THE EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CANCER

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A thesis submitted in partial fulfilment of the requirements of Manchester Metropolitan University for the degree of Doctor of Philosophy

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2025

Abstract

Background

Childhood cancers are life-threatening diseases that affect the child's entire family. Understanding the experiences of primary caregivers of children with cancer is vital. In the UK there is limited research exploring the parental perspective of children with cancer and therefore an inadequate understanding of the experiences of these caregivers.

Aim

The purpose of this phenomenological study was to explore the lived experiences of primary caregivers of children with cancer.

Methods

A family systems theoretical framework and phenomenological research method were used. Data was collected using purposive sampling and semi-structured in-depth interviews, and analysed via interpretative phenomenological analysis (IPA). Participants were recruited from charities across England. Five mothers participated in the study.

Results

Six superordinate themes were identified: "I learned what I needed to learn", "Complexity challenging the cancer journey", "Intersectional complexity in care", "A range of emotions", "Cancer-related changes", and "Impact of cancer". The findings demonstrate the challenging nature and complexity of what it means to parent a child with cancer-autism and Down's syndrome and how parents make sense of this. Gaps identified include a lack of research on primary caregivers of children with cancer with learning disabilities.

Conclusions

This study highlights how having a child with cancer, and additionally a learning disability or neurodiversity, is experienced as a caregiver and is one of the first studies to include this narrative. The research uniquely addresses the multifaceted challenges faced by these families, including the intersection of cancer, neurodiversity, and learning disabilities. Carers in paediatric cancer and disability contexts face complex challenges that appear under-reported. Understanding primary caregivers' experiences of paediatric oncological care is important to inform present and future healthcare responses. The study emphasises the importance of support for these caregivers and offers insights on how healthcare services can be improved to meet their specific needs. The research and clinical implications of the findings are discussed, the limitations of the current study are identified and recommendations for future studies in this field are also offered.

Contents

Acknowledgements

First and foremost, I would like to thank the five parents who volunteered their time to take part in this research. I felt honoured that you shared your stories and experiences so openly with me, during a very difficult time in your lives. Without your contributions, this research would not have been possible.

I would also like to thank my research supervisor team, Dr. Gary Witham, Dr. Kim Heyes, and Dr. Gayatri Nambiar-Greenwood, for their advice, ongoing support, encouragement and guidance over the course of the process of my doctoral training.

To the love of my life my husband, Caglar Gunes, who has been and continues to be my truest source of love and support. This thesis marks the end of a long, hard journey for me; one that I would never have been able to make without all of your support and understanding. It is with your on-going encouragement that I have been able to achieve a life-long dream. I owe my success to you. Thank you all so much. I would also like to thank my uncle Yunus Sahin, who always believed in me and encouraged me to pursue a PhD.

I would also like to express my profound gratitude to the Ministry of National Education of Türkiye who financially supported me during my studies in the UK. This scholarship opens many doors to me, so in particular, I am grateful to those who created this law that provides scholarships for students to gain degrees in foreign countries, and that gave me the chance to gain a high-quality education and invaluable life experience.

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Abbreviations

ASD	Autism Spectrum Disorder
ALL	Acute Lymphoblastic Leukaemia
CCLG	Children’s Cancer and Leukaemia Group
CCPAC	Childhood Cancer Parents Alliance Charity
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DS	Down’s Syndrome
DSUK	Down’s Syndrome UK
FCC	Family-centred care
GT	Grounded Theory
IPA	Interpretative Phenomenological Analysis
LMIC	Low and Middle Income Countries
NHS	National Health Service
NICE	National Institute of Clinical Excellence
RCGP	The Royal College of General Practitioners
TA	Thematic Analysis
TYAC	Teenagers and Young Adults with Cancer
UK	United Kingdom
WHO	World Health Organisation

Chapter 1

Introduction to the study

1.1 Chapter overview

A childhood cancer diagnosis is a life-changing event that has a profound impact on both children and their primary carers. This thesis' main goal is to provide an in-depth study of the phenomena of the experience of caring for a child with cancer. This research provides a unique contribution to knowledge that should allow healthcare professionals to gain a deeper understanding of the experiences of primary caregivers with a child with cancer as they go through the healthcare system in the UK. Phenomenological methodology was used in the study to better understand the experiences of primary carers. It is crucial to include background information in the introduction in order to help readers understand why research into the experiences of primary carers of children with cancer is important. This chapter covers the study's background and importance, as well as the research questions and aims, and concludes with a description of the structure of the thesis.

1.2 Structure of the thesis

This thesis presents findings from a qualitative investigation of the experiences of primary carers. The seven chapters that make up the thesis structure are listed below.

Chapter 1: This first chapter gives a summary of the rationale for the study, including its aims and objectives. The research topic, primary carers' subjective experiences of caring for a child with cancer, will be further examined in the chapters that follow, after first giving a brief introduction. Certain cancer-related phrases will be used frequently throughout the thesis, thus a preliminary familiarity with them is required. Therefore, I will present a brief general information of childhood cancer. As a research nurse, I will present general information about paediatric nursing and the importance of conducting qualitative research in the context of the nursing profession. Finally, I have presented the Family system theory framework.

Chapter 2: Offers an exploration of the available literature in order to understand the experiences of primary caregivers with a child with cancer. I will review all common themes from current studies on this topic in the literature. This will provide context for the issues primary carers encounter in helping a child with cancer, as well as a frame of reference for understanding their experiences with it.

Chapter 3: This chapter will discuss the study's methodological selection and research technique in detail, before offering an analysis and a discussion of the data outcomes. An examination of my own epistemological and ontological positions clarifies the methodology adopted. This chapter is founded on ethical considerations, which include the proper use and storage of data. The chapter provides clarification on the participant recruitment sampling method and the justification for the use of semi-structured interviews. I have also presented my reflexivity.

Chapter 4: This chapter presents the study's results and describes how primary carers interpret their experiences of caring for a child who has cancer. It covers the important themes taken from individual and cross-referenced testimony, with excerpts from each interview, used to facilitate interpretation in the discussion chapter. In total, five participants' responses were analysed. The findings were split into six main themes: "I learned what I needed to learn", "Complexity challenging the cancer journey", "Intersectional complexity in care", "A range of emotions", "Cancer-related changes", and "Impact of cancer".

Chapter 5: This chapter presents a discussion of the findings reported in Chapter 4 in relation to the literature from Chapter 2, using the wider literature to support our understanding of the issues.

Chapter 6: This chapter presents the conclusion to the research I have undertaken in this thesis. I discuss answers to the research questions posed in Chapter 1, and finalise the thesis with recommendations for future research. It reflects on the findings presented and summarised through earlier chapters on the importance of nurses as healthcare professionals to consider what kinds of experience they and their primary caregivers will have when caring for paediatric patients with cancer.

1.3 Significance of the study

As a Paediatric Nurse, my motivation for this research came from my desire to provide the best holistic care to both children with cancer and their primary caregivers. The objective of this research was to obtain an in-depth understanding of the meaning carers attach to their experiences of providing care for children with cancer in order to help health professionals support primary carers of children with cancer.

There has been substantial development in the treatment of children with cancer since the 1940s and 1950s when the first clinical trials of chemotherapy for leukaemia were performed. According to current estimates, more than 80% of children who are diagnosed with cancer will survive (Adamson, 2015; Siegel et al., 2020). These improvements in outcome have led to a more optimistic future for those who develop childhood cancer. This reduction in cancer-related mortality has allowed healthcare professionals to begin exploring the impact of childhood cancer from a psychosocial perspective. The physical and psychological effects of cancer on children have received a great deal of study attention since the 1980s. However, childhood cancer affects the whole family, and more specifically, the parents, who are usually the primary caregivers. Primary caregivers of children who have cancer hold a special position in the care of the child, both emotionally and medically, as they often have to make vital decisions and also help them to adjust to and cope with the demands of cancer.

1.4 Background

This chapter begins with the presentation of general information about paediatric oncology nurses and their roles when caring for children with cancer. The importance of nurses taking an active role in research and conducting qualitative studies will then be discussed. Finally, the present literature on family carers and children's cancer is discussed from the perspective of the wider cancer literature. The chapter ends with a review of the literature to highlight current issues.

1.4.1. Nurses’ roles when caring for children with cancer

To create favourable physical and psychological treatment outcomes for paediatric cancer patients, including those linked to their health-related quality of life, paediatric oncology nursing practice must combine both the science and the art of the discipline (Hockenberry et al., 2015; Sinclair et al., 2020). Children with cancer are treated and cared for mostly by paediatric oncology nurses (Pergert et al., 2020). Nurses provide physical, psychosocial, pharmacological and other supportive care aimed at promoting the quality of life and survival of children with cancer (Challinor et al., 2014).

Beginning in the 1960s, there was a considerable improvement in these children’s survival thanks to the creation of more effective treatment plans, as well as developments in chemotherapy, infection control, and paediatric intensive care. This environment encouraged the growth of advanced paediatric nursing practice, which in turn had a significant impact on nursing in paediatric oncology (Day et al., 2014). Paediatric oncology underwent the same introspection in the 1990s as a result of a movement in nursing schools that sought to include oncology topics in undergraduate courses (Gutiérrez et al., 2009). Therefore, even in the absence of formal training, nurses who were motivated to address the needs of this group for care looked for the support of technical and scientific knowledge in specialised courses in paediatric and/or oncologic nursing.

The requirement for parents or guardians to participate in care processes and decision-making, as well as due consideration for the child's right to have their thoughts and wishes honoured according to their degree of development and independence, makes paediatric care unique (Bartholdson et al., 2016). To care for a complicated, at-risk patient group, nurses who specialise in paediatric oncology need a diverse range of abilities. Oncology nurses engage in a variety of occupations and take part in specific therapies like radiotherapy, chemotherapy, and oncological surgery. In addition to providing technical and scientific knowledge, paediatric oncology nurses must also provide compassionate care to enhance the patient's health, quality of life, comfort, and general well-being (Al Balushi, 2019; Suryani et al., 2018).

Nurses play an important role in assisting patients and their families through their cancer experiences. Family-centred care, which is a core principle of children's nursing, recognises that families function as a unit (Shields, 2015). Compared to other health professionals, nurses are often the first to meet with children and families and spend more time with them (Kyle et al., 2013). Despite the fact that the child has an incurable condition, nursing care must continue in order to ensure both the child's comfort and quality of life in order for them to develop as well as possible. Positive treatment outcomes and long-term survival rates for paediatric oncology patients have had a significant impact on the goals and objectives of cancer nursing care for children (Ward et al., 2019). The current focus of paediatric oncology nursing practise is on putting these cooperative treatment protocols into practice, providing the best possible supportive care, informing children and their families about the short and long-term side effects of therapy, and offering psychosocial support throughout treatment to improve overall quality of life during therapy and into survivorship (Landier et al., 2016; Ringnér et al., 2011; Rodgers et al., 2018).

Oncology nurses have a significant influence on the family's ability to survive, cope and evolve throughout the course of the cancer care experience (Hudson et al., 2018). However, without adequate staff management, support, and education, the joint caregiver and patient approach to oncology nursing is unlikely to succeed (Gross et al., 2006; Marcus, 2014). The consequences of not providing caregiver and patient-centred care in oncology and community settings are too costly for the individual and for healthcare services. Caregivers will most likely need clinical care themselves if inadequate support is provided by healthcare professionals during stressful stages along the cancer care journey (Mollica et al., 2017; Sklenarova et al., 2015).

There are ethical requirements for all forms of care from a holistic perspective. Beneficence, justice, non-maleficence, and autonomy are the primary principles (Beauchamp & Childress, 2019). The establishment of a culture of moral respect, which is essential to the success of the treatment, is a responsibility that nurses have by virtue of their obligation to uphold these principles (Foster et al., 2010). It is a nurse's responsibility to be able to comprehend, meet, and appreciate the requirements of children with cancer, a condition that can result in a limited life expectancy, and their families (Stayer, 2012). Understanding cultural and religious practices is necessary for providing care. Throughout the entire time of care, nurses must recognise, understand, respect, and honour cultural ideas, distinctions, and priorities for each child and family (Foster et.al., 2010). Communication with the child and the family can be used to accomplish this.

It is acknowledged that working as a paediatric oncology nurse is difficult because the job entails caring for children who are terminally ill and their families while also having to see children and their families suffer (Adwan, 2014). In addition, stress in paediatric nursing has been linked to managing a significant workload, providing complex treatment regimens, and caring for patients with high levels of acuity (Teng et al., 2010; Vinckx et al., 2018). Meeting suffering family members on a regular basis is seen as being particularly difficult at both the professional and personal levels.

Paediatric oncology nurses are required to perform a variety of roles, including those of care provider, educator, facilitator, translator, supporter, and advocate, adding to their already lengthy list of duties (Pergert et al., 2020; Challinor et al., 2014). The qualified nurse is the first contact of the family, which is as feared and unknown as the hospital setting; therefore, the importance of the relationship between the patient, the nursing team, and the family in the care process includes knowing the family structure, dynamics, and existing and established interactions in the contexts it passes through in order to meet their real needs (Duarte et al., 2012). When family members have progressed from their initial state of shock about the diagnosis, they may need to learn more about the disease. They may be interested in the pathophysiology, treatment, and expected outcome or the prognosis. Caregivers should be asked what questions they have, and verbal explanations and written materials should be provided to clarify their understanding in these areas. Parents may be helpful to caregivers to be contacted with friends, purchase books, or search the Internet for information. Caregivers should be contacted to determine where they gain information and additional resources should be provided where appropriate; in addition, misunderstandings and misinformation need to be addressed (Grochowska et al., 2018; Qingying et al., 2018).

To encourage and instil hope amongst patients and caregivers, a paediatric nurse who exhibits honesty and transparent communication is important (Offen, 2015). Supportive, individualised, solace-filled, and healing care should be provided (Brimble et al., 2019; Mojen et al., 2018; Wheeler, 2016). Important components of healing include spending time with children and families, hearing their stories, and having open conversations. Children and families may have the chance to express their thoughts and feelings and form connections through such engagement.

Building therapeutic relationships and delivering holistic care are the cornerstones of the multidimensional, difficult area of practise of cancer care, which calls for nursing skills (Hammer et al., 2019). Professional communication, care management, altruism, and expertise have been listed as characteristics of paediatric nursing care (Alavi et al., 2015). The literature highlights the importance of developing positive interactions with nurses for young children’s health and well-being (Björk et al., 2006; Enskär et al., 2015). Thanks to a positive nursing connection, parents of children with cancer occasionally feel optimistic about their child’s prognosis and chances of survival (Ångström-Brännström et al., 2010). Good interactions between nurses and the children and their parents in a paediatric ward help children and their parents feel more comfortable (Ångström-Brännström et al., 2017). Additional training in interpersonal communication for nurses might help them feel more confident about their jobs, which will boost their ability to provide nursing care (Pergert et al., 2016). Given the chance for ongoing learning and introspection, nurses may feel satisfied with their ability to meet the needs of children and families and provide high-quality care (Enskär, 2012).

As the primary hands-on providers of oncologic care for children, nurses need to adapt to several supporting abilities. While their child is battling a life-threatening illness, parents may look to nurses for solace. They want to work together to “fight together” for the child’s survival in a relationship that is centred on optimism (Conway et al., 2017; Mooney-Doyle et al., 2014). Nurses must give the sick child developmentally appropriate advice, elicit the patient’s and family’s concerns and needs, engage in discussions about the goals of care, and mediate any conflicts that may develop between the family and the multidisciplinary cancer team in order to provide therapeutic communication. Nurses can improve the ability of children and families to cope with life with cancer and the challenges posed by invasive and distressing treatments by providing family-centred and child-centred care (Boden, 2023).

1.4.2 Why do I think it is important to take an active role in research?

Research is defined as “A systematic investigation with the goal of generating new knowledge or validating and improving already existing knowledge.” (Burns et al., 2009, p.2). The nursing profession is dedicated to producing new knowledge that guides their work and confirms best practices in healthcare delivery. Since they provide direct and ongoing care to people, families, and communities, nurses are in a strong position to come up with research questions. For example, I have worked as a nurse in many different clinics and interacted with many different patient populations. I have had the chance to observe each person I care for. Our observations can lead to the creation of new knowledge. It was determined via further examination that this is a global phenomenon (Smithells et al., 2009).

Health promotion, risk reduction, acute and chronic care settings, school health, and palliative care for terminally ill patients receiving care at home or in a hospice are just a few of the many contexts in which nursing care is provided. Community members, such as those living in rural or isolated locations or those who are poor, can also be our clients. Like other professionals, nurses must stay up to date on fresh information regarding research-based developing trends and advances in healthcare delivery. Since we care for all kinds of patients, I think that, as nurses, our information should be up- to- date so that we can provide the best care to the patient. The professions have become more aware of the necessity for clinical practice to be supported by research, which has led to an expansion of knowledge about nursing practise. Evidence-based practice is essential for nurses as well as the nursing profession as it offers a wide variety of benefits: it helps nurses to build their own body of knowledge, minimises the gap between nursing education, research, and practice, standardises nursing practices (Stevens, 2013), and improves clinical patient outcomes, improve the quality of healthcare (Emparanza et al., 2015). As a nurse, I think it is very important to take an active role in research indeed, one of the reasons I wrote this thesis is that I want the results of my research to contribute to the current literature.

1.4.3 Qualitative research and nursing

Since qualitative research aims to better understand human behaviour (Moser & Korstjens, 2017), it must take into account all the contexts in which these factors affect the lives of individuals and families. Qualitative research allows participants to explain how, why, or what they were thinking, feeling, and experiencing at a particular time or during an event of interest. It helps researchers to learn about the experiences of others and grasp the world from their perspective (Austin et al., 2014).

I selected the Interpretative Phenomenological Analysis (IPA) methodology because it acknowledges that gathering and analysing data is an interpretive process for both the participant and the researcher. Studies exploring the experience of illness from the perspectives of both patients and carers have been undertaken using this method since it has been employed in the setting of health research (Smith et al., 2011). IPA has been widely used to explore experiences in the context of cancer (Antoine et al., 2013; Maguire, 2011). It has a lot of potential to be employed in nursing phenomenological research because of its individual focus, which is pertinent to the concept of holism in nursing (Pringle et al., 2011).

Nurses can learn about patients’ preferences through qualitative research, which also produces evidence. Qualitative research can help expand and deepen our understanding of data or the results obtained from quantitative analysis (Tenny et al., 2022). Qualitative research provides rich data to explore a particular research question further, including participants' perceptions, intentions, requirements, and desires (Brayman et al., 2012; Cleland et al., 2017). Quantitative research can gather considerable amount of information about how many people have particular beliefs about their health and medical care, but qualitative research helps us understand why people have these beliefs and how they might affect how they respond to medical care and how it is delivered (in this way, qualitative and quantitative data are frequently complementary) (Austin et al., 2014). Although qualitative research cannot be generalised in the conventional sense, it aids nurses in becoming more receptive to the perspectives of others. Nurses, for instance, can safeguard patient autonomy by comprehending them and preventing them from being reduced to standardised procedures or plans. "Each person we encounter helps [us] discover what is best for [him or her]. The other person, not us, is truly the expert knower of [him- or herself]." says Munhall (2012:42). In addition to providing insights as we support other people's voices and quests for meaning, qualitative nursing research enables us to comprehend the complexity and myriad aspects of a given situation. Therefore, qualitative research is preferred by nurse researchers who wish to focus on the human experience and the processes through which people come to comprehend and interpret their daily environments. An understanding of the human condition in all its manners of expression, can be gained via qualitative study. The end result of a nursing qualitative study should ultimately be to offer us information that we could not have learned from earlier research or a cursory clinical understanding. A good qualitative nursing study, if it has done its job, informs us about a population or experience in a way that is both intriguing and provides opportunities for further practise or research (Thorne, 2020).

Nursing, whose ontological basis is the care of the human person, must learn from approaches that also enable us to perceive it as a philosophy to gain access to the human person, where both "people who receive care" and "people who provide care" are involved. These individuals, who are significantly more than the conceptualised roles they play, are real beings who have been involved in experiences that have had lasting effects (Waldow et al., 2014). In order to provide patients with the finest treatment, nurses want to learn how they have experienced health and healthcare (Berkowitz, 2016). According to Pratt (2012), the phenomenological perspective has considerable significance for nursing research since it enables researchers to comprehend other people's experiences with health.

Phenomenology enables means of conducting research that are congruent with nursing principles and theoretical conceptualisations, according to nurse researchers. A phenomenological framework enables nurses to account for the subjective aspects of human experiences, such as pain, suffering, stress and coping in health and illness, thereby allowing them to consider patients' specific circumstances, cultural backgrounds and personal beliefs (Benner, 2022, 2013; Benner & Wrubel, 1989). The philosophical underpinnings of phenomenology recognise the human experience as a significant source of knowledge, and its methodological approaches enable and even promote the expression of the complexity and depth of human experience (Patton, 2019). Providing high-quality care and having a humane understanding are priorities in nursing. Nurses engage in understanding and validating the full person and their unique experiences in order to understand the depth of their patients. Since phenomenological research considers the values of the individual's experience and their entire being, many nurses are interested in its use a methodological approach (Carel, 2012). As a result, when nurses consider undertaking phenomenological research, they must select the best strategy to ensure the quality of their work (Balls, 2009).

In-depth exploration of parents' experiences, ideas, and worries about raising children with cancer is best pursued through qualitative investigations. Qualitative methodology is particularly helpful to the generation of knowledge about complex processes and to explore phenomena in-depth (Thompson et al., 2020). Recent research (Forinder et al., 2010; Gibbins et al., 2012) has qualitatively studied parenting experiences in relation to life changes in child cancer survivability during and after treatment. To enhance treatment and outcomes for children with cancer, nursing research is crucial (Maru et al., 2013). Participating in nursing research improves nursing practice and produces data on the best ways to provide care for children with cancer. In clinical settings, where novice researchers' primary responsibility is patient care, nursing research might be challenging to adopt. Additionally, when resources are limited in terms of supporting multisite clinical trials, establishing such trials might be difficult. Successful nursing studies can result from paediatric oncology nursing research initiatives that concentrate on cooperative techniques for research implementation (Haugen et al., 2020). While nursing executives look for chances to work together on research projects across various contexts that are focused on improving outcomes for children with cancer, paediatric oncology nurses who are active in research should urge their co-workers to take part.

1.4.4 Paediatric cancer and challenges faced by children with cancer

1.4.4.1 General information about childhood cancer

Cancers that develop between birth and the age of 14 are collectively known as childhood cancers (Bahadur & Hindmarsh, 2000). Children and their families are affected by childhood cancers worldwide, which make up a significant portion of the world's illness burden. Children are now more likely to develop cancer than they were in previous decades (Toledano-Toledano et al., 2021). The World Health Organisation estimates that 100 children are diagnosed with cancer every year for every million children worldwide (Hassanipour et al., 2019). According to estimates from higher-income nations, the overall survival rate is more than 80%, but drops significantly to 20% in low- and middle-income nations (WHO, 2018). Several studies have reported that childhood cancer survivors experience late treatment side effects such as infertility or cognitive impairments (Cherven et al., 2016; Dionisi-Vici et al., 2023), and treatment for childhood cancer can be lengthy and rigorous and can involve chemotherapy, radiation, surgery, and transplants (Gibbins et al., 2012).

1.4.4.2 Challenges faced by children with cancer

Children with cancer experience various comorbid symptoms related to diagnosis and treatment that can profoundly affect their lives (Lewandowska et al., 2021). For their treatment and associated procedures, child patients must make repeated visits, frequently to a local paediatric speciality facility, over the course of anything from several months to several years. Additionally, Tsimicalis et al. (2018) discovered that children with cancer can miss between a few days and several months of school during treatment, typically due to side effects from the treatment, the increased risk of developing infection, and managing conflicting school and treatment schedules. The costs of these absences for the children include poor academic performance and disrupted or distant relationships with peers and classmates, and may last long after the treatment is over. As a result of their illness and its treatment, children can also experience a variety of physical and psychosocial symptoms (Linder et al., 2017; Miller et al., 2011).

Paediatric cancer patients frequently spend weeks or months in the hospital. Since they must miss their regular childhood activities due to such hospitalisation, which usually coincides with significant events, they are more likely to feel alone. Nurses can provide social connections for children that are essential to normal development and better coping skills by customising these events and incorporating them into the hospital setting (Christiansen et al., 2015).

Children with cancer frequently experience long-lasting difficulties with social adaptation due to the physical and emotional side effects of their treatment, as well as the social isolation they experience during it (Gurney et al., 2009; Kirchhoff et al., 2011; Pivetta et al., 2011; Wakimizu et al., 2011). Apart from somatic and mental conditions, the immediate effects of a childhood cancer diagnosis and treatment may include maladaptive coping, missed educational opportunities, isolation or decreased peer interaction and social engagements (Brinkman et al., 2018; Brand et al., 2017). Additionally, having a childhood cancer, enduring physical or mental late effects, or having other unhealthy health conditions may have an impact on social and family life as well as reduce socioeconomic success in later life (Frederiksen et al., 2018; Brinkman et al., 2018).

According to recent research, one in six school-aged children experience bullying (WHO, 2024). Some groups are more likely to experience bullying than others, such as children who identify as gender- or sexually- diverse, young people who live in social isolation, and children who have chronic illnesses or disabilities, such as obesity, food allergies, epilepsy, or craniofacial conditions (Fong et al., 2017; Garnett et al., 2014; Pinquart, 2017). Patients with childhood cancer, and indeed those who have survived it, may also be at risk. Research shows that friends may regard someone with cancer as “different” due to their symptoms and treatment plans (Pinquart, 2017). Moreover, children who suffer hair loss, or disfigurement as a result of surgery, for instance, might not adhere to the group’s aesthetic criteria (Collins et al., 2019).

Children with cancer who have impaired immune systems and who have been socially excluded for a long time because of the risk of infection (such as after a bone marrow transplant) may be particularly at risk. Even in the absence of a COVID-19 pandemic, immune system impairment in children and adolescents undergoing treatment require families to regularly manage infection risks. The pandemic made it even more important to comprehend how families make decisions about continuing treatment, “shielding” (isolation within the home), and going to the hospital (Darlington et al., 2021). When a child has a childhood cancer with a poor prognosis, parents must make difficult treatment choices (Pearson et al., 2022). The reporting on multisystem inflammatory disease in children (PICS, 2020; Whittaker et al., 2020), for example, makes this decision-making even more challenging.

1.4.5 My own role as a paediatric nurse

I had always wanted my career to involve caring for children because I have always admired how nurses interacted with the patients and their families. My friend used to work as a nurse at a paediatric clinic and she told me she felt that their job was extremely rewarding, and that they made a difference to so many vulnerable children and their families, whilst in practice I could see the burden of carers and felt that they were in a unique position in terms of providing support for their children in the course of the difficult process of cancer. This led me to reflect on the challenges faced by carers and parents, and I wanted to explore their experiences further. This has affected how I see the role of the nurse. Instead of assuming that I have to take control in a clinical encounter because I am a qualified nurse, I think it is necessary to listen more to the child and their primary caregivers and to share their experiences. Another clinical observation I made was that the patients and their relatives were most comfortable communicating with nurses. I noticed that when they want to meet with doctors or other health professionals, they usually communicate through nurses. As a nurse, I can say that knowing what the problems of patients and their relatives are, and wanting to build a bridge to enable them to reach the doctors and other health personnel they need, is amongst the factors considered in this study.

1.4.6 Primary caregivers of children with cancer

1.4.6.1 Definition

Carer is defined as “A person of any age, adult or child, who provides unpaid support to a partner, child, relative, or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help” by the Royal College of General Practitioners (RCGP). It can be difficult for a carer to provide end-of-life care for a loved one while also coming to grips with the person's impending passing (Candy et al., 2011). “Family carer” is defined as someone of any age, who, without payment, provides help or support to a family member or friend who would not otherwise be able to manage without their help (Department of Health, 2008). Children with chronic illnesses require more sophisticated care from primary carers in order to maintain their health (Kuo et al., 2011). A child diagnosed with cancer is likely to be cared for by a family member, such as a grandmother, sibling, or parent (Justin et al., 2021; Klassen et al., 2012; Mohammadi et al., 2020; Rosenberg-Yunger et al., 2013).

1.4.6.2. The need for and importance of primary caregivers

Over the years, research on family carers has grown with regard to the setting of cancer, as evidenced by the publication of several systematic reviews on the subject (Kotronoulas et al., 2012; Northfield et al., 2010). According to Ferlay et al. (2020), cancer was the primary cause of roughly 10 million deaths worldwide in 2020. The demand for healthcare and palliative care services has increased as a result of the rising prevalence and mortality of cancer worldwide (Bray et al., 2018). The burden of non-communicable diseases, such as cancer, is rising in low- and middle-income countries (LMICs) (WHO, 2018). According to Tefferi et al. (2015), LMICs will diagnose nearly two-thirds of all new cancer cases by 2035. According to the International Atomic Energy Agency (2019), this will put a tremendous amount of pressure and strain on LMIC health care systems because the majority of these nations are ill-equipped and too poorly organised to handle this growing burden whilst struggling with inadequate budget allocation and scarce resources (Prager et al., 2018).

Cancer remains the leading cause of death in children less than 15 years old in Western Europe (Royal College of Paediatrics and Children and Child Health, 2014). Long-term personal and socioeconomic impacts of treatment still remain substantial, with 20%-40% of childhood cancer survivors suffering major long-term disabilities due to the disease itself and/or its treatment (Grabow et al., 2018). It may share certain characteristics with chronic illness in that it is life-threatening and requires ongoing care through treatment, hospitalisation, and dealing with the side effects of therapy. The caregiving process has a significant negative impact on family carers’ psychological health, which can result in a low level of self-efficacy. As a result, the caregiving role restricts their social, personal, and professional aspirations. Additionally, they lack adequate training in caregiving, which just adds further to their burden (Lewandowska et al., 2020; Toledano-Toledano et al., 2020). Family carers offer patients considerable assistance during the course of their cancer treatment while also juggling a variety of other responsibilities (Kotronoulas et al., 2012; Romito et al., 2013).

Taking on a variety of new roles is necessary when caring for a child with cancer. For example, parents need to engage in nursing tasks, such as making treatment decisions that ensure the best outcomes, providing medicines to children, helping the child cope with the illness, and practical and emotional support whilst maintaining their role as a parents, not only for the child with cancer but any other children as well. Parents who discover their child has cancer must quickly become familiar with a wealth of cancer-specific knowledge and become oriented in the therapeutic environment (Sultan et al., 2016). The family system, including the parents, the child, and the sibling, must endure protracted treatment for months to years (Al Omari et al., 2020).

1.4.7 Experiences of primary caregivers of children with cancer

The caregiving experience is dependent on various factors unique to the individual’s gender, cultural background, relationships, and family roles and, therefore, cannot be predicted. Childhood cancer presents significant challenges not only to the diagnosed child but also to their family members (van Schoors et al., 2019). A cancer diagnosis serves as a substantial source of life stress for both the child and the family, impacting the child’s physical, psychological, and overall quality of life, as well as the family’s psychological and emotional well-being (Thambiraj et al., 2022). Primary caregivers of children diagnosed with cancer are deeply impacted by the diagnosis and the demands of subsequent treatment (Deribe et al., 2023).

1.4.7.1 Burden

A child with cancer is frequently treated as the primary duty of the family, placing a heavy strain on the parents in particular (Dabrowska & Malicka, 2022; Long et al; 2011). Being responsible for a child with cancer comes with a lot of additional responsibilities, which makes it in itself a very difficult responsibility (Hjelmstedt et al., 2021). Parents must take on new responsibilities. According to Kaplan et al. (2013) and Prchal et al. (2012), the sickness is frequently responsible for altering the family’s composition and the dynamics between its members. It is thus vital to rearrange current life and alter routines and family responsibilities. When a child is sick, new requirements arise that might affect all aspects of life (Lewandowska et al., 2020). It is important to note that parents of sick children typically do not get enough help, being effectively left to handle their difficulties on their own. Because of the numerous jobs and responsibilities they must fulfil, they are referred to as concealed patients in the literature (Stenka et al., 2018; Santos et al., 2016).

According to data from other studies, parents may face a variety of challenges as those who are directly responsible for a child’s care and the course of their treatment (Sharp et al., 2020; Compas et al., 2015). They must meet their everyday obligations, which imposes a substantial burden of duty and responsibility on them. They must work in two distinct locations, and in each of them, they must complete particular duties, which can cause overload and exhaustion on both the physical and emotional levels (Stenka et al., 2018). These studies illustrate the burden associated with having a child with cancer.

1.4.7.2 Family problem

Cancer should be regarded as a family disease because it is a major stressor that has an impact on every aspect of family life and places a financial, emotional, and social burden on each family member (Flury et al., 2011; Gibbins et al., 2012; Kent et al., 2016; Long et al., 2014; Willard et al., 2016). When a child is diagnosed with cancer, parents in particular face significant practical and emotional difficulties (Deatrick et al., 2009; MasaDeh et al., 2012; Wiener et al., 2017). Many parents experience feelings of being overwhelmed as a result of the additional obligations and role expectations that come with this life-threatening illness (Bjork et al., 2011; Leow et al., 2014). As the child's primary carer, the mother frequently faces challenging situations on a daily basis (Moreira et al., 2008; McLoone et al., 2013). Additional daily worries, such as giving affection and emotional support and determining how to discipline and raise their sick child in the most appropriate way, compound these new roles (Norberg et al., 2009). In order to balance their parental obligations with treatment requirements and to deal with their child’s retaliatory reactions to new parenting strategies, parents must negotiate their conflicting roles and duties (Kohlsdorf et al., 2012; Williams et al., 2012). These studies clearly demonstrate the impact a child’s cancer has on the entire family.

1.4.7.3 Psychological effect

Children with cancer and their families face a variety of difficulties and experiences. Cancer is unquestionably a painful experience for children. Cancer treatment practices continue to have an effect on patients’ physiological and psychological states even after they had survived the disease itself. When compared to adults, children are less able to adapt to the new, strange environment in which they find themselves. The child is also subjected to treatment that could be painful, and to separation from family members. The presence of family members is very reassuring to children, but also helps both parties to cope better (Mant et al., 2019). When talking about nursing, it is important to remember that the patient’s family and carers play a crucial role in the nursing process. The majority of the children’s family members, including their parents, carers, and siblings, eventually adjust and are able to cope with the cancer scenario (Behzadi, et al., 2018).

The devastating effects of childhood cancer have been further demonstrated by qualitative research that examined carers’ lived experiences throughout the course of treatment. According to some research (Al-Gamal et al., 2019; Clarke et al., 2009; Wilford et al., 2019), the fact that women often take on additional caregiving duties may account for mothers’ higher rates of psychological distress. Children with cancer have a profound effect on mothers’ lives, as Wakefield et al. (2014) observed that mothers’ employment is significantly disrupted both during and after their child receives treatment.

The entire family is impacted by a diagnosis of paediatric cancer, and there are significant psychosocial consequences for family members (Syse et al., 2011; Heath et al., 2006). All family members’ psychosocial functioning may be impacted by a child’s cancer, which is a painful experience (van Schoors et al., 2017). The shock of the diagnosis, ongoing reminders that the child’s life is in danger, and parents’ moral obligation to their offspring can all affect cognition and intensify emotions, which can encourage behaviours that may temporarily ease distress but ultimately result in worse outcomes (Doumit et al., 2017; Ross et al., 2018). Children diagnosed with cancer can cause long-term disruption to a family’s daily routine and necessitate modifications to parental roles and family structures in order to meet the needs of the sick child (Long et al., 2011).

The parents are abruptly confronted with the possibility that their child could die, as well as the potential for severe adverse and late effects from treatment. Parents may be more vulnerable to emotional stress reactions after learning of their child’s diagnosis if they are experiencing feelings of fear and uncertainty as well as high caring demands (Salem et al., 2019). Conflicts within the family may arise as a result of increased caregiving and practical obligations, as well as the psychological strain of having a child with cancer (van Schoors et al., 2017). Furthermore, parents are frequently forced to split up while their child is receiving treatment, with one parent spending time in the hospital and the other staying at home with the child's siblings or attending to work-related commitments (Roser et al., 2019; Kaul et al., 2016).

In families with children with cancer, it has been demonstrated that higher economic strains are linked to worse marital adjustment (Lavi et al., 2018). According to various studies (Bona et al., 2014; Eiser et al., 2007), financial stress is a substantial source of anxiety for parents of children with cancer. Parental anxiety is a result of the family’s financial difficulties, which are brought on by rising expenses and declining household income (Santacroce et al., 2020).

According to several studies (Compas et al., 2015; Sharp et al., 2020), carers of children with cancer are more likely to experience a variety of problems, including higher levels of sadness, anxiety, and posttraumatic stress symptoms. The disruption in family functioning that occurs when carers of cancer patients attempt to change their lifestyles in order to meet the requirements of the child has been linked to increased levels of depression. They are faced with a potentially fatal illness that typically requires prolonged treatment, which carries the danger of unpleasant side effects as well as the possibility of long-term recurrence (Long et al., 2018). The entire family system is impacted, leading to anxiety and changing relationships and communication styles (Thomas et al., 2017). The negative impact of carer load on the carers’ depression symptoms may be mitigated if they feel self-sufficient (Zavagli et al., 2022).

Primary caregivers are frequently terrified and distraught by their child's diagnosis, but they also have the added responsibility of attempting to support them as they go through this trying time (Koch, 2018). Unfortunately, parents are frequently ignored and have nowhere to turn for support when they have their own worries. Cancer patients now have more complex demands than symptom management and therapy monitoring alone; they also require aid with personal care, emotional and psychological support, and financial support (Bajwah et al., 2020). All of these studies demonstrate that having a child with cancer has a significant psychological impact.

1.4.7.4 Financial effect

A diagnosis of paediatric cancer in a child cannot be anticipated by any parent, psychologically or financially (Wakefield et al., 2014; Liu et al., 2020). The seriousness of the diagnosis causes parents to suffer (Bona et al., 2014; Smith et al., 2013), which is exacerbated by the associated financial distress (distress caused by a decline in one’s income (Bestvina et al., 2014) brought on by treatment-related costs (Russell et al., 2016). According to Santacroce et al. (2018), financial distress for 64%–92% of the parents who are impacted starts within six months of the diagnosis and lasts the duration of the illness. Systematic reviews (Santacroce et al., 2018, Tsimicalis as al., 2011, Pelletier et al., 2015) have extensively demonstrated the financial hardship caused by paediatric cancer and the negative consequences it has on parents.

Mothers, especially those who are breadwinners, may also experience financial trauma as a result of conflicts between caring for others and breadwinning (Morton et al., 2013). This could be the result of expensive medical care, healthcare support, or treatment expenditures that are greater than a family’s level of income. It is not unusual for one parent to leave their job to care for a sick child. In most cases, it is the woman who leaves her job or reduces the number of hours she works in order to meet the demands imposed by the child’s illness, which results in a loss of revenue for the family (Institute of Medicine (US) Committee, 2008). Shamsaei et al. (2010) emphasised financial requirements for care and treatment in their research. Numerous studies have shown the existence of financial demands and highly desired support in this area (Roser et al., 2019; Sneha et al., 2017; Warner et al., 2015).

Children’s cancer therapy is costly and resource intensive worldwide (Russell et al., 2013). Family members and carers frequently offer unpaid care, which can lead to job loss, financial difficulty, and poor physical and mental health (Romito et al., 2013). Children of cancer patients typically have poorer health outcomes (Mailhot et al., 2019). According to several research efforts (Hoven et al., 2013; Kelada et al., 2020), treatment-related employment disruptions, such as time off, leaving, or reduced workload, are common among parents of children with cancer. A significant amount of income can be lost as a result of these work interruptions. For families of children with cancer, these losses combined with non-medical out-of-pocket expenses for travel or lodging during the child’s treatment, may lead to severe financial difficulties (Eiser et al., 2007; Tsimicalis et al., 2018; Chan et al., 2019). According to research conducted in the United States with families of children with advanced cancer, these financial hardships caused 15% of such families living below the poverty line (Bona et al., 2014). It is crucial to identify families at risk of poverty since this puts children at risk of suffering from poor health outcomes (Fenn et al., 2014). These studies demonstrate that facing financial challenges is a result of a child's cancer.

1.5 Theoretical framework for the study

The theoretical framework for this study was family systems theory. Generally, family systems theory is concerned with the structure of complex systems, with a particular emphasis on how parts relate to each other and to the whole system. To further build on existing research, the theory was selected as the basis for this dissertation. With this family systems theory approach in mind, this study explored the lived experiences of parents of children with cancer. The following section discusses theoretical frameworks that underpin this thesis: Family systems theory (Bowen, 1950).

1.5.1 Family systems theory

Family systems theory, as developed by Bowen in the 1950s, is a significant theoretical framework that assists in the understanding of positive and negative family adaptations in the survivorship of childhood cancer (Yi, 2009). Bowen’s family systems theory provides a foundation for this study in that the caregiver is an integral part of the family unit who should strive for homeostasis in which they experience a level of optimal quality of life, while still feeling like their family’s quality of life is maintained. Studying the individual caregiver also links back to Bowen’s family systems theory in that the individual must be able to bring a balance and understanding to their own emotions and feelings, while also processing how these variables impact their interactions with family relationships and emotions. Family systems theory is a theoretical framework for viewing the family as an organised system with various connected subsystems, whereby changes in one part of the system result in changes to the others (Cox & Paley, 1997; Guerin & Chabot, 1997; Powers, 1991). Each individual family member interacts with the others within the family unit and with systems outside of the family (Cox & Paley, 1997). Family systems theory aims to understand the human experience within the broader context of the family dynamic (Priest, 2021). The underlying premise of this theory posits that the whole is greater than the sum of its parts, and thus that one family member suffering from an illness will have reverberations throughout the entire family system (Haefner, 2014). According to the family systems approach, cancer can be considered to be an experience that involves the whole family; each family member is interdependent on the others to cope with the disease (Gritti, 2012). Marcus (2012) states that it is imperative to integrate a family systems approach when dealing with families and children affected by childhood cancer. Similarly, participants in my study were affected by their children's diagnoses. The use of a general family-systems perspective is appropriate since children with cancer rely heavily on their families for support during their illness, and childhood cancer tends to have major impacts on all family members.

Family systems are understood to be structured and organised hierarchically (Smith-Acuña, 2011), with subsystems embedded within the overarching family system ‘that are really systems of their own’ (Cox & Paley, 1997: 245). Subsystems may include the couple/parental subsystem, the parent/child subsystem, and the sibling subsystem – along with subsystems involving extended family members and grandparents (Dallos & Draper, 2015). Only by understanding the subsystems can the wider family system be understood, and vice versa, as “any individual family member is inextricably embedded in the larger family system and can never be fully understood independent of the context of that system” (Cox & Paley, 1997: 246). Therefore, a focus on parents/caregivers and the parent/child subsystem has value from a family systems perspective.

The family systems theory is an approach that allows nurses to understand and assess families as an organised whole and/or as individuals within family units who form an interactive and interdependent system (Shajani & Snell, 2019). According to this theory, families are seen as interactive, interdependent, and reactive, where all members construct the characteristics of all parts but simultaneously impact everyone as a separate entity. In

Seligman et al.’s words, “when a deaf child is born into a family, to some extent, everybody is deaf” (2017, p.18).

Family systems approaches can include both the microscopic and macroscopic (Cridland et al., 2014). Macroscopic approaches focus on the ways families interact with other systems such as the community, social groups, and schools, while microscopic approaches relationships within the family such as mother-child, partner, and sibling relationships. This thesis utilises a microscopic approach, considering interactions within the family between the child with cancer and their primary caregiver. The primary purpose of this study is to expand the knowledge regarding caregivers of children with cancer using a family systems perspective.

The main topic of this thesis is to explore the experiences that primary caregivers of children with cancer have. It is unique to look at how primary caregivers deal with the problem of their child being diagnosed with cancer, from the interpretation of both the nurse and the IPA. The issues mentioned in the introduction act as a starting point in framing the reason for undertaking this study.

1.6 Research question

The research question is:

What are primary caregivers’ experiences of caring for a child with cancer?

1.7 Research aims

The purpose of this study is:

1. To explore the experiences of primary caregivers who have a child with cancer

2. To assess the psychosocial challanges faced by primary caregivers of children with cancer

This research could potentially make a unique contribution to healthcare professionals’ understanding of caregivers and adds to the current understanding of primary caregivers’ experiences of having a child with cancer, as it synthesises all the available literature to offer a new and deeper understanding. This study aims to fill the gap in the literature through exploratory qualitative research by delving deeply into the lived realities of the primary carers of cancer patients. To date, no qualitative research has been conducted by a nurse that could provide such an immersion in perceived experiences in the childhood cancer process in the UK. The study will present an exploratory review of events during cancer diagnosis, treatment, and beyond, with a focus on the journey’s lived experience. This study is expected to deepen our understanding of primary carers’ experiences, the inferences they draw about them and their requirements, and how this might influence how supportive healthcare professionals are.

1.8 Summary of chapter

The first chapter introduces the thesis by outlining key topics connected to the study’s context. This chapter provided the titles that highlight the current status of the topics that affect my choice of subject for my doctoral thesis in the literature. The following chapters present the search strategy, methodology, analysis, and findings. This thesis concludes with chapters on discussion and recommendations.

The following chapter is the literature review.

Chapter 2

Literature review

2.1 Introduction

The phenomenon being studied is the experiences of primary caregivers of children with cancer. A scoping review of published research was undertaken to highlight what is known about the subject area and what is missing from the knowledge. This chapter expands on the discussion by offering a review of the current research literature on the phenomenon of main carer experiences with children with cancer. The findings of the scoping review were then used to create the research question. This method was utilised to provide a thorough context for this research on primary carers caring for children with cancer. The purpose of this review was to provide a response to the following literature review question: “What are the experiences of primary caregivers of children with cancer?”

2.2 Procedure

My literature search centred mainly on qualitative studies since they are more relevant to the background and context of the issue being researched. With qualitative research, participants in the different studies would have the opportunity to authentically represent how they view and interpret the phenomena under investigation, rather than being restricted to responding to pre-set questions, which should lead to a greater knowledge of the phenomenon. As a result, I expect that qualitative research would provide information that captures the multifaceted context of the study issue. A qualitative scoping review was conducted.

2.3 Rationale for this scoping review

Undertaking this scoping review allowed for the consideration of a broad scope of the literature on what is currently known about the experiences of primary caregivers of children with cancer, the methods used to interpret them, and the similarities and differences between primary caregivers’ experiences. The most recent systematic review on the experiences of primary caregivers of children with cancer was conducted in 2012 (Gibbins et al., 2012). Therefore, the aim of this scoping review was to examine the current state of evidence on the experiences of primary caregivers of children with cancer, and identify areas for further research. To include current studies in this scoping review, studies conducted between 2010 and 2021 on the experiences of primary caregivers of children with cancer were included. Since this study will analyse the experiences of primary caregivers of children with cancer living in the United Kingdom using a qualitative method, qualitative studies on this subject were included within the scope of the literature review. In this way, similarities and differences between the experiences of primary caregivers in studies in the literature and the experiences of primary caregivers in this study can be determined. The findings of this review may highlight how qualitative methods have been used in implementation research to date, including those methods which are commonly used in studies of primary caregivers' experiences. The purpose of this scoping review protocol is to systematically map and explore the literature and experience of primary caregivers of children with cancer.

The goal of qualitative research is to gain comprehensive knowledge of human behaviour, emotion, attitudes, and experiences. According to Austin et al. (2014), the integration of data from a number of qualitative research efforts can reveal the breadth and depth of participant meanings, experiences, and viewpoints in various healthcare situations. Syntheses of qualitative research can bring together data from various contexts, produce fresh theoretical or conceptual frameworks, identify research gaps, guide the development of primary studies, and offer support for the development, implementation, and evaluation of health interventions (Tong et al., 2012; Flemming, 2010). According to Brown et al. (2013), qualitative study synthesis is acknowledged as a valuable contribution to the creation of evidence and policy. Understanding individuals' experiences can be improved by knowledge gleaned through qualitative data (Aromataris et al., 2017). When there is limited prior information, qualitative evidence is required because it allows the complexity of phenomena to be examined holistically (Pearson et al., 2011).

The World Health Organisation (WHO) estimates that 400,000 children worldwide between the ages of 0 and 19 years suffer from various forms of cancer each year (WHO, 2021). According to van Schoors et al. (2019), around 300,000 children worldwide receive a cancer diagnosis. Leukaemia and malignant neoplasms of the brain were the most frequent malignancies in children in 2016, accounting for 50.8% of all paediatric cancers (Office for National Statistics UK, 2015). Cancer continues to be the greatest cause of disease-related mortality amongst children (Siegel et al., 2018) despite advancements in therapy. Over the last 20 years, advances in cancer treatment have raised children's cancer survival rates, and the average five-year survival rate is currently nearing 80% (Trama et al., 2016). Each year, an estimated 1,600 children (aged 0-14 years) are diagnosed with cancer in the United Kingdom (Cancer Research UK, 2018).

Caring for a child is a natural characteristic of a parent. When a child is diagnosed with a life-threatening condition, the nature of the parental care role shifts (Pishkuhi et al., 2018). Cancer treatment regimens, associated visits, and waiting periods can all contribute to the disruptive impact on a child’s and family’s daily lives (Davies & O’Connor, 2023; Long et al., 2011). When a child is given a cancer diagnosis, a process known as psychological stress may begin. This process can cause long-term disruption to the family’s lives (Hovén et al., 2017).

A child’s life, as well as the lives of their primary carers, are significantly impacted by a cancer diagnosis. Family members must endure many challenges such as immediate distress, uncertainty, worry, sadness, post-traumatic stress symptoms, fatigue, and below-average quality of life, both when faced with their child’s diagnosis and at other critical moments throughout the subsequent treatment (Long et al., 2018; Remedios et al., 2015; van der Geest et al., 2014; Wakefield et al., 2013). The pressures of the circumstance might be difficult for some primary carers to manage (Bigalke, 2015). In addition to frequently finding it difficult to concentrate on their child’s suffering, the primary carers may feel exhausted, trapped, and isolated (Boufkhed et al., 2023; Enskär et al., 2011; Gibbins et al., 2012).

A child's cancer diagnosis is a major cause of stress that has an impact on numerous aspects of their main caregiver’s life, including physiology, self-concept, role function, and dependency (Roy, 2011). Some family members have mentioned the loss of career possibilities, lower income, and the loss of savings (Alves et al., 2013; Cohen, 2014; Fletcher et al., 2010). The primary carers of the children have frequently stated in several studies (Doumit et al. 2017; Syse et al., 2011) that the prolonged hospitalisation of their children leads to a lot of psychological issues, both for the patient and their carer. In conclusion, prior research has revealed that these parents frequently experience negative changes to their health, and it is thus crucial to further study and research the experiences of primary caregivers who have children with cancer.

Ghufran et al. (2014) found that mothers’ rates of depression were high; 78% of mothers were given a diagnosis of depression while their children were receiving cancer treatments. They had intense negative feelings, such as shock, anger, and fear about the diseases and prognoses, and they were distressed when they had to watch their children endure treatment and the associated adverse effects (Ljungman et al., 2016).

The socioeconomic burden of cancer and the increasing and more expensive methods of treatment have been documented in several research efforts. According to a number of parents (Syse et al., 2011; Rodriguez et al., 2012; Compas et al., 2015), they have lost their savings, seen reduced incomes, and have had fewer work options. Additionally, parents frequently report that the effects of prolonged child hospitalisation might result in mental health problems for both the patient and the family (Atout et al., 2021; Doumit et al., 2017; Syse et al., 2011). It should also be noted, though, that researchers have discovered that, despite the fact that caring for children with cancer typically has negative effects, there are also good effects (Hensler et al., 2013; Phipps et al., 2015).

This scoping review aims to guide future research and improve the support for primary caregivers by raising awareness of their experiences and clarifying the support they value and need. Therefore, a scoping review was chosen to develop and disseminate a broad understanding of the current state of the literature regarding the experiences of primary caregivers with children diagnosed with cancer.

2.4 Method

An iterative procedure for conducting a literature review called a scoping review enables evidence to be synthesised with the goal of presenting a comprehensive overview of the state of the art in research on a particular issue. To shed light on the literature on this topic, we conducted a scoping review using the Arskey and O'Malley (2005) methodology. A scoping review “helps to map rapidly the key concepts underpinning a research area, as well as the main sources and types of evidence available, and can be undertaken as standalone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before” (Mays et al., 2001:194). Instead of synthesising and aggregating findings as in a systematic review, scoping reviews can assist in the generation of hypotheses and chart available data according to significant themes (Arskey et al., 2005; Tricco et al., 2016). In contrast to a quantitative approach, a qualitative study methodology would be more appropriate since it would actively engage with the data to uncover fresh information on the ways in which each parent creates meaning in their own unique setting. According to Seers (2012), findings from primary qualitative research can contribute to a better understanding of a subject field through a qualitative synthesis. Because of this, my study will only incorporate qualitative articles. The scoping review technique was chosen because it attempts to map the essential ideas underlying a study subject and to clarify the working definitions of a given topic (Peters et al., 2015).

The scoping review design enables the discovery of extensive and varied results across a wide range of disciplines (Daudt et al., 2013). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Page et al., 2021) reporting criteria were used for this scoping study, which adhered to Arksey and O’Malley’s (2005) framework for scoping research.

The methodology developed by Arksey and O’Malley (2005) allowed for a thorough scoping review process to encourage transparency and enabled replication of the search technique, which improved the reliability of the results (Phillips et al., 2014). Six methodological stages are described by the approach: (1) identification of the research question, (2) identification of relevant studies, (3) selection of studies, (4) extracting and charting the results, (5) collating, summarising and reporting the results and (6) consultation with stakeholders (optional).

2.4.1 Step 1: identifying the research question and purpose

In this scoping review, the following question has been addressed: What is known from the available qualitative literature about the exploring parental experiences of having a child with cancer? The aim of this review is to understand primary caregivers' experiences of services used by their child with cancer.

2.4.2 Step 2: identifying relevant studies

In collaboration with a medical librarian, I developed a search method to find a complete list of the literature pertinent to parents' experiences of having a child with cancer. When performing the electronic search of the literature, the following databases were systematically searched with the goal of retrieving papers published in peer-reviewed scientific journals: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus via EBSCO, PubMed, Embase via OvidSP, Scopus, and PsycINFO via OvidSP.

I retrieved all journal papers published in English starting from 2010 (1 January 2010 to 1 December 2021). In each electronic database, I utilised the following search keywords relating to the experiences of main carers of children with cancer, in various combinations, while employing controlled language using the Boolean operators AND and OR.

The basic search terms used:

1. ((“Caregivers“ OR “family“ OR “fathers“ OR “mothers“ OR “legal guardian“ OR “guardian“ OR “carer“)) AND ((“paediatric“ OR “child“ OR “childhood“)) AND ((“neoplasm“ OR “cancer“)) AND ((“qualitative“))

Additionally, I checked all identified studies' and reviews' reference lists for any relevant publications.

2.4.3 Step 3: study selection

The search results and research selection procedure are shown in the PRISMA flow diagram (Page et al., 2021) (see Fig. 2.1). Inclusion and exclusion criteria were established to determine potentially eligible studies fit for the purpose of this scoping review. The inclusion criteria are studies that focus on: (1) evaluation of the experiences of primary caregivers living with childhood cancer; (2) study populations of adults (18 years of age and older) who were primary caregivers (fathers, mothers, legal guardians); (3) studies using including qualitative studies; (4) studies conducted after 2010; and (5) studies that were published in English. Research protocols, quantitative studies,letters, comments, conference abstracts, editorials, commentaries and grey literature were excluded.

Duplicates were removed after entering the chosen studies in the EndNote programme. Then, my primary supervisor and I examined the titles and abstracts of the papers separately to determine their relevance to the research questions. When the relevance of the research could not be determined based on its abstract, the whole text of the study was studied. The following stage involved obtaining and reviewing the whole texts of the studies that met the inclusion and exclusion criteria in order to make a judgement.

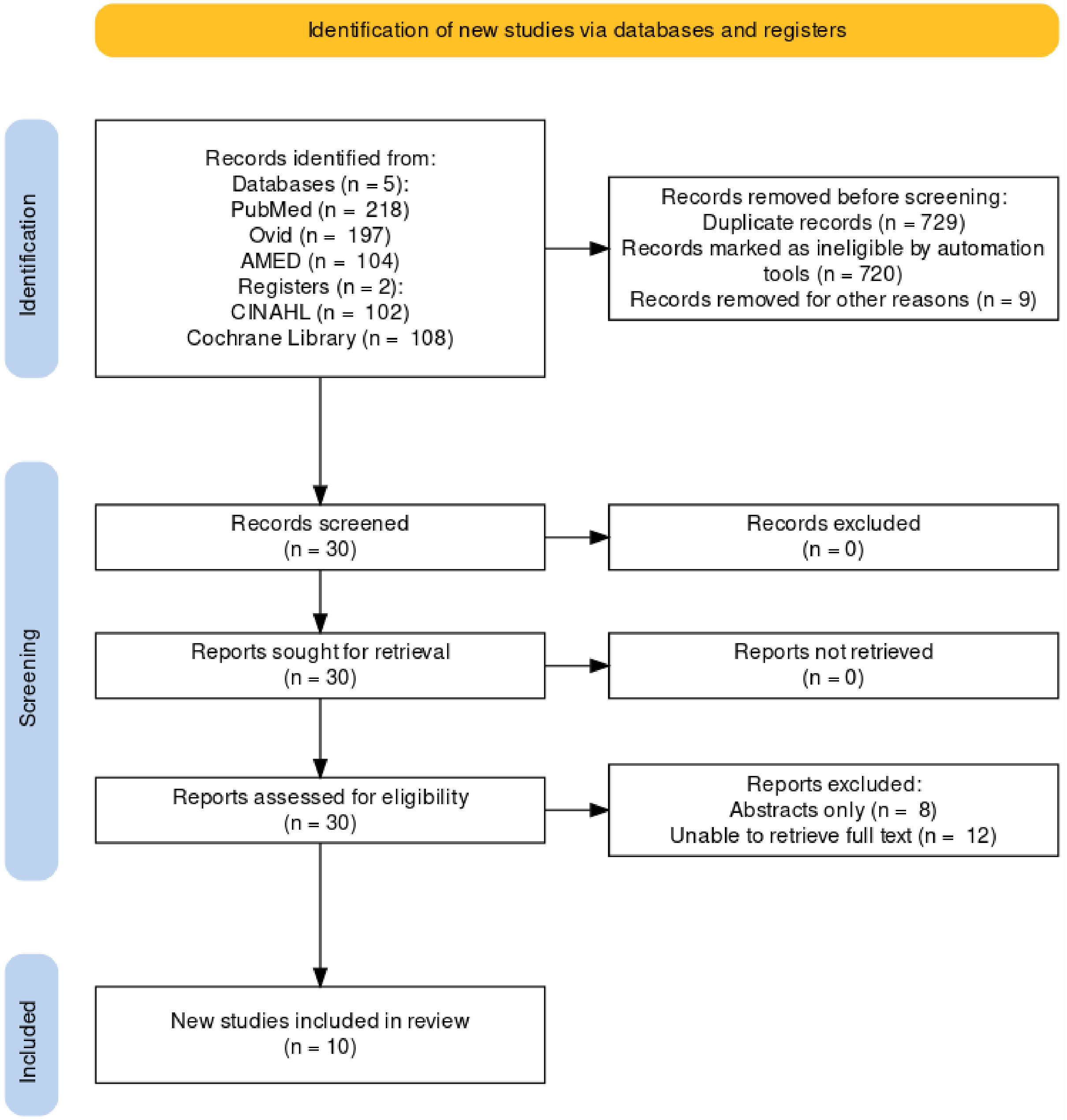


Figure 1.1 PRISMA: flow diagram of study selection process

2.4.4 Step 4: charting the data

At this stage, all the articles that meet the criteria for inclusion were summarised. According to the literature, the main goal of data extraction is to document the features of the included studies and important details pertinent to the review questions (Peters et al., 2015). I created a data chart based on the data extraction framework. The data chart was created using the general information and the qualitative conclusions of the included studies.

General information that will be included in this table includes: a description of study characteristics (eg, authors, year of publication, country of origin, methodology, sample size/setting, and primary research objective). The characteristics of studies included in the scoping review are reported in Table 1.

Authors/Year	Country	Study participants	Methods	Objective
Moridi et al., (2018)	Iran	20 mothers and 4 fathers (n = 24)	Qualitative methodology analysed through Benner's thematic analysis	To explain parents' experiences of childhood cancer.
Demirtepe-Saygılı et al., (2018)	Türkiye	Twenty parents (15 mothers, 5 fathers) (n = 20)	Qualitative methodology of the current study is based on Interpretative Phenomenological Analysis (IPA).	To examine the affective experiences of the parents of children with cancer qualitatively.
Pishkuhi et al., (2018)	Iran	13 parents (n = 13)	Qualitative research with phenomenological approach analysed via the Colizzi method	To clear the feelings of parents who experience the phenomenon of caring a child with cancer.
Tan et al., (2019)	Singapore	10 mothers (n = 10)	Descriptive qualitative study	To explore caregiving mothers' experiences within the active treatment phase of their children/adolescents diagnosed with cancer.
Beddard et al., (2019)	United Kingdom	Eleven parents (10 mothers, 1 fathers) (n = 11)	Qualitative study	To explore the lived experience of parents with childrenmwho have had retinoblastoma.
Khoury et al.,	Lebanon	12 parents (10	Heideggerian	To explore the

(2013)		mothers and 2 father) (n = 12)	interpretive phenomenological approach	experiences of Lebanese families living with a child with cancer.
Schweitzer et al., (2012)	Australia	11 parents (9 mothers and 2 fathers) (n = 11)	Interpretive Phenomenological Analysis	To explore the experiences of parents who have a child with cancer.
Taleghani et al., (2012)	Iran	15 parents (11 mothers and 4 fathers) (n=15)	Hermeneutic phenomenological study	To describe the lived experiences of parents of children diagnosed with cancer in Iran.
Ataout et al., (2021)	Palestine	14 family carers (9 mothers, 5 grandmothers and fathers) (n = 14)	Interpretative Phenomenological Analysis (IPA)	To explore the lived experiences of family carers in the care of children with cancer.
Benedetti et al., (2014)	Brazil	13 parents (5 fathers and 8 mothers) (n = 13)	Heideggerian interpretive phenomenological approach	To understand the experiences of parents of children and adolescents with cancer undergoing treatment.

Table 1. Characteristics of studies included in the scoping review

2.4.5 Step 5: collating, summarising, and reporting the results

To offer a summary of the gathered data, the extracted data will be summarised. The results are summarised and published in a descriptive manner, as is typical of many scoping reviews, because the study techniques used varied widely (Pham et al., 2014). A quality appraisal was not performed for the included articles because this is not typical for scoping reviews (Arksey and O'Malley, 2005).

2.4.6 Step 6: consultation

Arksey and O'Malley's scoping review process consists of five stages. However, Arksey and O'Malley suggest that including the perspectives of stakeholders such as practitioners and consumers might help to improve the results' application (Arksey et al., 2005). The consultation exercise was an optional sixth stage that could potentially "inform and validate findings from the main scoping review" (Arksey et al., 2005: 23).

Levac et al., (2010) highly recommend the inclusion of stakeholders in the review process and having them review the findings. This ensures that relevant literature is not overlooked, and the findings are meaningful to the relevant stakeholders. Stakeholder engagement may improve the relevance of research questions, increase the transparency of research activities, and accelerate the adoption of evidence into practice (Roehr, 2010). Further, patient and public involvement could increase understanding of issues that surround and modify effectiveness, such as acceptability, equity and efficiency (Anderson et al., 2013).

It is important to note that Arksey and O'Malley (2005) described the design of a scoping 'study', not simply the design of a scoping 'review'. Their study design was in effect a mixed-methods design involving a literature study (the scoping review) and an interview study (the consultation exercise), and for which argued that the consultation exercise could create 'added value' to both the literature study and the findings of the overall scoping study (p. 29). However, it remains unclear as to when and how to consult with stakeholders and how to integrate information from the consultation exercise with the review findings in the overall study (Buus et al., 2022).

Buus et al. (2022) showed that there is no widely accepted consensus on how to approach and report a consultation exercise in the sample of scoping reviews. Furthermore, this research shows that there was significant variation in the design of consultation exercises and the stakeholders selected for them. This study also notes that there was no general agreement about who was qualified to act as a stakeholder consultant. Although involving stakeholders in the review process is recommended and increases understanding of issues surrounding and changing effectiveness, such as acceptability, equity, and efficiency.

2.5 Results

My search resulted in a total of 729 studies. Abstract and title screening removed 690 non-relevant articles, and full-text review removed an additional 20, nine of which were duplicate studies, resulting in 10 retained studies. For the remaining 10 articles meeting the inclusion criteria, the full-text versions were then obtained. The studies included in our review were published between 2010 and 2021.

Overview of included studies

The most common study design was interpretative phenomenological analysis (n = 3) followed by thematic analysis (n = 2), Heideggerian interpretive phenomenological approach (n=2), qualitative research with phenomenological approach analysed using the Colizzi method (n=1) and descriptive qualitative study (n = 2). Studies originated from eight different countries in Iran (n=3) and the UK, Palestine, Singapore, Lebanon, Australia, Brazil and Türkiye (all n = 1). A total of 101 parents took part in these studies. Table 1 presents an overview of the study characteristics. The findings from the studies were explored, and superordinate themes were identified using Interpretative Phenomenological Analysis. The themes emerging from these studies were: An Emotional Rollercoaster; Financial Burden; Pivotal Moment; The Effect on Relationships and Valuable Experience. These are reported in Table 2.

Superordinate themes
Theme 1. An Emotional Rollercoaster
Theme 2. Financial burden
Theme 3. Pivotal Moment
Theme 4. The Effect on Relationships
Theme 5. Valuable Experience

Table 2. Superordinate themes

2.5.1 Theme 1: An emotional rollercoaster

The theme of “An Emotional Rollercoaster” perfectly expresses the constant emotional anguish that parents go through. Nine articles identified themes that explicitly linked emotions, psychological distress, and the uncertainty of what is to come (Atout et al., 2021; Beddard et al., 2019; Benedetti et al., 2014; Demirtepe-Saygılı et al., 2018; Khoury et al., 2013; Pishkuhi et al., 2018; Schweitzer et al., 2012; Taleghani et al., 2012; Tan et al., 2019). Primary caregivers reported that they experienced various emotional reactions during their child’s illness and treatment, such as being so shocked by the news it felt as though it had winded them (Beddard et al., 2019).

The feeling of not being able to do anything to help their child leaves them feeling scared. Usually it is the primary caregiver that protects the child, however, in this situation they feel helpless. Mother’s in particular reported that when they learned about the cancer diagnosis they experienced so many emotions it was difficult to describe exactly how it felt. The primary caregiver’s reaction after learning of the cancer diagnosis was “shocked” and they frequently did not even know how to react (Tan et al., 2019). Other primary caregivers also reported that seeing their children as unhealthy and observing painful procedures often caused them distress (Demirtepe-Saygili et al., 2018). These interviews with primary caregivers captured an initial sense of grief, shock, and fear (Taleghani et al., 2012; Tan et al., 2019; Moridi et al., 2017; Demirtepe-Saygılı et al., 2018; Beddard et al., 2019; Tan et al., 2019; Khoury et al., 2013; Schweitzer et al., 2011).

Beddard et al. (2019) and Tan et al. (2019) noted that most of the participants in their studies emphasised that the symptoms such as shock in the first stage had passed by later in the process, and stated that they reached the point of acceptance. After the initial shock, most parents found acceptance, with some even viewing the situation as fate (Taleghani et al., 2012; Tan et al., 2019). Caregivers feel that their children’s cancer diagnosis is a test for them, and they should accept it because they think that it is destined to be (Tan et al., 2019). According to Talenghani et al. (2012), this coping method is prevalent in certain cultures; for instance, in Iranian culture, a person's capacity to deal with a condition like cancer depends heavily on their religious beliefs and cultural background. One caregiver emphasised that she/he was afraid of the future and was going through a big test by God (Talenghani et al., 2012).

Primary carers highlighted their anxiety about the future and how this uncertainty affected their well-being (Khoury et al., 2013; Tan et al., 2019). The uncertainty surrounding the diagnosis and therapy left parents feeling powerless (Khoury et al., 2013; Tan et al., 2019). Moreover, primary caregivers described this process as “indefinite” because the drugs their children take as part of their for cancer treatment may have other significant side effects, and further that their children may be diagnosed with cancer again. Several primary carers in families reported having difficulties caring for their children, who were described as nervous, irritated, and difficult to approach. After taking their medicine, the children, in the opinion of the carers, would speak violently and aggressively to the treatment team and their parents (Atout et al., 2021).

This theme encompasses the feelings of grief, stress, shock, hope, fear, anxiety, and uncertainty. As seen by the thorough and insightful descriptions of primary caregivers in this study, having a child with a life-threatening disease like cancer can have a huge effect on the parent’s lives. The emotional rollercoaster has an effect on the mental health and wellbeing on the parents, which they feel they must conceal for the child’s sake.

2.5.2 Theme 2: Financial burden

The theme “financial burden” was reported in five of the identified studies (Khoury et al., 2013; Pishkuhi et al., 2018; Schweitzer et al., 2012; Taleghani et al., 2012; Tan et al., 2019). Burdens were mainly described as financial burdens and added responsibilities. In addition, parents and family have to bear indirect expenses like shorter working hours, which result in lower incomes, loss of livelihood, and loss of employment chances. Many parents reduced working hours to care for their child (Pishkuhi et al., 2018). Finances were a strain on primary caregivers because of expensive treatment fees, the imbalance between income and expenses, and reduced time spent at work (Khoury et al., 2013; Pishkuhi et al., 2018; Tan et al., 2019). Quotes from Khoury et al.’s study (2013) show how quickly their lives can change and the impact this financial burden can have on the entire family. Along with this, primary carers also explained how the decrease in their income unfavourably corresponded with the increasing costs associated with the child's condition (Khoury et al., 2013).

The mis-match between a falling income and growing expenses was a cause of continuing stress for families. Even if the primary caregivers had insurance to cover medical or other related costs, their general disposable income levels still decreased. This was also dependant on country-specific rules around cost implications for medical treatment, as some had higher costs associated with them than others. However, it was clear that the decrease in work impacted the majority of the primary caregivers in the studies (Tan et al., 2019).

Financial burdens were associated with distress, financial burden, and persistent thoughts about finances. The reasons for the financial difficulties were high costs of treatment, medical supplies, or when one of the parents had to leave their job to care for their child with cancer, according to the study participants. Although the financial and work situations were not the same for all the families, the diagnosis of cancer affected every family to some extent.

2.5.3 Theme 3: Pivotal moment

Five studies commented on the “pivotal moment” (Beddard et al., 2019; Benedetti et al., 2014; Khoury et al., 2013; Moridi et al., 2018; Schweitzer et al., 2012). Primary caregivers’ experiences in response to the pivotal moment of diagnosis in the studies were both profound and personal. Primary carers reacted differently, varying from shock and deep sadness to denial. Not only is the sick child is affected by the diagnosis, the entire family is, especially the mother and father. According to Beddard et al. (2019) and Moridi et al. (2018), a typical reaction was a lack of understanding as to why a child had been diagnosed with what was frequently thought to be a fatal ailment.

Primary carers2 stories frequently began by describing a pattern of recognising symptoms, seeking assistance, and then discovering that primary care providers were unable to offer a diagnosis. Parents reported being initially shocked (Beddard et al., 2019; Benedetti et al., 2014; Khoury et al., 2013; Schweitzer et al., 2012). Some primary caregivers experienced an overwhelming sense of helplessness (Khoury et al., 2013). Primary carers expressed great anxiety at this time, which they attributed in part to their feelings of being unprepared for the diagnosis (Schweitzer et al., 2012). Some of the primary caregivers pointed out their sense of helplessness and uselessness when they became aware of their child’s cancer (Moridi et al., 2018; Schweitzer et al., 2012).

Primary caregivers talked about the how they felt when they thought of the potentially fatal consequences of cancer. The life-threatening nature of the disease, especially the feeling of imminent death and their child’s near-death after their diagnoses with cancer, were among the top concerns and expressed by primary caregivers. Primary caregivers, generally, experienced the possibility of their child’s death as a profound and life-changing experience.

2.5.4 Theme 4: Effect on relationships

Seven articles identified themes explicitly linked to the effect on relationships, namely the importance of support and spiritual practices (Atout et al., 2021; Beddard et al., 2019; Khoury et al., 2013; Moridi et al., 2018; Pishkuhi et al., 2018; Schweitzer et al., 2012; Tan et al., 2019). Cancer may put a lot of demands on parents and lead to stress, which can drastically change the dynamics of the family. Parental relationships change in the face of a child’s illness. According to several studies (Khoury et al., 2013; Pishkuhi et al., 2018), the condition has been proven to worsen couple conflict in some families and even be the cause of conflict between them in some cases. Despite the numerous negatives, several parents felt their bond was enhanced as a result of the experience (Khoury et al., 2013, Pishkuhi et al., 2018).

Parental relationships often change in the face of a child’s illness. In some studies, primary caregivers stated that the child’s illness made them feel closer to each other and the relationships with their spouses also strengthened. They stated that their relationship was better than before the cancer diagnosis (Atout et al., 2021; Moridi et al., 2018). However, most of the changes were perceived as negative by the parents. Parents felt more nervous (Khoury et al., 2013; Pishkuhi et al., 2018). Participants stated that having these feelings caused the relationship between the couples to deteriorate and that problems arose between them.

Caregivers in these studies also emphasised that a cancer diagnosis had a negative impact on their relationships. Most parents in Atout et al.'s (2021) and Moridi's (2018) studies acknowledged that having a child with cancer led to them experiencing a lot of difficulties in several areas of their lives. They stated that they had difficulties due to issues such as families staying away from their homes and taking care of the child who needed to stay at home.

Most of the parents who participated in Schweitzer et al.'s study (2012) agreed that their child's cancer led to them facing various problems in different areas of life, such as housework, family life, and the inability to care for other children. Being away from home and living with their children for extended times had an impact on their numerous responsibilities. Parents who participated in the research considered the support they received to be a significant aspect of their experience. Some parents spoke positively about the emotional and practical support they received from friends and family (Beddard et al., 2019; Schweitzer et al., 2012; Tan et al., 2019). The emotional support that parents received from friends and relatives was reported to be helpful; the majority stated it was a satisfying experience to have other people's support.

Parents stated that their friends' support helped them both emotionally and practically, helping them through difficult times. While some parents gained support from their family and friends, others said that their child's sickness distanced them to the point that connections were negatively affected in the long term (Beddard et al., 2019; Taleghani et al., 2012; Tan et al., 2019). Some felt that support was insensitive. Parents said it was difficult to talk about their experiences with their friends and relatives (Beddard et al., 2019). Participants in another study stated that their friends wanted to help, but they caused more fatigue than help because they could not fully grasp the situation they were in (Tan et al., 2019). Spiritual practices gave parents the sense that they were doing something to assist their child's recovery. Some participants reported using spiritual practices as a kind of support and coping method (Pishkuhi et al., 2018; Schweitzer et al., 2012; Taleghani et al., 2012; Tan et al., 2019). They stated that their religious views helped them get through the treatment process. According to the families that did have strong belief in God, this was a highly benefical experience (Schweitzer et al., 2012).

Participants in the studies emphasised the importance of the presence of support. They mentioned the support that they received as an important component of their experience. They also stated that religious activities also helped them cope. Spiritual assistance has an influence on the feelings of primary carers. They stated that their religious beliefs helped them get through the treatment process.

2.5.5 Theme 5: Valuable experience

Three articles identified themes explicitly linked to this concept (Demirtepe-Saygılı et al., 2018; Moridi et al., 2018; Schweitzer et al., 2012). Many of the participants in the study by Moridi et al. (2018) noted that this helped them and their children cope with a difficult disease such as cancer, in the face of future challenges. In the study by Demirtepe-Saygili (2018), four of the participants noted a positive connotation to the changes that occurred following the diagnosis, such as realising the value of family unity, organising one’s priorities in life, and growing self-confidence. When a child is diagnosed with a condition that could potentially fatal, like cancer, parents must unavoidably reassess their goals and the way they want to spend their lives, both as a family and individually. In order to continue living as a well-functioning family, parents reevaluated what was crucial or significant to them (Schweitzer et al., 2012). Some participants from Moridi et al.’s (2018) study, which focused on their performance in coping with cancer, noted the fact that being able to get through such a difficult process made them feel stronger. The statements of another primary caregiver emphasised that the diagnosis of cancer was sudden and completely changed their lives (Schweitzer et al., 2012).

Participants in the studies reported that experiencing a cancer process made them mature, and from which they gained different perspectives. They stated that all kinds of situations could happen to them throughout their lives, and that everything changed after a difficult disease process, such as with cancer.

2.6 Discussion

This review's objectives are to comprehend and synthesise the results of qualitative research on the experiences of primary carers of children with cancer. Ten qualitative studies were found to fit the aims of this review, and the findings were collated into five main themes. These themes explored how the caregivers experience is understood in peer-reviewed academic literature between January 2012 and December 2021.

The cancer diagnosis is the start of a journey where a multitude of emotions are felt (Long et al., 2018; Remedios et al., 2015; Schweitzer et al., 2012; van der Geest et al., 2014; Wakefield et al., 2013). According to Schweitzer et al. (2012), parents, when learning of their child’s diagnosis, experienced a degree of shock and concern beyond anything they had ever previously known. Similar to this, Long et al. (2018) found that parents of children with cancer expressed anxiety about their children's health and social development, including concerns that their children would be seen differently from their normally developing peers. According to earlier research, parents of cancer patients reported significant psychological discomfort throughout their child's treatment, including symptoms of depression, anxiety, and posttraumatic stress disorder. According to several studies (Ljungman et al., 2016; Michel et al., 2020; Wikman et al., 2017), a significant proportion of parents express continuous distress, even though the degree to which they experience this lessens with time after receiving the diagnosis. A cancer diagnosis can, however, lead to positive outcomes that improve quality of life, such as prosperity, self-renewal, resilience, and achievement of personal and emotional growth, according to one of the studies found in the literature review (Demirtepe-Saygili et al., 2018; Duran et al., 2013; Rosenberg et al., 2013).

Caregiving for children with life-threatening diseases is difficult and time-consuming, putting enormous stress on many parts of life, including health, relationships, family functioning, socialisation, and financial stability, according to research (Wiener et al., 2016). The findings of this study are consistent with those of a qualitative study conducted by Jadidi et al. (2014), who described parents' complete helplessness and absolute frustration at having to continue living after learning that their child had cancer and that they equated this disease with death. Moreover, they shared the uncertainty brought about by cancer, how scared and helpless they felt for their children, and how stressful and painful the side effects of cancer treatment were. Uncertainty can lead to emotions of worry and concern about the future, including the possibility of a recurrence of an illness, the death of a beloved child, additional challenges, and the possibility that their hopes for a brighter future would be destroyed (Salem et al., 2019; Khoury et al., 2013). Information not only assists parents in terms of reducing their uncertainty and managing their children's and family's risk factors for the condition, but also provides them with a sense of control in an otherwise chaotic situation (Haase et al., 2016; Kerr et al., 2019). One of the key duties of paediatric oncology nursing, ensuring that parents are properly informed about their child's diagnosis and treatment, can make a significant contribution in this regard (Landier et al., 2016).

Trying to care for a child with cancer has far-reaching financial implications. The findings showed working hours were often reduced due to the intensity of the cancer treatment process (Pishkuhi et al., 2013; Russell et al., 2016). Accordingly, they may have lost their jobs, which alongside a potentially costly treatment process, increased their financial difficulties (Bona et al., 2014; Santacroce et al., 2018). Roser et al., (2019) and Santacroce et al. (2018) found that there were significant socioeconomic implications for parents as a result of their child's cancer, including income loss, employment disruption, and increased out-of-pocket spending. Similarly, previous research (Alves et al., 2013; Cohen 2014; Syse et al., 2011) has also found the theme of financial and work issues, especially working hours and the associated, costs of treatment causing financial hardship. Reduced working hours may result in lower family income (Roser et al., 2019). Financial strain occurs within six months of the diagnosis for 64% - 92% of afflicted parents (Bona et al., 2014; Bona et al., 2016) and remains throughout the illness trajectory (Santacroce et al., 2018). In Alves et al.'s (2013) study, half of the carers sought financial assistance from other family members. As a result, it is clear that parents required support and advice from healthcare staff and family members during their child's cancer treatment.

There is no doubt, as Khoury et al. (2013) and Moridi et al. (2018) note, that there is also the fear of that their child might die. According to Jadidi et al. (2014), all participants in their study expressed extreme despair about surviving their children, and because of their negative perspective, as they thought cancer to be synonymous with death, they were reluctant to carry on living themselves. In order for patients and their parents to be able to recover from illness and return to normal life, it is advised that clinics for parental mental therapy be established. Similarities to Altay et al. (2014) and Muskat et al. (2017) were identified, particularly with regard to the requirement for ongoing psychological, emotional, and educational support throughout the duration of the treatment in general and in particular when patients go through different stages of treatment or experience relapse.

Conflicts and issues that caused fractures in relationships were brought on after the child was diagnosed with cancer. However, some parents also felt that their relationship became better and stronger at this point than it had been previously. This review's findings support those of Da Silva et al. (2010), which found both positive and negative changes in the marital relationships of parents whose child had cancer. Although the relationship may suffer as a result of the child's illness, the couple's mutual commitment may be strengthened if trust and offers of support are maintained (Steffen et al., 2006). Cancer's impact on these relationships may lead to more joint activities and a greater appreciation for family support and time spent together. Furthermore, Clarke et al. (2008) reported that parents had ongoing support requirements, suggesting that parents may need help in addressing future consequences for their child following acute treatments. On the same subject, Schweitzer et al. (2012), which I included in the literature review, was also discussed in the study. According to their findings, all parents described the time of diagnosis as the most difficult part of their experience, emphasising the importance of helping parents in responding to their children's needs, facilitating their adaptation, making them feel empowered, and providing emotional and informational support. Support from family, friends, and other parents on the ward was found to be an important factor in a parent's ability to cope (van Schoors et al., 2017). Similarly, Bayat et al. (2008) discovered that when social support for parents of children with cancer increased, their depression, hopelessness, and anxiety decreased.

The synthesised theme, 'Pivotal Moment' addresses that cancer diagnosis was the turning point in the lives of the participants. This theme involves participants talking about their reactions when they learned of their cancer diagnosis; these are helplessness, shock, and denial. As mentioned earlier the potential fatality of cancer causes them to be constantly anxious. This finding is consistent with a previous study by Fletcher (2011), which found that mothers of children with cancer experience this is a traumatic event in their families and suffer from shock and disbelief when the disease is discovered. They are also forced to carry this is an additional burden as a result of the diagnosis.

The ’Valuable Experience’ theme includes the fact that primary caregivers stated that after the diagnosis of cancer, their lives were never the same again and changed completely. According to Moridi et al. (2018), the participants described the changes resulting from cancer therapy and its consequences as a never-ending war against the disease. Regarding this matter, it has been noted in the literature that some parents who are coping with cancer feel that this to be an ongoing struggle and question why the disease has invaded their children’s and their own lives (Angelo et al., 2010). Every parent interviewed by Khoury et al. (2013), in one of the studies covered in this review, noted their journey as a never-ending struggle against cancer and the effects of illness on their family life. Apart from the negative perspective brought about by the cancer diagnosis, there are also studies with participants who attribute a positive meaning to the changes that occur after the diagnosis. This result is in line with a qualitative study of fathers of childhood cancer survivors (Hensler et al., 2013), which suggested that fathers identified benefits in three areas: increased confidence in their ability to meet challenges in the future, a renewal or strengthening of their spiritual connection, and closer relationships with family (wives, children) and close friends. According to Phipps et al. (2015), the majority of parents report experiencing positive changes as a result of their child's cancer diagnosis in terms of their own behaviour, their relationships, and their plans for the future. In a similar way, participants in the studies by Kelada et al. (2020), Peikert et al. (2020), and Tan et al. (2019) highlighted how having a seriously ill child improved their parenting skills and underlined the importance of spending time with their children.

2.7 Conclusion

This scoping review gives a fuller picture of how a diagnosis of cancer impacts an individual as a primary caregivers caring for children and allows us to gain some perspective on primary caregivers’ experiences throughout the trajectory of the disease. This review provides a update on the recent literature on the primary carer experiences of children with cancer.

It can be seen that studies on primary caregivers are generally conducted by psychologists and nurses, and when we look at the studies included in the this scoping review, it is apparent that only one study was completed in the context of the UK, and by psychologists. It is also important to highlight the fact that very few papers on this topic have been completed within the context of the UK, and this gap in the literature base has to be filled.

Therefore, the present study fills this gap through a qualitative analysis of the experiences of a sample of primary caregivers of children with cancer.

As identified through a scoping review, the impact on primary caregivers of living with a child with cancer is considerable (Khoury et al., 2013; Tan et al., 2019; Moridi et al., 2018). The lack of use of theoretical frameworks in studies included in the scoping review was identified as an issue in providing context for continued research in this area to expand our knowledge about primary caregivers' experiences and how best to support them. Only one study mentioned a theory (Khoury et al., 2013), which was the family systems theory.

As mentioned in Chapter 1, the theoretical framework for this study was family systems theory. The implementation of family-centred care in the treatment of children was reported to have a wide range of benefits for both parents and children. There is growing evidence that this is associated with a lower caregiving burden (Crespo et al., 2016), increased child, family, and health providers' satisfaction (Crespo et al., 2016; Phiri et al., 2020), improved parents and child psychosocial health (Coyne et al., 2018; Dix et al., 2013), improved quality of care, improved parent perceived self-efficacy (Salvador et al., 2019) and increased trust (Coyne et al., 2018). In the review (Deribe et al., 2023), parents who have received family-centred care had better mental health and coping mechanisms, positive feelings, improved sleep quality, reduced caregiver burden and fatigue, and improved quality of life.

All primary caregivers are affected in some way by a child's cancer diagnosis. Nurses are the professionals who spend the most time with the patient and family members during the treatment period (Butler et al., 2018). As a nurse, this scoping review was conducted in order to understand the experiences of primary caregivers during the difficult process of cancer and to suggest ways in which healthcare professionals can help families like them in the future. Nurses can reduce uncertainty and promote healthy adaptation by making sure primary carers are informed about their children's treatment plan and the care that goes along with it. These studies clearly demonstrated the difficulty of caring for a child with cancer. The following chapter provides the methodology used to arrive at the findings, as well as the fundamental structure of the phenomena of caring for a child with cancer.

Chapter 3

Methodology

3.1 Introduction

This chapter will provide an exploration of my rationale, the progression from the theoretical underpinnings to my methodological approach, and my choice of paradigm for this research entitled "The Experiences of Primary Caregivers of Children with Cancer". I will also clarify how these choices were interlinked, affecting my selection of research method, choice of participants, the effect on ethical considerations and congruence of the analysis framework utilised in considering the research questions. In order to address my research aims to explore the primary caregivers' lived experiences of their child being diagnosed with cancer I have taken a qualitative approach. The aim of the study is to create insight into what it is like to be a primary caregiver for a child with cancer and make sense of their experiences. This study used interpretative phenomenological analysis, which is informed by phenomenology, hermeneutics, and idiography (Smith, 2011).

The first part of the chapter will begin with the ontology and then continue with the epistemological perspective by explaining the rationale for adopting a qualitative research design. The use of interpretative phenomenological analysis will be justified and discussed. Thereafter, I will discuss the three main theories that guided the research technique for this study: phenomenology, hermeneutics, and the idiographic model of inquiry. It will be argued that IPA is a more appropriate methodology than other methods to address the research questions. The issue of reflection on personal experience will also be covered. I will then describe the study design in some depth, including the sampling method, participant recruitment, and data collection procedure. I will then present ethical considerations relating to this research. The following section of this chapter will also detail the processes I engaged in to generate the themes and codes from the transcribed data, in order to analyse the findings of my research. The chapter will end by discussing with the validity and quality of qualitative research and its contribution to theory.

3.2 Ontology

Ontology is a philosophical concept that refers to how humans interpret their reality in light of the assumptions they have about how they exist in the world (Breakwell et al., 2012). I started by reading the ontological theories that have been identified in the literature to start the inquiry process as suggested by Creswell et al. (2007). When considering ontology as a continuum, a person's position may vary from that of the relativist, who holds the idea that there are several views, perspectives, and realities, to that of the realist, who believes the ideology that there is one objective truth (Willig, 2008).

This research has been positioned within a relativist ontology, according to which there is only one reality, commonly referred to as the "truth". (Levers, 2013). Relativist ontologies, on the other hand, call into question the notion that reality exists in a law-bound and consistent external reality. Relativist ontologies emphasise the variety of interpretations that can be made of what happens in the outer world, which is intertwined with the meaning that individuals construct from their life experiences (Willig, 2013). Taking this ontological perspective into consideration, my research methodology is based on a phenomenological framework. The interpretation of experience is the focus of phenomenology. It is assumed that what is known is gained from personal experience. The goal of the study from a relativist ontological standpoint is to attempt to comprehend how different people perceive reality and the existence of multiple truths (Levers, 2013).

It is critical for researchers to be conscious of their own epistemological viewpoints, since this can help in the identification and clarification of our underlying assumptions about knowing. With regard to my own ideals, epistemological position and aim to provide meaningful data, adopting a qualitative method felt more natural and personally connected to me.

3.3 Epistemological position

Epistemology deals with how knowledge is obtained and whether it is constructed subjectively or obtained objectively through science (Guba et al., 1994; Robson et al., 2016). In general, there are three epistemological positions: positivism, realism, and interpretivism.

According to a positivist position, there is a clear connection between the world (objects, events, and phenomena) and how we see and comprehend it (Willig, 2013, p.4). The goal of theory, according to a positivist perspective, is to produce testable hypotheses (deductivism), which is accomplished by employing an inductive approach to examine social reality using the methods of the natural sciences (Bryman, 2012). In a positivist approach, it is believed that research can produce objective knowledge that is unbiased and impartial, and unaffected by the researcher (Willig, 2013, p.4).

Positivism and realism share similarities in that the realist researcher believes in the existence of an external social reality. But in critical realism, the researcher's conceptualisation is considered a means of comprehending that reality, acknowledging that there is a separation between the things under investigation and the concepts employed to describe, analyse, and account for them (Bryman, 2012).

The last position, interpretivism, holds that objective analysis of the world is impossible; the world is socially created, and hence social phenomena do not exist independently of our understanding of them (Furlong et al., 2010). Accepting that there is no objective reality, this position acknowledges the researcher's role and the double hermeneutic, that is, the researcher incorporates not only the meaning and sense the participant has made of their lived experience, but also the researcher's attempts to interpret and understand how the participant made sense of their experience (Smith et al., 2009). Within this method, qualitative methodologies are adopted to explore how individuals understand the world around them. The methodologies, beliefs, and concepts of interpretivism are similar to many of those of modern nursing (Levers, 2013), including a dedication to patient-centred, holistic, and personalised care (NHS England, 2015b). In the type of information that is valued and sought after, the questions I have attempted to address through my research suggest the need for an interpretivist epistemology.

3.4 Interpretative phenomenological analysis (IPA)

Smith (1997) proposed interpretative phenomenological analysis (IPA) as the most recent iteration of operationalised phenomenology. The exact steps are described by Smith and Osborn (2008). Smith (1999) proposed IPA as a new method for performing qualitative research in health psychology, but it has since been embraced by other disciplines such as counselling, nursing, and education (Hefferon, 2011; Smith, 2011). Its rising popularity is mostly due to the analytic method's nearly prescriptive style, which attracts researchers of all experience levels, especially novices (Larkin, 2006).

IPA is particularly interested in examining how individuals interpret significant life events. Its objective, as suggested by Smith and Larkin (Smith, 2009; Larkin, 2006), is to draw on people's introspective descriptions of what these significant life experiences mean to them. This unique emphasis on meaning was a key factor in choosing IPA over other strategies.

According to Smith et al. (2009), IPA is a methodology for qualitative, experiential, and psychological research that is based on the philosophical ideas of idiography, hermeneutics, and phenomenology. This section summarises what IPA learns from each of these three categories.

3.4.1 Phenomenology

Smith et al. (2009) describe phenomenology as a philosophical approach to the study of experience. The phenomenological philosophy was developed by Husserl (1927), Heidegger (1927), Merleau-Ponty (2013), and Sartre et al. (1956).

Husserl’s emphasis on the analysis of lived experience is shared by IPA. Smith (2009:32), on the other hand, recognises the difficulties to gaining knowledge of the essence of a phenomenon; IPA seeks only to capture the distinct experiences that are experienced by certain persons. In order to obtain to the essence of a phenomenon, Husserlian phenomenology demands that we step away from our daily experience (Smith et al., 2012). Heidegger’s thinking has also had an impact; the IPA holds that humans always build their understanding of the world through their social interactions. Merleau-Ponty likewise advocated a view of the individual as immersed in the environment, but he placed a focus on how our embodiment shapes the way we perceive and interact with the environment (Langdridge, 2013). Finally, from Sartre’s perspective, the concept that the contextual interpretation of events is highly dependent on the existence or absence of people’s interpersonal and social interactions is accepted (Shinebourne, 2011). As a result, this involvement with making sense of human experience includes a “lived process, an unfurling of views and meanings, which are unique to a person's embodied and situated relationship to the world” (Smith, 2009:21). These ideas demonstrate the complexity of “experience” as a lived process, which leads to the development of viewpoints and significance particular to a person's “embodied and situated relationship to the world.” (Smith et al, 2009, p.21).

3.4.2 Hermeneutics

Hermeneutics is described as “an attempt to show the pre-philosophical understanding of humans in the world that is basic to various disciplines so that this understanding can become the basis of philosophical reflection” (Stewart et al., 1990:145). Hermeneutics is the theory of interpretation developed by Schleiermacher (1998), Heidegger (1927), and Gadamer (1992), according to Smith et al. (2009). Hermeneutic (interpretative) phenomenology is a research approach based on Husserl’s descriptive phenomenology (Heidegger, 1982). The phenomenological-hermeneutic method is fundamentally a philosophy of comprehending a specific phenomenon and the scientific interpretation of phenomena occurring in text or the written word (Creswell et al., 2017). Heidegger broadened this to encompass comprehending the phenomena of the world, how we go about knowing the reality offered to people and understanding the being itself (Cohen et al., 2000). The impact of Heidegger on IPA stems from his belief that phenomenology is an inherently hermeneutic activity. Gadamer (1998) viewed hermeneutics as a collaborative process in which meaning is created through a series of readings, writings of reflection, and interpretations. As we go through the phenomenology process, the phenomena can have an impact on our interpretation, which can have an impact on our fore structure, which can then have an impact on our interpretation, and so on (cited in Smith et al, 2009). Schleirmacher viewed interpretation as both grammatical and psychological, and he claimed that while a writer's intentions for a work are distinctive, the meaning of the text is open to interpretation by the reader within a larger context (Smith et al., 2009).

The hermeneutic circle is a basic principle of hermeneutics: a circular approach to viewing information. There is a dynamic link between the part and the whole: to comprehend the part, one must first perceive the entire, and to grasp the whole, one must investigate its unique pieces. The hermeneutic circle alludes to the repetitive aspect of IPA: during the analysis, the researcher swings back and forth in order to conceptualise the data, rather than adopting a linear approach where one phase follows another (Smith, 2009).

3.4.3 Idiography

Idiography is centred on the particular in the sense of how specific occurrences have been interpreted from the perspective of individual people in a specific setting, and it ensures that a study is detailed and in-depth (Eatough et al., 2008). In-depth examination of specific experiences of specific persons in specific circumstances is one of the IPA’s goals. However, from a methodological perspective, the analysis is extensive and in- depth in order to offer the experiences of a small number of participants (Larkin, 2006). Ultimately, it is always possible to go back to the level of the individual for claims made on behalf of the entire group. According to Larkin (2006), when performing IPA research, description and interpretation must always be balanced.

In conclusion, IPA is an inductive methodology based on phenomenology (experience), hermeneutics (interpretation), and idiography (the particular). It has been observed that while addressing research issues, health researchers, particularly nurses, are frequently drawn to interpretative phenomenology (Petrovskaya, 2014b). IPA was chosen because it enables a thorough examination of the ways in which primary carers of children with cancer interpret their specific experiences.

3.5 Qualitative methodology

Qualitative approaches allow researchers to peer deeply into the world of human experience (Guest et al., 2013) and enable in-depth exploration of the meanings people attribute to their experiences (Brookes, 2007; Merriam et al., 2015; Tuffour, 2017). One of the benefits of qualitative approaches is the use of open, exploratory questions that allow for the emergence of unlimited and emergent descriptions, which is especially useful when little is known about a research area or when the topic is highly complex (Anderson, 2010; Elliott et al., 2005); the current study meets both of those requirements. As discussed in Chapters 1 and 2, the research questions and the subjective nature of the data placed this study within the realm of qualitative research.

According to Smith, Flowers, and Larkin (2008:45), quantitative research attempts to assess “what happens at one remove, by inferring mental events from observations of behaviour”. A quantitative approach may have gathered information from a bigger pool of individuals, but the richness of experiences would have been lost. Qualitative research, on the other hand, “tends to focus on meaning, sense-making, and communicative action” (Smith et al., 2009:45).

Having established my ontology and epistemology, this in turn influenced my choice of methodology. As with all research endeavours, choosing the qualitative methodology that was best suited to the line of inquiry was vital to obtain the desired results. All qualitative methodologies vary in their application, dependent on the researcher, the research question, and whether a philosophical theory has been adopted to provide a form of focus. Three methodologies were examined to determine the most appropriate in this instance: Grounded Theory, Thematic Analysis and IPA.

3.5.1 Grounded Theory (GT)

The Grounded Theory (GT) approach uses a systematic and comparative method of analysis to understand the patterns of social processes (actions, behaviours, and interactions) over time to generate a theory (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 2015). GT is regularly regarded as the primary alternative to IPA (Smith et al., 2009) and has been widely employed in health-related/nursing research since Glaser and Strauss (1967). Purposive sampling is used in IPA to recruit participants with rich and diverse experiences of the phenomenon under study (Creswell & Poth, 2018). Likewise, GT also uses purposive sampling in recruiting participants who have varying experiences of a phenomenon in order to explore multiple dimensions of social processes with the aim of theory construction

(Morse & Field, 2013). However, theoretical sampling is additionally employed in GT to seek participants for specific information, which develops the properties of the theoretical categories until no new data emerges (Charmaz, 2014). Neither GT nor IPA prescribes an exact number of participants, as sampling depends on the particular study's goals. While there are similarities between this approach and IPA, GT differs in that explanations are typically based on a larger sample size and is more conceptual and explanatory (Smith et al., 2009).

3.5.2 Thematic Analysis (TA)

Thematic analysis (TA) is the process of identifying patterns or themes within qualitative data (Braun & Clarke, 2006). It is commonly used because of the wide variety of research questions and topics that can be addressed via this method of data analysis (Braun & Clarke, 2012). A further advantage is that it is a method rather than a methodology (Braun & Clarke 2006; Clarke & Braun, 2013). Unlike IPA and Grounded Theory, TA is not tied to a particular epistemological or theoretical perspective, and this makes it a very flexible method (Maguire & Delahunt, 2017). However, criticisms of the approach include limited depth when exploring the subject areas under analysis, a leaning towards unsubstantiated subjective bias relating to in-depth interpretations, and rich description being omitted or unrealised (Vaezi et al., 2015; Braun and Clarke, 2016). Thematic analysis is an appropriate and powerful method to use when seeking to understand a set of experiences, thoughts, or behaviours across a data set (Braun and Clarke, 2012). Since it is designed to search for common or shared meanings, it is less suited to the examination of unique meanings or experiences from a single person or data item (Kiger & Varpio, 2020). Braun and Clarke (2016) recognise that the scope of thematic analysis emphasises description and exploration, with less investment in the interpretative elements that IPA offers. This study aims to use a small sample to explore the rich and detailed experiences of primary caregivers of children with cancer; therefore, it is most appropriately matched to IPA methods and their individual focus (Smith et al., 2009).

3.5.3 Interpretative Phenomenological Analysis (IPA)

I perceived the methodology most congruent with my ontology and epistemology for this research to be IPA. According to Smith et al. (2009), Interpretative Phenomenological Analysis (IPA) has its origins in phenomenology, which focuses on how individuals interpret their experiences. The suggestion is that far from being a passive recipient, people 'interpret and understand their world by formulating their own biographical stories' (Brocki et al., 2006:88) and this helps them to make sense of what is happening to them. The participant's personal account of their experiences is at the heart of IPA, and acceptance of the interplay between the participant's narrative and the interpretation the researcher provides the process is key to the analytical process within IPA. Smith (2012) underlines the necessity for the researcher to strive to understand their own biases, which influence how they engage with data, as well as the relevance of reflexivity. I acknowledge how my own beliefs and values may have an impact on this research study and have sought to be as honest as possible in order to overcome potential personal biases (Roberts, 2013).

3.6 Why choose IPA?

My experience working with children and interacting with parents as a nurse in an oncology clinic led me to want to explore the unique journeys of primary caregivers by allowing me to see that their individual experiences differ from each other; therefore, I decided that IPA was the most appropriate method to both better understand and interpret their individual experiences. This approach allows the subjective nature of experience to be interpreted and understood in depth (Larkin et al., 2011). The appreciation of individual experiences within IPA in identifying both similarities and differences between respondents made this approach preferable to more narrative analytic methods. IPA research explicitly considers the 'interpretation' of an experience (Smith et al., 2009; Spiers & Riley, 2019). Interpretation can be thought about in many ways, one part of this being 'the hermeneutic circle'. The hermeneutic circle can be thought of as an iterative process involving moving between the smaller and larger units of meaning, or between the parts and the whole of the investigated phenomena or lived experience (Smith et al., 2009). This concept allows researchers to engage with their data in a dynamic, non-linear manner, in which the data is thought of as individual parts on their own as well as part of a wider context (Frechette et al., 2020).

The research questions are open and exploratory, focusing on meaning and individuals' understanding of their experiences, aligned with IPA's epistemological position (Smith et al., 2009). In IPA, concepts set the scene rather than provide a prescriptive framework. IPA is inductive and uses flexible techniques to allow unanticipated themes to emerge during analysis (Finlay, 2011). In this research, detailed analysis of primary caregivers' experiences was conducted utilising inductive principles. IPA is also interrogative as one of its central aims is to contribute to the existing body of literature (Larkin & Thompson, 2012). Even though IPA involves in-depth analysis of small sample sizes, the results can be discussed in relation to the broader extant literature (Smith et al., 2009).

In contrast, the GT process incorporates continuous analysis and the development of new data, allowing the researcher's examination of developing topics of interest to be influenced by both the researcher's interview and analysis experiences. When using GT as a research methodology, Smith et al. (2009) discussed the following:

"Grounded Theory is likely to be attractive to you if you have the time and space to deal with a lot of data, if your focus is not necessarily (or primarily) psychological, if you are keen to have a relatively structured protocol to follow… (p.44)."

GT involves concurrent data collection and analysis, which is an energy intensive process (Wuest, 2012). Another significant challenge in GT is the quality of the theory produced at the end of a study, depending on the researcher's theoretical sensitivity (Charmaz, 2014). As a novice researcher in the use of qualitative methods, I thought it would not be appropriate to use GT as a method in this study in case my theoretical sensitivity was insufficient. Grounded theory's central aim is theory-building (Thornberg & Dunne, 2019). The intention of this study is not to generate theory; rather it is to allow for new understandings of the ways primary caregivers experience caregiving for their children. GT is a more macro level of analysis, concerned with the development of codes and categories from data, to construct theories about social processes that are grounded in real-life experiences (Charmaz, 2006), and recruitment continues until data saturation is reached and no new themes emerge. In contrast, IPA employs micro-analysis of individual experiences, and is concerned with the generation of super-ordinate themes that reflect the texture and nuance arising from the detailed exploration, and presentation of 'actual slices of human life focused on the convergence and divergence of participants'. (Smith et al., 2009:292). The aim of this study is to provide a deep understanding of the meaning of family caregivers' lived experiences of children with cancer so as to identify the similarities and differences between the experiences of the participants, and to obtain results on how to improve the quality of nursing care in order to better support them in this difficult journey. IPA is the best choice of method to achieve this goal.

Another method, TA, offers a flexible methodological framework that may be supported by phenomenology and, in fact, a variety of different theoretical perspectives. As a result, it can assume a strong phenomenological focus thanks to this flexibility. However, because of its adaptability, it lacks a pre-existing theoretical framework, and as a result its method falls short of illuminating the underlying significance and depth of the research issues themselves (Maguire &Delahunt, 2017). This study's primary goal is to gather first-person reports of subjective and personal lived experiences. Therefore, it aims to highlight a strong idiographic focus with a limited and focused sample size. The IPA procedure is rather different from that of TA: IPA involves a detailed focus on the analysis of each case with an idiographic focus (Smith et al., 2009; Larkin et al., 2019), before developing themes across cases (Braun & Clarke, 2013). Idiography is also just one of a set of lenses IPA brings to the table which invites that deeper exploration. These lenses also include the embodied, existential, and relational elements of phenomenology (Smith et al., 2009). It is the introduction of these lenses that guides the researcher toward a deeper interpretation. The hermeneutic IPA lens sets out to use multiple layers of interpretation (Smith et al., 2009) to access the latent meanings within the data, offering deeper exposition. This is quite different from theme development in reflexive TA, where themes are developed across cases from codes following the coding of the entire data-set. IPA goes analytically much deeper or further with each data item, before taking an overall thematic orientation to develop themes across the data-set (Braun & Clarke, 2021). TA can be used when the sample is relatively large (i.e. larger than N = 10) and/or heterogeneous, such as when the aim is to capture diversity (Fassinger, 2005). As a result, TA was not selected because since it lacked the required precision and philosophical foundation; an idiographic focus was essential to this study, and a homogeneous sample was required.

IPA was selected as the best approach for this study because it places considerable emphasis on comprehending and interpreting primary carers' experiences in order to show how it is for them. Combining IPA with an idiographic focus allows for the possibility of highlighting the voices of the primary carers in this study, and helps readers comprehend their experience exactly as it is, which is in line with the research's main thesis. IPA was selected because it would allow for a thorough examination of carers' experiences by developing an "insider's perspective" (Reid et al., 2005) and by adhering to idioms, which would result in an interpretative account of their social and personal lives. The choice of IPA is further reinforced by the fact that several research efforts (Schweitzer et al., 2012; Tutelman et al., 2019) examining the experiences of parents of children living with chronic diseases like cancer have used it. IPA is considered a good methodology for research that focusses on phenomena that are not fully understood, are complex, or where there is a lack of previous exploration (Maltby et al., 2010). IPA is particularly relevant when people are having fundamental life experiences, as the multidimensional, embodied, cognitive, affective, and experiential aspects of their response to that experience emerge (Smith et. al., 2009).

In order to provide better care to paediatric patients with cancer and meet their needs, it is also necessary to explore the experiences of their primary caregivers. As a nurse, this study was conducted to provide holistic care to the child with cancer and their family. Holistic nursing practice involves paying attention to the individual patient's entire being through "bio-psychosocial-cultural-spiritual assessment" (Enzman Hines, 2017, p. 7). Thus, one qualitative approach that aligns quite closely to the goals of the holistic nurse researcher is phenomenology. Using interpretive phenomenological analysis can allow one to conduct phenomenological holistic nursing research, and hence it was used in this study.

In summary, Table 3 shows the differences between each method of framing qualitative research.

Approach	**Purpose**	**Sampling**	**Features**
IPA	To describe the essence of a phenomenon by exploring it from the perspective of those who experienced it so as to understand the meaning participants ascribe to that	Purposive sampling/ Interviews with up to 10 individuals who have experienced the phenomenon	*micro level of analysis *idiographic focus *hermeneutic circle *phenomenology *philosophical foundation

	phenomenon	being studied	
Grounded Theory	To develop theories grounded in the study data	Purposive sampling/ Interviews or focus groups with 15–30 individuals	*macro level of analysis *larger sample sizes *philosophical foundation
Thematic Analysis	To identify and interpret patterns or themes in a data set	Small or large data sets/ interview transcripts, survey responses, and observational notes	*looking for patterns in the meaning of the data to find themes

Table 3. Differences between methods

3.7 Research design and implementation

3.7.1 Sample size, selection and homogeneity

A homogenous sample should be used to reflect the participants in an IPA method in order to better understand their lived experiences and views (Alase, 2017). Smith (2009) proposes that given the goal of IPA is to construct fine-grained descriptions of individual persons in a specific setting, the sampling method should emphasise homogeneity to the greatest extent feasible. Samples should be purposeful in addition to being homogeneous (Smith, 2009). For the purpose of this study, homogeneity was achieved with mothers who are the primary caregivers of children with cancer. It is essential that each participant has a similar set of personal encounters with the phenomena under study (Creswell, 2013). Several IPA research papers were considered to gain a better understanding of how homogeneity is seen (Atout et al., 2021; López et al., 2020; McEvoy et al., 2021).

Purposive sampling allows researchers to pick participants based on their ability to demonstrate a trait of relevance for the study being conducted (Silverman, 2010). As a result, it presupposes a certain degree of critical thought about the precise criteria one should select from a given population. However, researchers should be realistic and more flexible in their inclusion criteria given the fact that real-world research may have other aspects, such as practical considerations, time restraints, and demographic characteristics (Smith, 2009).

There is no set rule for the optimal number of participants required for an IPA design, however, research with anything between 1 and 30 participants has been undertaken (Brocki et al., 2006; Pietkiewicz et al., 2014; Wagstaff et al., 2014). In order to be manageable and to allow for the necessary depth throughout the analysis, it is recommended that an IPA study have a small sample size. Purposive sampling, similar to an IPA (Smith et al., 2007), was used in this study. Therefore, for a master’s degree, three participants are adequate, for a professional doctorate, a sample size of up to ten participants is adequate, and for a study at the PhD level, sample size can vary according to the type of research question and the calibre of the data acquired (Smith, 2009). In order to preserve the idiographic quality of IPA, it is often advised to use a “less is more” approach (Smith, 2009; Hefferon, 2011; Brocki, 2006; Reid, 2005; Smith, 2004). Although smaller sample sizes are a general drawback of IPA research, they do allow for richer, more in-depth analysis by allowing for more time to be spent on each account. The sample size in IPA research should be chosen depending on the particular setting in which the study is to be performed, much as with the homogeneity problem. If more participants are required, snowball sampling can also be utilised (Kelly et al., 2015). Participants who are gathered by purposive sampling will serve as a source of additional participants for snowball sampling (Kelly et al., 2015).

A planned in-depth analysis of the data collected for a qualitative study on the experiences of primary caregivers who have children with cancer and interviews will be carried out with a purposive sample of five caregivers. To create this purposefully homogeneous sample, all individuals were chosen using the following criteria.

3.7.2 Inclusion and exclusion criteria

The inclusion and exclusion criteria are guided by the study's goal. For this study, a predetermined criterion was required in order to optimise the homogeneity of the sample, a necessity for studies utilising IPA (Smith et al., 2009).

Inclusion criteria are:

- Primary caregivers of a child aged 1-17 years old and diagnosed with any childhood cancer
- Primary carers who had been caring for children with any type of paediatric cancer for more than four months and who were at least 18 years old
- Primary carers of children with any type of paediatric cancer who were through treatment or had finished treatment
- Being able to speak and understand English
- Being able to provide informed and written consent
- Being able to participate in an interview at a place of their choosing

Exclusion criteria:

- Those who are unable or unwilling to provide informed consent
- Those unable to communicate with relative fluency in English, either written or verbal

3.8 Method of data collection

3.8.1 In-depth interviewing

This thesis' ontological and epistemological stance, as well as the theoretical underpinnings of IPA, indicated semi-structured interviews to be an effective data-gathering approach. These enable a dialogue between researcher and participant (Smith et al., 2008), acknowledging the social construction of meaning. They also provide participants the opportunity to direct the conversation, promoting a focus on what is "significant to the person" (Smith et al., 2009:33) as opposed to the researcher simply determining the topics to be asked.

Smith (2009) advocates that the best way to elicit people's meanings is through one-to-one, face-to-face interviews. To conduct an effective IPA study, researchers must strive for a specific amount of richness in their data, which necessitates the use of competent interviewing skills (Smith, 2011). Semi-structured interviews are commonly employed by researchers because they allow them to be better prepared for any potential challenges and to be a "more engaged and attentive listener and a more flexible and responsive interviewer" (Smith, 2009; Hefferon, 2011; Reid, 2005). The recommended length of an interview is 60 to 90 minutes.

All interpretations are grounded in the participants' data via verbatim quotes drawn directly from the interview transcripts. I made an effort to be data-driven throughout the entire process and to stay as near as I could to each participant's phenomenological experiences. Additionally, it must be remembered that my interpretations could not coincide with those of other researchers. All interpretations are founded on participant data via verbatim statements taken straight from interview transcripts. Throughout the process, I tried to stay data-driven and as near to the phenomenological experiences of each participant as possible.

3.9 Recruitment

Primary caregivers were recruited from the following charities Children's Cancer and Leukaemia Group (CCLG), Teenagers and Young Adults with Cancer (TYAC), and the Childhood Cancer Parents Alliance charity (CCPAC). Charities have online forums, and charity gatekeepers have also provided support by posting information sheets about the study on these platforms. Potential participants were recruited by sending an information letter with an e-mail to all families who met the inclusion requirements, as determined by authorised charity staff. Participants were invited to participate in the study; however, those who came forward and volunteered may have represented a biased group (Cheung et al., 2017; Accorsi et al., 2021). There is a risk that they may feel indebted to the charity and therefore are only participating out of a feeling of duty. Previous research that found that a personal connection to an organisation/charity or cause can be a motivating factor (Adams 1980; Dunn et al., 2016). No undue pressure was put on people to participate or remain in the study if they wished to withdraw. The participants were reminded, before starting the interview, that they agreed to participate in the research study and that their agreement was voluntary and free from pressure or undue influence. However, this can only be surmised. If at any point during the interview, the research participant appears uncomfortable or in distress, the researcher will offer breaks, to skip questions, and will remind them that they can withdraw at any time. During the interviews with the participants, if they feel uncomfortable while answering some questions, they will be reminded that they do not have to answer any question they do not want to. The information letter explained the goal of the study, informed potential participants, and invited them to participate in an in-depth interview. Semi-structured interviews allowed me to engage in a dialogue where their initial questions were modified in light of the caregivers' responses. This enabled me to probe any interesting and important topics that arose (Smith et al., 2009).

The primary carers were informed of the study's purpose and nature before completing the consent form. Primary caregivers were assured of complete confidentiality during all phases of the study and assured that the reported data would not contain any identifying information. All participants were informed that they had the opportunity to withdraw from the study at any time. Building trust and having comprehensive participant information and permission forms made participants realise that anonymity, confidentiality, and privacy would be respected. Prior to the start of each interview, written consent was sought. Participants expressed their experiences, and because sensitive topics were being discussed, they were made aware that pseudonyms would be used to ensure anonymity. A particular ethical issue associated with case study research is maintaining participant confidentiality. Anonymisation procedures were used to ensure which primary caregivers' data remains confidential (Moore, 2012; Tsai et al., 2016). When publishing results, care will be taken not to report information that will enable research sites or individuals to be identified for example geographical location.

Securing participant diversity and sample representativeness was difficult. Studies have found that middle-class parents are more likely to be involved in charities and have more social capital (Egerton, 2002; Hall, 1999). This majority of participants in this study were White British. Reaching study participants through charities may have influenced who was able to participate in the study and, as a result, what characteristics participants might share. My own research has found that women are more likely to put themselves forward to participate in qualitative research than men, which is in accordance with research showing a higher tendency toward self-disclosure in females than males. It is widely recognised that men are more difficult to recruit into health studies than women (Oliffe & Thorne, 2007), which Macdonald et al. (2008) suggest could be the result of researchers using data collection methods that are more women-friendly, and that may dissuade men from participating. Participants' motivations for volunteering to take part in research also affects recruitment. Altruistic individuals may be more inclined to volunteer for research (Newington & Metcalfe, 2014). Altruism is reflected in participants' desire to help others, to make a difference to existing knowledge, and to change practice (Clark, 2010; Coyne et al., 2016).

3.10 Challenges and amendments

Recruitment at the charity was difficult: Because of the COVID epidemic, people could not go to many charities, so they did not get the chance to see the information text about the study. The intensity of the cancer treatment process and the lack of time for people to work could also have been factors. This had a negative impact on the recruitment process. As a result of the aforementioned challenges, the recruitment technique was modified. For these reasons, we reapplied to the university's ethics committee for certain changes, which are as follows: to complete cancer treatment, and to use the snowball technique. The interval between submission of an ethics application and its approval by the research ethics board also impacts recruitment. Since the process of obtaining ethics committee approval for this study took some time, the recruitment process was negatively affected. Several authors have reported challenges in obtaining expeditious ethics approval, which caused delays in the initiation of recruitment (Coyne et al., 2016; Newington & Metcalfe, 2014; Vindrola-Padros et al., 2020). Snowball sampling is useful for accessing difficult-to-reach populations. A snowball sampling strategy is a linear, non-probability sampling technique used to recruit possible participants for research when potential participants are difficult to find (O'Byrne et al., 2008). This approach increased the number of possible participants. According to Tuckett (2004), the sampling strategy for qualitative research should be sufficiently flexible to allow for modifications to the criteria as the study progresses. This flexibility allows for a variety of sampling techniques to be used. Sampling in IPA studies is also dependent upon individual research situations and the pragmatic restrictions one is working under (Pietkiewicz & Smith, 2012). For this reason, professional connections and snowball sampling were used to continuously recruit participants. In keeping with the principles of IPA, I employed a snowball sampling strategy in my main study to identify a small homogeneous sample for whom the topic of my study was significant (Smith et al., 2009). This snowball strategy was based on soliciting the advice and help of the participants who had already agreed to participate in the research project to help to attract other participants to join in the research project (Shaghaghi et al., 2011; Sedgwick, 2013). More importantly, as a qualitative research approach, the essence of an IPA research project is to get “rich” and “thick descriptions” of the “lived experiences” of the research participants (Alase, 2017). After obtaining university ethics approval, with the support of my academic colleagues and study participants, I reached out to primary caregivers of children with cancer who met the inclusion criteria and who volunteered to participate in the study.

Coda about COVID and its impact

The original recruitment strategy for the study was planned through the NHS and the Royal Manchester Children’s Hospital. However, due to the COVID-19 pandemic, we decided as a team that it would be more appropriate to recruit participants from charities. After obtaining ethics committee permission, only one participant agreed to be interviewed for the project. After waiting for two months to find new participants for the study, the inclusion criteria for the study were updated by reapplying to the ethics committee. The new criteria were: recruitment via snowball sampling, including the new charities to recruit participants (Teenagers and Young Adults with Cancer and the Childhood Cancer Parents Alliance Charity) and to include carers of children who had completed treatment. The new inclusion criteria were updated to reach more participants for the study. All childhood cancer charities in the UK were contacted, and those that agreed to help recruit participants for the project were included in the recruitment sites. Because the research was originally planned to collect face-to-face data prior to the pandemic and unforeseen changes were required, adaptations to the research process were made online in light of COVID-19 restrictions. COVID-19 has required researchers in general to adapt their methodologies to allow for remote data collection. While virtual interviewing has traditionally received limited attention in the qualitative literature, recent adaptations to the pandemic have prompted its increased adoption (Keen et al., 2022). My original research design relied heavily upon face-to-face interviews; however, social distancing guidelines and consideration of the risk of infection of children with cancer due to the COVID-19 pandemic made face-to-face discussions impossible. I had to rethink my project design and envision how I could conduct interviews in a safe, appropriate, and feasible manner. My preference was online video conferencing, which I felt would be the closest substitute to face-to-face interviews and allow synchronous conversations with participants. Although my research design changed significantly due to the pandemic, I feel my study and skills as an academic have benefited from this change as it forced me to constantly reconceptualise, verify, and make pragmatic adjustments, which contributed to the overall phenomenological methodology and analysis.

3.11 Data collection

One of the study's aims was to provide rich, meaningful, and thorough experiences of this phenomenon (Pietkiewicz et al., 2014). Semi-structured interviews, according to Jamshed (2014), are "those in-depth interviews in which respondents answer pre-set open-ended questions" (p. 88). According to Smith (2015), interviews are talks with a goal that allows for a connection with the participants through discourse as well as flexibility and deeper data. I chose semi-structured interviews to acquire data.

The interviews were built on open-ended and non-directive questions (Kelly et al., 2015). An interview schedule was constructed using guidance from Smith et al. (2009) and Dallos et al. (2005). The interview schedule began with a question that allowed the participants to elaborate on what inspired them to participate in the study. The schedule's objective was not to limit comments, but to allow participants to discuss relevant themes and events from their own perspectives. Each interview began with the question, "Everyone's experiences are different. I really like to find out. Can you please tell me about the experience of having child with cancer?". An in-depth analysis of the participants' experiences was undertaken through conversation with them, which came from the change of initial questions and prompts depending on their replies (Smith, 2015; Pietkiewicz et al., 2014). To elicit further information about their experiences, probing and non-leading questions were used. I created eleven open-ended questions and several follow-up questions to invite participants to elaborate. See Appendix 5 for the research interview guide. Data collection for the study lasted two months, starting on 1st January, 2022, and ending on 1st March, 2022. Following recruiting, the researcher conducted in-depth interviews with the primary carers in a location of their choosing. The interviews were conducted online. It was very important for the families of the children diagnosed with cancer that these children did not get an infection, and they did not have sufficient time to hold and organise face-to-face meetings due to the intensity of the cancer treatment. Also, due to COVID-19 restrictions, interviews were conducted online.

3.11.1 Pilot interview

The goal of the pilot interviews was to provide the opportunity to become familiar with the interview process (use of the digital recorder, building rapport, etc.), to develop pertinent lines of inquiry and qualitative interviewing skills, and to make any necessary changes to the interview guide (Majid et al., 2017). This initial interview served as a test run for the interview method (the analysis of the data obtained was not included). After the interview programme was drafted, I conducted the pilot interviews with three identified participants with a chronically ill child. Small adjustments were made to the interview schedule, including the rearranging of some questions, after the pilot interview and a brief reflective conversation with these participants at its conclusion. The revised interview guide was created using the recommended questions and problems noted during my reflection on the pilot interview process and the field notes. The transcripts of my pilot interviews were shared with the supervisory team, and my pilot interview experience was discussed.

3.11.2 Interviews

Interviews were conducted face -to- face interviews, online, individually, and in a location preferred by the participant. IPA takes an open approach to data gathering in order to investigate the meanings that participants attribute to their experiences. As a result, IPA relies on flexible and open-ended questioning schedules. Interviews provide participants with the opportunity to express specifics about their experiences and seek deeper understanding of their subjective meaning and experiences. The interview schedule was guided by the literature in the field. I used the interview schedule while collecting my data from the participants.

Tuckett (2005:33) believes that using a recorder is required to “counter criticism” that qualitative research is “prone to systematic bias” paraphrasing May (1991:190). Seale and Silverman (1997) mention that among the measures necessary to assure “rigour and validity” in qualitative research is: “recording data objectively and comprehensively, including the use of audiotapes, videotapes, and different levels of detail in data transcription” (p. 380). Participants were informed that their interviews would be audio recorded, and their agreement to such was obtained. All of the interviews were recorded using a digital audio recorder. The participants were also informed that they could ask for the tape recorder to be turned off at any time if they wished.

After the interview, the participants were questioned to see if they had any other comments or inquiries. The audio recording was stopped when participants indicated that they had finished. After the recorder was switched off, the participants had the option of adding any further details. I always thanked the interviewees at the conclusion of the interview. Within an hour of the interview, field notes were created. The location of the interview, a description of the surrounding area, any nonverbal behaviour noticed, technical difficulties, the main points of impromptu conversations that took place with the participants before and after the interview when the digital recorder had been turned off, and anything else that was noticed or happened before, during, or after the interview were all included in the field notes. To guarantee complete memory of all pertinent events that took place during each interview session, the tapes were transcribed verbatim within 48 hours.

3.11.3 Interview schedule

The interview schedule (see Appendix 5) was thoughtfully created after consultation with my supervisors. The interview schedule included eleven open questions as well as various prompts and lasted 45-90 minutes; questions such as “why?” and “how did you feel?” were used frequently to delve further into participants’ experiences (see Appendix 5).

At the start of each interview, I used my skills to build rapport and to talk through the information-giving and consent procedure, taking appropriate steps to make this accessible to all participants. Participants were informed that their interview would be audio recorded and that their information would be used afterwards. The participants were reassured that there were no right or wrong responses; I was just interested in hearing about their unique experience, whatever that may be, after I asked a detailed “ice breaker” question with the purpose of making them feel comfortable. The interviews were conducted online using the Zoom and Microsoft Teams applications. After the interviews, field notes were made to ensure that nonverbal cues, emotions, and reflexivity were recorded.

3.11.4 Distress during and after data collection

It was crucial to pay attention to how the interview process was affecting the participant as we went through the interview because existential problems are connected to IPA research and the phenomena that were being addressed (Pietkiewicz et al., 2014). I made sure that all participants had access to options for extra help in the event that they encountered feelings of distress. A distress protocol developed by Haigh et al. (2013) for qualitative data, as well as my personal abilities as a nurse, were also used to assist assessment if a participant was feeling distress.

3.11.5 Data management

An encrypted USB stick was used to keep all electronic records, such as consent forms, video recordings, and transcripts. The names of the participants and some other identifying information were changed to protect confidentiality in the original transcripts of the recorded sessions, the study’s report, and any electronically stored materials. In order to preserve primary caregivers’ rights to privacy, the Data Protection Act 1998 and the General Data Protection Act 2018 were complied with. Zoom and Microsoft Teams are virtual platforms compliant with the European General Data Protection Regulation (GDPR, 2018; Zoom, 2020), which was used for the interviews. The day before the interview, participants received an email with a secure link and password for the sessions. Once the final report had been submitted, all personal details and audio recordings were destroyed.

3.11.6 Transcription

I used Otter.ai apps to transcribe interviews. To make sure that the sentences used in the interview were correct, I repeatedly listened to the audio recordings of the interviews and watched the video recordings and following each interview, I prepared reflective notes in which I aimed to capture the unsaid experiences of the interview as well as my observations of the process.

3.12 Ethical considerations

According to Bryman (2016), Deiner and Crandell (1978) classified ethical violations according to four categories:

- Whether there is risk of harm
- Whether there is a lack of informed consent
- Whether privacy is invaded
- Whether there is deception involved

Working with people to study their perspectives and perceptions raises ethical concerns about permission, violation of privacy, and potential injury. This would be regarding on participant identification and recruitment, clarity and storage of information and consent, anonymity during the study, and dissemination of information for this study. As a result, it is critical that any risk be anticipated and guarded against (Bryman, 2016). By receiving ethical approval, a planned study may be certain that any risks are anticipated and protected against. Manchester Metropolitan University has a thorough and organised process for receiving ethical approval, much like other universities. Full ethical approval was sought and was approved by the Manchester Metropolitan University Health, Psychology and Social Care Research Ethics and Governance Committee. The following ethical procedures were also followed.

3.12.1 Informed consent

To obtain informed consent, participants were sent an Information Sheet (PIS; see Appendix 3) which they were asked to read prior to being contacted for participation and signing the consent form (see Appendix 4). The PIS included details on the objectives of the study, voluntary involvement, the method used, data storage and utilisation, and potential advantages and disadvantages of participating. Each video call started with a screenshot of the consent form that had been signed. Although there were no physical dangers to participants in this study, it is understood that there may have been the possibility of sensitive or emotionally charged conversations.

3.12.2 Anonymity and confidentiality

All participants completed the participant information forms after being properly informed of the study’s objectives and given the assurance that their identity and confidentiality would be respected. All participants provided written informed permission after being promised that the study would keep any personal information private. All data acquired during this PhD study was kept private. No identifying information was connected with any of the study’s data. Pseudonyms were allocated to participants throughout the data processing phase to prevent quotes contained in any documentation emerging from this study from being recognised by a name. To ensure confidentiality, all identifiable information has been removed from quotes.

3.12.3 Right to withdraw

Participants were notified that they could withdraw from the research project for up to four weeks following the audio-recorded interviews. If this occurred, all data pertaining to the relevant individual would be immediately erased.

3.12.4 Debriefing

Following the interview, all participants were thoroughly debriefed. Each participant's perspective on the interviewing process has to be discussed in order to track any potential negative consequences. The application for ethical approval took participant well-being into account; this included a protocol for emotional distress, and withdrawal and complaint processes. The participants were provided with a debrief sheet (Appendix 7) with information regarding helpline services if they needed further support. The interview questions are not intended to cause distress, but it was felt that the nature of the discussion might well invoke an emotional response. I had spoken to my supervisors about how to handle these responses and was comfortable with offering breaks, rescheduling or terminating the interview should this become necessary. In each case, I asked the individuals at the beginning of the interviews about how they would like me to proceed should such an event occur, thus mitigating any further distress.

3.13 Data analysis

There are no set techniques for performing IPA; rather, there is a framework for analysis that can be employed in a flexible way (Smith et al., 2009). The data analysis method adhered to IPA principles and had a rigorous data analysis procedure that was relevant and coherent with the IPA's goal of acquiring an inside view of the experience under inquiry (Smith et al., 2007; Tebbet et al., 2012). In this part of the study, the researcher interacted interpretively with each transcript (Smith, 2015; Smith et al., 2007).

I examined the carer interviews one by one using the step-by-step technique for IPA described by Smith et al. (2015). Throughout the analysis, discussions with the research team were held to cross-check and aid with bracketing. The stages of the analysis proved to be a very iterative, intense, and difficult procedure. It was not until I found myself experiencing the actual process that I started to fully grasp the true nature of it. This personal insight confirmed the power of experience as a distinct and enlightening means of comprehending realities. I was able to stay as close to each participant's experience as possible by keeping this in mind. It was a difficult but satisfying process to distil the ideas, with many sub-themes blending into one another and potentially coming under more than one master theme.

The six steps outlined by Smith et al. (2009) served as a framework for assessing the interview data.

3.13.1 Step 1: Reading and re-reading

Smith (2015) stated that each transcript should be read twice to guarantee correctness and to capture the substance and content of each interview. New insights might also appear with each reading (Smith et al., 2007). The audio was listened to while the transcript was initially read, but was not included during the second reading. The data was organised using NVivo

12 program. Appendix 8 provides an illustration of how the data were structured in NVivo. All significant words, sentences, and insights were underlined in the right margin during the initial reading (Smith, 2015). There were some parts of the transcripts that were more detailed and hence required additional commentary (Smith et al., 2007). To guarantee that all nonverbal activities were recorded, nonverbal reactions such as laughing, sobbing, and silence were included in the transcript (Adolfsson, 2010). This procedure was repeated throughout the transcript.

The initial stage in IPA analysis is to become acquainted with each transcript. This entails reading and re-reading each individual transcript, which assists in ensuring that the participant is the focus of the study through active interaction with the data. During this step, I used a notebook to record my initial thoughts and ideas about each transcript, which would help to guarantee that the participants' experiences are not swamped by my own impressions of the data.

3.13.2 Step 2: Initial noting

The second reading began with initial notes being transformed into codes, followed by emergent subject titles (Smith et al., 2007). Appendix 8 contains an example of a coded transcript. All of the emergent themes were then compared to the transcript (Leung, 2015; Smith, 2015; Tebbet et al., 2011). Connections between the participant’s speech and the IPA theoretical framework were formed throughout this stage of the analytic process (Smith et al., 2007). This procedure was performed individually for each transcript.

This was the most time-consuming stage of the study, focusing on the semantic content and language employed in each transcript (Smith et al., 2009). At this stage, everything of relevance within the text was marked in the right-hand column of the transcript, which increased familiarity with the material and assisted in recognising how participants comprehended and discussed certain themes or concerns. This stage of the process involved taking a note of anything that stood out in the text. This idea resulted in a rich set of notes and comments defining the data set.

According to Smith et al. (2009), the requirements for first notetaking included noting the following three processes:

- Descriptive comments: This includes descriptions of things that mattered to participants (e.g. key objects of concern such as relationships, processes, places, events, and principles) and what these meant to the participant. This involved taking a note of key words, phrases or explanations used by the participant.

- Linguistic comments: This required paying attention to the use of pronouns, pauses, laughter, repetition, and metaphors.

- Conceptual comments: This stage of the analysis involved a shift away from simply identifying the explicit claims of the participant and instead focused on how participants understand what they describe. To do this I used a process of discussion, reflection, trial and error, and refinement of ideas and thoughts.

I typed up the fieldnotes on the surrounding circumstances, the interview venue, the interviewees' body language, and any prospective thoughts in the investigator's diary. In addition, I prompted participants to continue speaking after they finished outlining their experiences. The interview concluded when none of the participants had anything more to say.

3.13.3 Step 3: Identifying emergent themes

The five interviews generated 12 codes throughout the data-set. The codes for each transcript were reviewed to determine duplication of codes, which meant the same thing but were coded in different ways. For example, codes that were initially titled 'Hope' or 'Uncertainty' were grouped together under a new code entitled 'A range of emotions'. Five themes were crated once the dataset had been adjusted. These five themes were analysed by going back to the data and understanding what the participant was saying. The themes were then organised into themes that represented the experiences of the participants. After grouping all of the emerging ideas into clusters, I started reading back over the transcript to see if there were any links between the topics. To make sure that the participant's voice was correctly understood, each of the detected clusters was cross-referenced with the transcript. I presented the themes to my supervisors in a number of supervision meetings, and as we explored each emergent theme, it was suggested that I dig more into what the participants were saying. I was able to look at each subject from a higher level and then dig down to what the participants were saying thanks to the mind mapping activity, which allowed me to dive deeper.

This stage involves creating short statements that captured the main essence of specific parts of the transcript and were written in the left-hand column of the transcript. By mapping relationships and patterns between exploratory notes, I developed themes that emerged within the transcript. This stage of the study was an iterative process since it entailed close contact between myself, my supervisors, and the participants' voices (Smith et al., 2007). This stage also demonstrated the double hermeneutics of IPA, as I was attempting to understand both the participant's words and their interpretation at the same time (Smith, 2015; Smith et al., 2007).

3.13.4 Step 4: Searching for connections across emergent themes

The subordinate themes were represented by the clusters, which were then given an overarching name (Smith et al., 2007). A final table consisting of the superordinate themes across the data-set of each interview was constructed (Smith et al., 2007). The most difficult aspect of this procedure was prioritising and limiting the data to choose which topics to focus on (Smith et al., 2007). The superordinate themes were chosen not just for their occurrence, but also for their richness and how the participants' voices were reflected (Smith et al., 2007). This step of the study was iterative, with researchers returning to each transcript to capture any previously overlooked discoveries. I engaged with the data at a high level of interpretation during the analysis to detect parallels and how this matched with the overall theoretical framework combined with the characteristics of each participant (Smith et al., 2007). The superordinate themes were contextualised using verbatim excerpts (Kelly et al., 2015). The use of verbatim excerpts in IPA research demonstrates data sensitivity (Shinebourne, 2011).

A mapping of how the researcher thinks the themes fit together to produce a structure that outlines the most interesting and important aspects of the participant's account was developed. All of the themes were written into a Word document and then split up so that each theme was on its own strip of paper. All of the themes were then arranged in a table, and those that reflected related ideas or recurrent patterns of meaning were categorised as "master themes". Some themes stand alone and should so be placed on one side. Following that, each master theme and its accompanying emergent themes, were typed into an Excel spreadsheet, along with all of the corresponding transcript extracts.

3.13.5 Step 5: Analysing the next participant

Repeat steps 1-4 for the next transcript, treating the next case on its own merits.

3.13.6 Step 6: Looking for patterns across participants

Patterns and connections between samples were sought to create high-level themes and emerging themes that define the entire dataset. At this stage, a single-page Excel table was created for each participant detailing the main and emerging themes. In addition, for each main theme, a table of transcript abstracts was compiled to show the themes to register using line and page numbers. This formed the final stage of the analysis.

The role of the researcher is to conduct the research with objectivity and to not interfere in any ways in terms of orienting or guiding participants' responses. The participants' identities were kept anonymous to protect their privacy and the audiotapes and software used in the research were protected by copyright regulations.

3.13.7 Validity and quality

Smith et al. (2009) advocate adopting Yardley's (2000) four criteria to assess the validity and quality of qualitative research. Sensitivity to Context, Commitment and Rigour, Transparency and Coherence, and Impact and Importance are among these principles.

(i) sensitivity to context,

(ii) commitment and rigour,

(iii) transparency and coherence, and

(iv) impact and importance.

3.13.7.1 Sensitivity to context

Yardley (2000) states that quality research should demonstrate sensitivity to context. The researcher's selection of IPA demonstrated context awareness by adopting an idiographic approach and emphasising the circumstances and experiences of individuals. This was also demonstrated in the data analysis, where actual verbatim interview excerpts were given along with initial notes and codes; this allowed the researcher to back up any assertions made, offer reader-friendly interpretations, and capture the perspectives of the caregivers. Sensitivity was also achieved through providing participants with a summary of key findings.

3.13.7.2 Commitment and rigour

Commitment was demonstrated during the data collection process and via in-depth analysis. As a new IPA researcher, I demonstrated dedication to the study by expanding my understanding of the approach through books, attending an IPA masterclass, and seeking assistance from experts. The rigour that implies the completion of comprehensive research can be demonstrated by how the sample was selected and my efforts to maintain homogeneity.

3.13.7.3 Transparency and coherence

Transparency was achieved by including a comprehensive description of the processes involved in data collection and analysis, such as participant tables, a copy of the interview schedule, and examples of the analytic process, in the research write-up. Yardley (2000) addressed the importance of reflexivity in establishing transparency. I kept a reflexive journal to document my thoughts and feelings about conducting the research before and during data collection, analysis, and write-up. The clarity of the arguments made throughout the research process (from the literature review, stating research questions, and presenting findings through discussion) demonstrates coherency. The clarity with which the various stages of the research process are described is referred to as transparency, as is shown in data collection and data presentation. An audit trail, which keeps a record of all decisions made during the research process, is required for transparent research. Researchers keeping reflexive accounts is another technique that can be used to improve transparency. I utilised existential bracketing to consider how my theoretical orientation, assumptions, cultural background, and experiences may have impacted how I approached the study (Gearing, 2004).

3.13.7.4 Reflexivity

The role of reflexivity is an essential component of IPA. It adds rigour, validity, and transparency to the research findings by always reflecting on the impact and role of the researcher on the topic under exploration.

In order to adopt a reflexive process, I will keep a reflective journal in which I will write down my thoughts and ideas (Lincoln et al., 1985; Holloway et al., 2010) and discuss these reflections with my supervisory team. Additionally, I wrote my observations and any additional pertinent details I could recall from each interview session in my reflective notebook after their completion. The usage of the reflective diary was beneficial during the analytical process; however, inter-subjective reflexivity was particularly beneficial.

The data analysis took time, and the amount of data gathered through interviews felt overwhelming at times. I countered this by remembering that there was “no clear wrong or right way” (Smith et al., 2009) to conduct IPA and returned to the individual transcripts to ensure my interpretations reflected the words spoken by the respondents. It was difficult to study each interview independently without being affected by any of the earlier studies, which was one of the difficulties in doing the analysis of the interviews. It was challenging to keep previously noted themes from entering my head and affecting my conclusions when I was examining later interviews.

I questioned whether the process of developing interpretative themes was too reductionist for my personal style since I was worried I might miss the unique characteristics of each respondent's experiences. As I continued, though, I realised how useful the technique was for highlighting personal similarities and differences. Writing my results entirely in the respondents' own words and giving their experiences greater personal significance beyond the numerical capture of a quantitative approach was both enlightening and liberating. I came out of the analysis with tremendous regard for the individuals and the events they had gone through and recounted.

The reflective summary aims to give both reflective and reflexive comments regarding the research process and the study itself. It is hoped that the reader will find the major thoughts and themes that guided my research selections to be more transparent, helping to explain the rationale for the study as well as the guiding principles that guided my research path.

3.13.7.5 Impact and importance

According to Yardley (2000), the most important criteria for judging qualitative research are its usefulness, relevance, and application. In the discussion section, where I discuss the theoretical and practical consequences of the study, my aim is to illustrate the significance and influence of the research.

3.14 Summary of chapter

This chapter has presented the chosen methodology used to guide this study. With reference to the theoretical underpinnings, the researcher's ontological and epistemological position has been discussed, as well as the applicability of IPA. Details on participant recruitment, data collection, and the effect of COVID-19 on recruitment have been provided, as well as the steps employed to ensure the study adhered to ethical standards. Then, the processes used for analysis were presented. The IPA method entails participating in a double hermeneutic, thus it is stated that the themes given are dependent on the researcher's subjective interpretation of the participants' attempts to make sense of their reality; this is described in more detail in Chapter 5. Finally, issues of rigour and reflexivity in relation to the study were also discussed. The findings of the study will be presented in the following chapter.

Chapter 4

Findings

4.1 Introduction

The previous chapter outlined the methodology used in this research. This chapter explores the key findings that emerged from the study data in order to provide further understanding of the primary caregivers experiences and will inform the discussion chapter. This chapter contains an analysis of data collected from five interviews exploring the experiences of primary caregivers caring for children with cancer.

Smith et al. (2009) suggest that the findings section is the most important part of an IPA study. It needs to be substantive as the interpretation of a participant's experience depends solely on the understanding of the testimonies they provide. This can be achieved by ensuring the findings constitute transcript extracts, with the remainder consisting of detailed analytic interpretations of the text.

To stay in line with IPA's ideographic approach, I will take particular examples from participants to give voice to their unique and individual experiences of being a primary caregivers, as well as also seeking to draw out themes that are common to the sample. From my perspective, the steps to IPA offered an opportunity to relate the story of the analysis through the reflection process. One key benefit of using this approach is the following process detailing how themes were arrived at, thus giving confidence when writing the narrative around the themes, the detail of which lies within here in the current chapter. Each theme will be described individually in detail in order to accurately capture the theme. Verbatim extracts from the participants' transcripts will be utilised to illustrate the themes in full.

This chapter provides a summary of the themes and findings to allow the reader to see how themes have emerged. Each theme is then presented through the participant's 'voice', taken directly from transcripts, followed by my interpretation. This chapter begins with pen portraits of each of the primary caregiver who took part in the study. I then provide an overview of the themes identified for each participant.

4.2 Pen portraits

A pen portrait is a descriptive account of what is considered by the researcher to be meaningful (Holloway et al., 2000). The pen portraits provided aim to enable the reader to understand the context within which an individual's experiences have arisen. Focusing on individual "pen portraits" conveys the richness and complexity of these accounts, and provides important contextual information to more effectively situate and draw meaning from the findings (Nettleton et al., 2012). I used the "pen portrait" method to better understand the experiences of primary caregivers. I will also be providing reflections on my experience of the interviews with each participant.

I begin by presenting some biographical information about the primary caregivers. I hope that this information helps the reader to form a sense of how the parts of the interview, later presented thematically, form a whole and to 'hear' the findings in the context of the mothers' experiences. These short, selective biographies bring to light some of the contextual factors and provide a reflection of my understanding of the experience of the primary caregivers that influenced my subjective analysis of their interviews. These are reported in Table 4.

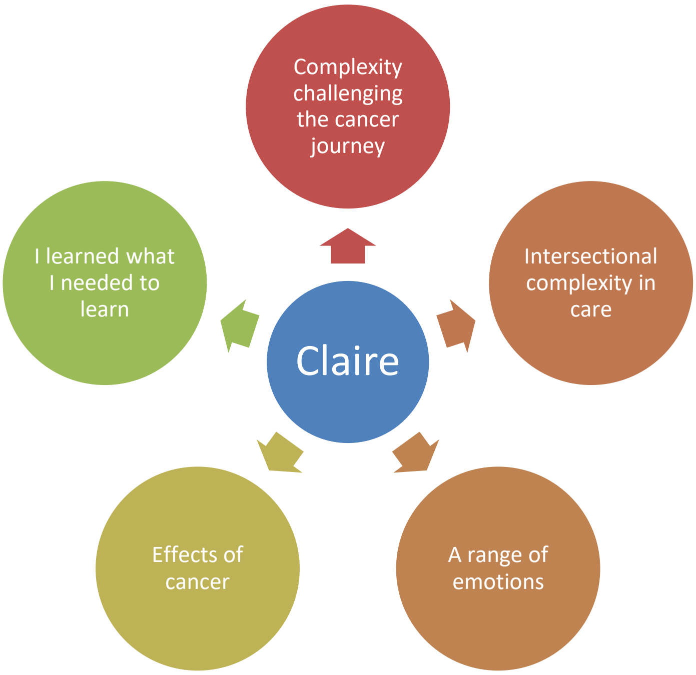
Pseudonym	Age	Ethnicity	Children's diagnosis
Claire	40s	White British	Acute Lymphocytic Leukaemia (ALL) and Down's syndrome
Beeni	30s	Pakistani	Wilms' tumour and Autism Spectrum Disorder
Julie	50-60s	White British	Non-Hodgkins lymphoma
Sam	30-40s	White British	Hepatoblastoma
Kate	40's	White British	Acute Lymphocytic Leukaemia (ALL)

Table 4: Information on interview participants

4.2.1 Participant 1- Claire

Claire is White British and in her 40s. Claire lives with her husband, son and daughter. She explained that her son has Down's syndrome and acute lymphocytic leukaemia (ALL). Claire does not work, but her husband does.

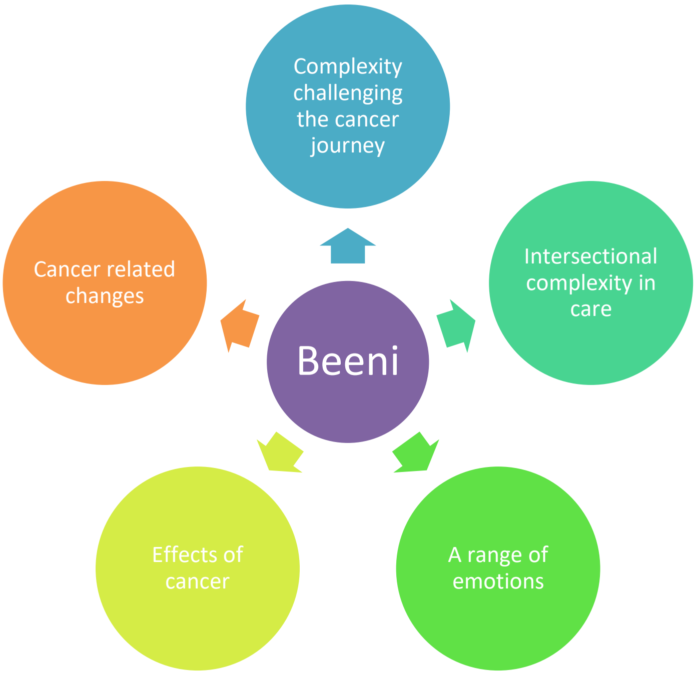
The superordinate themes identified in Claire's account are shown in Figure 2.1.



4.2.2 Participant 2- Beeni

Beeni lives with her husband and son who has Autism Spectrum Disorder (ASD) and Wilms' tumour type of kidney cancer. She is of Pakistani heritage and in her 30s. She stated that she is not working now, only her husband is working.

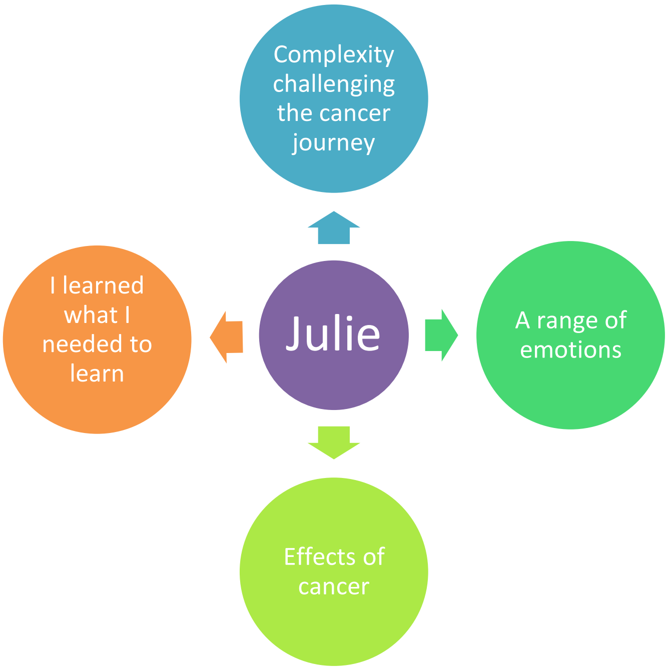
The superordinate themes identified in Beeni's account are shown in Figure 2.2.



4.2.3 Participant 3- Julie

Julie is White British between the ages of 50-60. She has three children. Julie's husband died and she lives with her elderly father, who is living with dementia. Her eldest child, her daughter, was diagnosed with non-Hodgkins lymphoma 17 years ago. Her daughter have survived childhood cancer.

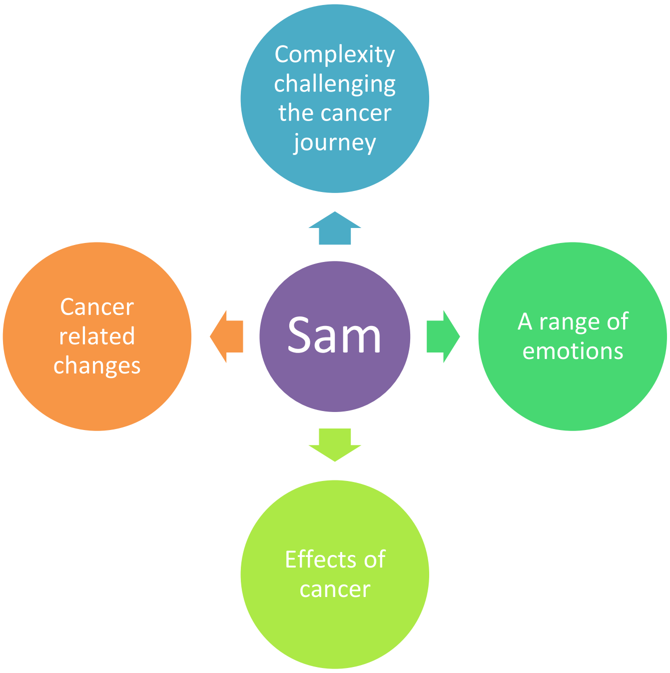
The superordinate themes identified in Julie's account are shown in Figure 2.3.



4.2.4 Participant 4- Sam

Sam is White British, she is in her 30-40s. Sam lives with her husband, E., her son, W., and her daughter, E. Her son's diagnosis was hepatoblastoma. Her son survived a cancer diagnosis thanks to a liver transplant. She also mentioned that she had to leave her job to take care of him when he received his cancer diagnosis.

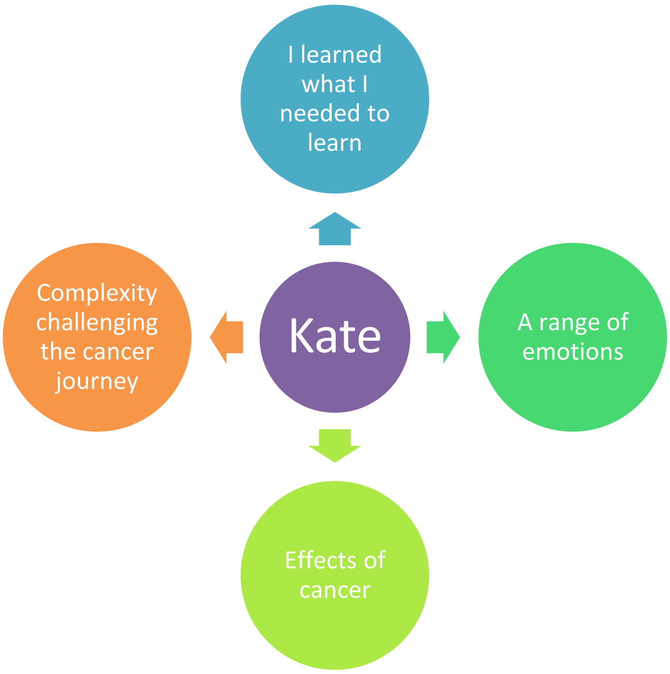
The superordinate themes identified in Sam's account are shown in Figure 2.4.



4.2.5 Participant 5- Kate

Kate was the last mother to be interviewed. Kate is White British, in her 40's, and lives at home with her son and her daughter who had acute lymphoblastic leukaemia (ALL). Her daughter survived her cancer diagnosis. She is a single parent. She stated that after her daughter was diagnosed with cancer, she carried out her full-time job as a part-time one and accordingly ran into financial difficulties.

The superordinate themes identified in Kate's account are shown in Figure 2.5.



All extracts are from fully anonymised transcripts, with the source of each extract indicated by the participant's assigned participant number.

4.3 Data selection

Following transcription of the original interview recordings, Smith et al. (2009) note the importance of the researcher familiarising themselves with the data by listening to the interviews and reading and re-reading each transcript in detail several times. Due to the idiopathic nature of IPA, each participant's account was considered to be an individual case before I moved on to engage with subsequent transcripts.

The next stage of the analytical process aimed to identify connections between the initially identified emergent themes from individual participant's accounts. The goal of this part of the process was to reduce the data without losing the essential quality of each participant's voice. This was achieved by listing all the emergent themes from a participant's account on a single page, then looking for connections across the emergent themes.

The generation of both subordinate and superordinate themes was performed through extensive academic discussion within a robust supervisory process. Texts were scrutinised by the supervisory team and justifications were made for the identification of both subordinate and superordinate themes. This rigorous process resulted in some minor modifications before consensus was finally achieved. The analysis resulted in five essential themes.

4.4 Themes

The opening interview question – ‘First of all, everyone's experiences are different. I would really like to find out: What is your experience as a primary caregiver?’ This broad question at the start of the interview was originally conceived of to settle participants in-to talking generally and provided something general and fairly innocuous to talk about. It proved to be a good ‘icebreaker’, putting participants at ease, but the replies also revealed unexpected insights into the caregiver’s views of their experiences.

As themes emerge from the individual cases, the analytic process reveals patterns and similarities in participants’ experiences across all cases. The themes that share higher-order qualities form superordinate themes. The process of analysis found all participants offered a similar account of their experiences that gave rise to six superordinate themes: “I learned what I needed to learn”, “Complexity challenging the cancer journey”, “Intersectional complexity in care”, “A range of emotions”, “Cancer-related changes”, and “Impact of cancer”. There was some overlap between the themes, which is inevitable in the IPA analytical process as one is expected to examine the similarities and differences across cases (Smith & Osborn, 2008). Therefore, some themes shed light on others to help understand the individual phenomena better. After close examination and re-examination of the overlapping themes and their locations, I felt each subtheme deserved a distinctively unique category that was the most appropriate to the superordinate theme. The data utilised for this dissertation provided a great deal of information about how cancer affects the family system.

The first superordinate theme, “I learned what I needed to learn", relates to the fact that the participants have expert knowledge about cancer treatment in order to be more helpful to their children while being parents of a child with cancer. Three of the five primary caregiver mothers talked about the experiences that led to the emergence of this theme.

The second superordinate theme, “Complexity challenging the cancer journey”, explores the support participants received from family members and health professionals. All primary caregiver mothers talked about experiences that gave rise to this theme. The support received from family members and health professionals varies among caregivers.

The third superordinate theme, “A range of emotions” represents the emotions that mothers experience from the moment they learn about their child’s cancer diagnosis. It describes the shock of receiving the diagnosis, and how they feel helpless, but also how they feel lucky, guilty, hopeful, stressed, and how they make sense of the uncertainty about the future.

The fourth superordinate theme is “Cancer-related changes”, which includes sub-concious recollections, for example of dates relating to their child’s cancer diagnosis even if it was a long time ago, making decisions about their child's cancer treatment, treatment processes and side effects related to cancer treatment, and living in a restricted world to reduce the risk of infection due to cancer diagnosis. All primary caregiver mothers in this study talked about the experiences that led to the emergence of this theme.

The fifth superordinate theme, “Intersectional complexity in care”, explores the challenges of primary caregivers when supporting children with special needs in the cancer journey.

The last superordinate theme, “Impact of cancer”, is about the changes in dyadic and family relationships after the participants’ children were diagnosed with cancer, their negative financial impact, and how the other children are also affected. All primary caregiver mothers talked about experiences related to this theme.

The final results for themes are presented in Table 5 below.

Superordinate Themes	Subordinate Themes
I learned what I needed to learn	no subordinate themes
Complexity challenging the cancer journey	no subordinate themes
A range of emotions	*Uncertainty related to survival and treatment *Guilt related to seeking professional help * Helplessness * Feeling lucky having treatment options and surviving * Significant shock in response to cancer diagnosis * Hope for cure and hope for a future * Anxiety about the future
Cancer-related changes	*Pivotal moment related to diagnosis * The necessity of treatment versus the psychological trauma * Decision making and consenting in paediatric cancer * Living in a shielded restricted world
Intersectional complexity in care	no subordinate themes
Impact of cancer	*Financial Implications * Dyadic Relationship Problems * Impact on Sibling * Changes in family dynamics

Table 5. Research Themes

4.4.1 I learned what I needed to learn

In addition to parenting their children, all primary caregivers in this data-set went through a learning process about their child's specific diagnosis, symptoms, and management in order to further assist their children during the course of the treatment process. None of the caregivers I interviewed were healthcare professionals. Despite this, they had expert knowledge about the treatment of the type of cancer their children had. The purpose of having this specialist knowledge appeared to be symptom and risk management, anticipating possible side effects of treatment, and gaining information about the type of cancer. When primary caregivers become informed about the cancer diagnosis, it appeared to allow them to take control of their lives and feel empowered. Caregivers' knowledge of their child's diagnosis and treatment, and thus feeling that they are contributing to their children's chance of survival, appeared to have allowed them to feel they had control over their lives. Claire, Beeni, Julie, Kate, and Sam talked about how they were learnt about their children's treatment processes, educated themselves, increased their health literacy, and supported their children in their treatments.

The quote below was in response to the first question I asked caregivers in this data set, "Can you tell me about your story?". Claire talked in detail about the treatment steps. She shared the following in this regard:

> "I don't know how much you know about the ALL treatment protocol. And okay, there's these five phases. The first one's really intense. He had temporary diabetes, from the steroids and treatment, manage food, blood sugar side effects of chemo complex system lung infections, and needed six months of daily IV, antifungal medicine. And the last one is really relaxed. And with lots of delays and infections and things so it can take sort of six to nine months.''

The phrase "really intense" that Claire used when talking about the treatment phases appeared to relate to her child's diagnosis of infection and diabetes, a consequence of the treatment. She also refers to the symptom burden that was very challenging for her child compared to the final phase of treatment. For the final stage of the treatment, she said it was "really relaxed" and stated that the symptoms were more manageable during than the first stage. Using this language for the chemotherapy cycle accentuates both the difference and burden at the beginning and end of treatment. The middle cycles appear to be minimised by Claire with her reference to "in and out" without elaboration or explanation. She then qualifies this comment, indicating delays (without specifying the nature of these delays) and infections as a route cause of a six-to nine-month time-frame. While talking about the cancer treatment process, Claire compares the difficulties they faced during the process. She mentioned her child had temporary diabetes because of steroid use during treatment. This necessitated learning about managing her child's temporary diabetes and also the chemotherapy-related side effects that may negatively impact Claire's, her child's and her family's quality of life. She also emphasises the possibility that the process may be prolonged due to an infection during the treatment. The possibility that her child will have to undergo painful procedures due to a longer treatment time for her child caused her distress.

Claire talked about a relationship with the consultant due to the new learning amassed in this journey:

> "I've amassed seven years' knowledge of oncology, and I can talk to consultants, you know, at quite a high level."

The fact that the Claire was able to talk to specialists about evaluating the treatment options for paediatric cancer was an indication of how much her knowledge on the subject had increased. For her, talking with consultants seems to provide her with another important information resource. This way, she appeared to have learnt to navigate the healthcare system and know which healthcare professional to talk to when she needs support and information regarding her and her child's healthcare and psychological needs. She appeared to be experiencing the extra challenges of navigating a system with a child who has a learning disability.

Beeni describes the impact of her son's cancer diagnosis on her husband:

> "I think he is obsessed with cancers, he spends all his time. So researching about the cancer, researching about different diagnosis, researching on online, reading medical papers, trying to find out more and more and more."

Beeni begins by using the word "obsessed" when describing her husband's process of learning and obtaining information about the treatment, and states that her husband reads both online and printed articles to learn more. Her husband was presented as being dissatisfied with the information he received about their son. She mentions her husband throughout the interview and his desire to gain control by increasing his knowledge after their child's cancer.

Julie, a mother whose daughter had survived cancer 17 years previously, still remembered everything she learnt about her daughter's treatment process:

> "The first protocol, the first stage was very light. And as I say she was able to go out during the day. And then there were four big hits then. And then the last two were slightly different combinations of drugs. And they were given over a five day to seven-day period. But she was often so poorly. Her blood counts just plummeted. You know, neutrophils were just rock bottom. So, I remember one time we came home thinking we were going to be home for a few days, she spiked in temperature. So we were home a few hours, and they said no, come straight back again. And they you know, she was on IV antibiotics then for a week in hospital again. And then as

> soon as her white blood cells hit a level as they started to come back again and recover. ”

Unlike Claire, Julie, when talking about her child’s cancer treatment, stated that the first stage was “light”, that is, it was not particularly impactful in terms of the quality of life, symptom management, and potential side effects of her child’s treatment. Julie talked about the medications used during her daughter's treatment and the resulting changes in her blood counts. These quotations show Julie has quite a significant amount of knowledge. She talked about how poorly her daughter was during treatment. It appears that Julie was vigilant in monitoring her daughter for treatment-related side effects and symptoms. As she gained knowledge about side-effects, the fear of missing a change in the health status of her child appears to have been a huge burden for Julie. She also mentioned that her daughter’s fever when they came home and they returned to the hospital. While talking about the effect of the treatment on her daughter's blood counts, she mentioned specific terms such as white blood cells and neutrophils, showing that she had acquired knowledge treatment protocol. Julie was aware now that neutropenia could lead to infections or even sepsis for her child, which was life-threatening. She seemed to be aware of the symptoms and signs of infection due to her daughter’s treatment. While she stated that the treatment planning consisted of medication and rest, she generally described this process as intense, involving constant risk assessment. Like Claire, Julie has also learnt about the cancer treatment processes and its potential harm on their child.

Another participant, Sam, talked about temperature, which could be a symptom of infection:

> “If you’ve got a child, he’s got cancer, you’re constantly concerned about their temperature, because if their temperature is any sort of, anything above normal you need to take them straight to the hospital because they could have, it could be a sign of sepsis, it could be a sign of infection.”

Like Julie, Sam also seemed to be aware of the signs of infection due to cancer treatment. Being in a constant state of anxiety clearly indicated that Sam has been negatively affected from monitoring her child’s vital signs.

In order to ensure that her child receives her needs, such as medications at home, as much as possible, Kate states that she has learned to give her child medication:

> “But I felt quite confident that I've learned what I needed to learn… I could manage her drugs. Well, I put the hours in to understand what was going on with the support of a good community nurse team, but we did really well at home, I think. I am petrified about being in the hospital and would rather be at home. It may be different for each person, but I felt quite confident I could manage the drugs quite well. I learned to do all of the things when they were.”

Kate, who asserted “I learned what I needed to learn”, highlights that she was focused on the essential caregiving aspect and learned how to give her daughter her medications to allow her to stay at home as much as possible. In this way, she also stated that she prioritises life treatment-risk management. She was eager to care for her child at home. In this way, she is built up her confidence and was able to feel a little bit more in control. She suggests that she loses control when they are in the hospital, and this brings with it anxiety; it may also be a sign, potentially, that a child is struggling with treatment. The fact that Kate ensures that her child receives treatment at home with the support of community nurses whenever possible makes her feel better. This may be related to her ability to support her child better at home and manage treatment and her daughter’s symptoms effectively. Kate, who has two children, appeared to be feel better at home, potentially being able to refocus on her own and her children's well-being. Also, she can re-engage with her other child and create a home life that maintains the family life she used to have before her child was diagnosed. This appeared to make her feel better because it is a more normalising situation for the whole family.

Over time, the primary caregivers in this data set learned how to manage medical tasks for their children and began to take care of their children’s medication and manage their symptoms, which increased their confidence in their knowledge. These comments show that Claire, Beeni, Julie, Kate and Sam did their best to increase their knowledge about their children’s treatments, do research online, read books, and talked to experts about how they best serve their children more during this difficult process. Caregivers in this data-set seem to blur boundaries between family caregivers and traditional nursing roles by monitoring their children’s well-being and treatment-related side effects such as fever and cough, and constantly being their children’s primary source of support. Claire, Beeni, Julie, Kate, and Sam conveyed the importance of knowing and learning about childhood cancer in different ways as ways to support their own children.

4.4.2 Complexity challenging the cancer journey

All the participants in this data set expressed the importance and value of having psychological support at different stages along the disease trajectory. This theme considers the positive and negative experiences of support. In the context of the negativities they experienced, Beeni stated that her child had additional needs related to ASD and she could not receive support from her family and some healthcare professionals. Kate also shared her experiences of not getting support from family members.

As Kate comments:

> “My brother came down from Scotland for a couple of weekends, but they can't cope with it. And so they disappear. And then you’ve got some friends who you thought

> would be there. One of my friends is very open and honest and she said I can't look at your because of our girls. I can't watch you go through it because I can't expose myself to that and I can't expose my children to that and they disappeared. Because they just couldn't. Which is fair enough. You know, it's hard to see."

Kate states that her brother came, but he could not cope with her daughter's cancer diagnosis. Additionally, not getting support from her friends appeared have made her feel stigmatised. Not knowing how to treat a child with cancer and feeling uncomfortable about it may be the reason why Kate's brother and friends chose not to continue seeing her. Interpreting the lack of support from both family members and friends as they "disappearing" was the term she used to indicate that she did not get any emotional support. Her friends saying they didn not want to be "exposed" to seeing a child with cancer, and Kate's friends not being able to see her, may have left her isolated.

In particular, Beeni, whose child had ASD, was the only participant in this study who emphasised that she did not receive emotional support from either family members or healthcare professionals. She rationalised the lack of family support from her family members as follows:

> "I have no family in the UK, my parents live abroad but it's got his family (my husband's) here in the UK but he's not very close to them. There has been no family support which has been really hard. No family support, sorry".

Beeni also talked about wanting to go and make a cup of tea or have a lunch break but needing to watch her son.

> "They won't offer that: Oh, do you want to have lunch break? Do you want to go get a cup of tea? Or can I get a cup of tea? They won't offer it unless you ask for it. And you don't want to ask because you think: Oh, they're so busy."

Beeni expects healthcare professionals to ask whether caregivers need support. Despite their child being under the care of healthcare professionals, she felt unable to leave her them, even for short periods of time. Beeni specifically feels that she cannot leave her child alone in the hospital due to his inability to communicate verbally and or to express any wishes. Beeni did not ask for any help, and she said the staff always described "busy". She expects nurses to show that they care about her by doing small acts of kindness like getting tea or asking how you are. She expected micro-communication skills by interacting and giving verbal and non-verbal signals that indicate nurses' awareness of the burden of being a caregiver. These quotes highlight the issue of nurses not proactively communicating with Beeni about the nature of caring responsibilities during her child's stay in hospital.

Beeni also expressed the need for peer support:

> “There must be more children because there are a lot more diagnoses of children with cancer going through the same thing as I am, but I don’t know them. And you know my other friends have normal children you can't relate to them, they can’t understand my journey. So that would have been important to share resources, make a peer group of parents agreeable to children with cancer, do get-togethers and meetings.”

Beeni talks about the number of children with cancer is increasing, but says, "But I don't know about them," about the children and families around her who have this diagnosis. She describes children who do not have cancer as normal children and thinks that by having a child who is not normal, she will not be able to relate to these families, and these families in turn not be able to understand her journey as a mother who has a child with cancer. What Beeni means by “my special problems” appears to be issues around isolation with having a child with cancer, and treatment related problems. The fact that she finds sharing resources with parents important, and also she thinks it is important to meet and hold get-togethers with the families of children with cancer. For Beeni, peer support could enable the sharing of needed resources, allow her to gain advice on issues related to her son’s cancer diagnosis, share personal experiences, and thus empower her.

Claire and Sam found support from family members and friends; Julie, and Kate found support from nurses, and Sam from a psychologist. Claire and Sam described the support they received as amazing.

The following quotations are from Claire about receiving support from her friends:

> “I have friends who wasn’t particularly close to, I told them that J. got leukaemia, they just stepped forward. And also who wants to take my daughter A., whom I met recently, out and have some fun, especially when we’re in London for six weeks. And that’s just you know, amazing. The first-time visitors at the hospital were allowed to come and visit J., and they gave me a chance to shower or sleep a little longer, when I had the opportunity to make phone calls and eat. Without them we just couldn’t have survived.”

Claire described her friends’ support and care for her other child as “amazing”. Not being able to care for her other child as much as she wanted while taking care of her child with cancer, and the emotional support of her friends may have made her feel this way. The fact that her child has been able to have fun may have made her feel better. Claire, who has been unable to sleep or shower properly due to the intensity of her son’s treatment, expressed the support she receives from her friends as “we just couldn’t have survived”, showing how important this support has been to her.

At the same time, Julie discussed the support they had received from health professionals:

> “So the nurse explained to us what the diagnosis and gave us some specific information about the different stages of the treatment that would happen. It was very positive about it being very treatable, and we suddenly felt we should be reassured that we knew that it wasn’t the worst type of cancer, but it could have been that the prognosis was good. And that we felt that we’d be well looked after. A senior nurse on that ward came and talked to us…And she said something like, you will see a lot of very poorly children on this ward. Don’t be alarmed…They are specialists, they know their field. The healthcare workers who were so lovely, there was an education team and a social team that looked after us. It just felt like you were being like you were being held and guided and that you just go along that your child will be looked after. ”

It is clear that the information they received from the nurse about the cancer treatment process helped Julie to go through the difficult process of cancer. Julie reported feeling reassured knowing that the type of cancer her child had was not the “worst type of cancer” and that it was treatable. When talking about her experiences with the support she had received from healthcare professionals, she mentioned the educational team and the social team, which shows that the hospital where her child is being treated specialises in support units for families. The kindness, humanity, and individual attention of the healthcare professionals made Julie feel grateful. Allocating time to family members of the child with cancer and answering their questions were seen as an indication that their children were in “safe hands”.

Kate also shared some comments regarding the support she has received from the community nurse team:

> “The community nurse teams were very good, so we did a lot of treatment at home. They came and did her blood tests a lot of times at school, because it was really important for me that she got back sooner…She could get back into as much of a normal routine as she could and the community nurse team really facilitated that. So, it’s just a finger prick and she could get back on with her day.”

Kate found that routine checks that could be performed at home with the child when possible made her and her child feel better. These quotes show how important it is for a mother to continue a child’s “normal routine”. She highlights the importance of the community nurse team and whether health professionals can support and facilitate her priorities, which is the normal schooling of her child. For Kate, it seems important that a child can continue their normal life, go to school, and spend time with their friends, despite a cancer diagnosis. She may think returning to school is a sign that her child doing well or is recovering.

Sam, who was able to get the support of a clinical psychologist during the treatment of her child, mentioned that she had positive experiences during this process:

> “He was in intensive care for about six weeks. And during that time there was a psychologist and on the intensive care ward who come. Looked after the parents of children and both myself and my husband spoke to her on a few occasions to talk through how we were feeling. She was absolutely fantastic and just to help us make sense of what was happening and what we could do to manage our own fears and anxieties. And in addition, we’ve both got really good friends who we were able to talk to as well, and give us a good support network if we felt we needed to chat.”

Sam describes having the opportunity to meet with a psychologist as “fantastic” and “really good”. The fact that both her husband and she, as family members, can meet with the psychologist and tell her/him how they feel and learn how to manage anxiety clearly shows that she is receiving support from a healthcare professional. Additionally, Sam’s mentioning having “very good” friends and a network means she has social support. Having support and being able to access support when needed may have contributed to Sam and her family feeling secure.

Experiences and levels of support varied among the sample of carers from this data-set. Claire describes having access to the support she needs from among her informal relations, and that it is important to have people from whom one can get support. When describing support from her close friends, she mentions that they take care of her other child, which can be understood as support, but also adds to her bridging and linking social capital. While Julie talks about the nurse who explained the treatment and gave time to her and her husband, Sam talks about the psychologist who helped her deal with anxiety and fears for her and her husband, and whilst Kate talks about the community nurse who helped perform her daughter’s blood tests. Beeni had a negative experience of not receiving the support she expected, not only family members but also from health professionals. Also, Beeni and Claire stand out among the primary caregivers in this study for raising issues regarding different support needs. This appears to be associated with having a child with special needs.

4.4.3 A range of emotions

4.4.3.1 Uncertainty related to survival and treatment

Claire, Beeni, and Sam described that one of the hardest parts of living with their children’s condition was the uncertainty of what might happen on a daily basis and in the future. Lack of certainty and control were frequently reported by Claire, Beeni, and Sam throughout their experience. The experiences of the primary caregivers in this data set often came from the cancer diagnosis itself and the uncertainty as to whether cancer would disappear or return.

This quote is from Claire:

> "It's just now, you know, fingers crossed, will it persist? And how many years will it persist for? And is that going to be long enough? And is it going to come back and there's just that sort of noise, this never-ending future of being immunocompromised. And it's sort of over but it's not over."

Since Claire's child had been diagnosed and treated for cancer, there is always the possibility of a its recurrence; she conveys the related uncertainty by asking questions. She is experiencing the fear of her child having a future cancer relapse. The difficulties experienced by a child being immunocompromised and the resulting inability to return to normal are a "never-ending future" for her. She expressed her desire for her son be able to get to back to normal, which may include being able to attend school or play with peers, as "normal, healthy" children do. Not knowing when they will return to their normal lives and the resulting uncertainty seem to be a source of considerable anxiety for Claire.

Beeni talks about cancer being a life-threatening disease within the scope of uncertainty:

> "You don't know if your son will make it even his life and that there's no guarantees. There's no guarantee treatment for cancer at the moment."

Beeni is afraid of the uncertain future that her child would have to face. She felt that there is no cure for her child's cancer yet, it seems to be one of the biggest challenges of living with uncertainty.

Sam talks about her anxiety about the future:

> "So the stress and strain on your marriage is hard, and it's hard when both of you are worrying about what's going to happen in the future."

Sam talked about the wider impact of uncertainty on her marriage and about the impact of uncertainty due to their child's cancer diagnosis on mother, father, and family. Not being able to do anything about this uncertainty may have made Sam feel helpless.

The above quotes show what primary caregivers in this data-set feel about uncertainty. One of the most difficult situations for Sam, Claire, and Beeni is the possibility of a recurrence of the cancer and having to live with it. The continuation of the end of treatment with the beginning of another treatment due to a recurrence, this possibly becoming permanent, and uncertainty about the future are among the concerns expressed by the participants in this data set.

4.4.3.2 Guilt related to seeking professional help

Claire, Julie and Beeni discussed a sense of guilt. Claire reported feelings of guilt when she thought she was ignoring her other child without cancer. During the interviews, guilt was either reported directly or indirectly beneath other negative emotions, such as sadness.

Claire describes the guilt she feels for not being able to adequately care for her other child.

> “You spent so long when your child’s got cancer, that you put them first and the cancer treatment comes first and everything else comes second, it really does. Because staying alive is more important than anything on the planet. The guilt of leaving her daughter and letting her think that he’s more important to me than she is which at times, she’s been upset and sad. And that’s just heart breaking to do that.”

Claire acknowledged that the needs of the child with cancer come first due to the nature of the child’s issues. This is one of the reasons why Claire feels “guilty” because her child with cancer has priority and needs more care and her child is “first” and everything else comes “second”. Having to make degrees of care/needs among children appeared to be one of the most challenging situations for this mother. She experienced guilt at not being able to adequately take care of her other child and the limited amount of time she had. She describes it as "heartbreaking" to think that her son has cancer and that her other child sees her son as more important. Seeing her daughter sad and having to pay more attention to her child with cancer made Claire feel guilty.

Julie also experienced a sense of guilt, questioning why they had not gone to the doctor and received the diagnosis earlier.

> “So to begin with, huge anxiety, not able to sleep, not knowing. And thinking the worst, you know, imagining the worst. And just completely eaten up with worry, and also guilt that I hadn't pushed quicker to get her seen by specialists sooner.”

In the above quotation, Julie expressed that she felt guilty about her child not getting the diagnosis earlier. Also, she used the expression “imagining the worst” when expressing anxiety dominated by fears about her child’s survival. The possibility of limited treatment options due to a late diagnosis of cancer and the possibility of her child losing life depending on the condition of the treatment caused Julie to experience feelings such as anxiety, guilt, and worry.

Beeni and Julie talked about the guilt they experienced and attributed this to the children's late diagnoses, whilst Claire talked about her inability to adequately care for her other children. Claire appeared to feel that she was neglecting her other child. Guilt can lead to feelings of inadequate parenting.

4.4.3.3 Helplessness

Kate and Beeni’s quotes indicate feelings of helplessness and a lack of influence in the face of inevitable cancer-related problems. As a caregiver and a mother, not being able to protect in a situation where their child would be adversely affected has contributed to Kate and Beeni’s feelings of being helpless.

Kate spoke about not being able to protect her daughter from the situations she witnessed while in hospital:

> “Think being in the hospital is so destroying it’s horrible place to be there. Very poorly children there. It’s the point in time where your baby sees other babies. Your child will die in without being too gentle about it. They’re not going to survive.”

And she sees that the hospital was some of the most difficult for navigate as a caregiver because she couldn’t protect her from seeing suffering:

> “…she saw a lot of the pain and the struggle 'cause, they make horrible noises when they're in pain and there's nothing quite as awful as a child whimpering. So, you get four beds on the ward, you sometimes you can have a private room…Well, doesn’t stop anything, does it? There’s no privacy.” (Kate)

Kate described the hospital as a “horrible place” and emphasises this several times. She talks about not being able to protect her daughter from seeing and hearing of the pain and struggle of other children while she was in the hospital. She emphasises the fact that cancer can be a fatal disease and reports that she has witnessed the deaths of other children. For Kate, the ultimate fear was that of her child dying. The lack of “privacy” in the hospital environment and the uncertainty of what to expect from this situation caused Kate to feel inadequate and helpless in terms of protecting her children.

Beeni talked about the effects of chemotherapy on her child:

> “You know, when you have chemotherapy, it’s kind of killing your body cells. So I’ve seen his hair, I’ve seen his skin paler and is like some liquid white in the brain and watching him not been feeling well, obviously, it’s probably his bones hurt his body hurt. Something’s hurting, it can’t tell me you know, he doesn’t talk. He’s nonverbal. That’s been really hard to know what he’s going through.”

Beeni stated that due to the side effects of chemotherapy, conditions such as pain in her child’s body, thinning of the skin layer, and hair loss made her feel helpless. Witnessing the physical changes caused by cancer in her child made her feel this way. She could see the impact of cancer on her child.

The quotations above show that Kate and Beeni felt that they were unable to fulfil their role of “protecting”' their children against the effects of cancer. Not being able to ensure the protection they would otherwise want due to the cancer made them feel “helpless”. Her child experiencing pain due to his cancer treatment and Beeni seeing this situation and not being able to protect him from painful procedures caused her to feel helpless. The fact that cancer is a life-threatening disease and therefore children have to receive treatment, seeing many children in this situation, and witnessing their deaths, are experiences Kate described as contributing to her helplessness. At the same time, the fact that the child has ASD led to Beeni's experience being even more difficult.

4.4.3.4 Feeling lucky having treatment options and surviving

Julie, Kate and Sam described themselves as "lucky" in this process because they were able to receive support from health professionals and because their children's cancers were curable. Sam's child was able to receive an organ transplant, it was felt that Julie's daughter's cancer would respond well to treatment, and Kate's daughter had treatment options.

According to Julie getting enough information from health professionals who deal with families and showing an empathetic attitude has a significant effect on feeling lucky.

> "I think they gave us some statistics saying, majority of young people with non-Hodgkins lymphoma, will respond well to treatment. They were really, really, really lovely in that in that teenage cancer unit. It's strange to say, but I felt lucky. I just felt lucky then just you know, which is weird, isn't it? Your child's got cancer, and she's going to have to have horrible, horrible treatment, but I felt reassured and positive. I think I was very lucky. Because as I say, the hospital was great. I was able to stay. So, it was either I or my husband. And that was very important for us to know through the night 24 hours. And sometimes I would go out and take some fresh air and talk to the children on the phone, it was at the hospital."

The high probability of being able to cure her child's cancer made Julie feel lucky. Although she felt it was "strange" to feel "lucky", the facilities of the hospital where her child was treated and the possibility of being treated for cancer are among the factors that caused her to feel this way. Another issue that was important to Julie and her family is that her daughter did not have to be left alone during her treatment; further, being able to stay in the hospital with her daughter was another reason why she felt lucky. Being able to talk to her children on the phone while Julie's daughter was receiving treatment also contributed to these feelings.

According to Kate, the fact of treatment options made her feel "lucky".

> "You know there is some treatment option or a bigger range of drugs we can try. I mean some childhood cancers have no drugs, it's awful. So, in the grand scheme of things we had options and we were lucky that her options worked. Because I know lots of strong and positive children who died."

Kate said that as a family they felt “lucky” after making comparisons with other children with cancer in terms of her own child's diagnosis, treatment opportunities, and chances of survival. Knowing that some childhood cancer diagnoses do not have a drug option shows that she is knowledgeable on this subject. She felt lucky that her daughter’s cancer had various with treatment options, and indeed that the options worked.

Sam, who also felt “lucky”, thought that her child could have an organ transplant and indeed recover over a relatively short timeframe.

> “We were so fortunate that W. was listed on the transplant list and he was only on the list for six hours and then we got a call… there was a liver available for him and that was it was terrifying. But it was also in the back of our minds. There was that tiny glimmer of this is hopeful. This is his cure, and which was amazing.”

Even though Sam’s child was only on the organ transplant list for a short time, she felt lucky that an organ quickly became available. Sam thought that a liver transplant was her child's cure, and interpreted this as “amazing”.

It seems that although cancer is a potentially life-limiting disease and generally has negative effects on people who experience this process, Kate, Julie, and Sam nevertheless consider themselves “lucky” which appeared to be because their children with cancer were successful in terms if their treatment, and that they survived.

4.4.3.5 Significant shock in response to cancer diagnosis

Claire, Beeni, and Sam described feelings of shock when first hearing of their children’s cancer diagnoses, which appeared to have a significant impact on them and reportedly led to initial feelings of shock.

This first quote is from Claire:

> “Shock. Absolute shock. When J. was little, we were given a book about Down’s syndrome. So a number of different chapters in it. A lot of children with Down’s syndrome have an increased risk of various health conditions, whether they’re born with heart problems, whether they develop vision problems or hearing problems. Obviously, they’ve got learning difficulties. That was a chapter on blood disorders, and I didn’t read that chapter. Everybody else in the family read it. So they were sort of immediately thought of leukaemia, but I’ve never known of anybody with leukaemia ever until J.’s. So, now I was just totally shocked. Totally shocked.”

Claire states that she was “shocked” when her child was diagnosed with cancer because she had never considered about the possibility of her child receiving such a diagnosis and focusing on the other problems her child had due to Down’s syndrome. As a mother of a child with special needs, her child’s risk of various health conditions encouraged Claire to read books. She had read a book about Down’s syndrome, but when her child's leukaemia was diagnosed, she wished there was no chance of it happening.

Beeni notes that she was in great “shock” when she received her child's diagnosis, as she had not considered the possibility of her child being so diagnosed.

> “Because he is nonverbal, so it’s difficult to find out what’s going on with what’s wrong he doesn’t tell me in stomach hurting or something is hurting or tell you that we have to assess him… We suddenly found a lump on his body. It was a big shock. I wasn’t expecting it, I thought it was just a scare. Because my husband already thought it was cancer. And I knew my husband always jumped to bad conclusions. But, sadly, it was cancer and it wasn’t a very good diagnosis even because it had spread to his lungs. It was quite extreme, like a high-risk stage four cancer of the testicles. It was quite a big surprise and shock.”

The reaction to the cancer diagnosis was shock, as the child was non-verbal, unable to say where it hurt, and Beeni hoped it was nothing serious. Wishing that her child would not be diagnosed with cancer similarly caused Beeni to experience shock. The shock was also a reaction to the advanced stage of the cancer and the fact that it had spread to other organs. While she explained her reaction when she learned about her son’s cancer diagnosis, she talked about her husband’s continued pessimistic attitude. Her husband appears to have taken a pessimistic view of cancer due to uncertainty about prognosis and treatment.

Similarly, Sam was shocked when her child was diagnosed since she hoped that her children would not be given such a diagnosis.

> “I was just in shock, and I think probably a couple of weeks I just didn’t believe that they’ve got it right. I thought it must be something else. It can’t be what they’re telling me it is. And it was only when they showed us the scans. It was only when he started chemotherapy that it really hit home that this is what we were dealing with. It’s almost like a grieving process.”

Sam talked about the difficulty of accepting the reality of a cancer diagnosis. She stated that she had to deal with her child’s cancer diagnosis when she was shown the scans and her child’s chemotherapy treatment started. The shock reaction then relates the situation to the grieving process. The feeling of grief that Sam had may be related to the uncertainty for her own, her child’s and her family’s future.

Claire, Beeni, and Sam gave similar accounts of shock and surprise at the unexpected diagnoses. In addition, according to Claire and Beeni’s statements, the “hope of not having a serious disease” was also associated with the shock phase. As mentioned in 4.4.3.5, on top of the shock of having a child diagnosed with cancer, the experience of Claire and Beeni was amplified by supporting a child with special needs. There were added complexities to their experience as their children were less likely to be able to express or pinpoint feelings of illness and discomfort, so that early detection or any disorder or illness could take place.

4.4.3.6 Hope for cure and hope for a future

Having the opportunity to be treated for cancer and not showing recurrence sypmtoms caused Claire and Sam to be hopeful for a cure for their children. Even when talking about the likelihood of the treatment being effective, Sam repeatedly used the word “amazing” about the treatment.

Sam, said she is hopeful that her child’s cancer may be cured.

> “We were so fortunate that (child’s name) was listed on the transplant list and he was only on the list for six hours and then we got a call to save it. And there was a liver available for him and that was it was amazing. There was that tiny glimmer of this is hopeful. This could work if this works. This is his cure and which was amazing.”

Sam talked about organ transplantation. She mentioned that even if there was a “tiny glimmer” possibility of of a cure, this would make her more hopeful. Her child had a chance of being cured, which made her hopeful for the future.

Claire expected to feel relief that treatment had ended and be hopeful for the future.

> “So we’re waiting really to be told, hopefully, at some point early in the new year that he can return to school whether that's January, February, Easter, I don’t know but we’re still hiding away. But he’s probably healthier now than he has been in seven years. Over from that little gap in between the first and the second treatments.”

Claire talked about her child being treated for cancer for seven years and about “hiding” from the cancer. She hopes that her long-term treatment for cancer will work and that her child will be healthy. It can be said that the possibility of her child being cured and returning to their normal routine after the treatment was making her impatient.

The predominant theme across the two interviews with Claire and Sam was hope that the treatment would work and that their children would be cured. Like hope for a cure, hope for the future seemed to serve as motivation to keep Claire going through some of the rougher patches of her child’s treatment. Claire also hoped her child will be healthy after the treatment was complete, and was looking forward to returning to school and, indeed, their normal lives.

4.4.3.7 Anxiety for the future

Constant anxiety was amongst the emotions mentioned by Sam and Julie as being part of their daily lives. From the point of receiving their child's cancer diagnosis, Sam and Julie spoke about their anxiety about what the future would hold for their children. According to Sam and Julie, the state of uncertainty caused them to experience ongoing anxiety.

This first quote is from Sam:

> "I still had a lot of anxiety, is one of the overriding fears you have throughout the treatment and diagnosis. What's going to happen next? But all parents of children with cancer probably feel the same, that the biggest anxiety is what if they don't get through this? And I think I had this sort of this anxiety inside of me for. Even though W. is now a year post treatment and he's doing really well and he's had a liver transplant and he's doing fantastically, I'm still anxious every single day and that, but that will never go away, unfortunately. And I can't let it doesn't affect me. It doesn't affect how happy we are as a family, but it's still there in the background and you have to learn."

Sam explained that families of children diagnosed with cancer all have a similar fear, namely the risk of recurrence. She asked herself what would happen in the future. She stated that her biggest fear was that her child's life would end. This is related to the fact that cancer is a life-threatening disease, and that Sam does not want to express based on her great anxiety and fear that her child would die if the cancer were not treated. Although her child's treatment was successful and he is now healthy, she expressed a certain anxiety about recurrence that always lives in the background, she added that she has to learn to control this.

Julie said that although her daughter was cured 17 years ago, she still has trouble sleeping due to anxiety about recurrence.

> "So very anxious, my anxiety, and I don't think that has ever really gone away. My sleep has never got back to normal. Since that time, I haven't slept well. Now. I've been through the menopause… since which didn't help. And then my husband died… And that didn't help. And now I'm caring for my elderly father, who's got dementia. And I just don't sleep well anymore."

Julie mentioned living in a constant state of anxiety related to potential new symptoms. The possibility of recurrence appears to cause her state of anxiety to be constant.

The quotes above show that Julie and Sam constantly felt anxious. Julie's and Sam's anxiety appears to arise due to uncertainty and fear of recurrence. Stress and anxiety were associated with uncertainty because the parents in this data set did not know what to expect in the future.

4.4.4 Cancer-related changes

4.4.4.1 Pivotal moment related to diagnosis

Receiving the diagnosis was an important milestone for Kate, Julie, and Sam. The pivotal moment represented the extent to which cancer truly affected the children’s and their families’ life stories. No matter how long it had been since their diagnosis, Kate, Julie, and Sam remembered the date of their children’s cancer diagnosis to the month and year. At the same time, they remembered how old their child was. When they talk about what they experienced during this whole process, it is possible to separate their lives into before and after the cancer diagnosis.

> “She just turned six and she got diagnosed with acute lymphoblastic leukaemia on the 18th of December 2018.” (Kate)
>
> “And she was 13, almost 14, when she was diagnosed. It was in May 2005. So it’s quite a long time ago now, 17 years, nearly 17 years ago.” (Julie)
>
> “So his diagnosis was hepatoblastoma, which is a very rare form of liver cancer, and he was diagnosed in June 2020.” (Sam)

In the above quotations, it shows that Kate, Julie, and Sam remember the month and day their children were diagnosed with cancer and the implications of the diagnosis, which shows that the experiences of the participants were amongst the most important turning points of their lives. Remembering the date when they learned that their child had a potentially life-limiting condition means that their lives were irreversibly changed by the diagnosis. This appeared to make Julie, Kate and Same think that it lead to issues such as anxiety about their children’s future and reflected upon the fact that their children would not be able to go to school. This theme is about that important moment experienced by the primary caregiver mothers in this data set when they realize that their lives as a family would never be the same again with the diagnosis.

4.4.4.2 The necessity of treatment versus psychological trauma

Children with cancer undergo a typically myriad of medical procedures. Sam noted a wide variety of stressors related to her children's cancer treatment and treatment-related side effects.

Sam had difficulties with her child's inability to eat due to the side effects of cancer treatment and the nasogastric tube for feeding. She commented:

> “At times really, really difficult and horrible. And W. had his nasogastric tube. That goes my husband knows to provide him with extra food because he wasn’t eating during his treatment and that was something I learned to do how to pass the tube down his nose down into his throat and into his stomach. And because W. was really sick when he had his chemotherapy he would be sick sort of 678 times a day and he bring his tube up so we'd have to get a new one down. And I learned how to do that to make you say that we didn’t have to keep going to hospital every time that happened. That’s horrible to have to do to that your own child, to put that back down their nose time and time again.”

Sam’s child's inability to eat during anti-cancer treatments alternatively caused the child to be fed through a nasogastric tube. The mother's statement that her child was sick multiple times per day due to the side effects of the treatment appears to suggest she wished to convey the intensity of the treatment and how significant the symptoms were. The fact that the nasogastric tube was frequently dislodged and she had to perform this painful procedure on her child every time this happened and had to live with it caused her to describe this experience as horrible.

The quotes above illustrate the challenges Sam faced when her child was receiving cancer treatment. The intense cancer treatment process and having to be a part of the treatment can be counted among the parts that Sam had difficulty with.

4.4.4.3 Decision making and consenting in paediatric cancer

Making decisions about the care and treatment of children with cancer is not always easy. This theme describes Claire and Kate’s difficulties of deciding what to do next about childhood cancer treatment options. Claire and Kate had a hard time deciding which treatment to choose for their children. They worried about doing their best and faced the uncertainty of having made the right decision regarding their child’s cancer diagnosis.

Claire was asked the question: “How did you feel emotionally at the time of diagnosis? And how did this change as time went on?” She responded by talking about the decision-making role and it’s difficulty, as see asserts.

> “I'm probably one of the longest serving oncology mums that I know of seven years of living this life for a long, long time. I’m not as good at decision making as I used to be, I think probably because consultants make the big decisions for J. and that affects me, they’re the experts, and they involve me in those decisions and decisions aren’t quick in the NHS. Particularly. So, you sort of slow down a little bit, I think and maybe

> I’ve picked up on that myself, but I do find that decision making isn’t. It’s affected me more than just emotionally it’s affected my personality, the way I function, it’s turned my world upside down.”

Claire has made many decisions for her child, who has been treated for seven years, and by comparing the past with the present, she stated that she was no longer as good at the decision-making role as she used to be. She has made many decisions regarding the fact that her child and therefore treatment options, may be limited, and the possible side effects of these treatments on her child with special needs. She appears to have felt a greater burden from the fact that her participation in important decisions about how her child would be treated was such a critical issue for her child, and the risk of adverse health outcomes. She talked about “her life being turned upside down” while taking on the role of decision maker. And this analogy she used is an indication that the responsibility of her decision-making role was significant. Claire acknowledged the expertise of the consultants. Although she educated herself about treatments, the fact that she was not an expert in oncology and did not know what the consequences of the decisions she made on behalf of her child would be appear to have caused Claire to feel this way. The responsibility of being asked to consent to a treatment that could be life-threatening seems to have been a burden to her.

Before treatment is administered, consent forms have to be signed. Kate expressed her discomfort about this issue.

She commented:

> “Maybe just about and this is ridiculous because there’s nothing you can do about consent forms. And you have to sign consent forms? I asked the question at one point and I said: What happens if they don’t sign the form. She's not well because it's lifesaving treatment. So, I understand that the consent form is about letting me know what might go wrong. And I am agreeing to give her this treatment, even if that stuff goes wrong, by still agreeing to it. That was really difficult. It was like that step away of blame. So, I also have to carry that. I also have to have that burden of. Well, what if this treatment does make her infertile. It felt like those forms added to my burden of caring.”

Kate had many unanswered questions while performing her role as a decision-maker. The questions Kate asked were about the uncertainty of the outcome of the decisions that needed to be made. She felt that there was no impact or otherwise a minimal role, in her decision-making regarding active treatment, saying “If I don't consent they will do it anyway because it's a life-saving treatment”. She asked if she could have chosen a different treatment for her daughter, she felt that she didn not have a choice. The uncertainty around the decision-making process was particularly stressful for Kate, given that it could have serious consequences for her child’s life, such as infertility. Accordingly, Kate appeared to feel disempowered and had a lack of agency with potentially the impact of what the treatment was going to cause, not just in terms of life and death, but also in the longer-term. She also stated that she experienced feelings of “self-blame” at the same time as her role as a decision-maker. It seems the decision-making role was emotionally and psychologically very challenging for her.

Since children are unable to make their own decisions, parents must play this important role in protecting their children’s interests and avoiding harm as much as possible. Hence, for Kate and Claire, participating in decision-making involved a considerable burden and significant emotional distress. The fact that cancer is a life-threatening disease and the burden of being a decision-maker shows that Kate and Claire had a hard time making decisions. In this decision-making scenario, Kate mentioned the concern that it would have negative consequences, particularly in relation to her child's future life. Kate explained how difficult it was for her to take on the decision-making role due to the impact that could have on her daughter's fertility as a result of the side effects of the drugs used in the treatment. Kate appears to have suffered some considerable psychological stress about having to consent to the treatment of her child and the possibility of her child experiencing long-term consequences of cancer. Because her child has special needs, Claire appears to have needed information about cancer treatments and the effectiveness of such.

4.4.4.4 Living in a restricted shielded world

In this theme, Claire and Sam shared their experiences of living in a “restricted shielded world” to protect their children from infection.

Childhood cancer treatment and immune suppression meant living in isolation with Claire commenting:

> “I don’t think we were affected by the COVID lockdown as much as other people because we we’ve been living in a shielded world, hiding away from soft play centres and people and diseases and germs and general public for quite some time. So, it wasn’t too bad. Certainly, for myself and J… We went down for a week, and then he had his magic cells, and then we sat there for four and a half, five weeks, to make sure that it was working, and then we come home, and we’re still hiding away from the world.“

Claire mentioned that, as other people were forced to isolate during the COVID-19 pandemic, they have been avoiding public places since her child started receiving cancer treatment. The general population may have found it difficult to adapt to the changes and social isolation imposed by COVID-19, but she expressed that these were similar to the changes her child experienced while receiving treatment. She stated that they live in a “shielded world” so that their child does not contract other diseases due to a low immune system while being treated for cancer. Even if there were no pandemic, Claire had to regularly manages infection risks in case her child faced problems with his immune system. She seemed particularly vigilant with regard to preventing her child from being exposed to infection. This fear of infection resulted in Claire adjusting her lifestyle to reduce the risk to her child. Living with an ongoing threat of relapse may have contributed to her feelings of isolation. Feelings of loneliness may also increase due to isolation. Claire mentioned “ring the bell” which is a ritual used to mark the end of cancer treatment, indicating the completion of the chemotherapy/radiation treatment. The bell serves as a celebratory symbol for patients on their cancer journey , for instance, receiving a positive diagnostic scan or achieving a personal accomplishment. During the interview, Claire talked about the Car-T treatment and described it as “magic”, and also considered the effect of this treatment on her child’s cells as “magic”. She may be hoping that her child will be able to recover thanks to this “magic” treatment, so they will not have to live in a sheltered world and can return home, to a normal life.

Sam, who has a newborn baby as well as a child undergoing cancer treatment, has to spend all her time at home, which is difficult, she comments:

> “And having two young children, both of who require a high level of care because the six-month old requires a lot of care as well, and it does make it very difficult to be stuck in the house all day, every day, with them.”

Sam explained that the fact that her two children are dependent on her and the isolation resulting from having to stay at home may have made her feel overburdened. Sam as a mother of an infant appears to have faced additional stressors in caring for her child with cancer and her infant sibling. She appeared to feel upset when she was unable to properly care for her six-month-old baby or do important things for the baby, such as breastfeeding, because she was caring for her other child. She appeared to feel guilty as she was cannot unable to give the care as she wanted to for her child with cancer.

Claire and Sam talked about the emotional consequences of living in a restricted world. These quotes show that living in a shielded world is crucial to protecting children with cancer, but that the impact of living in this world on Sam and Claire was fear of infection, social isolation, loneliness, being overburdened, helplessness, and sadness.

4.4.5 Intersectional complexity in care

This theme considers the challenges of supporting children with special needs in navigating the cancer journey. However, it is important to note that although there were some shared experiences, the differences in circumstances for each participant made the overall experience unique.

Among the primary caregivers in this data set, Claire was the mother whose child had been diagnosed seven years previously. She continued to share what she knows about treatment options:

> “Children with Down’s syndrome aren’t able to have bone marrow transplants because it's too harsh a process for them to survive. So we weren’t really that many other options but Car-T; they basically take the patient’s own leukocytes, and they mix them with this magic drug that was developed in America, and they grow them in the lab, and then they put those, but clear the body, the bone marrow activity, and they put the person’s own genetically engineered cells back in, and then give them time to grow and spread. And then they will seek and destroy any blasts that that arise in the future.“

She starts the dialogue by saying “Children with Down’s syndrome” and then explains the situation with information about Down’s syndrome that may affect the effectiveness of cancer treatment. She characterises and justifies this assertion based on the “harshness” of the bone marrow transplant procedure and then risk, a certainty of death. She closes this avenue emphatically and describes the alternative, demonstrating some medical knowledge in her description of Car-T. Not having options regarding treatments and worrying about their effectiveness may have caused her to delve deeper into and become more knowledgeable about treatment options. Also, worries regarding decisions related to cancer treatment regulation appear also have encouraged Claire to seek information.

Among the primary caregivers in this data set, Claire and Beeni stood out with a need for information regarding cancer treatment. These two caregivers, who were mothers of children with special needs, stood out compared to other families because they tended to have more information needs about their children’s diagnoses. Claire’s information needs appeared to be related to her child’s cancer treatment options, which were limited because of the child’s learning disability. Throughout the interview, Beeni mentioned that her child had been diagnosed with advanced-stage cancer and that her son’s behaviour could prevent the continuation of treatment. Having a child with ASD, the difficulty of managing her child's behaviour during treatment, and having an advanced-stage cancer diagnosis appeared to direct Beeni and her husband in obtaining more information about alternative treatment methods.

Beeni referred to the lack of support she received from her family (see also 4.4.2). She appears to have more difficulty accessing psychological support than other caregivers in this study, possibly because she may have comparatively lacked social capital and experienced stigma. To add to the complexity of her experience, Beeni also felt disappointed by the lack of support from health professionals who seemed focused only on the treatment of the cancer:

> "When I go to hospitals, I have to look after my son myself, even the nurses, there is never enough nurses, there is never enough staff. So, basically, I don't get any respite at home. And when I go to hospital, it's even harder. They should provide parents with some support, the nurse just comes and do the drugs and disappear again, you never see the nurse the whole day long was stuck there."

Beeni appeared to be asserting that there were not enough nurses, that she sometimes did not know what to do and that she too needed rest. The complexity of her personal experience appeared to have caused her to need greater support from the nurses. Beeni explained that due to her son's ASD, she could not leave her child alone in the hospital as follows:

> "Because I can't leave my son alone in the hospital. Obviously, you can't. Nobody can. Nobody's allowed to, you shouldn't and you can't. And especially as being autistic, he will try to run away and is attached to a pump. It's not safe to do that."

By saying, "Nobody is allowed to leave their child in the hospital" she actually sees it as something that "should not be done or is prohibited". Beeni personalises this prohibition, then universalises this by saying "nobody can", so "not only should you not but the hospital context means you can not". She describes her child trying to run away. She stated that the behaviour of her child, who is on a pump due to cancer treatment, makes it difficult to care for them in the hospital. Hospitals may be seen as a challenging environment for the child to adapt to. She gives a clear example of the risk that her child's responsive behaviour may cause treatment delays or even for it to be discontinued. Beeni has difficulty coping with the challenging behaviour of her child wanting to leave the ward. She clearly differentiates her child from children without ASD and situates the problem with risk and safety. Additionally, Beeni was required to be involved in and guide her child's cancer care without any adaptations or adjustments by healthcare professionals or the hospital to her child's neurodiversity with ASD. In response to the risk that the "run-away"behaviour of her child may prevent the continuity of cancer treatment, Beeni has been showing distress, and in this regard may expect more advice and support in the clinical environment and during treatment.

Beeni also thinks healthcare professionals should look at the cancer journey from the perspective of a child with ASD.

> "The focus on cancer, the autism side of my child is being neglected, he is not getting the support he needs for autism and that's gonna have a big lasting impact on his life. That's our long-term worry. He is not gonna have the quality of life I want him to have."

Beeni emphasised the importance of autism-related therapy support to improve her child's quality of life. She reported worry related to her child's condition and worry about the long-term impact of ASD on her child's future. She stated that her child's autism-related needs must also be addressed. She expressed her wish that ASD therapies could continue at the same time as the cancer treatment. Moreover, Beeni has been examining the impact on child development that a cancer diagnosis can have and focused on the life-long implications for her child. This is contrasted with immediate, treatment-related interventions in which health professionals could be perceived as focusing on process and compliance without having to explore these longer-term implications. Beeni shared her worry about her child’s future. In addition, she also thinks that her son’s ASD was neglected by healthcare professionals and the importance of ASD treatment and therapies in her son’s life. This may be due to healthcare professionals prioritising cancer treatment compared to ASD therapies.

Moreover, Beeni shared the following about her child’s late cancer diagnosis:

> “And because it was found out so late, it had grown quite a bit in his body, and it has spread to his lungs basically.”

Beeni’s child, who had ASD and was non-verbal, could not articulate any symptoms himself, which made diagnosis difficult. The late diagnosis of her child's special needs appeared to create feelings of guilt in the mother as the cancer spread throughout her child's body and lungs. She appeared to blame herself for her child's late-diagnosis. Her feelings of guilt appeared to be because Beeni though she should have been aware of the signs and symptoms of cancer. This finding is different from the parents who have children without a learning disability diagnosis.

She also reported that her son's inability to express himself due to his ASD, and the inability to convey to his mother how the side effects of the treatment affected him, caused her to feel helpless. Beeni interpreted her child’s symptoms by paying attention to how he acted.

The following example highlights how the Beeni found this experience “horrible” especially when her child did not fully understand what was happening.

> “He hates needles. I had to hold him and there was like, an entire department of people holding him. I was holding him everyone was holding him and then someone was trying to insert a cannula in his hand to get bloods out. And it just didn’t work. And even when the cannula was done, I think it was still broken. It wasn’t working. So that was a very horrible experience. I’m sure everything like this causes a lot of pain in him and like he goes through a lot of trauma because it can speak he can’t tell us he can’t express his frustrations.”

Beeni described the scenario that her son hates needles, and felt she had to hold him, had to restrain him. She accentuated the terror experienced by her son in the numbers involved by saying the “entire department” was holding her child. She identifyied this as a traumatic event. Beeni significantly identified her son's inability to articulate this trauma verbally. For Beeni, it must have been emotionally difficult for her to have to hold her son down. Needle-related procedural pain and the associated need to hold their children down was highlighted by Beeni as an aspect of the treatment she found hard to manage. She had a strong feeling that her child had been traumatised and was frustrated due to the pain he was experiencing. The associated medical procedures can be highly distressing to children with cancer and ASD. This may include a complete blood count, various types of X-rays, and bone marrow biopsies. The stress on the paediatric patient and caregiver associated with these procedures or other invasive interventions is amplified when healthcare staff fail to provide adequate explanations or alternative ways of supporting a traumatised child with ASD to have a cannula inserted.

The physical and emotional impact on the mother as well as the child, of trying to manage this is clearly articulated here. Emotionally, she appeared have felt guilty for not being able to protect her child and help her child in the way she wanted to. Beeni, who had difficulty communicating with her child and understanding her child's needs, was the only mother who reported experiencing "trauma" during treatment, compared to the other children's mothers in this study. While procedures such as blood collection are difficult for any child, those with ASD can sometimes be particularly vulnerable due to their limited understanding.

The intense chemotherapy treatment and the need to stay with her son constantly were the moments when Beeni expressed emotional difficulties. It appeared the staff were not willing to support her non-verbal child and left her with this responsibility. She also mentioned difficulties managing the child's expereince in many procedures:

> "It says the administration of all the appointments, he has the CT scans, he has Radiation Gen scans, X-rays, and he has ultrasounds…blood taken every week. That is a drastic change every week…chemotherapy every three weeks…we have to stay the whole day in hospital, then some chemo, and ultimately we also had to stay the night also in hospitals as a 24 hour chemotherapy per day… for four days… I have to keep him attached to the pump so he doesn't run away. You know, it's very hard."

The treatment methods applied while her child was being treated for cancer and the length of these processes were used by Beeni to express the difficulty of her experiences. The adjectives "drastic" and "hard" that she used regarding these processes emphasised her experiences in this regard. Her need to be present at all times, and her child's attempt to "run away" because he did not understand the need for continued treatment due to his ASD indicates that this mother had difficulty managing her child's expereince. She had previously mentioned that she expected more support from healthcare professionals on this issue.

4.4.6 Impact of cancer

4.4.6.1 Financial implications

Claire, Beeni, Kate and Sam mentioned financial problems related to cancer treatment. The financial situations of all the primary caregivers in this data set were affected in some manner. Claire stated that she had to had leave her job and she was instead receiving government benefits. Sam and Kate talked about the financial pressures that result from cancer treatment expenses as well as the additional daily living costs.

Beeni mentioned a career break, and this caused her financial difficulties:

> “So, financial constraints I could say. I was doing a part time study course. Because I was a mum with career break for a very long time. It’s like I was trying to get back into thinking of working being financially independent. And so, I can do more things for him, give him a sensory garden, give him lots of things, only make the house a very nice place for him. But obviously, I can’t work now. So, it's you know, it has a big financial constraint. It reduces when the parent loses independence reduces mobility.”

While Beeni is considering her career, she talks about losing her financial independence as she cannot work due to her son’s treatment. She mentioned that if she could continue working, she could create a sensory garden that would benefit her child’s ASD. This appeared to have also affected her emotionally, as financial constraints could have made Beeni feel more overburdened. The financial burden caused by paediatric cancer may have negative effects on Beeni’s family’s quality of life. These effects can be seen as a result of Beeni’s loss of financial independence and her child's inability to receive the necessary treatment due to his ASD.

Kate shared her experiences with life insurance, travelling to hospital and mortgage issues:

> “However, financially, it was a hit. It’s not covered on any kind of life insurances or anything. You also have to travel into the hospital all the time, so I’m still financially dealing with the hit of being a caregiver. There’s, you know, there’s financially really quite serious implications and if I didn't have the job, because I'm on my own. I don’t get any money at all. So, it financially was quite difficult and quite stressful, and there were huge amounts of stress attached to that to not being able to afford things.”

Kate talked about the nonmedical expenditures due to transportation during her child’s treatment that led to financial strains for her. She mentioned that no life insurance would cover expenses related to her child's cancer treatment and that she had to suspend paying the mortgage. She talked, as a single caregiver, about difficulties balancing income and expenses as the sole provider, with the additional demands of providing cancer care to her child. Being a single parent and not being able to cover the expenses appeared to have made Kate feel lonely and helpless. She noted that finances were a major source of stress and worry during treatment.

Similar to Kate, Sam also mentioned out-of-pocket expenses such as travel, food, parking, and fuel as financial burdens. (Out-of-pocket expenses by definition are not covered by insurance or government funding.) As she comments;

> "It has had an impact financially and we're fortunate enough that we were in a position that we could take that time off. But obviously that comes at the cost of having less money to do things with them, and traveling to and from the hospital all of the time is very expensive. Lots of money every week to parking car there and you're paying for food. We were really fortunate that we had a room at the R. M. Charity House in B. for a short period of time, which was great because it meant we didn't need to pay for hotel accommodation. This helped a lot financially, but it's still incredibly expensive."

Sam said that although they receive support from charities for accommodation, financial difficulties remain. She stated that they feel "fortunate" because they did not have to pay for the room they stayed at the hospital. The reason why she felt "fortunate" appears to be that she is not paying at least one of the expenses.

Claire mentioned that she left her job:

> "I used to have a well-paid job and I'm now on benefits."

Claire mentioned that she received government benefit because she was not working. She did previously have a well-paying job and that the child benefit she currently receives is less than what she earned. Her financial situation change and the reduced household income appeared to have negatively affected her family. Financial difficulties appeared to cause Claire and her family members to experience psychological distress, reduced psychosocial well-being, and poor quality of life.

Claire stated that her child has nutritional problems due to Down's syndrome and therefore needs nutritional therapy. This need may also negatively affect her financial situation.

> "He had problems eating before this all started because of his sensory processing. And he needs feeding therapy."

Claire stated that her child received feeding therapy for developmental delays related to eating due to oral sensory problems (feeding therapy aims to develop normal feeding/swallowing functions). Any additional therapies that the child must receive are likely to increase the financial burden on her family. She has another child who may themselves experience significant psychosocial stressors due to the financial burden, and that may thus affect her education and career choices. Claire's leaving her job may require her husband to work more and her relationship with him may be negatively affected.

Claire, Beeni, Sam, and Kate stated that they had financial difficulties due to issues related to cancer treatment, extra therapies, and nonmedical expenditures, decreasing their earnings.

The financial hardship experienced by the children of the four primary caregivers in this study during cancer care may increase their risk of experiencing psychological distress. Psychological distress can have a negative impact on quality of life, family functioning, and marital distress, and may further have an impact on the well-being, coping, and adjustment of the diagnosed child. Although all of the children in this study were diagnosed with cancer, Claire and Beeni, who have children with neurodiversity and Down's syndrome, experienced additional financial difficulties due to their need for specialised childcare treatment (such as feeding therapy, sensory garden).

4.4.6.2 Dyadic relationship problems

This theme captured Claire, Beeni, and Sam's experiences of a significant change in their family system, including increased problems with spouses.

Claire stated that she felt unsupported from her husband during this process.

> "My husband (name of husband "D.") and when (name of child "J.") was first ill it was me that took him to the doctor's, when he needed to stay overnight in hospital, there was no question it was me that wanted to do that needed to do that. And D. stepped back and I stepped forward. And I stayed in that role ever since. So, I'm very much J.'s carer. And it's got a stage now where I've amassed seven years of knowledge of oncology, and I can talk to consultants at quite a high level, and he can't. And so, it does put a big strain on your relationship… And I'm an egg and he's a potato and you know in a time of crisis, I just sort of jump in and deal with it, whereas D sort of stands back… So, we're different people and we handle it differently."

Claire talked about taking on the role of caregiver. The fact that her child has Down's syndrome and therefore has special needs was the reason why she sees herself more as her son's caregiver. She used the analogy of "I'm the egg, he's the potato" about her and her husband's behaviour in coping with their child's illness. According to her, the fact of the differences between men's and women's parenting and personalities are a significant strain on her relationship. For Claire, her child's diagnosis and treatment revealed differences in how she and her husband coped with the situation, with an adverse influence on her relationship.

Beeni stated that taking care of her son alone:

> "I'm very drastically busy. I'm a full time carer looking after my son. I'm literally like a single mum doing everything now and my husband is like in a depressed state. He's working from home. But he's mostly lying down in bed and depressed and thinking sad things."

Beeni presents herself as “drastically busy” and she feels like a “single mum, full time carer”. She indicated she was getting insufficient emotional support from her husband. While she seems to have taken responsibility for childcare in this family, the father appears to play no role in the care. Having to manage childcare tasks on her own seems to negatively affect her. She interprets her husband’s behaviour and thinks that he is depressed. She described mental health difficulties as having impacted the quality of her relationship with her husband in terms of affecting their communication.

Beeni also perceived fathers as being neglected. Because of her role as the primary caregiver of her child, friends and family members may neglect the father and talk to Beeni to gain information about her child’s condition;

> “Fathers get very neglected. Mums talk, at least talk to my friends, my family. But my husband, he won’t talk to anyone. He doesn’t want any help. It’s like a negative thing to see a mental health support person… It’s like such a taboo. Fathers have an ego problem. Mostly men or men need to grow up with an ego problem, that …they’re not allowed to share intimate thoughts, their worries with other people… like they wouldn’t want to see a counsellor.”

Beeni also stated that her husband does not want to receive mental support or talk to anyone. She stated that “fathers” have ego problems and their seeing mental healthcare professionals is perceived as “negative” and “taboo”. Cultural factors may be influencing this father’s opinion about receiving mental health support. In this family, the father’s lack of support and depression seems to have had a negatively effect on Beeni. She also concluded that, culturally, men do not want to see counsellors because they are not “allowed” to share their views and feelings. Traditional masculine norms, stereotypical gender expectations, and self-stigma may have acted as barriers to seeing a mental health support person for this father.

For Sam, who also has a newborn baby, cancer treatment resulted in her not being able to see her husband enough and spend time with him. She comments:

> “So, it makes it puts a massive strain on your marriage and your relationship with your partner, and particularly in those early months. And I think me and my husband, we saw very little of each other, other than to pass in the corridor on the way to the ward to change over when we went to the hospital for our son. And my husband stayed with W. for the first month when he was diagnosed because I just had a baby… We would swap every three to four days. So, we weren’t allowed to swap in the hospital, so we would just meet outside quickly for two minutes and then we’d swap. It’s hard when both of you are worrying about what’s going to happen in the future.”

Sam reported marital relationship challenges with her husband, including not being able to spend time together and talking and worrying about the future together. Physical separation due to hospital stays made it difficult for her and her husband to maintain effective communication and share the psychological burden of caring for their child. Having a newborn baby and having to take care of her also seems to have negatively affected their time together.

The above remarks from participants in this study show how childhood cancers negatively affect relationships between couples. Sam talked about how physical separation negatively affected her relationship with her husband. Claire talked about her husband’s parenting style, personality, and the impact of his coping styles on their relationship. Beeni talked about her husband’s mental health problems and his unwillingness to see a mental health professional and the negative impact this had on their relationship. Having children with special needs appeared to have contributed to the burden on Claire and Beeni’s marital relationships.

4.4.6.3 Impact on siblings

Childhood cancer not only presents challenges to the life of the child with cancer but also to the siblings’ lives. Sam, Claire, Julie, and Kate had various concerns about other siblings. Beeni has only one child.

According to Sam, her other child experienced negative consequences, such as not being able to spend time with both parents and her sibling having cancer. As Sam comments;

> “My daughter, the first three months of her life, she only knew one parent and so, she never had time with two parents. And I remember when my husband came home after a month of being in the hospital with W. and we swapped over and my daughter just cried for 24 hours because she didn’t know who he was. And it was heart breaking. Since W. got home, and then we got to spend more time together then, it’s had a good impact on her because we've spent so much time together as a family. They’ve got such a strong bond as brother and sister with parents as well. So that’s fantastic.”

Sam and her husband may have felt guilty about the limited amount of time they have had with their newborn baby, at not being able to provide for all their children equally, and that they thought they were neglecting the sibling. These feelings of guilt can lead to feelings of inadequate parenting. She describes it as “fantastic” for her children to spend time together and strengthen their bond as a positive development. She appears to be experiencing emotional turmoil when talking about the impact of the disease on her children, touching on both positive and negative effects.

Claire, who has a child with Down's syndrome, mentions that she was separated from her daughter for a long time to take care of her other child, and that this upset her very much.

> "And it's had an impact on my daughter. When this started, J. would spike a temperature in the middle of the night and because he had a central line that meant that we had to call for an ambulance because he couldn't take it into. She'd go to bed at night not knowing if we were going to be there in the morning, and that went on for two and a half years to a certain extent it carried on like that. But she's been an absolute superstar."

Claire's focus on the needs of the child with Down's syndrome has led to a lack of parental attention on their other child. She may feel guilty about "disappearing" from her child's life, and her other child may have been adversely affected by this. Sibling well-being may be profoundly affected by the experience of living in a family raising a child with Down's syndrome who also has ongoing health problems requiring additional care. The sibling may have experience abandonment as the mother spent more time with the child with Down's syndrome. Claire mentioned that she stayed in the hospital with her sick child, and that the other child usually stayed with his father, separate from the sick sibling and parent. She said the separation time was six weeks. These changes may trigger numerous difficulties for the sibling in their daily life and family relationships, affecting her health-related quality of life. She also adds that she acts like a "superstar" despite her young age. She seemed to have minimised the impact on her daughter by saying that her other daughter acts like a "superstar" and that she is actually mature and can handle being away from her family. To meet the changing needs of the family, the other child may have acted in a mature manner to adapt to her new role as the sibling of a child with Down's syndrome.

Claire described a sense of guilt associated with this identity for failing to adequately fulfil her parental responsibilities to her other child. She asserts that:

> "I want to do as my mum did for me and expose her to things and experiences and foods and places and theatre and cinema and stately homes in places. She can't even have a sleepover at her friend's house. It is annoying. Because when she goes, when it gets past bedtime and they're still awake, and she's overtired, she panics, and she calls us we have to collect and bring home. So, I wanted to teach her things that I enjoyed or learned as a child."

Claire stated that she wanted her other child to continue participating in as many activities as possible and that, as a parent, she wanted her child to have the same experiences and opportunities as her peers, but that this could not happen. Due to cancer in this family, the peer activities of the siblings decreased as they were difficult to maintain. She spoke with great sadness about being unable to fulfil her responsibilities as a mother for the other sibling due to the needs of her child with cancer and Down's syndrome. Not being able to give her a "normal" childhood appeared to lead her to feel guilty and cause her grief at the normal childhood she appears to have lost. The fact that her daughter wakes up at night and calls them in panic while describing the incident they experienced is also an indication that her daughter has been psychologically affected.

Julie also expressed that she did not spend enough time with her other children. At the same time, she added that the other children were also curious about the status of their older sister:

> “I was completely focused on that one child; I was aware that my other two children needed me. They were fantastic as well that the youngest one was only five-six. So very young, still needing her mum and missing her mum. And I was very aware that was happening that and I, wonder now sometimes how much of an effect has that had on them that because they have had children’s level of anxieties about what was going to happen to their sister and missing them.”

The fact that children are worried about their siblings diagnosed with cancer is an indication that the diagnosis has had a negative effect on the other children in this family. Siblings may feel a sense of loss in relation to their daily life activities and routine, as well as a loss of intimacy within their family. As reported by Julie, her children behave quite maturely for their age. Not being able to spend enough time with her other children may have made Julie feel helpless, guilty, and sad.

Another participant, Kate, mentioned that her other child, her son, could not accept the his sister’s diagnosis, and that she had not seen her other child for a long time.

> “So, he had just turned 18 when she got diagnosed. And it was difficult for him because he was old enough to know. Then, he disappeared. He did not cope well with it at all. We didn’t see a lot of him for a good few months.”

After hearing his sister’s diagnosis, Kate’s son may have experienced a range of emotions. As the sibling of a child with cancer, he may also have experienced maladjustment and withdrawal. The fact that Kate had not been able to see her son for a long time may have made her feel guilty and helpless.

It is understood from the experiences of primary caregivers in this data set that having a sibling diagnosed with cancer has a detrimental effect on other siblings. As primary caregivers, taking care of children diagnosed with cancer and being unable to spend as much time with their other children may have caused Claire, Julie, Sam, and Kate to feel guilty, helpless, and sad. Claire's other child also had a sibling with special needs, which may have contributed to her not being able to experience a normal childhood and being negatively affected psychologically.

4.4.6.4 Changes in family dynamics

Beeni and Julie talked about how family life was negatively affected by their diagnoses because parents ultimately spent more time with the child living with cancer.

Beeni talked about her husband's emotional reaction to their child's cancer diagnosis and how they, as a family, were affected by this. She comment:

> "I think it was a very torturous experience, especially for my husband. So, the day when we got the whole diagnosis for the cancer, I think my husband had a breakdown, he actually ran away from the consultants office, and he thought he was gonna kill himself. And D., there was police sent to look for him, because we thought it was going to harm himself. And they found and brought him back from the station. And he's come to terms with it, but he's quite depressed still. And because he's a man, men need lots of support and mental support. It's been worse for the father, I think."

Beeni reported that her husband had a very strong reaction to his child' diagnosis, following which she identified a marked difference in her husband's behaviour. The fact that her husband lacked well-being and could not cope with the diagnosis had a negative impact on them as a family. A cancer diagnosis of a child was a traumatic and highly stressful event for this father. She also makes comparisons about the coping of the parents, saying "it has been worse for the father."

Julie stated that the diagnosis of cancer in one of her family members affects all family members negatively. She commented:

> "They I remember one evening, I haven't cried about this for a long time. One evening, I came home and sat on the sofa with the children, I think we might have had the telly on, and we sat on the sofa and one on either side of me. And the three of us just cried together just because you know they were worried. B. said to me, is she going to get better? And I said, yes, she is, because by that point I was, you know, I wasn't 100%. But I was feeling, I knew that she was responding well to chemo, they were very happy."

Having the same anxiety and hoping for the recovery of siblings with cancer as a family is an indication that they are affected by cancer as a family. The fact that Julie said she has not cried for a long time shows that she may be presenting as "strong" for her other children. She stated that the siblings of the child diagnosed with paediatric cancer are concerned about the health and prognosis of that child. The fact that other siblings have insufficient information about the details of cancer may worry them. Julie tried to prevent the siblings from being upset about their sister, telling them that her sister was fine, although she was not absolutely sure of such. Other siblings may experience significant disruption to their usual daily routine due to the increased care needs of the child with cancer, which impacts their psychosocial physical and emotional well-being, academic performance, school attendance, and family/sibling relationships.

The above quotations illustrate that the fact that one of Beeni’s and Julie’s children having a life-threatening disease deeply affects every family member. While Julie talked about how cancer affected them as a family and talked about her children’s sadness, Beeni talked about her husband’s behaviour. As the father of a child with ASD and cancer, Beeni’s husband, reactions to the diagnosis may indicate that he is grieving.

4.5 Summary of the Chapter

This chapter has outlined the five group themes identified through the analysis of the transcripts using the IPA approach. The themes are drawn from this interpretation and analysis process capture the lived experience of the as primary caregivers in this data-set while maintaining a clear focus on their own words and stories. Analysis of interviews revealed five master themes: I learned what I needed to learn, Complexity challenging the cancer journey, Intersectional complexity in care, A range of emotions, Cancer-related changes, and Impact of cancer.

In these findings, primary caregivers talked about facing challenges. This study found that these parents experienced guilt, anxiety, stress, shock, helplessness, and uncertainty. They also talked about the negative effects of a cancer diagnosis on themselves and their families. There were also differences between these mothers' experiences. These differences were because two of the children with cancer also had Down’s syndrome and ASD, and further due to individual differences between the primary caregivers themselves.

Claire’s and Beeni’s experience of having a child with cancer on top of their other needs appeared to differ from those of the other three participants in this study regarding the first theme, ‘I learned what I needed to learn’. These primary caregivers are more likely to examine treatment options in more detail than families of children without special needs, suggesting that they should do so in case there is a situation that requires extra attention regarding their child's cancer treatment. Claire talked about the stages of her child’s cancer treatment in detail, her child’s inability to tolerate some of the treatments due to her genetic disorder, and mentioned that she had sufficient knowledge to discuss her child's condition with consultants. Beeni also mentioned that her husband is constantly doing research, spending much of his time doing it. Three other caregiver mothers in this study talked about monitoring the side effects of their children’s treatment and learning to give their medications at home. Unlike these three primary caregivers, Claire and Beeni talked about researching alternative treatment plans for their children and increasing their knowledge. The fact that their children have special needs may have motivated them to increase their knowledge.

The second theme emerged regarding the importance of psychological support, with Beeni the only caregiver who was unable to receive support from both family members and health professionals. Her child's diagnosis of ASD, her husband’s depression, her living away from family members and her inability to receive the support she expected from healthcare professionals during treatment due to her child’s ASD differentiated her from the other caregivers in this study. Also, Beeni stands out among the primary caregivers in this study with regard to raising issues about different support needs.

Regarding experiences related to the theme of cancer-related changes, Beeni was the only mother who reported that her child was restricted and experienced “trauma” during treatment.

Claire and Beeni emphasised that their children with learning disability and ASD need individual care due to their special needs. These two mothers, who stated that they were not receiving support from their husbands, noted that they had had negative experiences regarding dyadic relationships.

The main findings within these super-ordinate themes will be further discussed with reference to the original research questions and to the extant literature.

Chapter 5

Discussion

5.1 Introduction

This chapter contextualises major study results about primary carers' experiences with children who have been diagnosed with cancer by making reference to pertinent international literature, theory, and policy.

The purpose of this chapter is to interpret the significance of the findings in light of what is already known about primary carers who provide care for children with cancer, as well as to highlight new understanding and novel insights into this singular experience and how it is perceived by the mothers who participated in the research. This chapter will unpack and critically explore some of the findings of the participants within the discourses of interview conversation. These findings are significant because they present a comprehensive view of the difficulties faced by primary carers who have dealt with a child with cancer.

This study's findings demonstrate how a cancer diagnosis can have a profound impact on the family system. These findings have implications for healthcare professionals who need to be able to understand the complex impact of cancer on each member of the family, individually and together, within the family system. These findings also resonate with the family systems theory (Bowen, 1978) as it highlights how the family system functions as a whole and suggests that all members of a family are interdependent, with their emotions, thoughts, and beliefs all intensely connected (Bowen, 1978). Yet the experience of cancer of a loved one is an individual journey as well.

This study used the qualitative method of Interpretative Phenomenological Analysis (IPA) in conjunction with Family Systems Theory to explore the lived experience of primary caregivers of children with cancer. This qualitative, phenomenological study provides insight into the lived experiences of family members living with a child with cancer and learning disabilities. The IPA methodology was most congruent for this study as it allowed participants to share and expound on their unique lived experiences. Moreover, the utilisation of theory enriched participants' experiences by creating space for greater analysis within a family system.

This chapter starts with an examination of the connections and relationships between the five themes identified, and then goes on to explore each theme in more depth. The findings will be compared to the body of research on the experiences of the primary carers of children with cancer. A detailed explanation of each top theme will be discussed, with exceptions and inconsistencies among the participants included in the study to provide a rich explanation of the findings. It will examine the stigma, uncertainty and emotional work associated with cancer, learning disabilities and autism and the implications this has in the context of cancer care. Following that, the study's strengths and limitations will be explored. Finally, the clinical implications and recommendations for future studies will be presented.

Primary caregivers often share common experiences in providing care to their children with cancer, but at the same time, certain parts of their experiences may differ. The intersectionality is a theory framework developed by Crenshaw (1994) that allows for an understanding of how certain conditions and statuses impact on people's lives. The intersectionality approach provides increased opportunities to analyse the complexity of caregiving, and contributes to the provision of more tailor-made support for informal caregivers rather than generalised solutions (Hankivsky, 2012; Verdonk et al., 2015). Since the experiences and needs of the mothers of a child with autism and Down's syndrome in this study may be different from the mothers of children without disabilities with cancer, the use of an intersectionality framework may make it possible to better address the experiences and needs of these mothers.

Intersectionality does have a theoretical framework. This theoretical framework can be useful in gaining a better understanding of parents' circumstances. In this respect, intersectionality can help health professionals recognise how identities come together in parenting capacity assessments to create or reduce risk (Flynn, 2021). This can be applied to my research findings because parents' identities construct how effects and intersections with learning disabilities can influence the outcomes and experiences of cancer care. Intersectionality prevents health professionals from becoming preoccupied almost entirely with one identity, such as cancer. Intersectionality can explore two identity positions coming together, such as learning disabilities and cancer. In this context, intersectionality prompts health professionals to better recognise identities that come together and think about aspects of identity that might otherwise be overlooked or misinterpreted. As understood in the intersectionality framework, an individual’s experiences are not informed by a single identity (Hankivsky, 2012); rather, different identities combine to increase experiences of marginalisation and disadvantage. This study demonstrates that focusing solely on issues of cancer may blind providers to those experiences related to being a carer of a child with learning disabilities. Addressing the intersection between carer identities is important in improving carer–provider interactions, thereby improving access to services for their children.

The results of this thesis are intended to offer a distinctive lens through which primary carers' experiences of caring for a child with cancer may be seen. The inclusion of throughout intersectionality the study has been attempted in such a way as to complement and further expand on IPA’s idiosyncratic approach. IPA as research design and the incorporation of intersectionality theory serves to privilege primary caregivers’ accounts of their experiences, which can best be understood in the context of individuality. I elaborate further upon these findings via five superordinate themes derived from the participant’s interviews.

5.2 Themes

5.2.1 I learned what I needed to learn

This theme relates to the education of parents, and how they seek information to help their children during the treatment process. Healthcare professionals can expect parents to know a lot about their child’s condition and the process that they will go through. The participants expressed how the oncology team often expected parents to quickly learn and adhere to rigorous treatment protocols that often involve frequent medical appointments and/or lengthy hospital stays (Jones, 2012). Parents are ‘trained’ to identify and respond to severe and distressing side effects of treatments that can include nausea, vomiting, pain, eating and sleeping patterns, fever and neutropenia, distress, and suffering. In the case of paediatric cancer, parents cannot be considered mere companions for the sick; they are emotionally invested in the provision of their child’s medical care (Haugen et al., 2016). Research reinforces that acquiring information and new skills has been strongly linked with empowerment, as it increases parents’ confidence in providing necessary care (Coad et al., 2015). Parents in this study were strategic in their learning, developed expert knowledge focused on the steps in their children’s treatments, understanding how to give medications, and potential treatment-related side effects.

The focus was on cancer’s life-threatening implications. Parents felt a great moral burden and responsibility for the surveillance of their children. Similarly, in paediatric palliative care, parents experience moral distress regarding decisions made about their child’s illness (Evans et al., 2020; Fournier et al., 2017). Moral distress is ‘when one knows the right thing to do but constraints make it nearly impossible to pursue the right course of action’ (Jameton 1984:6; Campbell et al., 2016). However, research on how parents perceive moral challenges during childhood cancer care is sparse (Weiner et al., 2023; Mooney-Doyle & Ulrich, 2020). Weiner et al. (2023) describe that parents feel an overwhelming responsibility regarding their child’s care. Participants in this study and in Weiner et al. (2023) study reported similar thoughts regarding feeling a moral burden due to being heavily involved in their children's care. However, the participants in my study and in Weiner et al. (2023) study had different views regarding parents taking an active role in their children’s care and treatment. While participants in Weiner et al. study (2023) were involuntarily involved in treatment and care through caregiver roles that includes “nursing” and “medical responsibilities”, my research participants felt a moral burden to be actively involved in the care of their children.

Research has found that parents of children with cancer feel they have important information about their child, and saw themselves becoming the “expert” and “proficient” (Gessler et al., 2019; Roug et al., 2023; Coad et al., 2015). Primary caregivers in this study stated that when they had advanced knowledge about the particular cancer that their children had been diagnosed with, they felt more confident and that they had more control over their children's disease management. Mensah et al. (2023) and Granek et al. (2014) studies found that parents who are caring for a child with cancer monitor the child for related side effects of treatment and manage the child’s symptoms. Similarly, Lupton (2013) found that mothers caring for their children with allergies, illness, or developmental challenges, viewed their role as one of protecting their children’s health. They thus felt that they needed to be continually vigilant in monitoring their children’s current and future health. Sam and Julie also mentioned monitoring their child’s treatment side effects. This is supported by Tutelman et al. (2019) and Barrett et al. (2020), who found that the parents of children with cancer discussed being hypervigilant in terms of watching for signs of potentially life-threatening adverse events during treatment and being on high alert for signs (e.g., recurrence of cancer or serious late side-effects). Unlike the findings of these studies, my dataset also suggests that the constant monitoring of their children has an emotional impact on these primary caregivers, including emotional work.

The primary caregivers in this study were required to be constantly vigilant in observing their children and managing their children's risks and symptoms. The term “emotion work” was first introduced by Arlie Hochschild (1983) to refer to an individual’s intentional effort to manage or display one’s own feelings to influence those of others in desirable ways (DeVault, 1999; Steinberg & Figart, 1999). Hochschild (1983) makes a distinction between “emotional labour” and “emotion work”: the former is required by employers in paid employment, whereas the latter refers to the unpaid efforts that occur in family and personal life, often conducted by women (DeVault, 1999). It is important to note that “emotion work” refers to the efforts—the act of trying—taken in a broad sense to shape, evoke, or suppress a feeling, and not to the outcome which may or may not be successful (Hochschild, 1979, p. 561). Emotional labour is frequently used interchangeably with ‘emotional work’ (Dollard et al., 2007). The dividing line between emotion work and emotional labour can be hard to distinguish, especially so in situations where the labour itself is not clearly defined, like parental care work. A helpful distinction is that while emotion work targets one’s own and others’ emotions and can support or indeed distort relationships, emotional labour more directly affects job performance to the better or the worse (McCollum & Eric, 2002).

Emotion work is deeply intertwined with gender structures (Gabe, 2004). Women are often socialised to be nurturing, empathetic, and expressive, which can translate to an expectation that they will manage their own emotions in specific ways as well as the emotions of those around them (Hochschild, 1979). In the context of caregiving research, the idea of “emotion work” is significant as it draws attention to the often neglected emotional dimension of caregiving, which involves the emotional interactions between the caregiver and the recipients such of care and the management of their emotions. Emotion working in cancer-related contexts is fundamentally about managing feelings in order to sustain a sense of control over events, to stave off the nightmares of death, loss and major life change, and to promote healing (Thomas et al., 2002). Thomas and colleagues (2001, 2002) found that much of the work carers do for cancer patients involves emotion work: managing emotions to promote feelings of control over the cancer for the patient, friends, and family, and to maintain a degree of normalcy. In this study, primary caregivers’ emotion work involved maintaining as much normalcy as possible. Runswick-Cole (2013, p. 107) describes the emotional labour that mothers of disabled children perform as having to “wear it all with a smile”, that is, managing their emotions and the those of others.

Emotional labour is common in nursing and emotional labour within the literature appears to be more focused on nursing and healthcare professionals (Zamanzadeh et al., 2013; Gillman et al., 2015). Paediatric oncology nurses feel emotional labour at their work (Hopia & Heino-Tolonen, 2019; Aburn et al., 2021; Molinaro, 2021). Emotion work in caregiving has been extensively explored for informal caregivers of adult cancer patients. The caregivers helped the adult cancer patient stay strong and brave in the face of their diagnosis, even though these were not the genuine emotions they felt (Olson, 2014). Caregivers also put in work to suppress their negative emotions to remain strong or to evoke positive emotions for the adult care recipient and to do the right thing as a caregiver (Thomas et al., 2002).

There appears limited research within the literature on the emotional work of parents of children with cancer. Some of the findings from the participants in this study show the intense emotional work required to support their children through cancer treatment. Mothers often feel a great sense of responsibility to protect their child as much as possible from suffering, and express the need to be in close proximity to their children to maintain surveillance over them, to provide comfort, and to potentially assess risk. This finding is supported by research that caring for a child with major disabilities is fraught with emotion and requires emotional labour on the part of the mother to manage her own and her children’s negative emotions such as worry and emotional distress (Lupton, 2013). Similarly, Runswick-Cole (2013) found that mothers of disabled children experienced emotional labour as they worried about what the future would hold for their children.

There are limited studies on the emotional work/ labour of paediatric oncology caregivers in the literature. Mothers of children with cancer frequently engage in extensive emotion work, including navigating uncertainty and coping with intense emotions like fear and sadness within the family (Clarke, 2006). Young et al. (2002) found that mothers of children with cancer felt compelled to maintain a ‘’cheerful’’ disposition in the presence of their children indicating emotional labour. Emotional labour increases the risk of parental exhaustion and burnout (Lin et al., 2021). Parental burnout has severe consequences for the parent, their children, and the family system more broadly (Mikolajczak et al., 2018, 2019). This causes parents to experience depressive symptoms, addictive behaviours, sleep disorders and couple conflicts; it may also cause children to be neglected (Kawamoto et al., 2018; Mikolajczak et al., 2018,2019; van Bakel et al., 2018).

Another issue that emerged regarding this theme was related to seeking information and the desire to access more information. Beeni mentioned that her husband was constantly researching his child’s treatment and wanted to get more information. Beeni’s husband’s desire in this regard was his way of coping with his child's illness. Being informed and getting information is important to the adaptation of children with cancer and their parents to the illness and their coping efforts (Coyne et al., 2016). In terms of these findings, Schwitzer et al.’s (2012) study appears slightly different. One of the participants in Schwitzer et al.’s (2012) study said that it is not always good to have too much information about her child's treatment and took the approach of not having to think too much ahead.

Beeni’s husband seemed to be interested in information about alternative cancer treatment methods and alternative medicine, where this finding was different to the current evidence-based finding: parents of children with ASD wanted information about the healthcare network, professionals with experience in caring for children with this disorder, intervention/therapies (Edwards et al., 2018), support networks and social services (Liu et al., 2017). The issues most frequently emphasised by families of children with cancer regarding the need for information in the literature include current treatment and different treatment options, their side effects, information on the home care of the child, chances of survival, characteristics of cancer, late effects, and parenting of children with cancer and daily life changes (Doulavince et al., 2018; Keats et al., 2019; Maree et al., 2016; Masika et al., 2020; Rodgers et al., 2016; Tan et al., 2022; Aburn & Gott, 2014; Greenzang et al., 2018; Stub et al., 2021). Beeni’s husband’s coping strategy appeared to be information-seeking. This is corroborated by other studies that parents were most likely to utilise approach coping responses, with the most common methods being seeking support, guidance, and information (Cutillo et al., 2023; Palmer et al., 2011; Woodgate et al., 2016).

The focus of information needs within in this study was targeted on alternative cancer treatment methods and alternative medicine information and the late effects of treatment, such as infertility. Kate expressed her need for information about fertility during her child’s treatment decision-making. Similarly, parents in other studies expressed the need for information about the effects treatment on their children’s fertility (Vetsch et al., 2017; Wakefield et al., 2012). Among the studies in the literature, it has been found that families seek information about different treatment options because of the treatment's adverse effects (Masika et al., 2020; Greenzang et al., 2018). This finding appeared different in my example, as Beeni’s child was diagnosed with ASD and was non-verbal; she and her husband needed information about their son's specific condition’s effect on cancer treatment options and medications.

Caregivers in this study did not feel overwhelmed by the amount of information provided by healthcare professionals. In contrast, previous studies have reported that the amount of information health professionals provided was so extensive that parents of children with cancer became confused (Rodgers et al., 2016; Soanes et al., 2009). Caregivers feel overwhelmed by the amount of information they have to process and interpret, especially during the initial stage of the disease when they also experience intense emotional distress (Castellano-Tejedor et al., 2017; Kastel et al., 2011). Most parents, in previous research mentioned receiving large amounts of information prior to making treatment decisions, and at times experienced “information overload.” (Badarau et al., 2015). Moreover, parents, according to the literature, were not always satisfied with the information they received about their sons or daughters with ASD, and this prompted them to find out all they could (Ludlow et al., 2011; Lutz et al., 2012; Markoulakis et al., 2012; Safe et al., 2012). Mothers also expressed their disappointment with the information related to ASD provided by the professional, considered both insufficient and unsatisfactory (Höfer et al., 2019; Crane et al., 2016). Some parents felt that professionals simply bombarded them with ‘too much information’ that ‘doesn’t sink in’ (Galpin et al., 2018). The literature supports the conclusion that parents learn in different ways, have differing support and information needs, and adopt different ways of responding to condition management (Nightingale et al., 2015). The information provided needs to be tailored to the parents' unique, contextual needs.

There were different views reported about being at home and in the hospital among the primary caregivers in this study. Kate mentioned that she would rather be at home than in the hospital, of which she is petrified. She stated that she learned to give her child medication so that she could stay at home and continue normal life, and that she gained self-confidence. Childhood cancer is a major threat to the family system. As the cancer-treatment progresses and parents adjust to the new routine, they often have time to reflect on the cancer experience and its effects on the family. Many families of children with cancer, similar to Kate's wishes, try to return to what they deem “normal” conduct and routines (Darcy et al., 2014; Hildenbrand et al., 2011; Schweitzer et al., 2012). A loss of family normalcy occurs as families transition to a life that centres on the child with cancer (Darcy et al., 2014; Long et al., 2015; West et al., 2015). These families face profound changes in how they live and relate as a family (Darcy et al., 2014; Long et al., 2015). This appears consistent within the family systems theory because the entire family system is affected by cancer. Thus, family life is out of balance, and several parents experienced the fact that it is hard to keep everyday life together with a child in hospital and household chores at home (Alderfer et al., 2010). Alderfer et al. (2010) suggest that this experience contributes to increased parental stress and that many parents with children who suffer from cancer show symptoms of stress, anxiety, depression and traumatic stress and experience considerable emotional burden.

Beeni also mentioned that she could rest at home and feel the comfort of being at home. She stated that while she was in the hospital, she could not rest because she was taking care of her son with ASD alone, and there was not enough staff to help her in this regard. The findings of this study were in contrast with those of Sarı et al. (2013), who found that parents described themselves as feeling secure in the hospital environment and not wanting to be discharged because they lacked sufficient knowledge about handling emergencies at home. So, as the family systems theory implies, the experience of these parents are highly complex and those supporting them need to be careful not to expect similar behaviour from all parents. These parents experience concern, fear, and anxiety and fear making a mistake during the home care of their children. They also stated that, most of the time, they experienced difficulty in feeding their ill child at home due to nausea and vomiting, changes in taste, lack of appetite, or mucositis (Yıldırım Sarı et al., 2013). Similarly, from other research some parents described that they felt safer and more secure at the hospital, as they were close to the health professionals with all the necessary facilities should anything go wrong (Stevens et al. 2006b). The parents felt fear and insecurity during the initial care process of their sick child after the first hospital discharge and rationalised this as being due to the fragile state of the child, the complexity of care required and not executed, and the need to feel capable of self-managing care and remaining vigilant (Silva-Rodrigues et al., 2019). Parents are also fearful and apprehensive when they take their children home, feeling anxious about not knowing how to protect them from disease-related dangers, especially fever and infection (Rodgers et al., 2016; Desai et al., 2015; Roug et al., 2023). In contrast, Julie talked about feeling safer in the hospital and the difficulty with being responsible for her child alone at home. Claire talked about the increased workload and the difficulties in preparing medications while at home. Sam mentioned that she felt vulnerable because she was unable to secure professional healthcare support when she was at home. In contrast, Molinaro and Fletcher (2017) described how caregivers of children undergoing cancer treatment maintained as much normalcy and positivity for their children as possible. Similarly, Lindsay et al. (2021) found that parents who care for their children at home can gain a sense of security and control.

The topic of health literacy is also related to this theme, with Claire highlighting this topic by demonstrating her high level of health literacy. She was able to talk to consultants about her child's treatment. Claire used her health literacy to navigate the healthcare system, where finding was quite unusual compared to the current evidence-based conclusions. According to the literature, parents of children with cancer use their health literacy to obtain, understand and use information (Kilicarslan-Toruner & Akgun-Citak, 2013; Tan et al., 2023), whilst parents of children with learning disabilities use their knowledge to find health specialists, and gain access to educational and rehabilitation services for their children and to network (James, 2013; Sefotho et al., 2021). The fact that Claire's child has Down's syndrome, her child's long-term cancer treatment, her social capital and high health literacy appear to have contributed to navigating the healthcare system. This finding highlights that the intersectionality of Claire being a mother of a child with both cancer and learning disability has a direct impact on the ability to navigate healthcare for her child successfully. These findings show that competencies shape parents' abilities to navigate the healthcare system effectively and this finding was different compared to the current evidence-base. In contrast, studies found that navigating the healthcare system challenges those with low health literacy (Conroy et al., 2018; Jimenez et al., 2013; Shippee et al., 2012) or limited proficiency with English (Blumbergt al., 2010).

5.2.2 Complexity: challenging the cancer journey

Parents of children living with cancer appear to suffer from more psychological difficulties than parents in the general population, and thus they also have higher psychological and emotional needs (Stenka & Izdebski, 2018; Wiener et al., 2017; Santos et al., 2016). Loghmani et al. (2014) mentioned emotional needs among families, such as psychological support, empathy, and mutual understanding. Many studies have highlighted the need for proper psychological support from healthcare services for parents throughout their child's cancer care route, and how this plays an important role in modulating the parents' experiences (Al Omari et al., 2020; Andersen et al., 2019; Darby et al., 2014). My research found two opposing but related themes that are universal to caregiving experiences. While Claire mentioned that her friends were able to offer her emotional support and help care for her daughter, Sam and Julie talked about being able to speak to their friends and their family members and the emotional support they received was important to them. By contrast, Beeni and Kate mentioned that they were unable to get emotional support from their family members and friends, and that this created difficulties. Kate talked about the information support she received from the community nurse in helping with her daughter's treatment at home, whilst Julie talked about the nurses providing information support at the hospital, and Sam talked about the psychological support she and her husband gained from their meetings with the psychologist. In contrast, while Beeni was in the hospital and expected emotional support from the nurses regarding her child's difficult behaviour and care, she noted that she did not receive this support because she thought that the nurses were too busy.

Paediatric nurses often spend considerable time with patients and their families, causing them to experience a range of emotions and stress. This experience of stress and heightened emotion resonates with the idea of emotional labour (Hong & Yang, 2015). The extant literature has identified two broad strategies employed by nurses in the process of engaging in emotional labour: surface acting and deep acting (Hochschild, 1983). Surface acting involves masking actual emotions, such as using a fake smile to hide one's true feelings; in comparison, deep acting is concerned with regulating one's inner feelings to express desirable emotions; that is, it modifies internal emotional states to really experience the desired emotion (Grandey, 2015; Hochschild, 1983). Various studies (Humphrey et al., 2015; Yao et al., 2019) have found that, job stress, burnout, emotional exhaustion, psychosocial stress, anxiety, and frustration have all been reported to have significant positive associations with surface acting. Conversely, some researchers have suggested that it would be appropriate to develop interventions that improve deep acting and work engagement in order to reduce the adverse effects of emotional labour in clinical nursing settings (Han et al., 2018). These findings are supported by previous studies that have found that deep acting can have a positive effect on individual mental health and well-being (Humphrey et al., 2015; Yao et al., 2019). Under stressful nursing situations and when nurses become more involved with families, they must manage emotional labour through deep acting (Tafjord, 2021; Lee & Jang, 2019). Studies have found that nurses utilise avoidance and self-protecting strategies to protect themselves from the emotional impacts of working in such a sensitive and emotionally draining area of care in paediatric oncology (Arber & Odelius, 2018; Dencker et al., 2017; Tafjord, 2021). For these reasons, Beeni's emotional support needs may have been overlooked.

Health professionals, especially nurses, because of their frequent, long-term, and close contact with families, have excellent opportunities to support parents' coping, enhancing parents' ability to care for both themselves and their children (Nielsen et al., 2024). Paediatric nurses should be aware that their support is important for parents to cope with distress and should support effective coping methods used by parents. If nurses are able to learn how to use the deep acting strategy, it would benefit not only themselves but also their patients and patient's families (Lee & Jang, 2019). The data obtained from this study showed that while the support parents received from family members and friends was emotional in nature, they received more informational support from health professionals. This finding is different to those of other studies'; the literature mostly focuses on that healthcare providers have a significant role in providing emotional support (Atout et al., 2021; Benedetti et al., 2014; Ringnér et al., 2011). For Beeni emotional support is when nurses take care of her child, so that she can rest properly. The families in Atout et al.'s (2021) study associated the emotional support they received from healthcare professionals with the nurses' kindness, always smiling and using micro-communication skills, and the doctors informed them about their child's treatment process; Benedetti et al. (2014) and Ringnér et al. (2011) noted that the emotional support was well-informed and valued by healthcare professionals. However, in terms of type and sources of support, parents of children with cancer, in Gise et al. (2022) and this study, reported emotional support to be the most frequently received type, and family as the most prevalent source of support. Friends, healthcare personnel, and other parents of children with cancer were often noted as the second-most prevalent sources of support (Gise et al., 2022). A systematic review (van Schoors et al., 2015) and a meta-analysis (van Schoors et al., 2017) illustrated that family support helps families to cope with cancer.

Nurses are perceived as key in providing emotional support and quality care throughout the course of cancer treatment (Bohnenkamp & Anderson, 2022). However, several studies have shown that nurses tend to focus more on the physical, rather than the psychosocial needs of cancer patients, and that the latter is often not considered part of the routine practice of nursing (Chan et al., 2019; Lyu et al., 2024). Nurses do not view the assessment, management, and reporting of distress or other psychosocial needs as part of routine nursing practices (Palos et al., 2013). Nurses tend to accord the highest priority to required tasks with immediate and visible effects, and the lowest to emotional care (Guner et al., 2018). With nurses' busy workload, creating more time to provide emotional support may not be possible (Chan et al., 2019). The research also shows that cancer nurses may also be emotionally affected by the process of caring for patients, and there is a psychological burden of emotional labour (Lyu et al., 2024).

Claire and Sam stated that they received support from their friends in this study. In contrast, parents of children with cancer in Adu-Assiamah's (2022) study reported they lost old friends during the initial treatment stages. These parents felt rejected by people whom they thought they could rely on during such difficult periods (Adu-Assiamah, 2022). These parents seemed to have lost trust and hope of support from other people, as they were of the view their own families had abandoned them (Adu-Assiamah, 2022). Similarly, some parents in Nieto et al. (2022) study were disappointed by their friends because they did not support them. This may be due to a lack of experience or feelings of discomfort regarding supportive interactions with a friend who has been diagnosed with cancer (Ray, 2024). While all forms of support are important and beneficial for children with cancer and their parents, it is clearly not always available. Beeni and Kate mentioned that they did not receive emotional support from family members and friends. In contrast, parents of children diagnosed with cancer who were emotionally supported by their friends reported a positive impact of such (Abu-Raiya et al., 2015; Tan et al., 2020). The fact that Kate is a single mother may be related to her need for relatively more support. Single parents may have fewer resources at hand, including emotional and social support, and face additional stressors (Long et al., 2011). Nicolaou et al. (2015) found that single mothers report lower levels of support. Caregiving stressors may be a particular challenge for single-parent families because they are often the sole adult balancing the emotional, physical, and financial strains of caring for their families (Granek et al., 2012; Delemere et al., 2023).

5.2.3 Intersectional complexity in care

With regard to Beeni's child with ASD, studies have found families of children diagnosed with ASD who did receive support, and those who did not from family members (Matthews et al., 2011; Olsen, 2017; Samadi et al., 2012; Ludlow et al., 2012; Safe et al., 2012). In several cases, the extended family was perceived to be supportive, providing both emotional and practical support for families of children with ASD (Myers et al., 2009; Matthews et al., 2011). Participants from other studies also felt that their partners and extended family provided sufficient support for them via financial aid or by helping to take care of the children with ASD (Olsen, 2017; Samadi et al., 2012). Conversely, many parents in other studies stated that family members did not understand the disorder, even if they accepted the diagnosis, and thus could not provide the needed support for ASD (Ludlow et al., 2012; Safe et al., 2012; Papageorgiou & Kalyva, 2010). Beeni needed support with regard to care for her child due to her child's diagnoses of both cancer and ASD, but did not receive support from her family members. In the present study, although Beeni did not explicitly mention courtesy stigma, her lack of support from family members could have been related to such. Goffman defines stigma as 'a phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected because of the attribute. Stigma is a process by which the reaction of others spoils normal identity'(Goffman, 1963:3). The processes of stigma include "labelling, stereotyping, exclusion, loss of status, and discrimination"(dosReis et al., 2010:811). According to Goffman (1963), stigma is the adverse effects of negative attitudes and behaviours from the public on discredited individuals. Broady et al. (2018) conducted a qualitative study to explore caregivers' lived experience of stigma. They found that stigmatising experiences were related to rejection and lack of support. The perception of stigmatising was high among caregivers, with a third of the sample fearing discrimination for having a child with ASD (Kinnear et al., 2016; Liao et al., 2019; Mitter et al., 2019). Since individuals with ASD often show an absence of physical markers as signs of disability but rather exhibit certain behavioural and antisocial behaviours such as tantrums and aggression (Oduyemi et al., 2021; Patra & Patro, 2019) both their parents are commonly accused of poor parenting which results in inappropriate behaviour being displayed (Crowell et al., 2019). Therefore, parents often experience "courtesy stigma" (Goffman, 1963; Seeman & Goffman, 1964).

Courtesy stigma refers to the stigma of individuals having close connections to people with a stigmatising characteristic (Angermeyer et al., 2003; Goffman, 1963; Gray, 1993; Mak & Cheung, 2008). Courtesy stigma affects parenting and the psychological health of parents (Ali et al., 2012; Cantwell et al., 2015). In this study, Beeni seemed to be experiencing the courtesy stigma. She mentioned that the lack of family support made her life difficult. For Beeni, experiencing courtesy stigma meant no contact with family members. At the same time, she mentioned throughout her interview that her husband was not seeing anyone, was spending time at home, and was depressed; this ilustrates the negative effects of enacted courtesy stigma. One example of courtesy stigma in relation to ASD can be characterised as the “refrigerator mother”, in which parents of children with ASD were thought to cause symptoms of ASD through cold and insufficient caregiving (Bettelheim, 1967). Bettelheim applied the term “refrigerator mother” to emotionless parenting. During the 1960s and 1970s—a period when there was virtually no empirically-based understanding of autism’s etiology—the refrigerator mother theory became widely accepted within the medical establishment, effectively labelling parents as the ultimate “scapegoats” for their children’s challenges (Schopler, 1971). Family support as part of social support has been suggested to be significantly and negatively associated with stigma (Lyu et al., 2022). However, there is a lack of research into the relationship between social support and courtesy stigma in reference to ASD (Chen et al., 2023). Similarly, Broady et al. (2018) found that lack of support characterises carers’ expectations of how others should act. They expected that people close to them will provide both practical and emotional support, and described the disappointment associated with felt stigma when this did not materialise. This demonstrates at a practical level how the relationship dynamics play out for a family when stigma is perceived (Broady et al., 2018). Coping with courtesy stigma can add a significant burden to parents of children with special needs (Ng & Ng, 2022; Liao et al., 2019; Chen et al., 2023). Increased courtesy stigma amongst parents of children with disabilities has been associated with reduced parental quality of life (Werner & Shulman, 2013) and increased negative parenting (Mikami et al., 2015).

There are also misconceptions and inadequate knowledge about ASD among healthcare professionals (Mac Carthaigh & Lopez, 2020; van‘t Hof et al., 2020; Heidgerken et al., 2005; Bono et al., 2022). These coexisting conditions meant that there were further appointments with multiple providers, educators, and therapists before finding one who was able to understand the needs of a child with ASD. The difficulty in finding healthcare professionals with this specialty highlights a lack of awareness of children with disabilities who have physical illnesses. This suggests that there is a need for education amongst professionals, especially for primary care providers, who are often the first to hear parental concerns.

The relationship between ASD stigma and caregiver mental health suggests that there are both changeable factors (e.g., caregiver burden, self-blame, social isolation) and nonchangeable factors (e.g., culture, financial burden), both of which contribute to poor mental health and stigma (Papadopoulos et al., 2019). Cancer is also one of the more serious diseases that are often associated with stigma in many societies (Walter & Emery, 2006; Ghaljeh et al., 2024). Banerjee et al. (2011) found evidence of cultural stigma that childhood cancer is incurable and should be kept secret based on interviews with South Asian immigrant parents of children with cancer living in Canada. In-countries in the Middle East and Asia, parents are typically afraid to receive social support because they tend to accept the stigma of cancer suffered by children (Mezgebu et al., 2020). Caregivers in the USA also reported experiencing cancer-related cultural stigma regarding their child's diagnosis (Ochoa et al., 2023). My research participants, Beeni and Claire, indicated that this is a significant issue. The emotional consequences of the family experiencing stigma related to ASD and cancer are typically feelings of anxiety, depression (Oz et al., 2020; Papadopoulos et al., 2019), and social isolation (Adu-Assiamah, 2022; Delemere et al., 2023), all of which can lead to a decrease in families2 quality of life (Park & Park, 2014).

Social capital is a complex concept, with various definitions, perspectives, and dimensions (Woolcock & Narayan, 2000). Bourdieu (1986) defines social capital in terms of networks and connections between individuals that can provide support and resources, whilst Coleman (1988) conceptualises social capital as being a resource related to the social relations that exist between families and the communities that they are linked to, Putnam (1995) defines social capital as a characteristic of communities that includes community cohesion, reciprocity and trust. Parents who feel they have sufficient social capital enjoy better health (Schofield & Beek, 2009) and are better prepared to accept a diagnosis of ASD and cope with the daily stress of caring for their child. Beeni's child has ASD, and cannot receive social support this may be related to her social capital. The wider literature indicates that having a child with an intellectual disability effects social capital (Starke, 2022). Emerson et al. (2015) reported that parents with learning disabilities have reduced neighbourhood social capital and intergenerational support. During the interview, Beeni mentioned that she did not live in the same country as her family and so she could not get the support of both her own or her husband's family. She also left her job to take care of her child and felt isolated because no one around her had experience of having a child with cancer. She was also unable to get support from her husband due to his poor mental health. Additionally, the intensity of her child's treatments related to both cancer and ASD diagnoses caused Beeni's social interaction to decrease. The above seem to have negatively affected Beeni's social capital overall. Kate, who is a single parent, also mentioned during interviews that she did not receive support from her family.

Social class, family relationships, personal resources, educational status, and social interactions in the community are the most important predictors of social capital (Sharbatian & Aminian, 2013). Sam, Julie, and Claire expressed throughout the interviews that they received support from their friends while struggling with their children's illness; these mothers appeared to navigate care better, partly due to more social capital. Social capital is related to the mental health of mothers of children with learning disabilities (Kimura & Yamazaki, 2019). Hock and Ahmedani (2012) noted that the parents of children with ASD were more likely to report poor neighbourhood social capital, have difficulty coping, have lower levels of relationship satisfaction and mental health, and experience greater aggravation than parents of children without ASD. Caregiver burden, being associated with the decreased provision of quality of care, quality of life, and mental and physical health

(Bastawrous, 2013; Liu et al., 2020), has been found to be negatively correlated with social capital and mediated by reduced community participation (Papastavrou et al., 2015). Kojo and Fukumaru (2015) noted the negative relationship between social capital and depression among parents of children with disabilities, Thuy and Berry (2013) reported that certain components of social capital (e.g., spending time with friends and neighbours, involvement in educational activities, and trusting others) were related to better mental health, while others (e.g., engagement with activism, workmates, extended family and the immediate household) were associated with worse mental health among mothers of children with disabilities. Emerson and Spencer (2015) found that families of children with learning disabilities were more likely to live in households charcterised by socioeconomic position and to become poor and less likely to be able to escape poverty. The findings from my study also support this reference; Claire and Beeni mentioned that they quit their jobs to spend more time with their children and that their children needed treatment such as feeding therapy due to their special needs. When affordability, availability, and accessibility of services are limited, this hinders families' ability to care for children with disabilities, and the inability to meet basic needs increases the stress (van der Mark et al., 2017). Based on interviews with parents, Huiracocha et al. (2015) showed that limited financial and social resources, either because of poverty or disability stigma, shape the character of their experiences. Beeni's experience as her child's primary caregiver has been negatively affected by the intersection of social capital, stigma, and poverty risk.

Beeni reported being dissatisfied with health professionals regarding the overall support she received from them and their awareness of her child's disease. Similarly, Bultas (2012) found that parents believe that health professionals do not fully understand the holistic impact of ASD on every aspect of the child and family or how difficult it is to accommodate their child's needs. Moreover, parents of children with ASD think that many healthcare providers are focused solely on the medical aspect of the child's health and often ignored the developmental needs of both children with ASD and their families (Bultas, 2012). Many parents of children with ASD also mentioned that healthcare professionals were dismissive of their concerns (Ballan, 2012; Carbone et al., 2010). According to the findings of these studies these concerns included the child's future and quality of life, the well-being of their children, the impact of puberty on the children, their behaviour, their development, and their safety (Ballan, 2012; Carbone et al., 2010; Oulton et al., 2022; Papadopoulos, 2021). In contrast to these findings, Beeni's concern was that her son's ASD was neglected by healthcare professionals due to the priority given to her child's cancer diagnosis or not understanding ASD. Moreover, oncology nurses and other clinicians may not be very familiar with supporting children with ASD or learning disabilities (Datta et al., 2019). The above appear to have resulted in Beeni to receiving the level of support she had otherwise expected.

Beeni mentioned that healthcare professionals always seem to be busy and are not thoughtful. Similarly, most of the parents of children with cancer from the Akaberian et al.

(2021) study stated that nurses only cared about children and typically did not have the time to deal with mothers' problems. Parents of children with ASD described healthcare professionals' attitudes as cold, condescending, dismissive, judgemental and culturally insensitive (Bui, 2017; Jegatheesan et al., 2010; Milosevic et al., 2022). Parents also sometimes felt that healthcare providers do not listen to or support them (Carbone et al., 2010; Levy et al., 2016; van Tongerloo et al., 2015). Conversely, parents of children with disabilities in Ryan and Quinlan's study (2017) believed that if they expressed a need for help, they would be listened to and supported by such professionals. Interestingly, Claire, Kate, Julie, and Sam stated that the support they received from healthcare professionals was generally positive. Beeni's child being diagnosed with ASD indicates that she needs additional support. She mentioned during the interview her dissatisfaction with the support she had received from healthcare professionals compared to other caregivers due to her child's complex care needs or unmet health needs. Parents of children with ASD are known to be more likely to report having unmet healthcare needs compared with parents of children with other special healthcare needs, even those with other developmental and mental health conditions (Chiri & Warfield, 2012). A lack of knowledge and/or confidence in treating children with ASD likely contributes to greater unmet healthcare needs in this population (Menezes et al., 2021).

Families undoubtedly experience a wide range of feelings when faced with a childhood cancer diagnosis. For paediatric oncology nurse researchers and clinicians, caring for the psychosocial needs of children and their families is as important as dealing with the biomedical needs of the patient (Barrera et al., 2016). To meet the myriad of needs that families of children diagnosed with cancer have, nurses could adopt a more family-centred approach (Mooney-Doyle et al., 2020). Family-centred care (FCC) is known to be widely adopted theoretical perspective in nursing (Mikkelsen & Frederiksen, 2010) as this approach acknowledges the multifaceted bio-psychosocial needs of children and their families in paediatric oncology. According to Mooney-Doyle et al. (2020: p.7), "Family-centred care (FCC) is a philosophy and an approach to care that provides a pathway to engage with children and their families during their experience with cancer.".

Recently, nursing scholars have developed an FCC in paediatric oncology conceptual framework to help guide clinicians as they interact with and care for families of children with cancer (Mooney-Doyle et al., 2020). In addition, Livingston et al. (2020) recommends that psychosocial care should not only be provided for children with cancer but also for their families, which would help to improve their overall quality of life. However, the application of this framework fails to take into account the social and cultural barriers, stigma, and co-existing conditions associated with ASD and learning disabilities. At present, there is a lack of research focusing on the wider context of family-centred nursing for children who have cancer and a pre-existing disability.

Beeni expected healthcare professionals to be able to perceive her needs, distress and the burden of being a caregiver of a child with ASD. Since Beeni was unable to leave her child alone in the hospital and it is difficult to care for her child, she expected the kind of behaviours from healthcare professionals that would have showed that they cared about her. While some positive experiences have been shared (Muskat et al. 2015; Wilson and Peterson 2018), healthcare service users with ASD and their family members frequently report challenges associated with the patient-provider relationship in the healthcare system; citing communication barriers, perceived limited knowledge and skill of healthcare providers related to ASD, and limited recognition of the parental and family role (Chiri & Warfiled 2012; Strunk et al., 2014; Wilson & Peterson, 2018).

During the interview, Beeni mentioned that she needed peer support in terms of sharing resources, taking advice and meeting with the families of children with cancer. Similarly, a parent of a child with cancer in Nielsen et al.'s (2024) study explained that not establishing any peer relationships during the child's treatment had made them feel very lonely, particularly when they approached the end of the treatment. This was due to not knowing anyone to gain good advice from, or share worries with, and the emotional and practical struggles associated with being on their own (Nielsen et al., 2024). Opportunities to share experiences with other parents with similar experiences were valued (Arruda-Colli et al., 2018). Parents of children with learning and attention disorders and ASD both reported seeking out parents of children with similar diagnoses for social support (Chad-Friedman et al., 2022).

Parents of children with cancer experience a high level of needs, especially psychological and emotional (Lewandowska, 2021). At the same time, parents of children with ASD also report the need for support (Shivers et al., 2019). Beeni was the only primary caregiver who said that she did not receive support from family members and health professionals. Not being able to receive support as a caregiver for a child diagnosed with both cancer and ASD made caring for her child considerably more challenging.

Families who have a child diagnosed with cancer can face a myriad of challenges but FCC for children with cancer could be an effective approach to meeting their wider needs for support effectively (Wilson, 2023). Customised care was a common theme throughout existing literature on the concept of FCC in childhood cancer (Crespo et al., 2016; Garcia et al., 2017; Gerhardt et al., 2015; Gil et al., 2016; Lyu et al., 2019; Mooney-Doyle et al., 2020; Popp et al., 2015; Salvador et al., 2020; White et al., 2017) but it was not apparent in the case of the participants of this study. Gerhardt et al. (2015) recommended flexibility in care-planning that is considerate of each family's unique environment, lifestyle, and circumstances. Findings by Salvador et al. (2020) reaffirm the necessity of paediatric oncology nurses to provide customised care and reject the one-size-fits-all approach when caring for families who have a child diagnosed with cancer. FCC in childhood cancer can be a contextual, customised approach to the care of families who have a child diagnosed with cancer that involves interdisciplinary and family collaboration, communication that addresses family information needs and fosters trust, and that acknowledges the ripple effect of the diagnosis on the functioning of the family as a system, as well as individual members. However, one of the participants with a child with ASD found that she was not able to receive customised care, and health professionals did not meet her expectations.

5.2.4 A range of emotions

5.2.4.1 Managing uncertainty and guilt during the cancer journey

Primary caregivers expressed a range of emotions in the current literature; similar to these research findings, these included shock, anxiety, helplessness, hope, and lucky (Carlsson et al., 2019; Gill et al., 2021; Johansen et al., 2018; Naidoo et al., 2016; Rost et al., 2018; Wiener et al., 2017). However, the uncertainty mentioned by the participants of this study appeared different from those reported in the literature and some divergence from the common evidence base. In particular, since Beeni has a non-verbal child diagnosed with both ASD and cancer, the level of uncertainty with the child includes three intersectional factors that have not, to date, been explored in the current literature. Therefore, uncertainty will be discussed in detail. Additionally, the sense of guilt felt by Beeni, related to a child being nonverbal has also not been discussed in the extant literature.

Three primary caregivers in this study described the uncertainty related to the future they experienced throughout their child's treatment. Parents experience uncertainty and stressful events connected with the unknown effects of the illness from the moment their child is diagnosed (Khoury et al., 2013; Bretones-Nieto et al., 2022), similarly, Claire has experienced the anxiety of her child having a future cancer relapse. Sam mentioned the negative impact of uncertainty on her marriage. Similar results about the multiple sources of stress and uncertainty associated with a child's cancer that affected parents' relationships and caused difficulties in communication have also been reported in the literature. Studies reported distress and marital dissatisfaction, in addition to communication and marital dyad conflicts (Da Silva et al., 2010; Khoury et al., 2013).

Beeni and Claire also reported uncertainty related to her child's condition, about the long-term impact of ASD on the child's future and the possible recurrence of cancer. She was also worried about her child being non-verbal in nature. She will have to monitor her child for her lifetime due to ASD, thus it is clear that she needs support from health professionals in this issue. These findings were different to the current evidence-based ones. Some parents of children with ASD were concerned about their children's futures, wanted them to be able to live independently during adulthood (Aylaz et al., 2012; Koydemir-Özden & Tosun, 2010; Ludlow et al., 2011; Lutz et al., 2012). Feeling uncertainty related to cancer and learning disability or ASD about not being able to go back, nor being ready yet to move forward, is consistent with the concept of liminality. Liminality refers to the period of limbo in which one cannot return to life prior to the cancer diagnosis, but what is yet to come remains unknown (Dahlborg et al., 2013). First represented by van Gennep, the concept of liminality was further developed by the anthropologist, Victor Turner (1969). Liminality has been used in medical anthropology to conceptualise the cancer experience (Little et al., 1998). In the case of children who have ASD and Down's syndrome, with no opportunity to transition into independent adulthood, such enduring liminality may severely impact parents and families who are unable to escape from this liminal state (O'Loughlin et al., 2024). The unpredictability of the illness trajectory and uncertainty regarding access to opportunities for their children were experienced as constant sources of fear and risk, further reflecting an unending state of liminality (O'Loughlin et al., 2024). There is a limited amount of exploration within the current evidence base about primary caregivers who experience anxiety about potential cancer recurrence for their child and the impact on future quality of life. This is particularly significant within this dataset for both Claire and Beeni supporting children with ASD and learning disability. Support from healthcare providers represents an effective means of reducing parental uncertainty following a diagnosis of cancer and learning disabilities (Keim-Malpass et al., 2016; Howitt, 2010; Li & Lo, 2015).

Three participants in the study reported feelings of guilt for reasons such as not being able to adequately support their other children and not having their children diagnosed earlier. These findings are supported by the current literature (van Schoors et al., 2018; Demirtepe-Saygılı et al., 2018; Fernańdez-Alcántara et al., 2016). However, Beeni's child, being non-verbal due to his ASD and due to his late diagnosis of cancer, has made her feel guilty; this finding is in contrast to that in the current literature. Unfortunately, there are few studies in the literature about the experiences of caregivers of non-verbal children (Jaswal et al., 2020; Chu et al., 2020), and sparse knowledge about the parental experience of correlating the feeling of guilt with families of non-verbal children with ASD (Jaswal et al., 2020; Chu et al., 2020).

5.2.5 Cancer-related changes

5.2.5.1 The necessity of treatment versus the psychological trauma

In the findings chapter, on page 110, Beeni mentioned that her son hated needles and she thought her child was in pain due to and traumatised by the needle procedure, and how difficult it was for her to hold down her child. Parents can sometimes be asked to help the medical team by getting their child to comply and cooperate with invasive procedures. The role of 'caregiver' as defined by the medical team is often at odds with the definition of ‘caregiver’ in parental terms. The parental caregiver dilemma involves parents having to provide care that may be painful and frightening to the child while simultaneously having to explain, hold, nurture, comfort, and protect them. The use of ‘restraint’ or ‘clinical holding’ in paediatric clinical practice is common in many clinical settings with parents often asked to participate (Kirwan & Coyne, 2017). The incidence of restraint (restrictive physical interventions) within paediatric oncology is not clearly available in the literature (Hull & Clarke, 2011). However, a previous study shows that in cancer care 38% of children aged 3–10 years old had to be physically restrained during the procedure (Fradet et al., 1990). Parents have reported holding their children with no life-threatening illness through medical procedures as meaningful and supportive (Sparks et al., 2007; Karlsson et al., 2014), while other parents find it traumatic for children with intellectual and developmental disabilities (Slifer et al., 2011); the words ‘depressing’ and ‘anxiety’ were commonly used by parents of children with ASD, particularly when speaking of physical restraint (Stewart et al., 2016). There is a limited amount of evidence exploring physical restraint with children with ASD, particularly in the context of oncology. Some parents of children with learning disabilities believe the use of restraint caused their child physical pain or emotional trauma like Beeni appeared to suggest, and increases their child’s levels of fearfulness, aggression, and behavioural problems (Saloviita et al., 2016). Research findings show that children with ASD are more likely to be restrained (Donnelly et al. 2020; O’Donoghue et al. 2020; Perers et al. 2021; Webber et al., 2019; Murdoch & Chang, 2022). An approach has been developed to improve care in psychiatric units through autism-specific intervention strategies, which reduces the need for restraint amongst children and adolescents because of the introduction of the Autism Spectrum Disorder Care Pathway (Kuriakose et al., 2018). This intervention includes the implementation of a structured schedule with extensive use of visual supports, teaching patient coping skills, and training staff in the features of ASD. The proportion of children experiencing a hold/restraint was significantly reduced after the introduction of the Autism Spectrum Disorder Care Pathway.

Throughout her interview, Sam also talked about the difficulties she had had with inserting nasogastric tube to feed her child. Similar to Sam, the mothers from Bıcaklı et al. (2019) study were afraid that the nasogastric intervention would cause pain.

Beeni talked about her son’s behaviour in terms of attempting to leave the ward during treatment. This finding is supported by the studies that children with ASD may present with significant challenging behaviours (e.g., aggression, self-injury, and elopement) that contribute to prolonged hospitalisations (Kopecky et al., 2013; Siegel et al., 2014). Also, in Spinazzi’s (2024) study about the experiences of families of individuals with the dual diagnosis of Down’s syndrome (DS) and ASD, a mother mentioned that her child needed constant supervision due to his elopement and that she could not leave her child alone. The environments of medical care settings and the demands placed on children while in them may contribute to their challenging behaviour (Wilson & Peterson, 2018). Children with ASAD may experience negative reactions to particular sensory stimuli in hospital environments (e.g., bright lights, beeping of machines, and physical touch) (Wilson & Peterson, 2018). Similarly to Beeni, families in Bessette Gorlin et al.'s (2016) study reported significant difficulties managing challenging behaviours related to ASD, including self-injurious behaviours, meltdowns, aggression, and elopement. Elopement is defined as a dependent person exposing him or herself to potential danger by leaving a supervised, safe space or the care of a responsible person (Anderson et al., 2012). Elopement is a frequent and significant source of stress for parents of children with ASD (Anderson et al., 2012). These data exemplify family systems theory by showing that behaviours associated with ASD may impact parents by increasing parental stress. Mothers of children with ASD in Stewart et al.'s (2016) study raised concerns about their child's safety as a result of elopement causing them to be "hypervigilant". Similarly, Beeni mentioned that she was vigilant while her child was receiving treatment in the hospital. Most healthcare settings do not provide an environment that accommodates and supports people with ASD unique sensory needs (Gabriels et al., 2012). Furthermore, most healthcare providers do not thoroughly understand sensory features and their impact on behaviour and thus do not provide the required accommodations. This can place children with ASD, their families, and providers at risk of ineffective service delivery (Gabriels et al., 2012).

5.2.5.2 Decision making and consenting in paediatric cancer

Making decisions is particularly difficult in the setting of cancer (Levine et al., 2012; October et al., 2014; Parsons et al., 2012). Parents have described that they have to make treatment decisions that may have life-threatening consequences for their children (Johnson et al., 2015; Pye, 2013). Families of children with cancer reported feeling pressured to make decisions which contributed to their distress (Robertson et al., 2019). Similarly, Kate and Claire reported how difficult it is taking on a decision-making role. During the interview, Kate asked if she could have chosen a different treatment for her daughter; she felt that she did not have a choice and seemed stressed because of this. Conversely, some parents stated that the decision-making process was easy because they felt they had no choice (Stevens & Pletsch, 2002). Similar to this study's finding, parents in other studies indicated that they had insufficient information about alternatives to the proposed treatment of the clinical trial (Chappuy et al., 2010; Kupst et al., 2003; Stevens & Pletsch, 2002). With no option, they felt obliged to give consent for the clinical trial to go ahead (Levi et al., 2000; Alahmad, 2018). This research's findings suggest that parental understanding of the risks late effects may impact treatment decision making. Similarly, most parents in Greenzang et al.'s (2018) study wanted early and detailed information about their child's risk of late effects to in order to make treatment decisions and so they felt prepared for the future. While informed consent documents for paediatric cancer treatment contain information on potential late effects, the majority of late effects education typically occurs after the completion of the treatment, during long-term follow-up care (Landier et al., 2015; Lindell et al., 2015). This approach neglects the role of late effects information in initial treatment decision making (Greenzang et al., 2018). Parents in Greenzang et al.'s (2018) study valued late effects information around the time of diagnosis, because it helped them to prepare for what was ahead and informed the decisions they made about their children's care. Kate also expressed concern that about possible side effects of treatment, such as infertility; this finding is also emphasised in the literature (Stinson et al., 2015; Vetsch, et al., 2016). Conversely, some parents felt fertility concerns were not a priority given the other risks their children were facing (Ellis et al., 2016; Quinn et al., 2012). Parents and survivors in Ellis et al.'s (2016) study frequently described postponing their worry and/or the need to make decisions regarding fertility until it became necessary i.e., when they were ready to have children. Taking the decision-making role in cancer also creates a burden for Claire.

The literature shows that parental equipoise is often very difficult to reach, which leaves parents in the agonising position of wanting to do what is best for their children with cancer, while not knowing whether a clinical trial is the best course of action to reach this and being fearful of making the wrong decision (McKenna et al., 2010). Since Claire's child also has Down's syndrome, it should be noted that there are few studies available that consider parental decision-making regarding treatments for such (Bohnstedt et al., 2023; Reilly et al., 2010); Reilly et al. (2010) found that for parents of children with congenital heart conditions and Down's syndrome's decision-making regarding treatment responsibilities posed difficulty for them. There is only limited data in the literature on parental decision-making regarding treatments for Down's syndrome and cancer. Bohnstedt et al. (2023) found that parents of children with Down's syndrome and ALL worry about decisions related to treatment regulation since doctors tell families that children with Down's syndrome are more vulnerable and more sensitive to the side effects of cancer treatment than children without.

5.2.5.3 Living in a shielded restricted world

Participants in the current study talked about living in a "restricted world" to protect their children from infection. Claire, throughout her interview mentioned that they lived in a "shielded world" so that their child did not contract another disease because of having a compromised immune system while being treated for cancer. Similarly, Saifan et al.'s (2014) qualitative study, conducted among parents of children diagnosed with cancer, found that the mothers did not attend get-togethers and social functions in the attemption to avoid crowded places to protect their children from infection. Since the immune systems of the children were weak, some parents were unable to welcome friends to their homes and did not have time to engage with others (Kim et al., 2017). Sam mentioned that the fact that her two children were dependent on her and the isolation resulting from having to stay at home.

Similar to this, in studies, participants showed signs of feeling constrained because their lives revolved around their child's cancer treatment, disrupting their normal routines and prior obligations (Lindahl et al., 2016; Wikman et al., 2016; Bona et al., 2014). These participants talked about how they had to give up their obligations, such as work, socialising, and personal development, in order to help manage the daily routines and practical requirements of their sick child (Lindahl et al., 2016; Wikman et al., 2016; Bona et al., 2014).

Previous studies have shown that children with paediatric cancers also have a sense of social isolation (Darlington et al., 2021; Howard et al., 2014). In a relevant study, it was noted that a significant portion of children undergoing cancer treatment will be hospitalised during chemotherapy, leading to prolonged isolation from their schools, peers, and families (Liu et al., 2021). Children who are immunocompromised and socially isolated for long periods of time due to risk of infection (e.g., following bone marrow transplant) may be especially vulnerable (Christiansen et al., 2015). Claire's child, due to his dual diagnosis, was at particular risk of isolation. She talked about preventing her child from getting an infection for her child's cancer diagnosis. Parents of children with learning disabilities also reported feelings of isolation attributed to two major issues—the inability to leave the home or attend family gatherings due to the child's behaviour or sensory issues and being misunderstood as "bad parents" in public due to their child's symptoms and behaviours (Spinazzi et al., 2024). Parents of children with Down's syndrome are also frequently socially excluded due to stigma (Amorim & Shimizu, 2022; Batool et al., 2024), the consequences of which for individuals range from decreased self-esteem, discredit and shame to social restrictions, reduced life satisfaction, social hostility, job loss, financial strain, and apprehension about the future, negatively impacting health (Amorim & Shimizu, 2022).

Parents also play an important role in increasing the independence of children with Down's syndrome through special therapy and training, which has a positive impact on the development of communication skills and self-development (Situmeang et al., 2023). Social isolation does not help the development of children with Down's syndrome (Alhafiz et al., 2024). The cognitive development of Claire's child, who had to be isolated due to his cancer diagnosis, may be negatively affected because her child cannot participate in a range of activities that could contribute to his development.

5.2.6 Impact of cancer

5.2.6.1 Changes in family dynamics

Family systems theory states that profound illness has a life-changing impact on the family unit (Gritti, 2012; Mehta et al., 2009; Milberg et al., 2020). This study shows that a cancer diagnosis affects every family member, and through the perspective of the mother, this study explores what those effects may look like. Much of the existing research around childhood cancer suggests that this life-threatening illness can bring profound life changes for not only the child but also the child's family (Barrera et al., 2016; Popp et al., 2015; Salvador et al., 2019, 2020; Wiener et al., 2015). Upon receiving a cancer diagnosis, family relationships, dynamics, roles, and responsibilities are immediately shifted (Darcy et al., 2014; Schweitzer et al., 2012; West et al., 2015; Woodgate et al., 2011). Within this research, the child with cancer becomes the central focus of family life. Generally, the participants described how they stayed close to the child with cancer, providing care in the hospital, taking them to appointments, and ensuring they are safe within all other environments. The participants found that the role of the father was to return or continue to employment, as finances were difficult during this time. However, the father also assumed new roles, such as now being in charge of caring for siblings and running the household. Similarly, Björk et al. (2009), Fletcher (2010) and West et al., (2015) also showed that the father would take on running the household and ensuring financial stability, while the mother shifts her focus to the child with cancer. This family process has been described as learning to "tolerating living as a split family" (McCubbin et al., 2002, p. 105). According to the findings of my study, two mothers of children with additional needs appeared to undertake comparatively greater care responsibilities of their children. A child with special needs can bring other stressors to the family dynamic (Vitale et al., 2022; Karst & Van Hecke, 2012). Their spouses had to continue their jobs and were not able to provide day-to-day support for their wives. This finding is in contrast to the other three participants. These findings suggest that the primary caregivers of children with additional needs in my study had difficulty "tolerating living as a split family." (McCubbin et al., 2002, p. 105). Even in a 'normal' situation, raising children with special needs requires parents to provide greater and complex care for their children anyway. In having cancer as well, they appeared to struggle even more because the family dynamic was again different, and the child needing further care. In Beeni's case, she had previously mentioned that her husband has mental health difficulties, making her experience of "tolerating living as a split family" even more difficult.

Dynamics and role changes within the family are likely to happen when a child is diagnosed with cancer. During the initial diagnosis, the family, especially the parents, must adjust to this new identity and role shift. In addition to the parental nurturing provided when a child is well, parents of children with cancer often discover that they must become advocates, counsellors, and pseudo-nurses in this new role (Jones, 2012). Caregivers adopted pseudo-nursing roles by acutely monitoring their child's well-being and treatment side effects, examining medical results, supervising hospital staff, and constantly being their child's primary source of support. During the treatment of her child with ASD, Beeni had to explain her child's unique care needs to healthcare professionals, advocating for them. Claire stated that she educated herself about her child's health and felt that she became like a counsellor. Another participant, Kate, talked about taking on pseudo-nursing roles and ensuring that her daughter's treatment takes place at home as much as possible. Families of children with cancer may provide medical, emotional, financial, spiritual, or physical caregiving, or more likely a combination of all of these (Jones, 2006). According to the participants of the research, all members naturally fell into their new roles, interaction patterns, and their relationships within and outside the home, and had adapted to what is needed from them. This shows how families become performative in reaction to the cancer diagnosis (Modanloo et al., 2015). The fact that the caregivers of this study had children with both cancer and a learning disability or ASD, a new area according to current evidence, makes these findings more unique. As this study found, the parents whose child had a learning disability and one with challenging behaviours, these parents found a further role included ensuring their child received equitable care. This unique finding will further enhance the current evidence in the care of family focussed care of children with cancer.

The changes experienced by the families can be divided into three main categories that affect the family as a unit and the quality of life of individual members (Christensen, 2022; Steliarova-Foucher et al., 2017). First of all, cancer may be a threat to the previous model of family interaction. It brings the alternation of roles, which can be perceived by one as a loss and by others as an excessive overload. Secondly, the disease forces the alteration of future plans due to the fact that the presence of cancer introduces a sense of uncertainty. Three participants in this study stated that their lives were functioning at a level that was about survival and isolation. Prolonged uncertainty within a family can disrupt its ability to function effectively. Some families refrained from planning for the future, and this can destabilise family functioning, bringing a sense of a lack of agency, goals or postponement of plans. Thirdly, it affects the functioning of family members in external groups like, for instance, job or school environments (Yang et al., 2016). Also, new groups of functioning appear – doctors, nurses, and other patients and their families. All of these people create a new environment and are of tremendous importance for the patient and their family. Both children and families affected by childhood cancer emphasised the importance of nursing support and care during their cancer trajectory (McHaro et al., 2022). Nurses are able to gather information on how well the family is coping with and adapting to their new normal and they are particularly well-positioned to identify and manage the support needs of this population (Kiernan et al., 2010; McHaro et al., 2022). As Christensen et al. (2022), the three basic changes of family functioning was apparent in the participants' experiences: Claire mentioned that she has been her child's primary caregiver since her child's first diagnosis of Down syndrome, and that her responsibilities increased with the diagnosis of cancer. Likewise, Beeni mentioned that she did not have time to rest after her child's ASD diagnosis and her cancer diagnosis. Throughout the interview, Beeni talked about the negative effects of the inherent uncertainty related to cancer and ASD on her husband. Claire also mentioned that her child could not go to school due to his treatment, and four of the participating mothers in the study mentioned that they had to quit their jobs, which reflects the negative impact on the functions of family members. While four participants evaluated their interactions with nurses positively, Beeni mentioned that nurses were generally busy and did not pay enough attention to her child due to his diagnosis of ASD.

Even though family life changes occur in all three phases, the intensity of the change varies by the individual family. The extent to which a family finds itself in a well-known or new everyday family life is mainly dependent on four variables (De Fine Licht, 2017). These four variables may affect the impact of the changes on the individuals. They are:

1. The child's diagnosis and prognosis.

2. The course of the disease, including duration of treatment or hospitalisations, and time of separation of the healthy siblings and the remaining hospitalised family.

3. The diagnosed child's current state, including symptoms, side effects, intensive treatments, hospitalisations, and current risk of death or of relapses.

4. Whether previous and current needs have been met.

The first three variables are primarily somatic (having to do with the body) and structurally defined; however, the fourth variable is person-defined and can change. All four variables influence one another (De Fine Licht, 2017). These four variables, as observed in the participants of this study, show that time spent in the hospital, the current conditions of their children, the time they spent away from their families, and their unmet needs are different from each other. The unmet needs of children who are also diagnosed with learning disabilities may cause the family to need more support. The last variable - whether previous and current needs have been met - is often disregarded, because, in acute situations, it might not seem important for either the family or the healthcare professionals (Christensen et al., 2022).

The family dynamics change, and are responsive to the cancer treatment journey and the impact this has on the family member living with cancer (Given et al., 2012). In the diagnosis phase, depending on the type of family, a significant mobilisation, with readiness to give support to the patient, is observed. Family members try to get information about the diagnosis, treatment and chances of survival. The treatment phase is associated with the alternation of roles within the family (Given et al., 2012). Very often, all of the family need to cope with the treatment symptoms and accompany him/her to the hospital for chemotherapy or radiotherapy. My study showed how the participants interpreted this as somewhat of a burden both physically and psychologically. For example, Beeni, who has a child diagnosed with ASD, mentioned that she felt helpless in the face of the physical changes her child experienced after chemotherapy. Another participant, Julie, mentioned that she has had trouble sleeping since her child was diagnosed with cancer. This can be very burdensome, both physically and psychologically. The chronic phase of the disease may last for months or even years, including periods of treatment and remission (Given et al., 2012). It is also the time when the family slowly returns to its routine life. In some families the end of chemotherapy or radiotherapy is recognised as the end of the disease itself. The family then has to constantly face the fear that there could be a recurrence (Wakefield et al., 2011; 2020), and every check-up brings a tension that the tests could detect new carcinogenic cells. The strong stress reaction may be caused both by the fear of separation and of staying alone, as well as by the anticipated pain the patient will have to face, the lack of control over the situation, and the moment of death.

According to research by Svavarsdottir (2004), among the most burdensome and time-consuming activities that parents mentioned was managing the behavioural problems of both their sick child and the other offspring, planning and coordinating family activities, and giving emotional support to the spouse or partner. If there are other children in the family, the parents need to take care of their well-being too, and although a sick child is in an unusual situation, it still has a need to be raised and educated. Parents therefore have to learn how to negotiate between handling the sickness and 'normal' parental tasks. The data from this study provides a different and detailed perspective on how parents have to plan, coordinate and advocate for the child's adaptation to the hospital environment if their learning disability or ASD, other treatments the child receives due to learning disability or ASD, and the negative financial impact on families. The mothers of the child with learning disability, and one with autism mentioned that their children had sensory processing problems due to ASD and Down syndrome, and that they had further financial complications because they needed to receive treatment (feeding therapy, sensory garden) for these diagnoses.

The family systems theory was useful in understanding how the dynamics within a family unit change when the family is dealing with cancer. The dynamic within the family and the individual relationships within the family unit were no longer the same after the cancer diagnosis. Participants identified struggles in adjusting to their new family roles and navigating their family relationships during their children's cancer (Burke et al., 2022). According to Long et al. (2015), 'A child's cancer diagnosis can be a devastating event that leads to emotional strain and substantial changes in the day-to-day functioning of the family… which can chronically disrupt the family system' (p. 21).

Having a child with a learning disability or ASD has also been shown to affect family dynamics. Families of children with ASD must cope with understanding the diagnosis, seeking appropriate treatments, and adjusting to the specific needs (Viana et al., 2021; Sánchez Amate & Luque de la Rosa, 2024). When children receive an ASD diagnosis, they may need therapy sessions, educational assistance, and support through major transitions, which often stress the parents and overall family dynamic (Firat, 2016). The family dynamics of a child with a learning disability seem more complex from other families because of the added uncertainty about their child's future, such as potential problems in the academic, educational, financial and emotional fields. Added to this is the fear of recurrence, which is often relayed by the professionals to the parents at times of treatment or diagnosis. All these issues put pressure on the parents, and in this study, especially the mother, which in turn causes the peace and harmony of the family to break down, negatively affecting their compatibility and adaptability (Narimani et al., 2018; Hale et al., 2010). As this study showed, the mothers prioritised the needs of the children with ASD and focused on coping with the elevated childcare challenges, which resulted in newer and further changing family dynamics.

The concerns expressed by the mothers here echoed those in previous studies with parents of children with learning disabilities, which identified a breakdown in the relationship between family members and insufficient available time and energy for mothers to commit to their spouse or the siblings of the child with ASD (Smith et al., 2010). The stress resulting from continuous caregiving, the need to coordinate multiple specialist appointments, and the adaptation of the home environment can be overwhelming, affecting not only the parents but also other family members, who may feel that their own needs and experiences are being neglected (Papadopoulos, 2021; Sánchez Amate & Luque de la Rosa, 2024). The attention and time that parents must devote to children with ASD can lead to conflicting feelings and confusion among other family members (Rfat et al., 2023; Saini et al. 2015). Neglecting the emotional needs of other family members can contribute to a cycle of prolonged stress, where each individual struggles to find their own balance while managing the impact of ASD on family dynamics (McStay et al., 2015). This situation may lead to greater family dysfunction, affecting overall cohesion and the general well-being of all family members (Sánchez Amate et al., 2024). ASD is a lifelong condition that forces the families to make long-term changes to their lives, plans, and dreams to meet the long-term challenges of the condition. Like cancer, ASD also becomes the centre of family life, requiring every member of the family—mothers, fathers, and siblings— to adjust and adapt to the challenges associated with ASD (Frye, 2016).

The impact of having a child with ASD and a learning disability extends beyond caregivers to the entire family system. The increase in parenting stress, conflict, and child behaviour problems contributes to a higher rate of divorce for parents of children with ASD than in families of typically developing children (Freedman et al., 2012; Hartley et al., 2010). A diagnosis of ASD and learning disability significantly changed the primary caregivers' lives they stated that they had to structure their schedules around their children's lives, moods, and affect. In addition to changes in their personal and professional lives, families also were concerned about others' opinions of their children's behaviours (Sansosti et al., 2014). Sensory features are described as unusual behavioural responses to sensory experiences; they are common among children with ASD and are also found in some children with learning disabilities (Baranek et al., 2014). Sensory features can impact family functioning and routines (Karst & Van Hecke, 2012; Marquenie et al., 2011).

Due to the complex nature of ASD and the intricate subsets found within the family unit, it is necessary to develop a theoretical framework that addresses these complicated needs throughout the research process (Cridland et al., 2014). The Family Systems framework allows researchers to understand the intricate challenges family members face concerning the child with ASD and within the family as a whole (Cridland et al., 2014; Cridland et al., 2016). Autism behaviour problems were found to be the most consistent predictor for stress in the family unit (Roper et al., 2014; Walton, 2016). Caregivers reported increased parental burden, directly related to the level of autism severity, which in turn caused a disruption in the normal functioning of the family (Ingersoll & Walton, 2015; Lovell & Wetherell, 2015; Tomeny et al., 2019; Walton, 2016). Researchers have investigated the impact that living with a child with ASD has on the stress of family members, revealing significant challenges in obtaining direct care for the affected child, coping with ASD behavioural symptoms, stigmatisation, social isolation and strained family dynamics and functioning (Gardiner & Iarocci, 2014; Gorlin et al., 2016; Thullen & Bonsall, 2017; Whitehead, 2017; Zaidman-Zait et al., 2018).

Having a child with a dual diagnosis has a significant impact on a family (Spinazzi et al., 2023). This study has been able to explore the perspectives of caregivers with a child with cancer and Down Syndrome/ASD. Children with cancer and DS/ASD are a relatively understudied patient population, and this study offers valuable insight into their families' lives. Dynamics and role changes within the family when a child is diagnosed with cancer and has a learning disability or ASD bring extra challenges. This could be seen as an additional burden that has an impact on the parents in relation to their exhaustion in dealing with the added complexities of their child's cancer diagnosis.

Studies have reported both positive and negative changes in the marital relationship of parents whose child has cancer (Da Silva et al., 2010; Khoury et al., 2013; Schweitzer et al., 2012). Some couples underline how the disease improves their relationship (e.g., via improved trust, communication, support, and emotional closeness), while others highlight how it negatively impacted their sexuality (Da Silva et al., 2010; Wiener et al., 2017). Three participants in the current study talked about their children's cancer diagnosis's negative effects on their relationship. These primary caregivers provided a certain perspective about their husbands which is limited elsewhere in the data, and does offer some insight that helps create a picture that includes the entire immediate family system. Sam talked about how physical separation negatively affected her relationship with her husband. Beeni mentioned that having to manage childcare tasks without her husband's support negatively affected their relationship.

A family member's experience of stress has the potential to affect everyone else in the family system and its subsystems that can be explained by the family systems theory. Caregivers in this study talked about the negative impact of the couple/parental subsystem due to their child's diagnosis. This finding supports the idea that parents of children with ASD may face unique challenges related to their child's disorder (Serrata, 2012) and the that family system may also be negatively impacted. Similarly, due to highly demanding parenting duties, including unequal distributions of caregiving and prolonged hospital stays with children with cancer spouses hardly had time for each other, which led to marital conflicts (Divan et al., 2012; Hsu et al., 2017; Silva-Rodrigues et al., 2016; Wiener et al., 2017). Beeni presented herself as being “drastically busy” and she felt like a “single mum, full time carer”. This finding is supported by studies that this can be especially burdensome for parents who do not feel they have the support they need to care for the psychosocial needs of their children (Wiener et al., 2015). In my research sample, Beeni’s intersection of having a child with ASD and being a “single mum” appears to represent a burden. The subsequent care needs of their child with learning disabilities resulted in a caring role that lasted the length of the child’s life for all mothers and fathers, which was fraught with difficulty but shared between parents. This joint responsibility took its toll on couples and their marital relationship, which was illustrated by the parents’ accounts.

Some research has found that parents of children with learning disabilities are more likely to experience divorce or marital separation (Kousgaard et al., 2018; Hartley et al., 2010; Freedman et al., 2012). According to Claire, she presents differences between men’s and women’s parenting and personality, suggesting this has strained her relationship with her husband. Similarly, this finding supports that in the literature that mothers claimed that fathers did not react with the same instinct (Hjelmstedt et al., 2021). Mothers may be reluctant to relinquish the responsibility of care to fathers, based on their maternal instincts and perceived maternal responsibilities (Yogman & Garfield, 2016). With regard to family roles, fathers perceived the mothers as the primary caregiver (Friedman et al., 2015; Öjmyr-Joelsson et al., 2009). Fathers may be unwilling to take on additional responsibility, feel undervalued in their role caregivers, or take on more comfortable roles such as working outside the home and managing the finances (Friedman et al., 2015).

Beeni also stated that “fathers” have ego problems and seeing mental healthcare professionals is perceived as “negative” and “taboo”. The fact that her husband was not willing to receive psychological support, and is depressed negatively affects their relationship, both as a family and as a couple. This finding is supported by previous research that has found that fathers may not seek emotional support due to their own inability to express emotions (Swallow et al., 2012). Cultural-gendered roles and expectations also appear to have impacted fathers’ emotional responses to their children’s cancer diagnosis (Banchefsky & Park, 2016). Fathers expressed a need to be “strong” for their family (Robinson et al., 2019). Davies et al.’s (2023) study revealed that sociocultural norms requiring men to be “strong” are still prevalent, despite the changing roles of fathers. Two studies found that mothers used significantly more instrumental and emotional social support in seeking to cope than fathers (Gage-Bouchard et al., 2013; Hoekstra Weebers et al., 2011), particularly around the time of diagnosis.

Self-stigma is a subtype of stigma which occurs when negative attitudes are internalised (Pattyn et al., 2014). In terms of this research finding, Vogel et al. (2011) and Wasylkiw & Clairo (2018) indicate that self-stigma has been shown to have the largest direct effect size on help-seeking and to partially mediate the relationship between conformity to masculine norms and help-seeking. Financial challenges were another factor that contributed to marital conflict between parents of a child with cancer (Yi et al., 2021), given that increased economic strain is related to poorer marital adjustment among parents of a child with cancer (Lavi et al., 2018).

Mothers talked about their other children, that is, those who did not have cancer, during the interviews. Claire mentioned her other daughter acting like a “superstar” and that she was actually mature and could handle being away from her family. This finding is supported by a study found that parents spend significant time caring for children with life-limiting conditions and assume that older siblings are sufficiently mature to cope on their own (Tay et al., 2024). Research found that siblings highlight the need to be “grown-up” to support their family (Pariseau et al., 2020; van Schoors et al., 2019). From a theoretical framework, the results appear to support family systems theory, a child with cancer impacts the entire family unit, including the sibling. The children without cancer had to adjust to their new role as siblings of a child with a long-term condition, which included being more mature than other children of the same age (Piotrowski et al., 2022). This can lead to undue mental and emotional strain and take away some of the time spent interacting with others, negatively impacting peer relationships (Niedbalski, 2024).

Three reviews highlighted how siblings had limited social experiences as they often sacrificed their social interaction time to spend with the sibling with the long-term condition (Long et al., 2018; Tay et al., 2021; Weiner & Woodley, 2018). Yang et al. (2016) reported that siblings require appropriate support and guidance to understand their unique situation. Children without cancer needed and valued the opportunity to connect with peers and friends (Deavin et al., 2018). There appeared to be limited literature regarding the experiences of siblings of children with both cancer and Down’s syndrome. Siblings of children with Down’s syndrome noted they developed personal strengths, including increased levels of caring and kindness (Lemoine & Schneider, 2021), more helpful attitudes (Skotko et al., 2011), and greater patience and acceptance (Graff et al., 2012).

Kate mentioned that her son without cancer, could not accept the diagnosis of his sister and that he had not seen his sister for a long time. When a child is diagnosed with cancer, family roles, routines, and functioning have to be adjusted to fit the needs of the impacted child and family (Kobayashi et al., 2015; Long et al., 2015). Families’ adjustment to cancer varies (Long et al., 2018); they need to redefine their relationships, communicate effectively (i.e., “emotional closeness within the family”), and flexibly renegotiate roles and responsibilities (i.e., “family structure”) to accommodate the demands of cancer, and poorly functioning families who struggle with these demands may be at risk of adjustment problems in all family members, including siblings (Long et al., 2013; van Schoors et al., 2017; 2019b). While most siblings of children with cancer adjust with time (Alderfer et al., 2010), some experience challenges with regard to psychological functioning (Buchbinder et al., 2011; Long et al., 2018; van Schoors et al., 2017; Yang et al., 2016; Zegaczewski et al., 2016). These studies found that these siblings experienced behavioural maladjustment, anxiety, depression, and the symptoms of post-traumatic stress (Alderfer et al., 2010; Buchbinder et al., 2011; Long et al., 2018; van Schoors et al., 2017; Yang et al., 2016; Zegaczewski et al., 2016).

Siblings also reported worrying about the prognosis and potential death of the child with cancer (Prchal & Landolt, 2012), including anticipatory grief, even when the patient's prognosis was good (Jenholt Nolbris et al., 2014). Kumar and Nyatsuro (2020) define anticipatory grief as an active process of sadness that occurs before an actual loss. Kate’s other child also seems to have experienced behavioural maladjustment to his sister’s cancer diagnosis. Conversely, some siblings did show positive psychological and social growth, and developed adaptive behaviour, including increased responsibility, stronger family bonds, personal maturation, and an increased ability to exhibit empathy, especially as older siblings adopt a caregiving role (Prchal & Landol, 2012; Long et al., 2015; Nolbris & Ahlström, 2014). The findings relating to changes in siblings’ lives due to cancer may also have relevance to the context of family systems theory, which attempts to account for the variance of positive and negative family adaptation and the way behaviours and relationships are intertwined in family units (Burke & Dunne, 2023).

Julie shared her experiences about the fact that they could not be together as a family due to the intensity of the cancer treatment and that each of her family members had concerns. She experienced a situation in which she attempted to protect her family members by avoiding sharing worries with them and carrying out emotion work (Hochschild 2003). This is consistent with the family systems theory, in that changes in one family member influences all family members (Bronbrenner, 1986; Kaakinen et al., 2010). The thoughts, feelings and emotions of one member can significantly affect the thoughts, feelings and emotions of the other members within a given family unit. Kate mentioned that her other child had adjustment problems, Julie mentioned that her other children experienced significant anxiety, and Claire reported her other child’s significant isolation due to having a sibling with cancer. Beeni also mentioned her husband who was negatively affected by her child’s cancer. Family systems theory contributes to bringing social and cultural variables to the picture, such as the stigma attached to cancer and the family’s isolation from the community (Yi, 2009).

Beeni talked about her experiences of experiencing stigma. Cancer is a serious, life-threatening illness that impacts the entire family system, with implications not only for patients themselves, but their siblings, parents, and extended family (Rolland, 2018, 2019). In the case of childhood illness, family members’ previous roles and responsibilities can be affected by a shift in focus to the sick child’s care. Consequently, daily life is often disrupted for all members, changing the balance within the family unit (Bowen, 1974). Childhood cancer is a highly stressful experience that can challenge and disrupt the family dynamic and its members (Long et al., 2011; Kim et al., 2020). As cancer is a life-threatening illness, when a child is diagnosed with cancer the whole family is affected (Prchal & Landolt, 2012; Khoury et al., 2013). The family systems theory lens reinforces the importance of attending to the family’s needs as a whole as well as the individuals’ needs to support family functioning and well-being.

5.3 Conclusion

The discussion chapter has attempted to comprehend the experiences of primary carers of children with cancer in connection to the results chapter, theoretical frameworks, and the current literature. In this study, results were also obtained on which subjects primary caregivers expect support from nurses during the difficult treatment process.

Some of the findings in this study differ from those in the literature. One notable finding was that Claire used her health literacy to navigate the healthcare system, in contrast to the current evidence. The uncertainty noted by the participants of this study appeared different from the findings reported in the literature and somewhat divergent from the common evidence base. Also, Beeni has a non-verbal child diagnosed with both ASD and cancer and the intersectional nature of these three factors has not previously been explored in the literature; additionally, the sense of guilt related to a child’s being nonverbal has not been discussed in the extant literature.

There is a limited degree of exploration about primary caregivers who experience anxiety due to the recurrence of cancer in their child, quality of life due to ASD, and the child's non-verbal state, as Beeni experienced. Beeni and her husband needed information about their son’s specific condition’s effect on cancer treatment options and medications; this finding is also different from studies in the current evidence-base. Parents emphasised that they monitored their child’s symptoms while receiving active treatment. My data also finds that constantly monitoring and performing risk assessment for their children results in extra emotional labour for these primary caregivers.

These research findings reflect about family systems theory and the effects of diagnoses of childhood cancer on the family system (parents and well siblings). Nurses providing care for children with cancer must ensure that they help families adapt to the multitude of changes brought about by the cancer diagnosis. Emotional support from healthcare professionals is vital to the management of paediatric cancer. The emotional support provided by healthcare professionals should target multiple levels (considering subsystems) rather than the individual level to effectively assist the family to regain balance and adapt (Kaakinen et al., 2018).

This chapter has further investigated the specific meaning of the identified concepts and other experiences shared by the participants, making links between theoretical frameworks and this study’s findings. The concluding chapter, as follows, summarises the overall findings of the study and provides vital recommendations and implications for practice.

Chapter 6

Conclusion

6.1 Introduction

First, this chapter presents the key findings based on a qualitative study of the experiences of primary caregivers of a child with cancer. This concluding chapter gives an overview of the key findings from the research in this thesis and will address the research question and objectives outlined at its beginning. This is followed by a discussion of the strengths and limitations of the study, as well as possible directions for future research on caregivers of children with cancer and learning disabilities. Finally, this chapter ends with an overall summary of the entire thesis.

6.2 Interpretation of the findings

My unique contribution to knowledge is producing an in-depth analysis of what it is like to be a parent of a child who has been diagnosed with cancer and highlighting the specific issues of having children with cancer, who are also neurodiversity, and learning disabilities. This thesis has taken the opportunity to build on areas which have received an insufficient amount of attention to contribute new knowledge to the field. An important contribution of this dissertation is the interconnectedness observed in the family system. Families considered transitions in the lives of their family member with cancer and a learning disability and ASD to be transitions in their family life cycle, with effects on all family members. It has provided a greater understanding of the interrelatedness of individual and subsystem functioning, and the relationship between subsystems and overall family functioning in families of children with cancer and a learning disability and ASD. Primary caregivers of children with a diagnosis of cancer have various difficulties in the diagnosis and treatment of cancer and need support in this regard. Uncertainty, guilt, helplessness, shock and anxiety were prevalent among the caregivers of children with cancer in this research. Caregivers experienced psychological challenges in light of their children’s medical condition(s) and the therapy that their children were receiving. Primary caregivers also experienced emotional work, stigma, financial difficulties, disruption of their normal lives and inadequate emotional support, all of which point to gaps/inadequacy in the level of emotional support that they received. This indicated that the caregivers experienced a wide range of sociological challenges in light of their children’s medical condition(s). Learning more about the disease and its treatment, and seeking support from family members, friends and healthcare professionals were the principal ways the caregivers reported of coping with the associated psychological challenges. Primary caregivers need a nurse’s care, support, and information to address the psychological challenges.

The primary caregiver of a child with autism’s information needs were not fulfilled in this study. These information needs were different from those of the other caregivers. This primary caregiver needed information about the impact of her son’s ASD diagnosis on his cancer treatment options and medications. Assessment to understand the information needs of parents is essential to nursing practice. In order to meet the information needs of parents, nurses must accurately evaluate the needs of parents and, when necessary, share information with multiple professionals and receive support from them to meet their information needs. The information needs scale can be used to determine the issues that primary caregivers need to be addressed (Borjalilu et al., 2017; Motlagh et al., 2019). The Oncology Family App was also found to be an efficient and convenient way to provide the needed information (Slater et al., 2018). The results from this study thereby indicate that family-focused care could be improved with increased communication between staff and parents. Individualising communication practices by healthcare professionals to meet the needs of particular parents could assist them in their role.

The primary caregiver of a child with ASD in this research believed that the healthcare providers had ignored her concerns. Nurses can listen, address the parents' concerns, and assist with finding available resources and support for the children and their families. If the nurse who cares and supports the child with cancer and her/his family knew what the caregivers went through during the difficult cancer treatment process, they could be more supportive. Paediatric oncology nurses provide therapeutic relationships through application of their clinical expertise, therapeutic communication, and by being physically available and emotionally connected to the patient, a concept known as nursing presence (Kostovich, 2012; Kostovich et al., 2016). When establishing therapeutic relationships in paediatric oncology, nurses require an understanding not only of the child's needs, but also those of the parents, as these are inextricably linked.

The data utilised for this dissertation provided a great deal of information about how cancer affects the family system. A family-centred approach to dealing with the impact of childhood cancer should become the norm when a child is diagnosed with cancer. Childhood cancer has come to be a called a "family disease" and, in accordance with this designation it is imperative to treat it as one. As clearly demonstrated by the various data in this dissertation, all family members are affected by the presence of cancer and thus all need to be considered when doing assessments and devising interventions or resource plans. All family members of a child who has been diagnosed with cancer are affected by the diagnosis and should accordingly receive support (Lewandowska, 2021).

6.3 Strengths and limitations of the research

There are some strengths to this PhD study that should be emphasised. Firstly, this thesis uses the IPA methodology, which examines in depth the experiences of primary caregivers of children diagnosed with cancer. IPA permitted me to embrace and integrate my knowledge from past professional experiences into an understanding and interpretation of the primary caregiver's accounts of their experiences. Adopting the double hermeneutic approach promoted in IPA research enabled me to attempt to and synthesise the sense-making of the primary caregivers describing their experiences; this approach can be seen as a strength of the study. IPA enabled me to move from formulating themes effectively to coding the actual collected data, focusing on all the participants' outstanding characteristics and traits both collectively and individually. IPA has been largely used in health research, especially in studies investigating caregivers' subjective experiences (Atout et al., 2021; Cardon &

Marshall, 2021; Demirtepe-Saygılı et al., 2018; Schweitzer et al., 2012). The utilisation of in-depth interviews and the IPA methodology to examine the study's objectives are considered strengths of this study. Every step of this research study's methodology matched the steps in IPA (Smith, 2011). Semi-structured interviews with participants and using IPA methods to analyse interview data allowed me to collect "rich, detailed, first-person accounts of their experiences" (Smith et al., 2009:15), which was consistent with the study's objectives. The IPA methodology promotes small samples in order to allow for a deep, idiographic assessment of participant experiences. IPA is an inductive approach concerned with understanding how a particular cohort of people have made sense of a particular phenomenon (Gauntlett et al., 2017). IPA's open-ended, inductive research methodology aims to "give voice" to those accounts that tend to be from marginalised individuals or communities (Larkin et al., 2019). IPA's inductive principles are designed to facilitate the emergence of unexpected themes and the generation of expansive data. This methodology contributed to the exploration of this research's findings, such as emotional work and stigma.

Secondly, another contribution of this thesis to the literature is that this study explores how parents of children with cancer experience, make sense of, and narrate their stories of their child's additional diagnosis of ASD and Down's syndrome. This study uniquely increased the insight available to healthcare professionals into the range and complexity of perspectives and needs of mothers of children with ASD, Down's syndrome and cancer. This research makes a unique contribution to the literature on the complex and multi-level experiences of caregivers of children with ASD, Down's syndrome, and cancer in caring for their children, and what kind of support caregivers need regarding the intersection of the dual diagnosis of a child with these conditions.

Thirdly, this study shows that mothers experience significant emotional work while caring for their children with cancer, and it is one of the few studies that emphasise this finding. This is significantly detrimental to their emotional and psychological health. Emotional work is related to parental exhaustion and burnout (Lin et al., 2021). Burnout has a negative impact not only on the parent, the functioning of the family, and the relationship between partners, but also affects the parent-child relationship. Parental burnout is an area requiring attention from nurses in view of the potential negative impact on the health of both parents and children.

Finally, my background as a paediatric nurse and researcher solidified my understanding of this research data. I believe that through my varied experiences and background, I was able to connect effectively with the primary caregivers in this study. I have acquired a strong interest in paediatric health and disease, particularly since it affects not just the child patient but also the family as a whole. When a child is diagnosed with cancer, their parents are subjected to a variety of devastating stressors, starting with the diagnosis and continuing throughout their unique and personal journey. My experience as a paediatric nurse strengthened my grasp of the facts through reflective investigation, which has given me insight into from a health professional perspective in nursing. While mothers share their experiences about the process after their children are diagnosed with cancer, I would like to be there for them when they need it, so that I can support them as a nurse. Supporting not only children with cancer, but also their parents, and seeing the emotional and psychological challenges that parents often experience when supporting their children, influences my role in my own clinical practice. These research findings gave me insight and significantly strengthened my nursing experience.

Despite the study's contribution to the existing body of research, there are several limitations to consider. The present study has eight limitations that should be acknowledged. First, there are limitations with the sample of the current study that are gender related. Male participation could have been valuable to the study, however, there were five female participants. Similarly, in the family caregivers group, there were more women, in fact, mothers, participating than other family members relevant to the children's patients. Mothers seem to prefer participant research to share their experiences. In particular, fathers of children with cancer may be more difficult to reach because of "inaccessibility or lack of invitation" (Davison et al., 2017). This thesis focused on the parent/child subsystem. Future research should expand the family systems examined to include father, siblings, and other family member subsystems. Second, there was a lack of diversity in the sample with all parents identifying as female, and four out of five participants were White British. The majority of this research sample was not from a diverse ethnic or racial group, except for one participant who was Pakistani. This observed and reported lack of diversity impacts the transferability of the findings, and efforts should be made in future similar studies to attempt to recruit a more representative sample and collect more detailed demographic data, particularly regarding parental ethnicity. Future researchers may gain greater participant diversity by also recruiting from hospitals/ clinics (especially those serving a significant proportion of low-income and/or ethnic minority populations), regional and local and community organisations serving children with cancer. Third, although this study's inclusion criteria included all caregivers (i.e., single, mixed-sex, and same-sex were invited to participate), only one participant in the current study was a single parent whilst the rest were married. Fourth, due to the challenges that I encountered during the recruitment phase (as discussed in the 'Recruitment' section of the Methodology chapter), the inclusion criteria were broadened which meant that primary caregivers of children who have completed any childhood cancer treatment were also to be included. Although this facilitated the recruitment, it is an important methodological consideration as the children were at different stages of their illnesses (see 'Challenges and Amendments' section in the Methodology chapter). This may have led to different experiences among primary caregivers of children with cancer. As this could not be assessed in the current study, it could well be an important aspect for future research to take this into consideration and explore it further. Fifth, primary caregivers were recruited from charities. Given that the study used a voluntary convenience sample, it is likely that these participants volunteered to partake in telling their stories. Those who declined might have had a different experience. Sixth, due to COVID-19 pandemic restrictions interviews were conducted online. Qualitative methodologists historically recommended face-to-face contact for qualitative interviewing (Gillham, 2005; Rubin & Rubin, 2011), cautioning that remote meetings may impede rapport, engender participant fatigue, and restrict the depth of interaction (Irvine et al., 2013). However, as video-call platforms become increasingly advanced and widely used, methodological discussion of video interviewing has emerged in qualitative research (Archibald et al., 2019; Lobe et al., 2020). Using communication methods such as Zoom and Teams may have allowed for the convenience and sense of safety provided, whilst still allowing access to non–verbal communication between both parties (Daniels et al., 2019). Seventh, it is also challenging to support participants remotely if they experience emotional distress during online interviews (Keen et al., 2022). I addressed this limitation by using the distress protocol. A distress protocol developed for qualitative data by Haigh et al. (2013) was applied during the online interviews in case the participants felt stressed. Interviews were stopped when the study participants could not continue and only continued when the participants felt that they were able to. Finally, interpretation, especially the double hermeneutic process in IPA, is dependent on the researcher making meaning of the person's experience (Brocki et al., 2006). As a result, this is a complicated and intensive process, and it is acknowledged that novice researchers employing this technique frequently confine their studies to more descriptive accounts, rather than embracing the creative aspect of interpretation (Smith et al., 2015). The efficient use of supervision, reflexivity, and recording of how the individual superordinate and group themes were arrived at has demonstrated to me that they are effective facilitators of interpretation.

6.4 Implications for research/practice

The present study generates a number of clinical practice implications.

1. The implications of these data for research and practice would imply that the cancer treatment process is a considerable difficulty for primary carers of children with cancer. Increasing understanding of the needs and experiences of primary carers of children with cancer and learning disabilties is the key clinical implication of this research. Participants in the study reported that it was extremely distressing, and extremely traumatic and uncertain for their child to receive a diagnosis of cancer. Similar experiences are well documented in the available literature (Nurhidayah et al., 2023; Schepers et al., 2018; Ljungman et al., 2015; Lewandowska, 2021; Borrescio-Higa & Valdés, 2022; Bretones-Nieto et al., 2022), and given that primary caregivers play a key role in managing their child's illness, it appears vital that health professionals (nurses, doctors, psychologists) be able to provide appropriate emotional and informational support (Atout et al., 2021; Bohnenkamp & Anderson, 2022; Gibson et al., 2018; Ringnér et al., 2015). Emotional support also reduces parental stress,

which may then help them feel better placed to make decisions (Gage et al., 2013). Giving primary carers the chance to speak about their difficulties from their own points of view could be critical when developing a holistic and family-centred care plan.

2. This research's findings suggest that healthcare professionals should support parents in their emotional work. Emotion work is the critical component that constitutes caregiving and should be appropriately made visible and supported. Jeung et al. (2018) reported that both stress management programmes and personal coping skills are important to reducing the adverse outcomes of emotional work/labour. It can be suggested that parents meet with supportive psychological counselling services to offer a dimension of spiritual wellness and to promote healthy self-expression within roles that require the management of emotions. Nurses can teach parents effective coping strategies to enhance emotional labour to manage negative internal feelings. Hospitals also need to consider the institutionalising of ongoing support groups for parents (possibly led by parents who have already faced similar situations) directed towards acknowledging the exhausting emotion work required as mothers or other caregivers manage to negotiate with other family and friends and the medical care team. Peer support groups, counselling, psychoeducation and parenting support programmes are found helpful by parents (Wakefield et al., 2016; Archibald et al., 2021; Coulson et al., 2012). Some of the caregivers in this study also talked about grieving. The experience of grief is intense and individualised. Additional support early in bereavement is needed; this support should be tailored and include flexibility in its content and delivery.

3. The findings of this study and studies in the literature highlight the negative effects of stigma on the family and child. Policymakers should prioritise stigma-reduction policies that consider multiple intersecting stigmas to maximise improved health outcomes. Interventions that provide explanatory information about ASD, learning disabilities and increased awareness through education about cancer reduce stigma (Kim et al., 2023; Zheng et al., 2024). To overcome this, policy development can be aimed at increasing the awareness on learning disabilities, not only to the general public to reduce stigma but also to healthcare providers on the importance of communicating the availability and benefits of support groups to parents in order to reduce the judgment and isolation they feel.

4. Healthcare professionals are in a key position to offer guidance, support, and reassurance. Primary carers could benefit from healthcare providers preparing them for the time between diagnosis and treatment. Some of the participants in this study were dissatisfied with the help they received from their relationships with healthcare professionals. Primary caregivers of children with and without learning disabilities require multiple forms of support, including informational and emotional support. The caregiver of a child with ASD in this study felt that nurses did not understand her experience of daily struggle. As a consequence, her needs regarding communication and reassurance were not being recognised by nurses. This parent thought there was a lack of nursing input regarding emotional support. While psychosocial

nursing care is undoubtedly important, research indicates that psychosocial issues in paediatric cancer care are likely to be overlooked and unmet (Paterson et al., 2023; Lövgren et al., 2020). Healthcare professionals should recognise the value of helping primary carers talk about their “cancer stories” and relax by expressing themselves. Effective communication with patients and their families is crucial and integral to nursing. Nurses should listen to parents and encourage them to share their experiences; they can show empathy and provide comforting gestures, kindness, compassion and a caring attitude. Because children with learning disabilities and their parents are often positioned as different and sometimes marginalised, it is imperative that nurses take the time to understand their unique beliefs and practices. Nurses should pay particular attention to complaints related to parents’ difficulties and thus guide them adequately to deal with their children’s temperaments. Nurses can talk to parents about healthy coping mechanisms for stress and stigma related to ASD. Assessing the psychological and substantive needs of family members during diagnosis and treatment should be a fundamental care technique for nurses to develop supportive interventions. Nurses can support and encourage families, over time, to express their true feelings, through therapeutic conversations, and provision of time, and private spaces where their feelings can be expressed and processed. The acknowledgment and compassionate understanding of potential emotional difficulties associated with this challenging life journey will then be fundamental for oncology nurses, in engaging in family-centred care, tailoring and adapting to each family’s unique situation.

5. Another consequence that may be explored is for parents to talk to other parents who are in similar circumstances if this is likely to be beneficial to the parent's well-being and the parent is willing for this to happen. Nurses can contribute to the communication of primary caregivers whose children are diagnosed with cancer and thus bring them together; this way, they maintain social ties online. It may also be helpful for these caregivers to share the information they have learned with each other. Different parents could find this parent-to-parent communication beneficial. According to the most recent NICE guidelines, all parents of children with cancer should have access to specialised psychological and social care (NICE, 2014). Nurses should also assist in connecting parents to resources in their community, such as ASD and Down’s syndrome specialty centres or websites (Mencap, The Child Autism UK, Support from Ambitious about Autism and Together Matters, DSUK (Down Syndrome UK), Down’s Syndrome Development Trust). This research highlights that parents rely on building a community with the families of other children with cancer. Establishing dedicated emotional support provisions, for example, through formal parent support networks or a group psychosocial intervention (Lodder et al., 2020; Gomes et al., 2015) would also be useful to parents. In the UK, primary caregivers of children diagnosed with cancer can contact other primary caregivers who share their experiences through charities. The names of some of these charities are as follows: The Brain Tumour Charity, Children with Cancer UK, and Children with Cancer and Leukaemia. In addition, there are some hospitals that run support groups and/or parent-to-parent mentoring programmes for primary caregivers with a child with cancer. These programmes are conducted online or with in-person participation.

Additionally, there are Facebook groups for parents of children with cancer (CCLG parents and carers Facebook group) on social media platforms. Moreover, there is a specially designed camp, Barretstown, for children with serious illnesses and their families. In the UK, primary caregivers of children diagnosed with cancer can also receive support from healthcare professionals in charities. The names of some of these charities are as follows: Children's Cancer and Leukaemia Group, Young Lives vs Cancer, Kids Cancer Charity, Teenage Cancer Trust, Macmillan Cancer Charity, Cancer Research UK. Some hospitals within NHS England also provide support and information for parents of children with cancer, some of the names of which are: The Children's Cancer Support Group, Jenny Lind Children's Hospital, Great Ormond Street Hospital, and Chelsea and Westminster Hospital. These charities have teams to support caregivers. These teams consist of social care personnel and health professionals. These team members answer and offer support for any questions regarding money issues, benefits, emotional support or living with cancer in general. The priorities of these teams should be to make caregivers feel that they are not alone and to support their information needs.

6. The theme 'I learned what I needed to learn', which is one of the themes of this study, is clinically significant to nursing. Primary caregivers in this study stated that they needed information about managing the cancer treatment process. This need has resulted in their efforts to access the necessary information themselves. Since the participants in this study are primary caregivers whose children also have ASD and Down's syndrome, it is important that health professionals be aware of these families' possible needs, to make necessary arrangements in the treatment process, and to arrange consultation with experts on genetic diseases and learning disabilities for these families. Young Lives vs Cancer, a UK organisation that supports children with cancer, suggested a new model of care in 2009. The following were central to this model: every child and family should have a specialist nurse key worker responsible for the coordination of care and support in the community; their needs would be systematically assessed and reassessed using the Common Assessment Framework (Snowden et al., 2015); they would be able to easily access support/advice at any time; and they would be given information to enable them to understand/manage their illness, empowering them to make informed decisions (CLIC Sargent, 2009). In 2022, research was carried out to evaluate the key staff role connected with this project and its influence on patient and family experience; parental emotional well-being; and the delivery of care closer to home and its advantages for children and their families (Martins et al., 2022). According to the findings of this survey, about half of the parents reported receiving sufficient assistance on "learning the best ways of helping my child" (48%, n = 46) and "having someone to talk about my child with" (50%, n = 47). Giving primary carers assistance in the form of knowledge may enable them to deal with the situation successfully, enabling appropriate management of children who have been diagnosed with cancer. The expertise and experience of key workers such as nurses are at the heart of ensuring continuity in the needs of the primary caregivers of the child with cancer.

7. This research found that the staff working within oncology did not proactively engage with the primary caregiver of a child with autism-related needs. This highlights the need for more systematic training and support to meet the often complex co-morbidities and is reflected within the literature related to learning disabilities and cancer care. Training, knowledge, and awareness-raising for healthcare providers, family members, carers, and support services are essential; for example, training for healthcare providers in communicating with children who have learning disabilities and/or ASD and Down's syndrome. Educational interventions should also be emplaced to empower nurses and other healthcare providers currently working in oncology clinics and enable them to respond better to the challenging situations of families with children with Down's syndrome and ASD. The Oliver McGowan Mandatory Training on Learning Disability and Autism by trainers with lived experiences of learning disabilities and autism training can be used for training (Health Education England, 2023). This training is the UK government's preferred and recommended training for health and social care staff. Oliver's training is delivered in two tiers. Staff need to complete either Tier 1 or Tier 2. Both tiers consist of two parts. The first part of both Tier 1 and Tier 2 are e-learning. Everyone will need the e-learning regardless of where they work and the tier of training they require. Tier 1 of the training is for people who require general awareness of the support that people with ASD or people with a learning disability may need. Tier 2 of the training is for people who may need to provide care and support for people with ASD or people with a learning disability. The second part of the training is either a live one-hour online interactive session for those needing Tier 1, or, a one-day face-to-face training session for people who require Tier 2. There is a need to review routine policies and practices on the ward, to create an environment that values communication and encourages child-centred care by all staff. Information from recent studies and this research findings could also potentially be used as a training resource for staff working with families affected by ASD in order to facilitate optimal levels of empathy and care provision for the family. Sharing these findings through presentations and discussions can contribute to a better understanding of primary caregivers' experiences. The results provide a starting point for further study as well as a guide for nurses to deliver holistic and comprehensive healthcare for parents of children receiving cancer treatment. In addition, actively providing input into undergraduate and postgraduate training programmes will help equip future healthcare professionals with the necessary knowledge and skills to navigate diverse paediatric patient lists and cases. Training in learning disabilities needs to be firmly embedded in the undergraduate curriculum for all professional groups, as well as be consolidated in practice through mandated education that includes face-to-face learning with experts by experience (Oulton et al., 2022). Being better informed and trained should lead to increased confidence and a more equitable partnership between parents and staff when discussing and providing care for children with learning disabilities (Kenten et al., 2019).

8. This research found that parents need financial support. Policymakers must provide policies and improve mandates on allowing informal caregivers to take paid leave, and flexible hours to accommodate those whose children have longer treatment trajectories or

receive compensation or aid in caring for their children. Establishing a continuous economic support policy would be beneficial to lowering the financial burden on childhood cancer patients and their families.

9. One of the key messages from this research is that every children's unit should have a current restraint policy and training should be provided to guide and support all members of the multidisciplinary team. It is particularly important that healthcare professionals and parents talk with each other after a procedure has been performed that included physical restraint or that caused suffering to the child. All healthcare staff who care for children should familairise themselves with restraint policy and receive training in communication skills, therapeutic holding, guided imagery, and alternative techniques. The Autism Spectrum Disorder Care Pathway is recommended for use if restrictions are necessary during the treatment of children with cancer and learning disabilities. Paediatric oncology nurse education should include the issues of physical restraint in this patient population, encompassing the associated ethical, legal, and psychological factors, as well as holding techniques, and the use of alternative strategies.

10. Best practice suggests that children with learning disabilities should be flagged when admitted to hospital (Kenten et al., 2019). Practice implications may include, first, recognising the unique needs of families of children with ASD in the healthcare setting. Because of the behavioural and communication challenges of a child with severe ASD, the family may require additional support when the child has a health care visit to hospital. This should include more staff to support the family in assisting with procedures and healthcare providers who are sensitive to families experiencing significant stress. The findings from the current research could be incorporated into staff training for other health and social care professionals involved in assessing and supporting parents with cancer and learning disability.

11. The present study showed that the developmental needs of children diagnosed with learning disabilities must be taken into account when receiving cancer treatment. Children should also have access to support from speech/language therapists, occupational therapists, and child life specialists.

12. As this research findings can be useful in terms of providing insights that can help relevant policymakers to develop effective policy actions to address the challenges of mothers of children with cancer, ASD, and Down's syndrome, and improve their wellbeing and quality of life. Identifying the stressors for these mothers could lead mental health policymakers and service providers to coherent and appropriate planning to provide psychological, social, and cultural support for them.

13. The present study showed that parents of children with learning disabilities and ASD need practical ideas for managing their child's behaviour. This is related to the hospital services' lack of sensitivity and flexibility in cancer care for children with ASD and learning

disabilities. The process of cancer treatment care should be person-centred. Professionals working with different families of children with learning disabilities are in an ideal position to share strategies with other families who may be looking for such support. To meet the needs of children with learning disabilities and cancer, health professionals must imperatively and effectively collaborate with parent/families and other caregivers with the aims to constantly adapt communication and monitor/manage the clinical environment. Examples, such as having toys, specialist nursery nurses, a more sensory-friendly environment (Kopecky et al., 2013), and shorter wait times (Muskat et al., 2015) would help to reduce the challenges in a clinical environment, in the aim of reducing challenging behaviours.

14. Children with learning disabilities and ASD may be at risk of experiencing inequities at various points along the cancer continuum, including cancer diagnosis and treatment. There is a need to make special arrangements for these children and their families and to ensure equality of care to provide support. Nursing staff should adopt a flexible approach to the hospital care of children with a learning disability and hospitals make all staff aware of their duty to provide reasonable adjustments to the care of these patients. General staff training can improve understanding and awareness of reasonable adjustments and patient needs will help improve patient safety and outcomes. Cancer therapies can be lengthy and complex and involve procedures that are psychologically stressful to children with ASD and Down’s syndrome. For example, radiotherapy, chemotherapy regimens and diagnostic scanning can all require a level of co-operation and adaptation not easily available within these population groups. To address this problem health professionals within oncology settings would need to provide services that can adapt to the complex requirements of children with complex needs. Oncology teams need to be particularly vigilant to children with ASD, as their unique physiological and neuro-psychological (i.e., behavioural, cognitive, and motor) profiles might cause difficulties in their adherence/compliance with the “standard of care” clinical strategies in place for other patients. As with all care plans, reasonable and flexible adjustments must be monitored and evaluated. People’s needs change over time, so the type of adjustments needed can also change. It is important to reassess people’s needs at each admission and tailor reasonable adjustments accordingly.

15. The present study showed that children with learning disabilities often face additional challenges communicating their needs and wishes or reporting pain and discomfort, fears, or abuse. It is therefore vital that the systems, policies and practices in place to help safeguard them are joined up and underpinned by a robust strategy for ensuring good communication at every level. Examples of visual support methods related to care protocols for children with ASD can be used (Richards, 2017; Vuattoux et al., 2021). The Autism Speaks website is also valuable resource and provides toolkits for communication in many situations (www.autismspeaks.org/tool-kit).

16. The findings from this study highlight that professionals adopt a subjective approach when working with children with cancer and their families. They need to approach each child

and parent individually as they are each unique with their own histories and dynamics. Children with ASD, Down's syndrome and cancer need special consideration in nursing care. Taking into account the physical and cognitive abilities of each patient, nursing care should be individualised. These findings suggest individualised treatment and care to improve the outcomes and prognoses for these children and to better accommodate their needs. Each family will have its own strengths and limitations. Understanding these will help nurses tailor their support to the individual needs of the child or young person and the family. Providing individualised care promotes patient and carer satisfaction (Foster & Shields 2020). A multi-disciplinary approach also is important to promote the development of these patients and to support their families.

17. These research findings highlight the need for policy and interventions that focus on assisting parents in balancing the demands associated with caring for a seriously ill child, which include maintaining family finances, caring for their other children, and managing their sick child's medical care. Policy and intervention aimed at reducing the burden of these competing responsibilities would increase parents' abilities, build productive relationships with health professionals, and manage their child's treatment outside of clinical setting.

18. The present study showed that primary caregivers in this study reported uncertainty related to their children's condition, about the long-term impact of learning disabilities on the child's future, and the recurrence of cancer in their child. Nurses should attempt to understand parents' views of uncertainty. The constant provision of information and timely responses to the mother's uncertainty might be necessary to assure the quality of life of the mother and, in turn, the quality of care for the child.

19. Primary caregivers in this study reported that siblings are significantly impacted by a cancer diagnosis. Nurses can encourage parents to allow the younger siblings to the hospital visit and accompany the ill child and to let older siblings be involved in their care, which will help to enhance the siblings' self-autonomy and their ability to take charge. Nurses could help siblings' positive adjustment by encouraging the siblings participation in the sick child's life, and providing the siblings age-appropriate health education strategies and methods to understand ill-related knowledge. There is a need for a more comprehensive and coordinated programme to support siblings of children with cancer. Providing support to siblings has the potential to improve their well-being which ultimately supports the whole family.

20. The findings from this study also highlight the negative effects of cancer on fathers. It is important for healthcare providers to recognise the variety of roles that fathers play in the life of their child, including more, or less, of a direct role in care. Similar to mothers, the actual and desired role of fathers in their child's care needs to be considered and supported within family-centred models that honour varying caregiving configurations of families.

6.5 Future research and recommendations

It is hoped that this study will help healthcare professionals better understand what it is like to be the child's primary carer after receiving a cancer diagnosis, and that it will also guide future research that could lead to the development of interventions for this clinical population. This study has served as an opportunity for further exploration of families receiving treatment for childhood cancer through the NHS.

The research questions of this study were asked to better understand the experiences of primary caregivers of the child with cancer. The findings of this study have the potential to benefit policymakers in the health sector as it has the potential to inform the review of existing policies or the development of new policies regarding managing the psychosocial challenges faced by primary caregivers of children with cancer, including those experiencing the intersections of neurodiversity and learning disabilities. Improving family-centred care will necessitate changes in the healthcare system as well as explicit support for these practices through funding, recognition, and policy changes. These findings should be included in key policies and guidelines to ensure that individuals working with primary carers maximise beneficial interactions while maintaining engagement with support services. Collaborative care that includes addressing the needs of primary carers has the potential to enhance care quality and health outcomes at the individual, family, and community levels. By identifying and escalating priority issues and obstacles, nurses play a crucial role in system transformation. Nurses also provide on-the-ground input on protocol usability and efficacy, gaps in implementation or follow-through, and other general quality issues. To support nurses and other clinicians in the provision of ongoing psychosocial care to children with cancer and their carers, robust clinical procedures and system-level change will be necessary. I expect that the findings will be helpful in the identification of service gaps, assist clinical personnel in understanding their role throughout the survival period, and influence policy and service development.

The findings of the current study have opened up a plethora of potential areas that could be addressed by future research. To other academicians, this study could act as a literature source and reference point for those who may undertake further research on this subject. Researching the experiences of primary caregivers with different recent experiences, including those who have relapsed or transitioned to palliative care, is recommended for future research. It would be interesting for further research to consider both qualitative and quantitative exploration of parents' experiences in order to develop a broader understanding and improve generalisability. Among the primary caregiver participants of my study, there were those whose children had both cancer and ASD and Down's syndrome, it may be recommended that studies be conducted on this subject in the future. The participants of the present study were mothers. Future research could explore the experiences of other primary caregivers (such as fathers, grandparents, siblings etc.). It is important that future research examine how the experiences of other primary caregivers might be similar to, or indeed different from those of mothers who are caring for a child with cancer. Future studies are recommended that focus on children with cancer and with parents across the range of socio-economic, educational, and cultural demographics. It is also suggested that future research examine the experiences of siblings, fathers, and same-sex parents of children with both cancer and Down's syndrome or ASD. There is also a lack of literature focusing specifically on the experiences of families of children diagnosed with ASD who cannot communicate verbally. More autism research about such non-verbal children is needed as it will foster growth in research agendas for the future and help shape policy for completely nonverbal children with ASD.

It is recommended that lead medical and nursing staff be appointed as care coordinators who regularly follow up with children with learning disabilities and his/her family. The establishment of support services such as early counselling and bereavement services, peer support groups, and informational resources to help parents cope with the emotional distress and uncertainty that often accompanies childhood cancer diagnoses is needed. Given family caregivers' experiences of anticipatory grief and psychological distress, mental health and psychosocial services should be integrated within every unit where paediatric patients with cancer are treated to increase access to support for those who desire it.

6.6 Summary

The transcripts were extraordinarily rich, and it was an honour to hear the stories of the main carers who participated. However, there is still much to be discovered in this area, and more study is needed, but it is critical not to lose sight of the meanings that parents of children with cancer attribute to their own lives. Knowledge and comprehension of these meanings should remain fundamental to all academics and health professionals working with this extraordinary population in order to promote good results and reduce the risk of distress.

It is hoped that this study would provide healthcare practitioners with a better knowledge of the particular experiences of being a parent of a child with cancer, as well as influence future research into developing interventions for this specific clinical group. It is also hoped that the results and implications discussed above would enhance the assistance provided by nurses and the wider healthcare team to primary carers of children with cancer. Continued exploration of the experiences families have when a child is diagnosed with cancer will assist nurses in providing care which optimises health and development for families with a child with cancer.

In conclusion, the present study indicated that the primary caregivers' experiences were deep, life-changing, and complex. IPA made it possible to thoroughly illuminate and study these encounters. The participants in this study wanted to share their experiences as primary caregivers of children with cancer, raise awareness about this issue, and make their voices heard. I anticipate it will be valuable as a clinical resource for primary caregivers of children with cancer, as well as contributing to our overall understanding of what it means to be a primary caregiver of a child with cancer. Hopefully, these results will encourage healthcare practitioners to be more aware of the experiences primary carers have and how they affect other aspects of their lives.

Since nurses are on the front lines of patient care, they can see gaps in clinical practice and come up with concepts and plans to enhance patients’ access to healthcare. In order to provide nurses the chance to address the problems they observe in clinical practice, it is crucial that nurses be encouraged to engage in nursing research. We can bridge the gap between nursing research and practice by supporting evidence-based nursing care.

The experiences of the primary carers of children with cancer were examined in this study. The participants talked about the difficulties they experienced during the cancer process that their children had. As a nurse, I think it is our responsibility to support paediatric patients and their primary caregivers with a holistic approach. I hope this doctoral thesis will contribute to healthcare professionals’ better understanding of the experiences of primary caregivers while caring for their children with cancer, with the added knowledge that includes the intersectional experience of parents with children who are neurodiverse or has a learning disability.

In this thesis’ final chapter, the conclusion, I reviewed the study findings in relation to how they addressed the objectives set for this study. I also provided an overview of the study’s contributions to knowledge and implications for practitioners.

Nurses will be better able to care for families of children with cancer by maximising their health and development if they continue to research the experiences families have when their children are diagnosed with cancer.

References

Abu-Raiya H, Hamama L, Fokra F (2015). Contribution of religious coping and social support to the subjective well-being of Israeli muslim parents of children with cancer: a preliminary study. Health and Social Work, 40:e83–e91.

Aburn, G. E., Hoare, K., & Gott, M. (2021). “We are all a family” staff experiences of working in Children's blood and cancer centers in New Zealand—A constructivist grounded theory. Journal of Pediatric Oncology Nursing, 38(5), 295–306.

Aburn G, Gott M (2014). Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: the parents’ perspective. Pediatric Nursing, 40(5):243-8, 256.

Accorsi, E.K.; Qiu, X.; Rumpler, E.; Kennedy-Shaffer, L.; Kahn, R.; Joshi, K.; Goldstein, E.; Stensrud, M.J.; Niehus, R.; Cevik, M.; et al (2021). How to detect and reduce potential sources of biases in studies of SARS-CoV-2 and COVID-19. European Journal of Epidemiology, 36, 179–196.

Adolfsson A. (2010). Applying Heidegger's interpretive phenomenology to women's miscarriage experience. Psychology Research and Behaviour Management, 3 pp. 75-79. doi: 10.2147/PRBM.S4821.

Adams DS (1980). Elite and lower volunteers in a voluntary association: a study of an American Red Cross chapter. Nonprofit Voluntary Sector Quarterly, 9:95-108.27.

Adamson, PC. (2015). Improving the outcome for children with cancer: development of targeted new agents. CA: A Cancer Journal for Clinicians, 65, pp. 212- 220.

Adu-Assiamah, S. (2022). Exploring Psychosocial Experiences of Parents with Children Undergoing Cancer Treatment at Korle-Bu Teaching Hospital. Open Access Library Journal, 9: e8429. https://doi.org/10.4236/oalib.1108429

Adwan, J. Z. (2014). Pediatric nurses' grief experience, burnout, and job satisfaction. Journal of Pediatric Nursing, 29(4), pp. 329–336.

Akaberian S, Momennasab M, Yektatalab S, Soltanian M (2021). Spiritual needs of mothers having children with cancer: A qualitative study. Journal of Education and Health Promotion, 10:470.

Alahmad G (2018). Informed Consent in Pediatric Oncology: A Systematic Review of Qualitative Literature. Cancer Control, 25(1):1073274818773720. doi: 10.1177/1073274818773720

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. International Journal of Education and Literacy Studies, 5(2), pp. 9-19.

Alavi, A., Bahrami, M., Zargham-Boroujeni, A., & Yousefy, A. (2015). Characteristics of caring self-efficacy in pediatric nurses: A qualitative study. Journal for Specialists in Pediatric Nursing, 20, pp. 157-164.

Al Balushi, A. J. (2019). Psychosocial care needs of children with cancer and their families: perceptions and experiences of Omani oncologists and nurses. Baltimore: University of Maryland, Baltimore. http://hdl.handle.net/10713/12497.

Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. Psycho-Oncology, 19 pp. 789-805. doi:10.1002/pon.1638.

Alderfer, M.A, & Hodges, J. (2010). Supporting siblings of children with cancer: a need for family-school partnerships. School Mental Health, 2 pp. 72–81. https://doi.org/10.1007/s12310-010-9027-4.

Al-Gamal, E., Long, T., & Shehadeh, J. (2019). Health satisfaction and family impact of parents of children with cancer: a descriptive cross-sectional study. Scandinavian Journal of Caring Sciences, 33(4) pp. 815-823. https://onlinelibrary.wiley.com/doi/10.1111/scs.12677.

Ali A, Scior K, Ratti V, Strydom A, King M, et al. (2013). Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers. PLoS ONE 8(8): e70855. doi:10.1371/journal.pone.0070855

Al Omari, O., Roach, E. J., Shakman, L., Al Hashmi, A., Sunderraj, S. J., Francis, F., & Joseph, M. A. (2020). The lived experiences of mothers who are parenting children with leukemia. Cancer Nursing, pp. 374-381. https://doi.org/10.1097/ncc.0000000000000898.

Altay N, Kilicarslan E, Sarı C, Kisecik Z. (2014). Determination of social support needs and expectations of mothers of children with cancer. Journal of Pediatric Oncology Nursing, 31 pp. 147-153.

Alves, D.F.D.S., Guirardello, E.D.B., Kurashima, A.Y., (2013). Stress related to care: The impact of childhood cancer on the lives of parents. Revista Latino-Americana Enfermagem, 21 pp. 356-362. https://doi: 10.1590/s0104-11692013000100010.

Amador, D. D., Marcílio, A. C., Soares, J. S. S., Marques, F. R. B., Duarte, A. M., & Mandetta, M. A. (2018). The strength of information on retinoblastoma for the family of the child. Acta Paulista Enfermagem, 31(1), 87-94.

Amorim, Beatriz Yara Farias de; Shimizu, Helena Eri (2022). Stigma, caregivers and the child with Down syndrome: a bioethical analysis. SciELO journals. Dataset. https://doi.org/10.6084/m9.figshare.20036010.v1

Anderson, C. (2010). Presenting and evaluating qualitative research. American Journal of Pharmaceutical Education, 74(8) pp. 141.

Anderson C, Law JK, Daniels A, et al (2012). Occurrence and family impact of elopement in children with autism spectrum disorders. Pediatrics, 130:870–877.

Anderson LM, Oliver SR, Michie S, et al (2013). Investigating complexity in systematic reviews of interventions by using a spectrum of methods. Journal of Clinical Epidemiology, 66:1223–9.

Andersen, N.L., Nielsen, C.I., Danbjørg, D.B., Møller, P.K., Dieperink, K.B. (2019). Cancer & Caregivers. Caregivers’ needs for support during outpatient cancer settings. Oncology Nursing Forum, 46 (6) pp. 757–767. https://doi.org/10.1188/19.ONF.757-767.

Angelo M, Moreira PL; Rodrigues LMA. (2010). Uncertainties in the childhood cancer: understanding the mother's needs Escola Anna Nery.; 14(2) pp. 301-308. https://doi.org/10.1590/S1414-81452010000200013.

Angermeyer, M. C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma—A focus group study of relatives of schizophrenia patients. Social Psychiatry and Psychiatric Epidemiology, 38(10), 593–602. https://doi.org/10.1007/s0012 7-003-0680-x

Ångström-Brännström, C., Norberg, A., Strandberg, G., Söderberg, A., & Dahlqvist, V. (2010). Parents’ experiences of what comforts them when their child is suffering from cancer. Journal of Pediatric Oncology Nursing, 27 pp. 266-275. doi: 10.1177/1043454210364623.

Ångström-Brännström, C., & Norberg, A. (2017). Comforting measures described by staff working in paediatric units. Nursing Children & Young People, 29(4) pp. 24-30. doi:10.7748/ncyp.2017.e812.

Antoine P, Vanlemmens L, Fournier E, Trocme M, Christophe V. (2013). Young couples' experiences of breast cancer during hormone therapy: an interpretative phenomenological dyadic analysis. Cancer Nursing 36(3) pp. 213-220.

Arber, A., & Odelius, A. (2018). Experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children. Cancer Nursing, 41(3), 248–254. https://doi.org/10.1097/ncc.0000000000000491

Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. International Journal of Qualitative Methods, 18, 1–8. https://doi.org/10.1177/1609406919874596

Archibald SJ, Luk D, Potts S, Davis S, Kirby A (2021). Reflections on the experiences of attending peer support groups for fathers of children with cancer. Clinical Child Psychology and Psychiatry, 26(4):1208-1213. doi: 10.1177/13591045211038668

Arksey H, O'Malley L. (2005). Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8 pp. 19–32. https://doi:10.1080/1364557032000119616.

Aromataris, E., & Munn, Z. (Eds.). (2017). Joanna Briggs Institute reviewer's manual. Retrieved from https://reviewersmanual.joannabriggs.org/. cancers (accessed 20.12.21).

Arruda-Colli MNF, Bedoya SZ, Muriel A, Pelletier W, Wiener L (2018). In good times and in bad: what strengthens or challenges a parental relationship during a child's cancer trajectory? Journal of Psychosocial Oncology, 36(5):635-648. doi: 10.1080/07347332.2018.1485813

Atout M, Alrimawi I, Daibes MA, Abusalameh E. (2021). The lived experience of family members who care for children with cancer: An interpretative phenomenological approach. European Journal of Oncology Nursing, 52: 101978. https://doi.org/10.1016/j.ejon.2021.101978.

Austin Z and Sutton J. (2014). Qualitative Research: Getting Started. Canadian Society of Hospital Pharmacists. 67(6) pp. 436-440. https://doi.org/10.4212/cjhp.v67i6.1406.

Aylaz, R., Yilmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: A qualitative study. Sexual Disabilities, 30(4), 395–406. doi:10.1007/s11195-011-9251-3

Badarau, D.O., Wangmo, T., Ruhe, K.M., Miron, I., Colita, A., Dragomir, M., Schildmann, J., Elger, B.S. (2015). Parents' challenges and physicians' tasks in disclosing cancer to children. a qualitative interview study and reflections on professional duties in pediatric oncology. Pediatric Blood and Cancer 62 (12), 2177–2182.

Bahadur G, Hindmarsh P (2000). Age definitions, childhood and adolescent cancers in relation to reproductive issues. Human Reproduction, 15:227.

Bajwah, S., Oluyase, A. O., Yi, D., Gao, W., Evans, C. J., Grande, G., Todd, C., Costantini, M., Murtagh, F. E., & Higginson, I. J. (2020). The effectiveness and cost-effectiveness of hospitalbased specialist palliative care for adults with advanced illness and their caregivers. The Cochrane database of systematic reviews, 9(9),CD012780. https://doi.org/10.1002/14651858.CD012780.pub 2.

Ballan MS (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. Journal of Autism Developmental Disorders, 42(5):676–684.

Balls P. (2009). Phenomenology in nursing research: methodology, interviewing and transcribing. Nursing Times 105 pp. 30-33.

Banchefsky, S., & Park, B. (2016). The “new father”: Dynamic stereotypes of fathers. Psychology of Men & Masculinity, 17(1), 103–107. https://doi.org/10.1037/a0038945

Banerjee, A.T., Watt, L., Gulati, S., Sung, L., Dix, D., Klassen, R., Klassen, A.F. (2011). Cultural beliefs and coping strategies related to childhood cancer: the perceptions of south Asian immigrant parents in Canada. Journal of Pediatric Oncology Nursing, 28 (3) 169–178.

Barrera, M., Rokeach, A., Yogalingam, P., Hancock, K., Johnston, D. L., Cataudella, D., Cassidy, M., Punnett, A. S., & Shama, W. (2016). Healthcare professionals’ knowledge of family psychosocial problems in pediatric cancer: A pilot study. Cancer Nursing, 39(4), 263–271. https://doi.org/10.1097/NCC.0000000000000321

Barrett, P.M.; Mullen, L.; McCarthy, T (2020). Enduring Psychological Impact of Childhood Cancer on Survivors and Their Families in Ireland: A National Qualitative Study. European Journal of Cancer Care, 29, 5.

Bartholdson, C., af Sandeberg, M., Lutzen, K., Blomgren, K., & Pergert, P. (2016). Healthcare professionals' perceptions of the ethical climate in paediatric cancer care. Nursing Ethics, 23(8) pp. 877–888. https://doi.org/10.1177/0969733015587778.

Bastawrous M (2013). Caregiver burden—A critical discussion. International Journal of Nursing Studies, 50(3):431–41.

Batool, A. ., Aftab, D. M. J. ., Bibi, I. ., Shafiq, M. ., Irshad, S. ., & Laghari, M. S. N. . (2024). Addressing The Issues Faced By Children With Down Syndrome In Community Settings: Insights From Psychologists And Parents. Migration Letters, 21(S8), 397–407. Retrieved from https://migrationletters.com/index.php/ml/article/view/9307

Bayat M, Erdem E, Gul Kuzucu E. (2008). Depression, anxiety, hopelessness, and social support levels of the parents of children with cancer. Journal of Pediatric Oncology Nursing, 25 pp. 247–253. doi:10.1177/1043454208321139.

Beauchamp, T. L., & Childress, J. F. (2019). Principles of biomedical ethics (Eighth ed.). Oxford University Press.

Beddard N., McGeechan GJ.,Taylor J., Swainston K. (2019). Childhood eye cancer from a parental perspective: The lived experience of parents with children who have had retinoblastoma. European Journal of Cancer Care. 29(2):e13209. https://doi.org/10.1111/ecc.13209.

Behzadi, M., Rassouli, M., Mojen, L. K., Pourhoseingholi, M. A., & Karahroudy, F. A. (2018). Posttraumatic growth and its dimensions in the mothers of children with cancer. International Journal of Community Based Nursing and Midwifery, 6(3) pp. 209–217.

Benedetti G.M.S., Garanhani M.C., Sales C.A. (2014). The treatment of childhood cancer: unveiling the experience of parents. Revista Latino-Americana de Enfermagem. 22 pp. 425-431. https://doi.org/10.1590/0104-1169.3264.2433

Benner, P. (2022). Overcoming Descartes' representational view of the mind in nursing pedagogies, curricula and testing. Nursing Philosophy: An International Journal for Healthcare Professionals, 23(4), Article e12411. https://doi.org/10.1111/nup.12411

Benner, P. (2013). Patricia Benner. In A. Forss, C. Ceci, & J. S. Drommund (Eds.), Philosophy of nursing: 5 questions (pp. 19–31). Automatic press.

Benner, P. E., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Addison-Wesley/Addison Wesley Longman.

Berkowitz, B. (2016). The patient experience and patient satisfaction: measurement of a complex dynamic. The Online Journal of Issues in Nursing, vol 21. http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-21-2016/No1-Jan-2016/The-Patient-Experience-and- Patient-Satisfaction.html.

Bessette Gorlin, J., McAlpine, C. P., Garwik, A. & Wieling, E. (2016). Severe childhood autism: The family lived experience. Journal of Pediatric Nursing, 31, 580-597.

Bestvina, C. M., Zullig, L. L., & Yousuf Zafar, S. (2014). The implications of out-of-pocket cost of cancer treatment in the USA: A critical appraisal of the literature. Future Oncology, 10(14) pp. 2189–2199. https://doi.org/10.2217/fon.14.130

Bettelheim B (1967). The empty fortress: Infantile autism and the birth of the self. New York City, NY: Free Press of Glencoe.

Bigalke, K.L. (2015). Coping, hardiness, and parental stress in parents of children diagnosed with cancer. University of Southern Mississippi. Retrieved from https://aquila.usm.edu/cgi/viewcontent.cgireferer=https://scholar.google.com.sg/&httpsredir=1&article=1122&context=dissertations.

Björk, M., Nordström, B., & Hallström, I. (2006). Needs of young children with cancer during their initial hospitalization: An observational study. Journal of Pediatric Oncology Nursing, 23 pp. 210-219. doi: 10.1177/1043454206289737.

Bjork, M., Nordstrom, B., Wiebe, T., & Hallstrom, I. (2011). Returning to a changed ordinary life - Families lived experiences after completing a child's cancer treatment. European Journal of Cancer, 20(2) pp. 163–169. doi:10.1111/j.1365-2354.2009.01159.x.

Blatt J, Deal AM, Mesibov G (2010). Autism in children and adolescents with cancer. Pediatric Blood and Cancer, 54:144-7.

Blumberg SJ, Read D, Avila RM, Bethell CD (2010). Hispanic children with special health care needs from Spanish-language households. Pediatrics, 126 (supplement 3):S120-S128. doi:10.1542/peds.2010-1466E.

Boden R (2023). Integrating child-centred and family-centred approaches in children's cancer nursing. Cancer Nursing Practice. doi: 10.7748/cnp.2023.e1838

Bohnenkamp S, Anderson K (2022). Managing the storm of emotions exhibited by patients with cancer: part II. Medsurg Nursing, 31(5):331–8.

Bohnstedt C, Stenmarker M, Olersbacken L, Schmidt L, Larsen HB, Schmiegelow K and Hansson H (2023). Participation, challenges and needs in children with down syndrome during cancer treatment at hospital: a qualitative study of parents' experiences. Frontiers in Rehabilitation Sciences, 4:1099516. doi:10.3389/fresc.2023.1099516

Bona, K., Dussel, V., Orellana, L., Kang, T., Geyer, R., Feudtner, C., & Wolfe, J. (2014). Economic impact of advanced pediatric cancer on families. Journal of Pain and Symptom Management, 47(3) pp. 594–603. https://doi.org/10.1016/J.JPAIN SYMMAN.2013.04.003.

Bona K, London WB, Guo D, Frank DA, Wolfe J. (2016). Trajectory of material hardship and income poverty in families of children undergoing chemotherapy: a Prospective Cohort Study. Pediatric Blood Cancer, 63 pp. 105–111.

Bono LK, Haverkamp CR, Lindsey RA, Freedman RN, McClain MB, Simonsmeier V (2022). Assessing interdisciplinary trainees' objective and self-reported knowledge of autism spectrum disorder and confidence in providing services. Journal of Autism Developmental Disorders, 52(1):376–391.

Borjalilu, S.; Sharif, Z.; Azad, M.S.; Afzali, M.; Koochakzadeh, L.; Afzali, M. (2017). The information needs of parents of children with cancer: A qualitative study. Journal of Qualitative Research in Health Sciences, 6, pp. 228–237.

Borrescio-Higa, F.; Valdés, N (2022). The Psychosocial Burden of Families with Childhood Blood Cancer. International Journal of Environmental Research and Public health, 19, 599. https://doi.org/10.3390/ijerph19010599

Boufkhed S, Yurdusen S, Alarjeh G, Ahmed F, Alrjoub W, Guo P, Alajarmeh S, S¸engelen M, Cemaloglu M, Aydın B, Alnassan A, Al-Awady S, Kutluk T, Shamieh O and Harding R (2023). Concerns and priority outcomes for children with advanced cancer and their families in the Middle East: A cross-national qualitative study. Frontiers in Oncology, 13:1120990.doi: 10.3389/fonc.2023.1120990

Bourdieu, P. (1986). The Forms of Capital. In J Richardson (Ed.), Handbook of Theory and Research for the Sociology of Education. New York: Macmillan.

Bowen, M. (1978). Family therapy in clinical practice. Aronson

Bowen, M. (1976). Family reaction to death. In P. Guerin (Ed.), Family therapy (pp. 335–348). New York: Gardner Press.

Brand S, Wolfe J, Samsel C (2017). The Impact of Cancer and its Treatment on the Growth and Development of the Pediatric Patient. Current Pediatric Reviews;13(1):24-33. doi: 10.2174/1573396313666161116094916

Braun V, Clarke V. (2006). Thematic analysis. In: APA Handbook of Research Methods in Psychology: Vol. 2. Research Designs.

Braun, V. and Clarke, V. (2012). 'Thematic analysis.' In Cooper, H., Camic, P., Long, D., Panter, A., Rindskopf, D. and Sher, K. (eds.) APA handbook of research methods in psychology, Vol. 2. Washington: American Psychological Association., pp. 57-71.

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. Counselling & Psychotherapy Research, 21(1), 37–47. https://doi.org/10.1002/capr.12360

Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A (2018) Global cancer statistics (2018) GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA a Cancer Journal for Clinicians, 68(6) pp. 394–424.

Breakwell, G. M., Smith, J. A., & Wright, D. B. (2012). Research methods in psychology (4th ed). London: Sage.

Brimble, M. J., Anstey, S., & Davies, J. (2019). Long-term nurse–parent relationships in paediatric palliative care: A narrative literature review. International Journal of Palliative Nursing, 25(11) pp. 542–550. https://doi.org/10.12968/ijpn.2019.25.11.542.

Brinkman T.M., Recklitis C.J., Michel G., Grootenhuis M.A., Klosky K (2018). Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: current state of the literature Journal of Clinical Oncology 36 (21) pp. 2190–2197.

Broady TR, Stoyles GJ, Morse C (2018). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. Health and Socical Care Community, 25(1):224-233. doi: 10.1111/hsc.12297.

Bronbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. Developmental Psychology, 22, 723–742.

Brocki, J. M. & Wearden, A. J. (2006). A critical evaluation of the use of interpretive phenomenological analysis (IPA) in health psychology. Psychology and Health: 21(1) pp. 87 – 108.

Brookes, D. (2007). Understanding qualitative research and its value in healthcare. Nursing Times, 103(1) pp. 32-33.

Brown I, Gould J. (2013). Qualitative studies of obesity: a review of methodology. Health, 5 pp. 69–80. https:// doi:10.4236/HEALTH.2013.58A3010.

Bryman, A. (2012). Social Research Methods. 4th edn. Oxford: Oxford University Press.

Bryman, A. (2016). Social research methods (5th ed.). Oxford: Oxford University Press.

Buchbinder, D., Casillas, J., & Zeltzer, L. (2011). Meeting the psychosocial needs of sibling survivors: A family systems approach. Journal of Pediatric Oncology Nursing, 28(3), 123–136. https://doi.org/10.1177/1043454210384601

Bultas, M. W. (2012). The health care experiences of the preschool child with autism. Journal of Pediatric Nursing, 27, 460–470. https://doi.org/10.1016/j.pedn.2011.05.005

Burke, H., & Dunne, S. (2023). “You nearly feel a little bit like you’ve less right to grieve”: a qualitative study on the impact of cancer on adult siblings. Journal of Cancer Survivorship, 17(6), 1628-1638.

Burns, N. & Grove, S. K. (2009). The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence. St Louis, MI: Saunders Elsevier.

Butler, R., Monsalve, M., Thomas, G. W., Herman, T., Segre, A. M., Polgreen, P. M., & Suneja, M. (2018). Estimating Time Physicians and Other Health Care Workers Spend with Patients in an Intensive Care Unit Using a Sensor Network. The American Journal of Medicine, 131(8), 972. e9–972.e15. doi:10.1016/j.amjmed.2018.03.015.

Buus N, Nygaard L, Berring LL, Hybholt L, Kamionka SL, Rossen CB, Søndergaard R, Juel A (2022). Arksey and O'Malley's consultation exercise in scoping reviews: A critical review. Journal of Advanced Nursing, 78(8):2304-2312. doi: 10.1111/jan.15265

Buyukavci, M., Dogan, D., Canaloglu, S., & Kivilcim, M., (2019): Experience of mothers with Down syndrome children at the time of diagnosis, Archivos Argentinos de Pediatria, Vol. (117),No. (2), pp. 114-119.

Cancer Research UK, (2018). Children's cancer statistics. http://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers (accessed 21.12.21).

Candy B, Jones L, Drake R, Leurent B, King M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 6:CD007617.

Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. Journal of Intellectual Disability Research, 59(10),948–957. https://doi.org/10.1111/jir.12205

Carbone PS, Behl DD, Azor V, Murphy NA (2010). The medical home for children with autism spectrum disorders: parent and pediatrician perspectives. Journal of Autism Developmental Disorders, 40(3):317–324.

Carbone, P. S., Farley, M., & Davis, T. (2010). Primary care for children with autism. American Family Physician, 81(4), 453–460.

Cardon A, Marshall T (2021). To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in the United States and Senegal. Transcultural Psychiatry, 58(3):335-350. doi: 10.1177/1363461520953342

Carel, H. (2012). Phenomenology as a resource for patients. Journal of Medicine and Philosophy, 37 pp. 96-113.

Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & von Essen, L. (2019). Psychological distress in parents of children treated for cancer: An explorative study. PloS one, 14(6) pp. 1-18.

Castellano-Tejedor C, Blasco-Blasco T, Pérez-Campdepadrós M,Capdevila L (2017). The Hidden Sufferers: Parental Reactions to Childhood Cancer during Treatment and at Survival. The Spanish Journal of Psychology 20, e29, pp. 1–11.

Chad-Friedman, E., Kuhlthau, K. A., Millstein, R. A., Perez, G. K., Luberto, C. M., Traeger, L., Proszynski, J., & Park, E. (2022). Characteristics and Experiences of Parents of Children with Learning and Attention Disabilities and Autism Spectrum Disorder: A Mixed Methods Study. The Family Journal, 30(3), 427-436. https://doi.org/10.1177/10664807211052304

Challinor JM, Hollis R, Freidank C, et al (2014). Educational needs and strategies of pediatric oncology nurses in Low- and middle-income countries: an international society of pediatric oncology pediatric oncology in developing countries nursing working group initiative. Cancer Nursing, 37:E36–47. https://doi.org/10.1097/NCC.0000000000000100

Chan RJ, Gordon LG, Tan CJ, et al. (2019). Relationships between financial toxicity and symptom burden in cancer survivors: a systematic review. Journal of Pain Symptom Management, 57(3) pp. 646-660.e1.

Chan KKS, Lam CB, Law NCW, Cheung RYM (2018). From child autistic symptoms to parental affective symptoms: A family process model. Research in developmental disabilities, 75:22–31.

Chappuy H, Baruchel A, Leverger G, et al (2010). Parental comprehension and satisfaction in informed consent in paediatric clinical trials: a prospective study on childhood leukaemia. Archives of Disease in Childhood, 95(10):800-804.

Charmaz, K (2006). Constructing grounded theory: A practical guide through qualitative analysis. Los Angeles, CA: SAGE Publications.

Charmaz, K. (2014). Constructing grounded theory.In R. Barbour (Ed.), Introducing qualitative methods (2nd ed.). SAGE Publications Inc

Chen X, Tong J, Jiang B, Ma S, Wang X, Sun X, Liu Y, Yan D and Wang L (2023). Courtesy stigma among primary caregivers of children with autism spectrum disorder in eastern China. Frontiers in Psychiatry, 14:1236025.

Cherven B.O., Mertens A., Wasilewski-Masker K., Williamson R., Meacham L.R. (2016). Infertility education: experiences and preferences of childhood cancer survivors. Journal of Pediatric Oncology Nursing, 33 (4) 257–264, https://doi.org/10.1177/1043454215607342

Cheung, K.L.; Ten Klooster, P.M.; Smit, C.; de Vries, H.; Pieterse, M.E (2017). The impact of non-response bias due to sampling in public health studies: A comparison of voluntary versus mandatory recruitment in a Dutch national survey on adolescent health. BMC Public Health, 17, 276.

Chiang, H.L., Liu, C.J., Hu, Y.-W., Chen, S.-C., Hu, L.Y., Shen, C.-C., … Gau, S. S.F. (2015). Risk of Cancer in Children, Adolescents, and Young Adults with Autistic Disorder. The Journal of Pediatrics, 166(2), pp. 418–423.e1. doi:10.1016/j.jpeds.2014.10.029.

Chiri, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. Maternal and Child Health Journal, 16(5),1081–1091.

Choi, E. K., & Yoo, I. Y. (2015). Resilience in families of children with Down syndrome in Korea. International Journal of Nursing Practice, 21(5) pp. 532–541. https://doi.org/10.1111/ijn.12321

Christiansen, H.L., Bingen, K., Hoag, J.A., Karst, J.S., Velázquez-Martin, B., & Barakat, L.P. (2015). Providing children and adolescents opportunities for social interaction as a standard of care in pediatric oncology. Pediatric Blood and Cancer, 62(Suppl. 5), pp. 724–749. https://doi.org/10.1002/pbc.25774.

Christensen, S. R., & Carlsen, L. T. (2022). From well-known to changed everyday family life in families with childhood cancer: A grounded theory of disrupted family dynamic. Psycho-Oncology, 31(2), 282-289.

Chu, S. Y., Mohd Normal, S. N. S. A. b., McConnell, G. E., Tan, J. S., & Joginder Singh, S. K. D. (2020). Challenges faced by parents of children with autism spectrum disorder in Malaysia. Speech, Language and Hearing, 23(4), 221–231. https://doi.org/10.1080/2050571X.2018.1548678

Citak, E. A., Toruner, E. K., & Gunes, N. B. (2013). Exploring communication difficulties in pediatric hematology: Oncology nurses. Asian Pacific Journal of Cancer Prevention :APJCP, 14(9) pp. 5477–5482. https://doi.org/10.7314/APJCP.2013.14.9.5477.

Clark, T. (2010). On 'being researched': Why do people engage with qualitative research? Qualitative Research, 10(4), 399–419. https://doi.org/10.1177/1468794110366796

Clarke, N., McCarthy, M., Downie, P., Ashley, D., & Anderson, V. (2009). Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature. Psycho-Oncology, 18 pp. 907–915. https://doi.org/10.1002/pon.1515.

Clarke, S., Sheppard, L., & Eiser, C., (2008). Mothers' explanations of communicating past health and future risks of survivors of childhood cancer. Clinical Child Psychology and Psychiatry. 13 pp. 157–170. doi:10.1177/1359104507080997.

Cleland JA (2017). The qualitative orientation in medical education research. Korean Journal of Medical Education, 29(2) pp.61-71.

Coad J, Kaur J, Ashley N, Owens C, Hunt A, Chambers L, et al (2015). Exploring the perceived met and unmet need of life-limited children, young people and families. Journal of Pediatric Nursing, 30:45–53.

Cohen, M.Z., Kahn, D.L. and Steeves, R.H. (2000). Hermeneutic Phenomenological Research A Practical Guide for Nurse Researchers. 1st ed. Thousand Oaks: Sage Publications.

Cohen PN. (2014). Recession and divorce in the United States, 2008-2011. Population Research and Policy Review 33 pp. 615-628. http://dx. doi:10.1007/s11113-014-9323-z.

Coleman, J. (1988). Social capital in the creation of human capital. American Journal of Sociology, 94, S95–S120.

Collins DE, Ellis SJ, Janin MM, Wakefield CE, Bussey K, Cohn RJ, Lah S, Fardell JE (2019). A Systematic Review Summarizing the State of Evidence on Bullying in Childhood Cancer Patients/Survivors. Journal of Pediatric Oncology Nursing, 36(1) pp.55-68. doi: 10.1177/1043454218810136.

Compas BE, Bemis H, Gerhardt CA, Dunn MJ, Rodriguez EM, Desjardins L, Preacher KJ, Manring S, & Vannatta K. (2015). Mothers and fathers coping with their child's cancer: Individual and interpersonal processes. Health Psychology, 34 pp. 783–793. doi: 10.1037/hea0000202 [PubMed: 25622077].

Conroy, K., Rea, C., Kovacikova, G. I., Sprecher, E., Reisinger, E., Durant, H., Starmer, A., Cox, J., & Toomey, S. L. (2018). Ensuring timely connection to early intervention for young children with developmental delays. Pediatrics, 142(1), e20174017. https://doi.org/10.1542/peds.2017-4017

Conway, M., Pantaleao, A., & Popp, J. (2017). Parents' experience of hope when their child has cancer: Perceived meaning and the influence of healthcare professionals. Journal of Pediatric Oncology Nursing, 34(6) pp. 427–434.

Coulson, N.S., Greenwood, N. (2012). Families affected by childhood cancer: an analysis of the provision of social support within online support groups. Child: Care Health and Development, 38 (6), 870–877.

Coyne, E., Grafton, E., & Reid, A. (2016). Strategies to successfully recruit and engage clinical nurses as participants in qualitative clinical research. Contemporary Nurse, 52(6), 669–676. https:// doi.org/10.1080/10376178.2016.1181979

Coyne I, Holmström I, Söderbäck M (2018). Centeredness in Healthcare: A Concept Synthesis of Family centered Care, Person-centered Care and Child-centered Care. Journal of Pediatric Nursing, 42:45–56. https://doi.org/10.1016/j.pedn.2018.07.001.

Coyne I, Amory A, Gibson F, Kiernan G (2016). Information-sharing between healthcare professionals, parents and children with cancer: more than a matter of information exchange. European Journal of Cancer Care, 25(1):141–156. doi:10.1111/ecc.12411

Cox MJ, Paley B (1997). Families as systems. Annual Review of Psychology, 48(1):243-67. doi: 10.1146/annurev.psych.48.1.243

Crane L, Chester JW, Goddard L, Henry LA, Hill E (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. Autism, 20(2): 153-62.

Crenshaw, K. W. (1994/2005). Mapping the margins: Intersectionality, identity politics, and violence against women of color. In M. A. Fineman, & R. Mykitiuk (Eds.), The public nature of private violence (pp. 93–118). New York: Routledge.

Crespo, C., Santos, S., Tavares, A., & Salvador, Á. (2016). “Care that matters”: Family-centered care, caregiving burden, and adaptation in parents of children with cancer. Families, Systems & Health: The Journal of Collaborative Family Healthcare, 34(1),31–40. https://doi.org/10.1037/fsh0000166

Creswell, J. W. (2007). 'Qualitative Inquiry and Research Design: Choosing among Five Approaches .' 2nd ed. Thousand Oaks, CA: Sage.

Creswell, J.W. (2013). Qualitative Inquiry & Research Design, Choosing among five approaches. (3rd edn).

Creswell, J. and Poth, C. (2017). Qualitative Inquiry and Research Design: Choosing among Five Approaches. Sage, London.

Creswell, J., & Poth, C. N. (2018). Qualitative inquiry & research design: Choosing among five approaches (4th ed.). SAGE Publications

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. Autism, 18(3), 213–222. https://doi.org/10.1177/1362361312472261

Cridland, E., Jones, S., Stoyles, G., Caputi, P., & Magee, C. (2016). Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. Focus on Autism and Other Developmental Disabilities, 31(3), 196-207. https://doi.org/10.1177/1088357615583466

Crowell, J. A., Keluskar, J. & Gorecki, A (2019). Parenting behavior and the development of children with autism spectrum disorder. Comprehensive Psychiatry, 90, 21–29.

Cutillo, A., Zimmerman, K., Davies, S., Madan-Swain, A., Landier, W., Arynchyna, A., & Rocque, B. G. (2018). Coping strategies used by caregivers of children with newly diagnosed brain tumors. Journal of Neurosurgery: Pediatrics, 23(1), 30-39.

Dabrowska, A.; Malicka, I (2022). Pediatric Cancer as a Factor of Changes in the Family. International Journal of Environmental Research and Public Health, 19, 5002. https://doi.org/10.3390/ijerph19095002

Dahlborg Lyckhage E, Lindahl B (2013). Living in liminality-being simulta-neously visible and invisible: caregivers' narratives of palliative care. Journal of Social work in End-of-life and Palliative Care, 9(4):272-288.

Dallos, R., & Draper, R. (2015). An introduction to family therapy: Systemic theory and practice. Maidenhead: Open University Press.

Dallos, R., & Vetere, A. (2005). Researching Psychotherapy and Counselling. Maidenhead: Open University Press.

Daniels, N., Gillen, P., Casson, K., & Wilson, I. (2019). Steer: Factors to consider when designing online focus groups using audiovisual technology in health research. International Journal of Qualitative Methods, 18, 1–11. https://doi.org/10.1177/1609406919885786

Darby, K., Nash, P., Nash, S.(2014). Parents' spiritual and religious needs in young oncology. Cancer Nursing Practice, 13(4) pp. 16-22.

Darcy, L., Knutsson, S., Huus, K., & Enskar, K. (2014). The everyday life of the young child shortly after receiving a cancer diagnosis, from both children's and parent's perspectives. Cancer Nursing, 37 pp. 445-456. doi:10.1097/NCC.0000000000000114.

Darlington, A., Morgan, J., Wagland, R., Sodergren, S., Culliford, D., Gamble, A., & Phillips, B. (2021). COVID-19 and children with cancer: Parents' experiences, anxieties, and support needs. Paediatric Blood & Cancer,68(2), e28790. https://doi.org/10.1002/pbc.28790.

Da Silva FM, Jacob E, Nascimento LC (2010). Impact of childhood cancer on parents' relationships: An integrative review. Journal of Nursing Scholarship.; 42(3) pp. 250-261. https://doi.org/10.1111/j.1547-5069.2010.01360.x PMID: 20738735.

Data Protection Act, 2018. Data Protection Act (2018). [online] GOV.UK. Available at: <https://www.gov.uk/government/collections/data-protection-act-2018> [Accessed 27.07. 2021]

Datta, S. S., Saha, T., Ojha, A., Das, A., Daruvala, R., Reghu, K. S., & Achari, R. (2019). What do you need to learn in paediatric psycho-oncology?. Ecancermedicalscience, 28;13:916. doi: 10.3332/ecancer.2019.916

Daudt, H. M. L., van Mossel, C., & Scott, S. J., (2013). Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. BMC Medical Research Methodology 13, 48. http://dx.doi:10.1186/1471-2288-13-48.

Davies, J., O'Connor, M (2022). Mothers' Experiences Post-Childhood Cancer Treatment: A Qualitative Study. Journal of Child and Family Studies. (https://doi.org/10.1007/s10826-022-02379-x.

Davies, J., O'Connor, M., Halkett, G. K., Kelada, L., & Gottardo, N. G. (2023). Fathers' experiences of childhood cancer: A phenomenological qualitative study. Journal of Family Nursing, 29(2), 155-165.

Davison, K. K., Charles, J. N., Khandpur, N., & Nelson, T. J. (2017). Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. Maternal and Child Health Journal, 21, 267–274. 10.1007/s10995-016-2157-z

Day S, Hollis R, Challinor J, Bevilacqua G, Bosomprah (2014). ESIOP PODC Nursing Working Group. Baseline standards for paediatric oncology nursing care in low to middle income countries: position statement of the SIOP PODC NursingWorking Group. Lancet Oncology, 15(07) pp. 681–682.

Deatrick, J. A., Mullaney, E. K., & Mooney-Doyle, K. (2009). Exploring family management of childhood brain tumor survivors. Journal of Pediatric Oncology Nursing, 26(5) pp. 303–311. doi:10.1177/1043454209343210.

Deavin, A., Greasley, P., & Dixon, C. (2018). Children's perspectives on living with a sibling with a chronic illness. Pediatrics, 142(2), 1–11. https://doi.org/10.1542/peds.2017- 4151

de Fine Licht, S., Rugbjerg, K., Gudmundsdottir, T., Bonnesen, T. G., Asdahl, P. H., Holmqvist, A. S., ... & ALiCCS Study Group. (2017). Long-term inpatient disease burden in the Adult Life after Childhood Cancer in Scandinavia (ALiCCS) study: a cohort study of 21,297 childhood cancer survivors. PLoS medicine, 14(5), e1002296.

Delemere E., Maguire IGR (2023). "A Really Really Almost Impossible Journey" Perceived Needs and Challenges of Families Impacted by Pediatric Cancer: A Qualitative Analysis, Comprehensive Child and Adolescent Nursing, 46:4, 277-294, DOI: 10.1080/24694193.2023.2229429

Demirtepe-Saygılı D., Bozo Ö., (2018). Affective experiences of the parents of children with cancer: A qualitative study. Current Psychology 39, pp. 2211–2220. https://doi.org/10.1007/s12144-018-9905-8.

Dencker, A., Rix, B. A., Bøge, P., & Tjørnhøj-Thomsen, T. (2017). A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. Psycho-Oncology, 26, 2162–2167.https://doi.org/10.1002/pon.4440

Department of Health (2008). Carers at the Heart of 21st–Century Families and Communities. DH, London.

Deribe, L., Addissie, A., Girma, E., Abraha, A., Adam, H., & Berbyuk Lindstrom, N. (2023). Stress and coping strategies among parents of children with cancer at tikur Anbessa Specialized Hospital paediatric oncology unit, Ethiopia: A phenomenological study. BMJ Open, 13(1), e065090. https://doi.org/10.1136/bmjopen-2022-065090

Deribe, L., Girma, E., Gidey, A., Teferra, S., Lindström, N. B., & Addissie, A. (2023). Impact of family-centered care interventions on parental related outcomes among parents of children with cancer: A Systematic Review. https://doi.org/10.21203/rs.3.rs-3288453/v1

Desai AD, Popalisky J, Simon TD, Mangione-Smith RM (2015). The effectiveness of family-centered transition processes from hospital settings to home: a review of the literature. Hospital Pediatrics, 5(4):219-31. doi: https://doi.org/10.1542/hpeds.2014-0097.

Dionisi-Vici, M., Felicetti, F., Zucchetti, G., Biasin, E., Castiglione, A., Gatti, F., ... & Fagioli, F. (2023). The impact of infertility and physical late effects on psycho-social well-being of long-term childhood cancer survivors: A cross-sectional study. EJC Paediatric Oncology, 2, 100025.

Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. Autism Research, 5, 190–200. doi:10.1002/aur.1225

Dix DB, Klassen AF, Papsdorf M, Klaassen RJ, Pritchard S, Sung L (2013). Factors Affecting the Delivery of Family-Centered Care in Pediatric Oncology. Pediatric Blood and Cancer, 60(2, poster 619):S41.

Dollard M., Skinner N., Tuckey M. & Bailey T. (2007). National surveillance of psychosocial risk factors in the workplace: an international overview. Work & Stress, 21(1), 1–29.

Donnelly, L.J., Cervantes, P.E., Okparaeke, E., Stein, C.R., Filton, B., Kuriakose, S., Havens, J. and Horwitz, S.M. (2021). Staff perceptions and implementation Fidelity of an autism Spectrum disorder care pathway on a child/adolescent general psychiatric inpatient service. Journal of autism and developmental disorders, 51(1), pp.158-168.

dosReis, S., Barksdale, C. L., Maloney, K. & Charach, A (2010). Stigmatizing experiences of parents of children with a new diagnosis of ADHD. Psychiatric services : a Journal of the American Psychiatric Association, 61, 811–816

Doumit M.A.A., Khoury MN (2017): Facilitating and hindering factors for coping with the experience of having a child with cancer: A Lebanese perspective, Journal of Psychosocial Oncology, DOI: 10.1080/07347332.2017.1283654.

Duarte Maria de Lourdes Custódio, Zanini Lisiane Nunes, Nedel Maria Noemia Birck. (2012). The daily routine of parents of children hospitalized with cancer: nursing challenges. Rev Gaúcha Enferm, 33(3) pp. 111–118.

Dunn J, Chambers SK, Hyde MK (2016). Systematic review of motives forepisodic volunteering.Voluntas International Journal of Voluntary and Nonprofit Organizations, 27(1):425-464. doi:10.1007/s11266-015-9548-4

Duran, B (2013). Posttraumatic growth as experienced by childhood cancer survivors and their families: A narrative synthesis of qualitative and quantitative research. Journal of Pediatric Oncology Nursing, 30 pp. 179–197.

Eatough, V., Smith, J.A. (2008). Interpretative Phenomenological Analysis, in Qualitative Research in Psycology Ed. Willig, C., Stainton-Rogers, W. Sage LA, London.

Edwards AG, Brebner CM, McCormack PF, MacDougall CJ (2018). From ‘parent’ to ‘expert’: how parents of children with autism spectrum disorder make decisions about which intervention approaches to access. Journal of Autism Developmental Disorders, 48(6):2122-38. https://doi.org/10.1007/s10803-018-3473-5

Egerton, M. (2002). Family transmission of social capital: Differences by social class, education and public sector employment. Sociological research online, 7(3), 92-105.

Eiser C,Upton P (2007). Costs of caring for a child with cancer: a questionnaire survey. Child: Care, Health and Development, 33 pp. 455–459.

Elliott, R., & Timulak, L. (2005). Descriptive and interpretive approaches to qualitative research. In P. Gilbert, & J. Miles, A handbook of research methods for clinical and health psychology (pp. 147-159). Oxford: Oxford University Press.

Ellis SJ., Wakefield CE., McLoone JK., Robertson E & Cohn RJ (2016). A qualitative analysis of fertility concerns among child and adolescent cancer survivors and their parents in an Australian cohort. Journal of Psychosocial Oncology, 34(5):347-62. DOI: 10.1080/07347332.2016.1196806

Emerson, E., Llewellyn, G., Hatton, C., Hindmarsh, G., Robertson, J., Man, W. Y., & Baines, S. (2015). The health of parents with and without intellectual impairment in the UK. Journal of Intellectual Disability Research, 59(12), 1142–1154. https://doi.org/10.1111/jir.12218

Emerson, E. & Spencer, N. (2015). Health inequity and children with intellectual disabilities. International Review of Research in Developmental Disabilities, 48, 11-42 https://doi.org/10.1016/bs.irrdd.2015.03.001

Emparanza JI, Cabello JB, Burls AJ (2015). Does evidence-based practice improve patient outcomes? An analysis of a natural experiment in a Spanish hospital. Journal of Evaluation in Clinical Practice, 21(6):1059–65. https://doi.org/10.1111/jep.12460

Enskär, K. (2012). Being an expert nurse in pediatric oncology care: Nurses' descriptions in narratives. Journal of Pediatric Oncology Nursing, 29 pp. 151-160. doi: 10.1177/1043454212446344.

Enskär, K., Björk, M., Knutsson, S., Granlund, M., Darcy, L., & Huus, K. (2015). A Swedish perspective on nursing and psychosocial research in pediatric oncology: A literature review. European Journal of Oncology Nursing, 19 pp. 310-317. doi: 10.1016/j.ejon.2014.10.013.

Enskär, K., Darcy, L., Bj¨ork, M., Knutsson, S., Huus, K., (2020). Experiences of young children with cancer and their parents with nurses' caring practices during the cancer trajectory. Journal of Pediatric Oncology Nursing, 37 pp. 21–34. https://doi.org/10.1177/1043454219874007.

Enskär, K., Hamrin, E., Carlsson, M., & von Essen, L. (2011). Swedish mothers and fathers of children with cancer: Perceptions of well-being, social life, and quality care. Journal of Psychosocial Oncology, 29 pp. 51-66.

Enzman Hines, M. (2017). A view of caring within holistic nursing. Beginnings, 37(6), 6-24.

Evans, A. M., Jonas, M., & Lantos, J. (2020). Pediatric palliative care in a pandemic: Role obligations, moral distress, and the care you can give. Pediatrics, 146(1), e20201163. https://doi.org/10.1542/peds.2020-1163

Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: Grounded theory in counseling psychology research. Journal of Counseling Psychology, 52(2), 156–166. https://doi.org/10.1037/0022-0167.52.2.156

Fenn KM, Evans SB, McCorkle R, et al, (2014). Impact of financial burden of cancer on survivors' quality of life. Journal Oncology Practice, 10 pp. 332-338.

Ferlay J, Ervik M, Lam F, Colombet M, Mery L, Piñeros M, et al (2020) Global Cancer Observatory: Cancer Today. Lyon: International Agency for Research on Cancer.

Fernańdez-Alcántara M, García-Caro MP, Pérez-Marfil MN, Hueso-Montoro C, Laynez-Rubio C, Cruz-Quintana F (2016). Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD). Research in Developmental Disabilities, 55:312-21. doi: 10.1016/j.ridd.2016.05.007

Firat, S. (2016). Levels of depression and anxiety among parents of autistic children. Cukurova Medical Journal, 41(3).

Finlay L (2011). Phenomenology for psychotherapists: researching the lived world. Wiley-Blackwell, USA.

Flemming K. (2010). The use of morphine to treat cancer-related pain: a synthesis of quantitative and qualitative research. Journal of Pain and Symptom Management, 39 pp. 139–154. doi: 10.1016/j.jpainsymman.2009.05.014.

Fletcher, P. C. (2010). My child has cancer: The costs of mothers' experiences of having a child with pediatric cancer. Issues in Comprehensive Pediatric Nursing, 33 pp.164-184. doi:10.3109/01460862.2010.498698.

Fletcher P.C. (2011). My child has cancer: finding the silver lining in every mother's nightmare. Issues in Comprehensive Pediatric Nursing 34, pp. 40-55. doi: 10.3109/01460862.2011.557905.

Fletcher, P.C., Schneider, M. A., & Harry, R. J., (2010). How do I cope? Factors affecting mothers' abilities to cope with pediatric cancer. Journal of Pediatric Oncology Nursing 27, pp. 285–298. doi: 10.1177/1043454209360839.

Flury, M., Caflisch, U., Ullmann-Bremi, A., & Spichiger, E. (2011). Experiences of parents with caring for their child after a cancer diagnosis. Journal of Pediatric Oncology Nursing, 28(3) pp. 143–153. doi:10.1177/1043454210378015.

Flynn, S. (2021). Convergent identities, compounded risk: Intersectionality and parenting capacity assessment for disabled children. Children and Youth Services Review, 129, Article 106185. https://doi.org/10.1016/j.childyouth.2021.106185

Fong, A. T., Katelaris, C. H., & Wainstein, B. (2017). Bullying and quality of life in children and adolescents with food allergy. Journal of Paediatrics and Child Health, 53(7) pp. 630-635. doi:10.1111/jpc.13570.

Forinder, U., & Norberg, A. L. (2010). “Now we have to cope with the rest of our lives”. Existential issues related to parenting a child surviving a brain tumour. Support Cancer in Care, 18(5) pp. 543–551. doi 10.1007/s00520-009-0678-3.

Foster, L. Terrah & Lafond, Deborah & Reggio, Cheryl & Hinds, S. Pamela (2010). Pediatric palliative care in childhood cancer nursing: from diagnosis to cure or end of life. Seminars in Oncology Nursing, Vol 26 (November), Issue 4 (November) pp. 205-221. http://prc.coh.org/PPCCN.pdf.

Foster M, Shields L (2020). Bridging the child and family centered care gap: therapeutic conversations with children and families. Comprehensive Child And Adolescent Nursing.43, 2, 151-158. doi: 10.1080/24694193.2018.1559257

Fournier, V., Belghiti, E., Brunet, L., & Spranzi, M. (2017). Withdrawal of artificial nutrition and hydration in neonatal intensive care: Parents’ and healthcare practitioners’ views. Medicine, Health Care and Philosophy, 20(3), 365-371. https://doi.org/10.1007/s11019-017-9754-5

Fradet, C., McGrath, P. J., Kay, J., Adams, S., & Luke, B. (1990). A prospective survey of reactions to blood tests by children and adolescents. Pain, 40(1), 53–60.

Frechette, J., Bitzas, V., Aubry, M., Kilpatrick, K., & Lavoie-Tremblay, M. (2020). Capturing Lived Experience: Methodological Considerations for Interpretive Phenomenological Inquiry. International Journal of Qualitative Methods, 19. https://doi.org/10.1177/1609406920907254.

Frederiksen L.E., L. Mader, M. Feychting, H. Mogensen, L. Madanat-Harjuoja, N. Malila, et al. (2018). Surviving childhood cancer: a systematic review of studies on risk and determinants of adverse socioeconomic outcomes, International Journal of Cancer, 15;144(8) pp. 1796-1823.

Freedman, B.H.; Kalb, L.G.; Zablotsky, B.; Stuart, E.A (2012). Relationship Status among Parents of Children with Autism Spectrum Disorders: A Population-Based Study. Journal of Autism Developmental Disorders, 42, 539–548.

Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications. Journal of pediatric health care, 30(5), 453-463.

Friedman, D.; Masek, B.; Barreto, E.; Baer, L.; Lapey, A.; Budge, E.; McQuaid, E.L (2015). Fathers and Asthma Care: Paternal Involvement, Beliefs, and Management Skills. Journal of Pediatric Psychology, 40, 768–780.

Furlong, P. and D. Marsh. 2010. ‘A Skin Not a Sweater: Ontology and Epistemology in Political Science’. In D. Marsh and G. Stoker (eds.), Theory and Methods in Political Science (pp. 184–211). Basingstoke: Palgrave.

Gabe J. (2004). Key Concepts in Medical Sociology Jonathan Gabe, Michael Bury, Mary Ann Elston SAGE. SAGE 2004 (2004), 04–10.

Gadamer, H. G. (1992). Hans-Georg Gadamer on education, poetry, and history: Applied hermeneutics. SUNY Press.

Gadamer, H.G. (1998). Truth and Method. (2nd ed.) New York: Continuum.

Gage EA (2013). Social networks of experientially similar others: formation, activation, and consequences of network ties on the health care experience. Social Science & Medicine, 95:43-51. doi: 10.1016/j.socscimed.2012.09.001

Gage-Bouchard, E. A., Devine, K. A., & Heckler, C. E. (2013). The relationship between socio-demographic characteristics, family environment, and caregiver coping in families of children with cancer. Journal of Clinical Psychology in Medical Settings, 20(4), 478–487.

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). ‘The dots just don’t join up’: Understanding the support needs of families of children on the autism spectrum. Autism, 22(5), 571-584. https://doi.org/10.1177/1362361316687989

Gardiner, E., & Iarocci, G. (2014). Students with autism spectrum disorder in the university context: Peer acceptance predicts intention to volunteer. Journal of Autism and Developmental Disorders, 44(5), 1008–1017.

Garnett, B. R., Masyn, K. E., Austin, S. B., Miller, M., Williams, D. R., & Viswanath, K. (2014). The intersectionality of discrimination attributes and bullying among youth: An applied latent class analysis. Journal of Youth and Adolescence,43(8) pp. 1225-1239. doi:10.1007/s10964-013-0073-8.

Gauntlett L., Bickle E., Thomas G., Collins B., Heaslip V. and Eccles S. (2017). Interpretative phenomenological analysis: A means of exploring aspiration and resilience amongst Widening Participation students. Widening Participation and Lifelong Learning, 19(2), pp.1-25.

Gearing, R. E. (2004). Bracketing in research: a typology. Qualitative Health Research, 14(2) pp. 1429-1451.

Gerhardt, C. A., Lehmann, V., Long, K. A., & Alderfer, M. A. (2015). Supporting siblings as a standard of care in pediatric oncology. Pediatric Blood & Cancer, 62(S5), 750–753. https://doi.org/10.1002/pbc.25821

Gessler D, Juraskova I, Sansom-Daly UM, Shepherd HL, Patterson P, Muscat DM (2019). Clinician-patient-family decision-making and health literacy in adolescents and young adults with cancer and their families: A systematic review of qualitative studies. Psychooncology, 28(7):1408-1419. doi: 10.1002/pon.5110

Ghaljeh M, Pezaro S, Mardani-Hamooleh M (2024). Mothers' efforts to overcome difficult twists and turns in living with children with cancer: a phenomenological study. BMC Womens Health, 24(1):458. doi: 10.1186/s12905-024-03295-6

Ghufran, M., Andrades, M., Nanji, K., (2014). Frequency and severity of depression among mothers of children with cancer: Results from a teaching hospital in Karachi, Pakistan. British Journal of General Practice, 7 pp. 11-15.

Gibbins, J., Steinhardt, K., & Beinart, H. (2012). A Systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. Journal of Pediatric Oncology Nursing, 29(5) pp. 253–271.doi:10.1177/1043454212452791.

Gibson F, Kumpunen S, Bryan G, Forbat L (2018). Insights from parents of a child with leukaemia and healthcare professionals about sharing illness and treatment information: A qualitative research study. International Journal of Nursing Studies, 83:91-102. doi: 10.1016/j.ijnurstu.2018.04.008

Gil, S., Hooke, M. C., & Niess, D. (2016). The limited English proficiency patient family advocate role: Fostering respectful and effective care across language and culture in a pediatric oncology setting. Journal of Pediatric Oncology Nursing, 33(3), 190–198. https://doi.org/10.1177/1043454215611082.

Gill, F. J., Hashem, Z., Stegmann, R., & Aoun, S. M. (2021). The support needs of parent caregivers of children with a life-limiting illness and approaches used to meet their needs: A scoping review. Palliative Medicine, 35(1) pp. 76–96. https://doi.org/10.1177/0269216320967593.

Gillham, B. (2005). Research interviewing: The range of techniques: A practical guide. McGraw-Hill Education

Gillman, L., Adams, J., Kovac, R., Kilcullen, A., House, A., & Doyle, C. (2015). Strategies to promote coping and resilience in oncology and palliative care nurses caring for adult patients with malignancy: A comprehensive systematic review. JBI Database of Systematic Reviews and Implementation Reports, 13(5), 131–204.

Gise J, Cohen LL (2022). Social Support in Parents of Children With Cancer: A Systematic Review. Journal of Pediatric Psychology, 47(3):292-305. doi: 10.1093/jpepsy/jsab100. PMID: 34643692.

Given B, Given C, Sherwood P (2012). The challenge of quality cancer care for family caregivers. Seminars Oncology Nursing, 28: 205-212.

Glaser, B.G., Strauss, A.L. (1967) The Discovery of Grounded Theory. New York, NY: Aldine.

Goffman E (1963). Stigma: notes on the management of spoiled identity. Englewood Cliff, Prentice-Hall.

Gomes PT, Lima LH, Bueno MK, Araújo LA, Souza NM (2015). Autism in Brazil: a systematic review of family challenges and coping strategies. Journal of Pediatrics (Rio J), 91:111---21.

Gorlin, J.; McAlpine, C.; Garwick, A.; Wieling, E (2016). Severe childhood autism: The family lived experience. Journal of Pediatric Nursing, 31, 580–597.

Grabow D, Kaiser M, Hjorth L, et al (2018). The PanCareSurFup cohort of 83,333 five-year survivors of childhood cancer: A cohort from 12 European countries. European Journal of Epidemiology, 33:335-349.

Graff, C., Mandleco, B., Dyches, T., Coverston, C., Roper,S., & Freeborn, D. (2012). Perspectives of adolescent siblings of children with Down syndrome who have multiple health problems. Journal of Family Nursing,18(2), 175–199. doi:10.1177/1074840712439797

Granek L, Rosenberg-Yunger ZRS, Dix D, et al. (2014) Caregiving, single parents and cumulative stresses when caring for a child with cancer. Child: Care, health and development 40(2): 184–194. DOI: 10.1111/cch.12008

Gray, D. E. (1993). Perceptions of stigma—The parents of autistic children. Sociology of Health & Illness, 15(1), 102–120.https://doi.org/10.1111/1467-9566.ep113 43802

Greenzang KA, Dauti A, Mack JW (2018). Parent perspectives on information about late effects of childhood cancer treatment and their role in initial treatment decision making. Pediatr Blood Cancer, 65(6):e26978. doi: 10.1002/pbc.26978

Greenzang KA, Kelly CA, Al-Sayegh H, Ma C, Mack JW (2021). Thinking ahead: Parents' worries about late effects of childhood cancer treatment. Pediatric Blood and Cancer, 68(12):e29335. doi: 10.1002/pbc.29335

Gritti, P. (2012). A relational approach to the family in psycho-oncology. Neuropathological Diseases, 1(1).

Grochowska, A.; Bodys-Cupak, I.; Kubik, B.; Starzec, P (2018). Assessment of parental stress and anxiety in children with acute lymphoblastic leukemia. Polish Nursing, 2 pp. 173–181.

Gross, A., Bauer-Wu, S., Mills, J., O'Rourke, J., Ott, M.J., & Hanley, D. (2006). Developing and implementing a support and renewal program for nursing and patient care services staff [Abstract 297]. Oncology Nursing Forum, 33 pp. 478–479.

Guba, E.G., Lincoln, Y.S. (1994) Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (eds.) Handbook of Qualitative Research: pp.105-117. Thousand Oaks, CA, Sage.

Guest, G., Namey, E. E., & Mitchell, M. L. (2013). Collecting qualitative data: a field manual for applied research. London: SAGE.

Guner P, Hicdurmaz D, Yıldırım NK, İnci F (2018). Psychosocial care from the perspective of nurses working in oncology: A qualitative study. European Journal of Oncology Nursing, 34:68–75. https://doi.org/10.1016/j.ejon.2018.03.005

Gurney, J.G., Krull, K.R., Kadan-Lottick, N., Nicholson, H.S., Nathan, P.C., Zebrack, B.,Tersak, J.M., Ness, K.K., (2009). Social outcomes in the childhood cancer survivor study cohort. Journal of Clinical Oncology, 27 pp. 2390–2395.

Gutiérrez MGR, Domenico EBL, Moreira MC, Silva LMG (2009). Teaching Medical Oncology in Nursing in Brazil and the Contribution from Escola Paulista de Enfermagem at the Fedetal University of Sao Paulo. Texto Contexto Enfermagem, Florianópolis, Out-Dez; 18(4) pp. 705-712.

Haase, J. E., Kintner, E. K., Robb, S. L., Stump, T. E., Monahan, P. O., Phillips, C., Stegenga, K. A., & Burns, D. S., (2016). The Resilience in Illness Model Part 2: Confirmatory evaluation in adolescents and young adults with cancer. Cancer Nursing, 40 pp. 454-463. https://doi.org/10.1097/NCC.0000000000000450.

Haefner, J. (2014). An application of Bowen family systems theory. Issues in Mental Health Nursing, 35(11), 835–841. https://doi.org/10.3109/01612840.2014.921257

Haigh, C., & Witham, G. (2013). Distress protocol for qualitative data collection. Archives of Psychiatric Nursing, 23(5) pp. 343-350.

Hall, P. A. (1999). Social capital in Britain. British journal of political science, 29(3), 417-461.

Hammer, M. J., Cartwright-Alcarese, F., & Budin, W. C. (2019). Theoretical frameworks and philosophies of care. In J. K. Payne & K. Murphy-Ende (Eds.), Current trends in oncology nursing (2nd ed., pp. 1–46). Oncology Nursing Society.

Han, S.S.; Han, J.W.; Kim, Y.H (2018). Effect of Nurses' Emotional Labor on Customer Orientation and Service Delivery: The Mediating Effects ofWork Engagement and Burnout. Safety and Health at Work 9, 441–446.

Hankivsky O (2012). Women's health, men's health, and gender and health: implications of intersectionality. Social Science and Medicine, 74:1712–1720.

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. Journal of Family Psychology, 24(4), 449–457. doi:10.1037/a0019847

Hassanipour S, Fathalipour M, Delam H, Ghorbani M, Abdzadeh E, Arab-Zozani M, et al (2019). The Incidence of Childhood Cancer in Iran: A systematic review and meta-analysis. Iran Journal of Pediatric Hematology and Oncology, 9(3) pp. 193–206.

Haugen, M., Skeens, M., Hancock, D., Ureda, T., Arthur, M., & Hockenberry, M. (2020). Implementing a pediatric oncology nursing multisite trial. Journal for Specialists in Pediatric Nursing, 25(3). doi:10.1111/jspn.12293.

Haugen, M. S., Landier, W., Mandrell, B. N., Sullivan, J., Schwartz, C., Skeens, M. A., & Hockenberry, M. (2016). Educating families of children newly diagnosed with cancer. Journal of Pediatric Oncology Nursing, 33(6), 405–413. https://doi.org/10.1177/1043454216652856

Heath JA, Lintuuran RM, Rigguto G, Tokatlian N, McCarthy M (2006). Childhood cancer: its impact and financial costs for Australian families. Pediatric Hematology and Oncology, 23 pp. 439–448.

Heidegger, M. (1927) Being and time. Translated by J. Macquarrie and E. Robinson.

Heidgerken AD, Geffken G, Modi A, Frakey L (2005). A survey of autism knowledge in a health care setting. Journal of Autism Developmental Disorders, 35(3):323–330.

Hefferon, K., Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. Methods, vol. 24, 10: pp.756-758.

Health Policy Team: Why children die: Research and recommendations. Royal College of Paediatrics and Children and Child Health, 2014. https://www.rcpch.ac.uk/resources/why-children-die-research-recommendations

Hensler, M. A., Katz, E. R., Wiener, L., Berkow, R., & Madan-Swain, A. (2013). Benefit finding in fathers of childhood cancer survivors: A retrospective pilot study. Journal of Pediatric Oncology Nursing, 30 pp. 161-168. https://doi:10.1177/1043454213487435.

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping with pediatric cancer strategies employed by children and their parents to manage cancer-related stressors during treatment. Journal of Pediatric Oncology Nursing, 28, 344-354. doi: 10.1177/1043454211430823

Hjelmstedt, S.K., Forinder, U.M., Lindahl Norberg, A.M. et al (2021). A Balancing Act: Working and Caring for a Child with Cancer. Journal of Child and Family Studies, 30, pp. 1881–1894. https://doi.org/10.1007/s10826-021-01997-1.

Hjelmstedt S, Forinder U, Montgomery S, Lindahl Norberg A, Hovén E (2021). Facilitators and barriers to return to work and meet financial needs in parents of children with cancer. Pediatric Blood and Cancer, 68(10):e29245. doi: 10.1002/pbc.29245

Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. American Journal of Sociology, 85(3), 551–575. https://doi.org/10.1086/227049

Hochschild A.R. (1983) The Managed Heart: Commercialisationof Human Feeling. University of California Press, Berkeley.

Hock R, Ahmedani BK (2012). Parent perceptions of autism severity: exploring the social ecological context. Disability and Health Journal, 5(4):298-304. doi: 10.1016/j.dhjo.2012.06.002

Hockenberry, M. J., & Wilson, D. (2015). Wong's nursing care of infants and children (10th ed.).Missouri: Elsevier.

Holloway, I., Wheeler, S. (2010). Qualitative Research in Nursing and Healthcare (3rd ed). Wiley-Blackwell, Oxford.

Holloway W, Jefferson T. Doing Qualitative Research Differently. London: Sage; 2000.

Hong, E., & Yang, YJ. (2015). Factors affecting job stress of pediatric nurses: Focusing on self-efficacy, emotional labor, pediatric nurse-parent partnership. Child Health Nursing Research, 21(3), 236–243. https://doi.org/10.4094/chnr.2015.21.3.236

Hopia H, Heino-Tolonen T (2019). Families in Paediatric Oncology Nursing: Critical Incidents From the Nurses' Perspective. Journal of Pediatric Nursing, 44:e28-e35. doi: 10.1016/j.pedn.2018.10.013

Hoven E, von Essen L, Norberg AL (2013). A longitudinal assessment of work situation, sick leave, and household income of mothers and fathers of children with cancer in Sweden. Acta Oncologica, 52 pp. 1076–1085.

Hovén, E., Grönqvist, H., Pöder, U., von Essen, L., & Lindahl Norberg, A. (2017). Impact of a child's cancer disease on parents' everyday life: A longitudinal study from Sweden. Acta Oncologica, 56(1) pp. 93–100.https://doi.org/10.1080/02841 86X.2016.1250945.

Howard AF, de Bibiana JT, Smillie K, Goddard K, Pritchard S, Olsen R, Kazanjian A (2014). Trajectories of social isolation in adult survivors of childhood cancer. Journal of Cancer Survivorship: research and practice, 8:80–93.

Howitt, M. J. (2010). The family care coordinator: Paving the way to seamless care. Journal of Pediatric Oncology Nursing, 28, 107-113.

Höfer J, Hoffmann F, Kamp-Becker I, Poustka L, Roessner V, Stroth S et al (2019). Pathways to a diagnosis of autism spectrum disorder in Germany: a survey of parents. Child and Adolescent Psychiatry and Mental Health, 21;13: 16.

Hsu, Y. C., Tsai, S. L., Hsieh, M. H., Jenks, M. S., Tsai, C. H., & Hsu, M. T. (2017). On my own: A qualitative phenomenological study of mothers of young children with autism spectrum disorder in Taiwan. Journal of Applied Research in Intellectual Disabilities, 30, 147–156. doi:10.1111/jar.12229

Hudson J, Reblin M, Clayton MF, Ellington L (2018). Addressing cancer patient and caregiver role transitions during home hospice nursing care. Palliative and Supportive Care, 15 pp. 1–8. https://doi.org/10.1017/S1478951518000214.

Huiracocha L, Brito L, Peréz ME, Clavijo R, Sempertegui S, Huiracocha K, Blume S. (2015). ‘Suguagua no escucha nada’: Ecuadorian families confronting the deafness of a child. Disability & Society 30(4): 556–568.

Hull K, Clarke D (2011). Are paediatric oncology nurses acknowledging the effects of restraint? A review of the current policy and research. European Journal of Oncology Nursing, 15(5):513-8. doi: 10.1016/j.ejon.2011.02.001

Humphrey, R.H.; Ashforth, B.E.; Diefendorff, J.M (2015). The bright side of emotional labor. Journal of Organizational Behavior, 36, 749–769.

Humphrey, N., & Hebron, J. (2015). Bullying of children and adolescents with autism spectrum conditions: A “state of the field” review. International Journal of Inclusive Education, 19(8), 845–862. https://doi.org/10.1080/13603116.2014.981602

Husserl, E. (1927). Phenomenology. Encyclopaedia Britannica, 14 pp. 699-702.

Ingersoll, B., & Walton, K. (2015). Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: Risk and protective factors. Journal of Autism and Developmental Disorders, 45(9), 2764-2778. https://doi.org/10.1007/s10803-01502440-7

International Atomic Energy Agency: World cancer day 2019 – boosting capacity for cancer care 2019.

Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs; Adler, N.E., Page, A.E.K., Eds.; National Academies Press: Washington,DC, USA, 2008.

Irvine, A., Drew, P., & Sainsbury, R. (2013). ‘Am I not answering your questions properly?’ Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. Qualitative Research, 13(1), 87–106. https://doi.org/10.1177/1468794112439086

Jadidi, R., Hekmatpou, D., Eghbali, A., Memari, F., Anbari, Z., (2014). “Parents a dead end life”: the main experiences of parents of children with leukemia. Iranian journal of nursing and midwifery research,19, 600.

James N (2013). The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and mental health issues: what do carers say? Journal of Intellectual Disabilities, 17:1,6–23. https://doi.org/10.1177/1744629512472610

Jameton, A. (1984). Nursing practice: The ethical issues. Englewood Cliffs: Prentice-Hall

Jamshed, S. (2014). ‘Qualitative research method-interviewing and observation’. Journal of Basic and Clinical Pharmacology, 5 (5) pp. 87–88.

Jaswal VK, Dinishak J, Stephan C, Akhtar N (2020). Experiencing social connection: A qualitative study of mothers of nonspeaking autistic children. PLoS ONE 15(11): e0242661. https://doi.org/10.1371/journal.pone.0242661

Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. Disability & Society, 25, 797–811. doi:10.1080/09687599.2010.520894

Jeung, D.; Kim, C.; Chang, S (2018). Emotional labor and burnout: A review of the literature. Yonsei Medical Journal, 59,187–193.

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2013). The impact of parental health literacy on the early intervention referral process. Journal of Health Care for the Poor and Underserved, 24(3), 1053–1062. https://doi.org/10.1353/hpu.2013.0141

Johansen, S., Cvancarova, M., & Ruland, C. (2018). The effect of cancer patients' and their family caregivers' physical and emotional symptoms on caregiver burden. Cancer Nursing, 41(2) pp. 91–99. https://doi.org/10.1097/NCC.0000000000000493.

Johnson, L.M., Church, C. L., Metzger, M., & Baker, J. N. (2015). Ethics consultation in pediatrics: Long-term experience from a pediatric Oncology center. The American Journal of Bioethics, 15(5), 3–17. https://doi.org/10. 1080/15265161.2015.1021965

Jones, B. L. (2012). The challenge of quality care for family caregivers in pediatric cancer care. Seminars in oncology nursing (Vol. 28, No. 4, pp. 213-220). WB Saunders.

Jones, L., Totsika, V., Hastings, R. P., & Petalas, M. A. (2013). Gender differences when parenting children with autism spectrum disorders: A multilevel modeling approach. Journal of Autism and Developmental Disorders, 43, 290-298.

Justin P, Lamore K, Dorard G, Untas A (2021). Are there young carers in oncology? A systematic review. Psychooncology, 30(9) pp. 1430-1441. doi: 10.1002/pon.5708.

Kaakinen, J. R., Coehlo, D. P., Steele, R., & Robinson, M. (2018). Family health care nursing: Theory, practice, and research. FA Davis.

Kaakinen, J.R., Gedaly-Duff, V., Coehlo, D.P., & Hanson, S.M.H. (Eds.) (2010). 4th ed. Family health nursing: Theory, practice, and research. Philadelphia, PA: F.A.Davis

Kaplan, L., Kaal, K., Bradley, L., & Alderfer, M. (2013). Cancer related traumatic stress reactions in siblings of children with cancer. Families, Systems, & Health, 31 pp. 205–217. https://doi.org/10.1037/a0032550.

Karlsson K., Englund ACD., Enskär K. & Rydström I (2014). Parents' perspectives on supporting children during needle-related medical procedures, International Journal of Qualitative Studies on Health and Well-being, 9:1, 23759, DOI: 10.3402/qhw.v9.23759

Karst, J. S., & Vaughn Van Hecke, A. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. Clinical Child and Family Psychology Review, 15, 247-277.

Kästel A, Enskär K, Björk O (2011). Parents' views on information in childhood cancer care. European Journal of Oncology Nursing, 15(4):290-5. doi: 10.1016/j.ejon.2010.10.007

Kaul S, Korgenski EK, Ying J, et al (2016). A retrospective analysis of treatment-related hospitalization costs of pediatric, adolescent, and young adult acute lymphoblastic leukemia. Cancer Medicine, 5(2) pp. 221-229.

Kawamoto, T. K., Furutani, K., & Alimardani, M. (2018). Preliminary validation of Japanese version of the Parental Burnout Inventory and its relationship with perfectionism. Frontiers in Psychology, 9, Article 970. doi:10.3389/fpsyg.2018.00970

Keats MR, Shea K, Parker L, Stewart SA, Flanders A, Bernstein M (2019). After childhood cancer: a qualitative study of family physician, parent/guardian, and survivor information needs and perspectives on long-term follow-up and survivorship care plans. Journal of Cancer Education, 34:638–46. https://doi.org/10.1007/s13187-018-1349-1

Keen, S., Lomeli-Rodriguez, M., & Joffe, H. (2022). From Challenge to Opportunity: Virtual Qualitative Research During COVID-19 and Beyond. International Journal of Qualitative Methods, 21. https://doi.org/10.1177/16094069221105075

Keim-Malpass, J., Stegenga, K., Loudin, B., Kennedy, C., & Kools, S. (2016). “It’s back! My remission is over”: Online communication of disease progression among adolescents with cancer. Journal of Pediatric Oncology Nursing, 33,209-217. doi:10.1177/1043454215600424

Kelada, L., Wakefield, C. E., Vetsch, J., Schofield, D., Sansom-Daly, U. M., Hetherington, K., O’Brien, T., Cohn,R. J., Anazodo, A., Viney, R., & Zeppel, M. J. B. (2020). Financial toxicity of childhood cancer and changes to parents’ employment after treatment completion. Pediatric Blood & Cancer, 67 (7), e28345.https://doi.org/10.1002/pbc.28345.

Kelly, C. A., & O'Brien, M. R. (2015). An interpretative phenomenological analysis study of healthcare professionals' perceptions of oxygen therapy in palliative care. Palliative Medicine, 29(10) pp. 950-958.

Kent, E. R., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. S., Shelburne, N., . . . Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. Cancer, 122(13) pp. 1987–1995. doi:10.1002/cncr.29939.

Kenten C, Wray J, Gibson F, Russell J, Tuffrey-Wijne I, Oulton K (2019). To flag or not to flag: Identification of children and young people with learning disabilities in English hospitals. Journal of Applied Research in Intellectual Disabilities, 32(5):1176-1183. doi: 10.1111/jar.12608

Kerr, A.M., Harrington, N.G., Scott, A.M., (2019). Communication and the appraisal of uncertainty: exploring parents' communication with credible authorities in the context of chronic childhood illness. Health Communication, 34 pp. 201–211. https://doi.org/10.1080/10410236.2017.1399508.

Khoury M.N., Huijer H.A. & Doumit M.A. (2013). Lebanese parents' experiences with a child with cancer. European Journal of Oncology Nursing,17(1) pp. 16-21. doi:10.1016/j.ejon.2012.02.005.

Kiernan, G., Meyler, E., Guerin, S. (2010). Psychosocial issues and care in pediatric oncology: medical and nursing professionals' perceptions. Cancer Nursing, 33, E12–E20.

Kiger, M. E., & Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. Medical Teacher, 42(8), 846–854. https://doi.org/10.1080/0142159X.2020.1755030

Kilicarslan-Toruner E, Akgun-Citak E (2013). Information-seeking behaviours and decision-making process of parents of children with cancer. European Journal of Oncology Nursing, 17:176-83.

Kim M. A., Yi J., Sang J., Kim S. H., & Heo I.Y. (2017). Experiences of korean mothers of children with cancer: A Photovoice study. Journal of Psychosocial Oncology, 35(2) pp. 128–147. DOI: 10.1080/07347332.2016.1263265.

Kim, M. A., Yi, J., Sang, J., & Molloy, J. (2018). The impact of a child's cancer on the father's relationship with his spouse in Korea. Journal of Child and Family Studies, 27(1), 166–175. https://doi.org/10.1007/s10826-017-0862-x

Kim, M. A., Yi, J., Wilford, A., & Kim, S. H. (2020). Parenting Changes of Mothers of a Child with Cancer. Journal of Family Issues, 41(4), 460-482. https://doi.org/10.1177/0192513X19881191

Kim, S. Y., Song, D., Bottema-Beutel, K., Gillespie-Lynch, K., & Cage, E. (2023). A systematic review and meta-analysis of associations between primarily non-autistic people's characteristics and attitudes toward autistic people. Autism Research, 16, 441–457.

Kimura, M., & Yamazaki, Y. (2019). Having another child without intellectual disabilities: Comparing mothers of a single child with disability and mothers of multiple children with and without disability. Journal of Intellectual Disabilities, 23(2), 216-232. https://doi.org/10.1177/1744629517749129

Kinnear, S.H., Link, B.G., Ballan, M.S. and Fischbach, R.L., (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families lives. Journal of Autism and Developmental Disorders, 46, pp. 942-953.

Kirchhoff, A.C., Krull, K.R., Ness, K.K., Park, E.R., Oeffinger, K.C., Hudson, M.M., Stovall,M., Robison, L.L., Wickizer, T., Leisenring, W., (2011). Occupational outcomes of adult childhood cancer survivors. Cancer 117 pp. 3033–3044.

Kirwan, L., & Coyne, I. (2017). Use of restraint with hospitalized children:A survey of nurses' perceptions of practices. Journal of Child Health Care, 21(1), 46–54.

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

Klassen AF, Gulati S, Granek L, Rosenberg-Yunger ZR, Watt L, Sung L, Klaassen R, Dix D, Shaw NT (2012). Understanding the health impact of caregiving: a qualitative study of immigrant parents and single parents of children with cancer. Quality of Life Research, 21(9) pp. 1595-1605. doi: 10.1007/s11136-011-0072-8.

Kobayashi, K.; Hayakawa, A.; Hohashi, N (2015). Interrelations between siblings and parents in families living with children with cancer. Journal of Family Nursing, 21 pp. 119–148.

Koch K. D., Jones B. L. (2018). Supporting parent caregivers of children with a life-limiting illness. Children, 26;5(7):85. https://doi.org/10.3390/children5070085.

Kohlsdorf, M., & Costa Junior, A. L. (2012). Psychosocial impact of pediatric cancer on parents: A literature review. Paideia, 22(51) pp. 119–129. doi:10.1590/S0103-863X2012000100014.

Kojo, K., & Fukumaru, Y. (2015). Depression and related factors in parents of children with spina bifida: A focus on differences between fathers and mothers. The Journal of Child Health, 74, 638–645 (in Japanese).

Kopecky, K., Broder-Finger, S., Iaanuzzi, D., & Connors, S.(2013). The needs of hospitalized patients with autism spectrum disorders: A parent survey. Clinical Pediatrics, 52,652–660

Kostovich, C. T. (2012). Development and psychometric assessment of the presence of nursing scale. Nursing Science Quarterly, 25(2), 167–175. https://doi.org/10.1177/0894318412437945

Kostovich, C. T., Dunya, B. A., Schmidt, L. A., & Collins, E. G. (2016). A rasch rating scale analysis of the presence of nursing scale-RN. Journal of Applied Measurement, 17(4),476–488.

Kotronoulas G, Wenstrom Y, Kearney N (2012). Informal carers: A focus on the real caregivers of people with cancer. Forum of Clinical Oncology, 3(3) pp. 36-43.

Kousgaard, S. J., Boldsen, S. K., Mohr-Jensen, C., & Lauritsen, M. B. (2018). The effect of having a child with ADHD or ASD on family separation. Social Psychiatry and Psychiatric Epidemiology. 53(12), 1391–1399. https://doi.org/10.1007/s00127-018-1585-z

Koydemir-Özden, S., & Tosun, Ü. (2010). A qualitative approach to understanding Turkish mothers of children with autism: Implications for counseling. Australian Journal of Guidance & Counselling, 20(1), 55–68. doi:10.1375/ajgc.20.1.55

Kuo DZ, Cohen E, Agrawal R (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. Archives of Pediatric and Adolescent Medicine, 165 pp. 1020 1026.

Kupst MJ, Patenaude AF, Walco GA, Sterling C (2003). Clinical trials in pediatric cancer: parental perspectives on informed consent. Journal of Pediatric and Hematology Oncology, 25(10):787-790.

Kuriakose S, Filton B, Marr M, Okparaeke E, Cervantes P, Siegel M, et al (2018). Does an autism Spectrum disorder care pathway improve Care for Children and Adolescents with ASD in inpatient psychiatric units? Journal of Autism and Developmental Disorders, 48:4082–9. https ://doi.org/10.1007/s1080 3-018-3666-y

Kyle, T., & Carman, S. (2013). Essentials of pediatric nursing (2nd ed.). Philadelphia: Wolters Kluwer Health, Lippincot Williams & Wilkins.

Landier, W.; Ahern, J.; Barakat, L.P.; Bhatia, S.; Bingen, K.M.; Bondurant, P.G.; Cohn, S.; Dobrozsi, S.K.; Haugen, M.; Herring, R.A.; et al (2016). Patient/Family Education for Newly Diagnosed Pediatric Oncology Patients: Consensus Recommendations from a Children’s Oncology Group Expert Panel. Journal of Pediatric Oncology Nursing, 33 pp. 422–431.

Landier W, Chen Y, Namdar G, et al (2015). Impact of tailored education onawareness of personal risk for therapy-related complications amongchildhood cancer survivors. Journal of Clinical Oncology, 33(33):3887–3893.

Langdridge, D. (2013). Existential Counselling & Psychotherapy. Sage Publications.

Larkin, M., Eatough, V., and Osborn, M. (2011). 'Interpretative phenomenological analysis and embodied, active, situated cognition', Theory and Psychology, 21(3), pp. 318-337, doi:10.1177/0959354310377544

Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. Qualitative Research in Psychology, 16(2), 182–198. https://doi.org/10.1080/14780887.2018.1540655

Larkin, M & Thompson, A (2012). Interpretative phenomenological analysis. in A Thompson & D Harper (eds), Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners. John Wiley & Sons, Oxford, pp. 99-116. https://doi.org/10.1002/9781119973249

Larkin M, Watts S, Clifton E. (2006). Giving voice and making sense in interpretative phenomenological analysis. Qualitative Research in Psychology, 3(2) pp. 102-120.

Lavi I, Fladeboe K, King K, et al (2018). Stress and marital adjustment in families of children with cancer. Psychooncology,27 pp. 1244-1250.

Lee, M., & Jang, K.-S. (2019). Nurses' emotions, emotional labor, and job satisfaction. International Journal of Workplace Health Management, 13(1), 16–31. https://doi.org/10.1108/IJWHM-01-2019-0012

Lemoine, L., & Schneider, B. (2021). Growing up with a brother or sister with Down syndrome: Adult siblings' perceptions of their childhood relationships. Journal of Intellectual & Developmental Disability, 47, 39 - 52.

Leow M, Chan M, Chan S (2014). Predictors of change in the quality of life of family caregivers of patients near the end of life with advanced cancer. Cancer Nursing, 37(6) pp. 391–400.

Leung L. (2015). Validity, reliability, and generalizability in qualitative research. Journal of family medicine and primary care, 4(3) pp. 324–327. https://doi.org/10.4103/2249-4863.161306.

Levac D, Colquhoun H, O'Brien K.K., (2010). Scoping studies: advancing the methodology. Implementation Science, 20 pp. 65-69. https://doi:10.1186/1748-5908-5-69.

Levers, M.J.D. (2013). Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence. SAGE Open. pp.1-6. Available from: https://journals.sagepub.com/doi/pdf/10.1177/2158244013517243 [Accessed 12 June 2020].

Levi RB, Marsick R, Drotar D, Kodish KD (2000). Diagnosis, disclosure, and informed consent: learning from parents of children with cancer. Journal of Pediatric Hematology/ Oncology, 22(1):3-12.

Levine, D., K. Cohen, and D. Wendler. (2012). Shared medical decisionmaking: Considering what options to present based on an ethical analysis of the treatment of brain tumors in very young children. Pediatric Blood & Cancer 59(2) pp. 216–220.

Levy, S. E., Frasso, R., Colantonio, S., Reed, H., Stein, G., Barg, F. K., … Fiks, A. G. (2016). Shared decision making and treatment decisions for young children with autism spectrum disorder. Academic Pediatrics. Retrieved from http://www.sciencedirect.com/science/article/pii/S1876285916301425, 16, 571–578.

Lewandowska, A., Rudzki, G., Lewandowski, T., & Rudzki, S. (2020). The Problems and Needs of Patients Diagnosed with Cancer and Their Caregivers. International journal of environmental research and public health, 18(1),87. https://doi.org/10.3390/ijerph18010087.

Lewandowska, A (2021). Influence of a Child's Cancer on the Functioning of Their Family. Child, 8, 592.

Liao X, Lei X, Li Y (2019). Stigma among parents of children with autism: A literature review. Asian Journal of Psychiatry, 45:88-94. doi: 10.1016/j.ajp.2019.09.007. Epub 2019 Sep 7. PMID: 31542694.

Li, T. Y., & Lo, J. L. (2015). The predictors of uncertainty in mothers of children with autism spectrum disorder. Children's Health Care, 45(2), 147–164. https://doi.org/10.1080/02739615.2014.979924

Lin, G.-X., Hansotte, L., Szczygieł, D., Meeussen, L., Roskam, I., & Mikolajczak, M. (2021). Parenting with a smile: Display rules, regulatory effort, and parental burnout. Journal of Social and Personal Relationships, 38(9), 2701-2721. https://doi.org/10.1177/02654075211019124

Lincoln, Y.S., Guba, E.G. (1985) Naturalistic Inquiry, Sage, Newbury Park, California.

Lindahl Norberg A, Montgomery SM, Bottai M, Heyman M, Hoven EI (2016). Short-term and long-term effects of childhood cancer on income from employment and employment status: a national cohort study in Sweden. Cancer. 123 pp. 1238-1248.

Lindell RB, Koh SJ, Alvarez JM, et al (2015). Knowledge of diagnosis, treatment history, and risk of late effects among childhood cancer survivors and parents: the impact of a survivorship clinic. Pediatric Blood and Cancer, 62(8):444–1451.

Linder, L.A., Al-Qaaydeh, S., & Donaldson, G. (2017). Symptom characteristics among hospitalized children and adolescents with cancer. Cancer Nursing. 41(1) pp. 23-32. doi:10.1097/NCC.0000000000000469.

Lindsay A. Jibb et al. (2021). Home-Based Pediatric Cancer Care: Perspectives and Improvement Suggestions From Children, Family Caregivers, and Clinicians. JCO Oncology Practice, 17, e827-e839. DOI:10.1200/OP.20.00958

Little M., Jordens C., Paul K., Montgomery K. & Philipson B (1998) . Liminality: a major category of the experience of cancer illness. Social Science & Medicine 47(10), 1485–1494.

Liu Y, Fisher K (2017). Engaging with disability services: experiences of families from Chinese backgrounds in Sydney. Australian Social Work, 70(4):441-52. https://doi.org/10.1080/0312407X.2017.1324885

Liu Q, Petrini MA, Luo D, Yang BX, Yang J, Haase JE (2020). Parents' Experiences of Having a Young Child With Acute Lymphoblastic Leukemia in China. Journal of Pediatric Oncology Nursing, 38(2) pp. 94-104. doi: 10.1177/1043454220975463.

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. International Journal of Nursing Sciences, 7(4) pp. 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012.

Livingston, J., Cheng, Y. I., Wang, J., Tweddle, M., Friebert, S., Baker, J. N., Thompkins, J., & Lyon, M. E. (2020). Shared spiritual beliefs between adolescents with cancer and their families. Pediatric Blood & Cancer, 67(12), 1–9. https://doi.org/10.1002/pbc.28696

Ljungman, L., Boger, M., Ander, M., Ljotsson, B., Cernvall, M.,von Essen, L., & Hoven, E., (2016). Impressions that last: Particularly negative and positive experiences reported by parents five years after the end of a child's successful cancer treatment or death. PLOS One, 11, e0157076. https://doi:10.1371/journal.pone.0157076.

Ljungman, L., Cernvall, M., Grönqvist, H., Ljotsson, B., Ljungman, G.,& Essen, L. (2014). Long term positive and negative psychosocial late effects for parents of childhood cancer survivors: A systematic review. PLoS One, 9(7), e103340.

Ljungman L, Hoven E, Ljungman G, et al (2015). Does time heal all wounds? A longitudinal study of the development of posttraumatic stress symptoms in parents of survivors of childhood cancer and bereaved parents. Psycho-oncology, 24:1792–1798.

Lobe, B., Morgan, D., & Hoffman, K. A. (2020). Qualitative data collection in an era of social distancing. International Journal of Qualitative Methods, 19, 1–8. https://doi.org/10.1177/1609406920937875

Lodder, A., Papadopoulos, C., & Randhawa, G. (2020). Using a blended format (videoconference and face to face) to deliver a group psychosocial intervention to parents of autistic children. Internet Interventions, 21, 100336. https://doi.org/10.1016/j.invent.2020.100336

Loghmani, L.; Borhani, F.; Abbaszadeh, A (2014). Determination of the content of communication between the care team and family members of patients in the intensive care unit: The experience of nurses and patients’ families. Journal of Qualitative Research Health Science, 3,257–268.

Long, K. A., Keeley, L., Reiter Purtill, J., Vannatta, K., Gerhardt, C. A., & Noll, R. B. (2014). Child-rearing in the context of childhood cancer: Perspectives of parents and professionals. Pediatric Blood & Cancer, 61(2) pp. 326–332. doi:10.1002/pbc.24556.

Long, K. A., Lehmann, V., Gerhardt, C., Carpenter, A., Marsland, A., and Alderfer, M. (2018). Psychosocial functioning and risk factors among siblings of children with cancer: an updated systematic review. Psycho-Oncology 27 pp. 1467–1479. DOI: 10.1002/pon.4669.

Long, K. A., Marsland, A. L., & Alderfer, M. A. (2013). Cumulative family risk predicts sibling adjustment to childhood cancer. Cancer, 119(13), 2503-2510. https://doi.org/10.1002/cncr.28077

Long, K. A., Marsland, A. L., Wright, A., & Hinds, P. (2015). Creating a tenuous balance: Siblings’ experience of a brother’s or sister’s childhood cancer diagnosis. Journal of Pediatric Oncology Nursing, 32(1), 21–31. https://doi.org/10.1177/104345214555194

Long KA, Marsland AL (2011). Family adjustment to childhood cancer: a systematic review. Clinical Child and Famiy Psychology Review, 14:57–88.

Lovell, B., & Wetherell, M. (2015). The psychophysiological impact of childhood autism spectrum disorder on siblings. Research in Developmental Disabilities, 49-50, 226-234. https://doi.org/10.1016/j.ridd.2015.11.023

Ludlow A, Skelly C, Rohleder P (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. Journal of Health Psychology, 17(5):702–711.

Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. Journal of Pediatric Nursing, 27(3), 206–213. doi:10.1016/j.pedn.2011.03.013

Lyu QY, Yu XX, Wang JL, Wang XY, Ke QQ, Liu D, et al (2022). Self-esteem and family functioning mediates the association of symptom severity and parental affiliate stigma among families with children with ASD. Journal of Pediatric Nursing, 66:e122–9. doi: 10.1016/j.pedn.2022.04.019

Lyu, Q. Y., Zhang, M. F., Bu, X. Q., Zhou, X. Z., & Zhao, X. (2019). A qualitative study exploring coping strategies in Chinese families during children’s hospitalization for cancer treatment. Journal of Pediatric Nursing, 48(1), 27–34. https://doi.org/10.1016/j.pedn.2019.05.022

Lyu XC, Jiang HJ, Lee LH, Yang CI, Sun XY (2024). Oncology nurses' experiences of providing emotional support for cancer patients: a qualitative study. BMC Nursing, 20;23(1):58. doi: 10.1186/s12912-024-01718-1

MacDonald H and Callery P (2008). Parenting children requiring complex care: a journey through time. Child: Care, Health and Development; 34(2) pp. 207–213.

Mac Ca´rthaigh S, Lo´pez B (2020). Factually based autism awareness campaigns may not always be effective in changing attitudes towards autism: Evidence from British and South Korean nursing students. Autism, 24(5):1177–1190.

Maguire R (2011). Where is the Person in Symptom Cluster Research? The Experience of Symptom Clusters in Patients with Advanced Lung Cancer. Stirling: University of Stirling.

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. All Ireland journal of higher education, 9(3).

Mailhot Vega RB, Balogun OD, Ishaq OF, Bray F, Ginsburg O, Formenti SC (2019). Estimating child mortality associated with maternal mortality from breast and cervical cancer. Cancer, 125(1) pp. 109-117.

Majid, M. A. A., Othman, M., Mohamad, S. F., Lim, S. A. H., & Yusof, A. (2017). Piloting for interviews in qualitative research: Operationalization and lessons learnt. International Journal of Academic Research in Business and Social Sciences, 7(4), 1073-1080.

Maltby, J., Williams, G., McGarry, J., & Day, L. (2010). Research Methods for Nursing and Healthcare. Harlow, England, England: Pearson Education

Mant J, Kirby A, Cox KJ, Burke A (2019). Children's experiences of being diagnosed with cancer at the early stages of treatment; an interpretive phenomenological analysis. Clinical Child Psychology and Psychiatry, 24(1):3-18. doi:10.1177/1359104518788400

Marcus, C (2014). Strategies for improving the quality of verbal patient and family education: a review of the literature and creation of the EDUCATE model. Health Psychology & Behavioural Medicine, Vol. 2, No. 1, pp. 482–495. http://dx.doi.org/10.1080/21642850.2014.900450.

Maree JE, Parker S, Kaplan L, Oosthuizen J (2016). The information needs of South African parents of children with cancer. Journal of Pediatric Oncology Nursing, 33 pp.9-17.

Markoulakis, R., Fletcher, P., & Bryden, P. (2012). Seeing the glass half full: Benefits to the lived experiences of female primary caregivers of children with autism. Clinical Nurse Specialist, 26(1), 48–56. doi:10.1097/NUR.0b013e31823-bfb0f

Martins A, Aldiss S, Taylor RM, Gibson F (2022). Care coordination, consistency and continuity: the case of the key worker role in children's cancer care. International Journal of Qualitative Studies on Health and Well-being, 17(1):2092958. doi: 10.1080/17482631.2022.2092958. PMID: 35757984; PMCID: PMC9246033.

Maru, M., Gibson, F., & Hinds, P. S. (2013). Pediatric oncology nursing research goes global. Cancer Nursing, 36, 339. https://doi.org/10.1097/NCC.0b013e3182a34688.

MasaDeh, R., Collier, J., & Hall, C. (2012). Parental stress when caring for a child with cancer in Jordan: A cross sectional survey. Health and Quality of Life Outcomes, 10(88) pp. 1–7. doi:10.1186/1477-7525-10-88.

Masika GM, Gottvall M, Kohi TW, von Essen L, Dol JS (2020). Concerns and needs of support among guardians of children on cancer treatment in Dar es Salaam: a qualitative study. Cancer Nursing, 43:E342–8. https://doi.org/10.1097/NCC.0000000000000722

Matthews RA, Booth SM, Taylor CF, Martin T (2011). A qualitative examination of the work-family interface: parents of children with autism spectrum disorder. Journal of Vocational Behavior, 79(3):625–639.

Mays, N., Roberts, E., & Popay, J. (2001). Synthesising research evidence. In N. Fulop, P. Allen, A. Clarke, & N. Black (Eds.), Methods for studying the delivery and organisation of health services Routledge.

McCollum, J. L. C., & Eric, E. (2002). Obscured variability: The distinction between emotion work and emotional labor. In Managing emotions in the workplace. Routledge.

McCubbin, M., Balling, K., Possin, P., Frierdich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. Family Relations, 51, 103-111.

McEvoy B, Creaner M (2021): The experiences of mothers who have a child diagnosed with cancer, Psychology & Health, DOI: 10.1080/08870446.2021.1872791.

McHaro, S.K., Bally, J., Spurr, S. (2022). Nursing presence in pediatric oncology: a scoping review. Journal of Pediatric Oncology Nursing, 39 (2), 99–113.

McKenna K, Collier J, Hewitt M, Blake H (2010). Parental involvement in paediatric cancer treatment decisions. European Journal of Cancer Care, 19:621-630.

McLoone, J. K., Wakefield, C. E., & Cohn, R. J. (2013). Childhood cancer survivors' school (re)entry: Australian parents' perceptions. European Journal of Cancer Care, 22(4), pp. 484–492. https://doi.org/10.1111/ecc.12054.

McStay, R.; Trembath, D.; Dissanayake, C (2015). Raising a Child with Autism: A Developmental Perspective on Family Adaptation. Current Developmental Disorders Report, 2, 65–83.

Mehta, A., Cohen, S. R., & Chan, L. S. (2009). Palliative care: a need for a family systems approach. Palliative & supportive care, 7(2), 235-243.

Menezes, M., Robinson, M. F., Harkins, C., Sadikova, E., & Mazurek, M. O. (2021). Unmet health care needs and health care quality in youth with autism spectrum disorder with and without intellectual disability. Autism, 25(8), 2199-2208. https://doi.org/10.1177/13623613211014721

Mensah ABB, Nunoo H, Boamah Mensah K, Okyere J, Dzomeku VM, Apiribu F, Agyenim Boateng K, Asoogo C, Opare-Lokko E, Clegg-Lamptey JN (2023). Being the nurse for my child at home: A qualitative analysis of parental recognition, appraisal, and reactions to childhood cancer in Ghana. Journal of Child Health Care, 28:13674935231225715. doi: 10.1177/13674935231225715

Merleau-Ponty, M. (2013). Phenomenology of perception. Routledge.

Merriam, S. B., & Tisdell, E. J. (2015). Qualitative research: A guide to design and implementation. Jossey-Bass.

Mezgebu, E., Berhan, E., & Deribe, L. (2020). Predictors of resilience among parents of children with cancer: Cross-sectional study. Cancer Management and Research, 12, 11611–11621. https://doi.org/10.2147/CMAR.S276599

Michel, G., Brinkman, T. M., Wakefield, C. E., & Grootenhuis, M. (2020). Psychological Outcomes, Health-Related Quality of Life, and Neurocognitive Functioning in Survivors of Childhood Cancer and Their Parents. Pediatric Clinics of North America, 67(6) pp. 1103–1134. doi:10.1016/j.pcl.2020.07.005.

Mikami AY, Chong GK, Saporito JM, Na JJ (2015). Implications of parental affiliate stigma in families of children with ADHD. Journal of Clinical Child and Adolescent Psychology, 44: 595–603. doi: 10.1080/15374416.2014

Mikolajczak, M., Gross, J. J., & Roskam, I. (2019). Parental burnout: What is it and why does it matter? Clinical Psychological Science, 7(6), 1319–1329.

Mikolajczak, M., Brianda, M. E., Avalosse, H., & Roskam, I. (2018). Consequences of parental burnout: Its specific effect on child neglect and violence. Child Abuse & Neglect, 80, 134–145. https://doi.org/10.1016/j.chiabu.2018.03.025

Milberg, A., Liljeroos, M., Wåhlberg, R., & Krevers, B. (2020). Sense of support within the family: a cross-sectional study of family members in palliative home care. BMC palliative care, 19, 1-16.

Miller, E., Jacob, E., & Hockenberry, M. J. (2011). Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. Oncology Nursing Forum, 38, pp. 382–393.

Milosevic S, Brookes-Howell L, Randell E, Williams-Thomas R, Delport S, Busse M, Gillespie D, Ahuja AS, McKigney AM, Glarou E, McNamara R (2022). Understanding the support experiences of families of children with autism and sensory processing difficulties: A qualitative study. Health Expectations, 25(3):1118-1130. doi: 10.1111/hex.13465

Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. Research in Developmental Disabilities, 89, 10–21. https://doi.org/10.1016/j.ridd.2019.03.001

Modanloo, S., Rohani, C., & Farahani Shirin Abadi, A. (2015). Assessment of family function among parents of children with cancer. Iranian Journal of Nursing Research, 10(1), 56-65.

Mohammadi, F., Rakhshan, M., Houshangian, M., & Kyle, H. (2020). Evaluation of psychometric properties of the caregiver burden inventory in parents of Iranian children suffering from cancer. Nursing and Midwifery Studies, 9(2) pp. 102–109. https://doi.org/10.4103/nms.nms_22_19.

Mojen, L. K., Rassouli, M., Eshghi, P., Zendedel, K., Sari, A. A., Karimooi, M. H., & Farahani, A. S. A. (2018). Pediatric palliative care in Iran: Applying regionalization of health care systems. Asian Pacific Journal of Cancer Prevention, 19(5), 1303.

Mollica MA, Litzelman K,Rowland JH, Kent EE (2017). The role of medical/nursing skills training in caregiver confidence and burden: a CanCORS study. Cancer, 123 pp. 4481–4487.

Molinaro, M. L., & Fletcher, P. C. (2017). “It changed everything. And not all in a bad way”: Reflections of pediatric cancer experiences. Comprehensive Child and Adolescent Nursing. Advanced online publication. doi:10.1080/24694193.2017.1307471

Molinaro, Monica L. (2021). "“I can’t be the nurse I want to be”: Stories of moral distress in pediatric oncology nurses’ caregiving narratives" Electronic Thesis and Dissertation Repository. 7994. https://ir.lib.uwo.ca/etd/7994

Mooney-Doyle, K., Dos Santos, M., Szylit, R., & Deatrick, J. (2014). Parental expectation of support from healthcare providers during pediatric life-threatening illness: A secondary qualitative analysis. Journal of Pediatric Nursing, 36 pp. 63–172. https://doi.org/10.1016/j.pedn.2017.05.008.

Mooney-Doyle, K., dos Santos, M. R., Woodgate, R. L., & Hinds, P. S. (2020). Pediatric oncology nursing: Defining care through science. In P. Hinds & L. Linder (Eds.), Family-centered care in pediatric oncology (pp. 7–19). Springer. https://doi.org/10.1007/978-3-030-25804-7_2

Mooney-Doyle, K., & Ulrich, C. M. (2020). Parent moral distress in serious pediatric illness: A dimensional analysis. Nursing Ethics, 27(3), 821–837. https://doi.org/10.1177/0969733019878838

Moore, N. (2012). The politics and ethics of naming: Questioning anonymisation in (archival) research. International Journal of Social Research Methodology, 15(4), 331–340. https://doi.org/10.1080/13645579.2012.688330

Moreira, P. L., & Angelo, M. (2008). Becoming a mother of a child with cancer: Building motherhood. Revista Latino-Americana de Enfermagem, 16 pp. 355–361. doi:10.1590/S0104-11692008000300004.

Moridi G.,Valiee S., Fathi M., Nikbakht-Nasrabadi A., Khaledi S., (2018). Parents' experience of pediatric cancer: A qualitative study. Chronic Diseases Journal. 6 pp. 214-224. https://doi:10.22122/cdj.v6i4.358.

Morse, J, & Field, P. (2013). Nursing research: The application of qualitative approaches (2nd ed.). Springer.

Morton M, Klugman J, Hanmer L, Singer D (2013). Gender at Work: a Companion to the World Development Report on Jobs. Washington, DC: World Bank Group.

Moser A, Korstjens I (2017). Series: Practical guidance to qualitative research. Part 1: Introduction. European Journal of General Practice, 23(1):271-273. doi: 10.1080/13814788.2017.1375093

Motlagh ME, Mirzaei-Alavijeh M, Hosseini SN (2019). Information Needs Assessment among Parents of Children with Cancer. Asian Pacific Journal of Cancer Prevention, 20(6):1865-1870. doi: 10.31557/APJCP.2019.20.6.1865

Munhall, P.L. (2012). A Phenomenological Method. In: Munhall, P.L. ed. Nursing Research A Qualitative Perspective. 5th ed. London: Jones & Bartlett Learning, pp. 113-176.

Munhall PL (2012). Nursing Research: A Qualitative Perspective. 5th ed. Sudbury, MA: Jones & Bartlett Learning.

Murdoch L, Chang YS (2022). Parental experiences of caring for children who have learning disabilities and procedural anxiety in hospital: An interpretive phenomenological study. Child: Care, Health and Development, 48(5):809-819. doi: 10.1111/cch.12990

Muskat B, Burnham Riosa P, Nicholas DB, Roberts W, Stoddart KP, Zwaigenbaum L (2015). Autism comes to the hospital: the experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. Autism, 19(4):482-90. doi: 10.1177/1362361314531341

Muskat, B., Jones, H., Lucchetta, S., Shama, W., Zupanec, S., & Greenblatt, A. (2017). The experiences of parents of pediatric patients with acute lymphoblastic leukemia, 2 months after completion of treatment. Journal of Pediatric Oncology Nursing, 34(5) pp. 358-366. https://doi.org/10.1177/1043454217703594.

Myers BJ, Mackintosh VH, Goin-Kochel RP (2009). “My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. Research in Autism Spectrum Disorders, 3(3):670–684.

Naidoo, D., Gurayah, T., Kharva, N., Stott, T., Trend, S. J., Mamane,T., & Mtolo, S. (2016). Having a child with cancer: African mothers’ perspective. South African Journal of Occupational Therapy, 46(3) pp. 49–54. https://doi.org/10.17159/2310-3833/2016/v46n3a9.

National Institute of Clinical Excellence. (2014). Cancer services for children and young people Quality standard Published: 27 February 2014. www.nice.org.uk/guidance/qs55. Available at: https://www.nice.org.uk/guidance/qs55/resources/cancer-services-for-children-and-young-people-pdf-2098728855493 [Accessed 17.02.2022].

Nettleton S., Neale J., Stevenson C (2012). Sleeping at the margins: aqualitative study of homeless drug users who stay in emergency hostels and shelters. Critical Public Health, 22 pp.319–328.

Newington, L., & Metcalfe, A. (2014). Factors influencing recruitment to research: Qualitative study of the experiences and perceptions of research teams. BMC Medical Research Methodology, 14(10). https://doi.org/10.1186/1471-2288-14-10

Ng CSM, Ng SSL (2022). A qualitative study on the experience of stigma for Chinese parents of children with autism spectrum disorder. Scientific Reports, 12:19550. doi: 10.1038/s41598-022-23978-0

NHS ENGLAND. 2015b. Personalised care and support planning handbook. The journey to person-centred care. Core information. Available from: https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf [Accessed 08 June 2021].

Nicolaou, C., Kouta, C., Papathanasoglou, E., & Middleton, N. (2015). Perceived social support among Greek-Cypriot mothers of children with cancer and mothers of healthy children. International Journal of Caring Sciences, 8(2), 241–255.

Niedbalski J (2024). The impact of individuals with profound intellectual and multiple disabilities on peer relationships of typically developing siblings. Journal of Intellectual Disabilities, 28(2):514-532. doi: 10.1177/17446295231168184

Nielsen CL, Clemensen J, Callesen MT, Jensen CS, Smith AC, Holm KG (2024). Who is supporting the parents during their child's cancer treatment? A qualitative study through the lens of compassion. European Journal of Oncology Nursing, 70:102534. doi: 10.1016/j.ejon.2024.102534

Nieto BB, Muñoz P C, López MÁV. (2022). Needs Assessment in Parents of Children Affected by Cancer: A Qualitative Perspective. Children (Basel); 9(12):1957. doi: 10.3390/children9121957

Nolbris M, Ahlström BH (2014). Siblings of children with cancer—their experiences of participating in a person-centered support interventioncombining education, learning and reflection: pre- andpost-intervention interviews. European Journal of Oncology Nursing, 18(3):254-260.

Norberg, A. L., & Steneby, S. (2009). Experiences of parents of children surviving brain tumour: A happy ending and a rough beginning. European Journal of Cancer Care, 18(4) pp. 371–380. doi:10.1111/j.1365-2354.2008.00976.x.

Northfield S, Nebauer M (2010). The caregiving journey for family members of relatives with cancer: how do they cope? Clinical Journal of Oncology Nursing, 14(5) pp. 567-577.

Nurhidayah I, Nurhaeni N, Allenidekania A, Gayatri D, Rustina Y (2023). Uncertainty of parents due to having children with cancer: A concept analysis. Belitung Nursing Journal, 26;9(3):218-226. doi: 10.33546/bnj.2612

O'Byrne, P. and Holmes, D. (2008) 'Researching Marginalized Populations: Ethical Concerns about Ethnography'. Canadian Journal of Nursing Research, 40 (3) pp. 144-159.

Ochoa CY, Buchanan Lunsford N, Lee SJ (2020). Impact of informal cancer caregiving across the cancer experience: a systematic literature review of quality of life. Palliative and Supportive Care, 18(2):220–40. https://doi.org/10.1017/S1478951519000622.

October, T. W., K. R. Fisher, C. Feudtner, and P. S. Hinds. (2014). The parent perspective: “Being a good parent” when making critical decisions in the PICU. Pediatric Critical Care Medicine 15(4) pp. 291–298.

Oduyemi, A. Y., Okafor, I. P., Eze, U. T., Akodu, B. A. & Roberts, A. A (2021). Internalization of stigma among parents of children with autism spectrum disorder in Nigeria: A mixed method study. British Medical Clinics Psychology, 9, 182. https:// doi. org/ 10. 1186/ s40359- 021-00687-3).

O’Donoghue, E.M., Pogge, D.L. & Harvey, P.D. (2020). ‘The impact of intellectual disability and autism spectrum disorder on restraint and seclusion in pre-adolescent psychiatric inpatients’, Journal of Mental Health Research in Intellectual Disabilities, vol. 13, no. 2, pp. 86-109. https://doi.org/10.1080/19315864.2020.1750742

Offen, J. J. (2015). The role of UK district nurses in providing care for adult patients with a terminal diagnosis: A meta-ethnography. International Journal of Palliative Nursing, 21(3) pp. 134–141. https://doi.org/10.12968/ijpn.2015.21.3.134.

Office for National Statistics, (2015). Cancer Survival Statistical Bulletins Quality and Methodology Information. Office for National Statistics: Newport (accessed 26.12.2021).

Oliffe, J., & Thorne, S. (2007). Men, masculinities and prostate cancer: Australian and Canadian patient perspectives of communication with male physicians. Qualitative Health Research, 17, 149-161.

O'Loughlin, D., Gummerus, J., & Kelleher, C. (2024). It Never Ends: Vulnerable Consumers' Experiences of Persistent Liminality and Resource (Mis)Integration. Journal of Service Research, 27(3), 327-345. https://doi.org/10.1177/10946705231184610

Olsen, P. M. (2017). Raising a child with autism: Perspectives from Arab-Muslim mothers (Doctoral dissertation, The Chicago School of Professional Psychology). Retrieved from https://search.proquest.com/openview/02842908da27 3b5b608e3d992690430c/1?pq-origsite=gscholar&cbl=18750&diss=y

Olson RE (2014). Indefnite loss: the experiences of carers of a spouse with cancer. European Journal of Cancer Care, 23(4):553–61.

Oulton K, Wray J, Kenten C, Russell J, Carr L, Hassiotis A, et al (2022). Equal access to hospital care for children with learning disabilities and their families: a mixed-methods study. Health and Social Care Delivery Reserarch, 10(13). https://doi.org/10.3310/NWKT5206

Oz B, Yuksel T, Nasiroglu S (2020). Depression-anxiety symptoms and stigma perception in mothers of children with autism spectrum disorder. Archives of Neuropsychiatry, 57(1):50.

Öjmyr-Joelsson, M.; Nisell, M.; Frenckner, B.; Rydelius, P.-A.; Christensson, K. A (2009). Gender Perspective on the Extent to which Mothers and Fathers Each Take Responsibility for Care of a Child with High and Intermediate Imperforate Anus. Journal of Pediatric Nursing, 24, 207–215.

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., Shamseer, L., Tetzlaff, J.M., Akl, E.A., Brennan, S.E., Chou, R., (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. British Medical Journal, 372: n71. https://doi.org/10.1136/bmj.n71.

Palmer SL, Lesh S, Wallace D, Bonner MJ, Swain M, Chapieski L, et al (2011). How parents cope with their child's diagnosis and treatment of an embryonal tumor: results of a prospective and longitudinal study. Journal of Neurooncology, 105:253–259.

Palos, G.R., Tortorella, F.R., Stepen, K., Rodriguez, M.A. (2013). A multidisciplinary team approach to improving psychosocial care in patients with cancer. Clinical Journal of Oncology Nursing, 17 (5), 556–558.

Papadopoulos C, Lodder A, Constantinou G, Randhawa G (2019). Systematic review of the relationship between autism stigma and informal caregiver mental health. Journal of Autism Developmental Disorders, 49(4):1665–1685.

Papadopoulos, D (2021). Mothers’ Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. Brain Science, 11, 309. https://doi.org/10.3390/brainsci11030309.

Papageorgiou V, Kalyva E (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. Research in Autism Spectrum Disorders, 4(4):653–660.

Papastavrou E, Andreou P, Middleton N, Tsangari H, Papacostas S (2015). Dementia caregiver burden association with community participation aspect of social capital. Journal of advanced nursing, 71(12):2898–910.

Park, S. and Park, K.S. (2014). Family Stigma: A Concept Analysis. Asian Nursing Research, 8(3), pp. 165-171.

Pariseau E. M., Chevalier L., Muriel A. C., Long K. A. (2020). Parental awareness of sibling adjustment: Perspectives of parents and siblings of children with cancer. Journal of Family Psychology, 34(6), 698–708.

Parsons, S. K., D. L. Fairclough, J. Wang, and P. S. Hinds. (2012). Comparing longitudinal assessments of quality of life by patient and parent in newly diagnosed children with cancer: The value of both raters’ perspectives. Quality of Life Research 21(5) pp. 915–923.

Patra, S. & Patro, B. K (2019). Affiliate stigma among parents of children with autism in eastern India. Asian Journal of Psychiatry, 44, 45–47.

Patton, C. M. (2019). Phenomenology for the Holistic Nurse Researcher: Underpinnings of Descriptive and Interpretive Traditions. Journal of Holistic Nursing, 089801011988215. doi:10.1177/0898010119882155.

Pattyn, E.; Verhaeghe, M.; Sercu, C.; Bracke, P (2014). Public Stigma and Self-Stigma: Differential Association with Attitudes Toward Formal and Informal Help Seeking. Psychiatric Services: a journal of the American Psychiatric Association, 65, 232–238.

Pearson A, Robertson-Malt S, Rittenmeyer L., (2011). Synthesizing qualitative evidence. Lippincott Williams & Wilkins., Philadelphia, pp. 14. https://nursing.lsuhsc.edu/JBI/docs/JBIBooks/Syn_Qual_Evidence.pdf.

Pearson H H, Bryan G, Kayum C, Gibson F, Darlington AS (2022). Parent values and preferences underpinning treatment decision-making in poor-prognosis childhood cancer: a scoping review. BMC Pediatrics, 22(1):595. doi: 10.1186/s12887-022-03635-1.

Peikert ML, Inhestern L, Krauth KA, et al (2020). Returning to daily life: a qualitative interview study on parents of childhood cancer survivors in Germany. BMJ Open;10:e033730. doi:10.1136/bmjopen-2019-033730.

Pelletier W, Bona K (2015). Assessment of financial burden as a standard of care in pediatric oncology. Pediatr Blood Cancer, 62(S) pp. 619-631.

Perers, C., Bäckström, B., Johansson, B.A. & Rask, O (2021). 'Methods and strategies for reducing seclusion and restraint in child and adolescent psychiatric inpatient care', Psychiatric Quarterly, pp. 1-30.

Pergert, P., af Sandeberg, M., Andersson, N., Márky, I., & Enskär, K. (2016). Confidence and authority through new knowledge: An evaluation of the national educational programme in paediatric oncology nursing in Sweden. Nurse Education Today, 38 pp. 68-73. doi: 10.1016/j.nedt.2015.12.014.

Pergert P, Sullivan CE, Adde M, et al (2020). An ethical imperative: safety and specialization as nursing priorities of WHO global initiative for childhood cancer. Pediatric Blood Cancer, 67:e28143. 10.1002/pbc.28143

Peters, D.J., Godfrey, C.M., McInerney, P., Soares, C.B., Khalil, H., Parker, D., (2015). Methodology for JBI Scoping Reviews. The Joanna Briggs Institute Reviewers' Manual 2015. The Joanna Briggs Institute, Australia, pp. 3–24.

Petrovskaya O. (2014b) Is there nursing phenomenology after Paley? Essay on rigorous reading. Nursing Philosophy 15(1) pp. 60–71.

Pham, M.T., Raji´c, A., Greig, J.D., Sargeant, J.M., Papadopoulos, A., McEwen, S.A., (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. Research Synthesis Methods, 5 pp. 371–385. https://doi: 10.1002/jrsm.1123.

Phiri PGMC, Chan CWH, Wong CL (2020). The scope of family-centred care practices, and the facilitators and barriers to implementation of family-centred care for hospitalised children and their families in developing countries : An integrative review. Journal of Pediatric Nursing, 55:10–28. https://doi.org/10.1016/j.pedn.2020.05.018.

Phillips, C., Kenny, A., & Easterman, A. (2014). Pre-registration paid employment practices of undergraduate nursing practices: A scoping review. Collegian, 23(1) pp. 115-127. https:// doi.org/10.1016/j.colegn.2014.09.012.

Phipps, S., Long, A., Willard, V. W., Okado, Y., Hudson, M. M., Huang, Q., . . . Noll, R., (2015). Parents of children with cancer: At-risk or resilient? Journal of Pediatric Psychology, 40 pp. 914-925. https://doi:10.1093/jpepsy/jsv047.

Pietkiewicz, I., & Smith, J. A. (2012). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. Psychological Journal, 18(2), 361-369.

Pietkiewicz, I., & Smith, J. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. Psychological Journal, 20(1) pp. 8-12.

Pinquart, M. (2017). Systematic review: Bullying involvement of children with and without chronic physical illness and/ or physical/sensory disability—A meta-analytic comparison with healthy /nondisabled peers. Journal of Pediatric Psychology, 42(3) pp. 245-259. doi:10.1093/jpepsy/jsw081.

Piotrowski, C., Giesbrecht, A., Goldberg, A., Judd, D., Rempel, R., Strong, J., & Weavers, M. (2022). A scoping review of the experiences and well-being of siblings of children with chronic kidney disease: Implications for practice and research. Pediatric Nephrology, 37(12), 3019–3029. https://doi.org/10.1007/s00467-022-05559-5.

Pishkuhi M.A., Ahmadi M., Shoraka H., Chegeni M. (2018). Parents' Experience of Caring Children with Cancer: A Qualitative Study with Phenomenological Approach. J. Compr. Pediatr. 9(4):e65545. https://doi: 10.5812/compreped.65545.

Pivetta, E., Maule, M.,M., Pisani, P., Zugna, D., Haupt, R., Jankovic, M., Aricò, M., Casale, F., Clerico, A., Cordero di Montezemolo, L., Kiren, V., Locatelli, F., Palumbo, G., Pession, A., Pillon, M., Santoro, N., Terenziani, M., Valsecchi, M.G., Dama, E., Magnani, C., Merletti, F., Pastore, G.(2011) Italian Association of Pediatric Hematology and Oncology (AIEOP) Group, 2011. Marriage and parenthood among childhood cancer survivors: a report from the Italian AIEOP Off-Therapy Registry. Haematologica 96 pp. 744–751.

Popp, J. M., Conway, M., & Pantaleao, A. (2015). Parents' experience with their child's cancer diagnosis: Do hopefulness, family functioning, and perceptions of care matter? Journal of Pediatric Oncology Nursing, 32(4), 253–260.https://doi.org/10.1177/1043454214563404

Prager GW, Braga S, Bystricky B, Qvortrup C, Criscitiello C, Esin E, Sonke GS, Martínez GA, Frenel J-S, Karamouzis M, et al (2018). Global cancer control: responding to the growing burden, rising costs and inequalities in access. ESMO Open, 3(2):e000285.

Pratt, M. (2012). The utility of human sciences in nursing inquiry. Nurse Researcher. Vol 19(3) pp. 12-15.

Prchal, A., Graf, A., Bergstraesser, E., & Landolt, M. (2012). A two session psychological intervention for siblings of pediatric cancer patients: a randomized controlled pilot trial. Child and Adolescent Psychiatry and Mental Health, 6. https://doi.org/10.1186/1753-2000-6-3.

Prchal A, Landolt MA (2012). How siblings of pediatric cancer patients experience the first time after diagnosis: a qualitative study. Cancer Nursing, 35(2) pp. 133-140.

Priest, J. (2021). The science of family systems theory. Routledge: Taylor & Francis Group. https://doi.org/10.4324/9780367854591

Pringle J, Drummond J, McLafferty E, Henry C. (2011). Interpretative phenomenological analysis: a discussion and critique. Nurse Researcher, 18(3) pp. 20-24.

Putnam, R. (1995). Making Democracy Work: Civic Traditions in Modern Italy. Princeton, New Jersey: University Press.

Pye, K. (2013). Exploring moral distress in pediatric oncology; a sample of registered practitioners. Issues in Comprehensive Pediatric Nursing, 36(4), 248–261. https://doi.org/10.3109/01460862.2013.812693

Qingying, J.; Currin-McCulloch, J.A.; Zhang, A.; Streeter, C.L.; Jones, B.L.; Chen, Y (2018). Assessing the Needs of Parents of Children Diagnosed with Cancer in China: A Psychometric Study Developing a Needs Assessment Tool. Journal of Pediatric Oncology Nursing, 35 pp. 6–15.

Quinn GP, Knapp C, Murphy D, Sawczyn K, Sender L (2012). Congruence of reproductive concerns among adolescents with cancer and parents: pilot testing an adapted instrument. Pediatrics, 129(4):e930-e936.

Ray CD (2024). Nonsupport Experiences of Young Adult Cancer Patients: Prevalence, Acceptability, and Outcomes of Not Receiving Support. Health Communication, 39(6):1127-1139. doi: 10.1080/10410236.2023.2206178

Reid, K., Flowers, P., Larkin, M. (2005) Exploring lived experience: An Introduction to Interpretative Phenomenology Analysis. The Psychologist.18: pp. 2020–2023.

Reilly D, Huws J, Hastings R, Vaughan F (2010). Life and death of a child with down syndrome and a congenital heart condition: experiences of six couples. Intellectual Developmental Disabilities, 48(6):403-16. doi: 10.1352/1934-9556-48.6.403

Remedios C, Willenberg L, Zordan R. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. Palliative Medicine, 29 pp. 223–230. https://doi.org/10.1177/0269216314560008

Rfat, M., Koçak, O., & Uzun, B. (2023). Parenting challenges in families of children with a diagnosis of autism spectrum disorder: A qualitative research study in Istanbul. Global Social Welfare, 1-10.

Richards B (2017). Caring for children with autism spectrum condition in paediatric emergency departments. Emergency Nurse: : the journal of the RCN Accident and Emergency Nursing Association, 25(4):30–4. doi: 10.7748/en.2017.e1713

Ringnér, A., Jansson, L., & Graneheim, U. H. (2011). Parental experiences of information within pediatric oncology. Journal of Pediatric Oncology Nursing, 28(4) pp. 244-251. doi:10.1177/1043454211409587.

Ringnér A, Karlsson S, Hällgren Graneheim U (2015). A person-centred intervention for providing information to parents of children with cancer. Experiences and effects. European Journal of Oncology Nursing, 19(3):318-24. doi: 10.1016/j.ejon.2014.10.012

Roberts I, Izraeli S (2014). Haematopoietic development and leukemia in Down syndrome. British Journal of Haematology, 167:587–99.

Roberts, T. (2013). Understanding the research methodology of interpretative phenomenological analysis. British Journal of Midwifery. Vol. 21, No. 3: pp.215-218.

Robertson EG, Wakefield CE, Shaw J, Darlington AS, McGill BC, Cohn RJ, Fardell JE (2019). Decision-making in childhood cancer: parents' and adolescents' views and perceptions. Supportive Care in Cancer, 27(11) pp. 4331-4340. doi: 10.1007/s00520-019-04728-x.

Robinson, J. E., Huskey, D., Schwartz, J., & Weaver, M. S. (2019). The many roles of the rock: A qualitative inquiry into the roles and responsibilities of fathers of children with brain tumors. Children, 6(10), Article 113. https://doi.org/10.3390/ children6100113

Robson, C., & McCartan, K. (2016). Real world research. John Wiley & Sons.

Rodgers, C.; Bertini, V.; Conway, M.A.; Crosty, A.; Filice, A.; Herring, R.A.; Isbell, J.; Lown, D.E.A.; Miller, K.; Perry, M.; et al. (2018). A Standardized Education Checklist for Parents of Children Newly Diagnosed With Cancer: A Report From the Children’s Oncology Group. Journal of Pediatric Oncology Nursing, 35, pp. 235–246.

Rodgers CC, Laing CM, Herring RA, et al. (2016). Understanding effective delivery of patient and family education in pediatric oncology: a systematic review from the children’s oncology group. Journal of Pediatric Oncology Nursing, 33(6) pp.432-446.

Rodgers CC, Stegenga K, Withycombe JS, Sachse K, Kelly KP (2016). Processing information after a child’s cancer diagnosis: how parents learn: a report from the Children’s Oncology Group. Journal of Pediatric Oncology Nursing; 33(6):447-59. doi: https://journals.sagepub.com/doi/10.1177/1043454216668825

Rodriguez, E. M., Dunn, M. J., Zuckerman, T., Vannatta, K., Gerhardt, C. A., & Compas, B. E. (2012). Cancer-related sources of stress for children with cancer and their parents. Journal of Pediatric Psychology, 37(2), 185–197. doi:10.1093/jpepsy/jsr054.

Roehr B (2010). More stakeholder engagement is needed to improve quality of research, say US experts. British Medical Journal, 341:c4193.

Rolland, J. S. (2018). Helping couples and families navigate illness and disability: An integrated approach. Guilford Publications. https://doi.org/10.1080/07347332.2018.1541038

Rolland, J. S. (2019). Families, health, and illness. In S. Gehlert & T. Browne (Eds.), Handbook of health social work (pp. 331–357). John Wiley & Sons, Inc.

Romito F, Goldzweig G, Cormio C, Hagedoorn M, Andersen BL. (2013). Informal caregiving for cancer patients. Cancer, 119 Suppl 11 pp. 2160-2169.

Roper, S., Allred, D., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. Families, Systems, and Health, 32(2), 241-246. https://doi.org/10.1037/fsh0000047

Rosenberg, A.R.; Dussel, V.; Kang, T.; Geyer, J.R.; Gerhardt, C.A.; Feudtner, C.; Wolfe, J (2013). Psychological Distress in Parents of Children With Advanced Cancer. JAMA Pediatrics, 167(6) pp. 537-543.

Rosenberg-Yunger ZR, Granek L, Sung L, Klaassen R, Dix D, Cairney J, Klassen AF. (2013). Single-parent caregivers of children with cancer: factors assisting with caregiving strains. Journal of Pediatric Oncology Nursing, 30(1) pp. 45-55. doi: 10.1177/1043454212471727.

Roser K, Erdmann F, Michel G, et al (2019). The impact of childhood cancer on parents' socio-economic situation—a systematic review. Psychooncology, 28 pp. 1207–1226. doi: 10.1002/pon.5088.

Ross D, Coambs E. (2018). The impact of psychological trauma on finance: narrative financial therapy considerations in exploring complex trauma and impaired financial decision making. Journal of Financial Therapy, 9(2) 4.

Rost, M., Wangmo, T., Rakic, M., Acheson, E., Rischewski, J., Hengartner, H., Kühne, T., & Elger, B. S. (2018). Burden of treatment in the face of childhood cancer: A quantitative study using medical records of deceased children. European Journal of Cancer Care, 27,e12879. https://doi.org/10.1111/ecc.12879.

Roug LI, Jarden M, Wahlberg A, Hjalgrim LL, Hansson H (2023).. Ambiguous Expectations of Parent Caregiving for the Child and Adolescent With Cancer at the Hospital and at Home-An Ethnographic Study. Journal of Pediatric Hematology Oncology Nursing, 40(2):100-110. doi: 10.1177/27527530221140065.

Roy, C., (2011). Research based on the roy adaptation model: Last 25 years. Nursing Science Quarterly, 24 pp. 312-320. http://doi:10.1177/0894318411419218.

Rubin, H. J., & Rubin, I. S. (2011). Qualitative interviewing: The art of hearing data. SAGE

Runswick-Cole, K. (2013). 'Wearing It All with a Smile': Emotional Labour in the Lives ofMothers of Disabled Children." In Disabled Children's Childhood Studies: Critical Approaches in a Global Context, edited by T. Curran and K. Runswick-Cole, 105 –114. London: Palgrave Macmillan.

Russell H, Bernhardt M (2016). Bending the cost curve in childhood cancer. Current hematologic malignancy reports, 11 pp. 295-302.

Russell, H.V.; Panchal, J.; VonVille, H.; Franzini, L.; Swint, J.M (2013). Economic Evaluation of Pediatric Cancer Treatment: A Systematic Literature Review. Pediatrics, 131, pp. 273–287.

Ryan C, Quinlan E (2018). Whoever shouts the loudest: Listening to parents of children with disabilities. Journal of Applied Research in Intellectual Disabilities, 31 Suppl 2:203-214. doi: 10.1111/jar.12354

Safe A, Joosten A, Molineux M (2012). The experiences of mothers of children with autism: managing multiple roles. Journal of Intellectual & Developmental Disability, 37(4):294–302.

Saifan, A., Masa’Deh, R., Hall, C., & Collier, J. (2014). Experiences of jordanian mothers and fathers of children with cancer. Journal of American Science, 10(8), 29–39.

Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., et al. (2015). Couple relationships among parents of children and adolescents with autism spectrum disorder: Findings from a scoping review of the literature. Research in Autism Spectrum Disorders, 17, 142-157.

Salem H, Andersen EW, Dalton SO, et al. (2019). Psychotropic medication use in parents of children diagnosed with cancer. Pediatrics, 143 (5):e20182605.

Saloviita, T., Pirttimaa, R., & Kontu, E. (2016). Parental perceptions of the use of coercive measures on children with developmental disabilities. Journal of Applied Research in Intellectual Disabilities, 29, 11–20. https://doi.org/10.1111/jar.12154

Salvador Á, Crespo C (2019). The Benefits of Family-Centered Care for Parental Self-Efficacy and Psychological Well-being in Parents of Children with Cancer. Journal of Child and Family Studies, 1926–36. http://dx.doi.org/10.1007/s10826-019-01418-4

Salvador, Á., Crespo, C., Roberto,M. S., & Barros, L. (2020). Do parents of children with cancer want to participate in treatment decision-making? Supportive Care in Cancer, 28(3), 1059–1067. https://doi.org/10.1007/s00520-019-04909-8

Samadi, S. A., McConkey, R., & Kelly, G. (2012). The information and support needs of Iranian parents of children with autism spectrum disorders. Early Child Development and Care, 182, 1439–1453. doi:10.1080/03004430.2011.616931

Sánchez Amate, J.J.; Luque de la Rosa, A (2024). The Effect of Autism Spectrum Disorder on Family Mental Health: Challenges, Emotional Impact, and Coping Strategies. Brain Science, 14, 1116. https://doi.org/10.3390/brainsci14111116

Santacroce S, Tan K, Killela M. (2018). Costs of illness to parents of children diagnosed with cancer. European Journal of Oncology Nursing, 35 pp. 22-32.

Santacroce S, Kneipp S (2020). Influence of pediatric cancer-induced financial burden on parent distress and other stress-related symptoms. Pediatric Blood and Cancer, 67(3):e28093.

Santos, S; Crespo, C; Canavarro, M.C; Alderfer, M.A; Kazak, A.E (2016). Family rituals, financial burden, and mothers' adjustment in pediatric cancer. Journal of Family Psychology, 30 pp. 1008–1013.

Sartre, J. P., & Richmond, S. (1956). Being and nothingness: An essay in phenomenological ontology. Routledge.

Schepers, S.A.; Sint Nicolaas, S.M.; Maurice-Stam, H.; Haverman, L.; Verhaak, C.M.; Grootenhuis, M.A (2018). Parental distress 6 months after a pediatric cancer diagnosis in relation to family psychosocial risk at diagnosis. Cancer, 124, 381–390.

Schleiermacher, F. (1998). Hermeneutics and criticism and other writings. Cambridge University Press.

Schweitzer R, Griffiths M, Yates P. (2012). Parental experience of childhood cancer using interpretative phenomenological analysis. Psychology and Health. 27, 704–720. http://doi: 10.1080/08870446.2011.622379.

Schofield, G., & Beek, M (2009). Growing up in foster care: Providing a secure base through adolescence. Child and Family Social Work, 14(3), 255–266.

Schopler E (1971). Parents of psychotic children as scapegoats. Journal of Contemporary Psychotherapy: On the Cutting Edge of Modern Developments in Psychotherapy, 4:17–22. doi: 10.1007/BF02110269

Seale C and Silverman D (1997) Ensuring rigour in qualitative research. The European Journal of Public Health 7(4) pp. 379–384.

Sedgwick P (2013). Snowball sampling. British Medical Journal, 347.

Seers K. (2012). What is a qualitative synthesis? Evidence-based nursing. British Medical Journal Group. 15:101. http://doi: 10.1136/ebnurs-2012-100977.

Seeman, M. & Goffman, E (1964). Stigma: Notes on the management of spoiled identity. American Sociological Review, 29, 77.

Sefotho MN, Ferreira R, Lushozi BB (2021). The quest for ongoing support by parents of learners with intellectual disabilities. Journal of Education. https://doi.org/10.17159/2520-9868/i85a05

Seligman, M., & Darling, R. B. (2017). Ordinary families, special children: A systems approach to childhood disability. New York, NY: Guilford Publications.

Serrata, C. A. (2012). Psychosocial aspects of parenting a child with autism. Journal of Applied Rehabilitation Counseling, 43(4), 29–35.

Shaghaghi A, Bhopal RS, Sheikh A (2011). Approaches to Recruiting 'Hard-To-Reach' Populations into Re-search: A Review of the Literature. Health Promotion Perspectives, 20;1(2):86-94. doi: 10.5681/hpp.2011.009

Shajani Z, Snell D (2019). Wright and Leahey's Nurses and families: A Guide to Family Assessment and Intervention. 7th ed. Philadelphia: F.A Davis Company.

Shamsaei, F.; Kermanshahi, S.M.; Vanaki, Z. (2010). Survey of family caregiver needs of patients with bipolar disorder. Avicenna Journal of Clinical Medicine, 17 pp. 57–63.

Sharbatian MH, Aminian A (2013). Social Capital measurement in Payam nor student in Southern Khorasan and its effective factors. Jame e shenakhtie javanan;3(9):93–114.

Sharp KMH, Fisher RS, Clark OE, Zackery DO, Dunnells ZDO, Murphy LK, Prussien KV, Vannatta K, Compas BE, & Gerhardt CA (2020). Long-term trajectories of depression symptoms in mothers of children with cancer. Health Psychology, 39 pp. 89–98. doi:10.1037/hea0000826.

Shields L (2015). What is 'family-centred care'? European Journal for Person Centered Healthcare; 3, 2, 139-144. doi: 10.5750/ejpch.v3i2.993

Shinebourne P. (2011). The theoretical underpinnings of interpretative phenomenological analysis (IPA). Existential Analysis, 22(1) pp. 16-32.

Shippee ND, Shah ND, May CR, Mair FS, Montori VM (2012). Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. Journal of Clinical Epidemiology, 65:1041-1051.doi:10.1016/j.jclinepi.2012.05.005

Siegel R.L, Miller K.D, Jemal A., (2018). Cancer statistics, 2018. CA Cancer Journal for Clinicians, 68 pp. 7–30. http://doi:10.3322/caac.21442.

Siegel RL, Miller KD, Jemal A (2020). Cancer statistics, 2020. CA: Cancer Journal for Clinicians, 70 pp. 7- 30.

Siegel, M., Milligan, B., Chemelski, B., Payne, D., Ellsworth, B.,Harmon, J., … Smith, K. A. (2014). Specialized inpatient psychiatry for serious behavioral disturbance in autism and intellectual disability. Journal of Autism and Developmental Disorders, 44(12), 3026–3032.

Silva-Rodrigues,F. M., Pan, R., Pacciulio Sposito, A. M., de Andrade Alvarenga, W., & Nascimento, L. C. (2016). Childhood cancer: Impact on parents' marital dynamics. European Journal of Oncology Nursing, 23 pp. 34–42. https://doi.org/10.1016/j.ejon.2016.03.002.

Silverman D. Doing qualitative research. 3rd ed. London: Sage; 2010.

Sinclair, S., Kondejewski, J., Schulte, F., Letourneau, N., Kuhn, S., Raffin-Bouchal, S., Guilcher, G. M. T., & Strother, D. (2020). Compassion in pediatric healthcare: A scoping review. Journal of Pediatric Nursing, 51 pp. 57–66. https://doi.org/10.1016/j.pedn.2019.12.009.

Situmeang, E., Sagala, Y., Tika Zalukhu, Y., & Silvia Herlina, E (2023). Pentingnya Peran Pola Asuh Orang Tua Terhadap Kemandirian Anak Down Syndrome. Jurnal Pendidikan Sosial dan Humaniora, 2(3). https://publisherqu.com/index.php/pediaqu

Sklenarova H,Kreumpelmann A,Haun MW, et al (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. Cancer, 121 pp. 1513–1519.

Skotko, B., Levine, S., & Goldstein, R (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. American Journal of Medical Genetics. Part A, 155, 2348–2359. doi:10.1002/ajmg.a.34228

Slater, P. J., Fielden, P. E., & Bradford, N. K. (2018). The Oncology Family App: Providing information and support for families caring for their child with cancer. Journal of Pediatric Oncology Nursing, 35, 94-102. doi:10.1177/1043454217741874

Slifer KJ, Hankinson JC, Zettler MA, Frutchey RA, Hendricks MC, Ward CM, Reesman J (2011). Distraction, exposure therapy, counterconditioning, and topical anesthetic for acute pain management during needle sticks in children with intellectual and developmental disabilities. Clinical Pediatrics (Phila), 50(8):688-97. doi: 10.1177/0009922811398959

Smith, David Woodruff, "Phenomenology", The Stanford Encyclopedia of Philosophy (Summer 2018 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/sum2018/entries/phenomenology/>.

Smithells, R. W. & Newman, C. G. H. (2009). The Thalidomide Story. <www.thalidomide.org.uk/ Thalidomide.aspx>.

Smith, JA. (2004) Reflecting on the development of IPA and its contribution to qualitative research in psychology. Qualitative Research in Psychology, 1 pp. 39-54.

Smith JA. (2011) Evaluating the contribution of interpretative phenomenological analysis. Health Psychology Review, 5(1) pp. 9-27.

Smith, J., Cheater, F., & Bekker, H. (2015). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 18(4) pp. 452–474. https://doi.org/10.1111/hex.12040.

Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. Los Angeles: SAGE.

Smith, J.A., Flowers, P., Osborn, M. (1997) Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed) Material discourses of health and illness. London: Routledge.

Smith, J., Jarman, M., & Osborne, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), Qualitative health psychology: Theories and methods (pp. 218-240). London: Sage.

Smith, J.A., Osborn, M. (2007). Interpretative Phenomenological Analysis, pp. 53-70.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In Qualitative psychology: A practical guide to research methods (2nd ed.). London: SAGE Publications Ltd.

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (pp. 25-52). London, England: Sage.

Smith, J. A (2019). Participants and researchers searching for meaning: conceptual developments for interpretative phenomenological analysis. Qualitative Research in Psychology, 16, 166–181. doi:10.1080/14780887.2018.1540648

Smith AK, White DB, Arnold RM. (2013). Uncertainty-the other side of prognosis. New England Journal of Medicine,368:2448–50.

Sneha, L.M.; Sai, J.; Ashwini, S.; Ramaswamy, S.; Rajan, M.; Scott, J.X (2017) Financial burden faced by families due to out-of-pocket expenses during the treatment of their cancer children: An indian perspective. Indian journal of medical and paediatric oncology, 38 pp. 4–9.

Snowden, A., Young, J., White, C., Murray, E., Richard, C., Lussier, M. T., MacArthur, E., Storey, D., Schipani, S., Wheatley, D., McMahon, J., & Ross, E. (2015). Evaluating holistic needs assessment in outpatient cancer care–A randomised controlled trial: The study protocol. BMJ Open, 5(5), e006840. https://doi.org/10.1136/bmjopen- 2014-006840.

Soanes, L., Hargrave, D., Smith, L., & Gibson, F. (2009). What are the experiences of the child with a brain tumour and their parents? European Journal of Oncology Nursing, 13, 255–261. https://doi.org/10.1016/j.ejon.2009.03.009

Sparks, L. A., Setlik, J., & Luhman, J (2007). Parental holding and positioning to decrease IV distress in young children: A randomized controlled trial. Journal of Pediatric Nursing, 22(6), 440–447. doi:10.1016/j.pedn.2007.04.010

Spiers, J., & Riley, R. (2019). Analysing one dataset with two qualitative methods: The distress of general practitioners, a thematic and interpretative phenomenological analysis. Qualitative Research in Psychology, 16(2), 276–290. https://doi.org/10.1080/14780887.2018.1543099

Spinazzi NA, Velasco AB, Wodecki DJ, Patel L (2024). Autism Spectrum Disorder in Down Syndrome: Experiences from Caregivers. Journal of Autism and Developmental Disorders, 54(3):1171-1180. doi: 10.1007/s10803-022-05758-x

Starke, M (2022). Parents with intellectual disability and their reflections about relationships and support. Journal of Social Work, 22(5), 1276-1295. https://doi.org/10.1177/14680173221092703

Stayer, Debbie (2012). Pediatric Palliative Care: A Conceptual Analysis for Pediatric Nursing Practice. Journal of Pediatric Nursing, Vol. 27 (August), Issue 4 pp. 350-356. http://www.sciencedirect.com/science/article/pii/S0882596311002806.

Steffen, B.C., Castoldi, L., (2006). Surviving the storm: the influence of the oncologic treatment of a child on the conjugal relation. Psicologia Ciência e Profissão, 26 pp. 406-425. https://doi.org/10.1590/S1414-98932006000300006.

Steliarova-Foucher E, Colombet M, Ries LAG, et al. (2017). International incidence of childhood cancer, 2001-10: a population-based registry study. Lancet Oncology, 18:719-731.

Stenka, K.E.; Izdebski, P (2018). Parents facing their child’s struggle with cancer. Journal of Psychiatry and Clinical Psychology, 18 pp. 306–314.

Stevens B, Croxford R, McKeever P, et al (2006). Hospital and home chemotherapy for children with leukemia: a randomized cross-over study. Pediatric Blood Cancer, 47(3):285–92.

Stevens K (2013). The impact of evidence-based practice in nursing and the next big ideas. Online Journal of Issues in Nursing, 18(2):4.

Stevens, P. E., & Pletsch, P. K (2002). Ethical issues of informed consent: Mothers’ experiences enrolling their children in bone marrow transplantation research. Cancer Nursing, 25(2), 81–87. https://doi.org/10.1097/00002820- 200204000-0000

Stewart, D. and Mickunas, A. (1990). Exploring Phenomenology: A Guide to the Field and Its Literature. 2nd Edition, Ohio University Press, Athens.

Stewart, M., Knight, T., McGillivray, J., Forbes, D., & Austin, D. W. (2016). Through a trauma-based lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder. Journal of Intellectual & Developmental Disability, 42(3), 212–222. https://doi.org/10.3109/13668250.2016.1232379

Stinson JN, Jibb LA, Greenberg M, Barrera M, Luca S, White ME, Gupta A (2015). A Qualitative Study of the Impact of Cancer on Romantic Relationships, Sexual Relationships, and Fertility: Perspectives of Canadian Adolescents and Parents During and After Treatment. Journal of Adolescent and Young Adult Oncology, 4(2):84-90. doi: 10.1089/jayao.2014.0036

Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: The parents’ experience. Families, Systems, & Health, 32(3), 328–337.

Sultan S, Leclair T, Rondeau E, Burns W, Abate C (2016). A systematic review on factors and consequences of parental distress as related to childhood cancer. European Journal of Cancer Care, 25(4) pp. 616–637. https://doi.org/10.1111/ecc.12361.

Suryani, R. L., Allenidekania, A., & Rachmawati, I. N. (2018). Phenomenology study on nurses' experiences in understanding the comfort of children at the end-of-life. Indian Journal of Palliative Care, 24(2), pp. 162-166.

Svavarsdottir EK (2004). Caring for a child with cancer: a longitudinal perspective. Journal of Advance Nursing, 50: 153-161.

Swallow, V., Macfadyen, A., Santacroce, S. J., & Lambert, H. (2012). Fathers’ contribution to the management of their child’s long-term medical condition: A narrative review of the literature. Health Expectations, 15(2), 157–175. https://doi.org/10.1111/j.1369-7625.2011.00674.x

Syse A, Larsen IK, Tretli S (2011). Does cancer in a child affect parents’ employment and earnings? A population-based study. Cancer Epidemiology, 35 pp. 298–305.

Tafjord T (2021). Managing Strong Emotions: Nurses' Recognition and Responses to Personal Emotions When Approaching Parents With Cancer and Their Dependent Children. Qualitative Health Research,31(5):926-941. doi: 10.1177/1049732320983788

Taleghani F., Fathizadeh N. & Naseri N. (2012). The lived experiences of parents of children diagnosed with cancer in iran. European Journal of Cancer Care, 21(3) pp. 340-348. doi:10.1111/j.1365-2354.2011.01307.x.

Tan R., Koh S., Wong M.E., Rui M., Shorey S. (2019). Caregiver Stress, Coping Strategies, and Support Needs of Mothers Caring for their Children Who Are Undergoing Active Cancer Treatments. Clinical Nursing Research, 29 pp. 460-468. https://doi:10.1177/1054773819888099.

Tan CE, Lau SCD, Abdul Latiff Z, Lee CC, Teh KH, Mohd Sidik S (2023). Parents of children with cancer require health literacy support to meet their information needs. Health Information and Libraries Journal, 41(3):267-282. doi: 10.1111/hir.12491

Tay, J.,Widger, K., & Stremler, R (2021). Self-reported experiences of siblings of children with life-threatening conditions: A scoping review. Journal of Child Health Care, 13674935211026113. https://doi.org/10.1177/13674935211026113.

Tay J., Widger K., Steele R., Stremler R., Pole JD (2024) . Examining Emotional and Behavioural Trajectories in Siblings of Children with Life-Threatening Conditions. BMC Palliative Care. https://doi.org/10.21203/rs.3.rs-4145153/v1

Tebbet, M., & Kennedy, P. (2012). The experience of childbirth for women with spinal cord injuries: an interpretative phenomenology analysis study. Disability and Rehabilitation, 34(9) pp. 762-769.

Tefferi A, Kantarjian H, Rajkumar SV, Baker LH, Abkowitz JL, Adamson JW, Advani RH, Allison J, Antman KH, Bast RC Jr, et al (2015). In support of a patient driven initiative and petition to lower the high price of cancer drugs. Mayo Clinic Proceedings, 90(8) pp. 996–1000.

Teng, C., Shyu, Y.L., Chiou, W., Fan, H., Lam, S.M., (2010). Interactive effects of nurse experienced time pressure and burnout on patient safety: a cross-sectional survey. International Journal of Nursing Studies, 47 pp. 1442–1450. https://doi.org/10.1016/j.ijnurstu.2010.04.005

Tenny S, Brannan JM, Brannan GD (2022). Qualitative Study.. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan. PMID: 29262162.

Thambiraj, J., Kirshbaum, M. N., Liu, X. L., Waheed, N., & Valery, P. C. (2022). “You feel different in your body”: Experiences of fatigue among children undergoing radiotherapy for cancer treatment. Journal of Pediatric Nursing, 67, 7–14. https://doi.org/10.1016/j.pedn.2022.07.012

Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer:: the care given by informal carers in cancer contexts. Social science & medicine, 54(4), 529-544.

Thompson AP, Le A, Hartling L, Scott SD (2020). Fading confidence: A qualitative exploration of parents' experiences caring for a febrile child. Journal of Clinical Nursing, 29(5-6):964-973. doi: 10.1111/jocn.15165

Thorne, S. (2020). Untangling the Misleading Message Around Saturation in Qualitative Nursing Studies. Nurse Author & Editor, 30(1) pp. 1–9. doi:10.1111/j.1750-4910.2020.tb00005.x.

Thornberg, R., & Dunne, C. (2019). Literature review in grounded theory. In A. Bryant & K. Charmaz (Eds.), The SAGE Handbook of Current Developments in Grounded Theory (pp. 205–221).

Thullen, M., & Bonsall, A. (2017). Co-parenting quality, parenting stress, and feeding challenges in families with a child diagnosed with autism spectrum disorder. Journal of Autism and Developmental Disorders, 47(3), 878–886.

Thuy, N. T. M., & Berry, H. L. (2013). Social capital and mental health among mothers in Vietnam who have children with disabilities. Global Health Action, 6, 18886. http://dx.doi.org/10.3402/gha.v6i0

Toledano-Toledano F, Luna D, Moral de la Rubia J, Martínez Valverde S, Bermúdez Morón CA, Salazar García M, et al (2021). Psychosocial factors predicting resilience in family caregivers of Children with Cancer: A Cross- Sectional study. International Journal of Environmental Research and Public Health, 18(2):748.

Toledano-Toledano, F.; Moral de la Rubia, J.; Nabors, L.A.; Domínguez-Guedea, M.T.; Salinas Escudero, G.; Rocha Pérez, E.; Luna, D.; Leyva López, A (2020). Predictors of Quality of Life among Parents of Children with Chronic Diseases: A Cross-Sectional Study. Healthcare, 8, 456.

Tomeny, T., Rankin, J., Baker, L., & Eldred, S. (2019). Discrepancy in perceived social support among typically developing siblings of youth with autism spectrum disorder. Autism, 23(3), 594-606. https://doi.org/10.1177/1362361318763973

Tong A, Flemming K, McInnes E, Oliver S, Craig J (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology, 27;12:181. doi: 10.1186/1471-2288-12-181

Trama, A., Botta, L., Foschi, R., Ferrari, A., Stiller, C., Desandes, E., Gatta, G., (2016). Survival of European adolescents and young adults diagnosed with cancer in 2000–07: population-based data from EUROCARE-5. Lancet Oncology, 17 pp. 896–906. https://doi:10.1016/s1470-2045(16)00162-5.

Tricco AC, Lillie E, Zarin W, O'Brien K, Colquhoun H, Kastner M, Levac D, Ng C, Sharpe JP, Wilson K, Kenny M, Warren R, Wilson C, Stelfox HT, Straus SE (2016). A scoping review on the conduct and reporting of scoping reviews. BMC Medical Research Methodology, 16:15. doi: 10.1186/s12874-016-0116-4.

Tsai AC, Kohrt BA, Matthews LT, Betancourt TS, Lee JK, Papachristos AV, Weiser SD, Dworkin SL (2016). Promises and pitfalls of data sharing in qualitative research. Social Science & Medicine, 169:191-198. doi: 10.1016/j.socscimed.2016.08.004. Epub 2016 Aug 9. PMID: 27535900; PMCID: PMC5491836.

Tsimicalis, A., Genest, L., Stevens, B., Ungar, W. J., & Barr, R. (2018). The impact of a childhood cancers' diagnosis on the children and siblings' school attendance, performance, and activities: A qualitative descriptive study. Journal of Oncology Nursing, 35(2) pp. 118–131. https://doi.org/10.1177/1043454217741875.

Tsimicalis A, Stevens B, Ungar W, McKeever P, Greenberg M (2011). The cost of childhood cancer from the family’s perspective: a critical review. Pediatric Blood Cancer, 56 pp. 707-717.

Tuckett, A. G. (2004). Qualitative research sampling: the very real complexities. Nurse Researcher, 12(1) pp. 47–61. https://doi.org/10.7748/nr2004.07.12.1.47.c5930.

Tuckett AG (2005). Part II: rigour in qualitative research: complexities and solutions. Nurse Researcher 13(1) pp. 29–42.

Tuffour, I. (2017). ‘A critical overview of interpretative phenomenological analysis: a contemporary qualitative research approach’. Journal of Healthcare Communications, 2(4) pp. 52–67.

Turner, V. (1969). Liminality and communitas. In The ritual process: Structure and antistructure (pp. 94-114). Aldine Publishing.

Tutelman, P. R., Chambers, C. T., Urquhart, R., Fernandez, C. V., Heathcote, L. C., Noel, M., . . . Stern, M. (2019). When "a headache is not just a headache": a qualitative examination of parent and child experiences of pain after childhood cancer. Psycho-Oncology, 28(9) pp. 1901-1909.

van Bakel, H. J., Van Engen, M. L., & Peters, P. (2018). Validity of the Parental Burnout Inventory among Dutch employees. Frontiers in Psychology, 9, Article 697. doi:10.3389/fpsyg.2018.00697

van Breemen C (2009). Using play therapy in paediatric palliative care: listening to the story and caring for the body. International Journal of Palliative Nursing, 15(10) pp. 510-513.

van der Geest I., van der Heuval-Eibrink M., Passchier J., van der Hoed-Heerschop C., Pieters R. & Darlington A. (2014). Parenting stress as a mediator of parents’ negative mood state and behaviour problems in children with newly diagnosed cancer. Psycho-Oncology 23 pp. 758–765. https:// doi: 10.1002/pon.3475.

van Der Mark, E. J., Conradie, I., Dedding, C. W. M., & Broerse, J. E. W (2017). How poverty shapes caring for a disabled child: A narrative literature review. Journal of International Development, 29(1), https://doi.org/10.1002/jid.3308

van Schoors M, Caes L, Alderfer MA, Goubert L, Verhofstadt L (2017). Couple functioning after pediatric cancer diagnosis: a systematic review. Psychooncology, 26 pp. 608-616.

van Schoors, M., Caes, L., Verhofstadt, L.L., Goubert, L., Alderfer, M.A. (2015). Systematic review: family resilience after pediatric cancer diagnosis. Journal of Pediatric Psychology, 40,856–868.

van Schoors M, De Mol J, Morren H, Verhofstadt LL, Goubert L, Van Parys H (2018). Parents' Perspectives of Changes Within the Family Functioning After a Pediatric Cancer Diagnosis: A Multi Family Member Interview Analysis. Qualitative Health Research; 28(8):1229-1241. doi: 10.1177/1049732317753587 van Schoors, M., De Paepe, A.L., Norga, K., Cosyns, V., Morren, H., Vercruysse, T., Goubert, L., Verhofstadt, L.L. (2019). Family members dealing with childhood cancer: a study on the role of family functioning and cancer appraisal. Front. Psychol. 10, 1405. https://doi.org/10.3389/fpsyg.2019.01405.

van Schoors M., De Mol J., Laeremans N., Verhofstadt L. L., Goubert L., Van Parys H (2019). Siblings' experiences of everyday life in a family where one child is diagnosed with blood cancer: A qualitative study. Journal of Pediatric Oncology Nursing, 36(2), 131–142.

van Tongerloo, M. A. M. M., van Wijngaarden, P. J. M., van der Gaag, R. J., & Lagro-Janssen, A. L. M. (2015). Raising a child with an autism spectrum disorder: "If this were a partner relationship, I would have quit ages ago". Family Practice, 32(1), 88–93. https://doi.org/10.1093/fampra/cmu076

van 't Hof M, van Berckelaer-Onnes I, Deen M, et al (2020). Novel insights into autism knowledge and stigmatizing attitudes toward mental illness in Dutch youth and family center physicians. Community Mental Health Journal, 56(7):1318–1330.

Vaezi, A.A., Tavangar, H. and Javadi, M. (2015). "Factors influencing the process of continuous nursing education based on the experiences of nurses: a qualitative study", Strides in Development of Medical Education, Vol. 11 No. 4, pp. 508-522.

Verdonk P, Muntinga M, Leyerzapf H, et al (2015). Strategisch pendelen tussen gestolde categorieën en fluïde identiteiten. Tijdschr Voor Genderstudies; 18:433–450.

Vetsch, J., Rueegg, C. S., Gianinazzi, M. E., Bergsträsser, E., von der Weid, N. X., & Michel, G. (2015). Information needs in parents of long-term childhood cancer survivors. Pediatric Blood & Cancer, 62(5) pp. 859–866. doi:10.1002/pbc.25418.

Vetsch J. et al. (2016). "Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care, Patient Education Counselling. http://dx.doi.org/10.1016/j.pec.2016.09.013

Viana R., C.; Caldeira, S.; Lourenço, M.; Simões Figueiredo, A (2021). Parenting of Children with Autism Spectrum Disorder: A Grounded Theory Study. Healthcare, 9, 872. https://doi.org/10.3390/healthcare9070872

Vinckx, M.-A., Bossuyt, I., & Dierckx de Casterlé, B. (2018). Understanding the complexity of working under time pressure in oncology nursing: A grounded theory study. International Journal of Nursing Studies, 87, 60–68. doi:10.1016/j.ijnurstu.2018.07.010.

Vindrola-Padros C, Chisnall G, Cooper S, Dowrick A, Djellouli N, Symmons SM, Martin S, Singleton G, Vanderslott S, Vera N, Johnson GA (2020). Carrying Out Rapid Qualitative Research During a Pandemic: Emerging Lessons From COVID-19. Qualitative Health Research, 30(14):2192-2204. doi: 10.1177/1049732320951526.

Vitale, S. R., Schneider, H., Gardner, L., Alessandri, M., & Marker, C. (2022). Challenging behavior and parental depression: The effects of everyday stressors and benefit finding for parents of children with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 53, 3356–3368. https://doi.org/10.1007/s10803-022-05627-7

Vogel, D.L.; Heimerdinger-Edwards, S.R.; Hammer, J.H.; Hubbard, A (2011). “Boys don’t cry”: Examination of the links between endorsement of masculine norms, self-stigma, and help-seeking attitudes for men from diverse backgrounds. Journal of Counselling Psychology, 58, 368–382.

Vuattoux D, Colomer-Lahiguera S, Fernandez P-A, Jequier Gygax M, Choucair M-L, Beck-Popovic M, Diezi M, Manificat S, Latifyan S, Ramelet A-S, Eicher M, Chabane N and Renella R (2021). Cancer Care of Children, Adolescents and Adults With Autism Spectrum Disorders: Key Information and Strategies for Oncology Teams. Frontiers in Oncology, 10:595734. doi: 10.3389/fonc.2020.595734

Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., ... & Holland, F. G. (2014). The accordian and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. The Qualitative Report, 19 (24) pp. 1-15.

Wakefield CE, Butow P, Fleming CA, Daniel G, Cohn RJ. (2012). Family information needs at childhood cancer treatment completion. Pediatric Blood Cancer, 58:621-6.

Wakefield C., McLoone J., Butow P., Lenthen K., Cohn R. (2013). Support after the completion of cancer treatment: perspectives of Australian adolescents and their families. European Journal of Cancer Care, 22 pp. 530–539. https://doi:10.1111/ecc.12059.

Wakefield CE, Drew D, Ellis SJ, Doolan EL, McLoone JK, Cohn RJ, et al (2014). ‘What they’re not telling you’: A new scale to measure grandparents’ information needs when their grandchild has cancer. Patient Education and Counseling, 94 pp. 351-355.

Wakefield, C. E., McLoone, J. K., Evans, N. T., Ellis, S. J., & Cohn, R. J. (2014). It's more than dollars and cents: The impact of childhood cancer on parents occupational and financial health. Journal of Psychosocial Oncology,32(5) pp. 602–621. https://doi.org/10.1080/07347332.2014.936653.

Wakefield CE, Sansom-Daly UM, McGill BC, et al (2016). Acceptability andfeasibility of an e-mental health intervention for parents of child-hood cancer survivors: “cascade”. Support Care Cancer, 24:2685–2694.

Wakimizu, R., Hiraga, N., Furuya, K., Fukushima, T., Tsuchida, M., Koike, K., Yamamoto, T., (2011). Depression and health-related quality of life after discharge and associated factors in childhood cancer patients in Japan. Bioscience Trends, 5 pp. 264–272.

Waldow VR (2014). Nursing: the Care Practice from a Philosophical Point of View. Invest Enferm Imagen Desarro [Internet], 17(1) pp. 13-25. http://dx.doi.org/10.11144/Javeriana.IE17-1.epdc.deli.

Walter FM, Emery J (2006). Perceptions of family history across common diseases: a qualitative study in primary care. Family Practice, 23(4): 472–80.

Walton, K. (2016). Risk factors for behavioral and emotional difficulties in siblings of children with autism spectrum disorder. American Journal on Intellectual and Developmental Disabilities, 121(16), 533-549. https://doi.org/10.1352/1944-7558-121.6.533

Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Girardi F, Atun R (2019). Global childhood cancer survival estimates and priority-setting: a simulation-based analysis. Lancet Oncology, 20(07) pp. 972–983.

Warner, E.L.; Kirchho, A.C.; Nam, G.E.; Fluchel, M (2015). Financial burden of pediatric cancer for patients and their families. Journal of Oncology Practice, 11 pp. 12–18.

Wasylkiw, L.; Clairo, J (2018). Help seeking in men: When masculinity and self-compassion collide. Psychology of Men & Masculinity, 19,234–242.

Webber, L. J., Richardson, B., White, K. L., Fitzpatrick, P., McVilly, K., & Forster, S. (2019). Factors associated with the use of mechanical restraint in disability services. Journal of Intellectual and Developmental Disability, 44(1), 116–120. https://doi.org/10/3109/13668250.2017.1310814

Weiner, J. A., &Woodley, L. K. (2018). An integrative review of sibling responses to childhood cancer. Journal of Child and Adolescent Psychiatric Nursing, 31(4), 109–119. https://doi.org/10.1111/jcap.12219

Werner S, Shulman C (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: the role of affiliate stigma and psychosocial moderating variables. Research in Developmental Disabilities, 34: 4103–14. doi: 10.1016/j.ridd.2013.08.029 PMID: 24055712

West, C.H., Bell, J.M.,Woodgate, R.L., Moules, N.J., (2015).Waiting to return to normal: an exploration of family systems intervention in childhood cancer. Journal of Family Nursing, 21, 261e294.

Wheeler, M. S. (2016). Primary palliative care for every nurse practitioner. The Journal for Nurse Practitioners, 12(10) pp. 647–653. https://doi.org/10.1016/j.nurpra.2016.09.003.

Whitehead, A. (2017). Neighborhoods, family functioning, and mothers' mental health for families with a child with an autism spectrum disorder. Applied Research in Quality of Life, 12, 633-651. doi:10.1007/s11482-016-9480-9

Whittaker E, Bamford A, Kenny J, et al (2020). Clinical characteristics of 58 children with a pediatric inflammatory multisystem syndrome temporally associated with SARS-CoV-2. JAMA, 324(3) pp. 259-269.

Weiner, C., Pergert, P., Castor, A., Molewijk, B., & Bartholdson, C. (2023). Sheltering in chaos: parents' experiences when facing moral challenges in childhood cancer care. Ethics & Behavior, 1–14. https://doi.org/10.1080/10508422.2023.2267708

White, T. E., Hendershot, K. A., Dixon, M. D., Pelletier, W., Haight, A., Stegenga, K., Alderfer, M. A., Cox, L., Switchenko, J. M., Hinds, P., & Pentz, R. D. (2017). Family strategies to support siblings of pediatric hematopoietic stem cell transplant patients. Pediatrics, 139(2), Article e20161057. https://doi.org/10.1542/peds.2016-1057

Wiener L, Alderfer M, Pao M (2015). Psychiatric and psychosocial support for child and family. In: Pizzo PA, Poplack DG, eds. Principles and Practice of Pediatric Oncology. 7th ed. Philadelphia: Lippincott;:1124–1140.29.

Wiener, L., Battles, H., Zadeh, S., Pelletier, W., Arruda-Colli, M.N. F., & Muriel, A. C. (2017). The perceived influence of childhood cancer on the parents' relationship. Psycho-Oncology,26(12), pp. 2109–2117. https://doi.org/10.1002/pon.4313.

Wiener L, Pao M, Zadeh S, et al (2013). Socio-environmental factors associated with lone parenting chronically ill children. Child Health Care, 42(3):264–280.

Wiener L, Viola A, Kearney J, Mullins LL, Sherman-Bien S, Zadeh S, Farkas-Patenaude A, Pao M (2016). Lone Parent Study Group. Impact of Caregiving for a Child With Cancer on Parental Health Behaviors, Relationship Quality, and Spiritual Faith: Do Lone Parents Fare Worse? Journal of Pediatric Oncology Nursing, 33(5):378-86. doi: 10.1177/1043454215616610

Wikman A, Hoven E, Cernvall M, Ljungman G, Ljungman L, von Essen L (2016). Parents of children diagnosed with cancer: work situation and sick leave, a five-year post end-of-treatment or a child's death follow-up study. Acta Oncology, pp.1-6.

Wikman A, Ljungman L, Pingel R, et al (2017). The interdependence of posttraumatic stress symptoms in parental dyads during and after their child's treatment for cancer. Acta Oncology, 56(12) pp. 1698–1704. doi:10.1080/0284186X.2017.1355562.

Wilford, J., Hopfer, S., & Wenzel, L. (2019). Perceptions of changes in clinical, informational, and supportive relationships after end of treatment among parents of young childhood cancer survivors. Psycho-Oncology, 28 pp. 913–919. https://doi.org/10.1002/pon.5042.

Willard, V. W., Qaddoumi, I., Zhang, H., Huang, L., Russell, K. M., Brennan, R., . . . Phipps, S. (2016). A longitudinal investigation of parenting stress in caregivers of children with retinoblastoma. Pediatric Blood & Cancer, 64(4), pp. 1–7. doi:10.1002/pbc.26279.

Williams PD, Williams AR, Kelly KP, Dobos C, Gieseking A, Connor R, et al (2012). A symptom checklist for children with cancer: The Therapy-Related Symptom Checklist-Children. Cancer Nursing, 35 pp. 89-98.

Willig, C. (2008). Introducing qualitative research in psychology (2nd Edition). Maidenhead: Open University Press.

Willig, C. (2013). Introducing qualitative research in psychology. Third Edition. Maidenhead: McGraw-Hill/Open University press.

Wilson, S. A., & Peterson, C. C. (2018). Medical care experiences of children with autism and their parents: A scoping review. Child: Care, Health and Development, 44(6), 807–817.

Woodgate RL, Tailor K, Yanofsky R, Vanan MI (2016). Childhood brain cancer and its psychosocial impact on survivors and their parents: A qualitative thematic synthesis. European Journal of Oncology Nursing 20:140–149.

Woolcock, M., & Narayan, D. (2000). Social capital: Implications for development theory, research, and policy. The World Bank Research Observer, 15(2), 225–249. https://doi.org/10.1093/wbro/15.2.225

World Health Organisation. (2018). Cancer in children – Factsheet. https://www.who.int/newsroom/ fact-sheets/detail/cancer-in-children.

World Health Organization (2021). CureAll framework: WHO global initiative for childhood cancer: increasing access, advancing quality, saving lives. World Health Organization. https://apps.who.int/iris/handle/10665/347370 (accessed 26.12.2021).

Wuest, J. (2012). Grounded theory: The method. In P. Munhall (Ed.), Nursing research: A qualitative perspective (5th ed., pp. 225-256). Miami, FL: Jones and Bartlett Learning.

Xavier AC, Ge Y, Taub J (2010). Unique clinical and biological features of leukemia in Down syndrome children. Expert Review of Hematology, 3 pp. 175–186.

Yang, H. C., Mu, P. F., Sheng, C. C., Chen, Y. W., & Hung, G. Y. (2016). A systematic review of the experiences of siblings of children with cancer. Cancer Nursing, 39(2), E12–E21. https://doi.org/10.1097/NCC.0000000000000258.

Yao, L.; Gao, J.; Chen, C.; Mu, D (2019). How Does Emotional Labor Impact Employees' Perceptions of Well-Being? Examining the Mediating Role of Emotional Disorder. Sustainability, 11, 6798.

Yardley, L. (2000). Dilemmas in qualitative health research. Psychology and Health, 15(2), pp. 215-228.

Yi J (2009). Cultural influences on the survivorship of families affected by childhood cancer: a case for using family systems theories. Family System Health, 27(3):228-236.

Yildirim Sari H, Yilmaz M, Ozsoy S, Kantar M, Cetingul N (2013). Experiences of parents with the physical care needs at home of children with cancer: a qualitative study. Cancer Nursing ,(5):385-93. doi: 10.1097/NCC.0b013e3182a0e221. PMID: 23963194.

Yogman, M.; Garfield, C.F. (2016). Committee on Psychosocial Aspects of Child and Family Health. Fathers' Roles in the Care and Development of Their Children: The Role of Pediatricians. Pediatrics, 138, e20161128.

Young, B., Dixon-Woods, M., Findlay, M. and Heney, D. (2002). Parenting in a crisis:conceptualising mothers of children with cancer, Social Science and Medicine,55, 1835–47.

Zaidman-Zait, A., Mirenda, P., Szatmari, P., Duku, E., Smith, I., Vaillancourt, T., Volden, J., Georgiades, S. (2018). Profiles of social and coping resources in families of children with autism spectrum disorder: Relations to parent and child outcomes. Journal of Autism and Developmental Disorder, 48, 2064-2076. doi:10.1007/s10803-018-3467-3

Zamanzadeh V, Valizadeh L, Sayadi L, Taleghani F, Howard F, Jeddian A (2013). Emotional labour of caring for hematopoietic stem cell transplantation patients: Iranian nurses' experiences. Asian Nursing Research, 7(2):91-7. doi: 10.1016/j.anr.2013.04.004

Zavagli V, Raccichini M, Ostan R, Ercolani G, Franchini L, Varani S, Pannuti R (2022). Identifying the prevalence of unmet supportive care needs among family caregivers of cancer patients: an Italian investigation on home palliative care setting. Support Care Cancer, 30(4) pp. 3451-3461. doi: 10.1007/s00520-021-06655-2.

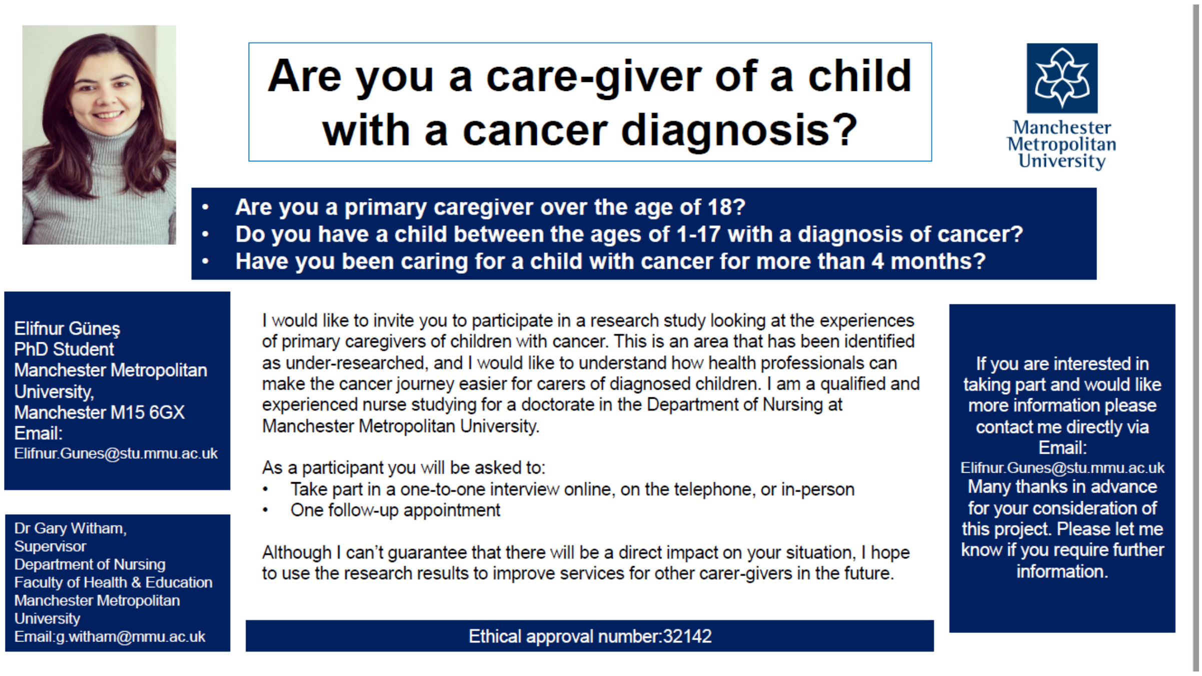
Zegaczewski, T., Chang, K., Coddington, J., & Berg, A. (2016). Factors related to healthy siblings' psychosocial adjustment to children with cancer: An integrative review. Journal of Pediatric Oncology Nursing, 33(3), 218–227. https://doi.org/10.1177/1043454215600426

Zheng, S., Liu, S., Yang, Q., Chan, S., Huang, W., Jiang, X., & Zhu, J. (2024). The effectiveness of interventions to reduce cancer-related stigma: An integrative review. Journal of Clinical Nursing, 33, 2438–2455. https://doi.org/10.1111/jocn.17014

Zoom (2020). Hiding or showing my video on my display. Zoom. Retrieved from https://support.zoom.us/hc/en-us/articles/115001077226-Hiding-or-showing-my-video-on-my-display. (Accessed 30.06.2022).

Appendices

Appendix 1: Invitation letter



Are you a care-giver of a child with a cancer diagnosis?

Manchester Metropolitan University

- **Are you a primary caregiver over the age of 18?**
- **Do you have a child between the ages of 1-17 with a diagnosis of cancer?**
- **Have you been caring for a child with cancer for more than 4 months?**

Elifnur Güneş
PhD Student
Manchester Metropolitan University,
Manchester M15 6GX
Email:
Elifnur.Gunes@stu.mmu.ac.uk

Dr Gary Witham,
Supervisor
Department of Nursing
Faculty of Health & Education
Manchester Metropolitan University
Email:g.witham@mmu.ac.uk

I would like to invite you to participate in a research study looking at the experiences of primary caregivers of children with cancer. This is an area that has been identified as under-researched, and I would like to understand how health professionals can make the cancer journey easier for carers of diagnosed children. I am a qualified and experienced nurse studying for a doctorate in the Department of Nursing at Manchester Metropolitan University.

As a participant you will be asked to:

- Take part in a one-to-one interview online, on the telephone, or in-person
- One follow-up appointment

Although I can't guarantee that there will be a direct impact on your situation, I hope to use the research results to improve services for other carer-givers in the future.

Ethical approval number:32142

If you are interested in taking part and would like more information please contact me directly via Email:
Elifnur.Gunes@stu.mmu.ac.uk
Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Appendix 2: MMU University Ethical Approval

Manchester
Metropolitan
University

22/11/2021
Project Title: Evaluation of Caregiving Burden in Caregivers of Children with Cancer

EthOS Reference Number: 32142

Ethical Opinion

Dear Elifnur Gunes,

The above amendment was reviewed by the Health, Psychology and Social Care Research Ethics and Governance Committee and, on the 22/11/2021, was given a favourable ethical opinion. The approval is in place until 04/04/2022 .

Conditions of favourable ethical opinion

Application Documents

The Health, Psychology and Social Care Research Ethics and Governance Committee favourable ethical opinion is granted with the following conditions

Adherence to Manchester Metropolitan University's Policies and procedures

This ethical approval is conditional on adherence to Manchester Metropolitan University's Policies, Procedures, guidance and Standard Operating procedures. These can be found on the Manchester Metropolitan University Research Ethics and Governance webpages.

Amendments

If you wish to make further changes to this approved application, you will be required to submit an amendment. Please visit the Manchester Metropolitan University Research Ethics and Governance webpages or contact your Faculty research officer for advice around how to do this.

We wish you every success with your project.

HPSC Research Ethics and Governance Committee

HPSC Research Ethics and Governance Committee

For help with this application, please first contact your Faculty Research Officer. Their details can be found here

Appendix 3: Participant information sheet

Participant Information Sheet

The Experiences of Primary Caregivers of Children with Cancer

1. Invitation to research

I would like to invite you to take part in my research project. My name is Elifnur Gunes and I am a PhD student at Manchester Metropolitan University, Faculty of Health, Psychology & Social Care department. My research project is about the burden of a caregiver who has a child with cancer and how her/him life is affected.

2. Why have I been invited?

You have been invited to participate in my study since you fit into one of the categories of people we would like to talk to and because we feel that you could help us gain a deeper understanding of experiences about a caregiver who has children with cancer. Your perspective would be really helpful in helping us contextualise our thinking and we hope that you will enjoy taking part in this work.

3. Do I have to take part?

It is up to you to decide. We will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

4. What will I be asked to do?

You will be asked to take part in an interview which will include your experiences and your feelings. It should 60 minutes take approximately. The information you give will be audio recorded for accuracy but your name and any identifying information will not be used. We will use the collected data to writing my thesis.

Only the research team will have access to these data. Your data will be anonymised and no personal information will be stored. All data will be kept on an encrypted and password protected drive. This information will be stored for a maximum of five years and then destroyed. You can withdraw from the study at any point without having to give a reason. If any questions during the interview make you feel uncomfortable, you do not have to answer them. Withdrawing from the study will have no effect on you whatsoever. If you withdraw from the study we will not retain the information you have given thus far, unless you are happy for us to do so.

5. Are there any risks if I participate?

There is no foreseeable risk or disadvantage for taking part in this study. If, however, you become distressed whilst taking part in the interview I will take a time out from the interview and the researcher, (who is an experienced health care professional) will offer immediate support. If necessary, with your consent, I would also be able to put you in contact with other health professionals for ongoing support.

6. Are there any advantages if I participate?

There will be no direct advantages or rewards for engaging in this study, but the information you provided will contribute to the literature and my thesis.

7. What will happen with the data I provide?

The Manchester Metropolitan University is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The Manchester Metropolitan University is registered with the Information Commissioner's Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

We will not collect personal data as part of this research.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained only if you consent for us to do so.

We will not share your data with any third parties.

We will only retain your personal data for as long as is necessary to achieve the research purpose. Data from this study will be confidential and held on a password and encrypted hard drive. All data will be destroyed within five years of this data collection period. Only the research team will have access to the data and no hard copies of photographs or data will be held unless in the form of written papers or articles.

For further information about use of your personal data and your data protection rights please see the University's Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

8. What will happen to the results of the research study?

The study will produce my thesis, research papers and articles together with presentations at conferences. The research findings will be published as part of my PhD. So that the nurses and doctors can learn from the results, I will publicize my findings more widely at health-related conferences and in medical/nursing journals to enhance their understanding of how it is like to as a caregiver who has a child with cancer.

9. Who has reviewed this research project?

This study has undergone ethics review in accordance with the Manchester Metropolitan University Research Ethics Policy and Procedure.

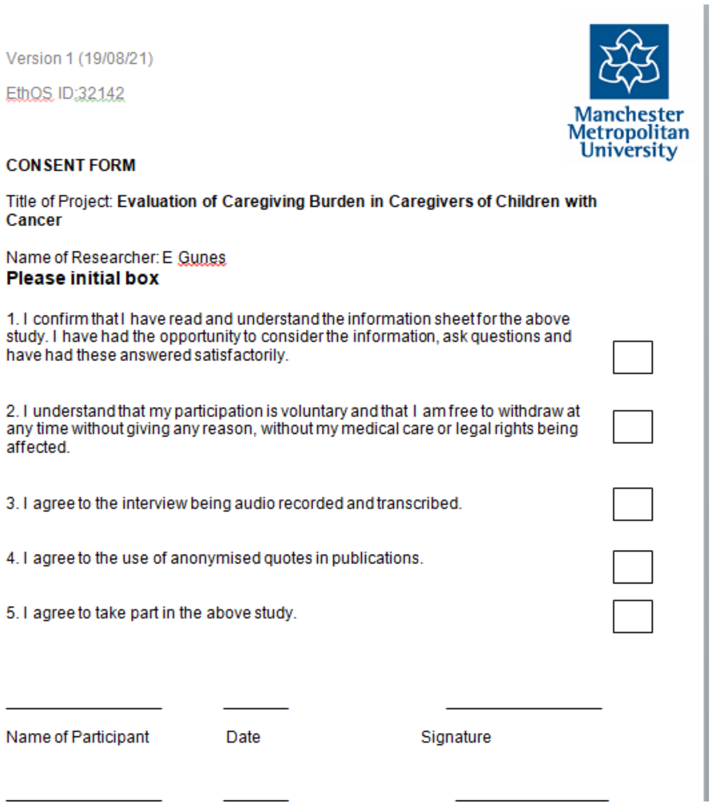
10. Who do I contact if I have concerns about this study or I wish to complain?

General questions about the project can be presented to Elifnur Gunes, email:elifnur.gunes@stu.mmu.ac.uk; tel:+44 07761060589 and supervisor Gary Witham email: g.witham@mmu.ac.uk; tel: +44 (0)161 247 2464. The Faculty ethics committee chair is Professor Khatidja Chantler, email:k.chantler@mmu.ac.uk; tel: 0161 247 2023 and can be contacted regarding concerns or complaints about the project. The address for each of us is the Faculty of Health, Psychology & Social Care, Manchester Metropolitan University, Brooks Building (1.06), 53 Bonsall Street, Manchester, M15 6GX.

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Appendix 4: Consent form



Version 1 (19/08/21)

EthOS ID:32142

Manchester Metropolitan University

CONSENT FORM

Title of Project: **Evaluation of Caregiving Burden in Caregivers of Children with Cancer**

Name of Researcher: E Gunes

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to the interview being audio recorded and transcribed. ☐

4. I agree to the use of anonymised quotes in publications. ☐

5. I agree to take part in the above study. ☐

________________ ________ ________________

Name of Participant Date Signature

________________ ________ ________________

Appendix 5: Research Interview Guide

Interview Guide

Research Title: The Experiences of Primary Caregivers of Children with Cancer

Research Aim: To explore the impact childhood cancer has on primary caregivers

Researcher's Notes: Focus on the experience of the research participant and what it means to them – Probe

Open with an introduction of the project, ensure the participant is comfortable being recorded and take them through the consent form. When consent form has been signed and the participant has asked any questions they may have, proceed with recording.

Q1. Everyone's experiences will be different. I'd really like to find out about how you experience things. Tell me about your child…

Q2. Please tell me what your child was diagnosed with and how long ago was this?

Q3. What can you remember about when your child was first assessed and diagnosed?

Q4. How did you feel emotionally at the time of diagnosis? And how did that change as time went on?

Q5. Can you tell me what it has been like for you being a caregiver of a child with cancer?

How does it impact on daily life?

-Family (other children and other parent/ extended family/ key relationships)?

-What is the most challenging thing about being _________'s parent?

-What’s the best thing about it?.

Q6. Did you have any support? Any healthcare professional, any friends? Family/Hospital/etc

Q7. Did impact on your daily life? negative effect or? Finances? Caring for other children?

Q8. What was your main long term worry for your child?

Q9. When you child came home, how did you cope with caring for them physically/emotionally?

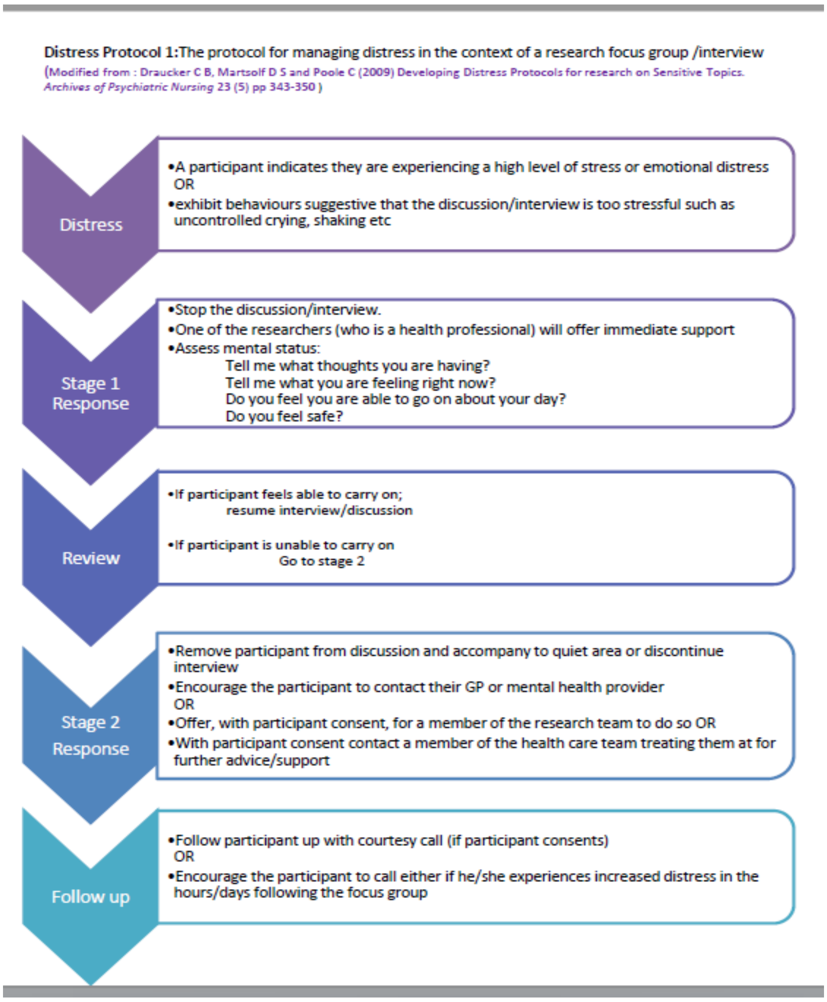
Q10. What is the situation now?

Q11. Do you have anything else you would like to share that you feel you did not have the opprtunity to say/express from that time, related to providing care for your child that was suffering from cancer?

Recap, thanks and close.

Appendix 6: Distress policy

The protocol for managing distress in the context of a research interview



Distress Protocol 1: The protocol for managing distress in the context of a research focus group /interview
(Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Distress

- A participant indicates they are experiencing a high level of stress or emotional distress
  OR
- exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 Response

- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status:
  - Tell me what thoughts you are having?
  - Tell me what you are feeling right now?
  - Do you feel you are able to go on about your day?
  - Do you feel safe?

Review

- If participant feels able to carry on;
  - resume interview/discussion
- If participant is unable to carry on
  - Go to stage 2

Stage 2 Response

- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider
  OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow up

- Follow participant up with courtesy call (if participant consents)
  OR
- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group

Appendix 7: Debrief Sheet

Thank you very much for agreeing to participate in this research.

I hope you found your participation in this research interesting and that our discussion following the interview has alleviated any concerns you may have had afterwards.

However, if your experiences as the primary caregiver of a child with cancer make you feel sad or stressed over the next few days and this continues, there are local support that you can contact.

Following this interview, if you would like to address your experiences in a safe environment further, you may find the following sources helpful:

1. You can contact your GP.
2. Childhood Cancer Parents Alliance (CCPA)- 01785 283435 (9am-5pm, Mon, Tue, Wed)

The interviews are audio-recorded and transcribed. All names, dates, addresses, and other identifying details will be changed to ensure that you cannot be identified and remain anonymous. Audio recordings will be destroyed after the completion of the research. Information provided for this study will remain strictly confidential.

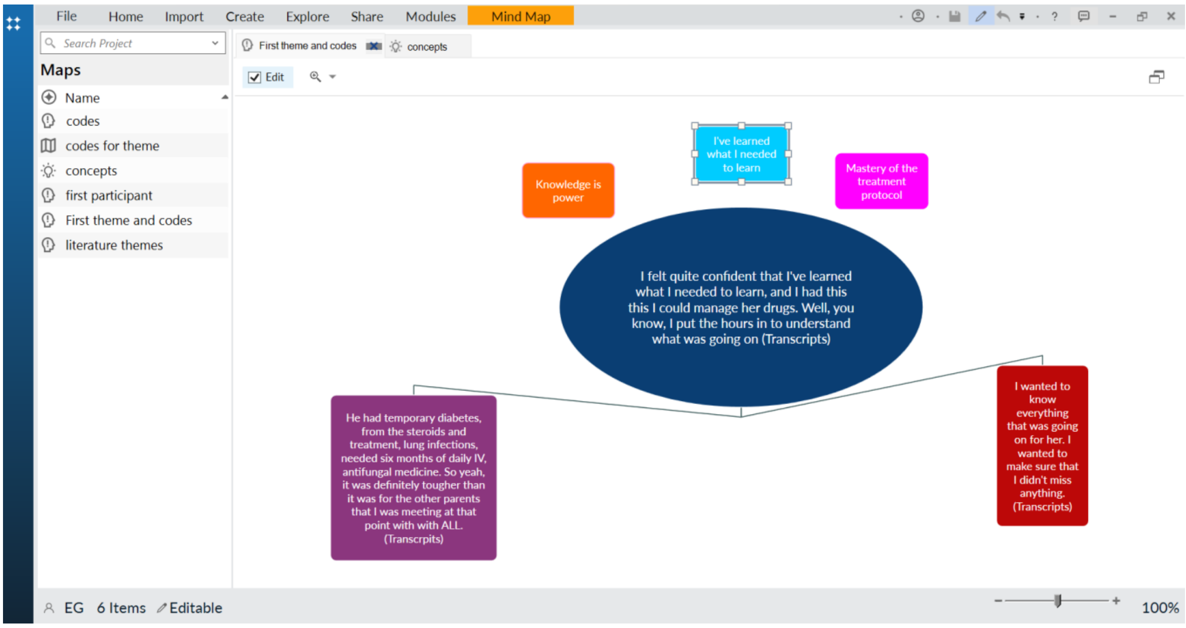
If in the future you would like more information about this study, you can contact me by telephone, via e-mail, or in writing c/o the university. My details are below.

Elifnur Gunes,

Email:19024110@stu.mmu.ac.uk

Thank you again for your participation.

Appendix 8: NVivo example of the organisation of data



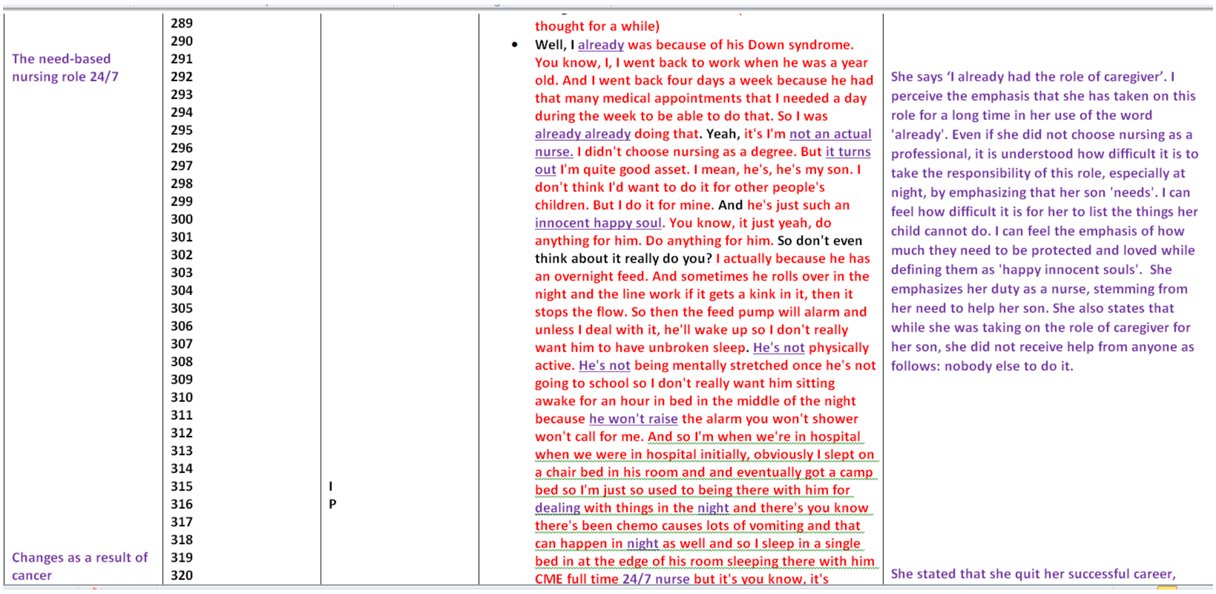
I felt quite confident that I've learned what I needed to learn, and I had this this I could manage her drugs. Well, you know, I put the hours in to understand what was going on (Transcripts)

He had temporary diabetes, from the steroids and treatment, lung infections, needed six months of daily IV, antifungal medicine. So yeah, it was definitely tougher than it was for the other parents that I was meeting at that point with with ALL. (Transcrpits)

I wanted to know everything that was going on for her. I wanted to make sure that I didn't miss anything. (Transcripts)

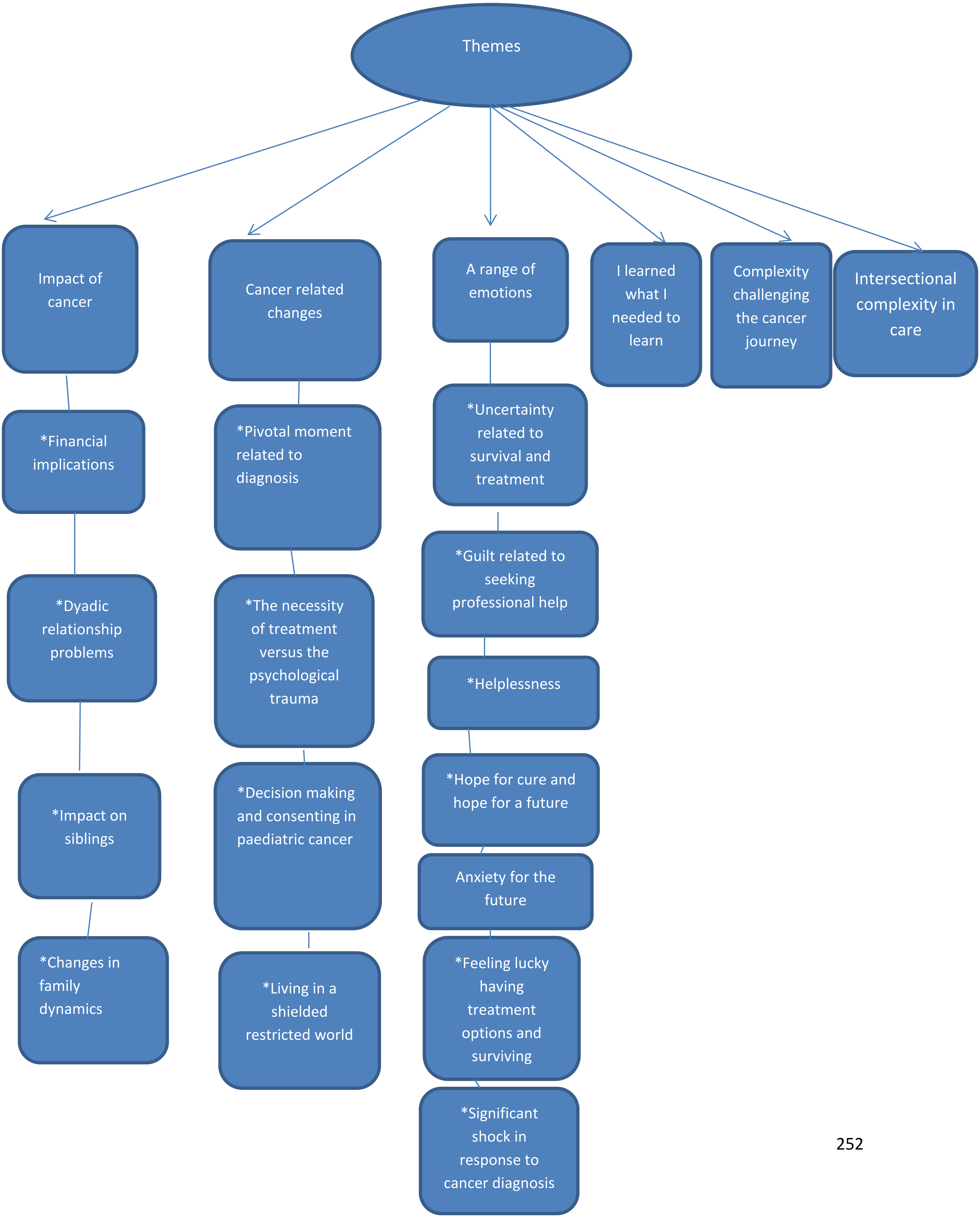
Appendix 9: Interview transcript excerpt

Claire's Transcript

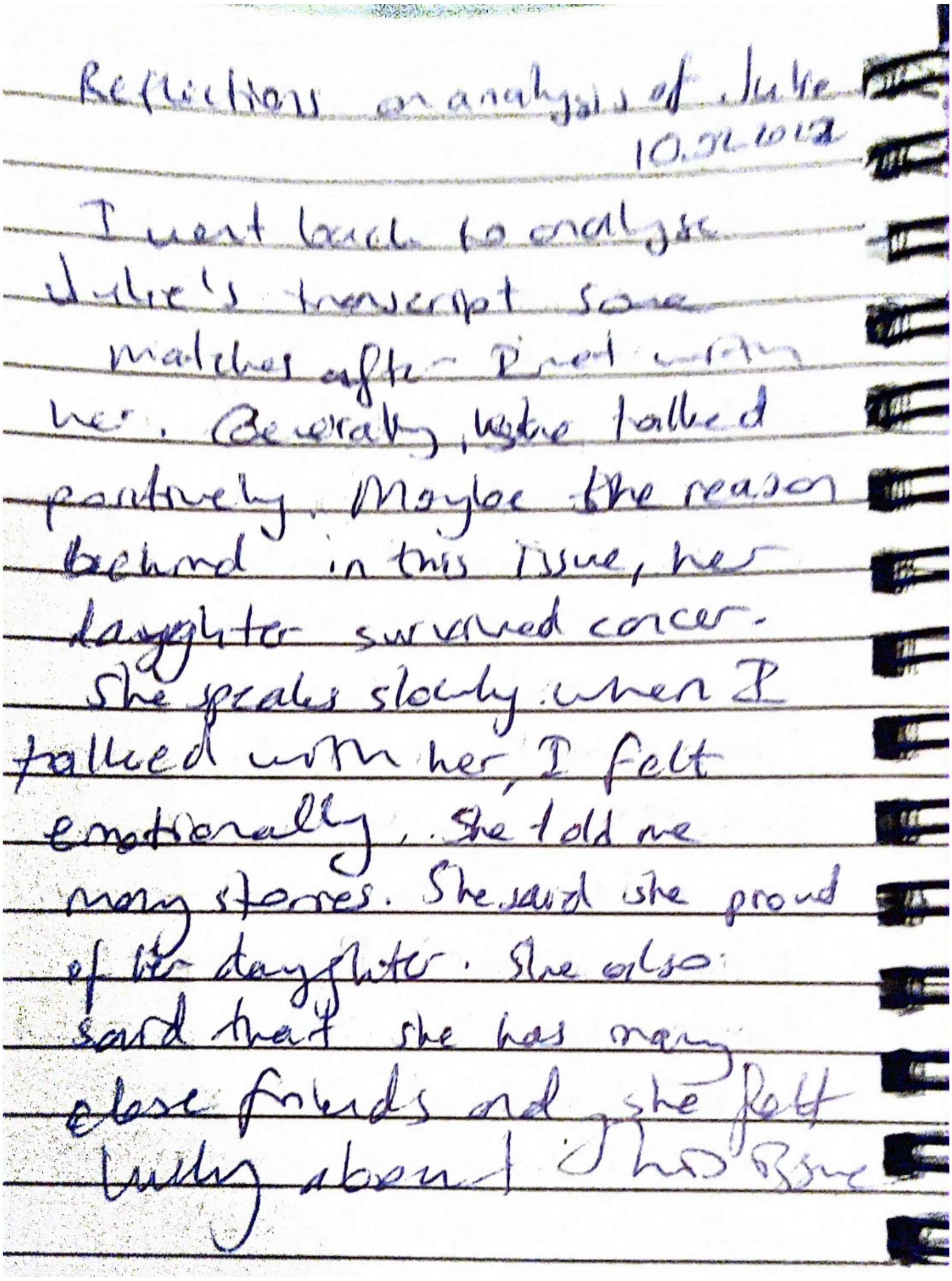


The need-based nursing role 24/7 Changes as a result of cancer	I P	thought for a while) • Well, I already was because of his Down syndrome. You know, I, I went back to work when he was a year old. And I went back four days a week because he had that many medical appointments that I needed a day during the week to be able to do that. So I was already already doing that. Yeah, it's I'm not an actual nurse. I didn't choose nursing as a degree. But it turns out I'm quite good asset. I mean, he's, he's my son. I don't think I'd want to do it for other people's children. But I do it for mine. And he's just such an innocent happy soul. You know, it just yeah, do anything for him. Do anything for him. So don't even think about it really do you? I actually because he has an overnight feed. And sometimes he rolls over in the night and the line work if it gets a kink in it, then it stops the flow. So then the feed pump will alarm and unless I deal with it, he'll wake up so I don't really want him to have unbroken sleep. He's not physically active. He's not being mentally stretched once he's not going to school so I don't really want him sitting awake for an hour in bed in the middle of the night because he won't raise the alarm you won't shower won't call for me. And so I'm when we're in hospital when we were in hospital initially, obviously I slept on a chair bed in his room and and eventually got a camp bed so I'm just so used to being there with him for dealing with things in the night and there's you know there's been chemo causes lots of vomiting and that can happen in night as well and so I sleep in a single bed in at the edge of his room sleeping there with him CME full time 24/7 nurse but it's you know, it's	She says 'I already had the role of caregiver'. I perceive the emphasis that she has taken on this role for a long time in her use of the word 'already'. Even if she did not choose nursing as a professional, it is understood how difficult it is to take the responsibility of this role, especially at night, by emphasizing that her son 'needs'. I can feel how difficult it is for her to list the things her child cannot do. I can feel the emphasis of how much they need to be protected and loved while defining them as 'happy innocent souls'. She emphasizes her duty as a nurse, stemming from her need to help her son. She also states that while she was taking on the role of caregiver for her son, she did not receive help from anyone as follows: nobody else to do it. She stated that she quit her successful career,

Appendix 10: Identifying patterns across themes



Appendix 11: Reflective Diary excerpt



Reflections on analysis of Julie
10.XI.2012

I went back to analyse Julie's transcript some matches after I met with her. Generally, she talked positively. Maybe the reason behind in this issue, her daughter survived cancer. She speaks slowly. when I talked with her, I felt emotionally. She told me many stories. She said she proud of her daughter. She also said that she has many close friends and she felt lucky about [illegible]

Appendix 12: Relevant conference presentations

2023: International Family Nursing Conference, Ireland, June 20 – 23th

Oral presentation: The Experiences of Primary Caregivers of Children with Cancer using Interpretative Phenomenological Analysis

2022: SIOP Congress, Spain, September 28th - October 1st

Poster Presentation: Primary Caregivers Experiences of Having a Child with Cancer: a Scoping Literature Review of Qualitative Studies