‘A Permanent Scar’

Exploring the Long-Term Experiences of Parents/Caregivers after their Child’s Cancer Treatment

A thesis presented in partial fulfilment of the requirements for the degree of

Doctor of Clinical Psychology

at Massey University, Auckland, New Zealand

Olivia Jennison

2023

Abstract

Due to medical advancements, the prognosis of childhood cancer has significantly improved. This means that more families are contending with life after cancer. Yet, research shows that some parents/caregivers continue to experience psychological distress for many years after the successful completion of their child's cancer treatment. The present study employed a social constructionist lens to qualitatively explore the long-term experiences of parents/caregivers after their child's cancer treatment. Semi-structured interviews were utilised to explore the experiences of ten parents/caregivers whose child had finished active cancer treatment and was at least five years post-diagnosis. The findings generated the fundamental idea that *'The Cancer Experience Remains With You'*. This idea reflected the cancer's continued impact and significant disruption to parents'/caregivers' belief systems and lives in the long-term. This central organising concept held three themes with several subthemes: *'Views about One's Self'* ('identity', 'purpose and meaning', 'suffering from memories'), *'Views about the World'* ('isolation', 'connection', 'vulnerability'), *'Views about the Future'* ('uncertainty', 'loss of an imagined future'). These findings suggest that the experience of their child's cancer was heavily integrated into parents'/caregivers' long-term self-concept, biography, relationships in the world, and expectations for the future. This research highlights the lasting presence of the childhood cancer experience and how this conflicts with societal expectations, which contributes to an understanding of parents'/caregivers' experiences in the long-term after their child's cancer treatment. The findings can be used to improve connection and support to those affected by childhood cancer through the terminology used and psychosocial support provided, with the aim of lessening the burden of the "permanent scar".

Acknowledgements

There are many incredible people for whom I am thankful as I mark the end of my clinical psychology doctoral journey. First and foremost, I would like to thank the parents and caregivers whose voices are echoed in this research. I was honoured to be entrusted with your stories. Your openness in sharing your experiences and determination to increase awareness about the long-term impact of childhood cancer for the benefit of future parents/caregivers cannot go unrecognised. I hope that I did your stories justice.

A huge thank you to my research supervisors, Associate Professor Kirsty Ross and Dr Kathryn McGuigan. You encouraged and guided me throughout this process. You were both a constant support and advocate for me particularly during times when this research went through changes. I am incredibly grateful to have learnt from two spectacular people who helped me to think critically and deepen my understanding and conceptualisation in both research and clinical practice. Thank you both for my growth as a future clinical psychologist.

I would like to thank Child Cancer Foundation for believing in this project and I'm thrilled to see the roll-out of the Cascade programme! I am very grateful for the financial support provided by the Massey University Doctoral Scholarship, Massey Postgraduate Research Fund, Child Cancer Foundation Health Professional Grant, and the Violet Wood Advanced Studies Grant.

To my cohort and clinical friends, I am very appreciative to have shared this journey that is clinical psychology training with you. In particular, thank you to Laura, Natasha, and Marike. Your encouragement and humour, particularly during the challenging times has been a source of strength for me. Thank you to my non-psychology friends for your unwavering cheering and championing. A special thank you to Em, your experiences facing health struggles when we were children is truly inspiring and I am very proud of the person you are today.

An enormous thank you to my parents, Penny and Tim, who gave me constant love and support as I pursued this path. It has been a long ten years to become a clinical psychologist, and I would not have been able to do it without such hard-working and caring role-models that you are. How exceptionally lucky I am to have you.

And finally, a huge thank you to Nick. I have finally finished, and I cannot thank you enough for walking alongside me every step of the way. Thank you for your endless belief in me and for knowing how to make me smile after a long day. You are caring, patient, and incredibly supportive. I’m very excited about our future adventures together!

Table of Contents

Abstract ii

Acknowledgements iii

List of Tables and Figures ix

Chapter 1: Introduction 1

  The Continuity of Cancer 1

  Epidemiology of Childhood Cancer 4

  The Aotearoa New Zealand Context 5

  Treatment Phases 9

    Diagnosis and Initiation of Treatment 9

    Active Treatment 10

    Treatment Completion 10

Chapter 2: Literature Review 12

  Survivor Terminology 12

  Socio-Cultural Understandings of the Cancer Experience 16

  Childhood Cancer and the Family 23

  Parental Experiences 26

    Diagnosis and Active Treatment 26

    End of Treatment 34

    In the Long-Term after Cancer Treatment 40

    Research in Aotearoa New Zealand 47

    Theories of Psychological Distress 48
  Summary & Considerations 51
Chapter 3: The Evolution of this Thesis 53
  ‘Cascade’ 53
  Preliminary Scoping Survey 55
  Research Purpose & Question 56
Chapter 4: Methodology 58
  Theoretical Framing 58
    Reflexivity 62
  Ethical Considerations 65
    Confidentiality and Informed Consent 65
    Avoidance of Harm 67
    Cultural Responsiveness 67
  Method 68
    Participants 68
    Recruitment 70
    Interviews 71
  Data Analysis 73
    Steps in Data Analysis 75

Chapter 5: Findings 79

- Theme 1: Views about One's Self 82
  - Identity 83
  - Purpose & Meaning 90
  - Suffering from Memories 98
  - Summary of Views about One's Self 106
- Theme 2: Views about the World 106
  - Isolation 107
  - Connection 120
  - Vulnerability 125
  - Summary of Views about the World 134
- Theme 3: Views about the Future 135
  - Uncertainty 135
  - Loss of an Imagined Future 146
  - Summary of Views about the Future 151

Chapter 6: Discussion 153

- Overview of Findings 153
  - Views about One's Self 154
  - Views about the World 156
  - Views about the Future 159
  - Beck's Cognitive Triad 161

        Biographical Disruption....163
    Clinical Implications and Recommendations....165
    Limitations and Directions for Future Research....169
    Conclusion....172

References....174

Appendix A: Descriptive Statistics from the Preliminary Scoping Survey....213

Appendix B: Study Information Sheet....214

Appendix C: Interview Guide....217

Appendix D: Research Case Study....218

List of Tables and Figures

Table 1: Demographic Information of the Participants……………………….………….. 70

Figure 1: Beck's (1979) Cognitive Triad……………………………...……….…………. 78

Figure 2: Map of Core Themes and Subthemes……………………………...……………. 80

Table 2: Overview of Themes and Subthemes……………………………....……………. 81

Figure 3: Beck's (1979) Cognitive Triad Adapted to the Present Study……………………. 162

Table 3: Descriptive Statistics for the Survey Responses Assessing Desire for a Psychosocial Programme……………………………..……………………..……...…………. 213

Chapter 1: Introduction

Medical advancements have substantially improved the prognosis of childhood cancer (Ballantine & NZCCR Working Group, 2017a). This means that, today, successfully completing childhood cancer treatment is the most probable outcome for those diagnosed. Life after cancer has therefore, become clinically important for an increasing number of children and their families. Yet, while the likelihood of successfully completing cancer treatment has increased, this end of treatment period is often coloured by complex and contradictory emotions (Duffey-Lind et al., 2006; Wakefield et al., 2010). Subsequently in the long-term, there are lasting physical, social, and emotional effects of the cancer experience, requiring continued medical involvement (Ander et al., 2018; Björk et al., 2011). Despite this, the long-term impact of the childhood cancer experience on parents/caregivers has not received adequate attention within research or clinical practice. As such, the nuances and intricacies of the long-term experience for parents/caregivers remains poorly understood.

Therefore, an exploration into long-term parental experiences of childhood cancer forms the basis for the present study. To begin, this introduction first explains the rationale behind exploring the experiences of parents/caregivers during the long-term period after their child's cancer treatment. Specifically, it considers the continued impact of the cancer experience in the years after completion of cancer treatment. This introduction then examines the epidemiology of childhood cancer, the context of Aotearoa New Zealand, and the phases of the cancer experience, to better situate this research within a context.

The Continuity of Cancer

Childhood cancer brings about significant change to family life that affect the roles and relationships between family members; and each family member has their own experiences, responses, and coping strategies to the cancer (Hosoda, 2014; Long & Marsland, 2011; Patterson et al., 2004). Therefore, the ripple effects of the childhood cancer experience means that not only the child, but the whole family is affected. In particular, parents/caregivers, as the heads of the family unit, can experience a number of stressors and challenges throughout the childhood cancer experience. For parents/caregivers supporting a child through treatment for cancer, a life-threatening illness, may be one of the most emotionally distressing and physically draining challenges they could face (Pai et al., 2007).

Following their child's cancer treatment, it is evident that a subgroup of parents/caregivers continue to report high psychological distress (Carlsson et al., 2019). A study by Vetsch et al. (2017) found that 42% of parents/caregivers whose child was at least five years post-diagnosis and had been previously treated at hospitals across Aotearoa New Zealand and Australia reported experiencing anxiety and/or depression. Thus, the psychological distress associated with cancer does not end once the child has completed active cancer treatment.

This is exemplified in the work undertaken by Dr Fitzhugh Mullan – a medical doctor and co-founder of the National Coalition for Cancer Survivorship in the United States who reflected on his own experiences of cancer:

> *Despite this success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can (Mullan, 1985, p. 273)*

In other words, while the disease is in remission, the 'experience' of cancer remains. Over the past few decades since Mullan wrote this article, a growing population of individuals affected by childhood cancer and their families have emerged, and research in this area has increased. However, most studies on the psychosocial impact and experience of childhood cancer have focused largely on experiences (i) at diagnosis and during active treatment (Gibbins et al., 2012; Long & Marsland, 2011); or (ii) at the end of treatment (Conway Keller et al., 2020; McKenzie & Curle, 2012). Consequently, little is known about long-term experiences after successful childhood cancer treatment; and when studies have explored long-term experiences, this has mainly focused on adults who were diagnosed with cancer as children and not the long-term impact on the wider family (Signorelli et al., 2017; Skinner et al., 2006).

As a result, understanding the complexities of parent/caregiver experiences in the long-term after their child's cancer treatment - and their perceptions of how their experiences of their child's cancer might be integrated into their sense of self and relationships with others - is not well understood. A more thorough and extensive insight into long-term parental experiences will contribute to understanding their perceptions of the long-term impact of childhood cancer. While there has been some valuable research conducted into the cancer experiences of patients, their siblings, and parents in Aotearoa New Zealand, these studies are few in number; and none of the Aotearoa New Zealand research has qualitatively explored the long-term experiences (considered to be at least five years post-diagnosis). One explanation for this is due to the framing of childhood cancer through a biomedical lens in which the child is considered to be biomedically 'cured' of the cancer. This is despite the potential for many ongoing medical, emotional, and social needs for the child and the impact this has on the parents/caregivers. Therefore, there is a need for exploration into long-term experiences in this period within Aotearoa New Zealand. While the present study explores the experiences of parents/caregivers in the long-term after their child's cancer treatment, it is first important to explain childhood cancer and the context of this research in Aotearoa New Zealand.

Epidemiology of Childhood Cancer

It is essential to set the scene for this thesis by providing an introduction and overview to childhood cancer, particularly in Aotearoa New Zealand. Under clinical definitions, cancer is an umbrella term that encompasses more than a hundred different diseases marked by abnormal and malignant cell growth (Cancer Institute NSW, 2018). Cancer can affect the cells in any part of the human body; cancer can differ in type (and consequently) symptomatology, treatment options, and prognosis (Cancer Institute NSW, 2018; National Cancer Institute, 2019). In 2019, 150 children (aged between 0 and 14-years-old) were diagnosed with cancer in Aotearoa New Zealand (Te Aho o Te Kahu, 2021) with this incidence not varying substantially year-to-year (Ministry of Health, 2016). Each year in Aotearoa New Zealand, over 320 children receive active treatment and this treatment can last several years (Ministry of Health, 2016). The four most common types of childhood cancer in Aotearoa New Zealand are leukaemia (cancer of the white blood cells), central nervous system and intracranial/ intraspinal neoplasms (brain tumours), lymphoma (cancer of the lymphatic system), and neuroblastoma (cancer of the nerve cells) (Ballantine & NZCCR Working Group, 2017b; KidsHealth NZ, 2011).

Childhood cancer also differs to adult cancers. Firstly, there are a number of lifestyle risk factors for cancer in adults, which are not thought to play a role in childhood cancers (Spector et al., 2015). Further, childhood cancer differs from cancer in adults in respect to incidence and characteristics. Paediatric cancer is rare, with an incidence rate of 15 per 100,000 Aotearoa New Zealand children aged 0-19 years old (Ministry of Health, 2016). Taken together, while many people may be affected by adult cancers, the experience of being affected by childhood cancer is less common.

The overall childhood cancer incidence in Aotearoa New Zealand is comparable across ethnicities (Ballantine & NZCCR Working Group, 2017b). Age and gender appear to be the only demographics that hold a significant difference in the incidence of childhood cancer, with males and children under the age of five-years-old having an increased incidence of a childhood cancer diagnosis (Ballantine & NZCCR Working Group, 2017b). Cancer is Aotearoa New Zealand's leading cause of disease-related death in children aged 1-14 years old (McDonald et al., 2018). However, due to advances in multimodal therapies, the five-year survival rate of childhood cancer (meaning the probability an individual will survive their cancer for five years after diagnosis) in Aotearoa New Zealand has increased significantly to 84% (Ballantine & NZCCR Working Group, 2017a; O'Leary et al., 2008). The five- and ten-year survival rate in Aotearoa New Zealand holds no statistically significant differences across ethnic groups, socio-economic status or geographic location (Ballantine & NZCCR Working Group, 2017a). Further, the survival rate of childhood cancer in Aotearoa New Zealand is comparable to other developed countries, such as Australia, Canada, the United States, Switzerland, and Germany (Ballantine & NZCCR Working Group, 2017a). To better understand the childhood cancer experience, it is important to next outline the Aotearoa New Zealand context and the healthcare system as it relates to childhood cancer treatment.

The Aotearoa New Zealand Context

The section that follows describes the Aotearoa New Zealand context, healthcare system as well as the context of Covid-19 as the backdrop of the present study. Research on the outcomes and experiences after childhood cancer treatment has been an increasing focus; however, much of this research has been conducted in North America, Australia or Europe (Engelen et al., 2011; Ljungman et al., 2016; Maurice-Stam et al., 2008; Ortiz & de Lima, 2007; Wakefield et al., 2013). While there are cultural and economic similarities between Aotearoa New Zealand and the contexts in which this field of psychosocial oncology research has largely been situated, there are also some distinct context-specific elements unique to

Aotearoa New Zealand. Studies on experiences after childhood cancer treatment in Aotearoa New Zealand can therefore complement this growing body of knowledge.

In Aotearoa New Zealand there is higher exposure to UV radiation that is potentially carcinogenic, which has led to increased awareness and campaigns around skin cancer (Health Promotion Agency & Melanoma Network of New Zealand, 2017). There have also been promotions of screening and preventative measures for other types of cancer in Aotearoa New Zealand (e.g. smoking cessation and lung cancer; male health charities and screening for prostate cancer; HPV vaccines and cervical cancer; and pink ribbon breakfasts and breast cancer). Despite the awareness programmes and increased screening for many cancers, the pervasive impact of cancer means that over the course of their lifetime, most of the Aotearoa New Zealand population will be affected by cancer, either through a personal experience of having cancer or through the experience of family/whānau or friends (Ministry of Health, 2022). Yet, as previously noted, childhood cancer differs from adult cancers, which means that screening programmes are not common for children.

Aotearoa New Zealand's healthcare system is uniquely structured. The healthcare system is funded and managed by the Ministry of Health. In July 2022, Aotearoa New Zealand's healthcare system transitioned from being made up of twenty District Health Boards (DHBs) which covered different geographical catchments, with each providing healthcare services for individuals within the area. These DHBs were merged into Te Whatu Ora, which is one healthcare system that delivers healthcare across the country (Ministry of Health, 2021). The healthcare system operates with more resources being commonly allocated to major population areas (i.e. Auckland, Christchurch, and Wellington).

The two main treatment hospitals for childhood cancer are Starship Child Health, Auckland and Children's Haematology and Oncology Centre (CHOC), Christchurch. In 2018, two thirds of children diagnosed with cancer received initial treatment at Starship, and one third were treated at CHOC (Ballantine & NZCCR Working Group, 2018). Consequently, many families who are located at a distance from the Auckland or Canterbury regions need to travel away from their homes and communities to attend treatments. This can cause an additional stressor for the family. Starship and CHOC work closely with 14 regional shared care centres across Aotearoa New Zealand that support children with cancer who live outside Auckland and Christchurch (Te Aho o Te Kahu, 2021). As a result, a large amount of communication and collaboration is required within Te Whatu Ora. This allows for treatments and follow-up care to occur as close to home as much as possible (Ballantine & NZCCR Working Group, 2017b). Nonetheless, the location of specialist services and individual treatment protocols means that many families will need to travel for treatment.

Alongside the public healthcare setting, non-government organisations such as Child Cancer Foundation provide valuable and vital support to families after cancer. Child Cancer Foundation is a non-government organisation established in 1978 by parents and healthcare staff due to the lack of support available for families affected by childhood cancer (Dawson, 2013). Child Cancer Foundation provides support to children who have been diagnosed with cancer, aged 0-20 years-old, as well as their families across Aotearoa New Zealand. The services offered by Child Cancer Foundation include individualised support from a Family Support Co-ordinator, national programmes for parents/caregivers to foster peer support, volunteer Connect Groups which promote social connections at a regional level, and Personal Development Grants to children affected by cancer to support their education. Organisations such as Child Cancer Foundation are increasingly raising awareness and offering education and support around psychological difficulties post-treatment, as well as directly addressing these difficulties experienced through the provision of informational support, resources, workshops, webinars, and interventions (Patterson et al., 2014). Child Cancer Foundation also works closely with the National Child Cancer Network, the governing body for childhood cancer in Aotearoa New Zealand. The National Child Cancer Network brings together health professionals and organisations for collaborative work and encompasses a spectrum of services to treat and support children with cancer and their family/whānau in Aotearoa New Zealand (Te Aho o Te Kahu, 2021). In summary, Child Cancer Foundation plays an important role in supporting parents/caregivers through childhood cancer treatment, bereavement, and after cancer treatment.

To give further background to the context, the present study took place against the backdrop of a global pandemic. The first case of Covid-19 in Aotearoa New Zealand was reported in February 2020. One month later, the World Health Organisation declared a global pandemic and Aotearoa New Zealand went into a nation-wide lockdown. The interviews for the present study took place between July and August 2021 when there was no lockdown and where an elimination strategy had (so far) successfully stopped the spread of Covid-19, meaning that there were zero cases of Covid-19 in the community at that time. This government strategy around the management of Covid-19 changed a few months later. Stating this context of Covid-19 in relation to Aotearoa New Zealand is important as at that time, the number of community Covid-19 cases and the strategy adopted by other countries was vastly different.

While there were no community cases of Covid-19 in Aotearoa New Zealand at the time of the interviews, the pandemic had amplified fears around the world for children and their parents/caregivers after cancer treatment (Darlington et al., 2020). This was commonly linked to the stress and uncertainty of having a child with a compromised immune system, a sequalae of cancer, which meant they had added susceptibility to viruses such as Covid-19 (Guilcher et al., 2021; Sullivan et al., 2020). Parents/caregivers also had to deal with the consequences of the cancer experience which were reportedly exacerbated by the challenges of the pandemic. These included financial difficulties and greater social isolation due to restrictions on visitors as well as reduced access to support services (Davies et al., 2022; Jammu et al., 2021). Nevertheless, a qualitative study by Davies et al. (2022) in Australia found that parents felt that the Covid-19 pandemic increased the community's awareness of infection control and therefore improved the community's understanding of their needs. This historical background mixed with the distinctive position of parents/caregivers of children who have undergone cancer treatment provides important context to participant accounts and forms a unique backdrop for experiences to form.

Treatment Phases

To better understand the childhood cancer experience, it is essential to outline the treatment for childhood cancer. Childhood cancer is typically viewed in distinct phases: diagnosis and the initiation of treatment, active treatment, and treatment completion (Vannatta & Salley, 2017). Each of the treatment phases brings unique challenges for the child and the family (Vannatta & Salley, 2017). This succession of relatively concrete stages of treatment is often likened to a journey (Miedema et al., 2007). While these are described as distinct phases, in actuality, the experience may not be linear and the child with cancer may move between such phases, with some facing a transition into palliative care. Therefore, rather than moving between binary notions of sickness and health, the cancer experience unfolds along a continuum, with the child and their family facing distinct challenges along the way (Lea et al., 2018). The section below factually describes these treatment phases, and a more detailed account of the psychological experiences of these phases for parents/caregivers is given in Chapter 2.

Diagnosis and Initiation of Treatment

A diagnosis of cancer brings understandable shock and emotional distress to the family, requiring parents/caregivers to make quick decisions and absorb a large amount of new and complex information (Hart et al., 2020). The initiation of cancer treatment causes significant stress and adjustments for the family who have to cope with a new reality (Conway Keller et al., 2020). It requires some families to make changes to their employment and they may have increased travel or need to move closer to treatment centres (Conway Keller et al., 2020; Gibbins et al., 2012).

Active Treatment

During active treatment, the child undergoes an intensive treatment regime that results in physical pain and side effects for the child, and which also shifts family routines and roles. Treatment for childhood cancer commonly includes one or a combination of three main oncology treatments: surgery, radiation therapy, and chemotherapy (Ward et al., 2014). In Aotearoa New Zealand, active treatment would occur in one of the two main paediatric oncology treatment centres (Starship or CHOC). Active treatment for childhood cancer varies in the type, length, and intensity of treatment, but typically the majority of children will remain on active treatment for at least one year (Kazak & Noll, 2015). Therefore, families can experience significant stress and change associated with cancer treatment for a long period of time.

Treatment Completion

The end of cancer treatment brings new challenges. The completion of cancer treatment is also often characterised as a period of ‘transition’ which is coloured with uncertainty, heightened anxiety and the re-establishing of a ‘new normal’ in the family’s life, roles and routines (Conway Keller et al., 2020; Vannatta & Salley, 2017). While this distress can be transitory, some families and parents can experience distress for years after treatment is completed (Sharp et al., 2022).

The end of treatment is also associated with regular ‘surveillance’ of the health of the affected child to monitor and identify the onset of ‘late effects’. These late effects arise due to the cancer’s intensive treatment which when administered to young people’s developing organs can increase risks for health issues throughout their life (Patenaude & Kupst, 2005; Stein et al., 2008). ‘Late effects’, ‘late sequelae’, or ‘late morbidity’ are health-related problems related to the cancer or cancer treatment (Signorelli et al., 2016). Late effects are experienced by over 60% of children who were diagnosed with cancer and may include: damage to a variety of organs (e.g. cardiovascular, neurological, and metabolic systems); emotional distress (e.g. anxiety and depression); cancer recurrence (e.g. secondary malignancies); developmental problems (e.g. deficiencies in growth and hormones); reproductive problems (e.g. infertility); learning difficulties; and physical health conditions (Hewitt et al., 2003; Hsiao et al., 2018). For example, late effects from intracranial/intraspinal neoplasms (brain tumours) may include hypothyroidism, diabetes insipidus, short stature, obesity, attention impairments, and vulnerability to psychological distress (Hocking et al., 2011). In addition, compared with adults who were diagnosed with cancer and the general population, children after cancer treatment are at increased risk of premature mortality, chronic morbidities, and poorer mental health (Hudson et al., 2013; Siegel et al., 2012; Stein et al., 2008). Yet, many late effects do not manifest until years or even decades after treatment (Diller et al., 2009).

Thus, for the majority of families, the impact of cancer lasts well beyond treatment completion. This long-term period after childhood cancer treatment forms the basis for exploration of the experiences of parents and caregivers in this thesis. The present study builds on the knowledge that cancer has long-term implications.

Chapter 2: Literature Review

The following chapter aims to provide a review of literature pertaining to the present study. This chapter will begin with a critical evaluation of terms central to the present study; in particular the terms ‘survivor’ and ‘survivorship’ are explored, to set the scene for common terminology used for the time period after cancer treatment. Following this, the chapter moves on to outline the centrality of socio-cultural contexts that are embedded within the experience and the ‘making sense’ of cancer. Next, research into the experiences of parents/caregivers at their child’s diagnosis, in treatment, at the end of treatment, and in the long-term is reviewed. During this critical analysis, attention is paid to reviewing the gaps in the research, particularly the gaps in understanding the nuances and complexity of parental experiences in the long-term. The final section discusses the rationale for the present study.

Survivor Terminology

Given the period after cancer treatment is at the centre of the present study, it is necessary to now explore the terminology related to this time period. In the section that follows, I will define and critically examine the meaning of terms such as ‘survivorship’, ‘survivor’, and ‘survival’. Throughout this section, I will outline key concepts and foci for the present study’s approach to this field of research.

It is necessary to clarify what is meant by the term ‘survivor’ in general and particularly in relation to cancer. The term ‘survivor’ is generally understood to mean a person who lives through an immediate threat to their life (Orgad, 2009). This term has come to be used to refer to a wide range of experiences and phenomena, such as individuals who have lived through the Holocaust, domestic violence, child abuse, natural disasters, and acute illness (Orgad, 2009). The term ‘survivor’ has become increasingly more prominent in our cultural and historical context in the last couple of decades. The increasing use of the term ‘survivor’ is argued to be due to a desire for a shift in language that reflects empowerment rather than passivity that is reflected in language such as ‘victim’ (Orgad, 2009). However, this term has not been without its critics, both in general discourse and within the illness literature.

The ‘survivor’ discourse has come into focus in health and illness, particularly in reference to cancer (Orgad, 2009; Saillant, 1990). Yet, the definition of cancer survivorship, as well as what makes someone a ‘survivor’ has been subject to ongoing debate within oncology (Berry et al., 2019; Cheung & Delfabbro, 2016). Dr Fitzhugh Mullan (1985), a medical doctor whom himself had cancer, wrote reflections of his own experiences with cancer which subsequently contributed to the term ‘survivor’ being used within oncology. Mullan (1985) construed survival as encompassing three stages (acute, extended, and permanent), while likening their continuous nature and transitions between stages to the changes of seasons. He defined ‘cancer survivorship’ as being aligned with the latter stage, the permanent stage, where the risk of cancer recurrence is low (Mullan, 1985). Mullan (1985) posits that survivorship is the middle ground between ‘sickness’ and ‘cure’, which emphasises remission (i.e. the abatement of the symptoms of disease), and relative survival (i.e. statistical probability of survival given the time since treatment). This formulation of cancer survivorship, which was developed over 30 years ago, was pivotal to increasing awareness and research on this latter stage of the cancer experience and highlights the ongoing psychosocial and medical needs of individuals who have undergone cancer treatment. Yet, only defining survivorship as being in the ‘permanent stage’ does not account for the people who survive with cancer for extended periods of time but cannot be ‘cured’ of cancer according to medicine (Cheung & Delfabbro, 2016; Feuerstein, 2007). To account for these multiple experiences of survivorship, and to be more inclusive of the multitude of experiences, the definition has been extended to describe the experience of living with and beyond cancer, which starts at diagnosis and continues throughout the lifespan (Shapiro, 2018). Despite this, Berry et al. (2019) emphasise that labelling these individuals as a cancer 'survivor' is a misapplication of the concept when many will die from cancer.

In addition, this formulation oversimplifies cancer survivorship, which is a complex and heterogeneous experience (Berry et al., 2019; Cheung & Delfabbro, 2016). Therefore, attempting to define cancer survivorship has resulted in constructing and producing a template for which lived experience is then mapped onto (Bell & Ristovski-Slijepcevic, 2013). Consequently, the cancer survivorship definition inescapably misrepresents and marginalises some experiences, while simultaneously reproducing normative experiences due to the singularity of a definition (Bell & Ristovski-Slijepcevic, 2013; Steinberg, 2015). The limitations of these templates of experiences - created from broad biomedical definitions around cancer survivorship - calls for a shift in focusing on how people who have had cancer want to be identified. This highlights the need for cancer survivorship to be understood as being a broad set of experiences, situated within (and influenced by) people's socio-cultural contexts, rather than relying on biomedical categorisations (Berry et al., 2019).

While many organisations state that survivorship begins at diagnosis, more recently, the focus has shifted to the post-treatment period (Jefford et al., 2013). The long-term survivorship period is now often marked as starting when someone is five-years post-diagnosis and is without signs of the disease (Vannatta & Salley, 2017). This change has come about due to an increasing population of individuals who have successfully finished cancer treatment and the acknowledgement of the distinct, ongoing, and complex needs that characterise the post-treatment period (Berry et al., 2019). For childhood cancer, the tensions of labelling survivorship are distinct from that of adult cancer due to the higher statistical likelihood of successfully completing cancer treatment and the issue of late effects. There is an ever-growing population of children who have completed cancer treatment. Yet, these children are impacted in the long-term by the cancer experience, with physical and psychological late effects. In addition, frequently, after active cancer treatment, children will continue with some form of other treatment, management, or surveillance. This adds to the ambiguity of locating when cancer is ‘survived’, as when an individual is in remission the possibility of cancer recurrence continues (Horlick-Jones, 2011; Rees, 2017). Consequently, defining when the disease ends is unclear (Feuerstein, 2007). Despite these issues with defining cancer survivorship, most perspectives agree that life after cancer treatment involves perpetual and lifelong demands (Frank, 2003).

The literature around the definition of ‘cancer survivor’ has also extended to include parents/caregivers, partners, and other family/whānau members supporting the individual with cancer (Rowland et al., 2006). Some definitions have labelled this wider support network as ‘cancer survivors’ due to the centrality of the support system while an individual is going through the experiences of treatment and post-treatment. However, just like cancer survivors themselves, parents/caregivers and support systems have their own unique and heterogeneous experiences (Weaver et al., 2021). The social and emotional impact of the cancer experience is not equivalent between the person with cancer and the family and support system. Furthermore, defining the support system as a cancer ‘survivor’ muddies the ability to make sound comparisons in the findings between those who have gone through the treatment themselves and those who have supported them (Feuerstein, 2007). Feuerstein (2007) argues that families and support systems have not themselves experienced cancer biologically or functionally and therefore should not be called cancer ‘survivors’. In line with this argument, while I acknowledge the issues with labelling support systems as ‘survivors’, it is clear that they are a group of people who have distinct psychological needs and unique experiences that need to be addressed alongside the ‘survivor’.

Empirical research has also indicated that the label ‘cancer survivor’ is embraced by some people with cancer while others feel neutral or alienated by the label (Berry et al., 2019;

Cheung & Delfabbro, 2016). A qualitative study by Smith et al. (2016) explored the salience of cancer in people's self-concept for individuals who had completed cancer treatment. The study found that not all interviewees espoused a survivor identity, and some explicitly rejected 'survivorship' in how they thought of themselves or how they presented themselves to others (Smith et al., 2016). Further, some presented a complex and multi-faceted view of a 'survivor' identity with the concept serving some limited utility at certain times or in certain situations (Smith et al., 2016). This illustrates how a 'cancer survivor' identity can be thought of as a social construction for which there is no universal understanding or definition, and that the term can be utilised differently across contexts. This has resulted in a calling for exploration into how people who have experienced cancer want to be identified, as well as actively involving those who have experienced cancer in defining cancer survivorship and what it means to be a cancer survivor (Berry et al., 2019).

This thesis recognises the definition of 'cancer survivor' and 'survivorship' as an evolving concept. Due to the term 'survivor' holding particular connotations and meanings with associated emotions in the context of childhood cancer, this thesis will focus on the more descriptive term of 'those who have completed cancer treatment'. It is noteworthy that no previous studies have specifically explored parents/caregivers' perspectives of 'survivor' terminology. An exploration into parents/caregivers' experiences and perspectives of survivorship will help weave together a greater understanding of attitudes towards these societal discourses and will add to this debate on 'survivor' terminology.

Socio-Cultural Understandings of the Cancer Experience

In the following pages, I will examine the importance of considering the socio-cultural context by exploring the dominant discourses surrounding cancer in the societal language and meanings of illness. This is important because I frame the research from a social constructionism framework that acknowledges the social, cultural, and historic context that experiences are embedded within. This section explores biographical disruption theory and critically examines cancer discourses and, in particular, the use of metaphoric language. This exploration of language further enriches the aforementioned critique of how dominant discourses do not sufficiently understand the cancer experience.

In the early 1990s, in her seminal article Saillant (1990) delved into the language used in cancer discourses, where she uncovered how the framing of the cancer experience was largely around biophysical issues (e.g. diagnosis, prognosis, illness trajectory), rather than the lived experience of those affected. Saillant (1990) identified the need to contextualise the experience of cancer beyond this biomedical framing. In the same vein, Frank (1997) viewed individuals affected by cancer telling their narratives as playing a key role in bridging the gap between biomedical knowledge and understanding lived experiences. People affected by cancer make sense of cancer experiences in a way that reflects how they are situated within their cultural, historical, and biographical landscapes. It is impossible to separate making sense of the cancer experience from the meanings that are culturally inscribed in cancer because experiences are embedded within one's context (Plage, 2020). In turn, socio-cultural contexts can influence the meaning-making of the cancer, the emotional and practical difficulties experienced by families, as well as the coping strategies utilised in the paediatric oncology field (Gray et al., 2014; Klassen et al., 2012).

In society, a cancer diagnosis is a significant life event with social effects, as individuals with cancer can become defined within sickness narratives and their experiences become situated within socio-cultural meanings of that illness (Plage, 2020). In this way, the experience of cancer is argued to disrupt the life narrative and may initiate the development of a new personal identity of an individual, a 'survivor' identity (Little et al., 2000). As discussed previously, whether this 'survivor' identity is espoused by the individual should be examined.

Furthermore, the lived experience of significant illness disrupting identity and how it does this should be explored through the voices of those impacted by cancer.

‘Biographical disruption’ is a central theory in sociological literature on chronic illness which relates to identity disruption (Bury, 1982). This was first described by Bury (1982), and refers to changes in biography and self-concept as well as the disruption of taken-for-granted assumptions in the structures of everyday life, expectations, and plans for the future due to an illness diagnosis. This can affect how people view themselves and how they believe they are viewed by others, which is associated with a sense of social isolation and re-negotiation of self-identity (Cayless et al., 2010; Mathieson & Stam, 1995; Wilson, 2007). In this definition, the concept of biographical disruption describes the deep impact an illness diagnosis can have on the trajectory of a person’s life. Childhood cancer can be considered to be a chronic condition because cancer and its treatment is associated with a range of long-term effects including disability and infertility (Erdmann et al., 2021). Therefore, childhood cancer carries the potential to disrupt the biographies of the affected child (Lackner et al., 2000; Young, Dixon-Woods, Findlay, et al., 2002).

While the idea of biographical disruption is popular among chronic illness literature, the exploration of this concept in relation to parents/caregivers’ experiences is limited. It is understood that, since infancy, a parent envisions a certain life trajectory for their child and for themselves as parents (Sevón, 2012). Therefore, while a cancer diagnosis may be given to a child, this could have biographical implications on the parent/caregiver. Young et al. (2002) explored biographical disruption in mothers of children with cancer and described how having a child with a life-threatening illness meant that mothers’ own biographies were disrupted and they experienced profound grieving for their former lives. Yet, little is understood about biographical disruption in the experiences of parents/caregivers in the long-term after a childhood cancer diagnosis.

Along with society defining individuals with a cancer diagnosis through illness narratives, comes discourse and language that is promoted by popular culture and the media (Bell, 2012). Cancer, like other illnesses, is commonly communicated through metaphoric language particularly as a ‘journey’ and ‘battle’. In this context, cancer is often positioned as the enemy, and undergoing cancer treatment is represented in discourse as a metaphorical battle, fight, or journey (Seale, 2002). This can be problematic for a number of reasons. Firstly, this imagery can elicit feelings of fear (Chapple et al., 2004) and images of death (Hammoudeh et al., 2017). Cultural connotations of cancer associated with death, brings a fear of cancer into public discourse (Clarke & Everest, 2006; Hammoudeh et al., 2017; Vrinten et al., 2017). Secondly, when ‘battling cancer’ is used as a metaphor for when an individual is currently undergoing treatment, it unintentionally posits the idea that the affected individual has an influence or level of control as to whether they ‘win’ or ‘lose’. This then further (re)produces the ‘survivor’ and ‘victim’ template of cancer experiences (Bell & Ristovski-Slijepcevic, 2013). This language also suggests that the individual with cancer could earn their ‘survivor’ status or ‘win’ their battle if they fight the cancer successfully with personal willpower and aggressive treatments (Steinberg, 2015).

Similarly, there are ideas that adopting a lens of ‘bright-siding’ and positivity will help an individual be successful in their ‘fight’ against cancer (De Raeve, 1997; Ehrenreich, 2009). However, the idea of personal determination in curing cancer is problematic. A number of studies have commented on the role of emotions and mindset throughout the cancer experience and there is little scientific evidence in support of the concept that a ‘correct’ mindset (e.g. optimism or a ‘fighting spirit’) positively affects cancer recovery (Coyne & Tennen, 2010). It is argued that these notions of positive psychology are popular in public discourse not through scientific evidence but due to reflecting strongly held cultural beliefs, media portrayals, and values of the locus of control an individual has over their future (Coyne & Tennen, 2010). This prominent idea of ‘positivity’ has been criticised for placing a burden on the individual with cancer. This view is supported by De Raeve (1997) who argued that the promotion of positive thinking in cancer discourse reflects the social pressures of the world. Positivity sits in stark contrast with commonly cited emotions through cancer such as fear and sadness. Therefore, society promoting a ‘positive’ mindset can result in the disallowance of emotions such as despair and suffering.

When the framing moves from cancer diagnosis and treatment into post-treatment, the narrative shifts to metaphoric language of triumph, bravery, and gratitude (Algoe & Stanton, 2012; Seale, 2002; Staneva et al., 2018). This framing often intersects with the ‘battle’ metaphor in cancer. The qualities associated with the identity of a cancer ‘survivor’ include bravery and stoicism (Seale, 2002; Staneva et al., 2018). This creates a dichotomous social construction of cancer and ‘black-and-white’ thinking, with cancer as ‘bad’ and being cancer-free as ‘good’. Consequently, ‘survivorship’ becomes something to aim for as this symbolises ‘wellness’ or ‘winning the battle’. This suggests that the post-treatment experience is an ideal that will be positive and enjoyable. Saillant (1990) argued these expectations of stoicism and feelings of optimism and hopefulness after successful cancer treatment are potentially muffling expressions of distress and downplaying diverse experiences in the post-treatment period. Therefore, this may explain why individuals can feel as if their needs are not fully understood by their support system and wider communities (Norberg & Green, 2007).

In this way, the metaphoric language used may be mirroring social expectations that the cancer experience has an end-point, which further contributes to framing post-treatment as an achievement (Plage, 2020). These dominant cancer discourses conflict with the extensive literature documenting psychological distress experienced by children and their families both during treatment and in the transition to life after cancer (Deimling et al., 2002; Muskat et al., 2017). Further, experiences of distress are reported long after cancer treatment is over

(Deimling et al., 2002; Muskat et al., 2017; Wakefield et al., 2010). Therefore, the dichotomous cultural representation of the cancer experience does not sufficiently represent experiences. Instead, it is important to highlight the dynamic nature of emotions which are often contrasting and co-existing, for example allowing the complexity in emotions of feeling grief alongside joy (Broom et al., 2019; Plage, 2020).

Along with the terminology and metaphor of a 'battle', there is the overlapping idea of cancer as being likened to a journey along relatively concrete treatment phases and clinical milestones, from diagnosis to treatment and then recovery and post-treatment (or possible recurrence). The metaphors of the 'cancer journey' or 'cancer story' indicates phases of the illness and are argued to structure the experience and what can be anticipated (Crossley, 2003). While a cancer diagnosis is argued to disrupt the life narrative, the use of this story-like metaphor is argued to restore a sense of predictability (Steinberg, 2015). Therefore, they act as directional metaphors which arguably promote empowerment, resilience and hope in cultural imagination (Steinberg, 2015).

However, this prescriptive ordering of the sequence of events suggests the person with cancer (protagonist in the developing story) must make the 'right' choices such as enduring treatment (Broom et al., 2019; Steinberg, 2015). Further, concrete phases do not elucidate the complexities and nuances of experiences. This idea is reflected by Little et al. (2000, p. 2) who stated "…survival is not simply the end of the story of illness." The ongoing needs and distress after cancer treatment is lost in this conceptualisation which could lead to disempowerment and feelings of hopelessness if milestones are not reached. In summary, these dominant discourses discussed so far fail to account for the 'messiness' of human experiences in regard to the complexity of seemingly contrasting emotions and reproduces the template that distress ends at the point of treatment finishing.

More specifically, when considering childhood cancer as distinct from adult cancers, the association of cancer with death persists even though the prognosis for childhood cancers has greatly improved (Hammoudeh et al., 2017). When considering childhood cancer discourses exclusively, media accounts of children with cancer have been found to primarily portray the child as heroic, stoic, and inspirational, while parents are painted as the unremitting guardians (Clarke, 2005; Dixon-Woods et al., 2003). Unintentionally, these portrayals may create public expectations that are hard for the parent and child to fulfil (Dixon-Woods et al., 2003). The discourse around embracing a ‘survivor identity’ could marginalise those whose cancer experience remains a source of distress after cancer treatment (Lewis & Weston, 2019). This idealised portrayal of the child and their parents/caregivers after treatment may have potentially negative implications through assuming that individuals feel ‘triumphant’ after cancer. This narrow representation of affected individuals may, unintentionally, exclude and stigmatise those who do not feel like they fit this ‘warrior’ or ‘winner’ description (Kromm et al., 2007).

To conclude this section, I have reviewed how cancer experiences are embedded in an individual’s socio-cultural contexts and meanings of cancer. Our understandings of the cancer and post-treatment experience can be viewed through commonly used discourses and the metaphoric language used. Media and societal portrayals of the cancer experience both in treatment and once it has been completed, remain narrow in focus with perspectives of cancer largely being thought of in illness and clinical terms. In this vein, the post-treatment milestone is purported as the ‘ideal’ absence of illness. Yet, the impact of cancer lasts well beyond the cancer being biomedically ‘cured’. Therefore, this requires a shift away from exploring cancer experiences beyond the presence/absence of disease and towards a more nuanced understanding of the post-treatment experience.

Childhood Cancer and the Family

The experiences of parents/caregivers in relation to their child's cancer is an important topic for research. This is not only due to the psychological impact the cancer experience may have on the parent/caregiver, but also because of the effects that parental wellbeing can have on the entire family unit including the child with cancer. The section below describes how the cancer experience affects and creates change for the entire family/whānau unit. Further, this section describes how in accordance with family systems theories, each family member's reactions to the challenges across the trajectory of the cancer experience can impact on the experiences of other family members. Accordingly, the importance of exploring experiences of parents/caregivers is outlined. It is also important to note that while I acknowledge the importance of the entire family/whānau system (inclusive of extended family members) in the valuable roles they play throughout the child's cancer experience, most research has been carried out in Western settings with a focus on the experiences of the nuclear family. Therefore, the following review focuses on immediate family members (i.e. parents, siblings, and the child with cancer).

According to family systems theory by Bowen (1966), the family unit is viewed as a complex social system in which all members are interrelated and interdependent. Family systems theory posits that any change in an individual within a family is likely to influence the entire family system (Bowen, 1966). A review of the literature suggests that, when a child is diagnosed with cancer, all family members are affected by the illness (Michel et al., 2020; Patterson, 2002; Patterson et al., 2004; Salem et al., 2017). What happens to the child (i.e. the cancer diagnosis) impacts the other family members. In a circular sequence of events, how the family responds to the cancer plays an important role in the responses and experiences of the individuals within the family (child, parents/caregivers, and siblings) (Patterson et al., 2004). These theories conceptualise the distress and wellbeing of the child who was diagnosed with cancer as being affected by the distress and wellbeing of the whole family support system around the child, and vice versa. Furthermore, the family systems theories support the idea that enhancing parental wellbeing will lead to not only providing adequate support for parents/caregivers themselves but also would support the entire family/whānau.

In the paediatric psycho-oncology literature, exploration into the connection between parental distress and the child's distress over the cancer experience supports the role of family systems theories (Pai et al., 2007). For example, Bakula et al. (2020) conducted a meta-analysis which evaluated 14 studies (seven of which were families post-cancer treatment) and found a significant relationship between parental psychosocial distress and child quality of life outcomes. Further, Alderfer et al. (2009) conducted a study in the United States investigating the relationship between family functioning and post-traumatic stress disorder (PTSD) in adolescents after cancer treatment. This study reported that 75% of adolescents with PTSD originated from families categorised as 'poor functioning' according to a Family Assessment Device measure (Alderfer et al., 2009). Additionally, a prospective longitudinal study found that prolonged parental distress was associated with internalising symptoms (e.g. depression, anxiety) of young adults after cancer treatment (Robinson et al., 2009). The methods in these studies utilised quantitative measures, such as assessments of 'family functioning' or assessing clinical symptomology according to clinical diagnostic criteria. These methods have their drawbacks as the family system is a complex structure and each family has unique interactions and multifaceted dynamics. Therefore, measuring 'family functioning' through a psychometric tool is not appreciating the complexity of the family as a multifaceted social system and not appreciating socio-cultural context which influences the understandings and experiences of illness. The complexity within experiences may not be synonymous with the binary categorisation of 'functioning well' and 'not functioning well'. Further, assessing clinical symptomology is problematic when a family is coping with understandable distress in the face of cancer (Kazak et al., 2007).

The complexity of experiences may also not be fully captured within family systems models, as previous studies have also found mixed findings in exploring the association between parental and child distress. For example, some studies have found that greater perceived family support may be predictive of higher posttraumatic stress or depressive symptoms for the child after cancer treatment (Corey et al., 2008; Kazak et al., 1997; Stuber et al., 1997). It has been postulated that these findings may be reflective of the child's distress being linked to greater parental dependence or enmeshment, which is at conflict with the developmental goals associated with adolescence (Corey et al., 2008; Sansom-Daly & Wakefield, 2013). Instead, what may be more important than assessing based on clinical diagnostic criteria or quantifying family functioning (as measured by mental health psychometrics), is perhaps the quality of the parent-child relationship and interactions (Schepers et al., 2019). For example, studies have found a link between parental overprotection and increased distress and decreased health-related quality of life in the child (Hullmann et al., 2010; Tillery et al., 2014). Other studies have found that positive parent-child relationships (e.g. parental warmth, perceived better quality of the relationship) were associated with higher quality of life for the child (Orbuch et al., 2005). Nonetheless, such surveys measuring 'quality of life' omit the complexity and nuances of the understanding of experiences.

While family systems theories point to the importance of a family's adjustment and coping in the cancer experience, it is clear that much of the research focuses on quantitative measures of psychological distress and is not focused on the families once the child has finished active treatment. Consequently, the intricacies of parental experiences on the child's experiences after child cancer treatment may not be currently fully understood, but should not be underestimated. It is important to move beyond the individual with cancer and into considering the unique experiences of those affected within the family system. Studies that concentrate on factors specific to individuals affected by cancer are making an assumption that the experience is isolated from the wider family/whānau. Thus, these do not take into account systemic theories or the importance of family/whānau within collectivist cultures. Parents/caregivers do play a significant role within the family unit, and it therefore is important to pursue a more in-depth exploration into understanding their experiences after their child's cancer treatment. Further, a social constructionist lens is useful in appreciating how each family is different in their values, responses, and experiences; and also allows for consideration of culture and a range of family structures.

Parental Experiences

In the following sections, I focus on reviewing the literature on the experiences of parents/caregivers across the stages of their child's illness. This review highlights that parents/caregivers of children with cancer face significant physical, psychological, social, and existential struggles. Firstly, I will examine research that has explored the experiences of parents/caregivers at their child's diagnosis and during active treatment. Then, I will evaluate research on parental experiences at the end of treatment and during the transition away from treatment. Following this, research on the long-term experiences after their child's cancer treatment is critically examined. This chapter identifies gaps in the research and provides a rationale for exploring the stories, experiences, and narratives of parents/caregivers in the long-term after their child's cancer treatment.

Diagnosis and Active Treatment

Much of the literature on parental experiences in relation to childhood cancer has investigated parental experiences and the impact of childhood cancer at the time of diagnosis and during cancer treatment (Björk et al., 2009; Flury et al., 2011; Gibbins et al., 2012; Kazak et al., 2005; Long & Marsland, 2011). These studies have illuminated the multidimensional and temporal aspects related to the experiences of parents/caregivers during this period. I will explore the literature's key topics that are characteristic of this period including shock, uncertainty, psychological distress, existential concerns, family adjustment, and social relationships under the subheadings below.

Shock and Managing an Uncertain Situation. A childhood cancer diagnosis is often experienced by parents/caregivers as completely unexpected (Carlsson et al., 2019). Parents' initial reactions to their child's cancer diagnosis can include a mix of emotions including shock, denial, worry, and loss (Wong & Chan, 2006). A sense of uncertainty in the face of a life-threatening situation has also been frequently discussed in the literature (Carlsson et al., 2019; Flury et al., 2011; Mishel, 1988). A state of increased uncertainty can be understood as being triggered from situations that are ambiguous, novel, and unpredictable such as a parent experiencing their child's cancer diagnosis (Hebert & Dugas, 2019). The literature describes this uncertainty as encompassing intense fears and worries about the outcome of their child's cancer treatment, particularly fears around their child dying. Despite the improved prognosis of childhood cancer (Ballantine & NZCCR Working Group, 2017a), parents/caregivers fear their child dying and have to confront the uncertainty of this life-threatening situation. A parent facing the possibility of their child's death increases this state of uncertainty, causing increased distress including feelings of anxiety, worry about potential consequences, and safety strategies intended to reduce negative consequences (Hebert & Dugas, 2019). To cope with these fears, the research has discussed how parents engage in various behaviours with the aim of protecting their child (van Warmerdam et al., 2019). Parents have reported they feel a strong desire to control this uncontrollable situation through closely observing and monitoring their child's health status in order to feel in control and detect any deteriorations in their health (van Warmerdam et al., 2019). In this way, the treatment period has been described as a chaotic and uncontrollable situation (Carlsson et al., 2019). A sense of powerlessness and a feeling as though their child’s future was in the hands of healthcare staff has been described as stressful (van Warmerdam et al., 2019).

Psychological Distress. Along with these feelings of uncertainty and stress, many studies have explored other psychological aspects experienced by parents/caregivers due to a diagnosis of childhood cancer and have argued for the considerable impact it has on the psychological wellbeing of the parents (Pai et al., 2007). Parents’ psychological distress has been described in studies at their child’s diagnosis (Pai et al., 2007), and throughout cancer treatment (Wijnberg-Williams et al., 2006). Particular attention in research has been paid to studying the presence of post-traumatic stress symptomology. This may be due to a diagnosis of childhood cancer having been referred to in the literature as a high-stress life event or crisis (Arnold, 1999; Tedeschi & Calhoun, 2004). The prevalence of trauma-related symptomology is marked, with a study by Kazak et al. (2005) that reported that only one parent out of a sample of 171 was assessed to not have post-traumatic stress symptoms. Similarly, a more recent study by Katz et al. (2018) found that during treatment 74.3% of parents/caregivers experienced depression symptomology and 37.3% of parents/caregivers had post-traumatic stress symptomology above clinical cut-offs. These studies are helpful in indicating the presence and extent of psychological distress that some parents/caregivers experience.

However, measuring psychological distress through symptom criteria for mental health disorders may pathologize an understandable reaction to the shock of diagnosis and the life changes and emotions in cancer treatment. Further, most previous studies on the psychological experiences of parents in relation to their child’s cancer have used symptom-focused perspectives, often utilising a PTSD framework (Bruce, 2006; Kazak et al., 2005). However, a more diverse manifestation of psychological distress may be present; therefore, only relying on certain presentations or frameworks may limit the overall understanding of the impact of the cancer experience on parents/caregivers. Further, as described in the previous section on socio-cultural understandings of the cancer experience, it is clear that experiences and meaning-making are embedded within socio-cultural contexts which influences how affected individuals psychologically experience their child’s cancer, and therefore it is important to contextualise this human experience (Banerjee et al., 2011).

In the same vein as being aware not to pathologize an understandable reaction to a major life stressor, studies have drawn comparisons between parents’ reactions and coping strategies in this period as similar to bereavement (Wong & Chan, 2006; C. H. Yeh, 2003). A qualitative study by Wong and Chan (2006) generated four themes to describe parental coping experiences during their child’s cancer treatment: shock and denial, confronting the reality, establishing the meaning of the situation, and establishing a new perspective. These themes illustrate the stages in parental reactions to their child’s cancer which is similar to bereavement with initial shock followed by confrontation and disorganisation, and then finally acceptance and reorganisation (Wong & Chan, 2006). This sense of grief or bereavement appears to be centred around grieving for the life they and their child had before cancer and adjusting to cancer treatment. This is a rich understanding which posits the question as to whether this process of grieving one’s life before cancer has links to the aforementioned theory of biographical disruption.

Existential Concerns. Studies that report on the psychological impact of a parent/caregiver receiving their child’s cancer diagnosis include notions of existential struggles. Theorists have posited that an existential crisis can be consequential to being confronted with an extremely stressful event (Carreno & Eisenbeck, 2022). This involves the breakdown and reorganisation of a person’s assumptive world (Calhoun & Tedeschi, 1999). In this way, the cancer diagnosis and treatment evoke existential concerns particularly centred around meaning in life and meaning-making processes (Carreno & Eisenbeck, 2022). The previously discussed study by Wong and Chan (2006) does not overtly discuss this concept but does point to hints of existential psychology with the way in which the study describes the reconstruction and establishment of meaning within the cancer experience and how parents cognitively process in treatment through comparing their experience with others' experiences of childhood cancer.

Similarly, a qualitative study by Yeh (2003) found one core central organising category for parents during their child's diagnosis and treatment of 'coming to terms', in which parents attempt to accept their new reality of the cancer and face each new hurdle which all come with themes of change, recognition, and adjustment. Other studies have described that the experience of their child facing a life-threatening disease and the change in future prospects can elicit existential questions for parents (Forinder & Lindahl Norberg, 2010; Van Dongen-Melman et al., 1998; Vance et al., 2004). For example, parents/caregivers may experience thoughts of the situation as unfair, and have thoughts about death and mortality with particular fears of losing their child (Forinder & Lindahl Norberg, 2010; Wong & Chan, 2006).

An existential crisis following a traumatic experience can result in several potential outcomes such as post-traumatic stress or post-traumatic growth (Forinder & Lindahl Norberg, 2010). This coincides with the aforementioned research over the past few decades which have studied the clinical and subclinical expressions of PTSD in parents of children with cancer (Kazak et al., 1998; Pöder et al., 2008). However, even though research has highlighted the link between existential psychology and the cancer experience, the exploration of existential questions with this population has not been extensively undertaken.

Family Adjustment. Following diagnosis, the whole family (including parents/caregivers) need to adjust to the changes in family life (Flury et al., 2011). This sense of adjustment to life in cancer treatment has frequently been reported in other studies and describes adjusting to a 'new normal' (Earle et al., 2007). This adjustment involves practical aspects of adjusting and it intersects with the parental psychological experience.

Studies have described that, for some, hospital becomes a part of life and a place of safety which potentially reflects an acceptance of the cancer diagnosis (Björk et al., 2009; Flury et al., 2011). Occasionally, moments of appreciation and connection are reportedly experienced at hospital, including the ability to spend quality time with their child (Carlsson et al., 2019). In contrast, staying in hospital during treatment has been described as psychologically draining, involving sadness, frustration, boredom, and tiredness (Björk et al., 2009). The treatment period for parents has been described as emotionally and physically exhausting with bouts of insomnia, eating difficulties, and nightmares (Carlsson et al., 2019). A recent qualitative interview study by Carlsson et al. (2019) reported how during cancer treatment, parents describe devoting their complete focus on supporting the child with cancer, who was described as their absolute priority. In turn, this can be exhausting and results in guilt when not being able to attend the needs of their other children.

Not only is there a shift in resources and attention to the child with cancer, but cancer treatment may also involve extensive travel or the moving of one parent or the whole family to be closer to treatment hospitals. This addition of geographic stressors has been noted in studies, where it is claimed that psychological distress in rural communities may be more pronounced, with logistical stressors exacerbating the sense of low peer support in coping with difficulties associated with cancer (Greening & Stoppelbein, 2007; Walling et al., 2019). As discussed in Chapter 1, in Aotearoa New Zealand, the paediatric treatment centres are located in metropolitan areas in Auckland and Christchurch. Long-distance and significant travel time carries added stress for the entire family, extra financial burden and considerable disruption, and separation from their support network (Wakefield et al., 2014; Walling et al., 2019).

Furthermore, paediatric cancer is rare. Therefore, in small rural communities, the chances of having multiple children diagnosed with cancer (and therefore peer support for parents/caregivers) is likely to be low. Consequently, parents/caregivers who live in rural areas (around 16% of the total Aotearoa New Zealand population) are at greatest risk of mental distress and poor outcomes following their child’s cancer treatment (Aitken & Hathaway, 1993; Butow et al., 2012; Statistics New Zealand, 2004).

Not surprisingly, a childhood cancer diagnosis and the experience of undergoing cancer treatment can put a major strain on the parents’ relationship as a couple (Wiener et al., 2017). A qualitative study by Silva-Rodrigues et al. (2016) conducted with 90 couples of children with cancer discussed how the couples’ relationship is affected because attention and focus turns to the child with cancer, and therefore, the couple’s intimacy and sexuality is affected. Further, Woodgate (2006) explored family experiences of childhood cancer and generated the core narrative of ‘life is never the same’ with subthemes that are a combination of experienced losses and a need to move forward; this demonstrates the extent to which family life and relationships are affected. Therefore, the whole family system is impacted and adjusts during treatment, which illustrates the appropriateness of a family systems approach to understanding the complexity of experiences at an individual and family level.

While many studies have described the distress and isolation during cancer treatment, some studies have indicated that there can be positive changes for parents and families during cancer treatment, such as the strengthening of family bonds, increased family cohesion, personal growth, and a positive shift in life perspectives (Patterson et al., 2004; Van Dongen-Melman et al., 1998; van Warmerdam et al., 2019). These discrepancies between some studies reporting more ‘negative’ or more ‘positive’ experiences may be due to diversity in the experiences of parents with differences in the severity of treatment and individual differences. In that way, more research is needed on the heterogeneity of experiences, which may illuminate the complexity and multifaceted nature of parental experiences.

Social Relationships. Along with research that reflects on the huge change within the family/whānau system, studies have also explored the experience of diagnosis and treatment on wider social interactions outside of the family system. Research has explored how parents express a desire and appreciation of social support at diagnosis and during treatment (Gise & Cohen, 2021). Yet, having to tell others about the news of their child's diagnosis and having to answer cancer-related questions has been described as a challenge (Carlsson et al., 2019). For some, this meant that they would isolate themselves from social interactions, and a sense of feeling isolated was commonly described in qualitative studies during treatment (Baenziger et al., 2020; McCarthy et al., 2018). At a time of significant stress and change, the implications of being isolated may tie into the vulnerability for experiencing psychological distress during this period. Studies have also discussed the value of support from other parents/caregivers on the hospital ward who are also going through their own child's cancer treatment (Gibbins et al., 2012). Having a shared experience with other parents/caregivers on the hospital ward has been noted as helpful in learning from others' experiences with side effects and treatments, as well as for getting emotional support (Njuguna et al., 2015). While in the hospital, families may also have access to support from the healthcare team and a hospital social worker who may help to organise practical and emotional support (Health Navigator New Zealand, 2022). Further, a range of community support options are available, including through Child Cancer Foundation. Yet, no studies to date have had an exploration into how these supports are perceived and experienced in Aotearoa New Zealand.

So far, this section has highlighted aspects of the parental experience during their child's cancer treatment. Yet, these studies do have some methodological shortcomings. In a couple of these qualitative studies, the authors claim that they have achieved saturation without explaining in depth how they utilised their qualitative analysis. Further, some of the studies are not transparent about the researcher's role in the research and are not clear in defining their epistemology, ontology, and theories, as well as how these relate to the methodology (Baenziger et al., 2020; Björk et al., 2009; Flury et al., 2011). The transparency in signposting a study's epistemology and the use of theoretical frameworks provide a useful structure to the complex and multidimensional nature of interactions within paediatric psycho-oncology. Despite these issues in the extant literature, it is clear that a cancer diagnosis and cancer treatment bring various difficulties psychologically, physically, socially, and existentially.

End of Treatment

The end of treatment period or the transition away from hospital after cancer treatment has been an increasing area of focus in recent research (Conway Keller et al., 2020; Karst et al., 2018; McKenzie & Curle, 2012; Wakefield et al., 2010, 2013). The previous section described how supporting a child through cancer, a life-threatening illness, and the long intensive treatment is one of the most stressful challenges a parent/caregiver may ever experience (McDonald et al., 2018; Pai et al., 2007). Thus, completing cancer treatment is typically considered a significant milestone and celebrated achievement for the child, the parents, and the family. The following sections explore the central aspects within this milestone, including psychological distress, identity, adjustment, and support needs.

A Milestone with Mixed Emotions. Studies have described how parents/caregivers experience treatment completion as bringing positive emotions, including relief and joy (Norberg & Green, 2007; Ortiz & de Lima, 2007; Suppiah et al., 2005). Unsurprisingly, parents/caregivers of a child at the completion of cancer treatment are also reportedly more resilient and less distressed than parents/caregivers of a child still on active treatment, or who has relapsed or is deceased (Wakefield et al., 2011). Despite this celebrated achievement of the cancer being in remission, this period is also met with psychological distress, with emotions of anxiety, fear (particularly of relapse), uncertainty, and sadness (Conway Keller et al., 2020; McKenzie & Curle, 2012; Muskat et al., 2017; Ortiz & de Lima, 2007; Stam et al., 2006; Wakefield et al., 2013).

These mixed co-occurring emotions are illustrated by a recent qualitative meta-synthesis by Caliskan (2021) on parental experiences at the end of treatment period through their analytic theme of "discrepancies and dualities: cautious celebration and desolation" (p. 33). This theme illustrates the complexity of the lived experience in how parents experience the end of treatment in a dual way, with simultaneously feeling celebration and relief alongside loss and desolation. Alongside that idea, this theme highlights the discrepancy between how parents expect to feel at the end of treatment (namely positive emotions) and how they actually felt, which was the dual emotional valance (Caliskan, 2021). This acknowledgement that two emotions that appear contradictory can occur at the same time highlights the complexity of this human experience and is a strength of these qualitative studies.

Psychological Distress. The extant literature also describes this period as a time of vulnerability with parents/caregivers at increased risk of psychological distress (Jurbergs et al., 2009; Maurice-Stam et al., 2008; Wijnberg-Williams et al., 2006). Specifically, these studies have noted at the end of their child's cancer treatment, parents/caregivers are at increased risk of anxiety, post-traumatic stress symptoms, and feelings of helplessness, loneliness, and uncertainty compared to parents/caregivers of children without a cancer diagnosis, and compared to population norms (Jurbergs et al., 2009; Lemos et al., 2020; Maurice-Stam et al., 2008; Wijnberg-Williams et al., 2006).

Studies have posited that parental emotional distress may be most elevated in the time immediately after cancer treatment, due to this period being beleaguered with uncertainty (Maurice-Stam et al., 2008). Parents/caregivers describe the transition between the certainty of the cancer being in remission at the point of ending treatment to the future which has perpetual uncertainty of cancer recurrence, alongside the fear of bringing the child home and the effects of treatment (Caliskan, 2021). This uncertainty has often been linked to heightened concern and fear about the risk of relapse at treatment completion (Duffey-Lind et al., 2006; Heathcote

& Eccleston, 2017; Horlick-Jones, 2011; Mertens et al., 2001). Late effects are also a significant concern for parents/caregivers after their child's cancer treatment, and Hsiao et al. (2018) reported that 70% of children who had a cancer diagnosis experience at least one late effect. Therefore, some parents/caregivers are contending with both the demands of late effects and the fear of cancer recurrence.

As noted, fear, anxiety, and distress are commonly reported as experienced by parents/caregivers at the end of treatment. All of these types of distress are evident in post-traumatic stress symptomatology (Ljungman et al., 2015; Norberg & Boman, 2013; Wikman et al., 2017). Similar to the active treatment stage, many studies have examined the end of treatment period alongside post-traumatic stress symptomology. These studies are helpful in quantifying parents' distress and indicating some dimensions of parental experiences. However, these ideas around coping and maladaptive adjustment focus heavily on the individual and can be inherently pathologizing. The understandable or normative reaction to the childhood cancer experience is not necessarily a pathological response (Kazak et al., 2007). In this way, these studies neglect the social context of life after cancer. Recognising the importance of wider social processes and the social context of exploring experiences surrounding childhood cancer is pertinent for the present study. Contextualisation when exploring experiences is important because social contexts influence the meaning-making of the cancer experience, as well as cognitions and behaviours in response to the experience that is embedded within one's context (Gray et al., 2014; Klassen et al., 2012; Plage, 2020). So far, little attention has been paid to the role of social contexts as many studies on the impact of childhood cancer treatment have focused on coping and maladjustment, which neglects the social context and is inherently pathologizing (Conway Keller et al., 2020; Wakefield et al., 2010, 2011).

A Period of Adjustment. It is clear that the end of treatment is another period of significant family adjustment. There is an adjustment at the end of treatment to having decreased hospital-based support and contact with healthcare staff (Wijnberg-Williams et al., 2006). Consistently, the research has noted this decrease in hospital care is experienced by parents/caregivers as a loss of support and with that a loss of perceived safety and security (Caliskan, 2021; McKenzie & Curle, 2012; Muskat et al., 2017; Stam et al., 2006; Wakefield et al., 2013). Although active treatment is difficult, parents/caregivers report feeling safe and secure due to regular visits, treatment, and monitoring with oncology staff who are seen as a secure base and a means of protecting their child (Enskär et al., 2020; Wilford et al., 2019). In contrast, the end of treatment means less contact with hospital staff and therefore the absence of the medical team is the absence of a predictor of safety (Enskär et al., 2020).

McKenzie and Curle's (2012) study described how parents felt "in limbo" at the end of treatment and they felt the end of hospital support was abrupt which made them feel abandoned in navigating the future and the unknown on their own (p. 4). Further, Davies and O'Connor (2022) described how mothers in their study felt vulnerable at the end of treatment with the shift in roles from being part of a team focused on their child's care to holding greater responsibility for their child's post-treatment care. Managing without the hospital team also meant a questioning of their ability to cope with their child's health without this support and contact (Carlsson et al., 2019; Ortiz & de Lima, 2007).

This significant adjustment period for parents/caregivers is illustrated by a recent qualitative study by Davies and O'Connor (2022) who explored the experiences of mothers after the completion of their child's cancer treatment. This study generated six themes: 'cast adrift', 'fear never ends', 'guilt and loss', 'everything is different', 'lack of self-care', and 'a way forward' (Davies & O'Connor, 2022). These themes exemplify the significant practical and psychological adjustment that takes place at the end of treatment including lost connections with others (‘everything is different’), reassessment of values (‘everything is different’), and feeling abandoned (‘cast adrift’).

Liminality. The end of treatment also marks a shift in the family’s life and identity, from cancer ‘patient’ to cancer ‘survivor’ (Conway Keller et al., 2020). Parents/caregivers at the end of treatment period appear to feel a sense of being trapped between the constructs of ‘illness’ and ‘health’ (Caliskan, 2021). Navigating this shift appears to be coloured by the uncertainty of potential relapse and needing to readjust and renegotiate their roles at home and in the community (Hosoda, 2014). This shows that the end of treatment is not experienced as the end but instead a liminal phase marked by transition and disorientation. Liminality is defined as a state of transition between two stages (Blows et al., 2012). This concept is evident in the way in which parents feel trapped between discrete stages of illness and health, and in how parents experience confusion in their parental role and identity at the end of treatment (Caliskan, 2021). Further, the awareness of this transitional state becomes apparent in the desire, pressure, and difficulty in returning to ‘normal life’ (Caliskan, 2021; Peikert et al., 2020).

These notions also pull into question what ‘normal’ looks like after cancer treatment, how identity is disrupted and reconstructed after cancer treatment, and whether this includes the espousing of cancer into one’s self concept. However, there are no studies that have explored the impact on the parent/caregiver’s sense of identity or how parents/caregivers conceptualise their identity in relation to the cancer experience. Therefore, exploring the parental identity (and ideas of biographical disruption, as discussed previously) may be central to understanding the parental experience (Young, Dixon-Woods, & Heney, 2002).

Influential Factors. A number of studies have examined factors that influence experiences at the end of childhood cancer treatment (Kunin-Batson et al., 2016; Norberg & Boman, 2013; Quast et al., 2016; Wikman et al., 2017). Unhealthy family functioning, less cohesive and adaptable families, decreased social support, and having negative experiences while on treatment have found to be predictive of negative outcomes at the end of treatment (as measured by lower health-related quality of life and wellbeing in the child who was diagnosed with cancer) (Engelen et al., 2011; Kunin-Batson et al., 2016; Maurice-Stam et al., 2008).

Yet, researchers classifying what they consider to be negative outcomes is problematic as it reinforces the template of how parents and families should operate after their child's cancer treatment. Further, quantitatively measuring quality of life and other concepts such as social support and family functioning is complex, and studies use different measures in considering what variables make up these concepts. Personal experiences can also be dependent on a multitude of factors including, the child's age, cancer type, treatment type, family's individual circumstances, family values, and background. This simplifying of complex and multifaceted factors removes the social contexts in which experiences are embedded. Instead, utilising research that is based on more inclusive models would better mirror the complexities of influences on peoples' experiences.

Informational and Support Needs. Thus far, this section has reviewed how the end of treatment period is experienced by parents/caregivers as encompassing mixed emotions, facing new challenges, and the loss of hospital-based support. Feeling a sense of loss and the perceived abruptness of having to adjust to life after cancer treatment is reportedly connected to receiving little guidance and preparation about the ending period (Caliskan, 2021). A systematic review by Conway Keller et al. (2020) explored what parents/caregivers perceived their needs to be at the end of cancer treatment and found they generally fall into two categories: educational support and psychological support. In this study, parents/caregivers expressed a desire for increased education, particularly around medical information, to prepare for navigating this early transition period. The informational and educational needs perceived by parents/caregivers include greater understanding of their child’s cancer and treatment, guidance for what to expect during the transition period, health information for the promotion of long-term survival, and discussions around late-effects, including fertility problems and cancer recurrence (McLoone et al., 2013; Muskat et al., 2017; Wakefield et al., 2012). This study’s findings are in line with the previously described research on the transition to life after cancer being described as a period of disequilibrium characterised by uncertainty, anxiety, and stress (Gibbins et al., 2012; Wilkins et al., 2014).

In addition to information needs and educational support, parents/caregivers have expressed a desire for psychosocial support. The literature has commonly cited that parents have a desire for psychosocial support to prepare for the emotional and physical challenges following the end of treatment, as well as wanting to know how to access the appropriate psychosocial resources (Karst et al., 2018; Wakefield et al., 2013). In addition, parents express the need for emotional support from family members, friends, schools, as well as relationships with other families affected by childhood cancer (Karst et al., 2018; McKenzie & Curle, 2012; McLoone et al., 2013; Muskat et al., 2017; Wakefield et al., 2013). This is in line with understandings of how the rarity of childhood cancer results in feelings of loneliness and a sense of social isolation felt by parents/caregivers (Maurice-Stam et al., 2008; Norberg & Green, 2007). In a study by Norberg and Green (2007), parents/caregivers reflected that they did not feel fully understood by their social support network. This need and experience potentially reflects this period of significant adjustment and change in daily life back to a new ‘normal’, when in fact, the cancer experience is still being processed and integrated into one’s self-concept in this early post-treatment period.

In the Long-Term after Cancer Treatment

Much has been researched about the experiences of parents/caregivers immediately following diagnosis and whilst undergoing treatment (Gibbins et al., 2012; Long & Marsland, 2011), and more recent attention has focused on the end of treatment transition (Caliskan, 2021; Conway Keller et al., 2020; McKenzie & Curle, 2012). Having explored the literature on parental experiences at diagnosis, during treatment, and at the end of treatment; I will now discuss the literature in regard to parents'/caregivers' long-term experiences after their child's cancer treatment. Research that focuses on the long-term period is frequently defined as being at least five years post-diagnosis or at least two years post-treatment (Eshelman-Kent et al., 2011; Ljungman et al., 2014). Studies that have specified this as their long-term period definition are the focus for discussion in the following review. However, there are very few studies on this long-term period; therefore, this review focuses more in-depth on the critique of this literature and the gaps in the research.

The Continuity of Psychological Distress. As discussed, studies have pointed to heightened psychological distress at the end of treatment, which for most parents/caregivers diminishes over time (Wilford et al., 2019). Similarly, post-traumatic stress symptomology in the long-term is reportedly decreased compared to diagnosis (Ljungman et al., 2015; Wikman et al., 2017). Yet, studies also indicate that there is a subgroup of parents/caregivers who report long-term psychological distress that persists for many years after their child's treatment completion (Ljungman et al., 2014; Wijnberg-Williams et al., 2006). For example, a systematic review by Ljungman et al. (2014), identified that 9-30% of parents reported clinical levels of general psychological distress and 21-44% of parents reported severe levels of post-traumatic stress symptoms in the long-term. This review on the long-term psychological effects of childhood cancer on parents at least five years after their child's cancer treatment comprised of 15 studies and only one of which utilised qualitative methodology. This is synonymous with the vast majority of research with parents/caregivers in the long-term after their child's cancer treatment that has been quantitative in nature and has not directly addressed the parental experience.

Quantitative studies have also documented the long-term post-traumatic stress symptomology in parents/caregivers after their child's cancer treatment (Alderfer et al., 2009; Kazak et al., 1997, 1998). These studies have found that the prevalence of symptoms can be significant, with a study by Kazak et al. (2004) reporting 99% of the 150 families who had completed cancer treatment approximately five years prior to the study having at least one parent meet symptom criteria for reexperiencing, and 20% with at least one parent meeting full PTSD criteria. In similar studies, while some parents/caregivers reach clinical levels of post-traumatic stress disorder, many experience post-traumatic stress symptomology (Barakat et al., 2006). A longitudinal study by Ljungman et al. (2015) into the post-traumatic stress symptomology of parents found that five years after the end of treatment, 19% of mothers and 8% of fathers reported post-traumatic stress symptomology. A systematic review by Bruce (2006) reported severe post-traumatic stress symptomology among 10-44% of parents after their child's cancer treatment. These quantitative studies have highlighted the psychological distress experienced by parents/caregivers in the long-term. Yet, there is little exploration into the nature of this distress to frame our understanding of the parental experience. Qualitative research within this field would be an invaluable contribution in exploring and understanding the nature of this distress and the nuances in experiences with this population (and that may have previously been omitted in quantitative research). Qualitative methods within this field would enrich the current understandings on a deeper level and allow for a contextualisation of this phenomena.

Post-Traumatic Growth. On the other hand, research has been increasingly exploring not only traumatic stress after the childhood cancer experience, but also ideas in relation to stress and adversity promoting positive psychological effects and change (Joseph, 2009; Tedeschi & Calhoun, 2004). This phenomenon of difficult times bringing forth growth, enhancing self-knowledge, and having a greater understanding of purpose and meaning of life has been conceptualised as post-traumatic growth (Tedeschi & Calhoun, 2004).

A narrative synthesis by Duran (2013) into the experiences of post-traumatic growth in children and their families after cancer treatment identified five themes in the analysis: 1) making sense of their cancer experiences, with perspectives becoming more positive; 2) newfound appreciation of and perspectives on life; 3) greater self-awareness, in improving themselves and their qualities; 4) positive attitudes towards family and greater closeness; and 5) a desire to give back to society. Duran's (2013) study illustrates that through enduring illness, the individual and their family system gets to know themselves and the world on a deeper level with new meaning.

Yet, only highlighting the positive impact of trauma can feel invalidating to those with the lived experience when they do not see themselves fitting this mould. Further, these studies that only focus on specific components of the long-term parental experience, such as post-traumatic growth or post-traumatic stress, do not allow for a holistic understanding of the participants' experiences and the construction of such experiences. This narrowed focus in the literature inherently implies that the only reason why parents/caregivers may still be distressed is because of PTSD or trauma appraisals (see 'Theories of Psychological Distress' section below for discussion of two theories of PTSD). This approach fails to account for a broader perspective in considering other and additional explanations for ongoing distress. These studies would have enhanced the breadth to understanding the long-term impact if they had considered a wider range of contributing factors on the parental experience. For example, family systems theories, continued uncertainty, and major periods of adjustment which may be contributing to long-term distress.

The Dichotomy of Experiences. Further to this point (that studies reflect potentially narrowed accounts of parental experiences), is the pattern of research classifying long-term experiences into ‘positive’ and ‘negative’ categories. A qualitative interview study by Ljungman et al. (2016) explored the positive and negative experiences of parents five years after either their child successfully completed cancer treatment or after their child’s death. This study reported that these parents had negative present experiences of impaired relationships with friends and family due to the cancer experience, coping with the child’s late effects, and psychological distress such as anxiety and depression (Ljungman et al., 2016). For positive present experiences, this study reported that parents had some improved relationships through deepening existing family relationships and new relationships with others who had gone through a similar experience, as well as positive long-term consequences for the child (e.g. more mature and empathetic), and personal development in terms of a new view of life and changed self-perception (Ljungman et al., 2016).

However, determining whether experiences are ‘positive’ or ‘negative’ is problematic when trying to categorise the diverse range of experiences into this dichotomy. Framing experiences in this dichotomous way neglects the nuanced ways that experiences can be both ‘positive’ and ‘negative’, neither of these, or somewhere in between, in complex and intertwined ways. This framing reflects a deficit-orientated tradition which simplifies experiences and overlooks the continuum of experiences. The idea of experiences being ‘positive’ or ‘negative’ perhaps may reflect the wider societal binary notions of sickness and health and the opposition these are often placed in (Frank, 2013).

Altogether, this study by Ljungman et al. (2016) is helpful in outlining the long-term experiences and showing the long-lasting impact the childhood cancer experience can have. Yet, while this study did outline differences between parents of bereaved and non-bereaved children it still included both in the analysis, which may miss some of the nuances which are particular to each population. To add to this research, it would be useful to examine further the experiences captured within these categories (‘positive’ and ‘negative’) and to specifically determine their relevance to parents/caregivers after their child’s successful cancer treatment. Further, greater depth into the exploration of parental experiences would enrich an understanding of the findings. For example, investigating the mechanisms underneath why there is fractured relationships with some people, yet improved relationships with others, would further enhance our understanding of the long-term experiences.

Integration of the Cancer Experience. Growing research into the childhood cancer experience is suggestive of crisis events challenging an individual’s worldview and values, which can lead to new perspectives, better coping skills, new priorities, greater self-knowledge, and enhanced social resources (Helgeson et al., 2009; Kalitzkus & Matthiessen, 2010; Stuber, 2006; Tomich & Helgeson, 2004). In line with this, a mixed-methods study which focused on in-depth interviews with parents of children after cancer treatment described that over three fifths of parents reported their child’s cancer had challenged their worldviews, and one third of parents perceived the cancer experience as making family and couple relationships closer (Quin, 2004). It appears that the cancer experience may deeply impact those affected through changing their schemas, beliefs, and goals due to the life-threatening nature of the illness, which in turn, means that after treatment, life may take on a new level of meaning, with greater appreciation and positive attitudes towards life, the self, and family (Duran, 2013). Despite this, the nature of these shifts in worldviews and changes in beliefs needs further investigation to understand the depth, complexity, and temporal aspects of these disruptions.

To build on this, a recent Australian study by Cox (2018) examined parents/caregivers experiences of their child’s cancer diagnosis and treatment retrospectively, with their child being in remission and five years post-diagnosis. This study reported the child cancer diagnosis as significantly disrupting the caregivers’ notions of control, certainty, and security; while requiring them to reconceptualise their view of a ‘normal’ life (Cox, 2018). This demonstrates the deep internal shifts that occur in definitions of ‘normality’ and how this impacts parents/caregivers' approaches in daily life. This also raises questions as to how parents/caregivers integrate these experiences of childhood cancer in the long-term, particularly their own identities, and how it affects their perceptions of themselves as parents/caregivers.

For the person diagnosed with cancer, previous studies have explored how these individuals experience and construct their identity after cancer treatment. Studies have illuminated the deep personal changes that occur in self-identity and social roles (Zebrack, 2000). For cancer patients themselves, there is a change in how they see themselves in the world and a new life philosophy (Zebrack, 2000). This involves a period of identity construction through which the cancer experience is integrated into one's self concept, new life path, and social role (Zebrack, 2000). Mathieson and Stam (1995) proposed a psychosocial framework for individuals who have had cancer that included the continual nature of identity reconstruction in the face of chronic illness. This framework suggests that identity changes are an evolving process which is not bound to a single event. Whether or not this conceptualisation of identity in the long-term applies to parents/caregivers is yet to be seen in the literature. Further, the question of how identity construction interacts with long-term psychological distress remains.

Altogether, it is clear that a child's cancer diagnosis is a significant event which has long-lasting repercussions for the parents/caregivers. What is missing from this literature, however, is a full picture of how experiencing childhood cancer impacts on a parent/caregivers' sense of identity, personal narratives, and the trajectory they envision for their child. This aspect of understanding a parent/caregivers' identity in the long-term after their child's cancer treatment would enhance the depth of the research. The present study seeks to delve into this area to address the lack of qualitative research both in the long-term experiences and in the context of Aotearoa New Zealand with parents/ caregivers affected by cancer.

Research in Aotearoa New Zealand

As was highlighted in the introduction to this thesis, Aotearoa New Zealand has a specific socio-cultural context which shares similarities to other Western contexts, but also has unique and distinct elements. Therefore, culturally situated and informed research within Aotearoa New Zealand is important to explore what it means to be impacted by childhood cancer in this context.

There have been few studies in Aotearoa New Zealand with parents/caregivers affected by childhood cancer. In one such study, Dockerty et al. (2000) compared mental health measures between parents of children with cancer to parents of children from the general population. This study found statistically significant differences between the groups; however, these differences were small, from which the researchers concluded that parents of children with cancer are resilient (Dockerty et al., 2000). To expand upon this finding, a study that explores in depth the unique ways that individuals psychologically and socially respond after cancer treatment would be beneficial, rather than making comparisons to the general population without cancer through a predetermined list of outcomes. Rather than focusing on comparing outcomes between healthy controls and parents of a child who was diagnosed with cancer, diving deeper into exploring the heterogeneity of experiences parents/caregivers have would be a reasonable approach to tackle this issue. Further, while many may not be considered to reach clinically significant levels of distress, there is still high symptomology. Additionally, qualitative research is valuable when quantitative research has found small statistical differences. Qualitative research provides the ability to explore insights and perceptions of experiences and can unearth nuanced differences and understandings (Creswell & Poth, 2016).

Conceptualisations of a parental identity and how it interacts with the cancer experience is an important area of investigation (as noted in the ‘Integration of the Cancer Experience’ section). One qualitative study in Aotearoa New Zealand by Cluley (2015) explored the experiences of fathers after their child's cancer treatment. Through a narrative analysis this study explored the role of fatherhood and masculinity and how experiences are constructed in the context of childhood cancer. An overarching role of 'cancer dad' was generated which encompassed four key ideas: taking control, managing relationships, juggling responsibilities, and finding strength (Cluley, 2015). This study helps to understand how fathers construct their role and place through the challenges of childhood cancer and is one of the few studies within the Aotearoa New Zealand context. Unfortunately, most psycho-oncology research has been conducted with mothers, whereas fathers/males are underrepresented in the literature (Wakefield et al., 2016). This means that the experiences of fathers is not well understood, and breaking down the differences and similarities between the maternal and paternal experiences is not possible (Wakefield et al., 2011). Therefore, this study by Cluley (2015) with fathers is a unique contribution to the field. Cluley (2015) recruited participants whose child had completed cancer treatment, yet did not specify a timeframe (whether short- or long-term after treatment completion). Therefore, while there has been some research in Aotearoa New Zealand with parents/caregivers affected by childhood cancer (Cluley, 2015; Dockerty et al., 2000), this research is limited, and there is no research on the long-term period in Aotearoa New Zealand in particular.

Theories of Psychological Distress

So far, this thesis has highlighted key theories to the present study such as family systems theory and biographical disruption. Alongside this, it is important to briefly underline theories of psychological distress due to the literature having highlighted the significant psychological ramifications that childhood cancer has on parents/caregivers. Trauma and uncertainty have woven throughout this literature review as key ideas. Three well recognised and researched psychological models that seek to explain these are the Uncertainty in Illness Model, the Cognitive Model of Posttraumatic Stress Disorder, and the Paediatric Medical

Traumatic Stress model. What follows is a brief explanation of these theories due to their relevance to understanding the findings in the literature.

Uncertainty in Illness Model. A theory that attempts to understand this sense of uncertainty throughout the illness trajectory is Mishel's (1988) Uncertainty in Illness Model. The Uncertainty in Illness model identifies how an individual's psychological adjustment is a function of their coping strategies (behaviours) and appraisals (thoughts). Mishel's (1988) Uncertainty in Illness Model focuses on an individuals' cognitive processes when coping with the stress of uncertainty in the anticipation of future unknown health outcomes. According to this model, parents/caregivers' appraisals of this uncertainty influence their psychological adaptation. If the uncertainty is framed as a 'danger' to their child's wellbeing - and if maladaptive coping strategies are utilised - then increased distress and poor adjustment to the uncertainty takes place (Wright et al., 2009). In contrast, parents/caregivers who appraise uncertainty as 'opportunity' for growth and practice adaptative coping strategies may have reduced distress (Wright et al., 2009). This model could also be applied to coping through diagnosis and active treatment, while also being a way to conceptualise the fear of relapse in the end of treatment stage. However, what is missing from this model is the messiness of cognitive appraisals. The potential of relapse might not be appraised as concretely 'opportunity' or 'danger' but may be appraised as both, and it may oscillate between the two depending on the context.

Cognitive Model of Posttraumatic Stress Disorder. There are many theories that attempt to unearth the mechanisms that underlie the development and maintenance of PTSD (Bruce, 2006). One such theory that has been described in studies on cancer-related trauma is Ehlers and Clark's (2000) Cognitive Model of Posttraumatic Stress Disorder. This model proposes that PTSD is maintained when the individual processes the traumatic event in a way that leads to a sense of current and future threat, and through the utilisation of maladaptive behavioural and cognitive strategies (Ehlers & Clark, 2000). A fear of relapse or cancer recurrence appears to be a major concern for parents/caregivers in the post-treatment period (Hsiao et al., 2018). Therefore, in applying this model to the cancer experience, a fear of relapse could be conceptualised as a sense of current and future threat and coping strategies could be attempts to control or stop this from occurring. This model also highlights the important role of cognitive appraisals in seeking to understand why PTSD is maintained, which is similar to the Uncertainty in Illness Model.

Paediatric Medical Traumatic Stress Model. Another model that seeks to understand post-traumatic stress symptoms - and which has been utilised more specifically within the paediatric medical context - is the Paediatric Medical Traumatic Stress Model by Kazak et al. (2006). This model was developed due to a lack of understanding of how medical trauma unfolds over various phases in the course of paediatric illness (Kazak et al., 2006). The Paediatric Medical Traumatic Stress Model breaks down the expected pathway most families experience during a traumatic medical event (such as childhood cancer) into three phases (Kazak et al., 2006). The family members' reactions to childhood cancer occur across a continuum from normative responses, acute stress responses, and long-term PTSS reactions.

Within the first phase (peri-trauma), it is posited that pre-existing factors of the family (e.g. parental mental health, coping skills) interact with the characteristics of the medical event and how it is perceived (e.g. life threat, helplessness) which influences the family members' responses making them vulnerable to PTSS. Within the second phase (early, ongoing, evolving responses), there may be continued experiences of trauma related to the medical event (e.g. ongoing pain, memories of treatment). The third phase (long-term), looks at the long-term traumatic stress that has not subsided over-time (Kazak et al., 2006). A core assumption of the Paediatric Medical Traumatic Stress Model (which also lends itself to the present study) is the importance of considering the child with cancer within the context of their family and this system around the child (Kazak et al., 2006; Long & Marsland, 2011).

Summary & Considerations

Existing research recognises that it is crucial for childhood cancer research to expand beyond the experiences of the individual with cancer, to capture the experiences and significant ripple effects onto their family/whānau members, including their parents/caregivers. Further, with the increasing success of cancer treatment, the question of the long-term impact of the childhood cancer experience arises. However, much of the research on childhood cancer experiences for parents/caregivers has investigated experiences at the time of diagnosis, during cancer treatment, and at treatment completion (Gibbins et al., 2012; Klassen et al., 2011; Wikman et al., 2017). Research that focuses on the experiences of parents/caregivers in the long-term period (frequently defined as at least five years post-diagnosis or at least two years post-treatment) after cancer treatment is less comprehensive (Eshelman-Kent et al., 2011; Ljungman et al., 2014).

Further, there are limited studies (and none in Aotearoa New Zealand) which have qualitatively focused on the long-term experiences of parents/caregivers. There are a large number of published studies that have highlighted the association between (i) parental mental health distress at the end of their child's treatment; and (ii) fear and risk of their child's cancer recurrence (Duffey-Lind et al., 2006; Horlick-Jones, 2011; Mellon et al., 2007; Norberg & Green, 2007). Over time, the risk of cancer recurrence decreases and it is assumed that mental health distress (for the majority of parents/caregivers) also declines (Mellon et al., 2007; Norberg & Green, 2007). Yet, while theoretically, the risk of relapse decreases with time, it is not clear why some parents/caregivers continue to experience distress many years after their child has completed cancer treatment. The voices of individuals and their families who have completed cancer treatment have historically been invisible due to them being considered ‘cured’ of cancer biomedically and due to public discourse, which paints ‘survivors’ as ‘heroic’ and ‘triumphant’. This thesis gave a voice to parents/caregivers impacted by childhood cancer and aimed to fill this research gap.

This literature review also highlighted important considerations to acknowledge and be cognizant of in the present study. Firstly, the present study recognises the relational system and the context around an individual. In this way, I endeavoured to have an appreciation for family systems theories, with the assumption that families are a system of influence that surround the child, and consequently, the parents’/caregivers’ experiences are important to the experiences of the whole family/whānau. This acknowledgement of relationships and social interactions is crucial to understanding how parental experiences are shaped.

Further, this study recognises the importance of contextualising the cancer experience and aims to privilege the perspectives and experiences of participants. This means being open to all experiences along the spectrum, from those experiencing distress to those who are flourishing, as well as those with complex and seemingly contrasting emotions. Exploring and privileging participants’ perspectives and experiences in this thesis allows for the previously mentioned template of ‘the cancer experience’ to be challenged and allows for support services and interventions to understand how best to support this population. In this thesis, I aimed to be cognizant of the cultural dimensions and connotations that reflect the variable meanings and experiences ascribed to the cancer experience and post-treatment experience in Aotearoa New Zealand. Further, in this thesis I endeavoured to move away from the focus on disease-centric perspectives on cancer and into the meaning of their experiences, along with being mindful of the language I utilised as well as the language articulated by participants in the construction of the cancer experience.

Chapter 3: The Evolution of this Thesis

This chapter introduces the process through which the present study's research question was developed. The research question originated from the findings of a preliminary scoping survey. That survey was designed as part of a wider multi-site community implementation study of an online group-based psychosocial intervention programme named 'Cascade'. This chapter briefly outlines the 'Cascade' intervention and the rationale for the preliminary scoping survey. Next, the findings from the preliminary scoping survey follow and how these findings lay the foundations for the research question of the present study. It concludes with explicating the qualitative research question.

'Cascade'

The literature review has illustrated the significant psychosocial impact of the childhood cancer experience on parents/caregivers. Alongside this, research has pointed to the early transition period at the end of active treatment and into post-treatment as a critical time for intervention to support adjustment and reduce distress (Michel et al., 2020; Wakefield et al., 2011). Therefore, delivering psychosocial interventions for parents/caregivers early in this transition period potentially presents an opportunity to prevent long-term mental health problems, in line with the Paediatric Medical Traumatic Stress model (Kazak et al., 2006).

In recent years, there has been an increasing number of treatment interventions developed to improve psychological outcomes for families affected by childhood cancer. 'Cascade' is one such psychosocial intervention programme developed by the Behavioural Sciences Unit in Australia. 'Cascade' is a group-based videoconferencing intervention based on cognitive-behavioural therapy (CBT) principles that involves peer support and skills-based coping strategies (Wakefield et al., 2015, 2021). 'Cascade' aims to promote helpful coping strategies for supporting the long-term quality of life and mental health of parents/caregivers of children who have successfully completed cancer treatment (Wakefield et al., 2015). It is a manualised programme that is led by a facilitator and teaches CBT coping strategies, including behavioural activation, thought challenging, acceptance, mindfulness, values identification, and relationship strategies, including assertive communication.

The pilot of ‘Cascade’ was conducted in Australia and the researchers considered the programme to be feasible and acceptable (Wakefield et al., 2016). There is currently no conclusive evidence on the effectiveness of ‘Cascade’ (Michel et al., 2020; Wakefield et al., 2021). Preliminary research looking at the outcomes of ‘Cascade’ found no significant effect of the Cascade group compared to controls on the quality of life, psychological functioning, or family functioning; however, fear of cancer recurrence did significantly reduce and 70% of participants rated Cascade as ‘quite’ or ‘very’ beneficial (Wakefield et al., 2016). Further details including the study protocol and outcomes of ‘Cascade’ is a separate project and is published elsewhere (Wakefield et al., 2015, 2016, 2021).

Following this pilot of ‘Cascade’ in Australia, the trialling of this intervention has expanded to evaluate its’ outcomes both in Australia and overseas, including in Aotearoa New Zealand. Massey University and Child Cancer Foundation are working collaboratively with Behavioural Sciences Unit to trial ‘Cascade’ in Aotearoa New Zealand. I was involved in the early stages of implementing ‘Cascade’ in Aotearoa New Zealand. This involved helping Child Cancer Foundation to adapt the ‘Cascade’ workbook for the cultural needs of parents/caregivers in Aotearoa New Zealand. Additionally, it involved creating and administering a preliminary scoping survey to assess the desire for this programme. This survey then led to research questions which guided the present study. The present study is independent of the ‘Cascade’ project, but it was intended that the present study’s findings would illuminate the needs of families whose children finished treatment some time ago, with a view towards whether ‘Cascade’ or a similar programme might be indicated as being useful.

Preliminary Scoping Survey

The aim of interventions such as ‘Cascade’ is to provide a solution to supporting parents/caregivers after their child’s cancer treatment. However, it was not clear if there was a desire or need for such interventions in Aotearoa New Zealand. Therefore, before the initiation of a ‘Cascade’ study in Aotearoa New Zealand (and before the conception of the present study), it was necessary to ascertain the desire for this psychosocial intervention in order to logistically prepare for the programme, such as estimating the number of groups and participants that might be needed, and consequently, the number of psychologists that would need to be trained to facilitate the intervention.

To achieve this, I created a preliminary scoping survey. The Massey University Health Ethics Committee: Northern (MUHEC) provided ethical approval for this survey through a low-risk ethics notification (ethics number 4000022936). Child Cancer Foundation circulated the survey through Child Cancer Foundation’s Facebook groups and e-Newsletter. The survey was administered through Qualtrics survey software.

The survey’s results, presented in Appendix A, showed a desire for this psychosocial programme in Aotearoa New Zealand and led to the rationale for the present study. There were 90 parents/caregivers who completed the questionnaire, which was made up of more females (93.3%) than males (6.7%). From the 90 who completed the survey, 66 (73.3%) and 20 (22.2%) parents/caregivers reported ‘yes’ or ‘maybe’ being interested in ‘Cascade’, respectively. In the survey, most respondents were in their first 12 months after finishing cancer treatment (24.4%). However, respondents varied in their time since treatment, including being more than ten years post-treatment (4.4%). This response to the questionnaire potentially reflects the research described in the literature review which reports that parental distress is higher in the period closer to the end of treatment (Maurice-Stam et al., 2008), with parental anxiety proposed to be linked to uncertainty and fear of cancer recurrence which wanes over time (Duffey-Lind et al., 2006; Mellon et al., 2007; Norberg & Green, 2007). Furthermore, a considerable body of evidence suggests that there is a subgroup of parents/caregivers who continue to experience long-term distress many years after treatment (Ljungman et al., 2014; Wijnberg-Williams et al., 2006). This 4.4% of respondents who were more than ten years post-treatment thus may represent this group, who continue to wish for (and need) support, and/or who continue to experience considerable impact from cancer.

This finding led to the rationale and research question that underpins the present study; why (after years of their child being finished treatment) are these parents/caregivers looking for psychological support and what are their experiences? Is this a product of unresolved past cancer-related stressors, current stressors, or perhaps is it due to the lack of free or cost-effective psychological support in New Zealand?

Research Purpose & Question

The purpose of the present study was to explore the long-term experiences of parents/caregivers whose child had finished active cancer treatment and was at least five years since diagnosis. The study focused on the perspectives of these parents/caregivers as their lived experiences have been largely invisible in literature that considers from a biomedical definition their children to be ‘cured’. The exploratory research question the study sought to answer was: *“What are the long-term experiences of parents/caregivers after the completion of their child’s cancer treatment?”*.

Due to an awareness of the diverse range of experiences along the phases of treatment and the understanding that needs of families in the long-term will vary from those at diagnosis or in treatment, I focus on the experiences of those in the long-term in order to recruit a relatively homogenous group. In this way, I aimed to explore the continual demands and the long-lasting impressions that cancer leaves long after treatment is completed. Understanding the perspectives and experiences of parents/caregivers will expand the knowledge and deepen the understanding of their long-term experiences.

This study aimed to explore participants’ accounts from the ground-up, letting participants discuss what was meaningful to them in order to better understand the construction of their experiences. Therefore, this research aimed to explore all aspects of parents’/caregivers’ experiences in the long-term. While taking into account the myriad of experiences, this study aimed to provide a comprehensive description of what it is like for parents/caregivers in the long-term after their child’s cancer treatment completion, to understand the complexity and the nuances of this human experience. As of yet, there is no qualitative research that solely focuses on parental experiences in the long-term period after their child’s cancer treatment in Aotearoa New Zealand. An in-depth exploration of the long-term experiences of parents/caregivers may help us to understand their needs and inform the provision of appropriate psychosocial care and services in Aotearoa New Zealand.

Chapter 4: Methodology

In this chapter I present the theoretical underpinning that has informed the project, and the rationale for a qualitative approach for gaining insight into the experiences of parents/caregivers after their child's cancer treatment. The next part of this chapter will provide a detailed account of the procedure including recruitment, interviews, and data analysis. Overall, this research aimed to explore the experiences of parents/caregivers after their child's cancer treatment, with a particular focus on the long-term impact of the cancer experience for those with a child who was at least five years post-diagnosis.

Theoretical Framing

A qualitative design was utilised in response to both the scarcity of qualitative research and to allow for the opportunity to capture the nuances and complexities in parental experiences during this long-term period after the successful completion of their child's cancer treatment. The study uses qualitative research methods in order to gain insight into participants' unique stories and, within that, the themes and meanings from their child's cancer experience. The use of qualitative methods offer a way of collecting rich and diverse data to account for the multiple realities of experiences, as well as providing a contextual backdrop to participants' experiences (Creswell & Poth, 2016). Qualitative research can encompass many different theoretical orientations, epistemological assumptions, and methodologies. Therefore, it is necessary to specify in which orientation a piece of qualitative research is grounded.

The present study explored and analysed parental experiences through a social constructionist lens. Social constructionism emerged relatively recently in the field of psychology and came from a long history, with origins in sociology and philosophy (Burr, 2015; Conrad & Barker, 2010). The social constructionist paradigm claims that knowledge is constructed through interactions within a sociocultural context (Burr, 2015). Social constructionism maintains that individuals construct their own representations of reality from within the context an individual is in, constructing their own subjective knowledge (Efran et al., 2014). Therefore, social constructionism rejects positivist perceptions of obtaining impartial knowledge from an objective ‘reality’ (Lincoln & Guba, 2016). Social constructionism argues that knowledge is not discovered but instead is created through interactions and exchanges in our socio-cultural context (Lincoln & Guba, 2016). Therefore, in this study, it is understood that participants create their reality from within the confines of their historical, social, and cultural context. This context is influenced by dominant discourses and belief systems. In this way, qualitative studies under a social constructionist paradigm prevent participants’ accounts from being decontextualised and provide an ideal framework for contextualising participants’ accounts through which they are embedded (Burr, 2015).

Social constructionism was considered to be the epistemology that best supported the objectives of the present study. Studies that employ a social constructionist lens have a focus on understanding the construction of phenomena and its implications, rather than understanding objectively exactly what phenomena ‘are’. Social constructionism emphasises the significance of culture and context in the construction of knowledge, and in turn, how this frames an individual’s understanding of society (and illness). In this way, the present study is not attempting to uncover one universal truth; instead, it recognises that truth is socially constructed. The study’s focus on participants’ experiences and the context in which their meaning-making took place aligned with a social constructionist epistemology. Further, the changing understanding and the societal constructions of cancer and parental experiences means that experiences and meanings of the cancer experience are heavily influenced by the social context in which we find ourselves. The requirement for a social constructionist epistemology became evident when exploring contemporary understandings of childhood cancer, demonstrating that it was impossible to disentangle social context from the experiences of parents/caregivers after their child’s cancer treatment. Thus, a qualitative approach allowed this research to gain a holistic understanding of participants' experiences, while taking into account how their social contexts influence and construct their reality.

There is ongoing debate in social constructionism about ontology with relativism versus realism (Burr, 2015; Locke & Strong, 2010). Burr (2015) suggests it is more useful to conceptualise ideologies within social constructionism in order to step back from issues of truth and falsity. Within this framework, this research would fit within ideology as lived experience based on ideas from Althusser where ideology is present in what we think, "what we feel and how we behave" (Burr, 2015, p.98). In addition, Burr (2015) argues there are multiple relativisms so materialism is not denied but once we start talking about events or experiences we have entered the realm of discourse and thus social constructionism. Lock and Strong (2010) argue that the practice of psychology is about how people make sense of and influence each other within intersubjective experiences. Therefore, even when trying to understand mental health distress, social constructionism fits because "talk is not a neutral 'tool' used to get 'the real work' done: talk is where the real work of therapy happens" (Lock & Strong, 2010, p.2). The relevance of this statement for this research, is how participants made sense of their experiences is socially constructed and revealed in their talk.

While it can be argued cancer is a 'real' disease that can be physically seen in the body, and is therefore not a social construction, medical discourse and biomedical models of illness construct a sense of 'truth' when it comes to knowledge about illness (Brown, 1995). Bryan Turner (1995), a medical sociologist, argued that diseases cannot be regarded as natural events but as a product of medical discourses which occur within the language in which they are described. In turn, medical discourse can influence experiences of illness and shape the identities and behaviours of those affected (Conrad & Barker, 2010). Social constructionist approaches to illness argue that the experience and understanding of illness is shaped by social interactions, shifting frameworks of knowledge, and shared cultural understandings (Conrad &

Barker, 2010). This means that perceptions of illness do not exist independently from our social reality. This applies also to parents and caregivers of the person affected by the illness (child with cancer), as their experience is not limited to one reality, but is constructed in many interactions in time and place.

Some illnesses, like cancer, are particularly embedded within cultural meanings which shape how society responds to those affected by the illness. As described in the literature review, dominant cultural and metaphorical connotations are often negative with representations of cancer as 'evil' (Bell & Ristovski-Slijepcevic, 2013). The stigmatisation of cancer then arises due to societal responses and assumptions of the cancer experience (Conrad & Barker, 2010). In turn, this impacts the cancer experience for those affected, including all family members. Therefore, employing a social constructionist perspective in the present study will help in the understanding of how participants' experiences are constructed. In this way, this thesis aims to utilise a social constructionist approach to engage in participants' narratives, whilst acknowledging how experiences are negotiated socially and culturally (Burr, 2015).

According to social constructionism, meaning-making in research is co-constructed between the researcher and the participants (Owen, 1995). This also means that while the researcher can have theoretical knowledge of what it is like to be a parent/caregiver of a child who has completed cancer treatment, the participants hold the power of their lived experience of it. Through being explicit in this understanding of the participant being the expert in their lived experience, there is an equalising of the power dynamic and advocation for collaboration in research with participants informing the research process (Brickell, 2006; Burr, 2015). In line with this, the research question was constructed through the research itself rather than solely by the researcher. In the data analysis, particular attention was given to considering historical, social, and cultural influences on participants' experiences which reflects the social constructionist lens of the study. This is demonstrated through consideration of ways in which participants cognitively and socially interacted with relationships to themselves, the world, and the future.

Reflexivity

When conducting research within a social constructionist epistemology, the researcher needs to acknowledge their active contribution to the process of meaning-making (Kim, 2006). The researcher does not decide whether a participant's account reflects an objective reality, but rather assumes a subjective reality to the experiences of participants (Rapmund & Moore, 2000). Social constructionism also acknowledges the co-construction of knowledge that is created through interactions between the researcher and participants (Rapmund & Moore, 2000). Further, the researcher's own socio-cultural context should be taken into account when sharing the research findings (Rapmund & Moore, 2000).

This process of reflexivity is important for quality and rigour in qualitative research (Olmos-Vega et al., 2023). In this way, the researcher must acknowledge their role in the construction of knowledge and reflect on themselves critically throughout the process (Olmos-Vega et al., 2023). I understood throughout the research project that it was impossible to have objective qualitative research and I worked to remain self-aware of how I influenced the research process. I engaged in reflective practices through reflective journaling after each participant interview. Following each interview I wrote reflections based on Gibbs' (1988) reflective cycle. This model of reflection consists of six stages: description, feelings, evaluation, analysis, conclusion, and action plan (Gibbs, 1988). Using this model as a template allowed me to reflect on what happened and my feelings towards the process and participants' experiences, as well as to consider what I can do with my learning and new knowledge moving forward. I also utilised supervision as a place of reflection and a place to challenge my assumptions and biases, particularly in the interviews and data analysis. I found utilising these reflective practices particularly helpful in engaging critically within a social constructionist paradigm around my assumptions of knowledge.

The overlap between mental health and physical health has always been of interest to me. This may be due to a close friend who experiences the impact of a significant physical health illness in childhood, and family members who have experienced distress in the face of physical health conditions. Through my clinical psychology training and through hearing the experiences of those close to me, it became clear to me the significant gaps in our understandings of the mental health of those facing physical health concerns. Cancer, in particular, is an illness where I am aware of the substantial influence of the media and society in constructing our narratives of cancer.

I needed to recognise my personal biases that may have arisen because of my own experiences, particularly due to not being personally affected by childhood cancer. I have a friend who faced a life-threatening illness when we were children and she had long admissions to hospital. However, she did not experience cancer; notably, her experiences in the hospital had both similarities and differences to the experience of participants in the present study. Further, I needed to reflect on my own cultural meaning of cancer, as I have had family members who have had adult cancers, which elicits culturally dominant understandings that are different to the experience and determinants of childhood cancer. As an 'outsider' to childhood cancer and to being a parent/caregiver, I needed to be aware of my relationship to the research. Yet through being an 'outsider' I felt that I was able to explore experiences at a deeper level through asking more questions without the taken-for-granted assumptions that can occur when you are an 'insider'. Taken together, I needed to be mindful of my own transference when interviewing participants to not impose my own experiences and assumptions onto participants' accounts.

During the interviews, I became cognizant of the countertransference that participants may be experiencing. For example, at the beginning of the interviews, I would do a genogram with participants to get an idea of the family/whānau system. One participant commented later in the interview how the piece of paper we drew the genogram on reminded them of an experience with a healthcare staff member at the beginning of their child's diagnosis. This made me reflect on the importance of the potential trauma reminders we give as clinicians and researchers, particularly for individuals who had high involvement with healthcare staff during their distressing cancer experience. Further, some participants had negative and invalidating experiences with healthcare staff, and so as a clinical psychology student, I needed to validate their accounts as well as consider the systemic experiences that become barriers for people I will work with clinically in future. Being in the healthcare sector and having close friends in the medical field, I needed to be mindful in discussions related to the practice of medical professionals. It is also noteworthy that I had engaged in reading psycho-oncology literature for over a year prior to commencing my research.

Furthermore, I had to be mindful of my role as a researcher, as distinct from my role as an intern psychologist. My aim was not to conduct a differential diagnosis and it was not my place to attempt to 'treat' participants' psychological distress. At times this was challenging, particularly since I had been trained in doing differential diagnosis in assessments and had a good understanding of cognitive behavioural therapy practices. I did engage in my clinical skills of Socratic questioning, active listening, summarising, and validating participants to support and ensure their wellbeing whilst remaining outside of the psychologist role. Finding the balance between psychologist and researcher was difficult and at times felt blurred. As the interviews progressed, I recognised my tendency to want to formulate and lead questioning towards clinical psychology models that I had become used to from my clinical training. I also noticed how I felt confused if I was not able to formulate participants' distress under traditional models. In turn, I got frustrated at myself for trying to put people into 'diagnostic boxes' with clinical symptomology. As interviews progressed, I learnt to let this go and endeavoured to avoid imposing diagnostic conceptualisations to allow for participants to richly articulate their experiences in a way that was authentic to them.

While I engaged reflectively and actively worked to increase my self-awareness around my own biases, it is unrealistic for me to expect that this study could have been done without any biases. As such, I am aware of how knowledge is not independent of the researcher. Nevertheless, engaging reflectively allowed me to critically examine the 'truth' of my own knowledge and biases as well as being present and responsive to individual participants.

Ethical Considerations

This research project complies with the Massey University Code of Ethical Conduct for Research, Training, and Evaluations involving Human Participants (Massey University, 2017). This research was approved by the Massey University Human Ethics Committee: Northern (Application: NOR 21/35) on 16th June 2021. Undertaking qualitative research in psycho-oncology requires consideration of ethical issues, meticulous planning, and an evidence-based approach as participants may be vulnerable to further distress (Reid, 2009). The ethical considerations of confidentiality and informed consent, avoidance of harm, and cultural responsiveness were identified as pertinent to the present project.

Confidentiality and Informed Consent

Throughout the research process, I took extreme care in ensuring that participant confidentiality was protected. This recognition and promotion of privacy is crucial in protecting and respecting the individual and their family (New Zealand Psychological Society, 2002). The importance of participants' confidentiality was emphasised on the information sheet and consent form. Participants were given the researcher's and supervisors' contact details and were encouraged to make contact and discuss if they had any questions or concerns about the study.

For data storage, all electronic files and data, including participant transcriptions, were password-protected and stored in a password-protected folder with access limited to only the researcher. The audio recordings of interviews were destroyed after the researcher had transcribed the interviews and after participants had checked the transcripts. The transcriptions will be kept for five years and then destroyed.

To ensure the confidentiality and anonymity of participants, each participant was given a unique pseudonym that was chosen by the participant themselves, which was recorded alongside the participant's name in a password-protected electronic file. One participant who identifies as female chose the name 'Oscar' as their pseudonym due to the personal meaning this name has for them and their family. Participants' real names were not recorded elsewhere, with all other data (including transcriptions) labelled with the participant's pseudonym and all identifiable information (e.g. rare diagnoses, names) removed. Along with the participants' names, the names of their children were also de-identified. This process allowed for the participant and their family to remain anonymous.

Participants were also made aware that they could withdraw from the study; in this situation, any of the participant's data or information yet to be analysed would be destroyed. Participants were also asked permission for the interview to be audio-recorded and were made aware of the transcription process, including their opportunity to edit their transcriptions to ensure the information gathered accurately depicted the way they wanted to voice their experiences. Participants were able to request a summary of the findings and were informed about the use of the data in a thesis.

Avoidance of Harm

It is necessary to be cognizant that while discussing topics related to cancer there is the possibility for participants to have an increase in distress in the short-term. Therefore, I developed a protocol and plan in the event of risk or heightened distress if that were to occur during the interview process. This included offering contact details of relevant support organisations and emphasising that the participant could take a break, pause, or stop the interview at any point. The researcher was to promptly discuss with Associate Professor Kirsty Ross (primary supervisor and senior clinical psychologist) any participants who were highly distressed during the interview and supervision was sought from the supervision team throughout the interview process. Participants spoke openly about their experiences and discussed aspects of their experiences that were distressing. A few participants became tearful during the interview when discussing the impact the cancer experience had on them and their child, or when recalling a memory of the cancer experience. When this occurred, I showed them support, validated their distress, and encouraged them to take a break from the interview if they wished. All participants were content to continue before proceeding with the interview again.

Cultural Responsiveness

Although this study did not focus solely on specific cultural groups, the research aimed to recruit individuals of any ethnicity including Māori and Pasifika. Cultural supervision was sought from a Māori clinical psychologist in the Massey University psychology department prior to the commencement of the study to ensure that cultural safety and an equity lens was observed throughout the design and planning stages as well as in the data collection, data analysis, and reporting of findings. The guiding principles of Te Tiriti o Waitangi (The Treaty of Waitangi) were acknowledged throughout the research process to ensure that the rights of Māori were prioritised, and dignity respected. To promote the Te Tiriti o Waitangi principles of partnership, participation, and protection, the use of Te Reo Māori words and greetings were used in advertisements and information sheets, and participants were asked if they would like a karakia or whakatauki to open and close their interview. I made sure during the interview and data analysis stages to consider a holistic approach to wellbeing and Te Ao Māori values through considering the Te Whare Tapa Whā model (Durie, 1984). In this way, the interview guide incorporated the four pillars of hauora (wellbeing) in Te Whare Tapa Whā which are: hinengaro (mental and emotional), whānau (family and social), tinana (physical), and wairua (spiritual) (Durie, 1984). This holistic exploration in the interviews allowed for data analysis that goes beyond the individual to consider the cultural, contextual, and relational aspects that contribute to long-term experiences.

Of the ten participants, one participant identified themselves as of both Māori and New Zealand European ethnicities. This participant was offered and accepted karakia to open and close our interview. In this interview, this participant discussed their wairua (spiritual wellbeing) in how their connection to religion and spirituality had evolved over time from their child's cancer experience and from the grief experienced from the death of their own parent. This participant also highlighted the importance of their extended family/whānau in supporting them and their child through the cancer experience. Notably, these two aspects relate to the pillars of 'Taha Wairua' and 'Taha Whānau' in the Te Whare Tapa Whā model. Considering these aspects of participants' wellbeing was important for being culturally responsive and considering the context and holistic aspects of the participants' lived experiences.

Method

Participants

This study comprised of ten parents/caregivers of a child who had been diagnosed with cancer at least five years ago and who had completed cancer treatment. Ten participants is considered to be an appropriate sample size due to the strength and quality of the dialogue and the dense sample specificity (Malterud et al., 2016). This number of participants is in line with recommended sample sizes when conducting thematic analysis (Ando et al., 2014; Guest et al., 2006). Moreover, it was important for the present study to maintain richness in the information provided by participants which is arguably more difficult to preserve with a larger sample size (Malterud et al., 2016). Even after interviewing three participants, it was clear that the data was incredibly rich, therefore after completing ten interviews, it was agreed with the research supervisors that ten participants were sufficient. The depth of the data was also considered more than sufficient to provide a comprehensive analysis to answer the research question and aim. Although the present study's sample size allows for a depth of information to be gathered, the study and the sample size does not intend to represent the experiences of all parents/caregivers after their child's cancer treatment.

The eligibility criteria for participants were that they would a) be a parent or caregiver of a child who completed active cancer treatment and who is at least five years post-diagnosis; and b) not currently have a child in palliative care or on active treatment. Each of the ten parents/caregivers was a biological relation (mother, father, or grandmother) of a child who had undergone a course of cancer treatment (surgery, radiation, and/or chemotherapy) (see Table 1). Participants ranged from 37 to 61 years old at the time of the interview, and identified as female, aside from one participant who identified as male. Participants identified themselves as New Zealand European (n=9), South African (n=1), and Māori/ New Zealand European (n=1). The children of the participants were between the ages of 1 and 8 years old during treatment and two of the participants' children relapsed after completing a course of cancer treatment. All participants' children were considered to in remission at the time of data collection. The time between the interview and the participants' child's diagnoses ranged from 5 to 34 years ago. The children had been diagnosed with a variety of different types of childhood cancer, including leukaemia (n=8), neuroblastoma (n=1), and soft tissue sarcoma (n=1). While a few participants' children had a rare form of childhood cancer, to protect confidentiality I have only reported on the diagnostic category.

Table 1
Demographic Information of the Participants (n = 10)

Pseudonym	Gender	Ethnicity	Age[1]	Relationship to child	Age of child[1]	Year of child's diagnosis	Relapse
Kate	F	NZ European	37	Mother	6	2016	N
May	F	NZ European	42	Mother	11	2013	N
Peter	M	NZ European	41	Father	11	2013	N
Lena	F	South African	49	Mother	11	2013	N
Abi	F	Māori & NZ European	61	Mother	37	1987	Y
Oscar	F	NZ European	61	Grandmother & Primary Caregiver	12	2012	N
Marie	F	NZ European	45	Mother	7	2016	N
Alexa	F	NZ European	48	Mother	12	2012	N
Louise	F	NZ European	42	Mother	12	2010	N
Emma	F	NZ European	54	Mother	19	2010	Y

Note. [1]Age at the time of the study (interviews were conducted in July-August 2021)

Recruitment

Relevant documents for recruitment, including the participant information sheet and interview guide can be found in Appendix B and C, respectively. Participants were recruited through advertisements circulated on Child Cancer Foundation's social media and other social media pages. To allow for perspectives into long-term experiences after child cancer treatment to be gained, I recruited participants who were at least five years since their child's diagnosis. This allowed the study to gain insight into the nuances of parental long-term experiences and to consider the long-term impact of the cancer experience. Those who responded to the advertisement circulated on social media were sent an information sheet and were encouraged to ask questions. Following further contact and satisfaction with understanding the study, the participants signed the consent form. We organised a suitable time and private, comfortable location for the interview.

Interviews

Semi-structured interviews were utilised to explore and understand participants' stories in regard to their child's cancer story and their experiences since the end of their child's cancer treatment. Under a social constructionist framework, the interview is a space of meaning-making between individuals where the interviewer and participant collaboratively construct knowledge (Holstein & Gubrium, 2008). Semi-structured interviews allow for detailed information about thoughts, perspectives, and experiences to be gathered as well as allowing for new ideas and meanings to be explored as specific questions are not determined ahead of time (Bolderston, 2012; Kvale, 1994; Kvale & Brinkmann, 2009). In this way, an interview in qualitative research should be guided by a list of topics based on the literature review, yet the exact wording or order of questions is not pre-determined (Bolderston, 2012). The structure of semi-structured interviews allows for the conversation to be led by the participant while allowing the researcher to prompt the interviewee to elaborate on the original response or follow lines of enquiry introduced by the interviewee (DiCicco-Bloom & Crabtree, 2006). This shows that the process rather than the structure of the interview is important. Therefore, the semi-structured interviews allowed the participant to voice what was important and meaningful to them and their experiences. Further, the nature of semi-structured interviews is inherently a social interaction which means that the participant and interviewer work together in the co-construction of knowledge through the ideas that are communicated and in illuminating meaning from the stories that are shared.

The interviews were constructed to answer the research question: what experiences parents/caregivers have had in the long-term after their child's cancer treatment. An interview guide was created and incorporated topics for discussion (see Appendix C for interview guide). The interview topics were developed to allow participants to tell their own story of their child's cancer, while also capturing the holistic nature of wellbeing. The interview questions were constructed with respect to Te Whare Tapa Whā model of health. Te Whare Tapa Whā was chosen due to the model's holistic approach to mental health and wellbeing and its cultural appropriateness to Aotearoa New Zealand (Rochford, 2004). Te Whare Tapa Whā has been commonly utilised in Aotearoa New Zealand as a clinical assessment tool and for clinical formulation (Bennett, 2009; Rochford, 2004). Further, Te Whare Tapa Whā has been used in psycho-oncology research, and in such research the multidimensional nature of how cancer impacts on holistic wellbeing has been reflected through this model (Matapo-Kolisko, 2021; Moeke-Maxwell et al., 2020; Ripia, 2013). For the present study, the interview guide included each of the four pillars of hauora (wellbeing) within Te Whare Tapa Whā to capture the spiritual, social/family, mental health, physical health aspects of the long-term experiences. If an aspect of hauora (wellbeing) was not already discussed in the semi-structured interview, then I would ask an open question around this pillar of wellbeing, for example: "What role does spirituality or religion play in your experiences since cancer?".

Given the geographic spread of Aotearoa New Zealand parents/caregivers and the context of the Covid-19 pandemic with cultural understandings around preventing the spread of infectious disease, it was fitting that interviews were offered over videoconferencing (i.e. Zoom) to participants outside of Auckland. If regional Covid-19 Alert Levels permitted, then videoconferencing (i.e. Zoom) or in-person interviews were offered to participants in the Auckland region. Five of the participants (50%) were interviewed in-person and five participants (50%) were interviewed remotely over videoconferencing. Nine participants were interviewed during Covid-19 Alert Level 1, and one participant was interviewed during Covid-19 Alert Level 4[1].

---

[1] Aotearoa New Zealand employed an elimination strategy in the management of Covid-19 cases during the data collection stage of this research. During this time of interviews, Aotearoa New Zealand had an Alert Level system.

At the start of the interview, I introduced myself and the purpose of the interview as well as spent time building rapport with participants to allow a level of comfort in sharing their experiences related to their child's cancer. The interviews were collaborative and conversational in nature. I allowed the participant to take the lead in the interview and used the interview guide to facilitate further questioning only when needed. This process allowed for the participant to discuss what was meaningful to them, while returning to other topics later in the interview if needed. It was important for participants not to be interrupted or re-directed as this would have impacted the richness of the data. The length of the interviews ranged from 63 minutes to 150 minutes. As a koha/gift for participation in the interview, all participants were given a $30 voucher. All interviews were audio-recorded.

Data Analysis

The data analysis aimed to explore the long-term experiences of parents/caregivers after their child's cancer treatment. The data was analysed with a reflexive thematic analysis to generate central themes, patterned data, and unique meanings of participants' experiences. Braun and Clarke's (2006) six phases method of reflexive thematic analysis was followed. This approach went beyond identifying themes to offering rich interpretations of the significance, meaning, and implications from the patterns identified in the data regarding parental experiences after childhood cancer (Braun & Clarke, 2020). More specifically, I hoped to discover and generate insights into the meaning-making, identity construction, and survivorship discourses within their experiences.

Alert Level 1, named 'prepare', meant that the virus was contained, and a range of measures applied such as all businesses being open, record keeping of locations visited for contact tracing, and wearing a face mask on public transport.

Alert Level 4, named 'lockdown', meant that the virus was likely not contained, and a range of measure applied such as staying home, no travel allowed except for necessities, work from home, no gatherings allowed, businesses closed, and wearing of face masks in public.

Reflexive thematic analysis is widely used with qualitative data obtained in psychology research. Reflexive thematic analysis is a method used to identify, analyse, and report patterns and meanings across participants' stories (Braun & Clarke, 2020). The patterns of meaning that are produced from the data set are also known as themes (Braun & Clarke, 2006). Themes that are generated from the data allow for examination into highlighting the similarities and differences across the data set, while also developing ideas as to the collective experience (Braun & Clarke, 2006, 2020). In this way, social constructionism informed the reflexive analysis, because social constructionism also considers how patterns emerge collectively and reflexive thematic analysis has themes which represent patterns of meaning within the data (Burr, 2015). A reflexive thematic analysis is an approach to thematic analysis which is distinct from other thematic analysis methods and was used in the present study (Braun & Clarke, 2013). Reflexive thematic analysis as an approach emphasises the researcher's subjectivity as an important analytic source, as well as the importance of the researcher engaging reflectively with theory, data, and interpretation (Braun & Clarke, 2019). Reflexive thematic analysis and social constructionism acknowledge that the researcher inherently plays an active role in the process of knowledge production (such as co-construction of meaning and knowledge in the interview process) and influences the analysis of data. In this approach, themes are conceptualised as meaning-based patterns which unite the data in a shared understanding rather than summaries of domains, as the latter tends to reflect surface-level meanings rather than depth (Braun & Clarke, 2013). Further, the data analysis coding process evolves and can be split, renamed, and changed while the researcher conceptualises the data. In this study, a combination of inductive and deductive approaches to reflexive thematic analysis were carried out. This hybrid approach was a useful way of balancing the benefits of inductive data-driven exploration alongside the depth and insights that can be gained from theory-driven perspectives (Swain, 2018).

Other qualitative approaches such as discourse analysis and interpretative phenomenological analysis (IPA) are bound to particular epistemological and ontological assumptions (Braun & Clarke, 2020). Although thematic analysis and IPA are epistemologically similar for the present study, there are differences in the initial stages of coding, meaning thematic analysis has open coding and could be utilised independent of specific theories or epistemology. Reflexive thematic analysis was considered most appropriate to this study, because of its flexibility in not being tied to a particular theoretical framework and because several orientations can underpin the analysis (Braun & Clarke, 2006, 2019). Social constructionism lent well to informing the reflexive thematic analysis through considering how meaning was socially and culturally constructed, particularly in how participants used language to construct their experiences, and how these language choices revealed the influence of social and cultural context in which they are embedded (Burr, 2015). Thematic analysis is also pragmatic in its approach and is well suited to research questions about people's experiences and the ability to give practical recommendations to Child Cancer Foundation (Linnan & Steckler, 2002; Ritchie & Lewis, 2003).

Steps in Data Analysis

Data analysis commenced with the process of transcription and participants having the opportunity to review the transcripts. I transcribed the interviews verbatim, which is an important part of the data analytical process. There are many conventions for transcribing speech (Lapadat & Lindsay, 1999). In the transcribing of these interviews, all utterances were transcribed as well as laughter, pauses, and trailing off. Further, any utterances which were emphasised speech by the participants were underlined. Participants were given the opportunity to review their transcripts. Seven participants took up this offer and reviewed their transcripts. Within these reviews, two participants chose to delete segments from the final transcript and the other five participants did not suggest any changes. This process of participants reviewing transcripts was an ethical decision and was used to uphold the principles of co-constructed knowledge. To ensure the protection of confidentiality, identifiable information was removed, including names, locations, and rare diagnoses. Pseudonyms were assigned to each participant, with participants having the ability to choose their own pseudonyms.

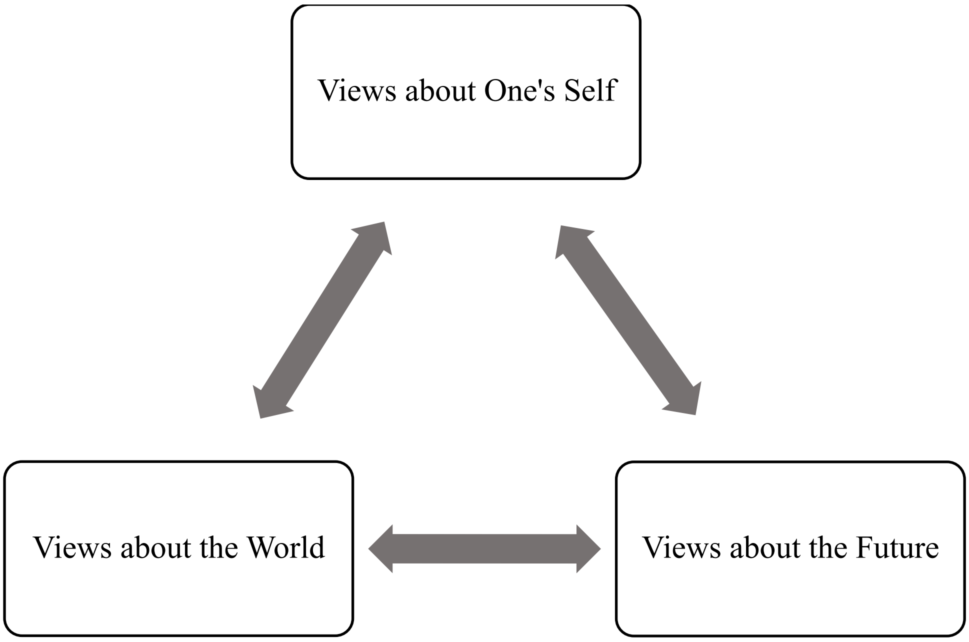
The next stage in reflexive thematic analysis is familiarisation with the data. This involved the transcripts being read and re-read numerous times to immerse myself in the data and to become familiarised with participants' stories. Next, initial codes were generated, coding line-by-line and identifying key features of the data relevant to the research question. To make sure that all relevant features were captured, a great deal of time was spent, and multiple iterations of codes were conducted. In the early stages of analysis, I utilised an inductive approach which means I did not start analysis with a preconceived theoretical framework in mind. In the later stages of analysis, after several iterations of coding, grouping of codes, and re-organising themes, I then incorporated a deductive element by applying predefined theory to help interpret the themes I had identified in the data. The theory I applied that helped me to conceptualise the data was Beck's (1979) 'cognitive triad'. Reflexivity in this stage of the analytic process was important, and therefore I shared these groupings of codes with my supervisors for feedback and decision making to make sure that there was cohesion and trustworthiness in the findings and to reflect on my positionality as a clinical psychology student. For example, I initially combined codes into meaningful groups including 'grief/loss' and 'benefit finding'. However, when reviewing and reflecting on this in supervision it became apparent that there was a deeper level to the participants' experiences through biographical disruption and Beck's cognitive triad. In this way, feelings of 'grief/loss' were due to permanent changes in how participants viewed themselves. Thematic maps were also utilised to support the generation of themes and subthemes (Braun & Clarke, 2013). Following this, themes were refined, reorganised, and reviewed several times to allow for accurately reflecting and capturing the data. The amount of overlap in themes and subthemes was difficult when it came to organising the themes and subthemes. For example, permanent changes to views on one's self impacted on feeling isolated, yet 'isolation' was organised as a subtheme for disruption to views about the world, due to feeling disconnected in interpersonal relationships and feeling like the world was an isolating place.

As I coded, it became clear that the frameworks of 'biographical disruption' and Beck's (1979) 'cognitive triad' captured the cancer experiences' long-term impacts on the self, the world, and the future. Biographical disruption (as described in the literature review) is a concept for the way in which illness threatens an individual's identity and initiates a reassessment of their life trajectory (Bury, 1982). Whereas, Beck's (1979) cognitive triad was first developed to describe how depression impacts three elements of an individual's belief system to produce pessimistic thinking patterns about the self, the world, and the future (see Figure 1 for a diagram showing Beck's cognitive triad). It is suggested that the cognitive triad in depression leads individuals to view themselves as unworthy and unlovable, to expect failure and rejection, and envision hopelessness in the future (Segal, 1988). Yet, in the present study the cognitive triad captured views in these three elements which is unique to parents/caregivers in the long-term after their child's cancer and is distinct from concrete diagnostic criteria such as depression. These two theoretical frameworks of the cognitive triad and biographical disruption captured the complexities and depth of the data.

As a social constructionist study, it is important to acknowledge the tensions between social constructionism and socio-cognitive theory in the present study. Social constructionism emphasises how an individual's experiences and the construction of meaning are influenced by sociocultural context, whereas socio-cognitive theory (and, in particular, Beck's cognitive triad) emphasises how an individual's experiences are influenced by the individual's cognitive processes (Martin & Sugarman, 1997). While I acknowledge that there is a tension between these two perspectives, the combination of these perspectives in this study provides a more nuanced understanding of the interplay between personal and social dimensions of experience. These perspectives are complementary through recognising that the construction of thought patterns is not solely an individual process but is influenced by social interactions and cultural beliefs. Therefore, integrating both socio-cognitive theory and social constructionism adds depth by exploring how an individual's thought patterns are shaped by external influences such as stigma, social expectations, and cultural narratives. This approach helped me to explore how participants navigated and negotiated their experiences within the socially constructed parameters of their lives which allowed for a more holistic and contextually sensitive analysis.

Figure 1

Beck's (1979) Cognitive Triad



The final stages of analysis involved reviewing the final themes and subthemes. Additionally, it included writing and discussing the analysis in the findings section of this thesis and relating it back to the research question and literature. The following chapter presents the findings from the data analysis.

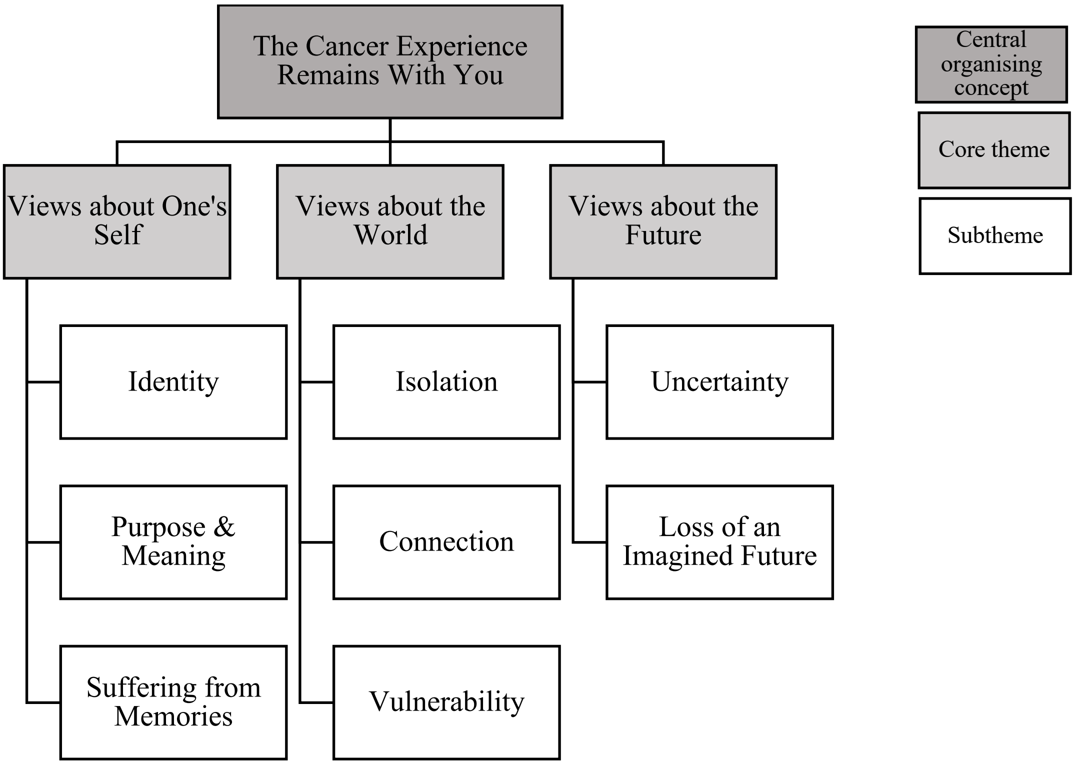
Chapter 5: Findings

The interview data highlighted the complexity in experiences of parents/caregivers across their child's illness trajectory, including reflections on their experiences at diagnosis and in-treatment. The present study aimed to specifically focus on the nuances of the long-term experiences. This focus elucidated the powerful presence the cancer experience had on the lives of parents/caregivers years after their child's cancer treatment. Findings indicated that parents/caregivers experienced long-lasting and definitive changes as a result of the experience of their child's cancer. Throughout the findings, I use the term 'cancer experience' to refer to the parent/caregivers' experiences from when their child was diagnosed to when they finished active cancer treatment. I use this term to define the boundaries of diagnosis and treatment as this past experience presented itself in their present experiences.

The central organising concept of the accounts was *The Cancer Experience Remains With You* (refer to Figure 2). This speaks to the significant and permanent changes across a range of aspects of life that occur for parents/caregivers due to the experience of their child's cancer. This led to three themes being produced under the central organising concept. These themes are: *Views about One's Self, Views about the World,* and *Views about the Future.* Each of these themes had a number of subthemes attached. The organisation of themes is presented in Figure 2.

Figure 2

Map of Core Themes and Subthemes



The themes and subthemes speak to the nuances and depth of the impact of the cancer experience for parents/caregivers. While these themes are presented in a distinct and categorical manner, in actuality, themes and subthemes are highly interrelated with each other. For example, changes to views about themselves impacted views about the world and views about the future, and vice versa. In this findings chapter, each theme and sub-theme is explained, and extracts illustrate facets of each theme. A brief description of each theme and an example extract is noted in Table 2.

Table 2

Overview of Themes and Subthemes

Themes	*Subthemes*	*Description*	*Example Quote*
Views about One's Self	Identity Purpose & Meaning Suffering from Memories	Explores the disruption to participants' views about themselves. Specifically, this theme describes participants' reflections on their change in self-identity, sense of purpose and meaning, and how memories from the cancer experience occurred in the present.	"Everything that I was kind of just got shelved, which anybody would do for their child. But I am struggling now, and I think I will struggle even more the more independent [child] gets. What the hell am I supposed to do now, because that's been my role for so long. So just trying to function as a normal human is a bit of a struggle." (Lena)
Views about the World	Isolation Connection Vulnerability	Explores the disruption to participants' views about the world. This theme illustrates participants' experiences of feeling emotionally isolated, their experiences of deep connection in pockets of the world, and their sense of vulnerability in the world to perceived dangers that threaten them and their child's health and wellbeing.	"Really put me in a shell of isolation… We don't trust people quite the same as we used to because those that we thought were friends didn't help us out at all, and weren't there for us. So we've withdrawn within ourselves. We don't commit to anything. So we don't have team sports; we have mountain biking, rock climbing, skiing, the things that we can keep to ourselves and to our family. Because that's how we've coped." (Marie)
Views about the Future	Uncertainty Loss of an Imagined Future	Explores the disruption to participants' views about the future. This theme speaks to the perceived uncertainty felt for the future with the possibility of their child's cancer recurrence or future late effects, and ideas of grief and loss of a future they and their child could have had if it was not for the cancer experience.	"I do have ongoing grief in the fact that she's infertile because she had a bone marrow transplant. That's with me quite strongly… she's a really nurturing child, she's always liked kids, she likes the dogs, and it's of enormous grief to her, so that's ongoing grief to me. And I'm surprised at how much and how often I think about it and try and find solutions." (Emma)

Throughout this chapter, some quantifying language is utilised in the exploration of individual themes and subthemes to demonstrate prevalence across the data set. This quantifying language is not attempting to ‘count’ thematic instances; rather, is used to provide an indication of the strength or consistency of occurrences of the theme (Terry, 2010). When I use the terms “most” or “almost all” it refers to eight to nine participants discussing this occurrence. Where the term “many”, “commonly”, “often”, or “typically” are used it will mean that at least six to eight participants referred to this occurrence. When I state “some” or “a few” this is to say that three to five participants discussed this utterance. This approach addresses concerns of vagueness or imprecision in qualitative research while also avoiding making conclusions based on saliency, which can be problematic (Braun & Clarke, 2013; Terry, 2010).

Theme 1: Views about One’s Self

All of the participants described the cancer experience as a significant event that disrupted their life, and participants described how the experience changed their relationship with themselves. This theme is comprised of three subthemes: ‘identity’, ‘purpose and meaning’, and ‘suffering from memories’ to reflect the layers in which views of one’s self are disrupted in the long-term after their child’s cancer treatment. The first subtheme, ‘identity’, was concerned with navigating and re-negotiating identity in relation to the cancer experience, participants’ perceptions that cancer had changed them, the degree to which they felt defined by cancer, as well as feelings of strength and resilience. The second subtheme, ‘purpose and meaning’, explores both experiences of loss of meaning and meaning-making in long-term post-treatment experiences. The third subtheme, ‘suffering from memories’, was concerned with how memories from the cancer experience interrupted the participants’ sense of self in the present.

Identity

All of the participants in some way described feeling like they had changed as a result of the cancer experience. The cancer experience was described as a significant life event that impacted their sense of self in the long-term. Oscar described the cancer experience as *"a permanent scar"*. This description evokes imagery to discursively represent a 'battle' that has left a lasting impact. This depiction of having endured a 'battle' fits with the growing body of literature that conceptualises childhood cancer as a traumatic experience for patients and their caregivers (Hungerbuehler et al., 2011; Kazak et al., 1997). While interviews focused on the long-term experiences after a child's cancer treatment, the participants described the diagnosis as *"a shock"* and *"traumatic"*, and described the cancer treatment as *"brutal"*, *"horrendous"*, and *"nasty"*. According to participants' accounts, the predominantly traumatic element of the cancer experience was watching their child suffer, as well as being faced with the threat to their child's life. This life event was described as traumatic at the time, and led to long-lasting identity changes.

This change in identity due to the cancer experience is reflected through the comparison some participants made between their perceptions of themselves in the present to a view of themselves in the past, specifically their identity pre-diagnosis.

> *I don't remember who I was before [child]'s diagnosis. Like I know that I was quite a different person, but I don't know who that was. (Lena)*

Lena's description conveys a disconnection between her present self and past self, tied directly to the cancer experience. This disconnection to a sense of identity relays the substantial disruption to self from the cancer experience; experiences of disconnection from the self are well-established in the literature to be linked to traumatic experiences (Nijenhuis & Van der Hart, 2011). This disconnection from one's self may reflect feeling numb and feeling like a passive or observing agent in your own life. Lena went on to consider the memories that form her sense of identity:

> *Maybe it's because when I look back at treatment time like I have such strong memories of how I felt in that time that I... I can't remember. I can't remember sitting with a new-born baby and how lovely that was. I've got no memory of that. So it's like cancer stole all my kind of emotional memories. (Lena)*

Here, Lena is contrasting her present self who has experienced trauma and significant distress, with a nostalgic view of her innocent past self. Lena's use of the word *"stole"* personifies cancer as the 'villain' or 'enemy' who has robbed her of happy memories and emotions associated with them, such as the joy of being with a new-born baby. Lena feels like she has been robbed of whom she was before and stripped of some of the happy memories that formed the foundation of her identity pre-cancer. These foundational memories of holding a new-born baby are central to one's identity and normative motherhood experiences (Laney et al., 2015). This extract demonstrates the shift in identity to that of an identity and motherhood experience that is branded by the cancer experience. This idea of an identity 'branded' by the cancer experience is discussed by Kate:

> *Kate: I vividly remember just not liking that word, not liking the thought of being known as 'the cancer family'. [laugh]*
>
> *Researcher: And what is the worst thing about being known as 'the cancer family'?*
>
> *Kate: [laugh] It's a weird one because I think you want empathy, but you don't want pity.*

Kate speaks to the shift that occurs due to the cancer experience from normative family and parenting identities to being 'the cancer family'. This change in identity is not only on the child diagnosed with cancer, or the parent/caregiver; instead, the whole family system's identity shifts and this shift is long-lasting. Kate said she did not want to be known through the illness narrative of 'the cancer family' due to the construction of a direct linkage between their past experience and current identity. In this way, she is commenting on how she does not want her identity and that of her family to be solely defined by cancer, but instead as something that happened to them.

This narrative of 'the cancer family' also speaks to how Kate is aware of a societal lens in the construction of her identity in the long-term. Kate subjectively feels that her identity and her family's identity is marked in the long-term by illness and that sparks reactions (such as pity and sympathy) from others. Kate states the tension she feels in wanting empathy and not pity; here she is reflecting on the pros and cons of making their identity public through disclosing the family's cancer experience. Pity reflects others feeling sorrow for the affected, whereas empathy reflects others understanding the experience of the affected. In the former, there is a sense of the affected feeling alienated and disconnected from others, whereas the latter reflects connection. These ideas of connection and alienation are noted here and linked to how participants represent their identity but are further unpacked in theme 2. Kate goes on to discuss how this resistance to taking on cancer as being the entirety of her identity furthered a long-lasting feeling of 'difference' from others:

> *But I'm aware of <u>burdening</u> them with it I don't want to be the person who's <u>defined</u> by it. But then, in a sense, it does define you completely, so it's this weird… You're trying to walk the line between being real to yourself, but not being someone who that's all they think of you as… But it's changed you,*

> *and it's always there with you… It becomes part of your identity… but you're aware that it's almost like a flaw or a thing that might put people off. (Kate)*

Kate grapples with the idea that having an identity that is defined by cancer is a 'burden' to others; a cancer identity, therefore, carries a heavy weight and may be 'tiring' to others, even in the long term. Kate is also internally grappling with how she relates to herself and others through acknowledging how in some ways the experience does define her; while she wants to embrace and be authentic in how she views herself, she also wants to distance herself from the cancer experience at the same time. Kate identifies what she perceives to be the social consequences she experiences by being redefined through illness narratives or being seen as 'flawed'. Kate's use of the word 'flaw' exemplifies how cancer is seen by society as a 'defect'. This adds to how enmeshed biomedical discourses are in our social language, as a 'defect' or 'flaw' is often due to a physiological issue that affects a body's ability to function (Bendelow, 2009). This analogy speaks to the dominant presence of the cancer experience on participants' sense of identity and adds to the conceptualisation of how isolating the cancer experience can be through feeling a sense of 'difference' to others in the long-term.

This conceptualisation and tension of feeling defined by cancer - yet wanting distance from a 'cancer identity' - was also expressed by other participants. A few participants also spoke of feeling like they were 'playing victim' by referring to their experiences or claiming them as part of their identity. Peter spoke of the fear of being perceived as using the cancer experience as a strategy to get positive favours based on sympathy:

> *My work brought it up when I was getting my new position, and… I didn't want to use it as a card to go 'oh you know, I've been through cancer you should give me a promotion' kind of scenario. And I was very aware of not bringing that into the conversation, but my employer brought it into the conversation to highlight that I have more empathy around people… So*

> *yeah, I had to go and talk about it there where I thought it was, playing a card to get what you want. (Peter)*

Peter discussed how he did not want to 'pull the cancer card' as a way of getting positive favours, and in this case a promotion. While he was self-aware of the cancer experience and how it had impacted him, he did not want to be defined by cancer. Peter's metaphoric language of 'playing the cancer card' is a common societal metaphor that speaks to ideas of life being a 'game' which includes notions of 'luck' and 'misfortune' (Semino & Demjén, 2017). Utterances of feeling 'lucky' and 'unlucky' were evident across all participants when discussing their cancer experiences. Yet, in this context 'playing the cancer card' appears to be seen as socially unfavourable as Peter did not want to want to use 'the cancer card' and felt using it did not reflect getting the promotion based on his own merits, but based on his identity built from illness narratives. Therefore, Peter distances himself from the 'cancer identity' in order to not perpetuate social perceptions and judgements derived from illness narratives.

While some participants discussed experiencing a tension between espousing a 'cancer identity' or not, there was a general acceptance for some participants in relation to the cancer experience forming part of their identity:

> *And I think I've probably come full circle with that like I realise I'm not ever gonna forget about it. It's part of our existence. Just embrace what you can about it, I guess. (Lena)*

Here, Lena is describing how she has *"come full circle"* which implies how 'journeyed' the process of acceptance versus distancing of the cancer experience within her identity has been over time. This phrase also conveys an arrival at an acceptance of the cancer experience as part of her identity which feels inevitable to her. In contrast, Alexa felt that she had achieved distance from the cancer experience and that over time her identity in relation to cancer had lessened:

> *I am still involved in that we do fundraising and… we do dinners at Ronald McDonald House, but I sort of tend to think of myself more as a volunteer rather than as being part of it… We're at the point now that I tend to forget that, that time even… which I never thought I would… it was a big huge part of our life for a really long time… And now, sort of, don't associate myself so much with it anymore. (Alexa)*

While Alexa was still engaged in the paediatric oncology space, such as helping out with fundraisers, she positioned herself as a 'volunteer', and so more of an 'observer' rather than 'member' of the cancer experience. This distancing of one's self from a 'cancer identity' was noted by a few participants. Some participants did not associate with the idea of their child being a 'cancer survivor' and there were several reasons for this. For Alexa, she described distance from the 'cancer identity' due to perceiving the cancer as being in the past and not a current problem, and therefore, not a current identity construct. This illustrates the differences in how identity is constructed in relation to the cancer experience, with how Alexa did not espouse a cancer identity while others, such as Kate and Lena, did. This self-identity evolves and changes with time and distance not in a linear way but a fluctuating and ever-changing process.

While there may be many factors that determine how much the participants espoused cancer as part of their long-term identity, it may be related to their child's late effects. For example, at the time of interview, Lena's child had many ongoing physical health and mental health late effects (e.g. infertility, hyperthyroidism, decreased lung function, and hearing loss), whereas, Alexa's child had few long-term late effects (e.g. toe walker). These late effects in the long-term may be a dominant reminder of the cancer experience, which means the parental identity feels permanently changed. Yet, these differences in identity construction reflect the changing nature of identity, with the impact of cancer being ongoing as identity unfolds. This displays how complex and multi-faceted the conceptualisation of identity is in the long-term after participants' cancer experiences.

Several participants discussed their identity in relation to the cancer experience as associated with more general personality characteristics. Some participants spoke to the resilience and strength in their identity that fostered within them as a result of the cancer experience. Louise explained:

> *I feel like it almost made me stronger like I was a bit of a wimp and, you know, me and [husband] went everywhere together and I'd get him to hold my hand, come with me and all of a sudden, I had to go on the plane and get myself from the airport to Ronald McDonald and the hospital on my own, and that sort of made me feel more confident. It made me grow stronger. (Louise)*

Louise described how the cancer experience disrupted her sense of self in the way that it fostered inner strength and confidence in herself in the face of a sudden challenge that she did not realise she had. For Louise, the confidence has remained to the present day, and she can use her cancer experiences to remind herself of what she is capable of. This conceptualisation of viewing one's self through growth and self-development lends itself to the literature on the positive psychological changes that can occur after cancer treatment (Duran, 2013; Tedeschi & Calhoun, 2004). May adds to this idea:

> *But you do have resiliency, because you've been through crap before, and sometimes I'm like, 'oh well, we've been through worse. I'm sure we'll manage this' [laugh] (May)*

In this extract, May said *"oh well"* in relation to managing more difficulties in life. The statement 'oh well' echoes the acceptance and perspective-taking that has changed as a result of the cancer experience and through understanding self-coping strategies she has available. It also reflects the construction of the nature of hardship in life, and how dealing with adversity becomes part of one's existence. May also commented on through having faced her worst-case scenario (of being confronted with her child's life-threatening illness and treatment), the experience has made her more resilient to deal with future stressors. This idea of strength and resilience being related to facing existential challenges and life-threatening illnesses is consistent with research that has found post-traumatic growth is experienced by some children and their families who have completed cancer treatment (Duran, 2013).

This subtheme examined the complexity of how the cancer experience is incorporated into self-identity and how participants relate to it, with participants feeling like a different person. Some participants espoused a 'cancer identity' while others felt distance from a cancer identity. Further, participants described general identity characteristics that had been cultivated due to the cancer experience, in particular feelings of strength and resilience. These notions of identity changes and a process of identity reconstruction from the cancer experiences echoes a biographical disruption that has taken place, which persists into the long-term.

Purpose & Meaning

A number of the participants discussed the long-term impact of the cancer experience on their sense of meaning and purpose. While some participants reflected on experiences relating to 'loss of meaning', many considered 'meaning making' in the way in which they had created a new sense of meaning. Lena discussed her sense of purpose and meaning being disrupted after her child's cancer treatment and how this linked to her identity:

> *Everything that I was kind of just got shelved, which anybody would do for their child. But I am struggling <u>now,</u> and I think I will struggle even more*

> *the more independent [child] gets. What the hell am I supposed to do now, because that's been my role for so long. So just trying to function as a normal human is a bit of a struggle. (Lena)*

Lena describes how her individual identity got side-lined for the identity of 'mum' to cope with getting her child through cancer treatment. Lena reported how she gained a new sense of meaning and purpose as her child's full-time carer and advocate, which started in cancer treatment. Then after treatment (and in the present), Lena discussed how she is currently struggling due to slowly losing that newfound role and purpose. This posits that getting back to her own identity and re-negotiating her sense of purpose and meaning has been a challenge. Further, this extract illustrates how identity is linked to purpose and meaning. This sense of loss of meaning and purpose appears to be continuous and compounding for Lena, as her child gets older and becomes more autonomous. This shows that the biographical disruption is continually undermining the parental identity by challenging Lena's confidence, expectations, and independence as a parent.

The cancer experience appeared to produce an internal re-negotiation of meaning for participants. Some participants discussed how the cancer experience made them re-evaluate the meaning they achieved from their life on a new level and what they evaluated as 'success' or a 'good day'. Kate discussed how the cancer experience suddenly changed her perspective on what was important to her:

> *It changes your perspective, your priorities. So, I mean, initially, every day out of hospital was a good day. Every day that she was happy, and smiling is a good day. (Kate)*

In the early stages of maintenance and post-treatment, a *"good day"* was evaluated based on whether her child was happy. Kate then explained how the cancer experience impacted her decision-making processes, priorities, and values and how they were linked to meaning in the long-term after treatment:

> *Every decision we make you know in terms of in my career and money and how much time I should spend with the kids at home. I'm always thinking because, if the cancer came back, if she died… What would I be happy with, in terms of my decision? So it's always there and it impacts every decision you make. (Kate)*

Kate discussed her thought processes behind evaluating her decision making and reflects on the monumental implications she feels that her decisions carry. The criteria for what is considered to be a 'right decision' appears to have been altered due to the cancer experience. The perception of making the 'right decisions' is emphasised; navigating decision-making that is filled with uncertainty and 'what if' worries for the future is spoken of as being challenging. The internal dilemma is around whether she should be prioritising spending time with family because time feels limited when facing the potential of her child's relapse or death, or whether she should be pursuing her personal goals and career direction. When making decisions Kate is wondering if her future self (and, in particular, a hypothetical version of future herself that is bereaved) will be satisfied with the decisions she is making. Kate continued:

> *Just always tossing up between wanting to spend money on fun things now while life's good and while she's healthy, or whether you should be putting it away because she will be at university… It's always that kind of toss-up between, should we throw in the suburban house and go, you know, sail around the world, [laugh] or should we do the more normal thing because our lives are gonna pan out normally… I don't know, I just think I take it,*

> *year by year and, just see what comes up and where she's at and where we're all at. (Kate)*

Kate is highlighting the biographical disruption that the cancer experience had. She is contemplating whether her family should be living with short-term pleasure-seeking or for long-term goals. Throughout these extracts, Kate emphasises how she feels like her life is on a different trajectory from what she expected and from what is normatively expected. Kate is reflecting on the normative expectations and taken-for-granted assumptions a parent has on their child reaching adulthood and going to university. Taken together, this demonstrates the shifts in expectations participants had for themselves and a shift in what society normatively expects.

Along with this, Kate is describing how the cancer experience made her gain a new level of awareness about her ability to make different choices. With increased authorship and awareness in different choices comes a sense of responsibility for whether or not she is making the 'right decision'. Similarly, some other participants also reflected on ideas of decision making and increased authorship in the present and into the future, such as tossing up their choices in their career and whether they should move to a new city or country.

In addition to the cancer experience affecting roles and decision making, participants also described wanting to prioritise their own needs, wishes, and gain a sense of normality. Alexa described the importance of getting back to normative activities, particularly work, after her child's cancer treatment:

> *So I think probably a couple of years after she finished treatment, I really threw myself into work because I just didn't want to be at home all the time and I wanted something else to focus on. I wanted something that wasn't thinking about the kids. (Alexa)*

Like all of the participants, Alexa's main focus and energy was on her supporting her child during their cancer treatment. This meant that after cancer treatment Alexa felt she needed to concentrate on something other than the cancer experience and corresponding worries. Alexa expressed her need to get back to work perhaps as a coping strategy to escape her thoughts on cancer and potential relapse, but mainly because it was important for Alexa to do something for herself after treatment and engage in an activity that is felt to be 'normal'. This desire of getting back to normative activities, particularly work, was expressed by almost all of the participants. This result of returning to work giving a sense of normality has been found in a recent qualitative study with parents after their child's cancer treatment (Peikert et al., 2020). This shift back into 'normative' activities after their child's cancer treatment also reflects the desire to re-focus back to other aspects of their identity (rather than 'mum', 'nurse', or 'advocate' which was centred on cancer) to expand into 'employee', 'individual', and 'friend'.

All the participants described the various ways in which they experienced a new sense of meaning since ending treatment, in terms of their overall outlook on the world along with their priorities, values, and personal qualities. This is reflected by Emma who said:

> *I think, I think it's made me more empathetic about some things and less about others, it's changed my outlook on the world. So I have much more sympathy for certain situations and less sympathy for others. So, I've changed. It's not more or less, I've just changed. I changed what matters to me in life. (Emma)*

Emma describes how the cancer experience has changed her outlook and how she feels like a different person. For Emma, this experience of purpose and meaning is also connected to her self-identity. Similar to Emma, many participants discussed how their priorities and perspectives had changed since treatment. Some participants reflected on how, before their child's cancer, they were a *"perfectionist"* (Emma) or felt they had *"generalised anxiety"* with worrying about lots of *"little things"* (Kate). After their child's cancer, these participants reflected that the experience of their child's cancer meant they had changed in their outlook on problems and the world and what was important to them. Further, some participants discussed how they were better managers in the workplace because they felt more understanding of others, and how they *"don't sweat the small stuff anymore"* (Peter) and how they now *"let things go"* (May, Emma). In this way, participants felt that they were living with a greater understanding and acceptance of how uncertainty was part of life and so would need to *"let things go"* (May, Emma) that were out of their perceived sense of control.

Many participants re-prioritised what was important to themselves and their child as valuing their child's health and happiness above *"good grades"* rather than *"worrying"* about if their child is going to be a *"rocket scientist"* (Peter). This shows a clarification of their values in the long-term which links to the concept of post-traumatic growth (Duran, 2013). Whereas other participants discussed how they felt it was important to, as May reflected, *"you've still gotta worry about the normal things as a parent."* Similar to May, Emma also reflected on how she felt it was important to still hold onto some of the same expectations and aspirations for your child from before the cancer experience:

> *So it's really important to match what they want out of their lives, not you just thinking, 'oh you're alive, don't worry about it.' Actually saying "well actually you do want to do well, you do want to have a good career" all that kind of stuff. "How can we make that happen," you know. None of those desires actually change. So it's really important to see the world a bit differently, not just how it was when you were going through it. But you evolve out of it, the evolving out of it in a way that is appropriate, I guess, to [inaudible] beyond life and death. (Emma)*

Similar to Kate, Emma reflects on the struggles of adjusting to allowing herself to have normative expectations for her child into adulthood. She states that while her perspective on the world has changed, her hopes and desires for her child has not. Emma's use of words like *"evolving out"* demonstrates how the cancer experience has the potential to restrict goals and aspirations, but how she suggests you have to actively move forward with the growth and learning from the cancer experience. For participants in this study there appeared to be a balancing of normative expectations for them and their child, along with gaining a new perspective which made the process of meaning-making challenging.

Another aspect of purpose and meaning that was expressed by participants was around enacting altruism. Many participants reported engaging in activities that fulfilled a desire to give back and help others. Participants expressed that wanting to give back to others was a value that had pre-dated cancer but was particularly important to them post-treatment. May explained:

> *I'd hope that even in ten years' time I would like to go back to Child Cancer Foundation and volunteer. That's not because I'm hanging on to it, but it's my way of giving back, I hope that I will do that because I see other parents that are in Child Cancer Foundation that volunteer and… their children are adults now, and they still come back, and it's not necessarily that they're stuck there. They just want to do something because it meant something to them when they were going through their hardest times. (May)*

May, like some other participants, was engaged in child cancer events and social media groups where she would share her own experiences and provide tips to oncology parents who were currently going through cancer treatment. She reflected that she values that she can help others who are going through the experience she went through. Along with this altruism, there is a level of expertise that is reflected in participants' accounts of giving back, as they have a level of ‘mastery’ due to having completed cancer treatment. May also commented that she was involved in oncology events *“not because I’m hanging on to it”*. This differentiation between ‘giving back’ from ‘hanging on’ appeared to be important for a few participants to make when they described their motives for engaging in the childhood cancer events and groups years after their child’s cancer treatment. In part, this distinction is due to ideas of purposefulness and connection, and in part pointing to the downsides of engaging in the oncology space after treatment, particularly that when faced with other’s child cancer experiences there are more reminders of the traumatic experiences they have endured. However, for May and a few other participants, it seemed that the benefits were outweighing the cons. Marie also spoke of her engagement on childhood cancer Facebook pages and what she achieved from this:

> *That’s the only part that I’ve felt valued in life if you know what I mean… that value that you’re there as a mum and you’re looking after your children, but I’ve been there to help others as well. (Marie)*

Marie explained that while there is personal meaning and purpose derived from the role of being a ‘mum’, along with this there was a specialness to viewing yourself as being valued in helping others going through the experience of childhood cancer. Marie takes on this new role of being an expert which is empowering and enables her to give back compared to her previous position of being the receiver of help. The rarity of childhood cancer also means it can be an isolating experience; so, this connection and sense of personal meaning can become attached to the views of one’s self. Like May and Marie, a study by Fletcher (2011) found that mothers of children who had been diagnosed with cancer found it important to give back to society after their child’s cancer treatment to help others who were facing the same distressing situation. Some of the participants in the present study reported giving back by being involved in fundraisers, Child Cancer Foundation events, Facebook support groups, and lobbied government and law changes with the aim of advocating for parents/caregivers affected by childhood illnesses.

To conclude this section, participants' sense of both loss of meaning and meaning-making was examined and illustrated. Participants discussed the challenges in re-establishing their sense of purpose and meaning after their child's cancer treatment. They considered how the cancer experience made them re-evaluate and prioritise their values in what was important to them along with shifting their expectations for themselves. This meaning-making and evaluation of values link to the idea of post-traumatic growth. Along with this, some participants had increased authorship in their ability to make different choices and so weighed up short-term and long-term goals. The quest for 'normality' also rang through from participants' accounts, with many feeling like resuming what was suspended from cancer treatment (work, social activities, aspirations for child) was important and meaningful to them after treatment. Participants also reflected on a desire to give back and the cancer experience giving them a new role as an 'expert'. This role gives knowledge and opportunity to enact with a sense of purpose they felt to meaningfully contribute to society.

Suffering from Memories

Another disruption to views on one's self that was experienced by all participants was that they were impacted by memories that would unexpectedly affect them in the present. This subtheme is named after a quote by Sigmund Freud (1893): "I think this man is suffering from memories". This subtheme aims to show how there is a cycle of past memories from the cancer experience that are continuous and are integrated into their identity, illustrating how the cancer experience is life-changing and not forgotten. Abi, whose child had been out of treatment the longest (34 years since diagnosis), noted *"the cancer is still in the background"*, conveying the continued presence and impact of the cancer experience. Participants reflected on how the impact of the experience might have lessened over time but had not disappeared. This idea of the impact of cancer being continuous on views of one's self is described by Emma:

> *You live in this constant anxiety. Someone described it to me once and I think this is a really good description… cancer is like this dark cloud over your head and it goes back but it never really goes away. It just goes further back, and I'd say that's true. (Emma)*

The analogy of a cloud evokes an image of the experience as ever-present and lingering, and that the impact of cancer sways backwards and forwards yet stays with you. Further, a cloud (and by extension the weather) is a natural occurrence that is out of our control. Emma also states that she feels like she is living in *"constant anxiety"* and this anxiety is making her feel on edge and hyperalert, but while it is constantly present it waxes and wanes. Similarly, May likened the cancer experience memories to *"little shadows"*:

> *I would say they're like little shadows that sometimes… like they're not a daily occurrence… but sometimes stuff pops up, and you're like 'oh yeah that's linked to…' you know there's still that little bit of something that sometimes lingers, or you might have memories suddenly that catch you. (May)*

Through the term *"little shadows"* May is explaining how she cannot escape the cancer experience but how it follows her much like a 'shadow'. This metaphor of a shadow may also embody the 'darkness' or 'trauma' of the cancer experience, much like the dark cloud metaphor that Emma used. For May, the little shadows also point to how the impacts of the cancer experience may not present themselves every day but are always lurking and can unexpectantly surface as she navigates through life post-treatment. Taken together, both Emma and May point to the ways in which the cancer experience continues to impact the sense of self in the present moment in an uncontrollable way. Oscar further explains:

> *I actually think it's a kind of post-traumatic stress disorder because… for me, for a long time I couldn't look at other children and not see all the things that you see when you're at Starship. So you can't help but be affected by that. I mean we spent a long time in hospital so we would see a lot of the kids… and that had a* massive *effect on me really to see them so ill, and it never goes out of your head. You still have that in your head for ages… So there's all those things that they have a kind of cumulative effect that you wouldn't be exposed to them in… any other normal way… if that hadn't happened to you, you would never have seen that… it became quite difficult at Starship to be surrounded by that and meet other kids and meet other parents and it just was traumatizing really… And I don't actually think I'm actually over that, I do feel that I've suffered a huge stress. That's just kept going, compounding. (Oscar)*[2]

Oscar reported that in the present that she *"couldn't look at other children"* without having a traumatic image or memory of the ill children seen at the hospital. This reflects that it is not just her grandchild's experience but the collective distress of going through other peoples' children's cancer experience which contributed to long lasting effects on Oscar. This is linked to the central organising concept of the cancer experience remaining with the participants and reflects how she views herself as having a *"permanent scar"* from the cancer experience. Oscar reflects that she feels like she has *"suffered a huge stress"* which has built

---

[2] Oscar identifies as female. She is the grandmother and primary caregiver of a child who went through cancer treatment. The name 'Oscar' was chosen by the participant due to the name's personal meaning and narrative within the family.

up over time showing the long-term and cumulative impact of the cancer experience on her sense of self. Oscar continued:

> *And so in my head are all these images that my brain has captured in the same way that I would take a photograph, and my brain is full of these things, and they're quite disturbing… and they sit in there. (Oscar)*

Oscar explained how traumatic images from the cancer experience are like photographs that have accumulated and stored to form an album in her mind. This explanation by Oscar of traumatic images could be understood as a form of intrusion which is a prominent feature of PTSD (Clark & Mackay, 2015). Like Oscar, many participants described how their mind has held these images of unwell-looking children (either their own or other children from the hospital) which increases their distress in the present. Many participants in the present study discussed intrusive imagery or memories, and a study by Norberg et al. (2005) found that 17% of participants experienced intrusive thoughts and images after their child's cancer treatment. Emma compared memories of her child going through treatment to the famous painting 'The Scream' by Munch:

> *When she was unwell, you know, all bald and looking sort of like, you know that painting 'The Scream' by Munch… I felt that that summed it up frankly. And she kind of looked like that… So I think photos of her being bald and looking really sick and terrible and I mean, the baldness is not what it's about. It's the fat face, it's the white skin because her particular medication made her pale and really puffy, so she looked weird too. So, photos will bring back that memory I've discovered, but I've only discovered that recently, yeah. (Emma)*

‘The Scream’ by Munch is a painting created in 1893 that according to Munch himself was a depiction of his emotions and a moment of existential crisis (Azeem, 2015). This painting symbolises the high stress, panic, and trauma that the painter was experiencing. Therefore, this comparison of Emma’s memories that she experiences of the way her child looked going through treatment to ‘The Scream’ painting by Munch implies not only the terrified and ghostly image of a child, but the existential crisis of the cancer experience and how that experience can be frozen in the present moment through the ‘perpetual scream’ of trauma. The vivid imagery Emma uses to describe her daughter during her treatment suggests the image has not faded with time, much like Oscar’s description of seeing unwell children during her time in hospital as a series of photos that are stored in long-term memory. Many participants described similar recollections of vivid images of their child while unwell and in hospital, and how still-present these images are many years after their child’s diagnosis. Given the literature that denotes a substantial subgroup of parents/caregivers who report clinically significant post-traumatic stress symptomology after their child’s cancer treatment, the existence of intrusive memories described by participants makes sense (Bruce, 2006; Kazak et al., 1997). Further, when examining post-traumatic stress symptoms, prior studies have noted the prevalence of re-experiencing symptoms. For example, in a study of 150 families of childhood cancer survivors, nearly all families (99%) had at least one parent meet symptom criteria for intrusion/ reexperiencing (Kazak et al., 2004).

Along with visual memories, participants also discussed how external reminders in their everyday lives caused an emotional reaction. Louise discussed her experiences of driving past the hospital:

> *I have moments where I’ll drive past the hospital and I’ll look at it and it will make me teary. Or I go… Our little [sibling #2], he’s seven, he’s got a peanut allergy, so I’m quite often going back there for check-ups with him, and we’ll*

> *go back there, and you know I'll smell the cafe, or I'll wash my hands in the toilet, and I'll smell the soap. And that you know sometimes that can set those things off. Or if I look back on photos, some of them when he's all bald and puffy they can make me upset, depending on the day. (Louise)*

Louise discussed how occurrences in her everyday life that are seemingly not cancer-related can cause her to feel sadness or become teary. Some participants, like Louise, also discussed this sense of external reminders causing them to be pulled back into the past. Participants described how reminders were often a smell, sound, or sight, such as the smell of disinfectant or the sound of beeping which reminded them of a ventilator. This caused an emotional reaction, and these moments were described as fleeting. This connects with ideas by Van der Kolk (2003) who points to the nature of traumatic memories as being fragmented, disorganised, and how traumatic memories present themselves as intense emotions, physical sensations, or images rather than having a beginning, middle, and end to the memory. In this way, Van der Kolk (2014) pointed to the importance of recognising that 'the body keeps the score' and thus reactions can be felt experiences that then need to be understood cognitively. Peter also discussed how he experienced his emotions after his child's cancer treatment:

> *And it doesn't have to be related to cancer it can be really weird, it can be like Shortland Street and someone gets diagnosed with cancer, and I'll start crying. And, it can just be sad things on children's movies, they're like "oh she's ill" and <u>that</u> will make me cry. And I can be talking to people, and they can… have some kind of emotional thing and then that makes me cry. And funerals where I don't even know the people [laugh] and I'm going to their funeral because, they're work-related, and I'll be much more upset than I <u>ever</u> used to be. Like none of that stuff affected me before… But now, whether*

> *I want to or not, I have no emotional control over those feelings, they're just there and they upset me and there's nothing I can do about it. (Peter)*

Peter recognises that triggers for feeling emotional and becoming tearful are related to his experience from his child's cancer. Yet, there is no observed connection with cognitions, which shows how the cancer experience is held in his body long after the cancer treatment is over (Van der Kolk, 2014). This demonstrates the way in which emotional reactions linked to the cancer experience presented themselves for participants in the long-term. Participants in a qualitative interview study by Carlsson et al. (2019) also described intrusive symptoms when faced with external reminders, and they experienced flashbacks to distressing situations from cancer treatment. These memories which take different forms remind participants of their past experiences during their child's cancer treatment and potentially remind themselves of their identity as someone who has gone through a self-described trauma. Participants seemed to experience a sense of these reminders as being perhaps 'forever inked' into their new sense of self.

Along with suffering from visual memories and emotional memories, participants also described the affective experiences that they have in the long-term due to the cancer experience. The most common emotions that were reported by participants were sadness, guilt, and anxiety.

> *That's been a big thing for me is kind of just reasoning that I kind of put her through all that, like I do suffer guilt from that, but also from just being absent from my son who was only seven at the time like he essentially didn't have a mother for three years. (Lena)*

Lena reported that she experiences guilt from the cancer experience. She feels guilt for putting her child through the pain of cancer treatment as well as guilt for the emotional absence for the sibling of her child with cancer. These lingering emotions impact views of the self particularly views of oneself as a ‘mother’. These feelings of guilt and regret wrapped up in a sense of self leave a permanent mark due to the cancer experience. Previous research has identified parents/caregivers as reporting feelings of guilt and self-blame in the long-term after their child’s cancer treatment (Ljungman et al., 2014). Lena’s account illustrates the nature of this distress and feelings of guilt and self-blame in the long-term. Comparably, other participants described feelings of guilt, self-blame, depression, traumatic stress, anxiety, and anger which all highlight the significant impact the cancer experience had on the psychological wellbeing of participants in the long-term. These complex and mixed emotions in the long-term are derived from memories in the past of the cancer experience but are long-lasting and continuous.

The ‘suffering from memories’ subtheme examined participants’ experiences of memories and how these impacted their emotions and sense of self in the present. This section spoke to how past memories cycled back and impacted participants in the present. These appeared as visual memories (snapshots in the mind, as illustrated by Oscar), emotions (self-blame, as illustrated by Lena), and a general feeling of presence (a dark cloud, as illustrated by Emma). This section showed how the cancer experience does not end at the end of treatment but persists into the long-term after cancer treatment through the ways in which participants see themselves. This section also demonstrates the importance of the social constructionist lens underpinning the study, as when thinking about ‘suffering from memories’ it is necessary to contextualise this distress instead of utilising clinical diagnoses to what is an understandable consequence to traumatic experiences. In this way, the participants’ distress is located within their context, through what happened to them, rather than locating the distress within the individual themselves.

Summary of Views about One's Self

It is apparent that the participants' views on themselves had been disrupted in the long-term from the cancer experience. Participants discussed how they felt their sense of self and identity had changed from the cancer experience; so much so that participants felt like they had a *"permanent scar"* and were a different person now. Participants discussed feeling 'defined by cancer' which brought a range of perspectives on embracing or distancing themselves from 'a cancer identity'. Along with discussing how much or how little they related to a 'cancer identity', participants also discussed general identity characteristics which had come from the cancer experience, in particular feelings of strength and resilience. A number of participants also articulated re-negotiating their sense of purpose and meaning with both experiences of loss of meaning and renewed meaning-making expressed. These subthemes provide evidence for the biographical disruption experienced by parents/caregivers after their child's cancer treatment. These themes also demonstrate the deep existential reflections that participants had from the cancer experience. Finally, participants spoke of internal experiences of suffering from memories that would occur in the present-day. These disruptions to views of themselves affected participants' emotional wellbeing and their accounts give insight into the nature of this emotional distress. As such, the importance of exploring participants' long-term experiences through a social constructionist lens is highlighted, bringing attention to the significance of how participants perceive themselves in shaping their experiences after their child's cancer treatment.

Theme 2: Views about the World

Participants all discussed their views of and interactions in the world in the shaping of their experiences after their child's cancer treatment. This theme is concerned with the perceptions and experiences participants had in relation to others. This theme is comprised of three subthemes: 'isolation', 'connection', and 'vulnerability' which capture the ways in which views of the world are disrupted in the long-term. The first subtheme, ‘isolation’, explores how participants felt misunderstood by society and social groups, as well as feeling fatigued for others’ problems which felt trivial in comparison to their own experience. Further, the ‘isolation’ subtheme speaks to feelings of mistrust towards healthcare staff and difficulties in intimacy in their couple relationship. The second subtheme, ‘connection’, was concerned with the supportive relationships and deep connections experienced in the long-term after their child’s cancer treatment. The third subtheme, ‘vulnerability’, reflects participants’ feelings of themselves and their child being vulnerable in the world. Participants felt a desire to protect their child from the threats and risks present in the world. The perceived vulnerability in the world appeared to be related to a heightened sense of mortality for both themselves and their child. This theme builds upon the first theme because these disruptions to views of the world appear to be underpinned by a biographical disruption and seem to be consequential to feeling that they had personally changed due to the cancer experience.

Isolation

Almost all of the participants discussed experiences of feeling isolated, emotionally lonely, or misunderstood by others. This ‘isolation’ subtheme is organised to highlight the perceptions participants had of the world. This section begins with experiences on a societal level, is followed by experiences with healthcare staff, then relationships with wider family/whānau and friends, and finally, within the couple relationship.

On a societal level, participants reflected on experiences of feeling isolated due to societal expectations and dominant discourses regarding what life was meant to look like after their child’s cancer treatment. Typically, these societal discourses were incongruent with the participants’ lived experiences. For many, this discrepancy between what participants perceived as what society thought they ‘ought’ to feel versus their ‘actual’ experiences led to feelings of alienation, difference from others, and, in summary, isolation that seemed to be of an emotional nature. Emma described how she perceived ‘shaving your head’ fundraisers as largely misunderstanding the cancer experience:

> *This whole ‘shave your head’ thing. I mean, frankly, to think that people think that they’re bonding with people because they’re shaving their head, it just doesn’t even start to begin to recognise it, and I get it’s a fundraiser, but it annoys me… I don’t want to be responsible for someone shaving their head and feeling like they look awful... and it doesn’t empathise at all. It completely misunderstands the whole experience which is: you lose all your body hair, and you lose it gradually because you’ve got cancer and you might die. It’s not even remotely similar so to pretend it is… Why make someone else upset or feel upset because they’ve shaved their head, which I’m sure for some they mind but why would you want to. I think it’s too radical to ask people to do. (Emma)*

Emma reflects that while raising money for cancer research is important and valuable, it is also misconstruing what the cancer experience is like for those who experience it. She reflects that it is too surface-level on what cancer ‘looks like’ to society (losing your hair) but does not deal with the core of the experience, which is emotional distress and a life-threatening situation. Emma is also saying she thinks it is too *“radical”* for the individual who chooses to partake in this type of fundraiser. Taken together, Emma is echoing a frustration in how she feels misunderstood by society which leads to feeling emotionally isolated. Emma’s narrative also highlights the lack of recognition of the experiences of those with lived experiences of childhood cancer. This highlights the need for greater inclusion of individuals with lived experiences of childhood cancer in campaigns for raising awareness and charity fundraisers.

Similarly, several participants discussed their thoughts on ‘battle’, ‘hero’, and ‘journey’ imagery and how these impacted on their experiences. These terms are prevalent dominant discourses in our sociocultural context. Some participants discussed how they did not like the 'battle', 'hero', and 'journey' terminology because it misrepresents the cancer experience. In contrast to dominant discourse, a participant reflected on how it was *"not a journey"* but a *"nightmare"* (Emma). Another participant reflected on how the children who go through cancer treatment have *"resilience"* but are not *"heroes"*, instead they *"do what they have to do"* to get through treatment (Marie). Several participants discussed the use of the word 'battle' and how the term implies 'winning' or 'losing', which indicates personal agency and choice in the outcome which is not fair.

These utterances from participants reflects how they viewed the world as not understanding them and society as not recognising their lived experiences. Due to public discourse not reflecting their lived experiences, participants felt different from society's view of them, and in turn emotionally isolated from the world. This is a notable finding as very little is found in the literature on parental experiences in relation to societal discourses on childhood cancer. In regard to the experiences of individuals diagnosed with cancer, this finding does corroborate the ideas of Raque-Bogdan (2019), who suggested that cancer survivors may experience feelings of isolation due to a sense of social stigma and from being discouraged by society from expressing their feelings.

Turning now to participants perceptions of healthcare staff, several of the participants who discussed their experiences with healthcare staff recounted invalidating experiences which had led to mistrust and feeling ignored and dismissed. Throughout their child's cancer treatment participants had to have frequent interactions with healthcare staff. Some participants reported feeling invalidated through being ignored and their concerns not being understood or acknowledged. In the long-term, participants discussed their views on healthcare staff which were coloured by a lack of acknowledgement of the impact of cancer treatment in the long-term, the lack of access to psychological services after treatment, and their experiences with healthcare staff from treatment impacting their views today.

Marie discussed how, due to her cancer experience, she finds it hard to trust healthcare staff:

> *Because we had all these complications along the way. We had PICC lines put in wrong places and me fighting for it all the time because it was me that could see things that weren't right. It was me chasing… I was watching every step of those nurses. And that's what I became. I became a person that I wasn't before. I would argue, I would put my foot down, and I'd question, and I, to this point, don't trust anymore. (Marie)*

Marie recounts her central role in her child's cancer treatment and how she considers that she was the person who picked up on the mistakes by the healthcare staff. Similar to Marie, several participants also described similar experiences of having a central role in their child's treatment and of noticing perceived mistakes by the medical team. The numerous perceived mistakes made by the medical team and Marie feeling like she was the only one noticing is reinforced when she correctly identifies the mistake. Psychologically, this creates a maintenance cycle of the behaviour of continuing to check for mistakes. This extract relays the sense of control she is attempting to have over an uncontrollable situation of her child getting cancer. The use of words like *"fighting"* and *"watching"* reflects the level of hypervigilance felt and how exhausting the experience was and how this impacted her sense of self in the long-term with becoming argumentative, assertive, and questioning of authority. Marie says *"I became a person I wasn't before"* which shows the biographical disruption and how her views on the world and views of herself are intertwined. This demonstrates a disruption in her identity because her role as her child's nurse and advocate had to take dominance over her role as a mother. She also feels that through this experience she finds it hard to build trust with healthcare staff in the long-term. This highlights the need for trauma-informed care when working with parents/caregivers of children who have completed cancer treatment. Trauma-informed care is a compassionate approach which changes the narrative from 'what is wrong with you' to 'what happened to you' (Hopper et al., 2010). In this way, trauma-informed care recognises the impact of prior experiences on current functioning and perspectives (Hopper et al., 2010). Marie went on to describe how she copes with her own physical health after her child's cancer treatment:

> *I don't go to the doctor as often as I should personally, because I don't have time. I don't have time for all of that nonsense because I'm dealing with my children. So I don't go and see a doctor very often either now, where I used to probably see a doctor so much more… I have aneurysms and stuff like that… You just cope with it at home. And one day I'm gonna cope with it at home and it's gonna be the wrong choice. That's my problem… I've spent too many hours sitting in an ED and arguing with doctors. If I can control it at home I will. (Marie)*

Marie described her experiences with healthcare staff as exhausting and predictable. Marie's perception of healthcare staff is that it is time-consuming and *"nonsense"* and therefore does not go to seek medical care when dealing with her own health condition. This speaks to how participants' invalidating experiences with healthcare staff can influence their behaviours and have a lasting impact on their interactions and perceptions of healthcare staff. Further, this shows how Marie sees her own self-care as a lower priority. Davies and O'Connor (2022) similarly found a lack of self-care continues to affect mothers years after the end of treatment due to neglecting one's own needs having become a pattern during treatment. The findings of the present study add to this understanding of low self-care through the fatigue of interacting with health services and invalidating experiences being additional contributing factors.

Like Marie, the participants who had negative experiences with healthcare staff felt that these experiences had permanently affected their relationships with healthcare staff. While Marie and some other participants discussed feeling like they were 'constantly fighting' with healthcare staff, other participants like Lena discussed experiences where they felt ignored:

> *I remember sitting on the floor in ED (emergency department) just sobbing my heart out and somebody saying, "are you okay," and I'm like "I just want to die." And they walked off and not a single person checked on me after that. (Lena)*

In this extract Lena described an experience she had in the hospital when her child was in maintenance and 5-years post-diagnosis. Lena discussed feeling ignored and dismissed in the face of her emotional vulnerability. This experience on top of her experiences in her child's cancer treatment has caused Lena to feel alone and isolated in her distress, which further perpetuates isolation from healthcare staff and the world in general. Several other participants also reported feeling like there was a disconnection in the hospitals between caring for patients' physical health and their mental health, with the latter being an 'after-thought' or not at all.

Participants also described invalidating experiences where their concerns about their child's late effects were dismissed, as Emma described:

> *They'll say, "Oh. Do you know, one in four people are infertile" or something… it's really irritating that comment. It's not comforting, it's just friggin annoying because it's like writing off the fact that this is quite a big thing… don't normalise it because it's not normal. Most people are not made*

> *infertile by treatment in their childhood… Like 'this isn't a big deal.' Well actually it's a fucking big deal. (Emma)*

Emma described an experience where a healthcare staff member attempted to normalise and reassure her that while her child has fertility issues that this is a common experience for people in adulthood. A previous study has reported that the fertility of a child who has had cancer treatment is an emotive issue for a parent, and information about fertility is a commonly cited unmet need for parents/caregivers after their child's cancer treatment (Wakefield et al., 2012). Altogether, these extracts by Emma, Lena, and Marie all speak of how invalidating interactions with healthcare staff during their child's cancer treatment had a significant impact on their perceptions of healthcare staff in the long-term, along with the deep level of isolation felt.

Further to experiences of isolation in the world, participants described their relationships in the long-term with their wider friends and family/whānau. The majority of participants recounted not feeling heard by their friends and family/whānau and a sense of difference from others. Kate described how the cancer experience was not over for her and yet how her friends and family assumed that it was:

> *They are there for the event, they are there for the drama… but the problem is, from the outside world, everyone sees an <u>event</u>, and then they see a cure or a remission, and then they move on. (Kate)*

Kate, like many other participants, described a narrowing of their social circle while their child was in cancer treatment, which was maintained in the long-term. This narrowing of friendships and social support was commonly described in participants' accounts as an initial flurry of support at diagnosis and then the gradual loss of friendships throughout treatment. Participants gave their thoughts on the reasons for this including: friends not being able to deal with it, friends not knowing what to say, friends feeling like the cancer experience went on for too long, and that they had supported enough. Kate's account reflects an isolation she experiences from the world due to her family and friends not understanding the long-term impact of the cancer experience. This reflects assumptions others have that when cancer treatment is over, and the child appears to be biomedically 'cured' then the cancer experience is over. This idea reproduces the dominance of the biomedical model in understanding cancer which is clearly at odds with the lived experience. Kate continued:

> *I just think that's the worst thing about the experience, everybody else is having these normal healthy babies and getting on with their life, and your whole world is… and it's hard to find a connection with someone that might understand where you're coming from. (Kate)*

Kate's account emphases how isolating the cancer experience continues to be as well as the biographical disruption. Kate seeks connection and understanding from others, yet feels isolated and different from others (specifically her peers). As such, this emotional isolation appears to be exacerbated in the post-treatment phase through a sense of otherness. The participants' sense of isolation to friends and family/whānau was striking, with similar accounts for other participants who also described feeling socially isolated because *"nobody really knows what you're going through"* (May), and *"people don't know what to say to you… so they say nothing, which isolates you more."* (Peter). Like Kate, many participants conveyed how other people did not understand what they had been through, and they did not understand the sequelae that follows the cancer experience, Marie said:

> *Then that kicks you in the butt, especially when your sister, who's a nurse, turns around and goes, "Oh, you're home. It's all over." Uh no. It's never*

> *gonna be over. And I think that's the hardest thing to get through to people it is* <u>*never ever*</u> *going to be over. (Marie)*

Marie reflected on how she felt let down by her sister, who she expected to be more understanding due to her sister's occupation and her close family relationship. Marie's sister seemed to be attempting to normalise being out of treatment, yet Marie perceived this as her sister in some way denying the negative consequences of cancer and its treatment.

It was evident that participants' social circles were narrowed during their child's cancer treatment, and in the long-term some participants reported that they remained the same and did not expand back. It is unclear as to the exact reason why social circles were not expanded back in the long-term. One reason may be due to a sense of safety and predictability when keeping to yourself and also due to experiences of feeling let down by others. Marie shared how the cancer experience made her retreat within herself:

> *Really put me in a shell of isolation… We don't trust people quite the same as we used to because those that we thought were friends didn't help us out at all, and weren't there for us. So we've withdrawn within ourselves. We don't commit to anything. So we don't have team sports; we have mountain biking, rock climbing, skiing, the things that we can keep to ourselves and to our family. Because that's how we've coped. (Marie)*

Marie recounts how the cancer experience impacted on her trust in friendships in the long-term. This aligns with the concept of centripetal families, with Marie seeking her needs from within the family rather than the outside world (Cipolletta & Amicucci, 2015). Marie's use of the words *"put me in a shell of isolation"* evokes imagery similar to a snail, which carries its house with it so that there is a safe place to retreat to protect against dangers in the world. This posits that there is safety and security in being isolated, whereas there is vulnerability to getting hurt outside of this shell. She highlights the self-induced isolation and withdrawal behaviours are a coping mechanism in place due to being let down by friendships from the cancer experience. Therefore, to decrease being rejected and disappointed by others she describes only participating in individual sports and not team sports. As such, it appears that this isolation is almost a self-fulfilling prophecy due to decreased opportunities for building positive relationships with others.

Another reason for the emotional distance and isolation from others in the long-term (which also connects with the first theme) may also be due to feeling like they have become a different person, with a change in perceptions of problems. May explained:

> *I'd get annoyed with people who would whinge about pointless crap. [laugh] And I would sit there and go 'oh my god,' but you can't go "You've got no idea like you should just stop whingeing," [laugh]… like your perspective has changed. You don't see that that matters. It's like, why's that a problem. How is that a problem in your life. (May)*

In this extract, May was referring to what she described as *"trivial stuff"* that people would *"whinge"* about. Yet, due to feeling like her perspective on what matters and what is a problem has changed since the cancer experience, she has found it hard to connect with others and their problems, which feel insignificant compared to the trauma that she has experienced. May also reflected how she recognised that problems were relative to personal experiences. This feeling of difference to others and a fatigue for others' problems was reported by some other participants as well. Some participants mentioned their increased tolerance to life's hassles came with the perception that the complaints of others were annoying or unnecessary. Yet this perception appeared to interfere with social relationships, meaning that this change in perspective on problems could have negative effects on relationships with others. A recent qualitative study by Carlsson et al. (2019) supports this finding, as their interviews found that parents reported no longer complaining about ‘trivial’ things in life as well as having a tougher attitude towards others in society, with less empathy for people who complained about, in their opinion, banal things. Similarly, Oscar also reflected on more fatigue in relationships with other people:

> *Just really not having the energy for other people… I just feel like I’ve been through too much. I don’t have any real friends, like any close friends… I don’t have the energy for other people. I can’t have that emotional investment in other people. So, I pretty much keep to myself. I’m easily offended by other people [laugh] think I don’t actually have very good people skills anymore; I think I’ve lost them all somewhere. I’ve become intolerant. (Oscar)*

Oscar also reported feeling emotionally isolated due to not having the emotional energy that is involved in maintaining a friendship. This extract demonstrates the huge impact that the trauma of the cancer experience had and the feelings of isolation it can bring. Oscar feels that the burden of maintaining social relationships is too high and so keeps to the safety and comfort of the family unit. Many participants discussed the challenges to relationships with wider family and friends in the long-term. As discussed, it was commonly cited that a lack of understanding of what they had been through, an expectation that the cancer experience was over, and a feeling of difference from others meant that there was an emotional isolation in social circles.

Finally, experiences of isolation in the world were described as they related to participants’ couple relationship. Notably, nine of the ten participants were still married to the partner that they went through their child’s cancer treatment with (the other participant was widowed). This is noteworthy as many participants discussed how they felt ‘lucky’ that they were still with their partner, and they discussed how the statistics on divorces/ separations after a child’s cancer treatment were high. However, according to several studies childhood cancer is not associated with an increased parental divorce rate (Mader et al., 2020; Syse et al., 2010). Even in studies on partner relationships in parents of long-term childhood cancer survivors, the rate of divorce/separation was similar to that of the general population (Mader et al., 2019).

Many participants discussed how they worked well with their partner during their child’s cancer treatment, and how they each carried out distinct roles and were supportive of one another. Yet, after cancer treatment (and in the long-term) some participants reported conflicting coping styles with their partner, namely with one partner seeking openness and reflection on the cancer experience and the other partner wanting to move on and suppress the traumatic memories of the cancer experience. Peter discussed:

> *I think it’s really important to be able to move forward… And that’s really hard for one part of the relationship to go, ‘Well I want to move in this direction.’ If the other side is, is still stuck… If one person wants to forget about it, and go forward and the other person is still lingering there then that’s probably the biggest hurdle to get over is to basically realign. (Peter)*

Peter discussed how the conflicting coping styles in the couple relationship was a present stressor with one person in the relationship looking back on the cancer experience while the other person was trying to look forward without the dominance of the cancer experience. Conflicting coping styles were reported by some other participants, particularly with one person in the relationship wanting to attend childhood cancer-related events and being engaged in the paediatric oncology space, whereas the other person wanted to disengage from childhood cancer reminders. These differences in coping styles and communication appeared to have gender-related differences. Peter (the only male participant in this study) reported wanting to move on without cancer reminders; whereas, other participants who described finding it helpful to reflect and remain engaged in childhood cancer relationships identified as female. While this finding may not be reflective of the general population, this could be an interesting area for future research. These two valid coping styles that are incompatible seemed to cause strain on the couple relationship and perpetuate a feeling of emotional isolation.

A few participants also discussed feeling closer to their partner than before due to bonding over a shared experience. Concurrently, they also found it hard to be intimate and go back to how their relationship was before due to both partners being affected and traumatised by the experience. May described:

> *You've spent so much time focused on surviving that then you have to somehow remember that you're a couple. And that doesn't seem like it matters anymore. [laugh]... it's like you then forget like because you don't spend time together, you're just, you're working as a partnership to get stuff done and get to appointments and do this and do that for a long time, it is a* <u>*functioning*</u> *type of situation really. So I can see how easily you'd lose each other and yourselves in that process... I can see how quickly and easily it happens. Because it's just no longer a focus. And it's not the priority, this sounds horrible, but it's not. Initially it's just not. And for quite a while it's not, and then you have to recalibrate and try. (May)*

May discussed how the focus on her child's cancer treatment was consuming and so intimacy and the couple relationship naturally took a backseat. Then in the post-treatment phase there is an active need to work on the relationship again and re-prioritise each other due to a sense of losing one's self in the process. This shows how couples can feel united in relation to their child's illness and treatment, yet, how distant they can feel as a couple. This extract demonstrates the isolation that can be felt on the level of the couple relationship. In reviewing the literature, studies appear to support this finding of couple relationship difficulties, due to not being able to meet each other's emotional needs (Ljungman et al., 2014; Quin, 2004).

This subtheme examined the layers in which participants felt emotionally isolated from the world. It revealed how on a societal level, participants felt misunderstood and misrepresented in dominant discourses and in the ways in which society made sense of their experiences. This section also spoke to feelings of isolation due to invalidating experiences with healthcare staff which made them feel ignored, dismissed, and fatigued. Next, the subtheme explored the ways in which participants felt isolated from wider friends and family and reasons why their social circle remained small in the long-term after their child's cancer treatment. Finally, this section recounted participants' experiences of isolation in relation to their couple relationship, particularly with experiencing conflicting coping styles and finding it hard to relax and be intimate again. Ideas of isolation were frequent in participants' accounts, and it was clear that they were evident in many social relationships in their world. In turn, this sense of isolation was linked to clear biographical disruption and impacted on perceptions on both how they were viewed by others in the world and how they viewed others in the world.

Connection

In contrast, while participants saw the world as an isolating place, they also reported discovering pockets of deep connection in some relationships in the long-term. This subtheme considers how the cancer experience allowed for the strengthening of the couple relationship, as well as deep friendships to foster with other parents/caregivers who had also experienced child cancer treatment. Further, this subtheme considers the tensions in this newfound connection with other parents/caregivers, and how connection over this traumatic experience can have its downsides.

As discussed in the previous subtheme, there were reports of difficulties in the couple relationship in the long-term after cancer treatment. Yet, several participants also discussed how their couple relationship was strengthened as a result of the cancer experience. Marie discussed her relationship to her husband:

> *Obviously, there's been tough bits, but I think we've got each other's back. I think it's actually built us stronger in the sense that we're there for the kids… He believed me when no one else believed me. He could actually sit there and go "actually, you got a point.", and back me up. And I think that, that to me was like he values me which… I felt no doctor seemed to at that time, you know at the time when no one was listening to me, felt like I'm hitting my head into a brick wall the whole time where at least I had somebody that was actually there listening, understood where I was coming from. So, I think it built that relationship. (Marie)*

Marie's narrative speaks to ideas of emotional isolation in her relationship with healthcare staff, reflecting her feelings of vulnerability and perceived loneliness experienced during her child's cancer treatment. Yet, she reflects on how her couple relationship grew stronger from the cancer experience due to feeling that they were on the same 'team', and they were in this collective 'fight' together which allowed for a deeper level of connection and togetherness after their child's cancer treatment. Other participants also reflected similar sentiments, explaining that their relationship was *"closer than ever before"* (Kate), and how they felt like a *"team"* or that their partner was *"supportive"* which *"took the pressure off"* (May). Peter described how he and his wife supported each other when experiencing emotional distress after their child's cancer treatment:

> *We took turns… Somebody had to hold up the family and be completely in control with themselves, and I did that until I saw [partner] get well. But, the <u>well</u>, was just her medication, it wasn't, that she was well. [laugh]… You were now capable. Now I can let go of holding the family together, and I can go into my depression, essentially. [laugh] And, and then come out of it. And we both came out of it. (Peter)*

Peter described how both he and his wife experienced depression after their child's cancer treatment. He reflected on how he felt a need to *"hold up the family"* while his wife was experiencing a depressive episode and then once her depression improved then he fell into a depressive episode himself. This demonstrates a deep connection that had been fostered through the traumatic experience and how they allowed each other the space for their emotional expression of the trauma and then how they supported each other in their mental health recovery. This possibly also speaks to the role of a 'father' in the family system while going through the cancer experience, indicating a need to act with strength and guide the family which is done through managing emotions that arise from childhood cancer experience. The reflections from this extract has a similar note to a study in Aotearoa New Zealand by Cluley (2015), who qualitatively explored the role of fathers in their child's cancer experience. This study had a theme named 'finding strength' with a subtheme of 'emotional rock' which reflects ideas of fathers feeling like they need to find the strength to sustain and support themselves and their families, which involves controlling their own emotional expression alongside balancing the acknowledgment of their own emotional trauma (Cluley, 2015).

A significant relationship that came from the cancer experience and that continued years after their child's cancer treatment was that of connection with other parents/caregivers who had also had a child diagnosed with cancer. Participants reported feeling emotionally validated, supported, and understood through this relationship. These relationships with other parents were fostered through a collective shared trauma they experienced, which fostered a mutual understanding and bond with one another. This was described as *"the only people who really get me"* (May). Lena explained:

> *The parents form quite a close bond. [laugh] Now it feels like some of those parents is talking like with old friends, you know, you don't need to explain stuff, they just get it. (Lena)*

Lena describes her relationship with other parents/caregivers who had a child diagnosed with cancer as being like *"old friends"* where there is a mutual understanding of one another that needs no explanation and can be unsaid. This not needing to explain one's self seemed to be important for participants due to a general fatigue from having to 'retell' their story and explain their child's needs and late effects to the general population and to healthcare staff. Therefore, these friendships show the power of peer support which appears to have a powerful presence and role in the long-term after treatment. Oscar had similar reflections:

> *That's what you've had in common, that whole journey has been something in common, so you don't have to explain how you feel about sending the kids to school if there's some illness going around or, you know we were talking about how funny it was that we never went anywhere except to each other's houses, because we had a common understanding about cleanliness and not being exposed to infection, all that sort of thing was just something that we had in common. You know the trauma of constantly having surgery, all these things. So you never ever have to say that to those people. But if you just talk to people who haven't had that experience, and it just becomes tiresome, having to do that. So I don't really have any real friends that haven't had that experience really. (Oscar)*

Similarly, Oscar reflects on the power of the shared experience on the connection and relationship with others who have been through it. Meanwhile, there is distancing and isolation from others who haven't been through the experience due to a sense of fatigue from re-telling and re-explaining. Along with this, participants described a collective trauma that bonded them with other parents/caregivers:

> *And we are each other's vent, and that's what gets us through because we both have very similar views on the hospital world because of the way that we were treated. She was there. She saw all of what went on with [child] and I saw everything that went on with [friend's child]. You know what I mean, we were there that whole time for each other. So we understand why we have that anger. (Marie)*

Marie explained how other oncology parents/caregivers were protective from isolation and interpersonal difficulties with hospital staff during treatment. Marie highlights how her friend and her shared the traumatic moments of their children's cancer treatment, and in the long-term, this mutual support led to a deep connection between them.

While participants reflected on a deep sense of connection that was maintained in the long-term with other parents/caregivers of children who experienced childhood cancer, some participants also discussed the tension they felt about continuing to engage with other oncology parents. Participants discussed how continuing relationships with oncology parents was at conflict with attempts to *"normalise our lives"* (Lena). Participants described how continuing to go to oncology events and remaining in contact with oncology friends was *"pulling you back in"* (Lena) and *"reminding you again"* (Oscar) of the traumatic experience. It was clear that the quest for 'normality' meant, for some, disengagement with childhood cancer reminders, and interactions with other affected parents/caregivers were one of such reminders.

The 'connection' subtheme explored the ways in which participants experienced connection in the long-term after their child's cancer treatment. This section compliments and contrasts the 'isolation' subtheme, as while the existential crisis of confronting their child's cancer experience and their own mortality meant that participants felt emotionally isolated, they also fostered and maintained connection to people in the world. Furthermore, experiences of connection appeared to be due to feeling like they were understood and validated, whereas experiences of isolation were due to feeling misunderstood, ignored, and invalidated by others. Experiences of connection appeared to develop through experiences of collective trauma. Predominantly, this included their partners and other parents/caregivers who had a child diagnosed with cancer. Shared experiences and a mutual understanding seemed to foster bonds and maintain a sense of connection, and it was unencumbered by the fatigue associated with the need to retell their experiences or explain their child's needs.

Vulnerability

The third theme about the world that recurred was that many participants perceived themselves and their child as vulnerable in the world. Many participants perceived threats and dangers in the world that may harm their child, including signifiers of potential relapse or secondary cancers, germs, and other people who pose a risk to emotionally hurting their child. In addition to discussing perceived threats in the world, participants discussed the ways in which they exerted control or tried to protect their child and themselves in order to feel as safe as possible. This subtheme also considers the behavioural aspects of both coping with uncertainty through monitoring and checking and the constant vigilance in the management of their child's late effects. It is important to also highlight that cancer recurrence is discussed in this subtheme 'vulnerability' and also in the third theme *Views about the Future* under the subtheme 'uncertainty'. While the topic of cancer recurrence is the same, these are discussed differently with the exploration in this subtheme as being present-focused, and in the next subtheme as future-focused. Taken together, this demonstrates how pervasive the current threat and future uncertainty of cancer recurrence is for parents/caregivers.

Feeling vulnerable to potential cancer recurrence was evident for many participants. Marie discussed seeing physical health signs that could indicate a potential relapse or secondary cancers in her child after cancer treatment:

> *That's when I start to worry it's like a daily thing you see things and you go… I wonder what those lumps are? I wonder what that is? (Marie)*

Due to Marie's experience of her child's cancer in the long-term she is on the lookout for threats to her child's health and wellbeing, particularly indicators of the cancer returning or of secondary cancers. This is a real worry for those affected by childhood cancer as there is a risk of late recurrence (Wasilewski-Masker et al., 2009). These 'what if' questions Marie experiences are linked to the anxiety and worry she experiences in the long-term and a hypervigilant watchfulness for the potential return of cancer. Many participants echoed Marie's anxiety, worry, and checking behaviours. Marie, reflecting that this is a daily experience, demonstrates how the cancer experience is not over when treatment ends and shows how she perceives her child's health as vulnerable to potential danger on an ongoing basis. A theoretical framework on the fear of cancer recurrence by Fardell et al. (2016) highlights the importance of metacognitions (unhelpful beliefs about the importance, impact, and controllability of cancer recurrence worries) and problematic cognitive processing styles to deal with the worry (rumination, attention towards threat-related information) in the maintenance of fear of cancer recurrence in the long-term. This framework was developed for patients and it could be extended to parents/caregivers. As applied to the present study, this formulation could mean that a metacognition of, 'if I worry about the cancer coming back, I will be more prepared' as well as processing this cognition through frequent monitoring could lead to significant distress in relation to the worry of cancer recurrence. This monitoring behaviour may also be due to self-blame participants have for not noticing the signs of cancer before their child's diagnosis, and therefore, wanting to closely monitor so that these signs are picked up earlier.

Like Marie, Emma also discussed a recent time when her child was tired and had received a blood test which had a worrying result. Emma said that she:

> *Completely freaked out, made her ring everybody and do all this stuff and so I go straight back into that mode. It's like, as soon as there's anything, I go right back to that place. (Emma)*

Both Emma and Marie reflect on how symptoms of physical illness can trigger anxiety and worry about what could be wrong. This worry leads to 'safety behaviours' of calling the doctor for reassurance or checking physical health signs. A safety behaviour in psychology is an action carried out in response to a feared catastrophe (cancer recurrence) that is intended to keep themselves safe, and while the safety behaviour can lead to short-term relief it can also reinforce beliefs about the perceived threat (Rachman et al., 2008; Salkovskis, 1991). Participants commonly discussed how they *"go straight back into that mode"*, and this demonstrates how the 'survival mode' from treatment is stored and the response from the cancer experience comes back in the long-term when confronted with a potential cancer-threat to their child's health.

As Emma and Marie described, participants commonly interpreted and worried about bodily sensations in their child as threats to their child's health and signals of cancer recurrence or illness. This interpretation of threat is not a cognitive distortion but a real possibility. In addition to this, Oscar discussed how difficult it was in the long-term to move away from these threat appraisals:

> *I mean he couldn't go out in the garden, he couldn't go near the compost heap, he couldn't touch dirt, you know, he couldn't do this, couldn't do that. So it was all these parameters and that's the way you had to learn to live and then you get to the end of it, and then you can just do what you like. [laugh] But you can't because you've reprogrammed yourself to live in this other way. And then you've got to get rid of all that out of your head and think 'well okay, I can go out and I can do that and he's not going to get sick'...*

> *Just learning to accept that there are normal childhood accidents and illnesses that you're going to get but not to frame it in the way that you used to. That actually takes a long time to get that out of your head to not keep thinking that 'oh maybe something else is underlying that,'... Yeah, it took a long time to get that out of your head and start just thinking 'well, things happen to kids' and then you just gotta learn to frame that up more normally. (Oscar)*

Oscar reflected on how difficult it was to transition from how she learnt to cope during cancer treatment and maintenance, into letting go of those strategies (e.g. hygiene protocols) in the long-term after child cancer treatment. Oscar spoke about how the cancer experience *"reprogrammed"* her into a new way of living and thinking about the child's vulnerability. Yet, in the long-term, the letting go of what was learnt in the cancer experience was very difficult, as the threats in cancer treatment to the child who is immunocompromised and vulnerable are seen everywhere. With this, Oscar discusses how there are *"normal childhood accidents and illnesses"* and so learning this without seeing the presence or return of cancer is incredibly difficult due to the all-consuming threat it had over their lives for so long. This extract demonstrates how the cancer experience changed the way that participants thought and how they continued to perceive their child's vulnerability, and how in the long-term re-adjusting thought processes away from threat appraisals is difficult.

Another perceived vulnerability when interacting in the world in the long-term was that of infectious disease. A sequelae of childhood cancer is the patient often has a compromised immune system, meaning they have added vulnerability to viruses (Guilcher et al., 2021). For some participants, this fear of *"catching something off someone"* (Oscar) remained in the long term. Lena stated:

> *And the anxiety that comes with it. I mean still, we'll go to the movies if somebody coughs in the cinema. It's like my automatic reaction, I'll just run out. [laugh] (Lena)*

This extract demonstrates how much the cancer experience has impacted Lena in the long-term, with automatic responses learnt from the cancer experience without particular cognitions that are intermediary. Much like classical conditioning, Lena describes a Pavlovian response in how her response to someone coughing (stimulus) which carries the potential for the spread of infectious disease is to automatically react by escaping (conditioned response). A few other participants also described similar reactions and described how it *"takes a long time to get out of your head"* (Oscar) the idea of catching an illness. This shows how the perceived threat of germs and infection is a real and long-lasting impact into the long-term period which has real implications on navigating in the world.

Participants tended to see their child as vulnerable in the world as a consequence of the perceived threat towards their child's health. This vulnerability was in respect to both non-living threats in the surrounding world and other people in the world who could hurt the child who had endured cancer treatment. Emma explained:

> *And, there's anger and grief, you know, and I think that anger I put into, if anybody dared hurt [child]. You know, even children. I wouldn't… but I hated them, I hated them. I hated the principal. I hated the doctor. I hated [hospital]. I wouldn't even go in the oncology ward. I made that very clear. I just became very… I got on really well with everybody, but if anybody did anything that I perceived… that other combative side of me came out really strongly. (Emma)*

Emma discussed how she was carrying anger related to the grief reaction from her child's cancer treatment and from what her child had to endure at that time. She described putting that anger she felt into protecting and fighting for her child against school bullies and others who potentially posed a threat to her child. Emma's use of the word *"combative"* again brings up imagery of a constant fight and battle. This statement also shows how close the bond is between Emma and her child, and how Emma feels that when her child is hurt, she is also genuinely hurt. Along with fighting the threats in the world, it also implies there is again a level of feeling isolated from the world and needing to insulate oneself and one's child. Several participants discussed how they felt that the 'fight' to protect their child was ongoing. Abi reflected on the implications of 'fighting' for her child in treatment which has led to a need to 'fight' for her child long afterwards:

> *Because you've battled all your way, and you've worked really hard to keep this kid alive. You don't want to just let someone else do whatever. So, in some ways, you can be overprotective, because you have that heightened sense of loss, possible loss. And so yeah, you know, I suppose that grieving is for a lot more than just potential, it's grieving for what they've had to put up with. And keeping them alive, through the normal world. (Abi)*

In this extract, Abi is referring to her child, who is now an adult, navigating dating and romantic relationships and how she does not want other people in the world to hurt and take advantage of her child. Similar to Emma, Abi also uses language which evokes imagery of a battle. Abi described how she had *"worked really hard to keep this kid alive"* which implies a personal determination and active role that participants felt in their child's outcome from cancer treatment of going into remission. In this way, Abi is conveying a sense of responsibility she feels for keeping her child alive. This heightened sense of responsibility also comes with a perception of control and that it is her actions which led to the outcome of remission. Further, this communicates a worry about others keeping her child safe in her absence. Abi did experience cancer recurrence in her child's cancer which she found traumatising and which she links to feeling *"overprotective"* over her child who is navigating the world in adulthood. Abi does not want other people (namely; dating relationships) to *"do whatever"* which reflects a potential of carelessness, disrespect, and disregard the world can have on her child which would impact on her child's health and wellbeing. This utterance also reflects how Abi searches for a sense of control over her ability to keep her child healthy and safe while navigating the threats in the *"normal world"* which adds to distress. Abi believes that this is due to a *"heightened sense of possible loss"* that she was confronted with in her child's cancer treatment. This extract has similarities to Emma's reflections and demonstrates the family systems' relationships with an increased level of involvement in their child's life. It also highlights the participants' role in wanting to 'rescue' their child who is vulnerable to the dangers of the world.

Other participants also commented on their parenting style in the long-term when guiding their child to navigate the world. One participant discussed how they had to *"beg"* for themselves to be in an earlier group for Covid-19 vaccinations due to their child's physical late effects. Another reflected on how they needed to know about what the school was teaching their child in relation to sex education in order to better prepare their child due to their child's fertility difficulties from cancer treatment. These examples further highlight how participants attempted to help their child in navigating the threats and vulnerability of life after cancer treatment.

Along with a perception of their child being vulnerable or susceptible to the dangers in the world, the cancer experience in the long-term seemed to bring a general sense of increased perceived vulnerability, which participants would be reminded of when interacting in the world. May discussed recognising her and her child's vulnerability when interacting with parents she knew from hospital who were bereaved:

> *I sometimes run into some of the other parents that still come to things… like [child from hospital]'s parents. And I do feel like, 'oh gosh,' yeah, like I said it felt a bit like a sick game of Russian Roulette, because it… it could have been any of us who, you know… (May)*

When May states *"like I said"* she is referring to an earlier point in the interview where she discussed how they *"went through a patch that was really awful"* where *"suddenly"* there was a *"string of deaths, and it felt like a sick game of Russian roulette"*. May, and many other participants, described the traumatic experience of being on ward when other children who were also there for cancer treatment died. Also, the imagery of Russian roulette depicts the luck and chance involved in successfully completing cancer treatment. Bereavements were experienced as 'random' through the statement *"it could have been any of us"*. This lack of control and randomness shows how in the long-term the cancer experience impacted on a sense of security and vulnerability in the world, with participants seeking to counter this through their monitoring, vigilance, and actions. Peter also discussed this:

> *They gave [child] a ninety five percent success rate. They said, "it's a <u>long</u> period of treatment but we have a ninety five percent success rate"... So you got a belief that it's all gonna go well. And then you see people exactly the same treatment, exactly the same diagnosis, just dying. (Peter)*

Peter conveys that after the initial shock of diagnosis you begin to trust that the odds will be in your favour and that your child will successfully complete treatment. Yet, the experience of other parents/caregivers who became bereaved during treatment who had similarities in treatment and diagnosis increased a sense of vulnerability and a confrontation with their child's mortality. These reflections by May and Peter reflect on how transformative the experience of other parents' bereavement is while on cancer treatment. This confrontation with their child's mortality and vulnerability is reminded in the long-term when interacting in the world, especially with other parents/caregivers from the cancer experience. The *"it could have been any of us"* conveys the lack of control and the sense of vulnerability.

This exploration into understanding the vulnerability experienced by participants may provide contextual information into understanding why a proportion of parents continue to perceive their child as vulnerable years after cancer treatment (Staba Hogan et al., 2018). Studies have discussed childhood cancer as associated with loss of control in perceiving an inability to manage or influence events (Van Dongen-Melman et al., 1998). This perception of having little control over the disease's outcome, may point to ideas of participants having an 'external locus of control' which is a perception of things happening to them which involves luck, fate, and circumstance (Lefcourt, 1991). Ideas of control rang through participant accounts, Lena recounted *"something so completely out of your control just really changes you"* which shows how perceived lack of control impacted participants in the long-term.

Along with ideas of having an external locus of control, there were also some participants who discussed a sense of personal responsibility in the cancer diagnosis which linked to blame and guilt. Participants discussed grappling with this through questions such as *"what have I done to create this"* or *"what have we done"* which *"eats away at you"*. The literature points to a hypothesis on a curvilinear relationship between locus of control orientations and stress which theorises that individuals with extreme internal or external locus of control may be vulnerable to distress whereas those who appraise their degree of control in a more balanced way may be more accepting and experience less distress (Krause & Stryker, 1984; Van Dongen-Melman et al., 1998). Therefore, the downside of perceived control is a heightened sense of personal responsibility and intense self-blame.

In summary, this 'vulnerability' subtheme examined how participants perceived threats in the world in relation to themselves and their child. Participants discussed their alertness to potential signs of danger in their child's health with the worry of cancer recurrence and potential indicators of this. They also illustrated their continued 'battle' against the threats in the 'normal world' in protecting their child against others who may hurt their child in school, social, and dating relationships. Imagery of 'battle' were present in these accounts which resulted from the already high investment of energy and effort that went into keeping their child alive through treatment. Altogether, the perceived vulnerability of interacting in the world along with the continued fight to protect their child through the dangers of the world demonstrates how the cancer experience is not over when cancer treatment is completed. Further, the cancer experience seemed to bring a general sense of feeling vulnerable especially when reminded of others' bereavements.

Summary of Views about the World

Using a social constructionism paradigm to explore parental experiences in the long-term after their child's cancer treatment demonstrated the importance of relationships and interactions in the world in shaping these experiences. This theme of *Views about the World* was concerned with the perceptions and experiences participants had with others in the world, namely: society, healthcare staff, wider friends and family, other parents/caregivers who had a child diagnosed with cancer, and the couple relationship. Participants discussed feeling like they were in a *"shell of isolation"* due to feeling different from others and from having had experiences where they felt invalidated and misunderstood. This sense of isolation appeared linked to biographical disruption due to the illness impacting on how they believed they were viewed by others. Along with this, they discussed experiences where they felt connection in the world; mainly these were to others who had gone through a similar experience or with whom they had experienced their child's cancer together. This theme was also concerned with the perceived vulnerability experienced in the present that is a lasting impact from the cancer experience. Here, participants discussed the challenges of protecting their child in a world that is dangerous and threats that may harm the child's health and wellbeing. These subthemes provide evidence for how the cancer experience does not end when treatment ends. Instead, threats to their child's health and wellbeing are ongoing, and social connection and isolation from the treatment period is maintained due to feeling like they have changed from the cancer experience. This change to self that was discussed in the first theme has implications on how participants viewed the world.

Theme 3: Views about the Future

Participants discussed views about their future, which reflected ideas of biographical disruption in how the cancer experience had shifted their expectations of the future. Changes to views about the future were also associated with changes in views of themselves and their world. The cancer experience reconstructed participants' views of the future, which included a new picture of continuous management of the sequalae of their child's cancer, and grief of what their future should have been like, as well as uncertainty about what the future might now be like. This theme is broken down into two subthemes of 'uncertainty' and 'loss of an imagined future' which encapsulate the long-term disruptions to views of the future. The first subtheme, 'uncertainty' discusses a cognitive sense of the fear of cancer recurrence, the possibility for future late effects, expecting the unexpected, and general worry. The second subtheme, 'loss of an imagined future' explores the participants' feelings of grief in themselves and their child having different life trajectories due to the impacts of their child's cancer. Psychologically, 'uncertainty' and 'loss of an imagined future' pulls the participants into the future which gives rise to anxiety and into the past which gives rise to sadness, grief, and regret, respectively.

Uncertainty

Participants experienced a disruption in their view of the future through a preservation of the uncertainty and lack of structure in life. This subtheme speaks to the uncertainty felt for the future in relation to the possibility of cancer recurrence, the possibility of future late effects, feeling a sense of expecting the unexpected, and a general worry about the future. The possibility of cancer recurrence was discussed in Theme 2 under the subtheme ‘vulnerability’, and it is brought up again in this subtheme of ‘uncertainty’ due to the former being about the present-focused nature of the threat of cancer recurrence and in the latter being about the future-focused anxiety.

Almost all of the participants discussed anxieties about the possibility of cancer recurrence, and they believed they would live with this anxiety for the rest of their lives. Alexa illustrated her feelings of uncertainty and worry around the possibility of her child’s cancer recurrence:

> *You just feel on edge, you know, a lot of the time. There’s a lot of worry that it’s going to relapse, you know, so that’s always in the back of your mind and so you’d be sort of noticing any little thing that that might crop up. But yeah, kind of feeling just quite anxious. (Alexa)*

Alexa described her worry of her child’s cancer recurrence and how this was linked to her experience of anxiety. This association between fear of relapse and anxiety for parents/caregivers after their child’s cancer treatment is well supported by the literature (Ljungman et al., 2015; Mellon et al., 2007; Norberg & Boman, 2013; Norberg & Green, 2007; Wikman et al., 2017). Alexa, like many other participants, described the fear of cancer recurrence as *“always in the back of your mind”* which shows how the cancer experience does not end; while the cancer may not always be the main thing she is thinking about in her everyday life, she is always aware of it and the memory has made a permanent mark on her thoughts and behaviours. It was also apparent in participants’ accounts that, like Alexa, there was a jumping to the ‘worst case scenario’ which fits with their lived experience of having been confronted with their child’s cancer diagnosis and it also fits with constructions of health anxiety, where people often experience catastrophic interpretations of physical symptoms (Marcus et al., 2008).

Two participants did experience their child's cancer recurrence and they found that traumatising. These two participants also experienced worries about cancer recurrence in the future. One of these parents was Emma; she describes:

> *You can't not be aware of it, especially if your child's relapsed. And it's a reality we face, is the situation that your child could die… Most people don't have to think like that about their children, and that's the reality is you've always got that thing hanging over your head that they could die. You know, and that's still relevant always, and will always be relevant, no matter how old she is. (Emma)*

Emma reflected on how the fear and worry of her child's possible cancer recurrence is always *"hanging over your head"* and will for the rest of their lives. She grieves that other people do not have to think like that about their children but that it is a reality for her because there is always the possibility of relapse. This comparison Emma makes between her own cognitive processes to others (*"most people"*) relays a sense of otherness and changed self-identity (theme 1) which perpetuates the sense of emotional isolation experienced (theme 2). Participants commonly described some degree of worry for cancer recurrence, which is a relevant concern since the risk of relapse is an ever-present reality (Wasilewski-Masker et al., 2009). This future-orientated realistic threat due to the nature of cancer and its treatment is a feature of this phenomena that is not readily applicable to conceptualisations and models of PTSD maintenance (Bruce, 2006). For example, a cognitive model by Ehlers and Clark (2000) which focuses on the maintenance of PTSD proposes that PTSD becomes persistent when the individual processes the traumatic event in a way that leads to a sense of serious current and future threat. However, in considering the experience of childhood cancer, there is the fact of a sense of threat located in the future (i.e. cancer recurrence and late effects) which make such models problematic in their application to this phenomena (Bruce, 2006).

Other participants described *"I'm always preparing myself"*, and *"It could come back… that's always there"* (Kate). The intensity of this uncertainty and worry was frequently discussed by participants, indicating that even long after treatment the cancer experience endured and impacted on their everyday lives. These reflections by participants could be understood under Mishel's (1988) Uncertainty in Illness model, where uncertainty of the future is framed as potential 'danger' which increases participants' distress. This uncertainty and fear of potential relapse also constructs the idea of the child as being vulnerable to the dangers in the world (as discussed in theme 2).

Participants also discussed the uncertainty and possibility of cancer recurrence through their perception of their child's 'survivor' status. Some participants, like Marie, discussed how they felt that cancer remission was a temporary state:

> *They've survived the cancer for now. And that's why I suppose, that's what us parents are always on the edge about. (Marie)*

Through saying that her child has survived *"for now"*, Marie is expressing how she views her child's cancer survivorship status as temporary, with the uncertainty around possible cancer recurrence linked to her feeling on edge and waiting in anticipation. Another participant had similar feelings stating that they were *"reluctant"* to use words such as 'survivor' in reference to their child because *"how long is she going to be a survivor for"* (Lena). This shows the nature of the cancer experience is not in the past but continuing into the present and future with a looming threat of uncertainty.

Utterances about uncertainty around possible cancer recurrence were also linked to ideas of 'luck' and not wanting to 'jinx' it. This points to the randomness and lack of control that is experienced throughout the illness trajectory and therefore, not wanting to take risks in their behaviours. For example, two participants discussed their reluctance to accept the 'purple heart bead' that Child Cancer Foundation gives children at the end of their cancer treatment to signify the termination of treatment due to feeling like it is bad luck and may curse the remission status. One of those participants, Lena, stated; *"as soon as they put an end to it, they think it's all just going to come back."* Other participants, including Kate, had similar reflections of the temporary state of cancer survivorship status mixed with feelings of luck:

> *Again because we have no idea of... of outcomes or predictions or statistics. And I kind of don't want to... touching wood as I say this, I don't want to get into a state where I feel comfortable with it completely. (Kate)*

Here Kate is conveying how long-term survivorship statistics are not clear and a continued cancer remission status is not guaranteed and so she can not feel comfortable and relaxed in feeling like the cancer will not return as it is an ever-present reality. Kate also said, *"touching wood as I say this"*, reflecting again ideas of luck and not wanting to 'jinx' the future. This utterance also demonstrates how her views of the predictability of the future have been shattered due to the cancer experience. Throughout the interviews, ideas of being 'lucky' or having 'bad luck' compared to others were reflected. This potentially indicates that participants have experienced a disturbance to their sense of security and feel the 'randomness' of life events, which brings a sense of not having control.

This idea of not wanting to espouse the 'survivor' label due to feeling like their child was not yet 'safe' and survival was a temporary state in anticipation of potential cancer recurrence was evident in several participant accounts. Earlier in this subtheme, Emma's worry about her child's potential cancer recurrence and how she perceives this as an enduring worry into the future was illustrated. Along with this, Emma discussed another aspect of her belief about uncertainty and her child's safety:

> *The other day I put up a picture of [child] and [sibling] and I think three of the people whose children have died liked it, and for the first time I understood survivor guilt… which made me think, 'Oh, this is kind of good because maybe I think she's in the clear now.' And this was only a month ago, it made me think, maybe subconsciously I think she is safe. (Emma)*

Emma's narrative speaks to ideas of safety, reflecting her feelings that the guilt she is feeling over her child's outcome from cancer treatment in relation to other bereaved parents indicates that on a subconscious level she believes that her child is no longer in danger. In participant accounts there appeared to be a connection between experiences of anxiety and distress in relation to their child being perceived as 'safe' or 'in danger'. Two participants did reflect on feeling like they had come out of that difficult period and felt their child was now safe. One of these participants, Louise, reflected on while the worry is *"always scary"* she said, *"it's not an easy thing to go through and you're lucky to be a survivor."* Louise's reflections show how she feels that they have gotten through the cancer experience with the desired outcome of survival, yet the worry (which is not as big as it used to be) is still present.

Participants not only experienced uncertainty about potential recurrence, but also about the management and appearance of current and future late effects in their child:

> *She's in ovarian failure. She's not going to go through puberty normally, we're gonna have to do hormone replacement. She's got hypothyroidism, she's got hearing loss. She's got sixty percent lung function. So it's sort of managing all of those things long term as well. It's like, it's never over… And those things won't improve… and like, twenty years down the track suddenly something can come up… I mean we'll be alright… our lives will be ok, but they're never gonna be easy. (Lena)*

In the interview Lena explained that there were several physical and psychological late effects that her child experienced due to cancer and its treatment. This carried a burden in the present, with managing the caregiving demands of having a child with a chronic condition, and into the future, with the worry and uncertainty that many years after treatment *"suddenly"* a related condition could arise. The potential for future conditions to develop is therefore seen as insidious, requiring heightened vigilance and surveillance.

Like Lena, Marie described her views of the future in the uncertainty of late effects that may appear:

> *And there will never be an ending for us. For these kids. There's always going to be that worry. There's always going to be that chance of what has this chemo done. We don't know enough about what the research and this chemo's done really; we have no idea. So, yeah, and we won't know. You know, we might find out next week, we might not know for the next ten, twenty years. We just don't know… It's not over for ourselves, we're constantly watching. We know [child] had a donor that was 42 [years old]… which means that [child] is going to get adult illnesses earlier in life. So we're on the watch for that, people don't quite realize, I haven't opened up and told them that he's sterile, you know, things like that that are going to be little things along the way that affect me. (Marie)*

Similar to Lena, Marie conveys how the cancer experience is not over for her or her family and that there will never be an end point due to coping with the uncertainty and worry about the impact of cancer treatment and the possibility of implications on her child's future. Marie's statement of *"we might find out next week, we might not know for the next ten, twenty years"* conveys an anticipation and sense of difficulties that feel like they could happen at any moment. This acute awareness of the potential for something to go wrong at any time highlights not only the constant awareness of potential markers of illness, but also connects with a sense of vulnerability (as described in theme 2). This implies a feeling of being ‘unsettled’ and ‘on edge’ with behaviours such as *“constantly watching”*, much like a detective. Marie also acknowledges that her child’s sterility is going to be something that will emotionally affect her in the future, which shows that views of the future are littered with distress and difficulties. Marie continued by discussing coping with her child’s current late effects in the long-term:

> *And are you a survivor when you have got other illnesses because of this as well. You can’t have children because of the chemo, but you’re a survivor… How I vision a survivor is you’re back to what you were, you’re back to a normal child. You’re never going to be back to a normal child. And he’s never going to be, you know, there’s always going to be problems and appointments, all the way through his life. (Marie)*

Marie considered how her child’s long-term needs are at conflict with the word ‘survivor’. She relays how she views being a ‘survivor’ as being past the cancer experience, and how she does not relate to this since they are currently and will in the future be dealing with the impact of the cancer experience. Altogether, these accounts connect back to the central organising concept that the cancer experience is not over and this demonstrates how ‘survivor’ terminology does not accurately capture this.

Not only were participants concerned about potential physical and psychological late effects on their child, but they were also concerned with the future psychological impact on their other children (the siblings of the child who was diagnosed with cancer). Participants discussed how *“the siblings are affected”* (May) and that they *“worry that the neglect is gonna cause mental health issues”* (Lena). Participants often discussed how they had missed out on experiences such as school events and one-on-one time with the siblings due to being *“consumed”* by caring for the child who was undergoing cancer treatment. They worried that this has and will have an impact on the wellbeing of the siblings in the future. This corroborates the findings in an Aotearoa New Zealand study by Armstrong (2019) on the unmet needs of the siblings of children with cancer. Qualitative findings from this study found that siblings were negatively affected by feeling 'invisible' and forgotten, as well as due to the disruptions to family life (Armstrong, 2019).

Some participants also described a general sense of worry that 'something bad may happen'. Lena described:

> *It's just there, like I'm on edge, all the time. I don't know why or what I'm waiting for… it's just a feeling that I can't shake. (Lena)*

Lena, like Alexa, examined how she felt anxious and *"on edge"* much of the time. Lena could not pinpoint exactly what she was anticipating but had a general sense of worry of something bad that was going to happen. This constant anticipatory anxiety demonstrates how the whole world view has shifted to a sense of constant instability and threat. She continued:

> *And realising I guess that you're not invincible is quite a thing. Like I remember when… there's a girl who went through the same treatment as [child] and just as she finished, her mum was diagnosed with breast cancer and, I remember thinking 'woah,' you know, like 'lightning really does strike twice.' And I guess I used to be the kind of person who was like 'okay we've had this bad shit so everything's gonna be fine now.' But it's really not like that. (Lena)*

Here Lena describes how the cancer experience led to a shattered sense of security and predictability in the future. The phrase *"lightning really does strike twice"* demonstrates a realisation in how unfair life can be with how even though she has experienced the trauma of her child's cancer that another traumatic or bad thing could happen again in the future. This idea connects with the concept of ‘personal specialness’ by Yalom (1989) in existential psychology. Personal specialness is the belief that one’s self is invulnerable and inviolable and that life will not be harsh to us like it will to other people (Yalom, 1989). While the ‘personal specialness’ illusion provides a sense of safety, it is disrupted by the cancer experience and Lena reflects this loss of belief in being invulnerable to life’s unpleasantness by saying that she realised *“you’re not invincible”*. This idea was echoed by Kate as well:

> *There was no relief for me. There was no, ‘oh this is something that happens to somebody else’. Yeah, so it’s very isolating in that. (Kate)*

In their accounts, both Kate and Lena reflect on ideas of the illusion of personal specialness in being exempt from traumatic events and how this was shattered by their child’s cancer experience, as not something that just *“happens to someone else”*. Kate also identified this as being connected to feeling emotionally isolated from others due to having had different experiences from her peers (theme 2). Along with realising the uncertainty in life, Kate and other participants also reflected on a sense of expecting the unexpected. Kate examined how she experienced the first Covid-19 lockdown in Aotearoa New Zealand back in March 2020:

> *And so Covid was quite in perspective, and I mean just the whole shock of it wasn’t... everyone’s like, “it just came out of the blue…” and I was like, “that’s life”, you know. So I guess in that sense, I’m more prepared for… [laugh] whatever is gonna happen. You are kind of aware that your whole world could literally change in an afternoon. (Kate)*

Kate compared how others experienced the Covid-19 lockdown to how she experienced it from within the context of having experienced her child’s cancer diagnosis and treatment. The statement *“that’s life”* conveys acceptance in the nature of hardship embedded within the course of life events that has changed as a result of the cancer experience. This extract also shows how the belief that coping with adversity is part of one’s existence. Kate locates this change in perspective of the acceptance of uncertainty in the future to the cancer experience through saying *“your whole world could literally change in an afternoon”*.

A few participants discussed their behaviours in response to coping with uncertainty of the future and expecting bad things to happen. Marie described her family’s behaviours in the response to the worry about a potential future death in the family:

> *And we’ve got an account, and this is sad, we’ve got an account for a funeral, whether it be [child]’s, [sibling]’s, or ours, we’ve got an account that’s got money in it to pay for a funeral. Now that’s a really strange thing to do as a family… and we just don’t touch it because that as far as I’m concerned that’s our funeral money. So [laugh]… and it’s like he’s doing well why am I thinking like this. (Marie)*

Marie’s family have a savings account for a funeral ‘in case’ anything happens to a member of the family. It seems feasible that this behaviour could be interpreted as a ‘safety behaviour’ to cope with the anxiety, uncertainty, and worries of the future. In turn, having this ‘safety’ bank account increases feelings of guilt due to her child’s current health status of being in remission. This further demonstrates how ever-present the impact of the cancer experience is on participants’ lives and how it impacts on their thoughts, feelings, and behaviours to cope with the uncertainty of the future.

This subtheme explored participants’ experiences of uncertainty in their visions of the future. It spoke to how the cancer experience was not over due to uncertainty as to what the future may bring in terms of: the possibility of their child’s cancer recurrence, the possibility of future late effects, and a general sense of feeling like something bad will happen. A sense of security and predictability of the future had been disrupted due to the cancer experience which was experienced as *“sudden”* and *“traumatic”* with increased awareness that *“your whole* *world could change in an afternoon"*. Many participants discussed how the potential of cancer recurrence was always going to be a reality and how they felt that survival was a temporary state. This meant that participants felt *"watchful"* in case of late effects or cancer recurrence and how coping with late effects was incongruent with people's expectations that the cancer experience was over. Further, participants reflected on realising they were not *"invincible"* and how hardship was part of one's existence. These ideas echo the biographical disruption and existential reflections that participants had in their visions of the future. In this way, it was evident that the cancer experience had disrupted participants sense of the future which was laden with uncertainty. In turn, this huge sense of uncertainty about the future might also have interrupted the process of establishing a sense of meaning and impacted their self-identity (as discussed in theme 1).

Loss of an Imagined Future

Many participants illustrated concepts of grief or loss in their views of the future. This subtheme explores how participants felt a biographical disruption in feeling like their life was on a different trajectory. They mourned an alternative future they and their child could have had, which did not have the burden of late effects or the impact of the cancer experience. Participants experienced stress in relation to the effects that the cancer treatment would have on their future lives and their child's future. They relayed a biographical disruption at the time of diagnosis which has impacted their life course so far and into the future. Lena described her experience at the time of diagnosis:

> *Like it probably would have been the time in my life that I would have been going back to work after my kids were old enough and actually ironically, I got offered my dream job the day she was diagnosed [laugh]. (Lena)*

Lena posits an alternative reality had cancer not been introduced into their lives. This alternative life course would have been about her own career aspirations in pursuing her *"dream job"*. This utterance conveys a loss and grief for a future that she wanted to have and the trajectory she was expecting to follow, which had ultimately changed when her child was diagnosed with cancer. Similar to Lena, other participants described how *"everything changed"* at diagnosis, including participants who wanted to live in more remote and idyllic parts of the country which was now no longer possible due to needing to be close to treatment centres. These sentiments reiterate feelings of loss that cancer had stolen a future from them. This exemplifies how, in the long-term, participants had a reconstruction of everyday life and what they expected the future might be like. In this way, participants experienced grief due to the affected hopes and aspirations for the future. These feelings also relate back to participants' views of their own identity construction (theme 1) which is restricted due to the impact of the cancer experience.

Participants also described a second category of loss forecast into the future, specifically loss with respect to their child, in terms of the late effects they have to cope with and the impact of the missed experiences due to the cancer experience. Abi discussed:

> *My issue is that I can see the potential to have had a normal life, and it's not. This is her normal. (Abi)*

Compared to other participants, Abi's child had experienced the most time since her first cancer diagnosis (over 30 years ago) and her child is now in adulthood. In this extract, Abi is comparing an alternative 'normal' life that her child could have had compared to this life course she has had thus far. Participants often compared their experiences to what was 'normal', which highlights the disruption to their everyday life and how this affected their views of themselves, their world, and their future. Comparisons between their experiences and normative experiences also appears to be associated with a sense of feeling different from others, which perpetuates social isolation (as discussed in theme 2). Abi continued by discussing her experiences of grief both while her child was in treatment and long-term:

> *You grieve for the possibility of loss of life. And you grieve for the pain that they're in. And the changes in their world and your world. But long-term, I think you grieve for the potential that you know that they had before. And what they have now in their life. And I think, <u>I know</u> I grieve the potential. And, and where her life has gone. (Abi)*

Abi emphasises the burden of grief that is present throughout the cancer experience and into the long-term after treatment. She is highlighting the ongoing loss that she is confronted with in respect to the psychosocial and physical impact of cancer treatment on her child which meant that she could not live up to the *"potential"* she had before. This restriction in her child's *"potential"* was a constant reminder for Abi due to the visibility of the long-term effects of the cancer experience. In particular, Abi yearned for her child to have greater autonomy, independence, and job security in her adulthood which was not her present reality. In this way, Abi was confronted with the fact that the impact of the cancer experience could not be left behind due to the perpetual reminders even 34 years after her child's diagnosis. This continuous grief may link to the concept of chronic sorrow (Roos, 2002). Chronic sorrow is a continuous grief response as a result of a non-death-related loss experience. The affected person experiences pervasive feelings of sadness, disruption, and grief, particularly at times of triggered memories and understanding of how life 'should have been' (Roos, 2002). Further, this type of sorrow is not socially recognised, and therefore, often not understood by social supports (which connects to 'isolation' in theme 2). Chronic sorrow is also harder to explain to social supports because there are no rituals (like a funeral) for this kind of grief and loss (Harris & Gorman, 2011). This concept may echo this unique sense of grief that is not understood by others and has no foreseeable end for participants like Abi.

Several participants, and particularly the participants whose child experienced physical late effects, expressed a grief and loss of an imagined future and image of a healthy child.

While their child had completed cancer treatment, they had to cope with the fact that the child had significant health needs that would extend into the future. Even relatively ‘minor’ physical late effects served as a reminder; for example, Alexa discussed the impact of her child being a toe-walker as a result of cancer treatment:

> *And it was really hard watching things like cross country, because she would do it, but she was so far behind. You know whereas she wouldn’t have been before. (Alexa)*

Similar to Abi, Alexa is grieving what her child’s abilities would have been or grieving her abilities had their lives not been impacted by cancer. Many of the reminders discussed by participants occurred in the context of ‘normal everyday activities’ such as running in a school cross country and imaginative play. Further, feelings of grief extended beyond the visibility of physical late effects and into the long-term psychological impacts of cancer treatment which were seemingly ‘positive’ effects such as resilience. Emma explained:

> *She’s really tough, but, you know, I would have rather she needn’t have been as tough, so I feel sad for what could have been. (Emma)*

Emma associates her child’s resilience and psychological toughness as being a product of the cancer experience. Yet she grieves the pain that her child had to endure to develop that toughness and, like Alexa and Abi, mourns for an alternative reality and future her child could have had. Participants discussed a variety of psychological, behavioural, and physical impacts that their children have due to the cancer experience, and they expressed loss and grief in respect to the future that their child has to cope with.

Along with late effects, participants also discussed the impact of psychosocial developmental experiences their child missed, and in turn worries about their child’s future as they navigate the world in social and occupational spaces.

> *She's behind in terms of... emotionally. Like she missed all her preschool years, all those years where you play, and you do all the fun things with your friends and you're imaginative and you go to kindy and you have all those really formative years. She missed those. She was stuck in a hospital bed or she was too sick to play a lot of the time or she was isolated… You couldn't tell which kids were immunized and there was too high a risk of measles or whatever. So she… missed a lot of developmental stuff. (May)*

May discussed how her child had missed out on formative childhood years due to the cancer experience, with associated loss of/delayed skills and development. This also entailed worry about her child's future experiences and psychological wellbeing. The majority of participants' children were around 3 years old when they were diagnosed with cancer. This period is often psychosocially associated with learning through imaginary play, exploration, and through engaging with other children; and cancer treatment can conflict with these important developmental opportunities (Brand et al., 2017). This 'lost' time due to the cancer experience was felt in the present and in worries for the future.

Another category of loss in an imagined future that some participants confronted was a mourning of the loss of future grandchildren. Emma described:

> *I do have ongoing grief in the fact that she's infertile because she had a bone marrow transplant. That's with me quite strongly… she's a really nurturing child, she's always liked kids, she likes the dogs, and it's of enormous grief to her, so that's ongoing grief to me. And I'm surprised at how much and how often I think about it and try and find solutions. (Emma)*

The psychological impact of known or suspected fertility issues in their child due to cancer treatment was described as a challenge by some participants. Emma describes *"ongoing* *grief"* due to her child's choice of having future biological children being taken away. This loss in a future generation brings up grief for a future that was hoped for and normatively expected. Further, there seems to be a collective grief as Emma's child has sadness in the fact that she will not be able to have biological children and this sadness extends to Emma which demonstrates the grief felt by the family system. This image of the lack of a potential future generation carried a heavy emotional burden for participants. This finding reflects those of Ellis et al. (2016) who qualitatively investigated the fertility concerns among child cancer survivors and their parents and found that parents expressed concerns around the long-term emotional and relational impacts of infertility on their child.

This subtheme illustrated participants' feelings of loss and grief in respect to the future. It explored how participants felt that their own life trajectory (not just their child's trajectory) was on a different path, which connected with a change in self-identity. Participants also identified feelings of loss in respect to their child who has to confront and manage late effects in the long-term, as well as cope with the impact of missed developmental experiences due to cancer and its treatment. On an everyday basis, participants were reminded of the impact of the cancer experience on their child's physical, social, and psychological wellbeing which brought up feelings of grief of a future they had hoped for. Finally, a loss of imagined grandchildren was discussed by a few participants which reflected loss of normative experiences, a loss of a parental identity for their child, and a loss of a grandparent identity for themselves. Throughout their views of the future, it was clear that the cancer experience had not left and how participants forecast the continuation of the cancer experience into the foreseeable future.

Summary of Views about the Future

A recurrent theme in the interviews was a sense amongst interviewees that their future and their child's future had changed due to the cancer experience. Two discrete perceptions of the future were discussed by participants. First, participants were beleaguered with uncertainty about the future which included worries about the possibility of their child’s cancer recurrence, the possibility of future late effects from treatment, and a general anticipation that something bad will happen again in the future. In turn, this made some participants feel like their child’s cancer remission status was temporary and so felt hypervigilant to the potential signs of danger. In this way, participants conveyed how the traumatic cancer experience had shattered an illusion of predictability and personal safety in the unfolding of life events. Further, there was an increased sense of responsibility for monitoring and picking up on threats for early intervention. Second, participants described feelings of loss and grief when looking to the future. The cancer experience had put them and their family on a different path to their peers and to what they had expected. Participants felt a loss for themselves and their child, whose future included managing the impact of the cancer experience both physically and psychologically. This theme also weaves into the previous themes, as participants felt that their identity changes and views of the world being an isolating place in which their child was vulnerable had implications on their visions of the future. Overall, these findings indicate that participants’ perceptions of the future had been disrupted due to the cancer experience which continued long after their child had completed cancer treatment.

Chapter 6: Discussion

The present study's research question was developed following a literature review and a preliminary scoping survey. This survey was devised for another project, yet the results of the survey were pivotal in designing the research question for the present study. The survey was developed to ascertain the desire for a psychosocial programme aimed at supporting parents/caregivers in the early transition to life after completing their child's cancer treatment. In this survey assessing the desire for this psychosocial programme, 4.4% of respondents were more than ten years post-treatment. This finding left the question as to why after ten years post-treatment were parents/caregivers seeking support, and what are their long-term experiences? This survey lay the foundation for the research question in the present study, with the aim of exploring the long-term experiences of parents/caregivers after the completion of their child's cancer treatment. The following chapter discusses the main findings of the study, highlights the study's unique contributions to the field (including theoretical discussions), provides clinical implications and recommendations, describes the limitations of the present study, and provides suggestions for future research.

Overview of Findings

The findings highlighted that the participants experienced significant and long-lasting changes as a result of the experience of their child's cancer. Their child's cancer diagnosis and treatment were described as a significant life event and experience. Even though their child had successfully completed cancer treatment and it was at least five years after their child's cancer diagnosis, participants felt that the cancer experience had permanently affected them, and it continued to impact them in the long-term. The experience of childhood cancer was heavily integrated into the parents'/caregivers' life narrative, relationships in the world, and perceived future life course. The fundamental idea was that *'The Cancer Experience Remains With You'*. This was reflected in the participants' experiences and reveals the continued impact the cancer experience has on parents/caregivers in the long-term. *The Cancer Remains With You* (refer to Figure 2, findings chapter) was the umbrella for three themes: *Views about One's Self*, *Views about the World*, and *Views about the Future*. The disruption to these three elements of participants' belief systems posits the development and maintenance of the cancer experience in the long-term. Under the next three subheadings, I will present the principal findings within each of these three themes. What follows is a discussion of how Beck's (1979) cognitive triad and Bury's (1982) theory of biographical disruption weave into the findings of this thesis.

Views about One's Self

Views about One's Self encapsulated 'identity', 'purpose and meaning', and 'suffering from memories'. The first subtheme, 'identity', showed how the experience of having a child who was diagnosed with cancer continually impacts the identity of participants, and shifts how they defined and saw themselves in the long-term. This key idea demonstrates the perpetual demands and continued process of identity changes that parents/caregivers face for many years after their child's successful cancer treatment. This reaffirms findings by Davies and O'Connor (2022) that having a child with cancer leads to a shift in participants' self-identity, with much of the process of accepting this new identity of being a parent of a child who was diagnosed with cancer occurring after the end of treatment period. In this way, participants described how they had permanently changed due to the cancer experience and spoke of the tensions in how they negotiated their self-identity. This idea of a changing self-identity is presented as a fluid and evolving process. Identity changes arising from the experience of cancer among cancer patients has been proposed in the literature. For example, Mathieson and Stam (1995) framed that cancer patients are involved in a continual readjustment of self-identity in the face of cancer as a chronic illness. This conceptualisation of identity changes has parallels to the present study, and the present study expands this understanding through its application to parents/caregivers and extending beyond the childhood cancer treatment period. However, further work is needed to consider how frameworks of identity formation and re-construction can be applied and extended to the parent/caregiver population.

Further, this thesis explored participants' feelings of distress ('suffering from memories') and meaning making ('purpose and meaning') as part of their views on themselves. The subtheme of 'purpose and meaning' captured how participants created new meaning and purpose and also how they experienced a loss of meaning. This appeared to involve a re-evaluation of their perspective and the purpose achieved from their lives. The long-term experience of meaning and purpose was coloured by the threat of potential relapse and therefore the toss-up between normative long-term goals or short-term pleasure-seeking. Yet, living with short-term goals and focusing on the present appeared to be viewed as a survival mechanism to cope with the ongoing uncertainty about the future (which connects to theme 3). Alongside this shift in purpose and meaning came an increase in authorship, a quest for 'normality', and increased empathy for others. Increased empathy and the development of a greater perspective has been noted by Ljungman et al. (2016) who described a new outlook on life and joy in appreciating the simple things. The present study also described this newfound perspective, yet there is a layering of complexity within this, due to this altered perspective simultaneously occurring on the background of significant losses. Two aspects of the cancer experience as a trauma are captured, being the feelings of post-traumatic growth (increased empathy, deeper meaning) and post-traumatic stress (hypervigilance, disconnection). This thesis recognises both post-traumatic stress and growth as a duality, rather than a binary categorisation that has been purported in other studies (Duran, 2013; Jurbergs et al., 2009; Kazak et al., 1997; Ljungman et al., 2015).

These notions of post-traumatic stress were also embedded within the third subtheme of 'suffering from memories'. Memories from the cancer experience continued to impact participants in the long-term, with long-standing visual memories, emotions, and a general presence that persisted. The memories that frequented were described as images, sounds, or smells which would intrude on participants' daily lives. The present study builds upon previous research by Ljungman et al. (2014) who found that 21-44% of parents reported severe levels of post-traumatic stress symptoms in the long-term. The findings from the present study deepens this understanding of the trauma symptomology with this population. In this way, it illustrates how against the backdrop of a traumatic experience, participants reassessed their identity as a parent, which is a role heavily embedded within societal context and is continually threatened by the guilt and trauma of having experienced their child's suffering in treatment. The cancer experience was ever-present and lingering for participants, with their sense of self impacted by the insidious reminders of the cancer experience, adjusted life perspectives, and the altered relationship to one's own identity.

Views about the World

Views about the World captured how participants' views of themselves also impacted on their views of the world and impacted their relationships in the world. Throughout the findings, it was clear that relationships were influential on parental experiences. This theme encompassed subthemes of 'isolation', 'connection', and 'vulnerability'. Experiences of isolation were particularly evident and were related to feeling different from others and from feeling that their identity had changed. On an individual level this change in identity (subtheme in theme 1) meant that at a social level, participants felt misunderstood or invalidated by others. In the present study, participants also described lack of social support and not feeling understood by their social circles. This idea is in line with previous studies that have found that the experience of childhood cancer is associated with perceived reduction in social support for many parents (Norberg & Boman, 2007). The present study shows that this narrowed social support group is maintained in the long-term. Participants also expressed a need to become self-reliant and get their needs met from within the family.

Previous research has highlighted that social support may buffer against psychological distress, but the cognitions associated with psychological distress (e.g. depression) includes a tendency to perceive support as not available (Matheson & Anisman, 2003). This means that at the points when parents/caregivers need social support the most, the perception of support availability is most threatened. This thesis adds to this literature through its exploration of the link between reduced social support and the depth of identity changes for participants.

Societal discourses also reflected a personal determination with language such as ‘survivor’, ‘battle’, and ‘journey’ which participants both employed and distanced themselves from. These discourses and others’ assumptions of the cancer experience ending at treatment completion reproduce the biomedical model of illness about the end of cancer treatment being the end of the cancer experience. Instead, these societal expectations and language around the post-treatment period were often incongruent with how the post-treatment period was experienced. Participants felt that society expected them to feel relief and a sense of having ‘moved on’ from cancer. However, the cancer experiences’ psychological impact on the participants and psychological and physical late effects for the child meant that there was an ever-present impact of the cancer experience. The discrepancy between the lived experience and how others perceived the parental long-term experience perpetuated feelings of isolation. There has been insufficient research on parental perceptions in relation to societal discourses on childhood cancer and this is a unique finding to the present study. Davies and O’Connor (2022) also described how the perceived continued impact of the cancer experience contributed to difficulties in forming connections with others who do not understand. The present study reflects this, and builds upon it, by additionally highlighting how the imprint of the cancer experience has impacted on feeling trusting of others and self-identity which further perpetuates isolation in the long-term.

Despite ongoing feelings of isolation, participants also reported experiencing closer relationships and deep connections in other relationships, largely due to feeling understood and validated or due to going through this shared collective trauma. Similarly, other studies also reported that these deep connections were limited to small social groups such as their couple relationship or other parents/caregivers who had gone through their own child's cancer experience (Davies & O'Connor, 2022; Gise & Cohen, 2021; Ljungman et al., 2016). This seems to be due to the unspoken bond of understanding and pain through their shared experiences. The present study also presents an additional layer, signifying that in the long-term these relationships of connection can also stir ambivalent or conflicted feelings. These mixed emotions appear to be due to these relationships also bringing to the surface the reminders and pain from the treatment experience. This may also reflect tensions in the differences between parental experiences (e.g. bereaved parents vs. parents whose child completed cancer treatment) or differences in coping styles (e.g. a desire to move away from cancer vs. a desire to give back to the cancer community).

Viewing the world as a dangerous place in which their child is vulnerable to harm from others or is susceptible to contaminants was also described by participants. This perceived vulnerability may have been due to a heightened sense of mortality, which reinforced a sense of protectiveness and insulation and which, in turn, perpetuates experiences of social isolation. This sense of their child's vulnerability was felt for cancer-related aspects of life (e.g. cancer recurrence) and other aspects of daily life (e.g. bullying, friendships). In the findings, a theoretical framework on the fear of cancer recurrence by Fardell et al. (2016) was discussed. This model was developed for patients, but can also be extended to parents/caregivers. The model demonstrates how the fear of cancer recurrence is maintained in the long-term due to the metacognitions and coping strategies employed (Fardell et al., 2016). Further, a sense of vulnerability was noted in reference to their child navigating future relationships in friendships and dating. Ideas of personal determination in the mental exhaustion of cancer treatment for the parent kept this sunk-cost fallacy going in the long-term, which continues the impact of the cancer experience in the long-term. This perceived vulnerability was a major thread throughout the findings, which linked to the continual impact of the cancer experience into the long-term.

Views about the Future

Views about the Future encompassed 'uncertainty' and 'loss of an imagined future'. A sense of anxiety was present due to the uncertainty and perceived lack of control over the future. This occurred particularly due to the threat of their child's cancer recurrence, the threat of future late effects, and a general anticipation that something bad may happen. Uncertainty was linked to a state of hypervigilance with feeling like 'remission' was only a temporary state, and this created feelings of rejection to words such as 'survivor'. The fear of relapse continuing in the long-term differed from the findings of Maurice-Stam et al. (2008) who found that heightened levels of distress and uncertainty decreased over time during the first two years after the end of treatment. Instead, the fear and worry of cancer recurrence remained a significant stressor for participants which extended into the long-term. The anticipatory concern about future cancer recurrence appeared to further perpetuate feelings of isolation from others (subtheme in theme 2) due to their lived experience being incongruent with other people's expectations that their cancer experience was 'over'. Therefore, this isolation was pronounced because it was difficult to form connections with others who do not understand their current sense of fear. Their perceived future was now coloured with a lost sense of predictability and security. Steinberg (2015) argued that due to a cancer diagnosis interrupting the life narrative, the use of story-like metaphors (e.g. journey, battle) are used to restore a sense of predictability. However, it is clear from the findings of this study that perceptions of predictability and stability were disrupted in the long-term and therefore this language only re-constructs the dominant discourses which misrepresent the lived experience.

Feelings of grief were also present alongside this anxiety. Participants felt grief and loss for both themselves and their child's future. This sense that their life trajectories had changed is also linked to a change in their own biography and self-identity (theme 1). Participants described grieving a future that they should have had if it were not for the experience of their child's cancer. Attig (2004) describes grieving as a process where individuals come to terms with their reactions to a loss, adapt their daily life structures, and redirect their life story in light of what has happened. Yet, grief is not confined to bereavement, as several researchers have described grief in relation to adapting to a new normal after difficult life experiences (Attig, 1996; Marris, 2014). This grief was a constant reminder for those participants, as their child continued to deal with the late effects of their cancer treatment. This continuous grief may link to the concept of chronic sorrow (Roos, 2002). Chronic sorrow is grief response that occurs after a non-death-related experience that permanently changes a person's life (Roos, 2002). The feelings in chronic sorrow are a sense of pervasive sadness, disruption, and grief. These sentiments are highlighted throughout participants' accounts and their projections into their future. This chronic sense of sorrow experienced by participants was also not understood, recognised, or talked about in society and therefore, seemed to contribute to participants' sense of isolation and lack of support. Therefore, there is a need for greater understanding of this type of sorrow to support parents/caregivers' sense of connection in the long-term.

One key area that some participants grieved for in their future was a loss of imagined grandchildren due to fertility problems associated with cancer treatment, which meant there was a loss of a future generation. This was a profound loss for such participants, which challenged their expectations of a normal life course for themselves and their child and disrupted their own identity in potentially not becoming a grandparent. In this thesis, the new picture of their future comprised of the continuous management of the sequalae of their child's cancer and wider grief for the affected hopes and aspirations for the future. Along with grief, there was an uncertainty and anxiety about the future which conveyed how the illusion of predictability and personal safety was disrupted in views of the future. This fear of relapse in the future and the ongoing nature of late effects (theme 2: vulnerability) makes it difficult for participants to reconstruct their identity and prevents them from developing a new narrative for themselves and their child.

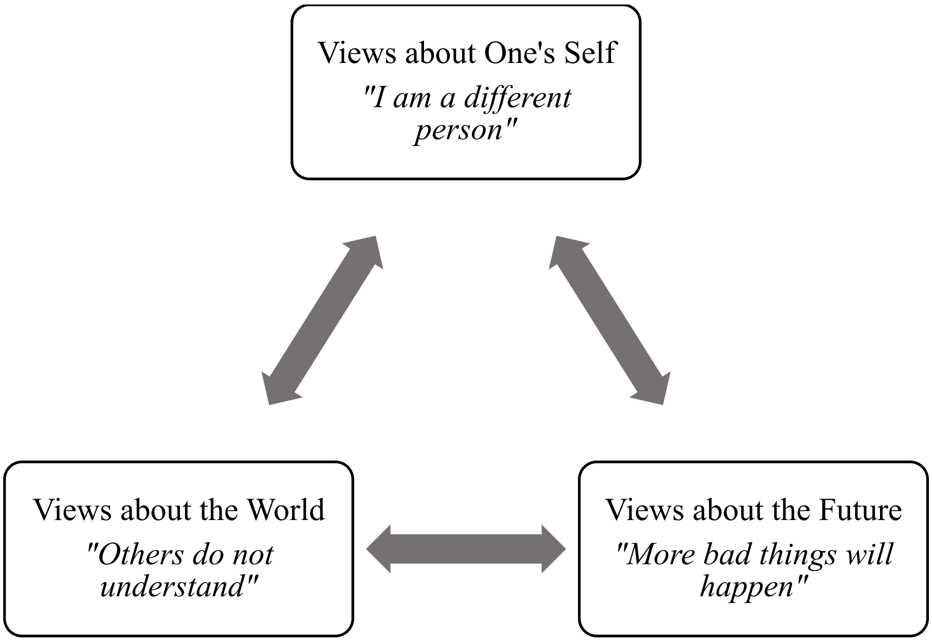
Previous studies on the long-term impact of childhood cancer on parents has reported that some parents continue to experience psychological distress in the long-term after their child's cancer treatment is completed (Ljungman et al., 2014; Wijnberg-Williams et al., 2006). The present study adds to this finding to show why after years of being finished treatment they experience distress. These findings show this is due to the ongoing nature of the cancer experience with the significant disruptions to views of the future which is coloured by uncertainty and grief. Taken together, this sense of grief and uncertainty left participants feeling that the childhood cancer experience would be part of their lives for the foreseeable future, placing perpetual demands on them.

Beck's Cognitive Triad

The findings were presented through Beck's (1979) cognitive triad as a way of formulating the depth of the disruption that takes place for participants in the long-term. Beck's (1979) cognitive triad is a multi-dimensional construct that refers to the individual's cognitions about the self, the world, and the future. In the present study, the cognitive triad highlighted the nuances and significant layers of change experienced by participants in the long-term, with disruptions to their perceptions on the self, the world, and the future. The findings conceptualised in this way is a unique contribution to the literature. While other studies have noted the significant impact that having a child diagnosed with cancer can have on a parent/caregiver in the long-term (Forinder & Lindahl Norberg, 2010; McKenzie & Curle, 2012), no study has utilised this unique framework to capture the depth of change that occurs. Figure 3 presents an adapted version of the cognitive triad, which includes examples of cognitions that are relevant to the experiences of participants in the present study.

Figure 3

Beck's (1979) Cognitive Triad Adapted to The Present Study



Note. This figure displays Beck's cognitive triad adapted to include example thoughts relevant to participants' experiences in the present study.

The cognitive triad was firstly developed by Beck (1979) in the genesis of depression. Yet, as seen in the present study, this broad framework can allow for conceptualising diverse manifestations of psychological distress without being diagnostic or relying on limited clinical diagnostic categorisations. This fits with the social constructionist paradigm in the present study, and adds to previous literature which has focused on particular manifestations of distress, such as depression, anxiety, or post-traumatic stress disorder (Greening & Stoppelbein, 2007; Kazak et al., 2005). Participants did describe ongoing distress related to the cancer experience, and the cognitive triad is broad enough to account for these diverse manifestations of this distress, while also reflecting the depth of the disruption. Moving away from diagnostic labels in this research is also important as it highlights the understandable reaction of going through the high stress of their child's cancer experience. Therefore, this model (as opposed to diagnostic criteria) moves away from locating the source of distress as a mental disorder within participants and instead acknowledges the wider context and experiences as influential forces for disrupting a sense of self and perceptions of the world and the future.

Biographical Disruption

A major thread throughout the findings was the long-term impact to participants' sense of identity and the permanence of change. This is in line with Bury's (1982) biographical disruption theory, which posits that chronic illness changes the self-concept, assumptions of everyday life, expectations, and life course. All three subthemes captured this biographical disruption that had taken place for participants. Under this framework participants had experienced changes in their self-concept and biography (theme 1), as well as changes in their relationships and assumptions of the world (theme 2), and their expectations for the future (theme 3). While notions of biographical disruption are popular in illness literature, this concept has rarely been captured with parents/caregivers of children with cancer (Young, Dixon-Woods, Findlay, et al., 2002), and no study had explored biographical disruption in relation to parents/caregivers affected by childhood cancer in the long-term.

The cancer diagnosis is temporally the critical point of biographical disruption and in the long-term the disruption was cognitively processed and remained. Participants reported feeling disconnected from the person they were before their child had cancer. This sense of not recognising who they were before cancer seemed to be exacerbated by societal perceptions that after cancer treatment they would return to their former daily lives and identity. Participants continued to process the loss of their previous life and described an acceptance that their lives had irrevocably changed.

Parents/caregivers envision a certain life trajectory for their children and for themselves as parents (Bury, 1982; Sevón, 2012). Yet, through the childhood cancer experience this imagined future has been disrupted. In the long-term, a sense of normality and certainty had been shattered and participants faced continual fear of relapse and the continual demands of late effects. This fear of relapse and the perpetual demands of late effects appeared to infiltrate many aspects of participants' lives. There remained a realistic and lifelong potential for late effects or cancer recurrence and therefore the cancer experience is not over and the possibility of ill health is incessant. This (alongside the significant stress of the memories of the cancer experience) seems to have prevented participants from being able to develop a new narrative for themselves.

Grappling with the perpetual demands of the present and the future seemed to be in conflict with their quest for 'normality' and altered their identity and perception of their role within family life and in society. What it means to be a 'good parent' and their perception of themselves as a parent appears to be challenged by the cancer experience. This was apparent throughout participants' accounts, particularly in their feelings of guilt around the intensive treatment their child had gone through and from the guilt of the impact of the experience on the siblings. Further, in the long-term, participants questioned a sense of authorship and their goals when weighing up short-term and long-term goals which additionally demonstrate the disrupted expectations of their life trajectory.

Notions of existential psychology also wove into aspects of the findings and supported the biographical disruption in participants' experiences. Participants' accounts conveyed existential reflections in their perceived vulnerability, isolation, meaning-making, uncertainty, and identity, which are all central concepts in existential psychology (Yalom, 1989). These existential matters appeared in their thoughts and feelings as a constant backdrop to their everyday lives. These existential struggles related to the long-standing perceived threat of their child's potential relapse and the change in life trajectory due to the impact of childhood cancer. These existential themes emanated from the awareness of the fatality of cancer as an illness, and from participants' present reality where the impact of cancer remained. The childhood cancer diagnosis and treatment had also brought to the foreground a heightened sense of mortality. This sense of mortality would otherwise usually be seen as distant from one's identity and life course, or seen as a remote possibility for one's self with being perceived as something that impacts others. These ideas within existential psychology relate to a 'personal specialness' which is disrupted. While there is some research on the processing of existential changes in this population (Forinder & Lindahl Norberg, 2010; Van Dongen-Melman et al., 1998) it has not been extensively explored. While existential experiences were not the foci of the present study, the processing of existential experiences was present and part of the biographical disruption that had taken place.

Participants' identity, their role as parents, their everyday life, and their future was irrevocably changed. These findings demonstrate how relevant the theory of biographical disruption is to parents/caregivers in the long-term. Biographical disruption theory shows the complexity of the long-term parental experience and how they are framed within societal norms and expectations.

Clinical Implications and Recommendations

Given the paucity of research in this area, this study presents a valuable contribution to the field of psychosocial oncology. The findings of this study present a detailed and nuanced understanding of the experiences of parents/caregivers in the long-term after their child's cancer treatment, which can provide valuable ideas for recommendations in practical and clinical settings. In their interviews, the participants discussed how their participation in this study was, in part, because they wanted to help other parents/caregivers going through the experience of their child’s cancer, and, in another part, because they wanted to improve how people (particularly healthcare staff, community organisations, and their social support network) might understand and respond to them and their experiences.

Firstly, as demonstrated by the present findings, the successful completion of childhood cancer treatment is not the end of the cancer experience for parents/caregivers. The end of treatment can also be the origin of a range of new challenges. First and foremost, this calls for healthcare staff in paediatric oncology care to recognise and acknowledge the significant psychological, social, and existential challenges that parents/caregivers experience in the long-term. The impact of the childhood cancer experience lasts well beyond the cancer being biomedically ‘cured’, which calls for a shift into recognising how the post-treatment experience is understood, and for working outside the solely biomedical model. Instead, more holistic and culturally nuanced models of health and wellbeing such as Te Whare Tapa Whā and family systems theory are valuable within clinical settings to better understand the context around an individual. This emphasis on the wider context helps us to understand distress and would mean that distress is not pathologized, because the source of distress is not located within an individual, but is understandable given the context.

Further, healthcare staff should be careful not to add to the traumatic experience. Previous research on the communication experiences with healthcare staff identify that parents are more likely to describe negative experiences if healthcare staff use unfamiliar language, communicate in a paternalistic manner, and do not engage the family in decision-making (Baenziger et al., 2020; Rocque & Leanza, 2015). For some participants in the present study, memories from dealing with healthcare staff were still central to their current experiences and sense of trust in the healthcare system. Therefore, it is important for healthcare staff to validate and acknowledge the concerns and emotions of parents/caregivers and recognise the nuances of these experiences, such as the fertility issues in childhood cancer patients compared to the general population. Along with this, healthcare staff are a source of important information on late-effects and coping with life after cancer treatment. So, they should strive to ensure they are consistent, clear, and supportive in communicating information on an ongoing basis.

A recurrent experience for participants in the present study was a sense of feeling isolated and not understood by their wider family/whānau and friends. This feeling of loneliness and isolation has been commonly described across the trajectory of parental experiences of their child's cancer (Baenziger et al., 2020; McCarthy et al., 2018). Participants in the present study described how their wider family/whānau and friends not understanding their experiences in the long-term caused persistent isolation was a source of distress. In light of these findings, it is recommended that an informational resource should be developed and designed for family/whānau and friends to better understand the experience of having had a child diagnosed with cancer. This could include practical advice on how to respond and actively support the affected family, both during childhood cancer treatment and in the long-term. This resource could be codesigned with consumers (both parents/caregivers and their family/whānau and friends) and healthcare staff.

The findings of the present study also contribute to the debates on reconsidering the 'survivor' terminology within oncology. This study highlighted parental perspectives on such terms in which the meaning of 'cancer survivor' was an identity construct through which participants embraced, distanced themselves from, or felt ambivalent about. In this way, it was clear that it is important to be aware of differing views of these terms and call attention to the importance of focusing on how people who have the lived experience want to be identified. Participants' attitudes towards terms such as 'survivor', 'battle', and 'journey' were nuanced and complex. This demonstrated the complexity of 'survivorship' as an identity and showed the evolving fluid nature of identity. This finding is important for future recommendations because it is critical that we understand the heterogeneity in the adoption of a ‘survivor’ identity and of ‘survivorship’ language. This means that psycho-oncology care and interventions need to be framed in ways that are congruent with the lived experience and the ways in which parents/caregivers self-identify. The acknowledgement of the diverse range of experiences in the long-term will help those affected feel more connected and less isolated.

Alongside acknowledging the importance of language to create connection rather than isolation, it was clear that parents/caregivers were continuing to cope with the psychological effects of the cancer experience. Improving the support offered to parents/caregivers in the long-term after their child’s cancer treatment is important and has a number of benefits. Participants in the present study described feeling persistently isolated, and (for some) they expressed benefits and a desire to connect with other parents/caregivers who had gone through a similar experience (while for others this was not desired as it was experienced as being reminded of the traumatic experience). In this way, organising support groups for parents/caregivers in the long-term period may allow opportunities for mutual support and understanding.

While peer support groups are very useful, some parents/caregivers may benefit from a more structured psychosocial intervention. While the early transition period after cancer treatment was not an area of focus for the present study, many participants pointed to this period as being particularly distressing. Further, delivering psychological interventions for parents/caregivers early in the period after childhood cancer treatment has been identified in previous research as presenting an opportunity to address their unmet needs and prevent long-term mental health problems (Michel et al., 2020; Wakefield et al., 2011, 2015). Psychosocial interventions, such as ‘Cascade’ (introduced in the Chapter 3) - an online group-based psychosocial intervention which aims to promote helpful coping strategies for supporting parents after their child's cancer treatment - may be beneficial and warrant further research investigation (Wakefield et al., 2016).

However, while participants in the present study noted that the early transition period would have been a helpful point of intervention, it is clear in the findings that there are distinct long-term needs which are ongoing and significant. Therefore, considering the development of interventions that address the holistic and long-term needs of parents/caregivers is warranted. Such interventions could aim to facilitate the process of reorganising the disrupted worldview brought on from the traumatic experience of having had a child diagnosed with a life-threatening illness. Within the third theme, it was clear that perceptions of the future were coloured by ruminations and grief about the past with what is lost, as well as anxieties about an uncertain future. Psychologically, this pulls the affected individual into the past and future, which gives rise to sadness and anxiety, respectively. Therefore, the utility of mindfulness as a tool to bring present-moment awareness could be investigated further. Similarly, values and meaning-making are reflected in the first theme and are linked to post-traumatic growth (Duran, 2013). Acceptance and Commitment Therapy (ACT) emphasises concepts of values-clarification and committed action in line with personally meaningful values (Hayes & Pierson, 2005). Research indicates that ACT may be effective for improving outcomes with those affected by chronic illness or long-term conditions (Graham et al., 2016). Therefore, exploration into ACT-based interventions with parents/caregivers in the long-term period may be justified. Through family systems theory, investigations into interventions supporting parents/caregivers will help the whole family/whānau system including the child's and the siblings' long-term experiences and mental health.

Limitations and Directions for Future Research

Certain limitations of the present study need to be recognised. Firstly, the findings represent the accounts of a group of ten participants situated within a particular moment in time, place, and sociocultural context. This is characteristic of qualitative studies which are not meant to be generalisable; however, it may mean that these participants may have shared different perspectives at other points in time and different participants would have shared different experiences.

Many participants in the present study said that they had previously sought psychological support or seen a psychologist, which shows that the participants represent a group who were willing to discuss their experiences. Further, this self-selection sample may show more distress or may have had a particular perspective they wanted to share in the interview. Therefore, the present study may not have captured the breadth of experiences held by the broader population of parents/caregivers in the long-term after their child's cancer treatment and some diversity in experiences may be missed.

The present study also only had one male participant. Fathers or male caregivers are often underrepresented in the paediatric psycho-oncology literature, which means that examining the nuances in paternal experiences is not possible (Norberg & Boman, 2007). Perhaps, this may be a consequence of the traditional societal assumption that mothers are more likely to take on the role of the 'primary caregiver' or due to societal expectations placed on men to be 'strong'. Further, the one male participant in the present study did discuss how he felt the need to be strong for his family and expressed how he coped with the cancer experience through suppressing those memories. It is therefore likely that the present study and the method of data collection (interview) was more attractive to female participants as a means of discussing their experiences and receiving validation.

The findings are also likely to be limited by other homogenous characteristics of the sample, which included nine of the participants who were married, and one who was widowed. This may have impacted findings as the experiences of non-traditional family structures are lacking such as single-parent families and gay and/or lesbian relationships were not represented within the sample. Studies with participants from diverse family structures would help in recognising their unique positioning in society. There was also limited cultural diversity with only one participant who identified as Māori/New Zealand European, and no participants from Pasifika or Asian backgrounds. Future studies should strive to recruit a less ethnically homogenous sample to provide valuable insight into the culturally diverse experiences of parents/caregivers within Aotearoa New Zealand. In future, studies could focus on Māori perspectives in order to explore the role of cultural values and Māori worldviews on parental experiences of childhood cancer, which would also facilitate an understanding of how best to support Māori families after childhood cancer.

It is also important to recognise the role and influence of the researcher on the present study. Alongside this research, I was studying to become a clinical psychologist. The clinical psychology training programme emphases the understanding of clinical diagnostic criteria in accordance with the DSM-5 and focuses on teasing apart differential diagnoses, which means that there is some objectivity in identifying symptom criteria to understand mental health distress. This approach is at conflict with the social constructionist lens through which the present study attempted to align with. Further, the study was advertised as an interview research study that was conducted by a clinical psychology student as part of the Doctor of Clinical Psychology. This may have been attractive to some participants who may have wanted to discuss the mental health difficulties they or their family were experiencing. It may have been interesting to see if different components of experiences would have been emphasised if a researcher from a non-clinical background was the interviewer.

Further, as the researcher I was not a parent and so I am an ‘outsider’ to the research topic. Yet, through identifying as an ‘outsider’ participants may have explained in more depth some of their experiences without the taken-for-granted assumptions that occur when the researcher is an ‘insider’. On a personal level, I found the reflexivity practices helpful in contributing to my growth as a clinician (see Appendix D for further reflections on how this research contributed to my clinical development as an intern psychologist). As a clinical psychology student, it is important to ground your clinical work in research and the reflections helped me to refine my interviewing skills, build rapport with participants, and reminded me of the importance of a trauma-informed approach and validating experiences.

Further research could expand on the current study in a number of different ways. Firstly, future research could explore in depth particular components of the illness experience found in the present study. For example, the concept of chronic sorrow was noted in the present study, but further validation of this concept with this population would be helpful. Further, in research on other long-term health conditions, the concept of embodiment (how the illness experience is grounded in bodily interactions with the environment) has been explored in parenting a child with long-term health conditions, such as in relation to caring for a child with diabetes (Rifshana, 2017). Exploring such concepts with regards to this population would allow for a deeper understanding of their experiences; for example, how the parenting expectations and needs are affected and embodied. Secondly, future research could use different methodologies and innovative methods to expand understandings.

Despite these limitations, this study builds upon previous research and fills a gap in the literature by exploring the experiences of Aotearoa New Zealand parents/caregivers in the long-term after their child's cancer treatment. This research - with the aim of having a rich understanding of parental experiences in Aotearoa New Zealand - provides a foundation from which interventions and practices can be derived and applied.

Conclusion

Parental experiences in the long-term period after a child's cancer diagnosis and treatment is a complex and idiosyncratic experience. The parental experience of their child's cancer is not a chapter that is closed at treatment completion. Instead, there is a continued impact on the parent/caregivers' identity, sense of meaning, relationships with others, and perceptions of the future. Within these experiences there is a prevailing sense of fear, isolation, and apprehension for the future. This thesis has shown how the experience of having had a child diagnosed with cancer lasts well beyond successful treatment completion and impacts on the construction of the self in the present and this projects into the future. This study sheds a light on the continued impact the experience of their child's cancer had on participants, as well as the many different meaningful ways to construct life after cancer. While participants discussed the lasting presence of childhood cancer on their lives, there was a tension between recognising cancer was part of their life, and findings ways to construct their identity and biography without being consumed by cancer. This exploration also highlighted ideas of biographical disruption and Beck's cognitive triad within parental long-term experiences which is a unique contribution to the literature. This provides an important insight into the long-term impact that childhood cancer has on the wider family/whānau system. This study suggests it would be useful for healthcare staff and support people around parents/caregivers affected by childhood cancer, to reflect on their relationships with those affected by childhood cancer and understand their role in the shaping of these experiences. Finally, it is hoped that this research is reassuring to other parents/caregivers affected by childhood cancer in seeing similarities in their experiences - and thus normalising and validating emotional responses and experiences within an extraordinary situation.

References

Aitken, T. J., & Hathaway, G. (1993). Long distance related stressors and coping behaviors in parents of children with cancer. *Journal of Pediatric Oncology Nursing*, *10*(1), 3–12. https://doi.org/10.1177/104345429301000103

Alderfer, M. A., Navsaria, N., & Kazak, A. E. (2009). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology*, *23*(5), 717–725. https://doi.org/10.1037/a0015996

Algoe, S. B., & Stanton, A. L. (2012). Gratitude when it is needed most: Social functions of gratitude in women with metastatic breast cancer. *Emotion*, *12*, 163–168. https://doi.org/10.1037/a0024024

Ander, M., Cederberg, J. T., Essen, L. von, & Hovén, E. (2018). Exploration of psychological distress experienced by survivors of adolescent cancer reporting a need for psychological support. *PLOS ONE*, *13*(4), e0195899. https://doi.org/10.1371/journal.pone.0195899

Ando, H., Cousins, R., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. *Comprehensive Psychology*, *3*, 03.CP.3.4. https://doi.org/10.2466/03.CP.3.4

Armstrong, K. (2019). *The unmet needs of siblings of children with cancer and serious chronic health conditions in Aōtearoa/New Zealand* [Thesis, Massey University]. https://mro.massey.ac.nz/handle/10179/15677

Arnold, E. M. (1999). The cessation of cancer treatment as a crisis. *Social Work in Health Care*, *29*(2), 21–38. https://doi.org/10.1300/J010v29n02_02

Attig, T. (1996). *How we grieve: Relearning the world*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780195074567.001.0001

Attig, T. (2004). Meanings of death seen through the lens of grieving. *Death Studies*, *28*(4), 341–360. https://doi.org/10.1080/07481180490432333

Azeem, H. (2015). The art of Edvard Munch: A window onto a mind. *BJPsych Advances*, *21*(1), 51–53. https://doi.org/10.1192/apt.bp.114.012963

Baenziger, J., Hetherington, K., Wakefield, C. E., Carlson, L., McGill, B. C., Cohn, R. J., Michel, G., & Sansom-Daly, U. M. (2020). Understanding parents' communication experiences in childhood cancer: A qualitative exploration and model for future research. *Supportive Care in Cancer*, *28*(9), 4467–4476. https://doi.org/10.1007/s00520-019-05270-6

Bakula, D. M., Sharkey, C. M., Perez, M. N., Espeleta, H. C., Gamwell, K. L., Baudino, M., Delozier, A. M., Chaney, J. M., Alderson, R. M., & Mullins, L. L. (2020). The relationship between parent distress and child quality of life in pediatric cancer: A meta-analysis. *Journal of Pediatric Nursing*, *50*, 14–19. https://doi.org/10.1016/j.pedn.2019.09.024

Ballantine & NZCCR Working Group. (2017a). Childhood cancer survival in New Zealand 2005-2014: A report from the New Zealand Children's Cancer Registry. *National Child Cancer Network.*

Ballantine & NZCCR Working Group. (2017b). *The incidence of childhood cancer in New Zealand 2010-2014: A report from the New Zealand Children's Cancer Registry*. National Child Cancer Network.

Ballantine & NZCCR Working Group. (2018). *NZCCR Report 2018*. National Child Cancer Network.

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. https://doi.org/10.1177/1043454211408106

Barakat, L. P., Alderfer, M. A., & Kazak, A. E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology*, *31*(4), 413–419. https://doi.org/10.1093/jpepsy/jsj058

Beck, A. T. (1979). *Cognitive Therapy of Depression*. Guilford Press.

Bell, K. (2012). Remaking the self: Trauma, teachable moments, and the biopolitics of cancer survivorship. *Culture, Medicine and Psychiatry*, *36*(4), 584–600. https://doi.org/10.1007/s11013-012-9276-9

Bell, K., & Ristovski-Slijepcevic, S. (2013). Cancer survivorship: Why labels matter. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *31*(4), 409–411. https://doi.org/10.1200/JCO.2012.43.5891

Bendelow, G. (2009). *Health, Emotion and The Body*. Polity.

Bennett, S. T. M. (2009). *Te huanga o te ao Maori: Cognitive behavioural therapy for Maori clients with depression: Development and evaluation of a culturally adapted treatment programme* [Thesis, Massey University]. https://mro.massey.ac.nz/handle/10179/1159

Berry, L. L., Davis, S. W., Godfrey Flynn, A., Landercasper, J., & Deming, K. A. (2019). Is it time to reconsider the term ‘cancer survivor’? *Journal of Psychosocial Oncology*, *37*(4), 413–426. https://doi.org/10.1080/07347332.2018.1522411

Björk, M., Nordström, B., Wiebe, T., & Hallström, I. (2011). Returning to a changed ordinary life – families’ lived experience after completing a child’s cancer treatment. *European Journal of Cancer Care*, *20*(2), 163–169. https://doi.org/10.1111/j.1365-2354.2009.01159.x

Björk, M., Wiebe, T., & Hallström, I. (2009). An everyday struggle-Swedish families' lived experiences during a child's cancer treatment. *Journal of Pediatric Nursing*, *24*(5), 423–432. https://doi.org/10.1016/j.pedn.2008.01.082

Blows, E., Bird, L., Seymour, J., & Cox, K. (2012). Liminality as a framework for understanding the experience of cancer survivorship: A literature review. *Journal of Advanced Nursing*, *68*(10), 2155–2164. https://doi.org/10.1111/j.1365-2648.2012.05995.x

Bolderston, A. (2012). Conducting a research interview. *Journal of Medical Imaging and Radiation Sciences*, *43*(1), 66–76. https://doi.org/10.1016/j.jmir.2011.12.002

Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, *7*(5), 345–374. https://doi.org/10.1016/S0010-440X(66)80065-2

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.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. SAGE.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2020). 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 and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Brickell, C. (2006). The sociological construction of gender and sexuality. *The Sociological Review*, *54*(1), 87–113. https://doi.org/10.1111/j.1467-954X.2006.00603.x

Broom, A., Kenny, K., Kirby, E., & Lwin, Z. (2019). The collective/affective practice of cancer survivorship. *The British Journal of Sociology*, *70*(4), 1582–1601. https://doi.org/10.1111/1468-4446.12616

Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 34–52.

Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, *26*(3), 233–256. https://doi.org/10.1016/j.cpr.2005.10.002

Burr, V. (2015). Social constructionism. *International Encyclopedia of the Social & Behavioral Sciences*, 222–227. https://doi.org/10.1016/B978-0-08-097086-8.24049-X

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Butow, P. N., Phillips, F., Schweder, J., White, K., Underhill, C., Goldstein, D., & Clinical Oncological Society of Australia. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: A systematic review. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *20*(1), 1–22. https://doi.org/10.1007/s00520-011-1270-1

Calhoun, L. G., & Tedeschi, R. G. (1999). *Facilitating posttraumatic growth: A clinician's guide*. Routledge.

Caliskan, H. I. (2021). *"The end" of paediatric cancer treatment: A qualitative study of parents' experiences and needs* [Doctoral Thesis, University College London]. https://discovery.ucl.ac.uk/id/eprint/10138606/

Cancer Institute NSW. (2018). *What is cancer?* What Is Cancer? https://www.cancer.nsw.gov.au/about-cancer/cancer-basics/what-is-cancer

Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & Essen, L. von. (2019). Psychological distress in parents of children treated for cancer: An explorative study. *PLOS ONE*, *14*(6), e0218860. https://doi.org/10.1371/journal.pone.0218860

Carreno, D. F., & Eisenbeck, N. (2022). Existential insights in cancer: Meaning in life adaptability. *Medicina*, *58*(4), 461. https://doi.org/10.3390/medicina58040461

Cayless, S., Forbat, L., Illingworth, N., Hubbard, G., & Kearney, N. (2010). Men with prostate cancer over the first year of illness: Their experiences as biographical disruption. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *18*(1), 11–19. https://doi.org/10.1007/s00520-009-0624-4

Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *BMJ (Clinical Research Ed.)*, *328*(7454), 1470. https://doi.org/10.1136/bmj.38111.639734.7C

Cheung, S. Y., & Delfabbro, P. (2016). Are you a cancer survivor? A review on cancer identity. *Journal of Cancer Survivorship*, *10*(4), 759–771. https://doi.org/10.1007/s11764-016-0521-z

Cipolletta, S., & Amicucci, L. (2015). The family experience of living with a person with amyotrophic lateral sclerosis: A qualitative study. *International Journal of Psychology*, *50*(4), 288–294. https://doi.org/10.1002/ijop.12085

Clark, I. A., & Mackay, C. E. (2015). Mental imagery and post-traumatic stress disorder: A neuroimaging and experimental psychopathology approach to intrusive memories of trauma. *Frontiers in Psychiatry*, *6*. https://www.frontiersin.org/articles/10.3389/fpsyt.2015.00104

Clarke, J. (2005). Portrayal of childhood cancer in English language magazines in North America: 1970–2001. *Journal of Health Communication*, *10*(7), 593–607. https://doi.org/10.1080/10810730500267605

Clarke, J., & Everest, M. M. (2006). Cancer in the mass print media: Fear, uncertainty and the medical model. *Social Science & Medicine*, *62*(10), 2591–2600. https://doi.org/10.1016/j.socscimed.2005.11.021

Cluley, S. M. (2015). *Fathers of children with cancer: A narrative inquiry* [Doctoral Thesis, Massey University]. https://mro.massey.ac.nz/handle/10179/8509

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, *51*(1 Supplement), 67–79. https://doi.org/10.1177/0022146510383495

Conway Keller, M., King, C., Hart, L., Engelke, K., Needham, A., Holden, E., Foy, K., & Lucas, R. (2020). The end of cancer treatment experience for children, adolescents, and their parents: A systematic review of the literature. *Journal of Psychosocial Oncology*, *38*(5), 573–591. https://doi.org/10.1080/07347332.2020.1769795

Corey, A. L., Haase, J. E., Azzouz, F., & Monahan, P. O. (2008). Social support and symptom distress in adolescents/young adults with cancer. *Journal of Pediatric Oncology Nursing*, *25*(5), 275–284. https://doi.org/10.1177/1043454208321117

Cox, T. (2018). Caregivers reflecting on the early days of childhood cancer. *European Journal of Cancer Care*, *27*(1), e12499. https://doi.org/10.1111/ecc.12499

Coyne, J. C., & Tennen, H. (2010). Positive psychology in cancer care: Bad science, exaggerated claims, and unproven medicine. *Annals of Behavioral Medicine*, *39*(1), 16–26. https://doi.org/10.1007/s12160-009-9154-z

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. SAGE Publications.

Crossley, M. L. (2003). 'Let me explain': Narrative emplotment and one patient's experience of oral cancer. *Social Science & Medicine*, *56*, 439–448. https://doi.org/10.1016/S0277-9536(01)00362-8

Darlington, A.-S., Morgan, J., Wagland, R., Sodergren, S., Culliford, D., Gamble, A., & Phillips, B. (2020). *COVID-19 and children with cancer: Parents' experiences, anxieties, and support needs*. https://doi.org/10.1101/2020.06.11.20128603

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. B., Kelada, L., & Gottardo, N. G. (2022). Parents' experiences of childhood cancer during the COVID-19 pandemic: An Australian perspective. *Journal of Pediatric Psychology*, *47*(2), 148–157. https://doi.org/10.1093/jpepsy/jsab125

De Raeve, L. (1997). Positive thinking and moral oppression in cancer care. *European Journal of Cancer Care*, *6*(4), 249–256. https://doi.org/10.1046/j.1365-2354.1997.00043.x

Deimling, G. T., Kahana, B., Bowman, K. F., & Schaefer, M. L. (2002). Cancer survivorship and psychological distress in later life. *Psycho-Oncology*, *11*(6), 479–494. https://doi.org/10.1002/pon.614

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, *40*(4), 314–321. https://doi.org/10.1111/j.1365-2929.2006.02418.x

Diller, L., Chow, E. J., Gurney, J. G., Hudson, M. M., Kadin-Lottick, N. S., Kawashima, T. I., Leisenring, W. M., Meacham, L. R., Mertens, A. C., Mulrooney, D. A., Oeffinger, K. C., Packer, R. J., Robison, L. L., & Sklar, C. A. (2009). Chronic disease in the childhood cancer survivor study cohort: A review of published findings. *Journal of Clinical Oncology*, *27*(14), 2339–2355. https://doi.org/10.1200/JCO.2008.21.1953

Dixon-Woods, M., Seale, C., Young, B., Findlay, M., & Heney, D. (2003). Representing childhood cancer: Accounts from newspapers and parents. *Sociology of Health & Illness*, *25*(2), 143–164. https://doi.org/10.1111/1467-9566.00329

Dockerty, J. D., Williams, S. M., McGee, R., & Skegg, D. C. G. (2000). Impact of childhood cancer on the mental health of parents. *Medical and Pediatric Oncology*, *35*(5), 475–483. https://doi.org/10.1002/1096-911X(20001101)35:5<475::AID-MPO6>3.0.CO;2-U

Duffey-Lind, E. C., O'Holleran, E., Healey, M., Vettese, M., Diller, L., & Park, E. R. (2006). Transitioning to survivorship: A pilot study. *Journal of Pediatric Oncology Nursing*, *23*, 335–343. https://doi.org/10.1177/1043454206293267

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*(4), 179–197. https://doi.org/10.1177/1043454213487433

Durie, M. H. (1984). 'Te taha hinengaro': An integrated approach to mental health. *Community Mental Health in New Zealand*, *1*, 4–11.

Earle, E. A., Clarke, S. A., Eiser, C., & Sheppard, L. (2007). 'Building a new normality': Mothers' experiences of caring for a child with acute lymphoblastic leukaemia. *Child: Care, Health and Development*, *33*(2), 155–160. https://doi.org/10.1111/j.1365-2214.2006.00638.x

Efran, J. S., McNamee, S., Warren, B., & Raskin, J. D. (2014). Personal construct psychology, radical constructivism, and social constructionism: A dialogue. *Journal* *of Constructivist Psychology*, *27*(1), 1–13. https://doi.org/10.1080/10720537.2014.850367

Ehlers, A., & Clark, D. M. (2000). A cognitive model of posttraumatic stress disorder. *Behaviour Research and Therapy*, *38*(4), 319–345. https://doi.org/10.1016/s0005-7967(99)00123-0

Ehrenreich, B. (2009). *Bright-sided: How the relentless promotion of positive Thinking has undermined America*. Metropolitan Books.

Ellis, S. J., Wakefield, C. E., McLoone, J. K., Robertson, E. G., & Cohn, R. J. (2016). Fertility concerns among child and adolescent cancer survivors and their parents: A qualitative analysis. *Journal of Psychosocial Oncology*, *34*(5), 347–362. https://doi.org/10.1080/07347332.2016.1196806

Engelen, V., Koopman, H. M., Detmar, S. B., Raat, H., van de Wetering, M. D., Brons, P., Anninga, J. K., Abbink, F., & Grootenhuis, M. A. (2011). Health-related quality of life after completion of successful treatment for childhood cancer. *Pediatric Blood & Cancer*, *56*(4), 646–653. https://doi.org/10.1002/pbc.22795

Enskär, K., Darcy, L., Björk, 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: Official Journal of the Association of Pediatric Oncology Nurses*, *37*(1), 21–34. https://doi.org/10.1177/1043454219874007

Erdmann, F., Frederiksen, L. E., Bonaventure, A., Mader, L., Hasle, H., Robison, L. L., & Winther, J. F. (2021). Childhood cancer: Survival, treatment modalities, late effects and improvements over time. *Cancer Epidemiology*, *71*, 101733. https://doi.org/10.1016/j.canep.2020.101733

Eshelman-Kent, D., Kinahan, K. E., Hobbie, W., Landier, W., Teal, S., Friedman, D., Nagarajan, R., & Freyer, D. R. (2011). Cancer survivorship practices, services, and delivery: A report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *Journal of Cancer Survivorship*, *5*(4), 345–357. https://doi.org/10.1007/s11764-011-0192-8

Fardell, J. E., Thewes, B., Turner, J., Gilchrist, J., Sharpe, L., Smith, A. 'Ben', Girgis, A., & Butow, P. (2016). Fear of cancer recurrence: A theoretical review and novel cognitive processing formulation. *Journal of Cancer Survivorship*, *10*(4), 663–673. https://doi.org/10.1007/s11764-015-0512-5

Feuerstein, M. (2007). Defining cancer survivorship. *Journal of Cancer Survivorship: Research and Practice*, *1*(1), 5–7. https://doi.org/10.1007/s11764-006-0002-x

Fletcher, P. C. (2011). My child has cancer: Finding the silver lining in every mother's nightmare. *Issues in Comprehensive Pediatric Nursing*, *34*(1), 40–55. https://doi.org/10.3109/01460862.2011.557905

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: Official Journal of the Association of Pediatric Oncology Nurses*, *28*(3), 143–153. https://doi.org/10.1177/1043454210378015

Forinder, U., & Lindahl Norberg, A. (2010). "Now we have to cope with the rest of our lives". Existential issues related to parenting a child surviving a brain tumour. *Supportive Care in Cancer*, *18*(5), 543–551. https://doi.org/10.1007/s00520-009-0678-3

Frank, A. W. (1997). Illness as moral occasion: Restoring agency to ill people. *Health*, *1*(2), 131–148. https://doi.org/10.1177/136345939700100201

Frank, A. W. (2003). Survivorship as craft and conviction: Reflections on research in progress. *Qualitative Health Research*, *13*(2), 247–255. https://doi.org/10.1177/1049732302239601

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). University of Chicago Press.

Freud, S. (1893). Studies on hysteria. *SE*, *2*, 185–251.

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: Official Journal of the Association of Pediatric Oncology Nurses*, *29*(5), 253–271. https://doi.org/10.1177/1043454212452791

Gibbs, G. (1988). *Learning by doing: A guide to teaching and learning methods*. Further Education Unit.

Gise, J., & Cohen, L. L. (2021). Social support in parents of children with cancer: A systematic review. *Journal of Pediatric Psychology*. https://doi.org/10.1093/jpepsy/jsab100

Graham, C. D., Gouick, J., Krahé, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, *46*, 46–58. https://doi.org/10.1016/j.cpr.2016.04.009

Gray, W. N., Szulczewski, L. J., Regan, S. M. P., Williams, J. A., & Pai, A. L. H. (2014). Cultural influences in pediatric cancer: From diagnosis to cure/end of life. *Journal of Pediatric Oncology Nursing*, *31*(5), 252–271. https://doi.org/10.1177/1043454214529022

Greening, L., & Stoppelbein, L. (2007). Brief report: Pediatric cancer, parental coping style, and risk for depressive, posttraumatic stress, and anxiety symptoms. *Journal of Pediatric Psychology*, *32*(10), 1272–1277. https://doi.org/10.1093/jpepsy/jsm057

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*, *18*(1), 59–82. https://doi.org/10.1177/1525822X05279903

Guilcher, G. M., Rivard, L., Huang, J. T., Wright, N. A., Anderson, L., Eissa, H., Pelletier, W., Ramachandran, S., Schechter, T., Shah, A. J., Wong, K., & Chow, E. J. (2021). Immune function in childhood cancer survivors: A children's oncology group review. *The Lancet. Child & Adolescent Health*, *5*(4), 284–294. https://doi.org/10.1016/S2352-4642(20)30312-6

Hammoudeh, W., Hogan, D., & Giacaman, R. (2017). From a death sentence to a disrupted life: Palestinian women's experiences and coping with breast cancer. *Qualitative Health Research*, *27*(4), 487–496. https://doi.org/10.1177/1049732316628833

Harris, D. L., & Gorman, E. (2011). Grief from a broader perspective: Nonfinite loss, ambiguous loss, and chronic sorrow. In D. L. Harris, *Counting our losses: Reflecting on change, loss, and transition in everyday life*. Routledge.

Hart, R. I., Cameron, D. A., Cowie, F. J., Harden, J., Heaney, N. B., Rankin, D., Jesudason, A. B., & Lawton, J. (2020). The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: A qualitative study involving adolescents and young adults with cancer and their caregivers. *BMC Health Services Research*, *20*, 25. https://doi.org/10.1186/s12913-019-4851-1

Hayes, S. C., & Pierson, H. (2005). Acceptance and Commitment Therapy. In A. Freeman, S. H. Felgoise, C. M. Nezu, A. M. Nezu, & M. A. Reinecke (Eds.), *Encyclopedia of*

Cognitive Behavior Therapy (pp. 1–4). Springer US. https://doi.org/10.1007/0-306-48581-8_1

Health Navigator New Zealand. (2022). *Childhood cancer*. Health Navigator New Zealand. https://www.healthnavigator.org.nz/health-a-z/c/childhood-cancer/

Health Promotion Agency & Melanoma Network of New Zealand. (2017). *New Zealand skin cancer primary prevention and early detection strategy 2017 to 2022*. https://www.sunsmart.org.nz/sites/default/files/documents/FINAL-Strategy-28Mar2017.PDF

Heathcote, L. C., & Eccleston, C. (2017). Pain and cancer survival: A cognitive-affective model of symptom appraisal and the uncertain threat of disease recurrence. *Pain*, *158*(7), 1187–1191. https://doi.org/10.1097/j.pain.0000000000000872

Hebert, E. A., & Dugas, M. J. (2019). Behavioral experiments for intolerance of uncertainty: Challenging the unknown in the treatment of generalized anxiety disorder. *Cognitive and Behavioral Practice*, *26*(2), 421–436. https://doi.org/10.1016/j.cbpra.2018.07.007

Helgeson, V. S., Lopez, L., & Mennella, C. (2009). Benefit finding among children and adolescents with diabetes. In *Medical illness and positive life change: Can crisis lead to personal transformation?* (pp. 65–86). American Psychological Association. https://doi.org/10.1037/11854-004

Hewitt, M., Weiner, S. L., & Simone, J. V. (2003). Late effects of childhood cancer. In *Childhood Cancer Survivorship: Improving Care and Quality of Life*. National Research Council. https://www.ncbi.nlm.nih.gov/books/NBK221735/

Hocking, M. C., Hobbie, W. L., Deatrick, J. A., Lucas, M. S., Szabo, M. M., Volpe, E. M., & Barakat, L. P. (2011). Neurocognitive and family functioning and quality of life among young adult survivors of childhood brain tumors. *The Clinical Neuropsychologist*, *25*, 942–962. https://doi.org/10.1080/13854046.2011.580284

Holstein, J. A., & Gubrium, J. F. (2008). *Handbook of Constructionist Research*. Guilford Press.

Hopper, E., Bassuk, E., & Olivet, J. (2010). Shelter from the storm: Trauma-informed care in homelessness services settings. *The Open Health Services and Policy Journal*, *3*(1). https://benthamopen.com/ABSTRACT/TOHSPJ-3-80

Horlick-Jones, T. (2011). Understanding fear of cancer recurrence in terms of damage to 'everyday health competence'. *Sociology of Health & Illness*, *33*(6), 884–898. https://doi.org/10.1111/j.1467-9566.2010.01325.x

Hosoda, T. (2014). The impact of childhood cancer on family functioning: A review. *Graduate Student Journal of Psychology*, *15*(1), 18–30.

Hsiao, C. C., Chiou, S. S., Hsu, H.-T., Lin, P. C., Liao, Y. M., & Wu, L.-M. (2018). Adverse health outcomes and health concerns among survivors of various childhood cancers: Perspectives from mothers. *European Journal of Cancer Care*, *27*(6), e12661. https://doi.org/10.1111/ecc.12661

Hudson, M. M., Ness, K. K., Gurney, J. G., Mulrooney, D. A., Chemaitilly, W., Krull, K. R., Green, D. M., Armstrong, G. T., Nottage, K. A., Jones, K. E., Sklar, C. A., Srivastava, D. K., & Robison, L. L. (2013). Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*, *309*(22), 2371–2381. https://doi.org/10.1001/jama.2013.6296

Hullmann, S. E., Wolfe-Christensen, C., Meyer, W. H., McNall-Knapp, R. Y., & Mullins, L. L. (2010). The relationship between parental overprotection and health-related quality of life in pediatric cancer: The mediating role of perceived child vulnerability. *Quality of Life Research*, *19*(9), 1373–1380. https://doi.org/10.1007/s11136-010-9696-3

Hungerbuehler, I., Vollrath, M. E., & Landolt, M. A. (2011). Posttraumatic growth in mothers and fathers of children with severe illnesses. *Journal of Health Psychology*, *16*, 1259–1267. https://doi.org/10.1177/1359105311405872

Jammu, A. S., Chasen, M. R., Lofters, A. K., & Bhargava, R. (2021). Systematic rapid living review of the impact of the COVID-19 pandemic on cancer survivors: Update to August 27, 2020. *Supportive Care in Cancer*, *29*(6), 2841–2850. https://doi.org/10.1007/s00520-020-05908-w

Jefford, M., Rowland, J., Grunfeld, E., Richards, M., Maher, J., & Glaser, A. (2013). Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. *British Journal of Cancer*, *108*(1), 14–20. https://doi.org/10.1038/bjc.2012.554

Joseph, S. (2009). Growth following adversity: Positive psychological perspectives on posttraumatic stress. *Psihologijske Teme*, *18*(2), 335–344.

Jurbergs, N., Long, A., Ticona, L., & Phipps, S. (2009). Symptoms of posttraumatic stress in parents of children with cancer: Are they elevated relative to parents of healthy children? *Journal of Pediatric Psychology*, *34*(1), 4–13. https://doi.org/10.1093/jpepsy/jsm119

Kalitzkus, V., & Matthiessen, P. F. (2010). Personal growth in chronic illness: A biographical case study of living with fibromyalgia. *Complementary Medicine Research*, *17*(4), 203–208. https://doi.org/10.1159/000317848

Karst, J. S., Hoag, J. A., Chan, S. F., Schmidt, D. J., Anderson, L. J., Englebert, N. E., Igler, E. C., & Bingen, K. M. (2018). Assessment of end-of-treatment transition needs for pediatric cancer and hematopoietic stem cell transplant patients and their families. *Pediatric Blood & Cancer*, *65*(8), e27109. https://doi.org/10.1002/pbc.27109

Katz, L., Fladeboe, K., King, K., Gurtovenko, K., Kawamura, J., & Friedman, D. (2018). Trajectories of child and caregiver psychological adjustment in families of children with cancer. *Health Psychology*, *37*(8), 725–735.

Kazak, A. E., Alderfer, M. A., Streisand, R., Simms, S., Rourke, M. T., Barakat, L. P., Gallagher, P., & Cnaan, A. (2004). Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: A randomized clinical trial. *Journal of Family Psychology: JFP: Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, *18*(3), 493–504. https://doi.org/10.1037/0893-3200.18.3.493

Kazak, A. E., Barakat, L. P., Meeske, K., Christakis, D., Meadows, A. T., Casey, R., Penati, B., & Stuber, M. L. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology*, *65*(1), 120–129. https://doi.org/10.1037//0022-006x.65.1.120

Kazak, A. E., Boeving, C. A., Alderfer, M. A., Hwang, W.-T., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, *23*(30), 7405–7410. https://doi.org/10.1200/JCO.2005.09.110

Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, *31*(4), 343–355. https://doi.org/10.1093/jpepsy/jsj054

Kazak, A. E., & Noll, R. B. (2015). The integration of psychology in pediatric oncology research and practice: Collaboration to improve care and outcomes for children and families. *The American Psychologist*, *70*(2), 146–158. https://doi.org/10.1037/a0035695

Kazak, A. E., Rourke, M. T., Alderfer, M. A., Pai, A., Reilly, A. F., & Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, *32*(9), 1099–1110. https://doi.org/10.1093/jpepsy/jsm031

Kazak, A. E., Stuber, M. L., Barakat, L. P., Meeske, K., Guthrie, D., & Meadows, A. T. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *Journal of the American Academy of Child & Adolescent Psychiatry*, *37*(8), 823–831. https://doi.org/10.1097/00004583-199808000-00012

KidsHealth NZ. (2011, September 13). *What is cancer?* (New Zealand). KidsHealth NZ; KidsHealth NZ. https://www.kidshealth.org.nz/what-cancer

Kim, K. (2006). *The Social Construction of Disease: From Scrapie to Prion*. Routledge. https://doi.org/10.4324/9780203008256

Klassen, A. F., Anthony, S. J., Khan, A., Sung, L., & Klaassen, R. (2011). Identifying determinants of quality of life of children with cancer and childhood cancer survivors: A systematic review. *Supportive Care in Cancer*, *19*(9), 1275–1287. https://doi.org/10.1007/s00520-011-1193-x

Klassen, A. F., Gulati, S., Watt, L., Banerjee, A. T., Sung, L., Klaassen, R. J., Dix, D., Poureslami, I. M., & Shaw, N. (2012). Immigrant to Canada, newcomer to childhood cancer: A qualitative study of challenges faced by immigrant parents. *Psycho-Oncology*, *21*(5), 558–562. https://doi.org/10.1002/pon.1963

Krause, N., & Stryker, S. (1984). Stress and well-being: The buffering role of locus of control beliefs. *Social Science & Medicine*, *18*, 783–790. https://doi.org/10.1016/0277-9536(84)90105-9

Kromm, E. E., Smith, K. C., & Singer, R. F. (2007). Survivors on cancer: The portrayal of survivors in print news. *Journal of Cancer Survivorship*, *1*(4), 298–305. https://doi.org/10.1007/s11764-007-0033-y

Kunin-Batson, A. S., Lu, X., Balsamo, L., Graber, K., Devidas, M., Hunger, S. P., Carroll, W. L., Winick, N. J., Mattano Jr, L. A., Maloney, K. W., & Kadan-Lottick, N. S. (2016). Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study. *Cancer*, *122*(10), 1608–1617. https://doi.org/10.1002/cncr.29946

Kvale, S. (1994). *Interviews: An introduction to qualitative research interviewing* (pp. xvii, 326). Sage Publications, Inc.

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research Interviewing*. SAGE Publications. https://books.google.co.nz/books?hl=en&lr=&id=bZGvwsP1BRwC&oi=fnd&pg=PR1&dq=Kvale,+S.,+%26+Brinkmann,+S.+(2009).+Interviews:+Learning+the+Craft+of+Qualitative+Research+Interviewing.+SAGE.&ots=q8KLydwuLg&sig=OWH5SauUnjPJdSi2mcFooVZE2so#v=onepage&q=Kvale%2C%20S.%2C%20%26%20Brinkmann%2C%20S.%20(2009).%20Interviews%3A%20Learning%20the%20Craft%20of%20Qualitative%20Research%20Interviewing.%20SAGE.&f=false

Lackner, H., Benesch, M., Schagerl, S., Kerbl, R., Schwinger, W., & Urban, C. (2000). Prospective evaluation of late effects after childhood cancer therapy with a follow-up over 9 years. *European Journal of Pediatrics*, *159*(10), 750–758. https://doi.org/10.1007/pl00008340

Laney, E. K., Hall, M. E. L., Anderson, T. L., & Willingham, M. M. (2015). Becoming a mother: The influence of motherhood on women’s identity development. *Identity*, *15*(2), 126–145. https://doi.org/10.1080/15283488.2015.1023440

Lapadat, J. C., & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positionings. *Qualitative Inquiry*, *5*(1), 64–86. https://doi.org/10.1177/107780049900500104

Lea, S., Martins, A., Bassett, M., Cable, M., Doig, G., Fern, L. A., Morgan, S., Soanes, L., Smith, S., Whelan, M., & Taylor, R. M. (2018). Issues experienced and support provided to adolescents and young adults at the end of active treatment for cancer literature: A rapid review of the literature. *European Journal of Cancer Care*, *27*(6). https://doi.org/10.1111/ecc.12972

Lefcourt, H. M. (1991). Locus of control. In *Measures of personality and social psychological attitudes* (pp. 413–499). Academic Press. https://doi.org/10.1016/B978-0-12-590241-0.50013-7

Lemos, M. S., Lima, L., Silva, C., & Fontoura, S. (2020). Disease-related parenting stress in the post-treatment phase of pediatric cancer. *Comprehensive Child and Adolescent Nursing*, *43*(1), 65–79. https://doi.org/10.1080/24694193.2019.1570393

Lewis, P., & Weston, K. M. (2019). Representations of young cancer survivorship: A discourse analysis of online presentations of self. *Cancer Nursing*, *42*(1), 79. https://doi.org/10.1097/NCC.0000000000000582

Lincoln, Y. S., & Guba, E. G. (2016). *The Constructivist Credo*. Routledge. https://doi.org/10.4324/9781315418810

Linnan, L., & Steckler, A. (2002). *Process Evaluation for Public Health Interventions and Research*. Jossey-Bass; John Wiley and Sons.

Little, M., Sayers, E., Paul, K., & Jordens, C. (2000). On surviving cancer. *Journal of the Royal Society of Medicine*, *93*(10), 501–503.

Ljungman, L., Boger, M., Ander, M., Ljótsson, B., Cernvall, M., von Essen, L., & Hovén, 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*(6), e0157076. https://doi.org/10.1371/journal.pone.0157076

Ljungman, L., Cernvall, M., Grönqvist, H., Ljótsson, B., Ljungman, G., & von Essen, L. (2014). Long-term positive and negative psychological late effects for parents of childhood cancer survivors: A systematic review. *PloS One*, *9*(7), e103340. https://doi.org/10.1371/journal.pone.0103340

Ljungman, L., Hovén, E., Ljungman, G., Cernvall, M., & von Essen, L. (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*(12), 1792–1798. https://doi.org/10.1002/pon.3856

Lock, A., & Strong, T. (2010). *Social constructionism: Sources and stirrings in theory and practice*. Cambridge University Press.

Long, K. A., & Marsland, A. L. (2011). Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Review*, *14*(1), 57–88. https://doi.org/10.1007/s10567-010-0082-z

Mader, L., Hargreave, M., Frederiksen, L. E., Bidstrup, P. E., Dalton, S. O., Kjær, S. K., Nielsen, T. T., Kroyer, A., Winther, J. F., & Erdmann, F. (2020). The impact of childhood cancer on parental separation, divorce, and family planning in Denmark. *Cancer*, *126*(14), 3330–3340. https://doi.org/10.1002/cncr.32901

Mader, L., Roser, K., Baenziger, J., Vetsch, J., Winther, J. F., Scheinemann, K., & Michel, G. (2019). Relationship status and quality of the partner relationship in parents of long-term childhood cancer survivors: The Swiss Childhood Cancer Survivor Study-Parents. *Psycho-Oncology*, *28*(2), 309–316. https://doi.org/10.1002/pon.4941

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Marcus, D. K., Hughes, K. T., & Arnau, R. C. (2008). Health anxiety, rumination, and negative affect: A mediational analysis. *Journal of Psychosomatic Research*, *64*(5), 495–501. https://doi.org/10.1016/j.jpsychores.2008.02.004

Marris, P. (2014). *Loss and Change (Psychology Revivals): Revised Edition*. Routledge. https://doi.org/10.4324/9781315755397

Martin, J., & Sugarman, J. (1997). The social-cognitive construction of psychotherapeutic change: Bridging social constructionism and cognitive constructivism. *Review of General Psychology*, *1*(4), 375–388. https://doi.org/10.1037/1089-2680.1.4.375-388

Massey University. (2017). *Massey University Code of Ethical Conduct for Research, Teaching, and Evaluations involving Human Participants*. https://www.massey.ac.nz/massey/fms/Human%20Ethics/Documents/MUHEC%20Code.pdf?2F3CBE296DD2345CC01794BF9CFCA13A

Matapo-Kolisko, M. (2021). *Experiences of physical activity and exercise in cancer patients and survivors using Te Whare Tapa Whā* [Masters Thesis]. Otago Polytechnic.

Matheson, K., & Anisman, H. (2003). Systems of coping associated with dysphoria, anxiety and depressive illness: A multivariate profile perspective. *Stress: The International Journal on the Biology of Stress*, *6*(3), 223–234. https://doi.org/10.1080/10253890310001594487

Mathieson, C. M., & Stam, H. J. (1995). Reneotiating identity: Cancer narratives. *Sociology of Health & Illness*, *17*(3), 283–306. https://doi.org/10.1111/1467-9566.ep10933316

Maurice-Stam, H., Oort, F. J., Last, B. F., & Grootenhuis, M. A. (2008). Emotional functioning of parents of children with cancer: The first five years of continuous remission after the end of treatment. *Psycho-Oncology*, *17*, 448–459. https://doi.org/10.1002/pon.1260

McCarthy, M. C., McNeil, R., Drew, S., Orme, L., & Sawyer, S. M. (2018). Information needs of adolescent and young adult cancer patients and their parent-carers. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *26*(5), 1655–1664. https://doi.org/10.1007/s00520-017-3984-1

McDonald, G. K., Hii, J., Szymanska, K. E., Davison, J. A., Wolfe, N., & Chalmers, S. H. (2018). NZ Child and Youth Mortality Review Committee 13th Data Report 2012-2016. *University of Otago*. https://ourarchive.otago.ac.nz/handle/10523/8024

McKenzie, S. E., & Curle, C. (2012). 'The end of treatment is not the end': Parents' experiences of their child's transition from treatment for childhood cancer. *Psycho-Oncology*, *21*(6), 647–654. https://doi.org/10.1002/pon.1953

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), 484–492. https://doi.org/10.1111/ecc.12054

Mellon, S., Kershaw, T. S., Northouse, L. L., & Freeman-Gibb, L. (2007). A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-Oncology*, *16*(3), 214–223. https://doi.org/10.1002/pon.1074

Mertens, A. C., Yasui, Y., Neglia, J. P., Potter, J. D., Nesbit, M. E., Ruccione, K., Smithson, W. A., & Robison, L. L. (2001). Late mortality experience in five-year survivors of childhood and adolescent cancer: The Childhood Cancer Survivor Study. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *19*(13), 3163–3172. https://doi.org/10.1200/JCO.2001.19.13.3163

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*, *67*(6), 1103–1134. https://doi.org/10.1016/j.pcl.2020.07.005

Miedema, B., Hamilton, R., & Easley, J. (2007). From 'invincibility' to 'normalcy': Coping strategies of young adults during the cancer journey. *Palliative & Supportive Care*, *5*(1), 41–49. https://doi.org/10.1017/s147895150707006x

Ministry of Health. (2016). *National Plan for Child Cancer Services in New Zealand*. Ministry of Health NZ. https://www.health.govt.nz/publication/national-plan-child-cancer-services-new-zealand

Ministry of Health. (2021). *District Health Boards*. Ministry of Health. https://www.health.govt.nz/new-zealand-health-system/key-health-sector-organisations-and-people/district-health-boards

Ministry of Health. (2022). *Cancer*. Ministry of Health NZ. https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/cancer

Mishel, M. H. (1988). Uncertainty in illness. *The Journal of Nursing Scholarship*, *20*(4), 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Moeke-Maxwell, T., Collier, A., Wiles, J., Williams, L., Black, S., & Gott, M. (2020). Bereaved families' perspectives of end-of-life care: Towards a bicultural whare tapa whā older person's palliative care model. *Journal of Cross-Cultural Gerontology*, *35*(2), 177–193. https://doi.org/10.1007/s10823-020-09397-6

Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, *313*(4), 270–273. https://doi.org/10.1056/NEJM198507253130421

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), 358–366. https://doi.org/10.1177/1043454217703594

National Cancer Institute. (2019). *Understanding cancer prognosis* [CgvArticle]. https://www.cancer.gov/about-cancer/diagnosis-staging/prognosis

New Zealand Psychological Society. (2002). *Code of Ethics For Psychologists Working in Aotearoa/New Zealand*. New Zealand Psychological Society.

Nijenhuis, E. R. S., & Van der Hart, O. (2011). Dissociation in trauma: A new definition and comparison with previous formulations. *Journal of Trauma & Dissociation*, *12*(4), 416–445. https://doi.org/10.1080/15299732.2011.570592

Njuguna, F., Mostert, S., Seijffert, A., Musimbi, J., Langat, S., van der Burgt, R. H. M., Skiles, J., Sitaresmi, M. N., van de Ven, P. M., & Kaspers, G. J. L. (2015). Parental experiences of childhood cancer treatment in Kenya. *Supportive Care in Cancer*, *23*(5), 1251–1259. https://doi.org/10.1007/s00520-014-2475-x

Norberg, A. L., & Boman, K. K. (2007). Parents' perceptions of support when a child has cancer: A longitudinal perspective. *Cancer Nursing*, *30*(4), 294–301. https://doi.org/10.1097/01.NCC.0000281723.34125.b3

Norberg, A. L., & Boman, K. K. (2013). Mothers and fathers of children with cancer: Loss of control during treatment and posttraumatic stress at later follow-up. *Psycho-Oncology*, *22*(2), 324–329. https://doi.org/10.1002/pon.2091

Norberg, A. L., & Green, A. (2007). Stressors in the daily life of parents after a child's successful cancer treatment. *Journal of Psychosocial Oncology*, *25*(3), 113–122. https://doi.org/10.1300/J077v25n03_07

Norberg, A. L., Lindblad, F., & Boman, K. K. (2005). Parental traumatic stress during and after paediatric cancer treatment. *Acta Oncologica*, *44*(4), 382–388. https://doi.org/10.1080/02841860510029789

O'Leary, M., Krailo, M., Anderson, J., & Reaman, G. (2008). Progress in childhood cancer: 50 years of research collaboration, a report from the Children's Oncology Group. *Seminars in Oncology*, *35*(5), 484–493.

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research. *Medical Teacher*, *45*(3), 241–251. https://doi.org/10.1080/0142159X.2022.2057287

Orbuch, T. L., Parry, C., Chesler, M., Fritz, J., & Repetto, P. (2005). Parent-child relationships and quality of life: Resilience among childhood cancer survivors. *Family Relations*, *54*(2), 171–183. https://doi.org/10.1111/j.0197-6664.2005.00014.x

Orgad, S. (2009). The survivor in contemporary culture and public discourse: A genealogy. *The Communication Review*, *12*(2), 132–161. https://doi.org/10.1080/10714420902921168

Ortiz, M. C. A., & de Lima, R. A. G. (2007). Experiences of families with children and adolescents after completing a cancer treatment: Support for the nursing care. *Revista Latino-Americana De Enfermagem*, *15*(3), 411–417. https://doi.org/10.1590/s0104-11692007000300008

Owen, I. R. (1995). *Social constructionism and the theory, practice and research of psychotherapy: A phenomenological psychology manifesto*.

Pai, A. L. H., Greenley, R. N., Lewandowski, A., Drotar, D., Youngstrom, E., & Peterson, C. C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology*, *21*(3), 407–415. https://doi.org/10.1037/0893-3200.21.3.407

Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, *30*(1), 9–27. https://doi.org/10.1093/jpepsy/jsi012

Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology*, *58*(3), 233–246. https://doi.org/10.1002/jclp.10019

Patterson, J. M., Holm, K. E., & Gurney, J. G. (2004). The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, *13*(6), 390–407. https://doi.org/10.1002/pon.761

Peikert, M. L., Inhestern, L., Krauth, K. A., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Returning to daily life: A qualitative interview study on parents of childhood cancer survivors in Germany. *BMJ Open*, *10*(3), e033730. https://doi.org/10.1136/bmjopen-2019-033730

Plage, S. (2020). Cancer survivorship reimagined: A qualitative study on evolving interpretative repertoires of cancer and survivorship using participant-produced photography. *European Journal of Cancer Care*, *29*(6), e13320. https://doi.org/10.1111/ecc.13320

Pöder, U., Ljungman, G., & von Essen, L. (2008). Posttraumatic stress disorder among parents of children on cancer treatment: A longitudinal study. *Psycho-Oncology*, *17*(5), 430–437. https://doi.org/10.1002/pon.1263

Quast, L. F., Turner, E. M., McCurdy, M. D., & Hocking, M. C. (2016). Health-related quality of life in parents of pediatric brain tumor survivors at the end of tumor-directed therapy. *Journal of Psychosocial Oncology*, *34*(4), 274–290. https://doi.org/10.1080/07347332.2016.1175535

Quin, S. (2004). The long-term psychosocial effects of cancer diagnosis and treatment on children and their families. *Social Work in Health Care*, *39*, 129–149. https://doi.org/10.1300/J010v39n01_09

Rachman, S., Radomsky, A. S., & Shafran, R. (2008). Safety behaviour: A reconsideration. *Behaviour Research and Therapy*, *46*(2), 163–173. https://doi.org/10.1016/j.brat.2007.11.008

Rapmund, V., & Moore, C. (2000). Women's stories of depression: A constructivist approach. *South African Journal of Psychology*, *30*(2), 20–30. https://doi.org/10.10520/EJC98080

Raque-Bogdan, T. L. (2019). Relational cultural theory and cancer: Addressing the social well-being of a growing population. *Practice Innovations*, *4*, 99–111. https://doi.org/10.1037/pri0000087

Rees, S. (2017). 'Am I really gonna go sixty years without getting cancer again?' Uncertainty and liminality in young women's accounts of living with a history of breast cancer. *Health (London, England: 1997)*, *21*(3), 241–258. https://doi.org/10.1177/1363459316677628

Reid, J. (2009). Conducting qualitative research with advanced cancer patients and their families: Ethical considerations. *International Journal of Palliative Nursing*, *15*, 30–33. https://doi.org/10.12968/ijpn.2009.15.1.37950

Rifshana, F. (2017). *The lived experience of parents caring for a child with Type 1 diabetes* [Doctoral Thesis, Massey University]. https://mro-ns.massey.ac.nz/handle/10179/12493

Ripia, L. M. (2013). *He kupenga mate pukupuku uu mo ngā wāhine Māori: Te Whare Tapa Whā : a multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors* [Doctoral Thesis, Massey University]. https://mro.massey.ac.nz/handle/10179/5149

Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. SAGE.

Robinson, K. E., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2009). Survivors of childhood cancer and comparison peers: The influence of early family factors on distress in emerging adulthood. *Journal of Family Psychology*, *23*(1), 23–31. https://doi.org/10.1037/a0014199

Rochford, T. (2004). Whare tapa wha: A Mäori model of a unified theory of health. *Journal of Primary Prevention*, *25*(1), 41–57. https://doi.org/10.1023/B:JOPP.0000039938.39574.9e

Rocque, R., & Leanza, Y. (2015). A systematic review of patients' experiences in communicating with primary care physicians: Intercultural encounters and a balance between vulnerability and integrity. *PloS One*, *10*(10), e0139577. https://doi.org/10.1371/journal.pone.0139577

Roos, S. (2002). *Chronic Sorrow: A Living Loss*. Psychology Press.

Rowland, J. H., Hewitt, M., & Ganz, P. A. (2006). Cancer survivorship: A new challenge in delivering quality cancer care. *Journal of Clinical Oncology*, *24*(32), 5101–5104. https://doi.org/10.1200/JCO.2006.09.2700

Saillant, F. (1990). Discourse, knowledge and experience of cancer: A life story. *Culture, Medicine, and Psychiatry: An International Journal of Cross-Cultural Health Research*, *14*, 81–104. https://doi.org/10.1007/BF00046705

Salem, H., Johansen, C., Schmiegelow, K., Winther, J. F., Wehner, P. S., Hasle, H., Rosthøj, S., Kazak, A. E., & E. Bidstrup, P. (2017). FAMily-Oriented Support (FAMOS): Development and feasibility of a psychosocial intervention for families of childhood cancer survivors. *Acta Oncologica*, *56*(2), 367–374. https://doi.org/10.1080/0284186X.2016.1269194

Salkovskis, P. M. (1991). The importance of behaviour in the maintenance of anxiety and panic: A cognitive account. *Behavioural and Cognitive Psychotherapy*, *19*(1), 6–19. https://doi.org/10.1017/S0141347300011472

Sansom-Daly, U. M., & Wakefield, C. E. (2013). Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. *Translational Pediatrics*, *2*(4), 167–197. https://doi.org/10.3978/j.issn.2224-4336.2013.10.06

Schepers, S. A., Okado, Y., Russell, K., Long, A. M., & Phipps, S. (2019). Adjustment in childhood cancer survivors, healthy peers, and their parents: The mediating role of the parent–child relationship. *Journal of Pediatric Psychology*, *44*, 186–196. https://doi.org/10.1093/jpepsy/jsy069

Seale, C. (2002). Cancer heroics: A study of news reports with particular reference to gender. *Sociology*, *36*(1), 107–126. https://doi.org/10.1177/0038038502036001006

Segal, Z. V. (1988). Appraisal of the self-schema construct in cognitive models of depression. *Psychological Bulletin*, *103*, 147–162. https://doi.org/10.1037/0033-2909.103.2.147

Semino, E., & Demjén, Z. (2017). The cancer card: Metaphor, intimacy, and humor in online interactions about the experience of cancer. In B. Hampe, *Metaphor: Embodied cognition and discourse*. Cambridge University Press.

Sevón, E. (2012). ‘My life has changed, but his life hasn’t’: Making sense of the gendering of parenthood during the transition to motherhood. *Feminism & Psychology*, *22*(1), 60–80. https://doi.org/10.1177/0959353511415076

Shapiro, C. L. (2018). Cancer survivorship. *The New England Journal of Medicine*, *379*(25), 2438–2450. https://doi.org/10.1056/NEJMra1712502

Sharp, K., Tillery, R., Long, A., Wang, F., Pan, H., & Phipps, S. (2022). Trajectories of resilience and posttraumatic stress in childhood cancer: Consistency of child and parent outcomes. *Health Psychology*, *41*, 256–267. https://doi.org/10.1037/hea0001132

Siegel, R., DeSantis, C., Virgo, K., Stein, K., Mariotto, A., Smith, T., Cooper, D., Gansler, T., Lerro, C., Fedewa, S., Lin, C., Leach, C., Cannady, R. S., Cho, H., Scoppa, S., Hachey, M., Kirch, R., Jemal, A., & Ward, E. (2012). Cancer treatment and survivorship statistics, 2012. *CA: A Cancer Journal for Clinicians*, *62*(4), 220–241. https://doi.org/10.3322/caac.21149

Signorelli, C., Fardell, J. E., Wakefield, C. E., Webber, K., & Cohn, R. J. (2016). The cost of cure: Chronic conditions in survivors of child, adolescent, and young adult cancers. *Cancer and Chronic Conditions: Addressing the Problem of Multimorbidity in Cancer Patients and Survivors*, 371–420. https://doi.org/10.1007/978-981-10-1844-2_13

Signorelli, C., Wakefield, C. E., Fardell, J. E., Wallace, W. H. B., Robertson, E. G., McLoone, J. K., & Cohn, R. J. (2017). The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Critical Reviews in Oncology/Hematology*, *114*, 131–138. https://doi.org/10.1016/j.critrevonc.2017.04.007

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*, 34–42. https://doi.org/10.1016/j.ejon.2016.03.002

Skinner, R., Wallace, W. H. B., & Levitt, G. A. (2006). Long-term follow-up of people who have survived cancer during childhood. *The Lancet Oncology*, *7*(6), 489–498. https://doi.org/10.1016/S1470-2045(06)70724-0

Smith, K. C., Klassen, A. C., Coa, K. I., & Hannum, S. M. (2016). The salience of cancer and the 'survivor' identity for people who have completed acute cancer treatment: A qualitative study. *Journal of Cancer Survivorship: Research and Practice*, *10*(3), 457–466. https://doi.org/10.1007/s11764-015-0489-0

Spector, L. G., Pankratz, N., & Marcotte, E. L. (2015). Genetic and nongenetic risk factors for childhood cancer. *Pediatric Clinics of North America*, *62*(1), 11–25. https://doi.org/10.1016/j.pcl.2014.09.013

Staba Hogan, M.-J., Ross, W. L., Balsamo, L., Mitchell, H.-R., & Kadan-Lottick, N. S. (2018). Parental perception of child vulnerability in childhood cancer survivors. *Pediatric Blood & Cancer*, *65*(11), e27364. https://doi.org/10.1002/pbc.27364

Stam, H., Grootenhuis, M. A., Brons, P. P. T., Caron, H. N., & Last, B. F. (2006). Health-related quality of life in children and emotional reactions of parents following completion of cancer treatment. *Pediatric Blood & Cancer*, *47*(3), 312–319. https://doi.org/10.1002/pbc.20661

Staneva, A. A., Gibson, A. F., Webb, P. M., & Beesley, V. L. (2018). The imperative for a triumph-over-tragedy story in women's accounts of undergoing chemotherapy for ovarian cancer. *Qualitative Health Research*, *28*(11), 1759–1768. https://doi.org/10.1177/1049732318778261

Statistics New Zealand. (2004). *New Zealand: An Urban/Rural Profile Update*. http://archive.stats.govt.nz/browse_for_stats/Maps_and_geography/Geographic-areas/urban-rural-profile-update.aspx

Stein, K. D., Syrjala, K. L., & Andrykowski, M. A. (2008). Physical and psychological long-term and late effects of cancer. *Cancer*, *112*(11), 2577–2592. https://doi.org/10.1002/cncr.23448

Steinberg, D. L. (2015). The bad patient: Estranged subjects of the cancer culture. *Body & Society*, *21*(3), 115–143. https://doi.org/10.1177/1357034X15586240

Stuber, M. L. (2006). Posttraumatic stress and posttraumatic growth in childhood cancer survivors and their parents. In R. T. Brown, *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach*. Oxford University Press.

Stuber, M. L., Kazak, A. E., Meeske, K., Barakat, L., Guthrie, D., Garnier, H., Pynoos, R., & Meadows, A. (1997). Predictors of posttraumatic stress symptoms in childhood cancer survivors. *Pediatrics*, *100*(6), 958–964. https://doi.org/10.1542/peds.100.6.958

Sullivan, M., Bouffet, E., Rodriguez-Galindo, C., Luna-Fineman, S., Khan, M. S., Kearns, P., Hawkins, D. S., Challinor, J., Morrissey, L., Fuchs, J., Marcus, K., Balduzzi, A., Basset-Salom, L., Caniza, M., Baker, J. N., Kebudi, R., Hessissen, L., Sullivan, R., Pritchard-Jones, K., & Authors, C. (2020). The COVID-19 pandemic: A rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global. *Pediatric Blood & Cancer*, *67*(7), e28409. https://doi.org/10.1002/pbc.28409

Suppiah, R., Patton, M. A., & McGrath, P. (2005). Re-entering life: Paediatric acute myeloid leukaemia at one year post treatment. *The Australian Journal of Holistic Nursing*, *12*(2), 23–34. https://doi.org/10.3316/informit.492140704675733

Swain, J. (2018). A hybrid approach to thematic analysis in qualitative research: Using a practical example. *Sage Research Methods*. http://doi.org/10.4135/9781526435477

Syse, A., Loge, J. H., & Lyngstad, T. H. (2010). Does childhood cancer affect parental divorce rates? A population-based study. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *28*(5), 872–877. https://doi.org/10.1200/JCO.2009.24.0556

Te Aho o Te Kahu. (2021). *He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020*. Cancer Control Agency. https://teaho.govt.nz/

Tedeschi, R., & Calhoun, L. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, *15*(1), 1–18. https://doi.org/10.1207/s15327965pli1501_01

Terry, G. (2010). *'It's such a pathetic little operation': Men, masculinities and vasectomy in New Zealand* [Doctoral Thesis]. University of Auckland.

Tillery, R., Long, A., & Phipps, S. (2014). Child perceptions of parental care and overprotection in children with cancer and healthy children. *Journal of Clinical Psychology in Medical Settings*, *21*(2), 165–172. https://doi.org/10.1007/s10880-014-9392-5

Tomich, P. L., & Helgeson, V. S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology*, *23*, 16–23. https://doi.org/10.1037/0278-6133.23.1.16

Turner, B. S. (1995). *Medical Power and Social Knowledge*. SAGE.

Van der Kolk, B. A. (2003). Psychobiology of posttraumatic stress disorder. In *Textbook of Biological Psychiatry* (pp. 319–344). John Wiley & Sons, Ltd. https://doi.org/10.1002/0471468975.ch11

Van der Kolk, B. A. (2014). *The Body Keeps the Score: Mind, Brain and Body in the Transformation of Trauma*. Penguin UK.

Van Dongen-Melman, J. E. W. M., Van Zuuren, F. J., & Verhulst, F. C. (1998). Experiences of parents of childhood cancer survivors: A qualitative analysis. *Patient Education and Counseling*, *34*(3), 185–200. https://doi.org/10.1016/S0738-3991(98)00031-7

van Warmerdam, J., Zabih, V., Kurdyak, P., Sutradhar, R., Nathan, P. C., & Gupta, S. (2019). Prevalence of anxiety, depression, and posttraumatic stress disorder in parents of children with cancer: A meta-analysis. *Pediatric Blood & Cancer*, *66*(6), e27677. https://doi.org/10.1002/pbc.27677

Vance, Y. H., Eiser, C., & Horne, B. (2004). Parents' views of the impact of childhood brain tumours and treatment on young people's social and family functioning. *Clinical Child Psychology and Psychiatry*, *9*, 271–288. https://doi.org/10.1177/1359104504041923

Vannatta, K., & Salley, C. (2017). Pediatric cancer. In R. G. Steele & M. C. Roberts, *Handbook of Pediatric Psychology* (5th ed., pp. 284–297). The Guilford Press.

Vetsch, J., Fardell, J. E., Wakefield, C. E., Signorelli, C., Michel, G., McLoone, J. K., Walwyn, T., Tapp, H., Truscott, J., & Cohn, R. J. (2017). "Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care. *Patient Education and Counseling*, *100*(2), 355–363. https://doi.org/10.1016/j.pec.2016.09.013

Vrinten, C., McGregor, L. M., Heinrich, M., von Wagner, C., Waller, J., Wardle, J., & Black, G. B. (2017). What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. *Psycho-Oncology*, *26*(8), 1070–1079. https://doi.org/10.1002/pon.4287

Wakefield, C. E., Butow, P., Fleming, C. A. K., Daniel, G., & Cohn, R. J. (2012). Family information needs at childhood cancer treatment completion. *Pediatric Blood & Cancer*, *58*(4), 621–626. https://doi.org/10.1002/pbc.23316

Wakefield, C. E., McLoone, J., Butow, P., Lenthen, K., & Cohn, R. J. (2013). Support after the completion of cancer treatment: Perspectives of Australian adolescents and their families. *European Journal of Cancer Care*, *22*(4), 530–539. https://doi.org/10.1111/ecc.12059

Wakefield, C. E., McLoone, J., Goodenough, B., Lenthen, K., Cairns, D. R., & Cohn, R. J. (2010). The psychosocial impact of completing childhood cancer treatment: A systematic review of the literature. *Journal of Pediatric Psychology*, *35*(3), 262–274. https://doi.org/10.1093/jpepsy/jsp056

Wakefield, C. E., McLoone, J. K., Butow, P., Lenthen, K., & Cohn, R. J. (2011). Parental adjustment to the completion of their child's cancer treatment. *Pediatric Blood & Cancer*, *56*(4), 524–531. https://doi.org/10.1002/pbc.22725

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), 602–621. https://doi.org/10.1080/07347332.2014.936653

Wakefield, C. E., Sansom-Daly, U. M., McGill, B. C., Ellis, S. J., Doolan, E. L., Robertson, E. G., Mathur, S., & Cohn, R. J. (2016). Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade". *Supportive Care in Cancer*, *24*(6), 2685–2694. https://doi.org/10.1007/s00520-016-3077-6

Wakefield, C. E., Sansom-Daly, U. M., McGill, B. C., Hetherington, K., Ellis, S. J., Robertson, E. G., Donoghoe, M. W., McCarthy, M., Kelada, L., Girgis, A., King, M., Grootenhuis, M., Anazodo, A., Patterson, P., Lowe, C., Dalla-Pozza, L., Miles, G., & Cohn, R. J. (2021). Providing psychological support to parents of childhood cancer survivors: 'Cascade' intervention trial results and lessons for the future. *Cancers*, *13*(22), 5597. https://doi.org/10.3390/cancers13225597

Wakefield, C. E., Sansom-Daly, U. M., McGill, B. C., McCarthy, M., Girgis, A., Grootenhuis, M., Barton, B., Patterson, P., Osborn, M., Lowe, C., Anazodo, A., Miles, G., & Cohn, R. J. (2015). Online parent-targeted cognitive-behavioural therapy intervention to improve quality of life in families of young cancer survivors: Study protocol for a randomised controlled trial. *Trials*, *16*(1), 153. https://doi.org/10.1186/s13063-015-0681-6

Walling, E. B., Fiala, M., Connolly, A., Drevenak, A., & Gehlert, S. (2019). Challenges associated with living remotely from a pediatric cancer center: A qualitative study. *Journal of Oncology Practice*, *15*(3), e219–e229. https://doi.org/10.1200/JOP.18.00115

Ward, E., DeSantis, C., Robbins, A., Kohler, B., & Jemal, A. (2014). Childhood and adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, *64*(2), 83–103. https://doi.org/10.3322/caac.21219

Wasilewski-Masker, K., Liu, Q., Yasui, Y., Leisenring, W., Meacham, L. R., Hammond, S., Meadows, A. T., Robison, L. L., & Mertens, A. C. (2009). Late recurrence in pediatric cancer: A report from the Childhood Cancer Survivor Study. *JNCI: Journal of the National Cancer Institute*, *101*(24), 1709–1720. https://doi.org/10.1093/jnci/djp417

Weaver, R., O’Connor, M., Carey Smith, R., Sheppard, D., & Halkett, G. K. B. (2021). “We’re on a merry-go-round”: Reflections of patients and carers after completing treatment for sarcoma. *Current Oncology*, *28*(4), Article 4. https://doi.org/10.3390/curroncol28040263

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), 2109–2117. https://doi.org/10.1002/pon.4313

Wijnberg-Williams, B. J., Kamps, W. A., Klip, E. C., & Hoekstra-Weebers, J. E. H. M. (2006). Psychological adjustment of parents of pediatric cancer patients revisited: Five years later. *Psycho-Oncology*, *15*(1), 1–8. https://doi.org/10.1002/pon.927

Wikman, A., Ljungman, L., Pingel, R., Hagedoorn, M., Sanderman, R., von Essen, L., & Cernvall, M. (2017). The interdependence of posttraumatic stress symptoms in parental dyads during and after their child's treatment for cancer. *Acta Oncologica*, *56*(12), 1698–1704. https://doi.org/10.1080/0284186X.2017.1355562

Wilford, J. G., 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*(4), 913–919. https://doi.org/10.1002/pon.5042

Wilkins, K. L., D'Agostino, N., Penney, A. M., Barr, R. D., & Nathan, P. C. (2014). Supporting adolescents and young adults with cancer through transitions: Position statement from the Canadian Task Force on Adolescents and Young Adults with cancer. *Journal of Pediatric Hematology/Oncology*, *36*(7), 545–551. https://doi.org/10.1097/MPH.0000000000000103

Wilson, S. (2007). 'When you have children, you're obliged to live': Motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness*, *29*(4), 610–626. https://doi.org/10.1111/j.1467-9566.2007.01008.x

Wong, M., & Chan, S. (2006). The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing*, *15*(6), 710–717. https://doi.org/10.1111/j.1365-2702.2006.01297.x

Woodgate, R. L. (2006). Life is never the same: Childhood cancer narratives. *European Journal of Cancer Care*, *15*(1), 8–18. https://doi.org/10.1111/j.1365-2354.2005.00614.x

Wright, L., Afari, N., & Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports*, *13*(2), 133–138. https://doi.org/10.1007/s11916-009-0023-z

Yalom, I. (1989). Existential psychotherapy. In *Current psychotherapies* (pp. 363–402). Cengage Learning.

Yeh, C. H. (2003). Dynamic coping behaviors and process of parental response to child's cancer. *Applied Nursing Research*, *16*(4), 245–255. https://doi.org/10.1053/S0897-1897(03)00054-5

Yeh, C.-H. (2003). Dynamic coping behaviors and process of parental response to child's cancer. *Applied Nursing Research: ANR*, *16*(4), 245–255. https://doi.org/10.1016/s0897-1897(03)00054-5

Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science & Medicine (1982)*, *55*(10), 1835–1847. https://doi.org/10.1016/s0277-9536(01)00318-5

Young, B., Dixon-Woods, M., & Heney, D. (2002). Identity and role in parenting a child with cancer. *Pediatric Rehabilitation*, *5*(4), 209–214. https://doi.org/10.1080/1363849021000046184

Zebrack, B. J. (2000). Cancer survivor identity and quality of life. *Cancer Practice*, *8*(5), 238–242. https://doi.org/10.1046/j.1523-5394.2000.85004.x

Appendix A: Descriptive Statistics from the Preliminary Scoping Survey

Table 3

Descriptive Statistics for the Survey Responses Assessing Desire for a Psychosocial Programme (n=90)

Characteristics of Parents/Caregivers	*n* (% of sample)
Gender Identity	
Male	6 (6.7%)
Female	84 (93.3%)
Ethnicity	
NZ European	65 (62.5%)
Māori	16 (15.4%)
Pasifika	6 (5.8%)
Chinese	0 (0.0%)
Indian	3 (2.9%)
Other	14 (13.5%)
Geographic Region	
Auckland	29 (32.2%)
Canterbury	14 (15.6%)
Waikato	10 (11.1%)
Wellington	10 (11.1%)
Bay of Plenty	5 (5.6%)
Gisborne	4 (4.4%)
Northland	4 (4.4%)
Hawkes Bay	3 (3.3%)
Manawatu-Wanganui	3 (3.3%)
Otago	3 (3.3%)
Marlborough	2 (2.2%)
Nelson	1 (1.1%)
Southland	1 (1.1%)
Taranaki	1 (1.1%)
Time Since Treatment Completion	
Still on treatment	8 (8.9%)
0-12 months	22 (24.4%)
1-2 years	18 (20.0%)
2-3 years	14 (15.6%)
3-4 years	8 (8.9%)
4-5 years	2 (2.2%)
5-6 years	6 (6.7%)
6-7 years	3 (3.3%)
7-8 years	4 (4.4%)
8-9 years	1 (1.1%)
9-10 years	0 (0.0%)
10+ years	4 (4.4%)
Interested in the Cascade Study	
Yes	66 (73.3%)
Maybe	20 (22.2%)
No	4 (4.4%)

Appendix B: Study Information Sheet

Study Information Sheet

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

Exploring the Experiences of Parents in their Child's Cancer Survivorship

INFORMATION SHEET

Kia ora,

Introduction

As a parent/caregiver of a child who has completed cancer treatment, would you like to share your experiences of your child's cancer journey? If so, I would like to invite you to participate in this interview study about the experiences of parents after their child's cancer treatment.

My name is Olivia Jennison, and I am a Doctor of Clinical Psychology student at Massey University, Albany. My supervisors are Dr Kirsty Ross (Senior Clinical Psychologist & Senior Lecturer) and Dr Kathryn McGuigan (Lecturer), also from the School of Psychology, Massey University.

Why is this research being done?

The purpose of this study is to explore and understand the experiences of parents/caregivers after their child's cancer treatment, particularly in the long-term survivorship period. The findings from this study hope to inform and improve how support is provided to parents/caregivers of child cancer survivors. You have been invited to participate in this study because you are a parent/caregiver of a child who has completed cancer treatment.

Who can take part in the study?

Eligible participants will:

a) Be a parent of a child who has completed active cancer treatment and who is at least 5-years post-diagnosis
b) Not currently have a child in palliative care or on active cancer treatment

The details of this project have been sent out via Child Cancer Foundation. It is estimated that 10-15 participants will be needed for the study.

What would participation in the study involve?

If you fulfil the requirements above and are willing to participate, you will be asked to take part in a one-to-one interview. I expect the interview to last approximately 60 minutes. Your participation in the interview is voluntary and will be confidential. The interview will take place over Zoom; if you are based in the Auckland region, your interview can take place over Zoom, or in-person at a safe and accessible place (e.g. a private room in a library), at a time that is convenient for you.

In the interview, I would ask you open-ended questions about your child's cancer story, your experiences since the end of your child's cancer treatment, your experiences in the context of Covid-19, and your thoughts on support services/ programmes.

You will be gifted a $30 petrol or groceries voucher as a token of appreciation for your time. In the event you would like to seek further support or discuss your experiences further, you will be directed towards available support services offered by Child Cancer Foundation or other relevant counselling services.

What will happen to information about me?
The interview will be audio recorded. This recording of your interview will be stored in a secure location and will only be able to be accessed by myself and my supervisors. No names or other identifying information will be linked to the stored data. I will transcribe the audio recordings word for word. To protect your privacy and confidentiality, the recorded interviews will be destroyed once the transcription is complete. The transcriptions will remain securely stored for 5 years and then disposed of safely.

If you wish, you will be sent a copy of the transcript from our interview for editing. Attached will be an Authority for Release of Transcript consent form. I would like to use quotes from your interview in my thesis/ report; however, no identifying information (e.g. names, rare diagnoses) will be included.

How and when will I find out what the results of the research study are?
At the conclusion of the project, you will be emailed a summary of the results. The results and findings may also be published as part of my thesis, at conferences, in scientific journals, and through Child Cancer Foundation. All information will be published in a way that will not identify you.

Your rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Ask for the recorder to be turned off at any time during the interview;
- Withdraw from the study (you can withdraw up until you sign the Authority for Release Transcript form, and your decision to withdraw will not affect your relationship with Massey University or the Child Cancer Foundation);
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Be sent a summary of the project findings when it is concluded.

Ethics approval
This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 21/35. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human

Ethics Committee: Northern, telephone 09 414 0800, x 43347, email humanethicsnorth@massey.ac.nz.

Project contacts
If you would like to participate, have any questions or would like further information at any time please contact either myself or my supervisors:

Researcher:
Olivia Jennison
Doctor of Clinical Psychology Student
School of Psychology
Massey University
olivia.jennison.1@uni.massey.ac.nz

Supervisors:
Dr Kirsty Ross
Senior Clinical Psychologist & Senior Lecturer
School of Psychology
Massey University
K.J.Ross@massey.ac.nz

Dr Kathryn McGuigan
Lecturer
School of Psychology
Massey University
K.Mcguigan@massey.ac.nz

Thank you for taking the time to consider this invitation. I would greatly appreciate sharing in your story and your collaboration in this study.

Noho ora mai,

Olivia Jennison

Te Kunenga
ki Pūrehuroa
School of Psychology – Te Kura Hinengaro Tangata
Private Bag 102904, North Shore Mail Centre, Auckland 0745
T +64 9 414 0800 extn 43095 **F** +64 9 414 0831 **www.massey.ac.nz**

Appendix C: Interview Guide

Interview Guide

Child's Cancer Story

1. Can you tell me about [child's name]'s cancer story?
    - When were they diagnosed? How old were they at the time?
    - What was the diagnosis? What treatment did [child's name] undergo?
    - When did they finish cancer treatment? How long ago?

Survivorship Meaning

2. Do you consider [child's name] to be a cancer survivor?

Experiences of Survivorship

3. Could you describe your experiences since [child's name] finished cancer treatment?
    - Emotionally (hinengaro)
    - Physically (tinana)
    - Relationships (whanāu)
    - Spiritually (wairua)
    - Financially
    - Socially
4. What and how have things changed since your child finished cancer treatment? (e.g. roles, home, caring tasks, working/ staying home, family relationships)
5. How has the cancer experience impacted you today?
6. What kind of support have you and your family had since your child finished cancer treatment?

Covid-19

7. Could you describe your experiences of Covid-19 (the pandemic itself, resulting national restrictions, and aftermath) within the context of your child's survivorship?

Looking to the Future

8. How do you think survivorship experiences for parents could be improved?
    - What kind of support do you wish parents would receive after their child's cancer treatment?
9. What are your hopes for the future?

Background Information

- Participant's age, gender, ethnicity, and relationship status
- Current age and gender of child in survivorship
- Child's diagnosis, date of diagnosis, type of treatment, end of treatment
- Relationship to child in survivorship (e.g. mother/ father/ grandmother etc.)
- No. of children in the family

Final Thoughts

10. Just before we finish up, I was wondering if there was anything else we haven't covered or is there anything I haven't thought to ask?

Appendix D: Research Case Study

As part of the requirements for the Doctor of Clinical Psychology, candidates include a ‘Research Case Study’ in the appendices of the thesis, and this is examined as part of the clinical component of the doctorate. This case study presents my learnings from the doctoral research and how these learnings contributed to my development as an intern psychologist. The case study is included below.

Massey University
Clinical Psychology

CASE STUDY 2

Reflections from my Doctoral Research and How it Contributed to my Clinical Practice during my Internship at Maternal Mental Health

Candidate : Olivia Jennison
Clinical Psychology Programme Massey University
Student ID : [redacted]
Setting : Maternal Mental Health, Counties Manukau DHB
Supervisors : Anna Hawkins & Meggan Lam

This case was completed during internship at Maternal Mental Health, Counties Manukau DHB in 2022 and represents the work of the candidate

---

Supervisor

Kirsty Ross
Senior Clinical Psychologist & Senior Lecturer
Massey University

KRoss

Student

Olivia Jennison
Intern Psychologist
[redacted]

Date : 18 May 2022

Abstract

This case study comprises my main reflections on what I have learnt whilst conducting the research component of my clinical psychology training, and how this has subsequently contributed to my development as an intern psychologist at Maternal Mental Health, Counties Manukau DHB. The present work begins with a summary of my doctoral research on the experiences of parents/caregivers in the long-term after their child's cancer treatment. This is followed by three main reflections I have discovered from my research and how they apply to and enhance my clinical practice. Firstly, I reflect on working clinically and in my research with parents, and I consider my own position of having an 'outsider' identity in not being a parent myself. Within this, I discuss how working therapeutically with those who have different experiences from my own has been both challenging and enlightening. Secondly, I examine how societal expectations of joyous experiences (i.e. becoming a parent or successfully completing cancer treatment) can silence voices and muffle experiences that do not conform to this societal template. Thirdly, I discuss the power of endings with recognising my own personal assumptions of endings as challenging, and the value of giving time and space to endings in therapy to allow for a validating and meaningful experience.

Research Case Study

Clinical psychology training is based on the scientist-practitioner model, whereby emphasis is placed on psychologists being knowledgeable in both research and clinical practice (Jones & Mehr, 2007). This model is an approach that integrates science and practice where each continually informs the other (Jones & Mehr, 2007). This means that a clinical psychologist's formulations and treatment approaches are based on strong theoretical underpinnings which ensures that clients receive effective psychological support that is empirically supported. My doctoral research addressed a gap in the literature by exploring the experiences of parents/caregivers in the long-term after their child's cancer treatment. This study enhanced my research skills and my understanding of the application of psychological research. The following case study presents my reflections and learnings from the research process during the Doctor of Clinical Psychology and how this has enhanced my clinical practice during my internship. This case study begins with an outline of my doctoral thesis including aims, methods, and findings. This is followed by an exploration of the three main reflections I had from the research and how these applied to my clinical practice and growth as an intern psychologist.

Doctoral Research Overview

My doctoral research qualitatively explored the experiences of parents/caregivers in the long-term after their child had completed cancer treatment. The following section presents an overview of the aims, methodology, and findings of the doctoral research. This overview of the research provides context for the reflections on how the research contributed to my development as an intern psychologist.

Study Rationale and Aims

Due to medical advancements, the prognosis of childhood cancer has substantially improved (Ballantine & NZCCR Working Group, 2017). While this is a celebrated milestone, this also raises the question of the long-term impact of childhood cancer on those affected. The childhood cancer experience affects not only the child but also the entire family, including parents/caregivers. For parents/caregivers supporting a child through treatment for cancer, a life-threatening illness, may be one of the most emotionally distressing and physically draining challenges they could face (Pai et al., 2007). Then after their child's cancer treatment, it is clear that there is a subgroup of parents/caregivers who continue to report high psychological distress (Carlsson et al., 2019). Yet, it is not clear why some parents/caregivers continue to experience distress, and little is known about the experiences of parents/caregivers in the long-term after their child's cancer treatment. Instead, most of the literature has focused on the treatment period and early transitional period to life after cancer treatment. The long-term parental experience has historically been invisible due to the cancer being considered biomedically 'cured' and due to public discourse which highlights the successful completion of cancer treatment as a joyous period of 'triumph' and 'heroism'.

An exploration into parental experiences in the long-term therefore formed the basis for my doctoral research. This research aimed to richly explore parental experiences to understand the complexities and nuances from the ground-up, letting participants discuss experiences that were meaningful to them to better understand the construction of experiences. The exploratory research question the study sought to answer was: *"What are the long-term experiences of parents/caregivers after the completion of their child's cancer treatment?"*. This research was designed to contribute to the psycho-oncology literature on the long-term experiences of parents/caregivers, particularly within an Aotearoa New Zealand context.

Methodology

A qualitative approach was utilised through semi-structured interviews to address the exploratory research question. A qualitative design was utilised in response to both the scarcity of qualitative research and to allow for the opportunity to capture the nuances and complexities in parental experiences during this long-term period after their child's cancer treatment. Qualitative methods offer a way of collecting rich and diverse data to account for the multiple realities of experiences, as well as providing a contextual backdrop to participants' experiences (Creswell & Poth, 2016).

Social constructionism was the epistemology that best supported the objectives of the research. This research was not attempting to uncover one universal truth; instead, it recognised that truth is socially constructed. The study's focus on participants' experiences and the context in which their meaning-making took place aligned with a social constructionist epistemology. Further, the changing understanding and the societal constructions of cancer and parental experiences means that experiences and meanings of the cancer experience are heavily influenced by the social context in which we find ourselves. The requirement for a social constructionist epistemology became evident when exploring contemporary understandings of childhood cancer, demonstrating that it was impossible to disentangle social context from the experiences of parents/caregivers after their child's cancer treatment. Thus, a qualitative approach allowed this research to gain a holistic understanding of participants' experiences while taking into account how their social contexts influence and construct their reality.

Data Collection. This doctoral research comprised of ten parents/caregivers of a child who had been diagnosed with cancer at least five years ago and who had completed cancer treatment. The eligibility criteria for participants were that they would a) be a parent or caregiver of a child who completed active cancer treatment and who is at least five years post-diagnosis, and b) not currently have a child in palliative care or on active treatment. Each of the ten parents/caregivers was a biological relation (mother, father, or grandmother) of a child who had undergone a course of cancer treatment (surgery, radiation, and/or chemotherapy). Participants ranged from 37 to 61 years old at the time of the interview, and identified as female, aside from one participant who identified as male. Participants identified themselves as New Zealand European (n=9), South African (n=1), and Māori/New Zealand European (n=1). The children of the participants were between the ages of 1 and 8 years old during treatment and two of the participants' children relapsed after completing a course of cancer treatment. At the time of the interviews, all the participants' children had completed their cancer treatment and they had no evidence of disease. The time between the interview and the participants' child's diagnoses ranged from 5 to 34 years ago. The children had been diagnosed with a variety of different types of childhood cancer, including leukaemia (n=8), neuroblastoma (n=1), and soft tissue sarcoma (n=1).

Participants were recruited through advertisements circulated on Child Cancer Foundation's social media and other social media pages. Semi-structured interviews were utilised to explore and understand participants' stories regarding their child's cancer story and their experiences since the end of their child's cancer treatment. Under a social constructionist framework, the interview is a space of meaning-making between individuals where the interviewer and participant collaboratively construct knowledge (Holstein & Gubrium, 2008). The interview topics were developed to allow participants to tell their own story of their child's cancer, while also capturing the holistic nature of wellbeing. The interviews were collaborative and conversational in nature. This allowed for the participant and interviewer to work together in illuminating meaning from the stories that were shared.

Data Analysis. The data analysis aimed to explore the long-term experiences of parents/caregivers after their child's cancer treatment. More specifically, I hoped to discover and generate insights into the meaning-making, identity construction, and survivorship discourses within their experiences.

The data was analysed with a reflexive thematic analysis to generate central themes, patterned data, and unique meanings of participants' experiences. Braun and Clarke's (2006) six phases method of reflexive thematic analysis was followed. This approach went beyond identifying themes to offering rich interpretations of the significance, meaning, and implications from the patterns identified in the data (Braun & Clarke, 2021).

Findings

The findings from this research elucidated the powerful presence the cancer experience had on the lives of parents/caregivers years after their child's cancer treatment. Findings indicated that parents/caregivers experienced long-lasting and definitive changes as a result of the experience of their child's cancer. The central organising concept of the accounts was *The Cancer Experience Remains With You*. This spoke to the significant and permanent changes across a range of aspects of life that happen for parents/caregivers due to their experience of their child's cancer. This led to three themes being produced under the central organising concept. These themes were: *Views about One's Self, Views about the World,* and *Views about the Future.* The subthemes under *Views about One's Self* were: 1) identity; 2) purpose and meaning; and 3) suffering from memories. The subthemes under *Views about the World* were: 1) isolation; 2) connection; and 3) vulnerability. The subthemes under *Views about the Future* were: 1) uncertainty; and 2) loss of an imagined future. The findings illustrated how participants experienced changes in their self-concept and biography as well as disruptions in their relationships in and assumptions of the world, and expectations for the future.

Clinical Psychology Internship

My clinical psychology internship began in March 2022 with Maternal Mental Health in Counties Manukau DHB. The Maternal Mental Health service is for women across the Counties Manukau region who are experiencing moderate to severe mental health distress during the perinatal period (pregnancy and up to one year after having a baby). The following reflections were made during my internship and are related to learnings from my doctoral research. These reflections include therapeutically working with those whose experiences differ from my own, the silence of distress in the face of societal pressures, and the value of endings in therapy.

'Outsider' Identity

My doctoral research was positioned under a social constructionist framework, which recognises the active contribution of the researcher in the process of meaning-making and co-construction of knowledge (Kim, 2006). Therefore, it is understood that making sense of data will include some projection from the researcher, and as such, my own experiences, assumptions, and biases played a role in how I perceived the data (Rapmund & Moore, 2000). In this way, it was important in my research to acknowledge the personal biases that may have arisen because of my own experiences, particularly due to not being a parent and not being personally affected by childhood cancer.

As an 'outsider' to being a parent, I needed to be aware of my role in the research. During my interviews with research participants, I recognised my own internal self-doubt about not being a parent myself and the resulting feeling of imposter syndrome. I felt myself projecting this transference in thinking that my participants may assume my lack of understanding due to my age and lack of experience from not being a parent. Yet, I was surprised that none of my participants questioned me about not being a parent myself, and participants did not dismiss me for this lack of personal experience. As the interviews progressed, I gained more confidence in my position regardless of being an 'outsider' and that helped my curiosity in asking about their experiences. I felt that my positioning in the research of being an 'outsider' meant I was able to explore experiences at a deeper level by asking more questions without the taken-for-granted assumptions that occur when you are an 'insider'. Even though I was not a parent, that did not mean that I could not be empathetic with participants, and I could still build trust and validate their experiences. While I was tempted at times to justify and defend my clinical and research skills in an attempt to reassure participants, I learnt that when working therapeutically with individuals who have different experiences from myself, how important it is to respect, empathise, and validate.

These learnings and this reflection of my position as an ‘outsider’ in my research were highly relevant for my work within Maternal Mental Health with women who were pregnant or mothers, as I am neither. At times in my internship, I have felt out of my depth as I have an academic understanding of the theories in attachment and bonding, yet I do not know how this experience is felt. Clients would sometimes say they felt guilt or shame around their bonding with their baby, and my naivety around this subjective experience has at times meant that I feel I do not know what to say or ask in response. Yet, as with my research, I have become aware of how being an ‘outsider’ means that I have a genuine curiosity in my exploration without projecting my own assumptions about their lived experiences. In general, I am also very open to learning about diverse experiences and know that I do not need to have the same experiences as clients in order to empathise and therapeutically work with them. I have learnt to trust more that there are two experts in the room in therapy, with the client being the expert in their own experiences, and the therapeutic relationship being about collaboratively working together. While I have not been questioned by clients about not being a parent myself, I have discussed this in clinical supervision, and I know I would approach this with honesty, exploration, and validation. I believe my doctoral research experience has helped me to self-reflect and remind myself of the value of rapport and how it is not dependant on having similar experiences with clients.

The Silence of Distress

When I first started my doctoral research, I was struck by the conflict between societal expectations of joyous experiences (successfully completing cancer treatment) and the mental health distress actually experienced by those affected. My interest in the muffling of mental health distress and the marginalisation of experiences that do not fit the template that dominant discourses create was further part of what initially drew me to this research area. In my research interviews, I was struck by how silence was woven throughout their experiences. In my findings, I described how the research participants felt isolated due to societal expectations and dominant discourses about what life was meant to look like after their child's cancer treatment. Typically, these societal discourses were incongruent with the participants' lived experiences. For many, this discrepancy between what participants perceived as what society thought they 'ought' to feel versus their 'actual' experiences led to feelings of alienation, feeling different from others, and isolation that seemed to be of an emotional nature. This research made me reflect on the association between successfully completing cancer treatment and being resilient, and how this subsequently linked to the construction of the end as an achievement.

Throughout these research interviews, there was a dominant narrative of isolation due to feeling different from others or from others' expectations of their experiences. Yet, throughout my interviews, I found myself cautious in not knowing how far to take my questioning, particularly with responses normatively considered outside of societal boundaries. For example, one participant said:

> *"I mean, probably the other thing that's changed about me since this is, I would not have children. I love my children, absolutely adore them. But oh my god like, to know that you could hurt that deeply like I had no idea."*

This participant felt deeply hurt and traumatised by her experience of her child's cancer and cancer treatment that she felt that in hindsight she would not have had children. There was a brief silence that followed this utterance, where I realised how little was said, yet how much was being communicated. I noticed how this utterance was breaking the silence from a societal taboo, and I wondered how my brief silence was being communicated. In general, throughout the interviews I found myself hesitant to follow-up on some questions; rather I found myself gently exploring while also respectfully moving the conversation on.

Further, during the research process, I became aware of how I tended to frame experiences as dichotomous, with some people's experiences of childhood cancer and its long-term impact as either difficult and traumatic or as easy and resilient. From supervision and through feedback on my written drafts, I became aware of how my language was binary and how I conceptualised experiences in this dichotomous way. This practice allowed me to recognise how experiences can be both 'good' and 'bad', and how I did not need to categorise these, rather how I could recognise the nuances and complexity within human experiences. By extension, I wonder if my dichotomising of experiences as 'good' or 'bad' reflects wider societal notions of sickness and health and the binary opposition these are placed in (Frank, 2013). In this way, recognising my tendency towards categorising experiences in these binary terms has helped me to challenge these and be more open to the complexity of experiences in the hope of lessening the silence of distress.

The silencing of mental health distress I noticed from the research interviews was also evident in my therapeutic work in my clinical psychology internship. Traditionally, there are societal expectations of pregnancy and the postpartum period as a joyous phase in life (Hoffenaar et al., 2010). Yet, I have noticed in my internship how often women communicate the silencing of their negative experiences of motherhood. Similar to my research interviews, women in the perinatal period who have experiences that deviate from social expectations describe feelings of isolation, particularly in comparing their own experiences to the imagined experiences of others. This, therefore, impacts their sense of safety in sharing negative or challenging experiences which brings feelings of shame. The amount of women in our service who have described feeling isolated further makes me wonder how many more in the community are silently suffering. Further to this, not only have I noticed the link between my research and my internship with themes of isolation, but also with themes of connection. As part of my internship, I facilitate an Acceptance and Commitment Therapy group for women experiencing anxiety during the perinatal period. In this group, many participants describe how they feel validated and reassured to hear about the experiences of other women in the group which demonstrates the importance of connecting with others to decrease their sense of isolation in the world.

Through the valuable experience I obtained from my doctoral research, I have been able to reflect on my own assumptions and challenge my ideas about the templates of lived experiences. In particular, I have been curious about how societal expectations can silence experiences of distress, particularly during times which are considered to be joyous (i.e. becoming a mum, having a child who successfully completed cancer treatment), and I believe this tension drew me to this research and my clinical psychology internship. This has given me insight into the diversity of experiences, enabled me to gently enquire and normalise a range of emotions and experiences, and I have learnt to allow opportunities for individuals to discuss experiences which do not fit the mould created by society. Finally, I have learnt about the importance of clients having opportunities for social connection to feel less alone in their experiences.

The Power of Endings

My doctoral research explored the long-term impact on parents/caregivers after the end of their child's cancer treatment. Through my findings, I challenged the idea of 'the end' as finite in light of how there was a continuous impact from the cancer experience. During this research, I reflected on my own perception of 'endings'. I came into this research with the assumption that endings mean change which brings feelings of loss and sadness. The significant change, adjustment and trauma that I imagined to be inherent in endings within childhood cancer treatment further drew me to this research. Through engaging with the paediatric psycho-oncology literature, I noticed how much of the literature perceived endings in cancer as negative with a focus on distress and maladjustment, rather than on coping or narratives of resilience. My own assumptions of endings as being difficult and my readings of the literature on traumatic experiences at the end of cancer treatment made me cognizant that I also could be biased towards exploring the negative or difficult aspects of endings within an individual's experience. Throughout the interviews, I tried to gain a holistic understanding of participants' experiences, rather than focusing on distress and negative consequences. This has helped me in my clinical practice by trying to attend not only to the trauma and difficulty within experiences but also to elicit strengths and experiences of resilience to better formulate and understand the person before me.

During my research interviews, I was struck by how often participants discussed invalidating experiences with healthcare professionals when their child was in cancer treatment, and how these interactions left their mark many years after treatment was completed, with some participants being able to recount the exact words that were said to them. Participants discussed not feeling heard and I wondered if their reason for accepting a research interview was to have this need met and to feel heard and validated. Further, many participants described how they felt that the end of their child's cancer treatment was not handled well, they said they felt like they had been 'dropped' with a sudden lack of support while figuring out how to cope and navigate life after cancer treatment. Participants spoke about the importance of being well informed and how they appreciated transparent communication in the improvement of their experiences. Reflecting on this was necessary for my internship in considering my interactions with clients and how to facilitate a trusting and therapeutic relationship. This has made me aware of the way that clients may view me, and my role as a healthcare clinician, as well as how I ease into the ending of therapy.

This doctoral research highlighted for me both the importance of validation and the value of endings in therapy. During my clinical psychology training the importance of endings in therapy has been emphasised, yet, through this research, I have seen just how important the role of endings is. This has made me think about the meaning of endings in therapy and made me think about giving endings a bit more time and space. There is the concept that within some therapeutic approaches you should be planning for the end from the very beginning (Beck & Beck, 2020). As I reflect on my doctoral research and my clinical practice I see that the attention I give endings in therapy has increased and I have called on supervision to explore how to close relationships in an appropriate way. The goal of therapy is for it to end and for the client to have the skills to be their own therapist. In this way, I have found that the end is an impactful part of the therapy. During my internship, I have found that asking clients how they had found our therapeutic work together is insightful into their learnings and how they have found this process as well as evaluating their readiness for ending therapy.

Summary

My doctoral research has greatly contributed to my development as an intern psychologist. The interviews I had with parents/caregivers about their experiences after their child's cancer treatment, and the reflections on the research process and my own position as an intern and a researcher, have been invaluable in improving my skills as a scientist-practitioner in my internship. Through my research and internship, I have been able to connect with those who have different experiences from my own, critically examine my own assumptions and allow room for experiences that may be silenced due to societal pressures, and consider the importance of endings in therapy to allow for empowerment and validation. Altogether, these learnings have enhanced my ability to build therapeutic relationships with clients in my internship. I believe that through this research process and through my clinical psychology internship, I am building a strong foundation from which to continuously grow as a psychologist.

References

Ballantine & NZCCR Working Group. (2017). Childhood Cancer Survival in New Zealand 2005-2014: A Report from the New Zealand Children’s Cancer Registry. *National Child Cancer Network.*

Beck, J. S., & Beck, A. T. (2020). *Cognitive Behavior Therapy, Third Edition: Basics and Beyond*. Guilford Publications. http://ebookcentral.proquest.com/lib/massey/detail.action?docID=6335114

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & Essen, L. von. (2019). Psychological distress in parents of children treated for cancer: An explorative study. *PLOS ONE*, *14*(6), e0218860. https://doi.org/10.1371/journal.pone.0218860

Creswell, J. W., & Poth, C. N. (2016). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. SAGE Publications.

Frank, A. W. (2013). *The Wounded Storyteller: Body, Illness, and Ethics, Second Edition*. University of Chicago Press.

Hoffenaar, P. J., van Balen, F., & Hermanns, J. (2010). The Impact of Having a Baby on the Level and Content of Women’s Well-Being. *Social Indicators Research*, *97*(2), 279–295. https://doi.org/10.1007/s11205-009-9503-0

Holstein, J. A., & Gubrium, J. F. (2008). *Handbook of Constructionist Research*. Guilford Press.

Jones, J. L., & Mehr, S. L. (2007). Foundations and Assumptions of the Scientist-Practitioner Model. *American Behavioral Scientist*, *50*(6), 766–771. https://doi.org/10.1177/0002764206296454

Kim, K. (2006). *The Social Construction of Disease: From Scrapie to Prion*. Routledge. https://doi.org/10.4324/9780203008256

Pai, A. L. H., Greenley, R. N., Lewandowski, A., Drotar, D., Youngstrom, E., & Peterson, C. C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology: JFP: Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, *21*(3), 407–415. https://doi.org/10.1037/0893-3200.21.3.407

Rapmund, V., & Moore, C. (2000). Women’s stories of depression: A constructivist approach. *South African Journal of Psychology*, *30*(2), 20–30. https://doi.org/10.10520/EJC98080