

Portfolio Volume 1: Major Research Project

**Childhood Cancer Diagnosis during the COVID-19
Pandemic: The Parent Perspective of the Impact on
the Family**

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A thesis in partial fulfilment of the requirements of University of
Hertfordshire for the degree of Doctorate in Clinical Psychology

Submitted: March 2023

Acknowledgements

My sincere thanks to the six parents who generously gave their time to share their experiences. I was greatly moved by your accounts, and I hope this thesis will be a platform for others to hear your voices that will contribute to some change.

To my supervisory team, Dr Shivani Sharma, and Dr Jen Heath – my grateful thanks for your constant support, encouragement, and enthusiasm for this project, and for helping me to strive forward with it, when at times it felt never-ending.

Huge thanks to my field supervisor, Dr Angela Kirby, for her clinical insight and persistence with recruitment. I am also grateful to the “expert by experience” parents, who gave valuable feedback that supported the project’s development.

I am thankful for the support of my course friends across Cohorts 18 and 19 with whom I shared the journey. Special thanks to Janine for the laughter, being a sounding board for ideas, and for being so supportive during the ups and downs of journeying on a different path. I am also grateful to my colleagues in the psychological medicine team, many of whom played a key role in keeping up my morale during the write-up phase.

As always, thank you to my family and friends for the continual support and encouragement in everything that I do. Especially to my parents who made the write-up possible by providing extra care for Oscar, and to Fabre for his patience in doing more than his fair share at times. I am more grateful than ever for the relationships that nurture my own resilience.

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List of Abbreviations

ALL	Acute Lymphoblastic Leukemia
AML	Acute Myeloid Leukaemia
CCLG	Children's Cancer Leukaemia Group
COVID-19	Coronavirus Disease (2019)
CP	Clinical Psychologist
CMM	Coordinated Management of Meaning
CNS	Clinical Nurse Specialist
COR	Conservation of Resources
CYP	Children and Young People
EBE	Experts by Experience
EOI	Expression of Interest
FCC	Family Centred Care
FSM	Family Stress Model
GET	Group Experiential Theme
HCP	Healthcare Professional
IPA	Interpretative Phenomenological Analysis
LFT	Lateral Flow Test
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
PCC	Parents of Children with Cancer
PET	Personal Experiential Theme
PIS	Participant Information Sheet
PPE	Personal Protective Equipment

PTSD	Post-Traumatic Stress Disorder
PTSS	Post-Traumatic Stress Symptoms
SARS-CoV-2	Serious Acute Respiratory Syndrome associated with Coronavirus
SLR	Systematic Literature Review
UK	United Kingdom
US	United States (of America)
WHO	World Health Organisation

Abstract

Paediatric cancer is rare, however, the significant impact on the whole family system is widely acknowledged. The COVID-19 pandemic posed many additional challenges for families, including fear of infection and social disruption caused by imposed restrictions. This study aimed to explore parents' perception of the impact of a paediatric cancer diagnosis during the pandemic on the family. Walsh's (2003, 2016) socio-ecological family resilience framework was used to highlight family processes, as well as to consider the broader influences on the family system, such as communication with healthcare professionals.

Six parents of children undergoing cancer treatment during the COVID-19 pandemic at Addenbrooke's Hospital, Cambridge, took part in semi-structured interviews. Using interpretative phenomenological analysis, three General Experiential Themes (GET) were identified. These themes simultaneously capture the stress that families experienced, while also describing family processes that buffered against the stress. *GET 1: 'Isolation versus Connection'*, describes feeling isolated from support networks, as well as building and strengthening connections. *GET 2: 'Managing Uncertainty'*, encapsulates parents' frustrations and fears related to information gaps linked to cancer treatment and COVID-19. *GET 3: 'Loss versus Solace'*, describes lockdown-related loss of routine and experience, and also positive factors to the imposed restrictions.

The study findings emphasise the dynamic relational aspects of resilience, where relationships and communication with other parents, children with cancer, and hospital staff, were important in fostering family resilience during the COVID-19 pandemic. Areas where structural and relational resources could be better promoted are also highlighted. The project's socio-ecological lens drew attention to the impact of other extrafamilial factors, such as organisational constraints and the impact of policy on single parents. The findings have applied implications for supporting family resilience in the aftermath of the pandemic, planning for future disaster situations, as well as relevance to paediatric cancer more broadly.

1. Introduction

1.1 Chapter overview

This qualitative study, using interpretative phenomenological analysis (IPA; Smith et al., 2022), explores parents' experiences of a childhood cancer diagnosis during the COVID-19 pandemic, and their perspective of how this impacted their family. This project takes a socio-ecological approach that considers the role of family resilience promoting factors, such as social relationships, as well as recognising the impact of stressors experienced. This chapter begins by situating myself as the researcher, followed by a brief discussion of language used in this thesis. Then an overview of the topic area is provided, summarising the NHS service context for paediatric cancer, and the context of the COVID-19 pandemic; finally, relevant theoretical frameworks and literature are outlined.

1.2 Situating the researcher

This section outlines my ontological and epistemological position in relation to this research, my relationship to the topic, and introduces a brief timeline of how this relates to the topic development. In acknowledging my position, and the co-construction of research between myself, the researcher, and study participants (Smith et al., 2022), the reflective sections will switch from the traditional, academic use of third person, to the first person.

1.2.1 Ontological and epistemological position

I begin by laying out both how I understand the nature of reality (ontology) and how we obtain knowledge (epistemology). This importantly influences all aspects of research, from methodology to analysis, to the way that quality is assessed (Carter &

Little, 2007). My ontological perspective is *critical realist*, resting on the assumption that reality is 'out there', which includes social processes, existing independently from how we interpret and conceptualise it (Bhaskar, 1993). A critical realist perspective also emphasises that reality is embedded in societal structures and social experience; it occurs in the mind of individuals who experience multiple realities in different ways, influenced by their attitudes, beliefs, perceptions, and experiences (Grbich, 2012). A critical realist ontological position was relevant because it attends to the reality of cancer and the COVID-19 pandemic, as well as other social structures that may influence the participants' accounts.

My epistemological position is *interpretative phenomenological*, as I am interested in parents' perception and experience of a childhood cancer diagnosis during the COVID-19 pandemic. Although it is recognised that experience is constructed through individual interpretation, it feels 'real' to the person having the experience (phenomenology). The process of active interpretation is also recognised: participants themselves are interpreting what they experience, and researchers are then influenced by their own experiences when interpreting the participants' interpretations, which is known as the *double hermeneutic* (Smith & Osborn, 2007). Finally, a critical approach was taken to phenomenology by acknowledging that these experiences were embedded in a social structure (Guenther, 2019).

1.2.2 *Relationship to the topic*

My relationship to this topic began professionally, having worked for a paediatric brain tumour service before entering clinical psychology training. Though mainly focusing on child neuro-cognitive and psychosocial effects, the small amount of work

participating in a family therapy reflecting team made a big impact on me. This work involved multiple family members, including biological parents and stepparents, siblings, and grandparents. The dynamics within families' responses to living with brain tumours, and their resilience using their collective resources, fostered my interest in capturing a whole family perspective in research.

Then came the COVID-19 pandemic, which undoubtedly touched everyone in some way. Although there were also positive factors, the pandemic has posed many challenges for parents, particularly for families with children with health conditions. While my experience does not have parity with that of the parents in this study, my first child was born just before the first 'lockdown', which challenged my usual resources and coping strategies, leaving me feeling isolated from my support network. My previous experience of working with families with a child diagnosed with cancer led me to be curious about families' lived experiences in the context of the pandemic, and how this may have challenged their families' resources; I saw value in learning about how they responded to it, and ways that their resilience may have been better promoted.

1.2.3 Timeline of topic development

In October 2019, my initial conceptualisation of the project was to investigate the impact of a cancer diagnosis on family resilience from multiple family members' perspectives, including the child with cancer and siblings, as family resilience or functioning involves all members of the family (Van Schoors et al., 2015). This influenced the focus of my systematic literature review to synthesise qualitative research that includes more than one family member (Chapter 2).

When I returned from maternity leave in January 2021, I returned to an NHS still amid a global pandemic. The project shifted focus to capture the experience of paediatric cancer specifically during the pandemic. With cumulative effects of the pandemic on the NHS, including delays in processing ethics applications, and staff being increasingly overstretched, in addition to the time constraints of the course, it felt realistic to narrow the focus to parents.

1.3 Terminology and language

The idiographic aspect of IPA requires close attention to language (Smith & Osbourn, 2007). Key terms are defined below in terms of how they are understood within the thesis:

Paediatric oncology

Paediatric oncology refers to cancer medical services that are commissioned for children and young people (CYP) up to 18-years-old (NHS, England, 2017). The service in which this study took place, at Addenbrookes, Cambridge, cares for CYP from birth to 16 years.

Parent

The social and relational component of parenthood was used to define *parent*, which refers to the rearing, nurturing, and loving of a child, whether biological, adoptive or stepparent (Steinbock, 2006). Terms that participants used themselves to describe their family relationships were used within the main study.

Family

The definition outlined by Kaslow (2010) was used to define *family*: “those who make a mutual commitment to regard one another as family, and to assume certain responsibilities to and for each other on a sustained basis” (p.55). Within this study, this included nuclear and extended families, stepfamilies, and adoptive families (Kaslow, 2010).

Family resilience

A relational definition of resilience was understood as: “the capacity of the family as a functional system to withstand and rebound from adversity” (Walsh, 2021, p.225). Resilience was understood in dynamic terms and through a socio-ecological lens, whereby risks or stressors can be countered, and resources can be mobilised, through family transactional processes with the community and social environment (Ungar, 2010; Walsh, 2021). Resilience is therefore seen as a *process* rather than an outcome. A dynamic systemic framework of family resilience is outlined in section 1.5.3.

Family functioning

A pluralistic definition of family functioning was used that accounts for the variety of structures that families take, focusing on the effective family processes and quality of relationships that are most important for the child’s well-being (Walsh, 2015; see section 1.5.3). Therefore, family functioning was understood as being context-bound and dependent on aspects such as family values, structural, situational, and relational resources and constraints, and challenges faced (Walsh, 2015).

1.4 Background literature: Situating the topic

As the study's focus is parents' perception of the impact of a cancer diagnosis on the family, the context of paediatric cancer and the importance of family centred care (FCC) are first outlined. Then the broader context of the COVID-19 pandemic and its restrictions are described that consequently impacted FCC.

1.4.1 Paediatric cancer

Paediatric cancer is rare compared to adult cancers: around 1,635 UK children (up to 15-years-old) are diagnosed yearly (Children with Cancer UK, 2021). CYP are diagnosed with a range of cancers in the UK, the most common being leukaemia (cancers of blood cells within bone marrow) and lymphomas (cancers of the lymphatic system; 41%), followed by brain tumours (25%), with the remaining comprising a range of solid tumours (cancers in organs; Children with Cancer UK, 2021). There are a range of intensive treatments that CYP could go through that includes: surgery to remove tumours; chemotherapy or radiotherapy to destroy cancer cells; and immunotherapy drug treatment that targets specific cancer cells (Children with Cancer UK, 2021). While cancer is the principal cause of death for CYP worldwide, within high-income countries, significant improvement in treatment means that around 80% survive (World Health Organisation (WHO), 2021a).

Most childhood cancer survivors and their families adapt well after diagnosis and treatment (Kazak, 1994, 2004). Yet childhood cancer poses a threat to life, and often intensive treatment is endured, where stress, nausea, and fatigue are experienced. A cancer diagnosis and its subsequent treatment can disrupt physical growth, and brain tumours and their treatment can also alter cognitive development (Marusack et al., 2018). Kazak and Noll (2015) refer to childhood cancer as a

“family disease”: a highly stressful experience that can challenge the whole family system (Fuemmeler et al., 2001; Kazak, 1998), with the time around diagnosis being one of the most distressing (Petino-Fènanchez et al., 2008).

1.4.2 Family Centred Care and the current NHS context

Following diagnosis, parents must adapt to a new caregiving role embedded within the healthcare world. FCC emerged as a concept in the 1980s, aiming to promote collaboration between parents and medical professionals (Rosenbaum et al., 1998). The guiding FCC principles are:

- Responsibility ultimately lies with parents for their child's care.
- Promoting family member involvement.
- Treating families respectfully.
- Giving families the option to decide how to be involved in decision-making around their child's treatment.
- Considering all family member's needs (Rosenbaum et al., 1998).

Based on FCC principles, guidelines from the National Institute for Health and Care Excellence (NICE, 2014), aimed at improving childhood cancer outcomes, recommend that healthcare staff address psychological, social and information support needs of those diagnosed with cancer and their families at key transition points, including diagnosis and during treatment. Assessment should include the needs of siblings, family information and coping skills. The service specification for delivering children's cancer services in England (NHS England, 2021) specifies that the impact on the wider family of a cancer diagnosis should be addressed through support of multi-disciplinary teams, including health/social care professionals (NHS

and charity-funded), involving specialist psychology provision, play specialists, and social workers (NHS England, 2021).

1.4.3 COVID-19 and restrictions

In January 2020, a global pandemic (COVID-19) caused by the spread of SARS-CoV-2 virus (WHO, 2020) was declared. An immediate response took place to protect public health, including imposing travel restrictions, infection control measures, and quarantine policies. The whole UK population was required to 'lockdown' in March 2020, involving restricted movement out of the home, except for essential purposes, and various levels of imposed restrictions continued until December 2021 (Institute for Government Analysis, 2022).

In the UK, children with cancer were initially considered 'clinically extremely vulnerable' due to immune suppression because of anti-cancer treatment and were required to 'shield' and remain at home (CCLG, 2020; Darlington et al., 2020). Data later collected suggested that risk of children with cancer developing complications was minimal in the UK (Millen et al., 2021), though other studies reported globally suggested elevated risk with socioeconomic and ethnic disparities in these effects (Khan et al., 2022). Restrictions in hospitals were also important to protect vulnerable staff and maintain sufficient levels of staffing to run services (Shemtob et al., 2022).

Oncology services in the UK continued diagnosing and treating CYP with cancer, but several restrictions were put in place for CYP, their families and staff to prevent the spread of infection (Bouffet et al., 2020). This included: limiting paediatric wards and clinics to one parent only; limiting outpatient appointments to digital/video communication where possible; reduced psychosocial services often limited to virtual

care (Moreira et al., 2021); respecting social distancing rules; closure of communal spaces; hygiene protocols through hand washing and wearing personal protection equipment (PPE) for staff, and face masks for parents; screening for COVID-19 with lateral flow tests (LFT) for patients and parents entering the ward (Bouffet et al, 2020); and segregating patients by isolating those with, or 'at risk' of having, COVID-19 (Amicucci et al., 2020). The combination of COVID-19 and restrictions imposed caused significant disruption to oncology services, including worsened staff shortages, fear of infection, and risk of burnout (Sniderman et al., 2022).

The next section and systematic review will consider the impact of cancer on families more broadly before returning to consider the specific context of the COVID-19 pandemic at the end of Chapter 2.

1.5 Overview of conceptual and theoretical frameworks

1.5.1 *Systemic theories of impact of illness on the family*

A child's cancer diagnosis is classed as a highly stressful and unpredictable event that challenges the adjustment of the whole family system (Kazak et al., 2009).

Centred on general systems theory principles, several models consider how families function within the context of chronic illness. General systems theory (Engel, 1980; von Bertalanffy, 1968) postulates that systems comprise interdependent parts, with relationships and rules that shape the way the systems behave and interact. Open systems like families are constantly in flux, attempting to reach homeostasis through continually exchanging between their subsystems (e.g., parent-child, parental, and sibling subsystems) and through interchange with wider systems within which they are rooted (e.g., extended family, community). To understand family systems, the

inter-relationships between them need to be considered, as well as how they are organised (Hildenbrand & Alderfer, 2019; Hildenbrand et al., 2021).

The Circumplex Model (Olson et al., 1983; Olson, 2000) considers how families function in response to stressors like cancer, based on how “*balanced*” and therefore, how “*functional*” they are on two dimensions: flexibility and cohesion. Cohesion is defined as emotional closeness of a family and focuses on a balance between “*separateness and togetherness*” (Olson et al., 2019). Flexibility is how well family systems can change in response to stress, considering factors like role changes and relationship rules. A third factor is communication, which has a facilitating role, including aspects such as clarity, openness and problem-solving (Olson et al., 2019). Though useful in identifying families’ adaptive processes and patterns in experiences, this model has been critiqued from a family diversity perspective, arguing that “normal functioning” is narrowly defined (Walsh, 1996). Walsh (1996) highlighted that high cohesion (i.e., “*enmeshment*”) may be culturally or situationally normative, including facing family crises such as a cancer diagnosis.

Social constructionist frameworks can offer a helpful lens to add to the understanding of family functioning (Anderson, 1987; Dallos & Urry, 1999; White, 1995). Within this framework is the acknowledgement that individual and families’ beliefs are shaped by the wider social context, and that language contains the building blocks for constructing experience (Dallos & Urry, 1999). As an alternative to individualising and seeing problems as determined by family dynamics, a social constructionist framework spotlights oppressive discourses and power structures and recognises that patterns or problems are not simply constructed by families (Dallos & Urry, 1999).

1.5.2 *Family stress models*

Several family stress models (FSMs) posit that families are vulnerable to adjustment difficulties because childhood cancer is an unpredictable stressor that unsettles homeostasis within the family. For instance, Hill's (1958) ABC-X model proposes that A represents the stressor event (cancer diagnosis/treatment); B represents resources, or the family's ability to adapt to illness; C represents the meaning that families attribute to the situation/illness; and X represents the crisis level that a family experiences. While useful in identifying factors explaining how families cope with stress, a key criticism of FSMs is the unidirectional nature that precludes envisaging ways that families can work proactively to transform their situation (McGoldrick et al., 2015; Usiskin-Cohen & Domakin, 2019). It also does not acknowledge multisystemic sources of stress that might impact families (McGoldrick et al., 2015; Usiskin-Cohen & Domakin, 2019).

Kazak & Baxt (2007) proposed a post-traumatic stress framework for children and parents for symptoms that may emerge across cancer treatment. Post-traumatic stress disorder (PTSD), and its related symptoms has been a dominant psychological outcome measured in children with cancer (Phipps et al., 2014) and their parents (Ljungman et al., 2014; Phipps et al., 2015). In psychiatric literature, PTSD is the consequence of disorganized/incomplete processing of emotions and cognitions from traumatic event(s) (Priya, 2015). In the context of cancer-related trauma, the term post-traumatic 'symptoms' (PTSS) is frequently used to account for the different experience in the medical context. The application of these criteria, however, needs careful attention to phenomenology, and normative responses to cancer need consideration (e.g., fear of progression; Cordova et al., 2017). Moreover, Phipps et al. (2014, 2015) posit that asking parents and children to

think of their experience as traumatic may bias their responses (i.e., “focusing effects”). This, in combination with a lack of appropriate control comparisons or consideration of other contextual factors (e.g., previous trauma, socioeconomic status; Cordova et al., 2017), has skewed the literature towards inflated prevalence of PTSD/S in children with cancer and their parents (Cordova et al., 2017; Phipps et al., 2014, 2015) and siblings (Long et al., 2018).

1.5.3 Family resiliency models

Several systems-orientated resilience frameworks have identified key processes thought to strengthen families’ ability to cope with stressful events (Simon et al., 2005). The Resiliency Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1996) identifies that families adjust to stressful life events, such as childhood cancer, depending on certain aspects of family functioning. In applying the model to parents of children who survived cancer, McCubbin et al. (2002) found that important resilience variables included the ability to rapidly mobilise and reorganise family structure (e.g., adapting roles and responsibilities), social support from healthcare teams, extended families and communities, and changes in appraisal to make sense of the situation.

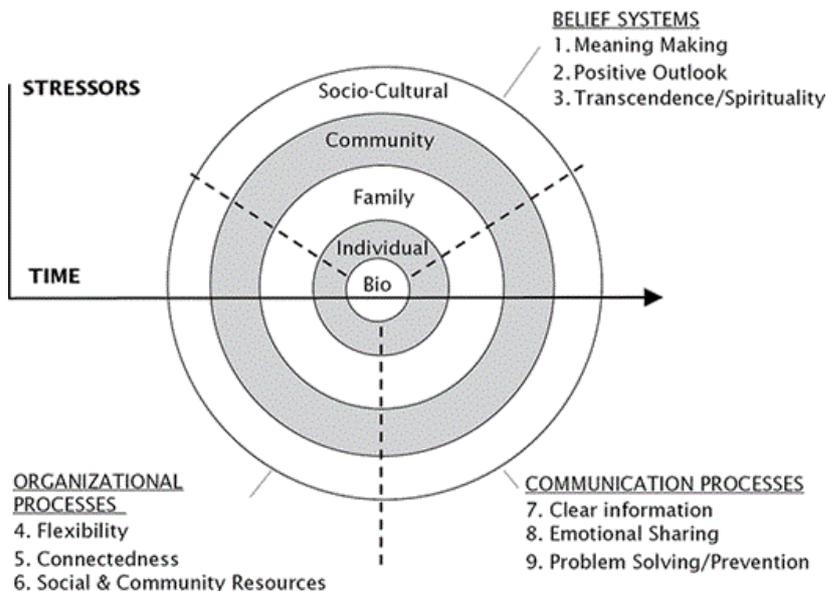
Arguably Walsh’s (2003, 2016) family systems model provides more flexibility as it can capture diversity and difference in family structure and context (Faccio et al., 2018). Taking an ecological and developmental view, Walsh (2003, 2016) defines family resilience as a function of the family system in coping with stress or “challenge”. The framework comprises three main domains: (1) belief systems, including making meaning of adversity, positive outlook, transcendence, and spirituality; (2) organisational patterns, including flexibility, connectedness, social and

economic resources; (3) communication/problem-solving, including clarity, open emotional sharing and collaborative problem-solving (Walsh, 2016).

The developmental aspect is important in the context of chronic illnesses like cancer, as it can evolve across its course (i.e., crisis of diagnosis versus chronic 'long haul'), requiring families to adapt across time (Rolland, 2018; Walsh, 2021). Finally, the eco-systemic aspect holds the family, peer group, community, and other social systems, such as healthcare, as well as the broader influence of political, economic, and socio-cultural factors, as nested contexts for resilience (Walsh, 2021). As such, social influences can be understood as dynamic processes within and across these system levels that can mobilise resources to promote family resilience (Ungar, 2010; Walsh, 2021; Figure 1).

Figure 1

Dynamic systems perspective of family resilience (from Walsh, 2016)



1.5.4 Communicating with the healthcare system

Walsh (2021) emphasises that an integrated systems perspective of resilience considers the dynamic nature of adaptation in children, adults and families and the role of other systems (e.g., healthcare) in their resilience. A recent systematic literature review by Sisk et al. (2018) summarised the importance of communication between clinicians and patients or parents in paediatric oncology. Sisk et al. (2018) utilized Epstein and Street's (2007) framework in mapping the findings to six functions of communication: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and fostering self-management. Sisk et al. (2018) highlighted that clear, honest communication was associated with parental trust and wellbeing. In the context of paediatric cancer, the healthcare system becomes a significant part of the ecology of the child and family, and thus the quality of interactions within this system is likely to shape the way a family adapts (Clarke & Fletcher, 2003; Kazak et al., 2009).

1.5.5 Family resilience in paediatric cancer

Within paediatric cancer, research has focused on evaluating family function in response to cancer as a measure of family resilience (Hillard et al., 2012; Van Schoors et al., 2015). Two systematic reviews (Long & Marsland, 2011; Van Schoors et al., 2015), summarising qualitative and quantitative research, conclude that families generally adapt well, showing good levels of family functioning in domains such as cohesion, communication, conflict, adaptability, and maintaining/increasing family support, while a subset experience difficulties. Van Schoors et al. (2015) highlights that families might be 'at risk' around diagnosis and treatment for difficulties in adaptation and conflict, however, this pattern may be situationally

normative at this stage (Van Schoors et al., 2015; Walsh, 1996). In a meta-analysis, Van Schoors et al. (2017) found that greater family cohesion, expressiveness of thoughts and emotions, support received, and less family conflict were each associated with more positive outcomes for children.

Several issues limit understanding of family resilience in this field. Family resilience has broadly been considered as an *outcome* measured through indices of family functioning (Van Schoors et al., 2015), whereas family resilience can be seen as a *dynamic process* (Walsh, 2016). This is notable when using quantitative measures of family function, as findings are static and acontextual, with family stressors that rise within social and developmental contexts missing (Walsh, 2021). With resilience models applied to paediatric cancer (McCubbin et al., 2002) focusing on parental experiences and survivorship, examination of the time around diagnosis and treatment may capture different processes in understanding family resilience. Finally, since the unit of interest is functioning of the whole family, arguably the majority of studies only including a single informant limits the breadth of understanding of how families experience a paediatric cancer diagnosis (Van Schoors, 2015).

2. Systematic Literature Review

Understanding how families make sense of a cancer diagnosis can provide helpful insights into understanding processes underpinning family resilience. While a previous qualitative review focused on parents' experience (Gibbins et al., 2012), there is no qualitative review focusing on qualitative data from multiple family perspectives. Where previous reviews have highlighted family function as an outcome (Van Schoors et al., 2015), this systematic literature review (SLR) sought to highlight processes and contextual factors within family resilience as described by multiple family members.

This SLR aims to address current gaps outlined above by 1) conducting a rigorous qualitative thematic synthesis on families of children 0-18 years and their experiences of how they cope as a family with diagnosis and treatment; 2) including only studies that sought to collect data from two or more family members. This SLR sought to understand how families perceive diagnosis and treatment of cancer of a child within their family, including studies carried out while the child was on treatment, or after recent completion (i.e., pre-survivorship). The first task was to evaluate research quality in this area. Second, to answer the following key question, within the family resilience framework (Walsh, 2016, 2021):

How do families cope with the diagnosis and treatment of cancer of a child within their family?

2.1 Method

An SLR following PRISMA guidelines (Page et al., 2021) was conducted (PROSPERO registration number: CRD42022286686). The design facilitated a meta-synthesis of evidence using techniques to compare, translate, analyse, and

form new interpretations from original studies, drawing on the principles of thematic synthesis (Thomas & Harden, 2008). The approach enabled a transformation from descriptive to analytical themes. The method involved four stages: a) a focused literature search; b) quality assessment of evidence; c), extracting data; and d) data synthesis.

2.1.1 Search and inclusion strategy

First, scoping of relevant literature was performed through examining existing SLRs (e.g., Van Schoors et al., 2015), and more recent studies in the area (Siddaway et al., 2019). Four electronic databases were then searched in January 2022: PubMed (04/01/22), Scopus (05/01/22), and CINAHL Plus (20/01/22), and PsycInfo (20/01/22). Databases were selected to target studies across a range of disciplines including medicine, nursing, social work and applied social sciences. Alerts were set up to include new studies published up to commencing data analysis. The search was repeated in October 2022, which yielded no further results.

Databases were searched using terms associated with families' experience of coping with paediatric cancer diagnosis and treatment. Search terms were determined by initial reading of articles generated by the scoping of relevant literature and were refined through individual searches in each database. Where appropriate, search terms were truncated (e.g., Child* = children, childhood), and Boolean operators (AND/OR) were combined within search terms (search terms are included in Table 1).

Table 1*Search terms used in systematic literature search***Search Terms**

Sample	Phenomenon of interest	Design	Evaluation
Family OR parent* AND Child* OR pediatric AND Cancer OR leukemia OR oncology	Coping OR resilience OR “family functioning”	Interview OR narrative OR phenomenological OR phenomenology OR theme OR thematic	Perception OR experience*

Inclusion criteria were drawn up to assess whether data was relevant to the research aim. Qualitative studies that focused on interviewing two or more family members were included. Due to the limited timescale, only English language papers were included. Full inclusion/exclusion criteria are summarised in Table 2.

If the outcome was unclear from viewing the abstract, the study was extracted in full. Full texts were then assessed against the eligibility criteria. A subset of randomly selected abstracts (15%) and full texts (15%) were assessed by an independent reviewer (assistant psychologist working in paediatric oncology), resulting in inter-rater reliability of 88% (Cohen’s $k = 0.66$; substantial agreement) and 83% (Cohen’s $k = 0.67$; substantial agreement) respectively (Landis & Koch, 1977). Discrepancies were resolved by discussion with the independent reviewer. The reference lists of accepted papers were also hand-screened, revealing no further papers.

Table 2*Literature search inclusion and exclusion criteria*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Studies that aim to explore the experience of two or more family members of a child diagnosed with cancer (e.g., child, parent (mother and/or father), sibling, grandparent etc). • Focuses on the experience of the family of diagnosis and treatment of cancer • Child is still on active treatment or within two years of completion • Child diagnosed with any type of malignant¹ cancer, aged 0-18 years • Study setting in hospital (paediatric oncology departments) or community settings • Qualitative studies • Articles were written or translated into English • Empirical studies carried out in middle- and high-income countries • Published in peer-reviewed papers from 1987² up to the point of analysis. 	<ul style="list-style-type: none"> • The cancer patient is an adult (>18 years) • The focus is on survivorship (i.e., >5 years since diagnosis, >2 years treatment completion, child cancer free; Masera et al., 1996) • Focus is only on the couple or individual family member's experience • Studies where the child is receiving palliative care or where the family have been bereaved as this is a different experience • Focus specifically on the treatment rather than the families' experience • Studies that include members of the wider system/non-family members (e.g., oncology staff) • Studies that include other paediatric health conditions (e.g., cystic fibrosis etc.) • Studies carried out in low-income countries, as it was felt that the experience of healthcare systems is likely to be different • The study is quantitative or mixed methods • Non-peer reviewed and non-empirical articles (e.g., dissertations, commentaries, systematic reviews)

¹A 'malignant' tumour is cancerous, whereas a benign tumour is non-cancerous - the difference being that the cancer cells of malignant tumours can spread beyond the original area of the body (Children with Cancer UK, 2021)

² 1987 is when paediatric departments formally recognised FCC within service delivery (Shelton et al., 1987).

2.1.2 Data extraction

Research methodology and sample characteristics were extracted and tabulated in Table 3. To check extraction accuracy and increase credibility, 30% of articles were randomly selected to be double extracted by the independent reviewer.

Studies' aims varied, with some broadly focusing on lived experience of cancer diagnosis and treatment from the family perspective of at least two family members (e.g., Björk et al., 2005, 2009), while others focused on specific aspects of family functioning, such as how families support each other (Van Schoors et al., 2020). However, they all contained aspects of family functioning and resilience, hence there was sufficient heterogeneity for a qualitative synthesis.

2.1.3 Data synthesis

A thematic synthesis, guided by the principles of Thomas and Harden (2008), was chosen as it aligned with the study's critical realist stance, considering that reality is moderated by individuals' perceptions and beliefs. The synthesis was also chosen for the scope to go beyond summarising studies' primary content, allowing the generation of new concepts. The process began in an inductive way, extracting data related to multiple family members' experience of childhood cancer. Then through discussion with the research supervisory team, it was decided that the deductive approach of applying theoretical perspectives on family resilience could also enable new understanding of families' experiences. Reviewing papers began with the oldest publications and followed Thomas and Harden's (2008) key phases: 1) initial line-by-line coding of results; 2) grouping of codes into broader level descriptive themes; 3) constructing overarching themes. The papers were stored and coded in NVIVO v.1.6.2 (QSR International, 2020).

During the whole process, I reflected on my positionality, including being a trainee clinical psychologist who has worked clinically in paediatric oncology, to maintain transparency. Coding was carried out by me, the researcher, but in consultation with the supervisory team to increase credibility.

Table 3*Characteristics of included studies*

Title(s), Author, Country	Aim	Participant/Sample	Parental marital status	Cancer patient demographics	Exclusion	Design/ Data collection	Data Analysis	Theoretical framework
Striving to survive: families' lived experiences when a child is diagnosed with cancer Björk et al. (2005) ^a Sweden.	To elucidate the family's lived experience when a child is diagnosed with cancer.	Purposeful, criterion sample from paediatric oncology department. 17 families T1: 17 mothers, 12 fathers, 5 patients, 5 siblings.	Not stated.	<i>Age:</i> 7-12 <i>Gender:</i> 80% M <i>Ethnicity:</i> -- <i>Cancer Type:</i> T1: Leu-U (9); BT (4); ST (4) <i>Time since diagnosis:</i> T1: within 1 month	Child age >13 years; unable to speak Swedish; not started treatment; relapse of cancer; child patient or both parents not wanting to participate.	Longitudinal (3 time points – time 1), descriptive inductive design Individual semi-structured interviews.	Hermeneutical Phenomenology (van Manen, 1997).	Brief mention of family systems theory.
An everyday struggle: Swedish families' lived experiences during a child's cancer treatment Björk et al. (2009) ^a Sweden.	To elucidate the family's lived experience during the course of a child's cancer treatment.	Purposeful, criterion sample from paediatric oncology department. 17 families T2: 9 mothers, 9 fathers, 4 patients, 4 siblings.	Not stated.	<i>Age:</i> 7-12 <i>Gender:</i> 80% M <i>Ethnicity:</i> -- T2: Leu-U (6); BT (2); ST (3) <i>Time since diagnosis:</i> T2: 2-10 months	Child age >13 years; unable to speak Swedish; not started treatment; relapse of cancer; child patient or both parents not wanting to participate.	Longitudinal (3 time points – time 2), descriptive inductive design Individual semi-structured interviews.	Hermeneutical Phenomenology (van Manen, 1997).	McCubbin's model of family stress mentioned in discussion.

Reconstructing reality: family strategies for managing childhood cancer. Clarke-Steffen (1997) USA.	To understand the process in which families engage as they adapt to the diagnosis of cancer in a child and to generate theory about the family transition to living with childhood cancer.	Purposeful, convenience sample from paediatric oncology service. 7 families (7 mothers, 7 fathers, 6 patients, 12 siblings)	All 2 parent families (married).	Age: 2- 11 Gender: 4 F, 3 M Ethnicity: White Cancer Type: Leu-U or Lym-U7- <i>Time since diagnosis:</i> 30 days post-diagnosis; 1 week after remission; 3 months later.	Expected survival rate <60%	Longitudinal – Individual (T1, T2) and whole-family (T3) semi-structured interviews.	Grounded Theory – constant comparative analysis (Glaser & Strauss, 1967).	Family Management Style Framework
Beginning treatment for paediatric acute myeloid leukaemia: diagnosis and the early hospital experience McGrath et al. (2004) Australia.	To explore the impact of diagnosis and early treatment.	Purposeful convenience sample at oncology ward. 3 families (3 mothers, 1 father, 1 adult sibling, 3 child patients)	2 married couples; 1 single-parent family (but contact with father)	Age: 12 -15 Gender: M 1; F 2 Ethnicity: -- Cancer Type: AML (3) <i>Time since diagnosis:</i> 2-3 months	Cancer other than AML.	Individual semi-structured interviews (T1 of Longitudinal study)	Descriptive, phenomenological approach (Spiegelberg, 1975)	None.
Beginning Treatment for Paediatric Acute Myeloid Leukemia: The Family Connection McGrath et al. (2005) Australia	To explore the experiences at home at the beginning of treatment of AML on all family members from the perspective of mothers, father, sibling and child patients.	Purposeful convenience sample at oncology ward. 3 families (3 mothers, 1 father, 1 adult sibling, 3 child patients)	2 married couples; 1 single-parent family (but contact with father)	Age: 12 -15 Gender: M 1; F 2 Ethnicity: -- Cancer Type: AML (3) <i>Time since diagnosis:</i> 2-3 months	Cancer other than AML	Individual semi-structured interviews (T1 of Longitudinal study)	Descriptive, phenomenological approach (Spiegelberg, 1975)	None.
Balancing grief and survival: Experiences of	To explore experiences of	Purposive convenience sample from brain	10 married, 2 separated	Age: 7 -14 Gender: 6 M, 6 F	Diagnosis <3 months; Child	Individual semi-structured	Constructivist Grounded Theory	Dual Process Model of coping with

children with brain tumours and their parents. Russell et al. (2016) Canada.	childhood brain tumours from the perspectives of children and parents, to gain a richer understanding of how they experience and cope with their emotions, and how family relationships are shaped by the illness and their responses.	tumour hospital programme 12 families (11 mothers, 1 father*, 12 child patients)	(but contact with fathers)	'Family' Ethnicity: Canadian/European (7) Eastern Indian (2), Middle Easton (1), Canadian-Aboriginal (2) Cancer Type: BT (12) <i>Time since diagnosis:</i> 3 – 36 months; All children were within 12 months or less of their last treatment*.	expected to die within 6 months; parents thought to be overwhelmed.	interviews (one child interviewed with parent)	(Charmaz, 2003, 2014)	bereavement (Stroebe & Schut, 1999)
Rural families' perspectives on having a child with cancer Scott-Findlay & Chalmers (2001) Canada.	To explore and describe families' experiences of having a child with cancer in a rural geographic area.	Purposive convenience sampling from a cancer treatment centre. 10 families 25 family members - 11 parents*, 2 grandparents, 10 child patient and 2 siblings.	Two parent families (not all married)	Age: 2- 18 Gender: 8 M, 2 F Ethnicity:-- Cancer Type: ALL (2), BT (2), WT (2), NHL (2), AML (1), Abdominal Tumour (1). <i>Time since diagnosis:</i> 3-36 months	Child with cancer is palliative.	Family/Couple semi-structured*, participant observations	Ethnographic approach - Exploratory descriptive analysis (guided by 4 principles of Morse & Field, 1995).	Brief mention of family systems theory.
Parents' Perspectives of Changes Within the Family Functioning After a Paediatric Cancer Diagnosis: A Multi	To explore changes in family functioning after the diagnosis of paediatric cancer	Random selection of a purposive sample across 4 Belgian hospitals. 10 couples	Married couples.	Age: 4-16 years Gender: 7M, 3F Ethnicity: Belgian Caucasian	Not speaking Dutch; developmental disorder in	Individual semi-structured interviews.	Multi-Family Interview Analysis (Van Parys et al., 2017; based on Interpretative	Family systems theory.

Family Member Interview Analysis Van Schoors et al. (2018) ^c Belgium.	from the perspective of the parents.	(10 mothers, 10 fathers)		Cancer Type: ALL (6); AML (1); NHL (3). <i>Time since diagnosis:</i> 6 – 33 months.	diagnosed child; relapse.		Phenomenological Analysis, Smith et al., 2009)	
The family practice of support-giving after a paediatric cancer diagnosis: A multi-family member interview analysis Van Schoors et al. (2020) ^c Belgium.	To explore how families support each other following a diagnosis of paediatric cancer.	Purposive sampling from a larger convenience sample across 4 Belgian hospitals. 4 families (4 mothers, 3 fathers, 5 siblings)	Married couples.	Age: 4-16 years Gender: 2M, 2F Ethnicity: Belgian Caucasian. Cancer Type: ALL (2); CML (1); NHL (1). <i>Time since diagnosis:</i> 5 -26 months	Not speaking Dutch; developmental disorder in diagnosed child; relapse; fewer than 2 family members participating.	Individual semi-structured interviews.	Multi-Family Interview Analysis (Van Parys et al., 2017).	None, but literature discussed on family support.

KEY:***Author was contacted for additional information****Papers that report the same sample:**

^a Björk et al., 2005 and 2009 report Time 1 and Time 2 data respectively, hence some participants are the same across papers. The data is different as the focus is on diagnosis and the second on the treatment phase, hence both papers were included.

^b McGrath et al. 2004 and 2005 report the same data set at the same time point - the two papers differ in that McGrath et al., 2004 focuses on the impact of diagnosis and early treatment, and McGrath et al., 2005 on experiences at home. For consistency, both papers were included.

^c Van Schoors et al. 2020 include some of the same parents that participated in Van Schoors et al. 2018, plus siblings, but the foci of the studies is different (changes to family functioning vs. family support, hence both papers were included).

Tumour types

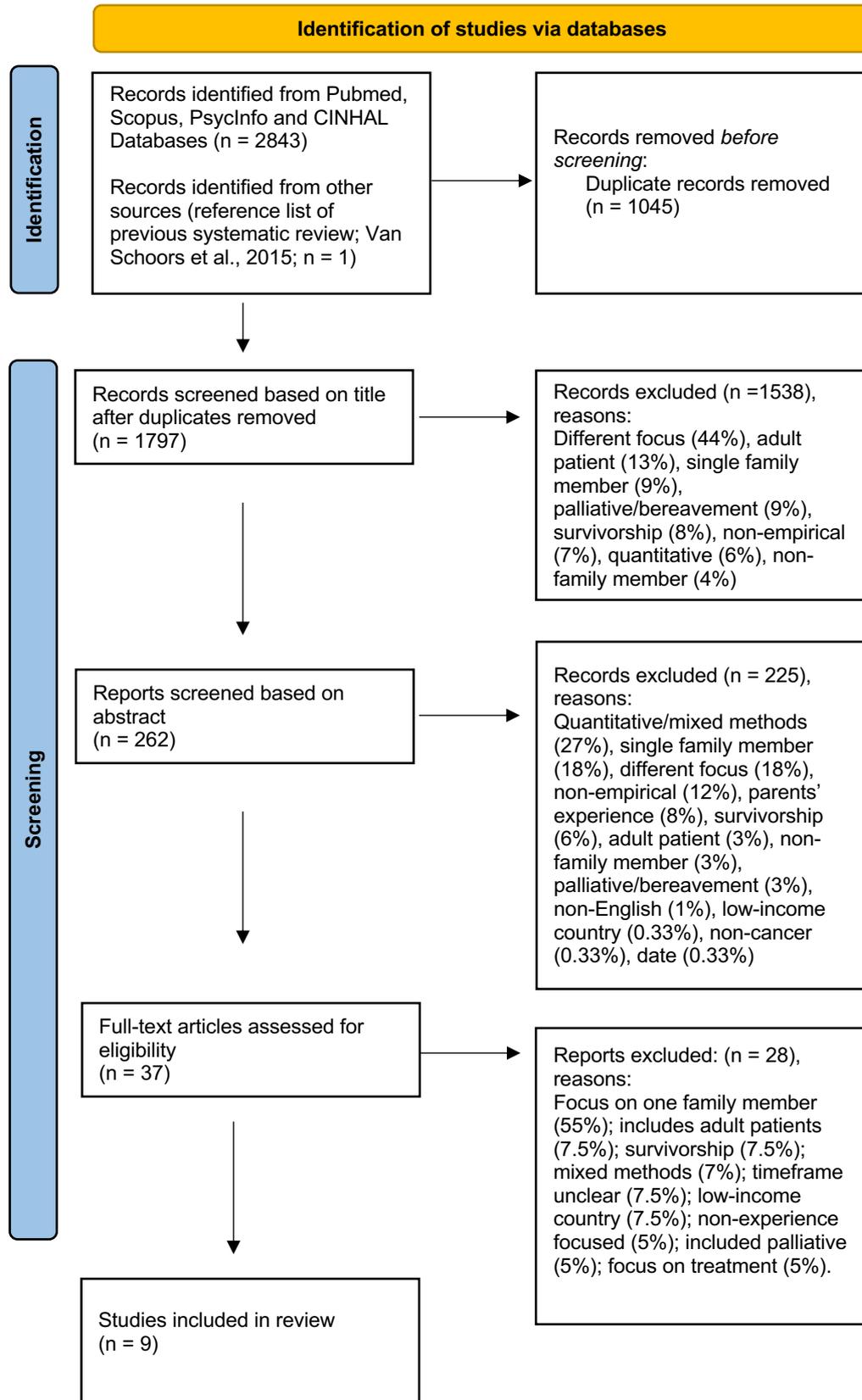
ALL: Acute lymphoblastic leukaemia; **AML:** Acute Myeloid Leukaemia; **BT:** Brain Tumour; **CNS-T:** Central Nervous System Tumour; **CML:** chronic myeloid leukaemia; **Leu-U:** Leukaemia unspecified; **Lym-U:** Lymphoma unspecified; **NB:** Neuroblastoma; **NHL:** Non-Hodgkin Lymphoma; **Sar-U:** Sarcoma unspecified;; **ST:** Solid Tumour; **RS:** Rhabdomyosarcoma; **WT:** Wilms' Tumour.

2.2 Results

Once duplicates were removed, 1797 articles were initially identified. Screening of titles and then abstracts took place against the inclusion/exclusion criteria, excluding a further 1538 and 225 articles respectively, leaving 37 full-text articles. Nine of which met the inclusion criteria (see Figure 2, PRISMA flow-chart). In six papers (i.e., three pairs: Björk et al., 2005, 2009; McGrath et al., 2004, 2005; Van Schoors et al., 2018, 2020), participants from the same samples were included across two papers. All six papers were included because the focus of analysis (and hence data) varied across the papers, and they were examined separately to allow for the evaluation of quality of each paper.

Figure 2

Systematic Literature Review (SLR) PRISMA flow-chart



2.2.1 *Quality assessment*

Study quality was evaluated using Tracy's (2010) "Big-Tent" Criteria for Excellent Qualitative Research. This framework was chosen as it provides detailed guidance to appraise qualitative studies that vary in epistemological stances and methods used (Gordon & Patterson, 2013; Tracy & Hinrichs, 2017). Table 4 summarises the critical appraisal.

Moderate levels of quality were noted in most studies, with three recent papers being rated at a higher level (Russell et al., 2016; Van Schoors et al., 2018, 2020). Areas of strength across most studies included achieving resonance through sufficiently evocative text and knowledge resonance. However, it was a bit unclear which family member was speaking in some papers (Björk et al., 2005; McGrath 2004, 2005). Credibility checks were mostly quite thorough, with thick description of findings given to illustrate support for themes generated. Most made use of multivocality (except McGrath et al., 2005), and where appropriate, member checking. Van Schoors et al. (2018; 2020) and Russell et al. (2018) stood out, as their themes were more nuanced: they capitalised on multiplicity by clearly highlighting contradictions as well as similarities (Mays & Pope, 2020), noting how accounts from multiple perspectives co-exist alongside, and relate to, each other (Larkin et al., 2019).

In terms of weaknesses, most studies did not achieve full criteria for rich rigour. Sufficient sample detail was mostly given, although five studies neglected to report ethnicity (Björk et al., 2005, 2009; McGrath et al., 2004, 2005; Scott-Findlay & Chalmers, 2001). Qualitative data collection and analysis when including multiple family members is a complex process (Reczek, 2014). Some rigour was shown through description of data collection and analysis. However, key limitations were a

lack of clear accounts of *why* multiple family members were included; and no description of *how* guiding epistemologies informed data coding for each family member (Reczek, 2014). While Van Schoors et al. (2018, 2020) did not explicitly state their epistemology, they provided a detailed account of how transcripts were analysed individually, then within family members, and then between families, using a multi-family member interview analysis (Van Parys et al., 2017). The discussion highlighted the advantage of this approach in illuminating families' experience of conflicting dynamics (Van Schoors et al., 2018).

Most studies gave sufficient attention to issues relating to including children, except Clarke-Steffen (1997) and Scott-Findlay et al. (2001): power dynamics were not discussed around deciding to interview families all together, and insufficient attention was given to how this was managed in the data analysis. Relational ethics were also limited, as children were interviewed but their views were not mentioned in the results.

Table 4*Systematic literature review quality appraisal*

Tracy (2010) "Big-Tent" Criteria for Qualitative Research

○ = Criteria met; ○ = Criteria partially met¹; ○ = Criteria not met

<i>Author(s) & Year</i>	<i>Worthy topic</i>	<i>Rich Rigour</i>	<i>Sincerity</i>	<i>Credibility</i>	<i>Resonance</i>	<i>Significant contribution</i>	<i>Ethical</i>	<i>Meaningful Coherence</i>
Björk et al, (2005)	○	○	○	○	○	○	○	○
Björk et al., (2009)	○	○	○	○	○	○	○	○
Clarke-Steffen (1997)	○	○	○	○	○	○	○	○
McGrath et al. (2004)	○	○	○	○	○	○	○	○
McGrath et al. (2005)	○	○	○	○	○	○	○	○
Russell et al. (2016)	○	○	○	○	○	○	○	○
Scott-Findlay & Chalmers (2001)	○	○	○	○	○	○	○	○
Van Schoors et al. (2018)	○	○	○	○	○	○	○	○
Van Schoors et al. (2020)	○	○	○	○	○	○	○	○

¹ 'Criteria partially met' meant that the paper met the criteria in some but not all aspects. In the example of ethics, Clarke-Steffen (1997) and Scott-Findlay & Chalmers (2001) discuss ethical approval and consent, but the studies are lacking in terms of relational ethics regarding the inclusion of children.

In terms of sincerity, there was some evidence of self-reflexivity and description of methodological limitations in most studies (Björk et al., 2005, 2009; McGrath et al., 2004, 2005; Van Schoors et al., 2018, 2000), although this was limited to stating professional background. Clarke-Steffen (1997), Scott-Findlay & Chalmers, (2001) and Russell et al., (2016) did not show evidence of self-reflexivity, though Russell et al. (2016) did show transparency in discussing difficulties faced.

Of note is the absence of theoretical frameworks or clear reference to previous research to guide the research question in more than half of the studies, except for the Family Management Style framework guiding Clarke-Steffen (1997), the Dual-Process model (DPM; Stroebe & Schut, 1999) of coping with bereavement guiding Russell et al., (2016), and family systems models of family function underpinning Van Schoors et al.'s (2018, 2020) studies. This partly relates to epistemology in studies using hermeneutical (Björk et al., 2005, 2009) and descriptive (McGrath et al., 2004, 2005) phenomenological approaches, where previous knowledge is 'bracketed' to remain purely with the participants' subjective experience (Matua & Wal, 2015). While these studies have some heuristic value, they were also limited in significant contribution as the discussion in relation to literature was descriptive rather than critical (Björk et al., 2005, 2009; McGrath et al., 2004, 2005).

2.2.2 *Summary of papers*

Nine papers with qualitative studies were identified, including multiple family members' experience (n = 153) of different childhood cancers (mostly leukaemia, lymphoma, and brain tumours). Time since diagnosis ranged from 1 month to 3 years. Sample sizes were small and varied from four to 17 families. Five studies included four family members, three included three family members and one included two (both parents). In total, there were 90 parents across studies: 48 mothers, 31 fathers, plus 11 parents non-specified. There were 36 child patients, 25 siblings, and 2 grandparents. Studies were conducted across several countries, mostly Anglocentric (n = 5) or European (n = 4). In terms of geography, most studies were based in urban hospitals, whereas Scott-Findlay et al. (2001) focused on families living in rural Canada. Where ethnicity was reported in four studies, the majority were White (83%). Studies' key characteristics are summarised in Table 3.

2.2.3 *Thematic synthesis*

A thematic synthesis resulted in five overarching themes, each with subthemes relating to how families describe the process of coping with, and adapting to, paediatric cancer within a family resilience framework (Walsh, 2016, 2021). Themes and their pattern of occurrence are outlined in Table 5. Table 6 contains data examples of each theme ('first-order constructs': participant quotations, and 'second-order constructs': authors' interpretations).

Table 6

Example quotations from within themes from the meta-synthesis

Author and date	First-order constructs (Participant quotations)	Second-order constructs (Authors interpretations)	Third-order constructs (Impression of first- and second-order constructs)
Björk et al., (2005)	<p><i>"It's really sad she [ill child] can't be at home with us... They [parents] disappeared...It wasn't any fun being without mom and dad"</i> (Sibling 109, p.272).</p>	<p><i>"Feelings of loneliness appeared when family members were separated from the persons they most of all wanted to be with during the day such as their own family, friends, and relatives, or when people did not see them...siblings missed their siblings..."</i> (p.272).</p>	Challenges and changes in relationships
	<p><i>"...a day doesn't go by when you don't think she's going to recover, of course she's going to be healthy, but a day doesn't go by either that you don't think she's going to die. You have both thoughts so I mean you have both in parallel the whole time"</i> (Mother 110, p.270).</p>	<p><i>"To reduce their feelings of fear and powerlessness, they strove to feel hope and to have a positive focus"</i> (p.270).</p>	Family beliefs and thinking styles
	<p><i>"Since we'd created a picture of leukemia as essentially the same thing as death, then number one, that it can be cured, was positive information..."</i> (Father 105, p.270).</p>	<p><i>"Parents stated that when they had the time to reflect on the information they were given, they felt confident"</i> (p. 270).</p>	Information seeking from 'experts'

"They ask me how I want the needle to be inserted. I say just put it in and then it's done..." (Child with cancer, 114, p. 271).

Patients and siblings asked for information and gained increased control over the situation when they were involved in the care, and when their thoughts were heard and valued" (p.271).

Björk et al., (2009)	<i>"I feel sorry her [child with cancer] because her life is not as it was...it is harder to be consistent, that a no is a no..." (Father 217, p.426).</i>	<i>"Ordinary tasks like raising children were experienced as hard as parents thought it was difficult to set limits for the ill child as well as for the siblings" (p.426).</i>	Striving for 'normal' family routine and rules
	<i>"So the cancer is gone?" they ask and you have to answer them "No, she still has cancer," (laughter). But, it is good, she doesn't have any infections. And if you carry matters to the extreme, you still don't know if she is going to survive, but you don't think so much about it, you live right here and now..." (Father 209, p.429).</i>	<i>"Most parents felt that they were quite strong and that time passed quickly. They thought that it could have been worse and that other families had a tougher time than they had. They tried to live in the present and felt hopeful about the future" (p.429).</i>	Family beliefs and thinking styles
Clarke-Steffen (1997)	<i>"[My son] is the main one that goes over and gives her medications at school and everything like this. So really all the responsibility is still on him." (Mother, p.284).</i>	<i>"Sometimes, the primary caretaker would delegate tasks to others. For example, one mother had divided the therapeutic regimen tasks among the older siblings..." (p.284).</i>	Shifts in roles
McGrath et al. (2004)	<i>"I put the medical schedule in the diary and I have my alarm clock on. I like to know the name of the medicines so I don't mix it up" (Mother, p.362).</i>	<i>"First, during the initial stage of treatment parents are stressed by the complexity of treatment and challenged by the need to keep track of medications" (p.362).</i>	Shifts in roles

	<i>"Information helped me to accept it. I can cope with it now"</i> (Mother, p.361).	<i>"The provision of adequate information was recorded as helpful for acceptance"</i> (p. 361).	Information seeking from 'experts'
McGrath et al. (2005)	<i>"I think he [sibling] got really upset, but afterwards he got used to it and now he is being really nice to me"</i> (Child with cancer, p. 107).	<i>"Indications are that the initial intense rivalry, with support and attention, will abate over time"</i> (p.107).	Challenges and changes in relationships
	<i>"I am not a very open person. I keep to myself but, yes...I play Aussie Rules. It does let a lot of the tension go"</i> (Male Sibling, p. 106).	<i>"The male response (adult and child) was reported as more reserved, less expressive of feeling, more physical, and less reliant on talking things through, as can be seen by the following comments on male coping strategies"</i> (p.106).	Family sharing and not sharing
	<i>"I parked at [the school]. She just ran to the school and she didn't care if somebody got measles in there. She was just very happy to see her teachers. I am so happy to see them"</i> (Mother, p.103).	<i>"Any opportunity to reconnect with any aspect of normal life is highly valued"</i> (p.103).	Striving for 'normal' family routine and rules
	<i>"We have gone from two incomes to one. But probably the most draining is transportation and parking. The price of petrol and the first day you don't think of parking. [explanation of the fees for parking]"</i> (Father, p.110).	<i>"The changes in work also translated into financial hardship. This is combined with increased expenses such as parking, transport, and food"</i> (p.110).	Impact of external stressors on resources
Russell et al. (2016)	<i>"It's a combination probably of everything...having awesome surgeons that know what they're doing and that</i>	<i>"Several children and parents described their faith in a god, medicine, or for many, belief in the child's abilities to overcome the</i>	Family beliefs and thinking styles

are willing to do this kind of thing, and God overlooking everything at the same time, making sure that he has a steady hand..." (Mother, p.385).
 illness...Some, like Sharon, cast a broad net..." (p.385).

"It's a big deal, but then it's not at the same time because you can still live your life more or less normally" (Child with cancer, p.389).

"These were cherished opportunities for your children and parents to maintain familiarity and consistency, which helped them to balance their grief over the impact of the tumor on their lives, shifting their focus toward persevering in spite of it" (p.389).

Striving for 'normal' family routine and rules

"Parents rarely shared information about treatment-related risks with infertility perceived as a particularly devastating threat. Generally, children were only made aware of risks that they could help to minimize, such as infections or injuries" (p.383).

Family sharing and not sharing

"If they ask me what's going on with me? I'm fine to tell them because they would understand and not make fun, because they are dealing with almost the same thing" (Child with cancer, p. 388).

"Children and parents felt accepted within the hospital, whereas on the "outside," they were treated differently" (p.388).

Support in hospital

**Scott-
Findlay &
Chalmers
(2001)**

"I remember in the beginning what was really hard...I needed him to hold me or whatever, but ...he couldn't. He felt like it was taking away from [the ill child]..." (Mother, p. 213-4).

"All family members said that because of the illness and the distances that they traveled for cancer care they did not see each other as often. One parent discusses how her marriage was affected" (p. 213).

Challenges and changes in relationships

Van Schoors et al. (2018)	<p><i>"He had to cope without us. I really struggle with that. I just hope that he will not blame us for it later, that we weren't there enough for him...But I don't know how we could have done it differently."</i> (Father of a boy, 9 years, p.1233).</p>	<p><i>"...parents indicated that the siblings had to cope with this extreme stressor with only limited parental support. And although parents were aware of this situation and felt guilty about it, they saw no other solution at that time"</i> (p.1233).</p>	<p>Impact of external stressors on resources</p> <p>Support at home</p> <p>Challenges and changes in relationships</p>
	<p><i>"I suppose that now I have a much stronger bond with my son than most parents would have with their eldest child. Because, right before puberty, so drastic, wiping his bum again..."</i> (Father of a boy, 14 years, p.1233).</p>	<p><i>"...parents explained the increased closeness between themselves and the diagnosed child as a result of the child's increased vulnerability"</i> (p.1232).</p>	<p>Coming closer together</p>
	<p><i>"Let's say, I used to live for my job and my career, but now I want to enjoy things more. Enjoying it for the full 100% and going on a holiday with the children"</i> (Father of a boy, 4 years, p.1232).</p>	<p><i>"...some parents not only described their family as growing closer postdiagnosis but also as playing a more important role. They recalled an increased desire to spend more time together as a family, instead of (for example) focusing on their careers"</i> (p.1232).</p>	

	<i>"I think the biggest change was for the two eldest, because in that period, they were mostly looked after and brought up by their grandparents" (Father of a girl, 5 years, p.1234).</i>	<i>"In most families, other family members took care of the siblings, helping them to cope with this life event" (p. 1234).</i>	Shifts in roles
	<i>"...she cannot sit in the sun, nothing's normal anymore, so when something is normal, then it's a gift..." (Mother of a girl, 16 years, p.1236).</i>	<i>"...“normal” behavior and “normal” situations were seen as a blessing. Parents reported appreciating the smaller things more..." (p. 2336).</i>	Family beliefs and thinking styles
	<i>"There were times when I thought everything was going fine, that everything would be alright. I almost pretended as if we had a normal life" (Mother of a boy, 6 years, p.1236).</i>	<i>"Although parents realized that their family life would never be the same as before, they recalled a constant striving for normality. Parents tried to live a normal life, although the diagnosis had changed everything" (p.1236).</i>	Striving for 'normal' family routine and rules
Van Schoors et al., 2020)	<i>"I visited her quite often, there is no other way right, 'cause she's my sister" (Sibling 14 years, p.3).</i>	<i>"For this sibling, visiting his ill sister showed that he was concerned about her health and wanted to help her with his presence" (p.3).</i>	Coming closer together
	<i>"Before, I almost never went grocery shopping, then [post-diagnosis] I went a lot more. I did bit more of this, then I vacuum cleaned...But that's obvious, right, when she [his wife] was in the hospital." (Father, p.5)</i>	<i>"...family members were forced to re-think their contribution to the family life and to make new arrangements. This was described by the father and the sibling of one family" (p.5).</i>	Shifts in roles
	<i>"I didn't feel like, I mean, maybe that sounds a little selfish: 'I will visit Lien</i>	<i>"They reported having a need to continue their daily life as well, and searched for a balance between supporting their ill brother/sister,</i>	Striving for 'normal' family routine and rules

often but I won't be there every day”
(Sibling, 15 years, p.4).

*attending school and maintaining their own
social life”* (p.4).

*“We kept talking to each other. That was
really, really important”* (Father, p.4).

*“The families in our study found it important to
talk about the illness and its consequences”* (p. 4).
Family sharing and not sharing

*“What I'm also afraid of is, when I touch
upon that fear or emotion, that I will elicit
it in somebody else as well”* (Father,
p.4).

*“The complexity of sharing emotions was also
experienced by another family. The father
described the concern that sharing his worries
could elicit worries in the other family members”*
(p.4).

*“Every day there were hugs. The
children cuddled each other, just as we
cuddled the children, and I hugged my
wife”* (Father, p.3).

*“In addition, the importance of physical contact
in order to cope with the cancer experience was
emphasized. Parents and siblings gave hugs to
express their love and to comfort each other”*
(p. 3).

2.2.3.1 Dynamic family adjustments

Participants in all papers discussed ways in which the experience of cancer diagnosis and treatment resulted in changes within family dynamics. Theme one describes family relationships, and how families adapt and organise themselves through roles and routines.

2.2.3.1.1 *Shift in roles*

Participants from eight papers described ways in which family members came together to cope with cancer treatment, through assuming new roles and responsibilities. This resonates with the organisational process of “flexibility to adapt” within the family resilience framework (Walsh, 2016).

Parents shared responsibilities between them. Typically, one parent cared for the child with cancer in hospital (usually mothers); although in some cases, parents alternated (e.g., Van Schoors et al., 2018). The other parent assumed household responsibilities and caring for other children at home. Parents adopted extra caring responsibilities and developed routines for their child with cancer at home (e.g., managing medications; McGrath et al., 2004). Additional responsibilities were reported as particularly stressful for rural Canadian parents, who assumed higher level care (e.g., “*giving chemotherapy in their home*”; Scott-Findlay & Chalmers, 2001).

Many parents described dividing responsibilities and adopting new roles as “*teamwork*” (Van Schoors et al., 2018) and “*joint effort*” (McGrath et al., 2005). In some cases, other family members, such as older siblings (Clarke-Steffen, 1997) and grandparents (Van Schoors et al., 2018) supported by caring for other children at home. Additional examples of support involved siblings assuming “*extra*

responsibilities” helping their sibling with cancer (Russell et al., 2016), by doing extra household chores.

Other significant role changes for mothers included pausing work or studying (McGrath et al., 2005). For those continuing work, usually fathers, this involved juggling work alongside trying to remain involved with their child with cancer (Scott-Findlay & Chalmers, 2001).

2.2.3.1.2 Challenges and changes in relationships

Seven papers described relationship challenges, mostly by parents. Difficulty in spending time as a whole family resulted because of the inevitable separation due to treatment and adapting to newly assumed roles. Parents’ key focus was on the child with cancer. Parents expressed the impact on the couple, parent-child, and sibling subsystems.

In three papers, parents discussed the impact on the couple relationship; some felt emotional distance had emerged between them, the key focus becoming the children (Scott-Findlay & Chalmers, 2001), which impacted intimacy (Björk et al., 2005). Parents varied in terms of whether this concerned them. For some, while it impacted intimacy and/or ability to combine parent and partner roles, it *“did not threaten their marital relationship”* (Van Schoors et al., 2018).

Parents were most concerned about the parent-child relationship with their other children. Siblings also described the stress of separation, missing contact with both their sibling and parents (Björk et al., 2009). Parents described a range of emotions that their other children at home felt in response to the separation, including sadness, jealousy, anger, and resentment. Both parents and children with

cancer talked about how sometimes this caused sibling rivalry, although this conflict later resolved (McGrath et al., 2005).

Adapting to grandparents taking a caring role caused stress for some parents, including concern about temporary stronger bonds with children at home. Guilt was expressed for reduced attention given to other children:

“He had to cope without us. I really struggle with that. I just hope that he will not blame us for it later, that we weren’t there enough for him...But I don’t know how we could have done it differently.” (Father of a boy, 9 years, Van Schoors et al., 2018).

Pressure parents feel to maintain all roles has previously been reported, known as the role-strain approach (Goode, 1960; Van Schoors et al., 2018). Although utilising the resource of extended family members during stressful periods can assist family functioning (Walsh, 2016), this adjustment caused additional stress for some parents.

2.2.3.1.3 Coming closer together

Despite challenges of managing changing family relationships, participants in seven papers described how the experience of cancer diagnosis and treatment brought the family closer together, making relationships stronger, suggesting increased cohesion. Two organisational processes of family resilience (Walsh, 2016) underpin this subtheme: “connectedness” and “mutual support” between family members, both within families living at home and extended families.

Some parents described that it *“enhanced their lives”* (Scott-Findlay & Chalmers, 2001). Getting through it together as family was an achievement, as they look back with *“satisfaction”* (Van Schoors et al., 2018). Parents described how the

experience helped them recognise *“the family’s strength and capacity to support one another”* (Russell et al., 2016).

Staying connected was important during hospital stays through visits and phone calls for siblings and the other parent (Björk et al., 2009; Van Schoors et al., 2018; 2020). Parents described how siblings showed *“closeness, concern and care”* for their siblings with cancer (McGrath et al., 2005).

Families highlighted important times spent together when the child with cancer was home, with siblings noting the specialness of having the whole family together (Björk et al., 2009; Van Schoors et al., 2020). Parents described reprioritisation of family time above other activities (e.g., work or time with friends; Van Schoors et al., 2020), reflecting the benefit of emotional security found in the strength of their relationships.

Parents described special strengthening of emotional bonds between children with cancer and parents who spent extensive time together; in one case this caring role was taken on by an elder sibling (McGrath et al., 2005). As one father described:

“I suppose that now I have a much stronger bond with my son than most parents would have with their eldest child. Because, right before puberty, so drastic, wiping his bum again...” (Father of a boy, 14 years, Van Schoors et al., 2018).

This parent describes how essential high-level intimate care, at a point where typically a child develops more independence, has brought them closer. In some families, the other parent (usually fathers) assumed other roles like caring for siblings or working, and bonds with the child with cancer were less strong.

2.2.3.1.4 Striving for 'normal' family routine and rules

Families experienced significant disruption to daily routines to accommodate treatment programmes for children with cancer, including disrupted schooling for children with cancer, feeling that life is “*on hold*” (McGrath et al., 2005), and missing opportunities for sport/activity participation (Russell et al., 2016). Disruption was extended to the wider family when children with cancer were home, leading to feelings of isolation and loss in parents and siblings. Opportunities to partake in social activities, holidays, and mix with friends were reduced to avoid risk of infection, or because the child with cancer was too unwell (Björk et al, 2009).

Following the initial crisis stage around diagnosis, families describe the process of maintaining normalcy by re-establishing routines where possible or adopting new routines (a ‘new normal’) to regain a sense of control/predictability (Clarke-Steffen, 1997; Scott-Findlay & Chalmers, 2001), connection and support (Russell et al., 2016). Russell et al. (2016) describes this process as balancing grieving the loss of normal with rebuilding lives with hope, mirroring the DPM (Stroebe & Schut, 1999). This also resonates with the family resilience organisational process of “flexibility to adapt” (Walsh, 2016), and with other literature in the context of paediatric cancer, highlighting that family routine and rituals lead to cohesiveness (Santos et al., 2015).

Children with cancer described living their lives “almost normally” (Russell et al., 2016); examples of re-establishing routine include schooling (hospital or former school; McGrath et al., 2005). Maintaining life outside the family (i.e., school and hobbies) was important for siblings. Siblings described searching for “*balance*” between visiting their siblings with cancer, and living their own life:

“I didn't feel like, I mean, maybe that sounds a little selfish: ‘I will visit Lien often but I won't be there every day’” (Sibling, 15 years, Van Schoors et al., 2020).

For some parents, striving for normalcy during more settled periods was described as *“pretending”* things were as they were before diagnosis, whereas actually *“life would never be the same”* (Van Schoors et al., 2018). There were also examples where striving for normalcy created stress for parents: when children with cancer were too ill for school, fears of infection, and *“frustration”* around inability to plan (McGrath et al., 2005). For parents, trying to maintain jobs was also stressful when they would rather spend time with their child with cancer (McGrath et al., 2005). This may also relate to illness severity, as the prognosis of AML is comparatively worse than other leukaemias (McGrath et al., 2005).

Some parents described difficulty in consistently maintaining boundaries for children with cancer, and sometimes also for siblings (Björk et al., 2009; Van Schoors et al. 2018). Parents in Van Schoors et al. (2018) described changing dynamics across time, from initially *“overindulging”* their child with cancer during treatment, and subsequently adopted *“stricter”* parenting to *“compensate”*. In contrast, some parents described how discipline and parenting expectations were consistent throughout (Russell et al., 2016; Scott Findlay & Chalmers, 2001). These findings illustrate conflicting dynamics that parents face in the extremity of cancer, both around adapting to a ‘new normal’ and maintaining rules and boundaries, and how this might vary according to illness severity and across time.

2.2.3.2 Family beliefs and thinking styles

Participants in six papers referred to shared family beliefs and thinking styles that helped contain, organise, and make sense of the cancer diagnosis. This maps onto Walsh's (2016) family belief systems in fostering resilience, particularly "transcendent thinking" and "fostering a positive outlook". Parents can buffer stress for children by helping contain the illness through family belief systems and thinking styles.

In four papers, participants displayed "transcendent thinking" (Walsh, 2016) when attributing their experiences to being controlled/influenced by something outside their own human experience. Faith and hope were placed in God "overlooking everything", and in medical staff's abilities that treatment would be successful (Russell et al., 2016).

Participants in five papers described how remaining positive was pivotal in coping. Children's coping focused on looking forward to future positive experiences (e.g., new baby; Björk et al., 2009). Parents had to manage significant stress, watching their child with cancer enduring painful treatments. To cope, maintaining hope was helpful – "curative optimism" (McGrath et al., 2004), and focusing on what was going well (Björk et al., 2009). One mother described it as striving to maintain balance between the unavoidable fear of child loss, and focusing on recovery:

"...a day doesn't go by when you don't think she's going to recover...but a day doesn't go by either that you don't think she's going to die...You have both thoughts...in parallel the whole time" (Mother 110, Björk et al., 2005).

Parents described life-changing loss of psychological safety (Björk et al., 2005; Van Schoors et al., 2018), having to live with uncertainty of treatment outcome, or chance of remission (Russell et al., 2016). In six papers, focusing on

living in the present to cope with uncertainty was described, taking it “*day by day*” rather than focusing on “*what ifs*” (Russell et al., 2016). Some parents spoke of how time spent together was valued more, appreciating small moments in the present (Van Schoors et al., 2018).

Parents in two papers described creating narratives for themselves and their children that minimised illness to help contain distress. For some participants, it was more manageable to think of cancer as “*an illness like any other*”, paralleling it to “*diabetes*” or “*asthma*” (Clarke-Steffen, 1997). In Russell et al. (2016), some parents encouraged children think comparatively, describing others with worse prognoses as “*sicker than me*” (Child with cancer, Russell et al., 2016). This can be labelled as a ‘positive reappraisal’ strategy (Lazarus & Folkman, 1984), which has been linked to resilience. However, evidence that these downward social comparisons are helpful in chronic illness populations is mixed (Arigo et al., 2014), whereas focusing on positive self-other contrasts may be more helpful (Van der Zee et al., 2000).

2.2.3.3 Communication: seeking and sharing

Participants in six papers discussed communication, which included cancer and treatment information-seeking from others outside the family, and how this information helped them cope. The second subtheme details ways in which family members communicate about cancer and treatment, and the ways in which they share (or do not share) emotional responses.

2.2.3.3.1 Information seeking from 'experts'

Open communication is a key process within the family resilience framework (Walsh, 2016). In the context of paediatric cancer, healthcare professionals (HCPs) become part of the family system (Kazak et al., 2002), and findings within this subtheme show that clear, open communication from HCPs was important for parents and children, which mirrors more recent findings summarising parent/patient and clinician communication (Sisk et al., 2018).

Participants in five papers discussed how sourcing information about cancer helped them cope. Parents described varying sources from the internet to other parents to HCPs (Clarke-Steffen, 1997; Russell et al., 2016). Having clear information and gaining knowledge about cancer and treatment helped contain parental anxiety about the prognosis, as well as helping with acceptance of the diagnosis (McGrath et al., 2004), and realisation that it may not be cured (Björk et al., 2005).

Being informed also enabled coping for both children with cancer, and their siblings. Children with cancer described how hospital staff prepared them for procedures, helping manage anxiety and regain some control (Björk et al., 2005). Whereas, in the absence of preparation, some children feared severe procedural pain (Russell et al., 2016).

Parents also discussed barriers around gaining information, such as when information requests were responded to negatively, or if language was too technical (Clarke-Steffen, 1997). Anxiety was also described as a barrier to absorbing information for parents and children, and the subsequent need for repetition of information (Björk et al., 2005; McGrath et al., 2004).

2.2.3.3.2 *Family sharing and not sharing*

Clear communication and emotional sharing are two key processes in the family resilience framework (Walsh, 2016). This theme captures strengths and challenges that families face through communication, and that there are different ways to express emotional support (verbal and non-verbal). It also demonstrates how beliefs around emotion expression moderates this process.

In six papers, family members discussed how details of the treatment, and their emotional responses, were or were not talked about. Children with cancer and siblings described their parents as an important source of information, aiding them to understand treatment, feel a sense of control, and maintain hope for the future (Björk et al., 2005; 2009). Parents described the ways that they managed information-sharing about the cancer, treatment, and prognosis. Some parents explained how they only shared what they felt was helpful, protecting children from certain information, for instance: *“treatment-related risks with infertility perceived as a particularly devastating threat”* (Russell et al., 2016).

Some parents helped contain the illness through the language used, such as externalising the tumour (Russell et al., 2016). Other parents found it challenging to share information about the illness with their children, and only did so with encouragement from HCPs (Clarke-Steffen, 1997), suggesting HCPs may aid parents in deciding what and how to share information with children.

Families varied in communication style, especially the extent to which they would talk. For some families, open verbal communication, including sharing feelings, was *“really important”* (Father), and experienced as *“relief”* and helpful in coping (Male Sibling, age 10; Van Schoors et al., 2020). Some families found it harder to share emotions, fearing that it might *“elicit it [fear] in somebody else”*

(Father), suggesting a role for talking about the fear of loss for friends or professionals for some individuals (Van Schoors et al., 2020).

Managing different coping styles was challenging for families when one would prefer to share emotions while the other did not. In some cases, there were gender differences where male family members (fathers and siblings) preferred not to speak about their feelings. For some, showing and seeking emotional support through physical connection such as “hugs” (Van Schoors et al. 2020), or by releasing “tension” through physical exercise (McGrath et al. 2005), felt more comfortable. Van Schoors et al. (2000) emphasises how emotional support can also be shown through physical presence rather than talking.

2.2.3.4 Support from outside the family system

Participants from seven papers spoke about the importance of, or dependency on, support from outside their family at home. This included developing trusting relationships with HCPs and other parents and receiving support from friends and communities when at home. Utilising social resources outside the immediate family is indicated as a key process underlying family resilience (McCubbins et al., 2002; Walsh, 2016).

2.2.3.4.1 Support in hospital

In six papers, members of family (including the child with cancer, parents, and sometimes siblings) who spent time in hospital, referenced the importance of relationships established in hospital to feeling secure. They described how members of staff and other parents become “like family” (child with cancer; Russell et al.,

2016), and eventually, the familiar reassurance of a hospital ward becomes like a “sanctuary” (Father), or “second home” (Sibling; McGrath et al., 2004).

The safety-net of staff support: Participants described a range of professional support, including allied HCPs (e.g., occupational therapists) and teachers, who provided engaging activities for children with cancer (McGrath et al., 2004; Russell et al., 2016); support included help with “*medical, practical and psychosocial issues*” (Russell et al., 2016). One parent described extensive trust in medical staff by comparing it to “*flying a plane. All you can do is trust the pilot*” (Father 102, Björk et al., 2005).

Coping without the safety-net: This safety-net of medical support made it hard for some to transition home, particularly for parents in rural Canada, living a distance from their tertiary centre without confidence in the local hospital service (Scott-Findlay & Chalmers, 2001). Mothers in one study reported hypervigilance as a way of coping with the absence of medical supervision (McGrath et al., 2004). These findings suggest that parents need support with transitioning home and adjusting to coping without immediate medical/professional support (Muskat et al., 2017; Wilford et al., 2019).

Where parents reported poor relationships with staff, usually attributed to staff being highly busy, it led to feelings of isolation, disconnection, and mistrust (Björk et al., 2005, 2009; Scott-Findlay & Chalmers, 2001).

Peer support: Importance of peer support was referred to by both parents and children with cancer as helping normalise and adjust to their experience. Children with cancer described the trust they felt in sharing with another child with cancer, as

they felt understood and accepted (Russell et al., 2016). It was important for children to have the opportunity to mix with other children, to have fun and play when possible (Björk et al., 2009; McGrath et al., 2004). The “*shared camaraderie*” was also described as important for parents coping with long hospital stays (McGrath et al., 2004). In a Swedish hospital, “*sibling supporters*” helped keep siblings informed (Björk et al., 2009).

Parents additionally highlighted a few drawbacks to support. Sometimes children were too unwell and needed personal space (McGrath et al., 2004). Likewise, parents needed space from other parents, as hearing others’ negative experiences could be overwhelming, and some parents did not feel connected to those they met (McGrath et al., 2004; Russell et al., 2016). Although valued, the distance and cost made it challenging for families in rural Canada to maintain peer relationships (Scott-Findlay & Chalmers, 2001).

2.2.3.4.2 Support network at home

All family members from six papers spoke of support from wider family members, friends, and local communities (e.g., schools and churches) that helped to sustain them. Maintaining contact with school and friends through visits, letters or phone calls was important for child cancer patients when in hospital (McGrath et al., 2005; Björk et al., 2009). Support offered to parents ranged from emotional, practical, and spiritual, as well as financial aid through fund raising (McGrath et al., 2005; Scott-Findlay & Chalmers et al., 2001). For siblings, spending time with friends was important, with one sibling explaining that their friend’s house “*felt like home*” (Björk et al., 2009).

Where support was not felt from friends or communities, it led to feelings of isolation and higher levels of stress. For instance, work colleagues not understanding illness severity, and friends and relatives not making contact due to fear of infection (Björk et al., 2005, 2009). While most children with cancer experienced good support from peers, some were treated differently, excluded, or bullied, causing further stress (Russell et al., 2016).

2.2.3.5 Impact of external stresses on resources

This theme highlights additional stressors that parents in four studies described, accounting for wider geographical and socio-political context that further challenged their well-being and adjustment. Treatment-related financial burden meant some fathers in the US had to work overtime to cover costs (Clarke-Steffen, 1997). Parents in rural Canada (Scott-Findlay & Chalmers, 2001), and those living significantly far from the treatment centre in Australia (McGrath et al., 2004, 2005), referenced mounting costs of accommodation, travel, parking, and food, creating additional stress in combination with income loss for one parent. Families living in rural Canada described additional strain in driving back and forth for treatment. Fathers described the stress of missing out on medical appointments due to distance, and difficulties in taking time off work (Scott-Findlay & Chalmers, 2001). While these studies were conducted 15-20 years ago, inequalities in rural healthcare access in both Australia (Australian Institute of Health and Welfare, 2022) and Canada (Wilson et al., 2020) remain, and poorer cancer outcomes are achieved for those living in rural locations globally (Carriere et al., 2018).

2.3 Discussion

This qualitative synthesis, including multiple family members (children with cancer, parents, and siblings), provides an overview of some dynamic processes that occur between family members when adjusting to, and coping with, a child undergoing diagnosis and treatment of cancer. By applying the theoretical lens of family resilience theory (Walsh, 2016), the findings highlight ways that families respond, individually and interpersonally, to buffer the effects of stress; this includes ways of adapting to new roles and routines, through strengthening relationships, their process of sense making, communication of information and emotions, and how they make use of wider support networks in hospitals and home communities (McCubbins et al., 2002; Walsh, 2016).

Previous SLRs on family functioning or resilience in this context summarise studies that rely on comparison with ‘control/norm’ families without cancer to assess whether families are “competent” (Van Schoors et al., 2015). The advantage of a qualitative synthesis is that the context can be illuminated, meaning that families’ responses can be viewed as adaptive to the circumstances. For example, a temporarily enmeshed relationship with a teenage child can be viewed as adaptive during the treatment stage (Alderfer & Standley, 2012; Olson, 2000; Van Schoors et al., 2015). The synthesis also highlights different ways that families foster resilience. To be supportive of this process, it is helpful for clinical psychologists (CPs) and other HCPs to be aware that this differs depending on family beliefs and ways of relating. For instance, a family that finds it hard to talk about feelings may find solace in being physically together (Van Schoors et al., 2020), and may prefer speaking about certain topics (such as fear of loss of the child) with others outside their family system, such as friends or HCPs, or ‘veteran’ peer support (Baron-Nelson

et al., 2018). HCPs also have an important role in supporting parents to communicate about cancer with their child. A recent SLR highlighted important roles for HCPs in ensuring that children's informational needs are met and supporting parents to achieving this in developmentally appropriate ways (Lin et al., 2020). Finally, this SLR highlights the advantage of viewing families within their socio-ecological context, and the importance of noting where there may be additional risk factors that can impact resilience (e.g., financial burden, limited support network).

With the inevitable focus of energy on children with cancer, these findings highlight the potential role of CPs in supporting families to explore the impact on the couple relationship, siblings, and normalising shifts in roles. For instance, it may be helpful to illuminate societal narratives such as the "intact nuclear family" to parents (Walsh, 2015) and how this influences perception of extended family support. These findings also illustrate conflicting dynamics that parents face in the extremity of cancer, both in terms of trying to adapt to a 'new normal' and maintain rules and boundaries, and parents may need support in navigating these changes. Transitioning home, and beginning the period of 'new normal', is reported in other recent literature as a support need for parents (Muskat et al., 2017; Wilford et al., 2019). As families recalibrate to cope without the "safety net" of HCPs' support, psychoeducation around emotions they may experience might assist them to adjust (Wilford et al., 2019). MDT support for the whole family is indicated by the NICE (2014) guidelines at key transition points, and these findings indicate the inclusion of transition home from hospital.

2.3.1 *Limitations*

Several caveats frame the interpretation of this review. First, the number of papers was limited, and no studies were explicitly informed by resilience theory. Some aspects of family resilience, for example family-level processes such as communication via problem solving (Walsh, 2016), are not captured in any of the studies. Several papers lacked any theoretical framework, which is a criticism of psycho-oncology research more broadly (Alderfer et al., 2010; Van Schoors et al., 2015). Although informative, the review is limited in its entire scope by the lack of theoretical orientation of included papers that may have led to missing key dimensions of family resilience.

Second, while it is a strength that fathers are well-represented, children's voices were underrepresented, particularly when the whole family were interviewed together (e.g., Clarke-Steffen, 1997), or where their data was not clearly included. Third, qualitative syntheses are limited by separating research from its original context (Thomas & Haden, 2008), and many of the studies were carried out 15-20 years ago, which may not reflect experiences of healthcare settings today. Fourth, the studies are lacking in diversity, both in terms of ethnicity, where the vast majority were White; and family structure, as most families were nuclear two-parent families. The fact that no studies conducted in middle-income countries met the inclusion criteria of this review, and that the search was restricted to the English language, will have led to the review's Anglocentric focus. Lack of inclusion of voices from minoritised communities is mirrored by inequalities in cancer care itself, where care and survival of minoritised patients falls behind (Moore et al., 2022).

2.3.2 *Implications for future studies*

This review highlights the need for further qualitative research to explicitly explore the impact of paediatric cancer on families through a family resilience framework. The following methodological considerations are outlined:

1. For studies to carefully consider epistemology and ethics when including multiple family members; it is important to detail *why* multiple family members are included within a single study and ensure that participating children are well-represented in the data.
2. With multiple family members, it could help to focus on a single area of family resilience (e.g., Van Schoors (2020) who considered family experiences of support giving), where the processes behind resilience and interrelationships can be explored in depth.
3. Studies with participating parent-child dyads (sibling-parent; child with cancer-parent) might help illuminate children's views, while also offering sufficient support in discussing highly emotive topics (e.g., Russell et al., 2016).
4. To diversify research to consider experiences of varying family structures that make up society, including same-sex parents, multi-generational caregivers, and single-parent families (Van Schoors et al., 2018), and families from different ethnic backgrounds who may have different beliefs and cultural practices that influence family resilience.
5. A range of family-level factors that influence family resilience were highlighted. What is missing is how other factors beyond the family's control can make this journey more complex, which will be a focus of this thesis.

2.4 Paediatric cancer in the context of COVID-19

The COVID-19 pandemic created multiple stressors for families, including fear of infection, social disruption, disruption to family routine, and confinement-related stress (Prime et al., 2020; see section 1.4.2). The cumulation of stressful life events increases the likelihood of adversely impacting family functioning and resilience (Walsh, 2015), making it an important context to consider for families of children already adjusting to a cancer diagnosis.

A small body of research has focused on families of children with paediatric cancer during the pandemic. A longitudinal, UK-based survey highlighted that parents' (of children with cancer) access to support, finances, education, and social lives were impacted, leading to psychological distress (Collaço et al., 2022; Darlington et al., 2020). Fear relating to COVID-19 infection slightly reduced over time; however, the need for clearer information/communication about COVID-19 was consistently raised (Collaço et al., 2022). Research from Italy conducted by Guido et al. (2021) similarly reported increased levels of distress in parents, concluding that parents were at high risk for PTSS. In contrast, a Dutch study noted an initial *decrease* in caregiver reported distress, later rising to pre-pandemic levels (Van Gorp et al., 2021; 2022). Relatively lower levels of distress were attributed to less disruption to psychosocial support and informational needs being met (Van Gorp et al., 2022).

Although useful for identifying support needs, questionnaires are limited in exploring depth of meaning a family ascribes to having a child diagnosed with cancer (Eatough & Smith, 2017). An Australian-based qualitative study captured multifaceted impacts of COVID-19 within parents' experiences (Davies et al., 2022). Parents descried feelings of social isolation and reduced access to support services

resulting from COVID-19-related restrictions. Positives included improved understanding of the public around infection control, and the benefit of remote working on income (Davies et al., 2022). Parents in Steinberg et al.'s (2021) qualitative US-based study described anxieties around keeping safe in hospital, and the importance of virtual communication to stay connected, and clear communication with HCPs. High levels of adaptability were also described, which the authors linked to resilience (Steinberg et al., 2021).

A recent US-based qualitative study (Gilbert et al., 2023) more directly considered family functioning through examining risks and resilience in the context of paediatric cancer during COVID-19. Gilbert et al. utilised Prime et al.'s (2020) conceptual framework that comprised systemic models of family development and family stress theory. Parents' experiences highlighted resilience through connecting to belief systems, and adaptation to COVID-19 via systems of communication and organization (e.g., additional family-time; infection control routines).

2.5 Rationale for current study

There is scope for further research on the impact of COVID-19 on the family from the perspective of parents with a child diagnosed with paediatric cancer. As outlined in section 1.5.3, Walsh's (2003, 2016) framework of family resilience can helpfully consider family processes that families engage in when responding to "challenging" contexts. Additionally, the eco-systemic component examines other social systems, such as healthcare, and broader political and socio-cultural factors as important contexts that can influence family resilience (Walsh, 2021). Although Gilbert et al. (2023) considered broader factors such as environmental vulnerability, single parent status and financial vulnerability, there remains an opportunity to focus on what can

be done to promote resilience when structural and relational resources are challenged. While parents identified communication with staff for family resilience in Gilbert et al.'s (2023) study, there was no exploration of the dynamic interplay of parent-HCP communication relating to their child's cancer and COVID-19. Providing families with opportunities to describe frustrations and satisfactions in the interaction with HCPs and healthcare systems spotlights their resilience in a stressful context (Clarke & Fletcher, 2003).

The aim of this study was to consider the impact of a paediatric cancer diagnosis on the family during the COVID-19 pandemic from the perspective of parents. IPA was used to capture the lived experience of each parent, and their shared meanings of these experiences (Eatough & Smith, 2017). A critical approach to IPA (Guenther, 2019) was used to take account of the social structures that challenged families' resources through using Walsh's (2003, 2016) eco-systemic framework of family resilience.

This study aimed to answer the following broad question:

How do parents perceive having a child diagnosed with cancer during the COVID-19 pandemic has impacted them as a family?

3. Methodology

3.1 Design

This study aimed to explore parents' experiences of having a child diagnosed with cancer during the COVID-19 pandemic, and their perception of the impact this had on their family. A qualitative approach employing semi-structured interviews was thought to be the most appropriate method to capture the rich and personalised accounts of participants. This approach is also sensitive to the social context of research, which is in-line with the project's critical IPA approach (Ritchie et al., 2014; Guenther, 2019).

3.1.1 Interpretative Phenomenological Analysis (IPA)

This research takes an interpretative phenomenological approach, with emphasis placed on how participants subjectively experience their world rather than seeking to determine something absolute (Harper, 2011). IPA has three key theoretical underpinnings, which are briefly outlined in relation to justification for choosing this methodology: phenomenology, hermeneutics and idiography (Smith et al., 2022).

First, *phenomenology* is a philosophical approach focused on studying 'insider perspectives' as closely as possible, which was consistent with the study's aims. Individuals are viewed as being rooted in a relational world of objects, language and culture, and meaning is created through relationships with these aspects (Smith et al., 2022). We are inseparably 'people-in-context', and meanings of experience are often inter-subjective (Larkin et al., 2019); the acknowledgement of which felt appropriate for the multiple perspectives that parents considered around the impact on family in this study.

An interpretative phenomenological study seeks to draw out patterns, connections, and differences in-between individuals. This is known as *hermeneutics*: the theory of interpretation (Smith et al., 2022). This methodology also acknowledges co-construction involved in interpreting participants' experiences when developing "*second-order sense making*" (Smith et al., 2022, p8), highlighting the importance of "*bracketing*" the researcher's own biases and preconceptions where possible (Smith et al., 2022). Given my professional and personal relationship to the topic, an important process was recognising my involvement in interpreting participants' experiences. An important part of this process was engaging in "*the hermeneutic circle*", acknowledging the iterative process of moving back and forth when interpreting the text: a process that is dynamic and non-linear (Smith et al., 2022).

Finally, the *idiographic* aspect of IPA is its commitment to detail; the emphasis lies on the value of personal accounts within context, rather than making population-level claims (Smith et al., 2022). IPA uses small, carefully selected samples to reveal experiences at individual and then group levels through examining similarities and differences. Arguably, it is useful for emotionally laden, multi-faceted topics, like the experience of a cancer diagnosis during the context of the COVID-19 pandemic (Larkin et al., 2019). It has been acknowledged as a useful way of hearing directly from service users to inform health services within organisations like the NHS (Reid et al., 2005).

3.1.2 Limitations of IPA and considered alternatives

Two limitations of IPA have been raised regarding language. First, the dependence on participants' language ability to express the complexity of their experiences (Willig, 2013). Arguably, this assumption can be seen as ableist as it presumes only the most articulate can sufficiently describe their experience (Taffour, 2017). It does, however, draw attention to the importance of diligence in collecting rich, exhaustive data (Taffour, 2017). Second, IPA has been criticised for not fully attending to the integral role of language in narrating someone's experience compared to narrative or discursive analysis, which consider how language constructs experience (Davidsen, 2013; Taffour, 2017). In rebuttal to this criticism, Smith et al. (2022) highlight that language (i.e., narratives, metaphors) is integral to the meaning-making process that is central to IPA, though the key focus is on experience.

IPA has also been criticised for limiting understanding by focusing on capturing lived experiences without explaining *why* they occur or acknowledging *conditions* that led to experiences located in past events/sociocultural contexts (Taffour, 2017; Willig, 2013). More recently, applying a critical lens to IPA can illustrate social structures that shaped participants' experiences (Guenther, 2019; Smith et al., 2022). It was the aim that the critical approach to IPA in this study would allow critical reflection on the effects of these structural influences.

A potential pitfall of IPA is that, while acknowledging the researcher's part in the analysis, guidelines are limited regarding how to employ reflexivity to avoid this from becoming problematic (Willig, 2013). Attention to the process of reflexivity was given careful consideration (outlined in section 3.6.3).

IPA was considered alongside other qualitative approaches to address how well each approach fitted the research questions and aims (summarised in Table 7).

Having critically considered its strengths and limitations, IPA was chosen since the research aims were to explore parents' experience, which IPA was best placed to achieve.

Table 7

Rationale for IPA

Qualitative methodology	Description	Reason for rejection
Narrative Analysis (NA) (Emerson & Frosh, 2009).	<ul style="list-style-type: none"> Like IPA, NA is concerned with sense-making processes of people's experience, which is co-constructed in relation to the social world around them (Smith et al., 2022). Focus of NA is on <i>content</i> and <i>structure</i> of people's stories, and the purpose of these stories. 	<ul style="list-style-type: none"> NA focuses strongly on narrative and how it is <i>structured</i>. IPA better suited to a wider process of sense-making focusing on <i>personal meaning</i> but within a particular context (Smith et al., 2022) without being constrained by vital attention to structure.
Discursive Analysis (DA)	<ul style="list-style-type: none"> Focused on the role of language, examining social and linguistic patterns (Smith et al., 2022) 	<ul style="list-style-type: none"> Although DA and IPA both consider language, IPA was preferred because it also considers concepts and meaning makings, as well as considering interactions with participants' contexts.
Grounded Theory (GT) (Charmaz, 2014)	<ul style="list-style-type: none"> Emphasis on theory construction to explain social processes. 	<ul style="list-style-type: none"> Research aim was not to develop a grounded

- Weight given to context. theory/model from the data/analysis.
- Study's aims were more concerned with participants' meanings than processes (i.e., 'what' more than 'how')

Thematic Analysis (TA) (Clarke & Braun, 2014).

- Identifies patterns and themes in qualitative data.
- Themes are broad across a larger number of participants.
- TA focuses on broad themes across a greater number of participants, but since the focus was to study lived experience in detail with an idiographic and interpretative emphasis, IPA was more appropriate.
- IPA also felt more appropriate for the complexity and sensitivity of the topic for parents of children with cancer compared with TA.

3.1.3 Consultation with Experts by Experience (EBE)

Two parents, a mother and father, with a child 18-months post-diagnosis but still undergoing treatment for cancer in March 2021, participated as experts by experience (EBE), in line with best practice recommendations for patient involvement in research (National Institute for Health Research, 2018). The EBEs were recruited by a CP working in the oncology and haematology service during a face-to-face hospital visit at Addenbrookes. The EBEs informed the study design and recruitment and helped shape the interview schedule. They have also been sent a lay summary of the research findings and there are plans to set-up a meeting to co-construct

ideas for disseminating research findings. Examples of their influence and changes made are given throughout sections 3.3. and 3.4. The EBEs chose to give written rather than verbal feedback via an email exchange due to personal convenience. The process was important in informing methodological reflexivity (Treharne & Riggs, 2015).

3.2 Sample and recruitment

A purposive sample of parents was recruited from the paediatric haematology and oncology department, Addenbrooke's Hospital, Cambridge. IPA's homogeneity criteria were met as all parents had a child diagnosed with cancer during the COVID-19 pandemic at the same hospital.

3.2.1 *A shift in focus in design and recruitment*

The initial design was multi-perspective, aiming to represent the experience of both parents who had a child diagnosed with cancer during the pandemic. The rationale was that previous research limits the breadth of the representation of family life by considering the perspective of only one family member, usually mothers (Van Schoors et al., 2015). Due to both recruitment difficulties (in engaging fathers) and the influence of EBEs' comments that many of their peers were single parents, this was shifted to enable one parent to participate. Shifting the approach to include single parents felt more aligned with my understanding of the construct, *'family'* i.e., bound by a mutual commitment within a diversity of structures (Hildenbrand et al., 2021).

3.2.2 Inclusion criteria

Table 8 outlines sample inclusion and exclusion criteria relating to parents and their child's cancer diagnosis.

Table 8

Study inclusion and exclusion criteria

	Criteria	Further comments
Inclusion Criteria: Parent	<ul style="list-style-type: none"> • One or both parents could participate • Age 18 years or above at the time of recruitment • Had access to a phone or computer/smartphone with internet access • Sufficiently fluent in English. 	<p><i>“Parent” was inclusive of any type of parental unit, (e.g., step or adoptive parent), and not limited to biological parent.</i></p> <p><i>Interviews could only be carried out in English due to my limitation in being fluent enough in only English. IPA rests on the assumption that experience is communicated through language.</i></p>
Inclusion Criteria: Child's diagnosis	<ul style="list-style-type: none"> • Child (up to age 16) diagnosed with cancer during the COVID-19 pandemic at Addenbrooke's Hospital, Cambridge • Child between 6- and 18-months post-diagnosis at the time of interview 	<p><i>This gave parents time to adjust to receiving the diagnosis and sufficient time to reflect on the experience.</i></p>
Exclusion Criteria: Child's diagnosis	<ul style="list-style-type: none"> • Child receiving end-of-life care 	

Due to high levels of distress, those children with a terminal diagnosis were excluded.

3.2.3 Recruitment procedures

Eligible participants were identified from a patient list by a CP working in the Haematology and Oncology department at Addenbrookes. Parents were told about the study either face-to-face during hospital visits, or during a follow-up phone call as part of a care review by CPs, counsellors or oncologists working in the team. Parents could either express interest to receive the participant information sheet (PIS; Appendix A) via post or email and complete and return an expression of interest form (EOI; Appendix B) via post or email to the researcher, or to consent for the researcher to contact them via phone or email directly to give further details. They were also provided details of the project website with the option of directly downloading the PIS and EOI forms, and learning about the project by watching a video (<https://tinyurl.com/cancercovid>). The project was advertised via posters (Appendix C) displayed in outpatient visiting areas, however, COVID-19 restrictions hampered these efforts. The EBEs provided feedback to improve the clarity of the recruitment materials. Examples included: re-recording the video on the website so that it was loud enough to be heard on a hospital ward; rewording of the PIS to make information clearer and more appropriate (see example in Appendix J); changing the colour of text from black to blue to make it easier for parents to read.

Thirty-one of 201 eligible parents were told about the project by oncology staff; twenty-four expressed interest and were provided further information, and nine participants consented to being directly contacted directly by phone or email. One

participant contacted the researcher directly via post. Eight of these parents verbally consented to participate, two of which did not go ahead due to nonresponse to follow-up phone/video calls.

Six parents were recruited and completed interviews, which is consistent with the recommended sample size for IPA studies conducted as part of professional doctorates (6-10 participants; Smith et al., 2022). This allows for sufficient depth of analysis required for IPA, while still capturing some breadth and difference.

3.3 Ethical considerations

Ethical approval was granted from both the Clinical Research Committee (R & D number: A095997) at Cambridge University Hospital (Addenbrooke's), and the NHS Health Research Authority (REC reference: 21/EM/0164; Appendix D). Full sponsorship was gained from the University of Hertfordshire's Ethics Board (Protocol number: LMS/PGR/NHS/02965; Appendix E).

This section continues with outlining ethical issues related to this research and how they were addressed.

3.3.1 *Informed consent*

Participants who were eligible and interested in taking part were provided with PISs (Appendix A). Parents had the opportunity to communicate with the researcher via email or phone to ask any questions to inform their decision around participating. By providing a video explaining the study on the website, it was hoped that this would make the information more accessible. All parents read and signed a consent form before participating (Appendix F), the details of which were recapped before the interview began.

PISs and consent forms notified participants of their right to withdraw their interview until the point of analysis (14 days post-interview at the earliest).

Participants were reminded of this during the interview debrief. This limit was set because it would have become challenging to extract data once analysis had begun.

3.3.2 Confidentiality

Participant confidentiality was maintained throughout the research process. Information around confidentiality, including its limits, was outlined to participants, both in writing and verbally. In compliance with the Data Protection Act (2018), interviews were audio-recorded, transcribed, anonymised, coded, and kept secure to maintain confidentiality. Data was stored on a secure drive that was password protected, complying with university regulations. Transcription documents were also password protected, and only the researcher and principal supervisor had access. All identifying information, such as names and places were removed to maintain anonymity. A discussion was had with participants at the end of interviews around any information that they would like to change or remove. No participants requested to amend any recorded information. A non-disclosure agreement was signed when working with the transcription company (Appendix G).

3.3.3 Managing distress

It was not expected that participation would itself be distressing, yet due to the sensitive nature of the topic, it was anticipated that some distress may be experienced. This was managed in the following ways:

- Parents were fully informed about participation, including being given an overview of what the interview would contain ahead of the interview day, detailed on PISs. Completing EOI forms gave parents further time to reflect on whether they wanted to participate.
- It was made clear to participants before beginning the interview that they did not have to respond to every question given. They were reminded that they only needed to talk about topics with which they felt comfortable.
- The interview was carried out in an empathic, responsive way. If the participant was experiencing a high level of distress, they had the option to take breaks or stop at any time if they wished. It was highlighted that the interview could be discontinued at any time, and that they had the right to withdraw without giving any reason. There were brief pauses taken in some interviews, but none were terminated. Participants guided interview pacing.
- To account for the time burden, interviews were arranged at a time that suited participants as best as possible. As recommended by the EBE, participants were also given the option of splitting interviews across two sessions, though all participants opted to be interviewed in one session.
- Participants were provided with debrief sheets (Appendix H) that detailed support networks that they could access (internal and external) and were reminded that they could speak with the team psychologist if they wished to.

The impact of the interviews on my own well-being was also acknowledged.

Regular supervision with the research team, my external supervisor, peer supervision, and reflective journaling were helpful strategies. It also helped to take breaks from interview coding, alternating this with less intense activities, to help manage the process.

3.4 Data collection

3.4.1 Development of the interview schedule

A semi-structured interview schedule was constructed in line with IPA guidelines (Smith et al., 2022), based on consultation with the literature, supervisory team, and EBEs. Semi-structured interviews are appropriate as they provide a certain level of structure to frame interviews to answer research questions, while having sufficient flexibility to adapt questions to responses given, affording richer levels of exploration (Smith & Osborn, 2007). The researcher is then able to be open and receptive to unexpected topics introduced by participants (Eatough & Smith, 2017).

Interviews began with closed questions to collect demographic data and key information about parents' children and their cancer. These simple questions were asked verbally, as it was helpful in building rapport and easing participants into the interview process before moving onto more demanding questions (Smith et al., 2022). The main interview schedule (Appendix I) contained three sections: (1) how parents learned about the diagnosis to set the context; (2) how having a child diagnosed with cancer during the COVID-19 pandemic had impacted parents individually; and 3) how having a child diagnosed with cancer during the COVID-19 pandemic had impacted them as a family, their relationships, and how their family functions.

The first section was to aid participants to 'set the scene', allowing some comfort in narrating a descriptive episode before moving onto evaluation or analysis of experiences (Smith et al., 2022). The second section provided questions and prompts that required participants to describe how they personally responded and coped with the experience and how the pandemic impacted this, before moving onto the impact on family more broadly in the third section, which also included

experience of access to social support, and experience of healthcare professionals. Finally, participants were asked whether there was anything else that they felt was relevant that they had not had the chance to discuss.

Consultation with EBEs improved my awareness that parents might feel that they needed to compare their experience to pre-COVID, which highlighted the need to make explicit that participants needed only to reflect on their own experiences. The interview schedule was also piloted, and the participant consented to using the interview in the analysis prior to taking part; as no substantial changes were made to the schedule, this participant's interview was included in the analysis. Reflecting on the piloting process both with the participant and in supervision was helpful in reshaping the conduct of remaining interviews. For example, it highlighted the importance of stating my position as a researcher at the start of interviews and how that differed from my clinical role (see reflective diary; Appendix J).

3.4.2 Interview procedure

Some flexibility was given to participants in terms of method of interview, as they were offered either online video or telephone interviews. However, face-to-face interviews were not possible due to COVID-19 restrictions. Some evidence suggests that offering flexibility may improve research access and uptake in participation, especially when samples are widely dispersed geographically, and when topics are sensitive in nature (Heath et al., 2018), both of which applied to this study.

All parents chose to participate via online video calls. Interviews lasted between 50 minutes and two hours. All parents, including the one participating couple, were interviewed separately. There is evidence that separate interviews

have been effective when exploring sensitive topics such as adjustment to a childhood cancer diagnosis (Eisikovits & Koren, 2010; Van Schoor et al., 2018).

Written consent was gained from participants before commencing interviews. Interviews began by reviewing the study information and re-checking consent. It was explained that the interviewer had a series of questions to ask but emphasised that these questions were just a guide for understanding their experience as a parent as best as possible. Once parents had answered the initial demographic questions, the answers to which were recorded in writing by the researcher, interview audio-recordings began.

The schedule was used flexibly both in terms of content and order, allowing the researcher to be guided by participants' thinking (Smith et al., 2022). There were lists of possible prompts for each question, but these were rephrased, or adapted based on participants' responses, adapting to their rhythm, and picking up on key words and phrases that they used (Smith et al., 2022).

At the end of the interview, participants were asked for feedback on the process, whether they wanted any information discussed not to be included in the analysis, and they were provided with debrief sheets detailing support available. They were also reminded of their right to withdraw up to the point of analysis.

3.4.3 Interview transcription

Project time constraints meant it was only possible for me to transcribe one of six interviews. An independent transcription company supported the initial process of transcribing other transcripts verbatim. The process of then editing transcripts and making amendments was useful for starting the important process of my immersion

in the data. Transcription of interviews happened soon after the interviews were completed to keep in mind the voice and non-verbal responses of participants.

3.5 Data analysis

The analysis was implemented following guidelines outlined by Smith et al. (2022), along with consultation with the supervisory team, and an IPA peer supervision group. Table 9 presents a summary of Smith et al.'s (2022) seven steps that were used as a heuristic framework to guide the analysis. Having read and listened to the audio-files several times, summaries of each interview were written in a separate file. I noted what felt most pertinent, relating this to my pre-understanding of the research topic. Each transcript was focused on individually in turn to maintain the idiographic focus of IPA. For steps two and three of the analysis (exploratory noting and experiential statements), the transcripts were annotated in a Microsoft Word document (see Appendix K for annotated transcript excerpt). Transcripts were then stored on NVIVO v.1.6.2 (QSR International, 2020) for organisational purposes.

When searching for connections across experiential statements (step 4), statements were copied into a new file and duplicates were removed. They were then printed and cut out into individual statements to aid the process of clustering and moving them around to find the best way of mapping inter-connections to develop personal experiential themes (PETs). Once statements were organised into PETs (see example in Appendix L), these were transferred to NVIVO to keep track of findings that were still linked to transcripts. This was an iterative process, where emerging themes were reviewed and adjusted, ensuring that it remained grounded in participants' data.

Table 9

Summary of IPA procedure (from Smith et al. 2022)

Step	Procedure
1	<i>Reading and re-reading</i> of the first transcript to become immersed and focused on the participant. Can include writing a summary of the interview, commenting on the most striking aspects.
2	<i>Exploratory noting</i> of the semantic content and language, maintaining a phenomenological focus in the left-hand margin. Key objects of concern are noted, such as relationships, processes, values etc., and meanings attributed to these. Interpretative noting includes examining the language used, and thinking about the context of their concerns, and making sense of the patterns of meaning.
3	<i>Constructing experiential statements</i> in the right-hand margin. This takes the work to a higher level of abstraction that combines the participants' original words and researcher's interpretation of what appears to be important.
4	<i>Searching for connections</i> across experiential statements, by charting or mapping how they fit together.
5	<i>Naming the Personal Experiential Themes (PETs)</i> . A list of themes for the interview is drawn up that relates to their experience that makes sense of the patterns noted across the transcript.
6	<i>Continue the process with other cases</i> (interviews).
7	<i>Develop Group Experiential Themes (GETs)</i> across cases by looking for patterns of similarity and difference across PETs.

The final stage, once PETs had been developed for each interview, was to develop group experiential themes (GETs), which examined patterns of similarity and difference across accounts (Smith et al., 2022). This process was similarly carried out by printing and moving around themes into clusters, condensing and relabelling emerging GETs. I met with my supervisors to discuss this process, and to

review the GETS that I felt best represented participants' experiences, capturing both similarities and differences. A narrative account that contextualised each of these themes was then written, supported by extracts from the transcripts.

3.6 Quality in qualitative research

There is no one way of evaluating validity and quality of qualitative research, and the current study referred to several frameworks. The study was informed by the comprehensive "Big-Tent" Criteria for Excellent Qualitative Research (Tracy, 2010), and a detailed evaluation against the criteria is presented in the discussion chapter. In addition, Yardley's (2000; 2008) criteria were also drawn upon, as they have been applied to many previous IPA studies (Smith et al., 2022). Levitt et al.'s (2018) reporting criteria, applied to IPA (Smith et al., 2022), were followed for each step of the thesis write-up, as the way a report is written can help readers gauge validity. There is much overlap in the criteria set out, and some of these, namely sensitivity to context, rigour of analysis, and coherence and transparency, are discussed below.

3.6.1 *Sensitivity to context*

Within qualitative research, sensitivity to context refers to the context of theory and previous literature, as well as considering the context of power throughout the research (Yardley, 2000). I drew on previous knowledge and theory to inform the interview and to support analysis. This included consciously situating the project within the NHS service context, and outlining restrictions imposed on families and staff. In addition, I sought consultation from EBEs who had been through the process of having a child treated for cancer during the COVID-19 pandemic, which helped to reshape the interview questions and the way that I engaged parents in interviews.

The project's critical lens meant that I tried to attend carefully to the socio-cultural and political context. I considered how this influenced parents' experience of the pandemic, drawing out the impact of some of the demographic and personal characteristics of participants.

3.6.2 Commitment and rigour

Commitment to rigour in qualitative data collection, analysis and interpretation is demonstrated through presenting a systematic and transparent account of the process (Levitt et al., 2018). In terms of data collection, I have provided a transparent account of how the interview schedule was developed in consultation with EBEs in section 3.4.1. An example of my commitment to IPA includes trying to remain connected to the iterative process by continually returning to transcripts and audio-recordings to stay connected to participants' accounts (outlined fully in section 3.5). In presenting my themes, I was conscious to represent the full range of participants and attend to accounts' complexity by noting divergence as well as convergence in my narrative (Levitt et al., 2018; Smith et al., 2022). Rigour in analysis was also ensured by the supervisory team checking that themes and interpretations linked back to the data (Yardley, 2000).

3.6.3 Coherence and transparency

Coherence between the research question, epistemology, and methodology (Yardley, 2000, 2008) was checked through regular consultation with the supervisory team and IPA research group. As evidence for transparency and coherence, data analysis excerpts have been provided to illustrate how themes were derived (Appendix K and L), as well as providing many quotations to exemplify the themes.

Throughout the research process, I kept a reflective diary, attempting to “bracket” my own biases and assumptions, and acknowledge my position and impact on the research, as well as to audit the quality of my work. For instance, when coding data, I kept a record of when I felt strong reactions to participants’ experiences. One such example is when a parent talked about the lack of support available, and I realised that my own professional position as a colleague of the oncology psychologists was impacting my response to what was said. It was important for me to “bracket” my experiences in my reflective journal, so that I could attend fully to the participant’s experience (Smith et al., 2022).

4. Results

This chapter presents an Interpretative Phenomenological Analysis (IPA) of parents' experiences of having a child diagnosed with cancer during the COVID-19 pandemic, and their perception of the impact on their family. The next section outlines sample characteristics, and sections that follow outline each theme.

4.1 Sample characteristics

Six parents partook in this study: one married couple (mother and father), and the remaining participants were mothers. Demographic information, including information regarding the child's cancer diagnosis, is presented in Table 10. Most parents were interviewed when their child was 13-18 months post-diagnosis. However, one interview was unable to take place until 22 months post-diagnosis, but the data was included as it was still within the timeframe of the pandemic. Pseudonyms were given to parents and their children; however, pseudonyms have not been matched to participant characteristics to maintain confidentiality.

Table 10*Sample characteristics*

Sample characteristics

Parent age	Range: 39 – 45 years
Parent sex	Female (n = 5) Male (n = 1)
Parent ethnicity	White British (n = 5) Mixed Asian (n = 1)
Parent's described relationship with child	Mother (n = 4) Adoptive mother (n = 1) Father (n = 1)
Parent marital status	Married (n = 4) Divorced (n = 2)
Child cancer diagnosis	ALL ¹ (n = 2) Brain tumour (n = 3)
Child's age	Range: 8 – 14 years
Child's sex	Male (n = 3) Female (n = 2)
Time since cancer diagnosis	13 – 22 months
Number of other children living at home	Range: 1 to 3 children
Age of other children	Range: 5 – 21 years

¹ ALL: Acute lymphoblastic leukaemia

4.2 Overview of GETs

Three Group Experiential Themes (GETs) and their subthemes were identified (Figure 3). Themes are described in detail, along with quotations to illustrate and evidence the credibility of interpretations. While GETs aim to reflect shared features from all interviews, distinctions are drawn out where similarities and differences exist between participants (Smith et al., 2022). It is also important to acknowledge that just one possible interpretation is presented, and that the analysis focuses on experiences most relevant to the research question rather than every experience shared (Smith et al., 2022).

Table 11 illustrates the recurrence of themes across participants. It is noteworthy that Aiden was the only participant who was a father and was also not present in the hospital with the child with cancer. He therefore did not have the same opportunity to form connections with other parents (Subtheme: New relationships - “the *hospital family*”) nor did he talk about accessing professional support in hospital (Subtheme: Accessing professional support) like the other participants who were mothers, who all also happened to take a primary role in looking after the child in hospital. There was otherwise a good fit across participants with themes. Aiden was included as he provided a useful alternative perspective as the parent at home that was also conveyed by several of the mothers through describing the impact on fathers and other family members at home.

Open family communication was also described by all participants (e.g., age-appropriate explanations for children), which has been reported in previous pre-pandemic studies (e.g., Van Schoors et al., 2020), and is identified as an important process in family resilience (Walsh, 2003; 2016); however, there was not sufficient depth for it to be a subtheme of its own, so this was omitted.

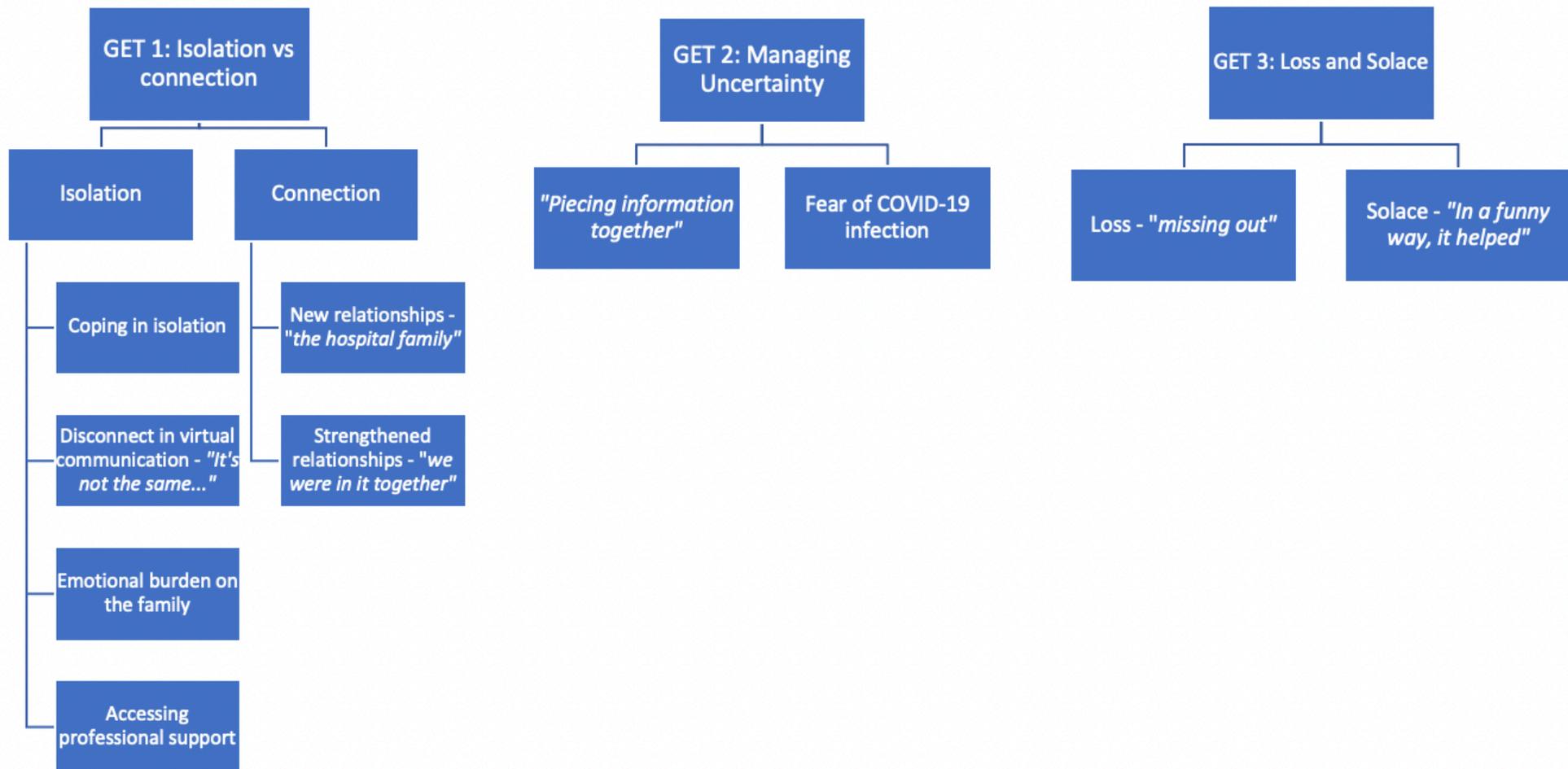


Figure 3: Group Experiential themes (GETs) and subthemes

Table 11*Recurrence of themes across participants*

	<i>Jenny</i>	<i>Jess</i>	<i>Katy</i>	<i>Aiden</i>	<i>Amy</i>	<i>Ellie</i>
GET 1: Isolation versus Connection						
Isolation						
Coping in isolation	x	x	x	x	x	x
Disconnect in virtual communication – <i>“it’s just not the same...”</i>	x		x	x	x	x
Emotion burden on family	x	x	x	x	x	x
Accessing professional support	x	x	x		x	x
Connection						
New relationships - <i>“the hospital family”</i>	x	x	x		x	x
Strengthened relationships – <i>“We were in it together”</i>	x	x	x	x	x	x
GET 2: Managing Uncertainty						
<i>“Piecing information together”</i>	x	x	x	x	x	x
Fear of COVID-19 infection	x	x	x	x		x
GET 3: Loss and solace						
Loss – <i>“missing out”</i>	x		x		x	x
Solace – <i>“in a funny way, it helped”</i>	x	x	x	x	x	x

4.3 GET 1: Isolation versus connection

This theme represents the complexity of the impact that going through a diagnosis of cancer during the COVID-19 pandemic had on families where restrictions were in place in hospitals. Visitation restrictions led to the disruption of, and isolation from, natural support networks, which had an added emotional toll on families. Yet parents also shared stories of connection that helped sustain them – both new connections with people (staff and other families) at hospital and strengthened connections with their family and friends.

4.3.1 Isolation

Four subthemes related to 'isolation' helped explain experiences of being isolated because of hospital restrictions, and the factors and consequences related to this. First, participants reflected on felt experiences of coping with being physically apart from loved ones, and how hard it was to feel isolated in hospital. Second, they spoke about the challenge of communicating through virtual methods and how this contributed to feeling isolated from family. Parents described barriers to having privacy to express yourself sufficiently, and miscommunication that ensued from practical challenges around making phone calls. Third, parents reflected on the emotional burden that this put on the family, particularly the complexity of emotions experienced by siblings. Fourth, some parents described challenges they experienced in accessing professional support linked to reduced services in operation during the pandemic, which left them feeling alone in trying to process a difficult experience.

4.3.1.1 Coping in isolation

All five parents who stayed with the child with cancer in hospital described how lonely some of the early experiences of receiving diagnosis news, or spending time in hospital was, without physical contact with family and friends. Ellie describes her experience of receiving the news of diagnosis alone without the emotional support she needed:

“The one thing that really sticks with me is the nurse that was next to me. She, obviously I was crying, she just, she put her crinkly gloved hand on my knee and then sort of whisked it away because she wasn’t allowed to touch me, but she sort of reached out and I, it was...I don’t know...it was a real nice moment but sort of sad that she, no-one was allowed to comfort me”(Ellie).

Ellie’s description is full of pathos, which emphasises how alone she was. The warm gesture of offering human comfort through touch contrasts with it having to be quickly withdrawn when the nurse remembers to follow social distancing rules. The image of further distance is created in the clinical description of PPE: *“crinkly gloved hand”*.

Two parents described their experience as feeling *“stuck”* (Jenny) or *“trapped”* (Katy) in hospital. For Jenny, this was not being able to see loved ones, and Katy described her distressing experience of being trapped in an isolation room. When there were other families with COVID-19 on the ward, she and her daughter were put in a room alone. Here, she describes being disturbed by another patient in distress:

“...this guy starts screaming for help and, and he would go on till like...one o’clock in the morning, and it was relentless...I do think that is awful, but equally it’s just as awful to have a child that’s got cancer and blood clots on their lungs and who’s really ill and you’re trapped in a room that you can’t get

away from and you got somebody screaming and screaming and screaming”(Katy).

Katy describes being in a physical space she could not remove herself from and being trapped by the relentlessness of the screaming. She expresses sympathy that another person was in distress, but her description also stresses how challenging this made it to care for and protect her unwell child alone.

Two single parents spoke of the additional isolation and stress they felt resulting from the parent visitation policy. When a policy allowed parents to alternate which parent was present with the child with cancer, this could only be a legal parent or guardian. Jess describes initially having no option to share the care for Johnny, which lasted for three months:

“...because of the whole COVID thing, I was 100% on my own. I got nobody with me, nobody at all. I couldn’t take one of my brothers, I couldn’t take my mum, nobody...Nobody could go on the ward and be with Johnny other than me because the whole issue was, you could only have your parents...”(Jess).

Jess’ repetition of “nobody” stresses how alone she felt. She goes on to describe the stressful process that she endured when trying to meet both children’s complex needs:

“I had to deal with everything. I had to be there as much as humanly possible but without ignoring his little brother, because of the complications his little brother’s got...So, it was literally pulling myself in 50,000 different directions.”(Jess).

Jess’ use of hyperbole - “50,000 different directions” - emphasises the impossibility of dividing her time to attend to both children’s needs, as she was not allowed

anyone else on the ward in place of the role of father. This put her in the anxiety-provoking position of leaving her child with cancer on the ward alone at night.

For Amy, being separated from her support network, and instead having to share the visitation rights with someone that she did not trust, was a painful experience:

"...to have that news is devastating, to have that news when you can't have anybody else there is, is the biggest impact...I think that was the hardest thing for me, was the only person who I did have face to face contact with, was a person who, who had broken my trust already...Yes, an immediate source of support for Jane...but not for me"(Amy).

Amy stresses that receiving the news of a cancer diagnosis alone compounded what was already difficult, and the visitation policy that was limited only to parents compounded it further. When support was most needed, she was only allowed contact with someone who had *"broken her trust"*. She raises how the policy considered who might best support the child and some families but did not consider single parents' circumstances. Amy describes how it's sometimes *"not two parents who are the most important"*:

"...it's not necessarily they're the person that they live with, you know, my mum...is a really important person for Jane...but mum, technically, because she's not her, her parent, wasn't allowed"(Amy).

Amy illustrates differences in family structure, and the parental role that some grandmothers play as another significant adult living at home. The visitation policy isolated Amy from accessing this support.

Five parents also described distress and isolation that other family members felt at home and being separated from family in hospital, and from wider support

networks. Aiden speaks directly from the perspective of the parent who was “*cut off*” from his wife and daughter, remaining at home with the other children:

“...that was a horrible time because we were cut off from seeing her... You know, our family is split up in two...you’d just be there and, to...in any way, emotional, practical, whatever, but you couldn’t, couldn’t be there”(Aiden).

Aiden conveys helplessness when he lists ways he wanted to help (“*emotional, practical*”), but could not, and the challenge of being isolated from his daughter. Amy also recognised the intense fear her mother experienced for her, and both daughters (“*threefold*”) when isolated at home. Amy’s mother looked after her other daughter without a support network:

“...she ended up looking after three dogs and the cat and my other daughter and a really heroic effort on her part here at a time where...we couldn’t have help at hand...lots of people were wanting to be able to help, people who were local people who were, you know, from [location], you know, a distance away...there wasn’t an awful lot that people could do...”(Amy).

Amy describes her mother suddenly having to assume all responsibility in the house and doing so in isolation. She describes her mother’s disconnection from an extensive support network, including people willing to travel a distance, which was not possible due to bans to travel or mix locally during the pandemic.

4.3.1.2 Disconnect in virtual communication – “*it’s just not the same...*”

Parents described virtual communication as being “*the only way*” (Jenny) of keeping connected, but their accounts outlined several constraints. Five parents expressed that virtual communication was no replacement for the comfort of being physically

present with loved ones. Aiden explains how he desired actual contact with his daughter who was unwell:

“It’s just not the same, is it? You know, you want to give your daughter a hug, you want to, you know, contact”(Aiden).

The way Aiden wanted to comfort and communicate with his daughter was not through words, it was to connect physically with her. In a rhetorical question, he states *“it’s just not the same, is it?”* There is a lessening in the degree of comfort that can be given without physical presence. Jenny also spoke about the disconnected feeling of having difficult conversations over the phone without non-verbal communication – she was unable to offer comfort through *“hugs”* or show empathy through facial expressions (*“they can’t read into your emotions”*) in response to the difficult things being said.

For Ellie, talking can be difficult, so the phone was an uncomfortable way to communicate:

“...it’s not the normal way to do it, I think. It’s a lot easier in person...I often find it quite difficult to, to talk and I think, I don’t know how I got the words out to be honest, I think I just blurted it out, I was quite matter of fact. Often I found that I’ve been too upset to manage a phone call at times and I’ve, I’ve messaged and I think that seems awful to send...”(Ellie).

Ellie describes how she can find it hard to get the words out, which meant that she was more direct than she felt comfortable being. Sometimes there are no words to fully express something distressing. She describes the barrier of having to manage emotions on a phone call, whereas in person emotional connection can be achieved through non-verbal empathy.

Four of five parents who spent time in hospital spoke of privacy and its impact on making good use of virtual communication. Jenny and Amy were concerned about their children “*overhearing*” conversations, wanting to protect them from certain details or intense emotions. Amy explains the impact of this lack of privacy:

“...it was a case of having, having those discussions when the other people on the ward can hear you or standing out in the corridor with lots of people walking past you, none of which was particularly appealing, I think, or helpful. Really, there is no, no privacy. Certainly not the kind of places where you would happily sit and be in tears, which is what you needed to do, and you can't sit and be in tears in front of your 7-year-old who's going through all of this. There was no place to go”(Amy).

Here, Amy expresses how lack of private space created a barrier to freely expressing her emotions.

Four parents described practical aspects of phone calls that impacted communication between families at home and those in hospital. The Wi-Fi connection was poor in the hospital at the start of the pandemic, and Ellie highlighted how this was particularly problematic for her son who was “*stuck in bed,*” meaning that he was often completely isolated from his family. Jenny spoke about miscommunication that resulted from relying on phone calls. She gave the example of how it was hard for her daughter to understand when she had to end a call when a doctor arrived. Without being able to read contextual cues when physically present, her daughter would misinterpret this as her “*not wanting*” to speak with her.

4.3.1.3 Emotional burden on the family

Five parents described how they focused on the unwell children over their own well-being, investing in couple relationships, and/or relationships with their other children. All parents spoke of the emotional toll of separation on siblings of children with cancer, and that this was also emotionally challenging for them. Despite inevitable family separation when a child is in hospital, distress was intensified for parents who were unable to see their other children during visits. Amy explains this difficulty at first when it was impermissible for her to leave the ward to see her other children:

“...it was very difficult for me having two children and not being able to see both children and, and to support Laura through what she was going through. You know, as a mum you want to be there for, for your kids and I wasn’t able to spend any time with her”(Amy).

Amy explains that the situation prevented her from fulfilling her supportive role “as a mum” when they were going through the challenging experience of cancer in the family. Jenny also spoke of the challenge of juggling her children’s needs. Within pandemic restrictions, parents were later allowed to briefly leave the ward to see their other children. Jenny described the quandary of leaving her very poorly son for the opportunity to see her other children in the hospital garden. Her description that she “*felt tied*” creates the sense that she felt duty bound as a mother to both and yet that was impossible.

Jenny describes her children’s complex feelings linked to being separated from her when she was devoting her time to their unwell brother:

“...I was out with Edward, and then the other children worry...one, what’s going to happen with him, but two, if you like that child more because you

have to spend more time with them...and they worry about what's gonna happen to that child which...makes them feel guilty for missing you, but also...they still miss you because you're not there"(Jenny).

Jenny tells of interacting layers of multiple emotions that her children experienced: primary emotions of fear of losing their brother, and sadness around being separated from their mother; secondary emotions of jealousy stemming from fear that their mother liked their brother more, and guilt for expressing how they felt, knowing that their brother is ill. Jenny also explained how her children's emotions impacted on one another, as she then explained that her son with cancer "*felt bad*" for getting ill as it made his sister "*sad*".

Four parents spoke of anxiety in children at home around being separated from their mother and/or sibling with cancer. One of Katy's children had learning difficulties that made separation difficult, and her other child had mental health difficulties. She described how, for both children, their anxiety was "*amplified*" by the long separation, which had cumulative negative effects on family relationships. Jess describes the difficulty that David had processing physical changes in his older brother, caused by cancer treatment:

"...it was another 14 days before those boys saw each other again. By that point, Johnny's hair was falling out. He was blown up and bloated on steroids...if he could have seen the progression...I think he'd have handled it a bit better...I think it was just a bit of a shock for David..."(Jess).

Jess describes "*shock*" that David experienced when witnessing the stark contrast in appearance within a two-week period of separation. Being unable to visit made preparation for physical changes more challenging.

Four parents felt that their other children's anxieties would have been moderated if hospital restrictions had allowed siblings to visit. Jess highlighted that while adults have more resources to cope with separation, it is *"so alien to a child to not have your family unit around you."* Parents also acknowledged the challenge of achieving this within the circumstances of the pandemic, illustrated by Katy:

"I think if, if something could have been done better...to in some way allow, allow it or something...I really don't know how it could have been done, but it would've helped as a family and especially for his insecurities...he still is struggling with those sorts of feelings"(Katy).

Katy cycles between repeating not knowing how, and suggesting that doing something (i.e., allowing contact) would have contained some of her son's insecurities. Parents highlighted the conundrum between the importance of restrictions in keeping people safe and the co-occurring psychosocial impact on siblings. Later in the pandemic, LFTs were used in hospitals for staff and visitors entering the ward. Amy suggested this testing could have been done for siblings too to mitigate some of the emotional impact of separation.

4.3.1.4 Accessing professional support

Three parents spoke about challenges in accessing professional counselling/psychological support for parents and siblings in hospital during the COVID-19 pandemic. For parents, there was counselling support available via the phone at the start of the pandemic, but no physical presence on the wards. Support services were advertised via posters on the wards, and through nursing staff. Jenny thought that there was no support available for parents, either suggesting she was not aware of the telephone support, or that she did not wish to use the phone, as it was not *"the*

same way you would have normally” (Jenny). Later into the pandemic, counsellors were limited to accessing wards once daily. Amy describes her experience of being approached by a counsellor, and raises the issue of timing of this support:

“It was very much my professional hat came on, because I couldn’t let myself fall to pieces at that particular point in time and talk about how I was really...I can’t remember her name, but whoever it was, was absolutely lovely. I probably presented as somebody saying, well, yes thanks, but no thanks. Bye. And that is really not who I am, but at that precise moment in time, I was just watching Jane breathe, thinking, I hope I can do the same thing again tomorrow. So, I, I wasn’t in the place to be able to access that support. And that’s the only time it’s been offered”(Amy).

For Amy, one of the most stressful moments, waiting for her daughter to go into surgery, was not a time that she could talk for fear that she would “*fall to pieces.*” She reflects on how she would have appeared to the counsellor as someone “*professional*” and not in need, and rejecting, of help, whereas later she did wish to have support. Amy went on to describe herself as someone who does not easily ask for help and thinks that others might be more in need.

Differences in parents’ approaches to asking for help influenced whether they accessed it. While Amy was not offered help again, or did not ask for help herself, for Ellie, support was accessed via her son’s clinical nurse specialist (CNS):

“I think I have quite a good relationship with...his CNS and...he’s been great...while I was in the ward, it was always, they’d sort of point me to the direction of the counsellor...the support was there when we were in hospital. The support is there if, if you ask”(Ellie).

Here Ellie describes the importance of her relationship with the CNS in accessing counselling, and that support was available *“if you ask.”* This raises the importance of keeping in mind parents’ differing beliefs around asking for help – some need to be directly asked, and more than once. It also highlights the role that nursing staff can play in checking in with parents whether they wish to access support at different time points during their child’s hospital stay.

Jenny and Amy both spoke about how professional support would have been helpful to them in hospital. Jenny highlights that she found it hard to process emotions on her own:

“Your emotions are all over the place and you don’t even know whether you’re dealing with it properly or not because there’s nobody to speak to about it”(Jenny).

Jenny expresses doubt about whether she was dealing with it *“properly”*, which highlights a need for someone to contain and normalise her experience. Amy voiced that she would have found it helpful to speak to someone impartial: *“Someone not emotionally invested in me or invested in Jane and everything that was going on”* (Amy); someone without the *“same trauma”* that limited how much she and her mother could help one another.

Three parents described effective professional help that supported their child with cancer:

“the play lady...was absolutely amazing with her. She’s been the only person to get Clara to lay still for an MRI”(Katy).

“[the psychologist] was great...she talked him through a lot”(Jess).

“there was information available for Edward to deal with stuff, but not [pause] other people”(Jenny).

In contrast, both Jenny and Amy stressed the unavailability of sibling support. Sibling groups previously facilitated by charity social workers were not running during the pandemic. Jenny described how her other children would have benefited from having someone to talk to, as they worried about being a “burden” to their parents. This highlights that some siblings also needed to speak to someone impartial. Katy explains that her older child’s mental health difficulties were exacerbated by the pandemic and he needed additional help:

“I wasn’t able to help him get the help he needed...Again, because I can’t be there for somebody if I’m not there, and even to this day he still needs mental [health] help, but now I wouldn’t even know how to start.”(Katy).

Katy describes the difficult position of being in hospital and not being able to help the rest of her family, and that she was unaware of how to access mental health services for her son. She suggested that contact details and leaflets about mental health services would have been a helpful starting point.

4.3.2 Connection

Two subthemes relating to connection describe the role of parents’ relationships in coping with their experience. First, parents’ new relationships that were formed (*“the hospital family”*) during long hospital stays. These relationships were particularly meaningful when separated from their natural support networks of family and friends; other parents were also a useful resource due to having shared experience of caring for, and protecting, a child with cancer during a pandemic. Second, the strengthening of existing relationships with their family and friends (*“we were in it together”*): both with family members with whom they spent intense amounts of time; and in general, family cohesion endured despite long periods of separation.

4.3.2.1 New relationships – “the hospital family”

Four of five parents who cared for their child in hospital spoke of connections made with members of staff, highlighting how staff went out of their way to promote parents’ self-care and support their child’s needs. Katy refers to them as becoming like “family”:

“...the staff there were all absolutely amazing and so lovely and it was like, in a funny way, it almost became like we had this other little family...our hospital family...”(Katy).

Katy uses intensifier adverbs (“*absolutely*”, “*so*”) to emphasise strong positive feelings, suggesting that she developed authentic relationships with members of staff involved in her child’s care. While Katy found the physical hospital challenging, relationally it seems that she experienced feelings of attachment after spending significant amounts of time with them.

Jess uses similar language in describing support received from nurses when she felt anxious about leaving her child with cancer in hospital since she was unable to have a family member stay with him:

“...the nurses were absolutely wonderful, and I could ring at any time, and I frequently did...when it came to me ringing them in panic mode at three o’clock in the morning, wanting to check on him, were amazing”(Jess).

Here, Jess describes the important role that the nurses played in containing her anxiety.

Both Katy and Jess also described physical contact with staff when they were at their most distressed, where some members of staff occasionally broke social distancing rules and displayed compassion through offering hugs. Jess describes a moment where she was given a hug soon after the diagnosis news:

Jess: *"I know [job title] in a million years weren't supposed to hug or do anything at all...[name] actually moved and sat on the sofa next to me...and hugged me, which to that point I hadn't started crying. But as soon as she did, that was it, I broke..."*

Interviewer: *"What was it like, getting that hug from her in that moment?"*

Jess: *"It's what I needed. I needed to be able to break."*

For Jess, this memorable physical contact through a hug communicated empathy that meant that she was able to *"break"* – Jess could express the emotion that she needed to at a time when she was without her support network.

Four of five parents who cared for their child with cancer in hospital talked about significant friendships formed with other parents during hospital stays. Restrictions were in place that presented barriers to parents meeting, such as the closure of communal rooms, and being restricted to allocated ward space. Jenny spoke of the challenge that this posed in the first two weeks of their hospital stay. Despite these challenges, parents and children made close connections with others staying in the same hospital bays:

"There was always a lot of support from...mums and that still carried on although we weren't supposed to mix...sometimes we'd get sort of told off [laughs] for maybe chatting in the corridors or something and they wanted to sort of keep us a bit separate...if we were in the same room together, there's, you know, four, six beds in a small room, you're sort of on top of each other, just separated by a curtain [laughs]. You can't really avoid people like that"(Ellie).

Ellie describes how parents managed to find ways around these restrictions. She draws the distinction between restrictions that emphasised being *"separate"* and the

close quarters of hospital rooms where parents were “*on top of each other*”, leading to the inevitability of bringing parents closer together. In the absence of their own family for support, parents described the valuable role that other parents played in getting through a difficult but “*shared experience*”. As highlighted by Jess – “*we really did only have each other.*” Katy describes her relationship with another parent:

“But there’s one particular lady that I shared a room with and she was just incorrigible, me and her, it was like, we’d look after each other’s children...it was like, you know, we did have lots of bad news, you’d have good news, but it, whatever was going on, we were there for each other...We’d do silly things for each other...we’d take our kids out when they eventually did let us actually get out”(Katy).

Katy playfully describes her relationship in calling the other parent “*incorrigible*”, giving the sense of camaraderie, where they created fun together (“*silly things*”) within difficult circumstances. Katy, along with other parents, described how they would facilitate self-care for one another through looking after each other’s children and enabling breaks. Sharing difficult experiences fostered cohesion through bonding and cooperation, making it more “*bearable*” (Jess). For Jenny, it was helpful to have shared experience of knowing what it was like to be “*stuck in hospital*” without family, but she also describes trust in the relationship. With the added worry of COVID-19 infection, Jenny (and Jess) explains that the other parent could be relied on to respect restrictions:

“We’ve got the same views and outlooks with the whole COVID and the restrictions and not being overly protective but make each other safe”(Jenny).

4.3.2.2 Strengthened relationships – “we were in it together”

All five parents who stayed with their child in hospital spoke of the strengthened bond with their child with cancer. With the intensity of sharing a small place for so long, Amy describes a sense of triumph that she and her daughter overcame “*tough times*” together:

“...there’s that sense of, yeah, we were in it together, definitely. And we can still sometimes reflect on that and say, you know, we went through some tough times, didn’t we?”(Amy).

Amy emphasises the combined joint action through repeating the pronoun, “we”, in describing pride in overcoming a challenging experience. For Jenny, the intense period together resulted in a special connection with her son. She explained, “*we...could tell more about each other,*” suggesting an intuitiveness to one another’s signals, and fine-tuning of empathic accuracy that comes from spending extensive amounts of time together.

Ellie and Katy described how their child’s positivity was pivotal in easing their own distress. Katy describes how her daughter’s ability to make others laugh helped her to keep going:

“We are really, really lucky...[pause] Clara is the most...Sorry [voice quavers; tearful]...It’s like she’s the most positive...She’s mental funny too. She has everybody laughing [pause]. And I used to think to myself, well, if she’s getting up, if she’s happy, then I’m getting up and I’m happy”(Katy).

Here, Katy was overcome with emotion when recalling how her daughter managed in the most challenging of situations, and she describes with fondness how she maintained her sense of humour. Ellie describes how the closeness and strength

drawn from the parent-child relationship was noted by her son too, when she recalled that he had some positive memories of time shared together in hospital:

“Josh still refers to things quite fondly...he’ll pick up a game and he’ll say, “Oh, we used to play this all the time in hospital,” and I think he’s managed to make nice memories out of stuff like that. I think that’s the only good, good thing to come out of it is, is the time that you spend together”(Ellie).

Ellie notes the silver-lining of increased time together while in hospital; their connection helped Josh endure a difficult experience, which is evident in his fond reminiscence.

Parents described a sense of coming together as families to support one other, or friends providing helpful practical or emotional support within the limitations of the restrictions. While parents were separated for long periods of time during hospital stays, pandemic restrictions meant that there were also long periods where families spent lots of time together. For example, Ellie described her family’s experience of travelling and spending the whole summer living in a small space to support her son’s treatment. Ellie and Jess also described younger siblings taking an empathic, caring role in reminding their brother with cancer to take his medication. All parents described the strengthening of existing family relationships having endured a challenging experience, as Amy emphasises:

“...it hasn’t weakened us, it hasn’t broken us, it makes us, we’re that kind of family, and we’re very lucky that we seem to get stronger out of every, every trauma, we do have a little bit extra strength”(Amy).

Here, Amy repeats the pronoun, “us”, when describing her family’s strengthening from trauma, which emphasises the important relational factor that facilitates growth.

Where there was a parent at home, they assumed new roles and responsibilities that helped sustain families and keep things going at home. Aiden described the learning he went through to become more involved with his son's school. While he described several tensions that had been difficult to overcome when the family were separated, having a common focus kept them going and brought them closer together: *"Keeping the kids well. That's the goal."*

4.4 GET 2: Managing Uncertainty

Parents are required to manage a great deal of uncertainty when going through diagnosis and treatment of a child with cancer, and during the pandemic, they were faced with additional uncertainties around the COVID-19 virus and its impact. First, *"Piecing information together"* encapsulates the anxiety-provoking experience and impact of having limited information, including challenges in relaying information to parents at home. Second, *"Fear of COVID infection"*, describes how this fear was experienced by parents and their families, in both the context of hospital and home, and describes how they managed their anxiety.

4.4.1 *"Piecing information together"*

Four parents described a lack of clarity around the COVID-19 restrictions including the need for updates on precise rules, and a clearer rationale for visitation restrictions. Ellie describes her confusion around the rationale for restrictions on the children's oncology ward:

"...when they started allowing visitors and stuff, that didn't change for the oncology ward, so it, that was a little bit frustrating, actually thinking that, you

know...you could visit someone on another ward but...all our children weren't allowed visitors and stuff... I didn't quite understand why there was no change there"(Ellie).

Ellie highlights that inconsistency in restrictions across different wards needed explanation, particularly given the impact that limitation on visitors had for her child.

All parents described their desire to know more information about their child's cancer and treatment. At the same, the parents acknowledged that staff may have given *"bite-sized chunks of information"* (Amy) about cancer treatment to take into consideration how much can be processed at once. They described it as being a balance between feeling well-informed and being overwhelmed. Parents explained that how well-informed they felt played a role in the level of anxiety experienced. Two parents described how they resorted to *"Google it"* (Aiden) in the absence of sufficient information, drawing attention to how limitless boundaries of information on the internet could lead to a high chance of getting something wrong, and therefore cause additional anxiety.

Ellie highlighted that for her son, while he was unaware of all the possibilities of what *could* happen, knowing what was *going to* happen and why was especially important in helping him cope. In contrast, Jess describes her son's traumatic experience when he was not prepared for a procedure:

"Normally, when you, anyone goes into surgery, they go into a prep room. Johnny didn't because they wanted his Hick line in immediately...He was absolutely terrified, totally terrified...But the surgical team is so matter of fact...There was a whole hoard of bright blue masks looking at him. And I mean, I don't know if you've ever been in a theatre...They are some big, scary, stainless steel rooms"(Jess).

Jess describes the intimidating environment of the sterile theatre room, and the distress that her child experienced without any preparation. She describes how the focus was on getting treatment started quickly, but without consideration of her son's well-being.

Amy also expressed her own anxiety resulting from not knowing several pieces of information around her daughter's treatment, such as why they might have had to move wards, and whether she would have had to have an operation. She describes the frightening experience of overhearing a conversation about her daughter's care:

"Perhaps people don't realise the things that you overhear when there's people talking in corridors and how that leads you to, to possibly make links or, or draw conclusions that aren't, that aren't right and there's just something really scary about having a palliative care consultant saying. "Well, we might be introduced to Jane later, we'll just wait and see," when you know that there's meetings happening, discussing what the treatment options are"(Amy).

Amy emphasises how scary it was to hear about the involvement of "*palliative care*", which presumably led her to conclude that they were talking about end-of-life care. This highlights the importance of discretion and potential consequences of talking about patients in public spaces, and the anxiety-provoking effect of overhearing incomplete information. Amy spoke of the importance of being explicit about plans to give some certainty where possible.

Parents described challenges around processing information about their child's cancer diagnosis and treatment, some of which specifically related to the context of COVID-19. Three parents spoke about the challenge of absorbing

information on their own due to the one-parent-only visitation policy, and how their husband at home felt left out of the information giving process. Jenny describes the pressure of having to do this without support from her husband:

“...they give you lots of information that you try to take in and understand, but really you can’t concentrate on everything at the same time, and you know, you’ve got too much going on in your head to think about what it all means, I suppose”(Jenny).

Jenny conjures an image of being overwhelmed in trying to understand the complexity of her child’s diagnosis and treatment while also managing her own understandably anxious thoughts. Jess similarly described this as challenging and explained that she recorded meetings with consultants as a memory aid. Katy explained the confusion caused by technical language and how it was challenging to make sense of the relative importance of different pieces of information. She describes pressure that she felt around trying to absorb information and relay it to her husband:

“My other half says, what he felt was the communication of what was going on was always difficult...you see so many people and sometimes they go to you, “What doctor said that?” And you’re like, you know, I can’t actually remember because he looked the same as everybody else because he had a mask on his face and all I could see was his eyes...if someone said the identical words to me, but was wearing a, a nurse’s or doctor’s outfit, then suddenly those words became real...and that in itself actually caused a lot of trouble and arguments...”(Katy).

Katy describes the challenge of keeping track of information due to the communication barrier created by wearing protective masks. In addition, having to

act as the go-between to relay information to her husband also created tension in her relationship as the information felt less credible than if it came directly from medical staff. It is challenging to absorb information during anxiety-provoking situations such as learning about a child's cancer treatment options, which was made more difficult without having a partner's support to take on board information together.

Three parents described that reliance on virtual communication led to feelings of confusion and misunderstanding around their child's cancer treatment for the parent at home. Aiden describes the confusing experience of being present at his daughter's operation via WhatsApp:

"...I remember [wife's name] went into the operating theatre and she had the video, you know, the WhatsApp video call going on, and Jess was conscious, and I could not get over that. I really wasn't expecting that...I had no idea what that operation would entail and what to expect"(Aiden).

Aiden describes how he was shocked that his daughter was conscious. Being at home, contextual information was missing that would have enabled him to prepare for being present at her operation. Aiden described *"feeling out of the loop"* about his daughter's care at several points in his narrative, having to rely on information passed on by his wife via virtual communication. As the parent at home, Aiden desired more frequent face-to-face meetings with consultants that involved him; although he acknowledged the practical limitations of this, he suggested the provision of details via written notes or emails.

4.4.2 Fear of COVID-19 infection

Fear and anxiety were expressed by some parents in relation to children with cancer getting infected with COVID-19 in the hospital and community. Four parents talked about fear of their child contracting COVID-19 (or family members getting the virus and passing it on) in the context of their increased vulnerability due to cancer and/or their suppressed immune system resulting from chemotherapy treatment. For Katy and Aiden, this was most strongly felt in hospital. Katy expresses her frustration around having felt unsafe in an isolation unit with other people with COVID-19:

“...we were told that they, there was like a colour banding that they were using for the COVID area...And then they decided that they would put people that were in amber and red together, which would have meant me and Clara, even though we tested negative every time, all these times, we were going to be put in with people who had COVID. And you’re thinking, so you’re going to put me and my daughter who’s got blood clots in her lungs in with people who have got COVID?...I’d be safer in my own home. You, you know, you’re putting us in these stupid damn restricted bubbles, but yet, my own family would be a safer environment to be in right now than this hospital is...”(Katy).

Katy begins in the past-tense when describing the system that meant she and her daughter had to mix with people known to have COVID-19, and then switches into the first-person present tense when she expresses the intensity of her feelings around this, which draws you to the immediacy of what she is saying. Her use of a rhetorical question to describe her daughter’s vulnerability highlights how unsafe and unfair this was.

Aiden also describes stress around knowing that his daughter with a “*fousy immune system*” was mixing with other children and parents with COVID-19:

"...so there was one point where they put Jess in isolation but then she had to use bathroom facilities with people who were known to have COVID. That stressed you out, you know. And looking back on it, well, what else could have happened. They can't magic another room, so you know what I mean?"(Aiden).

Aiden describes the stress he felt at the time, fearing for his daughter's safety. He reflected on how he sees it with hindsight, as he rationalises the situation, drawing attention to limited resources in the hospital and the practicalities of where to put people.

Jess talked about her worry about COVID-19 being brought into their home, and how she did everything she could to protect her son by making sure the house was free from "germs":

"I was worried about all of it [infection from other viruses], but more the COVID factor with the, with all the stuff that was coming out on the news...it was basically indicating that if you'd got any medical issue, you were at higher risk and more vulnerable...I think the way my brain dealt with that was, if the house is scrubbed from top to bottom and there's no bacteria, germs or anything in the house, then he's protected...once he'd had that diagnosis and his chemo started, that was it. His immune system was gone, so God forbid anyone that came in contact with him had any sort of virus...let alone a COVID variant. It, it [sighs]...it could have ended him. I know that sounds really dramatic, but it could have done"(Jess).

Jess' sources of information through the news and media contributed to her perception that her son was at high risk and her fear for his death caused by the virus. Unlike hospital, a parent can have more control over a home

environment. Jess aimed to maximise his protection and ease her anxiety by developing a thorough cleaning routine.

Jenny and Jess also spoke about anxiety that their children also experienced around COVID-19 infection. Jess explained that her son with cancer was “*nervous about getting the school bus*”, and that she continued to collect him by car. Jenny speaks of the worry her other children felt about mixing with others at school and potentially bringing back COVID-19 and infecting their brother with cancer:

Jenny: “*I think that the stress that... the siblings might go to school and pick something up I think, you know, they worried about that, and it made life more difficult as well.*”

Interviewer: “*what did their worry about that look like?*”

Jenny: “*Just, getting stressed about it and changing clothes when they got home and you know, it just made it more difficult I suppose. Just another dimension that wouldn't have been there before*”(Jenny).

Jenny's children's worry was seen through the extra precautions they took (e.g., changing clothes) to ensure that risk of spreading the virus was minimised as much as possible. Her description of it being “*another dimension*” highlights that this worry about COVID-19 was additional to all the other worries around coping with their sibling experiencing cancer.

There were differences between parents in terms of how they perceived risk of getting COVID-19 with cancer, and how anxious they (and their children) felt. Ellie seemed comparatively less concerned. In the context of expressing her view that she felt that the hospital visitation restrictions were too strict, Ellie said: “*As far as we were aware, Josh wouldn't have been sort of massively at risk had he caught it*”. Ellie's view seems to suggest that there was a risk, but he was not “*massively*” at

risk, hence feeling that, in balance, more social contact would have been more important for their family than additional isolation. She starts her sentence with “as far as we were aware”, which also emphasises the uncertainty around how the virus affects children with cancer.

4.5 GET 3: Loss and solace

Parents described their experience of having a child diagnosed with cancer during the COVID-19 pandemic within the context of a wider sense of loss. This was both in the sense of what *was*, in terms of routines, rituals, and social connections; and in terms of what *could have been*, as they reflect on lost opportunities to make the most of time spent together as a family. These lost opportunities could have helped ease the distressing experience of having a child diagnosed with cancer. At the same time, parents also described a range of factors that gave them comfort and acceptance of having experienced their child being diagnosed with cancer during the pandemic.

4.5.1 Loss – “missing out”

Katy described how long stays in hospital with her child with cancer led to missing out on many opportunities to celebrate significant festivals together as a family, which was particularly hard for her younger son living at home:

“We missed all Christmas and New Year and Valentine’s and all the things...I’m a sado mom, I do like, you know, whether it a heart-shaped ham sandwich or whatever [laughs]. I always do, I do like theme stuff for my kids, so I always have done... it’s almost like any time that was special, we weren’t there for it”(Katy).

Katy lists a series of special occasions that mark the passing of time throughout the three-month period they were in hospital. The *“heart-shaped ham sandwich”* is an example token gesture that she fondly remembers, which gives significance to Valentine’s for her kids. Celebrations are important for relationships through the creation of these special memories. There is a sense of sadness for both Katy and her other son at home that many of these important times could not be shared.

All parents described continuing to limit contact that they had with others outside the family living at home, beyond the government-imposed restrictions, to minimise risk and protect the child with cancer. Three parents also described the impact *“extending their isolation”* (Ellie) during periods of time at home had in terms of loss of experiences as a family. Jenny spoke about feeling as though they were *“missing out on time”* whenever she and her son with cancer were home from hospital:

Interviewer: *“And then what was life at home like doing not much, as you describe?”*

Jenny: *“Boring [laughs] just like I said, you just felt like you were kind of missing out on time that you could do stuff, you know, in case he was back into hospital again soon...you're home from hospital, you wanted to celebrate not being in hospital, but there was nothing you could do at the same time”.*

Here Jenny describes the desire to celebrate being back together again as a family, but the pandemic had taken away the opportunity to do something meaningful and worthy of creating memories to make the most of these times. Places they enjoyed, like the cinema, became the *“worst places”* due to ventilation. There is a sense of sadness and regret that this was not possible. Fear also underlies missing out on

time, with the impending possibility that her son will be back in hospital again – the window of opportunity gets increasingly smaller.

Jenny described how an extended period at home resulted in loss of routine for her other children. This routine previously provided “*differentiation between home and school*”:

“...there was no difference between being at school and being off school, because when they were home to do stuff, we couldn't do stuff...we played games and watched DVDs, but I think they missed the fact that they could go out...I think it's hard for them to mark time that passes and keep going because, you know, one, I wasn't there all the time, and two, there was, they couldn't do anything nice or see family”(Jenny).

Jenny emphasises that her kids had to cope without seeing her, and in addition to that, missed out on spending time with family or continuing normal activities that “*keep you going*”. In particular, she highlighted that this was hard for her son with cancer, as being unable to go out at all made him “*insular.*” Jess also spoke about loss of social contact and activity for her son with cancer:

“...he must have felt horrendous, but I must have just wrapped him in cotton wool because he was, he couldn't go anywhere, do something or see anybody without me...”(Jess).

Jess' use of the idiom of wrapping her son up in cotton wool suggests a high level of protection (and perhaps she is suggesting overprotection) in the context of the pandemic, which created a barrier from him engaging in any social contact.

Ellie also spoke of the impact of extended isolation on her other kids in terms of loss of opportunities to have social connection with their friends:

“He started chemo, we, we were very separate...The kids, they were, when they were at school, they were at school and they came home, they didn’t have friends round. And we just seemed to be very separate...I think the kids, even like we weren’t sharing lifts if they went to football and I think the kids kind of felt that, and at times have been little bit resentful”(Ellie).

Ellie draws emphasis to how the experience of her son going through chemo during the pandemic was isolating for her family with the repetition of the phrase “very separate”. With the extended isolation, Josh’s siblings were unable to get back to doing normal social activities. There was the sense that they longed for ‘normal’ social connection through simple activities, such as lift sharing and playdates, through the resentment they expressed.

4.5.2 Solace – “in a funny way, it helped”

All parents described a range of factors that helped them to accept the circumstances of the pandemic, offering a degree of comfort or consolation for the level of distress that it otherwise caused their families. Words like “*twisted*”, “*weird*” and “*funny*” indicate that they felt strange about benefiting from challenging circumstances. Two parents stressed the necessity to keep the child with cancer safe, with all extra measures meaning that they felt that they were doing everything possible. Aiden expresses sympathy for the restrictions:

“...as far as the pandemic is concerned, I could sympathise with the situation. You could see that things couldn’t be done for practical reasons. And like I said before, the priority at that time was survival, so you can, you can cope with that”(Aiden).

Focusing on the priority of his daughter's survival provided reason enough for his family to endure what they did. Throughout their narratives, Aiden and Jess both cycled between what was difficult and isolating, and practicalities of the pandemic, where people were doing their best within challenging circumstances. There is a protective nature in rationalising why they had to endure what they did. Aiden also spoke of a degree of comfort in knowing that others were missing out because *"everyone was restricted in what they could do"*:

"We don't feel almost like you're missing out...like you'd be doing something with them that you can't do, and you could feel guilty about that, but in a weird way that sort of helped"(Aiden).

His daughter's level of fatigue and illness were other factors, in addition to wanting to protect her from COVID-19, that would have stopped family activities. He refers here to removal of pressure and guilt in being able to do something with her siblings, as the COVID-19 restrictions were another factor meaning this was out of his control.

While many circumstances arising from the pandemic increased the level of challenge, there were some advantages that parents outlined in caring for a child with cancer at this time. Amy spoke of *"comfort"* in knowing that *"people just couldn't call in unannounced."* There was a sense that it gave her family a degree of privacy. In terms of space and facilities in hospital, Amy also highlighted the benefit she got from extended use of overnight accommodation that promoted her self-care, which she felt might not have been the case pre-pandemic. Ellie speaks of hospital restrictions benefiting their stay in hospital:

"I can't imagine being in a small bay with like four other beds in there and having mums and dads and siblings all being in around. There's no space and I honestly can't imagine what that would have been like...I know it sounds

funny because the biggest issue through the pandemic was not being able to have that support but I think in these tiny little rooms, I think...”(Ellie).

Ellie notes a paradox, as the factor that made the experience most challenging for them – lack of social contact – meant that her son’s experience in hospital was probably more comfortable, due to fewer people being around given the lack of space on hospital wards.

Three parents spoke of the advantage of being furloughed during the pandemic, or receiving sick pay, and benefits that brought without having work or financial worry. Jenny was initially given sick pay, and then was redeployed so that she could work from home:

“My husband and I, we used to work shifts, so we were out a lot, doing shifts and [pause] also, and you know, because we couldn’t do stuff, we were more together, I suppose...I think it’s enabled us you know in a funny way to have more time together because we were [pause] not working opposite shifts all the time.”(Jenny).

The pandemic meant that they were both working from home suggesting a greater sense of togetherness in contrast to the opposite shifts that they used to work. While she also described loss of opportunities to do memorable things together, they did benefit from more time together. However, another parent spoke of the additional stress of their job loss, highlighting that benefits of the furlough scheme were not universal.

5. Discussion

This chapter will discuss the research findings, beginning with an overview of the themes, followed by more detailed discussion of each General Experiential Theme (GET) in relation to theoretical and empirical literature. Clinical implications will then be presented, followed by critical evaluation of the study's quality, and suggestions for future research. Lastly, reflections and conclusions will be shared.

5.1 Overview of themes

GETs combine to describe parents' experiences of having a child diagnosed with cancer during the COVID-19 pandemic, and their perception of the impact on their family. There are threads related to family resilience (McCubbin et al., 2002; Walsh, 2015) that connect themes together, capturing the complexity of the dynamics of adjusting to cancer within this context. The themes capture significant experience of stress, and at the same time, describe family processes that buffered against stress. Parents describe polarised positions occurring in tandem in '*GET 1: Isolation vs Connection*': the experience of feeling isolated from their support network, as well as building and strengthening connections. '*GET 2: Managing Uncertainty*' captures parents' frustrations and fears around managing information gaps around their child's cancer treatment and COVID-19, and also identifies their communication needs. Finally, in '*GET 3: Loss vs Solace*', parents describe loss of experience and routine during lockdown, while also positively noting silver-linings in the restrictions that provided solace during times of uncertainty.

Many aspects that parents describe within the themes have commonalities with parents' experiences in pre-pandemic times in terms of the dynamic processes

that occur between families in a paediatric cancer context. This includes adapting to new roles and routines, strengthening relationships (cohesion), their process of sense making, and their use of support networks (both peers and HCPs), particularly in hospital (McCubbins et al., 2002; Walsh, 2016). While parents have previously described the impact of cancer treatment and hospital stays on family relationships and loss of routine, the pandemic restrictions heightened the degree of isolation and loss; families had to navigate extended periods of isolation, separation, and fear of COVID-19 infection in addition to the cancer-related stresses. Unique to this study is the eco-systemic framework that considered factors that impacted family resilience more broadly than the family-level. This includes navigating organisational constraints such as lack private space to utilise virtual communication; the impact of policy on single parents making use of family support; and the dynamic interplay of HCPs and parents in communication around cancer care and COVID-19.

The next section provides more in-depth discussion of each GET in relation to existing theories, and both pre-pandemic and pandemic focused literature.

5.2 GET 1: Isolation versus Connection

5.2.1 *Isolation*

Coping in isolation

Parents described the lonely and frightening experience of going through diagnosis without a significant other when restrictions were in place. This is similarly expressed in other pandemic-focused studies, both by parents in Davies et al.'s (2022) Australian-based paediatric oncology study, and clinicians reporting family distress in other paediatric settings (Diskin et al., 2021). In addition, parents described the impact social distancing restrictions had on feeling disconnected from the support of

friends, extended family, and community, both for those family members in hospital and at home, similarly reported by Davies et al. (2022). Parents in pre-pandemic studies have consistently reported the importance of family (McGrath et al., 2005; Van Schoors et al., 2015, 2020) and community support (Björk et al., 2009 McGrath et al., 2005, Scott-Findlay & Chalmers, 2001) in mitigating distress, highlighting the importance of this to resilience. These findings suggest that COVID-19 restrictions put significant strain on these resources and relationships for the parents in this study.

Parents' experiences in this study importantly highlight inequity in visitation policies. Single parents were not afforded another family member to come in place of a partner/father. This assumption of family structure consequently excludes other family members (e.g., grandparents) who could offer vital support to the child and parent (Raphael et al., 2021). Single parents have previously reported that support from extended family members was particularly important in promoting their resilience (McCubbins et al., 2002). Single parents in the present study also had to weigh up their presence in hospital versus caretaking of other children (Raphael et al., 2021), the stress of which is further heightened when, in Jess' case, other children have additional needs. These findings suggest that defining 'parent' more broadly (i.e., key caregiving role) within policy could have mitigated some additional pressure for single parents. From a social constructionist perspective, highlighting the potentially oppressive impact of hospital policy shifts the focus from parental struggle to a broader view of the factors contributing to the "problem" (Dallos & Urry, 1999).

Disconnect in virtual communication - "it's just not the same..."

Several parents highlighted limitations of virtual communication in providing connection and support, describing how it was no substitute for physical contact with loved ones separated during hospital stays. Physical touch is key in maintaining emotional connections to others (Long et al., 2022; Timmerman, 1991). The absence of physical contact during the pandemic echoes the findings of the importance of its presence in the SLR, where staying physically connected through hospital visits (Björk et al., 2009; Van Schoors et al., 2018, 2020) and physical presence (Van Schoors et al., 2000) were important ways of giving support to both siblings and parents of children with cancer (PCC).

Parents in the present study described logistical issues such as poor Wi-Fi and lack of space as barriers to feeling connected to family and expressing private emotions. Previous studies indicated that hospital ward designs present organisational barriers to maintaining patient confidentiality and providing sufficient private space to discuss sensitive issues (Hartigan et al., 2018; Jensen & Eg, 2022). The impact of poor connectivity was particularly isolating for some children with cancer who were unable to leave the room. These findings highlight the impact that lack of privacy and poor Wi-Fi connection had on maintaining networks of support to meet families' emotional needs during the pandemic.

Emotional impact on family

Mothers in this study described how visitation restrictions affected their relationship with their other children at home while in hospital, expressing guilt in not being able to fulfil their role to support them emotionally. This echoes the SLR findings on the impact of separation on parent-sibling relationships (McGrath et al., 2005; Van

Schoors et al., 2018), and Davies and O’Conner’s (2022) recent pre-pandemic study that similarly described mothers’ guilt, feeling as though they were overlooking siblings’ needs. Davies and O’Conner (2022) highlight dominant cultural norms defining ‘good’ mothering that expect mothers to care for all children equally (Sevón, 2011; Davies & O’Conner, 2022). It is possible that the pandemic exacerbated feelings of guilt, given that siblings were unable to visit hospital, and it is important to consider that these expectations of themselves, in the context of paediatric cancer within the pandemic may have a continued impact on their wellbeing and identity as mothers.

Parents in this study described concerns about the complexity of emotions experienced by siblings, and the impact of separation on them, which has been widely reported in previous studies (Alderfer et al., 2010; McGrath et al., 2005; Van Schoors et al., 2019) as well as a recent pandemic-focused study (Davies et al., 2022). Some parents in this study were particularly concerned about siblings with pre-existing learning or mental health difficulties that became amplified. Pride et al., (2020) emphasised that stress might increase for families with children with special needs or behaviours that challenge, given already heightened levels of parenting stress in combination with the reduction of support during the pandemic (Zhang et al., 2010). This study is unique in its contribution to illuminating contextual factors of siblings that added to PCC’s stress during the COVID-19 pandemic.

Accessing professional support

This study’s finding that siblings had unmet needs for external support from someone outside the family is of particular importance: while most siblings adjust well to the cancer diagnosis (Long et al., 2018), they are identified as psychosocially

'at risk' and should be provided with appropriate support services (Wiener et al., 2015). Indeed, the need for signposting to mental health services was highlighted by some parents in the present study for siblings whose needs were exacerbated by the pandemic and having a sibling with cancer (Pride et al., 2020). The worry of burdening their parents when managing their own struggles has similarly been reported in previous research (Prchal & Landolt, 2012; Van Schoors et al., 2019). These findings are important given reduced opportunities for sibling psychosocial support during the pandemic, whereas according to evidence-based standards for psychosocial care, support needed to be given greater priority given that they were not allowed hospital visits (Wiener et al., 2015).

Some parents described their own unmet need to talk to someone impartial to normalise their feelings, which has previously been associated with helping parents cope with childhood cancers (Demirtepe-Saygılı & Bozo, 2020). A key barrier raised was lack of face-to-face support from social workers, suggesting that telephone support may not have felt an acceptable replacement. Some previous research suggests that nonverbal cues in video conferencing (or face-to-face), that cannot be matched by telephone calls, is important in clinician-parent interactions (Mast, 2007; Hart et al., 2020). Alternatively, other studies have found that telephone support provided valuable emotional support (Ekberg et al., 2014), suggesting a range of options are necessary to meet parents' needs. Lack of private space to make calls, as previously outlined, may have further reduced the acceptability of telephone support in the hospital context.

A second issue raised was that support needed to be offered more than once. Within adult oncology, patients and their relatives' views have similarly reflected a need for support early in the cancer trajectory, and repeatedly thereafter,

regardless of whether initially accepted (Singer et al., 2022); introducing the service early into care also helped clarify misconceptions about counselling services (Bayer et al., 2022; Gunn et al., 2013). The CNS played a key role in linking another parent with counselling services in this study, but this may reflect individual differences around comfort in actively asking for help, as has been found in previous studies (Gunn et al., 2013; Singer et al., 2022). Findings in this study suggest that pandemic-related restrictions that reduced psychosocial support on wards interrupted the process of FCC in meeting some parents and siblings' support needs.

5.2.2 Connection

New relationships – “the hospital family”

All parents staying with their child in hospital spoke of important relationships developed in hospital with staff and/or other parents and children for themselves and their child with cancer. Parents described a range of support from staff, from practical assistance for self-care to emotional support, but importantly, with high levels of empathy and compassion. These findings echo the SLR, where similar recognition of the sense of safety and reassurance that hospital staff provide is highlighted (Russell et al., 2016; McGrath et al., 2004; Björk et al., 2005). This can be seen through an attachment lens, which has similarly been applied in an adult oncology setting (Holwerda et al., 2013): during times of threat, PCC form relationships with clinicians (i.e., “attachment figures”) with medical expertise to feel secure (Davies et al., 2017). From a socio-ecological perspective, tapping into social resources outside the family is a key process in family resilience (McCubbin et al., 2002; Walsh, 2015). These findings illustrate how HCPs become part of the family

system in the context of paediatric cancer, helping shape their adaptation (Kazak et al., 2002, 2009), with one parent explicitly describing them as *“like family”*.

Several parents described overcoming restriction-related barriers to make strong connections with other PCC, and their child with cancer’s important bonds with other children in hospital. This was principally achieved through sharing a living space together. The significance of these relationships is similarly described in other studies in the SLR (Björk et al., 2009; McGrath et al, 2004; Russell et al., 2016). The importance of “experientially similar others” has previously been linked to situationally specific and experienced-based information and emotional support for PCC (Gage, 2013; Gage-Bouchard et al., 2015; Gise & Cohen, 2022), which parents reported facilitates their ability to care for their child with cancer (Ångström-Brännström et al., 2010). Thoits (2011) argued that social comparison plays a role in the effectiveness of “similar others” support, both leading to role-modelling effective coping responses and stressor-specific empathy. These findings suggest that HCPs and other PCC played particularly important roles in buffering stress and sustaining parents and children when pandemic restrictions made it challenging to access the support of “personally significant others” (Thoits, 2011) during hospital stays.

Strengthened relationships - “we were in it together”

All parents described the strengthening of existing relationships within their family and support network despite the COVID-19 restrictions that were imposed. The reciprocal nature of these relationships relates to the organisational process of “connectedness” and “mutual support” within Walsh’s (2016) family resilience framework. Of note, is the mutual benefit of the parent-child relationships between the child with cancer and the parent that stayed in hospital (in this study, mothers).

This special parent-child bond, created through the intensity of the time spent together, has similarly been described in previous studies (McGrath et al., 2005; Van Schoors et al., 2018). In line with Ångström-Brännström et al. (2010), several mothers described how they drew strength from the child's positivity and humour despite the suffering.

Parents also described that family cohesion was strengthened by the experience, which is in line with previous qualitative studies reported in the SLR (Clarke-Steffen, 1997; Russell et al., 2016; Scott-Findlay & Chalmers, 2001; Van Schoors et al., 2018), quantitative studies (e.g., Beek et al., 2015) and a recent systematic review (Van Schoors et al., 2015). Parents in this study described the organisational process of "flexibility to adapt" that is attributed to family resilience (Walsh, 2015) in adopting to new roles, which is frequently described in the context of paediatric cancer (McGrath et al., 2004, 2005; Russell et al., 2018; Van Schoors et al., 2018). One father described the struggle and reflected on the learning process that came with adopting these new roles, resulting in clearer family goals, which can be described as post-traumatic growth in the family system (Berger & Weiss, 2009). In sum, despite the COVID-19 hospital restrictions placed on families, keeping them apart possibly even more than paediatric cancer usually divides families, parents still reported strengthening of relationships as a whole family.

5.2.3 Isolation versus connection: stress and resilience

It is possible that the high levels of stress that parents described in the "isolation" part of this theme, through the long periods of hospitalisation and isolation from support networks, may have led some parents and children to experience symptoms of post-traumatic stress (PTSS). In their pandemic-focused study, Guido et al. (2021)

reported increased levels of distress in PCC, concluding that they were at high risk for PTSS. Hobfoll's (1989) conservation of resources (COR) theory proposes loss of resources to be a primary driver of post-traumatic stress, which includes loss of relationship quality. The isolation of parents and children from their networks of support due to COVID-19 related restrictions could have resulted in such an experience of loss. The importance of relationships as a resource has been linked in pre-pandemic times, as Howard-Sharp et al. (2015) found that low levels of connectedness in children with cancer correlated with higher levels of PTSS, and vice versa.

At the same time, the parents' descriptions of new and strengthened relationships in the "*connection*" part of this theme highlights the role of relationships in mitigating distress and promoting resilience. According to COR theory, this illustrates how people are motivated to acquire, foster and protect what they value, including relationships as an attempt to limit losses and also maximise gains in response to traumatic stress (Hobfoll, 1989; Holmgreen et al., 2017). Promoting social 'connectedness' is one of the key components of trauma intervention for recovery after disasters (Hobfoll et al., 2007)

These findings together highlight the importance of understanding resource loss as a potential predictor of trauma responses to the pandemic in a paediatric cancer context, particularly as resource loss has been shown to be more impactful than resource gain (Hobfoll, 1989; Holmgreen et al., 2017). It also suggests the importance of promoting and protecting families' relationships and feeling of connection in reducing the impact of stress and promoting family resilience (Walsh, 2016).

5.3 GET 2: Managing uncertainty

“Piecing information together”

Parents in this study highlighted needs for more information about their child’s treatment and diagnosis, COVID-19 restrictions, and the reasons behind hospital restrictions, and the resultant anxiety from trying to source the information elsewhere, such as the internet, or overhearing bits of information. Exchange of information has been identified as a core function of communication between parents and physicians in paediatric oncology (Sisk et al., 2018, 2020): clear, specific information from clinicians is rated as being of utmost importance (e.g., SLR studies: McGrath et al., 2004; Björk et al., 2005), and has been linked with giving parents peace of mind (Mack et al., 2009). Findings in the present study also echo the SLR, in that sufficient information about treatment plans is containing for CYP, while absence of sufficient information is anxiety-provoking (Björk et al., 2005; Russell et al., 2016), highlighting the importance of fully informing children about treatment procedures/process.

Barriers to communication in the present study, raised by parents, included that clinicians may have felt too much information about their child’s cancer would be overwhelming. Despite struggling to receive the news, previous studies have reported parents’ wish to have a truthful rather than a partial disclosure of information (Sisk et al., 2018, 2020). Research into health information-seeking behaviour suggests the importance for clinicians to be aware of individual difference in informational-needs. For some, when facing highly threatening events, there is a natural preference for seeking health information. These are known as “high-level monitors” and “low-level blunterners”, whereas “low-level monitors” and “high-level

blunters” prefer shifting their attention away from health information (Plamann et al., 2018). This suggests that it would be helpful for clinicians to check with parents for their informational preference (Plamann et al., 2020).

A further barrier raised was uncertainty regarding the prognosis or course of treatment, and so information given was limited, resulting in anxiety. Managing uncertainty has been identified as another key function of communication between clinicians and patients/parents in paediatric oncology (Sisk et al., 2020). Previous research investigating parents’ experiences with communication suggests that clinicians who address, allow room for, and display comfort with uncertainty helped parents manage their uncertainty in turn (Sisk et al., 2020); where these discussions were delayed or deferred, parents similarly reported increased anxiety (Snaman et al., 2019). The experience of one parent in this study overhearing distressing information about her child amid an uncertain prognosis illuminates the importance of paying careful attention to how and where information is shared to avoid such distress/confidentiality breaches (Jensen & Eg, 2022).

Several parents also raised the challenge of receiving information on their own in hospital. In line with studies in the SLR, parents reported anxiety as a barrier to absorbing information about their child’s diagnosis and treatment (Björk, 2005; McGrath et al., 2004) as well as the challenge of interpreting technical language (Clarke-Steffen, 1997). Anxiety was likely to be further heightened by receiving the information alone. Parents also reported that the parent at home felt “*out of the loop*” in the information giving, and the challenge of having to act as a go-between to relay information to them, which in some cases caused conflict. The disruption to FCC that includes involving both parents in information-giving and decision-making has

also been reported in other paediatric contexts during the pandemic (Diskin et al., 2021).

From an FCC vantage point, these findings highlight the importance of including the parent at home in information-giving, to promote self-efficacy in meeting their informational needs, which has been linked to well-being (Salvador et al., 2019); to provide support for the parent in hospital receiving the news alone; and to reduce the burden of relaying the information. This is also important because parents who discuss their child's treatment with HCPs feel better able to make care-related decisions (Markward et al., 2013; Gage-Bouchard et al., 2015). The process of communication is a key aspect of family resilience theory (Walsh, 2003; 2016), which includes clarity of information. In taking an eco-systemic perspective to family resilience, these findings highlight the role of clear communication of HCPs as being impactful in helping to mobilise family resilience.

Fear of COVID-19 Infection

Several parents in this study described the fear they experienced that their immunosuppressed child would contract COVID-19. This included worry that the hospital was unsafe, increasing the chance of contracting COVID-19, similarly reported in survey studies capturing PCC's experiences in other UK hospitals (Darlington et al., 2022; Collaco et al., 2022). It was warned that policies adapted by health-care systems to prevent the virus spreading may unintentionally amplify underlying stress and anxiety about their children's health (Raphael et al., 2021). The banding systems isolating and mixing patients with COVID-19 and those deemed to be at risk of COVID-19 was particularly anxiety-provoking for some parents in this study.

Levels of COVID-19 related anxiety varied, with some parents and children taking more intensive infection control procedures into their homes, and fearing going into public post-treatment completion, while others were relatively less concerned. This was similarly reported in Collaco et al. (2022). Parents had to process and make sense of the information received, and make their own evaluations of risk, which depended on a range of factors such as their own child's illness, the risk information given, and their experience of the risk (e.g., whether they knew someone that had COVID-19; Attema et al., 2021).

Meeting parents' basic physical and emotional safety needs (Maslow et al., 1970) is a priority to enable them to care for and contain the anxieties of their child (Habibpour et al., 2019). While a degree of anxiety promotes vigilance in the face of genuine threat of COVID-19 infection, multiple stressors experienced over sustained periods increase the risk of impact on daily functions (e.g., sleep) and likelihood of experiencing distress (Hobfoll et al., 2007), and even developing PTSS if a person persistently appraises themselves (or their child/sibling) to be under threat (Bryant, 2021).

These findings, coupled with all parents expressing lack of clarity regarding the COVID-19 policies and reasoning for hospital procedures, indicate informational and emotional safety needs to help contain parents and children's COVID-19-related anxiety. This can be helpfully considered within Hobfoll's five principles for trauma prevention when coping with disasters, which includes promoting a sense of safety, calm, self-efficacy, connectedness and hope (Bryant, 2021; Hobfoll et al., 2007). Striving to create a 'sense of safety' and promote 'calming' to down-regulate the fight-and-flight response to traumatic stress (Bryant, 2021) are particularly relevant to these findings in responding to families' fear of COVID-19 as well as

cancer. In addition, promoting a sense of 'self-efficacy' (Hobfoll et al., 2007) is relevant in helping families manage uncertainty around COVID-19 and cancer outcomes.

At the same time, it is important to recognise the broader context of communication. Staff reported that restrictions were also unclear to them, suggesting communication problems at the hospital trust/government policy level (Bennett et al., 2020). Recent research has reported stress that medical teams experienced as the "face" of strict protocols (Wiener et al., 2021). Likewise, at a government level, lack of transparency around government restrictions led to lack of trust and confusion amongst the public (Hanson et al., 2021). In the early stages, the COVID-19 pandemic was a period of real uncertainty with a constantly evolving evidence base and changing guidance (Ratcliff et al., 2022); plus the period was also characterised by an "infodemic" (WHO, 2021b), whereby large amounts of conflicting and misleading information rapidly spread via sources such as the media and the internet, making navigating information difficult (Kreps & Kriner 2020; Ratcliff et al., 2022; Vraga & Jacobsen, 2020). Interpreting these findings within the context of organisational and government level communication difficulties suggests that this may in turn have interfered with parent-clinician communication around COVID-19 rules and restrictions. Considering Hobfoll's five principles for trauma intervention within an ecological context, it is important to recognise that the sense of safety that parents, children and HCPs experienced was strongly influenced by media and government announcements (Bryant, 2021; Hobfoll, 2021).

5.4 GET 3: Loss and solace

Loss – “missing out”

This subtheme captured the losses that families experienced both by being separated during hospital stays, and by being restricted on social mixing and contact. Losses included family routines and rituals, being able to do ‘normal’ enjoyable activities between hospital stays, and maintaining wider social contacts and support networks, impacting parents, children with cancer and their siblings. These findings are in line with previous findings in the SLR, highlighting interruptions that cancer causes to normal family life (Björk et al., 2009; McGrath et al., 2005; Russell et al., 2016).

Parents in this study described that feelings of loss were compounded by forgoing regaining a sense normality that has previously been described as an important process in helping regain a sense of control and feeling connected (e.g., Clarke-Steffen et al., 1997; Russell et al., 2016), especially for siblings (Van Schoors et al., 2020). Being able to reintegrate routines and rituals has been shown to be protective in the face of stress (Harrist et al., 2019; Prime et al., 2020). Parents’ decision to continue periods of isolation, beyond government-imposed restrictions, to minimise infection risk for the child with cancer has been described by parents in other recent studies (Darlington et al., 2020; Collaco et al., 2022), though some other parents leaned more towards regaining normality later into the pandemic as fear of COVID-19 reduced (Collaco et al., 2022). Parents in the present study highlighted concerns for their children with cancer being isolated for extended periods, in terms of impact on social confidence and independence skills, which is similarly reported by Darlington et al. (2020). These findings highlight that COVID-19 may have

exacerbated some challenges around adjusting to loss of normality, indicating a potential support need as families navigate and adjust to a 'new normal'.

Solace – “in a funny way, it helped”

While having a child diagnosed with cancer during the COVID-19 pandemic posed losses and additional stressors for families, parents also referred to several positives providing solace. The extra sense of safety related to infection control, provided by the restrictions and the sense of everyone being in the “*same boat*” with lockdowns, has similarly been described by parents in Davies et al. (2022). These findings are arguably supported by the “assimilation effect” within social comparison theory, whereby comparing oneself to others can elevate wellbeing so to be in the same category as other friends and peers (Collins, 2000), and therefore lead to feeling more connected to them (Ruggieri et al., 2021). In addition, from a trauma intervention perspective, these findings suggest that the infection control measures gave some parents a sense of safety and self-efficacy in responding to the COVID-19 restrictions (Hobfoll et al., 2007).

The benefit of more family time together at home when out of hospital (also reported in the *strengthened connections* subtheme) was particularly linked to an increase in homeworking/the furlough scheme for some (the government’s Coronavirus Job Retention Scheme, enabling employers to keep paying wages via a government subsidy). This suggests that the detrimental impact of cancer on parents’ income frequently reported (Roser et al., 2019) may have been mitigated for some. This finding is in line with parents’ experiences in Davies et al., (2022), though contrasts with parents’ accounts in Darlington et al. (2020), who shared frustrations of not being eligible for the scheme. In addition, others may have experienced a

worsened impact, as COVID-19 lockdowns disproportionately affected job security of the lowest incomes (Allas et al., 2020), which was the case for one parent in this study. From a COR perspective (Hobfoll, 1989), the loss of employment and financial security such as unemployment and financial difficulties may increase the chance of experiencing post-traumatic stress (and vice versa).

The parents' rationalisation of restrictions and seeing the positives can be described as a process of positive reappraisal (Lazarus et al., 1984), a form of meaning-based coping. This links to Walsh's (2015) family belief systems around fostering resilience: an important family process given that parents' positive thinking styles can buffer stress for their children. This may also depend on the level of combined pandemic and cancer stressors, where some families will have faced additional challenges that increase the likelihood of experiencing higher levels of stress.

5.5 Theoretical considerations

The present findings, and the SLR, provide support for the usefulness of family resilience frameworks in the context of paediatric cancer during the COVID-19 pandemic. Parents' experiences map onto some of Walsh's (2016) key family processes: facilitative beliefs, and organisational resources, such as connectedness and flexibility. The importance of support received from the HCPs for family resilience, as emphasised in McCubbin et al.'s (2002) resiliency model, is also supported by this study. Walsh (2021) stressed the need for a systemic conceptual lens to maintain an awareness of interrelations across personal and environmental factors influencing family resilience (Bronfenbrenner, 1979). Importantly, the present study illuminates extrafamilial factors, including public policy and communication with

staff, that are helpful for beginning to unpack the multilevel ways that family resilience can be influenced more broadly in the context of paediatric cancer. From a social constructionist perspective, this approach to viewing what families endured during the COVID-19 pandemic shifts the focus from solely the family and helps illuminate some of the power structures that can impact family resilience (Dallos & Urry, 1999).

5.6 Implications

While the research was conducted during the COVID-19 pandemic, the study's findings have many implications for supporting the resilience of families of children with cancer more generally in paediatric cancer contexts. It is acknowledged that the wider economic and political climate put strain on services and resources, posing barriers to change. Nevertheless, this section outlines ways that family resilience could be promoted by increasing access to parents' support networks, addressing families' psychosocial needs, and through communication with HCPs, as well as implications for NHS trust policy.

5.6.1 Supporting parents' access to support networks

The findings emphasise the importance of promoting family resilience in the context of paediatric cancer in a coordinated way. The primary need is to facilitate families' access to their established support networks that are key to promoting their wellbeing. From COR theory perspective, intervening early to maintain connectedness wherever possible reduces the likelihood of families being impacted by traumatic events (Hobfoll, 1989; Holmgreen et al., 2017). For parents, the pandemic highlighted environmental factors, such as the need for designated space in hospitals, to provide privacy for phone/video calls to family members and friends

to access emotional support. Hospital design literature describes the importance of providing both areas for privacy and social interactions that supports the principles of FCC (Rollins, 2009). This is particularly relevant in planning/designing new hospitals (e.g., Cambridge Children's Hospital (<https://www.cambridgechildrens.org.uk>)). In addition, free Wi-Fi access across the hospital (an improvement since made locally) would have further improved family connectedness and access to support.

An essential consideration emerging from this research is including the parent, or other significant family member, at home in information-giving and regular treatment updates. In pre-pandemic settings, the presence of both parents was found to support parental coping and mitigate decision-making conflict (Aarthun et al., 2019; Boland et al., 2017). Ensuring that families are kept fully informed, with parents being positioned as collaborative partners in their child's care provision, are best practice principles (Department of Health, Department for Children, Schools & Families, 2009; NICE, 2014). During the pandemic, family presence needed to be supported through nonphysical means such as video consultation to achieve FCC (Hart et al., 2020), or through providing written notes as suggested by one parent. These implications are also relevant more broadly to non-pandemic times, for instance, where families live at a great distance from hospitals and/or there is a financial requirement for the parent at home to continue working. It is important that there is the potential to foster the best possible conditions for virtual connection between family members. However, use of technology raises significant practical and ethical quandaries around offering remote connection without magnifying inequalities related to digital exclusion (Clare, 2021; Greenhalgh et al., 2021). The provision of 'safe areas' could be considered for families with poor access to online

resources, or when remote consultations are deemed inappropriate (Collaco et al., 2022; Wiederhold et al., 2020).

5.6.2 Addressing families' psychosocial needs

While highlighting positive aspects of family resilience, such as increased cohesion, a paediatric cancer diagnosis during the COVID-19 pandemic also posed several stressors on families' resilience. There are several implications that may be relevant for helping families to resolve their experiences during the pandemic. Parents may need space to acknowledge the losses that they experienced, such as loss of support, and loss of quality of their relationships, or loss of material resources (job/financial) in some cases. Some parents and other family members may need support for an ongoing threatened sense of safety in response to COVID-19, and utilising Hobfoll's (2007) trauma-informed principles would help restore a sense of safety, calm, self-efficacy, connectedness, and hope. Given the strength and validation that parents highlighted that they gained through peer support, this could be facilitated in a group setting. Approaches such as the coordinated management of meaning (CMM; Pearce, 2007) that considers that our narratives are informed by multiple levels of context (e.g., personal, interpersonal, family, community, cultural and political), and starts with the assumption that distress should be understood within the social context of the pandemic, could also be particularly helpful.

Together with the SLR findings, the need for clinicians to be aware of family dynamics that parents face is highlighted in this study. Parents may need support in navigating extra strain put on sibling-parent relationships because of extended hospital stays, and difficulties adjusting to a 'new normal' after extended periods of isolation (e.g., child with cancer's independence). More broadly, there is a role for

CPs and other HCPs to normalise parents' behaviours and feelings, recognise strengths, and support adjustment (Van Schoors et al., 2018). A growing evidence-base suggests family-based interventions help support adjustment to paediatric cancer (Meyler et al., 2010; West et al., 2015). A solution focused approach, respecting families own resources, based on the premise of building solutions and finding exceptions (De Shazer et al., 1986), complements a family resilience framework (Walsh, 2021).

The need for sibling support was an important finding, particularly considering evidence-based standards for psychosocial care stating that support should be offered especially when they are unable to visit the hospital (Wiener et al., 2015). The vulnerability of the sibling-parent relationship in this study and previous studies (Van Schoors et al., 2018), suggests that family focused interventions are warranted. A recent pilot programme offering parallel groups to parents and siblings using narrative, psychoeducation and problem-solving therapy ideas indicated self-rated improvements in understanding, family empathy and communication (Besani et al., 2018). Groups may be particularly appropriate given the findings that highlighted the strong benefits of peer support. CPs may be well-placed to work alongside other NHS/charity professionals, using knowledge linked to clinical practice, group dynamics and facilitation to help develop either face-to-face or online versions of these groups. Indeed, the COVID-19 pandemic has prompted creative ideas to overcome challenges in online therapy and groups with children and their families (Casdagli et al., 2022; Vermeire & Van den Berge, 2021).

The study's findings also highlight the importance of considering the family's broader context, where risk factors, such as sibling mental health can be identified, and signposting to other services may be warranted. Self-help resources created by

families and CYP could be shared with parents that cover mental health topics and building family resilience (e.g., <https://thismayhelp.me/>).

5.6.3 Promoting family resilience through communication with HCPs

The present study's findings highlight the importance of relationships and communication with medical staff, and its powerful impact on strengthening PCC's resilience. It also points to more difficult aspects of clinician-parent communication, such as challenges in providing the 'right' level of information required, and in dealing with parents' requests for information beyond what can be objectively provided. The findings suggest that parents may benefit from clinicians allowing space in conversations for expressing concerns, values and preferences, using frameworks such as Snaman et al.'s (2019) "what if?" guide to gently consider uncertain, feared scenarios.

A clinician's decision to limit communication may sometimes be an expression of discomfort when conversations move towards affective topics, rather than solely avoiding overwhelming parents, and some clinicians may default to the cognitive realm of sharing what is known (Drach et al., 2020; Snaman et al., 2019). Other barriers include time pressures and busy ward environments that can hinder clinicians' ability to engage in FCC (Drach et al., 2020), as well as medical training focusing more on objective communication rather than affective and reflective components (Mantzoukas & Jasper, 2004). Support for communication around uncertainty may require an interdisciplinary approach, in which CPs could play a supportive role through teaching, consultation and co-working. For instance, through joining key meetings with parents and qualified medical professionals and trainees,

such as at diagnosis, CPs could play a role in facilitating the expression of parents' affective/familial perspectives alongside the medical expertise.

The findings suggested that fear of COVID-19 exacerbated already significant levels of uncertainty experienced by some parents and children with cancer. Hobfoll et al's. (2007) empirically validated preventative principles to reduce the impact of the experience of a traumatic event has also recently been applied in medical settings (e.g., Archibald & O'Curry, 2020), including adult oncology during COVID-19 (Espinel & Shultz, 2020). Although potentially useful broadly in the context of paediatric cancer (see applications in Table 12), this framework could be useful to support nursing staff on the frontline with families when hospital restrictions lead to reduced support from psychosocial teams. CPs could disseminate this framework through online/in-person workshops to support staff wellbeing, as well as to aid staff in supporting families' wellbeing.

Table 12

Five Essential Elements of Trauma Intervention (Hobfoll et al., 2007) applied to a paediatric cancer setting

5 essential elements	Examples of application to paediatric cancer setting
1. Promote a sense of safety	<ul style="list-style-type: none"> • Give parents' permission to voice fears and stress around uncertainty of the impact of COVID-19/child's cancer treatment. • Provision of science-based resources about COVID-19 and strategies about how to prevent infection. • Transparency of information around hospital restrictions – up-to-date written guidance for parents.
2. Promote a sense of calming	<ul style="list-style-type: none"> • Normalise stress and fear responses to cancer and COVID-19.

- *Recommendations around reducing excessive media coverage.*
 - *Providing exercises that promote sense of safety and calm e.g., grounding exercises using senses to redirect attention to non-distressing things in the present environment that are safe; breathing exercises; meditation podcasts.*
3. Promote self-efficacy
- *Give space to listen to concerns about child's treatment and/or the impact of the COVID-19 restrictions.*
 - *Involve the parent at home in information-giving.*
 - *Support families in maintaining a routine at home adapting to the constraints of lockdown.*
4. Promote a sense of connectedness
- *In hospital, promoting connection with other parents/children with cancer - via online forums where there is a reduced opportunity to mix face-to-face.*
 - *Promote connection with family at home via online platforms/safe spaces for hospital visits.*
 - *Nursing staff make known the availability of the psychosocial team/repeatedly offer the service at different timepoints.*
 - *At home, provide video/telephone consultation for parent at home/post hospital discharge follow-up calls.*
5. Promote a sense of hope
- *Offer reassurance that support is available/sign posting to psychosocial team.*
 - *Encouragement of positive coping behaviours (individual and family resilience related).*
 - *Pandemic related: Information around restrictions and the hospital's role in protecting and improving patients' lives; updating knowledge of vaccine programme.*
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5.6.4 Implications for NHS trust policy

Single parents' experiences of hospital restrictions in this study highlight the importance of being aware of implicit assumptions about family normality (Walsh, 2015), and the impact this has on rules dictated through NHS trust policies. Indeed,

the Government's recent working definition of trauma informed practice highlights the importance of “*incorporating policies, protocols and processes that are responsive to the needs of individuals served*” (Office for Health, Improvement & Disparities, 2022). There is a responsibility to craft clinical service policies that respond to the realities and challenges faced by families at the centre of our care (Walsh, 2015).

This study importantly highlights several social and relational costs that resulted from hospital visitation restriction policies. These included parents being isolated from their support network, and the loss of physical contact with family members that online alternatives cannot effectively replace; this also impacted other family members, particularly siblings. The access to face-to-face psychosocial care on the wards was also limited, when research has demonstrated the importance of offering support from the time of diagnosis (Singer et al., 2022). When advances are made in reducing risk to health, such as significant progress in the rollout of vaccinations and with the availability of lateral flow tests, it is important to consider whether policies could have been amended earlier to address these relational costs (Long et al., 2022).

In addition, the findings highlight the importance of clear, regularly updated COVID-19 guidelines to meet the informational-needs of PCC, both to help contain added anxiety caused by misinformation (Dubey et al., 2020), and to increase understanding for the rationale (e.g., protecting staffing levels). It is of utmost importance that a trauma-prevention approach is taken at policy level; for instance, understanding how sense of safety that parents and children experience is linked to clarity of information provided (Bryant, 2021; Hobfoll, 2021).

5.7 Critical evaluation

Consistent with the SLR appraisal, the quality of this study was assessed with Tracy's (2010) quality assessment. This study's strengths are outlined in Table 13.

Table 13

'Big-Tent' criteria for qualitative research (Tracy, 2010)

Criteria (Tracey, 2010)	Evidence for meeting the criteria
<p>Worthy Topic <i>The topic chosen for research is relevant, timely, significant, interesting.</i></p>	<p>The study is timely in terms of its relevance to current events given that the focus is the impact of a child's diagnosis on families during the COVID-19 pandemic. The pertinence of this relates to lessons learned in stresses and resilience as described by PCC, helping consider their support needs in the aftermath of the pandemic, and lessons learned in preparing for future pandemics or other disaster situations. The findings are significant more broadly as they build on previous literature in the context of paediatric cancer and are considered within family resilience frameworks. This includes considering extrafamilial factors that facilitated or hindered family resilience, including relationships and communication with hospital staff, organisational constraints, and the impact of policy on single parents.</p>
<p>Rich Rigour <i>Sufficient richness and quantity of data sources, samples. Rigorous data analysis process (e.g., disclosure of number of transcript pages, dates and lengths of interviews, transparency around way of organising data): sufficiently complex to enable description of the phenomena studied.</i></p>	<p>The study has shown rigour through a systematic and transparent account of the data analysis process. Data from six participants is within the required range for an IPA study (Smith et al., 2022), and sufficient richness was gained through in-depth interviews varying between 50 minutes and 2 hours. The rigorous data analysis process is illustrated by keeping extensive reflective and field notes, an example of which is found in Appendix K. In addition, a thorough process of checking data analysis, interpretation and theme development was carried out with the supervisory team and IPA peer researchers. A table is also provided to illustrate recurrence of themes across participants (see Appendix M).</p>
<p>Sincerity <i>Evidence of self-reflexivity (e.g., researcher's background, bias, goals). Transparency about</i></p>	<p>The researcher's own position and perspectives along with the epistemological position of this research has been made transparent. By making clear the researchers' position, it enables the reader to be aware of the role of</p>

<p><i>research process, including difficulties faced.</i></p>	<p>the double hermeneutic in interpreting the participants' accounts. The researcher utilised critical self-reflexive processes, such as the use of bracketing and journaling to consider how the process might be being influenced (see reflective journal; Appendix K). Finally, challenges and changes during the research process are made transparent throughout the account in this thesis.</p>
<p>Credibility <i>Trustworthiness and plausibility of research findings (use of thick description, concrete detail, show rather than tell; crystallisation, triangulation – multiple theoretical frameworks, researchers; multivocality – multiple views, interpretation)</i></p>	<p>The engagement of experts by experience (PCC undergoing treatment during the COVID-19 pandemic) through consultation was used in the development of the research questions and interview and participant materials. Meaningful direct quotations from the research participants are provided that support the credibility of the findings. The supervisory team was involved in checking themes and interpretation, and the team included a clinical psychologist working in paediatric oncology.</p>
<p>Resonance <i>Ability to influence the reader by presenting text that is clear, evocative, and promotes empathy and identification. Study's ability to generate knowledge resonance for different contexts, situations, audiences (ability to generalise/transfer).</i></p>	<p>Efforts were made to present clear, accurate accounts of the participants within the narrative of the results chapter that included emotive quotes that evoked empathy. The research has current implications, which are likely to bring resonance for readers. As with all IPA studies, the generalisability is limited as the study contains a heterogenous sample of PCC, recruited from one local paediatric oncology department. However, the discussion chapter draws on both COVID-19 and pre-COVID-19 literature that highlights knowledge relevance for the present post-COVID-19 context, as well as more generally.</p>
<p>Significant contribution <i>Study makes important contribution to the field, improving or extending knowledge; findings have significance in one of the following domains - theoretical, heuristic, methodological, and practical (clinical).</i></p>	<p>The study extends knowledge related to the impact of a cancer diagnosis on the family in the specific context of the COVID-19 pandemic and makes significant links to a range of theories within a broad framework of family resilience theory. Several practical clinical implications are provided at policy, organisational and family level, and ways in which clinical psychology can facilitate change are outlined. The research also contributes to generating ideas for further research.</p>
<p>Ethical <i>Adherence to professional/research ethics guidelines (Procedural – e.g., human subjects); responding ethically to issues which arise in research processes (situational ethics); relational ethics; exiting ethics – thoughtful consideration of how to share findings.</i></p>	<p>Research design and methodology met with standards required by the NHS Health Research Authority (REC reference: 21/EM/016; see Appendix D for approval paperwork). Due to the sensitive nature of the topic, particular consideration was given to mitigate and respond to the potential distress of participants (see 3.3.3 Managing Distress).</p>

<p>Meaningful Coherence <i>Whether study achieves its stated aims. Coherence between epistemological position of research and research design, data collection, and analysis. The research is meaningfully connected to the literature.</i></p>	<p>The study achieved its stated aims, and IPA and semi-structured interviews were an appropriate methodological approach for these aims. The study's findings are meaningfully connected to literature as outlined above, as well as theory-practice links made in the suggestions for clinical practice.</p>
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5.7.1 Limitations

It is important to outline several caveats when interpreting the findings. In addition to the inherent limitation of IPA's generalisability with its small sample size from one hospital, arguably this study's sample is not wholly homogenous. Although all parents had a child with cancer diagnosed in the pandemic at the same hospital in common, difficulties in recruitment meant that predominantly mothers participated, and one father. This results in an imbalance of perspectives from the parent in hospital versus the parent at home, and mothers versus fathers. Careful attention was given to highlight divergence in narratives, and the change in direction required to support recruitment opened the possibility to also capture single parents' experiences. However, it would be useful for future research to directly consider the perspective of fathers/other adults at home, siblings, and children with cancer across different hospital settings. In addition, as the process of adapting to cancer is dynamic, and parents' perspectives were from a single point in time, longitudinal studies that follow the family could further clarify how they have adapted to a cancer diagnosis during the pandemic (Walsh, 2015).

In line with the SLR, the study is limited in ethnic diversity with participants mostly being of White heritage. The inclusion of families from different ethnic backgrounds who may have varying beliefs and cultural practices could illuminate how this influences family resilience. Racial inequity in the experience of cancer treatment is also an important story to highlight, for instance, where some blood

cancers are harder to cope with due to lower donation of stem cells in certain communities (Williams, 2022). Though recruiting participants from the same hospital resulted in a degree of heterogeneity, an alternative recruitment route via community methods may be a helpful way to increase ethnic diversity in participants.

Due to the COVID-19 pandemic, interviews were carried out via Zoom, which may have impacted the rapport built in comparison to conducting them face-to-face (Carter, 2011). For instance, internet connectivity can disrupt the flow of conversations, and using this medium to discuss emotional topics requiring self-disclosure and reflection differs from the usual context of utilising it for work purposes (Archibald et al., 2019). However, participants in the present study commented that they had become accustomed to using Zoom for multiple purposes during the pandemic. Video platforms do also afford several advantages, such as saving time and money by eliminating the need to travel, as well as being better for maintaining rapport with the researcher when compared with “non-visual” methods (e.g., telephone; Archibald et al., 2019).

Arguably, beginning the interviews with closed questions to collect demographic data may have felt formulaic and could potentially interfere with building rapport and showing genuine interest in the participants’ experience. However, the interviewer made efforts to engage with empathy, and the rationale of the structure of the interview was carefully explained, as well as an initial informal discussion being helpful in beginning to build a connection with participants.

It is noteworthy that the focus in the interviews was mainly on the hospital experience rather than everyday living. Importantly, several parents of children in this study experienced extended hospital stays of up to three months without face-to-face contact from anyone in their personal support network, which accounts for the

memorable impact that period would have had on their families. The hospital focus also likely reflects the researcher's position and role as a psychologist working in the hospital, leading to participants viewing the interview as a way to give feedback to oncology HCPs on what could have been done differently.

Although the study accessed belief systems when some participants described taking a positive outlook (i.e., in the subtheme, Solace: "*in a funny way it helped...*") which aided their acceptance of the pandemic situation, there was no mention of spirituality or faith. This might have been addressed if it were specifically included in the interview schedule and would be worth considering in future studies since it has been shown to be a helpful resource for family resilience (Russell et al., 2016; Walsh, 2016).

Finally, the need to protect the anonymity of the participants meant that the demographic data needed to be generalised, which perhaps detracts somewhat from the idiographic aspect of IPA. However, attempts were made throughout the results section to provide context and personal detail of each of the participants in highlighting what was felt to be most pertinent to them in their accounts.

5.8 Future research

Recent research highlighting the stress that medical teams faced in implementing restrictions (Wiener et al., 2021) and the unclarity that staff have reported regarding policies, suggest that important lessons could be learned by gaining nursing staff's perspective on caring for families during the COVID-19 pandemic.

There is also the potential to conduct service evaluations of the implementation of some of the study's recommendations. For example, a focus group could be used to share Hobfoll's (2007) trauma intervention framework applied to paediatric cancer context with parents and nursing staff; their feedback could be

elicited to incorporate their learning and recommendations to create a co-constructed framework for use in practice. A pilot of the “*what if?*” (Snaman et al., 2019) framework could be used to address parents’ uncertainty in joint consultations between medics and CPs, with the option of parents providing post-consultation feedback.

5.9 Final reflections

Throughout this writeup, I was aware of several ethical tensions in interpreting these findings within a family resilience framework. For parents, I was mindful of the multitude of ways that the concept of ‘resilience’ is perceived. I wanted to ensure that the accounts were contextualised well enough so that parents’ struggles amid this stressful context were not individualised and labelled as ‘not resilient’. At the same time, by highlighting family processes that provided some buffer to the stress experienced, I did not want to distract from their struggles or need for support; rather, I hoped to spotlight additional ways to better promote resilience.

Later into the process, I was also mindful of HCPs as an audience for the work, as the pandemic was a stressful experience for them too that would have challenged their resources. This represented a shift in my position as I transitioned back into work: at the project’s conception, I was as a new parent feeling isolated by the pandemic, whereas, at present, I am a colleague of those who faced challenges and moral distress of caring for families during the height of the pandemic. However, it is my ethical responsibility to honour the parents’ stories as they were told. This is one account of the experience of parents that has helpful implications for promoting family resilience, but there are many other stories that remain untold from multiple perspectives.

Conducting pandemic-related research in an NHS service and society that is still experiencing the effects has been challenging at times. From a privileged position of safety, witnessing the stories of what sustained parents was a helpful reminder for me to reflect on processes and relationships that have nurtured my own resilience.

5.10 Conclusion

This study has provided novel insights into how parents perceived the impact of having a child diagnosed with cancer during the COVID-19 pandemic on their family. It illustrates several ways that the pandemic and its related restrictions put strain on their resources and relationships, as well as emphasising family organisational processes and beliefs that buffered stress. The findings highlight the dynamic relational aspects of resilience, where relationships and communication with other parents and children with cancer, and hospital staff, are important in fostering family resilience. The project's socio-ecological lens also highlighted the impact of other extrafamilial factors, including organisational constraints and the impact of policy on single parents. It illustrates how existing inequities were perpetuated during the pandemic and were further impacted by a healthcare service in flux and constantly adapting. The findings have important implications for supporting family resilience in the aftermath of the pandemic and planning for future disaster situations, as well as having a wider relevance to paediatric cancer care.

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Appendices

Appendix A – Participant Information Sheet

14/12/2021 | Version 3.0 | IRAS Number: 298214



Participant Information Sheet

An invitation to take part in research...

Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family.

Are you parents of a child who was diagnosed with cancer in the past year?

Before deciding whether you wish to participate, it is important that you understand why this study is being carried out and what it involves.

Please take the time to read the following information carefully and take the chance to discuss it with others if you wish. If anything is unclear, or if you need further information to help you decide whether or not to participate, please do not hesitate to get in touch using the contact details at the end of this document.

What is the purpose of this study?

We would like to understand the experience of parents who have had a child diagnosed with cancer during the COVID-19 pandemic. We would like to learn how *both* parents perceive how this experience has impacted them as a family. Typically research only includes one parent, usually the mother. We feel that involving both parents will give a fuller picture of the impact on the family. However, there is the option for only one parent to participate.

The hope is that by better understanding families' experiences it will help better shape the support that they receive, particularly following the pandemic. The hope is also to inform care during future potential pandemics.

This research is being undertaken as part of Anna Jones' Doctorate in Clinical Psychology at the University of Hertfordshire.

Who can take part?

To be able to take part you, **the parents**, need to:

- Be over the age of 18 years
- We hope that both (parents)* will be willing to take part, and live together, however there is the option for one parent to participate.
- Be able to speak English**
- Have access to either a phone, or computer/smartphone with internet access if opting for a video call

Your **child** needs to:

- Have been diagnosed with malignant cancer in the past 6-18 months
- Be undergoing care at Addenbrooke's Hospital in Cambridge, UK
- Not be receiving end of life care

**By parent, we are inclusive of any type of parental unit (e.g., stepparents) and not just biological parent(s). The requirement that parents live together is because you will be asked to talk about your family's communication and relationships.*

***This is because you will need to describe your experience in some detail in the interview.*

What would this involve?

The lead researcher, Anna, will be doing the interviews with each parent separately. She would email or phone you to arrange a time to meet for the interview. This would either be over remote video technology, or the telephone (due to current COVID-19 restrictions). You can choose the method of interview with which you feel most comfortable. You will have the chance to first ask Anna any questions you have about the study. If you would like to continue, you will be asked to sign a consent form to show that you are willing to participate.

The length of the interview will be led by you, but it is likely to last for around an hour (maximum 90 minutes). This will allow you time and space to talk about your experience. There is a possibility to split the interview into two sessions if that would be most convenient for you. The interview is semi-structured, which means it will just act as a guide, as we want to understand your experience as a parent as best as possible. You will only be invited to talk about what you feel comfortable with.

To start with, Anna will ask some brief factual background questions about you, your child diagnosed with cancer, and your family. The main part of the interview will cover three areas. First, Anna will ask about how you learned about your child's diagnosis; second, Anna will ask about how having a child diagnosed with cancer during the pandemic has impacted you individually; and finally, Anna will ask about how you feel this has impacted you as a family, and how your family relate and communicate with each other. The interview will be audio-recorded, so that it can be transcribed for analysis afterwards.

What will happen to my data?

We will need to use information from you for this research project. This information will include your age, gender, ethnicity, job title, child's diagnosis, date of diagnosis, and age and gender of others living in your home, and your relationship to them. The research team will use this information to make sure that the research is being done properly. We will keep all information about you safe and secure. The audio-recording and transcription of your interview will be stored electronically, in a secure password-protected environment. Information that could identify you, such as your name and other details, will be removed or changed. The recordings will only be accessed by Anna and Dr Shivani Sharma (principal supervisor on the research team, University of Hertfordshire) and Dr Jen Heath (second supervisor). Personal identifiable information will only be accessed by Anna. The audio recording may also be sent to an independent transcription company. They must follow our rules about keeping your information safe.

Once we have finished the study, we will keep some of the data so we can check the results. The audio-recordings of your interview will be destroyed after Anna's degree is conferred, which is due to be in late 2022. Your consent form will be stored in hard copy at the University of Hertfordshire in a locked filing cabinet and will be destroyed under secure conditions at the end of the study. The transcription of your interview will be kept for 5 years after the date of any publications arising from this research.

How will you use this information?

The results of the research will be written up in a report for Anna's Doctorate in Clinical Psychology. This may contain anonymised quotes from the interview (i.e., comments you made in the interview that cannot be identified as something that you said). The research will be written up for submission to peer-reviewed academic journals and conferences, so that other health professionals can learn from the research. We will write our reports in a way that no-one can work out that you took part in the study.

Are there any situations when information I tell you will be shared?

Disclosure of any personal information from the interview would only occur in exceptional circumstances, such as if you revealed information that may indicate a risk to yourselves or others.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- 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.

Where can you find out more about how your information is used?

- At www.hra.nhs.uk/information-about-patients/
- Or contacting the University of Hertfordshire's Data Protection Team on dataprotection@herts.ac.uk.
- By sending an email to Anna on aj18abj@herts.ac.uk

Are there any potential benefits in taking part?

There are not any direct benefits for taking part, but we hope to provide a space where you can share your story of having a child diagnosed with cancer during the COVID-19 pandemic. Talking about your experience with someone who is impartial may be helpful in making meaning from the experience. You will also be contributing to a growing area of research, which may help shape the care that you and other families receive in the future.

Are there any potential risks in taking part?

There are no known risks, however, there is a chance that the interview may be emotionally distressing for some (e.g. during or after the interview). Anna has experience in providing emotional support to people who are experiencing distress, and will be sensitive in her interview technique and delivery. Should you feel too distressed to continue with the interview, you are free to pause or stop at any time. Anna will check in with you to ensure that you are still wanting to continue with the interview. You need only talk about the experiences that you feel willing to talk about, and in a way that feels manageable for you.

What happens after the interview?

Following the interview, nothing more will be required regarding input to the study. You will be offered a leaflet with some relevant contacts in case you would like some further support.

Following the end of the project, a summary of the findings will be documented and made available at Paediatric Day Unit at Addenbrooke's for those who took part. You also have the option to provide your email address so that the summary can be emailed directly to you, and you can opt to participate in future research projects in this area by ticking a box provided on the consent form if you wish. If

you change your mind about consenting to being contacted for future research, you can email Anna at any point to have your name removed from this list.

What happens if I agree to take part but then later change my mind?

You can withdraw from the interview at any point, including during the interview and up until the point of analysis. The earliest that data analysis will begin, will be 14 days after the interview. However, once data analysis has started, you could still request that no anonymised quotations from your interview are used. You can withdraw for any reason, and you do not have to explain to Anna your reason for withdrawing. Withdrawal from the study would have no impact on the care you and your family receive from the hospital.

Who is in the research team?

Name	Role	Email
Dr. Anna Jones	Lead researcher, Trainee Clinical Psychologist, Clinical Psychology Programme, Department of Psychology, Sport and Geography (PSG), University of Hertfordshire	aj18abj@herts.ac.uk
Dr. Shivani Sharma	Head of Psychology Division, Department of PSG, School of Life and Medical Sciences, University of Hertfordshire	s.3.sharma@herts.ac.uk
Dr. Jennifer Heath	Senior Lecturer in Clinical Psychology, Clinical Psychology Programme, Department of PSG, University of Hertfordshire	j.heath@herts.ac.uk
Dr. Angela Kirby	Lead Clinical Psychologist, Department of Haematology and Oncology, Addenbrooke's Hospital, Cambridge	angela.kirby@addenbrookes.nhs.uk

What do I do if I am interested in taking part?

1. Participation is entirely voluntary, so we first encourage you to **have some time and space to think** about whether you would like to take part. If you have any questions, or would like more information, you can email Anna, or if you would prefer, you can email to arrange a phone call.
2. If you decide you would like to take part, **please email Anna**: aj18abj@herts.ac.uk who will send you the Expression of Interest form.
3. Or visit the study website form to **download an Expression of Interest form**: <https://tinyurl.com/cancercovid>, and then complete and email it to Anna.

Please note that there is no guarantee that all those who apply to take part will be interviewed.

This research is being conducted as part of Anna's Doctorate in Clinical Psychology, sponsored by the University of Hertfordshire (UH protocol number: LMS/PGR/NHS/02965). It is supported by the NIHR Cambridge Biomedical Centre (BRC 1215 20014) at Addenbrooke's Hospital, Cambridge University Hospitals NHS Foundation Trust. The research team works in accordance with professional code of conduct including ethical practice. The project has received NHS ethical approval from Research Ethics Committee (REC approval reference: 21/EM/0164).

Appendix B – Expression of Interest Form

14/12/2021 | Version 3.0 | IRAS Number: 298214



EXPRESSION OF INTEREST FORM

'Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family'

Please make sure you have first read the Participant Information Sheet.

We hope that taking part in this research will contribute to better understanding how to support families of children receiving a diagnosis of cancer. This study is part of Anna's doctoral training, meaning that the project is time limited. It might be that more than the required number of parents register to take part, so it may not be possible for everyone who expresses an interest to participate in study. In this instance, parents will randomly be selected to take part.

PLEASE COMPLETE SECTIONS IN BLUE

	Parent 1	Parent 2
First and last name:		
Email address (<i>for contact to arrange interview</i>):		
Age:		
Gender:		
Relationship to child diagnosed with cancer:		
Who else lives at home? Please give a brief description (e.g., two children under 18)		
Any other information you think is important:		

Please confirm the following (please tick):

I have a child diagnosed with malignant cancer in the past 6-18 months

My child is not receiving end of life care

If you would like to take part, and you have read the Participant Information Sheet, please [email](mailto:aj18abj@herts.ac.uk) this completed form to aj18abj@herts.ac.uk

What happens to this information?

Regardless of whether you are selected to be interviewed, the above information you have provided will be kept **strictly confidential** in accordance with the Data Protection Act 2018. Hardcopies of documents containing information will be stored in a locked filing cabinet and only accessible by Anna, Dr. Shivani Sharma and Dr Jen Heath. Electronic documents will be password protected and stored as encrypted files on a secure OneDrive vault that will only be accessible to Anna. If you are selected to take part in the research, it will be ensured that you will not be identifiable.

Thank you for your time

Appendix D – NHS Ethical Approval Paperwork



Dr Shivani Sharma
Department of Psychology, Sport and Geography,
School of Life and Medical Science
College Lane Campus, University of Hertfordshire
Hatfield
AL10 9ABN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

28 July 2021

Dear Dr Sharma

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family
IRAS project ID:	298214
Protocol number:	TBC
REC reference:	21/EM/0164
Sponsor	University of Hertfordshire

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?

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 **298214**. Please quote this on all correspondence.

Yours sincerely,
Barbara Cuddon

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Ellie Hubbard*

**East Midlands - Leicester Central Research Ethics Committee**

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0207 104 8070

Fax:

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

28 July 2021

Dr Shivani Sharma
Department of Psychology, Sport and Geography, School of Life and Medical Science
College Lane Campus, University of Hertfordshire
Hatfield
AL10 9AB

Dear Dr Sharma

Study title: Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family
REC reference: 21/EM/0164
Protocol number: TBC
IRAS project ID: 298214

Thank you for your letter of 22 July 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation

as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at

<https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Poster]	2.0	22 July 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Certificate]	1	06 August 2020
Interview schedules or topic guides for participants [Draft interview schedule]	2.0	22 July 2021
IRAS Application Form [IRAS_Form_18062021]		18 June 2021
Letter from sponsor [Sponsor Letter]	1	10 May 2021
Other [Insurance certificate]	1	18 June 2020
Other [Non disclosure agreement transcription]	1.0	03 June 2021
Other [Contacts for further support]	1.0	03 June 2021
Other [Expression of Interest form]	2.0	22 July 2021
Other [Non disclosure agreement transcription]	2.0	22 July 2021
Other [Summary of amendments]	1.0	22 July 2021
Participant consent form [Consent form]	2.0	22 July 2021
Participant information sheet (PIS) [Participant Information Sheet (PIS)]	2.0	22 July 2021
Research protocol or project proposal [Research protocol]	1.0	03 June 2021
Summary CV for Chief Investigator (CI) [CI's CV]	1	03 June 2021
Summary CV for student [Student CV]	1	03 June 2021
Summary CV for supervisor (student research) [Second supervisor's CV]	1.0	17 June 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 298214 Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project.

Yours sincerely



Pp Mr Paul Smith
Vice Chair

Email: leicestercentral.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Ellie Hubbard

Lead Nation
England: approvals@hra.nhs.uk

**Cambridge University Hospitals NHS Foundation Trust
Research and Development Department
Box 277
Cambridge Biomedical Campus
Hills Road
Cambridge CB2 0QQ**

27/09/2021
Dr Angela Kirby
R&D ref: A095997
Cambridge University Hospitals
NHS Foundation Trust
Department of Paediatric
Oncology and Haematology

Direct Dial:
Switchboard: 01223 245151
E-mail:
jonathan.alvarezolieff@addenbrookes.nhs.uk
research@addenbrookes.nhs.uk
www.cuh.nhs.uk

Dear Dr Kirby,

IRAS ID: 298214
REC Ref: 21/EM/0164
Short Title: Family impact of a childhood cancer diagnosis during the pandemic

Thank you for sending details of the above named study.

The R&D department has received the HRA Approval letter and reviewed the study documents. The project has been allocated the internal R&D reference number of **A095997**. Please quote this in all future correspondence regarding this study.

Capacity and capability to conduct this study at Cambridge University Hospitals NHS Foundation Trust is confirmed. Any amendments that have been submitted whilst the project was in set up have been incorporated into our local confirmation of capacity and capability. Recruitment can commence at this site from the date of this letter; though this may change in light of further developments dictated by the Trust and or by Public Health England. Please note that whilst each required supporting department has given authorisation for the study, the capacity of the supporting departments is subject to change during the pandemic. At all times the safety of study participants who are continuing or discontinuing on the study protocol is a priority.

We would like to take this opportunity to remind you of your responsibilities under the terms of the UK Policy Framework for Health and Social Care Research, applicable to Researchers, Chief Investigators, Principal Investigators and Research Sponsors. We would also like to remind you of the requirement to:

- ✓ Notify R&D of any amendments to the protocol, changes in funding, personnel or end date. Amendments should be submitted in accordance with guidance in IRAS.
- ✓ Inform us of any research-related adverse events.
- ✓ Ensure that any staff working on this study at this site have been issued with a contract with CUH (honorary, substantive or bank) or a letter of access before they commence work on the study at this site.
- ✓ Maintain an Investigator Site File and/or Trial Master Files, ensure up to date GCP certification and Register the study on a publically accessible database (Clinical Trials only).
- ✓ Forward Annual Progress Reports and send copies of End of Study Reports to R&D as soon as they are available so that the study can be closed and archived.

Please remember that each recruited patient to your study should be logged on to our e-hospital to associate the patient's EHR to this study. Additionally, all recruitment figures for portfolio studies must be uploaded to the EDGE database on a regular basis and confirmed. R&D are able to provide EDGE and GCP training. Please note it is a Department of Health aim to enable fast patient access to research and as such we aim to consent the first patient within 30 days of study start.



The Trust is required to report regularly on its research activity and we request that you insert the following phrase into the acknowledgement section of any subsequent publication from this study: **This research was supported by the NIHR Cambridge Biomedical Centre (BRC 1215 20014)**. While this study may not have received funding from the Cambridge BRC, it will have been supported by campus infrastructure funded by it. We are very grateful for your help with this.

I wish you every success with this study. We are keen to support good research at Cambridge University Hospitals NHS Foundation Trust and are pleased that you have decided to conduct your project here.

Yours sincerely

A handwritten signature in black ink that reads 'Tracy Assari'.

Tracy Assari
Research Governance Lead

Appendix E – Sponsorship letter, University of Hertfordshire



John M Senior
BSc MSc DSc PGCE CEng FIET FRSA FHEA
Professor of Communication Networks
Pro Vice-Chancellor (Research and Enterprise)

University of Hertfordshire
Higher Education Corporation
Hatfield, Hertfordshire
AL10 9AB

Telephone +44 (0) 1707 284000
Fax +44 (0) 1707 284115
Website www.herts.ac.uk

Dr S Sharma & Ms A Jones
Department of Psychology, Sport and Geography
School of Life & Medical Sciences

10 May 2021

Dear Dr Sharma and Ms Jones

Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN PRINCIPLE for the following:
RESEARCH STUDY TITLE: Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family
NAME OF CHIEF INVESTIGATOR (Supervisor): Dr Shivani Sharma
NAME OF INVESTIGATOR (Student): Ms Anna Jones

This letter is to confirm your research study detailed above has been reviewed and accepted, and I agree to give University of Hertfordshire sponsorship in principle.

Before you commence your research you must be in full compliance with all Health Research Authority governance requirements. You must also secure full University of Hertfordshire sponsorship, for which you will need to have supplied the following documentation:

- Final version of the submitted IRAS form (pdf)
- Approval from the relevant Health Research Authority (HRA) Research Ethics Committee (REC) as well as confirmation of favourable opinion of any amendments arising during approval
- Evidence of relevant NHS Permissions (eg Research Passport) and Confirmations of capacity and capability as they are received
- Confirmation of University protocol number
- The final versions of the protocol, patient information leaflet and informed consent form
- For externally funded research, confirmation of adequate funding in the form of the award letter
- Any other regulatory permissions required, eg from the National Information Governance Board (NIGB), under the Human Tissue Act or the Ionising Radiation (Medical Exposure) Regulations
- If applicable, copies of any contracts/agreements with external organisations (eg funders, collaborators, co-sponsors) involved in your research study.

As a condition of receiving full sponsorship, it is the responsibility of the Chief Investigator to inform the Sponsor of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements. It is also the responsibility of the Chief Investigator to inform the funder, the HRA NHS Research Ethics Committee (REC) and any other relevant authority of any of these changes. Annual and end of study reports must be submitted to the HRA and copied to the Sponsor.

I look forward to receiving the above documents before you commence your research. Please email these to research-sponsorship@herts.ac.uk so the University can confirm sponsorship. In the meantime, we wish you well in pursuing this interesting research study.

Yours sincerely

Professor J M Senior
Pro Vice-Chancellor (Research and Enterprise)

Encl: Insurance certificate(s)



LMS/PGR/NHS/02965 NHS Protocol Registration Number

To: Shivani Sharma; Anna Jones [Student-LMS]

Cc: Research Sponsorship

Mon 04/10/2021 13:42

Dear Shivani,

The Vice Chair of the Health, Science, Engineering and Technology ECDA has confirmed that **Anna Jones** may quote UH protocol number **LMS/PGR/NHS/02965** on their submission paperwork and exam arrangements form.

Kind regards,

Harriet.

Harriet Hasler-Watts

Governance Services Administrator (Ethics)

Governance Services

University of Hertfordshire

Hatfield AL10 9AB

UK

Tel +44(0)1707 285568

Appendix F - Participant Consent Form

22/07/2021 | Version 2.0 | IRAS Number: 298214



CONSENT FORM

Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family

PLEASE COMPLETE SECTIONS IN BLUE

	PLEASE INITIAL
1) I confirm that I have read and understood the Participant Information Sheet for the above study. I understand what taking part will involve.	
2) I have had the chance to consider the information given. I have had the opportunity to ask questions, and I am happy with the responses that I received.	
3) I understand that my participation is voluntary and that I can withdraw at any time, without having to provide reason.	
4) I understand that my interview will be audio recorded. I understand that this recording will be transcribed word-for-word.	
5) I understand that when a report is written and published about the study, quotes from my interview may be used, but all identifying information will be removed or changed. I give permission for publication of these anonymised quotes.	
6) I have been told how information that I share (<u>i.e.</u> data obtained from the interview and data I provide about myself) will be handled: I have been informed of how it will be kept secure, who will have access to it, and how it will/may be used.	
7) I have understood that all interview recordings will be anonymised and destroyed at the end of the study.	
8) I understand that my participation in this study might bring up difficult feelings that lead me to wish to have advice and support. In that event, I will be invited to consult Dr Angela Kirby, Clinical Psychologist, at Addenbrooke's Hospital, who can redirect me to appropriate support contacts, or my GP. I am also aware that I will be emailed a list of contact details for support following the interview.	

22/07/2021 | Version 2.0 | IRAS Number: 298214

9) I confirm that I am over the age of 18 <u>years, and</u> agree to take part in the above study.	
	PLEASE TICK
Would you like to be contacted after the study to be given a summary of results?	YES NO <input type="checkbox"/> <input type="checkbox"/>
Would you like to be contacted about participating in future research projects in this area?	YES NO <input type="checkbox"/> <input type="checkbox"/>

PARTICIPANT:	NAME:	
	DATE:	
	SIGNATURE:	
	Email: <i>(If you would like feedback from the study once a report is complete)</i>	
LEAD RESEARCHER:	NAME:	
	DATE:	
	SIGNATURE:	

|

Appendix G – Nondisclosure agreement with transcription company



Confidentiality Agreement

Between Hertfordshire University and Wise Owl Solutions
for transcription services

	Please initial box to indicate consent
I consent to keep all data shared for transcription services confidential.	
I will not share data with anyone else and will only access data for transcription services.	
Study data will be stored on a password protected computer and only I as the transcriber will have access to this computer.	
Study data will only be stored for the length of time transcription services are being undertaken. Once complete all study data will be permanently deleted.	
I will not discuss the content of recordings with anyone outside the study team.	

Transcriber: Marianne Blomerus

Signature:

Date: 18/03/2022

Client: Anna Jones

Signature: Anna Jones

Date: 20/03/2022

Supervisor: Shivani Sharma

Signature: Shivani Sharma

Date: 20/03/2022

Appendix H – Debrief sheet for participants

03/06/2021 | Version 1.0 | IRAS Number: 298214



Contacts for further support

Lived experience of childhood cancer diagnosis during the COVID-19 pandemic: parents' perceptions of the impact on the family

Thank you for taking time to participate in this study. It is our hope that through exploring your experiences, it will help contribute to improving the support given to families coping with having a child diagnosed with cancer, particularly following the pandemic.

The information you have given will be kept confidential, and your anonymity will be protected in any publications or presentations that result from this research. Further details around how your personal data will be used and stored can be found on your copy of the Participant Information Sheet.

If taking part in the study and retelling your experience has been distressing, you may find it helpful to contact some immediate sources of support, which might include family, friends, your GP, or a therapist or counsellor. The professional code of conduct and ethical approval for this study means that Anna Jones cannot personally support individuals with support beyond the remit of the study. This is why we have created this debrief sheet with a list of contact details for further support.

- **GP or local Psychological Therapy Services:** Please think about contacting your GP if you feel that you may benefit from receiving psychological support. Your GP will be able to signpost you to local NHS services.
- **Samaritans:** A free and confidential helpline available 24 hours a day, 7 days a week, for anyone experiencing emotional distress.

Freephone: 08457 90 90 90

Website: www.samaritans.org

- **Macmillan Cancer Support:** The Macmillan Support Line offers confidential support, including to those caring for someone living with cancer, available 7 days a week, 8am to 8pm.

Freephone: 0808 808 00 00

Website: www.macmillan.org.uk

- **Dr. Angela Kirby, Clinical Psychologist:** You can speak to Dr. Kirby, Clinical Psychologist at Addenbrooke's Hospital who organise support from the psychology and counselling team in the oncology department, or signpost you to other services for support. If you would prefer, you can ask Anna to make contact with Dr. Kirby who can then make contact with you.

If you have any further questions, please contact Anna Jones by e-mail (aj18abj@herts.ac.uk). If you have any complaints or concerns about any aspect of the study, you can contact Dr. Shivani Sharma (Principal Supervisor) by e-mail (s.3.sharma@herts.ac.uk).

Appendix I – Research Interview Schedule

The order of the following questions will depend upon the responses of the parents, and so the order provided here would therefore just act as a guide. I would also aim to adapt the questions to the language/responses of the participants. For example, if they refer to ‘cancer’ in a particular way, I will adapt to use their term; I will use the names of family members that the parent provides, etc.

Introduction and ethical information

“The aim of this research is to understand parents’ perceptions on how having a child diagnosed with cancer during the COVID-19 pandemic has impacted them as a family. We hope that by learning about the experiences of parents like yourself, we will have a better understanding of how to effectively support families with a child diagnosed with cancer, particularly following the pandemic, and to also inform care in any potential pandemics in the future.

The interview should take around an hour, and I will be audio-recording it so that I can later type out the conversation. This information will of course be handled carefully, and only my research team and I will have access to it. Once it is typed, the conversation will be anonymised so that you and your family cannot be identified. The data will be used to write scientific articles and in conference presentations, and if we use quotations from your data, it will be ensured that it is not possible to recognise you.

During this interview, several questions will be asked. However, you do not need to feel that you should answer every question. If there are any questions you feel uncomfortable answering, you could take a pause, come back to it, or even skip the question. There aren’t any right or wrong answers, the questions are there just to act as a guide. I hope to understand as well as possible your experience as a parent.”

* Go through informed consent – See Appendix 2

* Explanation of my role as a researcher rather than clinician in this context.

Section 1: Background information¹

“Before we start, I’d like to ask some short questions just to get some background information about you, your child diagnosed with cancer, and the rest of your family living at home.”

1. How old are you?
2. How would you describe your ethnicity?
3. What is your marital status?
4. What is your job title?
5. What is the name and date of birth of your child diagnosed with cancer?²
6. What was the date of your child’s diagnosis?
7. What type of cancer has your child been diagnosed with?
8. What are the names² and ages of your partner, and other children living with you at home?

Section 2: Learning about the diagnosis

“Now I’d like to ask a bit about the very first experiences of when you found out about your child’s diagnosis of cancer.”

¹ Form to be prepared to record these answers

² Participants will be reminded that this is for ease in the interview, and all details will be anonymised

9. How did you find out about your son/daughter's diagnosis of cancer?

Probe Questions

- Did they have any symptoms prior to the diagnosis? What led you to seek support?
- What thoughts went through your head when the diagnosis was given?
- Who was there with you in the hospital when your son/daughter was diagnosed?
- How did the access restrictions that were imposed during the pandemic impact your experience?

(NB. For COVID specific questions, make it clear to parents that I am not expecting a comparison to how it might have been pre COVID, rather I am just interested in how COVID has impacted on their experience from their perspective).

Section 3: Impact on parent

10. What was it like for you having a child diagnosed with cancer?

Probe Questions

- What were the first few months like?
- What emotions have you experienced?
- How have you tried to cope with managing this experience?
- How did it impact your work? Did you have to continue, stop or manage both working and caring for your son/daughter?

11. How do you think the pandemic has impacted this experience?

Probe questions

- How did the pandemic impact the experience of caring for your child during hospital visits/stays?
- How did awareness of the virus impact your experience?
- How was information communicated to you about the virus? Did it make sense? How did it impact your experience?

Section 4: Impact on the family

“Now I'd like to find out more about how your family has experienced [your son/daughter/insert name] being diagnosed with cancer during the pandemic.”

12. How has [insert name]'s diagnosis impacted the way that your family functions?

Probe Questions

- How did you experience this period of time as a family?
- What has changed in your family as a result of the diagnosis?
- How have the government restrictions impacted your experience as a family?
- How have you communicated as a family during this period? Is the cancer talked about? Is the virus talked about?
- *If not:* Was there someone who you felt that you could talk to?
- Has the experience brought your family closer together or moved you further apart?
- What has social support for the family been like during this time?

- Did you feel supported by the health-care professionals involved in your care? How? Was there anything else that might have helped?
- Has it impacted your relationship with [your son/daughter/insert name]?
- Has it impacted your relationship with your partner?
- Has it impacted your relationship with your other child(ren)?

Section 5: Summing up

13. Is there anything else that feels important that you would like to talk about? How have you found the experience of answering these questions?
14. Is there anything you have said that you wouldn't want me to include? (Recheck with parents that they are happy for anonymised quotations from their interview to be used in publications).
15. Are there any questions you would like to ask me?

Appendix J – Reflective diary excerpts

Reflections following service user feedback on recruitment materials

27th May 2021

...The consultation with the EBEs has been really helpful for highlighting my assumption around cancer being a “highly stressful experience” – I need to change the wording to acknowledge a broad range of responses - that it is a challenging time, and that it may raise a whole range of emotions experienced by everyone in the family. The EBEs talked about the relief some families may experience having not known what was wrong for months...The issue around parents not being able to compare to pre-COVID is helpful in aiding me to make sure that I make clear to parents that I am not expecting a comparison to know what it would have been like pre-COVID interested in how COVID has impacted on their experience from their *perspective*...

Reflections following first (pilot) interview

19th January 2022

...Did I overdo the balance of not being overly empathic and end up not showing enough empathy? Or was it because I was too focused on what to cover? I did end up going through more of the prompt questions than I thought I might, although in a different order than given, so I hope I was following the lead of the interviewee. I did ask a lot of follow up questions also based on what she was saying.

I felt a bit uncomfortable in my role as a researcher as I am used to working clinically now, and am used to responding more and often influencing how people think. I think perhaps I overcompensated a bit and I could have been more empathic in the interview, and maybe this more distanced stance influenced both the way the interviewee connected with me and how I connected with the interview process? There are times when she laughed, which was perhaps a defence around comfort levels/ talking about something so difficult. Listening back to it she did seem to increase in comfort in answering questions as the interview progressed though.

On discussing this in supervision with Jen a few hours later, she explained how she stated her position at the start of a research interview, and I think that would really help with my own comfort in interviewing and help set the expectations for the remaining interviewees...

Reflections on recruitment difficulties

1st February 2022

...I'm finding the slow process of recruitment really stressful, particularly as I don't have much control over it. Without having a clinical contract for the NHS service from which I am recruiting, I am having to depend on staff who are already overstretched to do the initial approach. An additional challenge is that there are still limited face to face clinics running. My placement is not on the Addenbrooke's site at the moment, but I plan to have a meeting with the counsellors and psychologists next week to try to maintain my presence as emails isn't really enough...

...It's definitely been worth making the ethics amendment to be able to get consent to email and phone participants...many of these parents are managing chaotic lives still juggling their child's treatment. It has been helpful to gain consent to phone them about the study rather than sending an email or letter that gets lost amongst the many others that they don't have time to read or respond to...

Reflections during coding process (examples from different transcripts)

8th July 2022

...I found it difficult questioning her around the lack of support that she felt from healthcare professionals, and coding this section of the interview, because some people I know well worked as counsellors on the oncology wards throughout the pandemic. I must have been influenced by the fact that I know them personally, and know that they worked hard throughout the pandemic, although with certain restrictions placed on them (the precise details of which, I am not sure at the moment). There weren't many points in the interview where I asked a checking/confirming sort of question like I did in response to her feeling that there was no support available – I asked, “*so there was no support for parents or siblings?*” I wonder if she could hear any doubt or surprise in my voice. The experience of doing this first interview made me think more carefully about how I approached this topic in subsequent interviews. Also, I have been wondering what happened on the ward for her not to have had any access to the counsellors. What was it about the support during this time – was it harder to communicate the service to them? Was it that there was support offered online and that she didn't want this, and it is the fact that there wasn't any face-to-face support that she refers to?

My bias is that I have worked in this service, but pre pandemic times; I am also influenced by just how much I respect the psychologists and counsellors who work on that ward having worked with them previously - I need to make sure I get the full story of what the service was like during the pandemic to get a much better understanding of the context than I have right now. The fact that there was no support for siblings is an important thing to highlight...

15th July 2022

...Reading the account again in depth to be able to do the exploratory noting has made me realise the value of this approach of IPA. A couple of weeks ago when I listened to the audio file to check the transcribing, I did not really have anything to add more than what I had written immediately after the interview. She presents such a well processed, 'together' account, but reading the transcript line for line, I started really paying attention to the number of words she uses for emphasis of just how devastating the experience was for her, and that she had outlet for expressing this properly in the early months. I became much more immersed in the world of the participant by paying close attention to the way that her story is told.

I am thinking back to my conversation yesterday with Angela, the psychologist in the service, when I mentioned to her that some parents had said that emotional support wasn't available or not offered at the right time. She said that because the counsellors couldn't freely go onto the wards, the nurses had to refer them to the service. I am thinking about how she came across to me – so together and not needing help. It's making me think about how the nurses could be supported in asking the parents if they needed support even if they didn't appear to. Particularly given situations like the pandemic when they were so isolated and didn't have the privacy for conversations with their support network outside the hospital.

The conversation with Angela also reminded me of the need to get in-depth information about what the service was like at that time, and details of the restrictions that impacted on their work etc.

5th August 2022

...Now that I am reading the interview in more depth and writing exploratory notes, I am feeling more drawn into how traumatic it was to stay in hospital for so long when you are trying to look after a very unwell child. Her descriptions are evocative and detailed, and her use of repetition conveys the frustration of the monotony of it, and how little control that she had overhearing the man cry for help and being placed with others with COVID. There was little that they could do to move wards, and change the situation, except when she got quite angry and then was listened to a bit more.

I'm finding it quite difficult to read. I keep getting distracted by checking messages on my phone etc. And I was feeling a bit guilty for this at first, but then realized it's because it is difficult to sit with it for too long as I begin to also feel myself feeling trapped by her account. I realized it is important to take frequent breaks doing this coding. Although it probably makes more sense to try and sit with it a bit longer, and then schedule in frequent actual breaks so that I don't lose my 'flow' so much....

Reflections during generation of master themes

7th September 2022

...I'm writing up the theme around '*Fear of COVID-19 infection*' and thinking how I need to be careful not to put across my own views about the restrictions too strongly. I personally feel that some of the measures that some of the parents took for infection control were more than necessary, but then that reflects my different experience of COVID and how that has led me to evaluate risk. I hope that I have now brought out the differences between the parents' expression of fear and risk in this theme...

17th September 2022

...Need to think about providing a good level of information to set the context of the restrictions and impact on staff during the pandemic. I want to make sure that I present the information sensitively so that it does not feel blaming towards hospital staff. It was also a particularly challenging, and at times traumatic, experience for staff too. I need to be very mindful of my position here. My position in relation to the pandemic is more from the perspective of a parent rather than a member of staff, as I was on maternity leave during the height of the pandemic, and I only started working on placement in a hospital setting late in 2021 when there was more of a return to face to face working...

Appendix K – Transcript excerpt (‘Amy’)

Extract from ‘Amy’s’ Analysed Transcript (p.4-6)

Quotations in final analysis
 Red for linguistic comments

NB. Names used are all pseudonyms

Exploratory comments	Original transcript	Emergent themes
<p>Emphasis on how brief conversations were No time for feelings</p> <p>In shock Priority is unwell child and meeting her needs Separation of own feelings - ‘parked’</p>	<p>And you talked about not having space to have those conversations more privately and you had them in front of Jane. Can you tell me a bit more about that?</p> <p>P: I, I think it was, you know, because we never had anything... It took a few days to have a bit more clarity on exactly what, what was ahead of us. So, there, there were just very small, very discreet, very Jane-focused conversations, not necessarily conversations focusing on how we were feeling, or what was, was, you know, it was I think conversations where, you know, just how unbelievable it is, is that, that feeling in shock really and just prioritizing our focus very much on just meeting her needs, which was the basic, you know, the, the meeting of her physical needs, her care needs, her emotional needs, very much parking our own needs, so not too much discussion around that really. I can't think of... You know, in, in terms of how it felt as a process as Jane’s mum is very clear, but in terms of, of what discussions I had with John about how we were feeling, we didn’t get too far down that line really, apart from just how shocking it is, it’s unbelievable. What are we going to do, we just need to do what, what the medical advice is suggesting and keep going, one foot in front of the other really. Yeah.</p> <p>[09:20]</p>	<p>Lack of privacy away from the child with cancer to talk</p> <p>Needs of child with cancer take priority</p>

<p>Isolated from those at home for the whole time during hospital stay</p> <p>Father could visit but not the sister</p> <p>Difficult not being able to support other child</p> <p>Couldn't see her other child at all because the rules were so strict</p> <p>Really, so – emphasis</p> <p>Sense of injustice that father could see unwell child but not other daughter</p> <p>Risk is the same</p> <p>Needed space as a family</p> <p>Single parent, and they were only letting parents on the ward – other parent is not a safe source of support for recently divorced parent- the policy is aimed at the child rather than thinking about the whole family</p>	<p>A: Sure. Do you think there were any, anything else about the pandemic and the restrictions that impacted your experience?</p> <p>P: I think the hardest thing for me was, because of Jane and who, who, you know, some of the difficulties that, that she has, I think the rules made life particularly difficult for me and in the sense that... and probably for her as well, so, you know, Jane lives with myself and with her sister and with, with my mum, and that's our primary family unit. But because the, the rules were so strict, neither Jane or I were able to spend any time with, with Laura or Alison at all for the whole duration of our stay in hospital. And even, although John was allowed to visit, and Laura was sometimes staying with John, she wasn't allowed to, to, to visit with him. So it was very difficult for me having two children and not being able to see both children and, and to support Laura through what she was going through. You know, as a mum you want to be there for, for your kids and I wasn't able to spend any time with her. And, you know, my discussions with the ward were, I know the rules are really strict, but if we can test my daughter and if I go off-site to spend some time with her, would that be allowed, and certainly in the beginning, that wasn't, that wasn't permitted, I wasn't allowed to see her at all, because I think the ward rules were so strict, which in, in one sense did make sense to me but in another it didn't, because I was thinking, well, why is her daddy allowed in for three hours but not, not my other daughter even though she was spending time with him. So, if there was a COVID risk, I would have thought it would have been the same, it would have been the same. And obviously, Laura wasn't in school because we were locked down, so it wasn't like she was, she was in school. Well, actually, no, we... there was some school attendance, wasn't there, but it, it... she wasn't in school when we got that news because she wasn't able to, to be there. We, we needed a bit of space as a family to, to get through it. So, yeah, that, that's what made it incredibly difficult, was the only person who I could share how I was feeling with, was somebody really who I didn't want to, because of everything that was happening for us at that time. He wasn't, he wasn't my safe person, my go-to person. So, it made it difficult.</p>	<p>Isolated from key support network -family at home</p> <p>Difficult not being able to support other child</p> <p>Injustice in not being permitted to see other daughter during hospital stay</p> <p>Unable to have immediate source of support to share the experience with</p>
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<p>No privacy in the hospital</p> <p>Conscious that others needed the space so couldn't make calls</p> <p>Outside was too far from unwell child</p> <p>No privacy to be able to release emotion – be in tears - away from child</p>	<p>A: That sounds really difficult.</p> <p>P: Yeah.</p> <p>[12:13]</p> <p>A: And how did you communicate with Allison and Laura during that time?</p> <p>P: With Jane?</p> <p>A: Allison...</p> <p>P: Oh, with Allison and-</p> <p>A: And your daughter...</p> <p>P: It was really difficult because there was no privacy in the hospital, the only room in which I was able to be able to make phone calls, there were... it was the main kitchen where people, other parents were making, you know, needed to be able to make meals and drinks and, and have some privacy for themselves, so you didn't feel able to spend any time, really, in there on the telephone because it needed to be used by others and the rest of the hospital. You weren't, there wasn't anywhere for being able to, to make those calls unless you went outside, which wasn't ideal because to be that far away from where Jane was and needed me wasn't, that wasn't achievable until she was asleep. So, going out and standing outside the front entrance at 9, 10 o'clock at night didn't feel like it was the, the place to having those discussions either. So, it was very difficult. So, it was a case of having, having those discussions when the other people on the ward can hear you or standing out in the corridor with lots of people walking past you, none of which was particularly appealing, I think, or helpful. Really, there is no, no privacy. Certainly not the</p>	<p>No privacy to make calls in hospital</p> <p>No privacy to express felt emotion away from child</p>
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<p>Emphasis of age - inappropriateness of discussing information in front of her</p>	<p>kind of places where you would happily sit and be in tears, which is what you needed to do and you can't sit and be in tears in front of your 7-year-old who's going through all of this. There was no place to go. Yeah.</p>	
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Appendix L – Emergent Participant Experiential Themes (PETs) for ‘Amy’

Isolation from support network

1. Devastating news alone
2. Isolated from key support network
3. Inequity in visitation restrictions
4. Support was limited for the family living at home
5. Some comfort in being in isolation in the pandemic

Lack of privacy

1. Lack of privacy to make calls
2. Insufficient facilities for privacy
3. Emotions couldn't be expressed
4. Barrier to communication with family

Support needs

1. Timing and accessibility of counselling support
2. Difficult to ask for help
3. Need for support from someone outside the family
4. Staff supported parent self-care

Communication in hospital

1. Frustration of not getting more information
2. Frightening experience of overhearing information
3. Parental anxiety caused by unexplained decisions

Splitting of family

Burden of separation

1. Focus on diagnosed child
2. Unable to support another child
3. Sibling jealousy due to differential treatment
4. Parent's unmet needs

Strengthened relationships

1. Close and supportive family
2. Relationship with mother is stronger
3. Strengthened bond with child with cancer

Loss of normalcy

1. Never free from worry
2. Life's fragility brought into focus
3. Cancer trumps everything
4. New normal – now future orientated thinking