Supporting Whānau Through Child Cancer:
An Evaluation of the Child Cancer Counselling Network

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Abstract

Purpose

Child cancer can be considered to be a chronic traumatic event that challenges the functioning of the entire family unit. Whilst families may be well supported by medical teams and support services in hospital, there is often a lack of appropriate psychological support available in the community for those who prefer external support or whose child is not undergoing active treatment. In addition, research investigating the impact of counselling on child cancer parents is scarce. The purpose of this study was to contribute to an evaluation of the innovative Child Cancer Counselling Network (CCCN). In partnership with the Child Cancer Foundation, the CCCN provides free specialised counselling support across Aotearoa New Zealand either in-person or online, available to whānau at any point during their cancer journey.

Method

To evaluate the CCCN from parents' perspectives, seven semi-structured interviews were carried out with child cancer mothers who had accessed the counselling. The resulting qualitative data was thematically analysed.

Results

Five major themes were found. '*The Educated Outsider'* and '*A Safe Space',* described qualities of ideal social support for child cancer families and what counselling was able to provide that their social networks and treatment centre could not. '*Breaking Stigmas'* and '*Optimising Access'* outlined ways that access to support services could be improved, including what did and didn't work about the CCCN approach for the participants. Finally, *Future Focus Areas* identified potential improvements including Māori support, palliative support and investigations into other child conditions that do not receive the same support as child cancer.

Conclusion

The qualitative accounts of participants illustrated a range of benefits they experienced from access to the CCCN service. Potential areas for development include enhanced palliative focus and ensuring best practice support for Māori. Provision of a short-term, flexible delivery, specialised counselling support service for child cancer families appears valuable to address gaps in support and shows potential as a translatable model for supporting other child conditions.

Acknowledgements

First and foremost, to my amazing supervisors Associate Professor Kirsty Ross and Dr. Don Baken, thank you for your educational, and many times emotional, support. Your kindness and encouragement have meant the world to me, and I hope I have done you both justice.

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To the incredible participants – thank you for sharing your precious stories with me, I will always feel honoured, and I hope I have captured your experiences as you would have liked. Thank you for being so invested in the experiences of future child cancer whānau.

Finally, to my family – Mum, Dad, Imo and G, thank you for your endless encouragement and sharing my excitement. This is especially for you, John and Maisie, my everyday inspirations.

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He aha te mea nui o te au?

He tāngata, he tāngata, he tāngata.

What is the most important thing in the world?

It is people, it is people, it is people.

Chapter 1. Introduction

1.1 Child Cancer

Child[1] cancer is a life threatening and unpredictable traumatic journey that challenges the functioning and adjustment of not only the young patient, but their entire family system (Jibb et al., 2018; Kazak & Noll, 2015). Diagnosis and treatment involve innumerable trials such as painful and invasive procedures, frequent hospitalisations, travel or relocation for treatment, financial impacts, upsetting physical symptoms and side effects, social isolation from family and friends, and fear of terminality (Cox, 2018; Rodriguez et al., 2012; Tsimicalis et al., 2011). Often, the diagnosed child is young and unable to comprehend the situation or consent to treatment; hence, parents are abruptly thrust into a critical medical decision-making role whilst balancing conflicting emotional and practical caregiving demands (Kazak & Noll, 2015; Sulkers et al., 2015). Although survival rates for child cancer continue to increase, the aggressive treatments that achieve them can be taxing to navigate (Kazak & Noll, 2015). Therefore, the inclusion of psycho-oncology interventions is now strongly endorsed to improve the wellbeing and quality of life of child cancer patients and their families (Satapathy et al., 2018).

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[1] In the NZ cancer context, a child is defined as aged 0-14 years

1.2 Effect on the Family Unit

It has been suggested that parents[2] navigating child cancer experience significantly more stress and emotional strain than those managing other child chronic illnesses (Masa'Deh, 2015). Mounting evidence also indicates that parental distress is highly linked to children’s mental health, coping, and even treatment outcomes (Kearney et al., 2015; van Warmerdam et al., 2019). Family systems and social ecological tenets support this, with a diagnosis of child cancer representing an intense stressor that enters the family system, affects every individual member and can threaten family functioning (Kazak, 1989). Given the family is the most integral support for an ill child, managing the vulnerability placed upon them by child cancer is critical (Harris et al., 2009). Viewing these factors in conjunction with the remarkable advances in successful child cancer treatment (and an increasingly robust understanding of child cancer’s associated psychosocial and neuropsychological outcomes), the need for family-centred psychosocial care in clinical oncology is now well-established (Kazak et al., 2007; Vasilopoulou et al., 2022).

Particularly during the first year after diagnosis, the family is likely to navigate the most emotional and tumultuous times of their lives (Mu et al., 2015). Despite this early distress and likely exacerbation at known junctures in the cancer journey, evidence suggests that most families maintain remarkably sound functioning long-term, with a surprising lack of social dysfunction and psychopathology observed (Kazak & Noll, 2015; Noll & Kupst, 2007). However, whilst many families appear to adapt and cope successfully with the challenges of cancer treatment, a significant number suffer long-term distress (Alderfer et al., 2010; Kazak et al., 2015). Given that parent distress is known to adversely affect both parent and child (Rensen et al., 2019) - and family-focused interventions can in turn improve adjustment for both (Fedele et al., 2013) - authors have highlighted a need for continued focus on effective family screening and sustainable therapies in this area (Bakula et al., 2020; Luo et al., 2021).

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[2] The term parents will be used henceforth for simplicity, though it is important to acknowledge the variance in family structures and that not all primary caregivers are parents.

The amount and quality of social support available to families appears to be a critical factor in promoting adaptive coping and reducing distress (Gage, 2013; Melguizo-Garín et al., 2021).

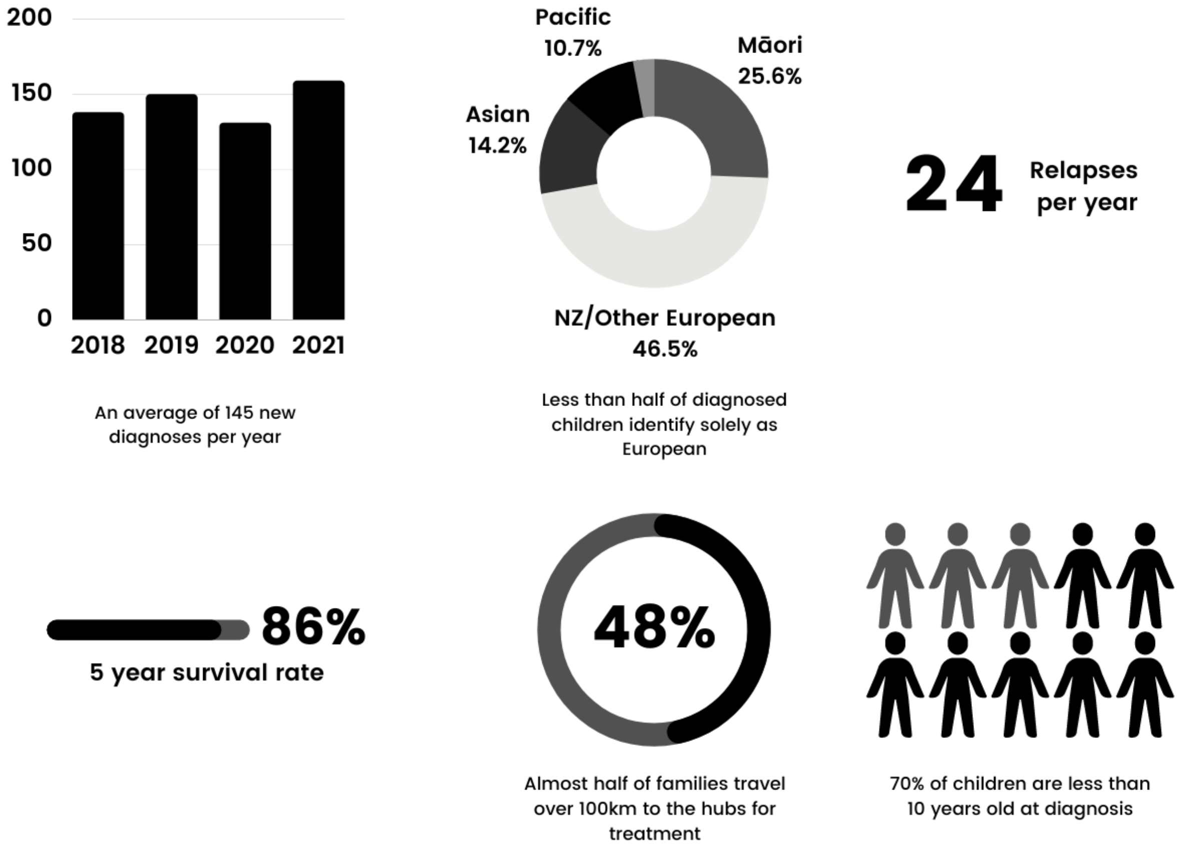
1.3 Child Cancer Incidence and Statistics

Traditionally, the field of psycho-oncology has focused on adult cancer, given its higher incidence compared to child cancer (Bautista et al., 2021). However, although child cancer comprises only 1-3% of human cancer rates, it is the leading cause of death from disease in children in industrialised countries (Steliarova-Foucher et al., 2017). Nevertheless, generally good access to health care, prompt diagnosis, advancements in pharmacology and technology, and increasingly effective multi-modal treatments have contributed to long term survival rates of over 80% (Bonaventure et al., 2017; Noone et al., 2018). In comparison, in the mid-1970s only 58% of US children aged 0-14 years would survive at least 5 years (Siegel et al., 2021).

As shown in figure 1, the five year survival rate in Aotearoa New Zealand (NZ) is 86%, in alignment with other high-income countries globally (National Child Cancer Network, 2022). An average of 143 children per year are diagnosed (National Child Cancer Network, 2018, 2019, 2020, 2021). Due to many child cancers requiring several years of treatment, the number of families navigating treatment each year is much higher. On average, 46 percent of children with cancer are European, with around 1 in 4 children of Māori descent, which is comparable to the NZ child population. Most children are under 5 years old at time of diagnosis. The most common types of cancer are leukaemia, followed by brain and central nervous system (CNS) tumours, and lymphoma, which echoes trends seen in the US (Islami et al., 2021).

Figure 1

Key Child Cancer Statistics for Aotearoa New Zealand (created by author using National Child Cancer Network data from 2018-2021).



1.4 Aotearoa New Zealand Context

1.4.1 Treatment Model

In NZ, child cancer treatment is delivered via a centralist model, with two specialist facilities acting as hubs: Starship Blood & Cancer Centre (SBCC) in Auckland, and Children’s Haematology Oncology Centre (CHOC) in Christchurch. Some treatments and follow ups can be conducted regionally, but many families face significant travel or relocation for treatment (an average of 48%).

In palliative care situations, there are additional challenges for families. In 1998, a Ministry of Health (MOH) national review established large gaps were present in paediatric palliative care service provision and staff expertise (Hynson & Drake, 2012). In 2010, a follow-up review found that only one recommendation had been acted upon, which was setting up a specialist palliative service at Starship in Auckland. The Starship team was also attempting to provide a national service via virtual support and visits to other facilities, which the MOH felt was untenable long-term. This area continues to be challenging, possibly due to the small numbers of paediatric palliative cases (Iupati et al., 2022). For the foreseeable future, Starship continues to act as a national resource offering collaboration with palliative care teams (Ministry of Health, 2009); there is also one child-focused hospice service based in the Waikato (Rainbow Place, n.d.). NZ is not alone in this challenge; a deficiency in the provision of quality paediatric palliative care is a global phenomenon (Downing et al., 2012).

1.4.2 Support Services

Several community service providers or non-government organisations (NGOs) currently exist to support child cancer patients and families in NZ, namely the Child Cancer Foundation (CCF), Leukaemia and Blood Cancer NZ (LBC), CanTeen (cancer support for young people aged 13-24 years), Kidshealth, Make a Wish NZ, and Ronald McDonald House. In addition, there is one main government agency, the National Child Cancer Network (NCCN). Two key stakeholders in the current study (in collaboration with Massey University) are the CCF (the funding partner) and the NCCN.

CCF deliver personalised whānau[3]-focused support in five main areas; building resilience, social connection, emotional wellbeing, practical support, and moving forward Child Cancer Foundation (n.d.). Their main delivery mechanism is through CCF Family Support Coordinators (FSCs), who support families in hospital and in the community as they navigate child cancer. The NCCN aims to facilitate consistent, best practice child cancer

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[3] Whānau means family in te reo Māori, the language of the indigenous people of Aotearoa New Zealand.

care across the country, by bringing together a diverse range of health professionals and key stakeholder organisations to participate in working groups, collaborate, and share information (National Child Cancer Network, n.d.) They also govern the NZ Children's Cancer Registry (NZCCR) and the Late Effects Assessment Programme Online database (LEAP-IT) which hold significant data for research and reporting purposes.

1.5 The Child Cancer Counselling Network

The use of psychosocial support with cancer patients in a hospital setting has been well researched (Banks et al., 2017). Whilst families may be well supported by in-house psychologists and treatment teams in hospital, there has been a lack of professional, cancer-specific psychological support available externally or via community-based mechanisms (Labay et al., 2004; Peikert et al., 2018). Given that the child cancer journey and its associated effects on families are not constrained to finite periods of active treatment or time in hospital, it follows that a longer-term and/or external support model be made available. In addition, NZ data indicated families would prefer psychological support be independent of their medical team and delivered outside the hospital environment (Esplin & Rook, 2015).

The Child Cancer Counselling Network (CCCN) was set up in collaboration between the NCCN, the CCF, and Massey University, with the aim of providing a world-first specialised counselling support service for whānau in or close to their hometown, available at any point during their cancer journey via a nationwide network of trained counsellors[4]. This bridges the gap in family psychological support when children are not undergoing active treatment, or for families who prefer support to be external to the treatment facility. The network was designed and implemented by two senior Psychologists at Massey University, Associate Professor Kirsty Ross and Dr Don Baken, and is overseen by a governance group comprising a cross-section of key stakeholders.

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[4] The term counsellors will be used throughout for simplicity, however the CCCN includes a variety of professionals such as psychologists, counsellors, and social workers.

A distress screening tool to identify families needing additional support was first developed by Associate Professor Ross and Dr Baken, by adapting existing tools to the needs of CCF and the cultural context of Aotearoa New Zealand. The ‘Wellness Check-in’ (see Appendix A) is designed to facilitate a discussion between the FSC and the family to identify support requirements. Comprehensive training for counsellors was then created by Associate Professor Ross, consisting of seven online modules with pre-recorded videos and assessments. The training aims to educate counsellors in key aspects of child cancer including the diagnostic process, treatments and their associated effects, palliative care, complex grief, pain and procedural distress, self-care for clinicians, and the impact on the family unit.

Registered professional counsellors have been recruited and trained across New Zealand. The counsellors offer a variety of backgrounds, ethnicities, and therapeutic approaches to the service. They have each undergone a specialised interview process prior to their online training and are provided with regular supervision.

CCF FSCs are currently the vital connection for families to access the CCCN. When a family accepts support from CCF, they are assigned an FSC who accompanies them on their child cancer journey, providing regular contact, along with practical and social support. Given they meet with families regularly, they are best placed to discuss the wellness check-in with the parents when appropriate. When a need for support is identified, CCCN clinical lead Associate Professor Ross assesses the wellness check in result and decides if the CCCN is appropriate for their needs. If deemed the best fit, Associate Professor Ross matches the family with a CCCN counsellor who is either in their geographical area or has relevant specialist skills or similarities to the family such as background or ethnicity. Referrals are managed confidentially and sensitively, and the service is entirely independent to the child’s medical team. Once accepted, the counsellor can then contact the family to organise the first session. The service is fully funded by the CCF for six sessions, with the option to extend if necessary. Sessions can be provided in person or via phone or video calls.

The CCCN support model for child cancer families is unique in that a community organisation carries out the distress screening instead of health professionals, and that counsellors are external to hospitals and form a supported national network. Its template has the potential to be applied in other countries and with other chronic child illnesses, and as such, has drawn international interest.

1.6 The Present Study

The CCCN was launched in May 2021, and over the first 18 months, 122 individuals were referred for counselling. It is important to understand how successfully it is supporting whānau through child cancer; hence, this Masters project contributes to a required evaluation for stakeholders. Data from semi-structured interviews was gathered and thematically analysed to learn about the experiences of parents with the CCCN, and answer the following research questions:

1. Did the CCCN assist families to cope emotionally with their child cancer journey?
2. Was the way it was offered, delivered, and timed right for them?
3. Did participants think it would be useful for other whānau or other contexts?

The structure of this thesis is as follows:

To understand the crucial need for supporting families navigating child cancer, an insight into its myriad impacts is necessary, along with important context such as cultural implications for Māori as the indigenous people of NZ and an acknowledgement of COVID-19 complications. Chapter two first provides the theoretical grounding for family responses to child cancer and the key models that informed the creation of the CCCN, followed by a high-level exploration of the general impact of child cancer and context. In chapter three, the lens is focused to psychological effects, and chapter four explores the current literature regarding psychosocial interventions that present similarities or salient contrasts to the CCCN approach. Chapter five provides a detailed account of how the present study was conducted and the approach taken to analyse the data. Chapter six then presents the results. Following that, chapter seven discusses the findings and their relation to current literature, acknowledges the limitations of the study, proposes areas for future research and development of the CCCN model, and closes with the conclusions.

Chapter 2. Understanding the Impact of Child Cancer

In this chapter, the theoretical grounding and key frameworks underpinning the CCCN will be overviewed. Then the general effects of cancer on families, particularly parents, are discussed, followed by considerations for Māori. Finally, given this research involved families navigating cancer during the COVID-19 pandemic, I briefly summarise this context.

2.1 Theoretical Grounding

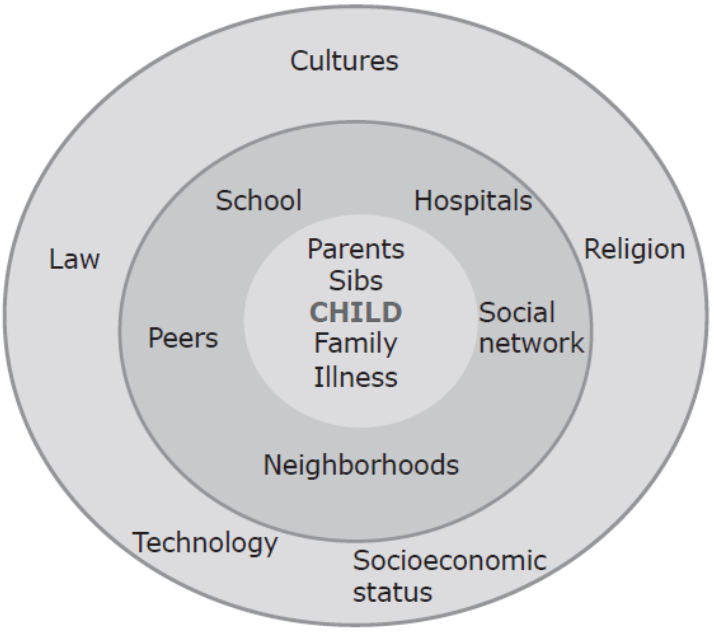
2.1.1 Family Systems and Social Ecology

Family systems theories are multidisciplinary and broad, but share the assumption of families as complex interactive systems in which the psychological functioning, behaviour and relationships of and between family members affects the functioning of the family unit (Kazak et al., 2002; Tillery et al., 2020). Behaviour is assessed with a wider lens (rather than just on the individual) and change attempts are focused at the family level, usually involving more than one generation, including systems outside the family in their formulation.

Based on the research of Urie Bronfenbrenner (1977, 1979), social ecology highlights that a child’s functioning and adjustment cannot be assessed in isolation from their family, nor any other social developmental contexts that they reside within (Kazak et al., 2017). It centralises the family role and the understanding that a child is embedded within many subsystems with increasingly distal degrees of influence (Kazak, 1989; Long & Marsland, 2011). The social ecological model was first applied in the child cancer context by Kazak (1989) and is now widely adopted to conceptualise the systemic impacts of child cancer (Bakula et al., 2020; Kazak et al., 1995). Kazak proposed that child cancer enters the social ecology as it represents an integral factor in the life of the child and their family (figure 2). The hospital becomes an additional microsystem, and the interactions between families, medical personnel, and schools become mesosystems (Kazak et al., 2017).

Figure 2

A Social-Ecological Model Applied to Child Health



From Kazak, A. E., Aldefer, M. A., & Reader, S. K. (2017), Families and Other Systems in Pediatric Psychology, in M. C. Roberts & R. G. Steele (Eds.), *Handbook of Pediatric Psychology* (5th ed., pp. 566-579), Guilford Publications. Reproduced by permission of Taylor and Francis Group, LLC, a division of Informa plc, permission conveyed through Copyright Clearance Center, Inc.

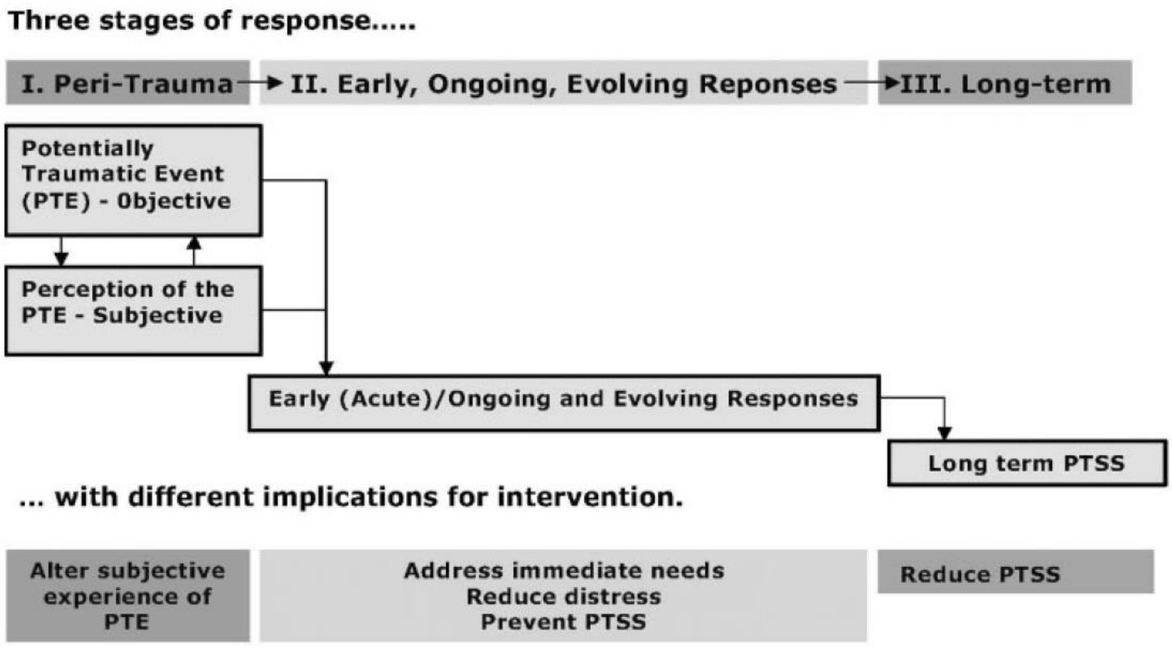
2.1.2 CCCN Frameworks

Paediatric Medical Traumatic Stress (PMTS) model

The PMTS model (figure 3) by Kazak and colleagues (2006) centralises the child, cancer, and family within social systems and considers how the family reacts to the cancer on a scale of post-traumatic stress symptoms from acute (normal) to longer-term reactions. This model acknowledges that in the context of child cancer, traumatic stress responses are not pathological, but expected, especially in parents (Kazak & Noll, 2015). It also acknowledges the subjectivity of trauma experiences and how they may be affected by myriad pre-existing factors (e.g., coping skills, perceptions, social support, and the mental health of parents); thus, medical events are considered “potentially traumatic”. This is aligned with the transactional stress model of Lazarus and Folkman (1984) which posits that psychological stress is a result of interactions between the environment and individual appraisals of that environment in terms of burden and/or risk to their well-being.

Figure 3

Paediatric Medical Traumatic Stress (PMTS) model



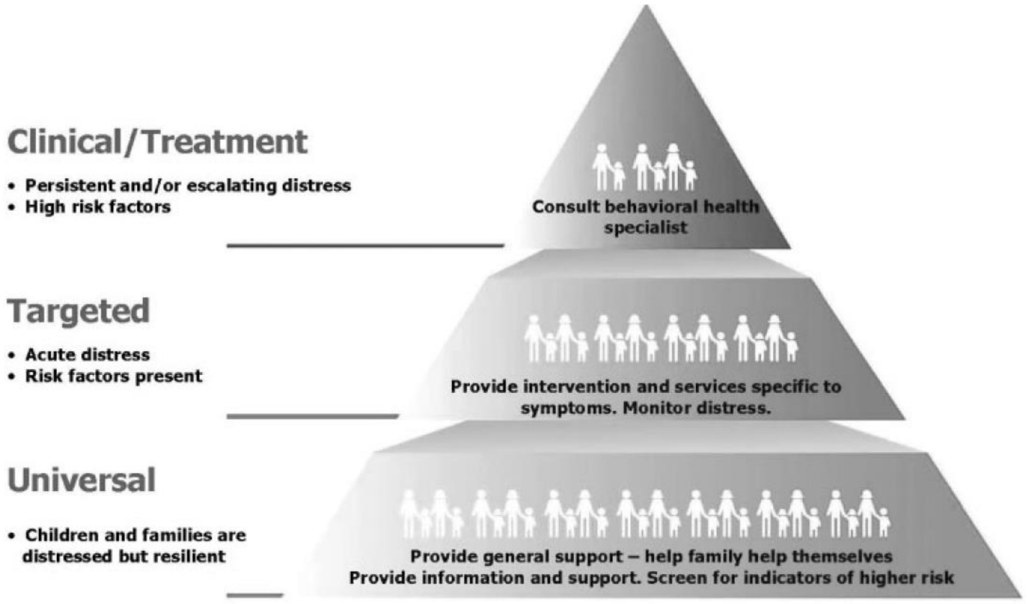
Figures 3, 4 & 5 are from A. Kazak, M. Rourke, M. Alderfer, A. Pai, A. Reilly and A. Meadows, 2007, Evidence-based assessment, intervention and psychosocial care in paediatric oncology: A blueprint for comprehensive services across treatment, *Journal of Pediatric Psychology*, 2007, 32:9, p1101-1103, reproduced by permission of the Society of Pediatric Psychology.

Paediatric Preventative Psychosocial Health Model (PPPHM)

Another model by Kazak (2006) that has taken into account research on adaptive adjustment, is the stratified PPPHM (figure 4). The PPPHM distinguishes between three levels of family risk and proposes associated treatments (Kazak et al., 2017; Kazak & Noll, 2015). At the base of the pyramid sit most families who experience short-term distress but can successfully cope and adapt. They generally benefit from basic psychosocial care such as provision of resources and education (Sahler et al., 2013; Sahler et al., 2005). In the middle sit a smaller number of families, who have moderate resources and some pre-existing risk, so are likely to derive benefit from targeted symptom-reduction interventions to facilitate positive adjustment (Kazak & Noll, 2015). This is where the CCCN can provide specialised support for families. At the top sit the families experiencing serious problems, where referrals to specialised mental health services should be provided. Families can move between PPPHM risk levels over time as risk factors change; therefore, regular screening for

Figure 4

Paediatric Psychosocial Preventative Health Model (PPPHM)



distress and difficulties is necessary. When Kazak and colleagues (2007) combined the two previous models, they determined a ‘blueprint’ for child cancer psychosocial care (figure 5), proposing that services should be available across all cells tailored to risk level and phase.

Te Whare Tapa Whā

Given NZ is a bicultural society, it is important to adopt culturally appropriate approaches for equitable outcomes for Māori. In 1985, Sir Mason Durie proposed a Māori holistic model of health representing four fundamental tenets of life – Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health), Te Taha Tinana (physical health), and Te Taha Whānau (family health) (Durie, 1985).These dimensions are represented by the four walls of a house, each a necessary component for strength and symmetry (figure 6). Interventions and assessment protocols based on Te Whare Tapa Whā aim to empower

Figure 5

PPPHM Combined with PMTS model

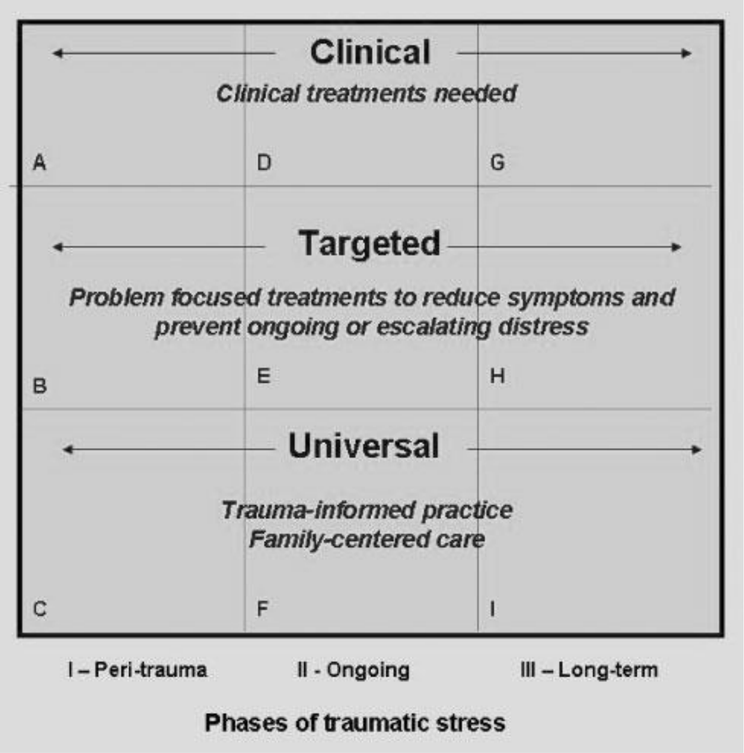
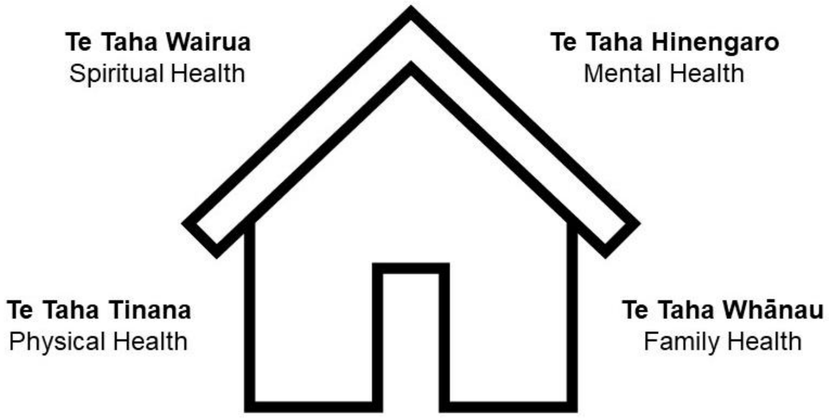


Figure 6

Te Whare Tapa Whā



Māori by acknowledging the indigenous perspective of holism and an integrated approach to wellbeing and health (Durie, 1995, 2001; Kingi, 2018a). It also accommodates diverse Māori realities or variance in cultural identity, hence providing a useful guide for culturally safe interventions.

2.2 Impact on Family

2.2.1 Ill Child

Cancer and its treatment affects children in a variety of ways (Jibb et al., 2018) with burden a result of key variables such as prognosis, treatment type, child age and gender, family demographics, and individual responses to treatment (Hudson et al., 2014; Rosenberg et al., 2013). Regardless of age and ability before diagnosis, child cancer burden is known to impact the child's developmental trajectory (Richter et al., 2015). Evidence suggests children may experience psychosocial late effects in social relationships, identity, self-esteem, academic achievement and employment (Abrams et al., 2007).

During the treatment program, patients experience a multitude of disease and treatment-related symptoms (Tenniglo et al., 2017), affecting the child's quality of life and negatively impacting schooling, social interaction and adherence to necessary life-saving therapy (Desjardins et al., 2019; Tonning Olsson et al., 2021). Symptom severity, occurrence and impact is noted to differ between children, contributing to each child's unique symptom experience (Jibb et al., 2022). Factors such as genetics and biology, socioeconomics, family dynamics, growth and development, social aspects, and treatment environment all play a part in influencing the symptom experience. Numerous problematic side effects are likely, which can affect children's quality of life, cause them to resent their therapeutic treatments, and impact their social relationships (Gunn et al., 2016).

School provides a critical social community for children (Boles & Winsor, 2019), and cancer can impact their ability to participate and therefore reduce their access to social relationships and non-familial support (Young, Bowers, Prain, et al., 2021). Social problems and bullying can also be a problem (Macartney et al., 2014); and parents, usually mothers, often add to their caring load by assisting with school activities, and volunteering to support the staff (Vanclooster et al., 2019b).

2.2.2 Siblings

Being a sibling to a child cancer patient can be a disconcerting and lonely experience, when it seems like the attention of their entire social world turns to the needs of the ill child (Kobayashi et al., 2015). Siblings have reported feelings of sorrow, denial, anger, anxiety, guilt and jealousy (Prchal & Landolt, 2012). Siblings often experience significant disruption to everyday routines, worry about their ill sibling, and reduced contact with their parents (Gerhardt et al., 2015; Kaatsız & Öz, 2020). They may also experience health anxiety, problems at school, routine disruptions, reduced quality of life, and poor psychosocial adjustment (Lummer-Aikey & Goldstein, 2021; Yang et al., 2016). Studies have noted unmet support needs in siblings due to lower attention from parents, and not asking for support when they sensed their parents were overwhelmed (Armstrong, 2019; Carlsen et al., 2019). Parents have also reported siblings representing a strong source of support for them and the ill child (Lucas et al., 2014), reflecting how siblings may prioritise the needs of the family over their own (Pariseau et al., 2020).

2.2.3 Reorganisation

The reorganisation and redistribution of responsibilities within the family unit is essential to accommodate the demands of child cancer treatment (Boles & Daniels, 2019; Boonchuaylua et al., 2023). Both on and off treatment, parents have reported difficulties balancing their ill child's needs with those of the rest of the family and their employers (McGrath et al., 2005), with a resultant reduction in family time (James et al., 2002). The shifting of priorities and roles can result in minor through to severe repercussions on family functioning, depending on the family's prior experiences, resources, and support available (Van Schoors, Caes, Knoble, et al., 2017). Most families manage these challenges successfully (Van Schoors et al., 2015); however, those that struggle can render the children at greater risk of maladjustment (Long et al., 2013).

2.2.4 Financial Impacts

Considerable employment and income disruptions for parents are well established in child cancer studies (Santacroce et al., 2018), and for some, financial consequences can persist into survivorship (Roser et al., 2019). Parents with an existing lower socioeconomic standing, and with children with haematological cancers or of younger age have been found to be at particular risk. Poverty has also been implicated in unfavourable prognostic outcomes and higher psychosocial risk (Bona et al., 2016); however, there is conflicting evidence (Neugebauer and Mastergeorge (2021). Nevertheless, an assessment of family financial burden is recommended as a standard of psychosocial care (Pelletier & Bona, 2015; Wiener et al., 2015).

2.2.5 Transitions

Transition points between child cancer illness phases are associated with increased parental uncertainty and distress (Kazak & Noll, 2015). Diagnosis, relapse, and transfer to palliative care are understandably significant, but so are seemingly positive events such as end of treatment and discharge from hospital (McGeehin Heilferty, 2018). Upon completion of treatment, parents have described feeling overwhelmed and apprehensive about tending to their child at home without the supports of a facility (Lucas et al., 2016; Smith et al., 2018), and they can experience frustration when their social networks perceive the family's struggles to be finished (Forinder & Lindahl Norberg, 2010). Transitioning back to regular routines is often challenging (Wakefield et al., 2013) and some parents have voiced concerns that feelings they put aside whilst supporting their child through active treatment would surface once home. Even in the joy of complete remission, the shift back to normalcy can be problematic (Wakefield et al., 2010), due to the child's reduced physical wellbeing compared to peers (Engelen et al., 2011), and persisting psychological distress within the family (Wenninger et al., 2013).

2.2.6 Social Support

Social support can be delivered in many forms, such as companionship, informational, emotional, instrumental and appraisal support (Wawrzynski et al., 2021). Family and significant others are generally the most common sources of social support for child cancer parents (CCPs), with medical personnel, friends, and other CCPs often ranked second (Bouchard et al., 2023).

In 1985, it was proposed that social support buffers the interaction between stress and psychological distress (Cohen & Wills, 1985), and researchers soon suggested that social support might be a key protective factor for CCPs (Kazak & Nachman, 1991). In support of this, a recent review found perceived social support had a consistently positive relationship with adaptive factors, wellbeing outcomes and coping styles (Gise & Cohen, 2021). Similarly, better social support networks have been linked to improved family adjustment (Melguizo-Garín et al., 2021). In a recent study with CCPs, emotional support was deemed the most helpful form of social support (from family or healthcare providers), with family was the most common source (Bouchard et al., 2023). However, family were also the most likely to disappoint CCPs by providing less support than they expected or required, demonstrating the importance of external social support mechanisms.

Lower levels of hope have also been documented in parents with limited social support (Hullmann et al., 2014), whilst some studies found longer treatment periods correlated with less perceived social support (Arab et al., 2020) and more social disturbance (Islam et al., 2021). Others have noted that CCPs with young children (0-4 years) are particularly at risk of poor psychosocial outcomes if social support is lacking (Morhun et al., 2020), an important factor to consider given cancer is most prevalent in younger children.

2.3 Impact on Parents

The integral role parents hold in taking care of their children, building emotional bonds, regulating behaviour, and providing an environment that facilitates development, becomes exceptionally evident when a family is under stress (Mu et al., 2015). A parent's traditional, predictable roles focus on nurturing their child's growth, not dealing with significant illness (Junkins et al., 2020). Upon diagnosis, the parent role is abruptly transitioned to a dual role of parent-caregiver, requiring rapid absorption of cancer-related information, new caregiving skills, and reorganisation of the family unit (Koumarianou et al., 2021; Sultan et al., 2016). Understandably, this parental transition is not often seamless and can lead to substantial and long-lasting emotional strain (Wijnberg-Williams et al., 2006).

During active treatment, parents have described striving for 'survival' as not just avoidance of their child's death, but also survival of the family itself (Björk et al., 2005). Often one parent is based at the treatment facility (generally the mother (Kars et al., 2008)), whilst the other is at home caring for sibling/s, the household, and/or continuing paid employment

(Nicholas et al., 2009). Parents are expected to play a key decision-making role in treatment during a time of extreme stress, pain and change (Demirtepe-Saygılı & Bozo, 2020; Lipstein et al., 2012). In addition, parental behaviours and responsibilities that are adaptive during active treatment may have unintended repercussions later; for example, necessary physical proximity to provide comfort and monitor health parameters during treatment may evolve into overprotection once the child is in survivorship, potentially hindering their autonomy and development of independence (Young et al., 2002).

Due to the increased risk of late effects, parents' active role in their child's medical care can continue for years or even decades after treatment (Hudson et al., 2018), and the constant threat of cancer recurrence often impacts carer's quality of life more than the patient (Stein et al., 2008).

2.3.1 Gender Differences

Child cancer often disproportionately affects the child's mother, with numerous studies outlining the myriad ways mothers provide for their children with complex needs, often for the rest of their lives (Eaton Russell et al., 2016; Hobbie et al., 2016; Van Schoors et al., 2018). Mothers are most likely to reduce or resign from paid work; manage complex tasks related to their child's care; identify and coordinate resources; organise suitable social and everyday activities (e.g. transport); and manage the family's physical and emotional wellbeing (Palma et al., 2015; Vanclooster et al., 2019a). Mothers also report poor levels of support, especially regarding practical training and advice, and in managing their own wellbeing (Wilford et al., 2017). Several papers have noted a lack of support from male partners (Deatrick et al., 2018; Shortman et al., 2013), and mothers can often rely on the support of other women and CCPs (Reay et al., 1998). Mothers also frequently wear the burden of an absence of health care to address the late effects of cancer survivors, especially in the transition into adulthood (Nicklin et al., 2019; Tonorezos et al., 2018).

The mother’s voice is often predominant in child cancer research, making assumptions about fathers’ problematic. In a recent review, very few findings could be extrapolated due to fathers making up just 33% of the parent sample (Young, Bowers, & Bradford, 2021). Predominantly, father roles are less disrupted by child cancer (Van Schoors et al., 2019), with studies noting they generally subscribe to traditional western masculine ideals (Polita et al., 2018; Robinson et al., 2019). Being a ‘good dad’ has been described as being the family ‘rock’, providing housing and insurance, helping manage their child’s symptoms, offering play opportunities, and they typically have issues expressing their feelings. A meta-ethnographic study that examined fathers’ experience caring for their children with life-limiting conditions reiterated that fathers’ experiences are affected by masculine assumptions (Postavaru et al., 2021).

Whilst coping strategies can be individual-dependent, certain types have often been attributed to genders (Sultan et al., 2016). Mothers have been found to utilise more social support and family coping, while fathers rely more on activities such as leisure or work and employ passive or avoidant coping. This echoes the “traditional” parent roles in child cancer (Bennett Murphy et al., 2008; Hall, 2010), though it remains unclear whether taking into account primary caregiver status would affect this phenomenon (Sultan et al., 2016).

It is important to note that many seminal studies generalise parent relationships as heterosexual, married couples, representing a need for more inclusive updates to the data. Whilst traditional gender roles may still be prevalent in child cancer caregiving (Clarke et al., 2009), qualitative data suggesting increasing involvement from fathers (Clarke, 2005; McGrath & Huff, 2003) is just the tip of the iceberg to be explored. The strain of single parenting is well established (Iobst et al., 2009; Patel et al., 2014); however other diverse family structures and their challenges regarding chronic illness remain unaddressed (Kazak et al., 2017).

2.3.2 Relationships

It is well acknowledged that parenting reduces couples' capacity for activities that maintain a strong relationship (Kluwer, 2010); however, it is a common misperception that relationship breakdown is unavoidable when dealing with a serious child illness (Kazak et al., 2017; Syse et al., 2010). Some authors note disagreements between fathers and mothers about their child's care (Hocking et al., 2017; Robinson et al., 2019); however, there is no clear association between relationship satisfaction and child cancer either during or after treatment. Some have suggested that data might instead point to an intensification of pre-existing relationship dissatisfaction following diagnosis (Van Schoors, Caes, Alderfer, et al., 2017).

The physical separations between parents often necessary during treatment can result in reduced communication and emotional closeness (Mercer & Richie, 1997); and conflict is common over parenting choices such as overprotecting or indulging the ill child (Lindahl Norberg & Steneby, 2009), and working out how to collaborate again after recovery (Patterson et al., 2004). Other challenges include the inclination of partners to pause the needs of the relationship and their partner during intense periods of treatment, and opposing coping styles (Long & Marsland, 2011).

Emotional response disparities are the most frequently noted source of conflict between husbands and wives (Wijnberg-Williams et al., 2015). Men have reported feeling that they grieve alone during their child's treatment; withholding their emotions to appear strong or protect their partner (Jones & Neil-Urban, 2003; Nicholas et al., 2009). In contrast, mothers have observed their partners as uncaring, not acknowledging the seriousness of the illness, or isolating themselves (Reay et al., 1998). Emotional distance, unmet needs, stress, and loneliness can result when this mismatch of response styles is combined with increased separation during treatment (Chesler & Parry, 2001; Fletcher & Clarke, 2003).

2.3.3 Caregiver Burden

The psychological, physical, financial and social effects that are often encountered in caregiving populations are referred to as caregiver burden or strain (Nijboer et al., 1998). Variables that are known to predict distress levels include female gender, younger age, extended care periods, and pessimism (Matthews et al., 2003). Depression and decline of physical health are associated with long term caregiving (Shaffer et al., 2017), and women are especially are at risk when fulltime work is combined with caregiving (Kenny et al., 2014). Specific to parents, factors such as personality, social support, family experience with illness, religious beliefs, illness course and treatment have been implicated in coping (Bautista et al., 2021). The strain of witnessing their child's suffering can cause an overwhelming sense of powerlessness, role dissonance, and subsequent psychological anguish in CCPs (Kearney et al., 2015).

Caregiver burden also affects the cared-for, with much research illustrating a bidirectional relationship between patient and carer emotional wellbeing and distress (Jacobs et al., 2017; Okado et al., 2014). Furthermore, high caregiver burdens have been linked to lower survival rates in advanced cancer patients (Dionne-Odom et al., 2016). Thus, the ways in which parents cope with the challenges of cancer is integral to the quality of life of the whole family (Bautista et al., 2021).

2.4 Impact on Māori

When discussing generalised implications for Māori, it is important to acknowledge the diversity present within the population (Durie, 2001). The reduction of Māori realities to a homogenous view represents antiquated thinking, and similarly there is no 'typical' Māori identity. What is apparent are shared attributes, shared heritage, and well-being patterns that contrast to non-Māori New Zealanders.

Echoing trends seen in indigenous populations worldwide, cancer disparities for Māori are evident across access, treatment, and morbidity (Kidd et al., 2019; Robson &

Ellison-Loschmann, 2016). International child cancer research has examined ethnic disparities, implicating parental lack of knowledge, socioeconomics, and pharmacogenetics in impacting access and adherence to effective treatment (Bhatia, 2011). In NZ, variances in access to and quality of care is known to influence poorer health outcomes for Māori (Dew et al., 2015).

Whilst inroads have been made in tackling institutional racism and culturally unsafe practices since the establishment of Māori healthcare providers in the 1990s, discrimination continues to affect Māori illness experiences (Robson et al., 2010). In a study with adult Māori, three key areas impacting the cancer journey experience were implicated: continuity of care, support experiences, and travel and income constraints (Slater et al., 2013). Māori health providers have concurred, citing finances, transportation, and information as the biggest obstacles to cancer care (Slater et al., 2016). Palliative care presents further complications due to critical misalignments with Māori customs and understandings (Jones et al., 2023; Moeke-Maxwell et al., 2019). Family-focused approaches, long-term relationships and trust appear critical for culturally safe mainstream care (Slater et al., 2016).

2.5 COVID-19 Context

In late 2019, a severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) emerged in China, causing a global pandemic of coronavirus (COVID-19) within a matter of weeks and the declaration of a public health emergency by the World Health Organisation (WHO) (Lai et al., 2020). The swift spread of the virus in conjunction with damaging misinformation created a public health catastrophe never seen before, as COVID-19 patients overwhelmed health systems worldwide (Moreira et al., 2021). Evidence suggests that child cancer patients may be at higher risk of serious infection and death (Seneviratne et al., 2022; Zhang et al., 2023). This has in turn increased CCP burdens, which can erode emotional resilience and coping strategies, negatively effecting the wellbeing of the entire family unit (Wimberly et al., 2021).

CCPs have described fears they will transmit the virus to their child, and no longer seeing the hospital as a safe space (Darlington et al., 2021). Isolation and loneliness as a result of the uncertainty of the pandemic have been linked to depression in caregivers (Gallagher & Wetherell, 2020), whilst others have noted increased distress, anxiety, and posttraumatic distress (Guido et al., 2021). The effect of the COVID-19 pandemic on general outcomes and survival rates is not yet clear, but nonetheless concerning (Isa & Nazman, 2023). What is clear, is that providing support for patients and survivors, such as psychosocial care, is more crucial right now than ever (McLoone et al., 2020).

2.6 Summary

This chapter has briefly touched on the theoretical models behind family adjustment to a chronic trauma such as child cancer, and the wide-ranging systemic impacts of child cancer on families. The cultural context represents additional challenges for Māori, and a COVID-19 pandemic clearly exacerbated family burdens. It is important to note the difficulty in clear demarcation between the impacts of child cancer (chapter two) and the psychological consequences (chapter three) as they are interlinked. For readability and structure, they have been addressed separately but there is some inevitable crossover. Nonetheless, in chapter three the psychological implications for child cancer families will be further explored.

Chapter 3. Psychological Implications of Child Cancer

In this chapter, I overview the psychological implications of child cancer for families, with focus on parents given they are the key users of the CCCN. This is followed by a brief overview of specific considerations for Māori.

3.1 Implications for Families

When a child has cancer, the family system as well as its individual members can experience negative psychosocial consequences (Long & Marsland, 2011), in alignment with the theoretical models discussed in chapter two. Overall functioning is disrupted, with some families experiencing prolonged strain on relationships and resources (Van Schoors et al., 2015). Studies have found numerous familial and contextual factors such as treatment severity, social support, family environment, and existing parenting strain that may act as integral links between child and parent distress (Okado et al., 2016; Stoppelbein et al., 2013).

Recent review evidence clearly shows the interconnectedness between family functioning and psychosocial outcomes in child cancer patients and their parents (Neugebauer & Mastergeorge, 2021). Parental distress is highly linked to children’s mental and physical health, quality of life and coping (Bakula et al., 2020; Willard et al., 2017). Studies have proposed that parent and child adjustment variables represent bidirectional pathways (Hutchinson et al., 2009). For example, stress in child cancer parents (CCPs) has been significantly associated with impaired child health and quality of life (QOL) (Haegen & Luminet, 2015); whilst the treatment status and cancer severity of the child has a joint impact on the parent’s health and QOL (Salvador et al., 2015). Parent distress has also been linked with greater family conflict (Patiño-Fernández et al., 2008), lower family supportiveness (Phipps et al., 2005), poorer communication (Kazak et al., 1997), and lower family cohesion (Witt et al., 2010).

Open and clear parent-child communication is critical to effective cancer care and improving child quality of life during the cancer journey (Boonchuaylua et al., 2023; Son et al., 2019). When parents struggle to share their feelings and concerns with their child, the child can feel isolated and suffer psychologically (Zebrack et al., 2010). If the child dies, the parents may suffer life-long regret that they did not foster open communication between them (Kreicbergs et al., 2004). A key challenge for parents is negotiating the delicate balance of making significant decisions for their child whilst including them and any siblings as much as developmentally appropriate (Coyne, O'Mathúna, et al., 2016; Lin et al., 2020).

Authors have agreed that in child cancer, the adjustment of children is significantly impacted by the way the family as a whole reacts to it (Rosenberg et al., 2014; Van Schoors, Caes, Knoble, et al., 2017). Readjustment is necessary and normal to cope with the physical and emotional demands of the journey, but there is substantial variation in how different families will react and function (Long & Marsland, 2011). The family's ability to successfully adapt may be a pivotal factor in patient and sibling outcomes, ranging from signs of growth and positive adjustment to signs of increased distress and at worst, psychopathology (Kazak et al., 2015). The pre-diagnosis functioning of the family is significant, as stronger families tend to strengthen and families under strain tend to experience more negative consequences (Harrington et al., 2009).

3.1.1 Ill Child

The nature of cancer treatment understandably puts children at heightened risk of psychosocial distress (Bakula et al., 2020; Rodriguez et al., 2012). Add to this the child's unique stage of psychological development and mental health issues can surface (Geue et al., 2018). Short-term distress is expected across the treatment course (Dolgin et al., 2007); but given adequate support, many children are remarkably resilient (Noll & Kupst, 2007). However, a significant subset experience negative psychosocial outcomes (Patenaude & Kupst, 2005; Pinquart & Shen, 2011), such as emotional and/or social difficulties during treatment (Kestler & LoBiondo-Wood, 2012), or following it (Kazak et al., 2001).

In a systematic review, Jibb and colleagues (2018) found children reported anxiety, sadness, and anger, along with social impacts especially in friend relationships. Anxiety and fear was linked to an acute awareness of their mortality, and a drive to protect their loved ones, which may partially explain why stress and worry are very common in child cancer patients (Hedén et al., 2013). It appears that mood is most affected for children when cancer or its treatment results in enduring physical or cognitive changes (Cataudella & Zelcer, 2012; Cheung et al., 2019).

Often observed in child cancer survivors are higher than normal rates of post-traumatic stress disorder (PTSD) (Ljungman et al., 2015), depression (Al-Saadi et al., 2022; Bitsko et al., 2016), and anxiety (Liu et al., 2018). Social difficulties, loneliness and suicidality have also been reported (Wakefield et al., 2010), along with neuro-cognitive issues which correlate with unemployment in adults (Prasad et al., 2015). Others have noted that fear (such as concerns about recurrence) lingers well into adulthood (Simard et al., 2013), and in a recent meta-analysis (2021), Chandeying and Thongseiratch found over half of child cancer survivors were in need of ongoing care for at least one chronic mental health issue.

3.1.2 Siblings

Whilst most siblings adjust well over time, a significant portion exhibit psychological and adjustment difficulties (Guan et al., 2021), and can clearly benefit from professional supportive care (Lummer-Aikey & Goldstein, 2021). Emotional distress may be intensified by feeling out of the information loop regarding their ill sibling (Long et al., 2015) and sleep disturbances (Nolbris & Ahlström, 2014). Posttraumatic stress symptoms (PTSS) (Kaplan et al., 2013), sadness and anxiety (Long et al., 2013), and social and academic difficulties have also been reported (Samson et al., 2016).

3.2 Implications for Parents

3.2.1 Distress and Coping

Parents are at the epicentre of family functioning and healthy child development, hence their wellbeing and mental health are key concerns following a child cancer diagnosis (Kazak et al., 2017). Parents often report feeling drained physically, mentally and emotionally throughout the cancer journey, which can reduce their ability to cope with additional stressors and increase the risk of psychological distress (Elcigil & Conk, 2010; Yeh, 2003). Given that a caregiver's wellbeing directly influences the care they are able to provide, the importance of supporting parents has drawn much attention in child oncology due to the combined stressors of concurrent parenting and caregiving (Junkins et al., 2020; Tang et al., 2020).

Despite efforts to stay strong, CCPs are at heightened risk of negative psychosocial outcomes (Morhun et al., 2020). Whilst wellbeing may improve over time, nearly one third of parents experience clinical levels of distress up to five years into their child's survivorship (Canter et al., 2022; Vrijmoet-Wiersma et al., 2008). Compared to population norms, CCPs experience more emotional distress, reduced quality of life, increased anxiety and depression, more somatic symptoms, sleep issues, excessive fatigue and worry, uncertainty, and PTSS (Eche et al., 2019; Eche et al., 2022; Vernon et al., 2017; Wikman et al., 2018). Following treatment, uncertainty can result in heightened anxiety (Conway Keller et al., 2020), and PTSS are common even after successful treatment (Kazak & Noll, 2015). In fact, a child cancer diagnosis is a life event so traumatic for parents, that it was added to the Diagnostic and Statistical Manual IV (DSM-IV) as a risk factor for PTSD (American Psychiatric Association, 2000).

Parental distress can be influenced by many aspects, such as individual parent factors (e.g. gender, optimism, pre-cancer mental health, and self-efficacy), external parent factors (e.g. family functioning and social support), child variables (e.g. type of cancer, age, treatment, degree of suffering and care quality), and environmental influences (e.g. income, employment, and level of education) (Crespo et al., 2016; Edmond et al., 2016; Nam et al., 2016).

Child cancer mothers tend to experience higher levels of distress across the journey than fathers (Barrera et al., 2012; Reinfjell et al., 2009), and are more prone to PTSS (Landolt et al., 2012; McCarthy et al., 2012). In a systematic review, researchers found that mothers reported more anxiety, uncertainty, psychosomatic issues, and depression symptoms than fathers, which they proposed could be associated with traditional unequal distributions of caregiving responsibilities (Vrijmoet-Wiersma et al., 2008). Others have agreed, attributing the variance to complex societal and cultural expectations, reporting differences, caregiving roles, and biological differences (Nolen-Hoeksema, 2001; Wool & Barsky, 1994).

3.2.2 Complex Grief

Whilst grief is commonly associated with bereavement, a diagnosis of child cancer brings with it more complex conceptualisations of grief. The threat of and navigating death is still a significant factor, however the loss of potential or the life ‘that was’ is often not considered by outsiders. Parents have expressed grief in the form of their family’s lives not being ‘normal’, especially during survivorship, which was often attributed to fear of recurrence and worry about a future lack of independence for their child (Lucas et al., 2016; Rabelais et al., 2019). Mothers especially grieved the loss of potential they had hoped for their child and themselves (Lindahl Norberg & Steneby, 2009) and were particularly determined to set their child up for adult independence (Deatrick et al., 2018). They were afraid for their child’s wellbeing if something should happen to them (Wilford et al., 2017), and worked hard to equip their child to care for themselves physically and financially, and make good decisions (Palma et al., 2015).

The death of a child is widely acknowledged to cause grief more persistent and intense than other kinds of bereavement (Kreicbergs et al., 2007). This grief has been described as complex and non-linear, due to the unique parent-child emotional bond, irreversibly altering a parent’s relationships, emotions and priorities (Gilmer et al., 2012). It defies the natural order of life, and can affect a parent’s perception of themselves as a protector of their child (O'Connor & Barrera, 2014). Mothers’ have reported blaming themselves, feeling that they had failed to adequately care for their child or birth them with a healthy body (Lou et al., 2015). Bereaved parents must carve out for themselves and their families a new identity, reality, and purpose, that involves living alongside this profound sorrow (Arnold & Gemma, 2008; Denhup, 2017). Bereavement is often cited as a predictor of long-lasting adverse mental health outcomes for CCPs (Lichtenthal, Corner, et al., 2015; McCarthy et al., 2010), and the prevalence of depression in parents who have lost a child to cancer is almost triple the rate of the general population (Kessler et al., 2005; van Warmerdam et al., 2019).

Chronic sorrow is a term that has been applied in the child chronic disease context for some time (Nikfarid et al., 2015), to capture the losses resulting from changed life circumstances. It originated in 1962 to describe the pervasive and recurrent grief reaction experienced by parents of children with cognitive delays (Olshansky, 1962). It is characterised by unresolved grief and cyclical episodes of intense sadness triggered by internal or external stimuli (Batchelor & Duke, 2019). Various risk factors may play a part, including socioeconomic status, access to supports and gender with women most effected.

3.3 Considerations for Māori

It is important to acknowledge the unique contextual implications for indigenous populations and that much psychological research is with predominantly European samples. Culture can impact the presentation (and subjective experience) of a disorder and many psychological measures are culture-bound (Durie, 2001). What is considered ‘normal’ in one culture may be perceived very differently by another (Kingi, 2018b). For example, Māori can tend to utilise metaphorical expressions that could easily be misinterpreted as distorted thinking (Durie, 2018). In addition, many Māori can be reluctant to engage in serious discussion before a relationship is established or the interviewer's motives have been assessed. These reciprocal or two-way processes can require more time than often allowed for typical assessments or interventions.

Māori views typically look for explanations outside the mind or the body (Durie, 2018). In addition, views on mental health do not translate easily into syndromes or symptoms; for example, anxiety is more likely to be seen as an indicator of imbalance between the body, social relationships, emotions and spirituality. Poor mental health is often associated with an insecure Māori identity, and inequities in resources and power.

Without population data, the specific psychological effects of stressors such as child cancer on Māori cannot be adequately determined. Historically, most Māori data regarding mental health was based on hospitalisations, which severely limits its application (Kingi, 2018b). Significant headway was made in 2006 with the release of *Te Rau Hinengaro: The New Zealand Mental Health Survey* including mental health data from 2500 Māori (Baxter et al., 2006). Data highlighted concerning rates of disorders, with anxiety the most prevalent. Despite the high incidence and severity, engagement with mental health services was low. In addition, younger age groups were more affected, as were those in lower income households, with lower education, or residing in more deprived areas. These final factors are particularly concerning given that socioeconomic hardship, travel and financial issues are implicated in child cancer family distress, meaning Māori may be more at risk of adverse psychological outcomes.

3.4 Summary

In this chapter, the potential psychological impacts for families have been overviewed, showing the heightened risk of distress and adverse mental health outcomes due to the cancer journey's inherent trauma and grief. To add to the NZ context of this study, Māori differences in conceptualisations of mental health and risk factors were discussed. In chapter four, psychosocial interventions aimed at assisting family adaptation to child cancer will be discussed.

Chapter 4. Psychosocial Interventions in Child Cancer

In the current study, the individual therapeutic approaches of the counsellors within the CCCN are not known; however, parents are generally the focus of treatment. Therefore, in this chapter I briefly outline psychosocial approaches that have demonstrated benefit for child cancer families with emphasis on parental interventions. This is followed by counselling in cancer contexts, and implications for Māori. Finally, key aspects of intervention design and approach are discussed.

4.1 Beneficial Approaches

4.1.1 Child-Focused

Interventions providing psychosocial benefits for child cancer patients vary widely from coping interventions for physical symptoms and health (Kato et al., 2008; van Dijk-Lokkart et al., 2016), to information provision and decision-making (Sisk et al., 2016), through to wider focused quality of life and mental health programs (Lyon et al., 2014; Shoshani et al., 2016). Child-centred interventions that improve decision-making capabilities and communication can impact a child's treatment adherence, quality of life, and better equip them for survivorship (Coyne, Hallström, et al., 2016; Sisk et al., 2016; van Dijk-Lokkart et al., 2016). Similarly, sibling interventions utilising informational support, companionship, skill building, and problem-focused coping have been successful in reducing fear, and building confidence, emotional control and self-reflection (Løkkeberg et al., 2020; Nolbris & Ahlström, 2014; Packman et al., 2008; Toft et al., 2019).

Social support is clearly linked with adjustment and health outcomes in child cancer patients and siblings (Noughabi et al., 2016; Sigurdardottir et al., 2014; Wawrzynski et al., 2021) and children have reported that interventions helped their family relationships improve (Barrera et al., 2018; Long et al., 2018). In sum, the child-focused intervention literature indicates the need for developmentally appropriate therapies with a systemic focus, involving parents and family alongside professionals (Carr, 2016, 2019; Jibb et al., 2018; Kazak et al., 2004).

4.1.2 Family-Focused

Given the linked relationships between family member functioning, it makes sense that when a child is diagnosed with cancer, assessment, support and intervention is provided to the whole family (Bakula et al., 2020; Peikert et al., 2018). In addition, supporting children effectively entails working with the family (which aligns with the Child Cancer Foundation values), and both systemic and family therapies which utilise this approach have demonstrated their effectivity.

The Family Talk Intervention (FTI) has shown promise in improving communication and relationships and filled a social support gap 2-3 months after diagnosis or relapse (Eklund & Lövgren, 2021; Ivéus et al., 2022; Lövgren et al., 2021). Similarly, the family therapeutic conversation intervention (FAM-TCI) delivered by oncology nurses reported enhanced family cohesiveness and communication (Svavarsdottir & Sigurdardottir, 2013). This study demonstrated the clear need for families to be able to openly express their emotions and feelings whilst navigating child cancer.

The Surviving Cancer Competently Intervention Program (SCCIP) incorporates four family sessions and shows positive effects on family well-being, and significant reductions in parental distress (Kazak et al., 2004; Kazak et al., 1999). It has also been adapted to support newly diagnosed families via the three-session SCCIP-ND (Newly Diagnosed) (Kazak et al., 2007; Kazak et al., 2005). However, uptake can be low (Stehl et al., 2009), with many families citing overwhelm at this point in their journey as reason for declining. Additionally, the SCCIP programs stipulate the involvement of two parents which can further limit their uptake and impact (Hocking et al., 2014).

The FAMily-Oriented Support (FAMOS) home-based program is CBT-based and made available following treatment completion, showing benefits for PTSD and depression

(Salem et al., 2021). A key point of difference is that it is delivered in the family's home, in which the familiar environment can make difficult tasks easier.

4.1.3 Parent-Focused

Support for parents is a key focus in child cancer psychosocial care (Kearney et al., 2015; Wiener et al., 2015) and support of parents can in turn help their children (Mullins et al., 2016), demonstrating again the systemic nature of effective child cancer support. Attention is improving in regards to recognising, supporting and equipping family caregivers as the crucial yet vulnerable resources they are (Junkins et al., 2020). Although the CCCN is undoubtedly a systemic service which can be tailored to the immediate needs of various family members, the focus is on parents; hence, the current parent intervention literature will be summarised here in more detail than the previous sections.

In a recent systematic review of manualised programs targeting child cancer parents (CCPs), various methods were utilised such as psychoeducation, family therapy and cognitive behaviour therapy (CBT), with varying degrees of supporting evidence (Ogez et al., 2019). A subsequent review found most studies either utilised CBT or Problem-Solving Skills Therapy (PSST), two approaches with key benefits in the literature, especially for mothers (Koumarianou et al., 2021). Bright IDEAS is an example of a PSST intervention, targeting mothers of children recently diagnosed and showing promising decreases in distress and enhanced problem-solving skills (Sahler et al., 2013; Sahler et al., 2002). Cascade ('Cope, Adapt, Survive: life after cancer') is a CBT-based intervention which shows promise for parents of child cancer survivors, delivered over four modules by a Psychologist via group videoconference (Wakefield et al., 2016).

Other CCP-focused approaches include stress management interventions (Marsland et al., 2020); and self-compassion or strengths-based approaches which have been found to be effective in improving emotion regulation, hope, resilience and wellbeing (Damreihani et al., 2018; Khosrobeigi et al., 2021; Shafiee et al., 2019; Van Schoors, Caes, Knoble, et al., 2017). Communication-focused interventions can improve family functioning through child cancer (Belpame et al., 2016; Boonchuaylua et al., 2023; Kreicbergs et al., 2004), and psychoeducation can assist parents to manage their emotional reactions and improve psychological and coping outcomes (Sánchez-Egea et al., 2019; Tang et al., 2020).

A wide variety of approaches have been employed across the child loss literature, illustrating the various preferences for individuals in navigating grief (Pelacho-Rios & Bernabe-Valero, 2022). For example, Meaning-Centred Grief Therapy (MCGT) and other CBT-based approaches (Lichtenthal & Breitbart, 2015; Lichtenthal et al., 2019; Sveen et al., 2021), family-focused interventions (Aho et al., 2011), peer support (Raharjo et al., 2020) and communication approaches (Foster et al., 2011; Toller, 2011), can assist CCPs in managing long-term grief symptoms and creating a sense of meaning and purpose. Parents have proposed key components for effective bereavement interventions, such as personalisation (as no family journey is the same), readily available throughout the grief journey (including key transitions pre-bereavement), and tangible (providing contacts and concrete resources for families) (Lichtenthal, Corner, et al., 2015; Snaman, Kaye, et al., 2016).

Studies have shown that emotional support for CCPs is critical, with CCPs describing a need to voice and process front of mind issues that they did not wish to burden family or friends with (Ringnér et al., 2021). The importance of trained mental health professionals is also evident, with CCPs reporting that nurse-led sessions left them unfulfilled, and emotional management for themselves and their child was a key concern (Ringnér et al., 2023). CCPs sought coping strategies, assistance with supporting their child emotionally, communication and relationship help, and understanding crisis and stress reactions. These studies raise interesting points in favour of the CCCN’s flexible approach, to provide parents with the psychological support they need. It appears that overall, interventions that focus on normalising the emotional nature of the journey for families and assisting them to communicate their experiences are beneficial.

Authors have recommended psychosocial screening to provide information regarding which families are suited to interventions and inform how they are implemented. Indeed, when parents have been asked about the support they require, they have expressed a need for flexible interventions tailored to the needs of families based on diagnosis, level of distress and phase of cancer journey (representative of a traumatic stress framework) (Boonchuaylua et al., 2023; Hocking et al., 2014). Another recent study concurred, concluding that supportive interventions should be personalised to the individual experience of each parent (Scarponi et al., 2023). Structured or manualised interventions, despite their benefits, cannot fully accommodate these needs, indicating the strength of a flexible counselling service such as the CCCN.

4.2 Counselling in Cancer Contexts

Counselling by definition is a type of psychoeducational intervention which can vary widely in form, from addressing problematic behaviours or maladaptive thinking patterns, understanding and expressing emotions, information provision, to guidance or advice (Scheel et al., 2011). Overall, counselling involves the creation of a safe space via empathy, genuineness, and lack of judgement, to enable the client to work through and resolve their personal challenges via critical reflection, thus fostering empowerment, personal growth and improving coping skills, as outlined by the seminal works of Fallowfield (1988; 1991). Clients can experience increased empowerment due to strengthening of their internal and external resources, improvement of communication, and enhanced self-acceptance and self-awareness.

In patients, counselling can be a humanistic solution to cancer-related distress (Fallowfield & Roberts, 1992; Towers & Diffley, 2011), however investigations regarding the impact of counselling with CCPs are scarce to non-existent (Haunberger et al., 2020). A recent small-sample quantitative study examining the effect of social counselling with parents yielded mixed results, with some effects on psychosocial burden and quality of life, but with clear moderating factors such as child health status (Young, 2018a). Understanding the child cancer journey, its inherent stressors and likely emotional consequences appears to be imperative for empathetic counselling with CCPs. It has been suggested that counsellors should have an awareness of likely developmental issues for child patients, along with therapeutic strategies to assist with adherence to treatment, as these are key concerns for parents. Other examples include understanding the extended social isolation and parents' tendency to attempt to 'stay strong' or maintain emotional composure for their child. Informed counsellors can recognise periods of higher parental strain and normalise emotions during these times or help prepare for potential setbacks.

Scarce investigations into group counselling for CCPs have noted the limitations of group-based support for this population (Young, 2018b). Relationship issues, phase of cancer journey, child prognosis and higher degrees of trauma can all render CCPs inappropriate for group counselling. Group settings also pose concerns around confidentiality, and they appear better suited to structured interventions or less-distressed populations.

Simply providing a safe space for parents to cathartically express emotion without judgement and process their challenges with an empathetic person (who can also provide some relief from isolation) can be therapeutically valuable. It appears that even if an intervention is not specifically focused on emotional support, parents will seek this out due to the emotionally taxing nature of their situation (Ringnér et al., 2021). This was eloquently expressed by two participants in Ringnér et al.'s study, who said *"When your life is turned up-side-down like that, you have to talk in order to not, as a parent, perish"* (Mother of a 3-year-old, pg 4) and "*Here I was given an opportunity, if I needed it, to be pitiful and small, worried and angry, or devastated, which I wouldn't have wanted to be in front of my child"*. (Mother of a 15-year-old, pg 4).

Whilst Ringnér et al.'s (2021) study showed clearly that parents needed and appreciated the space in which to process their emotions and feelings, it also highlighted the need for providers to have appropriate psychological training. While parents appreciated the nurse facilitator being medically knowledgeable, some felt they weren't adequately supported emotionally, and some wanted to understand the mechanisms behind their reactions. Similarly, others have noted the limitations of nurse counselling, citing untenable workloads, lack of psychological education and limited supervision (Fallowfield, 1988; 1991). Further supporting evidence has been provided by meta-analyses reporting significant relationships between therapists' professional mental health training and effect sizes (Sánchez-Egea et al., 2019).

4.3 Māori and Counselling

It is important to acknowledge the western values implicated in the origins of counselling; for example the focus on independency and self-actualisation as a health indicator is in opposition to the Māori view (Durie & Hermansson, 1985). In Māori culture, knowledge about wellbeing is not obtained by dissecting or looking deeper inwards, but rather outwards to the relationships between people, their wider systems and environment. The parallels of this worldview with holism and dialogical medicine which brings the mind and body back together are clear. Māori view 'emotions' as whole-body experiences, hence being asked to talk about feelings is non-sensical, given feelings speak for themselves.

When working with Māori clients, Māori professionals are best placed to support given their shared reality and indigenous knowledge (Durie, 2018). International research concurs, concluding that therapeutic outcomes are likely to be better when the ethnicity of the counsellor matches the client (Atkinson & Lowe, 1995). The central tenet of Kaupapa Māori psychology is 'by Māori for Māori' (Glover & Robertson, 1997), and in cancer studies, these types of support services have shown the most benefit for whānau (Slater et al., 2016).

Mainstream providers are increasingly designing care approaches based on Māori health models and employing Māori staff (Kingi, 2018c). However, simply adding on a Māori component to interventions can be perceived as tokenistic and problematic, with nonacceptability of western paradigms and cultural alienation two of the key barriers for effective Māori uptake of mental health services (Durie, 2001). Clients can feel misled when supposedly Māori-friendly approaches turn out to be lacking in cultural sense or provide little room for whānau involvement or traditional healing. Furthermore, screening and testing intricacies abound when analysing for normal or ‘abnormal’ mood or behaviour if cultural backgrounds are not shared or understood. Ultimately, the need for culturally safe care incorporating long-term relationships and a foundation of trust is imperative.

When counselling Māori, three critical dimensions have been recognised: 1) Whanaungatanga is concerned with familial relationships; 2) Whakamanawa means to encourage and includes manaakitanga or caring, and awhi or touch, two concepts that are exceptionally foreign for western professionals; and 3) Mauri meaning essence or vitality, which includes wairua or spirit, and whakapapa or genealogy (Durie & Hermansson, 1985). Practically, incorporating these elements means the setting is crucial, and interventions and training of those delivering them are bicultural in nature. It also must be acknowledged that not all Māori represent the same cultural background and therefore will benefit from the same Māori insights to the same degree (Durie, 2001). Hence, providers have a duty to empower Māori clients to access and choose the approach best suited for them (Kingi, 2018c).

4.4 Other Considerations

Guidelines and position statements highlight that families need psychological support from well-trained individuals offered across the illness journey (Steele et al., 2015). However due to varying factors, interventions are not provided consistently to the people who need them, even within specialist paediatric oncology programs (Kazak & Noll, 2015). Whilst parents note support from the personnel caring for their ill child is generally good, they experience significant deficits in their access to emotional support for themselves and their family (Plessis et al., 2019). Some of the key factors regarding access and optimisation of interventions for CCPs and their families are outlined below.

4.4.1 Timing of Support

Hocking et al. (2014) noted a clear preference from parents for intervention delivery within six months of diagnosis. However traumatic stress responses evident soon after diagnosis make this a period focused on ‘survival’, with parents saying they were reluctant to divert attention away from their child, explaining recruitment difficulties encountered by SCCIP and Bright IDEAS (Sahler et al., 2013). Metanalyses have concluded however that interventions are more effective earlier than later in the cancer trajectory (Sánchez-Egea et al., 2019).

Although parents express a clear desire for support from diagnosis onwards, contrarily they have noted they unlikely to accept interventions in the initial days and weeks following diagnosis (Canter et al., 2020). They have proposed ‘soft’ introductions such as a handout during initial treatment planning, with multidisciplinary teams reminding them throughout treatment. The need for multiple offers was emphasised due to parents feeling overloaded with information, especially during the early phases of treatment, to keep the intervention ‘on their radar’ and allow access at the right time for them. Many parents noted an abundance of support around diagnosis and successive fading across the treatment trajectory. This was of particular concern as they felt ongoing access to interventions and resources was important, suggesting community partnerships could bridge this gap and ensure families experiencing elevated distress were adequately cared for. Interventions which have focused on end of treatment coping support this, showing decreases in distress and positive effects on quality of life (Mckenzie & Curle, 2012; Quast et al., 2016; Wakefield et al., 2013).

Standardised grief services are required not only after death but through difficult transitions such as entering hospice care, and pre-bereavement (Snaman, Kaye, et al., 2016; Snaman, Torres, et al., 2016). Palliative communication support can be critical in reducing familial distress, such as provision of anticipatory guidance and how to discuss death with children (Kassam et al., 2015). Following loss, follow up support and assistance with re-entering the community can be beneficial (Bradshaw et al., 2005; D'Agostino et al., 2008), as families commonly fear burdening friends and family with their ongoing pain (Barrera et al., 2009; Donovan et al., 2015; Welch et al., 2012). The cessation of treatment-centre supportive interactions following child loss can create a secondary loss for families and compound grief reactions; unfortunately, limited staff resources can make follow-ups difficult and at best sporadic (Lichtenthal, Sweeney, et al., 2015).

Due to the chronic nature of child cancer, there is widespread agreement that regular and routine psychosocial screening is essential to monitor familial distress (Scarponi et al., 2023; Wiener et al., 2015), as whilst some families may present obvious risk factors, and transitions may exacerbate distress, adjustment capabilities vary considerably and distress can fluctuate over the course of the journey. The phenomenon of chronic sorrow illustrates this; given its cyclical nature, interventions need to be accessible long-term, as triggering events create further need for support (Coughlin & Sethares, 2017). Similarly, bereaved parents have described a requirement for psychological support two to four years post-loss (Lichtenthal, Corner, et al., 2015).

4.4.2 Intervention Length

Published interventions have adopted various numbers of sessions and lengths, and authors have highlighted the need for interventional brevity, balanced with strong theoretical grounding and ability to disseminate (Kazak, 2005). Some of the shorter interventions have failed to adequately support CCPs (two sessions) (Lamanna et al., 2018), whilst others have described both short and long term benefits from only two to three sessions (Svavarsdottir & Sigurdardottir, 2013). Numbers of sessions appears to be related to intervention timing; however, given some of the longer programs (12 sessions) were reported as too short by parents (Marsland et al., 2020), and others reported drop out due to conflicting priorities at start of treatment (Sahler et al., 2013). In addition, structured interventions may be more affected by length than those providing therapeutic flexibility. This may explain the issues encountered by a short version of Bright IDEAS, developed to address poor uptake, which found two sessions wasn’t long enough for effective problem solving and had no significant effects on distress (Lamanna et al., 2018).

Most brief-intervention studies utilise around six sessions, though some outlined a clear need for extensions due to a scarcity of supports available (Lövgren et al., 2021). Other reviews have concluded that best results are obtained when interventions are of longer duration and lower intensity (Sánchez-Egea et al., 2019).

4.4.3 Mode of Delivery

With the chronic and unpredictable nature of child cancer coupled with events such as the COVID-19 pandemic, interventions utilising flexible delivery methods represent sensible futureproofing. Telepsychology services have been proposed to help overcome critical delivery gaps in behavioural health fields (Hasselberg, 2020). mHealth (mobile health) and eHealth (electronic health) interventions are also becoming more common in holistic oncology literature, though many studies are focused on patients (Estapé & Coups, 2020; Jibb et al., 2017), with a particular scarcity of interventions for parents (Canter et al., 2022). A review in 2018 suggested that health technology interventions to support cancer caregivers are still in their infancy, with most weighted towards information provision (Shin et al., 2018).

Some in-person programs have been adapted, such as the SCCIP to the eSCCIP (Electronic SCCIP) (Canter et al., 2019). A web-based version of Bright IDEAS has also been trialled with slightly inferior results to the original in-person model; however, the ease of delivery benefits warrant further development (Phipps et al., 2020). A recently published study also trialled a novel internet-based low-intensity CBT (LICBT) guided intervention for parents, reporting positive results (Thiblin et al., 2022). For bereaved families, evaluation of technology-mediated interventions is a key need to reduce access barriers (Lichtenthal, Corner, et al., 2015).

4.4.4 Setting

In child cancer, psychologists (as part of an interdisciplinary treatment team) are noted as a contributor to the positive adjustment observed in many families (Kazak & Noll, 2015). However, some settings lack sufficient mental health professionals with expertise in child cancer; thus, families' ability to access support is at times limited (Selove et al., 2012). Community providers with experience in child cancer and evidence-based approaches are even less commonplace, leading authors to highlight this as an area for necessary expansion (Kazak & Noll, 2015). Many distressing junctures do not occur during hospitalisation, and some families also prefer separation between treatment teams and psychological support (Esplin & Rook, 2015). Services external to the hospital may also be critical for traumatised or bereaved families, for whom returning to treatment facilities can be particularly upsetting (Lichtenthal et al., 2011). Interventions carried out in family homes have shown promise, citing time savings and increased participation of families due to the safe environment (Lövgren et al., 2021; Salem et al., 2021). Videoconferencing or online therapy may provide similar environmental benefits.

4.4.5 Optimising Access

Parents have highlighted factors to improve access to support services, cautioning against rigid universal recruitment approaches and highlighting the need for flexibility and tailoring to cancer experience and parents' needs (Canter et al., 2020). They also noted the importance of offering support to all caregivers within a family and felt buy-in from medical teams was important, due to the strong relationships they formed with hospital staff. Explaining potential benefits for parents and emphasising program flexibility they also felt would increase uptake, as would dissemination of materials in various formats such as paper handouts and informational videos. Previous studies have utilised similar strategies such as partnering with medical teams, offering flexible delivery mechanisms, and leveraging community networks such as endorsements and word of mouth referrals (Lim et al., 2011).

Other reviews have reported that in-person recruitment predicted higher participation, along with approaching parents at diagnosis or during treatment as opposed to after (Wakefield et al., 2017). Kazak and colleagues (2004) noted that more distressed families are more likely to benefit from interventions but are also more likely to drop out, possibly due to wanting to avoid further distress from recounting upsetting memories or trauma. They highlighted the need for psychosocial risk screening to improve adherence.

Some studies have noted poor uptake of supports from bereaved families, citing a number of factors such as access barriers (particularly for minorities), desire to evade painful memories, and avoiding accessing support at the facility where their child was treated (Darbyshire et al., 2013; Lichtenthal, Corner, et al., 2015). If medical teams are able to provide follow-up contact, offering families grief services at these times would be optimal given their existing trusted relationship with parents (Lichtenthal, Sweeney, et al., 2015). In addition, screening can help identify those most in need and should be carried out at least to the end of the second-year post-loss (Hudson et al., 2012).

One study also demonstrated the importance of a positive therapeutic relationship, with authors finding fathers did not receive the same benefits from an intervention as mothers (Svavarsdottir & Sigurdardottir, 2013). They proposed a potential a lack of fit with the nurse interventionist., which supports the capacity of the CCCN to match clients with appropriate counsellors and reassign if the relationship is not optimal.

4.5 Summary

The impact of existing interventions for CCPs and their families is mixed, and authors agree that more quality research is required (Bautista et al., 2021; Peikert et al., 2018). Whilst structured programs offer benefits for targeted intervention and dissemination, the accounts of CCPs outline a clear requirement for professional emotional support and flexibility in interventions, regarding timing, therapeutic focus, length, setting, and mode of delivery. These findings support the implementation of a child cancer-specific, community-based counselling intervention such as the CCCN to address this clear gap in support.

The following chapter outlines the methodology adopted by this study in order to evaluate the CCCN from CCPs' perspectives.

Chapter 5. Method

This chapter initially describes the research approach and ethical considerations. I outline how participants were recruited and provide a summary of the resulting sample. The procedure taken to collect data is then described, and the analytic approach. Lastly, the trustworthiness of the research is discussed.

5.1 Research Approach

The epistemological approach underpinning this research is social constructionism, which assumes that meaning and knowledge is subjectively constructed within contexts, particularly human interactions (Chamberlain, 2015). The research design was driven by phenomenology, which is concerned with understanding the subjective human experience (Larkin, 2015). Adopting a qualitative approach enabled the collection of rich accounts from participants to understand their CCCN experiences. Qualitative methods enable deep exploration of people's thoughts, experiences, and views through their descriptive accounts - in essence, words are used as data (Braun & Clarke, 2013). By examining patterns across the accounts, the experiences regarding the CCCN design and implementation were able to be explored in depth. The analytic approach is justified and described in detail in section 5.5.

5.2 Ethical Considerations

A full ethics application was submitted and approved by the Massey University Human Ethics Committee: Southern B, Application 22/32 (see Appendix B).

5.2.1 Participants Rights

Participants' rights were upheld through informed consent, participation being entirely optional and confidential, and participants being able to withdraw from the study up until two weeks after their interview. Additionally, demographic information collected was used to describe the sample as a whole only and identifying information was removed from transcripts and quotations as much as practicable. Finally, all interview findings and participant information were stored securely.

5.2.2 Minimisation of Psychological Harm

Although the focus of the interviews was on participants' CCCN experience, some psychological distress was inevitable in recounting the context surrounding it. Each participant voluntarily shared their story to frame their counselling experience, and noted a strong desire to help future cancer families get the help they need. Participants were also offered the option to be referred to a counsellor for further support after their interviews. It was also important to ensure I as the researcher was adequately supported, especially through the interview phase. As a mother to a young child, hearing accounts of child cancer and bereavement posed potential for personal distress if self-care was not well managed. We ensured I had regular contact with my supervisors, along with family support throughout.

5.2.3 Cultural Considerations

In Aotearoa NZ, around 1 in 4 children diagnosed with cancer are of Māori descent (National Child Cancer Network, 2021). Hence, it was important to acknowledge Māori as potential participants at the outset and ensure the study was conducted respectfully in accordance with the values of Te Tiriti o Waitangi (The Treaty of Waitangi). Given my worldview as a Pākehā New Zealand European student, specialised cultural guidance was essential. Supervision with a Māori Psychologist from Massey University, Dr Hukarere Valentine, was sought during study design and ethics, and during data analysis. Detailed information about the project's cultural considerations can be found in Appendix C.

5.2.4 Issues Encountered

A key ethical issue acknowledged was the perceived conflict of interest of supervisor Associate Professor Kirsty Ross, given she prepared the CCCN training for counsellors, and previously assisted with managing referrals. Therefore, Associate Professor Ross acted in an advisory and support supervisory role and was not involved in recruitment or data analysis to maintain a degree of separation.

Secondly, this study cannot be considered an independent review of the CCCN, due to both supervisors being involved in its design, implementation, and ongoing governance. However, the other interested parties (CCF and NCCN) were aware of and supported their involvement.

Thirdly, unwittingly revealing the identities of participants was a significant ethical concern for this study. Participants shared highly personal and sensitive information during their interviews, and as a small sample representing part of a highly connected community, deductive disclosure or internal confidentiality violations was a real risk (Tsai et al., 2016). There is unequivocal acknowledgment that ensuring confidentiality when presenting qualitative findings is problematic, but little published guidance exists beyond the use of pseudonyms (Kaiser, 2009; Morse, 1998). I was concerned that readers, especially those in the child cancer community, could piece quotes together and potentially recognise a participant. On the other hand, if quotes are overly edited they can lose their true meaning, as noted in a classic ethnography by Woolcott (2003); “To present the material in such a way that even the people central to the study are ‘fooled’ by it is to risk removing those very aspects that make it vital, unique, believable, and at times painfully personal” (p. 4).

Hence, many methods were considered for anonymising published quotes in this study, such as altering key demographic characteristics, or ‘checking back’ with participants about how their data would be reported (Wiles et al., 2008). Ultimately, the decision was made to not include participant pseudonyms with quotes, to preserve the integrity of the data, the anonymity of participants, and avoid embargo. This approach was suggested by Morse (1998), who stated attributing quotes to participants was irrelevant to readers, who only need to know what category or theme the quote represents. In addition, a table of participant information has not been presented in 5.3.3 as including ages ranges with ethnicities was deemed too identifiable. Instead, a written summary was prepared, and several ethnicities grouped as “other” (in alignment with the NCCN statistics).

5.3 Participants

5.3.1 Inclusion Criteria

Qualitative studies generally adopt a purposeful and criterion-based sampling strategy, to select participants who can produce information-rich data about a pre-determined criterion (Lyons, 2015; Morrow, 2005). In this case, participants needed to be a parent or caregiver who had been referred to and accessed the CCCN service and undertaken at least two sessions. In addition, they needed to be English-speaking and able to provide informed consent. In criterion sampling, researchers will ideally select participants that share the criterion, but represent a variety of individual experiences and other characteristics (Moser & Korstjens, 2018). However, within the confines of time for this research, ongoing recruitment to procure an ‘ideal’ sample was not possible. Regardless, authors have noted that if participants are aligned with the aims of a study, view their participation as meaningful and engage with the interviews, the resultant data is likely to be relevant, rich and valuable for all parties (Lyons, 2015).

5.3.2 Recruitment

The Child Cancer Foundation (counselling referrals manager and administration staff) assisted with recruitment, by emailing an invitation (Appendix D) to families who had been previously referred for counselling. The invitation contained a link to the study’s online information sheet (Appendix E), the researcher and supervisors contact details, and the digital consent form (all housed in Qualtrics). This informed potential participants about the nature of the study, and the time commitments. Participants were invited to indicate their interest in taking part within a time window of one month. Brief calls or emails were offered to talk through any questions and concerns potential participants might have. Once interested parties had filled in the digital consent (Appendix F) and the subsequent demographic questions, I was notified by Qualtrics and able to access their responses.

5.3.3 The Sample

The sample comprised seven parents from separate families. All identified as female and mothers and were in heterosexual relationships with the father of the child with cancer. Two participants were in the 25-34 years age group, three were 35-44 years and two were 45-54 years. Three participants indicated their primary ethnicity as NZ European, one as Māori, one as Asian, and two ‘other’. They represented a wide geographical spread of hometowns spanning both the North (57%) and South (43%) Islands of New Zealand, with only two living in the same city as a treatment centre. Three participants were bereaved, and four had children in varying stages of survivorship or treatment. Child age at diagnosis also varied from young infants to early teens, and many types of cancer were represented.

In the methodological literature, it has been established that six to twelve participants are sufficient for qualitative interview research such as this, with no clear benefits evident for recruiting larger sample sizes (Guest et al., 2006; Starks & Brown Trinidad, 2007). Authors have noted that the number of participants in interview studies mean very little; rather that validity, insights and meaningful data is more associated with selection and careful analysis of information-rich cases (Morrow, 2005; Patton, 2015).

5.4 Procedure

5.4.1 Initial Contact

Once I received each participant’s information via Qualtrics, I emailed them to thank them for their response and arrange a time for their interview. An appointment was subsequently sent, with a short guide on joining via Microsoft (MS) teams. I sent each participant a text message reminder the day prior to their interview.

5.4.2 Interviews

Online interviews have many benefits aside from the obvious cost-reductions; they can facilitate access to participants who might not otherwise take part in research due to personal circumstances or locality (Lyons, 2015), and can be less-threatening for participants due to the familiar physical environment (Salmons, 2015). In this study, the geographical spread of potential participants, an ongoing COVID-19 pandemic, plus potentially immune-compromised families made online an obvious choice. We were also able to accommodate work and parenting demands by conducting interviews at times that were most convenient for the participants, such as lunch breaks, child nap times and evenings. These benefits outweighed the acknowledged shortfalls of online interviews, such as limitations on observing non-verbal communication, restricted ability to manage the interview setting due to the inability to observe the room outside the webcam view, and loss of potential participants due to access to, or reluctance to use online methods (Salmons, 2015).

Interviews were carried out across a three-month period. The mean duration was 81 minutes (range 52-175 minutes). All participants attended their interviews alone, though several were joined by their children at various points. When this occurred, attention was diverted to chatting with the child and interview questions paused, unless it was appropriate for the child to be involved at that point (such as giving their opinion on the counselling or counsellor).

Interviews commenced with an introduction about the study, reiteration of participant rights, and then a personal introduction in which I shared some details about my family and why I was drawn to the research. This helped to open dialogue and build a connection. For the participant that indicated her primary ethnicity as Māori, I also gave a short pepeha[5]. Then I invited the participants to talk about themselves and their family, which often flowed

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[5] A Pepeha is an introduction in Te Reo Māori that shares your affiliations with people (ancestry) and places.

organically into details about their CCCN experience. A semi-structured interview outline (Appendix G) was used to guide the interview and draw out information regarding each participant’s experience. Semi-structured interviews allow for flexibility of phrasing and expansions dependent on interview flow (Anne, 2013), aligning with the flexibility that is characteristic of data collection within qualitative research (Moser & Korstjens, 2018).

Although I prepared a very detailed and structured outline ordered around time points in the CCCN process, I used it predominantly to practice. In the interviews it acted as a guide and reminder of topics to cover only, as per semi-structured protocols (Hays & Singh, 2012). The aim was to encourage participants to share their thoughts, feelings, and perceptions; focusing on whichever aspects of their experience they felt most important. I prompted for more detail or clarification when required. If participants became emotional, pauses and breaks were offered, along with the option to stop or postpone the interview, though no participant took these. I took brief ‘field notes’ during each interview, which included comments about non-verbal expressions, visible emotion, gesturing and notable happenings in our environments (such as interruptions), along with salient details such as the participants levels of social support and specifics about their journey that might assist me during the interview or data analysis.

5.4.3 After the Interviews

The transcript and recording produced by MS Teams were downloaded and securely saved upon completion of each interview. I also recorded each interview on a portable voice recorder as a backup, which I deleted immediately after saving the MS Teams recording. The transcripts were then manually checked against the recordings to ensure they were verbatim and amend any errors. I then replaced names with pseudonyms and removed or changed other potentially identifying information such as other names, family specifics, treatment centres, and places. Transcripts were returned via email to two participants who accepted the opportunity for review and comment within a two-week window (neither requested any changes). A thank you card and grocery voucher koha[6] were also couriered to each participant the day after their interview.

5.5 Data Analysis

Thematic analysis (TA) was implemented for this study, adhering to Braun and Clarke's reflective framework (Braun & Clarke, 2006, 2013). TA is often utilised to identify, examine, and report patterns in qualitative data due to its inherent flexibility. However it is important to acknowledge that, in contrast to many other analytic approaches, it is a method and not a methodology, hence the theoretical underpinnings behind its application should be outlined (Braun et al., 2015). Phenomenology is the epistemology behind this study, and phenomenologically-driven methods apply well when seeking to understand experiential consequences of certain contexts, such as understanding whether an intervention is meaningful or acceptable from the point of view of the people experiencing it (Larkin, 2015). TA's ability to facilitate description and interpretation of others' lived experience through identification of common themes across interview data, aligns well with phenomenology (Moser & Korstjens, 2018). An inductive TA approach was utilised, meaning the coding and analysis commenced 'bottom up' starting with the data, and coding focused on semantic (overt or 'surface') meanings (Braun et al., 2015). This is aligned with Braun & Clarke's (2015) recommended approach for evaluating a service or intervention.

Described below is Braun & Clarke's (2006, 2013, 2019) six-part TA approach along with the steps I undertook during each phase. Coding and grouping of excerpts were aided using Atlas.ti qualitative software (web version v5.0.0-2023-05-09).

Phase 1: Familiarisation with the Data

Phase one encompasses immersion in the data through repeated readings, in order to familiarise oneself with the semantic meanings of what was said whilst beginning to note

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[6] Koha means gift or contribution in Te Reo Māori. It is a symbol of reciprocity and means of maintaining social relationships.

analytical points of interest (Braun et al., 2015). This commenced with checking, editing, and anonymising the transcripts and associated noting of thoughts and ideas. I listened to the audio of each interview at a reduced speed to ensure comments were captured verbatim. During this phase, I added my field notes to the transcripts as appropriate to enhance meaning and context.

Phase 2: Coding the Data

Coding entails a thorough and systematic process of applying descriptive labels across the dataset (Braun et al., 2015). I achieved this by highlighting relevant sections of text in the Atlas.ti program and creating a descriptive code for that section. Most sections of text were assigned many different codes. As I progressed through the transcripts less new codes were generated. After re-checking to ensure thoroughness and removing duplicate codes, the final list comprised 287 descriptive codes.

Phase 3: Searching for Themes

In phase three, the focus shifts from codes to themes, which usually identify higher-level meanings (Braun et al., 2015). To start, I used the Atlas.ti program to review each code and collate them into more manageable ‘code groups’ or clusters of shared meaning. I then used these to inform an initial list of potential themes and drafted a thematic map. This helped me identify shared characteristics and how they worked together in potential overarching themes and subthemes, as I considered relationships between them. Once I was satisfied with the draft map, I collated codes into the resulting themes.

Phase 4: Reviewing Themes

Phase four is concerned with quality control and ensuring themes provide a thorough and accurate representation of the relevant data (Braun et al., 2015). I achieved this by revising and refining my initial themes to ensure they were distinct, codes within them were coherent, and there were enough meaningful data to support each theme. I then checked every coded extract against its assigned theme to ensure that what the participants had told me was the story I was reporting. I also reviewed the themes carefully regarding their relation to the research question and checked my reasoning with my supervisors at several points.

This was a difficult phase as there were several poignant themes regarding the child cancer journey and its impact on families that were not directly related to their CCCN experience. Reluctantly, these themes were removed from the thematic map and instead listed in Appendix H for interested readers, given their strength and potential for application in other settings.

Phase 5: Defining and Naming Themes

Phase five involves refining the focus and scope of themes through detailed analysis of the data within them (Braun et al., 2015). During this phase, my thematic map went through many iterations as I reorganised and refined the themes and their names, using the key messages within each to inform the process. I then used the Atlas.ti program to rearrange codes into their final themes and used my thematic map to write a plan for the results chapter. Whilst doing this I considered which excerpts would provide the most vivid examples to illustrate each analytical point.

Phase 6: Producing the Report

Finally, phase six commenced with the production of the following results section, which identified the themes, subthemes, and the dominant narratives within each. Compelling examples from the transcripts were selected for inclusion in the write-up as supporting evidence, which also supports the reader in determining if the final themes I've chosen are supported by the data. Many excerpts were carefully edited to remove unnecessary distractors such as repetition or verbal pauses, to allow the key message to be succinctly conveyed without alteration of meaning.

5.6 Trustworthiness

Regarding qualitative research, the phrase ‘researcher-as-instrument’ is often used, referring to the researcher’s integral role in not only collecting the data, but also analysis and interpretation, meaning personal values, beliefs and experiences can influence outcomes (Onwuegbuzie et al., 2010; Starks & Brown Trinidad, 2007). Whilst interview studies centre the subjective experiences of participants, attributes of the researcher can influence how those experiences are expressed given they are collected in a social context (Green & Thorogood, 2014). Consequently, reflexivity and self-awareness throughout is of utmost importance (Lyons, 2015). Social similarities and differences between the researcher and participants should be recognised, documented, and included in analysis. Therefore, my reflexive statement follows:

I am a white NZ European, cisgender married woman, a mother, and live with mild chronic illness. I was drawn to this research as my child has previously had surgery for a heart condition. I have a generally good understanding of medical terminology and lived experience of parenting plus navigating the health system with a child. Care was taken not to assume the universality of my experience and maintain an open mind whilst interviewing participants with differing backgrounds. Throughout the research I had regular consultation with my supervisors to identify and minimise bias, including specialised cultural supervision regarding the handling of Māori data to reduce the risk of misrepresenting participant experiences.

To further support the trustworthiness of this research, each step of the analysis was checked and discussed with supervisor Dr Don Baken, and the research process has been explained in detail in this chapter. This included assumptions regarding the design, participant selection and analytic process to ensure transparency and a clear understanding for readers of how results were obtained.

5.7 Summary

This chapter has outlined the research approach for this study, including ethical considerations, recruitment, interview process, analytic approach, and a brief analysis of the trustworthiness of the research. In chapter six, the results of the study are presented.

You have to unload these feelings at some point. You can do it as you go along, or you can try and hold them in and bury them - that'll only come back to bite you in the arse later.

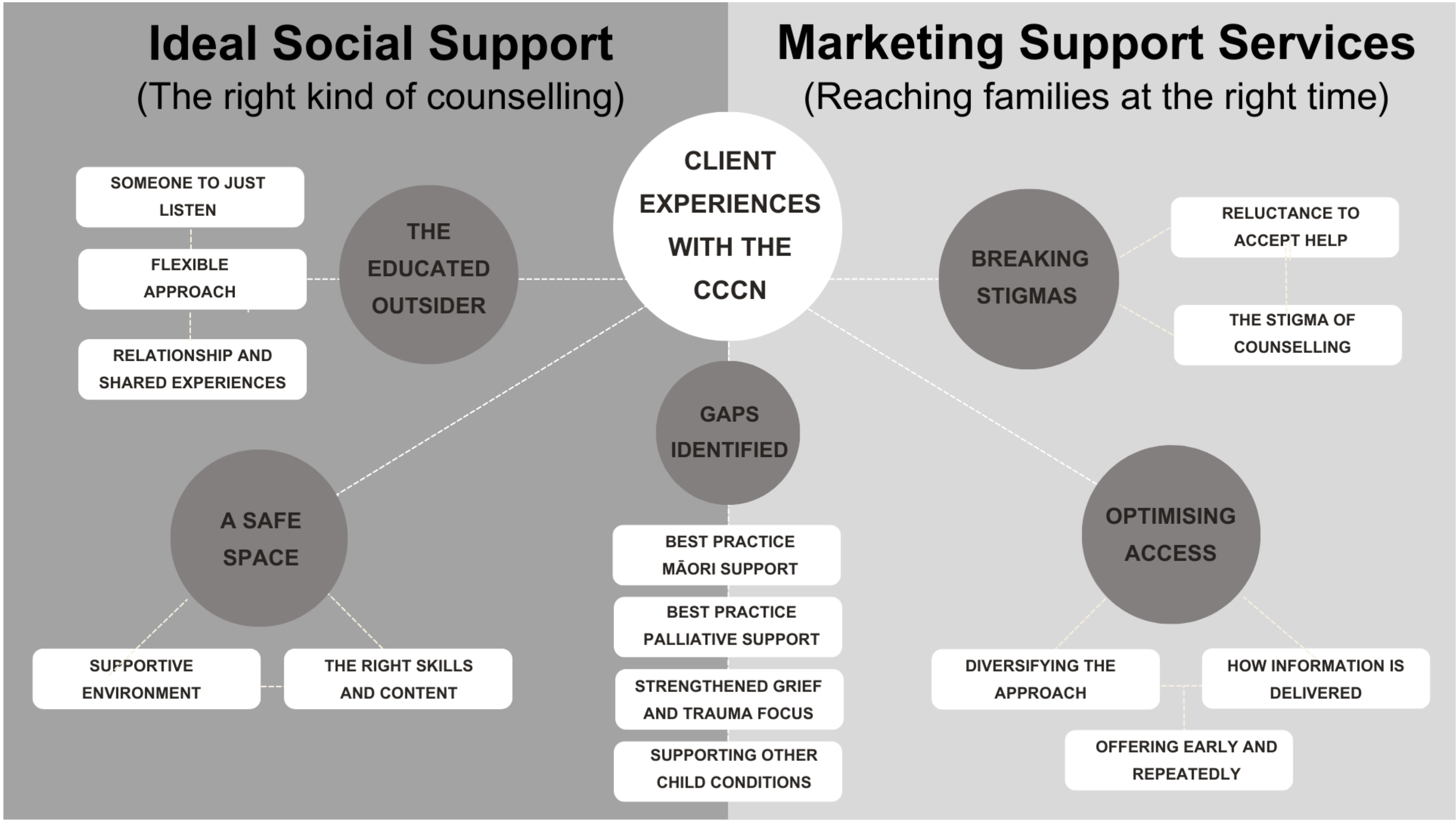
Chapter 6. Results

This chapter sets out the findings of this study by describing the six main themes regarding whānau experiences with the CCCN, along with their associated subthemes, as shown in figure 7. The final themes were organised into two main categories. *Ideal social support* contains the themes concerning what constitutes a great counsellor and the attributes of great counselling. The second category, *Marketing support services* addresses the stigmas surrounding counselling (and help in general), along with considerations regarding optimising the approach to families. Future focus areas sit in the middle.

Some themes have not been reported as they are not directly related to the research question; rather, they are centred on the nature of the child cancer journey and its effect on families. They are summarised in Appendix H, and further information can be requested from the researcher. One such theme regarded COVID-19 impacts, as although each participant talked about the complications it added to their journey, it had little to no impact on their CCCN experience, potentially due to its flexibility in delivery (video calls versus in person). Some however noted an impact on CCF supports available to them, which could in turn impact the ability for families to access the CCCN, though it was not the case for these participants.

Figure 7

Thematic Map of Findings



Ideal social support themes

6.1 The Educated Outsider

This theme emerged as participants described what counselling did for them, filling a role that people in their family or community were not able to fill. They needed someone who wasn’t emotionally invested in their families, who wouldn’t be shocked or upset by what they needed to say and wouldn’t require support from them in return. This person could listen and acknowledge without offering opinions or advice or adding their own emotional reactions. Ideally, they were knowledgeable about families, communication, grief and trauma, in order to safely hold space for conversations about child cancer and offer gentle direction or coping mechanisms when required.

> *I feel like [counselling’s] essential, and not just from the grief [bereavement] perspective. I also feel throughout the cancer journey… any experience of having your child in hospital, it's a form of grief. And you need that support, because the images and the books and the movies and the expectations that family have, and well-meaning support… from lay people in your life - just won't give you that.*

6.1.1 Someone to Just Listen

As we progressed through the interviews, the picture of an ideal counsellor was built through the participants accounts of what they received from counselling. One participant talked about the key benefits of saying out loud what she needed to and how she worried about burdening others with her grief and pain. Her account also shows that counselling for others can relieve parents of the need to support them when they have no emotional capacity to do so.

> *One of the things about the counselling which I think is really important, is that there’s a point in your journey, where the things that you really feel and you really want to say… you can't …say to anyone that you care about because… you don't want your child to know how scared you are …you don't want your [partner] to know how scared you are, you don't want [others] to know how scared you are, because then they will worry about you. And it's*

> *bad enough what's going on. …you're trying to manage …your own grief and your own feelings …I convinced [a relative] to go to a counsellor too …[they were] needing a rock and I just couldn't be a rock for [them] …I was already just holding up enough people …and [they] found it useful too, just for the exact same reason… you can… give your grief and all your bad feelings [to the counsellor].*
>
> *…because everyone wants to hear your good feelings …if you go "Actually... I'm on the edge, and if I get one more ounce of bad news, I don't think I can hold it together much longer", people can't handle that. …even the people who care about you most …they can't handle seeing you in so much pain.*

Similarly, another participant described how having someone to listen and acknowledge without being emotionally invested in their family really helped. Her counsellor didn't offer opinions but made occasional suggestions about parenting aspects which she appreciated. Another echoed this sentiment of therapy as a place to let out her feelings while her counsellor listened.

> *I think I got a lot out of the therapy because I was really seeking a place to just literally verbalise some of the horrific things that I had witnessed through the course of my child's passing. …which I think any well-trained therapist could have offered as well. You know, just actual time and space to let out some of those things.*

Others talked about the huge burden mums carry and how they found benefit and relief after just having a good cry in a counselling session, as though a little bit of weight had been lifted off them. One talked about how her counsellor just seemed to 'get her' immediately.

> *She just always knew the right thing to say …she never once made me feel like it was a job to her… at one point I thought …we're just missing a drink here, and we could be at a bar anywhere, you know?*
>
> *She… got me, from day one. …she knew exactly when to listen and when to talk …she never tried to make me go deeper into feelings and deeper into feelings …what she did instead was give me coping mechanisms.*

Others talked about the need for an outsider to discuss deeply personal intimate difficulties, and how they could not talk about relationship issues with people they knew.

> *There was a point of time where there was quite a bit of bit of …stress, between me and [partner] …old issues as well we had in the past. …I had to talk to someone else. Because you know when two people start on an argument, you both think you're right. …it's just not ideal situation where we could talk to family or other people or friends. We did try to go and see [church leaders], once, but I just felt that it was too personal.*

Another participant talked about how she appreciated the invitation for dialogue that counselling provided, despite acknowledging that she was coping well during her child's treatment.

> *…it was that outlet to just say stuff …it was sort of more about the day-to-day trying to deal with [sibling], and …the family unit and how I was doing… My [partner] probably would have heard a lot more and… doesn't necessarily want to listen to the emotional side of things. So, it was nice to be able to …just be heard.*

6.1.2 Flexible Approach

The counsellors who really clicked with their families tended to exhibit very flexible approaches and were great at interacting with and relating to each member that attended counselling. Several participants talked about how well their therapists worked with their partners when they attended.

> *[I] was most surprised by how much my [partner] opened up to it, because [laughs], men just don't, usually. And for my [partner], it's been difficult. He tries, but there are very particular people that he either relates well to or doesn't, and our therapist felt like she was just the perfect fit.*

> *I think she did an amazing job of walking us through it at our pace. And I think that's an incredible skill as a therapist …I think especially with a couple that must be quite difficult.*

One participant talked about how her counsellor listened and adapted to her needs and what she wanted to achieve through therapy.

> *She did sometimes bring up some other very accurate details, more related …to my relationship with my mother …or mothering in general …so I was pretty quick to say "I think you're right about that. But I don't really want to spend …our time talking about that". …I really wanted to get into the nitty gritty details of [child's] actual passing… and the time leading up to that. So, I felt like she did well to hold space for that.*

The same participant took ownership for the ultimate outcome of the therapy and was directive in her approach as to what she wanted to achieve, whilst other participants went into counselling with no set expectations.

> *…she really was wonderful in meeting me where I was. I think I walked into our first session being …very explicit about what I had hoped to accomplish with our time, which was that I wanted some relief from the intrusive thoughts, and sort of work through… some of the guilt and pain that I was feeling around the amount of suffering that I witnessed my child go through at the end of her life. And I feel like she did very well to… allow us to stay pretty firmly rooted to that goal.*

One participant talked about how she appreciated her counsellor embracing humour in their sessions as that was a coping mechanism she used when most anxious.

> *…when I'm probably at my most uptight, I use humour to cover how frightened I am. And when I was unloading some of my deepest feelings and thoughts to her, she would just sit and listen, and then I would always finish with some wisecrack at the end, and we'd both end up just pissing ourselves laughing.*

Several therapists made sure to mention that they may not be the right fit for every client and that they could request to try another. While this was experienced as a positive approach (as it empowers clients to seek the help they need), not all clients in this study felt comfortable to take them up on this. One participant who was less enthusiastic about her relationship with her counsellor said she “always find things like that difficult” and it would have to be “pretty bad” for her to speak up.

Another participant talked about her counsellor’s reflexivity when it came to different ethnicities or backgrounds.

> *I feel like it doesn't really matter which background you come from, in that there's always difference with people, isn't there? Just the fact that people grow up differently, even in the same country, even in the same house, different experiences shape us so differently. And I think it's very important for a therapist to be able to work with that. And what I felt with [counsellor] was that even though she didn't have specific knowledge of what my background might bring to it, she very much flowed with it, and nothing was made to feel alien or irrational or anything.*

One participant who had both parent-focused and child-focused therapy with her counsellor talked about how her counsellor assisted with her son’s treatment adherence. They had initially sought counselling for relationship issues then realised how much she could help their child. Having an outside influence who her son liked and trusted was huge in helping them through treatment.

> *…I'm in his face all the time, telling him everything he needs to do, and he's lost absolutely all the control of making decisions… [counsellor] just said, “…Mum is doing everything for you at home, and you are sick now so you don't have to do any of the housework… any of your schoolwork… your only job is to make sure you …take these [medication]. And you know you can do them, right? And if you take them …then maybe you could get a little reward…” …so that worked really well. We've seen improvements pretty much straight away.*

> *…she will normally draw a picture …so visualising it. And she can be quite strict… but in a very, very soothing way. I don't know how she does it… I'm thinking “That's exactly what I've been saying!” But sometimes it does take a third person… to come in and do that.*

Another talked about how her counsellor adapted and included their child in sessions when they didn’t have a carer for them, reiterating how important it is for family-focused therapists to be offering this service.

> *Because we didn't have a babysitter at the time… [counsellor] was so great with it. …she would have a separate table for her. We would set her up with her iPad… and when… as [children] do, interrupt things... [counsellor] just made it feel organic. …she would stop and listen …and gently redirect her or be patient if we needed to attend to her …so even having our [child] there… didn't feel disruptive.*

6.1.3 Relationship and Shared Experiences

Participants talked about how the excellent counsellors took the time to build relationships with the families and work with them holistically. This was most evident in the stories participants told about their children and counselling. One participant described how much her child opened up over the course of counselling, due to the counsellor’s effort to build rapport and meet him where he was at.

> *I think being there was quite healing for [child]. …he is so comfortable there. He just goes around and pick which game that he wants, what picture he wants to draw on the board. And sometimes he will go in and just chit chat for 15, 20 minutes - tell [counsellor] about what happened at school, and what …sort of cool thing he's done over the weekend. … she's seen him from the …very bad …to who he is today, and what kind of difference that she's able to make and help him along the way.*

> *…it was pretty much from …crying for half an hour of the session, to [crosses arms on chest] “No, I'm not going to talk at all today” for half an hour of the session, til …he would come in and say, “Hey, you promised me we'll be playing that game…” and he will choose a game to play to start the session and then it will be [counsellor’s] part of what she wants to talk about for the second-half of the session. …it's been working really, really well.*

One participant talked about the differences in approach between hospital supports and their CCCN counsellor. The psychosocial support in hospital provided lots of resources and information but didn't seem to focus on relational aspects.

> *…what I found was the [support] on ward… there wasn't a relationship built beforehand. And when [child] hit the absolute bottom, they came in trying to rescue. But… for children, if there wasn't a relationship, it just doesn't work that way.*

Another participant had a good experience with their hospital psychology support but said they met a few families who wouldn't meet with them because it's someone attached to the hospital, and they had "*a lot of anger towards the medical establishment*". She understood this as her family had similar feelings themselves at times.

Another factor that contributed to a strong therapeutic relationship was similarities between the participants and their counsellors. Key areas mentioned included personal experience with grief and loss, parenting, and similar aged children that made them a good match with their families. One participant appreciated that her counsellor was a woman around her age who was married and a mum to teenage children, which really helped them bond and they had lots of discussions about parenting teenagers. She said matching people up carefully with the right counsellor is the magical part of the CCCN.

> *[counsellor]'s …been a huge help. …I went to tell her one day and I just burst into tears… so, I sent her a text of exactly …what she had done for me …it was huge to have somebody. …[partner] and I were having quite a few problems at that point. …as a person my age who was married, and with …kids …she got it. …if I'd had …a new graduate…it just wouldn't have been the same. So, I think the counselling itself is important, but also getting the right person.*

Another cited similarity between herself and her counsellor in terms of education backgrounds and said they bonded over "mum stuff". She also felt like her counsellor genuinely cared about her and her family. Another talked about how they accessed counselling through

Hospice and that her partner really appreciated seeing a male therapist who had lost a child so understood what they were going through. She noted that such criteria were a big ask but that real-life experience was invaluable.

6.2 A Safe Space

6.2.1 Supportive Environment

Participants talked about counselling environment, with “supportive” and “safe” adjectives commonly mentioned.

> *I was taken aback by how well we resonated with her. How… comfortable and safe, she made the space.*

A key component for effective counselling was that participants felt safe and supported to vent, talk about life issues, work on relationships, cry, shout, and let their guard down away from their child. One participant who hadn’t had counselling before described how the first session wasn’t easy. She wasn’t sure what was supposed to happen, but once she was invited to talk about her child, she was able to let out a lot of bottled-up thoughts and emotions.

> *…she said “Well, what do you wanna talk about?” And I was like, “I don't know, I just figured you'd ask me some questions”. …“Well, do you wanna talk about [child’s] story and what happened?” …So, I told her the story and …started to undo… the layers I guess. …before I knew it, I was telling her all these things that …I hadn't told anybody, and not anything sordid, but just things that I was like, wow! …I didn't know I felt like that, but that is actually how I feel.*

Welcoming Physical Space

An inviting physical space appeared to be key for successful counselling. Participants talked about the good spaces being family-friendly, warm and inviting, and not based in the hospital. One participant talked about the difference between the hospital environment and her CCCN counsellor’s rooms.

> *…in the [local] oncologist ward… they don't actually have a room. …It's just a …very small meeting room. …Where the place we've gone to see the [CCCN] counsellor …she's just got lots of toys and …lots of fidget things …and you walk in there's this really warm feeling. …he could draw on the board. He could play with any of the toys while we were talking …and he get lots of choices of which chair you wanna take, or is it a bean bag? And where at [hospital] …for children to be taken to a separate room …that's a meeting room, I think… in a sense [child] was feeling that he's going to be… told off.*

This was reiterated by her child who joined us during the interview and animatedly told me that his CCCN counsellor had comfy pillows, a bean bag, and toys. He described how they did lots of drawing on her whiteboard, how well she explained things, and about her fun card games. Other participants reiterated this sentiment, such as "Any reason not to go back to the hospital was a good one". Another who utilised the hospital support for their sibling talked about how they arranged to have their sessions off-site.

> *We did continue our relationship with the hospital counsellor for our eldest child. …helped her through her grief journey …but we arranged with CCF to use one of their rooms… they have a office not too far from the hospital. …that was a great help in not having to go into the hospital. … I think for myself and [partner], we probably were OK, it was difficult. …But for [child] it was traumatic going every time.*

The mode of delivery preferences of the participants was variable, with some preferring in-person sessions, some preferring video calls (zoom) and others who didn't really mind, each referencing a variety of reasons. These comments demonstrate the benefit of interventions that provide flexibility in this area.

> *We had a few chats on zoom …I didn't feel the same kind of connection …as I did when we were in a room together.*

> *I actually prefer to go in [to CCCN counsellor's office] cos most of the time throughout the treatment I have …children …at home... It's …not a very comfortable place for us to talk about problems between Mum and Dad.*
>
> *I actually liked the zoom …it meant I could get it quicker, too. Because …it didn't have to be somebody from the area. …I sort of liked the fact that I always knew that I was gonna get upset, and …at the end of it I could just click off and I was at home. …it was quite good being able to fit in with [child] sleeps and not have to …find a babysitter.*
>
> *Maybe that was …the point of difference …she was working from home, and I was in my home, and so we could feel that comfort of space? Rather than meeting in like a clinical space or… office …where potentially it might not have had the same effect.* (Participant talking about her good experience via video call)

Sufficient Sessions

Regarding the number of sessions, one participant felt six sessions was never enough for effective therapy, and that it could take that time just to build a therapeutic relationship. She was glad she had the ability to extend but was still acutely aware of time and as such, was very clear with the counsellor about what she wanted to achieve. She noted her training in a similar field likely had some bearing on this. Another participant felt six sessions was just right for her, and that nothing was left unresolved. One was not aware that she could access further funded sessions (until I advised her in our interview), which is unfortunate as she felt "fell apart" after her child's treatment finished. She felt more sessions could still help her work through some issues so may now pursue them.

> *I don't know if it was assumption or whether it just wasn't clear enough …the counsellor said … "if you need to come back …let me know". …But I thought that …it would be on me …to pay for. And whilst I would if I was really needing it … you know it's always a factor …could I be spending that money on someone else? …knowing that it's an option to still get them paid for, then it's probably something I would have taken up earlier.*

Another participant opted to keep a session “spare” in case she needed it after her friend passed away from cancer. She said she was sure if she really needed something, her FSC would “tweak” it to get her some extra help. When I assured her extending her sessions is not “flouting the system”, she said she would certainly use them if she felt she needed them but at this point was doing ok.

Two participants described how fundamental the extension availability was for them, with both still currently accessing counselling - one for managing complex grief, and the other primarily for supporting her child through treatment.

6.2.2 The Right Skills and Content

Family Relationships and Communication

Most counsellors helped families at some point with relationship issues, primarily regarding communication. Several participants talked about how important counselling was in keeping their relationships intact. One participant talked about how she got to a point where she left her partner, and she didn’t know how troubled relationships could possibly last through child cancer.

> *We’d had a huge blow up, and I’d actually left him. …cause I just couldn't cope with that part anymore, and I knew that our… cancer journey wasn't finished …we had a strong relationship going into this. …I love him to pieces, but he didn't cope. …he found out I was going to see [counsellor] …and he was like, “Can I come?” …[counsellor] was really, really good …and it's fair to say probably saved our marriage.*

> *I just can't imagine how it would feel …to find out your child has cancer when you've already got relationship problems. …that must just be instantly the end. …we saw lots of couples not survive who had turbulent relationships already, and …that was just too much pressure for them.*

One participant talked about games the counsellor utilised to foster family dialogue, helping them learn about how each other was feeling, and how she noticed her partner making changes in his behaviour after the sessions.

> *…we've done quite a few ones with …all three of us …playing cards games with …different expression of feelings …that just got all of us …talking… that was a time where [child] could say things about me and Dad as well. …where at home if you ask him "Hey… what do you think of me, or what do you think of Dad, doing this?" You know …it's never, quite right thing to do at home between us. But when there is a third party and she's got the professional training and the games to open up the topic, [child] was really, really good about sharing his feelings …there were a lot of things we've never heard of before.*
>
> *…[partner's] just not someone who's very open about his feelings. …[child] can be quite shut down …and straight away [counsellor] was asking, "What about Dad? Is he very open about his feeling?" And I …thought ohh, maybe it's not so strange cause you know they need the male example at home. But …[partner's] been really focused during the sessions. …you could see how he's made the change afterwards. …he's putting things in action. Which I think was quite nice.*

Another participant talked about how having her counselling sessions as an outlet to talk and share her emotions might have helped her relationship even though she had individual therapy, as her partner prefers not to have those kinds of discussions.

> *I think we were both very similar in the way that we did deal with it …real sort of practical, pragmatic …I know that he could have had the opportunity to go [to counselling] as well, but I don't think he would have… taken it up, and would have spoken but… we have moments of… having those sort of emotional chats but …they're not really deep enough for me …well it's sort of like been and gone now so we don't talk about it… [counselling] just probably helped me be a little bit more sane, maybe? …So, it could have been worse if I didn't have it, let's put it that way. Our relationship… if I hadn't been able to cope so well.*

Each participant described how cancer impacted various members of their family and how their counsellors helped with issues like understanding individual reactions and communication. Several talked about how this understanding helped them down the track with other life events.

> *The thing that made a huge difference for us was, she helped us realise that, even though you're experiencing as two people, the same thing, the same situation, you might have very different experiences of it, and that your responses to that might be very different. And that that's not in itself, a disharmony. It's just what is. …And for us as a family, that's been quite profound, because …we all withdrew, but each person did it in their own way. And I think remembering that and truly understanding that at that time, has helped us with what we're going through now*.

One described how her counsellor helped her unpack her frustration about her partner's reactions which had a big impact on helping her move forward.

> *When [child] was first diagnosed and had their treatment …because [partner] was able to just move on …very quickly …that was really, really frustrating. …over time, I …was like, OK, it's just how he is and we're very different… And then this time around …feeling like, why am I …the only one affected by this? …how can he still be OK?*
>
> *…just having those discussions with her about it …reminded me that …people deal with things in their own way. …they're not my emotions that I have to figure out. So …if he's got it sorted, then he's got it sorted, and if he ever needs my help then I'm here, or …the service is there if he needs it. But I don't need to worry myself about that because I've got to deal with my stuff.*

Trauma Support

The importance of a safe space for parents to process complex trauma was discussed by one participant, who talked about herself and other parents struggling to find a suitable outlet to discuss trauma and grief. She talked about how she wasn't sure how to move on with life after grief. Her experiences with group therapy reiterates the need for one-on-one counselling for this kind of specialised support.

> *…in my parent group …I very nervously brought up …that I was really struggling with …traumatic memories …it seemed as though the other parents wanted to also talk about that? But …it didn't feel like our facilitator was comfortable facilitating that type of conversation. …they sort of steered us in a different direction… to me it felt very important to acknowledge that there is this need to say and talk about the really, really ugly and terrible and awful parts of that journey. …people do want to talk about it, and …especially with someone who's capable and able …to facilitate and process through …all that stuff.*
>
> *…hearing other parents experiences - we're all just seeking some …relief, and trying to make some sense of… this big incredible thing that has happened to us …how do we incorporate that into our sense of self, into our parenthood …and being a partner?*

One participant whose child had been in survivorship a long time, talked about how her counsellor helped her unpack the journey and revisit it with her child, to work through trauma that was being retriggered by cancer in her social circle. She talked about how constructive her counsellor was in helping her utilise previous coping strategies, uncover unresolved emotions and identify how and why she was feeling triggered. They discussed bringing out a memory bag of items from her child’s cancer treatment journey in a type of symbolic act to not have things hidden away, like her feelings about that time of her life. She felt this was integral in helping her move forward.

> *I hadn't actually unpacked the journey. …it was really good. …just sitting down with [child] and …looking at their beads and discussing them and… looking through all the little mementos and treasures and coming up with ways that we can not have them hidden away. …going through that process …helped me to work through something that's …been suppressed for so long.*

> *…Previous counselling sessions I've been to, I always get… that anxious feeling? But this was …a positive feeling …because I felt like I had growth in between our sessions. And so, I was… quite …excited to go into the meeting.*

Several other participants also described trauma retriggering, which led them to seek further counselling sessions or extensions.

> *"My visual memories… audio memories …all my memories through that time… became very triggering and very sensitive".*

Grief Support

Many participants talked about how they were supported through grief. They talked about counsellors helping them better understand grief reactions and the complexities of grief, not only in relation to loss of a child but the entire experience of child cancer, and how everyone reacts differently and at different times.

> *I think the most profound thing it did is, gave us a framework to give ourselves grace for the days when we can't cope. …because there are days, and that's how it goes. Sometimes the grief feels very big and very consuming, and other days it feels …almost not there at all. And that's not a time thing, and it's not a reflection of being better or not better. It's just how it is. And I think knowing that …you …cope better. But also, when you're not coping, you don't pathologise it as much. …it's not so catastrophic that you're not coping for a week or two, it's just, this is how it is. It's just a wave, kind of. …And I think knowing that made it feel… more liveable.*

Several participants talked about seeking assurance from their counsellor that they were grieving 'normally' and how this understanding helped them.

> *…probably the …best thing [counselling] did is… let me… not have too much expectation of managing it [grief]. Just making peace with it, that you cry, you fall apart, you scream, you shout. Some days you're numb, some days …it's very easy to see the joy in things,*

> *and that all of that is normal and OK. I think it's when we feel it's not OK to fall apart or there's something wrong with you for feeling the anger or …all the things that come up. That's when it becomes really… dangerous and …sort of unmanageable…*

> *I can't imagine how families go through a grief journey without this kind of support. …without that knowledge, without that safe space, without that secure feeling that you're not abnormal. You're not broken, you're not doing it wrong …this is hard. And that's just what it is, and it's OK.*

> *[Partner] and me just had one appointment together. It was kind of enough for us …talking to somebody that didn't know anything and we could just pour it out, and she could sort of say, "Yeah, you're grieving normally" or "You've got something you need to sort out" or whatever.*

Others talked about different complexities of grief such as guilt or worry, for example that they could have done more for their child.

> *I'd… had …lots of worries that we hadn't done enough. …there was nothing that we could do for [child], …there's 0% survival rate with that sort of [cancer]. Which in a way was kind of good …that there's nothing that was gonna get rid of it. And you kind of accept it. …But, I …sort of went through a patch of worrying …what if we could have… got [child] into some trial in America, or… done something… and… [counsellor]… really …drilled down and talked through that… and… worked it out. Which was awesome. …she didn't …try and brush over it and move on.*

Some participants described amazing grief support for their child's siblings. One talked about how much of an impact the counsellor had on their child by working through her grief in a way that was age-appropriate and meaningful to her.

> *It started off just with counselling for our child, cause they were sort of like twins. They were pretty close. And that was... amazing. …you know …when you actually say your problems out loud sometimes …that sort of lessens them? …she gave her quite a few good little tips*

> *and things to do when she was feeling sad …asked her …what things… were big in her mind… the first session was the burial… because that's so… literal …with kids. …she got her to draw it which was quite neat… draw what she was thinking.*
>
> *…after she really knew [sibling] and what she …liked doing …she suggested that …we got a little nice box. And when she was wanting to sort of tell [child] something, or she was feeling especially sad …she could write him a letter and put it in the little box. …She still writes him letters… it helped her so much. …a lot of them were just pictures of the family or trying to sort of draw heaven and where he'd be.*

One participant was assigned a grief-specific counsellor and she felt this was a major strength of the CCCN service. She learnt a lot from her sessions, and it helped her family adjust their lens' of what grief should look like.

> *Like in the movies… that's how we expect grief to go. We expect it to go for a short time, and you do a bit of talking, a bit of crying, and then you're better. …so when we first went into the session …that's what my [partner] and I were expecting, even though it felt like that could never be the case. …you feel in your heart how could you ever be better? But there is an expectation that that's how it would go. …but being through all of the sessions and having a better understanding of grief and loss and love, I don't feel that there was anything that was missing [from the counselling].*

She also talked about friends who had pursued private counselling with less success than she felt they would have had with the CCCN.

> *I think the fact that… the CCF already …had access to these grief counsellors …was amazing. It wasn't just walking into a generic office… [it] made the therapy itself go as well as it can… we've got friends who did their own private counselling, and they went with counsellors who are not so versed in grief and their experience has been very different.*

Child Cancer Knowledge

There were positive and less than positive examples recounted of counsellors demonstrating that they were versed in child cancer. Only one of the participants verbalised that she knew her counsellor had been educated about child cancer. Several said they wondered what sort of experience their counsellor might have around supporting families with child cancer.

> *…her journey with grief hadn't been cancer specific. But …I think her life experience and her way that she does her therapy, didn't make it feel like an obstacle that she didn't have personal experience with the child cancer journey. She was very open and …listened well, and immediately understood the nuance and things when we explained it and took that on board.*

An example of why the CCCN counsellors are given child cancer specific training was described succinctly by a participant whose child was seeing a private counsellor they found via the internet.

> *…their first appointment, [child] had just found out that she'd relapsed, and it's fair to say he didn't cope very well with that, which in hindsight was pretty unprofessional. But at the time …his emotions came out and …he wasn't expecting that. None of us were. …I think there were times when he's kind of in over his head.*

Another talked about how she struggled to open-up during counselling. She was outwardly coping well during her child’s treatment, but had a sense that things were going to catch up with her later, which can be typical in child cancer. She wondered if the counsellor had questioned her differently, maybe she could have let her guard down and worked through some of her concerns earlier.

> *…the counsellor said …we're very pragmatic people. We just sort of got on with things and as nice as that was …to have that acknowledged …I did almost feel like I don't wanna be… ‘all together’ because …I did feel like it was gonna come out at some other stage or some other way… maybe just …a different line of questioning might have helped me really get down to things?*

> *…a lot of the stuff I was talking about wasn't really to do with …the cancer and [child]. It was more around how I was around… the rest of the family, or how the rest of the family were coping, and especially [sibling], which is great because …that's all part of the package… how it affects everybody else. …I think …a lot of it was me trying to deal with everything else so that I could… be there for [child], I suppose.*

Gentle Direction and Coping Mechanisms

Participants talked about their counsellors helping them look at things in a different way, assisting with gentle advice and coping mechanisms when useful. Some discussed different ideas the counsellors had to help them process emotions, and many talked about discussing aspects of parenting.

> *She …has this practical side of parenting. …I was like… "how am I meant to tell [child] off for saying some really awful things to me? [and]…what if …I waste what little time I have left with her by sending her to school?" …she would sort of give me a psychological slap, is what I used to call it… "That's ridiculous. You told me …that you hadn't given up hope. But that's the sound of somebody who's given up hope". And I'm like, "oh my God, you're right!" …I found… her quirkiness very… constructive for me.*

Several talked about the need for empathy, not sympathy, and how they appreciated their counsellors suggesting supportive coping mechanisms and a different perspective on things.

> *I don't think there's one magic answer to how do I deal with all of this? …That's why you go to counselling - you just want someone to give you a quick fix on how you can cope with all of this. But there isn't one. …there's a different one for every day, because every day …it felt like …something would go wrong and …would need a different fix, but she …gave me coping mechanisms as a general help, rather than specific…*

> *[Counsellor] …was the exact right person. …she had a way of… listening to me while giving me …not advice, but… a different way to look at things.*

Others talked about their counsellors helping them work things out themselves with gentle suggestions. One participant said she really appreciated the chance to sit down and talk in the sessions with her partner as felt that with the busyness of life, people do not really take the time to focus on and talk about issues.

> *…she's got a completely different style to the other person we see on the ward. …once we start talking, I think a lot of times we would be working something out within ourselves. She was there as a supporting person …and she will see things from different angle and …suggest… "what if you look at things different way", or "would you be prioritising this, while [child] is sick?". And she would …like kick the ball back to us and made us actually think …it just worked really well for us.*

Marketing support services themes

During the interviews participants suggested ways to help "market" support services more effectively to child cancer whānau, which may improve help-seeking and accepting behaviours. Several mentioned that counselling has a stigma which can make people want to avoid it, and others said even accepting support from CCF can be stigmatised, or families might feel guilty about accepting it if they think their situation is easier than others. Some thought if people understood what counselling could do for them, they would be more likely to accept it. Unanimously, participants talked about how crucial it is to have the right person offering the right information about counselling, in the right way and at the right time during the cancer journey, to ensure families can access it.

6.3 Breaking the Stigmas of Help and Counselling

6.3.1 Reluctance to Accept Help

Several participants talked about being uncomfortable with accepting support, and many knew other families who had said no immediately, who they felt could have really done with the support. Some hypothesised it might be due to a reluctance to let people in, feeling like they should be able to manage on their own, not wanting to be a burden, privacy concerns, differing backgrounds, or pride. One noted that it took her a while to be comfortable with the additional support system of CCF.

> *As someone who doesn't like to ask for help in general… them offering to bring us groceries or… our caseworker would come regularly for a check in. …it took me a little bit of time to be comfortable with… just another person, another layer of support.*

Others talked about how they realised early on they needed all the support they could get, especially those who didn't have a lot of support from their partners, or their support was limited by COVID-19 impacts.

> *You can't do everything on your own. …I think the other thing was realising that accepting help isn't weak. …And …as mums I think we're expected to …do everything. And …there comes a time when you just can't. …you have to know that you've got the right people on your team, and …man we were lucky.*

Many participants talked about how great their FSC support through CCF was, such as checking in on them, providing practical supports and visiting when they were at home. One participant talked about how supportive, intuitive and aware of their needs their FSC was.

> *…over time …[FSC] …became a lot like a counselling …person who would listen very kindly and give gentle feedback, and we aired out a lot of… very personal and private issues we were having and concerns about our child's care. And I always felt that she held that space …very professionally and very appropriately. …we grew to have a very trusting relationship with her.*

Many participants said they felt if people were told about CCF in terms of “what was in it for them” then they might be more likely to accept (covered further in 6.4.2).

6.3.2 The Stigma of Counselling

Most participants had not had counselling before, so talked about the surprises and benefits they experienced that could be used to promote counselling to others and dispel myths around it being a thing people access when they’re not coping. All participants said they now felt counselling could help every family at some point in their journey. Many thought acceptance could be improved by outlining the key ‘selling points’ of the CCCN, such as that the counsellors have child cancer knowledge, it’s external to the hospital, fully funded, available at any stage in the journey and can be extended, family focused, and that it is there to help you with everyday ‘life plus cancer’ issues not mental health crises.

> *[FSC] said, “…there's …therapists around New Zealand who are trained in dealing with whānau of child cancer patients. …we'll pay for it”. …I burst into tears. …I felt like …I was getting somebody who knew what they were doing.*
>
> *…if the [FSCs] are able to sort of talk about the counselling sessions and more than just like, “oh, it's to help you through your journey, or it's to help you with the grief”.*
>
> *We had amazing family support …and the counselling was like a add-on …to that …and it was a huge help for us. But I think people that haven't got much support, it would be like a lifeline for them I would imagine.*

Another participant thought the biggest challenge was that those who really need counselling might be the ones who are more likely to say no.

> *I don't know how they can word it …to tell people …there are statistics that tell us if you don't work out these feelings as you're going along, it's all gonna hit you at the other end. …one of my really good friends… is having a rough time. …they’re angry… they're looking for someone to blame …but …they really didn't have anybody in their corner because they never let anybody in the box, you know?*

One bereaved participant described how fundamental the CCCN's ongoing access was for them, demonstrating how processing grief or trauma isn't a one-off event for some families.

> *…in the last two months …my [partner's] usual coping mechanisms... hiding and escaping into various things, have become very problematic, and so through CCF …we're having [more] sessions …it feels like …if we didn't have that support to fall back onto, I'm not sure we would have made it through this period as a family.*

One participant thought counselling needed rebranding from a thing people access when they can't cope to something more positive or strengths-based. She suggested listing different scenarios it could help families with to increase acceptance.

> *…when you think of counselling, it can sometimes come across as being like you need help… and I know that that's what it's there to do [laughs].*
>
> *I openly talk about counselling and when I've had it before… because I don't want it to have a negative stigma. …if you're going through something as traumatic as this, the last thing you want is …people to be like "Ohh, your child had cancer …I feel really sorry for you. Ohh, now you have to have counselling, I'm* ***really*** *sorry for you". …it just feels like it's this added burden that you …want to steer clear of.*

Another participant talked about how other mothers who didn't take up counselling were very interested about what happened in her sessions, corroborating with others' sentiments that more dialogue about counselling and what it entails could help people move past the stigmas.

> *…the mums that I know who didn't have counselling asked me a multitude of questions about what we talk about …what's it like …it's almost like they're afraid to do it.*

6.4 Optimising Access

Participants talked about how they and people they knew struggled with and processed emotions at different phases of the cancer journey, and why it is imperative that help and counselling are offered the by right people, in the right way, at the right times.

6.4.1 Diversifying the Approach (Who)

Participants described the need to ensure families are aware of what they can access. For some, this could have been improved by diversifying who suggests the support. Some key figures mentioned by the participants included medical staff, social workers and psychologists in the treatment facilities, and once families are off treatment, potentially other CCF avenues.

FSC-Dependence

The current CCCN model relies heavily on the FSC role as the main conduit for families to access counselling. Almost all participants talked about what an amazing source of social and practical support their FSC was. One said her FSC seemed to know exactly what she needed and when, and that she suggested the CCCN to her at exactly the right time. However, others had slightly less optimal experiences. One talked about not being assigned an FSC until a few weeks into her child's treatment. She would have very much appreciated the support of her FSC and potentially the CCCN as well in those early days as she spent a lot of time by herself in hospital caring for her child and trying to process what was happening. Another participant noted a lot of CCF staff turnover, resulting in them having multiple different FSCs in a row. She wondered if it was perhaps a COVID-19 impact. Another participant's FSC left, and she wasn't assigned a new one. It became clear that if the FSC continuity of care breaks down or if they do not pick up on when a family is struggling, families can miss out on crucial resources such as the CCCN. Many of the participants talked about diversifying who could suggest counselling so that FSCs aren't the main access route to the CCCN for families.

Alternative Routes

One participant suggested that Doctors could mention CCF, the importance of trained social support, and the CCCN in the family meeting when they go over their child's initial treatment plan, as she found the social worker she encountered slightly off-putting.

> *…get the doctors in that family meeting to say… "this is probably a good time to talk to you about CCF. They have an incredible support system and it's good to have an extra person as an advocate, who …isn't medical and can explain things to you …and they're there to help you".*

Others thought that hospital support staff could be briefed on the CCCN and suggest it to families if hospital-based psychological support wasn't the right fit for them. One participant who didn't have consistent FSC support was informed about the CCCN by a social worker. Ensuring that all social workers are aware of and equipped with information about the CCCN would present another route. Another participant mentioned that CCF could promote the CCCN in their emails to families, as a reminder particularly for families who aren't on treatment. Similarly, other CCF groups such as Connect or grief groups could mention the CCCN to whānau. These alternate avenues are crucial if FSC support ends. One participant who did not have an FSC anymore, was a regular at her local Connect group. Luckily, she happened to mention she was struggling to the coordinator and was referred to the CCCN by them. Another was under the impression that the FSC relationship and CCF support ends when Beads of Courage is complete, hence thought that was the end of any counselling access as well.

Counselling Advocates

As the interviews progressed, it became clear that most participants received significant benefits from their counselling sessions and wanted to assist other families to receive the same. All participants were very invested in the study and requested a summary of findings after completion of the study.

Participants talked about their new outlook on mental health and counselling. When people have a good experience, they are more likely to seek help in future, as was demonstrated by some participants accessing the CCCN several times in their journey. A strong sense of loyalty to other cancer families was also evident in the accounts of all the participants, with most saying that was why they agreed to take part in this study. They wanted other families to get what they need, and to help improve the service for future families. One mentioned this at the end of her interview, after noting that it was difficult in parts due to her grief.

> *I think the feeling that we're helping other families get support, that they would need, is the overriding feeling, if that makes sense. …So even though it was difficult, it feels worthwhile.*

6.4.2 How Information is Delivered (How)

Participants talked recounted different ways that information about support services and the CCCN was delivered to them, and how they thought it could be done better.

Not Relying on Brochures

An infamous 'welcome pack' that was given upon arrival for treatment was mentioned across the interviews, which without exception was not read, at least not early in the journey. Parents didn't have time to read through brochures and absorb information as they were too busy caring for their child, managing logistics and being caught up in the whirlwind of meeting treatment teams.

> *They give you this pack …the first thing you see is Make a Wish. The second thing you see is CCF with a bald kid and a tube, and you just go, how did we get to this? I'm not ready for this. …it's got the booklet about cancer and your journey and what's gonna happen. And I don't actually know a single person who read it till about halfway through their journey… it's extremely overwhelming.*

> *I just remember a booklet with a whole lot of information. [I didn't read it] I just used it to poke any paperwork in.*

One participant who didn't have consistent FSC support talked about not reading the brochures and how she wasn't aware of the CCCN until she opened up with a social worker about her struggles.

> *…I still think that …if I went and read through the booklet that they provided there might even be more things that I could discover or benefit from …but it's just not our priority …the information [about the CCCN] was there, when I …gone back to the booklet I was like ohh …look, they… say they can provide these counselling services. But I just didn't know, and I didn't need them. I guess I've asked the right time, and I've got the right person.*

Applying the Wellness Check-In

The wellness check-in is designed to be a way that FSCs can assess whānau functioning and support needs, ideally via a conversation. One participant perfectly articulated how the wellness check-in should be used for family assessments.

> *I think the way that they do the assessments, which is very flexible, is very good. …Sometimes with those kinds of things, there's a tendency to over-formalise the process. …with children in hospital and with bereavement …having a flexibility where the assessment could be done over the phone or in person… and …having those calls made in a very timely way, was very good. …It was very different than …when you try to access counselling or support …through your GP, there's a whole… bureaucracy, and then you get put off. …So, I think the way it's being done now is very good, and I feel it's important to state that and emphasise it so that it doesn't become like trying to access support through a GP!*

Unfortunately, others did not have this experience, with two participants being asked to fill out the wellness check-in like a form which made them feel like they were completing an eligibility test. Both were concerned at the time that they wouldn't be eligible. One participant described her concern as she wanted the counselling but felt she was coping well during her child's treatment.

> *At that stage …I wanted to take the opportunity of getting… the additional support, but I was also …I'm coping alright …I knew that I needed to talk about stuff, but I also knew that I was …getting on with it and I wasn't… in tears or anything every time [FSC] came… I was*

> *just very in control … [but] I didn't want it to come across as I was doing totally OK. …I wanted to be …eligible enough to get it.*

She did note that she wasn't bothered by the experience and was aware that the CCCN was very new so her FSC might have only just been trained on it. She was very grateful to have the counselling. The other participant was sent paperwork to complete via email (she didn't have a current FSC). She was also very concerned about her eligibility due to the length of time since her child's treatment and was not aware the only criteria she needed to meet was having had a child with cancer.

> *…I had to fill in a form, and then I sent that back …it felt like an eligibility thing. Which at the time I was really nervous about, because obviously it had been so long.*
>
> *…I know that there has to be some kind of …boundaries, but I was like 99.99% sure that I wasn't gonna be able to get it because I felt like my situation was …outside of that scope… maybe that could put people off?*
>
> *…if you're a family that's further on down the track; potentially… not sending the forms! …somebody just reaching out, having the discussion …over the phone or in person, and letting them know that …we'll just do the wellness check in. …or even just asking them why they feel like they need [counselling].*

These experiences are unfortunate and may have been representative of a new service that CCF staff weren't fully accustomed to. Most participants said their FSCs mentioned something like 'there's this support available, I think this might be a good idea for you?', and then the next thing the families knew they got contacted to organise an appointment, which is ideal.

Providing Accurate Information

As noted previously, successfully marketing the CCCN means promoting its key aspects, for example the funding, number of sessions available, eligibility criteria, matching of therapists to families, and that it is external to the hospital. Most participants said this was done well and they felt they understood the service they were getting.

> *[FSC] did an excellent job of introducing us to the [counselling centre] ...and the counsellor …what's offered, the confidentiality, all those parameters. [FSC] made sure that we knew that there were six …funded sessions, and that they could do a review for further funding if needed. So, it was amazing in that… we felt completely reassured and didn't have to worry about the logistics of it. We could just engage with it.*

However, several participants mentioned some gaps in the approach or information provision. Some were not aware that the only acceptance criteria are having a child with cancer, leading to two participants being quite worried they wouldn't be "eligible" for counselling, as per the last section on the wellness check-in. Others were not aware that they could extend their number of sessions if required and that they would still be funded.

One noted that it wasn't made clear to her initially what CCF does for families. This is an important comment as if this isn't approached well and families turn down CCF, then they also will not be able to access the CCCN. Several participants mentioned the CCF 'Beads of Courage' and one felt that some people see this as the main or only program CCF offers. To some parents this can look like more work for them to do while their child is on treatment.

> *The social worker comes along quite near the beginning and says, "would you like support from the CCF?" But they don't actually explain what they do … "…they send a person over here and they can help you, and …they do the Beads of Courage" …there are families …that just say no to CCF because they think it's all about the beads and all they see …is work… they don't …see it for what it is, which is a massive form of support.*

6.4.3 Offer Early and Repeatedly (When)

Every participant said the CCCN service should be offered right at the start, as even though the families may not be in the state to accept or retain the information at that point, there will be some that will and might find it a huge support. Others may remember down the track when they need it. Some might go through their pamphlets later and decide to take it up, and for others, hopefully their FSC will bring it up at the right time. Many talked about the need to continually remind families that it was available.

Participants highlighted that families struggle at different times and people accept or seek out help when they are ready, but they need to know what is available to them. In addition, some need help at more than one point in the journey, so it is important to offer repeatedly, promote the extension process, and keep contact with families into survivorship.

> *[Counselling is] definitely needed throughout the whole journey… even post… you don't know what might trigger you into …needing it. …if anyone else out there was like me and …put all those feelings aside and just tried to get on with normal daily grind …they are gonna resurface so …having …that service available has been good.*
>
> *I do think… at some point throughout the journey every family would benefit from having these sessions. It's such a… life turn around.*
>
> *The counselling is vital… all they can do is …highly recommending it …over and over again. …And when they get home, maybe it's easier? …they know where they're at, maybe.*

Most participants described the whirlwind of arriving in hospital, diagnosis and start of treatment. The families were meeting many new people and trying to retain a lot of medical information. So, whilst they agreed the offer of support (both CCF and counselling) should be made early, the caveat was that a brief introduction was key and to not expect families to accept immediately whilst they are grappling with their new reality.

> *The first day people offered us support and counselling …I just remember thinking …I'm not gonna be a hero here …I've really gotta hold this together. So… I'll go see a Psychologist, see what happens*.

> *I do really feel strongly that … if a child has been diagnosed terminally, that an early intervention… just to say, "These are the people that are available to you …they can be now, it can be later, it can be after the fact". But just …making that early introduction*.

Some participants talked about the rush for their child to start treatment immediately after diagnosis. One participant said that at that time she was more concerned about being with her family and the logistics of where they would be staying than hearing about support services. Many said timing the information is key, with one suggesting perhaps waiting a week or two until families have a firm diagnosis and treatment plan, as a better time to introduce the support services.

> *A lot of it is about timing …if someone had said to me…" [CCF] can offer you free counselling", I would have been like… "No, we don't need that", cause at the time …you're getting your head around the fact that you're suddenly a child cancer family, let alone, you know? …It's a lot to sink in… I just said "Yes" [to CCF]… and [social worker] said… "I'll get someone to come over this afternoon". …like the second day we were at [hospital] and I was like, "No, please …It's too overwhelming" …we were meeting …it felt like a new face every half hour, and we didn't know who we needed to remember and who we didn't. So, to meet [FSC] then would have been a complete waste.*

Some participants talked about how they held it together during their child's treatment and 'fell apart' after, or experienced relationship issues due to stress. Their ability to cope fluctuated and they acknowledged that people aren't always outwardly struggling. If an FSC only sees the mother most of the time, family issues might be hidden unless she confides in the FSC. Some participants felt if they weren't as open about their situation they wouldn't have got access to the CCCN.

> *Some people may not like to share …family issues with others …I was able to share my feelings with the social worker at the time when we needed it or I struggled the most, and I got the help that I needed.*

The same participant suggested that after treatment might be an ideal time to have family sessions including siblings.

> *I just think it's so important cause it's such a big change to the lifestyle as well. …even if it's after the treatment …having a whole family counselling session …having the …siblings talking about their feelings about …how they see this whole thing affected on them.*

Several participants talked about needing help one year later, a common time that the emotional effects of the journey can impact people. One participant accessed counselling during treatment and needed it again later but wasn't aware she could still access funded sessions until we talked.

> *One of the things [they] said during [Cascade program], was it hits people a year later …it definitely did for me, and …still going through that …guilt about we're all good now and there's so many families that aren't… I still feel like there's room for it …during was useful, but more so afterwards.*

One participant felt she wasn't made aware that the service was available earlier than end of life. She reiterated that it was important to support families before they get a terminal diagnosis and throughout palliative care, then offering specialised grief services after a loss (more in 6.5.2).

Smooth Referrals and Extensions

Each of the participants felt their referrals were dealt with promptly. Some said they heard from their counsellor within a week, another was only a day or two. One however described feeling like she was given the only counsellor available at that time and had no other options if that relationship didn't work out.

> *It felt like she was the only person available …for …immediate start …maybe [hometown] doesn't have very many people who have the ability to start a new client straight away? …I didn't …feel like there were many individual options.*

Several talked about how much they appreciated that counselling was available when they needed it and how simple the extension process was.

> *I just thought it was awesome to have… a year down the track …I knew that I was gonna have down days but… after a couple of weeks of struggling to sort of get up and get going… I knew that I could still ask [FSC] if it was available, and it's good... just knowing there's something to fall back on… [it was] all done …via one text [to FSC].*

Similarly, two others noted their counsellors requested an extension on their behalf to allow continuity of support, requiring no administration or follow up from them.

6.5 Gaps Identified

6.5.1 Best Practice Māori Support

In this study, there was one participant who identified as Māori. It was important to address part of her experience as a separate theme as it indicated an area that requires evaluation to ensure the CCCN can provide optimum support for Māori whānau navigating child cancer. Although this section represents a single participant's experience, it is important to highlight potential learnings, whilst acknowledging that to fully understand Māori experiences with the CCCN, further study is required.

The key finding from her experience was that she requested a Māori counsellor and was not provided with one. She was not clear on why, other than a potential geographical issue which was odd as she was happy to access counselling via Zoom.

> *I'd asked if I could have a Māori counsellor. …When [CCF staff] went through the list, I think from memory there was one, but I think they were situated somewhere else? …out of the others …she said that …they'd done… some cultural stuff anyway. And …the one that I ended up doing, we were gonna have to do it all over Zoom anyway.*

When I asked if she would have preferred the Māori counsellor if it could have been possible via Zoom, she provided a bit more perspective on her request.

> *I was more interested …in [a Māori counsellor] …because I felt like there were …things that I wanted to talk about that …only another Māori person could probably relate to? …but …I was satisfied with how things came about. I don't feel like there's anything sitting there that maybe was unresolved …but that point of difference in having that opportunity would have been great.*

The participant described how she was happy with the counsellor she chose, and the cultural accommodations made. However, she wondered if there would have been some additional perspectives a Māori counsellor could have provided.

> *I would have been interested if maybe there were some different …cultural-type strategies? …we talked about holistic-type things… and ways that I could …through like meditation and … going to places where I can feel …calm and at ease... But …I don't know if potentially there could have been something different from a Māori perspective.*

She talked about her counsellor offered her the ability to switch to another provider, and that she felt safe and supported.

> *After the first session… she… said… "If after this session… you feel like… I'm not giving you the support… the advice you need, or you don't feel like there's any kind of… connection… you can just go back and let them know… not a problem. …I'd rather you go and get the help that you need than keep continuing on, not happy with what I'm providing". …I really liked her.*
>
> *It just felt like a really comfortable, safe space. …right from the very beginning… I always just felt supported, which was the main thing.*

She also described how her counsellor provided accommodation for sharing of pepeha and a karakia[7] to open each session. Aside from that there weren't any other cultural accommodations or questions regarding her Māori view that she could remember.

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[7] Karakia are Māori prayers or blessings that invoke spiritual protection and guidance.

> *…we had karakia before every session, which was really cool. And she allowed me to …have those discussions anyway. …I'm pretty sure she had said right from the beginning …I can't provide cultural …advice …or guidance in that sense. But …I felt like it was a safe space that I didn't need to be concerned about cultural things.*

> *She had asked me if I would… like to have our sessions opened with a karakia, and …if there were any ones in particular that I wanted. …gave me the space… to share my pepeha …wasn't necessarily …any other things prompted, from memory …cultural things …other than what had already been established. But I feel like if I wanted to… because that had already been set right at the beginning, that I could… I didn't feel like they were any barriers to it.*

She noted that she knew people who perhaps could have provided her with Māori-centric advice or guidance, but that she would have preferred someone more removed from her whānau. This echoes the need for an educated outsider, in this case someone educated in not only supporting the wellbeing of child cancer families, but also Māori-specific support that can only be provided by someone with Māori heritage and indigenous health knowledge.

> *There are people that I know of, like friends of family, that I could have gone to for that kind of support, but …I didn't. …I feel like I probably wouldn't approach them in particular. …maybe I find it easier when they're not as close? That I can open up more.*

6.5.2 Best Practice Palliative Support

Two participants in this study talked about their palliative care experiences, with one describing in depth the shortfalls in support she experienced through this phase.

> *How can we help support families get through an experience like that without having their lives completely fall apart?*

One participant talked about how hospices in Aotearoa aren't trained or set up for child patients, both from a medical and a support perspective. She described how she and her partner were left with significant trauma from a difficult end of life experience.

> *Paediatric palliative care is very limited in New Zealand, and especially if you live in a rural setting ...we …were working with a Hospice that …had never had a paediatric case before… people who are used to and comfortable with adult dying patients and not children… that heavily impacted our experience.*

One participant discussed perceived gaps in counselling and mental health support available to palliative families. Specifically, she requested support to be able to appropriately discuss end-of-life with her child, such as a Child Psychologist who could provide age and developmental-stage-based advice. Via a friend she was given contact details for someone who might be able to help, but when she contacted them they advised she was outside of their geographical treatment area and therefore could not provide support.

> *Particularly… the six months before [child] passed away, I started to ask about support services for end-of-life care… as it became clear that [child's] situation was terminal, I really wanted to talk to a child's therapist who had some experience with end-of-life care… It just felt a little bit out of reach for me …to talk to my child about what was happening.*
>
> *…The main element for the child psychology was …how to support my child… I was left with a lot of guilt and feeling like we didn't handle that part of [child's] passing as well as I would have liked.*

Unfortunately, she was not made aware of the CCCN service until after her child had passed away. She noted she would have taken up the counselling immediately, had it been offered earlier. It was not clear why this wasn't offered to her as she reported a good relationship with her FSC. This reflects the need for continuously offering the CCCN throughout the entire cancer journey, and if parents are asking for help every attempt should be made to assist them.

> *There are a lot of things that could have been in place to support us as parents, as a family, especially in a terminal life situation. …I think often …the end-of-life question becomes clarified well before the actual death. …so, there is a time period where parents know that their child is going to die, and yet… don't really have support services in place to deal emotionally with that? …after [child] passed is when I first started to hear about the counselling services.*
>
> *I remember through lot of [child's] care… the palliative team themselves were introduced to us very early on… "Once…we get to this point, these people will be the ones that will be part of your… care team" …and I think that's …an appropriate place to say… "and there are also these services… for mental health and well-being".*

Sadly, in this participant's case, she realised she and her partner would need to process a lot after their child's death, due to the unfortunate combination of medical and mental health support shortfalls.

> *Both [partner] and I were very aware that as the end-of-life was sort of evolving, the palliative care was… coming up short for our child. …that we were going to end up with this baggage after [child's] death, that we were gonna have to circle back around and [process] through.*

She also noted that had her other child been older at the time, another opportunity to improve palliative support would be regarding how to talk with and involve siblings during this phase. She noted there were some helpful resources available for supporting families after bereavement, but a scarcity of information regarding navigating the phase leading up to the death.

A similar case for early support was described by another participant. She also did not access counselling until after their child's death. Their FSC had offered counselling during the palliative phase, which she accepted, however their child passed before the first appointment. She felt that it was good timing that the appointment was already set up and they were able to go straight in, though in hindsight noted it would have been helpful earlier for some coping strategies to navigate the palliative phase.

> *The hospice team …all came to our house and had a… round table meeting. …it was [partner] and me and they were talking about …what the last days would be like and… they sort of had to warn us, I guess, about what could happen …but it was a bit overwhelming.*

6.5.3 Strengthened Grief and Trauma Focus

A minor finding was regarding improving grief and trauma specificity in the CCCN. One participant thought that the grief content of the counselling they received could be improved, such as compiling and presenting some different tools and outlets for people to navigate their grief.

> *I think there's definitely some scope for …an introduction to grief counselling… what… statistically helps people, or …helpful ways to move through grief, …and offering some of those tools to people. Because it's taken me now the better part of two years to go out and access …like grief support groups. …there's some really great things happening out there. I think a lot of the challenge is just consolidating it, and then presenting it in an appealing and accessible way for people.*

> *I focused that therapy primarily on the trauma… that felt very big, very unmanageable. I felt like …the consequences of our experiences was having an impact on my day to day living …outside of the norm of …grief impact. So, I was …wanting to give myself the best chance of moving through this time and space with more healing…*

One participant also felt that the trauma focus of the CCCN could be strengthened, and specific to child loss as she felt her counsellor wasn't fully equipped to deal with a parent with this kind of trauma.

> *While she did a great job, I don't think she was trained to …support a parent with such difficult [trauma]… I think losing a child is a very specific type of trauma now that I've been*

> *through it. And having …some professional training around that in order to support parents who are going through that [would be useful].*

6.5.4 Supporting Other Child Conditions

In this study, many participants talked with a combined sense of appreciation and guilt about child cancer being so well supported compared to other chronic illnesses and disabilities. Because the family experience is similar and there is potential for the CCCN model to be applied in other contexts, it was valuable to discuss briefly.

Several participants talked about other wards having no supports, whilst the wraparound service in the cancer ward was amazing.

> *[Counselling is vital] in other illnesses as well. …we met lots of families with cystic fibrosis and lots of digestive problems …that are in hospital for years and… they don't have anything. They've got no agencies at all.*

Many talked about cancer being so well publicised, with all the pictures of ‘bald kids with nose tubes’ in fundraising and the media, and how it attracts so much support and research.

> *The support for children with cancer is off the chart. …anybody who goes through child cancer in New Zealand and feels unsupported, either isn't listening or is turning people away because it's from everywhere.*

Several participants talked about feeling guilty about the amount of support they got, when others get none. One talked about a person she knew whose child had a rare disease. who said to her (before her child was diagnosed) “I wish my kid had cancer …because cancer kids get everything. Everyone knows about it. They're pouring money into it”.

One participant had the unique perspective of supporting her child with an existing chronic condition through cancer. She outlined how cancer treatment compared to her everyday experience managing her child’s health needs. Her story represents the experience of many conditions in which parents are trying to fulfil dual roles of parenting and caregiving with no end in sight. She described how shocked she was by the level of support for families navigating child cancer.

> *Going into this whole thing with cancer was… like a double whammy… because we're already dealing with quite a lot. …one of the things that I just can't get out of my head ever since we've done this counselling …is that there's nothing available like this …any of the support that we received from CCF, for children with [other conditions]. …it really overwhelms me …it just makes me feel quite sick …that there are lots of families struggling, and not having the people to talk to or the means to get access to people to talk to, in the same way as what CCF have been able to do for us. …it's light years apart …I'm still blown away by it.*

We discussed how she felt cancer was so much easier than managing her child's other chronic condition. She noted the cancer experience was more predictable and finite compared to their everyday struggles, that there was so much support available, and her child coped remarkably well with the treatment protocols.

> *It's just an everyday struggle …it's harder than [cancer]. …with the cancer treatment …we knew what we were doing every day …we had certain days that you'd go into the hospital and get bloods …it was like we knew everything that was on the plan… and we were very hyper-focused on that.*
>
> *…the everyday …hard stuff for [child] …it's just normal practice. …it was almost easier to just go and do the hospital thing.*

She also talked about how her social support networks mobilised during the cancer journey and then dissipated after, creating a feeling of abandonment and frustration. Outsiders just didn't understand how hard the family's everyday experience is outside of cancer.

> *As soon as it's over …it's completely forgotten about in everybody else's lives. …we used to keep them updated…and …have lots of people touching base and seeing how we were, and just doing…kind things for us. And that was amazing. But as soon as it… finished, it*

> *finished… they move on with their life …that was really hard actually. It still is… we were still going through lots of… [health] stuff that still comes up regularly. …and…the whole [non-cancer condition] is still there and that's way harder. …that part makes us really sad.*

6.6 Summary

This chapter presented the findings of the study as five key themes relating to the ideal scenario of psychosocial support for child cancer families, which most CCPs experienced from the CCCN, along with suggested areas for improvement. The following chapter will discuss these findings in the context of the current literature and present the implications for the CCCN and future research.

I feel for the people who can't unload their emotions …and can't go to someone like that and talk to them.

Chapter 7. Discussion

Given the undeniable strain and distress experienced by families navigating child cancer - and evidence of the benefits of adequate and timely psychosocial support to assist coping - this study sought to evaluate a new support service in Aotearoa New Zealand, the Child Cancer Counselling Network (CCCN). Through semi-structured interviews with seven mothers who varied in background, geography and cancer journeys, an understanding of their experiences with the CCCN was explored. All participants described benefits gained from the intervention and that access was generally good. Five main themes relevant to the research questions were identified. ‘*The Educated Outsider’* and ‘*A Safe Space’,* outlined the key aspects of successful social support and counselling for child cancer families. ‘*Breaking Stigmas’* and ‘*Optimising Access’* discussed the stigmas associated with accepting help and undertaking counselling, along with the best ways to “market” counselling to ensure it is available to families when they need it. *Future Focus Areas* included potential improvements for the CCCN regarding best practice Māori support and increased palliative focus, along with a clear narrative that child cancer is well supported whilst other child conditions are not, representing a future expansion opportunity.

This chapter provides a discussion of the key findings of this research in relation to existing literature. Following this are suggestions for future research, an overview of the limitations of the study, and concluding thoughts.

7.1 The Impact of CCCN Counselling

7.1.1 The Educated Outsider

The key benefit of counselling for child cancer parents (CCPs) appears to be the provision of a safe space to talk with an empathetic and suitably skilled outsider. Participants talked about the forum it provided to process, vent, react emotionally and let their guard down, and counsellors filling a gap that family or friends could not. This narrative is strongly supported by other studies finding that CCPs need a space to openly express their feelings and experiences with an outsider who can listen, provide appropriate encouragement and normalise the emotional nature of child cancer experience (Hocking et al., 2014; Ringnér et al., 2021; Svavarsdottir & Sigurdardottir, 2013). Being able to cathartically express their emotions and fears (instead of tempering to make them more palatable for people who knew and cared about them) meant most participants expressed a sense of relief following their counselling sessions. This is supported by other studies noting that expressing emotion without judgement was therapeutically valuable and provided some relief from the isolation inherent in child cancer caregiving (Young, 2018a).

Counselling provided a place where CCPs could be listened to and supported, without having to worry about burdening someone or supporting them in return, a finding also noted by Ringnér et al. (2021). The space wasn't affected by social 'taboos' such as a reluctance to talk about child cancer, or a disinclination to have emotional conversations, and thus helped those who experienced processing disparities with partners and family. It also was a family-friendly space for children to work through their emotions, whether they were dealing with treatment, or grieving the loss of a sibling. The clear progress and positive outcomes experienced by children across CCCN therapy and the affinity described with their counsellors supports the assumption that child adjustment is improved with good social support (Uchino, 2009). Siblings also received support through the CCCN, supporting previous conclusions that they can also benefit from a safe outsider to talk to (Toft et al., 2019; Wawrzynski et al., 2021).

Although the therapeutic approaches within the CCCN service varied, counsellors appeared to share a focus on fostering of positive therapeutic relationships which was in contrast with accounts of treatment centre services. Hospital support seemed to be more focused on acute solutions, information and resources, than on relational psychosocial support. Along with counsellor approach, shared experiences and background between the CCP and counsellor assisted the therapeutic relationship, with qualities such as age, gender, parenting, education, and experience with grief mentioned. The majority of participants talked about how their therapist felt like exactly the right person to meet them where they were and that they seemed to genuinely care about their family. This shows that overall, the participants were well-matched with their counsellors during the referral process, representing a strength of the CCCN model.

The supportive outlet provided by the CCCN was clearly important to the mothers in this study who all adopted the primary caregiver role, a phenomenon well established in the literature (Eaton Russell et al., 2016; Young, Bowers, & Bradford, 2021). Many participants expressed some degree of lack of support from their male partners, both physically and emotionally, a narrative that is common in the child cancer literature (Deatrick et al., 2018; Shortman et al., 2013). Mothers tend to bear the strain of an unrelenting first-hand experience of their child's suffering (Kearney et al., 2015), which in this study resulted in varying degrees of acute and chronic grief and trauma. Other studies have agreed that providing mothers with specialised counselling can help manage their caregiver burden and facilitate their ability to cope, which in turn helps their child (Bautista et al., 2021; Kaushal et al., 2019) given parental distress is highly linked to child's (Bakula et al., 2020; Willard et al., 2017). In this study and others, mothers have shown they often utilise more dialogue-based and emotional support means of coping, so the counselling was able to provide space for deeper conversations that partners, friends and family could not or did not want to engage in.

The literature has clearly pointed to the need for knowledgeable counsellors to support CCPs and their families. Many studies have noted the benefits of psychologically-trained individuals as opposed to nurses or medical support staff in provision of psychosocial support (Fallowfield, 1988; 1991). In Ringnér et al.'s (2021) study, parents wanted to talk with someone who could help them understand and work through their emotional reactions, whilst professional mental health training has been linked to effect sizes in other research (Sánchez-Egea et al., 2019). This and the overwhelmingly positive response from the current sample supports the CCCN's inclusion of only trained and accredited mental health professionals to deliver counselling.

Understanding the child cancer journey has also been reported as imperative for empathetic counselling with CCPs (Young, 2018a). In the current study, only one participant was aware that the counsellors were educated about child cancer, and some participants even questioned what experience their counsellor might have had in this context. This is unfortunate given the specialised training counsellors receive to ensure they can provide appropriate support and poses the question of whether the training was sufficient. A stark contrast however was reported by one participant whose child's external counsellor reacted emotionally and "unprofessionally" upon discovering the child had relapsed. This example could suggest that the CCCN counsellors were adequately equipped for the realities of the child cancer journey given no similar situations were reported through the CCCN. Another explanation might be that the counsellors focused the sessions on what was important for the families to cover rather than explicitly demonstrating their knowledge of child cancer. Regardless, reviewing the training content and ensuring the service is adequately explained to CCPs would help address these points.

7.1.2 A Tailored Intervention

Given the approach of individual counsellors is not known, it is not possible to compare or contrast with the current majority of studies that assess the application of CBT or problem-solving skills (Koumarianou et al., 2021). In addition, the varying therapeutic foci for individual families meant a wide range of content was represented. However, what can be discussed is the general approach and outcomes detailed by participants. The variability represents a key strength of the CCCN, its flexibility, as participants described various approaches and how they each worked for their unique situations. This is in alignment with previous studies emphasising the parent-reported need for flexible interventions, tailored to distress, diagnosis and phase, or in other words, application of a traumatic stress framework (Hocking et al., 2014).

Whilst the CCCN is aimed at supporting parents, its inherent flexibility means any member of the family can receive support, and the accounts of participants noted uptake for individual (mother-only) therapy, child-focused, couples and families. This is a key strength in comparison to other family-focused interventions such as the Surviving Cancer Competently Intervention Programs (SCCIP & SCCIP-ND) which stipulate the involvement of both parents in each session (Kazak et al., 2007) and can result in reduced uptake (Hocking et al., 2014). However, given many participants talked about marked absences along with communication and coping disparities with their male partners, requiring the involvement of fathers could also be seen as a strength of these interventions. A balance could be found in retaining the flexibility of the CCCN so that mothers can still access support alone but increasing the focus on encouraging fathers to attend as well.

Most counsellors demonstrated their ability to interact with and aid different members of the family and provide a space facilitative of family-focused work. They interacted well with husbands who attended, and their family focused approaches were appreciated by those who took their children. This sample utilised the CCCN for a wide range of assistance, for example coping mechanisms, relationship help, communication support, understanding grief, trauma support, child-focused grief work, and child treatment adherence. Examples were also provided of counsellors accommodating client expectations and therapy preferences, cultural inclusions, and differing backgrounds. The CCCN counselling also allowed families to work on whatever was most front of mind or whoever was struggling the most, evidenced by participants who commenced counselling for themselves, then switched to child focused or relationship assistance.

A key benefit of the CCCN was grounded in fostering family dialogue, helping individuals learn about each other’s feelings and helping children open-up emotionally with their parents. This is supported by other studies who noted understanding each other’s perceptions of the cancer journey was key for familial relationships (Salem et al., 2021). Open parent-child communication has been shown to impact child quality of life during cancer (Son et al., 2019) and children’s adjustment is highly influenced by the way the family reacts (Rosenberg et al., 2014; Van Schoors, Caes, Knoble, et al., 2017). One participant noted positive changes in her husband and child’s behaviour following counselling. This supports the family systems and social ecological grounding of the model by demonstrating the changes with individuals and the family unit as a result of a family-focused intervention (Kazak et al., 2017). Similar family interventions have also noted improvements in communication, family functioning and relationships (Kazak et al., 1999; Lövgren et al., 2021; Svavarsdottir & Sigurdardottir, 2013).

CCCN counsellors appeared to act as advocates and mediators in family and couple sessions, with gentle suggestions and a different way of looking at things. In addition, they provided ideas to process emotions, and practical parenting suggestions. Generalised coping skills were reported as beneficial for emotion management, which aligns with other work noting that an enhanced feeling of control can help manage emotional distress (Levesque et al., 2023). Participants also appreciated gaining understanding about individual differences in coping reactions. The provision of reassurance that it is normal for everyone to react differently even when a family is going through the same experience, helped families understand each other better and move forward.

Counsellors showed effort to build rapport and trust with the children they worked with and were able to assist with issues such as emotional regulation and treatment adherence. Previous findings have proposed similar benefits, indicating that child-centred interventions that improve communication can impact treatment adherence (Coyne, O'Mathúna, et al., 2016; Rokitka et al., 2017). The family sessions utilised through the CCCN appeared to offer similar benefits. Other studies have highlighted treatment adherence as a key concern for parents, and that developmental knowledge of counsellors can assist with strategies tailored to age and stage (Young, 2018a).

Provision of flexible and specialised grief therapy is supported by previous studies highlighting the importance of personalised interventions based on the family’s unique situation (Snaman, Kaye, et al., 2016). In this sample, several families sought endorsement and normalisation of grief reactions, and counsellors were able to assist them in understanding individual responses, and the length and complexity of the child cancer grief journey. This psychoeducation component appeared key for bereaved families, helping them to show empathy to themselves and other family members, and let go of outside expectations about how or when grief ‘should’ appear, progress or resolve. This finding is similar to Ringnér et al. (2021) who noted parents wanted to understand the mechanisms behind their emotional reactions. Siblings and husbands also benefited and the provision of specialised grief support for the whole family was highly valued by most participants and seen as a key strength of the CCCN. This is supported by previous findings demonstrating the benefits of family-focused grief interventions (Aho et al., 2011).

Grief support was not limited to bereavement, with counselling assisting those navigating treatment and experiencing grief about watching their child suffer, the changes in their lives and altered futures. In fact, bereaved participants acknowledged the inherent experience of grief across the child cancer journey, echoing previous findings (Lindahl Norberg & Steneby, 2009; Rabelais et al., 2019). CCPs sought help with historical trauma and retriggering, underlining these as common concerns experienced after transitioning back to 'normal life'. Understanding emotional response disparities was again valuable and helped CCPs focus on taking control of their own journey rather than trying to 'fix' others or seek emotional support from people who could not provide it.

7.2 Mode of Delivery

A key strength of the CCCN as described by participants lies in its community delivery mechanism; this could be seen to meet a need that previous authors have identified, with regards to a scarcity of psychologists knowledgeable about child cancer (Kazak & Noll, 2015). Having a provider who is external to the hospital presents benefits for families on many fronts, from a desire to avoid a physical building that represents fear, trauma and grief for both parents and children (Lichtenthal et al., 2011), to feelings of generalised anger and distrust towards the medical establishment resulting in reluctance to utilise hospital-associated supports. This is supported by previous NZ research highlighting a clear preference for separation between treatment teams and psychosocial support (Esplin & Rook, 2015). There was less agreement in this regard found in the current study, with several participants utilising both in-house and CCCN psychological support, though in-house supports were generally reported as less beneficial.

The CCCN counselling approach and environment was primarily described as warm, welcoming, and family-friendly. Whether attended locally in-person or virtually, the participants described the environment as facilitative to successful counselling and in stark contrast to the environments in treatment facilities.

Clear preferences were observed in the sample between face to face and virtual counselling, indicating that a flexible delivery mode is also important to CCPs. Benefits received did not seem to be effected by the method of delivery, perhaps given video-delivered therapy is still person-to-person (Phipps et al., 2020). Interestingly, each preference was strongly evident, with those preferring traditional in-person counselling noting they didn't think they would have had the same chemistry with their counsellor if it was virtual, or opting to pause their sessions during lockdown when they could not attend in-person. However, those who preferred virtual methods outlined their appreciation for the comfort of their home space, noting their ability to feel at ease and release their emotions freely. This is an interesting finding and aligns somewhat with other home-based interventions, which noted the environment could facilitate therapeutic outcomes due to its familiarity (Lövgren et al., 2021; Salem et al., 2021). One bereaved participant particularly appreciated that she could access counselling virtually as she knew she would become upset during the sessions, suggesting that virtual methods may be especially beneficial for parents working through grief or trauma.

Virtual therapy may hold other benefits for access such as time and cost-savings which is particularly important given financial strain can be a strong contributor to CCP distress. This is especially salient for Māori given financial and transportation constraints have been implicated as key access barriers (Slater et al., 2016). Virtual methods also serve to futureproof interventions for events such as the COVID-19 pandemic which can increase CCP burden (McLoone et al., 2020). Other studies have emphasised the guilt and logistical challenges CCPs experience when they are required to leave their child to attend an appointment (Ringnér et al., 2021). Participants in this study also experienced emotional and practical challenges in leaving their child for appointments for their own needs, but it was exacerbated by the timing with regards to the cancer journey. The start of treatment was particularly challenging to accommodate appointments, as families were adapting to a new reality and trying to establish a routine. These represent issues that virtual methods cannot fully address. However, the importance of offering virtual options is clear, and is supported by other research such as grief therapy delivered via videoconference to assist CCPs in managing long-term grief symptoms (Lichtenthal & Breitbart, 2015; Lichtenthal et al., 2019), and the Cascade group program which is currently offered to NZ child cancer families in survivorship via videoconference (Wakefield et al., 2016).

Six sessions of counselling (as is initially provided) appeared enough for most CCPs, but not enough for others. Some participants were also not aware of the ability to extend their sessions, highlighting the importance of adequately describing the service during referrals. The literature shows that six sessions is a common intervention length; however, Lövgren et al. (2021) found most families needed an extension in their family therapy study. These authors noted a scarcity of other supports available for families and given this was an international study it may not be representative of the NZ child cancer context. Some authors have noted that even brief (two-three session) communication-focused interventions can offer long term benefits (Svavarsdottir & Sigurdardottir, 2013), whilst more structured programs such as problem solving skills training may be more affected by length of intervention, as was demonstrated by the short version of Bright IDEAS (Lamanna et al., 2018). If families are to be offered support across their cancer journeys, then it is highly likely that extensions will be common due to the chronic nature of cancer and its associated psychological effects. This was evidenced by participants accessing counselling at multiple points such as immediately post-bereavement along with a year down the track or following a retriggering event, and extensions to support families through prolonged treatment.

7.3 Optimising Access

Themes regarding optimising access have been separated into categories of who, what and when for ease of discussion, though it should be noted that there is significant crossover between them, making delineation difficult.

7.3.1 Who

The CCCN relies heavily on the CCF FSC role as key conduit for family access. Participants clearly articulated the need to diversify beyond this approach, to improve access for future users. This was evidenced by participants who had strong FSC relationships being provided with timely and well-informed access to the CCCN, whilst others with less optimal relationships experienced barriers to access. It was clear that when FSC support falls short, families can miss out. CCF staff turnover, delays in support provision, miscommunication, and cessation of FSC support were all described by participants, building a case for diversification of approach. Participants suggested various hospital personnel who could mention the availability of the CCCN, such as medical staff, social workers, and treatment centre psychologists, given families respond to different types of people. This is supported by literature stating that buy-in from medical teams with regards to referrals to psychosocial support is important (Canter et al., 2020), and suggesting medical personnel offer grief services when following up with bereaved families, given their existing foundation of trust with families (Lichtenthal, Sweeney, et al., 2015). This approach could be particularly beneficial for Māori given their preference for trusting and long-term relationships (Slater et al., 2016).

However, in clear opposition to these recommendations, others described periodic feelings of anger and mistrust towards the medical facility and problematic interactions with treatment staff. Previous research has also suggested that CCPs prefer a clear separation between their treatment teams and psychosocial supports (Esplin & Rook, 2015). These factors suggest a hybrid approach may be best suited. Previous studies have partnered with medical teams in conjunction with word of mouth referrals and community endorsements (Lim et al., 2011). Participants in the current study suggested similar approaches, noting the strength of the cancer community and their investment in future whānau being able to access the same beneficial support they did. Via good CCCN experiences, counselling advocates are being created whose testimonials could increase uptake. Participants also proposed that CCF communications could be utilised to promote the CCCN, especially for families who are no longer in active treatment or for whom FSC support has ceased.

7.3.2 How

Ensuring whānau can access the CCCN entails provision of the right information at the right time. For CCPs, this again meant diversification was key. Almost universally, participants talked about not reading the ‘welcome pack’ they received upon arrival at treatment facilities, which contained written material about the cancer journey and support services available to them. Having this provided during the overwhelming diagnostic and start of treatment phase meant families immediately set it aside and didn’t return to it until much later down the track, if at all. Hence reliance on this medium alone is not effective and participants noted they all found out about CCF and CCCN through discussions with support staff. This finding is supported by literature stating that in-person recruitment strategies are most successful (Wakefield et al., 2017). Other media proposed by previous research include informational videos and CCP endorsements (Canter et al., 2020; Lim et al., 2011), along with the CCF emails noted above, which could be considered to improve access for future families through diversification.

Participants also described the importance of offering counselling to both parents, a narrative which is supported by other studies (Canter et al., 2020). However, given all participants adopted the primary caregiver role and most spent most time at the hospital alone, the ability of FSCs to interact with their husbands was limited. Diversifying the media through which counselling is promoted could help to address this.

A key learning from this study was regarding how the wellness check-in (screening tool) was applied. The purpose of the wellness check-in is for FSCs to monitor wellbeing and ideally takes the form of a conversation. In this study, the screening and referrals were predominantly delivered informally and smoothly with minimal effort required from CCPs. One participant succinctly contrasted the ‘bureaucracy’ of requesting psychological support through a GP with the ease of accessing counselling through the CCCN. This preference is supported by other CCP studies noting flexibility is imperative for uptake (Canter et al., 2020). Unfortunately, it was misapplied with two participants who were given the check-in to complete alone, leaving them concerned they would not meet the eligibility criteria. This misstep could have been due to the novelty of the CCCN at that point meaning FSCs involved were not clear on protocols. The worry experienced by these participants is a clear example of why the wellness check-in was designed to be an informal guide, as CCPs do not need another admin task or additional stress when trying to access support. Several participants were unaware that the only 'eligibility criteria' for accessing the CCCN is having/had a child with cancer, which highlights the need for screening and referrals to include a clear and complete information regarding what the service entails so CCPs understand what they're being offered.

A common theme in the data was that help and counselling hold stigmas. Many talked about the reluctance of many people to accept help in any form due to various reasons such as pride, privacy concerns, differing backgrounds, or guilt (i.e., feeling they are 'better off' than other families). Some proposed that those who turn down help are the ones who need it the most, which has been supported by other studies (Kazak et al., 2004). The reflexive rebuttal of support at the outset can mean families do not access CCF and therefore will not be able to access the CCCN, so is important to understand. Importantly, several participants noted that CCF is often assumed to only involve 'Beads of courage' which can look like additional administration work for CCPs and therefore be off-putting. Increasing acceptance of CCF support through accurate information provision is critical to enable families to access the CCCN.

For those who haven't accessed counselling previously, there is often some trepidation as noted by one participant who had no idea what would happen at her first session and another getting a lot of questions about counselling from other mums. Counselling can be seen as something people access when they're unable to cope or need professional help, so some thought it needed 'rebranding' to something more positive or strengths based. Others suggested CCPs needed specific examples of what counselling could help with rather than a vague statement that it could help them with their journey. The encouragement of more dialogue about counselling and what it entails could help people move past the stigmas, especially promotion of the unique advantages of the CCCN and the non-clinical populations it is designed for (as per the PPPHM and PMTS models (Kazak et al., 2007)). This approach is supported by others who noted that explaining benefits and program flexibility increases uptake (Canter et al., 2020), and may also aid in addressing the poor uptake observed by bereaved families in previous studies (Darbyshire et al., 2013; Lichtenthal, Corner, et al., 2015).

Along this vein, it is important to ensure CCPs are aware of the ability to extend their sessions, if required, as this was not common knowledge across the study sample. The child cancer literature shows financial concerns are common for CCPs, especially Māori, and can increase distress (Santacroce et al., 2018; Slater et al., 2016). It was also clear that CCPs should be empowered with the knowledge they can change to another counsellor if desired, as some felt they had limited options, though this was not a major concern. Some studies have noted reduced therapeutic effects due to lack of fit with the interventionists (Svavarsdottir & Sigurdardottir, 2013), supporting the need to address this factor.

7.3.3 When

In this study, counselling was offered at the right time for most families, whilst some wished they'd had it earlier, and many described a need for support at multiple points across their journey. Participants felt all child cancer families could benefit from access to the CCCN, and there was a strong theme across the data of offering counselling early and repeatedly. This is aligned with the key theoretical models stating psychosocial support should be provided across the cancer journey, tailored to phase and family risk level (Kazak et al., 2007). The benefit of regular application of the wellness check-in screening measure means parents should be able to access the CCCN when they need it. This is supported by studies that found disparities in parents thoughts about timing, with some finding a six-session intervention offered 2-3 months post diagnosis too late (Lövgren et al., 2021).

In alignment with other research, participants agreed it would be helpful to know about the CCCN from the start, coupled with ongoing reminders so that families can access when they are ready (Canter et al., 2020). They noted that they may not take it up immediately, but other families might and find it very helpful. Others suggested waiting a week or two until families have a clear diagnosis and treatment plan. Regardless, there was clear consensus that everyone struggles at different times, and CCPs need to know what's available to them in advance. Many described the whirlwind of diagnosis and start of treatment which is well established in child cancer literature as a period of focused on survival (Hocking et al., 2014; Koumarianou et al., 2021; Sultan et al., 2016).

Studies have found that approaching parents at diagnosis or during treatment has resulted in more uptake than after (Wakefield et al., 2017); however, no participants in this study commenced counselling soon after diagnosis, with uptake typically being during treatment, survivorship or following bereavement. During the diagnostic phase and start of treatment, participants described a clear message of overwhelm, managing logistics, and trying to get their head around the realities of being a 'cancer family'. Previous research supports this, with parents saying they were unlikely to accept help or divert attention from their child during this phase (Canter et al., 2020). Further evidence is found in interventions specifically targeting this phase experiencing poor uptake (Sahler et al., 2013; Stehl et al., 2009) and a need for extensions, reflecting the long-term and evolving nature of cancer (Marsland et al., 2020).

Aside from the initial start of treatment, transitions appeared to be implicated in the timing at which participants sought counselling, which aligns with previous descriptions as periods of increased distress (Kazak & Noll, 2015). The CCCN's key benefit is its inherent flexibility as an intervention that can be accessed across the cancer journey and tailored to the family needs, and aligning reminders with transitions may assist uptake.

A clear narrative was a feeling of supports disappearing once off-treatment or in survivorship, which is in agreement with previous CCP research noting an abundance of hospital-based support at the start of the treatment trajectory followed by successive fading (Canter et al., 2020; Lucas et al., 2016). Added to this can be a concurrent fading of social support networks as outsiders deem the family's troubles over (Forinder & Lindahl Norberg, 2010). Many participants described a 'rallying' at the start and throughout treatment with people checking in and doing kind things for them, which abruptly ceased once children were in survivorship. This feeling of abandonment can render families at greater risk of poor psychosocial outcomes and isolation, especially when the ongoing effects of the cancer journey are very much a factor for their daily lives but seemingly invisible to others. Additionally, the narrative reported by others that mothers put their feelings aside to hold it together during treatment was strong (Wakefield et al., 2013; Young, 2018a). Various interventions are focused on this juncture due to its inherent vulnerability (Kazak et al., 1999; Lövgren et al., 2021; Salem et al., 2021; Wakefield et al., 2016), though most are structured and predominantly manualised. The CCCN represents a contrasting approach with its flexibility and tailored approach that may improve uptake for families.

Once children aren't on active treatment, a community-based partnership such as that between CCF and the CCCN, when operating optimally, means families have ongoing access to educated psychosocial support at these difficult transitions. This is supported by other studies, who proposed community partnerships as a way to bridge the gap and ensure families are adequately supported when children aren't on active treatment (Canter et al., 2020). Ensuring FSCs administer the wellness check-in in a regular and ongoing manner with CCPs is optimal due to the variance observed in family adjustment capabilities and risk, an approach supported by other studies (Wiener et al., 2015).

Long term struggles were clear, with trauma and grief retriggering observed across the data. Others have reiterated that interventions need to be available when grief or trauma are retriggered (Coughlin & Sethares, 2017), underlining the need for continued reminders, promotion of the extension process and continued contact into survivorship. It was evident that one year down the track families can often struggle, both in survivorship and post-loss. Other studies have detailed the importance of continued contact following bereavement, with support required sometimes up to four years post-loss (Hudson et al., 2012; Lichtenthal, Corner, et al., 2015). The current sample demonstrated grief support needs up to two years after the bereavement, with two bereaved CCPs still accessing therapy and the third who had sessions one-year post-loss describing the comfort of knowing she could reach out to her FSC if she needed further assistance.

7.4 Content Improvements

7.4.1 Māori Support

Given discrimination is common for Māori in health sectors (Robson et al., 2010), the inclusion of a single Māori perspective in this study does not negate the need for reflection on their experience and utilisation as an indicator for further investigation and improvements. The primary concern from this participant's experience regarded the lack of provision of a Māori counsellor following her request. Whilst she was ultimately satisfied with the counselling and cultural accommodations offered, she wondered if a Māori counsellor could have offered different insights and strategies. Her question is confirmed by Māori researcher conclusions that cultural training cannot replace Māori heritage and indigenous support (Durie, 2018).

The participant also indicated that she preferred someone external to her existing networks with which to seek cultural support strategies, highlighting the importance of an 'educated outsider' incorporating the Māori element for psychosocial support of Māori CCPs rather than leaving them to seek cultural advice for themselves as an adjunct activity. The CCCN program is informed by Māori philosophy through Te Whare Tapa Whā and systems theories that align with Māori holism (Durie & Hermansson, 1985), so has a duty to provide genuine bicultural care. Whilst the therapist did appear to successfully include facets of effective Māori counselling, such as Whakamanawa (encouragement and caring) and Mauri (spirit and genealogy) through the incorporation of pepeha and karakia; they did not appear to address Whanaungatanga (family), and no offer was made to include whānau in sessions.

A Pākehā counsellor cannot offer more than basic cultural accommodations; only Māori can provide Māori insight. Given 'by Māori, for Māori' is widely acknowledged as best practice (Durie, 2018; Glover & Robertson, 1997; Slater et al., 2016), it also raises the question regarding Māori involvement from the initial introduction to CCF, through to the provision of Māori counsellors. If Māori social workers are not available to approach families and talk through the benefits of CCF, then partnering with a Māori health provider or community organisation who can act as advocates might improve access. Similarly, it is unknown how many Māori FSCs are available to provide support to families through CCF, administer the wellness check-in and talk through the benefits of the CCCN in a manner that is meaningful to Māori, given their cultural worldview and conceptualisations of health are often in opposition to western approaches (Durie & Hermansson, 1985).

There are currently two Māori therapists in the CCCN, so it is unclear why the Māori participant in this study was not provided with a Māori counsellor after she requested one. What is clear is that it is imperative that every effort be made to optimise Māori access to culturally appropriate support, given indigenous disparities in cancer outcomes (Kidd et al., 2019; Robson & Ellison-Loschmann, 2016), access to quality care (Dew et al., 2015), and higher risk of distress (Baxter et al., 2006). Other authors have noted the duty of providers to empower Māori clients to select the approach best suited to them (Kingi, 2018c), which acknowledges the variability inherent in individual Māori identities. Given the use of Te Whare Tapa Whā dimensions in the Wellness Check-in, it is especially important that culturally appropriate therapy can be made available to Māori CCPs as Māori can feel misled when supposedly Māori-friendly approaches turn out to be lacking in cultural accommodations (Durie, 2001). It is imperative that the CCCN service and providers prioritise the importance of the Māori worldview for culturally safe care, and a plan be in place if a Māori counsellor is not available. To better understand if this was an isolated case or a more systemic issue for Māori child cancer families, further research is required.

7.4.2 Palliative Support

A scarcity of palliative support was also a minor theme, but given the emphasis placed upon it by one participant and the existing acknowledgement in the literature that palliative care in general is a problematic and under-resourced area not just in NZ but internationally (Downing et al., 2012; Iupati et al., 2022), it is important to understand if palliative support can be improved for CCPs and their families.

Though one participant reported a good CCF FSC relationship, they were not made aware of the CCCN until after their child's death, despite requesting support as soon as they knew their child's condition was terminal. This is a key learning in ensuring the CCCN is offered across the journey, especially when CCPs are verbalising a need. One participant particularly wanted professional assistance to communicate with her child about end of life concerns and experienced lingering regret that she was not able to access this, a finding in line with other studies (Kreicbergs et al., 2007). Similarly, others have cited that well-trained support is required in the pre-bereavement phase, such as during transfer to hospice care and provision of anticipatory guidance (Kassam et al., 2015; Snaman, Kaye, et al., 2016). From the current study and previous literature, assisting parents to navigate appropriate communication tailored to their child's developmental stage during this phase appears crucial (Belpame et al., 2016; Lin et al., 2020) and requires some evaluation as to whether the CCCN is best placed to provide this. In this study, the participant wanted a Child Psychologist or similar, which may fall outside of the current scope of the CCCN.

Regardless, there were several examples in this study of extended periods where terminality was established and specialised supports were not made available to families. One participant felt it was following bereavement that the majority of supports were offered. This finding is in contrast to other research which concluded that most supports were provided during illness and palliative phases with little after bereavement (Bradshaw et al., 2005). A potential explanation could be that the two families in question were well-supported by family and therefore their FSCs did not recognise a need for further support. In addition, COVID-19 and lockdowns may have had some bearing on the availability or provision of services given both palliative journeys occurred during the early phases of COVID-19 emergence in NZ. One participant proposed palliative care team introductions as a key point at which to promote the CCCN (and CCF if there isn't an existing relationship) to families, aligning with the previously proposed approach of coinciding support offers with key transitions.

The formation of a clearer understanding of this particularly traumatic phase and the support requirements of CCPs in NZ requires further focused investigation. One participant felt very strongly that hospices in Aotearoa aren’t equipped to provide successful care for paediatric patients and their families. The CCCN may not be best placed to address all concerns raised, and there is a need to ascertain whether other whānau have had similar experiences. However, the data from this study clearly highlights the need to adequately support families once they receive a terminal diagnosis, throughout palliative care and post-loss.

7.4.3 Grief and Trauma

The main dialogue regarding grief counselling in this study was that it was highly valued by bereaved participants and represented a key strength of the CCCN. One participant however thought the grief focus could be strengthened and made more specific to child death, as she didn’t feel her counsellor was equipped to deal with the type of traumatic grief she was grappling with. Certainly the literature notes that child loss has been described as more complex, persistent and intense than other forms of grief, requiring parents to redefine their identity and purpose (Denhup, 2017; O'Connor & Barrera, 2014). In addition, others have reported parents discontinuing therapy due to feeling that therapists were unable to understand the degree of pain they were experiencing (Lichtenthal, Corner, et al., 2015), which aligns with this participants account. Ensuring counsellors are sensitive to the intensity of distress and aching for their lost child that bereaved CCPs can experience is imperative to adequately support this at-risk group.

Existing literature suggests support is required for community re-entry after child loss, and to prevent social isolation from efforts concealing their pain (D'Agostino et al., 2008; Donovan et al., 2015). This was evident in the study, with parents describing the reluctance of others to talk about child cancer, and even more so surrounding child death. This demonstrates that the outlets for bereaved parents to talk about and maintain the connection with their deceased child that is noted as beneficial (Foster et al., 2011; Toller, 2011) is limited.

It was suggested by one participant that CCPs could benefit from a consolidated resource regarding grief processing avenues, as many are available, but the challenge was for parents to find and access them. A consolidated list of the various support groups and activities on offer, or evidence-based suggestions could be provided during counselling or via CCF. Other parent samples have noted the importance of provision of tangible resources for families (Snaman, Kaye, et al., 2016), and the wide variety of approaches in the child loss literature are reflective of individual preferences for navigating grief (Pelacho-Rios & Bernabe-Valero, 2022).

It was also noted in this study that group-based options may not be equipped or appropriate spaces to facilitate more traumatic grief discussions, as suggested by other studies (Young, 2018b), and the one on one counselling with a trained professional that the CCCN offers (or a clinical referral, if required) is best placed to address this need for CCPs. However, the trauma content of the CCCN training should be reviewed to ascertain if it can be strengthened or made more specific to child cancer and loss.

7.5 Future Research

Future research regarding the impact of the CCCN could attempt to quantify effects for CCPs through the application of a quantitative measure pre and post counselling, such as other studies who measured effects on distress, well-being or quality of life (Lamanna et al., 2018; Quast et al., 2016; Wakefield et al., 2013) though the broad range of therapeutic approaches represented in the CCCN may make assumptions difficult. Additionally, the long-term effects of the CCCN could be assessed by multiple follow ups to understand if benefits were retained.

Further qualitative studies could target a variety of family structures, such as single parents and fathers to fill gaps in the literature regarding how different caregivers experience child cancer. Single parenting has been implicated in increased strain (Iobst et al., 2009; Patel et al., 2014), and some authors have hypothesised that secondary caregivers may not receive the same benefit from interventions as primary (Svavarsdottir & Sigurdardottir, 2013), hence it would be valuable to investigate different family structures and caregiver status on counselling uptake and outcomes.

Finally, to provide best practice Māori and palliative support, more research is required with larger samples of these particularly at-risk populations. Further, it would be useful to understand if treatment adherence is a widespread concern for NZ CCPs and whether developmental-stage training strategies might benefit CCCN counsellors.

7.5.1 Supporting Other Child Conditions

A clear theme across the data in this study regarded the abundance of attention, resources and support dedicated to child cancer in NZ. Participants recounted with a combined feeling of appreciation and guilt the differences they observed across other wards of the hospital and with people they knew whose children had other child chronic illnesses. This disparity was described from the unique perspective of one participant, whose child had an existing chronic condition before being diagnosed with cancer. She described how astounding and saddening the experience was for her, to go from no institutional supports for her child's rare condition, to a wealth of support when diagnosed with cancer and through treatment, and then back to no support again after her child's cancer treatment was completed.

The loss of support post-treatment was felt even more keenly, as the cancer experience still wasn't over, but more so their everyday trials as parent-caregivers continued which their social circles didn't acknowledge, and they had no external support with. This loss was compounded by the misunderstanding that she thought the CCF support was also over after the Beads of Courage program was complete. She talked about how the cancer treatment seemed easier than her everyday life, as they knew what would happen each day and it was for a set period only. This representation of cancer as finite, predictable and easier to manage than another child chronic condition, is in clear opposition to the child cancer literature, which suggests that CCPs are subjected to significantly more distress and strain than parents managing other child chronic illness (Masa'Deh, 2015).

This contrasting experience is important to acknowledge as an opportunity for future research. Some child conditions may represent a more distressing and drawn-out caregiving experience journey and the adverse psychological implications for parents may be more prevalent, yet no specialised institutional or community-based supports are available. Child chronic conditions are often combined in the support literature, including in the thinking behind the theoretical models informing the CCCN, as highlighted by the seminal study by Kazak (1989), indicating the similarities in family experience. It follows then that the CCCN as a flexible community-based support model could be used as a template to be applied to other contexts, with the appropriate further investigation and funding.

7.6 Strengths and Limitations

All participants in this research were mothers, primary caregivers, and in heterosexual relationships, which is common in the literature (Young, Bowers, & Bradford, 2021) but limits the extrapolation of CCCN benefits to varying parental roles. Whilst several participants described their husbands attending sessions and experiencing benefits, it would have been useful to have some first-person father perspectives, given this is a well-established gap in the literature (Robinson et al., 2019). The low levels of men in this and other studies may be due to their more distant caregiving role, traditional masculine ideals or more passive or avoidant coping styles (Sultan et al., 2016). However, given mothers are often the primary caregiver as was the case in this study, tend to utilise more social support and family coping mechanisms, and gender differences render them at greater risk of distress and lower quality of life, the impact of successfully supporting mothers should not be discounted. In fact, one of the most well-known current interventions specifically targets mothers (National Cancer Institute, 2020; Sahler et al., 2013).

A strength of the study also lies in the sample, as participants represented a broad geographical spread and mix of experiences across treatment centres, a range of ethnicities similar to the child cancer incidence proportions, and a variety of cancer trajectories, outcomes and current phase at the time of interview. Though the sample was small, the number of participants means little in interview studies when cases are information-rich and carefully analysed (Morrow, 2005; Patton, 2015).

Most families appeared to be well-resourced which can limit extrapolations to other scenarios given existing resources can affect families ability to cope and adapt (Van Schoors, Caes, Knoble, et al., 2017). Financial impacts for participants were not specifically addressed, which may be worth including in future given its link to psychosocial risk (Pelletier & Bona, 2015; Wiener et al., 2015), especially for Māori (Slater et al., 2016; Slater et al., 2013). In addition, all participants reported some degree of family or community support, which has been linked as a key protective factor for CCPs (Gise & Cohen, 2021). This limits the ability to assume benefits for others with less social support or resources, though the literature indicates they may receive greater benefits.

Other limitations include the potential of recall bias given the length of time elapsed since counselling was accessed by several participants. However, given participants self-selected into the study, this indicates that those who came forward felt confident participating in research and had the time and ability to do so.

Finally, as noted earlier, a single Māori participant reduces the ability to generalise findings to this group, especially given the inherent diversity of Māori realities in the population (Durie, 2001).

7.7 Conclusion

The predominant finding of this study was that CCPs need a safe space with an educated outsider to process thoughts and feelings and receive help navigating their reactions (and those of their family unit) to factors inherent in the child cancer journey. The CCCN is well-placed to provide access to a mental health professional educated in grief, trauma, coping, and communication therapies, who understands child cancer and offers a family-friendly relationship-focused approach. Though well-grounded in family systems, social ecology and Te Whare Tapa Whā health theory, the flexibility of delivery inherent in the CCCN model is a key strength, from the mode (in-person or virtual), the ability to tailor interventions to key concerns, to the timing of access and extension options. Psychosocial support is clearly required across the cancer journey, and repeated offers from diverse sources should be made to CCPs to ensure they can access counselling when they need it. Most of the participants in this study experienced this ideal scenario of support when they were offered and accessed counselling through the CCCN. Some minor issues in implementation were noted, along with suggestions of ways to improve the service in terms of counsellor training content and reducing access barriers.

Given parents represent the epicentre of family functioning (Kazak et al., 2017) and caregiver wellbeing directly affects the quality of care they can provide, adequate support for child cancer parents is essential (Junkins et al., 2020; Tang et al., 2020). The findings of this study support the implementation of the CCCN in the Aotearoa New Zealand child cancer context and reiterates the fundamental need for psychosocial support provision across the cancer trajectory (Steele et al., 2015). This unique community-based network provides a psychosocial service for families when treatment-centre supports, group-based supports, or structured interventions are unavailable or unsuited. Given specialised support mechanisms external to treatment facilities are rare (Kazak & Noll, 2015; Plessis et al., 2019), the CCCN represents a valuable addition to child cancer support in Aotearoa New Zealand and a template that could be adapted internationally and in other child chronic illness contexts.

The counselling experience that we've had, the access that we've had, the support that we've had for ongoing access, if we need it; has all been what we needed and when we needed it. …we want to help …to make sure other families have that.

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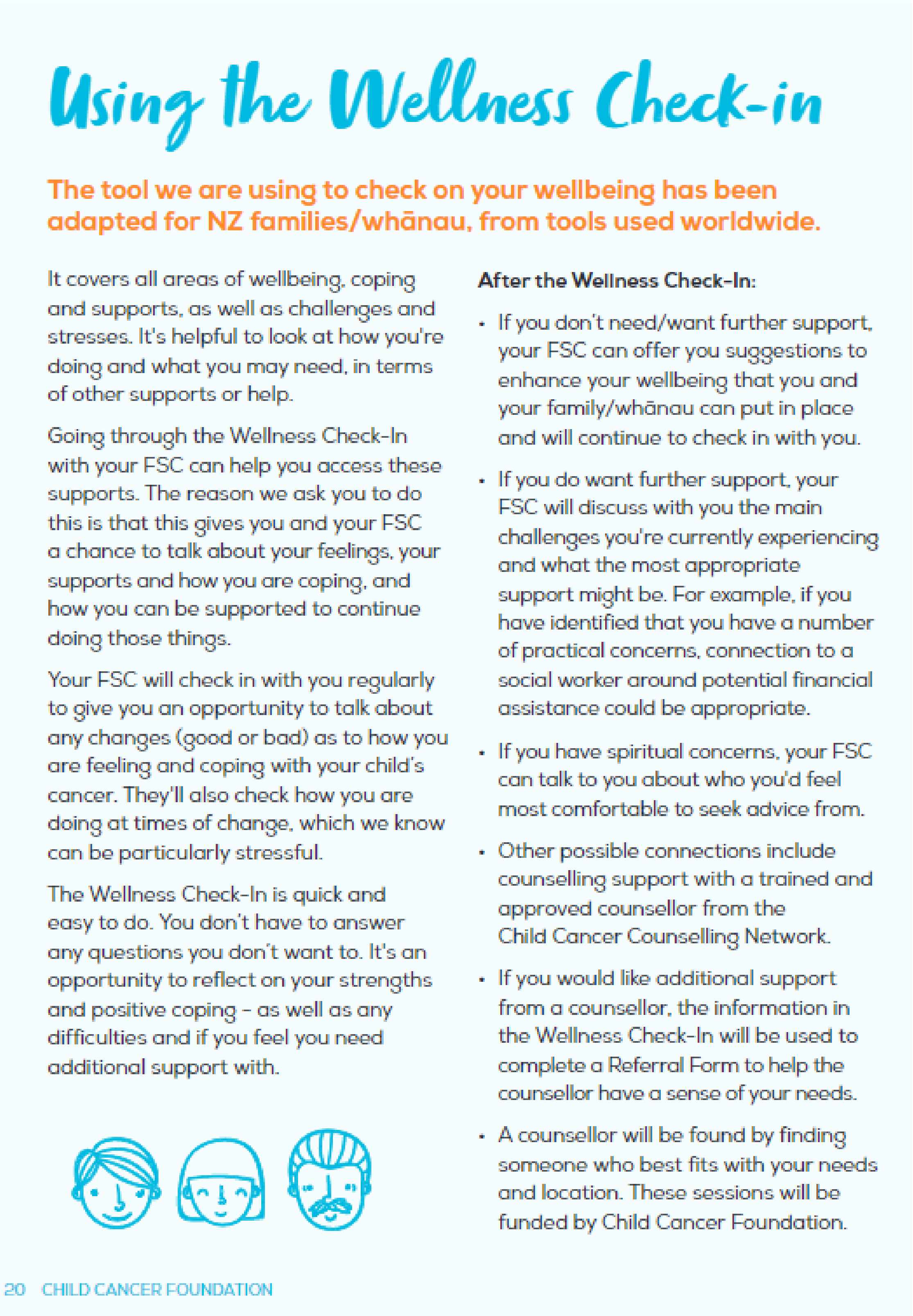
Appendices

Appendix A. The Wellness Check-In



Using the Wellness Check-in

The tool we are using to check on your wellbeing has been adapted for NZ families/whānau, from tools used worldwide.

It covers all areas of wellbeing, coping and supports, as well as challenges and stresses. It's helpful to look at how you're doing and what you may need, in terms of other supports or help.

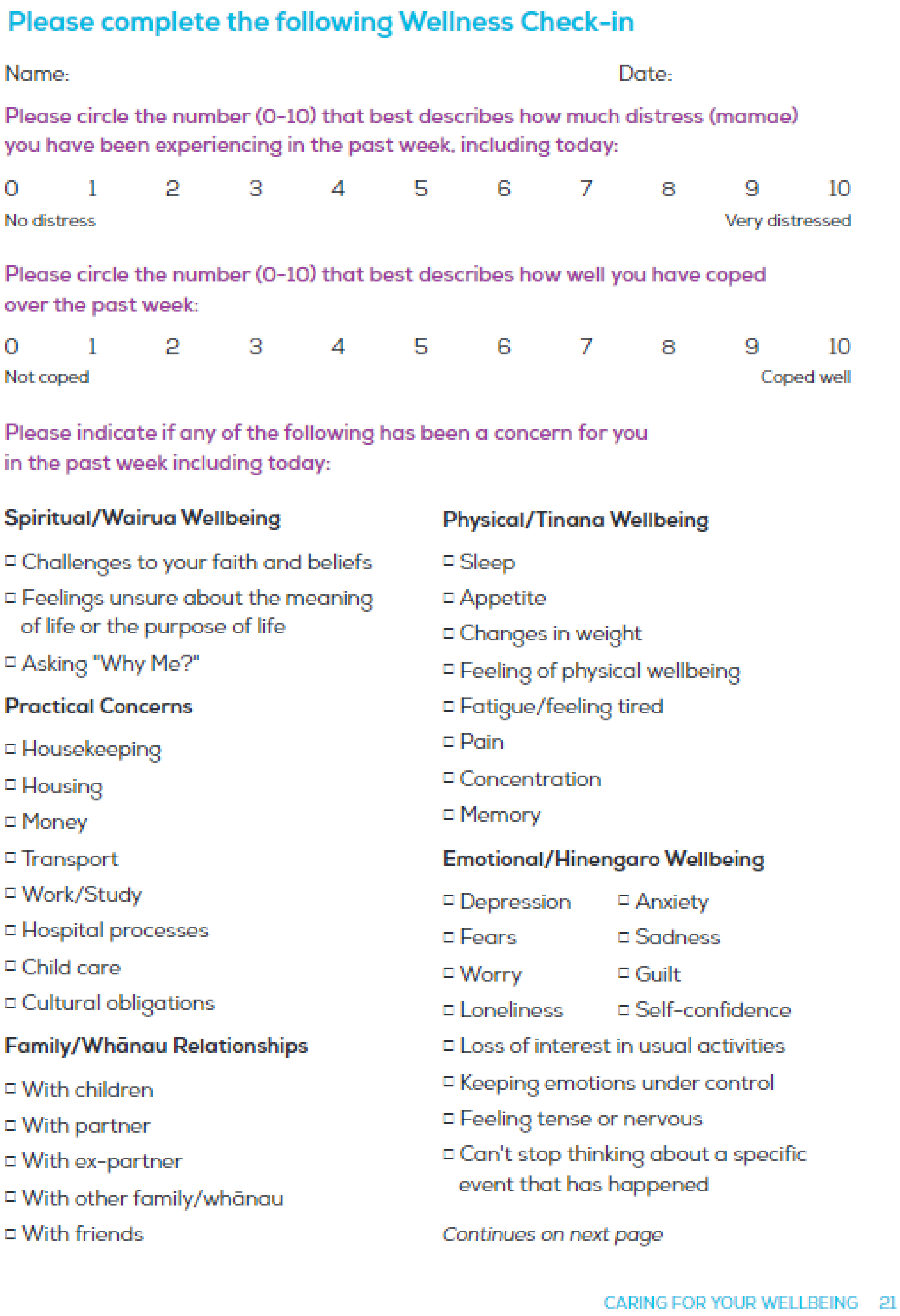
Going through the Wellness Check-In with your FSC can help you access these supports. The reason we ask you to do this is that this gives you and your FSC a chance to talk about your feelings, your supports and how you are coping, and how you can be supported to continue doing those things.

Your FSC will check in with you regularly to give you an opportunity to talk about any changes (good or bad) as to how you are feeling and coping with your child's cancer. They'll also check how you are doing at times of change, which we know can be particularly stressful.

The Wellness Check-In is quick and easy to do. You don't have to answer any questions you don't want to. It's an opportunity to reflect on your strengths and positive coping – as well as any difficulties and if you feel you need additional support with.

After the Wellness Check-In:

- If you don't need/want further support, your FSC can offer you suggestions to enhance your wellbeing that you and your family/whānau can put in place and will continue to check in with you.
- If you do want further support, your FSC will discuss with you the main challenges you're currently experiencing and what the most appropriate support might be. For example, if you have identified that you have a number of practical concerns, connection to a social worker around potential financial assistance could be appropriate.
- If you have spiritual concerns, your FSC can talk to you about who you'd feel most comfortable to seek advice from.
- Other possible connections include counselling support with a trained and approved counsellor from the Child Cancer Counselling Network.
- If you would like additional support from a counsellor, the information in the Wellness Check-In will be used to complete a Referral Form to help the counsellor have a sense of your needs.
- A counsellor will be found by finding someone who best fits with your needs and location. These sessions will be funded by Child Cancer Foundation.



Please complete the following Wellness Check-in

Name: Date:

Please circle the number (0-10) that best describes how much distress (mamae) you have been experiencing in the past week, including today:

0 1 2 3 4 5 6 7 8 9 10

No distress Very distressed

Please circle the number (0-10) that best describes how well you have coped over the past week:

0 1 2 3 4 5 6 7 8 9 10

Not coped Coped well

Please indicate if any of the following has been a concern for you in the past week including today:

Spiritual/Wairua Wellbeing

☐ Challenges to your faith and beliefs
☐ Feelings unsure about the meaning of life or the purpose of life
☐ Asking "Why Me?"

Practical Concerns

☐ Housekeeping
☐ Housing
☐ Money
☐ Transport
☐ Work/Study
☐ Hospital processes
☐ Child care
☐ Cultural obligations

Family/Whānau Relationships

☐ With children
☐ With partner
☐ With ex-partner
☐ With other family/whānau
☐ With friends

Physical/Tinana Wellbeing

☐ Sleep
☐ Appetite
☐ Changes in weight
☐ Feeling of physical wellbeing
☐ Fatigue/feeling tired
☐ Pain
☐ Concentration
☐ Memory

Emotional/Hinengaro Wellbeing

☐ Depression
☐ Fears
☐ Worry
☐ Loneliness
☐ Anxiety
☐ Sadness
☐ Guilt
☐ Self-confidence
☐ Loss of interest in usual activities
☐ Keeping emotions under control
☐ Feeling tense or nervous
☐ Can't stop thinking about a specific event that has happened

Continues on next page

Parenting your child that is (or has been) receiving treatment for cancer can be challenging. Have any of the following been a concern for you in the past week, including today:

- ☐ Feeling connected with your child
- ☐ Managing with your child's emotions
- ☐ Your child's development
- ☐ Talking about the disease and consequences with your child
- ☐ Caring for your child
- ☐ Helping your child with their emotions
- ☐ Your child's sleeping
- ☐ Following advice about treatment/ giving your child their medication

The following questions can help identify the support you currently have and help you decide if you would like/need further support:

1a. Do you feel you receive enough support from people around you?
☐ Yes ☐ No

1b. If yes, what kind of support do you receive? Practical/emotional/other...

1c. If no, what kind of support would you like?

2. Do you feel people understand your situation and what you are going through?
☐ Yes ☐ No

3. Do you have ongoing heath issues?
☐ Yes ☐ No

4. How do you get along with medical staff?
Very well Well Fair Poorly Very poorly

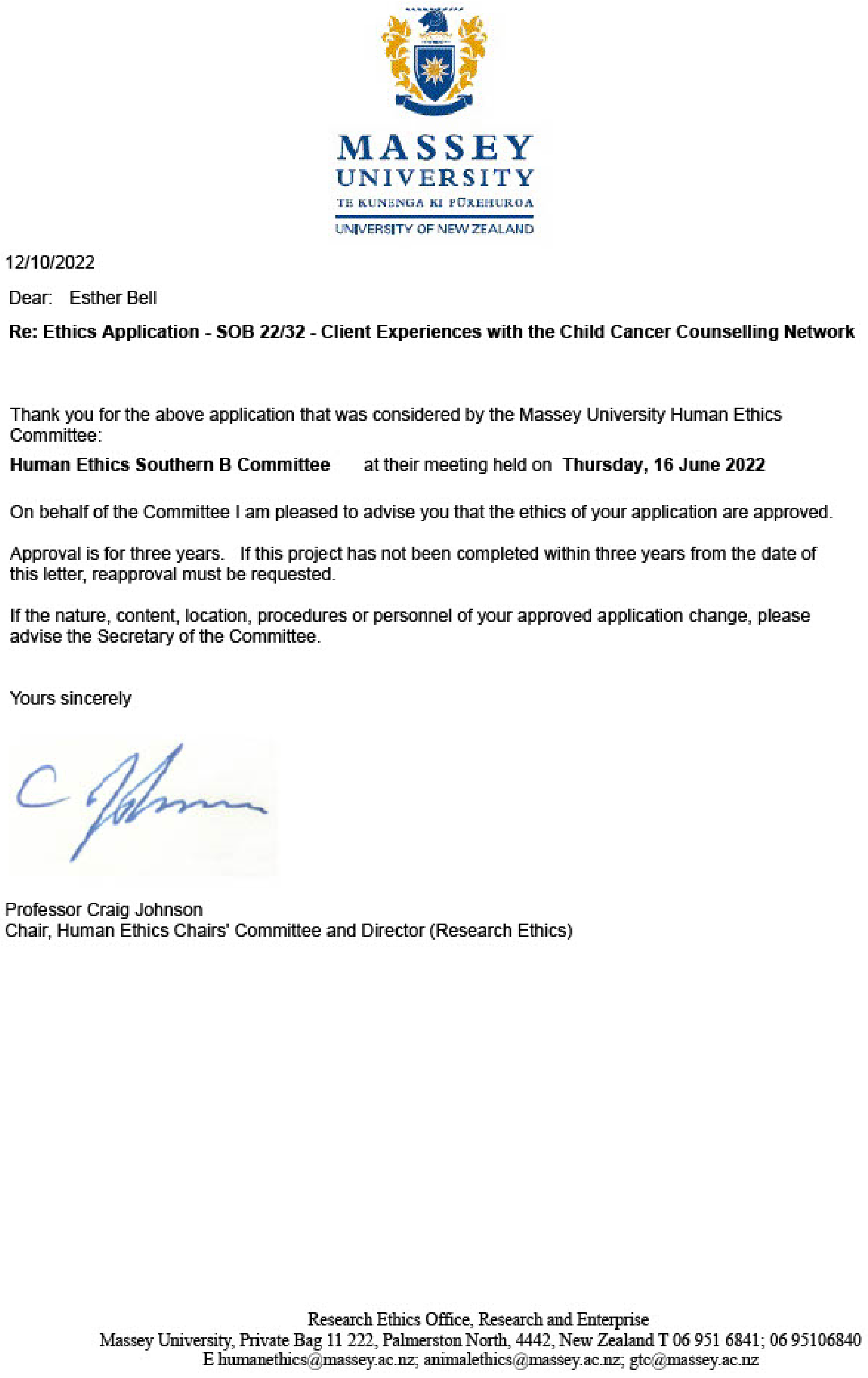
5. Would you like to talk about your situation to a professional?
Yes Maybe No

Please list any other concerns you would like to talk about:

Would you like us to connect you to additional support?
☐ Yes ☐ No

Do you give consent for this information to be shared when we connect you with additional support?
☐ Yes ☐ No

Appendix B. Ethical Approval – Massey University



MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

12/10/2022

Dear: Esther Bell

Re: Ethics Application - SOB 22/32 - Client Experiences with the Child Cancer Counselling Network

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Human Ethics Southern B Committee at their meeting held on **Thursday, 16 June 2022**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix C. Cultural Considerations

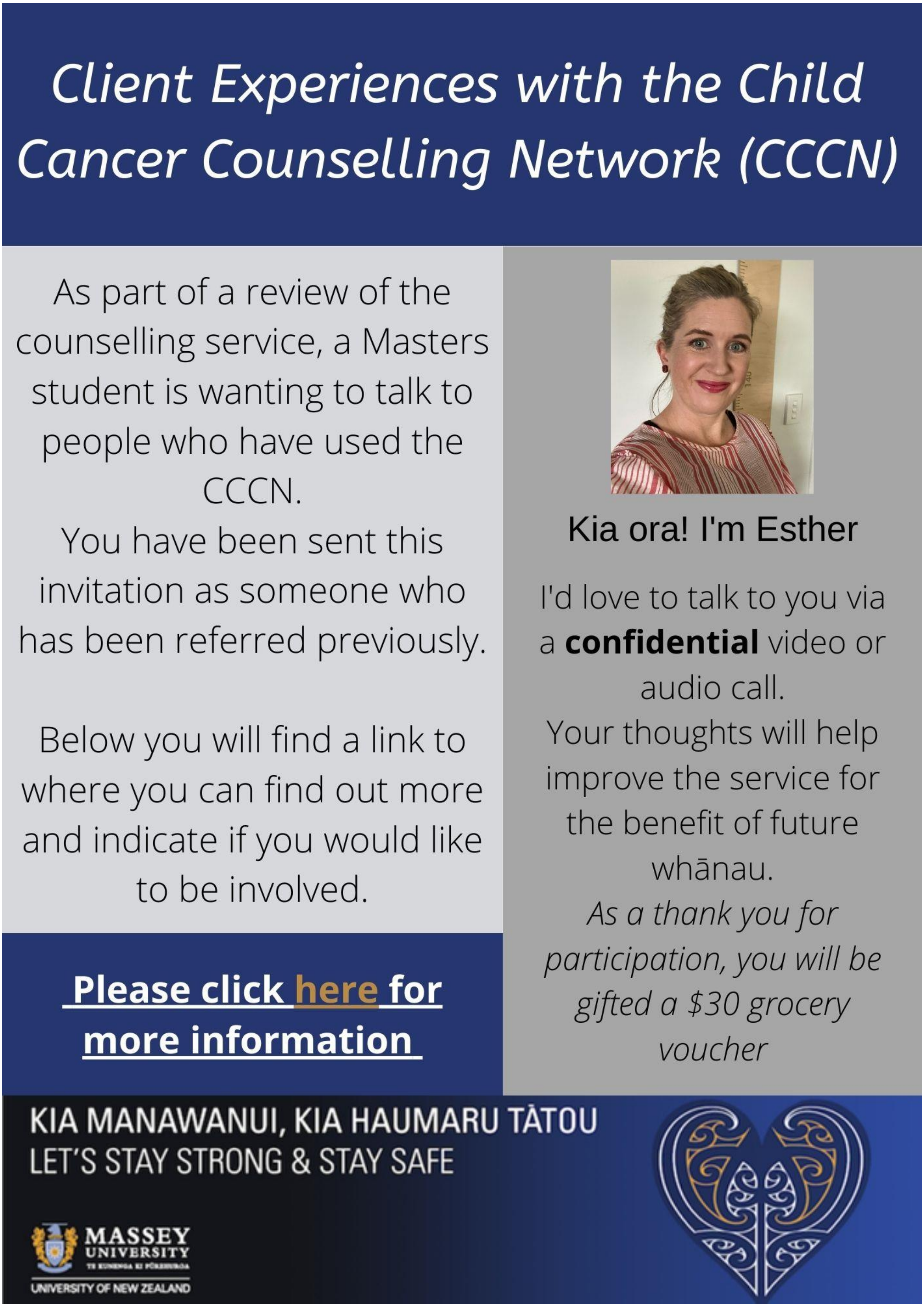
The first meeting with Dr Hukarere Valentine was during study design and pre-ethics submission. The following aspects of the study and design were discussed and agreed upon:

- A Whakataukī (proverb) with special meaning to the CCCN programme headed up the information sheet, along with a brief introduction of the researcher to add personal context (e.g., from Taranaki, and have a child of my own who had heart surgery)
- Some te reo Māori was included in the invitation with an acknowledgement that I am not fluent
- Māori imagery was also included in the written information
- The provision of koha (gift) in the form of a $30 grocery voucher would be sent to participants following the interviews to acknowledge the social relationship formed and express reciprocity (especially important since the interviews were online so kai (food) could not be provided)
- I would commence each interview with Māori participants with a short pepeha (introduction) and an invitation for the participant to reciprocate. This act of revealing some personal information about myself helps to build connections and relationship
- In addition, an acknowledgment would be made that participants might need something that I have not thought of in order to feel comfortable to proceed with an interview (e.g. a particular custom, karakia (prayer), questions etc.), so I would ask if there was anything we required before we started (using indirect language to reduce pressure on the participant, acknowledging that direct questions like “do you…?” can be confronting)
- Cultural questions were included in the interview schedule to ascertain how therapists were interacting with clients in this respect (e.g., “Is it important that your therapist understands your cultural world view? Did that occur for you? What did they do that appealed to your cultural sense of self?”)

- During the interview, I would continually check meanings using such phrases as “you mentioned this… what did you mean by that?”, to acknowledge that Māori often tell stories instead of directly answering a question, thus meanings can be easily missed
- Ethnicity data would be collected on the sample to ensure any Māori data would be reported appropriately and handled correctly
- Ensuring the involvement of Dr Valentine during data analysis (if Māori had participated)

The second meeting was after completion of data analysis. Given there was one Māori participant, I wanted to ensure I was handling her data correctly, so I met with Dr Valentine again to discuss my assumptions before writing up the findings.

Appendix D. Study Invitation



Client Experiences with the Child Cancer Counselling Network (CCCN)

As part of a review of the counselling service, a Masters student is wanting to talk to people who have used the CCCN.
You have been sent this invitation as someone who has been referred previously.

Below you will find a link to where you can find out more and indicate if you would like to be involved.

Please click here for more information

Kia ora! I'm Esther

I'd love to talk to you via a **confidential** video or audio call.
Your thoughts will help improve the service for the benefit of future whānau.
As a thank you for participation, you will be gifted a $30 grocery voucher

KIA MANAWANUI, KIA HAUMARU TĀTOU
LET'S STAY STRONG & STAY SAFE

MASSEY UNIVERSITY
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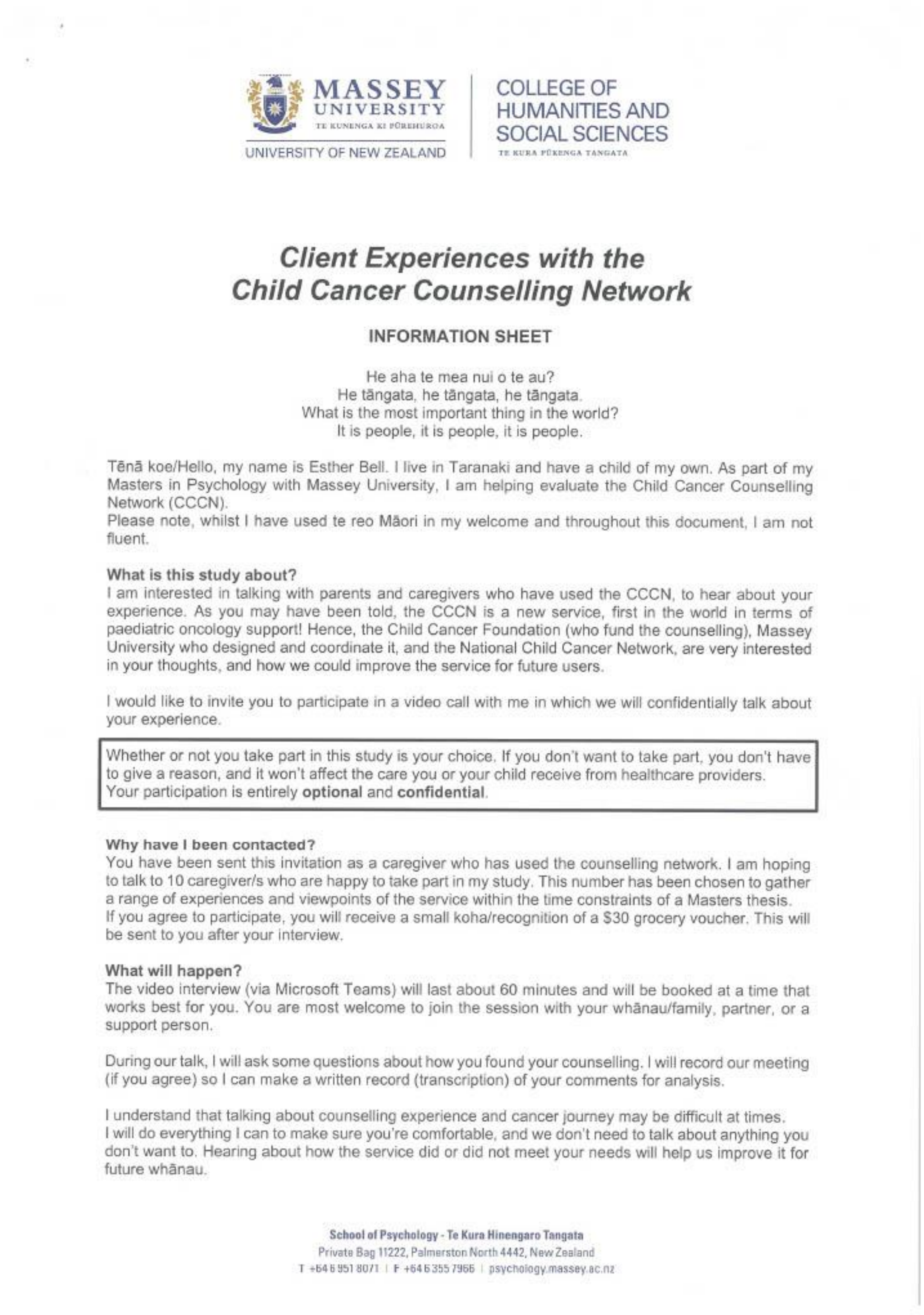
UNIVERSITY OF NEW ZEALAND

Appendix E. Participant Information Sheet



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UNIVERSITY OF NEW ZEALAND

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

Client Experiences with the Child Cancer Counselling Network

INFORMATION SHEET

He aha te mea nui o te au?
He tāngata, he tāngata, he tāngata.
What is the most important thing in the world?
It is people, it is people, it is people.

Tēnā koe/Hello, my name is Esther Bell. I live in Taranaki and have a child of my own. As part of my Masters in Psychology with Massey University, I am helping evaluate the Child Cancer Counselling Network (CCCN).
Please note, whilst I have used te reo Māori in my welcome and throughout this document, I am not fluent.

What is this study about?
I am interested in talking with parents and caregivers who have used the CCCN, to hear about your experience. As you may have been told, the CCCN is a new service, first in the world in terms of paediatric oncology support! Hence, the Child Cancer Foundation (who fund the counselling), Massey University who designed and coordinate it, and the National Child Cancer Network, are very interested in your thoughts, and how we could improve the service for future users.

I would like to invite you to participate in a video call with me in which we will confidentially talk about your experience.

Whether or not you take part in this study is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you or your child receive from healthcare providers.
Your participation is entirely **optional** and **confidential**.

Why have I been contacted?
You have been sent this invitation as a caregiver who has used the counselling network. I am hoping to talk to 10 caregiver/s who are happy to take part in my study. This number has been chosen to gather a range of experiences and viewpoints of the service within the time constraints of a Masters thesis.
If you agree to participate, you will receive a small koha/recognition of a $30 grocery voucher. This will be sent to you after your interview.

What will happen?
The video interview (via Microsoft Teams) will last about 60 minutes and will be booked at a time that works best for you. You are most welcome to join the session with your whānau/family, partner, or a support person.

During our talk, I will ask some questions about how you found your counselling. I will record our meeting (if you agree) so I can make a written record (transcription) of your comments for analysis.

I understand that talking about counselling experience and cancer journey may be difficult at times.
I will do everything I can to make sure you're comfortable, and we don't need to talk about anything you don't want to. Hearing about how the service did or did not meet your needs will help us improve it for future whānau.

What will we do with your information?

To make sure your personal information is kept confidential, information that identifies you will not be included in any reports. Only I (Esther) will know your identity. In reports you will be identified by a pseudonym/alternative name, which you can choose if you like!

The results of the study may be published or presented.

The data (recording & transcriptions) will be stored in a secure password-protected location (cloud & external drive) and only be used for the purpose of analysis and writing of a report. The data will be retained securely for five years, after which it will be destroyed.

Your rights as a participant

You do not have to accept this invitation. If you would like to participate, you have the right to:

- not answer any questions you aren't comfortable with;
- withdraw from the study up until two weeks after the interview;
- 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;
- ask for recording to be turned off at any time during the interview;
- ask to have your interview transcription returned to you for review and feedback regarding any changes, within a two week window;
- be given access to a summary of the project findings when it is concluded.

If you are interested in taking part in this study, please click through to the next page to view a virtual consent form and provide a few details so Esther can contact you to book your interview.

If you would like to ask some more questions before you decide, please contact Esther using the details below.

Project Contacts

Researcher	*Supervisor*	*Supervisor*
Esther Bell	Dr Kirsty Ross	Dr Don Baken
Esther.Bell.4@uni.massey.ac.nz	Senior Clinical Psychologist/ Senior Lecturer	Senior Clinical Psychologist/ Research Coordinator
	Massey University	Massey University
	K.J.Ross@massey.ac.nz	D.M.Baken@massey.ac.nz

Please contact either Esther, Kirsty, or Don if you have any questions or concerns regarding this study at any time.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 22/32. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz

Appendix F. Participant Consent Form

MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

COLLEGE OF
HUMANITIES AND
SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

Client Experiences with the Child Cancer Counselling Network

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read and I understand the Information Sheet.

I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time, up until two weeks after receiving my interview transcript (if requested).

1. I agree to the interview being recorded (this is very helpful to allow your comments to be captured accurately for analysis) Yes/No
   a) If no, do you agree to having notes taken during the interview? Yes/No
2. I would like to have a transcription of my interview returned to me for review, under the understanding that I will have two weeks to provide any comments or change requests Yes/No
3. I agree to participate in this study under the conditions set out in the Information Sheet Yes/No
4. I would like a summary of the project findings when it is concluded Yes/No

Declaration by Participant:

I ____ (full name) hereby consent to take part in this study.

Digital Signature: _______________________ Date: ________________

School of Psychology - Te Kura Hinengaro Tangata
Private Bag 11222, Palmerston North 4442, New Zealand
T +64 6 951 0071 | F +64 6 355 7966 | psychology.massey.ac.nz

Appendix G. Semi-Structured Interview Outline and Prompt Sheet

Introduction

Kia ora and welcome, my name is Esther Bell, and I am a student at Massey University. Thank you so much for agreeing to have this meeting with me today!

Check they are comfortable with recording and turn on

I thought we could start by introducing ourselves and I'll share a bit about how I came to be doing this project.

I live in rural south Taranaki and am from New Plymouth originally. I have a husband and a young child, and we have lots of animals. I was very excited to pick up this project as I am so passionate about supporting parents and caregivers dealing with child illness as I have been in a similar situation myself as a parent.

(For Māori participants) - I'd like to do a quick mihi/pepeha

Tēnā koe

Ko Esther tōku ingoa	*My name is Esther*
Ko Bell tōku whānau	*Bell is my family*
Nō Britain, Spain, Ireland, Scotland ōku tīpuna	*My ancestors are from Britain, Spain, Ireland & Scotland*
Ko Taranaki te maunga Nāna ahau I whakaruruhau	*Taranaki is the mountain who sheltered/protected me*
E mihi ana ki ngā tohu o nehe, o Taranaki e noho nei au	*I recognise the ancestral and spiritual landmarks of Taranaki where I live*

Would you like to share a bit about yourself and your family life?

(Prompts if needed to get the convo flowing - where they live, family structure, number of children, did they have to move for treatment etc.)

Thanks so much! It is wonderful to be having this chat with you.

Remember in the information you first read that I won't use your real name in the study? Do you want to choose a name you'd like for yourself now or would you prefer I just assign you a name? OK cool.

So, the aim of today is to talk about your experience with the Child Cancer Counselling service. I am interested in hearing your stories to find out what worked for you and what didn't, in order to carry out a review for the Child Cancer Foundation, write my thesis, and improve the service for future whānau.

There are no wrong answers! Anything you say to me will in no way affect the care you and your child receive. I am interested in any experiences you are happy to share. Please feel free to voice your honest point of view. I'm just as interested in negative comments as positive comments to get an understanding of what was helpful or unhelpful about your counselling experience.

You absolutely do not have to answer any questions you don't feel comfortable with.

I'd like to acknowledge that I take you talking about your experience with me as a great honour. I know that recounting your counselling experience means thinking back over some stressful and emotional times and that this may be hard. Please know this is a safe space for you to let those emotions out or let me know if you want a break or to stop or would like to reschedule.

I'd also like to acknowledge that there are things I may not understand due to our different backgrounds, so please feel free to stop and correct me if I am on the wrong track at any point.

(For Māori participants) - I also want to note that I used te reo in my greeting, but I do not speak it fluently.

Just a few housekeeping items:

- I am recording the interview so that I don't miss any of your comments, and to allow me to transcribe afterwards.
- Your identity will remain completely confidential; no names are attached to your comments, and I will change any other information that might identify you.
- Remember you can withdraw from this study up to two weeks after this interview, for any reason.
- I'm here to ask questions and listen. I want you to feel free to talk and I'll move the discussion from one question to the next as needed to keep to time.

Do you have any questions for me?

Is there anything else we require before we start?

All good? Ok, let's begin.

Q1. Entry into counselling (Time check ~10mins in)

- Was the timing at which you were offered the counselling service helpful? Would another time period have been more beneficial?
- Was the service adequately explained i.e., what it was, that it didn't cost anything, how many sessions, external to hospital etc. and what potential benefits you could get from it?

Q3. Contact by therapist (~15mins)

- Was your referral handled promptly i.e., did you hear from your counsellor reasonably quickly?
- Was it a smooth process? What do you think could have been done differently to make it better?

Q4. Relationship (~20mins)

- Did your therapist seem to know what they were doing? Did you have confidence in them?

- Was it comfortable/genuine? Did you feel supported? (Why/why not? What could they have done differently?) Did you feel like you were provided with a safe space to share your feelings, thoughts and concerns without judgement?
- Did your whānau attend with you, and did you feel they were made welcome? Did this add to the experience?
- Is it important to you that your therapist understands your cultural world view?
  - Did that seem to occur?
  - What difference did that make for you? Beneficial or not?
  - What did they do that appealed to your cultural identity?

Q5. Content/Structure (~30mins)

- Were your sessions face to face or virtual? How did this work for you? Would you have preferred a different format or mode of delivery?
  (Elicit - Covid19 impact)
- Can you give me an example of something your counsellor did or said that stuck with you, or something that you were able to use that made a difference to your/your child's experience?
- Did you like the fact that the counselling service was external to the hospital environment and your child's treatment team? How come?
- Was there anything you wished you had got from your counselling experience that you didn't?

Q6. Outcomes (~40mins)

- Do you think it made a difference to your ability to cope with what was happening at the time/daily functioning?
- Do you think it helped you better manage your emotions?
  (How so?)
- Did you notice any differences in your relationships?

- Did you notice any differences in your child?

  (Can you give me an example?)

- Reflecting on your experience, do you think this service would be helpful to other families, or other situations? How so?

Q7. Exit from service (~50mins)

- How many sessions did you have with your therapist? Was this about right or would more or less have been useful?

  (Elicit - was 6 sessions enough/too much)

If they only had one session – other questions to ask to get more info on why

  - *Was that because of their situation? Cancer or COVID?*
  - *Or was it to do with the service or the counselling? Mode of delivery?*
  - *Did they had their needs met within their peer support group?*
  - *Or was one session enough? How come?*

- Anything that stood out as really great from the experience? How about not so great?

Close (~60mins)

- So, we're coming to the end.
- If you could give some feedback to the service coordinators, to the people who run the service, what are the things that you think based on your experience would be important for them to know in terms of the service or your needs?
- How was that for you? (How did you find the interview process?)

Thank you so much for taking part in this study, and all the best to you and your whānau!

Prompt Sheet

Extensions:

How come?
Tell me more?
Can you explain that?

Repeat…so what you're telling me is…

How did that help/not?

How did you feel when…?

Check understanding:

For negative experiences/problems that arise:

It sounds like that was a really difficult/upsetting experience for you

Or I can tell you're pretty upset about this.

Do you want to pause and take a break?

That doesn't sound like something that was appropriate for this service.

Have you spoken to someone about this? (If yes, move on)

(If no) - I can tell you about a couple of options

You can talk to your Family support coordinator for another referral for counselling

You can talk to Kirsty Ross from Massey University who manages the counselling service

You can make a complaint to the Health & Disability Commission.

I can send you contact info/links if you are interested.

For non-cancer-related issues -

Do you know that your GP can organise referrals to you to services in your area?

Lifeline/Samaritans

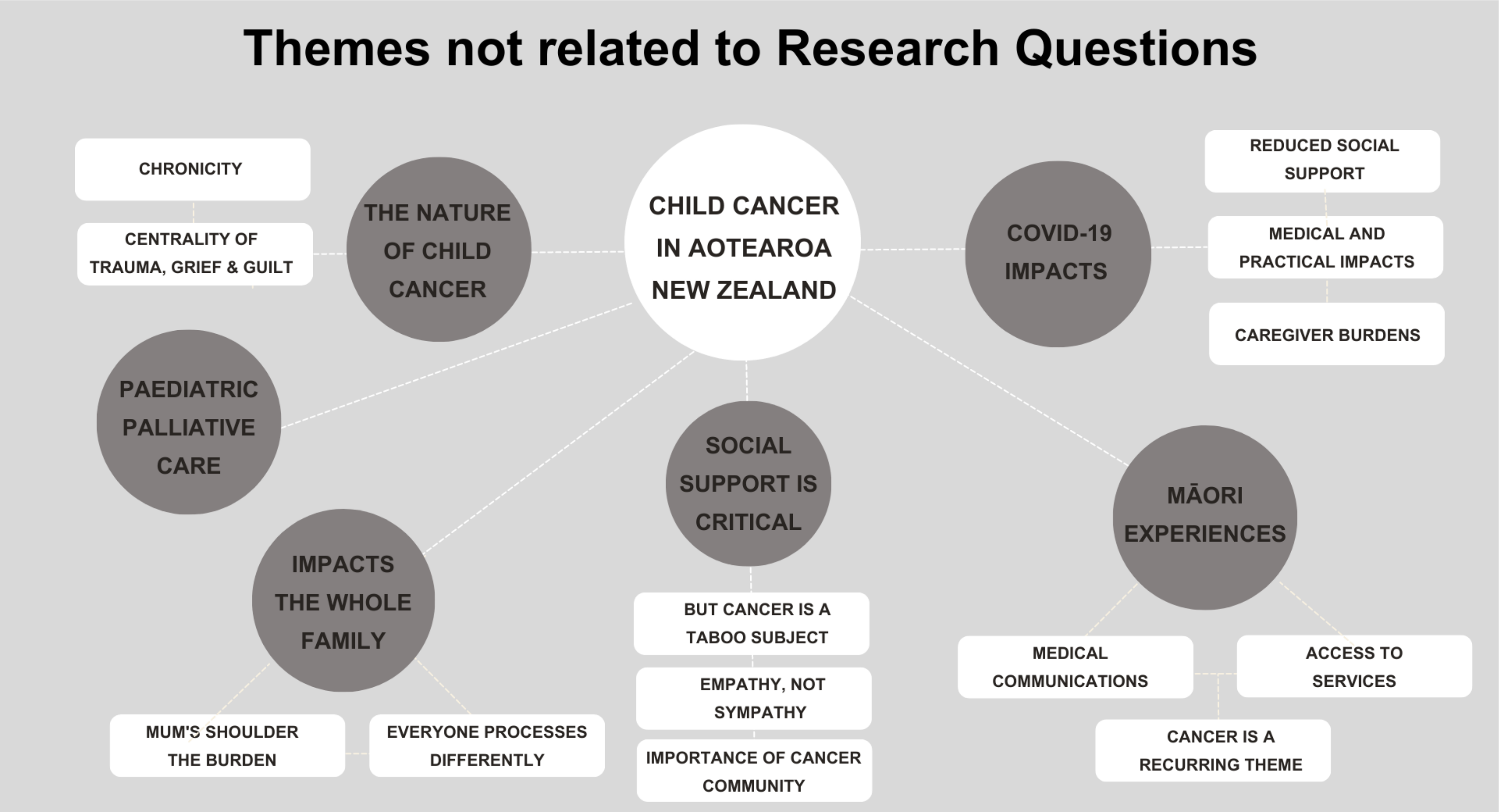
Appendix H. Non-Reported Themes

Following is a summary of additional themes (see figure 8) found through this research that were not reported due to not being directly related to the research questions. Additional information regarding any of these can be requested from the author.

1. **The nature of child cancer**
    a. Chronicity
        i. Transitions are particularly hard
        ii. Supports can disappear once families leave the hospital
        iii. The journey doesn't stop in survivorship
        iv. It's a journey that needs to be unpacked
    b. Centrality of trauma, grief & guilt
        i. Trauma is complex and drawn out
        ii. Grief isn't just about death
        iii. Multifaceted guilt
        iv. Cancer and its effects reappear in people's lives
2. **Cancer impacts the whole family**
    a. Mum's often shoulder the burden
        i. Primary caregiver impacts (coordination, communication, staying at hospital etc.)
        ii. 'Holding the family together'
        iii. Pregnancy, birth, and new mother experiences during cancer journey
    b. Family members process differently
        i. Impact on husbands, ill child and sibling
        ii. Stress can fracture relationships or exacerbate previous issues
3. **Social support is critical**
    a. But child cancer is a taboo subject
    b. Families want empathy, not sympathy

Figure 8

Non-Reported Themes



  c. The importance of cancer community

4. **Māori experiences**
    a. Medical communication during the diagnostic process
    b. Cancer as recurring theme in families
    c. Access to healthcare and support services
5. **COVID-19 impacts on cancer whānau during 2019-2021**
    a. Social support impacts
        i. Hospital-based - access to family support, visitor support and other cancer families, closures of Ronald McDonald house
        ii. Community-based – reduced or paused support groups and family activities
        iii. Lockdown a positive due to increased family time in palliative phase
        iv. Family impacts (such as child and sibling activities restricted)
    b. Impact on diagnostic process and start of treatment
        i. Parent initial concerns discounted as Covid anxiety
        ii. Restrictions on number of caregivers
    c. Impact on caregiver burden

Appendix I. Project Summary (Pre-Commencement) for NCCN and CCF

Client Experiences with the Child Cancer Counselling Network

PROJECT SUMMARY

Researcher introduction

Tēnā koe/Hello, my name is Esther Bell. As part of my Masters in Psychology with Massey University, I am helping evaluate the Child Cancer Counselling Network (CCCN).

Project Description

I am interested in the perspective of parents and caregivers who have used the CCCN. I will be inviting users of the service to participate in an interview with me, in which we will openly and confidentially discuss their experience.

Participant Identification and Recruitment

I am hoping to talk to 10 caregiver/s who are happy to take part in my study. This number has been selected to gather a range of whānau experiences and viewpoints of the service within the time constraints of a Master's thesis.

An invitation and link to an information sheet will be emailed out by the Child Cancer Foundation (CCF) to all clients who have accessed the counselling service between 1st June 2021 and 1st June 2022. Potential participants will be invited to contact the researcher directly to find out more and confirm participation.

Project Procedures

- Interviews will be conducted with the participants via video/audio call and will be approximately 60 minutes in length.
- The researcher will conduct all the interviews, independent of the supervisors and CCF/National Child Cancer Network (NCCN) staff.
- Participants will be asked questions relating to their experience with the CCCN, to gather specific information and examples of how they found the service and opportunities for improvement.

- Sessions will be recorded and transcribed.
- Participant’s confidentiality will be preserved by removing all identifying information from transcripts.
- After all interviews and transcription are completed, the researcher will code excerpts and conduct a thematic analysis.
- The data will be used to complete a summary report for the NCCN and CCF, and produce a Master’s Thesis.

Data Management

Data will be managed in accordance with Massey University regulations.

Recordings, transcriptions, consent forms and sample information will be securely stored by the researcher on a password-protected computer drive (plus secure cloud storage) and destroyed after five years.

Ethics Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 22/32. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz

Project Contacts

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Appendix J. Glossary of Terms

CBT	Cognitive Behaviour Therapy
CCCN	Child Cancer Counselling Network
CCF	Child Cancer Foundation
CCP	Child Cancer Parent
FSC	Family Support Coordinator (CCF position)
Karakia	Māori prayers or blessings that invoke spiritual protection and guidance
Koha	Te Reo Māori for gift or contribution - a symbol of reciprocity and means of maintaining social relationships
NCCN	National Child Cancer Network
Pākehā	A non-Māori person, generally used to refer to white New Zealanders
Pepeha	An introduction in Te Reo Māori that shares your affiliations with people (ancestry) and places
PSST	Problem Solving Skills Training
PTSD	Post Traumatic Stress Disorder
PTSS	Post Traumatic Stress Symptoms
Survivor	A child cancer survivor is someone who has been diagnosed with child cancer at some point in their life and no longer requires treatment
Whānau	Te reo Māori meaning family

Appendix K. Keywords (For Search Purposes)

Child cancer, paediatric oncology, chronic illness, counselling, psychosocial support, psychology, parents, caregiving, family intervention, qualitative, New Zealand