Experience of Family Support Coordinators for the Child Cancer Foundation in the development and use of the Wellbeing Check-in Booklet Distress Screening Tool

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Abstract

A paediatric cancer diagnosis presents many psychosocial complications for the patient and the family/whānau involved. Therefore, implementing systems that asses for early distress screening and the adverse sequelae cancer presents can reduce long-term psychosocial problems and, by virtue, reduce pressures on secondary health systems in Aotearoa, New Zealand. However, despite the wealth of literature supporting distress screening as evidence-based practice, there is still a need for support services to implement distress screening, particularly within paediatric cancer care successfully, and specifically care that extends beyond the patient towards the family/whānau.

Hence, in the second part of the Distress Screening Project, working collaboratively with the Child Cancer Foundation and Family Support Coordinators (FSC), this research project aimed to understand the experiences of FSCs in the use of the Wellbeing Check-in booklet distress screening tool. Through using the qualitative methodology of Interpretative Phenomenological Analysis (IPA), a total of five FSCs were interviewed. The results revealed six major themes with subsequent subthemes: Flexibility of the Wellbeing check-in booklet distress screening tool; Providing a framework to conversations; Facilitating conversations; Parent/Caregiver focussed outcomes; Overcoming barriers; and Benefits and suggestions.

The results indicate that the Wellbeing Check-in Booklet Distress Screening Tool is an effective and holistic distress screening tool in assessing the wellbeing of families/whānau of a child cancer patient within paediatric oncology. Furthermore, it was a valuable tool for the FSCs to use in their role and was well received by the parents and caregivers in their care. Future research should acknowledge the strengths of the booklet identified through this study and review the barriers discovered for future research. The results of this study have implications for the future of paediatric psychosocial oncological care in Aotearoa, New Zealand.

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This accomplishment would not have been possible without everyone aforementioned, Thank you.

Ehara Taku toa I te toa takitahi, engarri he toa takitini

My success is not mine alone, it is the success of the collective.

Māori Proverb.

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Structure of the thesis

This thesis is structured into six chapters. Chapter One begins with a brief introduction outlining the New Zealand health care system, including the role of Non-Governmental Organizations (NGO's), Primary Health Organizations (PHOs), and unique not-for-profit institutions such as the Child Cancer Foundation. Following the introduction will be a critique and review of the literature highlighting the purpose of this research. The literature review is presented in two parts, encompassing Chapter Two and Chapter Three. Chapter Two covers an introduction to Cancer, Paediatric Cancer and the impact on families/whānau. Chapter Three covers Distress screening, the function of Implementation Science, and the purpose of the current research. Chapter Four presents the methodology in which the data for this research has been obtained. Chapter Five presents the qualitative results gathered. The Sixth Chapter details the results discussion, strengths, limitations, conclusions and recommendations for future research.

Chapter One - Introduction

Ki te kotahi te kākaho, ka whati; ki te kāpuia, e kore e whati

If a reed stands alone, it can be broken; if it is in a group, it cannot.

When we stand alone, we are vulnerable, but together we are unbreakable.

Māori Proverb.

Health Care in Aotearoa, New Zealand

Aotearoa, New Zealand, is one of the few developed countries to provide a comprehensive range of publicly funded health services to the general population (Goodyear-Smith & Ashton, 2019). A publicly funded health care system aims to promote equitable access to health care for the New Zealand population free of charge. Although equitable health care access is a contentious topic within the New Zealand population today, ideally, equitable health care reflects a single system culture that promotes the population's needs (Goodyear-Smith & Ashton 2019). A publicly funded health care system enables a preventative, non-fragmented, integrated delivery system approach to health care in contrast to a fragmented approach. An integrated approach allows for care coordination across all settings, from inpatient to outpatient care, facilitating a seamless continuum of services. Thus, allowing for a patient-centred and population health focus approach, improving healthcare quality and outcomes (Enthoven, 2009).

The health care system in Aotearoa, New Zealand, can be understood by the division into three categories: Primary, Secondary, and Public health services (Southern District Health Board, n.d). The primary health sector will be the predominant health sector discussed for this research. The primary health sector represents the broader range of health services such as diagnosis, treatment, health education, screening, prevention, counselling and support (Ministry of Health, 2020). Primary and Secondary health services are governed by District Health Boards (DHB's), which are run by publicly elected and government-appointed members responsible for providing health services within their geographical regions (Ministry of Health, 2020). It is acknowledged since the time of data collection this system has now been changed to Te Whatu Ora (Te Whatu Ora – Health New Zealand, 2022). DHB's objectives are to protect and improve the community's health and work together to create strategies to improve the health care system within Aotearoa, New Zealand, leading to the launch of the primary health care strategy in 2001 (Ministry of health, The Primary Health Care Strategy, 2001).

The Primary health care strategy launched in 2001 had the aim to reduce health inequities and address socio-economic disparities as a cause for poor health status within the communities in Aotearoa, New Zealand (Ministry of Health, The Primary Health Care Strategy, 2001). The Primary health care strategy pushed for community-based services, targeting prevention and promoting population health (Ministry of Health, The primary health care strategy, 2001). This strategy aligns with the philosophy aforementioned that underpins a publicly funded health care system; that is, the integration of finance and service delivery and eliminating income as a cause for health outcome disparities between various population groups (Ashton, Cumming & McLean, 2004).

However, in 2016 an amendment to the previous health strategy was released, refreshing the future direction of health care within Aotearoa, New Zealand (Ministry of Health, 2016). The previous health care strategy had made significant progress in affordability and equitable access. However, this new direction focuses on integrating different parts of the health system to become a more cohesive unit and increase the effectiveness and efficiency of health services (Ministry of Health, 2016). This direction acknowledges that health care ought to integrate community services that support wellness, illness prevention and long-term illness management. The integration of community support into health services allows for services that are catered to specific needs and inclusive of cultural differences, thus increasing the effectiveness of health services. Additionally, this direction also acknowledges and presents opportunities to address differences between minority groups at greater risk of poorer health outcomes, such as Māori and Pasifika communities (Ministry of Health, 2016).

Health and Culture in Aotearoa, New Zealand - Hauora[1] and Tikanga[2]

Therefore, a unique strength of the New Zealand healthcare system is acknowledging factors that may alter the effectiveness of health care services available such as access, income and culture (Goodyear-Smith & Ashton 2019). Incorporating principles from the Treaty of Waitangi/ Te Tiriti o Waitangi into health promotion increases the effectiveness of health care service and delivery, aligning with the goal of the New Zealand Health Strategy. The Treaty of Waitangi/ Te Tiriti o Waitangi is Aotearoa, New Zealand's, founding document between the British Crown and Māori Rangatira[3] that reinforces the protection of Māori culture, reaffirms Māori sovereignty and gives Māori equal citizen rights (Came, Cornes & McCreanor, 2018).

Health for Māori is a taonga[4]; however, Māori experience disproportionate health effects and diseases. Many of these inequities are due to the intergenerational effects of colonisation and institutional racism (Came, Kidd, Heke,& McCreanor, 2021). Therefore, to address the disproportionate representation and honour the importance of health for Māori, the Treaty of Waitangi/ Te Tiriti o Waitangi is required by law to be incorporated into health care by including

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[1] Hauora – Māori philosophy and terminology for health and wellbeing
[2] Tikanga – Māori terminology for customs, traditional values, culture
[3] Rangatira – Māori terminology for chief
[4] Taonga – Māori terminology for something treasured or of value

the Treaty principles of partnership, protection and participation. The incorporation of the treaty principles allows for a more progressive approach to public health and health research (Came, Cornes & McCreanor, 2018). Additionally, the inclusion of principles such as Te Whare Tapa Wha the Māori holistic health model encompassing 4 dimensions of health (Te taha tinana (physical wellbeing), Te taha hinengaro (mental wellbeing), Te taha wairua (spiritual wellbeing), Te taha whānau (family wellbeing)), aligns with the Tangata Whenua[5], provides and facilitates optimum arrangements for the most effective and efficient delivery of health services to meet the needs of the New Zealand population (Durie, 1994; Durie, 2001; Goodyear-Smith & Ashton 2019; Kara et al., 2011; Rochford, 2004).

However, in addition to acknowledging and accommodating cultural differences, the next step to gain the most value from a publicly funded health system is to connect people with appropriate health services and systems, reflecting a holistic approach to health extending towards the community (Ministry of Health, 2016).

Primary Health Organizations (PHOs) and Non-Governmental Organisations (NGOs)

Not-for-profit organisations such as Primary Health Organizations (PHOs) and Non-Governmental Organisations (NGOs) have been developed with the sole purpose to provide support for both the individual and those around them (family/whānau). Not-for-profit organisations relieve the pressure from the broader healthcare system by integrating communities and health services (Ministry of Health, 2020). PHOs and NGOs are not-for profit-organisations that act as providers for the community. Health and Disability NGOs receive funding from the government or the Ministry of Health. They typically provide a range of frontline delivery

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[5] Tangata Whenua – Māori terminology for the indigenous people of the land

services, often in primary care, such as mental health, disability support services and personal wellbeing. These services often include Kaupapa services (which focus on the inclusion of principles from Te Whare Tapa Wha), as well as Māori and Pasifika providers for these support services (Ministry of Health, 2020); in contrast, PHO are services funded by the DHB's. A not-for-profit organisation of particular interest for this research is the Child Cancer Foundation (CCF).

Regional and National Cancer Support Service - The Child Cancer Foundation (CCF)

Cancer is one of the most prevalent illnesses in Aotearoa, New Zealand, with 23,000 individuals diagnosed yearly (Ministry of Health, Cancer Registration, 2020). However, there is an even greater need for support towards paediatric cancer patients and their family and whānau. This is due to the length of treatment, the vulnerabilities that arise with the paediatric age group and the impact of a cancer diagnosis across the entire family/whānau system (Bitsko et al., 2016).

The Child Cancer Foundation (CCF) is a family-centred not-for-profit nationwide charity that offers and provides individualised and coordinated support services to children and their families during every stage of their cancer journey (Child cancer Foundation n.d). Cancer is an illness with multi-faceted levels of impact, from physical treatment to emotional wellbeing, affecting resilience, social connections, practical support and long-term coping (Child cancer Foundation n.d). When a child is diagnosed with cancer, New Zealand's publicly funded health system provides a spectrum of sustainable services available for the children and their families/whānau. The CCF is one of these available support pillars (Ministry of Health. 2019). The CCF acknowledges the importance of psychosocial care to be extended and directed towards the patient and their family/whānau, but also understands the importance of emotional and practical support that is separate from a clinical setting which is individualised and dedicated to the family/whānau (childcancer.org.nz).

To achieve such a high level of individualised care, the CCF provides every family/whānau in Aotearoa, New Zealand, with a Family Support Coordinator (FSC) to help them navigate through their cancer journey (childcancer.org.nz). FSCs provide personalised support in five key areas: social connection, emotional wellbeing, practical support, building resilience, and moving forward. The role of FSC allows them to check in on families/whānau wellbeing regularly. The consistency of FSC's increases the opportunities for discussions with families/whānau about their emotions and coping adjustment since the diagnosis and throughout the entirety of the child's cancer journey.

Aotearoa, New Zealand's Health Care system and Cancer Care 'Today'

Aotearoa, New Zealand's health care system has evolved for the population of New Zealand by removing barriers (such as income) to facilitate equitable access to health care. Additionally, it has continued to improve by implementing methods to increase health service effectiveness, such as the inclusion of culture and Kaupapa in service delivery—not-for-profit organisations such as the CCF aid in integrating health and community. The CCF acknowledges the burden of illness and cancer by providing support irrespective of where affected families live, promoting equal access to supportive care - overall representing a health care system that works to cater to the entire population's needs.

However, it is essential to acknowledge that the health care system in New Zealand today, 2022, is currently undergoing significant changes (Ministry of Health, 2021). Our health workforce is not only facing increasing stress regarding managing demands and services of limited resources amidst the Covid-19 pandemic, but is also facing structural changes pushed by local leadership (Labour NZ, 2021). Nonetheless, with change arises the opportunity to build and improve the current health system. Incorporating evidence-based practices into standard practice will lead to timely and appropriate access to services preventing distress and impairment. Additionally, timely access to services reduces the pressure of secondary health services through early intervention at a community level (through NGO's such as the CCF) in bettering the health and wellbeing of New Zealand families/whānau facing cancer.

Paediatric Cancer Care and The Distress Screening Project

A cancer diagnosis presents many psychosocial complications for the patient and the family/whānau involved. Therefore implementing systems in place that assess for early distress screening and the negative impact cancer presents can reduce the long-term psychosocial problems and, by virtue, reduce pressures on secondary health systems. However, despite the wealth of literature supporting distress screening as evidence-based practice, there is still a need for support services to successfully implement distress screening within paediatric cancer care, particularly care that extends beyond the patient towards the family/whānau.

Therefore, given the unique position of FSC in the CCF, the Distress Screening Project was initiated by the New Zealand National Child Cancer Network (NCCN) with support from the CCF and in association with Massey University. The Distress Screening Project was an initiative to create and provide a tool that could be used within a paediatric cancer care setting for the patients family/whānau. The purpose of the distress screening tool is to facilitate discussions around distress and present as a stepping stone to assess those who may require additional support (Ross, Baken, MacFarlane & Kiddle, 2019).

Initially, Ross, Baken, MacFarlane and Kiddle, (2019), developed a distress manual for FSC to implement, to meet the needs of family/whānau in Aotearoa, New Zealand. The Wellness Check-in distress screening tool was incorporated into the initial manual with the goal in mind to support families/whānau wellbeing throughout the cancer journey in Aotearoa, New Zealand. Through a collaborative consultation process with the FSCs, the manual quickly evolved to a booklet as the initial tool did not meet the principles and goals of the organisation, as it was felt to be too 'clinical'. These considerations then shaped the development of the Caring for your Wellbeing Booklet.

The Caring for your Wellness Booklet covers the areas of wellbeing, coping, support, and the challenges and stressors that arise throughout the cancer journey. The booklet is designed to be used to explore not only the distress experienced but identify the needs of the parents, family/whānau including the patients siblings. It incorporates principles from Bronfenbrenner's (1979) social-ecological model and Te Whare Tapa Wha principles. By assessing the needs of the wider family/whānau, the booklet presents a strengths, competency, and resilience focus to reflect and enhance a holistic understanding of wellness (Ross, Baken, MacFarlane & Kiddle, 2019).

Incorporating Te Whare Tapa Wha principles acknowledges the bicultural society in New Zealand, Aotearoa, and our Tangata Whenua, Māori. The incorporation of Te Whare Tapa Wha principles ensures inclusivity of cultural differences cultural sensitivity. It also indicates the promising adaptability of the Caring for your Wellbeing Booklet and Wellness Check-in for implementation towards other cultures. The inclusion of questions reflecting Te Whare Tapa

Wha allows for the facilitation of further conversations, reflecting a narrative approach to the Wellness Check-in tool. Thus, this facilitates conversations about the families/whānau's wellbeing in a community context and provides insight into differing perspectives of patients and their family/whānau. The Wellness Check-in is based on the Distress Thermometer (DT) and the Impact thermometer (IT) with a 0-10 rating scale with 10 reflecting high levels of distress and 0 reflecting no distress experienced.

The Wellness Check-in distress screening tool within the Wellness Check-in booklet addresses the research to practice gap in psychosocial care in paediatric cancer directed towards the family/whānau of the patient. Additionally, the Wellness Check-in distress screening tool provides support and facilitates the opportunity for a korero[6] between FSC and the families/whānau around the cancer journey; it is also a preventative tool in identifying families/whānau that may require additional support throughout the cancer journey. Thus, it presents the opportunity for early identification for those who may need additional psychosocial support, reducing pressures on secondary health systems allowing for effective and efficient distribution of psychosocial care and required resources, bettering the population health of Aotearoa New Zealand.

However, in alignment with evidence-based practices and implementation science, the booklet needs to be evaluated. In order to ensure best practice and the successful implementation of the Wellness check-in booklet, it was imperative to involve key stakeholders, consumers and the FSC in both the development of the booklet and the implementation of it now it is in use. The collaborative involvement of critical stakeholders and the FSC allows for the assessment of the booklet in a realistic setting with the actual application. Therefore, this research project presents

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[6] Korero – Māori terminology for conversation, discussion, meeting

as a second part to the Distress Screening project with the goal to explore the experiences of Family Support Co-ordinators for the Child Cancer Foundation in the use of the Wellness Check-in booklet distress screening tool.

Chapter Two Literature Review – Part one

Introduction to General Cancer - Te Mate Pukupuku[7]

Cancer, Te Mate Pukupuku, is a prevailing illness and a leading cause of death in Aotearoa, New Zealand, accounting for approximately one-third of mortality rates (Ministry of Health 2016b). Cancer is an illness or disease defined as the uncontrollable proliferation of abnormal cells, often resulting in a genetic alteration causing dysregulation within the body (Jones & Baylin, 2007). The post-effects of cancer and its treatments can lead to chronic consequences, ensuing residual disabilities or changes to the patient, which can be both physical and psychological and may be irreversible (Page & Adler Eds, 2008).

In Aotearoa, New Zealand, cancer registrations have increased by approximately 18% since 2013, rising from 22,166 to 26,158 new cancer registrations in 2018 (Ministry of Health, 2020). This increase of 3,992 patients over a five-year time frame indicates that cancer is not only an invasive illness present within our communities but has a growing reach and influence, one which is forecast to continue to increase over the coming years. Aotearoa, New Zealand, has one of the highest overall incidence rates and cumulative risk for cancer in men and women in the world (Bray et al., 2018; Global Cancer Statistics, 2018). This increase in risk is partly due to the causal relationship between the increase in ultraviolet radiation as a results of the ozone layer depletion of Aotearoa, New Zealand thus, causing higher rates of melanoma and skin cancers in comparison to other countries. Additionally, the awareness and detection of cancer over the years has also improved adding to the increase in incident rates and risk awareness (Global Cancer Statistics 2018; Parker, 2021). Furthermore, with New Zealand's increase in population size and

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[7] Te Mate Pukupuku – Māori terminology for cancer.

aging population, it has been predicted by Bray et al., 2018 that by the year 2040, there will be approximately 52,531 diagnoses per year. Thus, it is logical to assume that the effects of cancer will impact the majority of the New Zealand population, either through direct individual experiences or indirect emotional, economic, and social impacts on family/whānau (Ministry of Health. 2019: New Zealand Cancer Action Plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029).

However, although there is an increasing rate of cancer diagnosis within our communities, adjacently, there is also an increasing rate of cancer survivorship (Ministry of Health, New Zealand Cancer Action Plan 2019–2029). Cancer survival refers to the time lived after an initial diagnosis of cancer and can be used as a measure to represent the success of cancer control (Ministry of Health, Cancer Patient Survival 1994-2011). Survivorship is dependent on a multitude of factors, such as the cancer type. For example, the survival for Testicular, Melanoma, Thyroid, and Hodgkinson Lymphoma has a one-year relative survival of 90% or higher; in contrast, Pancreatic cancer represents the lowest one-year survival of 18% (Ministry of Health, Cancer Patient Survival 1994-2011). The extent of cancer also refers to the spread of cancer either being localised, regional or distant, where survival decreases as cancer spread increases.

Other contributing factors such as gender and age also influence cancer survivorship. Additionally, the patient's ethnicity may also be a factor for cancer diagnosis and survival, as cancer outcomes vary within particular population groups. For example, Māori are 20% more likely to receive a cancer diagnosis and are twice as likely to die due to cancer than those who are non-Māori (Ministry of Health, New Zealand Cancer Action Plan 2019-2029). However, once accounting for age and population growth, cancer mortality rates have decreased from 142 to 123 deaths per 100,000 between 2004 to 2013, indicative of an increase in survivorship (Ministry of Health, Cancer: New Registrations and Deaths 2013). This increase in survivorship is an excellent advancement in modern medicine, early cancer detection, treatment, and public health. However, with this increase in survivorship arises the additional complication of patients adjusting to life post-cancer with potentially permanent physical and emotional impacts either caused by the cancer illness itself, side effects of treatments or the cancer journey experience (Page & Adler Eds, 2008; Stein, Syrjala, & Andrykowski, 2008).

Long-term and Late Effects of General Cancer (Adults)

Predominantly, cancer treatments consist of one or more treatments, including chemotherapy, radiation therapy, hormone therapy, and surgery, permanently impacting the body's physiology and neurological functioning (Page & Adler Eds, 2008). Therefore, traditionally a large part of the cancer journey was primarily treatment-based, meaning that once a patient was successfully treated, there was a consensus that care is completed. A treatment-based approach disregarded issues surrounding later effects and any psychological impacts of a cancer diagnosis and the subsequent journey (Simone & Hewitt, 1999; Stein, Syrjala, & Andrykowski, 2008).

Post-cancer, physiological and psychological problems can emerge either during treatment, many months after or even years later, and can persist long-term, affecting daily functioning and a cancer patient's quality of life (Stein, Syrjala, & Andrykowski, 2008). Although most cancer survivors return to normal functioning and can live relatively normal, symptom-free lives post-treatment, there is substantial support within the literature that care ought to extend into survivorship. Moreover, there needs to be a drive for strategies to promote evidence-based, compassionate, and coordinated care throughout a patient's cancer trajectory, including the psychological impacts (Page & Adler Eds, 2008; Stein, Syrjala, & Andrykowski, 2008).

Initial efforts in addressing the long-term and late effects of cancer patients tended to focus on causes of later mortality such as second cancers, delayed medical effects and other physiological risks (Stein, Syrjala, & Andrykowski, 2008). Long-term and late effects tend to develop during the cancer treatment phase or after-treatment persisting through survivorship. Long-term and late effects can consist of pain, fatigue, weakness, cognitive difficulties, musculoskeletal and cardiovascular complications, depressive and anxiety symptoms (Stein, Syrjala, & Andrykowski, 2008). The National Health Interview Survey (NHIS) from 1998-2000 indicated that individuals who had a medical history of cancer were twice as likely to report experiencing the long-term effects aforementioned and other functional disabilities post-cancer. Hence, it is evident that cancer presents physiological and psychological chronic side effects limiting daily living (Stein, Syrjala, & Andrykowski, 2008).

A cancer diagnosis is often considered life-threatening and can lead to significant distress in patients; when present at a consistently elevated level, this distress can lead to anxiety, depression, or both (Smith, 2015). However, regardless of whether a symptom arises during or post-treatment, it is evident through a large body of literature that these present physical and psychological problems for cancer survivors that do not resolve after treatment (Stein, Syrjala, & Andrykowski, 2008). A comprehensive study conducted by Zaora et al., (2001) identified that from a cohort of 4,500 cancer patients aged 19 years and older, 29-43% reported significant psychological distress post a cancer diagnosis and cancer treatment. This can include significant low mood.

Depression rates in cancer patients are approximately three times higher than those in the general population. Although depression is considered a relatively normative and universal reaction to an illness like cancer, it can often be underdiagnosed or undertreated, presenting further psychological life-long complications (Linden, Vodermaier, MacKenzie, & Greig, 2012; Smith, 2015). Some cancer symptoms and treatment side effects such as weight loss and sleep disturbances can mimic symptoms of mood disorders such as depression, and anxiety, masking severe psychiatric distress, often contributing to depression and anxiety.

Depression and anxiety affect an individual's quality of life and can compromise patient outcomes, as depression has been linked to higher mortality rates in cancer (Colleoni et al., 2000; Pinquart & Duberstein, 2010). A meta-analysis conducted by Satin, Linden & Phillips (2009) concluded that minor and major depression increased patient mortality rates by 39%. Additionally, patients who expressed minor depressive symptomology were at a 25% increased mortality risk. Depressive or anxious behaviours can interfere with screening procedures and treatments and can inhibit patient uptake of psychosocial support only to further psychological distress (Spiegel & Giese-Davis, 2003). This can then exacerbate negative emotions surrounding treatment, the hospital, care services, and personal health, leading to alternate adverse medical outcomes, further complicating diagnosis and treatments within the cancer journey (Spiegel & Giese-Davis, 2003).

In addition to negatively impacting medical treatment, depressed or anxious patients may display a lower level of social functioning, greater risk for disability, and more significant functional impairment than those who do not express anxious or depressive symptoms (Spitzer et al., 1995; Katon, 2003). Additionally, adult cancer patients with depressive symptoms display more significant rates of unhealthy behaviours such as smoking and sedentary lifestyle choices

(Page & Adler Eds, 2008). Thus, mood and mental wellbeing are influential on cancer progression and treatment adherence (Smith, 2015).

However, it is essential to acknowledge that patients who may not develop clinically diagnosable syndromes will still experience psychological stress such as worries, loss of control, confusion, anger, and fear that still cause significant distress (Charmaz, 2000; Stanton et al., 2001). These emotional states can also have detrimental effects on health; this is supported by evidence from psychoneuroimmunology, eliciting the adverse effects of prolonged stress on behaviour, the brain, and the immune system impacting overall health and wellbeing (Mariotti, 2015). Mental health conditions, either at a clinical level or subsyndromal level (such as anxiety, depression, mood disorders, and fears for the future in patients with cancer), thus reflect deleterious effects on the quality of life. Physical impairments due to cancer, such as pain or fatigue, can inhibit daily functioning, which can cause frustrations, increased stress, and mood disorders impacting psychological wellbeing. In addition to physical impairments that can trigger adverse emotional outcomes, cancer itself can lead to negative emotional sequelae following diagnosis and treatment (Charmaz, 2000; Mariotti, 2015; Stanton et al., 2001).

Therefore, understanding the long-term and late effects of cancer allows for clinicians and support staff to implement appropriate follow-up measures, educate the patients and promote early detection in healthcare; thus, by virtue, improving the quality of life of cancer patients and survivors (Stein, Syrjala, & Andrykowski, 2008). Physical and psychological problems for cancer survivors that do not resolve after treatment can affect normal functioning, which is a concern in general but particularly for paediatric cancer survivors due to the developmental vulnerabilities within this cohort.

Paediatric Cancer – Tamariki[8]

Paediatric cancers represent less than one per cent of cancer diagnoses within the New Zealand population. Paediatric cancer is the second most common cause of death in children aged 1-14 years old after traffic accidents (NZ Childhood Cancer Incidence 2010-2014). However, with this said, survival rates for paediatric cancer have increased over the past few decades. Before 1970, most children under the age of 20 years diagnosed with cancer had relatively low survival and remission rates. Since then, cure rates have increased to 85% for the five-year relative survival estimate (Ballantine & NZCCR Working Group, 2017).

Furthermore, a child diagnosed with leukaemia, the most common form of cancer, currently has a 90% chance of long-term survival (Askins & Moore, 2008). However, often not recognised are the unintended consequences of such a high success rate of childhood cancers; as the survival rates of paediatric cancer increase, so does the need and quality for psychosocial oncological care (National Research Council, 2003; Askins & Moore, 2008). Paediatric cancers are developmental, meaning they arise during the child's growth and development phase, corrupting developmentally regulated genes. Therefore, childhood cancers and long-term and late effects differ from adult cancers which can be highly influenced by health behaviours and lifestyle factors (NZ Childhood Cancer Incidence 2010-2014). Moreover, a child's response to the cancer journey will also differ, eliciting the need for specialised psychosocial long-term care that accounts for these differences (NZ Childhood Cancer Incidence 2010-2014).

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[8] Tamariki - Māori terminology for children.

Immediate Effects of Paediatric Cancer

Paediatric cancer treatment can consist of six months to three years of medical appointments. Moreover, it will often require travel to specialised oncology centres (IOM and NRC, 2003; Askins & Moore, 2008). In Aotearoa, New Zealand, there are currently only two specialist oncology centres (Auckland's Star Ship Children's Hospital and the Christchurch Children's Haematology Oncology Centre (CHOC)) (Ministry of Health, NZ 2010). Thus, for many families, travel to one of these two treatment centres is a necessary part of the cancer experience. The requirement for travel can lead to significant disruption in environments, regular daily routines, activities and family cohesion, all of which may be experienced as a lack of control in a child's life and contribute to significant distress during treatment (Askins & Moore, 2008

A cancer diagnosis for a child can be an extremely confusing experience affecting everyday life, health and wellbeing (Darcy, Knutsson, Huus & Enskar, 2014). Understanding health and illness for young children depends on their cognitive abilities. However, as a child, health is a concept that is primarily associated with the participation and involvement in what they recognise and understand to be daily activities with their peers and family/whānau, reflecting subjective measurements of health and wellbeing (Almqvist, Hellnäs, Stefansson, & Granlund, 2006). Thus, as a child, daily life, activities, how they feel and what they do with whom can be expressions of health and wellbeing, and any changes or limitations to these aspects, such as that presented by a cancer diagnosis and treatment, can hinder health and wellbeing of the child (Darcy, Knutsson, Huus & Enskar, 2014).

A study conducted by Darcy, Knutsson, Huus and Enskar (2014) explored a child's everyday life after receiving a cancer diagnosis and concluded with three emerging themes. The themes expressed were 'feeling like a stranger', 'feeling powerless', and 'feeling isolated'. A cancer diagnosis creates a sudden shift in the child's independence, self-image, energy levels and mobility. Throughout development, children constantly gain independence and self-control in daily tasks and bodily functions. The shift from having gained some self-control, prior to a diagnosis and treatment, to requiring assistance in basic needs they had once mastered (such as going to the toilet or getting dressed) can be emotionally challenging; previously independent children may now need additional support from a parent or a caregiver. This shift in independence and control can create a separation from the child's sense of self from prior to diagnosis and treatment to post-diagnosis and treatment; thus, the expression of 'feeling like a stranger' and ‘feeling powerless’, as children often express feeling different and a changed self-regarding their illness (Darcy, Knutsson, Huus & Enskar, 2014).

Additionally, a symbol of children's health and wellbeing is play and the need for play and interaction with their peers. A cancer diagnosis and the subsequent treatment dramatically affects a child's ability to play due to energy levels, physical abilities and access to other children. In turn, this can lead to a sense of loneliness experienced by the child. Children expressed a strong sense of isolation and longed to return to their preschool/school and friends (Darcy, Knutsson, Huus & Enskar, 2014).

Hospitals and treatment centres have acknowledged the central role of play for a child's health and wellbeing by including play departments within care facilities. However, the play facilities can often still fail to mimic and encourage regular play due to the play now changing from carefree play to minimal play or mirrored hospital play, and to an activity that is now more individualistic or with adults rather than with their peers (Darcy, Knutsson, Huus & Enskar, 2014).

Thus, a cancer diagnosis not only has physical impacts on a child's health but can cause emotional reactions in adjustment to the diagnosis, which can cause psychological distress through the shift in perception of self, lack of control/power and a sense of isolation. This distress can be significant enough to meet criteria for a diagnosable mental health condition. Studies have indicated that children diagnosed with cancer can present with symptoms that meet the criteria for post-traumatic stress (PTSD) and post-traumatic stress syndromes (PTSS). According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013), the experience of a life-threatening medical illness can be classified as an event for PTSD.

Additionally, it is essential to acknowledge that patients may not develop clinical syndromes but may still experience worries, fears, and psychological distress that can cause significant distress. A child cancer patient will undergo cancer treatment during a period of life where children typically master everyday social skills and specific behaviours in daily living. These skills aforementioned can consist of self-sufficiency, social independence from parents, emotional growth, building personal relationships, skill development, and performance in normative roles (Rodriguez et al., 2012; Bakula et al., 2019). The effects of cancer treatments during such a vulnerable age can disrupt and delay the development of all these skills. Additionally, children may begin to feel isolated from social activities (play) and normative roles, which in turn will heighten their risk for psychological distress (Meadows, 2003; Rodriguez et al., 2012; Bakula et al., 2019). Thus, children are not only more susceptible to physical developmental alterations as a result of cancer, but they are emotionally more vulnerable due to their developmental vulnerabilities and their less developed capacity for emotional regulation during this age (Bakula et al., 2019).

Long-term and Late effect of Paediatric Cancer

Cancer treatments are often invasive procedures designed to suppress cell growth to eliminate cancerous malignancies. Although cancer related medical procedures are intended to preserve life they are however, capable of causing permanent changes to a child's developmental trajectory, as cancer therapies target rapidly growing cells presenting physiological long-term and late effects for childhood cancer survivors (Meadows, 2003; Ness & Gurney, 2007). Long-term and late effects aforementioned can be due to physiological treatment effects consisting of cosmetic or functional impairments interfering with daily activities - such as amputations, alopecia, developmental disturbances (such as delayed endocrine functioning), cognitive and emotional development delays which may affect social skills, survivors' health and quality of life (NZ Childhood Cancer Incidence 2010-2014).

The challenges of childhood cancer go beyond successful treatment and cancer remission; up to 75% of paediatric cancer survivors will develop an alternative chronic health condition, and approximately 37% will develop debilitating or life-threatening long-term and late effects (Signorelli et al., & ANZCHOG Survivorship Study Group, 2017). A retrospective study conducted by Oeffinger et al., 2006, identified that of 10,000 adult survivors of childhood cancer who were diagnosed with a form of cancer before the age of 21, 62% had at least a chronic health condition, with 27% presenting with a severe or disabling chronic health condition such as seizure disorder.

The timing of a cancer diagnosis and treatment also has an important influence on a child's cognitive development. The younger the age of diagnosis, the greater the risk of cognitive impairment, resulting in lower cognitive functioning post-treatment as brain development continues until young adulthood. (Anderson, Spencer-Smith & Wood, 2011). Therefore, a diagnosis at a young age consequently means that there will be disruptions to cerebral development during vulnerable stages of brain maturation (Gogtayet al., 2004).

For example, a study conducted by Siegwart et al.,(2021) concluded that cancer survivors aged between 7 and 16 years displayed atypical working memory activation compared to the healthy controls of the same age. This study found that childhood cancer survivors' working memory (a core component of cognitive functioning, daily life, and academic abilities) decreased when demands increased, and they performed worse than the control group in visuospatial working memory tasks.

Furthermore, neurocognitive long-term and late effects can contribute to language development, reading and arithmetic problems which can have other implications on a child's quality of life, school performance and learning (Siegwart et al., 2021). It is essential to acknowledge that childhood cancer survivors may not initially show any neurocognitive difficulties; however, deficits can develop later, affecting re-entry to school and everyday activities (IOM and NRC, 2003; Butler and Mulhern, 2005).

Cognitive dysfunction and chronic illnesses are unfortunate long-term, late effects post-cancer treatment. However, it is imperative to recognise that long-term and late effects are not limited to physiological impairments; many childhood cancer survivors will also experience psychological difficulties (Ness & Gurney, 2007).

Additionally, the increased absenteeism due to hospitalisations and treatments, means that a child's schooling, social development and the performance of specific skills and normative roles learnt during this age are hindered. These are critical factors that can impact childhood and, by virtue, lead to the development of psychological and psychosocial distress and negatively impact the quality of life (Zebrack and Chesler, 2002; Page and Adler Eds, 2008). These effects can increase a child's risk of poor emotional adjustment during their cancer journey, which may continue until survivorship (Bakula et al., 2019). Poor emotional adjustment can result in increased anxiety around hospital environments, the development of body image issues, relapse concerns, family separations due to treatment travel, and anxiety surrounding the reintegration back into a real-world setting; all factors which can exacerbate an already emotional experience (IOM and NRC, 2003; Askins & Moore, 2008).

Psychological and psychosocial problems such as depression and anxiety are experienced by many childhood cancer survivors (Ness & Gurney, 2007). A study conducted by Hudson et al. (2003) indicated an approximate twofold increase in mental health problems in the Childhood Cancer Survivors Study (CCSS) group compared to their siblings. However, whilst psychological and psychosocial distress is a known risk in childhood cancer, it is essential to acknowledge that not all childhood cancer survivors will decrease quality of life and negative psychological and psychosocial sequelae post-cancer. At the successful conclusion of treatments and until survivorship, some patients express a generally positive quality of life and high coping abilities, reflecting a notion of resilience for those children who experienced a life-altering event (Parry & Chesler, 2005; Zebrack & Chesler, 2002).

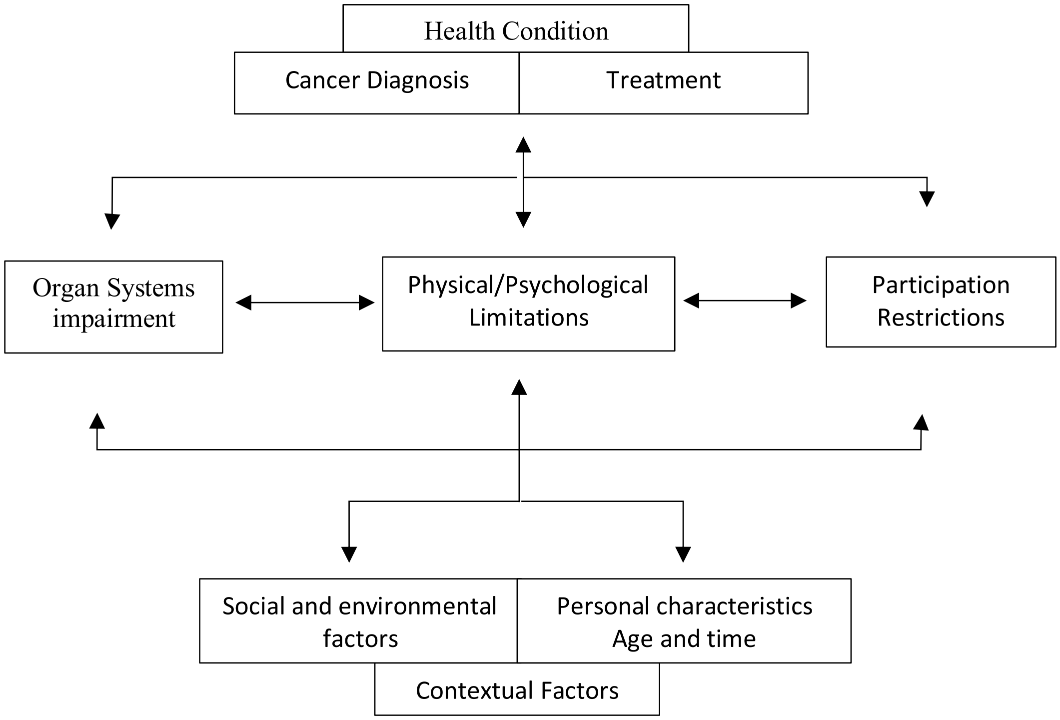
There is a complex relationship between the physiological and psychological long-term and late effects of a cancer diagnosis, subsequent treatments and survivorship, and the functional limitations and the implications these may have on the quality of life for childhood cancer survivors (Ness & Gurney, 2007). Therefore, it is helpful to understand childhood cancer's long-term and late effects through a conceptual framework from the epidemiological disablement model adapted from Nagi, 1969 and Ness & Gurney, 2007.

Conceptual Disablement Model for Paediatric Cancer Survivors

The Conceptual Disablement model for Cancer Survivors presented in Figure 1 describes the impact of a cancer diagnosis and treatment upon physical and emotional health and the possible consequences on the quality of life for a childhood cancer survivor (Ness & Gurney, 2007; Askins & Moore, 2008; Bakula et al., 2019). The model demonstrates how a cancer diagnosis and treatment causes anatomical shifts and alterations to organ functionality; thus, leading to physiological long-term and late effects. This limitation in a loss of structure then leads to a limitation across other domains of performance either represented by physical, cognitive and emotional performance - psychological and psychosocial long-term and late effects. Limitations in performance influence participation and restrict the patient's abilities or inabilities to participate in everyday tasks. Limitations to these tasks can have detrimental developmental effects and psychological consequences, which will affect the quality of living.

For example, a patient may not experience organ system impairment, but this does not exclude them from facing participation limitations, as participation limitations can result from psychological impairments such as anxiety or depression. However, it is essential to acknowledge that the adverse sequelae that proceed with a cancer diagnosis and treatment are not limited to one domain and can occur independently.

Figure 1: *Conceptual Disablement model for Paediatric Cancer Survivors*



Adapted from Nagi, 1969; Ness & Gurney, 2007.

Summary

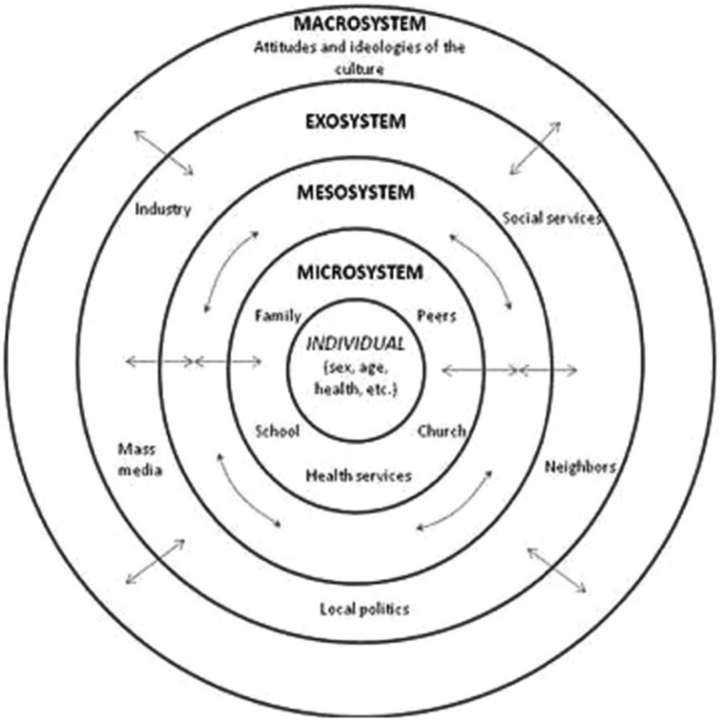
Thus, in addition to the goal of cancer amelioration and treatment, the new reality of paediatric cancer is to identify and acknowledge the psychological and psychosocial consequences during diagnosis, treatment and post-cancer and both the immediate, long-term and late effects of these consequences. The aim is to provide adequate interventions to promote psychosocial adjustments and aid in navigating through the cancer journey from diagnosis, treatment into survivorship. Overall, childhood cancer and its journey pose profound challenges for the patient during and after treatment. These challenges, however, also extend to the patient's family/whānau, indicating that psychological and psychosocial impairment due to a cancer diagnosis and treatment is also experienced by those involved in the patient's life.

Extending Paediatric Cancer Care (Beyond the Patient)

Childhood cancer and the subsequent journey can be a life-altering situation for the child but can also be a traumatic experience for the family/whānau. Receiving the news that a child has a life-threatening illness can be a traumatic situation evoking feelings of fear, uncertainty and helplessness among parents and siblings of the cancer patient (Alderfer et al., 2009; McCubbin et al., 2002). A cancer diagnosis presents a stressful uncertain shift in family functioning with the family/whānau response to the cancer diagnosis depending on family typology, family strengths and coping responses (Svavarsdottir, 2005). Therefore, it is logical to assume that a child's cancer diagnosis impacts the patient’s entire family/whānau, and it is essential to identify and understand how the family/whānau is adapting and coping psychologically.

Bronfenbrenner's social-ecological theory (1979), (Figure 2) suggests that an individual's wellbeing is based on social systems and their surrounding resources instead of being due to their characteristics. Bronfenbrenner's theory explains how particular qualities of children and their multiple environments, also known as ecological systems, interact to influence children's growth and development. The theory organises the ecological systems into five levels of environments (The individual, Microsystem, Mesosystem, Exosystem, Macrosystem and Chronosystem) that influence development, categorised from the most intimate to the broadest (Bronfenbrenner, 1979). This theory focuses on the context and quality of the child's environment and the interactions between these that influence a child's development; it reflects the different types of influences on human behaviour. In alignment with this theory, therefore, a cancer patient's family/whānau system is within the microsystem and is an essential proximal factor in wellness and psychosocial health.

Figure 2: *Bronfenbrenner (1979) Social-ecological Theory*



Extracted image from Velez-Agosto et al., (2017). Individual: This is the child in the middle. Microsystem: Closest and direct influences on the child. Mesosystem: The connection between the child's microsystem and outer influences. Exosystem: The larger social structure which influences the mesosystem and the higher levels of the child's microsystem. Macrosystem: The outer most layer of larger social conditions and culture that influence the interactions of all other layers. Chronosystem: (not included within the image) The influence of time upon change and consistency of the environment, the larger historical context, societal changes and generational differences.

A family/whānau inclusive approach to health and health care is of particular importance in Aotearoa, New Zealand. The Tangata Whenua[9] of Aotearoa, Māori culture, reinforces a systems perspective (like that of the Bronfenbrenner (1979) social-ecological model) with a framework known as Te Whare Tapa Wha.

Te Whare Tapa Wha is the Māori model for health (Refer to Figure 2.2), which indicates that an individual's overall Hauora/wellbeing is represented by four interconnection dimensions illustrated as four walls of a wharenui[10]. These walls are represented by; Te taha wairua/Spiritual, Te taha hinengaro/Mental and emotional, Te taha tinana/Physical, Te taha whānau/ Family and social wellbeing (Rochford, 2004; Kara et al., 2011). Thus, this model proposes an integrative approach to assessing wellbeing by recognising there are multiple interconnected dimensions acting together to contribute to an individual's wellbeing (Durie, 1994; Durie, 2001). This framework indicates that external systems such as Whanaungatanga (family connections) and whānau (family), are essential proximal factors to wellness and psychosocial health for Māori (Evans et al., 2010).

Thus, in alignment with both Bronfenbrenner (1978) Social-ecological Theory and Te Whare Tapa Wha the Holistic Maori Health Model*,* the adjustment to a diagnosis of cancer and the associated stressors experienced by a child can be influenced by the adjustment of those around them (Robinson et al., 2007).

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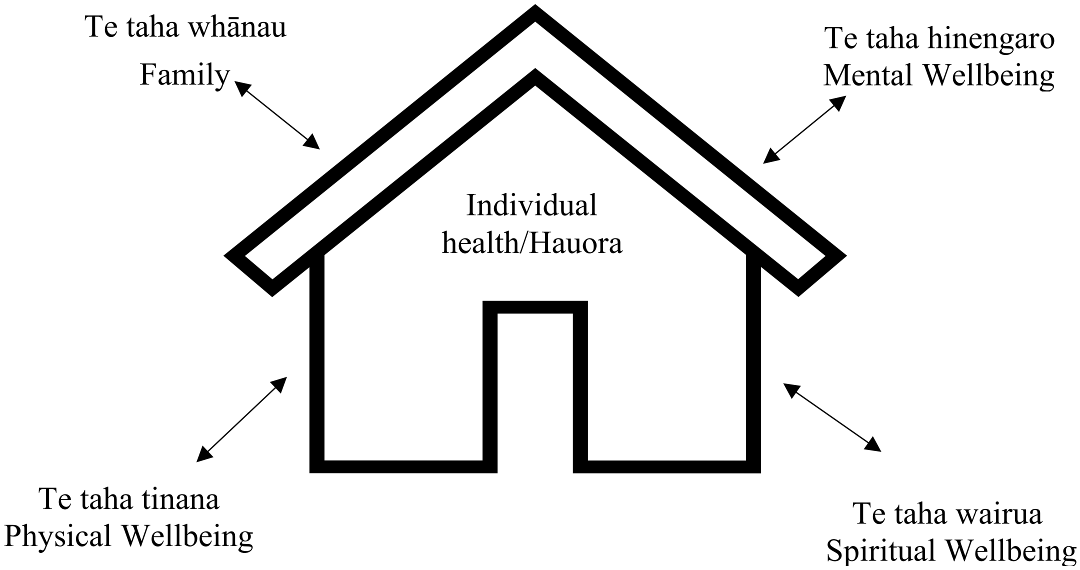
[9] Tanagata Whenua – Māori terminology for People of the land.

[10] Wharenui – Māori terminology for Meeting house.

Figure 2.2: *Te Whare Tapa Wha, Holistic Maori Health Model*



Adapted image from Durie, 1984 Māori perspective on health. Four walls of a wharenui (meeting house) symbolises the 4 dimensions of health/Hauora. Te taha tinana (physical wellbeing), Te taha hinengaro (mental wellbeing), Te taha wairua (spiritual wellbeing), Te taha whānau (family wellbeing).

Family/Whānau Oriented Psychosocial Care

In the initial stages of receiving the news of a cancer diagnosis, the patient's family/whānau will also often go through similar experiences to the cancer patient themselves, such as fluctuating emotional reactions in adjustment to the diagnosis of the illness, subsequent phases and treatments that follow. The emotional transitioning surrounding cancer can cause considerable stress, eliciting the need for psychosocial care for both the patient and their family/whānau (Woźniak & Iżycki 2014). A cancer diagnosis affects several areas in family/whānau functioning, as cancer is an illness that brings change to already established models of family interactions and dynamics (Woźniak & Iżycki 2014).

A cancer diagnosis forces a shift in family roles, creates uncertainty by disrupting plans, and unsettles the everyday rhythm (McGrath, 2001). The family/whānau subsume into multiple roles throughout the cancer journey according to the cancer phase and the patient's needs (Given et al., 2012). For example, during the diagnosis phase, many families/whānau will experience shock and often begin taking on a more research-orientated role and gather as much information about the journey ahead, beginning at diagnosis, then treatment through till survivorship (Woźniak, & Iżycki 2014). During the treatment phase, family/whānau tend to take on more of a caregiving role. Following a cancer diagnosis, the patient's family/whānau will need to re-establish a newfound family dynamic to substitute for the patient's household obligations, provide emotional support and take on additional caregiving roles such as treatment-oriented at-home-care (Rossi Ferrario et al., 2003).

Due to the changing nature of cancer care over the recent years regarding treatment and treatment outcomes, there has been a shift from inpatient to outpatient care. This shift has increased the demand upon (and the importance of) informal caregivers, that often are the patient's family/whānau members, which are often unprepared emotionally and physically, and may not have the resources and skills to meet the patient's needs (Papastavrou et al., 2009; Haley, 2003). These changes can be highly exhausting, bringing individual risks for the family/whānau regarding their psychological and physical health.

Parents and Caregivers – Matua[11]/Kaitiaki [12]

Anxiety and distress experienced by parents of paediatric cancer patients has been found to be positively associated with anxiety and distress in children (Robinson et al., 2007). Additionally, children of depressed parents tend to display internalising and externalising symptoms above those that are displayed by children with non-depressed parents (Robinson et al., 2007; Compas et al., 2002).

A longitudinal study on parents with a child with cancer under the age of 18 years conducted by Svavarsdottir (2005) concluded that not only did families with a child with cancer differ in their experiences from each other, but there were differences between the parents/caregiver's experiences within the same household. The mothers, in particular, found it challenging and time-consuming to manage behavioural problems, maintain a sense of structure for the family/whānau, and provide care for the child with cancer. Furthermore, mothers of children with cancer tended to display more internalising difficulties than mothers with healthy children. This may result in the children with cancer being more vulnerable in also displaying internalising difficulties (Robinson et al., 2007). However, in contrast, the fathers, whose voices are often missed in research, expressed difficulties in managing work and providing care for a child with cancer while providing emotional support for their spouse (Svavarsdottir, 2005). Parents often take on different roles when caring for their child with cancer; this results in different experiences (as reported in the Svavarsdottir (2005) study), influencing the child's adjustment.

The stress for families of a child with cancer is thus well documented, encompassing a range of practical and emotional consequences. Of concern is that studies have documented high

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[11] Matua – Māori terminology for parent.
[12] Kaitiaki – Māori terminology for caregiver.

rates of trauma-related symptomology in the parents of these children, to the extent that the severity of these symptoms are comparable to those who are diagnosed with post-traumatic stress disorder (PTSD), (Libov et al., 2002; Bruce, 2006). Although research indicates that the stress reactions to a child's cancer diagnosis tend to be non-diagnostically significant, it is crucial to recognise the effects of long-term exposure stress on subjective and objective health, reflective of psychoneuroimmunology (Kangas et al., 2002; Bruce, 2006).

Importantly, research suggests that parents will continue to experience high levels of cancer-related stress beyond successful treatments (Ursin & Eriksen, 2004; Norberg et al., 2005). A comparative study investigating traumatic stress in parents of children undergoing cancer treatment (compared to parents after treatment) indicated higher traumatic stress levels in parents whose child is undergoing treatment. However, the stress levels did not seem to decrease in the parent group post-treatment. Alternatively, stress shifted from the initial treatment to relapse concerns and social implications for the child in survivorship. Furthermore, it was concluded that parents in lower education and those in lower socioeconomic population groups expressed even greater levels of traumatic stress, reflecting the influence of demographics and income-related stressors and echoing Bronfenbrenner’s theory (Norberg et al., 2005).

Parents and caregivers often adopt an informal caregiving role which is a stressful role in itself; however, in particular, parents are in the position to experience additional stressors that all add to exacerbating the development of adverse psychosocial outcomes. A common predictor reported to be associated with caregiver burden, and parental coping is the support that the parents receive (Papastavrou et al., 2009). Caregiver burden is a well-documented outcome in the literature regarding family/whānau members experiences of caring for a child or family member with cancer (Papastavrou et al., 2009). Adopting an informal caregiver role can often result in an imbalance between the time spent caregiving and personal time, social roles, and managing emotional and physical states. This reprioritisation of tasks can often feel burdensome, adding to psychological stressors additional to the cancer news itself. Thus, informal caregiving is most often reported by the family/whānau as a negative experience instead of a more fulfilling positive experience (Grunfeld et al., 2004; Northouse et al., 2000).

Caregiving can be a mixture of positive and negative experiences and outcomes. Caregiving can be a positive experience, where those caregiving express feeling rewarded, satisfied, a sense of accomplishment and pride in successfully managing care responsibility (Lee & Li, 2021). In contrast, it can also be a tiring and stressful experience, particularly over an extended period. Therefore, it is essential to recognise that those who take on an informal caregiving role may be at an increased risk for developing depression and anxiety due to caregiving stress and stress-induced mood disturbances (Fortinsky et al., 2002).

The current literature indicates that many factors can be associated with caregiver burden (Woźniak & Iżycki 2014). In paediatric cancer particularly, a parent may need to resign from their job to take on the informal caregiver role. An employment shift adds additional stressors such as financial consequences, re-distribution of caregiving tasks, sibling support, and couple functioning. These additional stressors can affect the parent's psychosocial well-being (Ursin & Eriksen, 2004; Norberg et al., 2005). Additionally, informal caregivers' resources, such as socioeconomic status, pre-existing mental disorders, will also impact their approach to caregiving and the amount of burden experienced (Woźniak, & Iżycki 2014). Therefore, caregiving and the cancer journey is a significantly individualised experience within households.

Consequently, the care provided ought to be tailored to suit the family's individual needs, inclusive of many factors such as income, culture and gender (Robinson et al., 2007; Compas et al., 2002). Additionally, tailored parental social support may be the buffer required to mitigate the association between parent and child distress. Parental and caregiver directed support either will ameliorate or provide a step for early identification of the negative psychological consequences associated with a cancer diagnosis and stressors related to informal caregiving. This support will increase the parent's and caregivers psychosocial wellbeing and, by virtue, increase the child's psychosocial wellbeing, overall enhancing the family/whānau psychological and psychosocial functioning (Robinson et al., 2007; Cohen & Wills, 1985).

Hence, in assessing the adjustment of children experiencing cancer, it is logical to assess the adjustment of their parents (Robinson et al., 2007). Inevitably, there are long-term impacts of a child's cancer diagnosis and journey upon the parent's wellbeing and surrounding family/whānau. Interventions that recognise these impacts and focus on the emotional needs of the parents ought to be implemented in routine systematic cancer care as it is essential to identify and understand how the parents and caregivers are adapting and coping psychologically with the responsibilities they are required to take on.

Siblings of Children with Cancer (SCC)

In addition to the parents of a child with cancer, the siblings lives are significantly impacted. The parents can often overlook a cancer patient's sibling's needs, due to the parent's primary focus being on the ill child (Askins and Moore, 2008). This lack of parental focus can result in adverse emotions, adjustment difficulties, behavioural problems and feeling a loss of intimacy within the family (Yang et al.,2016). Moreover, these consequences can influence the family dynamic as parents may have a minimum reserve for the other children after taking on additional roles and stress due to a cancer diagnosis.

Siblings of children with cancer (SCC) seem to experience more internalising and externalising symptoms than siblings of healthy children. SCC often report feelings and attitudes of neglect, anxiety, a decreased quality of life, disrupted academic and social functioning, and concerns regarding their sibling's illness (worries of death, guilt, anger, jealousy, neglect). Without the appropriate support (and if left unattended), these emotional impacts can lead to adverse psychosocial outcomes in later life (Guan et al., 2021). A study conducted by Barrera, Fleming, and Khan (2004) concluded that siblings of those with a cancer diagnosis who reported receiving social support indicated fewer symptoms of depression and anxiety and decreased behavioural problems than those who received less or no support. The SCC did not tend to show an increase in psychiatric disorders compared to a normative group; however, they did report an increase in cancer-related stress, emotions around guilt, worry, academic and schooling difficulties and expressed a lower quality of life (Long et al., 2018). Of concern, 25% of the SCC group met the PTSD diagnostic criteria, with 66% reporting moderate to severe cancer related post-traumatic stress (Long et al., 2018). An earlier review by Katz, Kellerman and Siegel (1980) demonstrated that the younger siblings with cancer tended to exhibit a higher level of distress and increased anxious responses over time compared to the older siblings. This suggests that not only does social support prove to be a practical intervention, but that age is also a factor that ought to be considered in psychosocial distress screening directed towards siblings.

A recent Aotearoa New Zealand study by Armstrong (2019) concluded that SCC expressed needing support in having a clear role within the new family dynamic, being included in the ill sibling's cancer journey and requiring the information about their ill sibling to be delivered in a comprehendible, age appropriate manner to them. Additionally, SCC reported the need to communicate their feelings in a space catered to them without feeling guilty for adding more stress or additional concerns to their parents for conveying any concerns.

However, it is essential to acknowledge that SCC may also report positive experiences. Throughout the literature, SCC have also indicated that the cancer experience promoted social and psychological growth, independence, maturation and increased competence and compassion towards their ill sibling (Alderfer et al., 2010; Williams et al.,2009). Additionally, Nolbris et al., 2007, indicated that the SCC reported feeling that the bond between the family and their ill sibling strengthened, increasing the family bond and cohesion. Therefore, there is a need to acknowledge the various perspectives and individualised experiences of siblings who have a brother or sister with cancer and their personal needs.

Summary

Childhood cancer is an illness that can happen to anyone of any gender, culture or ethnicity; it has consequences that extend to the patient's family/whānau. A cancer diagnosis is destabilising for the patient diagnosed and the family/whānau involved as well. Cancer creates a shift in family dynamics and results in ever-changing environments within the family structure itself. Changes in jobs, school, and the introduction of external parties such as doctors, nurses, and support workers all contribute to shaping the cancer journey (Woźniak & Iżycki 2014). Therefore, it is crucial to recognise that families/whānau experiencing cancer will express different concerns and challenges and have differing needs according to these factors (Woźniak & Iżycki 2014). Thus, not only is attending to the psychosocial needs of cancer patients and the family/whānau around them necessary but providing tailored support is also an integral part of quality cancer care. In order to be able to provide appropriate, tailored and timely support, accurate identification of needs is required through the use of distress screening. The following chapter will explore current understandings of distress screening within oncology, particularly paediatric oncology.

Chapter Three Literature Review – Part two

Distress – Hiki taumahatanga[13]

The previous chapter discussed the increasing recognition of the emotional and social consequences cancer has on patients and their family/whānau psychosocial wellbeing and the effects on overall health. It has established the argument that psychosocial care directed towards the patient's family/whānau ought to be an integral part of cancer care. Psychosocial health care interventions enable patients, families/whānau, and health care providers ways to support and manage any psychological effects of cancer to achieve better health outcomes (Page & Adler Eds, 2008). Psychosocial care and interventions within a psycho-oncology discipline aim to address cancer's diverse impact and ameliorate the psychological, social, and emotional sequelae that proceed with a cancer diagnosis and treatment (Page & Adler Eds, 2008).

One common theme apparent in the literature regarding psychological functioning is the term 'distress' associated with cancer patients' emotional concerns and experiences, including those of their family/whānau (Funk et al., 2016). Psychosocial distress in cancer is defined as an unpleasant experience, either social, emotional, psychological, cognitive, or spiritual, that interferes with coping effectively with a cancer diagnosis and subsequent treatment (Funk et al., 2016). Distress falls on a continuum of experience, ranging from normal adjustment feelings associated with cancer, such as vulnerability, sadness, and fears to progressing to adjustment disorders of clinically significant emotional and behavioural symptoms that cause impairment.

Furthermore, these adjustment disorders, if unrecognised, can develop into diagnosable mental health disorders such as major depressive disorder and anxiety, emphasising the need for

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[13] Hiki taumahatanga – Māori terminology to alleviate distress.

an appropriate routine distress screening tool (National Cancer Institute, 2014, August 20). Rates of distress experienced concerning cancer can range from 22% to approximately 58%, depending on population, setting, and measurement mode (Funk et al., 2016). However, a consistent finding is that although distress levels can vary throughout the patient's cancer journey and treatment trajectory, distress seems to remain for extended periods from the initial diagnosis and over the entirety of the experience for both the patient and their family/whānau (Funket al., 2016). For this reason, the National Comprehensive Cancer Network (NCCN) recommends that for managing distress, all patients ought to be routinely screened throughout their cancer journey and subsequent care and treatment trajectory. Routine screening will also aid in detecting any anxious or depressive emotions early on in the patient's cancer journey (Spiegel & Giese-Davis, 2003).

Identifying Distress in Cancer Patients

A vast body of literature identifies the importance of distress screening in cancer. For example, Buchmann et al., (2015) evaluated the levels of psychosocial distress in thyroid cancer patients, in which 43.3% of the patients displayed significant levels of distress. Additionally, upon assessment of breast cancer patients, it was concluded that one-third of breast cancer patients reported that they were experiencing significant distress with greater risk for those with a younger age of diagnosis (Schubart et al.,2014).

Therefore, through the literature and research it is apparent that there is a significant representation of patients expressing high levels of distress, emphasising the importance and need for additional emotional support during cancer therapy. Furthermore, upon follow-up, breast cancer patients indicated that the symptoms of distress experienced persisted up to10 years after treatment (Hegel et al., 2006; Schubartto et al., 2014). Moreover, there is evidence suggesting that a patient's distress may act as a predicting variable for overall 5-year survival, accentuating the need for prompt interventions of distress detection at all stages during the cancer journey (Østhus et al., 2013).

Additionally, evidence suggests that health professionals may struggle to identify distress in time or as a result of poor clinical settings (Fradgley et al., 2020). For example, a study conducted by Gouveia et al., (2015) concluded that oncologists had difficulty in accurately identifying depressive symptoms in cancer patients, where within the sample of 201 adult cancer patients, distress was detected by a health professional with a 64% sensitivity and a 65% specificity, representing low accuracy of detection. Such low levels of distress detection accuracy are further supported by an earlier study by Werner, Stenner & Schüz (2012), in which upon assessment it was found that the primary health professional correctly identified distress or identified distress symptoms in only 1 in 10 of the cancer survivors.

Such low levels of accuracy in distress detection are problematic as primary health professionals and oncologists are often the liaison to psychosocial services and further care if needed, emphasising the need for systematic and accurate distress screening for distress management. Therefore, due to the inaccuracy and inconsistency of health professionals gauging the presence and the severity of distress in cancer patients, all patients ought to be routinely assessed regarding their emotional wellbeing (Fradgley et al., 2020). Systematic screening for emotional distress in cancer patients promotes equal access to psychological services in contrast to a system based on clinician, or patient-initiated referral, which may fail to identify emotionally distressed patients who need supportive care (Vodermaier et al., 2009).

It is evident that the experiences of distress, particularly prolonged episodes, are often accompanied by psychiatric syndromes such as depression, adjustment disorder, anxiety, and other behavioural disorders, i.e. substance abuse, which negatively impact the quality of life as touched on above. A study conducted by Spiegel (2001) concluded that a year of psychosocial support and distress screening appeared to reduce anxiety and depression and increase overall coping, reduced psychiatric symptomology, and reduced pain. Additionally, randomised control trials establish the promising positive effect and importance of distress screening in reducing emotional distress, patient satisfaction and patient to professional communication (Fradgley et al., 2020). Hence, routine screening for emotional distress for cancer patients now has widespread acceptance.

Distress Screening Tools and Models

The assessment of patient distress in an oncological setting is conducted using distress screening tools which are widely accepted psychometric instruments (Buchmann et al., 2015). There are several psychometric tools, such as the Hospital and Anxiety Depression scale (HADS), the Brief Symptom Inventory (BSI), and the General Health Questionaire-12; all of which are clinical tools to be used routinely within a cancer setting to improve wellbeing by detecting psychosocial distress (Gil et al., 2005). However, of particular interest to this current study is the Distress Thermometer (DT).

The Distress Thermometer (DT) is a non-invasive, brief, practical, and widely acceptable rating tool developed by Roth et al. (1998) in identifying how distressed an individual may be feeling on a scale that ranges from 0 (not distressed) to 10 (highly distressed), with the addition of a problem list. The problem list covers practical, social, emotional, spiritual, physical and cognitive, which provides information about the sources of distress (Haverman et al., 2013). The DT has been most often suggested for use in daily practice due to its rapid nature for identifying patients who may require further psycho-oncological support (Gil et al., 2005).

A comparison within prostate cancer patients between the Hospital Anxiety and Depression Scale (HADS) and the DT, conducted by Roth et al., (1998), found that the DT appeared to identify patients needing further psychological assessment at a greater rate than the HADS. Additionally, the relatively easy to implement nature of the DT, where no particular skill or specialist administration is required, indicates the flexibility of the screening tool in an array of situations and adaptability to community and culture (Gil et al., 2005). The simplicity of the DT also promotes implementation regardless of location, addressing accessibility/barriers such as pain, fatigue, and transportation problems which can inhibit the uptake of these resources (Jerant et al., 2005). However, the 'simple' nature of the DT also presents its limitations. Thus, additions have been implemented to the DT, such as the Impact thermometer (IT), to increase the sensitivity in identifying psychosocial needs and, by virtue, increase the validity of the DT as an adequate screening measure (Baken & Woolley, 2011).

The IT has a similar format to the DT, of a 0-10 rating scale; however, it requires the patients to indicate the level of impact the distress experienced has on their wellbeing and daily living (Akizuki et al., 2005). A New Zealand study conducted by Baken and Woolley (2011) indicated that the accuracy of the distress thermometer in identifying distress increased when used in combination with the Impact thermometer. Furthermore, combining the responses from the two tools did not increase any administration complexity that may deter clinicians or support staff from administering them, indicating that there is promise in successful implementation in practicality of these screening tools.

Summary

Thus, the negative trajectory distress can have on a cancer patient's emotional and mental wellbeing is evident, mainly through the adult cancer patient literature aforementioned, emphasising that psychosocial intervention at critical times surrounding a cancer diagnosis is imperative. Psychosocial distress detected in cancer patients can be missed, or the perceived severity of distress may be misinterpreted, failing to address the emotional needs of patients. The routine and systemic provision of Distress Screening removes any discrepancies in referrals for Distress Screening that may have previously relied on the clinician’s discretion. This reduces pressure on a clinician around the misidentification of distress and removes any prior beliefs or skill sets held by the clinician as a barrier to distress screening. Systematic distress screening also creates an equal opportunity for all to engage in discussion around distress and psychosocial wellbeing.

Furthermore, screening tools such as the Distress screening tool (DT) and the Impact Thermometer (IT) show great promise as screening tools that can be administered systematically and outside of a clinical setting due to the relatively easy administration of these tools. However, given the research discussed in Chapter 2, there is a need for a holistic, systematic approach to distress screening. To acknowledge and consider the influence cancer has on the patient's and the family/whānau psychological wellbeing, extending psychological assessments toward the patient's family/whānau needs to occur.

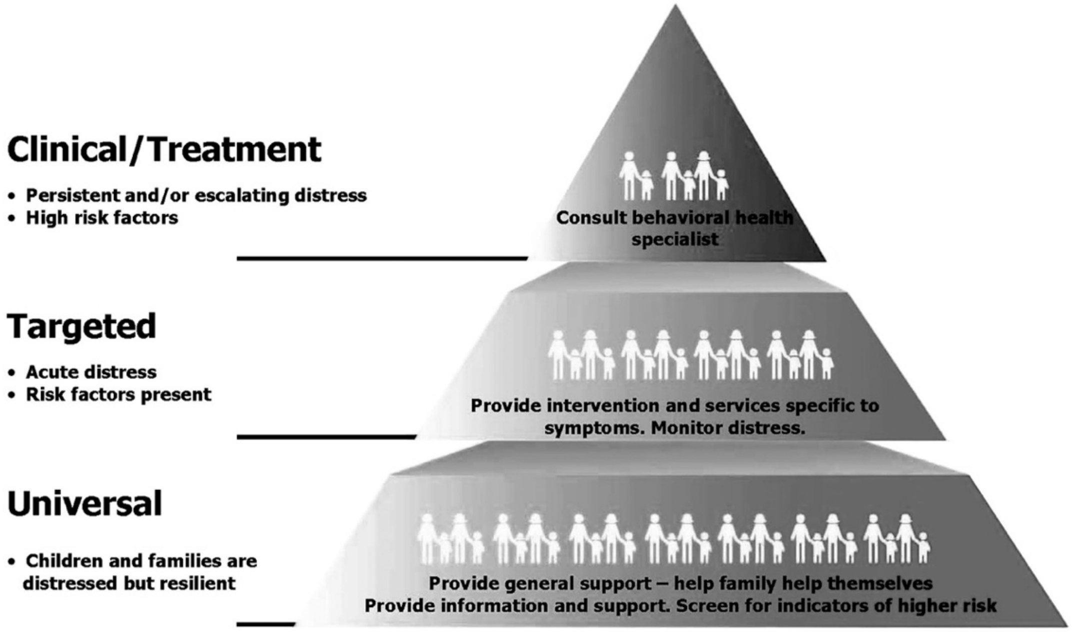
Distress Screening Beyond the Patient – Family/Whānau

As discussed above, the family plays a crucial and reciprocal role in the child's psychological functioning with cancer. Parental emotional wellbeing is associated with the child's emotional adjustment to treatment. Healthy, stable, and functioning family relations have been associated with increased psychosocial functioning and adaptation, reflecting a symbiotic relationship between childhood cancer psychosocial and the family/whānau (Page & Adler Eds, 2008). Therefore, assessing psychological and psychosocial distress through systematic screening offered by interdisciplinary teams may be the step required to extend care to families/whānau and may aid in reducing any hesitations that may inhibit care uptake by the family/whānau.

A study conducted by Hegel et al., (2006) identified that highly distressed parents did not disclose emotional concerns stemming from fears of being stigmatised as a parent unable to cope with psychological problems or a fear of distracting their clinician from treating their child's cancer. Thus, more social-ecological systematic evidence-based screening tools that focus on the inter-related nature of the family have been widely recommended. These are interventions such as The Psychosocial Assessment Tool (PAT) (Pai et al., 2008; Kazak et al., 2001), which is based on the Paediatric Preventative Psychosocial Health Model (PPPHM) (Kazak, 2006), and the Distress Thermometer – Parent (DT-P); both are designed to assess psychosocial distress in the cancer patients family/whānau. These are valuable tools that can cater to families' individual needs and identify families that may be at heightened risk, requiring further assessment (Haverman et al., 2013; Kazak et al., 2015).

The Paediatric Preventative Psychosocial Health Model (PPPHM) is a systematic assessment model to address family psychosocial risk and health. The PPPHM uses a three-tier pyramid structure (Refer to figure 3) to understand a family's psychosocial risk. The pyramid's base is represented as Universal, indicating low-risk families concerned or distressed about their child's health but who are resilient and generally able to adapt. The middle is the target tier meaning medium risk; this represents families with pre-existing concerns or variables that may exacerbate distress or contribute to an escalating vulnerability, such as financial factors and ethnicity. The top of the pyramid is classified as clinical or high risk reflecting those with the greatest need for intervention (Kazak et al., 2015). The PPPHM is consistent with the Competency-Based Coping model, which proposes that while families will experience psychosocial distress when dealing with cancer, it is assumed that most families will be able to adapt and cope (Kazak, 2006; Kazak et al., 2007).

Figure 3: Paediatric Preventative Psychosocial Health Model (PPPHM)



Extracted image from Kazak, A.E. (2006). Paediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in paediatric family systems medicine. Families, Systems, & Health, 24, 381-395.

Thus, the PPPHM and the Competency-based coping model allow early identification of families/whānau who may be at greater risk, and the assessment of risk levels allows the provision of adequate evidence-based treatments that cater to their specific needs (Kazak et al.,2007; Kazak et al., 2015). Furthermore, the development of the Distress Thermometer for Parents (DT-P), derived from the Distress thermometer (DT), allows for identifying the distress level experienced by the parents instead of confining the assessment of distress experienced by the patient (Haverman et al., 2013). The DT-P is similar to the DT in that it consists of a 0-10 rating scale of 0 representing no distress to 10 representing extreme distress. The DT and the DT-P are both proactive and preventative, which acknowledge the ever-changing needs of families/whānau regarding their cancer journey.

However, there still seem to be discrepancies in the uptake of referrals to supportive care for distressed patients and their families/whānau (Funk et al., 2016). A study conducted by Funk et al., (2016) assessed referral rates to supportive care and patient uptake. From a cohort of 644 patients, 30% reported significant distress, with approximately a third of these patients pre-emptively declining support care contacts. This indicates a discrepancy in the uptake and follow-up care; thus, despite the substantial array of research emphasising the importance of psychosocial support, there appears to be a research-to-practice gap. Although there have been attempts to integrate tailored and sophisticated care into a paediatric oncology setting, children and families may still be being overlooked.

Translation of Distress Screening to Practicality

Through the literature mentioned above, the need for adequate distress screening directed toward cancer patients and their families/whānau is evident (Buchmann et al., 2015; Funk et al., 2016; Hegel et al., 2006; Mitchell et al., 2008; Page & Adler Eds, 2008). Unfortunately, clinical services and interventions designed explicitly for distress screening in oncology are not consistently administered or produce the intended patient, clinical and economic outcomes. The majority of Distress Screening tools are often oriented towards adult cancer patients, or the few designed for paediatric oncology or inclusive of assessing the psychosocial well-being of the patient's family/whānau still fail to be successfully implemented within routine systematic care (Livet et al., 2018). This lack of implementation reflects a lack of translation of evidence-based practices onto routine clinical care. Additionally, this indicates a need to amend this research-to-practice gap to facilitate better patient outcomes and population health through implementation research (Jacobsen & Norton, 2019). For research findings to be translated and successfully adopted in practice requires years and can often lead to further research. However, the focus needs to be drawn on how these interventions should be used in a real-world clinical setting through implementation science (Livet et al., 2018). Therefore, health care faces increasing pressure to successfully implement evidence-based interventions and practices (EBP) designed to improve patient care and quality (Schofield et al., 2006).

Implementation Science

Implementation science is the scientific study of methods to promote the uptake of evidence-based practices into regular clinical care and policy, thus improving the quality and effectiveness of health services and (by virtue) population health (Eccles & Mittman, 2006). Implementation science aims to close this research-to-practice gap by evaluating barriers and processes that may hinder the uptake of an EBP of interest onto routine care and policy (Bauer and Kirchner, 2020). Implementation science has the goal for generalised knowledge to be successfully replicated across multiple contexts and settings. Implementation Science differs from classic clinical research, often conducted under tight regulations and controlled conditions. Classic clinical research assesses internal validity; in contrast, implementation science addresses the application of interventions in the current population setting and looks at external validity and generalisability (Rankin et al., 2019).

Implementation science can be understood to be part of translational research. According to the National Institute of Health and Medical Science, translational research can be defined in two areas. First, it is considered to be the translation of where science and preclinical research (T0) is followed through to human participant research (T1) and subsequently translated onto clinical trials and further research findings (T2); this is known as 'bench to bedside' translations. The second area is considered the 'bedside to community translation; this is where implementation science is considered to fit into the translational model. It is the area that is concerned with how the knowledge from (T0) to (T2) is translated into clinical settings (T3) and the effectiveness of the translation of this knowledge (T4)(Fort et al., 2017; Khoury et al., 2011; Rankin et al., 2019). Thus, implementation research begins with identifying what facilitators and barriers are present and the determinants of these barriers to practice (Livet et al., 2018).

Barriers of Implementing Distress Screening in Practicality

Within the scope of psycho-oncology and distress screening, Schofield et al., (2006) investigated barriers to service delivery of psychosocial support through the precede-proceed framework. This model proposes to classify potential barriers to the successful application of evidence-based and recommended practices into three domains: Predisposing factors which influence the motivations of particular behaviours; Enabling factors that facilitate the enactment of the behaviour; and Reinforcing factors that maintain the continuation of the behaviour over time.

Predisposing factors reflect personal characteristics either by the clinician or the patient, influencing behaviour and the provision/acceptance of psychosocial care; these include attitudes, beliefs and knowledge (Schofield et al., 2006). For example, clinicians in oncology understand their role to be primarily concerned with disease treatment and thus, by virtue, tend to perceive psychosocial concerns as a secondary issue (Schofield et al., 2006). Upon consultation assessments, clinicians and oncologists appear to respond to informational cues such as questions about treatments and the effects of treatments more often (72%) in comparison to emotional cues (28%) (Butow et al., 2002). Alternatively, clinicians may expect that patients will raise any psychosocial concerns, thus relying on the patient to initiate the conversations (Schofield et al., 2006).

However, ironically, there are reports that patients may be expecting clinicians to instigate discussions around psychosocial well-being. A study conducted by Detmar et al., (2000) indicated that approximately 90% of cancer patients reported wanting to discuss their psychological adaptation to the cancer diagnosis and subsequent journey. However, 25% indicated they were only willing to do so if the clinician initiated the subject matter. Additionally, patients and their families/whānau can be hesitant to verbalise these needs and often express these concerns indirectly through missed cues (Jansen et al., 2010). The misconception of who ought to be initiating discussions around psychosocial issues may be inhibiting the conversations of emotional adjustment to cancer and Distress Screening. Additionally, the patient's unwillingness to discuss psychological concerns, as identified through the Detmar et al., (2000) study, may be cementing clinicians beliefs that patients expect them to be providing medical care primarily. This can be problematic for successfully implementing a distress screening tool and assessing the psychosocial health of patients and their families/whānau.

Enabling Factors are factors in which will facilitate a behaviour. These often consist of systematic and environmental factors that influence the individuals' behaviours and the overall organisation (Schofield et al., 2006). Evidence indicates that clinicians often miss patients and family/whanau members who express high levels of psychosocial distress during their cancer journey (Buchmann et al., 2015; Butow et al., 2002; Vodermaier et al., 2009). However, as previously mentioned, a predisposing factor for missing psychological distress experienced may be due to a misconception of roles; alternatively, an enabling factor inhibiting distress screening may be time and staff. Being short on time and understaffed may enable behaviours that reprioritise other medical assessments over distress screening.

However, despite the literature indicating that brief psychosocial screening can take as little as two minutes - and that as little as an additional 40 seconds in consultation dedicated to acknowledging psychosocial needs in cancer patients can reduce anxiety - there are still several barriers to implementation (Fradgley et al., 2020; Schofield et al., 2006). In a two year program in distress management, participants in a study conducted by Mitchell (2013), reported experiencing 65 barriers to distress screening and management. The most common barriers reported were limited staff and competing demands.

Research suggests that identifying and responding to patients’ and family/whānau psychosocial needs shortens consultation times (Butow et al., 2002). However, clinicians express concern about time-consuming screening interventions as they already have limited time available to provide patient care, let alone assess the psychosocial health of the patients and their family/whānau members (Schofield et al., 2006). Additionally, there is the reciprocated concern from patients and family/whānau members about consuming clinicians’ time regarding emotional support and non-medical considerations, distracting clinicians from providing the medical cancer care required (Mitchell et al., 2008; Hegel et al., 2006). Thus, intervention time and those administering the intervention are enabling systematic factors. Hence, to reduce these concerns experienced by patients and the family/whānau, as aforementioned, psychosocial interventions could be implemented outside the clinical setting and by interdisciplinary teams (Schofield et al., 2006).

Reinforcing factors relate to the consequences of the behaviour and the likelihood of behaviour repetition (Schofield et al., 2006). These often include feedback systems, peer influence and performance indicators. Regarding barriers to implementing routine Distress Screening, a reinforcing factor may be the lack of consequences in disregarding the provision of psychosocial care, further contributing to the lack of adherence to best practice. It is essential to recognise that clinicians are not ignorant of psychosocial needs or this research-to-practice gap. However, there is still a lack of Distress Screening provision, which can be further perpetuated by patients not voicing their psychosocial distress, therefore disguising the need for addressing psychosocial care by a clinician.

Summary

There is a lack of knowledge in successfully applying evidence-based research methods into routine use and understanding the 'why' implementation of an EBP may fail in a real-world setting (Livet et al., 2018). Understanding the barriers at the implementation level of EBP in psychosocial care - and developing strategies to overcome these - is a promising way forward in oncological care (Schofield et al., 2006). However, barriers often present in tandem; thus, more than one barrier should be addressed to achieve a successful effect. For example, for care to be successfully administered, there ought to be adequate service providers and equal access of these providers to patients and their families/whānau. Additionally, it is crucial to recognise that barriers exist in multiple settings; those present in a hospital setting will differ from home-care settings. Different barriers will be present for rural patients and their families/whānau versus those in larger cities. This points to the need for flexibility and adaptation within interventions to accommodate these differences. Implementation science acknowledges this gap in translating evidence-based practices into clinical practice within cancer care. A common barrier to applying and implementing current interventions is that clinicians experience challenges interpreting and applying the best evidence. Thus, moving forward, shifting towards 'how can this intervention be successfully implemented?' is a promising way forward in paediatric oncology and psychosocial care, and the use of the precede-proceed framework facilitates opportunities for EBP and distress screening tools to be successfully implemented within paediatric cancer care (Rankin et al., 2019).

Moving Forward - Implementing Distress Screening in Practicality

Identifying barriers and the effect of these barriers in implementing evidence-based practices within realistic clinical settings allows for developing strategies to overcome these barriers. Thus, a starting point to ensure effective implementation of evidence-based practice is using the precede and proceed framework. In acknowledgment of predisposing and enabling factors, attending to role definition at an organisational level (where a particular organisation or group is designated to attend to the psychosocial needs of cancer patients and their family/whānau) will reduce any role misconceptions earlier. This may either be clearly defining the role of the primary health provider in terms of the provision of psychosocial care, ensuring that those providing the psychosocial care have the adequate skills required by the role, and ensuring there are support systems in place for the health professionals providing psychosocial care (Schofield et al., 2006). Furthermore, the delegation of a specific organisation or group designed with the sole purpose of providing psychosocial care reduces any enabling factors surrounding time constraints and limited staff. The collaboration between interdisciplinary teams consisting of clinical providers, patient advocates, and caregivers allows care to be implemented outside of a clinical setting and to achieve high-quality cancer care. Additionally, having a specific organisation dedicated to distress assessment will reduce any parental fears around distracting the clinician, or pressures felt by the clinician and creates a space which is dedicated to psychosocial care. Further, the likelihood of supportive care uptake appears to increases when the patient and the family/whānau are familiar or have established rapport with the team (Funk et al., 2016). Therefore, one strategy to increase the uptake of additional care for cancer patients and their families/whānau is to increase the engagement of support workers (such as the Family Support Coordinators of the CCF) throughout the cancer journey. Providing a consistent support network enhances coordination and communication and fosters feedback mechanisms (Funk et al., 2016).

Reinforcing factors regarding distress screening and EBP can be performance feedback. A formal feedback system will allow assessing both the patients and family/whanau psychosocial concerns and the provider's experience in using the assessment tool in managing these concerns; and the effect of such care on the patient outcomes (Schofield et al., 2006). Additionally, in alignment with the literature findings supporting the use of distress screening and the psychosocial benefits of distress screening expressed by patients and their families/whānau, a feedback system will reinforce and acknowledge the positive effects of distress screening. It will promote the uptake of distress screening provisions. Feedback systems can be descriptive methods, such as focus groups and interviews with service providers, support workers and key informants. These systems will facilitate identifying barriers in a real-world setting and an assessment of the intervention in a clinical application and setting, joining research and practice together.

Summary

Overall, research indicates that Distress Screening in a paediatric oncology setting is often inadequate and incomplete. Despite the adverse psychosocial and psychological effects of cancer aforementioned, it is apparent that cancer patients and the family/whānau express feeling that there is a significant lack of addressing the psychosocial sequelae that follow a cancer diagnosis in oncological care. Support for psychosocial needs requires screening for and identifying such needs early and regularly. Although there is significant evidence supporting the positive outcomes of distress screening tools, there seems to be a research-to-practice gap inhibiting the effective uptake of distress screening tools within an oncological setting. Thus, there are barriers to providing effective and comprehensive psychosocial care accommodating paediatric cancer, including their family/whānau who are at risk for subclinical levels of dysfunction. Furthermore, empirically validated assessments and distress screening tools specifically designed for use within a paediatric oncology capacity that extends towards the families/whanau's of the children with cancer are limited, indicating an avenue for future research should be directed towards. Hence, this brings us to the topic and contribution of this thesis and research.

Current Research

The literature considered above shows that cancer is an illness that presents chronic consequences and has a high prevalence within our communities in Aotearoa, New Zealand (Ministry of Health 2016b). Furthermore, a cancer diagnosis, treatment, and post-treatment can often result in psychosocial vulnerabilities and experiences of distress for the patient and their family, which (if not attended to) can develop into severe mental disorders which may continue in survivorship (Funk et al., 2016; National Cancer Institute, 2014, August 20; Pandey et al., 2021; Spiegel & Giese-Davis, 2003). Thus, timely and routine distress screening tools such as the Distress Thermometer (DT) and the Impact thermometer (IT) can be used to assess psychosocial care, identifying families/whānau who may be experiencing distress and those who may require further care (National Cancer Institute, 2014, August 20).

Paediatric cancer patients should receive specialised psychosocial oncological care and regular distress screening due to the developmental vulnerabilities associated with this cohort (NZ Childhood Cancer Incidence 2010-2014). Moreover, not only is distress experienced by the patient, but it is apparent that the patient's family/whānau also experiences distress; their distress is not confined to the initial diagnosis and treatment but often extends through into survivorship (Barrera, Fleming & Khan, 2004; Grunfeld et al., 2004; Guan et al., 2021; Norberg et al., 2005; Northouse et al., 2000; Page & Adler Eds, 2008; Robinson et al., 2007; Svavarsdottir, 2005; Ursin & Eriksen, 2004; Woźniak, & Iżycki 2014).

However, despite the wealth of literature and evidence-based practices emphasising the need and benefits of distress screening in oncological care, there is an apparent lack of implementation of distress screening tools in practice (Jacobsen & Norton, 2019). Furthermore, there is a need to ensure effective implementation of distress screening that caters specifically to the assessment in a paediatric oncological setting, inclusive of the patients family/whānau emotional needs. Additionally, considering potential predisposing and enabling factors that may be acting as barriers discussed above, this care ought to be implemented outside of a clinical setting and be administered by designated social support outside of the child's cancer medical team. Moreover, to ensure the successful implementation of a Distress Screening tool, reinforcement factors are required, such as a feedback system post Distress Screening, to understand the application, reliability and validity of a distress screening tool in a realistic setting by those who have experience in applying it.

Research Aim

Therefore, previously attended to through the Distress Screening Project discussed in Chapter 1, the first step was to identify and address the barriers discussed through implementation research that may inhibit the effective implementation of a distress screening tool. Hence, the appropriate psychosocial services that will successfully deliver the appropriate distress screening tool were identified as being Family Support Coordinators (FSC) from the Child Cancer Foundation (CCF). Additionally, it was vital to identify and develop an appropriate distress screening tool to assess the psychosocial needs of the family/whānau in a paediatric oncological setting. As covered through the literature, a holistic health approach utilised within a community setting instead of restricted to treatment centres is imperative to quality care. Therefore, these models and theories and extant research led to the development of the 'Wellness Check-in distress screening tool within the Wellness Check-in booklet.

Hence, drawing us to the primary aim of this research project, the second step; in alignment with implementation science and reinforcing factors (following on from The Distress Screening Project), the aim of this research project is to understand the experiences of Family Support Coordinators (FSC) for the Child Cancer Foundation, in the use of the 'Wellness Check-in' booklet distress screening tool. Understanding the experiences of the FSC in the use of the Wellness Check-in distress screening tool acts as part of a feedback mechanism allowing for examining the effectiveness of interventions in psychosocial care.

Providers such as FSC are in the position to initiate and implement psychosocial care towards the family's/whānau. Hence, if the FSC experience any reservations or apprehension about the Wellness Check-in booklet distress screening tool, it will not be utilised within psychosocial care, further perpetuating this discrepancy in evidence-based practices uptake in routine care. Conversely, understanding aspects within the Wellness Check-in booklet distress screening tool, which was favoured or considered to be a strength by the FSC, will provide insight to future research in psychosocial tools in a practical and realistic settings. Hence, understanding the experiences of FSC in the use of the Wellness Check-in booklet distress screening tool is critical to ensure successful uptake of the Wellness Check-in booklet distress screening tool after implementation of the intervention.

This research project aligns with implementation science and aims to contribute towards achieving the ultimate goal in paediatric oncological care of alleviating the distress and emotional sequelae experienced by cancer and its subsequent journey for the patient and their family/whānau, thus bettering the future of health and health care in Aotearoa, New Zealand.

Chapter Four - Methodology

This chapter will highlight the process used for analysing the qualitative data collected. For the current study Interpretative Phenomenological Analysis (IPA) was used for the methodology and qualitative data analysis (Alase, 2017). This chapter will also describe the procedures surrounding ethical research approval, participant criteria, recruitment, and final data collection.

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is an interpretative process of meaning-making of an experience. IPA focuses on personal experiences in a specific context and the sense-making process through this experience, often referred to as the 'whatness' of the experience (Behal, 2020; Smith & Shinebourne, 2012). In this study, data collection consisted of in-depth interviews with the Family Support Coordinators (FSC) focusing on questions assessing what it was like for the Family Support Coordinators (FSC) to use the Wellness Check-in booklet distress screening tool. The aim was to interpret these individual experiences of the FSC engagement with the Wellness Check-in booklet distress screening tool by identifying superordinate and subordinate themes, allowing for identification of the overarching thematic essence of their experience (Behal, 2020; Smith & Shinebourne, 2012).

There are three theoretical underpinnings of IPA: Phenomenology, Hermeneutics, and Ideography. Phenomenology is to understand the experience from the first-person point of view. IPA focuses on the intentionality of the experience in its terms instead of understanding an experience through predetermined systems. As a researcher, this indicates the possibility of bracketing one's preconceptions to allow the true essence of the experience to be understood and portrayed (Behal, 2020; Smith & Shinebourne, 2012;). Assumptions, pre-conceived notions, and paradigmatic lenses often relate to the study phenomenon and are essential factors. However, in IPA, these ought to be set aside - bracketed.

As a researcher conducting IPA, the conscious process of bracketing biases and assumptions allows for reflexivity and an awareness of how the study and interview process can be impacted by the researcher or, conversely, how the study and interview may impact the researcher. Bracketing facilitates a non-intrusive role as a researcher and allows a co-creation of knowledge between the participant and the researcher in understanding and interpreting the experience. (Alase, 2017; Behal, 2020).

In this way, IPA presents a unique, novel approach to studying an experience or phenomenon. It allows and encourages the experiences and phenomena to show in the utmost original forms. The objective of IPA is not to validate or invalidate a participant's experience but aligns with inductive reasoning. As a researcher conducting IPA, it is the goal to bring out the essence of the participant's experience by drawing meanings from the participant's understanding of the experience without directing or adding personal narratives to the interview process (Alase, 2017; Behal, 2020; Knight, Wykes & Hayward, 2003).

Although IPA focuses on analyses of experiences, the meaning of these experiences is understood and translated through interpretation and a process of engagement of a researcher; thus, IPA is guided by hermeneutics (Smith & Shinebourne, 2012). Hermeneutics is the interpretation of a text, either written, verbal and non-verbal—Hermeneutics in IPA presents as another point of differentiation of IPA to other qualitative design methods. In alignment with Smith and Osborn (2003), the description of the psychological process of interpreting experiences, IPA, and the process of translating an experience can be understood as double and triple hermeneutics. IPA and research consist of multiple layers of understandings and interpretations (Behal, 2020; Smith & Shinebourne, 2012). Initially, the participant recalls an experience and tries to understand what this meant to them and relay it to the researcher. The researcher's role is to make sense of this experience narrated by the participant and go further in-depth, engaging in a more systematic process of interpretation of experience than the participant does typically. The researcher maintains a separation from the participant and bracketing their own biases, presenting a double hermeneutic. Finally, as a reader, making sense of the study and understanding the researcher's interpretation of the participants' experiences results in a triple hermeneutic.

The third theoretical underpinning of IPA is its ideographic approach of analysis. Ideography is the understanding of an individual 'retrospective' account on their terms, in their own words and that every individual is a separate entity. This approach differs from alternate qualitative research approaches, which are nomothetic and tend to analyse a population or group level (Smith & Shinebourne, 2012). IPA dedicates the time for analysis for each participant, and each specific case is analysed in turn and separately, capturing the individual experiences. Although as a researcher in IPA, identifying patterns and converging themes across the cases is a core element to IPA, the individuality and nuance of each case are retained with best efforts; thus, IPA presents a divergence and a convergence of analysis (Smith & Shinebourne, 2012). Qualitative research methods such as IPA allows for the individual perspective of participants who traditionally may be excluded from academic discourse to be portrayed (Knight, Wykes, & Hayward, 2003).

IPA Design

Thus, IPA focuses on an in-depth systematic analysis which focuses on participant lead narratives of an experience. Therefore, IPA studies are classified as open and use exploratory research questions in the interview process. Interview questions in IPA prompt the participant to narrate and detail a lived experience and open space for reflection of this experience and how they interpret and make sense of this experience. The researcher often provides prompt questions that encourage the participant to focus on precise detail and elaborate on specific aspects of the narration (Alase, 2017; Behal, 2020; Knight, Wykes & Hayward, 2003; Smith & Shinebourne, 2012). These interviews aim to understand how the participants describe their experiences, the context in which the experience occurs, how they interpret their experience and any striking individual differences in these recollections.

IPA Analysis

Given the individualistic focus of IPA, each of the participant's audio recordings are transcribed following an iterative step by step process. The initial stages of IPA involve immersion in the data by reading and re-reading the participant interview transcripts. During this stage, the researcher will begin identifying patterns within the transcript and take notes of any observations in the margins. These can be notes on the language used, context, distinctive phrases and emotional responses. During this stage, the researcher only makes sense of the interview and what has emerged in the data collected without putting a theoretical or interpretative spin on it (Behal, 2020; Smith & Shinebourne, 2012).

The next stage in IPA is the transformation of the initial observations and notes into emerging themes and patterns that best captures the participant's experience . This is followed by identifying any connection between the emerging themes identified from the previous step, grouping them by similarities, forming 'clusters' or 'families' and labelling each cluster (Alase, 2017; Behal, 2020; Knight, Wykes & Hayward, 2003; Smith & Shinebourne, 2012).

The iterative process of IPA ensures that the clusters identified are accurate reflections of what was in the original transcripts. As a researcher, the consistent fluidity between the various analytical stages ensures for integrity and preservation of what the participant has said. Each interview transcript is analysed separately, and this process is repeated for all the remaining interview transcripts, carefully noting the emerging themes and clusters. Finally, a comprehensive master listing of superordinate and subordinate themes for all the transcripts are created. The master list is presented graphically in a table of themes illustrating the master themes, themes, and subthemes, including extracts from the transcripts for context and providing evidence to the study's themes (Alase, 2017; Behal, 2020; Knight, Wykes & Hayward, 2003; Smith & Shinebourne, 2012).

IPA allows for transparency and provides clear presentations of the participant experiences. IPA is concerned with a detailed examination and understanding of this experience allowing for the true essence of the experience to be portrayed in contrast to traditional nomothetic qualitative study approaches. Thus, IPA was chosen for this study to ensure a rigorous and transparent analysis and account of the experiences of Family Support Coordinators (FSC) for the Child Cancer Foundation (CCF) in the development and use of the Wellness Check-in booklet distress screening tool.

Research Method

Ethical Approval

The ethical issues of this research were peer-reviewed and were judged to be of low risk (refer to Appendix A). Consequently, a low-risk notification was made to, and accepted by, the Massey University Human Ethics Committee.

Participant Criteria

Participants were recruited in a purposive manner, from a sample of Family Support Coordinators (FSC) from the Child Cancer Foundation (CCF) who were involved and had experience in using the Wellness Check-in booklet distress screening tool. The participants read and indicated via email whether they were willing to participate and have their interviews audio recorded and shared anonymously in this thesis and subsequent journal articles and presentations.

Sample Demographics

Data collection commenced in February 2022 till August 2022. A total of five FSCs agreed to participate in the study. The FSCs were from varying geographical locations throughout Aotearoa, New Zealand. In order to honour participant anonymity, the specific locations have been excluded. The FSCs ranged from working as FSCs from 5 months to 16 years, all identified as female and the age brackets of the FSCs was not identified. None of the participants had a previous connection to the researcher.

Procedure

Recruitment Process: The recruitment of potential participants began by sending out a Participant Information letter (refer to Appendix B) via email by Dr Kirsty Ross to frequent referrers who were regular users of the wellbeing check- in booklet. The FSC that wished to participate contacted myself directly via email at their discretion, allowing for participation and response anonymity from the CCF and Dr Kirsty Ross. Initial slow recruitment required some request for more participants from Dr Kirsty Ross. However, the anonymity of the participants who replied and agreed to participate in the study was maintained. Furthermore, the transcripts were only disclosed to Dr Don Baken, further limiting any conflict of interest and the potential of participant identification. A total of five emails agreeing to participate were received. Interviews were arranged with the respondents through zoom at varying times and dates depending on their preference.

Materials: Each of the participants responded to the following questions from a semi-structured interview schedule (Refer to Table 1).

Data collection and Management: IPA interviews are audio-recorded and transcribed entirely verbatim by myself, the researcher, in consultation with my research supervisor Dr Don Baken. This began the process of identifying themes and making analytic notes. The data collected was treated with confidentiality and stored securely.

Table 1: Semi Structured Interview schedule. Themes, topics for discussion and prompts.

Theme:	***Questions:***
Establishing Rapport	1. How has your morning/day been so far? *Possible prompts:* *- How's the weather, had a cup of coffee?*

Experiences of support prior to the Wellbeing Distress booklet	1. If you don’t mind me asking how long have you been a FSC? 2. Could you briefly walk me through how support is offered to the family/whānau’s in your care? *Possible prompts:* - *Currently* - *Before the WBD – (if applicable)* - *Any barriers you experienced/identified* - *Type of support*
Experiences of using the wellbeing Distress screening booklet	1. Have you used anything like this booklet before or come across anything similar over your time of work? 2. Could you talk about what your experience was of using the wellbeing distress tool? *Possible prompts:* *-Easy, problems/difficulties/limitations faced?* *- Easy or difficult to communicate/understand?* *- Any Challenges/Benefits as a FSC* *- In what way was it easy/difficult?* *- How did you cope/adjust with the difficulties/any changes?* *- Cultural Aspects* *- Did it make anything better/worse?* 3. Could you tell me in your experience if there have been any benefits of using the wellbeing distress screening tool? *Possible prompts:* - *Reduce any pressure as a support coordinator?* - *Influence on work style or changes* - *Facilitate conversations? Uncover additional concerns* - *How do you feel about these changes? If applicable* - *Increase communication ie get information perhaps you may not have.* 4. Do you think the booklet allowed for gathering any information or insight that perhaps you normally wouldn’t? - *Was there any information that you think you may not have gotten without the booklet?* 5. What did you view as the most valuable aspects of the wellbeing distress screening tool? 6. Can you describe how the families/whānau interacted/engaged with the wellbeing distress screening booklet

	Possible prompts: *-Hesitations, feedback, accepting* *any notable differences from prior to using the booklet* *-Any common themes* 7. Is there anything you would add or change to the Wellbeing distress screening booklet? *Possible prompts:* - *Anything for future use* - *Next steps*
Additional prompts, probes and encouragement:	1. How did you feel? 2. What happened? 3. Could you elaborate on that point? 4. Could you please say more about that? 5. Can you please tell me about that in more detail if you don't mind? 6. Can you remember a particular example? 7. In what way was it?

Analysis:

Preliminary Coding: Following in line with the principles of IPA, analysis began by preliminary coding each of the audio recordings from the zoom interviews. The FSC interviews were approximately twenty to thirty minutes in length. Interviews were transcribed verbatim and were sent to the participants who indicated they wished to receive the transcripts via email to recheck, ensuring the transcript was what they intended to convey in the interviews. Each of the participants were given a two-week period to indicate whether they wished to withhold or release their interview transcript. It was indicated in the initial information letter sent out to the participants that if no reply was received after the two-week period, it was assumed that they were willing to have the interview transcript released.

Each transcript was read entirely to identify any preliminary themes and recurring patterns within the transcripts. These consisted of words, phrases, ideas, and converged patterns recorded within the margins of the transcript, representing the raw data. Any emergent themes, patterns or specific phrases that captured the essence of the FSC experience in using the

Wellness Check-in booklet distress screening tool was noted. Once a general understanding of the transcript was achieved, each was re-read again, where the major themes were divided into meaning units, and subthemes. For example, ‘Flexibility of the Wellbeing check-in booklet distress screening tool’; each major theme describes the essence of the unit. The transcription and analysis of a single interview were completed before moving on to the next. Each of the interview transcriptions and analyses followed this process until all the interviews were completed. This processing method of analysis follows an idiographic approach allowing for the emergent and identification of themes in original forms; consistent with the IPA methodology (Alase, 2017; Behal, 2020; Smith & Shinebourne, 2012).

Final Coding: Once the transcripts were coded, the codes were grouped into ‘clusters’ or ‘families’ of themes. Each cluster or family of themes represented similar topics. These were then further divided into superordinate and subordinate themes, allowing for identifying master themes that represented the overarching thematic essence (Alase, 2017; Behal, 2020 ; Smith & Shinebourne, 2012;). Each theme is accompanied by a short, verbatim extract from the actual interview transcript.

Interrater agreement on Coding: At various points throughout the coding process, extracted quotes were shared with the research supervisors, Dr Kirsty Ross, and Dr Don Baken, to achieve a consensus and clarify code themes while maintaining FSC anonymity. As qualitative analysis is subjective, this collaboration facilitated reflection on the analytical process and promoted the credibility and trustworthiness of the identified themes. The following chapter presents the findings that arose from the analysis.

Chapter Five – Results

This chapter presents the qualitative results from the Interpretative Phenomenological Analysis (IPA). The aim of the IPA was to identify the major themes emerging from the interview transcripts and to translate these themes into a narrative context to understand the experiences of Family Support Coordinators (FSC) using the 'Wellbeing Check-in' booklet distress screening tool with their clients.

The participant interviews resulted in the emergence of six major themes (refer to Table1): Flexibility of the Wellbeing check-in booklet distress screening tool; Provides a framework to conversations; Facilitates conversations; Parent/Caregiver focussed outcomes; Overcoming barriers; and Benefits and suggestions. Within each of the major themes, subthemes were identified refer to Table 1; which also includes a description of the essence of the major themes. Pseudonyms have been used in reporting the results to maintain the anonymity of each of the participants.

Table 1: Major themes, the associated Subthemes, and the theme descriptions

Major Themes	**Subthemes**	**Essence of the Theme**
Theme 1: Flexibility of the Wellbeing check-in booklet distress screening tool	**1.1** 'User -Friendly' **1.2** Flexible and Non-threatening way to open up conversations	The FSCs expressed that the Wellbeing booklet was 'user-friendly' and easy to cater to differences with the families in care. Furthermore, encouraging the parents and caregivers to complete the

		check-in tool in their own space was more productive than completing it together
Theme 2: Provides a framework to conversations	**2.1** Facilitating direction in discussions	The Wellbeing Check-in booklet distress screening tool aided in directing conversations and provided as a reference point throughout the conversations being had.
	2.2 'Backs – up' Conversations	
Theme 3: Facilitates conversations	**3.1** More information gathered	Through the use of the Wellbeing booklet, the FSC's were able to attain a greater depth of information and, thus, be able to identify those who may benefit from additional care.
	3.2 Identifies who may need extra support	
Theme 4: Parent/Caregiver focussed outcomes	**4.1** Addresses an area of support that can often be forgotten	The Wellbeing booklet redirects the lens of care back towards the parents. Additionally, it allowed the opportunity for the parents and caregivers to have the
	4.2 Opportunity for self-reflection	

		space to self-reflect on their Wellbeing.
Theme 5: Overcoming Barriers	**5.1** Other people around **5.2** Hesitancy to speak	Through the accounted experiences of the FSCs barriers affecting the efficiency of the check-in tool were identified, with suggestions to overcome these barriers.
Theme 6: Benefits and suggestions	**6.1** Suggested alterations **6.2** Time efficient	This theme explores suggestions from FSCs for future modifications for the Wellbeing Check-in booklet distress screening tool. Additionally, the time efficient nature of the booklet is discussed.

Theme 1: Flexibility of the Wellbeing check-in booklet distress screening tool

The first major theme represents the participants' experience in using the Wellbeing booklet, which is easy to use in practical settings and adjustable when needed. There were three subthemes within this major theme: 'User Friendly'; a ‘flexible non-threatening way to open conversations’; and ‘Adaptations in using the booklet’.

Subtheme 1.1 User- Friendly:

A consistent theme throughout the interviews with the FSCs was the ‘user-friendly’ and ‘helpful’ nature of the Wellbeing check-in booklet distress screening tool.

"this book presented, I suppose it's just very easy to read it for all the tips and um health recommendations and self-care plan it's just you know it's really user friendly, and I find it really helpful"– Sam.

"it's really, it's really beautifully done, yeah, it just checks in on everything, and yeah, no, there's nothing. I really think it's a lovely tool for families and for us to work with," – Sam.

Furthermore, the FSC’s reported that the booklet was not only ‘user- friendly’ for them in their roles, but many of the families/whānau also expressed the booklet being a good resource for them to have.

"and families have said to me, I mean when I have asked families if this has been helpful, the families have always said yes" – Sam.

"I've had lots of positive feedback saying, oh actually, it was really good to read about this or to have tips on self-care" - Linda.

Subtheme 1.2 Flexible and Non-threatening way to open conversations:

Throughout the interviews, the FSC indicated that the Wellbeing Check-in booklet distress screening tool aided in increasing communication between themselves as FSCs and the families in a manner that was organic and suitable to each family, depending upon their needs.

"easy to introduce and work with, it's actually a really good wee booklet" – Linda

"just think it's a great concrete thing for them to have a look at and read in the initial stages of a cancer diagnosis with children, you know just to put things into place for them to see and be able to know that they're not doing this alone" – Sam

The booklet presented a stepping stone to initiate conversations about wellbeing with the parents and caregivers. FSC reported that introducing the booklet was 'easy' and a great cohesive tool for parents and caregivers to have whilst navigating their cancer journey. However, throughout the interviews, the participants emphasised and recounted that each family in their care, understandably, was processing and reacting to the cancer diagnosis differently; therefore, the time of introduction to the booklet varied between families. Thus, it was essential for the FSC to make a judgment and assess the family's needs and the appropriate time to introduce the booklet.

"each family is different, so when we have a new family who's diagnosed, they will be allocated to us [um] we make contact with them, we gauge the level of support that they want, and the first few weeks, there's just so much turmoil for families you know they are absorbing so

much information that sometimes whilst we like to introduce the book as soon as possible sometimes it can be a few conversations down the track"- Amy

The participants indicated that (due to the varying responses and stages of processing each family is at) they would often encourage the parents and caregivers to take the booklet home and read it in their own time. Thus, creating a space for the parents and caregivers to process the information at a more suitable time. Given the traumatic and overwhelming nature of cancer, having the booklet as a resource to refer to at an alternative time was important due to the parents and caregivers potentially not being able to take in more information at that time or engage in conversations when initially presenting the booklet.

"and I mean you get varying degrees of response to that; you know some people, [um] they need to sit with that for a little bit longer before they are ready to do something" – Terry.

"they are in a daze I mean, they're in shock, yeah, they are working through a whole lot of emotions and or how they're going to cope, so I think it's a really good thing for them to have just to pick up when they feel they can" – Sam

"they've got something to go away with, then they can read through at a time when you know they might have a spare 10 minutes to read about something" – Terry

"a non-threatening way to [um] put the information in the families hands and then be able to build on that with conversation" – Amy

The physicality of having a booklet for the parents and caregivers to take away allowed for flexibility in introducing and implementing the booklet when deemed appropriate by the FSC. This flexibility created a non-threatening approach to conversations and introduce the Wellbeing Check-in booklet distress screening tool, particularly when the parents and caregivers may be oversaturated and still processing the initial stages of receiving a cancer diagnosis. Additionally, the FSCs expressed that having a tangible copy of the booklet, with the information in an organised manner to hand over to the parents and caregivers, helped initiate a conversation about wellbeing in a non-threatening approach. Moreover, a physical booklet encouraged flexibility by creating the time and space for the parents and caregivers to take the booklet home, read through it, and process all the information at a time that suited them better, further reinforcing a non-threatening approach to initiating care.

"it's really good to have it actually all in one place and just say have a read, you know look over this" – Linda

"it's nice to have a tangible copy to hold in their hands, and it enables you to more easily open up conversations" - Amy

By creating the space for the parents and caregivers to process the information on their own time, mutual respect and rapport was formed between the FSC and the parents and caregivers, allowing for honest and open communication. This approach provided for otherwise potentially confronting conversations to occur in a more natural and non-threatening manner when the parents and caregivers are in a more receptive space. Moreover, being in a more receptive space may motivate them to open up and disclose more in discussions.

Overall, this major theme and subthemes reflect that the Wellbeing check-in booklet distress screening tool was user-friendly and adaptable depending on the families/whānau's needs. The FSCs expressed that the Wellbeing check-in booklet distress screening tool was helpful in their role. However, it was also a helpful resource expressed by the families and whānau. Additionally, given the varying responses from the families and the different stages they were at, the booklet allowed for flexibility in how the FSCs initiated the conversations around care and accommodating the families' various stages of processing. Flexibility in how these conversations are initiated presents the opportunity to start the care process led by the parents and caregivers, thus creating a non-threatening approach to care and giving a sense of control back to the parents and caregivers. Furthermore, having a tangible and physical booklet presented as a non-threatening tool for the families to have the flexibility to take it away, read it and start up a conversation about their wellbeing at their own pace.

Theme 2: Provides a framework to conversations

The second major theme represents the experience reported by the participants that the Wellbeing booklet provided the opportunity to open and build on conversations and created a framework for the discussions to follow if needed, supporting the FSC in their role. There were two subthemes within this major theme: ‘Facilitating direction in discussions’ and ‘backs-up conversations’.

Subtheme 2.1 Facilitating direction in conversations:

The FSCs expressed that through the use of the Wellbeing booklet, they could have structured conversations with the parents and the caregivers.

"definitely, it just opens up conversations, and it's a really good conversation starter" – Linda.

The FSC indicated that the booklet supported their role as FSC in initiating and directing the conversations with the parents and caregivers. The booklet is a prompt for starting initial discussions.

"I think it's a great tool. I think it's really it's valuable for us to have that sort of direction on where to come where you about, you know, raising conversations with parents" – Jean.

"definitely think it's provided a framework for particularly with that Te Whare Tapa Wha framework just addressing each of the areas so that nothing gets missed in terms of, you know, their overall wellbeing. I think that's a bit of really helpful thing and in terms of the discussion" – Amy.

"having the points to kind of remind yourself what you need to come to find out about where the family was with a parent or parents or whoever the caregivers cause sometimes it's a grandparent that's the caregiver of the child, so it's just great to have um you know that structure" – Jean.

Overall the FSCs indicated that the Wellbeing Check-in booklet distress screening tool was valuable in initiating conversations with the parents and caregivers and was an excellent tool for them to use in their role. The Booklet provided conversation prompts and created a framework that could be used with any family member.

Subtheme 2.2 Backs-up conversations:

In addition to aiding in the structure and direction of the conversations, a consistent subtheme was that the Wellbeing Check-in booklet distress screening tool ‘backed up’ and supported the conversations between the FSCs and the parents and caregivers.

"it's really good to have the conversations and then have a booklet that backs up what you been talking about" – Linda.

The Wellbeing Check-in booklet distress screening tool presented as a 'reference' point in conversations between the FSCs and the parents and caregivers. This 'supported' the FSCs in their role and the families in their care. Furthermore, having the booklet's contents as a reference point 'backing-up' the conversations may also serve to validate the parents' and caregivers' emotions and experiences.

"just a great tool to have, so I'm pretty happy with it. It's good to have on hand, yeah, it's positive, and I think it's a bit of a reference point" – Terry.

"a supportive tool for us as well because it's, you know, there's some really clear guidelines there for families, and you know, even if you're in conversation and something comes up where you can, it's something you can refer them to and say are you know in the in the well-being booklet just check that out" – Terry.

This theme and subthemes indicate that the booklet was a guide/framework for the FSC to use during their meetings in initiating conversations or as a prompt. Additionally, the FSCs indicated that the Wellbeing Check-in booklet distress screening tool acted as a reference point and 'backed up' the conversations being had with the parents and caregivers, further supporting the FSCs in their role.

Theme 3: Facilitates conversations

This major theme reflects that through the booklet and the check-in tool, more in-depth conversations between the FSC and the parents and caregivers were facilitated and encouraged conversations that may not have occurred without the booklet. Two subthemes emerged from this major theme which appeared to follow a sequential order, whereby attaining the first subcategory of 'More information gathered' enforced the progression of the second category, 'identifying who may need extra support'.

Subtheme 3.1 More information gathered:

Throughout the interviews, the FSC expressed that the booklet and the Wellbeing check-in distress screening tool helped them attain information. This was the account that, through the booklet and the check-in tool, further insight into how the parents and the caregivers were coping was attained; thus, the FSC could get more information about the parent's and caregivers' wellbeing.

"you're talking about those check-ins and stuff, so it's a really good prompt and reminder as well, you know, just to have it, and then they do start talking because they'll read that, and yeah they really open up" – Linda.

"the scale has opened up a bit of discussion around, yeah, in the past week, how much distress how would you describe your distress, so then sometimes I've asked questions to unpack what was the most distressing, you know, did you notice when you distress this highest with the things that help their distress, so it's allowed [um] further conversations really" – Amy.

The booklet and check-in acted as prompts to encourage conversations and created a space for the parents and caregivers to 'open up' and relay more information to the FSC.

"I think it really [um] it just really adds to that interaction, and I think it deepens their self-awareness and enables them to, you know, I guess, draw upon things that they might not necessarily have thought of before and then that, you know, we can sort of respond to that because they are better informed as well of themselves and so I guess you can have it can provide better support" – Terry.

"whole set of areas that they might not really think to share [um] you can ask about them, but if they haven't actually taken the time to attend to it, then they're not really well informed themselves" – Terry.

Using the check-in and booklet increased self-awareness in coping and areas of wellbeing that may need additional attention by the caregivers and parents, thus allowing the parents and caregivers to identify these needs and communicate them to the FSC. Furthermore, 'Linda' expressed that through the booklet and the check-in tool, more information about how the parents or caregivers were doing could be attained compared to not using the booklet.

"I'm getting more information probably by using the booklet" – Linda.

Subtheme 3.2 Identifies who may need extra support:

This subtheme reflects the account of the FSCs that the use of the booklet and the check-in enabled the identification of parents and caregivers who may require additional support and a referral to counselling services.

"a lot of it is done pre-going through the counselling process, so some of them start to realise that they need extra support, and so it's a really good tool for that obviously because it informs that referral, and yeah, it just sort of makes a little bit more concrete what they're dealing with" – Terry.

The Wellbeing Check-in booklet distress screening tool presents the opportunity for FSCs to make initial judgments of coping at the early stages of care, allowing for the identification of those who may require immediate support and encouraging a proactive preventative approach to care.

"it's been a really valid tool for me, yeah, because then I can assess straight away what needs for an individual or for the whanau what coping mechanisms they have, what um support systems I've got in place, and then I can identify that from the Wellness check-in form because they write that down you know how they are coping so it's a really good check-in initially for me just to see apart from being in their home and assessing their needs space yeah it's just another tool just to work alongside them for me and it's really valuable" - Sam.

Additionally, the Wellbeing booklet and check-in distress screening tool aided in identifying and separating parents and caregivers who are showing normative feelings about their child's cancer diagnosis and those expressing responses that may require counselling. Thus, enabling the FSC to make this identification of coping and, therefore, a referral if needed.

"when your child gets diagnosed, it's really normal to feel all of those feelings they are feeling, so counselling doesn't necessarily need to happen, you know, it would be further down the track, so maybe in that respect, you know, it's good to have that kind of extra information around actually they really are struggling, and counselling could be beneficial" - Linda.

"really good when it gets a little bit more complicated for them and things starting to get on top of them because you can really identify actually maybe counselling would be beneficial here whereas before maybe you would send them counselling before they needed to be sent"- Linda.

The FCS indicated that the booklet allows for a continual check-in with the families from their initial stages in the journey through to survivorship, facilitating an ongoing preventative approach and identifying any challenges if they were to occur later stage. Furthermore, a continual ongoing practice ensures that every caregiver and parent can complete the check-in. Through regular and consistent check-ins, FSCs can identify parents and caregivers whose wellbeing may have deteriorated throughout the cancer journey and who may not have presented difficulties initially.

"I think it's a really good tool for checking off those things having those conversations in going back to them when there's a change" – Jean.

Additionally, the continual and regular use of the wellbeing check-in booklet distress screening tool not only introduces wellbeing conversations and reinforces the conversations about parent and caregiver-centred wellbeing, which may be particularly beneficial when there is a change in a parent or caregiver's wellbeing.

"we know parents put themselves last or at the time, and it's not until things are really bad that they actually realise that they need to do something, so this is a little bit more proactive – Terry.

Overall, this major theme and subthemes reflect that the FSCs perceived that their experience of using the Wellbeing Check-in booklet distress screening tool with their clients appeared to foster an increase in communication. Therefore, through increased communication, the FSCs could attain more information about the parent's and caregivers' wellbeing than if they were not using the booklet. Furthermore, by fostering more communication and increasing information, the FSCs were able to gain more insight into how the parents and caregivers are coping throughout the cancer journey at differing stages. With the increase of information received from the parents and caregivers - and as a result, greater insight into their wellbeing and coping - the FSCs were able to identify those who may require additional support and benefit from a referral to counselling and other support services. This presents an early intervention opportunity to provide parents and caregivers with the need they require at the early stages of potential wellbeing deterioration, presenting as a preventative approach to wellbeing management and psychosocial care. Additionally, the regular use of the check-in tool throughout varying stages of the cancer journey with the parents and caregivers provides the FSCs with the opportunity for a continual 'assessment' of wellbeing. Through this, the FSCs can identify parents and caregivers who may present a shift in their wellbeing and may require additional support at a later stage throughout their cancer journey.

Theme 4: Parent and Caregiver Focused outcomes

This major theme depicts outcomes recognized by the FSC, which appear to address the research-to-practice gap within the space of psychosocial oncological care. These were outcomes that concentrated on the parent's and caregivers' wellbeing and the information attained by the FSC. This major theme contains two sequential subthemes: ‘It addresses an area of support that can often be forgotten’ and an ‘opportunity for self-reflection’.

Subtheme 4.1 Addresses an area of support that can often be forgotten:

The FSCs identified that through the Wellbeing check-in booklet distress screening tool, parents and caregivers were able to readjust the lens of care towards themselves, in contrast to care solely directed towards the ill child. It is evident that parents and caregivers direct their attention towards the sick child's needs during a child's cancer diagnosis and may often disregard their own needs.

"definitely an added resource, and it provides good talking points on things to do with self-care [um], which I think parents find very hard to attend to naturally when they've all focused on their child, and then they might have others, you know, siblings with their child but also needed attention" – Terry.

"it makes them think about what needs they might have, you know, from this diagnosis" – Sam.

"the too busy worried about their child to really look after themselves and [um] you know their focus is that so it can be hard sometimes to talk about you know looking after yourself" – Linda.

"whereas a lot of it can be just up in their head they know they're not travelling well, but they can't put their finger on it, or they haven't had the time to think about themselves" – Terry.

"with that kind of information in it, it's sort of an area that they, you know, is often forgotten and needs to be attended to, you know, whether it's with themselves or checking in with someone else" – Terry.

Additionally, FSC reported a sense of discovery in self-directed care emerging from the parents and caregivers through the booklet. The booklet allowed parents and caregivers to re-evaluate their wellbeing, creating the space to identify avenues that may require support that may have been neglected due to focus directed towards the ill child.

"all they are worried about is their child, but once they do engage with and read the booklet, especially if I'm referring them onto counselling, [I find that, you know, we can start looking for counselling] in a crucial time where they are really kind of overwhelmed they will really interact with that, they'll really engage" – Linda

The booklet facilitates a shift in care oriented towards the parents and caregivers, an area of care that can often be forgotten. Although parents and caregivers are in a high-stress situation and often direct all their attention towards their ill child, the FSCs reported that once introduced to the booklet, the parents and caregivers appear receptive to considering their own needs. Furthermore, the booklet aids in identifying how the parents and caregivers are coping with their wellbeing and provides the opportunity for the appropriate steps if further care is needed.

Subtheme 4.2 Opportunity for self-reflection:

The FSC indicated that the check-in distress screening tool within the Wellbeing booklet not only redirected attention to wellbeing of the parents and caregivers but also facilitated deeper self-reflection of their wellbeing, allowing them to recognise areas of their wellbeing that may require additional support.

"I've had quite a lot of comments on that that they have found it really helpful because they didn't realise that this area was a bit of a highlight which they might not have thought of unless they did that they worked through their tool" – Terry.

The FSC reported that although many of the parents and caregivers found the check-in tool confronting, it brought attention to necessary aspects of wellbeing that needed to be addressed, as observed through subtheme 3.1. The check-in brought attention to areas of care that may not have been perceived as needing care by the parents and caregivers. This process allowed the parents and caregivers to reconnect with themselves and facilitated self-reflection on their wellbeing. Through the Wellbeing Check-in booklet distress screening tool, parents and caregivers could address their wellbeing and coping and evaluate their emotional and behavioural processing, thus allowing for a reflective awareness/consciousness process. Additionally, the use of the check-in challenged the parents to assess their wellbeing, which may need attending. The FSC indicated that although this process may be confronting, it is always well-received by the parents and caregivers.

"people found it a bit confronting when they, you know, [um] had to work through their checklist like some of them were probably a bit shocked by, you know, when they took the time to go through the check-in, [um], it probably highlighted to them things that maybe they hadn't thought about [um] you know and some people aren't overly comfortable with that they realised" – Terry.

"some of them have found it quite confronting not I think any of the questions are difficult, but they really, you know, they compel you to self-assess, and I think that's really important" – Terry.

"say that it's confronting they've admitted that it was necessary like, you know, it's one of those things that sometimes people don't realise, and then it's like, Oh my gosh, I'm actually, you know, this area in that area aren't really, working well for me [um] so yeah the feedback has always been quite positive because it's helpful and it's supportive for them" – Terry.

These two subthemes indicate that the Wellbeing booklet firstly redirects the parent's and caregiver's attention of care towards themselves, beginning the assessment and identification of their own coping and wellbeing throughout the cancer journey. Parent and caregiver wellbeing is often an area of care that can be neglected, particularly by the parents and caregivers themselves, as they focus all their energy into caring for their sick child, disregarding their wellbeing. Thus, through the FSC's account of using the booklet, it appears that the booklet redirects the attention of care towards the parents and caregivers, hence addressing the research to practice gap of psychosocial oncological care directed towards the parents and caregivers with successful uptake and implementation.

Secondly, the check-in tool allows for self-reflection from the parents and caregivers on their wellbeing and coping styles. Through self-reflection, the parents and caregivers can understand their wellbeing and relay more information to the FSCs.

Theme 5: Overcoming barriers

This theme explores the barriers identified through the accounted experiences of the FSCs in using the distress screening tool in a practical setting and the suggestion to overcoming these barriers. There were two subthemes identified within this theme: ‘Other people around’ and ‘Hesitancy to speak’.

Subtheme 5.1 Other people around:

Across the interviews with the participants, there was a common theme of needing to adapt when the check-in tool was completed due to the barrier of the sick child (or other siblings) being present while working through the check-in tool.

“sometimes you have the child around [um], which makes, puts a bit of pressure on those conversations; I never have the same conversation with people when they haven’t got their children in and around as to when they have, cause they are very guarded on what they want their child to know”- Linda.

“bit of a barrier sometimes to having a very in-depth personal conversation with a parent when there is a sick child in the room or other children other family members might be there” – Jean

The FSCs identified that whilst working through the check-in tool, parents and caregivers displayed hesitation or appeared to be producing surface-level answers when working through the tool due to their children being present in the room. Therefore, the flexible nature of having a tangible booklet that the parents and caregivers can take away provided the opportunity for them to complete the check-in tool at a time that was better suited, overcoming barriers of completing the check-in tool, reflective of theme 5.

“wellness check-in of doing it together that I was finding that it just wasn’t that bit wasn’t working as well; it worked better if I said to them fill it in in your own time and then made another time that I could, usually with the child may be not around to sit down with them and talk about it again” – Linda.

Subtheme 5.2 Hesitancy to speak:

Completing the check-in tool in their private space accounted for any hesitations the parents and caregivers expressed due to having the child present. Additionally, the opportunity to complete the check-in privately removed any other barriers to engaging with the check-in tool, separate from a child being present such as a hesitation to speak and open up about their wellbeing. Furthermore, the FSCs indicated that the parents and caregivers appeared to produce more informative and in-depth answers to the check-in tool than when it was completed with the FSCs present.

"there I found that the parents were a bit reluctant to do it in front of me or what with my just maybe it was a bit hard sometimes to really open up" – Linda.

"with the actual check-in [um], you know, the list of checking aspects, I've found that [um] people probably do it better if they do it on their own that's probably been my experience" – Terry

" I think it's really good used when they can do it in their own space and time. I tend to find it's a much more thorough response, and I think instead of responding to me as a person, they're responding to what's on the page" – Terry.

Furthermore, allowing the parents and caregivers to work through the check-in tool in their own time without the FSCs reduced the difficulty in re-organising a suitable time without a child present to work through the tool with an FSC, as expressed by 'Jean'.

"most difficult part is trying to get the parents on their own private space" – Jean.

The take-home approach and adaptation of completing the distress screening tool accounted for the barrier identified of completion being a child present during the initial attempts of completing the distress screening tool. Additionally, the take-home approach addressed the barrier of hesitations in verbalising needs and opening up exhibited by the parents and caregivers in the initial attempts of completing the check-in tool.

Theme 6: Benefits and suggestions

This major theme depicts the benefits identified by the FSCs of the Wellbeing Check-in distress screening tool in a practical setting. Additionally, recommended suggestions for the future use of the booklet were identified. There were two subthemes identified within this major theme; Suggested alterations and Time efficient.

Subtheme 6.1 Suggested alterations:

Although not a consistent theme across all of the participant interviews, there were a few suggestions from FSCs regarding future adaptations to the booklet that may enhance the FSCs interactions with parents and caregivers.

'Amy' expressed that when using the booklet in practicality with the parents and caregivers, there appeared to be a slight disconnect between solo parents and parents who were estranged in regards to the communication section of the wellbeing booklet due to the booklet focussing on couples. Thus, an alteration to include suggestions for communication for solo or estranged parents within this section was considered to be beneficial.

"I've had one family comment on this it's very geared to having a partner, so it's very geared to start [with you can improve your feeling of connection to your partner by] and I've got several families where mum is on her own or dad is on his own, or I'm working with mum and dad as separate entities "– Amy.

" maybe be a little bit more inclusive for whanau where the partner is not on the scene or where you may be needing to communicate with an ex-partner to coordinate" – Amy.

In addition to the recommendation of making amendments to the communication section, 'Amy' identified that bereavement and the concept of 'what's next' (a conversation brought up in some of the interactions between the parents and caregivers) was not addressed in the booklet.

"it doesn't address bereavement at all, and that may be a purposeful leaving out of [um]. I get that it might be just interesting that I have worked with two bereaved families already, and

we've used this, particularly the distress scales and Wellness check-in for bereaved families and prior to being referred to counselling, but none of the booklet deals with what next if my child dies" – Amy.

Adding a bereavement section may support the FSC in their role when these conversations surrounding 'what's next' occur. Furthermore, 'Amy' expressed that grandparents' grief is a consistent concern among some of the caregivers and parents in care. A lack of information directed towards grandparents within the booklet may be a beneficial adaptation to include, aligning with cultures that encompass a wider collective whānau approach and concept (acknowledging principles of Te Whare Tapa Wha and Bronfenbrenner's ecological theory).

"would be helpful [um] one thing that's missing, and I've worked with a couple of grandparents, is any addressing of grandparent grief in addressing of the role that the extended family plays, and there's talk about siblings, and there's talk about you and your family or your whanau but yeah two families in particular and I have just noticed significant grief on behalf of the grandparents" – Amy.

"a useful tool for grandparents to or as a parent how do you deal with grandparents who are struggling" – Amy

Moreover, given the year the Wellbeing booklet was implemented, some effects were identified due to restrictions from the Covid-19 pandemic. Parents and caregivers expressed feeling 'isolated' due to the Covid-19 limits in place during the varying traffic light system in

New Zealand as a response to the pandemic. Thus, a suggestion is to include a section dedicated to Covid-19 related responses and coping. However, it is acknowledged that the Covid-19 pandemic was an unpredicted event post the development of the Wellbeing Check-in booklet distress screening tool.

"emotional responses following a child cancer diagnosis on page 4, particularly covid related probably, but I'm noticing families telling me I'm feeling very alone in very isolated because families are sticking to themselves up on the ward [um] you know they're not mixing in, Ronald McDonald House in quite the same way the playroom is closed so I'm not meeting other families just those things, so that feeling of being very alone and isolated is coming up again and again" – Amy.

Additionally, a technicality discussed was the confusion between the scales within the booklet due to the conflicting score directions.

"confusion over the distress and coping scales because one goes from zero to 10 the other goes you know the other way you're scoring the other way" – Amy

Subtheme 6.2 Time efficient:

The FSCs reported that the length of the check-in tool was suitable for making sound assessments and judgments on the parents' and caregivers' coping and wellbeing whilst also being mindful of the time available between the FSCs and the parents and caregivers.

"yeah, it's just a great tool. I just really love having access to something like that, which is, you know, you're not going through some interview interrogation of somebody they. It's quite, you know it's reasonably short, but it also identifies key issues, so it's I think it's quite usable the people [um] it's not going to take them a massive amount of time to work through it, so then it becomes a barrier" –Terry

"not doing a massive counselling process, so this is a really good abbreviated version of that that keeps it a good snapshot of where somebody is at" – Terry.

"it's nicer doing that, giving a little booklet then, you know, a few sheets of paper on this issue or a few, you know or working through, you know, a lot of the scaling sort of self-assessment, so I've done a lot lengthier [um], and I think can be a bit overwhelming, particularly at people who have already got a lot going on" – Terry

Overall the Wellbeing Check-in booklet distress screening tool was well received by the parents and caregivers and in the account of the FSCs was discussed as being an excellent tool to use in their role. The 'user-friendly' structure and tangibility of the booklet was said to be a strength. Through the flexible nature of the booklet, the FSCs said they could make sound judgments of when to introduce the booklet at the most appropriate and beneficial time for the parents and caregivers, depending on their needs. Furthermore, introducing the booklet at a time that best suited the families/whānau presented the opportunity for a non-threatening approach to care. They began the conversations about wellbeing that the parents and caregivers initiated. The booklet presented a framework for FSCs to use, creating structure and conversation prompts, thus providing direction in discussions. Moreover, the booklet 'backed up' the conversations between the FSCs and the families/whānau, further supporting the FSCs in their role and the parents and caregivers in their experiences. The FSCs spoke of how the booklet aided in facilitating conversations, which elicited more information on how the parents and caregivers were coping and discussions around how their wellbeing status could be enhanced.

Thus, by the FSC's attaining greater insight into the families/whānau coping and wellbeing, the FSCs were able to identify those who may require additional help and benefit from referrals to counselling services. This contributes to a more proactive preventative approach to psychosocial oncological care. Through the booklet, the FSC indicated that the parents and caregivers redirected the focus of care towards themselves, an area of care that can often be disregarded. Furthermore, the redirection of care provided the opportunity for self-reflection for the parents and caregivers to assess and understand their needs.

By gaining insight to the experience of the FSCs in using the Wellbeing Check-in booklet distress screening tool in practicality (representing a feedback process), potential barriers faced by the FSCs were explored (such as a child being present) or hesitancies were noted in parents being reluctant to verbalise their needs whilst attempting to complete the check-in tool. Additionally, the solutions to these barriers identified by the FSCs were discussed, pointing to a sense of ownership of the booklet as a living document. In addition to barriers, the benefit of the booklet in being time efficient was also identified. Although some suggestions are identified through the Theme 6, Subtheme 6.1 (Suggested alterations), for the most part, the FSC expressed that in their experience, using the booklet added value to their work. The Wellbeing Check-in booklet is both a preventative and responsive approach to the parent's and caregiver's wellbeing.

Moreover, upon analysis, it is apparent that there may be convergences and links between the themes and subthemes, which will be explored and discussed in the next chapter.

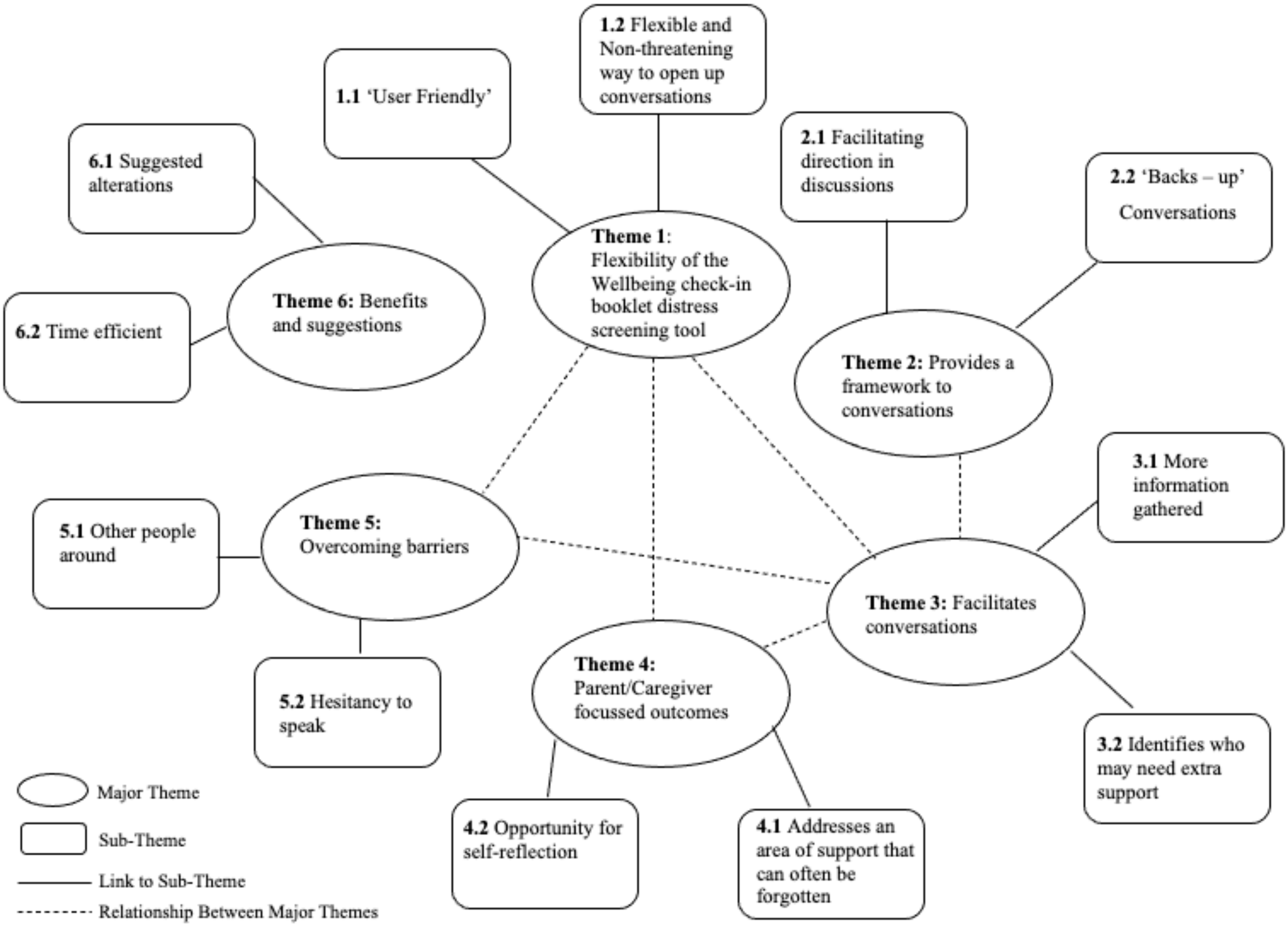
Chapter Six – Discussion

Through this chapter, the study's key findings will be discussed in relation to the existing literature on paediatric cancer, distress screening and implementation science principles. The key findings will be followed by a conclusion, implications of this study's findings, strengths, limitations, and recommendations for future research within this field. This study plays an essential role in gaining an understanding of the experiences of those facilitating psychosocial oncological care in Aotearoa, New Zealand, in relation to the utilization of the Wellbeing check in Booklet distress screening tool.

Key findings

Six major themes with subsequent subthemes were established through the interviews through an Interpretative Phenomenological Analysis (IPA). Links and convergences have been discovered between the themes identified through the Thematic Map (refer to figure 4).

Figure 4: Thematic map identifying the links between the Major Themes.



Theme 1: Flexibility of the Wellbeing check-in booklet distress screening tool

The FSCs expressed that the 'user-friendly', flexible and adaptable nature of the wellbeing check-in booklet distress screening tool was a strength in supporting them in their roles as FSCs and the parents and caregivers in their care.

Subtheme 1.1 User Friendly

A standard limitation to the effective uptake of a distress screening tool in a practical clinical setting can often be the complex nature of a distress screening tool, discouraging clinicians and support staff from administering them (Baken & Woolley, 2011). Furthermore, distress screening tools that are relatively easy to use promotes implementation regardless of common barriers such as location, skill requirements, and culture, which may inhibit the uptake of a distress screening tool. Furthermore, the straightforward implementation indicates flexibility and adaptability to differing communities (Gil et al., 2005; Jerant et al., 2005).

The Wellbeing check-in distress screening tool, as reported by the FSCs, presents as a 'user-friendly' easy tool to administer. This increased the likelihood of implementation within a clinical setting, and presents as a promising tool within paediatric psychosocial oncological care in Aotearoa, New Zealand.

Subtheme 1.2 Flexible and Non-threatening way to open conversations

It is evident through the literature and the accounted experiences of the FSCs that a childhood cancer diagnosis and the subsequent journey are life-altering. (Alderfer et al., 2009; McCubbin et al., 2002; Svavarsdottir, 2005). Furthermore, it is a unique experience for each family reflecting each family/whānau will have individual needs, typology, strengths and coping responses (Svavarsdottir, 2005). Therefore, care tailored to suit the family/whānau's needs is imperative to ensure the effective uptake of psychosocial interventions and effectively provide adequate care (Cohen & Wills, 1985; Compas et al., 2002; Robinson et al., 2007).

Through the interviews with the FSCs, it is evident that the Wellbeing Check in booklet distress screening tool was able to be implemented and introduced at the FSCs discretion and judgment based on when it seemed most appropriate for the families/whānau in their care. A tangible, physical booklet presented the opportunity for flexibility in the time of introduction to the booklet that was best suitable for the parents and caregivers depending on their needs. Additionally, the FSCs expressed that often by encouraging the parents and caregivers to take the booklet home it appeared to be a beneficial and non-threatening approach to instigate conversations about their wellbeing, placing a sense of control back on the parents and caregiver.

This approach allowed for flexibility in the space where the parents and caregivers read the booklet and each family's differing coping and processing styles were accommodated for. This allowed for the parents and caregivers to process the information presented within the booklet both in a space that is more comfortable to them and at a time that may be better suited, adhering to the importance of care that is tailored to suit the family's needs as identified through the literature (Robinson et al., 2007; Compas et al., 2002).

Through the literature, it is apparent that a cancer diagnosis changes already established family structures and dynamics and creates a sense of uncertainty, creating a loss of stability in the parent's and caregiver's life (McGrath, 2001; Woźniak & Iżycki, 2014). Thus, providing the opportunity for their wellbeing and care process to be directed by the parents and caregivers may provide them with a sense of control in a time when things often feel out of their control - further fostering a sense of stability and care, and strengthening the relationship between the FSCs, parents, and caregivers.

Additionally, the flexible and non-threatening approach of initiating conversations around parental/ caregiver coping and wellbeing accounts for potential barrier presented through predisposing factors. Predisposing factors influence the motivation of certain behaviours such as personal characteristics or knowledge which affect the service delivery of psychosocial support

(Schofield et al., 2006). Encouraging the parents and caregivers to take the booklet home after the FSCs introduce the contents indicates that the FSCs start the conversations, the parents and caregivers are then initiating the proceeding discussions around theor wellbeing. Thus, removing any misconception about who ought to be initiating discussions around psychosocial wellbeing (Detmar et al.,2000; Jansen et al., 2010).

Theme 2: Provides a framework to conversations

Through the accounted experiences of the FSCs in using the booklet, it is apparent that the booklet presented as an aide in providing a framework to initiate and reinforce conversations and to use as a reference point to guide them in their role. Therefore, the role of the FSCs is to make an assessment, adapt their approach, and provide the care that best suits the family/whānau needs. Thus, through having a framework for the FSCs to refer to, and guide them in their role, ensures an efficient approach to care.

Additionally, through the account of Amy an additional strength of the booklet in providing a framework is the booklet's holistic approach to addressing the parents and caregivers' wellbeing. It is evident that a child's cancer diagnosis results in a shift between family dynamics, obligations and caregiver roles. These changes may place the family/whānau as a whole at risk or affect the individual parent's/caregiver's psychological health but also their physical and spiritual wellbeing, thus representing the four dimensions of health/Hauora (Durie, 1984; Rossi Ferrario et al., 2003; Woźniak & Iżycki, 2014). The inclusion of Te Whare Tapa Wha principles within the booklet was acknowledged by the FSCs regarding discussions around wellbeing, promoting an integrative and holistic approach to assessing wellbeing. Moreover, the inclusion of Te Whare Tapa Wha acknowledges and attends to Whanaungatanga (family connections) and whānau (family), honouring the importance of an inclusive and culturally appropriate and inclusive approach to health care in Aotearoa, New Zealand (Evans et al., 2010).

Furthermore, linked to that discussed in Theme 1, Subtheme 1.1 (‘User Friendly’), a potential barrier to the effective uptake of evidence based practice (EBP) in routine systematic care is the complexity of the intervention tool or the need for additional skills required to administer the tool successfully, limiting those who can administer the tool (Gil et al., 2005; Jerant et al., 2005). Within Subthemes 2.1, (Facilitates direction in discussions), and Subtheme 2.2, (‘Backs-up’ conversations), the experiences of the FSCs points to using the wellbeing check-in booklet distress screening tool appearing to support them in their role. This indicates that the wellbeing check-in distress screening tool is an intervention method that was not complex, did not appear to require specific skill sets to administer, and enriched the overall care process.

Theme 3: Facilitates conversations

As identified through the literature, successful interventions ought to accommodate for and recognise the unique impacts, emotional needs and changes experienced by the families/whānau, which can be done by attaining a greater understanding of how the parents and caregivers are coping and identifying those who may require additional support (Compas et al., 2002; Cohen & Wills, 1985; Robinson et al., 2007). Through the use of the Wellbeing check-in booklet distress screening tool, the FSCs were able to facilitate sensitive conversations surrounding wellbeing with the parents and caregivers, and thus, attain a sense of understanding of how the parents and caregivers are adjusting and coping.

Subthemes 3.1 More information Gathered

There are barriers for clinicians and service providers in identifying the parents and caregivers needs due to fears of opening up and stigmatisation expressed by the parents and caregivers (Hegel et al., 2006). However, the FSCs expressed that using the wellbeing check-in booklet was a valuable tool in initiating conversations and encouraged in-depth conversations supporting the parents and caregivers to 'open up' This encouraged in-depth conversations and thus addressed concerns that may have been raised with the booklet. This addressed the barriers identified through the literature inhibiting the effectiveness of a distress screening tool in a practical clinical setting (Hegel et al., 2006).

Subtheme 3.2 Identifies who may need extra support

A sequential outcome of subtheme 3.1 (of more information gathered) is the ability of the FSCs to identify those who may require additional support. It is imperative to be able to regularly assess the parents' and caregivers' wellbeing in order to identify any effects of long-term stress exposure - or those who may have initially presented with 'normative responses' to a cancer diagnosis but are now presenting with a deterioration in their wellbeing (Kangas et al., 2002; Bruce, 2006). However, it is apparent through the experiences from the FSCs use of the booklet (and the conversations facilitated) that the FSCs were able to gain a greater understanding of the parents and caregivers distress levels, thus identifying those who may be at risk and benefit from additional support, and at an earlier stage in their distress.

Furthermore, the wellbeing check-in booklet distress screening tool presents as a promising intervention tool that allows a routine systematic assessment of the parents' and caregivers' wellbeing and coping, aiding in recognising those who may benefit from additional support. The FSCs identified that through the use of the wellbeing check-in distress screening tool and a systematic approach to care, they were able to differentiate between the 'normative feelings' to the ill child's cancer diagnosis and the not-so-normative feelings expressed by the parents and caregivers. It is evident that parents and caregivers experience distress and anxiety and can exhibit high trauma-related symptomology rates, which are often non-diagnostically significant (Libov et al., 2002; Bruce, 2006). Additionally, consistent with the PPPHM and Competency-based coping model, it is apparent that psychosocial distress arising from a child's cancer diagnosis is an understandable and expected response. While most parents and caregivers will adapt, it is important to identify those that are having difficulties coping, have a shift in coping or mask their true coping abilities (Kazak, 2006; Kazak et al., 2007).

Furthermore, frequent routine check-ups provide more opportunities for the parents and caregivers to disclose their coping, encouraging those who may not raise emotional concerns in the initial check-ins due to fears of appearing as a parent or caregiver with psychological problems or being unable to cope (Hegel et al., 2006). Through a continual check-in process, facilitated by the Wellbeing booklet, FSCs can identify whether the families/whānau are adjusting psychologically to their new responsibilities. The booklet aided the FSCs in gaining greater insight into how the parents and caregivers were coping at multiple stages throughout the cancer journey and identifying those who may require additional support, facilitating a proactive and preventative approach to psychosocial health care in Aotearoa, New Zealand.

Theme 4: Parent/Caregiver focussed outcomes

The need for adequate distress screening tools oriented towards families/whānau of a child cancer patient within the psychosocial oncology space is evident throughout the literature

(Buchmann et al., 2015; Funk et al., 2016; Hegel et al., 2006; Mitchell et al., 2008; Page & Adler Eds, 2008). Although there is acknowledgment and recognition of the importance of assessing the psychosocial wellbeing of the families/whānau of a child cancer patient, there is still a gap in successfully implementing the few distress screening tools designed for the families/whānau (Livet et al., 2018). However, in alignment with implementation science, the FSCs' experience of using the wellbeing check-in booklet distress screening tool, designed for family/whānau-oriented care, presented a successful tool in practicality.

Subtheme 4.1 Addresses an area of support that can often be forgotten

Through the interviews with the FSCs, a common theme was that the parents and caregivers were often forced to redirect the lens of care towards themselves through the wellbeing check-in booklet distress screening tool. The literature review shows that upon receiving the news of a cancer diagnosis, the family/whānau also experience distress and similar emotional reactions to the cancer patient themselves (Woźniak & Iżycki 2014).

Moreover, it is evident that throughout the cancer journey the parents and caregivers will often subsume into multiple roles such as a research-oriented role in the beginning of the diagnosis and then move towards a caregiver role through the subsequent cancer journey (Rossi Ferrario et al., 2003; Woźniak, & Iżycki 2014). These roles are often dependent upon the cancer phase and the patients' needs, indicating that the parents and caregivers will often place their own needs aside (Given et al., 2012). Placing the lens of care towards their ill child and away from themselves is an understandable reaction as a parent or caregiver. However, through this redirection of focus, parents and caregivers are often navigating through a completely novel experience (one they could not have prepared for), disregarding their own emotional and psychological needs - placing them at psychosocial risk (Haley, 2003; Papastavrou et al., 2009). As identified through the Bruce (2006) and Libov et al. (2002) studies (in which rates of trauma-related symptomology, comparable to post-traumatic stress (PTSD) were documented in the parents of children with cancer), the importance of attending to the psychosocial wellbeing of the parents and caregivers throughout the child's cancer journey is well established. Furthermore, as identified through the Bronfenbrenner's social-ecological theory and Te Whare Tapa Wha the Māori model for health, wellbeing for both the patient and the parents and caregivers are interconnected (Bronfenbrenner, 1978; Durie, 1994; Durie, 2001; Kara et al., 2011; Rochford, 2004). Therefore, attending to the parents' and caregivers' psychosocial wellbeing attends to the child's microsystem and will inherently effect the child's psychosocial wellbeing.

Accompanying the adoption of multiple roles, the family/whānau of a cancer patient will also often face additional stressors such as restructuring family dynamics, financial consequences, employment shifts and caregiver burden, thus further establishing the importance of assessing the family's/whanau's psychosocial health (Norberg et al., 2005; Papastavrou et al., 2009; Rossi Ferrario et al., 2003; Ursin & Eriksen, 2004; Woźniak & Iżycki, 2014). It is evident through the FSCs accounted experience of using the booklet that it created the space and the encouragement for the parents and caregivers to acknowledge their psychosocial wellbeing and attend to it, addressing the shifts in roles, demands and the parents' emotional, psychological and physiological adjustments.

Subtheme 4.2 Opportunity for self-reflection

Subtheme 4.2, the Opportunity for self-reflection, reflects that through the use of the wellbeing check-in booklet distress screening tool, the parents and caregivers could reconnect with themselves and reflect on their wellbeing. Subtheme 4.2 presents as a sequential theme to Subtheme 4.1, as naturally the next step after refocussing the lens of care towards the parents and caregivers is to then allow the parents and caregivers to process and identify the areas in which they may require additional support, thus allowing for a self-reflective space. Through the interviews, the FSCs indicated that although the parents and caregivers found the check-in tool 'confronting', they found that they were able to identify aspects of their wellbeing that they had not initially recognised as requiring care and attention. Through this, the families/whānau could be in a more self-reflective space and evaluate their wellbeing and needs with adequate support systems available to them; they could also give attention to areas of wellbeing that they may not have thought about without the use of the booklet. Furthermore, although the parents and caregivers expressed that the check-in was 'confronting', it was always reported to be well received. This indicates the adequate balance of assessing key psychosocial issues that may be challenging to face, yet presented in a manner that did not appear overwhelming and daunting, which meant the parents and caregivers still chose to engage in the conversations. Thus, this represents a strength of the wellbeing check-in booklet distress screening tool.

Theme 5: Overcoming Barriers

Through assessing the experiences of the FSCs, barriers were identified and feedback was attained regarding the feasibility and practicality of using the booklet with their clients, particularly about completing the screening tool. This study encompassed a formal feedback system of the implementation of the Wellbeing check-in booklet distress screening tool in practicality. Through understanding the FSCs experience of using the booklet, barriers and the effect of these barriers in implementing the booklet as an EBP within a realistic clinical setting were identified. Furthermore, strategies to overcome these barriers were attained. Therefore, this study aligns with implementation science and moving forward in implementing distress screening tools in practicality (Livet et al., 2018; Schofield et al., 2006).

Subtheme 5.1 Other people around

A common barrier that the FSCs identified was the presence of either the ill child or siblings during attempts to complete the check-in with the parents or caregivers. The FSCs indicated that upon attempting to complete the check-in tool with the families/whānau in their care, it became apparent that the parents and caregiver expressed hesitations when an ill child or sibling was in the room. Therefore, the adaptation was made by the FSCs to instruct the parents and caregivers to complete the check-in in their own time and space to mitigate this barrier. Additionally, this strategy may reduce any hesitations about verbalising their needs in general or due to the confronting nature of the check-in and the reluctance to 'open up' whilst completing the check-in with an FSC present, leading to Subtheme 5.2.

Subtheme 5.2 Hesitancy to speak

It is evident within the literature that a barrier present within the effective uptake of psychosocial interventions may be that the patients' families/whānau are either hesitant to verbalise their needs, or if they do express their needs, it can be through indirect cues which can often be missed (Jansen et al., 2010). Therefore, having a physical, tangible booklet for the parents and caregivers to take home provides the opportunity for them to complete the check-in without any barriers and hesitations, and it provides a space to place immediate needs on paper, reducing the need for the FSCs to identify cues. Additionally, the FSCs indicated that by encouraging the completion of the check-in at home, the parents and caregivers appeared to provide ‘thorough responses’ and it removed the need to re-organise a time to go through the check-in where barriers are no longer present.

Summary of Theme 5:

In order increase the effective uptake of distress screening tools is to understand how these tools are used in a real-world clinical setting to promote the successful uptake of evidence-based practices (Eccles & Mittman, 2006; Livet et al., 2018). Through this study, identifying a child present as a barrier and hesitations on ‘opening up’ regarding the check-in is a promising step in the right direction of ensuring the effective uptake of an intervention, aligning with implementation science (Jacobsen & Norton, 2019; Livet et al., 2018). Implementation science focusses on methods to promote the uptake of evidence based practices (EBP) into regular clinical care, reducing the research-to-practice-gap by encouraging the feedback from key stakeholders to improve the use of a tool, and to evaluate any barriers that may inhibit the successful uptake of a tool that is evidence based (Bauer and Kirchner, 2020; Eccles & Mittman, 2006).

Through this study, factors identified through these themes provide insight into the practical use of the wellbeing check-in booklet distress screening tool and the barriers faced by the FSCs. Identifying these barriers provides insight for future use of the booklet and recommendations for FSCs in using the check-in tool with their clients, ensuring the effective uptake of the Wellbeing booklet and its intended use as an EBP. The FSCs identified potential barriers and hesitations of the Wellbeing check-in booklet distress screening tool at the implementation level. This represents the identification of 'why' implementation of an EBP may fail in a practical setting and potential solutions to these barriers (Schofield et al., 2006). Furthermore, the FSCs developed strategies to overcome these barriers, such as encouraging the parents and caregivers to take the booklet home, providing their ‘on the ground’ expertise to improving the booklet and it’s use.

Additionally, barriers to distress screening tools often present in tandem as identified through the literature, and this is supported by the findings from this study where barriers are a child being present, hesitations in verbalising needs, or differing family needs, as discussed in Subtheme 1.2. Therefore, the flexibility and adaptation of an intervention to accommodate for differences are crucial to achieve a successful effect (Rankin et al., 2019). Through this study and the feedback attained by the FSC, it is evident that the booklet presented as an adaptable psychosocial intervention despite the barriers that sometimes arose.

Theme 6: Benefits and Suggestions

Through understanding the experiences of the FSCs in using the Wellbeing check-in booklet, an understanding of the benefits of the Wellbeing Check-in distress screening booklet at the implementation level was attained. Through identifying reinforcing factors, the positive effects of a distress screening tool is acknowledged and thus, promotes the uptake of distress screening provisions.

Subtheme 6.1 Suggested alterations

Alterations to a distress screening tool may only be recognised by evaluating the experience of those who use the tool regularly within practical settings. The suggestions were to include sections dedicated to bereavement, grandparent grief (acknowledging a collective whānau approach aligning with principles of Te Whare Tapa Wha and Bronfenbrenner’s ecological theory); and adjusting to Covid-19, into the booklet. Additionally, amendments to the scale scoring and the communication section to include single or estranged parents may be beneficial for the future. Thus, through understanding the FCSs experience, these suggestions can be identified and acknowledged for the future, thus ensuring distress screening tools are effective for their intended use and are used to their potential - hence, bettering psychosocial oncological health care in Aotearoa, New Zealand.

Subtheme 6.2 Time efficient

Through the interviews, intervention time did not appear to be a concern in the FSCs experience using the wellbeing check-in booklet distress screening tool. The distress screening tools length presented as a strength, thus reflecting promise in the effective uptake and use of the wellbeing check-in booklet distress screening tool in broader health care within Aotearoa, New Zealand. Furthermore, through the interviews, the FSCs expressed that the length of the distress screening tool was optimal, and that the booklet was concise. This finding aligns with the barriers discussed through implementation science and enabling systematic factors to interventions. It is evident through the literature that psychosocial interventions ought to be conducted outside of a clinical setting and by interdisciplinary teams to reduce barriers such as 'consuming clinicians time' to which the FSCs role adheres too. However, the intervention length may still be a concern faced by both the parents/caregivers and the FSCs (Schofield et al., 2006; Mitchell et al., 2008; Hegel et al., 2006).

Links Between Themes:

Link between Theme 1 and Theme 3:

The FSCs gave the families/whanau a sense of control by allowing them to complete the Wellbeing booklet in their own time and location; this creates a non-threatening approach to wellbeing, as discussed through Theme 1. However, nurturing a non-threatening approach to care and conversations around wellbeing may encourage the families/whānau to 'open up' and provide 'thorough responses' facilitating more in-depth conversations (Theme 3) than if they were to only go through the booklet in a meeting that is a FSCs driven process. Thus, more information can be gathered reflective of subtheme 3.1 and, this aids in achieving the sequential subtheme 3.2. Through more information, the FSCs can better understand the parents' and caregivers' coping and identify those who may require additional support. Furthermore, this approach may increase therapeutic rapport and trust and foster informal and open communication between the parents, caregivers, and FSCs (Funk et al., 2016; Schofield et al., 2006).

Link between Theme 1 and Theme 4:

Allowing the parents and caregivers to take the booklet home and process it in their own time and space allows for more processing time. It may inherently facilitate more profound thought from the parents and caregivers about their wellbeing, thus fostering a more self-reflective space, reflective of Subtheme 4.2 (Opportunity for self-reflection). By encouraging the parents and caregivers to take the booklet home to encourage a non-threatening approach to care (and as an adaptation to barriers being a child present or hesitations in verbalising needs), a secondary result is the additional time to reflect on the contents of the booklet and their own unique situation and needs. This facilitates a self-reflection process outside of a formal space, or within the session with a FSC, into a more natural setting representative of the parents' and caregivers' wider life.

Link between Theme 2 and Theme 3:

Through the use of the Wellbeing check-in distress screening tool, the FSCs indicated that parents and caregivers were able to prompt and broaden conversations encompassing the four dimensions of the parents' and caregivers' wellbeing/Hauora (Te taha wairua/Spiritual, Te taha hinengaro/Mental and emotional, Te taha tinana/Physical, Te taha whānau/ Family and social wellbeing). By including conversations that address holistic aspects of wellbeing, it is logical to assume that the FSCs may attain more information regarding the parents' and caregivers' wellbeing, hence reflecting Theme 3 (facilitates conversations), Subtheme 3.1 (More information gathered). By initiating conversations inclusive of the four pillars of wellbeing/Hauora, a broader and in-depth understanding of wellbeing is attained.

Link between Theme 1 and Theme 5:

Through Theme 1, Subtheme 1.2 (Flexible and non-threatening way to open up conversations) it is evident that the booklet facilitates a comfortable approach to begin initiating conversations about wellbeing and care that is tailored to suit the family/whānau's needs. Furthermore, as discussed, the nature of having a tangible, physical booklet presents as a strength in allowing for the parents and caregivers to take the booklet home and process it in a more suitable space, which places a sense of control back towards the parents and caregivers and strengthens the collaborative relationship between the FSCs and the parents and caregivers. Thus, by virtue of the effects of Subtheme 1.2, hesitations felt by the parents and caregivers in verbalising their needs may be mitigated, reflective of Theme 5, Subtheme 5.2 (Hesitancy to speak). Additionally, the benefits of having a flexible, tangible booklet became prominent, in particular around the flexibility about when and where to complete the distress screening tool, as having children present while attempting the completion of this section presented as a barrier. Thus, the adaptation of completing the booklet at home (in contrast to the meeting with the FSCs) was more productive, reflecting a link between Theme 1 and Theme 5.

Link between Theme 3 and Theme 5:

As identified through Theme 3, Subtheme 3.1 it is evident that the Wellbeing check-in booklet distress screening tool was valuable in prompting in-depth conversations and encouraged the parents and caregivers to ‘open up’; this reduces hesitations to speak, a barrier identified through Theme 5, Subtheme 5.2.

Links between Theme 4 and Theme 3:

Through Subtheme 4.1 and 4.2, (Addresses an area of support that can often be forgotten and Opportunity for self-reflection) as discussed in Theme 4, the parents and caregivers are able to redirect the lens of care towards themselves and can understand their wellbeing in a better space; and thus, they can relay more information to the FSCs. This reflects Theme 3, Subtheme 3.1(More information gathered); through addressing their own wellbeing and allowing for self-reflection, the parents and caregivers can provide more information about how they are coping. Moreover, the FSCs can make assessments of those who may require additional support reflecting Subtheme 3.2 (identifies those who may need extra support). Furthermore, the shift in the lens of care, explored within Subtheme 4.1 (Addresses an area of support that can often be forgotten), reinforces parents to begin thinking about their wellbeing and coping. Thus, by virtue of relaying information to the FSCs about their wellbeing, this facilitated conversations reflective of Theme 3 and the subsequent Subthemes (3.1, 3.2).

Strengths:

Due to the nature of the purposive sample and the Child Cancer Foundation being a nationwide service, the FSCs interviewed within this study were from differing geographical locations, indicating a geographically inclusive sample. Moreover, the diverse locations of the FCSs presented the opportunity to identify whether the Wellbeing check-in booklet distress screening tool accommodated different cultures of the parents and caregivers, regional dynamics, and barriers due to differing settings.

Another strength is the range of time the participants worked as FSC. The participants work experience as FSCs ranged from 5 months to 16 years, indicative of a sample with varying experience as FSCs. This means that the study provides the views of both those very new to the work and who have done it for an extended period of time. It suggests the wellbeing booklet was able to be integrated, accepted and valued by both groups. Furthermore, the inclusion of those with more experience provides a comparative insight into the FSCs role pre and post the implementation of the booklet, highlighting the effect or changes experienced with the implementation of the booklet. Additionally, the diverse nature in experience indicates that the Wellbeing check-in booklet distress screening tool can be used irrespective of experience, indicative of a universally useable distress screening tool.

Limitations and Further Research:

A limitation of this study is the small sample size. Although, IPA produces an in-depth analysis of each participant's experience using the Wellness Check-in booklet distress screening tool, the small sample size of five participants this study may not be an accurate depiction of the population, in contrast to having a larger participant pool which may be a more substantial representation. However, it is important to acknowledge that through IPA, lived experiences are understood generating knowledge and discussions, not necessarily generalisable and representative information.

Additionally, it is essential to acknowledge that the participants willing to participate in this study may result from voluntary response bias. This is because those who participated may have done so as they felt positively about the Wellness Check-in booklet distress screening tool. Thus, the interview results may be skewed to reflect the opinions and experiences of those who had a good experience using the Wellness Check-in booklet distress screening tool.

Future research may benefit by exploring the experiences of a larger participant sample size as this will allow a broader understanding of the experiences of the FSC in using the Wellness Check-in booklet distress screening tool. Additionally, a larger sample size may reflect a more holistic experience of using the wellbeing check-in booklet distress screening tool and avoid results reflective of response bias.

Conclusion:

As discussed through the introductory chapters, a childhood cancer diagnosis is a significant life-changing event for the patient and the patient’s family/whānau. The literature review shows that the critical step in psychosocial oncological care is acknowledging that psychosocial care ought to be catered towards (and inclusive of) the patient’s family/whānau.

However, support directed towards the family/whānau and appropriate screening tools that attend to the family/whānau should be designed and evaluated in practical use (Barrera, Fleming & Khan, 2004; Grunfeld et al., 2004; Guan et al., 2021; Norberg et al., 2005; Northouse et al., 2000; Page & Adler Eds, 2008; Robinson et al., 2007; Svavarsdottir, 2005; Ursin & Eriksen, 2004; Woźniak, & Iżycki 2014).

This study provides insight into the experiences of Family Support Coordinators (FSC) from the Child Cancer Foundation (CCF) in administering and using the Wellness Check-in booklet distress screening tool in practicality with families/whānau through their paediatric cancer journey. Through this study, attaining an understanding of the FSCs experience of using the Wellbeing Check-in booklet distress screening tool facilitated the opportunity for feedback on the Wellness Check-in distress screening tool as an intervention in a practical setting, providing information on how to bridge EBP gaps and how practitioners and researchers can work together to provide solutions to real life issues in the community. Thus, aligning with principles from implementation science and evidence-based practices. Thus, it can be identified that the Wellness Check-in booklet distress screening tool presents as a promising distress screening tool for family/whānau-oriented paediatric psychosocial oncological care.

This study falls within the second area of translational research, the ‘bedside to community’ translation where the focus is on the understanding of how the knowledge is translated into a clinical setting (T3) but with emphasis on the effectiveness of the translation of this knowledge (T4) - identifying the barriers and benefits of the Wellbeing check-in distress screening tool and the determinants of these in practice (Fort et al., 2017; Khoury et al., 2011; Livet et al., 2018; Rankin et al., 2019). Consistent with previous research, this study found that the family/whānau of children going through a cancer journey are receptive and appreciative of psychosocial oncological distress screening care directed towards them.

Furthermore, FSCs reported that the Wellness Check-in booklet distress screening tool presented as an excellent screening tool for the parents and caregivers to use and take away to process in their own time and space. However, it was also well received and appreciated by the FSCs, who were introducing the Wellness Check-in booklet distress screening tool to the parents in their care.

The Wellbeing check-in booklet was a 'user-friendly' effective tool for assessing the wellbeing of the families/whānau. It provided a framework for conversations by aiding the FSCs in structuring their discussions, and 'backed-up' conversations around wellbeing. FSCs reported they could initiate conversations in a non-threatening manner and adapt to barriers that arose, such as children being present, and hesitations in verbalising needs, whilst completing the check-in due to the flexible nature and design of the booklet. The booklet aided in facilitating conversations between the FSCs and the parents and caregivers; by virtue of the promotion of conversations about wellbeing, an increased amount of information about the parents and caregiver wellbeing could be gathered by the FSCs. Thus, the FSCs were able to assess who may require additional support, representing a proactive approach to psychosocial health.

The booklet addressed an area of support (parent/caregiver support) that can often be forgotten and initiated the opportunity for the parents/caregivers to reflect upon their wellbeing. Moreover, although the experiences and feedback from the FCSs were predominantly positive, the FSCs identified potential alterations to the booklet for future use. This is representative of real-life engagement of the tool and the effectiveness of the booklet as an intervention in psychosocial care, eliciting ways forward for future development, research and engagement with the wellbeing check-in booklet distress screening tool.

Implications:

The findings of this study have implications for the future of paediatric psychosocial oncological care in Aotearoa, New Zealand. The findings support the use of the wellbeing check-in booklet distress screening tool, as an effective distress screening tool for psychosocial paediatric oncological care in assessing the wellbeing of families/whānau of a child cancer patient. The findings provide a rich understanding of the type of support parents and caregivers wish to receive through their child's cancer journey, in addition to the feasibility and practicality of providing the support using the Wellbeing check-in distress screening booklet. Future research ought to acknowledge the strengths of the booklet identified through this study and review the barriers discovered and the results of these findings into an updated or amended Wellbeing check-in distress screening tool. Thus, providing an opportunity to increase the effectiveness of the Wellbeing check-in distress screening booklet as an EBP into routine clinical care and to ensure the application of this booklet with the current population - and improving the quality and effectiveness of health services in Aotearoa, New Zealand.

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Appendices

Appendix A

Ethics Approval

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Dear:

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

at their meeting held on

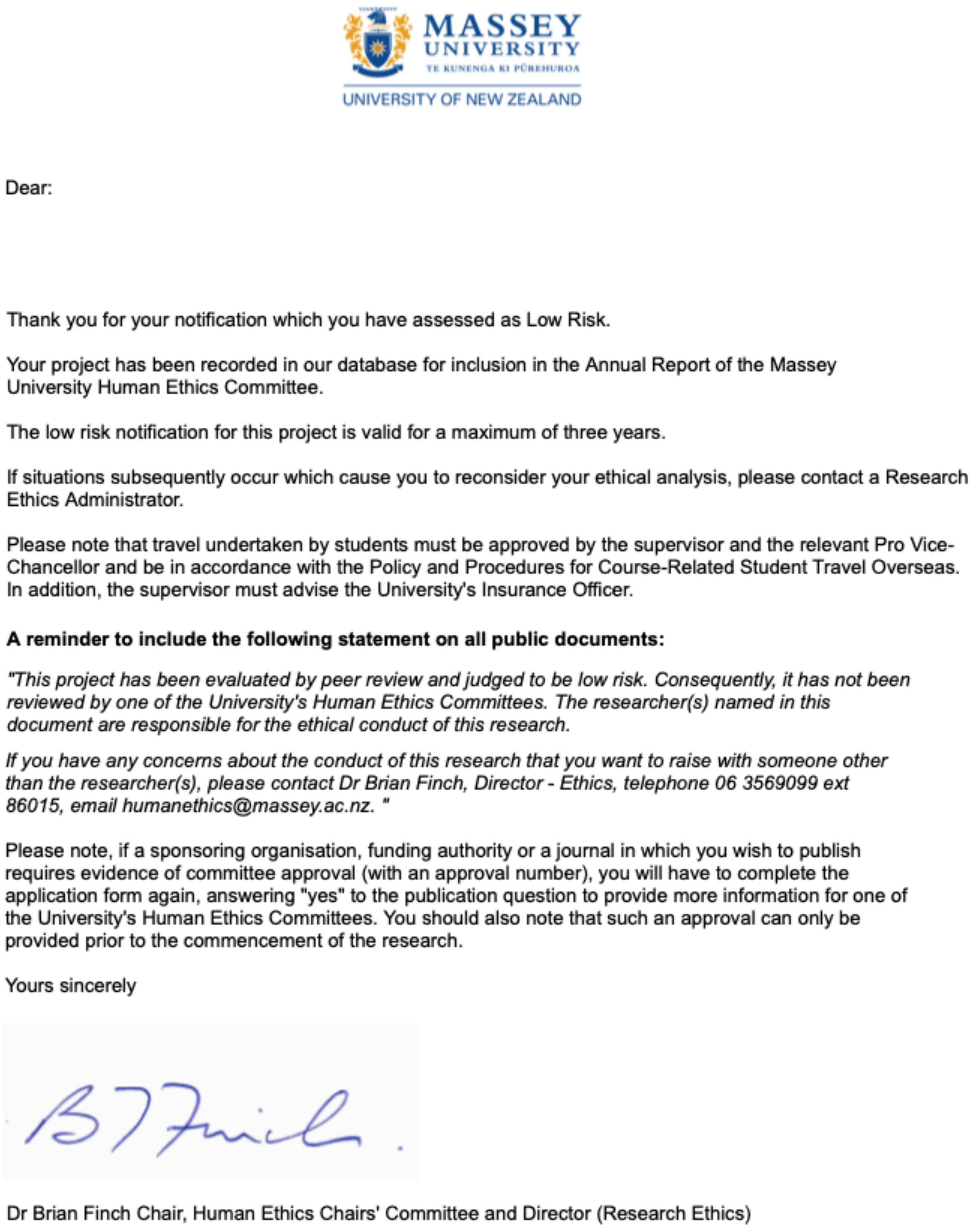
On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

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

Dr Brian Finch Chair, Human Ethics Chairs' Committee and Director (Research Ethics)



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Dear:

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our database for inclusion in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please contact a Research Ethics Administrator.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

A reminder to include the following statement on all public documents:

"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 3569099 ext 86015, email humanethics@massey.ac.nz. "

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

BJ Finch.

Dr Brian Finch Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Appendix B

Participant Information Sheet

Participant Information Sheet

Study title: **Wellness Check-in booklet: Experiences of Family Support Coordinators in its development and use**.

Researcher: Nandini Prasad

Massey University Campus, Auckland

Ethics notification number: 4000024713

Contact: [redacted]

You are being invited to take part in this study exploring the **Experiences of Family Support Coordinators (FSC) for Child Cancer Foundation in the development and use of the 'Wellness Check-in' booklet distress screening tool.**

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to understand the experiences of Family Support Coordinators (FSC) for the Child Cancer Foundation, in the development and use of the 'Wellness Check-in' booklet distress screening tool.

WHAT WILL MY PARTICIPATION INVOLVE?

If you participate the study will involve you taking part in a semi-structured interview conducted through Zoom at your convenience

IF YOU PARTICIPATE, WHAT ARE THE BENEFITS AND RISKS OF BEING INVOLVED?

We do not anticipate that there are any risks from being involved in the study as we will be discussing your experience of the booklet and we do not anticipate you will be discussing anything that might make you uncomfortable. Additionally, you will have the ability to choose not to discuss anything that comes up that you do not want to discuss. You will be given the opportunity to review and edit the transcript of your interview data. Your Interview data will be reported using an alias.

IF YOU PARTICIPATE, HOW WILL YOUR DATA BE MANAGED AND STORED?

- It is important that we maintain your privacy throughout this study. Your name and contact information and data will be stored securely in password protected electronic files used only for the purpose of this research.
- We will not inform the Child Cancer Foundation of your involvement in this research. The only person who will know that you participated will be myself as the researcher.

- My Supervisors will not have access to information about who participated.
- We anticipate that the results of this study will be published in a peer-reviewed journal.

IF YOU PARTICIPATE, WHAT ARE YOUR RIGHTS?

- You are under no obligation to accept this invitation.
- If you don't want to take part, you don't have to give a reason.
- If you decide to participate, but change your mind later you have the right to withdraw from the study up until a week after participant release of the transcript. If no reply is received within two weeks, it will be assumed that you are willing to have the interview transcript released.
- You can: ask any questions about the study at any time during participation; decline to answer any particular question (or reflect on any particular issue); and provide information on the understanding that your name will not be used.
- You have the option to receive a copy of a summary of the project when the study is concluded.

WHAT DO TO IF YOU CHOOSE TO PARTICIPATE, AND IF YOU HAVE ANY CONCERNS ABOUT THE RESEARCH

If you agree to take part in this study, please read the *Participation Consent Form* and *Declaration* on the last page of this document (pg3) and please respond via email indicating that you have read the information sheet and consent form and are willing to participate in this study on the basis of the information consent form.

If you have any questions, concerns or complaints about the study at any stage, you can contact:

- Researchers in the Study: Nandini Prasad, [redacted]
- Alternatively, you can contact my respective supervisors
  Dr Kirsty Ross: K.J.Ross@massey.ac.nz, and Dr Don Baken D.M.Baken@massey.ac.nz

This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher, please contact Professor Craig Johnson, Director (Research Ethics), email humanethics@massey.ac.nz.

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Wellness Check-in booklet: Experiences of Family Support Coordinators in its development and use

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read, and I understand the Information Sheet attached. 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. I may withdraw from the study up until a week after I as the participant have read the transcript of the interview conducted with me and replied via email indicating either to release or withhold the transcript. I understand that if no email reply is received within two weeks of receiving the transcript it will be assumed that I am willing to have the interview transcript used within the study.

Declaration by Participant:

Please respond via email to [redacted] indicating that:

(copy and paste the template below)

I, (Insert name) have read the Information Sheet and Consent Form and I am willing to participate in this study under the conditions set out in the Information Sheet provided.

Please include your responses via email by deleting what does not apply:

- *I agree / do not agree* to the interview being sound recorded.
- *I wish / do not wish* to have my recordings returned to me.

If you would like to receive a summary of the study, please indicate this in the email. This will be emailed to you at the end of the study.