countries (Huang et al., 2008; Israëls et al., 2008; Mostert et al., 2014; O'Neil, 1996; Renner & McGill, 2016; Sitaresmi et al., 2010). This financial support was useful for different reasons. A parent in

O'Neil's USA (1996) study talked about how a friend had started fundraising on the family's behalf; this was specifically because the family were struggling to cover the cost of travelling to and from the hospital so regularly. For the families in Mostert et al.'s (2014) and Renner and McGill's (2016) studies, this financial support was provided by the parents' relatives, friends and wider communities, and was extremely significant as it enabled the families to pay for the medical bills and drugs that their child needed. The focus of both of these African studies was around treatment retention versus abandonment, and as one of the factors for

Participants	Key findings in relation to this literature review	Study limitations
Parents of children with cancer who had abandoned cancer treatment (n = 46)	In many cases, extended family and other members of the community advised parents to abandon conventional treatment. Other parents of children with cancer also influenced the parents' decisions.	An open question in the interview is alluded to but there is no reported analysis of responses.
Parents of children with relapsed cancer (n = 6 family units)	Support from family and friends was helpful if it was non-judgemental, emotionally reassuring and provided practical / financial help. However, sometimes the help offered was misdirected and detrimental.	
Mothers of children who had died of cancer (n = 15)	The findings suggest that having practical and emotional support available from extended family influenced the mother's decision to care for her child at home.	- Small sample size for a mixed methods study and therefore statistical analysis is limited. - Emphasis in the paper is therefore on qualitative analysis. - No identification of how the information from medical records was integrated into the analysis.
Parents of children with cancer (interviews n = 12, focus groups n = 7. Of this total of 19 participants, 13 were mothers and 6 were fathers)	Parents sought information from relatives, friends and other members of the community. Some parents made decisions to use native / herbal medicine because of influence of these people. Financial support from these groups also influenced their decision-making.	Authors suggest that a limitation is that the findings are not representative of the general population, but this is misaligned with a qualitative perspective.
Two groups of participants: (i) parents of children with cancer (n = 25: 23 mothers, 2 fathers); (ii) adolescents with cancer (n = 5)	Parents sought informational support from online parent forums and from other families on ward.	Authors acknowledge that only one site was accessed and there was limited diversity of participants.
Families of children with acute lymphoblastic leukaemia (n = 37)	Other people in their community, and other families of children with cancer, influenced the parents' decisions. Financial support from other people was also a factor that influenced their decisions.	No information reported about how the questions were developed or piloted.
Parents of children with cancer (n = 15: 9 mothers, 6 fathers)	Findings suggest that parents do not want involvement of their social network when they make major treatment decisions.	Authors acknowledge that there was a lack of cultural diversity within their group of participants.
Parents of children with cancer (n = 31: 20 mothers, 11 fathers)	This suggests that advice from 'expert' family / friends is supportive.	- Authors acknowledge the retrospective nature of the study but also that the opportunity to reflect on decision-making is a strength. - There is a lack of diversity represented in the group of participants.
Parents of children with cancer who had dropped out of cancer treatment (n = 19: 14 mothers, 5 fathers)	Decision to abandon treatment significantly influenced by other parents of children with cancer. Some parents also influenced by religious beliefs.	Authors suggest that the study is limited by its small sample and that the sample is not representative; however, neither of these limitations are in line with a qualitative perspective.

abandonment was linked to financial pressure, this support likely contributed to the parents' decision to continue cancer treatment for their child.

An opposing perspective was shared by Israels et al. (2008) and Sitaresmi et al. (2010). The parents in both of these studies acknowledged that they consulted with people on whom they were financially dependent (such as their relatives). These people had a strong influence on the decision-making process, and in Sitaresmi et al.'s (2010) study, parents' financial dependency on others influenced their decision to abandon treatment.

Another aspect of financial support related to parents' employment. Sitaresmi et al. (2010) found in their Indonesian study that 54% of fathers lost their job because of having to accompany their child to hospital. Huang et al. (2008) discussed how, in Taiwan, the combination of financial assistance and practical support that relatives provided allowed the parent to leave their child temporarily so that they could keep their job. However, it is not clear if, or how, that affected making decisions. However, Gage-Bouchard (2017) reported that parents felt excluded from healthcare decisions because they were working and therefore not at the hospital with their

child. The parents in this American study felt that if they could have received sufficient financial support to be able to take leave from work, they would then have been able to be more involved with making decisions.

3.2 | Expectations of decision-making support

Parents' experiences of support were influenced by their expectations of their own role (sub-theme 3.2.1) and other people's roles (sub-theme 3.2.2) in decision-making. Their expectations and roles were affected by their relationships with other people, and these relationships could have both a positive and negative impact on parents' feelings of being supported.

3.2.1 | Parental expectations of their role

The parents in several studies strongly believed that as an advocate for their child, it was their responsibility to make decisions about their child's care, and nobody else's (Huang et al., 2008; Kelly & Ganong, 2011; O'Neil, 1996; Papadatou et al., 1996). For the parents in Kelly and Ganong's (2011) study, this responsibility was an extension of their parental role, and similarly, Papadatou et al. (1996) expressed that this responsibility was enmeshed with the culture of Greek family functioning, where parents take an active and protective role in decision-making. Further explanation about this responsibility was highlighted by a parent interviewed by Kelly and Ganong (2011) who explained that taking full responsibility to make the decision avoided the risk of blaming others if the outcome was negative, suggesting that this process would protect both the significant others and also protect the parents from this feeling. Interestingly Huang et al. (2008) uncovered a different perspective. They found that parents would rely only on themselves, suggesting a lack of trust in others. It should be noted that the focus of Huang et al.'s (2008) study was on parental experiences in single-parent families, and Kelly and Ganong (2011) focused on single-parent and re-partnered family structures, so perhaps this sense of responsibility lying solely with the parent stemmed from a history of potentially complex relationships. Indeed, Kelly and Ganong (2011) acknowledged the difficulty of making decisions in families with pre-existing conflict as some parents felt very mistrustful.

However, this sense of responsibility and self-expectation that their role, as a parent, was to make difficult decisions about their child's care could come to feel burdensome. This was particularly the case for single-parent families (Kelly & Ganong, 2011) where a mother talked about feeling alone, and struggled with not being able to share this decision-making burden with anybody else. Parents in Woodgate and Yanofsky's (2010:14) study also talked about the immense difficulty of trying to meet the expectations of being a 'good parent' by making the 'right' decision for their child. This burden and emotionally charged context could lead parents to lose confidence in their ability to make decisions (Stewart et al., 2012) and thus their

confidence in performing their role as the child's advocate. This could then lead, in some cases, to parents looking to their significant others to play a role in supporting the decision-making process.

3.2.2 | Parental expectations of the role of significant others

Parents had varied expectations of the role that significant others should play when decisions needed to be made. For the parents who felt strongly that nobody else should be involved in decision-making (as acknowledged above by Huang et al., 2008; Kelly & Ganong, 2011; O'Neil, 1996; Papadatou et al., 1996), the expectation was that other people should give them the time and space to make this decision. Whilst parents acknowledged that other people may provide support during this time (such as the informational, emotional or instrumental dimensions of support explored in Theme 1), they were not expected to take a role in actually making, or influencing, the decision. Kelly and Ganong (2011:355) described this process in terms of step-parents being expected to 'step back'. However, in other cases, parents needed their significant others to become more involved with directly supporting decision-making.

In these situations, when parents turned to others to discuss the decision that they were facing, they needed to talk through their thoughts and essentially needed significant others to listen and to act as a sounding board (Blakeley et al., 2000; Eder et al., 2007; Huang et al., 2008). A parent in O'Neil's study (1996: 210) described this as 'being able to hear your own voice'. In some cases, this role of being a sounding board evolved to significant others providing advice to parents (Israel et al., 2008; Kelly & Ganong, 2011; McKenna et al., 2010; Woodgate & Yanofsky, 2010). Parents acknowledged that it could be helpful to hear other people's perspectives about the decision that they were making (Eder et al., 2007). Woodgate and Yanofsky (2010) found that parents would seek out key family members or friends who had specific knowledge, and that they would ask these people for advice. This is consistent with the informational dimension of support where it was also acknowledged that parents would seek information from members of their network who had specific knowledge. However, Woodgate and Yanofsky (2010) suggested that by specifically asking for advice from these people, parents could cope better with the stress and guilt that they were experiencing about making decisions. This was though, dependent on relationships, as Stewart et al. (2012) noted that some parents limited the involvement of their social network in decision-making because of pre-existing conflict. Interestingly, McKenna et al. (2010) found that where parents sought advice from other people (such as family members) they reported that their decision was more difficult to make. However, the authors acknowledged that it cannot be assumed that this meant that seeking advice made the decision-making harder, as it is also possible that parents who were already finding the process difficult sought the advice.

The literature reviewed demonstrated that there was a fine line between significant others offering supportive advice to parents,

and this being perceived by parents as interference. The step-parents interviewed by Kelly and Ganong (2011:357) referred to this as needing to 'tread lightly', as whilst they could offer opinions it was important that they recognised that it was not their place to make the decision. The crossing of the boundary from support to interference was particularly noted in Llang's study from Taiwan (2002:213) where parents sometimes felt pressurised to listen to suggestions from elder family members, citing an example of a parent who said 'I have to listen to my mother-in-law's suggestions to give my child herbs sometimes'. A similar story from Ghana was cited by Renner and McGill (2016) where the child's grandmother would not allow the parents to make the decision to access hospital treatment, and instead insisted that the child should be treated with native medicine. Yeh et al. (1999), who similarly conducted their research in Taiwan, also found that in a small number of cases (3 out of 19), the decision to abandon treatment was made by the grandparents, rather than the parents. In all three of these studies, it was unclear how this involvement of grandparents in the decision-making process affected the parents' experiences. However, O'Neill (1996) found that interference from others felt to parents like an assault on their advocacy for their child, suggesting that the arguably self-appointed role of others was in direct conflict with the role identity of the parents.

4 | DISCUSSION

The analysis process led to the development of two themes. Wider reading around the topic area identified that the three sub-themes in Dimensions of Decision-Making Support (informational, emotional and instrumental) aligned to the social support framework identified by House and Kahn (1985). Gage (2013) applied this framework to support within the children's cancer context, and so, it was of interest to explore whether these categories would also apply to social support specifically with decision-making. The findings of this literature review suggest that, to an extent, this is the case. However, within the context of decision-making, there seemed to be another aspect that was also important which was not captured within these three categories. This broadly related to people's expectations of support, and in particular to their roles and responsibilities of decision-making, and whether or not it was considered helpful for significant others to offer advice or opinions about the decisions that were being made.

It is clear throughout the themes and sub-themes that the behaviours of significant others could be perceived as supporting parental decision-making. However, there appeared to be a fine line, and in some situations, these behaviours could be perceived as unsupportive. This suggests that parents' support needs vary, which is unsurprising as every family's experience is situated in a different personal, social and cultural context (United Nations Convention on the Rights of the Child, 1989).

Of all the support dimensions, informational support was portrayed with most prevalence in the review and with a wide

geographical representation. This resonates with wider legal perspectives about decision-making, as receiving sufficient information is critical when making informed decisions (Griffith & Tegenah, 2017). Within the context of children's cancer care, Mack et al. (2006) suggested that most parents want as much information as possible. However, this review demonstrates that the type, and source, of information preferences varies. Whilst the majority of parents in Stewart et al.'s (2012) study valued information from healthcare professionals above other sources, the parents in many of the other studies identified in 3.1.3 sought information from their significant others, whether this be in the form of formal information management, or informally learning from other people's stories and experiences. It is of significance that some parents placed higher credibility on these sources of information, than from their healthcare professionals. The fine line between supportive and unsupportive behaviours is apparent in this theme, which is particularly noted in studies from Taiwan (Yeh et al.'s 1999) and Kenya (Mostert et al.'s 2014) where parents abandoned treatment for their child as a result of watching others' experiences, and misinformation circulating within networks.

The variation in parents' support needs is similarly evident in both the dimensions of emotional and instrumental support. An example of the way that social and cultural contexts may influence this variation is highlighted within the financial aspect of instrumental support. Several studies discussed financial influences on decision-making. Some found that financial support from significant others either enabled treatment to be continued (where members of the community could enable families to pay for the medical bills and drugs, or enable parents to take time away from work). Others found that financial dependency on a significant other led to parents deciding to abandon treatment. It is interesting that the countries represented in this sub-theme were Taiwan (Huang et al., 2008); Malawi (Israelis et al., 2008); Indonesia (Sitaresmi et al., 2010); Kenya (Mostert et al., 2014); Ghana (Renner & McGill, 2016); and United States (Gage-Bouchard, 2017; O'Neill, 1996). With this diversity of national representation, comes diversity of healthcare funding and employment protection, and perhaps, this goes some way to explaining the variation within this aspect of decision-making support.

Again, there was a fine line between emotionally supportive behaviours and harmful behaviours (particularly parents feeling like they were being judged). However, the extent to which these behaviours directly affected parents' decision-making is unclear. There was also a lack of depth about how or why this behaviour was supportive or unsupportive. This presents an opportunity though to draw the two themes together, as perhaps the effects of the support dimensions are influenced by the individual's perspective of their role as a parent, and their existing relationship dynamics.

The role of the parent of a child with cancer has been discussed by Gagnon and Recklitis (2003), Pyke-Grimm et al. (2006), and Hinds et al. (2009) among others. In particular, Hinds et al. (2009), who framed this role as parents needing to be a 'good parent', highlighted that many parents felt that their role was to advocate for their child. Gagnon and Recklitis (2003) expressed this as a natural extension

of the parental role during times of health, when parents are used to functioning as proxy decision-makers for their child. However, Pyke-Grimm et al. (2006) found that the parent's role as decision-maker became increasingly difficult in the period following diagnosis as often the parents were in a state of shock and felt pressured into making a rapid decision. These sentiments are echoed within this review. However, whilst the parents in Pyke-Grimm et al.'s (2006) study turned to healthcare professionals for support, the parents represented in this review sometimes turned to their significant others for support and advice.

Interestingly, literature around supporting surrogate or proxy decision-making in adult healthcare shares similar findings. Iverson et al. (2014) note that seeking support from the decision-maker's extended network could boost confidence in their role and act as a buffer to the burden of decision-making. Batteux et al. (2017) suggest that seeking advice from others can cast a different perspective. Other people in a network are arguably in a position where they can provide more objective advice than the decision-maker, but more subjective advice than a healthcare professional.

Whilst there are difficulties with comparing the role of surrogate decision-making on behalf of an adult family member, and the role of a parent making decisions on behalf of their child (Lipstein et al., 2012), this concept of confidence and need for advice from the right person is significant. It is notable within the review that the parents in O'Neill's (1996) study seemed to turn to others less often than in some other studies. This was a small study and not intended to be generalisable. This may though relate to the focus of O'Neill's study, relapsed cancer, where the parents had more experience of, and thus increased confidence in, their role as decision-maker. Similarly, by the time that a child has been diagnosed with relapsed cancer, it is likely that the parents will have built up strong and trusting relationships with the healthcare professionals, and are likely to place more credibility in support from their medical team at this stage as they trust that they can provide both objective and subjective advice. Arguably, a parents' confidence in their role, and their dependent relationships on others, may evolve over time—this would warrant further exploration.

The findings of this review suggest that relationships influenced the role that parents felt others should take, and again, this sense of a fine line is evident between advice and interference. These relationships may have extended and influenced more than the expectations and balance of roles in decision-making, and influenced the perceived supportive influence of the three dimensions. Again, this suggests that the unique family contextual position is significant. In addition to the variation in social dynamics among each family's social network, Barbarin and Chesler (1984) note that a child's cancer diagnosis can have a significant impact on these dynamics, and thus, relationships and networks evolve over time, further impacting on roles and dimensions of support.

Jackson et al. (2008) define decisional support as anything that helps people to gather information and clarify their values. Whilst the findings of this literature review support the importance of informational support, it also demonstrates that supporting

decision-making extends beyond Jackson et al.'s definition and is placed within a complex personal, social and cultural context. In addition to informational support, emotional and instrumental support can also play a role in parental decision-making, and expectations of support are strongly influenced by people's perceptions of decision-making roles and relationships with significant others.

4.1 | Implications for research

Whilst this review has synthesised current research across a number of countries, many questions are left unanswered due to the lack of focus on this specific topic. This review adopted a broad approach around the identification of significant others, but further research should allow parents to self-identify their networks. It would be interesting to explore whether parents identified other parents of children with cancer to be a member of their significant other network. Thoits (2011) and Gage (2013) delineate between 'significant others' and 'similar others' and exploration around whether parents would themselves separate these groups would also be worthwhile. Further exploration around support needs for different decisions is warranted. Coyne et al. (2014) found that parents drew a distinction between 'major' and 'minor' decisions. It would be of interest to explore whether significant others had a different supportive role to play within the context of these different decisions. Other factors that affect decision-making support would also warrant further exploration such as demographic and clinical characteristics, and the extent to which the support from significant others actually influences the final decisions that parents make. Finally, greater understanding about what it feels like to be a parent being supported by their significant others with decision-making would facilitate development of important knowledge around this topic.

4.2 | Strengths and limitations

There are several general limitations acknowledged within this review. The publication dates of the retrieved studies spanned a significant time (from 1996 to 2021). It is important to be mindful of this, as social and cultural practices may have evolved during this time and it cannot be assumed that findings would still be the same today. Similarly, the research reviewed was representative of a variety of countries, and cultural transferability cannot be assumed. That said, this breadth of social and cultural practices has brought greater depth to the findings and could be perceived as a strength rather than a limitation of the review. Whilst some authors acknowledged the lack of cultural diversity as a limitation to their study (Cohen et al., 2017; Kilicarslan-Toruner & Akgun-Citak, 2013; Renner & McGill, 2016; Robertson et al., 2019; Stewart et al., 2012; Woodgate & Yanofsky, 2010), the ability to synthesise studies from a range of countries and cultures in this review has afforded a much greater diversity than would be possible in a single study.

TABLE 4 Types of decision and sources of support

Author and year	Type of decision	Source of support (significant other)
Alam and Kumar (2019)	Treatment abandonment	Other parents of children with cancer
Blakeley et al. (2000)	Choice of central venous access device	Family member
Cohen et al. (2017)	Nutrition (enteral tube feeding)	Other parents of children with cancer
Eder et al. (2007)	Enrolment in research trial	Family / friends / other parents of children with cancer
Gage (2013)	Not specified - any decision relating to child's cancer care	Other parents of children with cancer
Gage-Bouchard (2017)	Not specified but focus is on 'navigating the healthcare system'	Not specified but refers to 'personal networks' and suggests that this includes relatives and friends. There is specific reference to members of networks who are healthcare professionals
Hamama-Raz et al. (2012)	Surgical treatment (removal of eye as treatment for retinoblastoma)	Other parents of children with cancer
Holm et al. (2003)	General decisions about cancer care	Family / friends with medical expertise and other parents of children with cancer
Huang et al. (2008)	Various decisions; the focus of this research is not on decision-making but there is discussion about general decisions, place of care, education, and other lifestyle choices, all of which relate to the child's cancer care in a broad context	Family / friends and other parents of children with cancer
H-Yazdi and Meadows (2021)	Proton Beam therapy	Family / friends with specialist expertise; other parents of children with cancer and online support groups
Israels et al. (2008)	Treatment adherence / abandonment	Relatives, mainly grandparents
Jong et al. (2020)	Complementary and alternative medicine	Family / friends
Kelly and Ganong (2011)	Major treatment decisions and daily decisions	Step-parents
Kilicarslan-Toruner and Akgun-Citak (2013)	General decisions and information, for example mouth care, diet, and bigger treatment decisions	Relatives / friends / other parents of children with cancer
Levi et al. (2000)	Treatment / research decisions	Friends / family / other parents of children with cancer
Liang (2002)	General care decisions including diet, alternative medicines (e.g. Chinese medicine / herbal medicine)	Friends / community (elders) / religious community / grandparents / other parents of children with cancer
McKenna et al. (2010)	General treatment decisions	Grandparents and other relatives / family members
Mostert et al. (2014)	Treatment abandonment	Grandparents and other relatives / friends / community / religious community / other parents of children with cancer
O'Neill (1996)	Relapse treatment decisions	Family / friends / neighbours / religious communities / employer / NOT other parents of children with cancer
Papadatou et al. (1996)	Place of death of child with cancer	Relatives / grandparents / other parents of children with cancer / religious community
Renner and McGill (2016)	General treatment decisions	Friends / relatives / religious communities / herbalists / other parents of children with cancer / grandparents
Robertson et al. (2019)	General but emphasis on treatment decisions, also acknowledges minor decisions.	Online parent forums / other parents of children with cancer
Sitairesmi et al. (2010)	Treatment abandonment	Relatives / people on whom they are financially dependent / religious communities / other families of children with cancer
Stewart et al. (2012)	Major treatment decisions	Family / friends / religious figure
Woodgate and Yanofsky (2010)	Research trial enrolment	Family / friends with expertise
Yeh et al. (1999)	Treatment abandonment	Grandparents / parents of other children with cancer / religious communities and figures

A further consideration relates to the study participants. Kilicarslan-Turuner and Akgun-Citak (2013); Robertson et al. (2019); and H-Yazdi and Meadows (2021) acknowledged that a limitation of their studies was that fathers were underrepresented in their samples. Indeed, exploring the participant demographics highlighted that many studies within this review recruited a majority of respondents who were mothers. Robertson et al. (2019) noted that it is common to recruit mainly mothers in psycho-oncology research. It is therefore important to take into account that the prevailing voices in the findings of this review were from mothers, rather than fathers, of children with cancer.

There is potential bias in this review as only papers in the English language were included. Whilst significant efforts were made to retrieve all relevant studies, it is acknowledged that no search strategy is perfect and further networking and snowballing may have yielded further studies.

5 | CONCLUSION

Making decisions about a child's cancer care can be challenging for parents. Whilst attention has previously been given to how health-care professionals can support parents, little focus has been given to how parents' significant others can offer support. This integrative literature review has synthesised what is currently known about how parents are supported by their significant others when they are faced with these decisions.

Current international research suggests that significant others can support parents in three dimensions: informational, emotional and instrumental support. However, parents' perspectives of their own and others' roles in decision-making also influences how support may be provided and received. Sources of social support range from parents' family members and friends to other parents of children with cancer, and there is a fine line between supportive and unsupportive behaviours. The uniqueness of each family's personal, social and cultural context strongly impacts on their support needs, and healthcare professionals should be mindful of how parents may access support from their significant others in order to enhance provision of family-centred care.

6 | RELEVANCE TO CLINICAL PRACTICE

Whilst this review demonstrated that parents' decision-making support needs varied, it is evident that some parents did turn to their significant others for support. It is important that nurses and other healthcare professionals are aware of this and consider how decision-making may be influenced. Various strategies to support this are discussed in the literature such as sharing information booklets with families' social networks (Mostert et al., 2014), engaging local communities in educational programmes (Sitaresmi et al., 2010) and inviting other people to consultations (Eder et al., 2007; Massimo et al., 2004). The appropriateness of these strategies will

depend on families' individual contexts but should be considered in order to enhance provision of family-centred care.

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CONFLICT OF INTEREST

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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[Appendix 15: Reflections from the library: my transformation](#)

7th August 2023

I sit in the library writing the final words of Act 3. The sun is shining and above my laptop I look out at the beautiful view. I watch the glistening sea and the silhouettes of the other islands in the background.

An elderly man is sitting on a bench in the library gardens. He reminds me of my grandpa, who was a true Guernsey man and had lived here during the occupation of the Second World War. He died when I was 11 and although this was a long time ago I always think of him as being the family member who has influenced who I want to be more than any other – he was calm, gentle and wise, and I adored him.

Sitting here, I feel so closely connected to my life. I feel that I can see the clouds of my whole past move across the sky, ghosts walking along the path around me. I remember my childhood and walking through these gardens on our way to go shopping. I remember being a teenager and sitting in the gardens doing exam revision with my friends. I remember becoming an auntie and pushing my nephew in his pram up and down the hill. I remember the lockdown period when Henry and I moved here to be with my Mum, and we would go for beautiful walks every day. I remember the months following Mum's death when I was here alone, clearing her house and surrounded by not only my lifetime of memories but her lifetime – a life that I realised I had only known a part of.

All of these memories are with others – a child with my family, a teenager with my best school friends, an adult with my husband, and then most recently, a bereaved mother and daughter whose son and parents will always be part of me.

In the library gardens is a display of old Guernsey photographs. I realise that my memories here are a fraction of the lives and memories that this same view would have brought to others before me. I think of my grandpa looking out at this view the morning that the British troops arrived to liberate the islands on 9th May 1945.

I imagine that one day I will look at this view and remember the months that I spent watching it as I wrote my thesis. I find it difficult to imagine what those future days will be like.

I am listening to my PhD soundtrack. I realise that I am crying as I write. I have learnt to understand myself so much more clearly through doing this, and feel a sense of peace that I did not know possible. I feel transformed.

Appendices

Appendix 16: List of presentations delivered during the project

Year 1		
20.05.2020	Oxford Brookes University Children and Families Research Group	The evolution of my project: from proposal to ethics amendments
Year 2		
20.01.2021	Oxford Brookes University Supportive Cancer Care Research Group	What are parents' experiences of being supported by significant others, when faced with making decisions about their child's cancer care? Overview of literature review and study design
12.05.2021	Centre for Nursing, Midwifery, Health and Social Care, Research Away Day	3 minute presentation: overview of literature review and study design
16.06.2021	British Psychosocial Oncology Society Student and Early Career Researcher Event	Poster and 5 minute presentation (2 nd place): Overview of study and impact of covid-19 on research
22.07.2021	Hermeneutic Phenomenology course presentation (University of Central Lancashire)	Background of study with a focus on pre-understandings; and planned study design
28.07.2021	Great Ormond Street Hospital, Haematology / Oncology Strategic Research Meeting.	Presentation of the aims of my project with a focus on recruitment.
Year 3		
09.09.2021	Royal College of Nursing International Research Conference	Poster and short presentation. The ecomap: a tool to navigate nursing research.
12.05.2022	Oxford University Hospitals: Haematology / Oncology team journal club	Presentation of the aims of my project with a focus on recruitment.
Year 4		
12.10.2022	Oxford Brookes University Children and Families Research Group	Study update with focus on methodology.
12.01.2023	Oxford Brookes University Faculty of Health and Life Sciences Postgraduate Research Symposium	Poster presenting findings of literature review.
22.04.2023	British Psychosocial Oncology Society Conference Poster presentation	Poster presenting findings of literature review.
27.06.23	Oxford Brookes University Children and Families Research Group with visiting academic from Sweden	Shaping Confidence to Advocate for My Child. Overview of early findings.
04.07.23	ERICA International Research Symposium	Shaping Confidence to Advocate for My Child. Brief overview of early findings

Appendices

		and focus on next steps and implications.
06.07.2023	Hermeneutic Phenomenology course presentation (University of Central Lancashire)	Online Presentation – findings with early thoughts about philosophy / interpretive leaps.
Year 5		
22.11.2023	Sigma (Phi Mu Chapter): Children and Young People Themed Meeting	Online Presentation (international group) Shaping Confidence to Advocate for My Child. Focus on findings and philosophical basis.
15.01.2024	Oxford Brookes University Faculty of Health and Life Sciences Postgraduate Research Symposium	In person oral presentation (first prize awarded) Shaping Confidence to Advocate for My Child. Focus on findings and arts-based approach to interpretations