The Prevalence and Nature of Psychosocial Distress in Post-Treatment Haematological Cancer Survivors

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Health Sciences, the University of Auckland, 2020

Abstract

Background

Haematological cancers are the fourth most common cancer in the developed world. Although the incidence of haematological cancers is increasing in many countries, new and improved treatments have led to increased survival. Haematological cancers often require aggressive treatment, causing both late and long term physical and psychosocial effects lasting years. Those survivors faced with psychosocial issues in the post-treatment period may not always receive the support they need. Research into psychosocial outcomes for post-treatment haematological survivors is limited. To enable these cancer survivors the opportunity to receive any support they may require, it is first necessary to know the size and nature of the problem.

Aim

To investigate the nature, magnitude, and timing of psychosocial distress post-treatment amongst haematological cancer survivors in NZ and explore their post-treatment support experiences.

Methods

This study used a two-phase exploratory sequential mixed methods design underpinned by a critical realist philosophy and the theoretical model of Psychological Health in Cancer Survivors. In Phase One, 23 post-treatment haematological cancer survivors participated in a semi-structured interview. Data were analysed using thematic analysis. Phase Two comprised a cross-sectional survey of post-treatment haematological cancer survivors (n = 409). Logistic regression was used to identify predictors of distress. Chi-Square analyses were used to calculate the differences in the need for psychological support. Open text responses were analysed using quantitative content analysis. The integration of the two phases was conducted using a narrative approach.

Findings

Qualitative findings showed that the barriers to psychosocial wellbeing in post-treatment haematological cancer survivors largely revolved around the lack of information and discussion around psychosocial issues and the gap in promoting the relevant psychosocial resources available to survivors. Quantitative results expanded on these findings demonstrating that nearly a quarter (24.6%) of haematological cancer survivors reported needing more psychological support from a health professional in the post-treatment period. Significantly, quantitative results showed that 21.9% of post-treatment haematological cancer survivors were suffering from significant distress. There was a higher prevalence of significant distress in younger people aged 18–39 (36.7%), those unemployed or on sick leave (32.6%), and women (28.2%). Logistic regression analyses identified three significant predictors of distress: not being born in NZ, low social support, and high fear of recurrence.

Conclusion

This study has provided new and important evidence regarding psychosocial distress in post-treatment haematological cancer survivors. There may be distressing aspects of the cancer trajectory that cannot be avoided, such as side effects of treatment and cancer's physical symptoms. However, this research has shown that more could be done in the post-treatment period to ease the psychosocial consequences of cancer and its treatment. Distress screening needs to be implemented as part of post-treatment follow-up, to identify those haematological cancer survivors who may be struggling. There is also a need for more psychosocial discussion and implementation of individualised psychosocial interventions.

Acknowledgments

First and foremost, I would like to acknowledge all the amazing cancer survivors that took the time to participate in my research. I had the chance to speak with so many great people through interviews, and also with those who called to enquire about the study. I also really appreciate all the encouraging comments written by those who completed the survey. Those conversations and words of encouragement motivated me to keep going.

I would like to thank my fantastic supervisors, Prof Merryn Gott and Dr Rosemary Frey, for all your support and encouragement, and especially your patience. Thank you for always being available and approachable, I did not ever have a moment when I felt I could not ask you for guidance.

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List of Abbreviations

ASC - Assessment of Survivor Concerns

DT - Distress Thermometer

FoR - Fear of recurrence

HL/HD – Hodgkin's lymphoma/Hodgkin's disease

HP - Health Professional

HRQoL – Health related quality of life

MDS - Myelodysplastic syndromes

MM - Multiple myeloma

MSPSS - Multidimensional Scale of Perceived Social Support

NCCN - National Comprehensive Cancer Network

NHL - Non-Hodgkin's lymphoma

NZCR - New Zealand Cancer Registry

QoL - Quality of Life

DR – Deborah Raphael

MG – Merryn Gott

RF – Rosemary Frey

Glossary of Terms

Māori: the indigenous people of New Zealand.

Aotearoa: the Māori name for New Zealand.

Haematological cancer: cancers of the blood and blood-forming tissues (National Institute for Clinical Excellence, 2003).

Cancer survivor: an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (National Cancer Institute, 2014).

Post-treatment Cancer survivor: a survivor who has finished their primary treatment and is considered cured or in remission (Institute of Medicine, 2008).

Psychosocial: the psychological and social components of a disease and its treatment. Some of the psychosocial parts of cancer are its effects on patients' feelings, moods, beliefs, the way they cope, and relationships with family, friends, and co-workers (National Cancer Institute, 2014).

Psychosocial Distress: an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis (National Comprehensive Cancer Network, 2007).

Structure of Thesis

As this is a thesis with publication it includes all published manuscripts in their entirety and exactly as they were published and in accordance with the University of Auckland's 2011 PhD Statute and the Guidelines for Including Publications in a Thesis (2014). Pages, tables, and figures have been numbered consecutively within the thesis for clarity and continuity. All references have been included at the end of the thesis. All relevant supporting documentation has been included in the appendices, including ethical approvals, data collection forms, participant information sheets, and consent forms.

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Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work. Chapter Two, pp 13-29: Psychosocial distress in haematological cancer survivors: An Integrative Review of the Literature	
Nature of contribution by PhD candidate	Conception, design, data collection and analysis, writing manuscript
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Professor Merryn Gott	Conception, design, providing feedback, editing manuscript
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Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and
- that the candidate wrote all or the majority of the text.

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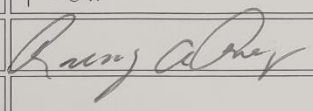
Dr Rosemary Frey		20/10/2020

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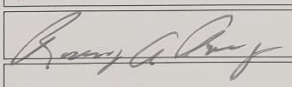
Dr Rosemary Frey		20/10/2020

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Chapter One: Introduction

"A common complaint of survivors is the apparent belief of those around them that, once the last treatment is over, the cancer is over. Family, friends et al may expect an immediate return to full family and work responsibilities and not appreciate the lingering fatigue. They are unlikely to understand, or to want to understand, the existential dread that remains and the hard facts of uncertainty." (Schnipper, 2001).

This chapter locates the researcher in relation to this thesis and explains my interest in the area of psychosocial distress in haematological cancer survivors. It then introduces the background to this research and the significance of this topic internationally and within Aotearoa New Zealand (NZ). I will first discuss the overall prevalence and incidence of haematological cancers both worldwide and in NZ before focusing on cancer treatment and survivorship in the NZ context. I will finish the chapter by discussing survival rates and issues of treatment and remission in relation to the most prevalent haematological cancers worldwide.

Locating the Researcher

My Interest in This Topic

My interest in cancer survivorship comes from my own experiences with family and friends who have had cancer, and the physical and psychological effects they have been left with once their treatment ended. In particular, a close friend whose daughter had leukaemia led me to an interest in haematological cancers, and made me realise that the psychological impact of cancer and its treatment does not just disappear when the treatment ends and the patient is now labelled as in remission or 'cured'.

All of my experiences in life, with this research topic and in general play a part in how I engage with the research process. Indeed, Burr (1999) proposes that we are a 'product of our cultural and historical background and therefore we accept that we cannot remove this culture and history from ourselves, as this in part is what underpins our knowledge of the world.' It is therefore important I situate myself in relation to the research I present in this thesis.

Reflexivity in Research

Reflexivity is the process whereby a researcher can 'reflect upon their standpoint concerning the phenomenon they are studying' (Willig, 2001). Being reflexive enables the researcher to have an awareness of how their actions, values, and observations affect how they collect and analyse data (Gerrish & Lacey, 2006). Part of using reflexivity as a strategy in research means a constant self-examination of the researcher's assumptions and biases that could impact the research (Morrow,

2006). As a way of recognizing how my past may influence the way I choose to conduct research, I will now provide a brief overview of my background and how it informed my choice of research topic.

My Educational and Employment Background

My interest in this topic comes from both my educational background and my current role. I obtained my undergraduate and master's degrees in psychology, which is where I became interested in the psychological factors relating to health and illness. Additionally, for the past 10 years I have worked as a Research Assistant at the University of Auckland School of Nursing where I developed an interest in how services are delivered to consumers in the public health system. I have worked on a range of studies, which have focused on the consumer point of view regarding their illness and how they engage with health care services, including projects focusing on caregivers satisfaction with care at the end of life (Frey, Robinson, Old, Raphael, & Gott, 2020), how people with COPD manage their condition (Sheridan, Kenealy, Salmon, Raphael, & Rea, 2011), older people's experiences of nurse-patient telephone communication in the primary healthcare setting (Waterworth, Raphael, Parsons, Arroll, & Gott, 2018), and what older adults with chronic conditions prefer from their clinicians (Sheridan et al., 2015). I became particularly interested in what health consumers identify as important to them in terms of how services are provided and how they may be enhanced.

My Cultural Background

My whakapapa (genealogy) can be traced back many generations to England, Scotland, and the Czech Republic. People of European descent began settling in NZ in the early 1800s (Phillips, 2015), and those descended from these settlers who are born in NZ are commonly known as NZ European. Currently, NZ Europeans make up 70.2% of the NZ population, with the next highest ethnic group being Māori (16.5%) (Statistics New Zealand, 2018). Māori are the indigenous people of NZ, also known as tangata whenua (people of the land). Although the 1840 Treaty of Waitangi (founding document of NZ) was in large part intended to protect the rights of Māori, colonisation has nevertheless caused serious detrimental effects to Māori health and wellbeing (Hill, Sarfati, Robson, & Blakely, 2013; Moewaka Barnes & McCreanor, 2019; Robson & Harris, 2007).

I recognise that my cultural and ethnic background as a NZ European has shaped my way of seeing the world, and that other ethnicities and cultures have different worldviews (Frost, 2011). I recognise that coming from a NZ European background I have had advantages that others may not have experienced. I am fortunate to have been born and raised in Auckland (New Zealand's largest city), which is very multicultural and this has allowed me to experience other cultures. In my personal life I have always attempted to gain a better understanding of other cultural practices.

In my role as a Research Assistant, I have worked on many projects that have been conducted with other cultural groups and explored issues around culture in relation to health and healthcare (Clark et al., 2010; Crengle, Robinson, Ameratunga, Clark, & Raphael, 2012; Frey et al., 2013; Sheridan, Kenealy, Salmon, Rea, et al., 2011; Sheridan et al., 2015). This research has enabled me to

understand some of the issues around cross-cultural research and underlined the importance of cultural consultation when undertaking research with people from other cultures. I outline how I addressed these cultural issues in Chapter Three, in particular ethical issues associated with research involving Māori participants.

Prevalence and Survival of Haematological Cancers

Combined, haematological cancers are the fourth most common cancer in resource rich countries (Smith, Howell, Patmore, Jack, & Roman, 2011). Worldwide in 2018 there were an estimated 1,186,600 new cases of the main haematological cancers (Lymphoma, Multiple Myeloma and Leukaemia), representing 6.5 % of all new cancer cases (Ferlay et al., 2019). The incidence of haematological cancers is increasing in several countries (Chihara et al., 2014; Fisher & Fisher, 2004; Howlader et al., 2014; Ministry of Health, 2010a), especially those cancers which increase in incidence with age such as myeloma (Dvorak, 2006), non-Hodgkin's lymphoma (Lowry & Linch, 2013), and most types of chronic leukaemia (Berger et al., 2003). Although many haematological cancers are not curable, new and improved treatments have led to increased survival (Hall, Lynagh, Bryant, & Sanson-Fisher, 2013; Sant et al., 2014).

Prevalence and Survival of Haematological Cancers in Aotearoa New Zealand

Cancers overall are the leading cause of death in NZ (Sarfati & Jackson, 2020). In NZ, haematological cancers contribute significantly to the overall cancer burden (Leukaemia and Blood Foundation, 2011). Combined, the three main haematological cancers — leukaemia, lymphoma, and myeloma (National Institute for Clinical Excellence, 2003) — are the fifth most diagnosed cancers in NZ, with the latest statistics reporting 2,508 people were diagnosed in 2016 (Ministry of Health, 2018). Table 1.1 shows the incidence rates and age-standardised incidence rates of haematological cancers in NZ and worldwide for those aged 20+ (Ferlay et al., 2018).

Table 1.1 Estimated number of new cancer cases in NZ in 2018 aged 20+

Cancer Type	Number	Crude rate	ASR	Worldwide ASR
Non-Hodgkin's lymphoma	798	22.8	15.8	8.8
Leukaemia	586	16.7	11.0	6.5
Hodgkin's lymphoma	93	2.7	2.5	1.3
Multiple myeloma	498	14.2	8.8	2.8

The latest NZ Ministry of Health data collected in 2011 reports five-year survival for adults in NZ with Hodgkin's lymphoma at 84.5%, non-Hodgkin's lymphoma at 67.8%, myeloma at 45.2%, and leukaemia at 51.5% (Ministry of Health, 2015). Table 1.2 shows the increases in survival in NZ from the 1998/99 period through to 2010/2011 period.

Table 1.2 Five-year survival of haematological cancers in Aotearoa New Zealand

Cancer type	Five-year survival 1998/99 (%)	Five-year survival 2010/11 (%)
Hodgkin's lymphoma	83.0	84.5
Non-Hodgkin's lymphoma	49.2	67.8
Myeloma	27.8	45.2
Leukaemia	40.2	51.5

Cancer Treatment and Survivorship in Aotearoa New Zealand

Ethnic Disparities in Cancer Incidence and Survival

Research has shown that Māori fare worse than other ethnic groups in NZ when it comes to cancer incidence and survival (Teng et al., 2016). Māori are not only more likely to die from cancer but also more likely to die sooner than non-Māori New Zealanders with cancer (Robson et al, 2010). The total cancer incidence for Māori is 20% higher than for non-Māori — and the mortality rate is twice as high (Robson, Purdie, & Cormack, 2010). Inequalities in cancer survival are driven by a range of factors including socioeconomic status, barriers to screening and early diagnosis, higher rates of comorbidity, and poorer quality cancer treatment (Hill et al., 2013). A recent report (Came, Kidd, & Goza, 2020) evaluated the New Zealand Cancer Control Strategy (Ministry of Health, 2003) in relation to the principles of the Treaty of Waitangi. They found that the New Zealand Cancer Control Strategy does not align with the Treaty of Waitangi, and that Māori worldviews and solutions to health policy are missing from this strategy.

The Aotearoa New Zealand Health System

Cancer treatment in NZ is primarily delivered through the national public health system which provides free secondary and tertiary care for NZ citizens and residents (Sarfati & Jackson, 2020). There are also private oncology services in NZ that offer cancer treatment (Sarfati & Jackson, 2020). However, these private services are only available to those who can afford them, or who have private health insurance. The most recent NZ Ministry of health data shows that 35% of adults had private health insurance, and Māori were less likely to report having health insurance than non-Māori (Ministry of Health, 2016). Primary care services in NZ are provided by a number of different public and private entities (Goodyear-Smith & Ashton, 2019). Many primary care services (such as prescriptions, blood tests, General Practitioner (GP) visits) are fully or partially funded by the government (Crampton, 2019). Partially funded services (such as GP visits) require a co-payment by the service user which varies by primary care service, with those services with higher need populations receiving more government funding and therefore being able to offer lower co-payments (Jeffreys et al., 2020).

Overview of Prevalence and Survival for the Most Common Haematological Cancers

Overall haematological cancers comprise a very mixed group of cancers, with extremely varied treatment paths. Some treatments are delivered with curative intent, some aim to increase life expectancy for people with incurable cancers, and some provide palliative care (National Institute of Clinical Excellence, 2016). Additionally, those with haematological cancers often transition between different treatment pathways, however, unlike many solid tumour cancers, transitions in haematological cancers can be indistinct and prognoses difficult to predict (McCaughan et al., 2018).

Leukaemia

Leukaemia falls into four major sub-types: acute myeloid leukaemia, acute lymphoblastic leukaemia, chronic lymphocytic leukaemia, and chronic myeloid leukaemia (Rodriguez-Abreu, Bordoni, & Zucca, 2007). Worldwide, over 250,000 people are diagnosed with leukaemia each year, which accounts for 2.5% of all cancers (Rodriguez-Abreu et al., 2007).

Acute myeloid leukaemia represents 80% of acute leukaemia in adults (Gheihman et al., 2016); it is a disease that is fatal without treatment (Short, Rytting, & Cortes, 2018). Acute myeloid leukaemia has an overall 5-year survival rate of 24.7% (Tremblay, Sokol, Bhalla, Rampal, & Mascarenhas, 2018). However, this rate increases for younger people whose 5-year overall survival is 40% (Dombret & Gardin, 2016).

Chronic lymphocytic leukaemia is the most common form of adult leukaemia in high-income countries (Hallek, 2017). Chronic lymphocytic leukaemia patients are most often asymptomatic at the time of diagnosis and the disease is found through routine blood count testing (Kipps et al., 2017). As opposed to acute myeloid leukaemia as described above, the clinical course of chronic lymphocytic leukaemia is variable, with some staying asymptomatic for years and others needing urgent treatment soon after diagnosis (Kipps et al., 2017).

The outlook for those with chronic lymphocytic leukaemia has improved greatly over recent years (Kipps et al., 2017). Moreover, it is expected that in the future new drug combinations will potentially lead to long-lasting remissions in people living with chronic lymphocytic leukaemia (Hallek, 2017). Survival has also significantly improved for the other main chronic leukaemias (Damlaj, El Fakih, & Hashmi, 2019).

Lymphoma

Lymphoma is divided into two main types — Hodgkin's Lymphoma and non-Hodgkin's lymphoma — with non-Hodgkin's lymphoma making up 85% of all lymphomas (Lowry & Linch, 2013).

Non-Hodgkin's Lymphoma

Non-Hodgkin's lymphoma is between the 5th and 9th most common cancer in most countries, with 509,590 cases diagnosed in 2018 (Bray et al., 2018). The overall incidence of non-Hodgkin's lymphoma has steadily increased in most developed countries between 1970 and 2000. While other cancers have increased by around 25% in the past 25 years, non-Hodgkin's lymphoma has increased over 80% (Rodriguez-Abreu et al., 2007). The highest incidence rates of non-Hodgkin's lymphoma for men are in Australia and NZ (16.4 per 100,000), whereas the highest incidence rates for women are in the United States (14.8 per 100,000) (Bray et al., 2018).

Most types and sub-types of non-Hodgkin's lymphoma can be divided into either indolent (low grade, slow-growing) or aggressive (high grade, fast-growing) (Canadian Cancer Society, 2019). Aggressive lymphomas are fast-moving and make up 60% of all non-Hodgkin's lymphomas. Indolent Lymphomas are slow-moving and less symptomatic and make up 40% of all non-Hodgkin's lymphoma (Leukemia & Lymphoma Society, 2019). Aggressive lymphomas progress more rapidly, and without treatment could lead to death within months (Sehn & Connors, 2005), whereas indolent lymphomas take on a more chronic course with often repeated treatment and relapse (Blaes, Ma, Zhang, & Peterson, 2011).

Non-Hodgkin's lymphoma has around 60 subtypes (Leukemia & Lymphoma Society, 2019). However, a few subtypes make up a large percentage of non-Hodgkin's lymphoma diagnoses (Lowry & Linch, 2013). The most common type of non-Hodgkin's lymphoma is diffuse large B-cell lymphoma, an aggressive cancer that accounts for 30% to 40% of non-Hodgkin's lymphoma cases (Ferlay et al., 2015). Diffuse large B-cell lymphoma is also one of the two most common haematological cancers overall (Smith et al., 2011). Follicular lymphoma is the second most common non-Hodgkin's lymphoma and is an indolent lymphoma (Sorigue & Sancho, 2018). Follicular lymphoma is considered an incurable disease but can have a good response to treatment, and new treatments are leading to increased survival in this cancer (Luminari, Bellei, Biasoli, & Federico, 2012).

Aggressive non-Hodgkin's lymphomas are treated with the aim of cure, whereas indolent non-Hodgkin's lymphoma is often treated with a relatively gentle chemotherapy aimed at keeping the disease at bay and minimising adverse effects (Lowry & Linch, 2013). The 5-year survival rate for non-Hodgkin's lymphoma is around 80% in higher-income countries but varies by sub-type and patient age; survival is also lower in low and middle-income countries (Allemani et al., 2018).

Hodgkin's Lymphoma

Hodgkin's lymphoma has an incidence rate of around three per 100,000 in Western Europe and the United States (Rodriguez-Abreu et al., 2007). The incidence of Hodgkin's lymphoma is consistently lower than that of non-Hodgkin's lymphoma and has remained stable over the last 25 years (Rodriguez-Abreu et al., 2007). Hodgkin's Lymphoma is predominately an aggressive form of

lymphoma (Shanbhag & Ambinder, 2018) which was considered the first type of lymphoma to be deemed curable in certain patients (Lowry & Linch, 2013).

Hodgkin's lymphoma has a 5-year survival rate of between 81-90% (Howlader et al., 2014), but high survival rates come at a cost, with Hodgkin's lymphoma survivors often suffering high levels of late effects associated with treatment (Nijdam et al., 2019). Indeed, Hodgkin's lymphoma survivors are at higher risk of dying from treatment late effects than from Hodgkin's lymphoma itself (Ng, 2014). Furthermore, treatment effects of Hodgkin's lymphoma (such as cardiovascular disease and risk of secondary cancers) can last as long as 40 years after treatment (Schaapveld et al., 2015).

Multiple Myeloma

Along with diffuse large B-cell lymphoma DLBCL, multiple myeloma (also known as myeloma) is one of the two most common haematological cancers (Smith et al., 2011). Myeloma has a worldwide age-standardised incidence rate of 1.7 per 100,000 (ASR =2.8 for those aged 20+) (Ferlay et al., 2019). NZ has one of the highest incidence rates of myeloma worldwide (ASR = 8.8 for those aged 20+) and the incidence is increasing in NZ, unlike many other countries (Sneyd, Cox, & Morison, 2019).

Internationally, the relative 5-year survival rate for myeloma is approximately 50% (Howlader et al., 2014). In many countries, survival rates have been increasing in myeloma patients with advances in treatment leading to greatly improved life expectancy (Pulte et al., 2015). The life expectancy for myeloma patients has also increased substantially in NZ, with survival rates for myeloma doubling between 1990-2009 (Sneyd et al., 2019).

One of the key issues with myeloma is that it takes much longer to diagnose than other cancers (Neal et al., 2014). Consequently, this has been shown to lead to more disease-related complications and reduced disease-free survival (Kariyawasan, Hughes, Jayatillake, & Mehta, 2007). Furthermore, amongst those with haematological cancers, myeloma patients have the highest level of physical symptoms and health problems such as back pain, bone pain, fatigue, and anaemia (Dvorak, 2006).

Remission in Haematological Cancers

People with the major subtypes of haematological cancers all have a chance for remission, but some are more likely than others to go into remission and stay in remission. For example, acute leukaemia and aggressive lymphomas have a high chance (80-90%) of achieving remission from treatment (Coiffier et al., 2010; Dombret & Gardin, 2016; Eichenauer et al., 2018; Larson, 2018; Lin & Corcoran, 2019; Lowry & Linch, 2013), whereas those with indolent lymphomas and chronic leukaemia have less chance (28-75%) of going into remission and may follow a chronic course of remission and relapse (Jamy, Sarmad, & Costa, 2019; Kipps et al., 2017; Rogers et al., 2020; Sorigue & Sancho, 2018). Those with multiple myeloma are also more likely to have periods of remission and relapse

(Snowden et al., 2017), however the of chance of going into remission, with modern treatment, has increased to 50-75% (Morè et al., 2020).

Myelodysplastic Syndromes

Although myelodysplastic syndromes have been classified as a haematological cancer for nearly 20 years (Rodger & Morison, 2012) there are still many health professionals who do not describe these conditions as cancer to their patients (Steensma, 2006). Because of the risk of distress to those with myelodysplastic syndromes it was decided that they were out of scope for this project.

Defining Cancer Survivorship and the Post-Treatment Phase

Definitions of Cancer Survivorship

The term 'survivor' regarding cancer was first coined in 1985 by physician Fitzhugh Mullan after he had been diagnosed and treated for cancer (Mullan, 1985). In his much-cited 1985 article, he described his cancer experience and proposed distinct survivorship phases for cancer patients: 1) Acute Survival (the diagnosis and treatment period); 2) Extended Survival (the early post-treatment period comprised of recovery from treatment and watchful waiting); and 3) Permanent Survival (where the focus moves from cancer to dealing with re-entry into life whilst dealing with late and long-term effects of cancer). Dr Mullan defined a 'survivor' as someone who had been treated and was cured or in remission from cancer. This remained the most commonly adopted definition for many years (Lai-Kwon & Jefford, 2017).

A more recent definition of survivorship proposed by the US National Cancer Institute (NCI) has become increasingly popular internationally: 'An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life' (National Cancer Institute, 2014). Notably, this definition includes those with cancer at any stage. The NZ Ministry of Health has provided a similar definition 'Survivorship refers to the period of time extending from the time of diagnosis through to death' (Ministry of Health, 2010b). However, both internationally and in NZ there is still a lack of agreement about the correct definition of a cancer survivor (Marzorati, Riva, & Pravettoni, 2017; O'Brien, Signal, & Sarfati, 2018).

The definition of survivor used in this thesis aligns with the post-treatment phases described by Dr Mullan as Extended Survival and Permanent Survival. However, for clarity, the term post-treatment survivor is used in this thesis.

The Post-Treatment Phase of Survivorship

Cancer survivorship is often divided into short-term (0-5 years post-diagnosis) and long-term survivors (over five years post-diagnosis) (Gotay & Muraoka, 1998). One of the reasons for this is that most

recurrence of cancer happens within five years of diagnosis (Gotay & Muraoka, 1998). The focus of this research is on short-term survival because of the particular challenges faced by cancer survivors as they transition from cancer patient to survivor (Hewitt, Greenfield, & Stovall, 2006).

The post-treatment phase was brought into focus by the Institute of Medicine in 2006 with their seminal report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006), which recognised that post-treatment survivors were often overlooked. They created a list of recommendations aimed at improving care for those in the post-treatment phase. In a more recent review (Kline et al., 2018), they identified an improvement in the area of cancer survivorship policy, health care and research, but highlighted that there are still huge gaps in knowledge and the delivery of high-quality post-treatment survivorship care. Indeed, research into psychosocial outcomes for post-treatment survivors continues to be more limited than other stages of the cancer trajectory (Stanton, Rowland, & Ganz, 2015).

Psychosocial Distress in Cancer Survivors

The National Comprehensive Cancer Network in the US reports that all cancer patients experience some level of distress, regardless of where they sit on the cancer trajectory, and provide the following definition of distress in cancer: 'Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis' (National Comprehensive Cancer Network, 2013). Distress is, therefore, a useful concept in the measurement of psychosocial sequelae in cancer survivors as it encompasses not only clinical diagnoses such as anxiety disorders and depression, but also the 'worries, fears and other forms of psychological stress' that affect many patients (Institute of Medicine, 2008).

A large German multi-centre study found that 55.6% of mixed cancer survivors in remission were suffering high levels of distress (Mehnert et al., 2018). Another study of 1360 mixed cancer survivors from the United States found that post-treatment survivor's levels of distress were persistent across the trajectory from treatment to five years post-treatment (Reed et al., 2017). This led me to develop an interest in psychosocial distress specifically within the context of haematological cancer survivors. I present the integrative literature review I conducted to examine evidence of psychosocial distress within this group in the next chapter.

Chapter Summary

This chapter has located the researcher in relation to this thesis and explained my interest in the area of psychosocial distress in haematological cancer survivors. I have also introduced the background to this research and the significance of this topic internationally and within NZ. I have also explored the

prevalence and incidence of haematological cancers both worldwide and in NZ before focusing on cancer treatment and survivorship in the NZ context. The chapter also presented survival rates and issues of treatment and remission in relation to the most prevalent haematological cancers worldwide.

Chapter Two: Psychosocial Distress in Haematological Cancer Survivors: An Integrative Review of the Literature

In the previous chapter I presented the background and rationale for this research. In this chapter, I present an integrative review which aims to appraise the current literature regarding psychosocial distress in post-treatment haematological cancer survivors, with a particular focus on those in the 0-5 years post-treatment phase. The review informed my final research aims and objectives which are presented at the end of the chapter. The review was published in the *European Journal of Cancer Care*.

The following article is cited as:
Raphael, D., Frey, R., & Gott, M. (2017). Psychosocial distress in haematological cancer survivors: An integrative review. European Journal of Cancer Care, 26(6), e12640. doi:10.1111/ecc.12640

 This journal has an impact factor of 2.161, and journal ranking of 49/102 (Health Care Sciences & Services) (Clarivate Analytics Journal Citation Reports). As of May 2021, this article has been cited 13 times (Google Scholar Citations).

Article: Psychosocial Distress in Haematological Cancer Survivors: An Integrative Review of the Literature

Abstract

Haematological cancers are becoming more prevalent, however, survival is also increasing. Many survivors are faced with psychosocial issues after treatment ends, and they may not receive the support they need. This review aims to examine peer reviewed literature reporting psychosocial distress faced by haematological cancer survivors in the early post-treatment period. Database and hand searches were conducted between August and September 2015, with no year restriction. Eligible studies were those reporting on psychosocial sequelae in haematological cancer survivors up to 5 years post-treatment. The search yielded 512 studies, of these only seven (five quantitative and two qualitative) included data that addressed psychosocial distress in early post-treatment haematological cancer survivors. Data were thematically analysed to explore the presence and nature of distress. Most studies reported mild to moderate distress for survivors, with some evidence that younger age was an indicator of increased distress. However, predominately this review identified a gap in current literature regarding distress among this group of survivors. More research is needed to address the psychosocial issues facing this growing survivor group, to enable them to receive the support required to maintain good physical and psychological health in this period of the cancer trajectory and into the future.

Introduction

Haematological cancers are the fourth most common cancer in the developed world (Smith et al., 2011). The incidence of haematological cancers is increasing in many countries (Chihara et al., 2014; Fisher & Fisher, 2004; Howlader et al., 2014; Ministry of Health, 2010a), especially for those cancers which increase in incidence with age, such as myeloma (Dvorak, 2006), non-Hodgkins lymphoma (Lowry & Linch, 2013) and most chronic leukaemias (Berger et al., 2003). Survival rates in many countries are also improving (Hall et al., 2013; Leukaemia and Blood Foundation, 2011; Sant et al., 2014); due to factors such as improved treatment and early detection (Jefford et al., 2008). However, previous research has shown that cancer survivors who have successfully finished treatment are often left with residual physical, psychological and social sequelae (Aaronson et al., 2014; Wallwork & Richardson, 1994). Haematological cancer survivors may particularly be at risk of psychosocial sequelae because of the often intensive and aggressive treatment they receive (National Institute for Clinical Excellence, 2003). In fact, recent literature has shown psychosocial concerns are the biggest unmet need for haematological cancer survivors (Barata, Wood, Choi, & Jim, 2016).

The National Comprehensive Cancer Network (NCCN) in the US reports that all cancer patients experience some level of distress, regardless of which stage they are at, and provides the following definition of distress in cancer: “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis” (National Comprehensive Cancer Network, 2007). Distress is therefore a useful concept as it encompasses not only clinical diagnoses such as anxiety disorders or depression but also the “worries, fears and other forms of psychological stress” that effect many patients (Institute of Medicine, 2008).

The early post-treatment stage may create a particular challenge for survivors (Stanton, 2012). Fear of recurrence may dominate at this time, as well as worry about how one might manage with symptoms on their own away from medical care, and what steps might be needed for further care (Hewitt et al., 2006). Although this is an understudied phase in the cancer trajectory (Stanton et al., 2005; Stanton et al., 2015), the existing research shows that the time immediately after treatment ends can be difficult for survivors as they “re-enter” their normal lives (Stanton, 2012). For example, research looking at symptoms in a mixed cancer group of lung cancer, colorectal cancer and lymphoma survivors (Brant et al., 2011) showed that psychological symptoms persisted for 16 months following treatment.

Previous research also confirms that the transition from cancer patient to cancer survivor can often be a problematic time for survivors, with survivors often suffering negative psychological sequelae in this

period (Stanton, 2012). It is therefore worrying that they have also reported a lack of support services to cope with these psychological issues (Beckjord et al., 2014). Interventions aimed at reducing psychosocial problems in cancers survivors have been shown to decrease distress (Garrett et al., 2013). For example, research conducted with breast cancer patients has shown that a psychological intervention can lead to both decreased recurrence of cancer and lower mortality in patients whose cancer recurred (Andersen et al., 2010). It is important to understand the nature of, and factors associate with, psychosocial distress experienced by cancer survivors to ensure adequate services are available to help these individuals (Institute of Medicine, 2008; Stanton, 2006). Therefore, this paper presents a comprehensive integrative review aimed at identifying empirical research reporting psychosocial distress in haematological cancer survivors in the early post-treatment stage, to determine the level and explore the nature of distress in this group. Research questions specifically asked are “did the participants report distress,” and “what was the nature of this distress?”

Method

An integrative review of the literature was undertaken guided by the framework created by Whittemore and Knafl (2005). This framework consists of five stages: Problem Identification; Literature Search; Data Evaluation; Data Analysis and Presentation. An integrative review allows the inclusion of both qualitative and quantitative designs, therefore providing a fuller picture of the phenomenon of interest (Whittemore & Knafl, 2005). It is particularly suitable for exploring aspects of patient experience, where qualitative methods are often used. For this review, distress was defined using the above description used by the NCCN. Therefore, all studies that reported any psychosocial sequlae that fell within the defined spectrum were considered eligible for inclusion in the review.

Search Strategy

A systematic search was conducted of the following electronic databases: Medline, CINAHL, PsychInfo, Web of Science, and EMBASE. There was no year restriction. All searches were conducted between August and September 2015. In addition to the database searches, reference lists of related articles found in the search and the last 3 years of specific journals were hand searched (Psycho-Oncology, Supportive Care in Cancer, Journal Of Psychosocial Oncology, Journal of Cancer Survivorship, Leukemia & Lymphoma, Critical Reviews in Oncology/Haematology, Blood Cancer Journal, Haematological Oncology, Cancer) to find any articles not identified by the databases.

Search Terms

The following search terms were used: Haematological cancer, Blood Cancer, Haematological Malignancy, Lymphoma, Leukaemia, Myeloma, Hodgkin's Disease, Survivorship, Survivor, Survival, Post-treatment, Treatment Completion, Late effects, Long-Term Effects, Psychological, Social, Psychosocial, Distress, Emotional, Mental Health, Post Traumatic Stress Disorder, Anxiety,

Depression, Stress, Adjustment Disorders, Panic Disorder, Loneliness, Social Isolation, Social Alienation, Quality of Life, Prevalence, Epidemiology.

Inclusion Criteria

Studies

- Original peer reviewed research articles
- Articles from any year
- Quantitative or qualitative studies
- English language
- Studies focusing on both single and multiple haematological cancers
- Studies measuring potential psychosocial sequelae

Participants

- Studies using adult (defined as over 18 years of age) survivors of haematological cancers.
- Survivors 0–5 years post-treatment. This includes any type of treatment and measured from the point at which they have had their last treatment and are discharged from inpatient or outpatient care (excluding follow up appointments with haematologist).
- Those considered free of disease, or in remission.

Excluded

- Cancer patients still in primary treatment for their haematological cancer
- Terminal or palliative patients (i.e. those who have not responded to curative treatment)
- Review articles
- Gray literature

Data Extraction

Articles were first screened by the first author (D.R.) using title and abstract to determine whether they meet basic criteria using a data extraction form created for this review. They were then checked by a second reviewer (R.F.) to confirm eligibility and if thought ineligible were further reduced. Once all the eligible articles were selected, data were extracted using items from a checklist created by Hawker, Payne, Kerr, Hardey, and Powell (2002). The form included the following categories: study design; location of study; sample description; sample size; aims; research questions/hypotheses (if any); method and analysis; intervention (if applicable); results; and conclusions, comments, and issues raised.

Quality Assessment

The guidelines created by Hawker and Payne were also used for quality assessment. These guidelines contain nine sections: title and abstract; introduction and aims; method and data; sampling;

data analysis; ethics and bias; results; transferability or generalisability; implications and usefulness rate. Each section is rated on a 4-point scale (very poor to good). The minimum score possible is nine and highest score possible is 36. Once the primary assessor (D.R.) had assessed the quality, a second independent quality assessment was also undertaken by a second reviewer (R.F.). The reviewers agreed on the quality of most articles, and any disagreements were resolved through discussion until a consensus was reached.

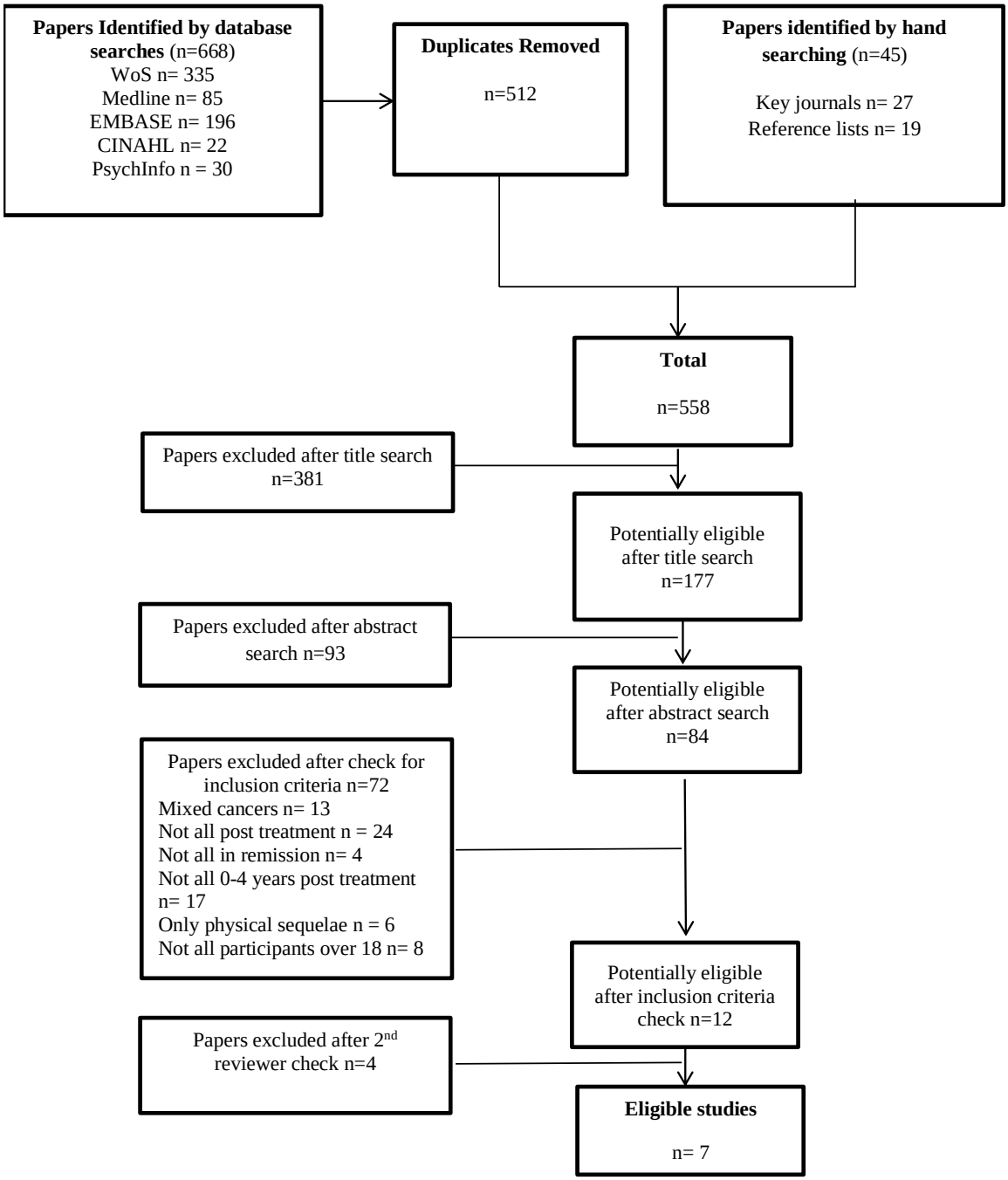

Figure 2.1 Flowchart of literature search

Data Analysis

To be able to answer the question about the nature of the psychosocial distress for haematological cancer survivors, a thematic analysis was used (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005) where qualitative and quantitative findings were integrated to answer the research questions (Sandelowski, Voils, & Barroso, 2006). The data were extracted and coded by D.R. into a standardised framework (Whittemore & Knafl, 2005), and then organised into tabular form. The table ultimately contained information addressing the main research questions posed by the review, namely: did the participants report distress, and what was the nature of this distress? From this themes were identified by D.R. and discussed with R.F. and M.G. until there was agreement on the themes. To explore the identified themes, results for the relevant psychological measures used in the quantitative studies were reported. For qualitative studies this meant identifying categories within the data that addressed these questions.

Findings

The initial search yielded 512 studies (excluding duplicates); of these seven studies were found that examined psychosocial distress in post-treatment haematological cancer patients (see Prisma flowchart). Five of the identified studies were quantitative and two were qualitative. Three of the papers come from the same research project, one quantitative and two qualitative, with the two qualitative papers using the same sample and interview schedule.

Sample Characteristics

Six of the studies were from the USA (Cella & Tross, 1986; Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015; Parry, Morningstar, Kendall, & Coleman, 2010; Smith, Crespi, Petersen, Zimmerman, & Ganz, 2010; Smith, Zimmerman, Williams, & Zebrack, 2009), and one was from the UK (Pettengell et al., 2008). All studies reported data from a sample with a similar mean age (ranging between 50.3 and 62.7), except Cella and Tross (1986) whose participants had a considerably younger mean age of 31.1 years. Sample sizes of overall participants and those relevant to this review are described in Table 2.1. All studies included participants of both genders, with almost equal numbers of men and women in all studies, with the exception again of Cella and Tross (1986) who only included men in their study. In terms of ethnicity, the participants were predominately reported as being Caucasian or white (ranging between 88% and 95%), with the exception of Pettengell et al. (2008) who did not report the ethnicity of their participants.

The studies included samples of participants who had been diagnosed with various types of leukaemia and/or lymphoma. Three studies included leukaemia and lymphoma patients (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015; Parry et al., 2010), two Non-Hodgkin's lymphoma (NHL), one Hodgkin's disease (HD) and one follicular lymphoma (a type of NHL). All studies were published between 2008 and 2015 except the Cella and Tross (1986) study which is considerably older being published in 1986.

Purpose of the Studies

The studies identified by the review all varied as to the actual stated purpose of their research (see Table 2.1). However, all the quantitative studies used instruments that measure some form of distress, and the two qualitative studies included questions that explored distress in some manner. Quantitative studies measured psychological adjustment (Cella & Tross, 1986), cancer-specific distress (Jones, Parry, Devine, Main, Okuyama, et al., 2015), depression and anxiety (Pettengell et al., 2008), post-traumatic stress disorder (Smith et al., 2009), mental health, emotional wellbeing (Smith et al., 2009, 2010). The two qualitative studies looked at how lifespan stage shapes the nature of distress (Jones, Parry, Devine, Main, & Okuyama, 2015) and survivor perspectives on care delivery and supportive care needs at the end of treatment.

Table 2.1. Summary of papers

Study (location)	Purpose	Haematological Cancers included	Sample	Psychological Measures	Relevant Findings
Cella, & Tross (1986) USA	To examine psychological adjustment in men who were successfully treated with Hodgkin's Disease	Hodgkin's Disease	60 male HD survivors, 20 aged matched healthy sample	-Brief Symptom Inventory (BSI) - Impact of Event Scale (IES) - Death Anxiety Questionnaire (DAQ)	- 30 people in 6-24 mth post treatment group (15early stage at diagnosis and 15 late stage). -No difference between patients and controls in most measures. - late stage participants were more anxious (on the BSI Phobic Anxiety scale) than the other three groups (t(58) = 2.41, p<.01), but less so than non-patient group(t(33) = 1.46, p<.07) - late stage also scored higher on IES intrusion test -DAQ higher in those more recently finished treatment
Jones et al (2015a) USA	To provide insight into how lifespan stage shapes the nature of distress in post treatment leukaemia and lymphoma survivors (LLS)	Leukaemia, Lymphoma	51	Interviews	- Nearly half the sample reported persistent emotional sequelae stemming from cancer and its treatment (worst for young adults- 67%) - Heightened levels of worry or anxiety were reported by nearly 2/3s (65%) of survivors (young adults 75%)
Jones et al (2015b) USA	To examine predictors of cancer-specific distress among posttreatment adult leukemia and lymphoma survivors (LLS).	Leukaemia, Lymphoma	477	- Impact of Event Scale-Intrusion Subscale (IES-I)	31.2% of LLS in the sample reported elevated distress, up to 4 years after completion of treatment, operationalized as an IES-I score above 8.5 (capturing moderate and high distress). -Over one fourth (26.0%) experienced moderate distress (IES-I score between 8.6–19), and 5.2% reported high distress (IES-I between 20–35).

Study (location)	Purpose	Haematological Cancers included	Sample	Psychological Measures	Relevant Findings
Parry et al (2010) USA	To explore survivors' perspectives on care delivery and supportive care needs during re-entry	Leukaemia, Lymphoma	51	Interviews	- Although some survivors described the end of treatment as a non-event, the majority of survivors reported the end of treatment and re-entry process was a time of confusion, psychological and social adjustment, and a key transition point. -Survivors' descriptions were frequently characterized by a sense of feeling abandoned, unsupported and unsafe, and unprepared for what was to come next.
Pettengell et al (2008) UK	To determine whether there was a relationship between disease activity and health functioning, as measured by a range of patient-reported outcome (PRO) measures in patients with follicular lymphoma (FL).	Follicular Lymphoma	222 38 in remission or disease free	- Hospital Anxiety and Depression Scale (HADS) - Functional Assessment of Cancer Therapy – General (FACT-G) (only Emotional Wellbeing scale relevant)	- The remission group acted as a significant predictor of high anxiety scores as measured by HADS - The majority of the participants reported anxiety or depression levels within the normal range. A total of 81.7% of participants had anxiety scores in the mild to normal range and 94.5% had depression scores in the mild to normal range. - Participants in the 'disease-free' category had the lowest mean anxiety and depression scores (3.78 ± 3.27 and 2.30 ± 2.45, respectively).
Smith et al (2009) USA	To compare QOL status of individuals who reported having active NHL with the QOL status of individuals who were disease-free short-term survivors (STS) (2-4 years post diagnosis) and long-term survivors (LTS) (≥5 years post diagnosis).	Non-Hodgkin Lymphoma	Short-term survivors: 150 (Overall: 761)	- Medical Outcomes Study Short Form (SF-36) - Functional Assessment of Cancer Therapy- General (FACT-G) (only Emotional Wellbeing scale relevant) -Impact of Cancer Scale (IOC) - PTSD Checklist (PCL)	Survivors with active disease (n = 109) demonstrated worse physical and mental health functioning, worse QOL, and less positive and more negative impacts of cancer compared with disease-free survivors (n = 652; all $P \leq .01$). -No significant differences were observed between STS and LTS.
Smith et	To examine the association	Non-Hodgkin	151- 2-4 years	-Impact of Cancer Scale	Results for 2-4 year post-diagnosis group

Study (location)	Purpose	Haematological Cancers included	Sample	Psychological Measures	Relevant Findings
al (2010) USA	between the Impact of Cancer Version 2 Scales (IOCv2) and these outcomes in a large sample of survivors of adult non-Hodgkin lymphoma (NHL).	Lymphoma	since diagnosis (Whole sample 652)	- Medical Outcomes Study Short Form (SF-36) - Functional Assessment of Cancer Therapy – General (FACT-G)	SF-36 MC: mean= 50.5 (sd= 9.9) Fact-G: mean= 88.6 (sd= 13.5) IOCv2: mean= 2.2 (sd= 0.6)

Methods used to Measure Distress

Quantitative research: Five of the seven identified studies used instruments to measure concepts that come under the umbrella of psychosocial distress, as defined by the NCCN as mentioned previously. All quantitative studies used standardised and validated measures (see Table 2.2.). Qualitative research: The two qualitative papers (Jones, Parry, Devine, Main, & Okuyama, 2015; Parry et al., 2010), which were published from the same research study, both reported data generated by using the same semi-structured interview schedule. Topics covered included: survivors end of treatment and post-treatment experiences regarding physical, psychological, social, and existential wellbeing, and support service usage and need.

Table 2.2 Quantitative Measures

Instrument	Construct(s) measured	Study
Impact of Event Scale (IES)/ Impact of Event Scale revised (IES-R)	Subjective distress caused by traumatic events	Cella & Tross, (1986) Jones et al. (2015)
Medical Outcomes Study Short Form (SF-36)	Mental health subscale which includes scales about psychological distress and well-being.	Smith et al (2010) Smith et al (2009)
Brief Symptom Inventory (BSI)	Psychiatric symptoms including depression, anxiety, and global distress	Cella & Tross, (1986)
Death Anxiety Questionnaire (DAQ)	Death anxiety	Cella & Tross, (1986)
PTSD Checklist (PCL)	Post-traumatic stress disorder	Smith et al (2009)
Hospital Anxiety and Depression Scale (HADS)	Anxiety and depression	Pettengell et al., (2008)

Did they Find Distress?

Most studies reported some form and some level of distress (see Table 2.1). However, as such different methods, measures and samples were used, it was hard to compare the results. Four publications report clear indicators of distress in their studies (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015; Parry et al., 2010, Smith et al., 2009).

However, with the remaining three studies, signs of distress were variable. The aim of the study undertaken by Smith et al. (2010) was to look at the association between the IOC scale and various outcomes in NHL survivors. The authors did not provide much analysis between the two survivorship groups (2–4 years versus 5+). However, results for the SF-36 MCS for 2–4 year post-diagnosis group may indicate slightly better mental health as their scores are higher than the 5 years+ survivor group, and slightly higher than the general U.S. population mean. While younger participants (24–49) did appear to show lower mental health status (as indicated by their SF-36 MCS score) this was not broken down into the two survivor groups (2–4 year and 5+ years post diagnosis).

Pettengell et al. (2008) found that the majority of the follicular lymphoma survivors in their study reported anxiety or depression levels within the normal range. Participants in the “disease-free” category had the lowest mean anxiety and depression scores. However, they did report that being in remission acted as a significant predictor of high anxiety scores as measured by the Hospital Anxiety and Depression Scale. They found that various aspects of patient-reported health outcomes differed according to disease state in patients with FL. Relapsed patients were more likely to experience worse HRQoL and other patient-reported health outcomes than patients newly diagnosed, in partial or complete remission or when completely disease free. However, the study lacked a control group and no comparison was provided to scores in non-patient populations.

The final study, conducted by Cella and Tross (1986), did use a control group, but it consisted of friends of the HD survivors who may have had higher distress than the general population; indeed, they scored higher than normal on the BSI than population norms. Overall, they found no significant difference between patients and controls for most measures. The late stage participants were more anxious than the other three groups, and also scored higher on the IES intrusion test, meaning they were more distressed. The DAQ score was higher in those more recently finished treatment, signifying that this group felt more anxious about dying than the other groups. Within the patient group, late stage (aggressively treated) patients were found to be at highest risk for psychological distress and psychosocial disruption during the first 2 years following treatment.

Indicators of Distress

As each study was analysing different variables, they unsurprisingly all identified different indicators of distress. The exception to this was the Jones et al. studies (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015) which were from the same research project and consequently analysed the same variables. In the quantitative studies, age was reported to be a predictor of increased distress, with results showing there were significant differences in mean distress levels for younger adults when compared with older adults. Indeed, the young adult group (18–39) had the highest mean distress scores, with nearly half of the 18–39 age group reporting elevated levels of distress compared to one-third of midlife survivors, and one-fifth of older survivors. These quantitative findings were supported by data generated from the qualitative analyses reported from the same study, where the 18–39 age group reported a higher number of distress sources (Jones, Parry, Devine, Main, & Okuyama, 2015).

In their qualitative study, Parry et al. (2010) found that survivors felt abandoned when they completed treatment, and no longer felt supported by the medical system. In fact, some described feeling that the end of treatment was “traumatic, and many described re-entry as a time of feeling lost distressed, depressed, anxious and confused about where to turn to and what to do next.” Cella and Tross (1986) looked at differences between time of diagnosis and time since treatment, and found that the late diagnosis 6–24 months post-treatment group had the highest anxiety amongst other survivor groups.

Also, the late diagnosis 6–24 months post-treatment group also scored highest on the IES Intrusion subscale. This study also reported that Death Anxiety was greater in those who had recently completed treatment (whether early or late diagnosis).

Pettengell et al. (2008) made comparisons made between variables relating to the stage of disease of their participants. The stages included “active disease” (divided into newly diagnosed or relapsed), “partial response to treatment” and the two groups relevant to this review—“remission/complete response” and “disease free.” They found that the remission group were more anxious and depressed than the disease free group. Smith et al. (2009) also compared active versus disease-free survivors, and noted that those with active disease had worse outcomes. They found no difference between short-term and long-term survivors for these outcomes, but do not report on whether these are higher than population norms. Smith et al. (2010) found that the 2–4 year post-treatment group had higher SF-36 MCS scores (signifying better mental health) than the 5 years and over post-treatment group. However, they did not look at the variables by these groups, so hard to know what the predictors are for the 2–4 year group.

Discussion

The aim of this review was to identify research that reported psychosocial distress in post-treatment haematological cancer survivors. Using rigorous methods, only seven studies were identified that in some way reported distress in this patient group. Overall these studies showed that post-treatment survivors do experience some distress, although the need for more research in this area is evident. Although there is a growing interest in research regarding post-treatment cancer survivors (Stanton et al., 2015), this review has shown there is little that focuses on post-treatment psychosocial distress in haematological patients, who have their own particular problems and needs relating to their cancer treatment and survivorship (Bugos, 2015). In particular, this review highlights a need for research from countries other than the US and across different cultural and ethnic groups.

Because psychosocial distress is an overarching concept, incorporating a range of psychological and social sequelae, it was not easy to compare studies in a straightforward manner. Only three studies had the specific aim of measuring “distress,” the others did not have this as a specific aim making it more difficult to extrapolate the amount and nature of distress in their participants.

In this review, a lack of consistency in psychological measures used by researchers working in this area was identified. This may partly be due to the fact that there are now so many different instruments available to screen for psychological issues (Carlson & Bultz, 2003). Distress is a relatively new concept in the field (Mitchell, 2013), but even so there are now a number of different measures of distress, the most commonly used being the Distress Thermometer (Zabora et al., 2001) (designed by Roth et al. 1998). However, there is no one instrument to measure distress that is currently considered to be the gold standard (Zabora et al., 2001).

Furthermore, some of the articles in this review used Quality of Life (QoL) measures that made it difficult to separate the psychosocial sequelae from the physical sequelae. QoL measures are frequently used to measure psychological sequelae, however, although often used interchangeably, distress and QoL are different concepts with the latter encompassing a much larger "spectrum of issues, including physical, social, cognitive, spiritual, emotional and role functioning, as well as psychological symptoms such as pain, nausea and vomiting and fatigue" (Carlson & Bultz, 2003).

In three studies clear indicators of distress were identified in post-treatment participants. The fact that these three studies were only looking at post-treatment survivors, and the two of them were specifically trying to measure distress, made it easy to determine if these survivors were distressed. One study where distress was variable, Cella and Tross (1986) was conducted much earlier than the other studies meaning there could have been differences in treatment regimens compared to the more recent studies. Moreover, the sample comprised of only men and were overall younger in age than the other studies. Furthermore, as the other studies did not have this as a specific aim, it was not as easy to extrapolate the amount and nature of distress in their participants. There were also some other methodological issues that made it more difficult to determine the levels of distress in the other studies.

One of these issues was a lack of consistency with the definition of survivorship. For example, some studies categorised the length of survivorship by time since diagnosis, whereas others categorised it by time since the end of treatment. This creates difficulties when the aim is to measure distress post-treatment. Indeed, it was apparent that one of the problems in measuring psychological distress (or other psychological outcomes) within this population related to the fact that there is no universally accepted definition of survivorship within the cancer field, partly because "survivorship" is a relatively new field of research, and lacking a solid theoretical framework (Doyle, 2008). Indeed, although cancer survivorship is now growing as a discipline, "survivor" remains a term used to describe people at all stages of the cancer trajectory from diagnosis to end of life (Brearley et al., 2011). Others who have conducted reviews involving survivors with different types of cancer have encountered the same issue (Brearley et al., 2011), confirming the difficulties this lack of consistency raises in making comparisons among survivors.

Another methodological issue encountered in the studies reviewed was the lack of distinction between those survivors with active disease versus those who are disease free. The studies that contain both in treatment and post-treatment survivors make more effort to compare the survivor groups than comparing the results against healthy populations. This does not necessarily highlight the difficulties experienced by those post-treatment as it may just indicate they are faring better than those still in treatment rather than functioning as well as the general population. The National Cancer Coalition for Cancer Survivorship define survivorship as "the period of health and wellbeing experienced by survivors after active cancer treatment (and before diagnosis of recurrence or a new malignancy)" (Rowland, Hewitt, & Ganz, 2006). This definition highlights that, even if cancer survivorship is defined

as the day a person is diagnosed with cancer, the post-treatment phase should be seen as an important and distinct period in the cancer survivorship continuum.

Indeed, some authors argue that the post-treatment phase is a “critical moment” (McIllmurray et al., 2001). This is not to say that other periods of cancer survivorship are not important, but that there needs to be recognition of the specific needs at each stage of survivorship. It is notable that there is a far smaller body of literature that focuses on the immediate post-treatment phase (the first 12–18 months) of survivorship (Stanton, 2012). Other reviews in on cancer survivors have commented on the psychological assessment of cancer survivors at different stages as a limitation (Mitchell, Chan, et al., 2011) and that time form diagnosis is often used as a substitution because data regarding time from the end of treatment is often not available or as easy to access (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010).

Finally, it was hard to identify predictors of psychosocial distress in the studies included in the review as they all had such varying aims and used different methods. However, three of the studies found younger age was associated with a higher level of distress (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015; Smith et al., 2009). This finding aligns with other cancer literature which finds that younger survivors have higher rates of distress (Burgoyne et al., 2015) and younger age is the most common predictor of poor QoL in cancer survivors (Stanton, 2012). There was also some evidence indicating that the end of treatment may be a time of greater anxiety (Cella & Tross, 1986; Pettengell et al., 2008; Smith et al., 2010). However, overall further research is required to explore this issue in more detail. Particularly research that focuses on haematological survivors experiences once they have finished treatment and explores any distress they may be feeling during this time. It is also important to find out from these survivors what support might benefit them during this period.

Strengths and Limitations

As far as we are aware, this review is the first to examine psychosocial distress experienced by early post-treatment haematological cancer survivors. The strengths of this review are the systematic and thorough methods used. However, some limitations must be acknowledged. First, only English language studies were included and relevant articles in other languages could have been missed. Also, comparing psychosocial distress between studies conducted at different points in time is also problematic given the rapidly changing nature and effectiveness of available treatments. Furthermore, as mentioned three of the studies were from the same research project which could mean there is some bias in the results.

Conclusion

This review has identified a significant gap in the research evidence regarding the nature and extent of distress amongst haematological cancer survivors, particularly those who are in the early post-

treatment stage. More research is urgently needed to address the issues facing haematological cancer survivors, who are growing in number, and will continue to do so as the population ages. The specific needs and concerns of this group need to be determined to ensure that appropriate health services and support are available to enable them to maintain good psychological and physical health in this period of the cancer trajectory, and into the future.

Supplementary Information

It is important to note that studies that included multiple cancers were eligible to be included in the review if they presented separate results for haematological cancer survivors. Also, if a study was considered eligible but did not provide separate results for haematological cancers, the authors were contacted and asked to provide this data if possible. However, whilst the authors of six studies were contacted, only two authors were able to provide the requested data. Unfortunately, the data received did not contain separate categories for haematological cancer survivors in the 0-5 years post-treatment period and was not able to be used in the review.

The literature search was updated and monitored continuously throughout the research period. An auto-alert was created based on the search criteria used in the integrative review and any articles identified by the alert were screened for eligibility. Hand searching of articles published in key journals was also ongoing to ensure any new eligible articles were captured. These searches identified three additional articles published since this review that met the inclusion criteria; these are discussed at the beginning of the discussion chapter (chapter 8).

Chapter Summary

The integrative review presented above identified a gap in the literature regarding psychosocial distress in post-treatment haematological cancer survivors. To be able to really understand the psychosocial sequelae in this survivor group I deemed it important to not only discover the prevalence of distress in this group, but also explore the issues leading to distress, and the support and resources survivors draw on to cope with distress. I therefore formulated the following aims and objectives.

Research Aims and Objectives

Aim

To investigate the nature, magnitude, and timing of psychosocial distress post-treatment amongst haematological cancer survivors in Aotearoa New Zealand and to explore their experiences of post-treatment support.

Objectives

1. Explore the nature and timing of psychosocial distress experienced by post-treatment haematological cancer survivors
2. Calculate the prevalence of psychosocial distress suffered by post-treatment haematological cancer survivors.
3. Identify, the (self-defined) supports and barriers for post-treatment cancer survivors when dealing with psychosocial distress
4. Develop recommendations to improve service delivery to haematological cancer survivors

Chapter Three: Methodology

This chapter begins by explaining my rationale for adopting a critical realist philosophical framework to underpin the research. I then provide an outline of the theoretical framework that was used to explore potential factors associated with psychological health for post-treatment cancer survivors. I then present a summary of the mixed methods study design used in this thesis, and link the aims and objectives to their relevant phases. Integration of the qualitative and quantitative phases is then outlined. Finally, this chapter discusses research rigour and key ethical issues encountered.

Philosophical Framework

Empirical research sits within a philosophical framework which outlines a set of beliefs and assumptions that guide the research process (Creswell & Plano Clark, 2012). Three of the key assumptions within a philosophical framework involve ontology, epistemology, and axiology (Creswell & Plano Clark, 2012). Giddings and Grant (2006) describe these assumptions as follows: ontological assumptions relate to 'beliefs about what reality is', epistemological assumptions look at 'what counts as knowledge', and axiological assumptions are about 'the values one holds'. The differences in these assumptions across research paradigms shape how research is planned and conducted (Creswell & Plano Clark, 2012).

The four most commonly recognised paradigms are post-positivism, constructivism, transformative, and pragmatism. Traditionally qualitative and quantitative methodologies are located within paradigms that are underpinned by contrasting philosophical frameworks, with qualitative research located in the interpretivist tradition and quantitative within the postpositivist tradition (Brannen, 2005). However, some argue that we should move beyond comparisons to recognise the usefulness of both approaches (Johnson & Onwuegbuzie, 2004). Indeed, I felt that both qualitative and quantitative methodologies had value in addressing my research aim and objectives. I therefore explored critical realism as an alternative to the four paradigms mentioned above (Christ, 2013; Hall, 2013) and a viable option as a paradigm for mixed methods research (Hall, 2013; Zachariadis, Scott, & Barrett, 2013).

Critical Realism

Critical realism is a form of post-positivism (Cruickshank, 2012) which sits between positivism and intrepretivism (Zachariadis et al., 2013). Critical realism is ontologically realist (acknowledges there is a real world outside of our thoughts, theories, and constructions), but accepts an epistemological relativism (the world is constructed through our own worldviews and perspectives) (Maxwell, 2012). One of the key beliefs in critical realism is that there are levels of objective truths that can be uncovered, but it is not possible to discover absolute truths concerning social phenomena (Christ, 2013).

Critical realism considers reality to be a layered concept, with distinct differences between the natural and social world. For example, in the natural world some aspects exist regardless of our perception and action, such as genetic markers for breast cancer. Similarly, aspects of our social world — such as cultural differences in discourses about cancer — only exist because of our perception and action (Clark, Lissel, & Davis, 2008).

These layers of critical realism occur on three levels: the real, the actual, and the empirical (McEvoy & Richards, 2006). The *real* domain includes structures and mechanisms that have the ability to generate actual phenomena; the *actual* refers to the phenomena which occurs due to activation of these structures and mechanisms; and the *empirical* describes the phenomena which is actually experienced (McEvoy & Richards, 2006). Critical realism also emphasises the importance of structure and agency in causing events, where agency describes individual factors such as beliefs, attitudes and contextual factors, and structure includes culture and the environment, including the social environment (Archer, 1995).

The critical realist position has gained widespread acceptance as an alternative to naïve realism and radical constructionism (Clark et al., 2008; Maxwell, 2012; McEvoy & Richards, 2006). The ultimate goal of research for critical realists is 'not to identify generalisable laws (positivism) or to identify the lived experiences of beliefs of social actors (interpretivism)', but to 'develop deeper levels of explanation and understanding' (McEvoy & Richards, 2006, p.69).

There is no specific method associated with critical realism itself (Danermark, Ekström, Jakobsen, & Karlsson, 2002); critical realists believe the methods used should be decided by the research question (McEvoy & Richards, 2006). However, critical realism provides a philosophical stance that is compatible with the essential methodological characteristics of qualitative, quantitative and mixed methods approaches (Maxwell & Mittapalli, 2010).

Critical Realism and Mixed Methods

It is the critical realist stance of examining multiple outlooks to develop a deeper understanding of topics that makes this philosophical approach well suited to mixed methods (McEvoy & Richards, 2006). A goal of critical realist research is to develop a 'family of answers' derived from different contexts to create a single complex reality (Pawson & Tilley, 1997, p. 152). Therefore, mixed methods provide an opportunity to obtain answers from different methods and perspectives to create this one 'reality'.

Zachariadis et al (2013) describe seven goals of combining a mixed methods approach with a critical realist perspective: complementarity, completeness, developmental, expansion, corroboration/confirmation, compensation, and diversity (see Table 3.1).

Table 3.1 Using mixed methods in critical realism (Zachariadis et al., 2013, p. 865)

Purpose of Combination	Description	Implication from Critical Realism
Complementarity	Mixed methods are used in order to gain complementary views about the same phenomena or events	Different levels of abstraction of a multi- layered world demand different methods
Completeness	Mixed methods research design is used to ensure a complete picture (as detailed as possible) of the phenomenon under study	Requires meta-theoretical considerations (i.e., angle of approach)
Developmental	Inferences of one type of research are being used as questions for another type of research	This being part of the retroductive approach of CR, inferences need to hypothesize about the causal mechanisms whose recovery will then inspire additional research
Expansion	Mixed methods are being implemented to provide explanations or expand the understanding obtained in previous research	Quantitative methods can be used to guide qualitative research which (subject to the context) is more capable of uncovering generative mechanisms
Corroboration/ Confirmation	Mixed methods are used to confirm the findings from another study	Epistemic fallacy occurs when trying to validate qualitative results with quantitative methods
Compensation	The weakness of one method can be compensated for by the use of another	The weaknesses of different methods are recognized so alternative methods can be used to compensate
Diversity	Mixed methods are used to obtain divergent views on the same phenomena	Different levels of abstraction of a multi-layered world demand different methods

Critical Realism in Health Research

Jones-Devitt and Smith (2007) discuss the use of critical realism in health and social care research. They provide key facets of a critical realist stance (seen in Table 3.2 below) and explain how they can be related to health and wellbeing (Jones-Devitt & Smith, 2007).

Table 3.2. Critical realism applied to wellbeing (Jones-Devitt & Smith, 2007, p. 111)

Critical Realism Descriptor	Wellbeing application
The world keeps turning	People have enduring social and physical wellbeing needs and expectations
Developing an understanding of the turning world is complex. Some knowledge can be made 'real' via observations	Context and understanding play key roles in wellbeing outcomes and aspirations. Wellbeing is reified via social processes
Knowledge development and production are complex processes	Building a concept of wellbeing is complex and evolving
All structures in the world have meaning	People have an opinion about wellbeing, regardless of its personal relevance
Certain structures are catalysts for making things happen	There are some fundamental elements that impact on both social and physical wellbeing
All occurrences are relative to context	People make and take lifestyle choices in accordance with meeting their perceived needs
Scientific processes are not neutral	Conventional wellbeing approaches are underpinned by specific agendas
Linguistic mechanisms are central to knowledge and processing	People are sold lifestyle 'choices' through jargon, expert knowledge and persuasive social marketing techniques

Critical realism can be useful in helping to understand the complex factors influencing health by understanding interactions between context (i.e. social environment) and individual characteristics (i.e. age, gender, ethnicity) (Clark et al., 2008). Furthermore, critical realism has a focus on going beyond identifying superficial causes (such as measuring quantifiable health indicators/outcomes) to uncover the more complex and extensive causes of health outcomes (Clark et al., 2008).

Critical Realism in the Current Research

As the current research seeks to answer questions that necessitate the use of both qualitative and quantitative approaches, critical realism provides an appropriate foundation on which to situate this research. A critical realist perspective encourages a focus beyond just the numbers of cancer survivors who may be distressed and also to look at the interplay of factors that may cause some survivors to be distressed but not others.

Critical realism recognises an external reality, and therefore aspects of this reality will usually have been researched before. Therefore, it is considered important for previous research to be considered before data collection starts (Perry, Riege, & Brown, 1999), and acceptable to consider a preliminary conceptual or theoretical framework before starting to collect data (Sobh & Perry, 2006).

Theoretical Framework

A theoretical framework provides a structure for research through identifying the predominant elements, variables or concepts relating a particular subject and can be used as a guide for the research process (Ennis, 1999). A theoretical framework is a useful tool for researchers to ensure their research design has a coherent structure (Green, 2014). Merriam (2000) proposes five functions

that conceptual and theoretical frameworks can be used for: 1) to build a foundation, 2) to demonstrate how a study advances knowledge, 3) to conceptualize the study, 4) to assess research design and instrumentation, and 5) to provide a reference point for interpretation of the findings.

I was keen to use a theoretical framework for these reasons but identified a lack of frameworks designed specifically for cancer survivorship (Hoffman, Lent, & Raque-Bogdan, 2013). Other research in the area of cancer survivorship have utilised general psychological models of health such as the cognitive model of stress and coping (Lazarus and Folkman, 1984) and the Common-Sense Model of Self-Regulation (CSM) (Leventhal, Meyer, & Nerenz, 1980).

The Transactional Theory of Stress and Coping was developed by Lazarus and Folkman (1984) and revised by Folkman in 1997 (Folkman, 1997). Lazarus and Folkman's theory of stress, appraisal, and coping has had a major influence on research regrading psychological stress and coping since the 1980s (Folkman, 2010). Their cognitive model of stress and coping has been widely used to examine how individuals adapt to stressful events (Folkman, 1997). The cognitive model of stress and coping has previously been found useful to explain patients' adjustment after cancer treatments (Kusaka et al., 2020; Janz et al., 2014; Parelkar, Thompson, Kaw, Miner, & Stein, 2013).

The cognitive model of stress and coping revolves around two main processes: appraisal and coping. Appraisal relates to an individual's evaluation of the personal significance of a given event and whether an individual has adequate resources to facilitate coping (Folkman & Greer 2000). Coping refers to the thoughts and behaviours used by an individual to regulate distress (Folkman & Greer 2000).

The appraisal process assumes that people are constantly appraising their relationship to the environment. Stress (or distress) may begin as a result of the appraisal process when a person becomes cognizant of a change or potential change in their circumstances (Folkman & Greer 2000). The cognitive model of stress and coping proposes two types of appraisal: primary and secondary. Primary appraisal represents the assessment of the personal significance of an actual or threatened change, whereas secondary appraisal involves an evaluation of the potential options for coping (Folkman & Greer 2000).

The original cognitive model of stress and coping proposed two major coping categories: emotion-focused coping and problem-focused coping. Emotion-focused coping explains how an individual regulates the emotions that arise from the appraisal process, for example a person might feel anxious or frightened when a stimulus is appraised as a threat. Problem-focused coping explains how an individual attempts to manage the actual problem (Folkman, 2010). In the updated version of the model (Folkman, 1997) a third category was added, meaning-based coping, where a person uses coping thoughts and behaviours to maintain positive wellbeing.

The Common-Sense Model of Self-Regulation (CSM) (Leventhal, Meyer, & Nerenz, 1980) provides a 'framework for examining the perceptual, behavioural and cognitive processes involved in individuals' self-management of ongoing and future health threats' (Leventhal, Phillips, & Burns, 2016a. p. 932). The CSM proposes the concept of illness representations that are perceptions triggered by somatic and functional changes (Leventhal, Phillips, & Burns, 2016b). The generation of illness representations are thought to help a person cope with their illness by helping them create action plans and plan other forms of self-management (Leventhal et al., 2016b).

Illness representations are perceptions an individual has about their condition which fall within five dimensions: 1) identity – symptom severity and their possible meaning, 2) timeline – duration of illness and rate of onset and decline, 3) consequences – functional, social, and financial consequences of illness and treatment, 4) control – the extent to which their illness can be controlled/managed, and 5) cause – underlying mechanisms/reasons for their illness (Leventhal et al., 2016b). These illness perceptions are thought to be both emotional and cognitive representations and are based on an individual's knowledge and previous experiences (Ashley, Marti, Jones, Velikova, & Wright, 2015)

In short, it is thought that illness representations influence behaviour and coping which directly influence physical and psychosocial outcomes (Hagger, Koch, Chatzisarantis, & Orbell, 2017). When used to look at psychological outcomes in people with cancer, the CSM has shown to be a potential predictor of distress (Zhang et al., 2020) and associated with increased stress (Miceli et al., 2018), anxiety and depression (Nelson, Juckett, Coe, & Costanzo, 2019).

Although commonly used, the two models described above are predominately focussed on an individualistic view of health and illness that often ignores or downplays an individual's social environment (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998). This individualistic focus would not allow for a thorough examination of the interplay between contextual factors surrounding a cancer survivor that may influence distress and the resources they have to cope. Other existing frameworks also did not fit the current research well. Other frameworks often focused on coping strategies (Bowman, Smerglia, & Deimling, 2004; Fillion et al., 2008; Hoffman et al., 2013) or quality of life (Ashing-Giwa, 2005; Butt, 2012; Pedro, 2009), neither of which were the focus of this research. However, I did identify synergies with the conceptual framework of psychological health in cancer survivors from Andrykowski, Lykins and Floyd (2008) and decided to use this to guide the research. This conceptual framework addresses factors associated with psychological health amongst cancer survivors and was developed by reviewing literature in the area of cancer survivorship.

Temporal Trajectories

Andrykowski et al (2008) propose that all survivors experience a psychological 'dislocation' after a cancer diagnosis. However, how survivors adapt to this dislocation may vary. The authors propose

that survivors will take one of four different trajectory patterns (Figure 3.1). In the first trajectory, survivors experience growth in terms of their psychological health. In the second trajectory, survivors experience psychological distress followed by a return to their normal level of psychological health. The third trajectory proposes that some survivors rebound, but do not completely return their normal level of psychological health. Finally, in the last trajectory, psychological health continues to deteriorate and never recovers.

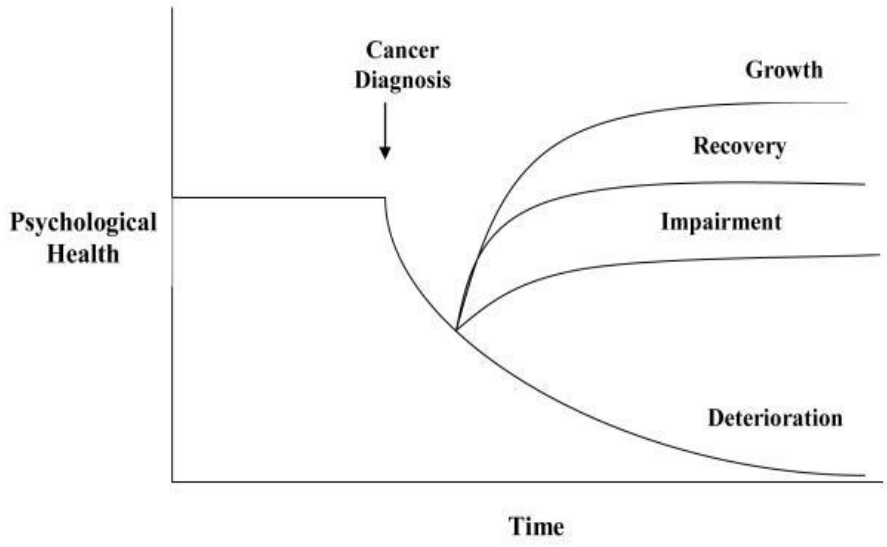

Figure 3.1 Temporal Trajectories of Psychological Health in Cancer Survivors (Andrykowski et al., 2008, p. 13)

Psychological Response to the Cancer Experience

Andrykowski et al., (2008) suggest that the response to psychological stress is related to two variables, stress and burden. Figure 3.2 illustrates the relationship between stress and burden and how the resources a survivor possesses mediate the impact of cancer survivorship on their psychological health. The authors argue that the greater the stress or burden, the greater the risk to psychological health; conversely the greater the resources a survivor has, the lower the risk to psychological health.

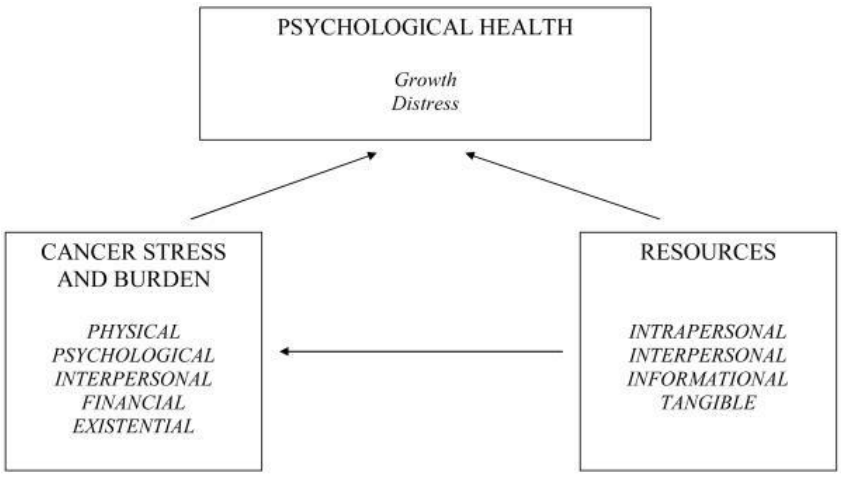

Figure 3.2 Factors associated with psychological health in cancer survivors **(**Andrykowski et al., 2008, p 12)

The authors propose a complex relationship between stress and burden and psychological health which may be affected by a combination of the domains described in Figure 3.2. They argue that the resources available to cancer survivors are also multidimensional; these resources are explained in more detail in Table 3.3 below.

Table 3.3 Resources available to survivors

Resources	**Explanation**
Intrapersonal	Characteristics internal to the cancer survivor i.e. optimism or self-efficacy
Interpersonal	A key interpersonal resource is social support
Informational	Access to clear and accurate information about their disease, treatment and prognosis
Tangible	Actual physical psychological and other support services

This framework was considered relevant for the current research because it proposes that survivors vary in the psychological trajectories that they experience after a cancer diagnosis, and that psychological health changes over time, a proposition I was keen to explore empirically. This framework is also valuable in examining the individual stress and burden for the cancer survivor and the resources they may draw upon to deal with any psychosocial stressors. The framework has been corroborated previously in research on post-treatment survivors with mixed cancers (Syme, Delaney, Wachen, Gosian, & Moye, 2013). Furthermore, parts of the model have been cited as useful and supported empirically by other authors, in both their theories about temporal trajectories of psychological health (Beckjord et al., 2014; Leal et al., 2014; Syme et al., 2013) and the factors associated with psychological health (Beckjord, Reynolds, & Rechis, 2013; Boot, Holcombe, &

Salmon, 2010; Bush, 2009; Lin, Hu, Chang, Lin, & Tsauo, 2011; van den Berg, Van Amstel, Ottevanger, Gielissen, & Prins, 2013).

Study Design

A two-phase sequential exploratory mixed methods approach was chosen because it best suited the aims and objectives to be addressed in this PhD research. Johnstone (2004) define mixed methods as "research in which a researcher or team of researchers combines elements of qualitative and quantitative approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purpose of breadth and depth of understanding and corroboration".

It is argued that a mixed methods approach allows for a greater understanding of the phenomenon of interest than would be achieved by employing a qualitative or quantitative approach on their own (Creswell & Plano Clark, 2012). Moreover, Brannen (2005) describes mixed methods as a way of thinking outside the box.

Wisdom and Creswell (2013) specify five main features of a well-designed mixed methods study which guided the design of this research:

1. Collecting and analysing both quantitative (closed-ended) and qualitative (open-ended) data.
2. Using rigorous procedures in collecting and analysing data appropriate to each method's tradition, such as ensuring the appropriate sample size for quantitative and qualitative analysis.
3. Integrating the data during data collection, analysis, or discussion.
4. Using procedures that implement qualitative and quantitative components either concurrently or sequentially, with the same sample or with different samples.
5. Framing the procedures within philosophical/theoretical models of research.

An exploratory sequential mixed methods design is one which usually involves two distinct phases. It starts with the collection and analysis of qualitative data and is then followed-up with quantitative data which in part can be used to help test the qualitative data (Creswell & Plano Clark, 2012).

The phases are linked to the overall aims and objectives as described below.

Research Aims and Objectives

Aim

To investigate the nature, magnitude, and timing of psychosocial distress post-treatment amongst haematological cancer survivors in Aotearoa New Zealand and to explore their experiences of post-treatment support.

Objectives

1. Explore the nature and timing of psychosocial distress experienced by post-treatment haematological cancer survivors (Phase One and Phase Two)
2. Calculate the prevalence of psychosocial distress suffered by post-treatment haematological cancer survivors (Phase Two).
3. Identify, the (self-defined) supports and barriers for post-treatment cancer survivors when dealing with psychosocial distress (Phase One and Phase Two)
4. Develop recommendations to improve service delivery to haematological cancer survivors (Discussion chapter)

Figure 3.3 below displays the overall design for this research, including the design, sample, methods and analysis for each phase.

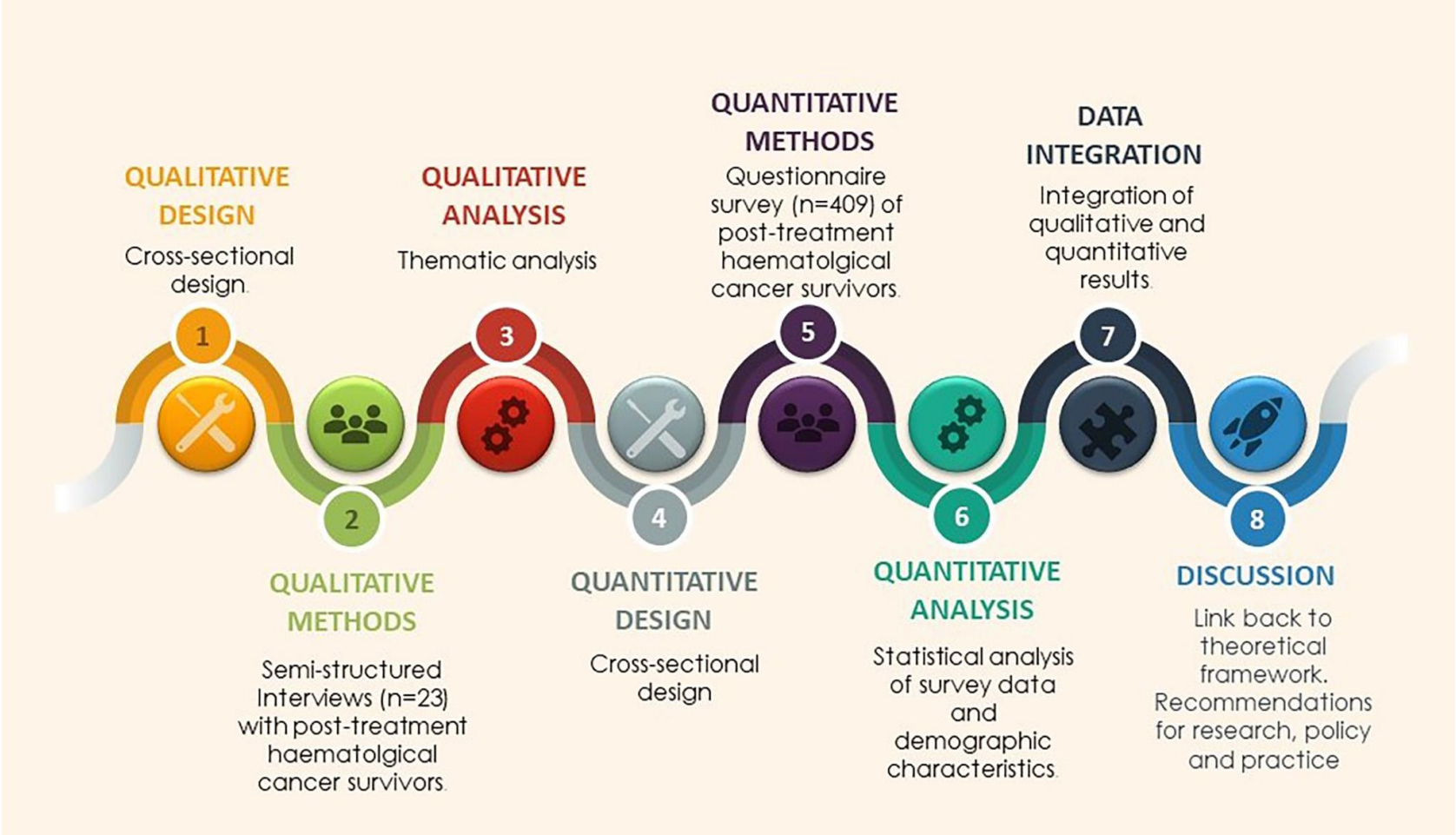

Figure 3.3. Research design

Data Rigour

All research should aim to collect data of high quality (Teddlie & Tashakkori, 2009).
Both qualitative and quantitative research must use procedures that ensure the rigour of their data and results and interpretation (Creswell & Plano Clark, 2012). Almost all mixed methods research determines rigour using separate techniques for both qualitative and quantitative strands (Teddlie & Tashakkori, 2009). I chose this approach and describe the procedures used for the qualitative and quantitative phases separately. The steps to ensure rigour in the qualitative phase are described in the next chapter and the steps to ensure rigour in the quantitative phase are described in Chapter six.

Integration of Quantitative and Qualitative Phases

Morse and Field (1995) propose that qualitative and quantitative methods should be analysed separately because of the disparate ways in which data are collected. This separate analysis is common in mixed methods research where quantitative and qualitative findings are often analysed separately before the data is integrated (O'Cathain, Murphy, & Nicholl, 2010). A strength of mixed methods is the ability to integrate quantitative and qualitative methods, with this integration of different methodologies thought to maximize the strengths and minimize the weaknesses of each data type (Creswell, Klassen, Plano Clark, & Smith, 2011).

Integration can occur at various levels of the research, design, methods, or interpretation (Fetters, Curry, & Creswell, 2013). In the case of the research presented in this thesis, it occurred at all three levels. As the current research employed a sequential exploratory design, integration occurred in the study design phase with the qualitative phase being used to inform the second (quantitative) phase. Fetters et al. (2013) propose integration in the methods phase can happen in a variety of different ways – connecting, building, merging, or embedding. In this research, integration at the methods level occurred through building, with survey items influenced by the qualitative data, where specific psychosocial sequelae were identified and then included in the questionnaire.

Table: 3.4 Levels of integration in mixed methods research (Fetters et al., 2013)

Integration Level	Approaches
Design	***Basic Designs***
	Exploratory sequential
	Explanatory sequential
	Convergent
	Advanced Frameworks
	Multistage
	Intervention
	Case study
	Participatory
Methods	Connecting
	Building
	Merging
	Embedding
Interpretation and Reporting	Narrative: weaving, contiguous or staged
	Data transformation
	Joint display

In the interpretation/reporting level, there are three approaches available: Integration through narrative (weaving, contiguous, or staged), integrating through data transformation, and integrating through joint displays (Fetters et al., 2013). In this research integration at the interpretation stage was achieved through the narrative approach, drawing in particular upon the contiguous and weaving approaches. The contiguous approach means the quantitative and qualitative results are presented in separate chapters, but also the weaving approach is displayed in the integration section of the discussion (Chapter Eight) where all key results are reported. The next section of this chapter will key ethical issues encountered in conducting this research.

Ethical Issues

Details of specific ethical considerations and permissions granted in each study phase are addressed in the papers presented in the findings chapters. I also provide any supplementary information at the end of each chapter specific to each phase. In the first results chapter (Chapter Four) I present the key principles that guided my approach to ethical issues and specific considerations of ethical issues for Māori participants.

The three key principles outlined in the Belmont Report were used to address the ethical considerations in this research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

I was guided by the Belmont Report, considered a foundational document regarding ethics in research with human participants (Adashi, Walters, & Menikoff, 2018), and its guiding principles have continued to evolve to inform ethical research at the present time (Miracle, 2016). The authors of the Report recommend that the ethical principles they outline are best used as an analytical framework,

rather than a checklist or formula for ethical practice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). As the research was conducted in Aotearoa New Zealand it was also important to ensure ethical principles were also responsive to Māori participants. As such the relevant sections of the NZ Health Research Council Guidelines for Researchers on Health Research Involving Māori were utilised (Health Research Council of New Zealand, 2010).

Principles

Respect for Persons

Two ethical principles are incorporated within respect for persons: 'individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.' Some people will need to be excluded from research because of their need for wide-ranging protection, whereas others require little protection besides ensuring they participate completely voluntarily, and are aware of the possible risks of participation. In this case, it is imperative that participants receive all necessary information about the study and can provide informed consent.

Beneficence

In the Belmont report (1979) beneficence is described as the effort to ensure the wellbeing of people. Furthermore, beneficence in relation to research is considered an obligation. The report also specifies two general rules that encapsulate beneficent actions: (1) do not harm and (2) maximize possible benefits and minimize possible harms. Researchers must consider carefully whether the risks outweigh the benefits and whether the benefits justify conducting the research in light of the risks.

Justice

The Belmont Report (1979) describes justice as the question of who should receive 'the benefits of research and bear its burdens?' An injustice may occur in when a benefit is denied to a person who may otherwise be entitled to it, without justification. Alternatively, injustice may occur when some burden is unjustifiably imposed upon a person. Justice should have an important influence on the selection and recruitment of participants. People should not be targeted because of their easy availability, susceptibility to coercion, or vulnerable positions in society, but only be selected for their relevance to the research questions.

Applications of the Principles

The three applications of the general principles are informed consent, risk/benefit assessment, and the selection of subjects of research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Informed Consent

Informed consent is incorporated in the principle of 'respect for persons' and emphasises the importance of a person's capability to consent to research and that they receive the opportunity to make choices about what aspects of the research they are willing to participate in. The consent process is divided into three elements: information, comprehension and voluntariness.

Information: Participants must receive appropriate information to ensure they are fully informed about the study. This includes information about risks and benefits, the opportunity to ask questions and knowledge that they may withdraw from the study at any time. As outlined in the papers presented in the subsequent chapters, in the current research, potential participants were provided with detailed written information about the study and given the researcher's contact details for further information. The participant information sheet also gave a detailed explanation of the research, made clear the explicit and risk's and benefits, and clearly outlined the opportunity to withdraw from the research at any time with no explanation.

Comprehension: It is important to ensure the information is conveyed in a manner that is acceptable and understandable to potential participants and also given with enough time for a person to properly read and make a clear decision about their participation. In the current research, all efforts were made to write the information sheets in plain language, by eliminating any complicated medical terms or other complicated words. The information sheets were also checked using the Flesch Reading Ease Score (Flesch, 1948) which ensures that the text is suitable for most adult reading levels. It was also important to make the text big enough for older readers or those who may have trouble with small print.

Voluntariness: A component of voluntariness is that consent is only valid if it is given of the participants own volition, and free of coercion or unwarranted pressure. In this study, the information sheets highlighted that participation was completely voluntary and that participants could withdraw at any time without explanation. Also, whenever the situation arose where potential participants contacted the researcher to discuss participation, no pressure was ever applied to coerce participation.

Assessment of Risks and Benefits

This application is related to the principle of beneficence and requires that conducting a risk/benefit assessment would find that the benefits outweigh the risks. The relevant ethical guidelines provided by the NZ Health and Disability Ethics Committee (HDEC) showed that both phases of the current research were considered low risk. However, other measures were taken to make sure no harm would come to participants. For example, for both phases I ensured anonymity and confidentiality, and safe storage of any identifying data. As mentioned earlier, I decided those with myelodysplastic syndromes should not be included in the research to prevent any distress that may be caused because these patients are often not told their condition can be termed 'cancer'. I also provided a list

of support services that could be accessed by all those invited to participate in the study, not just those who actually participated. The potential for this research to make a difference for cancer survivors in the future was also highlighted.

Selection of Participants

Selection of participants includes the principle of justice, with the moral imperative to treat everyone fairly in terms of research recruitment, procedures and outcomes. The current research endeavoured to ensure all possible persons within the haematological cancer population were given an equal chance to participate. Random stratified sampling was used in both phases to ensure that people in smaller ethnic groups had an equal chance to participate. This was important as two of these ethnic groups — Māori and Pacific peoples — are underrepresented in NZ health research (Mhurchu et al., 2009).

Ethical Considerations Specific to Māori Participants

In line with the Treaty of Waitangi, researchers have a specific obligation to address the ethical dimensions of research with Māori participants. I was guided by the following ethical considerations from the Guidelines for Researchers on Health Research Involving Māori (Health Research Council of New Zealand, 2010):

- Does the research topic involve Māori as a population group?

- How will this proposed research project impact on Māori health?

- What are the benefits for Māori?

- How will Māori be involved? (e.g. as researchers, participants, advisors etc.)

The ethical process regarding Māori participants started initially by considering the circumstances for Māori in terms of prevalence and survival rates of cancer. Recent cancer statistics showed that the age-standardised cancer registration rate for Māori was 409.8 per 100,000 population, compared to the non-Māori rate of 324.3 per 100,000 population (Ministry of Health, 2014). Registration rates for most haematological cancers (such as non-Hodgkin's lymphoma, leukaemia and myeloma) were also higher for Māori (Ministry of Health, 2014). Statistics also showed lower survival for rates for Māori in the majority of haematological cancers (Ministry of Health, 2015). Furthermore, studies reported that Māori cancer patients required additional support and continuity of care across the cancer trajectory, including the survivorship phase (Slater et al., 2013). Therefore, stratified random sampling was used in both phases to obtain higher numbers (than would be expected through random sampling alone) of Māori participants to increase the chance of being able to explore any issues Māori cancer survivors may face, and to ascertain their particular needs in the post-treatment phase.

Before any recruitment began, consultation with a Māori Research Advisor was sought. A meeting was held with Dr Helen Wihongi (Māori Research Advisor for Waitemata and Auckland District Health Boards) to discuss the research. Dr Wihongi raised some potential cultural issues and discussed how they could be addressed to ensure cultural safety for potential Māori participants and to help encourage more Māori to participate. Dr Wihongi also signalled her availability throughout the research as a cultural advisor to discuss any issues that may have arisen throughout the course of conducting the fieldwork. As a result of this meeting, adjustments were made to the participant information sheets to ensure Māori participants knew they could speak to a Māori advocate about the research. The participant information sheet also emphasised that participants may choose to speak with whānau (extended family) when making the decision to participate. The Phase One interview schedule and Phase Two questionnaire were also examined by Dr Wihongi to ensure that the questions were congruent with the Māori worldview around health, especially the role of whānau support. Dr Wihongi encouraged conversation with Māori colleagues to obtain their cultural views and experiences.

An important cultural issue for Māori is the importance of whānau. As well as encouraging participants to speak with whānau when deciding to participate, they were also encouraged to have whanau with them during the Phase One interview if they choose. Another cultural issue related to the Māori preference for face to face interviews rather than telephone interviews. However, as participants were obtained from around the country, it was not possible because of financial and time constraints to travel everywhere in New Zealand to conduct the Phase One interviews. Nonetheless, the option of a face to face interview was given to any participant in the Auckland region.

Ethical Approval

Ethical approval for both phases of this research was granted by the Southern Health and Disability Ethics Committee before any data collection commenced (Ref: 15/STH/82).

Chapter Summary

In this chapter I have discussed the choice of mixed methods as an appropriate approach to use in this research. I have also demonstrated that this research design is compatible with the philosophical approach of critical realism. Furthermore, I discuss how the relevant ethical issues involved in conducting this research have been addressed. In the next chapter I present findings from my Phase One qualitative study around the experiences of post-treatment cancer survivors, specific issues they face, and post-treatment periods they find most challenging.

Chapter Four: The Nature and Timing of Distress among Haematological Cancer Survivors

Preface

The integrative review presented in Chapter Two found that research in the area of distress in post-treatment haematological cancer survivors is limited. Undertaking qualitative research was therefore appropriate to explore this research gap. In this chapter I present an article published in the European Journal of Cancer Care, containing findings from my Phase One qualitative study in relation to the experiences of post-treatment cancer survivors, specific issues they face and post-treatment periods they find most challenging. I also provide an outline of the measures adopted to enhance qualitative data rigour. I present additional findings relating to strategies and barriers haematological cancer survivors face in maintaining their psychosocial wellbeing in Chapter Five.

The article presented in this chapter is cited as:
Raphael, D., Frey, R., & Gott, M. (2019b). The nature and timing of distress among post-treatment haematological cancer survivors. European Journal of Cancer Care, 28(1), e12951. doi:10.1111/ecc.12951

 This journal has an impact factor of 2.161, and journal ranking of 49/102 (Health Care Sciences & Services) (Clarivate Analytics Journal Citation Reports). As of May 2021, this article has been cited ten times (Google Scholar Citations).

Article: The Nature and Timing of Distress among Post-Treatment Haematological Cancer Survivors

Abstract

Many people with haematological cancers will not meet the diagnostic criteria for a psychological disorder, but will still suffer distress during treatment and beyond. The current study aimed to explore the nature and timing of psychosocial distress experienced by haematological cancer survivors. Twenty-three post-treatment haematological cancer survivors participated in a semi-structured interview. Data were analysed using thematic analysis which involved identifying, analysing and reporting themes. Four themes were identified: Apprehension about leaving the safety of the health care system comprises the struggles encountered when transitioning from patient to survivor, Uncertainty and life transitions in the post-treatment period encompasses the changes survivors face when attempting to re-enter their "normal" lives, Distress associated with ongoing physical problems or impairment describes issues associated with the ongoing physical sequelae, and Fear of recurrence encapsulates how the continuing threat of cancer recurrence impacted survivors. This study has found that distress is ongoing for many haematological cancer survivors in the post-treatment period. It is imperative that distress is identified and support offered to those in need to prevent further psychosocial issues. It is especially important to consider the psychosocial needs of survivors in the post-treatment stage who are discharged from the health system may be unsure where to seek help.

Introduction

Globally, haematological cancers contribute significantly to the overall cancer burden (Ferlay et al., 2015). In economically developed countries, haematological cancers are the fourth most common group of cancers (Smith et al., 2011). In New Zealand, the setting for the current study, combined, haematological cancers are the fifth most diagnosed cancer, with approximately 1,500 new diagnoses each year (Ministry of Health, 2014). The incidence of most haematological cancers is rising in most resource-rich countries (Ministry of Health, 2010a; Rodriguez-Abreu et al., 2007), however, so is the survival rate due to factors such as improved treatment and early detection (Jefford et al., 2008; Wallwork & Richardson, 1994).

Although these "survivors" have successfully finished treatment, they are still frequently left with residual physical, psychological and social problems (Beckjord et al., 2014; Wallwork & Richardson, 1994). Treatment for haematological cancers is complex and often more intense than treatment for other cancers (Carey et al., 2012; Lobb et al., 2009). Aggressive therapies can cause both late and long-term physical and psychosocial effects that can appear years after treatment ends (Klemm, 2008). However, there is limited research identified that focuses on psychological and social issues facing haematological cancer survivors (Leukaemia and Blood Foundation, 2011; Parry et al., 2010;

Smith et al., 2009). Furthermore, although research on survivorship issues is increasing, little has focused specifically upon haematological cancer (Lobb et al., 2009).

Many people with cancer will not meet a diagnostic criteria for a psychological disorder, but will still suffer from distressing emotional problems (National Cancer Institute, 2017). The concept of "distress" is useful to capture the experience of this group experiencing emotional upheaval. Distress has been defined as "an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness and fears, to problems that are disabling, such as true depression, anxiety, panic and feeling isolated or in a spiritual crisis" (National Comprehensive Cancer Network, 2007). Psychosocial distress has also been associated with reduced quality of life (Shim et al., 2006), reduced satisfaction with medical care (Von Essen, Larsson, Oberg, & Sjoden, 2002), poor treatment adherence, additional visits to health professionals (National Comprehensive Cancer Network, 2007), and higher mortality (Hamer, Chida, & Molloy, 2009). These negative effects have led to distress being characterised as the 6th Vital Sign in cancer care (Bultz & Carlson, 2005) and demonstrate why it is essential to detect distress as early as possible.

The time where treatment is coming to an end, and a patient is transitioning into survivorship, brings its own set of challenges (Stanton et al., 2005). However, a recent integrative review conducted by the authors (Raphael et al., 2017) concluded that there is very little literature that focuses on distress among haematological cancer survivors in the early post-treatment phase. Only seven papers were identified that contained data on post-treatment haematological survivors; however, these studies did show that the majority of survivors suffered at least mild to moderate distress. Findings from the review also suggest that younger age may play a part in increased levels of distress for haematological cancer survivors (Jones, Parry, Devine, Main, & Okuyama, 2015; Jones, Parry, Devine, Main, Okuyama, et al., 2015). However, the key finding was the gap in the literature regarding this particular survivor group.

Further research is therefore essential to understand the issues that affect haematological cancer survivors post-treatment. It is necessary to explore the timing and extent of distress, as well as what support is needed to cope with this distress. Evidence of this nature could help inform the provision of appropriate post-treatment support and services for this under-researched group of survivors. It was within this context that the current study was designed to explore the nature and timing of psychosocial distress experienced by post-treatment haematological cancer survivors. An exploratory qualitative methodology was chosen given the dearth of existing research in this area.

Methods

Ethical approval for this research was granted by the Southern Health and Disability Ethics Committee. (Ref: 15/STH/82). Participants were recruited through the New Zealand Cancer Registry

(NZCR). The NZCR provided a database containing information about all cancer survivors who had been diagnosed with a haematological cancer between July 2007 and July 2015. Alongside other selected information (including date of birth, gender, diagnosis date and ICD10 code), a postal address was provided for those on the database. The goal was to recruit those who had finished primary treatment within the 0–5 year period. The 0–5 year time period was chosen because it is in this period that cancer survivors of most types are more likely to be affected by psychological and social problems (Kattlove & Winn, 2003; Mullan, 1985; Stanton, 2012). This is also known to be the period where the fear of cancer reoccurrence may dominate a survivor's thoughts (Hewitt et al., 2006). In the case of haematological cancer, research shows that most relapses in Hodgkin's disease, non-Hodgkin's disease and acute leukaemia patients occur within the first 5 years (Specht, Gray, Clarke, & Peto, 1998).

Potential participants were contacted by mail with a letter inviting them to participate in an interview exploring the psychosocial issues they may had faced during the post-treatment phase of their haematological cancer. Those who were interested in participating sent back a reply form which included their phone number. They were then contacted by DR who confirmed their eligibility by checking they were currently in remission (as indicated by their physician) and had also finished their primary treatment. If they met these criteria an interview was then scheduled for a day and time suitable for the participant. The number of interviews was guided by the method of saturation; interviews were conducted until no new codes or themes were occurring in the data (Hennink, Kaiser, & Marconi, 2016). This process involved DR assessing the data gathered from each new interview and comparing to previous interview data to ascertain whether any new issues were identified, or whether data was beginning to repeat, and not add anything unique (Kerr, Nixon, & Wild, 2010). Data obtained from the interviews were also discussed with RF and MG to gain a consensus on whether anything new was occurring in the data.

Data Collection

A semi-structured interview schedule was developed to address the aims and objectives of the research. The interview questions were informed by our previous integrative review (Raphael et al., 2017) and an extensive review of cancer survivorship literature reporting on psychosocial issues in survivors of other types of cancer. The interview guide was also pilot tested on a convenience sample of three people (one cancer survivor, one family member of a cancer survivor, and an oncology nurse) to ascertain whether the questions were easily understood, and to assess the length of the interview. Interview topics are described in Table 4.1 Participants were invited to take part in a face-to-face semi-structured (for resource reasons these could only be offered for those in, or close to, the Auckland region) or telephone interview (depending on their preference).

Participants were also asked demographic information including age, ethnicity, marital status, employment status, treatment end date, and current health conditions. No age limit was applied (except that all participants be adults i.e., over 18) because it was considered important to explore the

experiences of a diverse range of survivors. While phone interviews are typically seen as inferior to face-to-face interviewing (Block & Erskine, 2012), a recent study found that participants spoke positively about their experience of participating in telephone interviewing, and found it had benefits over face-to-face interviewing, such as feeling less inhibited and not feeling judged by the interviewer (Ward, Gott, & Hoare, 2015).

Table 4.1. Interview topics

The semi-structured interview schedule topics included
Their thoughts and feelings when treatment was ending
Their adjustment back into normal life after cancer treatment
Any information received about what they might expect post-treatment
Information or advice received post-treatment
Psychological or emotional strain during and post-treatment
If they had a support person/people in their life
Support needs post-treatment
Fear of recurrence
Any changes in their personal relationships as a result of their cancer diagnosis and treatment

Analysis

Interviews were audio recorded with consent and transcribed verbatim by the researcher. Interview transcripts were read three times and then entered into the NVivo text analysis programme to help organise the data. Data were analysed using thematic analysis (Braun & Clarke, 2006, 2013) which involves identifying, analysing and reporting themes from qualitative data. The six phases of thematic analysis are as follows: familiarisation with the data; coding; searching for themes; reviewing themes; defining and naming themes; and writing up (Braun & Clarke, 2006). A coding framework was created by DR and then discussed with RF and MG. The coding framework was generated by carefully reading each transcript and identifying features in the data (words or short phrases) that were relevant to the research questions (Braun & Clarke, 2013). These codes were then organised into areas of commonality and recoded where needed. Once the coding framework was discussed by all researchers and subsequently refined, the initial themes and sub themes were generated. Creating the themes involved looking at the ways in which codes grouped together to form a coherent pattern in the data (Braun & Clarke, 2013). As the analysis progressed themes were often reorganised and either grouped with another theme or separated out to form a new theme. The process of reviewing and revising themes was a lengthy process which continued through to the writing up period.

Participant Information

The sample consisted of 23 participants from various geographical areas of New Zealand (Table 4.2). Participants ranged in age from 33 to 77 years. The majority were NZ European (52%), and had Non-Hodgkin's Lymphoma (61%). The self-reported time since end of treatment ranged between 2 and 8 years with a mean of 4.1 years. Although most participants fell within the previously discussed 0–5 year post-treatment, there were five participants who had completed treatment 6–8 years previously. A decision was made to include these participants to ascertain whether there were any issues found in this period that might not be found in the group who had finished treatment earlier. All but one of these participants was interviewed over the telephone, with only one person (from six in Auckland) choosing a face-to-face interview.

Table 4.2 Participant demographics

	n
Age	
30–40	5
41–50	3
51–60	6
61–70	6
Gender	
Male	10
Female	13
Ethnicity	
NZ European	12
Māori	4
Asian	3
Other European	4
Cancer type	
Non-Hodgkin lymphoma	14
Hodgkin's disease	3
Acute myeloid leukaemia	3
Multiple myeloma	3
Time post-treatment (years)	
2–3	6
3–4	5
4–5	7
5–8	5

When comparing the five participants who had completed treatment 6–8 years previously to the rest of the sample, there was nothing apparent in the data that differentiated the groups; however, the number was small for the 6–8 year group compared to the 0–5 year group so this was limiting. Therefore, the data were analysed as a whole rather than separating these two groups.

Findings

The analytical process led to the construction of four themes that describe the nature of distress experienced by participants in the post-treatment period. *Apprehension about leaving the safety of the*

health care system, Uncertainty and life transitions in the post-treatment period, Distress associated with ongoing physical problems or impairment, and Fear of recurrence.

Apprehension about Leaving the Safety of the Health Care System

Several participants felt distress around the time that they were finishing their primary treatment and leaving the constant support of the health system and the health professionals they were used to seeing regularly during chemotherapy and radiation. For many, it was a period that made them feel like they were now "on their own".

> *…you're pretty much, you know, jump into the cold water kind of thing. You're pretty much on your own… (P09)*

> *I think I felt a little bit strange to be discharged completely, but they can't keep seeing everybody, it was sort of just reality that you know that they can't just keep monitoring everybody who's had it. (P01)*

> *The last day of treatment was really quite emotional, far more emotional than I expected. You go in and do your last treatment and radiation and they give you that last thing with the green mask that goes over your face and you just shake their hands and walk out and go oh, it's done, yes! And hang fire I feel a little bit weird about this, I wasn't expecting to feel this way and sort of choked back some tears. (P22)*

Most survivors had formed relationships with hospital staff and for some, they were considered "like family." This was particularly true for people without other significant sources of support.

> *I found it quite hard because I felt like the people at the hospital were my second family and it felt hard letting that go. And it took me a long time to get used to that, not going back there. Because it was so much a part of my life, pretty much all for that 6 months. (P19)*

> *I suppose there was a little bit of - not mourning – but the end of a story with the doctors and stuff. But it was fine, it wasn't you know…it's just the way it is. (P01)*

Uncertainty and Life Transitions in the Post-Treatment Period

For most participants, the post-treatment period was one of uncertainty in many aspects, including lack of information, their disease status, not knowing whether they would get back their normal selves, employment issues and issues around children.

Most participants reported receiving limited information about what to expect in the post-treatment period. One participant spoke of a frightening experience he had because of this lack of knowledge regarding the physical limitations he now experienced as a result of his cancer.

So I had a lung infection and it reduced my lung capacity by about 20 per cent, and that's what they told me, and it was going to reduce some things. A while later I was out diving, and I nearly drowned…I went back and I was talking to the specialist, he said, oh you know, sometimes that can happen. (P17)

Furthermore, although some participants spoke about seeking alternate sources of information online, this could be troublesome as they would read conflicting information or things that were just frightening.

I had my daughter over in Perth and she was starting to have a look, and reading stuff on there…there's a lot of information which is too much, and it's scares the hell out of people. (P17)

For many waiting for the confirmation that they were actually in remission took months. This waiting period invoked considerable distress:

It was a progressive thing. Each time I went he said, no you're looking good, it's good no you've had no response, you've had good side effects, you've had a good response from the chemo, and there are no problems with the nodes. So as we went through each visit, I got a clearance. (P13)

But the thing is when you've finished you have to do a scan, a CT scan to see if you still have you know…even though you are finished, before that, it's not guaranteed that you're cured. It's only until that moment when you've done your scan, everything is clear then you think oh yay. (P18)

The downside of finishing treatment was described in terms of exhaustion and depression. For example, one participant described being diagnosed with depression because of her inability to do physical things, particularly her normal activities. This was indicative of some participants' experiences that once they were feeling physically better, emotional stress surfaced.

It was funny because I was healing, everything was going well but I got depressed by the end…you get cancer and something happening in your life and instead of getting better you get worse with the diagnosis and with the treatment, everything gets really much much worse. (P05)

… You just feel different and when you try and explain when they say, well how do you feel? I don't know, it's different and it's not as good as you used to feel and it's not as pleasant as you used to feel, but at the end of the day it's better than what could have been. (P17)

Participants sometimes worried about their reduced capability and the long-lasting effect this had on their ability to carry on with their previous employment. Many struggled when attempting to go back to full-time work because they became tired easily. Indeed, some could not manage to go back full time because of this fatigue.

> *And then though what you can't prepare for is the mental fatigue when you go back to work. I wasn't particularly mentally fatigued at home during or after the training, but the work demands is completely different. I think I had headaches each day after work for probably three years. (P09)*

Those who had to make major employment changes were left financially far worse off than before cancer. For example, one participant had to sell his business and his house near retirement age and begin again in a whole new place.

> *I mean we put everything into it and had to start again. So it's a bit late in life to start again. (P12)*

Unique to younger female participants was the theme of children. Most of the younger female participants spoke about the stress associated with potentially being infertile after treatment. Not all had the opportunity to harvest eggs before they started treatment so had no idea whether they would be able to have children.

> *My main thing was that I probably wouldn't be able to have kids. I thought oh shit, we waited and waited and now we probably won't be able to. (P01)*

There were additional factors to consider when contemplating reproductive issues or what the future held for the children they already had. One participant was concerned that her cancer could be potentially passed down to her children and wondered whether she should even have children. Another talked about making her children a top priority now as she felt there was a good chance her cancer would return.

> *I did get a job offer but I had to turn it down, I was like nah my kids…especially I don't know what's going to happen in the future now with this you know. So I have to think that I have to spend more time with the kids than thinking about having a dream job. (P04)*

Distress Associated with Ongoing Physical Problems or Impairment

Most participants mentioned ongoing physical sequelae associated with their cancer and treatment. For some, these physical complaints were significant and changed the way they now lived their lives. Some had permanent damage to hearing, vision or speech which caused ongoing distress.

I had to teach myself to talk again; my tongue swelled up that much that I couldn't speak properly. I still don't speak like I used to. (P12)

Other participants felt an overall difference in how they felt physically, and though they could not always describe why, they just felt they were not physically the same as they were before. This physical change caused distress for participants and a sense of loss because they did not feel they were "the person they once were." However, some participants acknowledged that these physical deficits were better than the alternative:

I will never, ever be where I was. I've most probably lost, hard to put a quantity on it, but I've lost quite a bit of my strength, and there's things that I just can't do…but I'm also aware that it's a trade-off; if I didn't have the stuff then, I would be dead. (P17)

Fear of Recurrence

Fear of recurrence is something that caused distress for almost all participants. Some described it as something that is always in the back of their mind. Participants noted that they were still uncertain about whether the cancer was gone for good.

You know, I've just been positive about my future and just moved on, yeah. But it's always in the back of my mind. Because for me, I've seen a lot of my own whanau people just get treated and some months or years down the line they're gone, you know. (P11)

So I know that cancer has to be treated quickly in most cases and the end of treatment is quite scary because you never know to this day when it's going to rear its ugly head again. It probably will, but just umm…even living day to day is quite scary. (P03)

For some participants, every little physical symptom caused concern. Part of this related to the vague symptoms many experienced when first diagnosed with their haematological cancer, which often mimicked common illnesses such as the common cold or influenza. Also, many participants spoke of the time and multiple visits it took to obtain their diagnosis because the symptoms were sometimes so innocuous. Participants were more aware of subtle changes in their body, for example, weight loss or fatigue. They were more likely to check their body for lumps, and go to GP where they would not in the past. There was also more concern if colds or flu's did not go quickly enough.

You know, every time, even four years down the track now, every time something goes on with your body which is a little bit out of the ordinary, you straightaway think, oh, is this the first sign of things coming back, you know. (P09)

Well I'm sure if I started to have night sweats or something I would…but to tell you the truth I have longish hair sort of just below my shoulders but it's constantly up in a ponytail and I never

brush it. But when I wash it quite a lot of hair comes out and that makes…sort of just…I suppose pretty much every time I was it I just think "I wonder". (P01)

Probably if I wasn't going for those (blood tests) I might be a bit more apprehensive, you know sort of thinking "oh I wonder". You're crook one day and you think "oh, it's not coming back is it?" (P02)

Some participants seem to obtain some sort of peace of mind through continuous monitoring from their health professional team. However, while having blood tests and check-ups alleviated the worry somewhat for many survivors, these tests also brought a lot of anxiety as well.

… you do get a bit worked up before you go and see him because he pokes around and things and it's like is he going to find…has it grown back. Because I couldn't feel it, he could feel it (P23)

For some, the fear was related to the belief that they could not cope emotionally or physically with recurrence. One participant talked about methods he used to distract himself from the fear that his cancer may return.

I talk to my kids about what if it comes back, I may not be able to handle the next one, you know what I mean? But I just keep that out of my mind and just carry on. I'll go fishing and whatever, keep on top of things. (P11)

Yeah. But I don't know if I can I can go through that…because that time is your first time, you don't know what you're getting yourself into. (P18)

Overall, participants seemed to be seeking reassurance regarding their fear of recurrence, and did not always have the option to speak to someone who could assist with these fears.

Discussion

This study addresses a significant gap in current international evidence by exploring distress experienced by post-treatment haematological cancer survivors. Most participants reported some manner of distress in the post-treatment period. Each phase in the post-treatment period brought its own challenges and individuals had different needs depending on their stage in the trajectory, as well as their own personal circumstances. This information has important practical implications for the types of supports required by this growing cancer survivor group.

Participants reported distress in many different aspects of the post-treatment phase. The first challenge was the transition from cancer patient to survivor which was very stressful for some participants as they felt they were now on their own or away from the built in support system of the

hospital environment. This is a similar finding to a study on leukaemia and lymphoma survivors focusing on the re-entry period which found survivors found one of the factors related to distress in this group was discontinuity of care at end of treatment (Parry et al., 2010). Other research that included post-treatment cancer survivors of mixed cancers found, as in the current study, that the immediate post-treatment period was a time of anxiety (Firmin, Pathammavong, Johnson, & Trudel, 2013). A study which interviewed nurses around barriers to care for haematological cancer survivors found that there was a difficulty in pinpointing the actual point where treatment ended for these patients, as because of the types of cancer it meant the end point was not always black and white. Therefore the nurse felt they hesitated in having survivorship discussions with these patients because they did not want patients to misunderstand the status of their disease (think they are cured) or that patients would not see themselves as survivors if they were still receiving additional treatment or monitoring (Langbecker, Ekberg, Yates, Chan, & Chan, 2016).

Another issue was the lack of information experienced by some participants regarding cancer survivorship after treatment. Other research examining unmet information needs for other types of cancers has found those with unmet information needs are more likely to be distressed (Uchida et al., 2011) and have higher rates of anxiety and depression (Faller, Koch, et al., 2016). Another struggle many participants encountered was the challenge they faced trying to get back to their normal lives. Some of this was because of physical impairment caused by their cancer and treatment, or for others because of psychological sequelae including issues such as depression, anxiety, fear or a sense of vulnerability. Research from Australia that reports similar results to the current study explored the needs of a group of mixed cancer survivors. They found the most common needs reported at treatment completion by both survivors and health professionals were dealing with fatigue, anxiety about cancer recurrence, others expecting you to be back to normal, having to create new expectations about physical ability, and anxiety about leaving the hospital system. They also found that one of the most common needs at the 1 year post-treatment was anxiety about medical check-ups and results (Jefford et al., 2008).

The most common concern for survivors in this study was the fear of recurrence, especially because the symptoms they experienced of their haematological cancer were very similar to other common illnesses, and therefore difficult to separate from minor illnesses. Heightening the fear of recurrence is an added concern that is particularly relevant to haematological cancer survivors, namely the difficulty in diagnosing their cancers. A study from the UK has shown that is not uncommon for the diagnosis period for haematological cancers to be long and protracted (Howell et al., 2013) and diagnostic delay has been shown to cause increased distress in other cancer patients (Miles et al., 2017; Risberg, Sørbye, Norum, & Wist, 1995). The concern regarding their prolonged diagnostic period was carried through to participants in the post-treatment period and contributed to their increased self-monitoring.

The limited literature on post-treatment haematological cancer survivors shows one of the most frequently endorsed unmet needs was help managing the fear of recurrence (Lobb et al., 2009). Fear

of cancer recurrence has been found to be one of the most common psychosocial concerns reported by cancer survivors (Simard et al., 2013), and has been associated with increased psychological distress (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Jones, Parry, Devine, Main, & Okuyama, 2015).

Recommendations

The information from the current study has important practical implications for the types of supports required by haematological cancer survivors. There may be distressing aspects of the cancer trajectory that cannot be avoided such as side effects of treatment and the physical symptoms of the cancer itself. However, this research has shown that from diagnosis to the post-treatment period more could be done to ameliorate the psychosocial consequences of cancer and its treatment. This study has found that the appropriate information and relevant support could be improved for post-treatment survivors. Furthermore, survivors especially need more information about psychosocial issues, it seems to rarely be discussed by health professionals, and if those in the health system make it a low priority patients may not see it as an important issue either. A good way to identify those who may be suffering distress is to implement distress screening for survivors at different points in the trajectory, including post-treatment. Without an effort to actively identify distress, it is unlikely survivors will feel comfortable enough to raise this issue on their own. However, more research is needed to explore both current, and preferred, sources of support among haematological cancer survivors.

Limitations

This study enabled unique in-depth knowledge to be generated regarding the experiences of an under-researched survivor group. However, limitations must also be noted. Self-selection bias may have influenced who took part. Also, participants had to rely on their memory to look back to the time when they were diagnosed with cancer, and for some, this was up to 8 years before so there may have been recall issues. Also as this was a qualitative study which included a small sample, findings are not intended to be representative and generalisable to other populations. Finally, this was a cross-sectional study therefore data were only collected at one time point.

Conclusion

Distress for haematological cancer survivors starts at diagnosis for many people, and can continue throughout the cancer trajectory. It is important that psychosocial distress is identified and support offered to those who need it to prevent escalation of psychosocial issues, and other negative consequences related to untreated distress. It is also important to consider the psychosocial needs of survivors in the post-treatment stage who are discharged from the health system and not always sure where to turn for help. The post-treatment stage has its own particular set of challenges, especially the transition from patient to survivor. Our study has identified the need to measure the prevalence of distress in haematological cancer survivors in the post-treatment period to ascertain whether there are particular transitions and time periods that cause the most distress. There also needs to be more

research ascertaining the support survivors receive currently and what support they need going forward.

Conflict Of Interest

All authors declare that they have no conflict of interest

Supplementary Information

Due to the journal word limit it was not possible to include detailed information about the techniques used to ensure the rigour of this phase of my research. I therefore present this below, along with contextual information about how rigour in qualitative research can be promoted.

Rigour in Qualitative Research

Rigour in qualitative research is deemed essential to ensure the findings from qualitative research carry conviction and strength (Long & Johnson, 2000). Lincoln and Guba (1985) proposed four criteria for assessing the rigour of qualitative research, contrasting them with the criteria used in quantitative research.

Table 4.3 Alternative criteria for assessing the validity and reliability of qualitative research (Lincoln and Guba, 1985)

Quantitative Research	Qualitative Research
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

The criteria are described in more detail below (Lincoln & Guba, 1985):

- **Credibility** – having confidence in the 'truth' of the findings; proving that they are believable.
- **Transferability** – showing that the findings can be applied in other contexts or settings.
- **Dependability** – proving the consistency of the findings and the degree to which they could be repeated.
- **Confirmability** – the extent to which the findings can be corroborated by others, or the degree to which the findings of a study are shaped by the respondents and not the researcher.

These criteria were addressed in the qualitative results chapters (presented in Chapters 5 and 6) as follows:

Credibility

One technique to ensure data and results have credibility is triangulation. Triangulation commonly involves the use of multiple data sources, data collection methods, or researchers (Long & Johnson, 2000), and is often used in qualitative research (Johnson, 1997). As part of the integration of the mixed methods, triangulation was used by obtaining multiple interviews and comparing across them, but also comparing and contrasting the quantitative and qualitative data.

Transferability

Transferability is the extent to which the study findings can be applied to other settings (Lincoln & Guba, 1985). To demonstrate this the researcher must provide a rich description of the research context, location, and participants (Amankwaa, 2016). In this research, all aspects of the context and participants have been discussed in the methods sections in the four results chapters.

Dependability

Dependability was achieved partially through a peer-review process (with thesis supervisors) which included questioning of the methods, and interpretation of data, which provided an external check of the data (Devers, 1999). Discussions with supervisors also added to the dependability through the process of discussions throughout the data analysis process to discuss and reach consensus on emerging themes (Noble & Smith, 2015). The peer-review process involves activities such as discussing one's research with colleagues who are knowledgeable in the research area, and presenting findings at seminars and conferences and inviting feedback (Long & Johnson, 2000). Throughout the research process, all these methods were used, numerous discussions were had with colleagues with expertise in the health care system, and research results were presented at several seminars and conferences.

Confirmability

Confirmability can also be attained through triangulation and the peer review processes as described above (Devers, 1999). Another way to establish confirmability is through the process of reflexivity, which encourages a researcher to reflect on how they as a person influence the research and its findings (Willig, 2001). A way of working reflexively is to keep a journal that encourages a researcher to examine their own thoughts and ideas about all elements of the research process (Willig, 2001). Being reflexive aids the researcher by giving an awareness of how their actions, values, and observations affect how they collect and analyse data (Gerrish & Lacey, 2006). Part of using reflexivity as a strategy in research means a constant self-examination of the researcher's assumptions and biases that could impact the research (Morrow, 2006). Reflexivity has been discussed earlier, describing how recognizing how my past has influenced me and the way I choose to conduct my research, I have provided a brief overview of my background, this exercise took place before any research was conducted to help make me aware of any potential influences or biases that

may affect the research process and analysis. Also, throughout the entire research process notes were taken to document every stage of the research and why decisions were made.

Chapter Summary

This chapter has provided findings from the qualitative phase of this research, and in particular, explored the nature of distress for haematological cancer survivors, as well as the times in which distress was more likely. Importantly it showed that distress started at the time of diagnosis for many and was something that could continue for a long period. Furthermore, it was shown that the post-treatment period provided its own set of unique challenges. Finally, this chapter has addressed issues of rigour in qualitative research and how it was addressed in the current research. The following chapter builds on these findings to provide additional insights gained from the qualitative phase regarding the strategies used by haematological cancer survivors to maintain psychosocial wellbeing in the post-treatment period, and examine the barriers they identify to maintaining wellbeing.

Chapter Five: Maintaining Psychosocial Wellbeing for Post-Treatment Haematological Cancer Survivors: Strategies and Potential Barriers.

Preface

This chapter presents further results from the qualitative phase of this research which were published in an article in the European Journal of Oncology Nursing. Following from the previous chapter where the nature and timing of distress were explored, this chapter explores how haematological cancer survivors aimed to maintain their psychosocial wellbeing as well as the barriers they faced to maintaining their wellbeing.

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Article: Maintaining Psychosocial Wellbeing for Post-Treatment Haematological Cancer Survivors: Strategies and Potential Barriers

Abstract

Purpose

Haematological cancers often require aggressive treatment which can cause both late and long term physical and psychosocial effects that can appear years after treatment ends. However there is a paucity of studies that focus on psychosocial issues among post-treatment haematological cancer survivors. This research aimed to explore the strategies used by haematological cancer survivors to maintain psychosocial wellbeing in the post-treatment period, and examine the barriers they identify to maintaining wellbeing.

Method

This research utilised a qualitative research design. Participants were recruited through the New Zealand Cancer Registry. Semi-structured interviews were conducted with 23 post-treatment haematological cancer survivors. A thematic analysis was conducted to analyse the data.

Results

The analysis identified three themes describing the strategies that enabled participants to maintain psychosocial wellbeing: inner strength; support from personal connections; support from health professionals/support organisations. Two themes were also identified describing the barriers to psychosocial wellbeing: barriers to utilising personal connections; barriers to utilising support from health professionals/support organisations.

Conclusions

Psychosocial support from others was essential in maintaining wellbeing for survivors. The participants who had ready support from family and friends reported needing less psychosocial support from other sources. However, those who needed more psychosocial support did not always receive it, or know where to find it. The key barriers to this type of support were informational gaps and not having a specific contact person to ask for help. Further research is needed to support the development of interventions to reduce psychosocial distress among this underserved group of cancer survivors.

Introduction

Haematological cancers are a diverse group of cancers, which differ markedly in their progression and prognosis, resulting in varying approaches to treatment and treatment intensity (National Institute for Clinical Excellence, 2003). The most aggressive therapies can cause both late and long term physical and psychosocial effects that can appear years after treatment ends (Klemm, 2008). It is therefore surprising that a review conducted by the authors (Raphael et al., 2017) found a paucity of studies that focus on psychosocial issues among post-treatment haematological cancer survivors.

The limited evidence there is available demonstrates that haematological cancer survivors may experience a number of psychological and social problems such as anxiety and depression (Molassiotis, Wilson, Blair, Howe, & Cavet, 2011), distress and poorer quality of life (Korszun et al., 2014).

Worldwide, haematological cancers are the fourth most diagnosed cancer in economically developed countries (Smith et al., 2011) and in New Zealand, where the study presented in this paper is set, approximately 1500 people are diagnosed with haematological cancer each year (Ministry of Health, 2014). A key issue for post-treatment survivors is that they are less likely than those in treatment to have frequent contact with health professionals who may be able to monitor and assist with concerns (Parry et al., 2010). Furthermore, there is evidence that limited attention is paid to psychosocial needs during follow-up appointments (Recklitis & Syrjala, 2017). Therefore it is important to identify those factors that affect psychosocial wellbeing for post-treatment survivors. The aim of this research was to explore the strategies used by haematological cancer survivors to maintain psychosocial wellbeing in the post-treatment period, and examine the barriers they identify to maintaining wellbeing. For the purpose of this study post-treatment haematological cancer survivors are considered those who had completed treatment and were currently in remission.

Methods

Sample

Ethical approval for this research was granted by the Southern Health and Disability Ethics Committee. (Ref: 15/STH/82). Participants were recruited through the New Zealand Cancer Registry (NZCR). The NZCR provided a data base with the names and addresses of all people diagnosed with a haematological cancer between July 2007–July 2015. Recruitment was targeted at those who had finished their primary treatment within 5 years or less. This period was chosen because it is within this time frame that cancer survivors of most types are most likely to be affected by psychosocial problems (Kattlove & Winn, 2003; Mullan, 1985; Stanton, 2012) and when the fear of cancer reoccurrence may dominate a survivor's thoughts (Hewitt et al., 2006). Furthermore, relapses in haematological cancers such as lymphoma and acute leukaemia's are most likely to happen in the first 5 years after remission (Specht et al., 1998).

Potential participants were mailed a letter inviting them to participate in an interview exploring the psychosocial issues they may have faced from the diagnosis of their haematological cancer through to the post-treatment phase. Those who were interested in participating returned a reply form with their phone number. They were then contacted by the first author (DR) who confirmed their eligibility by checking they had completed their primary treatment and were currently in remission (as indicated by their physician). Those who met this criteria were invited to participate in an interview at a day and time that suited them. The method of saturation was utilised to determine the number of interviews. Interview data were analysed after each interview had been conducted, with interviews ceasing when

no new codes or themes relevant to the primary research question were found in the data (Hennink et al., 2016).

Data collection

An interview schedule was developed to address the aims and objectives of the research, with questions informed by our previous review (Raphael et al., 2017) and other relevant literature. Topics covered by the interview schedule were: thoughts and feelings about when treatment was ending, adjustment back into normal life after cancer treatment, information received about what they might expect post-treatment, information or advice received post-treatment, any psychological or emotional strain during and post-treatment, if they had a support person/people in their life, support needs post-treatment, and fear of recurrence. However, although these topics were used as a guide, participants were encouraged to talk about the elements of their cancer survivorship experience that were important to them. Participants were invited to take part in a semi-structured telephone interview (with the option of face-to-face if they lived in the Auckland region). During this interview, demographic information was also collected, including age, ethnicity, marital status, employment status, treatment end date, and current health conditions. Although phone interviews are sometimes considered inferior to face-to-face interviewing (Block & Erskine, 2012) a recent study found that participants had a positive experience with this type of interview, in that it made them feel less inhibited and did not make them feel judged by the interviewer (Ward et al., 2015).

Analysis

Interviews were audio recorded with consent and transcribed verbatim by the researcher. The interview transcripts were then read multiple times before being entered into NVivo (QSR International Pty Ltd, 2012) to help organise and categorise the data. A thematic analysis (Braun & Clarke, 2006, 2013) was conducted that involved identifying, analysing and reporting themes from the data in six phases: familiarisation with the data; coding; searching for themes; reviewing themes; defining and naming themes; and writing up (Braun and Clarke, 2006). First author DR created a preliminary coding framework which was then refined through discussions with the other authors (RF and MG). Themes and sub themes were then generated, reviewed and revised, a lengthy process which continued through to the writing up period.

Results

Interviews were conducted with 23 participants from all around New Zealand (Table 5.1). Participants ranged in age from 33 to 77 years. The majority of participants were NZ European (52%), and had Non-Hodgkin's Lymphoma (61%). Participants reported being between two and eight year's post-treatment (mean 4.1 years) at the time of the interview. Eighteen participants fell within the previously discussed 0–5 year post-treatment range, and there were five participants who had completed treatment 6–8 years previously. Although the primary aim was to recruit those 0–5 years post-treatment, the participants in the 6–8 year group were interviewed to determine whether there were

any differences between the two groups in terms of the issues they faced. Only one Auckland-based participant chose a face-to-face interview, with the remainder of participants (including 5 residents in Auckland) interviewed over the phone. The interviews lasted between 20 and 80 min (mean 40 min).

Table 5.1 Participant demographics.

		n
Age	30–40	5
	41–50	3
	51–60	6
	61–70	6
Gender	Male	10
	Female	13
Ethnicity	NZ European	12
	Māori	4
	Asian	3
	Other European	4
Cancer Type	Non-Hodgkin Lymphoma	14
	Hodgkin's Disease	3
	Acute Myeloid Leukaemia	3
	Multiple Myeloma	3
Time post treatment	2–3 years	6
	3–4 years	5
	4–5 years	7
	5–8 years	5

No obvious differences were identified between the data from participants who had completed treatment 6–8 years previously and the 0–5 year group. Consequently the data were analysed as a whole, rather than analysing these groups separately. The analysis identified three main themes that describe the strategies that enabled participants to maintain psychosocial wellbeing: 1) inner strength; 2) support from personal connections; and 3) support from health professional and support organisations. An additional two main themes were also identified that described the barriers to psychosocial wellbeing: 1) barriers to utilising personal connections and; 2) barriers to utilising support from health professional and support organisations.

Inner Strength

An important factor that helped many participants following their diagnosis of cancer, including during the post-treatment period, was their own perceptions of inner strength which they felt helped them to maintain a positive attitude. Many participants mentioned the power of positive thinking, and described how this helped them recover and move forward. Sometimes participants felt a positive attitude lessened the need for extra support from the health system in the post-treatment period.

> *I feel like I was really positive the whole way through so I don't think my haematologist was too worried about me in regards to needing to offer me anything … any other kind of support. I'm*

sure there would have been if I'd been in a different frame of mind but I'm pretty much just kind of deal with it, move on … (P10)

Some believed that a positive attitude could help heal them physically as well as helping them psychologically.

I read a book by … a health professional, and she's also a naturopathic practiser now … she got breast cancer and cured herself through a state of mind. So that was very interesting to read, learning that you can help your own body without medication, through the mind-set. (P13)

Some participants spoke of the techniques they used to maintain their positivity. These included talking to themselves in a positive manner, and focusing on the encouraging advances in the treatment of cancer.

I'm really positive about medical science and its leaps and bounds. So that is playing heavily in my mind as well, so just hanging on to glimmers of hope and things like that. But also the hope of it not coming back … and I think your own body created this, well your own body can help medical science to get rid of it and keep it away. (P23)

There was a feeling from some participants that they wouldn't 'let cancer win', and ruin their chance of living a good life.

… I didn't want it to win and to consume me and take over. Once it was done I kicked it to the curb. (P02)

Support from Personal Connections

Most participants utilised support from family for both emotional and practical needs, although it is important to note that not everyone had this type of support available. For those who did have close relationships with family living nearby, they often offered emotional support to help survivors resume their routines. Some felt reassured that they had family to call on if they ever felt sick again:

… I have 3 children and I've got 13 grandchildren, and 5 great grandchildren. And they always worry about me, and I say oh don't worry about me, I'm alright … but if I do get sick I will call on them, and they will be here for me. (P11)

Many participants mentioned they hadn't asked for extra psychosocial support because friends and family were providing this type of support. However, some also recognised that there was extra support there if they needed it.

I was on to it enough that if things really weighed me down I would actually have sought help, Cancer Society help, I would have started there. Because they know what they're doing, they deal with it all the time. It's hard because I didn't need any extra. I had friends, family, I knew I had the Cancer Society at my fingertips. (P23)

Family were also useful in providing informational support, both in helping to retain information, but also helping with comprehension when needed.

My wife understood a lot more, because she having gone through the medical side, she was able to comprehend it a lot quicker than me … (P13)

Some survivors received financial support from family members which supported their psychosocial wellbeing as it meant they were not worrying about the financial implications of the cancer and its treatment. For example, those who had partners with well-paying jobs were able to take more time off work without struggling financially. One participant described how she lived with her parents, which enabled her to survive financially and take extra time after treatment to ease back into working.

In the end it was about a year that I took off, after the treatment I took an extra 3 months. I let the hair grow back a bit because it's a bit hard trying to apply for a job with a very short haircut that did nothing for me (laughs). (P23)

Some survivors were fortunate to have emotional support from friends who had the same cancer, and were able to know what they were going through. It made a difference when survivors were able to speak with someone who understood their issues. Some participants also spoke of the bond they formed with other patients who they had met during their treatment and who had been through the same medical experiences as them.

And the guy next to me, he had a couple of really bad nights, and they thought he wasn't going to make it, and he made it … we're great friends at the moment. And we've still kept in contact with each other. We've got that thing in common … he can relate to me, it's coz we went through something. And I guess when you go through something with somebody that only you know about, there's no one else that you can really share that experience with, or know what it's like. (P20)

Some people had friends in the community, (for example, from the same cultural or ethnic group, through church, or in local place-based community) that offered both practical and emotional support. This form of support from friends was especially important for those with no extended family in New Zealand.

In our community also if someone was sick we help each other, this is really really good. Because we are here … we are immigrants, we don't have any family here. Our family is our friends, that's why we are so close. (P21)

Barriers to Utilising Personal Connections

Not all participants received support from family and friends. This was often because they did not have strong social networks around them, and in some cases they had immigrated to New Zealand and the remainder of their family lived overseas. Those without a friend or family member they felt they could talk to about psychological issues struggled to know who to turn to discuss these issues with, and reported that, in most cases, they were not offered this type of support from health professionals.

There should be someone there to talk, not every family have families to support them but there should be someone there. (P04)

But every so often, you could be out driving, or you could be sitting and it gets into your head and you cannot stop thinking about it. And it gets you in a bit of a mess … and I've nowhere to go, nobody to talk to about it. But I think people think once the cancer's gone, you don't think about it. But they don't know that you do. (P15)

There was also a perception by some, that even though they had family or friends to talk to, these people would not really be able to understand their concerns:

… I find you can't talk to people. You can't tell them about it, because it's something that I can't put into words how I feel. You just feel different and when you try and explain when they say, well how do you feel? I don't know, it's different and it's not as good as you used to feel and it's not as pleasant as you used to feel, but at the end of the day it's better than what could have been. (P17)

Support from Health Professional and Support Organisations

Far fewer participants mentioned obtaining psychosocial supports from outside their personal networks, but for those who did, such supports often came during routine follow-up appointments with health professionals. For example, many found that monitoring appointments and blood tests with the haematologist at the hospital gave them peace of mind:

The monitoring is very good, and the fear of what's happening in the future is put to rest because you know that every six months or 12 months there's going to be a check done. (P13)

Others were grateful for and reassured by the easy access to their haematologists:

> *My haematologist she's fantastic, she handed her cell phone number and said if you've got any questions just give me a call. And the couple of times I've had them she's always answered. (P22)*

A few participants relied on their general practitioner (GP) for reassurance about the possibility of cancer returning, symptoms that were worrying, or what they might expect in the post-treatment stage.

> *I am quite aware of it now … before I never used to say, but I will go and tell the GP I need a full blood count, blood tests done asap or I ring the nurse and tell her to send me a blood test form. Because I don't want to take any more risks. (P04)*

Only one participant spoke of receiving home visits from a community nurse in the post-treatment period. The participant spoke of the nurse being the main health professional with whom he was able to discuss any psychological problems:

> *Yes, she followed up; she was good because you don't know what's normal and what isn't normal. So I did find that I was able to talk to her and she was able to … she had a lot of experience seeing other people. (P06)*

Many participants spoke positively of their experiences with cancer organisations, especially the Cancer Society which offers various services to cancer survivors in New Zealand. These include a free massage service, the Look Good Feel Better programme and a counselling service:

> *And I know they do for women that Look Good, Feel Better, I think that's a really good thing to have as well. I went to one of those and I found that really quite helpful. Especially with people that are on their own and don't actually have anybody. (P19)*

> *And the Cancer Society they gave me counselling … because I wanted to do something because of my family and my wife. I didn't want to be in a bad mood or low mood. (P06).*

Barriers to Utilising Support from Health Professionals and Support Organisations

Most participants were still having follow-up appointments with their haematologist, however this was not usually an opportunity to receive psychosocial support. Indeed, most reported that psychosocial issues were not discussed by health professionals, and little was offered in the way of psychosocial

resources post-treatment. Apart from the services mentioned above, the psychosocial service most frequently discussed by participants was support groups.

Support Groups are not 'One Size Fits All'

Although support groups were one of the main sources of support participants were informed about, they were not always deemed suitable:

> *I wouldn't do a support group because I would hate to get close to anyone that had it come back, to have to deal with that. It's bad enough having to deal with your own one and as much as I'd like to help like that I just couldn't. (P23)*

Another issue mentioned in relation to support groups was the mix of people at different stages in the cancer trajectory. Some participants felt distressed by mixing with people who had a terminal diagnosis and who were discussing their end of life plans:

> *I went to that and I wanted to shout to everybody, yes I'm cured, I've got the all clear. But the group that they sent me to was everybody was all terminal. And I'm thinking, and the things they're talking about were hospices and this and that … I thought, this is the wrong place for me to have been sent. And I never got any other any groups, and nobody else coming to me, or telling me I could go somewhere else. (P15)*

Some participants did not go back to the support groups because of the distress they felt having to hear stories from members whose cancer was incurable:

> *… she said her treatment hadn't worked and she was terminal and she was thinking about end of life preparation … she was starting to talk what she would leave behind for her 3 year old daughter. And then … the person that convenes these groups, she said, oh well why don't we all talk about what we would leave behind. And I'm feeling really uncomfortable cos the whole point for me is to try and stay positive … I never went back after that. I was, that really was actually a quite traumatic experience I found. (P09)*

Some participants also felt there was a lack of groups specific to haematological cancers:

> *… the Cancer Society offers a lot of different groups, on a monthly basis, they're not specific to blood cancers … they've got a lot for breast cancer. They've got prostate support group, they've got a lymphedema support group … they've got a 'god knows what' support group … (P09)*

Another restriction participants associated with support groups was the limited availability of these groups in terms of frequency and times. Meeting times were sometimes difficult to manage with work commitments:

… the support groups are only like every 3 months. Well, what's the point of that, you know? You can't form a supportive relationship or environment or support where you feel supported once every 3 months. (P09)

Gap in Informational Needs

The other major barrier relating to support from health professionals and support services participants reported was the lack of information about issues such as: who to contact about any psychosocial problems, what services were actually available, and what they might expect in the post-treatment period. Some participants were confused about who the correct point of contact when having unexplained symptoms or health concerns.

Well, there's actually quite a big difference during and post, just because how things are organised. So, during the treatment, I would say yes. I always knew who I could contact, I could call the community nurses 24/7 … I think sometimes it would be good to have that contact person that you could just email and ask, just to put your mind at ease. You don't always need to go to a doctor, specialist, GPs, they often don't know anyway. (P09)

A number of people who were not offered any psychosocial support had no idea what support options were available. One participant spoke about wanting to access support in her area but not knowing if there was a cancer support organisation locally:

It would've been handy having someone, maybe even now, or somebody months ago. Because once the treatment finished and I was sitting in the house one day, and then I just burst into tears. And I wanted to throw the television out the room, I wanted to smash the windows, I wanted to go haywire and damage everything. I don't know what came over me. It was horrible. And every so often even now, I'll think to myself, 9 out of 10 times, I'm fine. But there's that one time the cancer creeps back into my mind, what if I get it. What if it comes back? And you think, I've nobody to talk to, to tell all my fears, my woes. (P15)

The continuing physical deficits, such as fatigue, once treatment had ended were unexpected and caused distress for a number of participants:

… it took me a long time to actually realise how far down I'd gone, and then to try and build yourself up. That's where I think if there's anything needs improving, it's after, coz no-one sort of tells you, well you can do this, or we can help build you up, or you can go the gym and start. (P17)

The distress related to physical deficits post-treatment was often attributed to a lack of information about building up physically, especially in relation to managing fatigue and transitioning back into the workplace:

… your employer is sort of thinking, well, when are you going to be back? And there wasn't really clear advice on how to manage your reintegration back into work. So I think that there could be more information about that …. there wasn't really any advice on how to slowly build up your stamina to be able to go back to work. (P09)

Discussion

This study explored the strategies haematological cancer survivors use to maintain psychosocial wellbeing in the post-treatment period, and also examined the barriers they face when trying to maintain wellbeing. This paper makes an important contribution to understanding the psychosocial issues experienced by post-treatment haematological cancer survivors and their perceptions of the support they need to deal with these issues. Overall, we identified a gap in current support, particularly for those people who did not have extensive social networks and did not have support from family, for example because they were living in another country.

Our findings are consistent with research on psychosocial wellbeing among other groups of cancer survivors which has shown that most of the support received by survivors post-treatment is from family and friends (Girgis & Lambert, 2009; Kattlove & Winn, 2003). We found that family and friends provided not only important emotional support, but also informational, financial and other practical support which meant survivors could focus on their own health without extra stresses. Emotional and informational support from family and friends has been shown to have a significant positive association with the health-related quality of life of cancer survivors (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007).

Many participants mentioned not asking for extra support because of friends and family filling this role. However, it is important to note that there were some people who did not have family or close friends to call on when they needed support and therefore needed additional support. Few participants spoke of seeking or being offered psychosocial support from health professionals. The biggest element of existing support was through haematologist follow-up appointments. The haematologist provided peace of mind for some participants by monitoring physical health and confirming their cancer had not returned. However this may be because health professionals are not always the chosen source of support for survivors, a recent study showed that only a minority of post-treatment survivors with psychosocial issues wanted to discuss them with a health professional (Philip & Merluzzi, 2016).

Many participants mentioned they drew an ‘inner strength’ to help them get through their treatment and beyond. They felt this enabled them to remain positive, and not require extra support. Some also considered that their positivity was connected to improving their physical health. Research with women cancer survivors (including those post-treatment) showed that inner strength was one of the strongest predictors of quality of life (Dingley & Roux, 2014). However, research has shown there are many factors that contribute to inner strength in people with serious illness (Alpers, Helseth, &

Bergbom, 2012) and that the pressure to remain positive can be stressful for some people (Tod, Warnock, & Allmark, 2011). Also, there are known associations between reporting 'inner strength' and strong social support (Dingley, Bush, & Roux, 2001). This association was evident in the current research where those participants who had less social support were less likely to mention inner strength, but more likely spoke of needing more supportive people around them.

Overall, post-treatment psychosocial support from sources other than the individual affected and their family and friends was considered to be suboptimal by this group of haematological cancer survivors. In particular, the information needs of many participants were not met with many reporting they wanted more information on a range of issues. Our findings are consistent with a previous review which found that one of the key unmet psychosocial needs for haematological cancer survivors is informational needs (Swash, Hulbert-Williams, & Bramwell, 2014). Participants reported needing information about a range of topics including rebuilding their physical health and stamina, ongoing symptoms, and knowing who to contact when they had concerns.

Most participants were not offered any psychosocial support from health professionals. Similar results were seen in previous research with a mixed group of cancer survivors where one fifth of participants reported the need for psychosocial support, but were not receiving it (Ernstmann et al., 2009). This lack of psychosocial support for post-cancer survivors has also been recognised by health professionals themselves. For example, research conducted in New Zealand found that 77% of health professionals surveyed felt there was a gap in psychosocial and spiritual care in the cancer post-treatment period (Egan, McKechnie, Jobson, Herbison, & Richards, 2013). Our findings confirm this gap for haematological cancer patients, an under-researched group.

Our participants also identified that some supports on offer were also not deemed suitable. Notably, support groups were not a good fit for many people. This was for reasons such as lack of continuity, limited availability of groups and also, crucially, not having groups specific to haematological cancers. Participants felt haematological cancers were different to other cancers and therefore they had specific concerns that might not apply to other cancers. This feeling of 'being different' was also reported by previous research with post-treatment patients with non-Hodgkin's lymphoma (Swash et al., 2014). Similarly, our participants concerns, and for some significant distress, about mixing with people from different cancer stages has also been reported previously (Avery & Nyhof-Young, 2003; Butow et al., 2007) and for some cancers has led to different groups being set up for people at different points on the cancer trajectory (Sweet Louise Support for Incurable Breast Cancer, 2018). A study which interviewed post-treatment lymphoma survivors also found that participants felt a more person-centred individualised approach to meet their support needs (Monterosso et al., 2017).

Overall, our study found that the barriers to psychosocial wellbeing in haematological cancer survivors in the post-treatment period largely revolve around the lack of information and discussion around psychosocial issues, and the gap in promoting the available psychosocial resources available to

survivors. There is also potentially a significant missed opportunity for some sort of survivorship care plan (SCP) for those finishing treatment and potentially struggling in the post-treatment period. Although reviews on the use of SCPs in other cancers have shown mixed results, results show that survivors report a high level of satisfaction with SCPs (Brennan, Gormally, Butow, Boyle, & Spillane, 2014). However, there has been little evaluation of SCPs for haematological cancer survivors (Taylor, Chan, & Monterosso, 2015). Chan and Chan (2015, p. 414) state that haematological cancer survivors need 'complex, tailored survivorship interventions'. Further research assessing the efficacy of this type of tailored survivorship care plan within the context of haematological cancer is needed.

Limitations

This research provides in-depth knowledge relating to the experiences of post-treatment haematological cancer survivors, an under-researched group of survivors. However, there are also limitations that should be acknowledged. There may be a self-selection bias influencing who chose to participate. Also, as this was retrospective, participants had to rely on their memory to answer certain questions about their initial post-treatment experiences, which may have led to recall issues. Finally, as this was a cross-sectional study data was collected at only one time point.

Conclusion

Haematological cancer survivors have their own set of unique psychosocial needs that carry through to the post-treatment period. Many of the participants in this study had ready support from family and friends, and those with strong support from family and friends reported needing less psychosocial support from other sources. However, those who needed more psychosocial support did not always receive it, or know where to find it. The key barriers to this type of support were informational gaps and not having a specific contact person to ask for help. Further research is needed to support the development of interventions, such as individually tailored survivorship follow-up plans, to help identify and reduce psychosocial distress among this underserved group of cancer survivors.

Conflicts of Interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

Chapter Summary

This chapter has outlined further findings from the initial qualitative phase of this research. The strategies used by haematological cancer survivors to maintain psychosocial wellbeing in the post-treatment period were explored, and the barriers they identified to maintaining wellbeing examined. Overall, the findings showed that many participants had good support from family and friends and this lessened their need for psychosocial support from the health system and other sources. However, often those who did need support from the health system and other sources faced barriers in receiving this support.

Phase One findings informed the design of Phase Two which is presented in the next chapter. The aim of Phase Two was to investigate the characteristics, magnitude, and timing of psychosocial distress amongst post-treatment haematological cancer survivors.

Chapter Six: Distress in Post-Treatment Haematological Cancer Survivors: Prevalence and Predictors

Preface

This chapter presents findings from Phase Two of the research: a survey to ascertain levels of distress post-treatment in haematological cancer survivors. I begin by discussing strategies I used to promote research rigour and the pilot testing procedure for the survey. Findings are then presented in relation to the characteristics, magnitude, and timing of psychosocial distress amongst post-treatment haematological cancer survivors. In the next chapter I present additional findings which explore psychological supports.

Rigour in Quantitative Research

Rigour in quantitative research examines the quality of research; if strategies to maximise the quality are not adopted it raises questions about the accuracy and validity of the results (Marquart, 2017). The major issues to consider that ensure rigour in quantitative studies are reliability and validity. Issues of reliability and validity of the questionnaire used in Phase Two are discussed in the pilot testing section below.

Pilot Testing

Questionnaire Development

The questionnaire was created by drawing on a combination of relevant cancer survivorship literature (Chapter Two) and the results from the Phase One interviews of this research (Chapters Three and Four). The survey instrument contains measures related to psychosocial distress, which encompasses a broad set of concerns. As noted in Chapter One, the definition created by the National Comprehensive Cancer Network (2013) was used to guide this research. The areas measured were therefore aligned with this definition and aimed to measure distress of a 'psychological (cognitive, behavioural, emotional), social, and/or spiritual nature' (National Comprehensive Cancer Network, 2013). Furthermore, as social support was identified as an important component relating to distress in Phase One, a measure of social support was added to the questionnaire as listed below.

The questionnaire (Appendix 2.4) consisted of the following validated instruments: Distress Thermometer (National Comprehensive Cancer Network, 2013), Kessler 6 (Kessler et al., 2003) SF-12 (Ware, Kosinski, & Keller, 1996), Assessment of Survivor Concerns (Gotay & Pagano, 2007), Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), and Satisfaction With Care Scale (Watson et al., 2016). These scales measure distress, depression, anxiety, fear of recurrence, social support, and satisfaction with health care. Additionally, there were

four questions especially created for this research, relating to whether participants felt they received sufficient psychological support from health professionals and other support services.

The questionnaire also gathered the following socio-demographic information about participants: age, gender, nationality, ethnicity, marital status, number of children, employment status, living arrangements, cancer type, treatment type, and time since treatment ended. The choice of variables was guided by the Phase One findings which highlighted certain demographic factors and issues that would be explored further in Phase Two. The questionnaire was offered in either a paper and pencil format (to be mailed back) or an online option.

Questionnaire Pretesting

Before the questionnaire was distributed to the participants it was pretested to determine whether it was suitable and comprehensible for the target population. Indeed, no matter how much time and effort goes into questionnaire design, there are always problems that cannot be anticipated which will likely be picked up in pretesting (Willis, 2014).

Cognitive Interviewing

The first stage of the pre-test consisted of cognitive interviewing, which is now considered the dominant mode of testing questions and questionnaires (Dillman, Smyth, & Christian, 2014). Cognitive interviewing is a technique that aims to explore how participants interpret and understand the questionnaire text (Collins, 2003). A positive aspect of cognitive interviewing is that it can be done with a small number of participants and still provide enough useful information to help in the assessment of the questionnaire (Willis, 2005). Cognitive interviews can help identify a wide range of problems in a questionnaire and generate suggestions that will help improve the questionnaire (Lenzner, Neuert, & Otto, 2016). Cognitive interviews are also thought to be suitable for all survey modes — that is they are applicable whether the survey is administered by telephone, paper and pencil, or online (Lenzner et al., 2016).

Procedures

Five cognitive interviews were conducted, which is seen as acceptable for a cognitive interviewing sample, as the aim is not representativeness (Willis, 2005). Four interviews were conducted with a convenience sample of haematological cancer survivors recruited through a local cancer organisation. A partner of one of the haematological cancer survivors also chose to participate, and whose interview data was included as his experiences allowed him to offer insight regarding the questionnaire. Cognitive interviewing was used to evaluate whether people understood the questions, interpreted them in the way intended by the researcher, and in a similar manner to each other. Another important aspect was to determine whether the questionnaire would be acceptable in terms of how it affected the participants psychologically, with the aim to minimize any distress the questions may have raised. Interviews were conducted over the phone (n= 3) or face-to-face (n= 2) and were

audio-recorded. Participants were asked to read the questions out loud and the questionnaire was completed verbally by the participant with the interviewer writing the responses. The interviews were audio recorded with consent and notes were also taken by the researcher.

As the participant read through the questionnaire aloud and answered the questions, verbal probing was used to draw out more information when they hesitated or sought clarification over a question. Verbal probing is when the interviewer follows up on questions with probes aiming to gain further information about particular questions and answers (Willis, 2005). The participants were not only asked to read out the questions but also respond verbally. This enabled the researcher to ascertain whether the participant understood the questions in the way in which they were intended. It also indicated areas where the terminology was not clearly understood and highlighted questions which may not have provided the suitable response options to enable the participant to answer appropriately.

Cognitive Interviewing Analysis

Audio from the interviews was transcribed and the notes taken during the interviews were added to the transcripts. This helped by highlighting problems identified by each individual and across the interviews as a whole. An informal analysis (Lenzner et al., 2016) was conducted where all participant comments relating to questions were categorised and grouped by section. During the interview process, whenever a participant showed any difficulty answering a question the interviewer discussed it further with them and asked their opinion about how it could be improved; these suggestions were combined to create a list of questions that needed refining. Although some problems were pointed out by only one participant, if it was deemed likely there was potential that it could affect other participants then changes were made.

Cognitive Interviewing Results

Overall, the participants commented that they found the questionnaire simple to follow and the majority of the questions were easy to understand and answer. Most of the questions that needed refining were in the demographic section and mainly revolved around clarification of terminology and the need for some additional response options. Another problem area was the questions about follow-up care. It was obvious from participant responses that they were missing the instruction that questions related to the post-treatment period and that these instructions needed to be made clearer. The rest of the questionnaire was relatively problem-free for the participants and most had no concerns with the validated measures beyond minor formatting issues. No participants identified that the questions caused them distress. Table 6.1 below provides an overview of the questionnaire content, the full questionnaire is provided in Appendix 2.4.

Table 6.1 Overview of content contained in the questionnaire

Section	Content
Introduction	- Instructions - Consent - Screening questions to assess eligibility
Section A	- Demographics - Diagnosis - Treatment type - Open text: top three physical or psychological health concerns
Section B	- Kessler Psychological Distress Scale - Distress Thermometer and Problem Checklist
Section C	- SF-12
Section D	- Assessment of Survivor Concerns scale
Section E	- Multidimensional Scale of Perceived Social Support scale
Section F	- Psychological/emotional support received during treatment
Section G	- Psychological/emotional support post-treatment
Section H	- Satisfaction With Care Scale
Conclusion	- Open text: Is there anything that you would like to say or aspects of your post-treatment care or support that have not been covered?

Pilot Test

Pilot studies can provide important information about how individual items are performing and the efficacy of the overall questionnaire (Dillman et al., 2014). Therefore, the second phase of pretesting was a pilot study using the same recruitment methods as the main study. The questionnaire was sent to a random selection of participants who had been diagnosed with a haematological cancer (n =145) selected from the New Zealand Cancer Registry database. Twenty questionnaires were received and used for the pilot analysis. The pilot study enabled evaluation of the survey in exact test conditions and also allowed statistical analyses to be conducted to determine the reliability of the questionnaire in the target population. The sample for a pilot test should be as similar to the target population as possible (van Teijlingen & Hundley, 2002). In this research, the sample was representative of the haematological cancer survivor population in New Zealand in terms of gender, ethnicity, age, and cancer type. This was ascertained by comparing the data from the whole NZ haematological cancer population to the characteristics of the current sample.

Pilot Test Analysis

Descriptive statistics (mean, frequency, etc.) were used to detail the characteristics of the pilot sample. Cronbach's alpha coefficients were used to test for internal consistency reliability. The assessment of validity is described in Table 6.2. As the Distress Thermometer is an analogue scale it is best assessed for sensitivity and specificity, rather than reliability. Receiver operating characteristic (ROC) curves were used to measure the sensitivity and specificity of the Distress Thermometer. ROC curves measure sensitivity (the true positive rate) and specificity (the true negative rate) through a

statistic called the area under the curve (AUC), which is an indicator of the accuracy of a measure (Hong & Tian, 2013). AUC values range from 0 to 1, and values over 0.80 indicate the measure has high accuracy in identifying positive cases (Hajian-Tilaki, 2013).

Pilot Test Results

Participant responses showed that further changes were needed in sections F and G of the questionnaire as there was some repetition in the questions that led to confusion for the participants (See Appendix 2.4 for questionnaire).

Descriptive Statistics

The pilot included 20 participants, 75% of whom were male (n = 15). The age range was between 48-86 years (mean = 70.8). The ethnicity of participants was NZ European (75%), Māori (5%), Pacific (5%), Asian (5%) and Other Ethnicity (10%).

Reliability and Validity

Internal consistency was evaluated using Cronbach's alpha coefficients. Cronbach's alpha coefficients for the measures were: Kessler 6 (α = .826), SF-12 (α = .961), Assessment of Survivor Concerns (α = .936), Multidimensional Scale of Perceived Social Support (α = .922), and Satisfaction With Care Scale (α = .861). These alpha coefficients showed that all measures had high internal consistency. George and Mallery (2003) provide guidelines for acceptable values of alpha is >0.9 = Excellent, >0.8 =Good, >0.7 = Acceptable, >0.6 = Questionable, >0.5 = Poor, and <0.5 = Unacceptable. The Distress Thermometer was shown to have high accuracy in determining positive cases (AUC = 0 .98; 95% confidence intervals [CI] 0.93–1.00).

The main types of validity are criterion, content, and construct validity (Coolican, 2009). These are described in Table 6.2 below (Coolican, 2009; Shuttleworth, 2009) with an explanation of how each type of validity was addressed in the current research.

Table 6.2 Assessment of validity in Phase Two questionnaire

Type of validity	Definition	How it was assessed
Criterion	There are two types of criterion validity: ***Concurrent validity*** compares the measure against a benchmark test and if it correlates highly it shows the measure has strong criterion validity. ***Predictive validity*** tests the predictive abilities of a measure. Subjects are tested for a certain construct and then results are compared with results obtained at some point in the future.	***Concurrent validity*** was established by comparing all measures to a similar test with good validity. ***Predictive validity*** was not relevant for this research as the measures were not used as a predictive test.
Content	A measure of how well each element in the construct is represented.	This was assessed through the pretesting phase of the questionnaire development.
Construct	There are two types of construct validity: ***Discriminant:*** A test of how much constructs that are supposed to be unrelated are actually unrelated. ***Convergent:*** The degree to which the measures used to represent constructs are consistent with other indicators of the same constructs.	***Discriminant validity*** was assessed by correlating the questionnaire scales and other existing reliable and valid scales which measured a different construct. Correlation coefficients showed low inter-item correlation between scales. ***Convergent validity*** was established through correlation analysis between the questionnaire scales and other existing reliable and valid scales which measured similar constructs. Correlation coefficients showed high inter-item correlation between scales.

Conclusion from Pilot

The issues identified based on the cognitive interviewing and the pilot testing were addressed by making minor changes in the wording and organisation of the questions. When assessing the rigour of the questionnaire it was found to be reliable and valid, as described above.

Article Preface

Building on the findings from the qualitative phase which found most participants experienced distress in some manner, the study presented in this paper from the quantitative phase of the research aimed to measure the prevalence and predictors of distress in post-treatment haematological cancer survivors.

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Article: Distress in Post-Treatment Haematological Cancer Survivors: Prevalence and Predictors.

Abstract

Objectives: To calculate the prevalence of psychosocial distress, and identify factors that predict distress, in early post-treatment haematological cancer survivors.

Design: Cross-sectional survey containing self-report measures.

Sample/Methods: Post-treatment haematological cancer survivors in remission (>18 years) ($n = 409$) completed questionnaires. Distress was measured with the distress thermometer (DT). Logistic regression was used to identify predictors of distress.

Findings: Overall 21.9% ($n = 93$) of respondents reported significant distress (DT ≥4). Significant distress was twice as high in those born overseas (OR = 2.09, $p = .03$), 3.5 times higher in those with lower social support (OR = 3.51, $p = <.001$) and five times higher in those with increased fear of recurrence (OR = 0.17, $p = <.001$).

Implications for Psychosocial Providers: Early identification of distress may decrease psychosocial issues in the post-treatment period, especially as psychosocial services have been shown to improve wellbeing for those who are distressed.

Background

Combined, haematological cancers are the fourth most common cancers and make up approximately 9% of cancers in economically developed countries (Smith et al., 2011). In New Zealand (NZ), haematological cancers also contribute significantly to the overall cancer burden, and are the fifth

most diagnosed group of cancers (Ministry of Health, 2014). This century has seen a dramatic increase in survival rates for most common haematological cancers, including NZ where five-year survival has steadily increased overall in the last decade for most haematological cancers (Ministry of Health, 2015).

However, those surviving these cancers are often left with sometimes debilitating late effects and long-term effects, both physical and psychosocial (Beckjord et al., 2013) due to aggressive and prolonged treatments (Klemm, 2008) that may last for years into the post-treatment period (Kuba et al., 2019). The post-treatment stage is an important and often overlooked period in the cancer trajectory (Stanton et al., 2015). In this period, survivors are often struggling with the transition from patient to survivor (Stanton et al., 2015).

The early post-treatment stage (up to 5 years post-treatment) may be particularly challenging, with survivors often worried about fear of recurrence (FoR) and dealing with ongoing symptoms with less health professional support than when they were in treatment (Hewitt et al., 2006). In NZ after cancer treatment, haematological cancer survivors will initially have regular outpatient follow-up appointments (decreasing in frequency as time passes) with their haematologist (Leukaemia and Blood Cancer New Zealand, 2015). However, for many post-treatment survivors' their most frequent health professional contact is their General Practitioner, which can be problematic because it is reported that in primary care psychosocial distress often goes undetected (Mitchell, Vahabzadeh, & Magruder, 2011). Distress is a common measure of psychosocial sequelae in cancer survivors (National Comprehensive Cancer Network, 2003). Distress has been associated with reduced survival (Hamer, Chida, & Molloy, 2009), decreased quality of life (Shim et al., 2006), and reduced satisfaction with medical care (Von Essen et al., 2002).

Evidence of the negative outcomes associated with distress has led many cancer organizations to highlight distress screening as a necessary part of cancer care (Institute of Medicine, 2008). For example, distress screening is recommended by a number of major cancer organizations (National Comprehensive Cancer Network, 2003). The National Comprehensive Cancer Network maintains it is essential to screen for distress from diagnosis and throughout the cancer trajectory, including the post-treatment period (National Comprehensive Cancer Network, 2003). However, there has been a dearth of research focusing on distress in the post-treatment stage (Girgis, Smith, & Durcinoska, 2018), although, research on post-treatment survivors with other cancers has found prevalence rates of psychosocial distress between 26% and 55.6% (Mehnert et al., 2018; Philip & Merluzzi, 2016).

Distress as a measure of psychosocial sequelae is useful because many cancer survivors may be suffering from emotional upheaval which will not necessarily meet the diagnostic criteria for a psychological disorder (National Cancer Institute, 2017). Distress has been defined as "a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioural, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical

symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (National Comprehensive Cancer Network, 2003).

Prevalence of distress for specific cancers and patient groups is important because cancer is a vastly heterogeneous set of diseases, with different treatments and trajectories (Kattlove & Winn, 2003). For example, haematological cancer patients often face aggressive and prolonged treatment which may increase their risk of psychosocial sequlae (National Institute for Clinical Excellence, 2003). Therefore, knowing the number of people in specific survivor groups that may suffer distress is important because it can ensure psychosocial resources are aimed at these people first.

A review examining distress in post-treatment haematological cancer survivors (Raphael et al., 2017) found only seven eligible articles, and only one that reported prevalence of distress. This study found that 31% of haematological cancer survivors reported distress and that distress was associated with younger age (18-39), financial burden, and FoR (Jones, Parry, Devine, Main, Okuyama, et al., 2015). However, this study was only conducted in one state in the United States, and as pointed out by the authors, it is a state with little ethnic diversity. Furthermore, research on haematological cancers in NZ populations is very limited and no research has been identified that has assessed psychosocial issues facing haematological cancer survivors in New Zealand. Therefore, there is still a large gap in research measuring the prevalence of distress in post-treatment haematological cancer survivors which the study presented in this article aims to address. The purpose of the study was to calculate the prevalence of psychosocial distress, and identify factors that may predict distress in haematological cancer survivors who had completed their primary treatment within 5 years, and were in remission.

Methods

Procedure

Participants were recruited from the New Zealand Cancer Registry (NZCR). The NZCR provided a dataset containing information about every person diagnosed with a haematological cancer between March 2012 and March 2017 who had not been registered as deceased. Information provided included, name, postal address, ICD-10 code, and date of diagnosis. Recruitment took place between December 2017 and May 2018. Those diagnosed with myelodysplastic syndromes (MDS) were excluded because in New Zealand (NZ), as in other countries, many with this disease are not told it is a cancer (Steensma, 2006). Therefore, the risks of inviting participation were considered to outweigh the benefits.

Stratified random sampling was used to ensure 20% of each major ethnic group in NZ (NZ European; Māori; Pacific; Asian) (comprising the groupings Chinese, Indian, South East Asian, and other Asian) were given the opportunity to participate. A further 20% was sent to those who were in the "Other"

category, this group comprised of other ethnic groups (Middle Eastern, Latin American, African, and other European) and those who had no listed ethnicity. Selected participants were mailed a questionnaire by the researchers with an information sheet that outlined the study and also provided a URL address to the online version of the questionnaire if they wished to complete it online. They were also provided with a postage paid envelope to return the completed questionnaire.

Ethical approval for this research was granted by the Southern Health and Disability Ethics Committee. (Ref: 15/STH/82).

Inclusion Criteria

Inclusion criteria comprised: aged >18 years, diagnosed with a haematological cancer between March 2012 and March 2017 (this was inclusion criteria for data requested from the NZCR), had completed their primary treatment, and were told by their doctor that they were in remission, or free of cancer. Treatment completion and remission status was asked at the beginning of the questionnaire and potential participants were only invited to continue if they answered yes to being post-treatment and in remission. The screening questions were (1) Have you finished your main/primary treatment for your haematological cancer? (2) Have you been told by your doctor that you are you currently in remission, or cancer free, or cured?

Questionnaire

The questionnaire was designed using results from a previous qualitative research conducted by the authors, and current literature in the area of cancer survivorship. Fear of recurrence (FoR) and social support stood out as important factors in our previous research, and therefore, were included as measures in this questionnaire (Raphael et al., 2019a; Raphael et al., 2019b). The definition of FoR used in this study is “Fear, worry, or concern relating to the possibility that cancer will come back or progress.”

Demographics

Demographic information collected included age, gender, ethnicity, country of birth, and living situation (alone or with others). Clinical information collected included months since treatment ended and type of cancer.

Measures

Psychological distress was measured using the Distress Thermometer (DT) (National Comprehensive Cancer Network, 2003). The DT is a widely used valid and reliable measure of psychological distress in cancer patients (Donovan, Grassi, McGinty, & Jacobsen, 2014). It has also shown to be reliable in NZ populations (Baken & Woolley, 2011). The DT is a single item visual analogue scale ranging from 0 (no distress) to 10 (extreme distress). Participants are asked to “circle the number (0–10) that best describes how much distress they have had during the past week, including today.” A cut off point of

≥4 is has shown good sensitivity and specificity in identifying those with significant distress (Mitchell, 2007). Single item screening tools have been shown to be as valid as multidimensional tools for measuring cancer-related distress (Mitchell, 2010).

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) was used to measure perceptions of social support. The MSPSS is a 12-item inventory using 7-point Likert scales ranging from 1 (very strongly disagree) to 7 (very strongly agree), with higher scores indicating higher levels of perceived social support. The MSPSS is a reliable and valid measure ($\alpha = 0.88$) (Zimet et al., 1988). The scale had a high level of internal consistency when used for the current sample, as determined by a Cronbach's alpha of 0.95.

FoR was measured using the Assessment of Survivor Concerns (ASC) cancer worry subscale (Gotay & Pagano, 2007). This subscale has three questions with participants indicating the degree they worry about future diagnostic tests, another type of cancer, and their cancer coming back. The response format is a 4-point Likert scale ranging from 1 (not at all) to 4 (Very much). This scale has been shown to have good psychometric properties (Gotay & Pagano, 2007). The subscale had a high level of internal consistency when used for the current sample, as determined by a Cronbach's alpha of 0.90.

Statistical Analysis

Data analysis was conducted using SPSS version 25. Descriptive statistics were calculated to explore participants' scores on the Distress Thermometer, MSPSS, and ASC Cancer Worry Subscale, as well as assess demographic characteristics, and clinical variables. Pearsons Chi-square analysis was used to measure differences between distress and clinical variables, demographic variables, MSPSS scores, and ASC Cancer Worry Subscale scores. Variables in the Chi-square analysis that were found to be significantly associated with distress (at $p < .05$) were entered into a hierarchical logistic regression model. Participants with missing responses in the ASC and MSPSS were excluded.

Hierarchical logistic regression was used to identify the variables that predicted higher significant distress (DT ≥ 4). Significant distress was coded as a dichotomous variable (presence of significant distress: 1 = yes, 2 = no). Predictors were entered in two blocks, demographic factors were entered into the first block, then social support (MSPSS) and FoR (ASC) into the second block. Independent variables were categorized dichotomously to ensure there were sufficient numbers per each independent variable as required in the assumptions of logistic regression. Other relevant assumptions of logistic regression were met, namely: a dichotomous dependant variable; independence of observations; no evidence of multicollinearity as Variance Inflation Factors (VIF) values were between 1.04 and 1.72, and no significant outliers.

Results

Participants

A total of 1500 questionnaire were mailed out to participants, however, 34 were returned as the addresses were not current, and 9 people were reported as deceased, making the total eligible questionnaires 1457. Reasons for ineligibility are shown in the flow chart (Figure 6.1). Another 45 (3.0%) potential participants declined, of whom 24 provided a reason, including: not aware of their diagnosis (*n* = 10); unable to complete because they were unwell (*n* = 8); they feel mentally well (*n* = 2); preferred not to think about cancer again (*n* = 2). The overall response rate was 31.0%, however, this is a conservative estimate as there was a high likelihood that a number of the nonresponders were also ineligible.

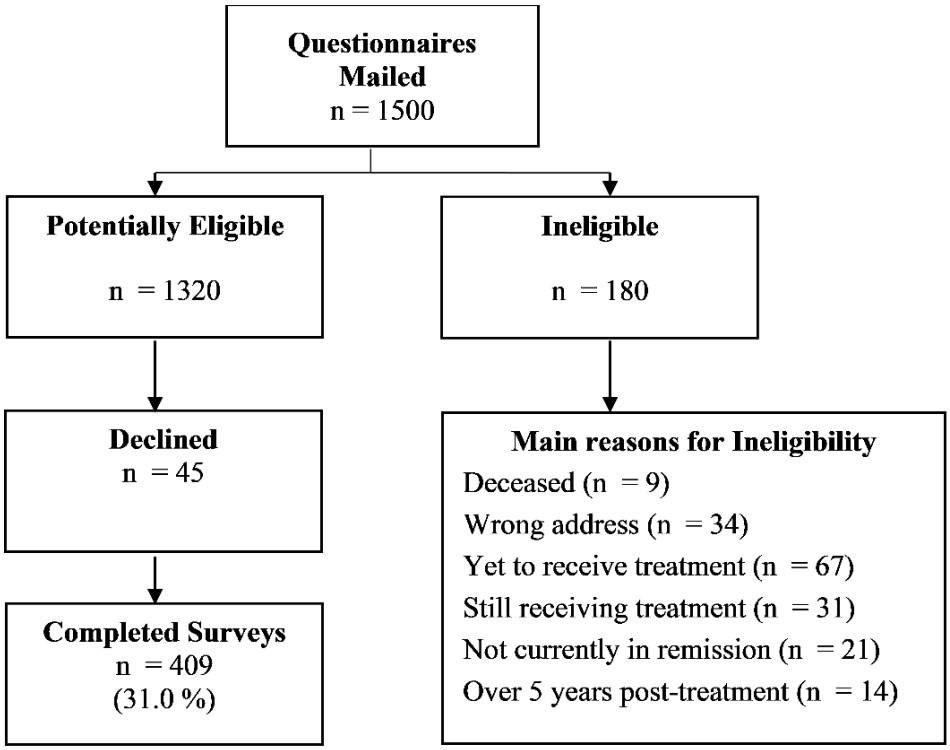

Figure 6.1. Study recruitment flowchart

Sample Characteristics

Participants were aged between 19 and 93 years old (mean = 63.3), slightly more were male (58.9%), and the majority were New Zealand European (82.2%). Over half had been diagnosed with non-Hodgkin's lymphoma (56.8%). Participants reported finishing treatment between 1 and 60 months prior to the survey (mean = 27.9; See Table 6.3). These characteristics are overall representative of the overall study population characteristics which are: age (mean = 62.3), males (58.2%), New Zealand European (70.5%), and non-Hodgkin's lymphoma (46.9%)

Table 6.3 Overall sample characteristics (*n* = 409).[a]

Gender	***n***	**%**
Male	241	58.9
Female	168	41.1
Age		
18–39	30	7.5
40–65	164	40.8
66 +	208	51.7
Ethnicity		
NZ European	336	82.2
Māori	31	7.6
Pacific	9	2.2
Asian	16	3.9
Other	17	4.1
Born in NZ		
Yes	306	75
No	102	25
Partnership status		
In relationship[b]	310	75.8
Single[c]	99	24.2
Employment status		
Fulltime	125	30.6
Part-time	51	12.5
Unemployed	17	4.2
Not working/on sick leave because of cancer-related issues	29	7.1
Retired	186	45.6
Time post-treatment		
0–12 months	89	22.3
13–24 months	122	30.6
25–36 months	65	16.3
37–48 months	64	16.0
49–60 months	59	14.8
Cancer type		
Non-Hodgkin's lymphoma	226	56.8
Hodgkin's lymphoma	30	7.5
Acute leukaemia	42	10.6
Chronic leukaemia	34	8.5
Multiple myeloma and other MPCN[d]	66	16.6
Treatment type[e]		
Chemotherapy	362	88.5
Radiotherapy	123	30.1
Surgery	60	14.7
Stem cell transplant	82	20.0
Fear of recurrence (FoR)		
Low FoR	312	79.4
High FoR	81	20.6
Social support		
Low/moderate support	84	21.6
High support	305	78.4

[a] Not all totals add to 409 because of missing data. [b] incl. married, civil union, de facto. [c] incl. divorced, separated, widowed. [d] Malignant Plasma Cell Neoplasms. [e] Not mutually exclusive categories.

Table 6.4 Distress by demographic and clinical variables.

Characteristics	Categories	Total[a] *n* (%)	Significant distress *n* (%)	95% C.I	χ2	*p*
Age	18–39	30 (7.6)	11 (36.7)	19.9, 56.1	8.34	.01
	40–65	162 (41.1)	42 (25.9)	19.4, 33.4		
	66+	202 (51.3)	34 (16.8)	11.9, 22.7		
Gender	Male	238 (59.4)	42 (17.6)	13.0, 23.1	6.32	.01
	Female	163 (40.6)	46 (28.2)	21.5, 35.8		
Ethnicity	New Zealand European	329 (82.0)	71 (21.6)	17.3, 26.4	0.79	.70
	Māori	31 (7.7)	6 (19.4)	7.5, 37.5		
	Other	41 (10.2)	11 (26.8)	14.2, 42.9		
Partnership status	In relationship	302 (75.3)	61 (20.2)	15.8, 25.2	2.18	.14
	Single	99 (24.7)	27 (27.3)	18.8, 37.1		
Living with	Alone	70 (17.5)	18 (25.7)	16.0, 25.7	0.70	.40
	With others	331 (82.5)	70 (21.1)	16.9, 25.9		
Employment status	Employed full-time	123 (30.8)	35 (28.5)	20.7, 37.3	10.15	.006
	Unemployed/sick leave	46 (11.5)	15 (32.6)	19.5, 48.0		
	Employed part-time	231 (57.8)	38 (16.5)	11.9, 21.9		
Born in NZ	Yes	300 (75.0)	59 (19.7)	15.3, 24.6	3.06	.08
	No	100 (25.0)	28 (28.0)	19.5, 37.9		
Cancer type	Non-Hodgkin's Lymphoma	226 (56.8)	53 (23.5)	18.1, 29.5	2.03	.73
	Hodgkin's Lymphoma	30 (7.5)	6 (20.0)	7.7, 38.6		
	Acute Leukaemia	42 (10.6)	11(26.2)	13.9, 42.0		
	Chronic leukaemia	34 (8.5)	5 (14.7)	5.00, 31.1		
	Multiple Myeloma & other MPCN[b]	66 (16.6)	13 (19.7)	10.9, 31.3		
Time post-treatment	0–12 months	87 (22.3)	21 (24.1)	15.6, 34.5	1.37	.85
	13–24 months	119 (30.4)	28 (23.5)	16.2, 32.2		
	25–36 months	64 (16.4)	11 (17.2)	8.9, 28.7		
	37–48 months	62 (15.9)	13 (21.0)	11.7, 33.2		
	49–60 months	59 (15.1)	14 (23.7)	13.6, 36.6		
Treatment type[c]	Chemotherapy	355 (88.5)	79 (22.3)	18.0, 26.9	0.18	.68
	Radiotherapy	120 (29.9)	25 (20.8)	14.0, 29.2	0.12	.72
	Surgery	58 (14.5)	11 (19.0)	9.9, 31.4	0.35	.55
	Stem Cell Transplant	80 (20.0)	18 (22.5)	13.9, 33.2	0.02	.89
Fear of recurrence (FoR)	Low FoR	307 (79.3)	45 (14.7)	10.9, 19.1	46.25	.000
	High FoR	80 (20.7)	40 (50.0)	38.6, 61.4		
Social support	Low/moderate support	83 (21.6)	33 (39.8)	29.2, 51.1	22.99	.000
	High support	301 (78.4)	47 (15.6)	11.7, 20.2		

[a] Totals vary from overall sample (n = 409) because not everyone answered the distress question. [b] Malignant Plasma Cell Neoplasms. [c] Not mutually exclusive categories. Chi Square calculated for yes versus no for each treatment type.

Prevalence and Associated Factors of Significant Distress

Overall 21.9% (*n* = 88) [95% C.I. 17.9, 26.3] of participants indicted they were suffering significant distress (DT ≥ 4; Table 6.4). Chi square analyses identified higher numbers of significant distress for the following groups: those aged 18–39 (χ2 = 8.34, *p* = .01), females (χ2 = 6.32, *p* = .01), those unemployed or on sick leave status (χ2 = 10.15, *p* =.006), those with low social support (χ2 = 22.97, *p* <.001), and those with high FoR (χ2 = 46.25, *p* <.001; Table 6.4).

Predictors of Distress-Regression

To identify predictors of significant distress (DT ≥ 4) logistic regression with hierarchical entry was used. Significant distress was coded as a dichotomous variable (as above). The initial model contained the following variables: age, gender, ethnicity, living situation, employment status, born in NZ (block one) and FoR and Social Support (block 2). After eliminating non-significant predictors (gender and employment status) the final model included demographic variables: age, ethnicity, living situation, born in NZ (block one) and FoR and Social Support (block 2). The final model accounted for 24% (R^2 = 0.244) of the variance in distress. The overall model fit was significant ($\chi 2 = 61.79$, p <.001), with the model correctly classifying 80% of those with significant distress as measured by the percentage accuracy in classification test. Results for the final model show that the odds of significant distress (DT ≥4) was two times greater in those not born in NZ (OR = 2.09, SE = 0.33, p = .03), 3.5 times greater odds in those with lower social support (OR = 3.51, SE = 0.32, p = <.001) and five times greater odds in those with increased FoR (OR = 0.17, SE = 5.51, p = <.001; see Table 6.5).

Table 6.5. Predictors of distress in haematological cancer survivors.

	B	**S.E.**	**Wald**	***p***	**OR[a]**	**CI[b]**
Living with	–.026	.390	.004	.947	.975	.45–2.09
Age	.445	.411	1.168	.280	1.560	.70–3.49
Ethnicity	–.300	.395	.578	.447	.741	.34–1.61
Born in New Zealand	.739	.333	4.914	**.027**	2.093	1.09–4.02
Social Support	1.255	.319	15.520	**.000**	3.507	1.88–6.55
Fear of Recurrence	1.707	.312	29.829	**.000**	5.511	2.99–10.17

* p < .05.
[a] OR equals odds-ratio.
[b] Confidence Intervals.

Discussion

Prevalence of Distress

This study importantly fills a gap in research pertaining to distress in early post-treatment haematological cancer survivors. In this sample of post-treatment haematological cancer survivors, 21.9% were suffering significant distress. The one other study focusing on distress in early post-treatment haematological cancer survivors reported that 31% of survivors report distress (Jones, Parry, Devine, Main, Okuyama, et al., 2015). A second study looked at depression and anxiety (which fit within the umbrella of distress) in long-term haematological cancer survivors, however, they provided results for participants between 2.5 and 12+ years post-treatment (Kuba et al., 2019). The closest post-treatment time category to participants in this current study was 2.5–5.9 years, so the key period relevant to the current study (0–2.5 years post-treatment) was not a focus. The Kuba et al. (2019) study found and reported that in the 2.5–5.9 group that 19% of survivors had depression, and 12% had anxiety. Furthermore, neither of these studies (Jones, Parry, Devine, Main, Okuyama, et al., 2015; Kuba et al., 2019) used the DT as a distress measure, so exact comparison is difficult. Another study looked at distress in Hodgkin lymphoma (HL) survivors across the survivorship continuum,

however, they measured distress by clinical encounter rather than by person (Troy et al., 2019). They did report that for those ≥ 5 post-treatment the rate of distress per clinical visit was 20.4%, this is comparable to the overall prevalence of distress (20.0%) in the HL survivors in the present study.

Of particular interest in the current study is the prevalence of distress in certain groups: younger people aged 18–39 (36.7% reported significant distress), those unemployed or on sick leave (32.6% reported significant distress) and women (28.2% reported significant distress). The association between younger age and increased post-treatment distress has been shown in previous research (Jones, Parry, Devine, Main, & Okuyama, 2015). One study looking at employment issues in haematological cancer survivors found those currently not working had higher levels of anxiety and depression than the survivors who had returned to work (Horsboel et al., 2015). Also, the finding in this current research aligns with previous studies examining gender differences in distress with cancer survivors that has shown that overall women report more distress than men (Loscalzo & Clark, 2018).

Predictors of Distress

Regression analyses showed the three factors that significantly predicted distress in this group of participants were whether a person was born in NZ, low social support and high fear of recurrence FoR. The issues surrounding those who were not born in NZ are most likely multifactorial. One potential issue is the lack of extended family that is often associated with immigrating to a new country. Having less extended family around can mean people are missing that extra support system that may provide extra emotional or practical support during cancer treatment and into the survivorship period (Raphael et al., 2019a). There may also be cultural aspects that impact those in a new country influencing how they cope with illness and the health system, as well as a lack of familiarity with the health system (Lassetter & Callister, 2009). There is limited research focusing on the psychosocial effect cancer has for migrants but available research shows that being a migrant with cancer leads to poorer psychosocial and health-related quality of life outcomes than non-migrants (Sze et al., 2015).

Social support is thought to be a buffer for people dealing with cancer (Mishel, 1988), and research shows that those cancer survivors with better perceived social support report lower distress (Harding, 2014). A recent meta-analysis showed that perceived social support was significantly associated with lowered mortality in cancer patients, and with a stronger association in leukaemia and lymphoma patients than in other patients (Pinquart & Duberstein, 2010). Lack of social support in cancer survivors has been associated with increased emotional distress and depression (Ranchor et al., 2002).

It is not surprising that fear of recurrence FoR was a significant predictor of distress with research showing between 22 and 87% of cancer survivors report FoR (Simard, Savard, & Ivers, 2010). Previous literature also shows FoR is associated with higher distress (Ness et al., 2013). FoR

has been described as an “intense multidimensional experience, that extends along a continuum of adaptive and maladaptive responses” (Almeida, Elliott, Silva, & Sales, 2019, p. 13). FoR is considered a distinct phenomenon, and although similar to other psychological sequelae (such as anxiety disorders), it has its own unique elements. Therefore, it is important that FoR is treated according to its own particular features separate to distress as although they may have similarities, they are different phenomena. A particularly relevant study of a large sample (n = 1281) of survivors with mixed cancer types found that having a haematological cancer was a predictor of FoR (Mehnert, Koch, Sundermann, & Dinkel, 2013). The same study also reported that lower social support was a predictor of FoR, which aligns with the finding above regarding increased distress in those with lower social support.

Helping to identify those with the above predictors would potentially help those haematological cancer survivors who may be struggling in the post-treatment period. There appears a need to especially target those who have migrated to NZ and may not have the resources to cope with cancer. There also seems a strong link to lack of social support and attention needs to be paid to those who do not have others around to support them.

Recent research shows the importance of distress screening in enabling early intervention and improvement in psychological wellbeing (Rana et al., 2019). However, the researchers point out that, although there are many quick and simple methods of distress screening available, it is still not widely implemented, and using new and innovative methods (using emerging technologies) may increase screening (Rana et al., 2019). As mentioned earlier, distress is often not detected in primary care settings (Mitchell, Vahabzadeh, et al., 2011), however, in NZ it is important to implement effective distress screening in primary care settings as post-treatment survivors are likely to see their GP more frequently than a haematologist. The introduction of screening at least starts a process that enables cancer survivors to talk with health professionals, research examining the sustainability of distress screening found that a positive outcome was that screening started a dialogue between health professionals and patients, and improved communication (Groff, Holroyd-Leduc, White, & Bultz, 2018).

Study Strengths and Limitations

This study is cross-sectional, therefore, does not infer causality. Another limitation is the fact that participants were recruited through a cancer registry, which provided no indicator of treatment status. Because we did not have information about whether a person was post-treatment we had to rely on the participant to include or exclude themselves regarding their treatment and remission status. This may have meant those who were unsure about their status would not participate. Although many participants called the researchers to discuss eligibility, there may have been some that just opted out because they were unsure or incorrect about eligibility.

However, this study also has many strengths. First, it is only one of two studies that have measured the prevalence of distress in post-treatment haematological cancer survivors, and the only study conducted on a nationwide scale. Also the sample is highly comparable to the overall haematological cancer survivor population in NZ, so could be generalized to the wider population.

Clinical Implications

Early identification of distress may decrease psychosocial issues in the post-treatment period (Beckjord et al., 2013). Psychosocial services have been shown to improve wellbeing (Grassi, Spiegel, & Riba, 2017) so identifying those with distress is essential. Our findings point to the specific attention that needs to be directed at cancer survivors who are migrants and may not have the social networks to cope with cancer and also may have difficulty navigating a foreign health care system. Our previous research confirms that health professionals need to be more proactive in helping identify sources of social support for survivors (Raphael et al., 2019a). It is also important the clinicians are aware of the propensity for haematological cancer survivors to suffer from high levels of fear of recurrence, especially considering this is associated with higher distress.

Conclusion

Over a fifth of haematological cancer survivors in this study were dealing with distress after treatment ended, with migrants and survivors lacking social support particularly at risk of distress. Fear of recurrence has also shown to be a significant predictor of distress for participants. Distress screening is essential for cancer survivors as it provides the opportunity to identify those in need of psychosocial support and offer solutions to improve their psychosocial wellbeing.

Disclosure Statement

No potential conflict of interest was reported by the authors.

Chapter Summary

This chapter demonstrated that the questionnaire used in Phase Two was reliable and valid. Results were also presented showing that nearly a quarter of post-treatment haematological cancer survivors were distressed, with migrants and those lacking social support being more likely to be significantly distressed. The following chapter presents further findings from Phase Two, addressing the association between distress and the psychological support requirements of haematological cancer survivors and outlining the type of psychological support survivors prefer.

Chapter Seven: Psychological Support Requirements of Haematological Cancer Survivors: How can Health Professionals Meet Their Needs?

Preface

The previous chapter reported the prevalence and predictors of distress in haematological cancer survivors, with a key finding that survivors lacking social support were more likely to suffer significant distress. This chapter presents further quantitative results from the second phase of this research in relation to the association between distress and psychological support from health professionals. The number of survivors who wanted more psychological support from a health professional is also considered, along with information about the preferred nature of this support.

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Article: Psychological Support Requirements of Haematological Cancer Survivors: How can Health Professionals Meet Their Needs?

Abstract

Complex and intensive treatment may lead to psychosocial issues for haematological cancer survivors, which may endure after treatment. Psychological support is important for cancer survivors but not always available. This study aimed to determine the health professional psychological support needs of post-treatment haematological cancer survivors, through the use of a cross-sectional survey. Chi-Square analyses were used to calculate the differences in need for psychological support. Open text responses were analysed using quantitative content analysis. Four hundred and nine questionnaires were completed. Around a quarter (24.6%) of participants reported needing more psychological support from a health professional, especially those who were aged 18–39, females, 'Other' ethnicity, single, living with other family/roommates, unemployed/on sick leave, suffering significant distress, and those with low/moderate social support. The majority of those desiring more support preferred it from a psychologist/counsellor (58.3%), or a haematologist (39.3%). Haematologists are a regular point of contact for these survivors and not only have the opportunity to discuss psychological issues with patients but to determine who needs referring to further psychological treatment. Furthermore, the number of participant's reporting the need for extra psychological support from a psychologist/counsellor means it is imperative that these services are available and known to those requiring them.

Introduction

Five-year survival is increasing for most haematological cancers (Pulte, Jansen, & Brenner, 2016) due to innovative and more effective treatments (Sant et al., 2014). Though increasingly successful, these treatment regimens for haematological cancers are often complex and intensive (Lobb et al., 2009) and have been associated with higher psychological distress compared to those with other cancer types (Carlson et al., 2004).

Psychosocial issues relating to cancer and its treatment can often endure once treatment has ended (Philip & Merluzzi, 2016). Research shows although psychosocial issues may continue for haematological cancer survivors in the post-treatment phase, support is not always available, especially psychological support (Swash, Bramwell, & Hulbert-Williams, 2017; Swash, Hulbert-Williams, & Bramwell, 2016). Post-treatment survivors often rely on informal support (family friends etc.) because psychological support from health professionals is lacking (Pascal, Johnson, Dickson-Swift, & Kenny, 2015). However, research also shows that support decreases from informal networks as well as health professionals as time progresses (Arora et al., 2007) meaning post-treatment support may be limited.

Not all psychological support has to be provided by a mental health professional. A National Institute for Health and Care Excellence (NICE) report recommends that health professionals dealing with cancer patients should offer informal psychological support to patients as following 'All staff directly responsible for patient care should offer patients general emotional support based on skilled communication, effective provision of information, courtesy and respect.' (National Institute for Clinical Excellence, 2004, p. 76). The report also suggests that health and social care professionals should be able to identify distress and know when a cancer patient needs advanced help to deal with it, and then refer on to a more specialised service. Higher levels of their psychological support framework deal with a more complex assessment of distress and treatment, which they recommend should be handled by psychological specialists.

It is important to note that psychological support is used interchangeably in the literature with terms such as psychosocial support and emotional support (Skilbeck & Payne, 2003). In this paper, these terms are considered analogous to psychological support. There are varying types of psychological support that may be used in helping cancer survivors (as described above in the NICE framework) which may range from general emotional support through to professional psychological treatment. Previous research reports mixed results regarding the efficacy of psychological intervention for cancer survivors (Faller et al., 2013). However, there is evidence that psychological interventions have shown benefits such as improving quality of life (de la Torre-Luque, Gambara, López, & Cruzado, 2016) and reducing distress (Faller et al., 2013).

Research has also shown that a survivors' psychological health can be improved by improving relationships between health professionals and cancer survivors (Tremolada, Bonichini, Basso, & Pillon, 2018). The Tremolada et al. (2018) study also found that survivors in remission who have formed good relationships with medical staff are more likely to have positive experiences during hospital follow-up visits.

Alongside psychological support from health professionals, survivors often rely on social support from their own social networks (especially family and friends), while in treatment, and in the post-treatment phase. Social support is described as a multi-dimensional concept, consisting of three main components: emotional support, informational support and instrumental support (Thoits, 1986). Emotional support is thought to be particularly important for a survivor's adjustment to cancer (Helgeson & Cohen, 1996). Pinquart and Duberstein (2010) found social support was associated with decreases in mortality especially for leukaemia and lymphoma survivors, and they suggest that these patients may benefit more than other cancer types from increased social support. Higher levels of social support in cancer survivors are also associated with decreased levels of distress (Kavitha & Jayan, 2014); lower levels of anxiety and depression (Şengül, Kaya, Şen, & Kaya, 2014) and improved quality of life (Ng et al., 2015).

The aims of this study were to 1. Determine how many post-treatment haematological cancer survivors feel they receive psychological support from health professionals. 2. Determine how many post-treatment haematological cancer survivors require more psychological support from health professionals. 3. Examine whether the need for more psychological support is associated with distress and particular demographic variables. 4. Identify from which health professionals survivors prefer more psychological support. 5. Examine whether having lower levels of perceived social support increases the need for more psychological support from health professionals.

Methods

Design and Setting

A cross-sectional survey of haematological cancer survivors was conducted. Participants were selected from a national database which included all persons in New Zealand diagnosed with a haematological cancer between March 2012 and March 2017.

Participants

Adults (aged 18 years and over) who had completed treatment for a haematological cancer within the last 5 years were eligible for participation if they had been told by their doctor that they were in remission, or currently free of cancer. Treatment and remission status were ascertained at the beginning of the questionnaire with participants being invited to continue if they indicated they were post-treatment and in remission.

Data Collection

Participants were recruited from the New Zealand Cancer Registry (NZCR). The NZCR provided a database comprising all people (minus those recorded as deceased) diagnosed with a haematological cancer between 2012 and 2017. The NZCR data included name, postal address, date of diagnosis, and ICD-10 code (International Classification of Diseases, Tenth Revision). Recruitment was conducted between December 2017 and May 2018. A sample size calculation estimated that at least 350 participants were needed (Daniel, 1999). To ensure greater representation of different ethnic groups stratified random sampling was used. To ensure the sample size was adequate 1500 participants were selected comprising 20% of each major ethnic group in NZ (NZ European, Māori, Pacific, and Asian) were selected for recruitment. A further 20% were selected from the ‘Other” category, which comprised other ethnic groups (predominately Middle Eastern, Latin American, African, and other European). Those selected were mailed an information sheet which provided a thorough outline of the study, and the questionnaire. The information sheet also provided a URL address for the online version of the questionnaire if they preferred to complete the questionnaire electronically. Informed consent was obtained from all participants. Ethical approval for this study was granted by the Southern Health and Disability Ethics Committee (Ref: 15/STH82)

Measures

The following Demographic information was collected; gender, age, country of birth, ethnicity, and living situation (living alone or with others). There was also clinical information collected which included the type of cancer and the number of months since their treatment had ended.

Distress

The Distress Thermometer (DT), which has proven to be a valid and reliable measure of distress in cancer patients, was used to measure psychological distress (Donovan et al., 2014; National Comprehensive Cancer Network, 2013). The DT comprises a single-item visual analogue scale which ranges from 0 (no distress) to 10 (extreme distress), with participants asked to circle the number which represents how much distress they have felt in the last week. A cut-off point of ≥ 4 has shown good sensitivity and specificity in identifying those suffering significant distress (Mitchell, 2007).

Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) was used to measure perceptions of social support (Zimet et al., 1988). The MSPSS consists of 12 items which use 7-point Likert scales ranging from 1 (very strongly disagree) to 7 (very strongly agree), with higher scores indicating higher levels of perceived social support. The MSPSS has proven to be a reliable and valid measure (α = 0.88) (Zimet et al., 1988) and showed a high level of internal consistency when used with the current sample (α = 0.95).

Health Professional Support

As no existing measure was suitable to answer our research questions relating to psychological support from a health professional, a measure was created. This measure included questions regarding the participant's receipt of psychological or emotional support from health professionals in the post-treatment period. Participants were asked 'do you feel you need more psychological support from health professionals since your primary treatment ended? If they indicated yes to this question they were asked to indicate who they would like this support from (haematologist, nurse, GP, psychologist/counsellor, or social worker), and complete an open text box asking what type of support they would like.

Statistical Analysis

All statistical analyses were conducted using SPSS version 25. Descriptive statistics were conducted to explore sociodemographic variables and calculate scores on the MSPSS, DT, and the Measure of Health Professional Support. Pearson's Chi-Square analyses were used to calculate the differences between the need for HP psychological support with the MSPSS, DT and various sociodemographic and clinical variables. Open text responses were analysed using quantitative content analysis (White & Marsh, 2006). The content analysis process involved coding data, analysing patterns and

relationships among the codes which were organised into categories. Descriptive statistics were then used to calculate counts and percentages. As some of the responses contained more than one code, the number of codes was higher than the number of respondents.

Results

Sample

Using stratified random sampling 1500 questionnaires were needed to ensure 20% of the ethnic groups (described earlier) were sent questionnaires. The flowchart (Figure 7.1) shows the recruitment and response rates and provides the number and description of ineligible participants. The final number of eligible questionnaires was 409, meaning a response rate of 31.0%. However, this is a conservative estimate because of the high probability that a number of non-responders were ineligible as NZCR data provided did not provide information about whether a person was post-treatment. Overall, 45 potential participants declined, and the main reason for those who provided a reason (n = 24) was they did not see their diagnosis as relevant (n = 10) or inability to complete because they were unwell (n = 8). Sample characteristics are provided in Table 7.1.

Participants were aged between 19 and 93 years (mean = 63.3), over half were men (58.9%) and the majority were of New Zealand European descent (82.2%). Non-Hodgkin's lymphoma was the most common diagnosis (56.8%) and respondents reported finishing treatment an average of 27.9 months previously (range 1-60 months).

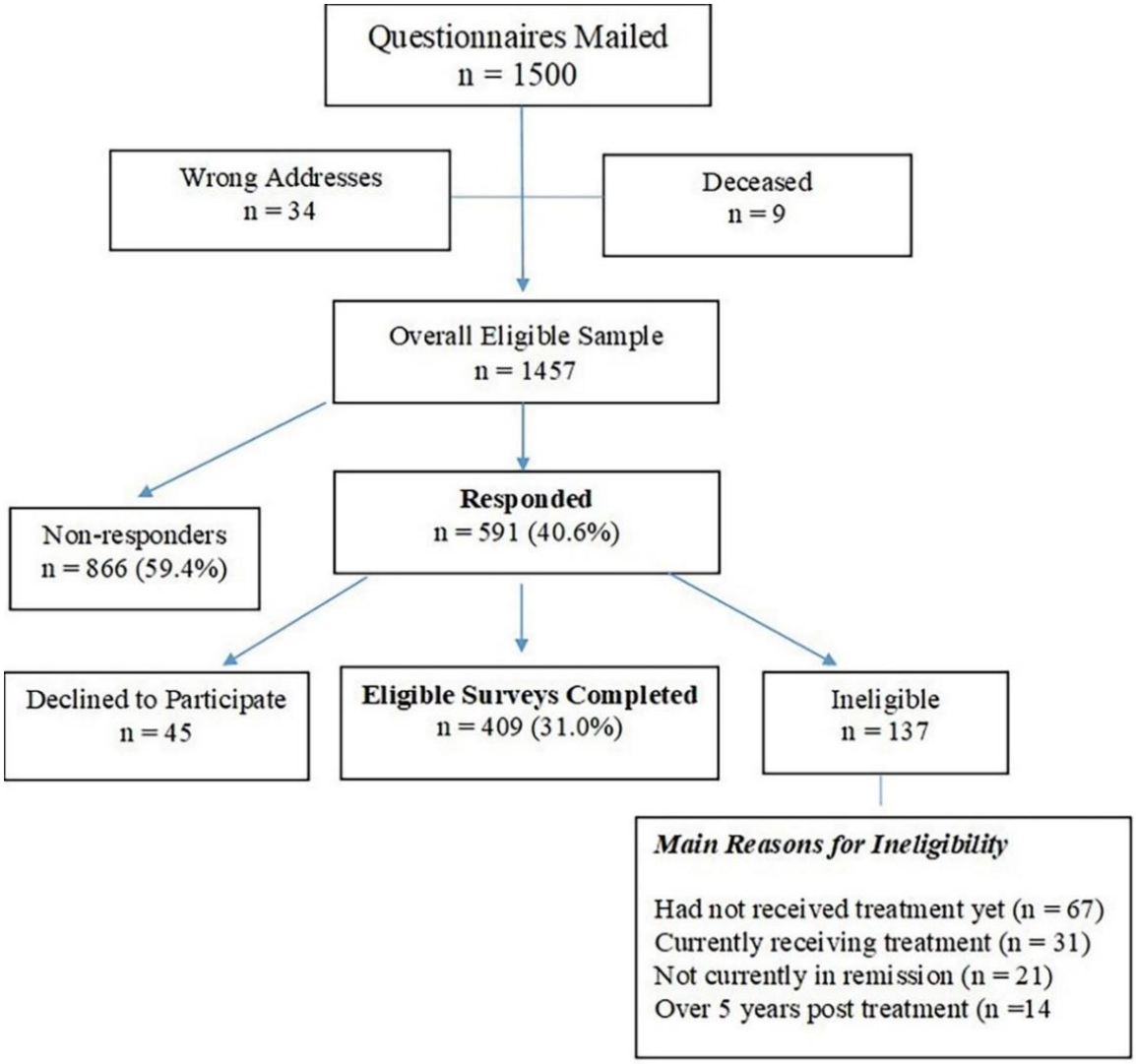

Figure 7.1. Recruitment flowchart

Table 7.1. Sample characteristics

Gender	n	%
Male	241	58.9
Female	168	41.1
Age		
18-39	30	7.5
40-65	164	40.8
66 +	208	51.7
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Māori	31	7.6
Pacific	9	2.2
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Born in NZ		
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No	102	25
Partnership Status		
In relationship*	310	75.8
Single**	99	24.2
Employment Status		
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Part-time	51	12.5
Unemployed	17	4.2
Not working/on sick leave because of cancer-related issues	29	7.1
Retired	186	45.6
Time post-treatment		
0-12 months	89	22.3
13-24 months	122	30.6
25-36 months	65	16.3
37-48 months	64	16.0
49-60 months	59	14.8
Cancer Type		
Non-Hodgkin's Lymphoma	226	56.8
Hodgkin's Lymphoma	30	7.5
Acute Leukaemia	42	10.6
Chronic leukaemia	34	8.5
Multiple Myeloma and other MPCN***	66	16.6
Significant Distress		
Yes	88	21.9
No	314	78.1
Social support		
Low/moderate support	84	21.6
High support	305	78.4

**incl. married, civil union, de facto. **incl. divorced, separated, widowed. ***Malignant Plasma Cell Neoplasms*

Health Professional Support

Just over half of participants (53.2%) reported receiving psychological support from a health professional, including a haematologist (68.3%), GP (57.6%), nurse (28.8%), psychologist/counsellor (16.1%) and social worker (5.9%). Of the participants who reported receiving no psychological support from a health professional (46.8%), 24.6% reported feeling like they needed more psychological support from a health professional. Of those who signalled the desire for more health professional support, the majority indicated they preferred psychological support from a psychologist/counsellor (58.3%), followed by a haematologist (39.3%), a social worker (28.1%), a GP (28.1%) and a nurse (15.6%).

The content analysis (Table 7.3.) explored further the type of support participant's wanted from haematologists and psychologists/counsellor as they were the top two preferred providers of support. Participants reported needing three categories of psychological support from a haematologist: Interpersonal behaviours (39%), Increased follow-up and general support (37%), and Information/advice regarding ongoing physical concerns (24%). Four categories of support were reported to be needed from a psychologist/counsellor: A person who listens (43%), Strategies to assist with problems/concerns (22%), Increased availability of counselling/psychological services (22%) and Need for counselling/therapy in general (13%).

Table 7.2. Differences in need for health professional support

Characteristics	Categories	Total* *n* (%)	Need HP Support *n* (%)	χ2	*p*
Age	18-39	30 (7.9)	17 (56.7)	**26.79**	**0.00**
	40-65	162 (41.1)	47 (29.9)		
	66+	202 (51.0)	31 (15.9)		
Gender	Male	231 (59.4)	37 (16.0)	**22.95**	**0.00**
	Female	158 (40.6)	59 (37.3)		
Ethnicity	New Zealand European	322 (82.8)	70 (21.7)	**8.77**	**0.01**
	Māori	27 (6.9)	10 (37.0)		
	Other	40 (10.3)	16 (40.0)		
Partnership status	In relationship	296 (76.1)	65 (22.0)	**4.92**	**0.03**
	Single	93 (23.9)	31 (33.3)		
Living with	Alone	67 (17.2)	18 (26.9)	**21.24**	**0.00**
	Spouse only	199 (51.2)	31 (15.6)		
	Spouse and child/other relative	88 (22.6)	33 (37.5)		
	Other family or roommates	35 (9.0)	14 (40.0)		
Employment status	Employed Full-time	122 (31.4)	35 (28.7)	**10.11**	**0.006**
	Unemployed/Sick leave	45 (11.6)	18 (40.0)		
	Employed Part-time/Retired	222 (57.1)	43 (19.4)		
Born in NZ	Yes	289 (74.5)	65 (22.5)	3.08	0.08
	No	99 (25.5)	31 (31.3)		
Cancer type	Non-Hodgkin's Lymphoma	215 (55.7)	49 (22.8)	1.16	0.89
	Hodgkin's Lymphoma	30 (7.8)	7 (23.3)		
	Acute Leukaemia	40 (10.4)	11 (27.5)		
	Chronic leukaemia	34 (8.8)	9 (26.5)		
	Multiple Myeloma & other MPCN**	67 (17.4)	19 (28.4)		
Time post-treatment	0-12 months	84 (22.0)	20 (23.8)	1.41	0.84
	13-24 months	113 (29.7)	31 (27.4)		
	25-36 months	65 (17.1)	14 (21.5)		
	37-48 months	61 (16.0)	16 (26.2)		
	49-60 months	58 (15.2)	12 (20.7)		
Significant Distress	Yes	85 (22.1)	41 (48.2)	**32.37**	**0.00**
	No	299 (77.9)	54 (18.1)		
Social support	Low/moderate support	81 (21.6)	34 (42.0)	**15.73**	**0.00**
	High support	294 (78.4)	60 (20.4)		

** Not all totals add to 409 because of missing data. ** Malignant Plasma Cell Neoplasms.*

Table 7.3 Participant's preferences for psychological support from health professionals

Haematologist	**n**	**%**
Interpersonal behaviours	**18**	**39**
More reassurance/encouragement of current health status	5	
Better communication	4	
More interest in psychological wellbeing as well as physical aspects	3	
More caring and understanding attitude	3	
More time to talk about problems/concerns	3	
Increased follow-up and general support	**17**	**37**
More regular follow-up/monitoring	8	
Generally more support	4	
Follow-up with the same haematologist to build a relationship, and rapport	3	
Referral/information regarding psychosocial services	2	
Information/advice regarding ongoing physical concerns	**11**	**24**
Information/Advice about medical concerns and physical health	7	
Advice on lifestyle factors (i.e nutrition)	2	
Talk about fear of recurrence, or chances of another cancer	2	
Total	**46**	
Psychologist/counsellor		
A person who listens	**20**	**43**
Talk about psychosocial issues (incl. depression, guilt, work, the future)	11	
Just needing someone to talk to	9	
Strategies to assist with problems	**10**	**22**
Strategies to deal with unresolved issues and emotions	4	
Strategies to deal with post-treatment issues (incl. improving lifestyle habits)	3	
Strategies to deal with 'new normal' (physical and emotional changes)	3	
Increased availability of counselling/psychological services	**10**	**22**
More regular appointments/contact	4	
Having services available/offered	3	
Follow up services to check up on survivors	3	
Need for counselling/therapy in general	**6**	**13**
Counselling	4	
Psychotherapy	1	
One on one counselling	1	
Total	**46**	

Differences in Need for Health Professional Support

Chi Square analyses (Table 7.2) showed there were significant differences in specific demographic and clinical variables relating to their need for HP support. Those in the following groups reported needing more support: those aged 18-39 ($\chi 2 = 26.79$, $P = <0.000$); females ($\chi 2 = 22.95$, $P = <0.000$); those in the 'Other' ethnicity category ($\chi 2 = 8.7$, $P = 0.01$); those who were single ($\chi 2 = 4.92$, $P = <0.03$); those unemployed or on sick leave ($\chi 2 = 10.11$, $P = 0.006$); those suffering significant

distress ($\chi 2 = 32.37$, $P = <0.000$); those with low/moderate support ($\chi 2 = 15.73$, $P = <0.000$); and those living with other family/roommates ($\chi 2 = 21.24$, $P = <0.000$).

Discussion

This study aimed to ascertain the number of post-treatment haematological cancer survivors requiring more psychological support from health professionals. A secondary aim was to explore the type of psychological support they would find most helpful. Nearly a quarter (24.6%) of haematological cancer survivors reported needing more psychological support from a health professional in the post-treatment period. Those who expressed a desire for more support predominately wanted it from a psychologist or counsellor and reported wanting someone to talk to about psychosocial issues. Participants also mentioned wanting increased availability of psychological services. It is possible that some survivors were not aware of the availability of existing services, which stresses the need for them to have a health professional point of contact who can refer to additional support services if needed (Hackett & Dowling, 2019). Furthermore, in order to refer to psychosocial services, a physician must be able to either recognise a patient's need for psychological support or allow the patient to express any psychosocial concerns. However, physicians providing follow-up care for post-treatment survivors have very low recognition of psychosocial distress (Werner, Stenner, & Schuz, 2012).

A number of participants also indicated that they wanted more psychological support from their haematologist. This aligns with a review of post-treatment survivor's experiences with follow-up consultations that showed that patients valued psychosocial support but that it was lacking in follow-up appointments (Lewis et al., 2009). The fact that a high percentage of participants wanted psychological support from their haematologist could be because not everyone is comfortable seeing a mental health professional (Arts et al., 2018).

When asked what type of psychological support from a haematologist would be helpful for them in the post-treatment period, the content analysis showed that participants desired more support in relation to the physician's interpersonal behaviours (such as encouragement, caring, understanding, and better communication). This aligns with previous research which showed that cancer patients report more satisfactory treatment experiences when treated with compassion by health professionals (Staren, 2006). Research also shows that patients are more likely to speak of anxiety and fear if the health professional is showing empathy (Anderson et al., 2008). Furthermore, cancer patients treated with attentiveness and empathy by physicians show lower emotional distress (Zachariae et al., 2003). Empathy and improved communication from health professionals has also shown to improve patient satisfaction in young adult post-treatment cancer survivors (Tremolada et al., 2015).

Participants also indicated wanting more time to talk with their haematologist about their problems, and psychological issues, rather than just focus on physical problems. Previous literature shows that having a discussion with a health professional about the emotional impact of cancer was correlated

with increased patient satisfaction (Bonito, Horowitz, McCorkle, & Chagpar, 2013). Furthermore, health professionals are also aware of this need as shown by a study of primary care physicians and oncologists which reported that they actually saw themselves as responsible for providing psychosocial care for survivors, however only half of them report actually providing this care (Forsythe et al., 2012). Other research has shown that health professionals often report not providing psychosocial care because of factors such as lack of time and resources (Schouten, Bergs, Vankrunkelsven, & Hellings, 2019), lack of skills and training in psychosocial issues, and organisational barriers (Dilworth, Higgins, Parker, Kelly, & Turner, 2014).

The finding that those with higher distress reported needing more psychological support from a health professional is consistent with existing literature. Previous research has shown high distress in post-treatment cancer survivors with mixed cancers was a predictor of whether a person wanted to speak to a health professional (Philip & Merluzzi, 2016). It has also been found that oncologists find it challenging to deal with patients' distress because of factors such as lack of time, a lack of a protocol to deal with distress, and limited psychosocial resources to be able to refer patients to (Granek, Nakash, Ben-David, Shapira, & Ariad, 2018). Distress also links back to the discussion around participants wanting particular interpersonal attributes from their haematologist. With a recent study featuring mixed cancer patients visiting outpatient's services showing that participants who were emotionally distressed were more likely to view their physicians as disengaged, lacking empathy, and only focused on physical aspects rather than emotional concerns (Meggiolaro et al., 2015).

There was a significant difference in desire for psychological support for those aged 18-39 versus older participants and female gender compared to male. This aligns with a large multicentre study, which included post-treatment cancer survivors, which found that younger age and female gender was an indicator of the need for more psychosocial support (Faller, Weis, et al., 2016). There is also evidence that younger age and gender are related to distress in post-treatment haematological cancer survivors (Jones, Parry, Devine, Main, & Okuyama, 2015) which relates to our finding that higher distress is related to increased need for psychological support from a health professional.

There was also a significant difference in those with low levels of social support in their need for health professional support. This is shown in previous research which reported post-treatment cancer survivors with lower amounts of social support were significantly more likely to desire increased follow-up from health professionals (Philip & Merluzzi, 2016). It is also important for health professionals to recognise that having a social network of people around does not always equal adequate psychological support. A study of post-treatment lymphoma survivors (Monterosso et al., 2017) showed that some survivors felt that their family and friends do not always understand what they were going through. Furthermore, the expectation by family and friends was that once treatment was over a survivor should be back to normal and physically healthy, even though they might actually be struggling (Monterosso et al., 2017).

There are some limitations that should be acknowledged in this study. This is a cross-sectional study, therefore causality cannot be inferred. Furthermore, participants were recruited through a national cancer registry which was unable to provide information about treatment status. Because of the lack of information about treatment status we had to rely on the participant's ability to judge their eligibility for inclusion in the study. Although a number of potential participants contacted the researchers to discuss their eligibility it is possible that some suitable participants opted out because they were unsure or incorrect about their eligibility. However, the strengths of this study include that it was conducted on a nationwide scale, and with a sample highly comparable to the New Zealand haematological cancer survivor population, allowing generalisability. This study also adds to the limited psychosocial research on post-treatment haematological cancer survivors.

Conclusion

Approximately a quarter of post-treatment haematological cancer survivors want more psychological support from a health professional. Haematologists and oncologists are a regular point of contact for these survivors and not only have the opportunity to discuss psychological issues with patients but to determine who needs a referral to more advanced psychological treatment. As the majority of participant's who wanted extra psychological support wanted it from a psychologist or counsellor, it is imperative that these types of services are available and known to those who need them.

Conflict of Interest

The authors declare that they have no conflicts of interest.

Chapter Summary

This chapter reported additional results from Phase Two of the research which found that almost a quarter of post-treatment haematological cancer survivors wanted more psychological support from a health professional. Results also showed that the participants wanted additional support from a psychologist or counsellor, or their haematologist. The implications of these findings – and the findings of all research reported in this thesis – are discussed in the following chapter.

Chapter Eight: Discussion/Conclusion

In this chapter I will briefly reiterate the method of integrating the qualitative and quantitative phases, then present the main findings of this research in relation to the stated aim and objectives. I then discuss the findings in relation to the Andykowski et al (2008) framework and build upon this framework with results from the current research. I will conclude by outlining the recommendations for policy and practice and future research that have been derived from this research.

This research used an exploratory sequential mixed methods approach to address the following aim and objectives.

Aim

To investigate the nature, magnitude, and timing of psychosocial distress post-treatment amongst haematological cancer survivors in Aotearoa New Zealand and to explore their experiences of post-treatment support.

Objectives

1. Explore the nature and timing of psychosocial distress experienced by post-treatment haematological cancer survivors.
2. Calculate the prevalence of psychosocial distress suffered by post-treatment haematological cancer survivors.
3. Identify, the (self-defined) supports and barriers for post-treatment cancer survivors when dealing with psychosocial distress.
4. Develop recommendations to improve service delivery to haematological cancer survivors.

Integrated Findings

The integration of findings is discussed in more detail in the methodology chapter (Chapter Three). Below I present the integration of findings at the interpretation stage. This integration was achieved through a narrative approach, in particular the contiguous and weaving approaches. The contiguous approach means the quantitative and qualitative results were analysed and reported separately. The weaving approach involves amalgamating and writing both qualitative and quantitative findings together and organizing them by themes or concepts (Fetters et al, 2013). The themes I developed from working with Phase One and Phase Two findings in this way are presented below and discussed in relation to the literature. Furthermore, the literature relevant to this research has been updated since the integrative review was conducted and has been used to inform this discussion.

The Prevalence and Timing of Distress in Haematological Cancer Survivors in the Post-Treatment Period

Prevalence of Distress

The Phase One interviews found that most haematological cancer survivor participants reported some manner of distress. Building on this, the prevalence of distress was measured in the Phase Two survey. The results showed that 21.9% of participants from this group were suffering significant distress. This is an important finding because, as identified in Chapter Two, this is the first and only study to date that has measured distress in post-treatment haematological cancer survivors on a national level.

The one other study focusing primarily on distress in early post-treatment haematological cancer survivors concluded that 31% of survivors report distress (Jones, Parry, Devine, Main, Okuyama, et al., 2015). However, this study only measured distress in one US state. Another study, published since the integrative review (Chapter Two), looked at distress in Hodgkin lymphoma survivors across the survivorship continuum. However, they measured distress by clinical encounter rather than by person (Troy et al., 2019). This meant that most patients visited more than once and so their distress score was calculated at each visit and counted as a separate score. This made it hard to know the prevalence of distress for individuals with lymphoma as the scores were not independent of each other. They did report that for those ≥ 5 year post-treatment the rate of distress per clinical visit was 20.4% which was comparable to the overall prevalence of distress (20.0%) among the Hodgkin's lymphoma survivors found in the present research.

Two further articles that met the inclusion criteria for the integrative review were published subsequently. Walburg et al (2019) primarily aimed to measure fear of cancer recurrence amongst post-treatment lymphoma survivors, but also used the Hospital Anxiety and Depression Scale (HADS) to measure anxiety and depression. The scores they presented showed that overall mean scores for anxiety and depression were within the normal range (HADS anxiety score = 4.7 and HADS depression score = 3.8). However, they report that survivors with clinical levels of fear of cancer recurrence reported significantly higher anxiety and depression scores, although these scores still fall within a normal range (HADS anxiety score = 6.1 and HADS depression score = 4.7).

Trachtenberg et al (2018) assessed the incidence and characteristics of cancer-related cognitive impairment (CRCI) in Hodgkin lymphoma survivors who were six months to five years post-treatment. They also measured depression (using The Beck Depression Inventory) and anxiety (using the Hamilton Anxiety Rating Scale). They report 4% of participants had severe anxiety, but do not report on the number that had mild or moderate anxiety. They also report that only 2% of participants had severe depression, but again do not report on the participants who may have had mild to moderate depression.

Timing of Distress

Phase One findings showed that each stage in the post-treatment period brought its own challenges, and individuals had different needs depending on their stage in the trajectory, as well as their personal circumstances. In particular, participants reported that the re-entry period was a time that caused much distress. The re-entry period presents the difficult challenge of transitioning from cancer patient to survivor, which was very stressful for some participants as they felt they were now on their own or away from the built-in support system of the hospital environment. Other research has presented similar findings for leukaemia and lymphoma survivors, finding discontinuity of care at the end of treatment is one of the factors related to distress (Parry et al., 2010). Other research that included post-treatment cancer survivors with mixed cancers found, as in the current research, that the immediate post-treatment period was a time of anxiety for many (Firmin et al., 2013).

The end of treatment phase has also been seen as a difficult period for nurses working in haematology. An interview-based study around barriers to care for haematological cancer survivors found they reported difficulty in determining the actual end of treatment for haematological cancer patients (Langbecker et al., 2016). Therefore, these nurses hesitated in having survivorship discussions with patients because they did not want patients to misunderstand the status of their disease (think they are cured). Additionally, nurses had concern that patients would not see themselves as survivors if they were still receiving additional treatment or monitoring (Langbecker et al., 2016).

Building on Phase One findings, the Phase Two survey measured distress in specific post-treatment time periods (0-12 months; 13-24 months; 25-36 months; 37-48 months; and 49-60 months). Part of the aim of this analysis was to ascertain whether there was higher distress in the re-entry period (0-12 months). However, these results (Chapter Six, Table 6.4) showed that there was no statistically significant difference in the prevalence of distress by time period. Nevertheless, descriptive data showed that the prevalence of distress was highest in the 0-12 months period, then decreased slightly, only to peak again at the 49-60 month period. As this study was cross-sectional participants were not followed over time so it is difficult to say whether these cancer survivors maintained the same distress level over time, or whether there was an increase or decrease in distress over time. However, it does show that almost a quarter of haematological cancer survivors were still significantly distressed 4-5 years after treatment ended.

A recent longitudinal study (Lotfi-Jam, Gough, Schofield, Aranda, & Jefford, 2019) measured distress trajectories in a mixed group of post-treatment cancer survivors (including haematological cancers) using a model describing common trajectories of grief or potential trauma (Bonanno, 2004). The Bonanno model proposes four unique trajectories for how people respond to adverse events over time: *resilience* (short-lived symptoms with minimal impairment, and a relatively stable trajectory of healthy functioning); *recovery* (elevated symptoms and some functional impairment, followed by a gradual return to normal levels of functioning); *chronic distress* (a sharp increase in symptoms and

functional impairment that may last for years); and *delayed distress* (an initial increase in, and recovery from symptoms, but then a gradual worsening across time). The Lotfi-Jam et al. (2019) study found 80% of cancer survivors were in the resilience trajectory, with low distress that was stable over time. Almost one-tenth of survivors (9%) followed the chronic distress trajectory reporting persistent, 'clinically significant' distress. A smaller proportion were in the recovered (6%) and delayed trajectories (5%). These findings indicate that participants in the current research may have been distressed at the re-entry period and have stayed distressed over time.

Contributors to Distress in Haematological Cancer Survivors in the Post-Treatment Period

Phase Two examined the differences in significant distress between certain demographic categories and found a higher prevalence of distress in younger people aged 18–39 (36.7% reported significant distress), those unemployed or on sick leave (32.6% reported significant distress) and women (28.2% reported significant distress). This association between younger age and increased post-treatment distress has been shown in previous research (Jones, Parry, Devine, Main, & Okuyama, 2015). Research examining employment issues in haematological cancer survivors has also found that those currently not working have higher levels of anxiety and depression than survivors who have returned to work (Horsboel et al., 2015). Findings from this current research also align with previous studies examining gender differences in distress with cancer survivors by showing that women report more distress than men (Loscalzo & Clark, 2018).

Phase Two logistic regression analyses showed that three factors significantly predicted distress in this group of participants: whether a person was born in New Zealand, low social support, and high fear of recurrence. The issues surrounding those who were not born in New Zealand are most likely multifactorial. One potential issue is the lack of extended family that is often associated with immigrating to a new country. Phase One findings showed that having less extended family around could mean that people were missing that extra support system that may provide extra emotional or practical support during cancer treatment and into the survivorship period. There may also be cultural aspects that impact those in a new country, influencing how they cope with illness and a new health system, as well as a lack of familiarity with the health system (Lassetter & Callister, 2009). Although there is limited research focusing on the psychosocial effect cancer has for migrants, one study showed that being a migrant with cancer leads to poorer psychosocial and health-related quality of life outcomes than non-migrants (Sze et al., 2015).

The finding that low social support is a predictor of distress is corroborated by previous research with mixed cancer survivors, which found that a lack of social support in survivors was associated with increased emotional distress and depression (Ranchor et al., 2002). Another study found that breast cancer survivors with better perceived social support reported lower distress (Harding, 2014). Furthermore, a recent meta-analysis showed that perceived social support was significantly

associated with lowered mortality in cancer patients, with a stronger association for leukaemia and lymphoma patients than for other patients (Pinquart & Duberstein, 2010).

It is not surprising that fear of recurrence was a significant predictor of distress, with research showing between 22 and 87% of cancer survivors report fear of recurrence (Simard et al., 2010). A particularly relevant study comprising a large sample (n = 1281) of survivors with mixed cancer types found that having a haematological cancer was a predictor of fear of recurrence (Mehnert et al., 2013). The same study also reported that lower social support was a predictor of fear of recurrence, which aligns with the finding above regarding increased distress in those with lower social support. Previous literature also shows fear of recurrence is associated with higher distress (Ness et al., 2013).

Fear of recurrence as a predictor of distress was also an important finding from Phase One, with the most common concern for survivors being the fear of recurrence. The fear of recurrence was often a concern because the symptoms they experienced from their cancer were very similar to other common illnesses and therefore difficult to distinguish. Heightening the fear of recurrence is the added concern that is particularly relevant to haematological cancer survivors, namely the frequent difficulty in diagnosing these types of cancers. A UK study found that is not uncommon for the diagnostic period for haematological cancers to be lengthy and protracted (Howell et al., 2013). Furthermore, diagnostic delay has also been shown to cause increased distress in other cancer patients (Miles et al., 2017; Risberg et al., 1995).

This concern relating to their prolonged diagnostic period often continued for participants in the post-treatment period and contributed to their increased self-monitoring. The limited literature on post-treatment haematological cancer survivors shows one of the most frequently endorsed unmet needs was assistance managing the fear of recurrence (Lobb et al., 2009). Fear of cancer recurrence is one of the most common psychosocial concerns reported by cancer survivors (Simard et al., 2013) and has been associated with increased psychological distress (Deimling et al., 2006; Jones, Parry, Devine, Main, & Okuyama, 2015). Furthermore, fear of recurrence is considered a distinct psychological phenomenon and, although similar to other psychological sequelae (such as anxiety disorders), it has its own unique elements (Mutsaers et al., 2016). Therefore, fear of recurrence must be treated according to its own particular features, and as separate to distress because, although they may have similarities, they are different phenomena.

Barriers and Supports to Psychosocial Wellbeing

Phase One of this research explored the strategies used and the barriers encountered by haematological cancer survivors to maintain psychosocial wellbeing in the post-treatment period. Overall, a gap was identified in current support, particularly for those people who did not have extensive social networks or support from family. These findings are consistent with research on psychosocial wellbeing among other groups of cancer survivors which has shown that most of the

support received by survivors post-treatment is from family and friends (Girgis & Lambert, 2009; Kattlove & Winn, 2003).

Psychosocial Support from Family and Friends

For those participants who did report support from family and friends, it was found that family and friends provided not only important emotional support but also informational, financial, and other practical support which meant survivors could focus on their own health without extra stresses. Other research has found that emotional and informational support from family and friends has been shown to have a significant positive association with the health-related quality of life of cancer survivors (Arora et al., 2007). Findings from Phase One also showed that many participants mentioned not asking for extra support because their friends and family were filling this role.

However, the people who did not have family or close friends to call on when they needed support, expressed the need for additional support from the health system. It is also important for health professionals to recognise that having a social network of people around does not always equal adequate psychological support. For example, a study of post-treatment lymphoma survivors (Monterosso et al., 2017) found that some survivors felt that their family and friends did not always understand what they were going through. Furthermore, the expectation by family and friends was that once treatment was over a survivor should be back to normal and physically healthy, even though they might actually be struggling (Monterosso et al., 2017).

Psychosocial Support from Health Professionals

To build on the findings from Phase One regarding the need for extra psychological support, one of the aims of Phase Two was to ascertain the number of post-treatment haematological cancer survivors requiring more psychological support from health professionals. Results from this phase showed that nearly a quarter (24.6%) of haematological cancer survivors reported needing more psychological support from a health professional in the post-treatment period. Another finding from this phase showed that there was also a significant difference in the need for health professional support for those with low levels of social support. This is demonstrated in previous research which reported post-treatment cancer survivors with lower amounts of social support were significantly more likely to desire increased follow-up from health professionals (Philip & Merluzzi, 2016).

Phase One found that few participants spoke of seeking or being offered psychosocial support from health professionals. Similar results were seen in previous research with a mixed group of cancer survivors where one-fifth of participants reported the need for psychosocial support but were not receiving it (Ernstmann et al., 2009). This lack of psychosocial support for post-cancer survivors has also been recognised by health professionals themselves. For example, research conducted in NZ found that 77% of health professionals surveyed felt there was a gap in psychosocial and spiritual care in the cancer post-treatment period (Egan et al., 2013).

Statistical analyses in Phase Two also showed there was a significant difference in desire for psychological support from a health professional for those aged 18-39 versus older participants, and female gender compared to male. This finding aligns with a large multicentre study, which included post-treatment cancer survivors, which found that younger age and female gender was an indicator of the need for more psychosocial support (Faller, Weis, et al., 2016).

A secondary aim of Phase Two was to explore what type of psychological support haematological cancer survivors would find most helpful from health professionals. Those who expressed a desire for more support predominately wanted it from a psychologist or counsellor and reported wanting someone to talk to about psychosocial issues. Participants also mentioned wanting increased availability of psychological services. It is possible that some survivors were not aware of the availability of existing services, which stresses the need for them to have a health professional point of contact who can refer them to additional support services if needed (Hackett & Dowling, 2019).

Furthermore, in order to refer a patient to psychosocial services, a physician must be able to either recognise a patient's need for psychological support or allow the patient to express any psychosocial concerns. However, physicians providing follow-up care for post-treatment survivors have reportedly very low recognition of psychosocial distress (Werner et al., 2012). Other research has shown that health professionals often report not providing psychosocial care because of factors such as lack of time and resources (Schouten et al., 2019), lack of skills and training in psychosocial issues, and organisational barriers (Dilworth et al., 2014).

Distress also links back to the Phase Two content analysis finding that participants desired particular interpersonal attributes from their haematologist. A recent study, featuring mixed cancer patients who were visiting outpatient services showed that emotionally distressed participants were more likely to view their physicians as disengaged, lacking empathy, and only focused on physical aspects rather than emotional concerns (Meggiolaro et al., 2015).

Phase Two results showed that several participants indicated that they wanted more psychological support from their haematologist. This aligns with a review of post-treatment survivors' experiences with follow-up consultations that showed that patients valued psychosocial support, but that it was lacking in follow-up appointments (Lewis et al., 2009). The fact that a high percentage of participants wanted psychological support from their haematologist could be because not everyone is comfortable seeing a mental health professional (Arts et al., 2018). The need for psychological support from a haematologist is supported by Phase One findings, which showed that some participants reported receiving psychological support from a haematologist in their follow-up appointments. Haematologist visits provided peace of mind for these participants by monitoring physical health and confirming their cancer had not returned.

Phase Two results also showed that participants indicated wanting more time to talk with their haematologist about their psychological concerns, rather than just focus on physical problems. Previous literature has shown that discussions with health professionals regarding the emotional impact of cancer is correlated with increased patient satisfaction (Bonito et al., 2013). Furthermore, health professionals are also aware of this need as shown in a study of primary care physicians and oncologists who identified themselves as responsible for the provision of psychosocial care to survivors; however, only half of them report providing this care (Forsythe et al., 2012).

The Phase Two content analysis, which explored the type of psychological support survivors would find helpful from a haematologist in the post-treatment period showed that participants desired more support in relation to the physician's interpersonal behaviours (such as encouragement, caring, understanding, and better communication). This aligns with previous research which showed that cancer patients report more satisfactory treatment experiences when they are treated with compassion by health professionals (Staren, 2006). Research also shows that patients are more likely to convey their feelings of anxiety and fear if a health professional is showing empathy (Anderson et al., 2008). Furthermore, cancer patients who report being treated with attentiveness and empathy by physicians show lower levels of emotional distress (Zachariae et al., 2003).

Phase Two results also showed that those with higher distress reported the need for more psychological support from a health professional, which is supported by existing literature. Previous research has shown that increased distress in post-treatment cancer survivors with mixed cancers was a predictor of whether a person wanted to speak with a health professional (Philip & Merluzzi, 2016). Other research has also shown that oncologists find it challenging to deal with patients' distress because of factors such as time deficits, absence of protocols to deal with distress, and limited psychosocial resources to refer patients to (Granek et al., 2018).

Barriers to Psychosocial Wellbeing

Phase One of this research found that the informational needs of participants were unmet, with many reporting they required more information on a variety of issues. This finding is consistent with a previous systematic review which found that informational needs were one of the key unmet psychosocial needs for haematological cancer survivors (Swash et al., 2014). Participants reported needing information covering a range of topics including rebuilding their physical health and stamina, ongoing symptoms, and knowing who to contact when they had concerns.

Participants also believed that some supports on offer were not suitable for their needs. Notably, support groups were not considered a good fit for many people. Support groups were seen as unsuitable for reasons such as lack of continuity, limited availability of groups, and also, crucially, the dearth of groups specific to haematological cancers. Participants felt haematological cancers were unlike other cancers, and therefore they had specific concerns that might not always apply to other

cancers. This feeling of 'being different' was also reported in previous research with post-treatment non-Hodgkin's lymphoma patients (Swash et al., 2016).

Similarly, Phase One participants concerns, and for some significant distress, about mixing with people in different cancer stages has also been reported previously (Avery & Nyhof-Young, 2003; Butow et al., 2007) and for some cancers this distress has led to different groups being set up for people at different phases of the cancer trajectory (Sweet Louise Support for Incurable Breast Cancer, 2018). Research which involved interviews with post-treatment lymphoma survivors also found that participants felt they needed a more person-centred individualised approach to meet their support needs (Monterosso et al., 2017).

Overall, the Phase One findings showed that the barriers to psychosocial wellbeing in haematological cancer survivors in the post-treatment period largely revolve around the lack of information and discussion around psychosocial issues, and the gap in promoting the available psychosocial resources available to survivors. The Phase Two results (discussed above) built on this to show that nearly a quarter (24.6%) of haematological cancer survivors report needing more psychological support from a health professional in the post-treatment period. Again, these findings align with those from Phase One where a gap in psychosocial resources for some survivors was identified.

Linking Back to the Theoretical Framework

As discussed in the theoretical framework section (Chapter Three) two commonly used theoretical models, cognitive model of stress and coping (Lazarus & Folkman, 1984) and the Common-Sense Model of Self-Regulation (Leventhal, Meyer, & Nerenz, 1980) were not considered suitable as frameworks for this current research because of their individualist nature. However, in considering them in relation to the results of this research they have some utility. Coping styles (as proposed in the cognitive model of stress and coping) were not measured in the current research, so it is not possible to know if a particular coping style may have impacted levels of distress. However, qualitative findings indicate that haematological cancer survivors spoke more about problem-focused coping than the other coping styles, nevertheless emotion-focused coping and meaning-based coping styles were seen in some participants. In relation to the Common-Sense Model of Self-Regulation, illness perceptions were not something that were measured quantitatively in the current research, however there is some evidence from qualitative data that perceptions participants held may have affected how they coped with their cancer diagnosis and treatment, in terms of both stress reactions and coping behaviours.

Although both the models discussed above have their utility, a focus on individual factors does not fully explain the results of the current research. As the aims of the current research were broader than could be explored with these types of models, the Andykowski framework was a much more appropriate option. The Andykowski framework was beneficial for this current research as it was less

focused on individual cognitive aspects of a person, and more focused on the interplay between cognitive, behavioural, and psychosocial aspects (Andrykowski et al., 2008).

The use of Andrykowski et al. (2008) theoretical framework to guide this research was described in Chapter Three. In the following section I will discuss the similarities and differences between the findings from this current research and the framework. As outlined earlier, Andrykowski et al. (2008) propose a person's psychological response to a cancer experience is a function of the stress and burden posed by the cancer trajectory and the resources available to cope with this stress and burden. Increased stress and burden are seen to lead to a greater risk for poor psychological health. However, the authors propose that this is a dynamic process with factors most likely varying across time, meaning psychological health can change over time. Furthermore, even when stress and burden is low, psychological health may be poor if resources are also low. Equally, a person might be at low risk for poor psychological health even when the stress or burden is high if there are significant available resources.

Andrykowski et al. (2008) suggest that the nature of the stressors cancer survivors encounter may be physical, psychological, interpersonal, financial, and/or existential. Furthermore, stress and burden are subjective to those experiencing them; stressors which might be experienced as highly stressful by some cancer survivors might seem far less so by other survivors. Andrykowski et al. (2008) also suggest that there may be different issues that will manifest depending on the stage in the trajectory. This was shown in the current research with participants reporting more distress at the re-entry period of the trajectory.

Andrykowski et al. (2008) suggest that the resources survivors may use to deal with stress and burden are multifaceted. These resources are grouped into four general categories: intrapersonal, interpersonal, informational, and tangible (Andrykowski et al., 2008).

Intrapersonal resources are the characteristics which are internal to the cancer survivor. Such characteristics may be related to intrinsic personality traits, which influence a person to think or act in specific ways. People who have particular intrapersonal resources are better at coping while those without these intrapersonal resources do not cope as well (Andrykowski et al., 2008). This is seen in the current research with the finding in Phase One findings (Chapter Five) where many participants felt their inner strength helped them to maintain a positive attitude, supporting their recovery. Also, sometimes participants felt a positive attitude lessened the need for extra support from the health system in the post-treatment period.

Interpersonal resources primarily signify social support, which has been linked to better psychological health in cancer patients and survivors. Overall, being entrenched in a supportive social environment enhances the coping process (Andrykowski et al., 2008). Social support was a key factor in this current research with findings from both phases showing the importance of a social support network

for post-treatment cancer survivors. As mentioned earlier, Phase One findings showed that social support from friends and family was important in helping survivors maintain psychological wellbeing. Phase Two results showed that a lack of social support was a predictor of significant distress.

Informational resources mean access to correct and comprehensible information about their cancer, treatment, prognosis and what support services may be available (Andrykowski et al., 2008). Need for information was found to be an important factor in this current research, with Phase One findings showing that participants perceived a gap in informational needs in the post-treatment phase, which caused distress for some. The Phase Two content analysis showed that participants expressed the need for increased information from health professionals about both physical and psychological issues.

Tangible resources comprise psychological support services, including services such as psychologists, counsellors, social workers, support groups, or informal peer-to-peer networks. Decreased access to this kind of tangible support is associated with a higher risk of poor psychological health (Andrykowski et al., 2008). The current research shows that few survivors were being offered or accessing these types of tangible resources outside of routine follow-up appointments. Not everyone wanted or needed these types of resources, but those who did often did not know how to access them. This ties back to the previous discussion around the lack of information and discussion from health professionals regarding psychosocial issues and services.

The element of timing depicted in the updated model is discussed more fully at the beginning of this chapter. Timing predominately relates to the re-entry period which was a distressing time for many participants. The transition from patient to survivor caused some participants to feel alone, and lacking the support they once had while in treatment.

In summary, Andrykowski et al., (2008) provides a useful framework for explaining the factors associated with psychological health in cancer survivors. Survivors in this current research had variable stress and burden to contend with, and also variable resources to draw upon to cope with these stressors. Participants who described having numerous resources reported far less psychological concerns than those who felt they did not have these resources. I have added the factors specific to the haematological cancer survivors identified in this research to this framework as presented in Figure 8.1 below. The Andykowski et al. (2008) framework is represented by the blue text boxes and my amendments based on the findings of this current research in the orange text boxes.

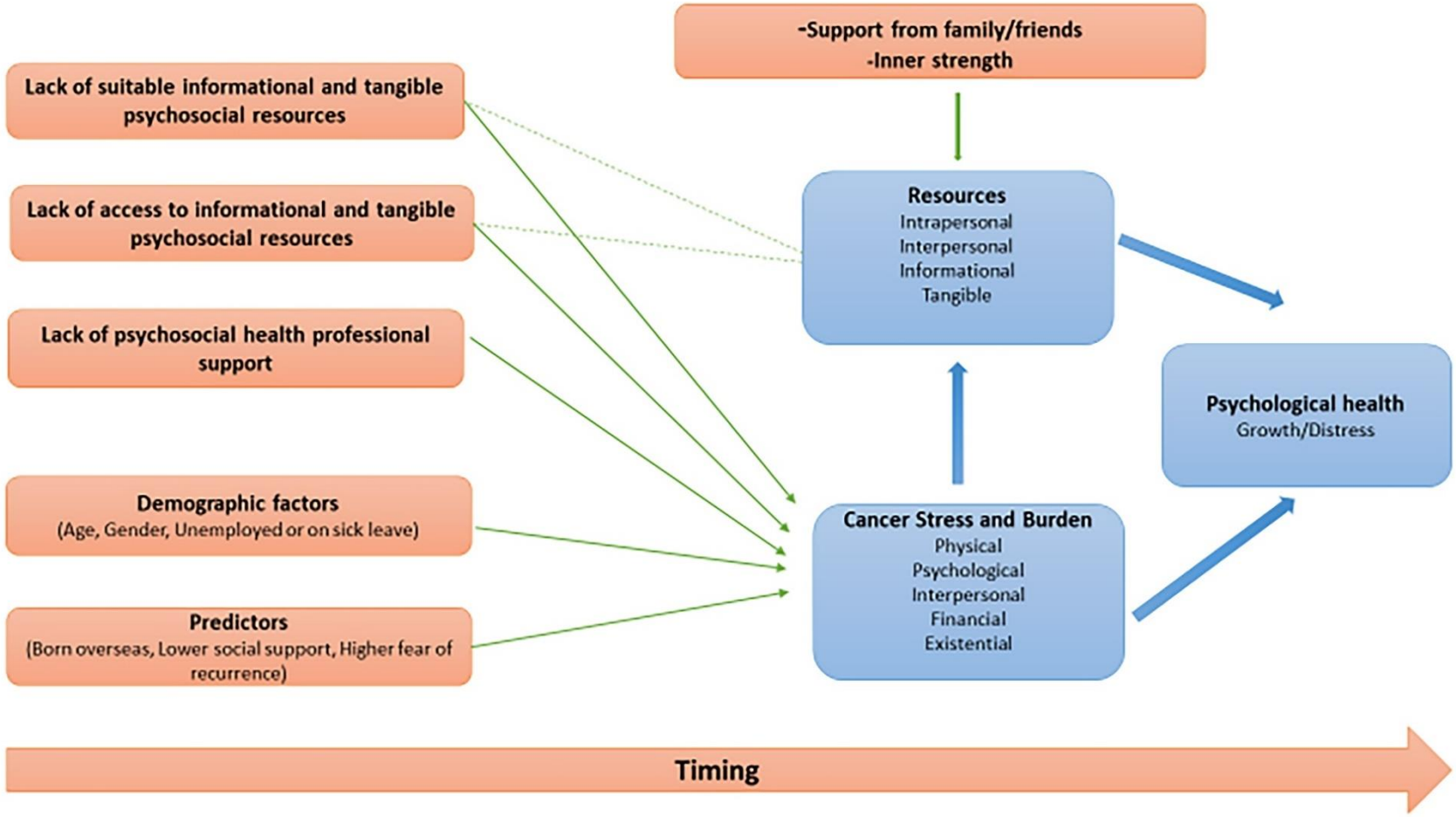

Figure 8.1 Revised framework

Strengths and Limitations

Strengths and limitations are reported at the end of each results chapter (Chapters 5-8) and expanded upon here.

Strengths

This research has enabled unique in-depth knowledge to be generated regarding the experiences of an under-researched survivor group. The integrative review demonstrated the limited amount of research focusing on psychosocial distress in post-treatment haematological cancer survivors which makes this current research important. My research has therefore made a unique contribution to the literature, as reflected in acceptance of the five articles embedded in the thesis for publication in international peer reviewed journals.

Another strength of this research is the use of mixed methods which enabled multiple perspectives to be generated on this topic. The qualitative phase allowed deeper insights into the experiences of haematological cancer survivors and pinpointed the areas that were important to them regarding their cancer experience. The quantitative phase identified the prevalence of significant distress in this survivor group and also provided the opportunity to calculate the number of people needing more support and the preferred forms of support.

Another strength of the quantitative phase of this research is that it was conducted on a nationwide scale and with a sample highly comparable to the New Zealand haematological cancer survivor population, allowing for generalisability.

Limitations

Self-selection bias in the qualitative phase may have influenced who took part. Also, interview participants had to rely on their memory to look back to the time when they were diagnosed with cancer, and for some, this was up to eight years before so there may have been recall issues. Another limitation is the fact that both Phase One and Phase Two participants were recruited through a national cancer registry, which provided no indicator of treatment status. Because there was no information about whether a person was post-treatment, recruitment was dependant on the participant to include or exclude themselves based on their treatment and remission status. This may have meant those who were unsure about their status would not participate. Although many participants called the researcher to discuss eligibility, there may have been some that just opted out because they were unsure or incorrect about eligibility. Finally, this was a cross-sectional study therefore data were only collected at a single time point, consequently causality cannot be inferred.

Recommendations for Policy and Practice

This research explored the nature and timing of psychosocial distress in post-treatment haematological cancer survivors, as well as their needs and preferences for support. From these findings a number of recommendations for policy and practice can be identified.

Recommendations for Policy

Although Phase One of this research found that many participants reported receiving psychosocial support from their family and friends, those who did not have family or close friends to call on when they needed support, expressed the need for additional support from the health system. Phase Two of this research identified that almost a quarter of participants reported wanting more psychological support from a health professional.

In 2014 the New Zealand Ministry of Health announced of funding of $4.2 million a year would be provided for a new enterprise called the Cancer Psychological and Support Initiative (Ministry of Health, 2019). This initiative aimed to 'address gaps and to improve overall access and timeliness of access to psychological and social support services for adults with cancer within the public health system' (Ministry of Health, 2019, p. 1). This initiative aimed to fill the gap in the existing provision of psychosocial services, which are limited by issues such as regional variation of psychosocial services, huge gaps in psychosocial services in certain regions, lack of funding, lack of skilled workforce, unclear referral pathways, and variable knowledge about screening, assessment, and knowledge of psychosocial services by health providers (Health Outcomes International, 2011).

An independent evaluation was conducted in 2018 (Esplin, Smith, Cherrington, Boyle, & Niemi, 2018) with interim findings showing that patients and whānau have responded positively to the initiative. However, it is recognised that this initiative is not open to everyone and is currently only aimed at those with high and complex needs. Furthermore, the initiative has not been widely advertised and only specific people such as clinical nurse specialists and oncology wards, have been targeted as referral sources. Primary care health professionals have not been used to refer survivors to the initiative.

The Cancer Psychological and Support Initiative appears to be a step in the right direction in increasing psychosocial care for cancer survivors in NZ, but unfortunately, it was not designed to provide psychosocial care to cancer survivors in the post-treatment period. The Ministry of Health acknowledges that support is needed in the post-treatment phase, but that this phase is not in the scope of the initiative (Ministry of Health, 2019).

There may be distressing aspects of the cancer trajectory that cannot be avoided, such as side effects of treatment and the physical symptoms of the cancer itself. However, this research has shown that more could be done from diagnosis to the post-treatment period to ameliorate the psychosocial consequences of haematological cancer and its treatment. This research has found that

information and support could be improved for post-treatment survivors. Furthermore, survivors need more information about psychosocial issues as these have been found to be rarely discussed by health professionals; if those in the health system make it a low priority, patients may not see it as an important issue either.

Summary of recommendations for policy:

- The New Zealand Cancer Psychological and Social Support Initiative needs to be expanded to include cancer survivors in the post-treatment period.
- Health systems need to fund the integration of psychosocial health into follow-up haematology appointments. Additional funding would allow more time for discussion of psychosocial issues, and if needed, referral to psychosocial services.

Recommendations for Practice

A good way to identify those who may be suffering distress is to implement distress screening for survivors at different points in the trajectory, including post-treatment. Recent research shows the importance of distress screening in enabling early intervention and improvement in psychological wellbeing (Rana et al., 2019). Psychosocial services have been shown to improve wellbeing (Grassi et al., 2017), so identifying those with distress is essential. Furthermore, the introduction of screening at least starts a process that enables cancer survivors to talk with health professionals. Indeed, research examining the sustainability of distress screening found that a positive outcome was that screening started a dialogue between health professionals and patients, and improved communication (Groff et al., 2018).

There is also a significant missed opportunity to provide a survivorship care plan for those at the end of treatment and potentially struggling in the post-treatment period. Although reviews on the use of survivorship care plans in other cancers have reported mixed results, some studies have shown that survivors report a high level of satisfaction with survivorship care plans (Brennan et al., 2014). However, there has been little evaluation of survivorship care plans for haematological cancer survivors (Taylor et al., 2015). Chan and Chan (2015, p. 414) state that haematological cancer survivors need ‘complex, tailored, survivorship interventions’. Further research assessing the efficacy of this type of tailored survivorship care plan within the context of haematological cancer is needed.

Furthermore, as mentioned earlier, distress is often not detected in primary care settings. However, in New Zealand, it is important to implement effective distress screening in primary care settings, as post-treatment survivors are likely to see their GP more frequently than a haematologist. In this research findings showed that one of the key barriers to psychosocial support for survivors was the lack of a specific contact person to ask for help.

One useful type of intervention that has the potential to improve psychological distress is the stepped care approach. A stepped care approach refers to the practice of beginning with the least intrusive

and least expensive intervention and only moving on to a more expensive and/or intrusive intervention if needed to achieve the desired therapeutic progress (Davison, 2000). Psychological stepped care interventions in cancer patients have shown positive results such as reducing stress reactions (Arving, Assmus, Thormodsen, Berntsen, & Nordin, 2019), improved referral to psychological services (Singer et al., 2017) and reducing fear of cancer recurrence (Lynch et al., 2020). Research has also shown that health professionals endorse the use of a stepped care approach in the management of psychological sequalae (Shaw et al., 2016).

Research is limited on psychological stepped care interventions targeting distress in post-treatment cancer survivors. However, one such study, (Krebber et al, 2016) describes the implementation of a stepped care programme targeting psychological distress amongst post-treatment head and neck cancer survivors. The programme included: 1. watchful waiting, 2. guided self-help via the Internet or a booklet, 3. face-to-face problem-solving therapy, and 4. specialized psychological interventions and/or psychotropic medication. This study found the stepped care intervention led to a faster recovery from distress compared to the control group who received usual care.

Summary of recommendations for practice:

- Distress screening needs to be implemented in the post-treatment period. This screening could be conducted at outpatient haematology follow-up appointments with the majority of survivors having regular monitoring in the first five years after treatment. Furthermore, particular attention needs to be paid to vulnerable groups, such as survivors who are younger, female, migrants, have low social support, and high fear of recurrence (as identified in this research).
- Psychosocial issues need to be discussed by health professionals in hospital haematology clinics or with health professionals in GP practices when possible, and if necessary referred on to more specialised psychological services.
- There needs to be a contact person or department that can coordinate any services or support for unmet psychosocial needs in the post-treatment phase.
- Tailored survivorship care plans need to be implemented by hospital haematology staff for haematological cancer survivors finishing treatment.
- Stepped care interventions need to be considered to address different psychosocial needs of post-treatment cancer survivors.

Recommendations for Further Research

The current research has identified a significant number of haematological cancer survivors are distressed in the post-treatment period and that many require more psychosocial support. As this was a cross-sectional study distress was not measured over time, therefore it was not possible to determine how long a survivor may have been distressed, or whether distress dips and peaks at certain points. Longitudinal research is needed to assess how much distress levels might change over time for haematological cancer survivors.

The lack of psychosocial support identified in this research needs further exploration from the perspective of health professionals who work with haematological survivors. It is important to explore the views of NZ health professionals working with haematological cancer patients, in relation to the barriers and facilitators they see to providing psychosocial care.

A need for specifically tailored interventions for haematological cancer survivor's has been identified (Chan & Chan, 2015). However, there is also a need for more research regarding the efficacy of psychosocial interventions designed specifically for haematological cancer survivors. Furthermore, research to support the development of these psychosocial interventions, and consequent pilot studies, would be invaluable. There is also a need for more research into the area of survivorship care plans specific to haematological cancer survivors. To date there has been little evaluation of care plans for haematological cancer survivors (Taylor et al, 2015). A study of survivorship care plans would be helpful in determining their value for this survivor group. As mentioned above (in the recommendations for practice) a stepped care approach is a potentially useful type of intervention for cancer survivors. However more evidence is needed to show its efficacy in cancer survivors, particularly post-treatment haematological cancer survivors.

Summary of recommendations for further research:

- Measure the changes in distress levels over time using longitudinal research.
- Explore the views of health professionals regarding the provision of psychosocial support within the hospital/primary care setting.
- Explore the efficacy of specifically tailored interventions for haematological cancer survivors, with a particular focus on stepped care interventions.
- Assess the usefulness of survivorship care plans designed specifically for haematological cancer survivors.

Summary

This thesis has provided new and important evidence regarding psychosocial distress in post-treatment cancer survivors. Firstly, it is the only research focusing on post-treatment survivorship in NZ haematological cancer survivors. Furthermore, it is the only research to date in NZ or internationally that has examined the prevalence of distress in post-treatment haematological cancer survivors at a national level. A key finding of this research, that 21.9% of haematological cancer survivors are significantly distressed in the post-treatment period, shows that more attention needs to be paid to this unique survivor group.

A mixed methods approach has enabled an in-depth exploration of the issues facing post-treatment haematological cancer survivors. Not only has this research shown that a considerable amount of haematological cancer survivors are experiencing distress in the post-treatment period, but that there are gaps in the support available to them. This research has also demonstrated that haematological cancer survivors experience unique issues that may set them apart from other cancer survivors, and

therefore would benefit from tailored psychosocial resources. It has also shown that the post-treatment phase has its own problems and that psychosocial resources do not always cover this period.

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Appendices

Appendix 1: Phase One Documentation

Appendix 1.1: Ethics approval letter

Health and Disability Ethics Committees
Ministry of Health Freyberg
Building 20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

25 June 2015

Dr Rosemary Frey
The University of Auckland School of Nursing
Private Bag 92019
Auckland 1142

Dear Dr Frey

Re:	**Ethics ref:**	**15/STH/82**
	Study title:	Psychosocial distress associated with survivorship from haematological cancers

I am pleased to advise that this application has been ***approved*** by the Southern Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Southern Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

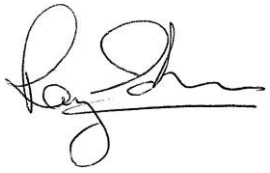
Your **next progress report** is due by **24 June 2016.**

Participant access to ACC

The Southern Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Ms Raewyn Idoine
Chairperson
Southern Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A

Documents submitted

Document	*Version*	*Date*
CV for CI: Rosemary Frey CV	version 1	29 May 2015
Evidence of scientific review: peer review	version 2	12 June 2015
Protocol: protocol	version 1	29 May 2015
PIS/CF: PIS	version 2	12 June 2015
PIS/CF: Consent Form	version 1	29 May 2015
Survey/questionnaire: Interview Schedule	version 1	29 May 2015

Covering Letter: cover letter for participants	version 1	29 May 2015
Application	-	3 June 2015
Response to Request for Further Information	-	5 June 2015

Appendix B

Statement of compliance and list of members

Statement of compliance

The Southern Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008713) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Ms Raewyn Idoine	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Mrs Angelika Frank-Alexander	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Dr Sarah Gunningham	Non-lay (intervention studies)	01/07/2012	01/07/2015
Assc Prof Mira Harrison-Woolrych	Non-lay (intervention studies)	01/09/2014	01/09/2015
Dr Fiona McCrimmon	Lay (the law)	01/09/2014	01/09/2015
Dr Nicola Swain	Non-lay (observational studies)	01/07/2012	01/07/2015
Dr Devonie Waaka	Non-lay (intervention studies)	01/07/2013	01/07/2016
Dr Mathew Zacharias	Non-lay (health/disability service provision)	01/07/2012	01/07/2015

Appendix 1.2: Research invitation letter

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tāmaki Makaurau

School of Nursing
Faculty of Medical and
Health Sciences

Deborah Raphael
Telephone: 923-6661
Email: d.raphael@auckland.ac.nz
Private Bag 92019

Dear.....,

My name is Deborah Raphael and I am a PhD student conducting research in the area of haematological cancer survivorship. I am looking for haematological cancer survivors to participate in an interview that will help me develop a questionnaire. The questionnaire will be used to survey survivors about their experiences post treatment, in particular and psychological or social concerns they might have experienced in the post treatment phase.

Haematological cancers are the fourth most common cancer in the developed world, and because of improved treatment regimens and early detection the survival rates in many countries are also improving. However, survivors who have successfully finished treatment are often left with residual physical, psychological and social problems. Previous research involving haematological cancer survivors has reported psychosocial problems such as fear of recurrence, decrease in social activities; sexual health concerns; economic difficulties; anxiety and depression; and post-traumatic stress disorder. These problems are not always recognised, and therefore survivors may not receive the support they require. This research seeks to explore the issues for haematological cancer survivors in New Zealand with the aim of understanding what their needs are in regard to psychosocial support.

I am looking for volunteers who have finished their primary treatment for a haematological cancer, and are currently considered in remission. The interview would take 30-40 minutes and you would receive a $20 fuel voucher for your participation.

I have enclosed a Participant Information Sheet which provides more information about the study, and a consent form for you to sign if you wish to participate. If after reading this information you are happy to participate, please contact me on (09) 923-6661 or by email d.raphael@auckland.ac.nz

Thank you for your assistance

Yours faithfully,

Deborah Raphael

Approved by the Southern Health and Disability Ethics Committee on 25/06/15 (Ref: 15/STH/82)

Appendix 1.3: Participant information sheet

School of Nursing
Faculty of Medical and
Health Sciences

Deborah Raphael
Telephone: 923-6661
Email: d.raphael@auckland.ac.nz
Private Bag 92019

Participant Information Sheet

Project Title: Psychosocial distress Associated with Haematological Cancer Survivorship

Principal Investigator (PI) - Professor Merryn Gott and Deborah Raphael (PhD Student)

You are invited to take part in a study examining the extent and nature of distress post treatment for a haematological cancer.

Your participation is entirely voluntary. If you do agree to take part, you are free to withdraw at any time, without having to give a reason. You will be able to withdraw any data relating to your interview. To help you make your decision, please read this information sheet carefully.

Who are we?

This study is being conducted by Deborah Raphael, a PhD student from the School of Nursing at the University of Auckland. The research team comprises myself (Deborah Raphael – PhD student), my primary supervisor (Professor Merryn Gott) and co-supervisor (Dr Rosemary Frey). These interviews form the first phase of my PhD study

What is the purpose of the study?

The study aims to explore any psychological or social concerns you may have encountered once you had completed your treatment. This study is phase one of a larger PhD project, the data from these interviews will be used to help design a survey which will be used in phase two. You have been chosen to participate in this interview because you will have recently finished treatment for a haematological cancer.

What will it involve?

The study involves taking part in a face to face interview conducted by a member of the research team (Deborah Raphael), who is an experienced interviewer. The interview will take approximately 40-60 minutes. You will be able to stop the interview at any time. For demographic purposes, we would also like to record some simple information such as your age and ethnicity (subject to your agreement). This form will be general and will in no way be able to identify you.

Will the interview be recorded?

Yes. With your permission, each interview will be audio-recorded. Audio files will be stored on a password protected computer and transcripts in a locked filing cabinet at the University of Auckland and only members of the research team will have access to them. Tapes will be transcribed by a third party who has signed a confidentiality agreement. No material that could personally identify you will be used in any reports on this study. The recordings will be destroyed after the analysis is complete (within 12 months). Following the completion of the study, all transcripts and other information will be stored in a locked cupboard and password protected computer at the University of Auckland for 10 years.

What is the time-span for the study?

The study is expected to start in March 2015 and will run for one year.

The risks of the study

There are no specific risks associated with participating in this study. However, if the interview makes you feel upset or distressed in any way you can stop at any time. Should you require additional support after taking part in this study, please contact the Health and Disability Services Consumer Advocate on free phone: 0800 37 77 66.

The benefits of this study

The information you choose to share with us will help to gain a better understanding of your experiences as cancer survivor. By participating in this study, you can help health professionals understand the needs of cancer survivors. This study will also give you a chance to voice your opinion and share your experiences as a consumer of health care services.

What will happen to the results of the study?

The results will form part of my PhD thesis and will be reported in professional and academic journals as well as academic conferences, locally and internationally. The results would be disseminated at a local level. You will have an option to receive a summary of the results if you wish.

Contact for further information

If you require any further information, please contact:

Deborah Raphael (09 923 6661) / d.raphael@auckland.ac.nz

Approved by the Southern Health and Disability Ethics Committee on 25/06/15 (Ref: 15/STH/82)

Appendix 1.4: Consent form

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES
SCHOOL OF NURSING

The University of Auckland
School of Nursing
Level 2 – Boyle Building
85 Park Road
Grafton
Auckland

for further information contact:
Deborah Raphael
PH: 923-6661
email: d.raphael@auckland.ac.nz

Consent Form

This form will be kept for a period of ten years

Project title: The Wellbeing of Haematological Cancer Survivors after Treatment

- I have read the Participant Information Sheet dated 25/06/15 and I have understood the nature of the research and why I have been selected. I have had the chance to ask questions and have them answered to my satisfaction. I agree to take part in the study.
- I understand that taking part in this study is voluntary and that I may withdraw my transcript within two weeks of submission. I understand that I can do this without giving a reason.
- I understand that information gathered from my questionnaire may be included in academic publications and that all personal information will remain strictly confidential. No material which could identify me will be used in any reports on this study.
- I understand that I do not have to answer any questions that I do not want to.
- I understand all information and data will be stored securely for a period of ten years, after which it will be securely destroyed.
- I **wish/do not wish** to receive a summary of the findings.

Please write down your email or postal address if you would like a copy of your interview transcript and/ or summary of the findings.

……

……

……

Name _____ Signature _____ Date _____

Name of researcher _____Signature _____ Date _____

Appendix 1.5: Interview schedule

Psychosocial distress Associated with Haematological Cancer Survivorship
Interview Schedule Phase One

- Introductions/ explanation of the project/ Explain the purpose of the interview
- Answer any questions participants may have
- Review consent form
- Complete demographic questions
- *Remind participants that they do not have to answer any question they don't want to. Can stop the interview at any time. If they become distressed the interviewer will check with the participant whether they want the interview to continue.*

1. Do you mind telling me a bit about the period when you **were diagnosed** with cancer? *(Prompt: ask type of cancer if not mentioned)*

2. What was **treatment** like for you? How did you cope?

3. What **health care and support services** were you involved with **during treatment**? *(Prompt: GP, hospital, other support services, peer support, online groups, for **Māori**- were there any Māori support services?)*

4. When you were in treatment did the **health professionals** you saw ever talk about **emotional or mental health**? Did you feel like you could ask?

5. What were your initial thoughts and feelings when you were told your **treatment was ending**?

6. Have you been given information about what to **expect post-treatment**? *(Prompt: are they expecting medical follow-up by HP in hospital, GP or other?)*

7. Do you feel you need **information** or **advice** now you have **finished treatment**? *(Prompt: if so, what type of information, from whom?)*

8. Did you feel any **emotional distress** during your treatment? If so has this changed since your treatment has ended? *(prompt: explain distress may include feeling sad, hopeless, powerless, afraid, guilty, anxious, panic, discouraged, depressed)*

9. Have you had any trouble **adjusting** back into your **normal life** post cancer treatment?

10. Do you have a **support person** in your life? If so who? Do you feel you need support now you have finished your treatment? *(prompt: ask about family/whanau support)*

11. Do you have any **worries** and **concerns** about your health now you have **finished** your **treatment**? *(Prompt – do you have any concerns about the future?)*

    If there are **concerns**, what kind of **support might be helpful**? Is **online** support an option?

12. Have you had any change in your **personal relationships** as a result of your cancer diagnosis?

13. Were you **working** before your cancer diagnosis? Did you have to stop or cut down you work schedule? If so have you returned to work?

14. Has having cancer led to any **financial strain**? Will this affect you now you have finished treatment?

15. Is there anything else you would like add to the discussion? Is there anything else that I haven't asked you about your **experience** with **cancer** that would like me to know?

Thank you for taking part in this interview. Remind participant that you will send out a copy of their transcript if they want to read this.

Appendix 2: Phase Two Documentation

Appendix 2.1: Ethics approval letter

Health and Disability Ethics Committees

Ministr
y of Health
133
Molesworth
Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

12 October 2017

Ms Deborah Raphael
The University of
Auckland School of
Nursing
Private Bag 92019
Auckland 1142

Dear Ms Raphael

Re:	**Ethics ref:**	**17/STH/184**
	Study title:	The Wellbeing of Haematological Cancer Survivors after Treatment

I am pleased to advise that this application has been ***approved*** by the Southern Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Southern Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *a given* locality in New Zealand, it must

be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

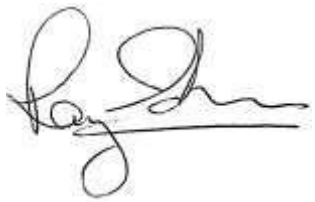
Your next progress report is due by 11 October 2018.

Participant access to ACC

The Southern Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Ms Raewyn
Idoine
Chairperson
Southern Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A

Documents Submitted

Document	*Version*	*Date*
Evidence of scientific review: Peer review form	1	12 September 2017
Protocol: Protocol	1	14 September 2017
CV for CI: CV	1	12 September 2017
PIS/CF: PIS V2	2	04 October 2017

Survey/questionnaire: Questionnaire V2	2	04 October 2017
Brochure V2	2	04 October 2017

Appendix B

Statement of compliance and list of members

Statement of compliance

The Southern Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008713) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Ms Raewyn Idoine	Lay (consumer/community perspectives)	27/10/2015	27/10/2018
Dr Sarah Gunningham	Non-lay (intervention studies)	27/10/2015	27/10/2018
Assc Prof Mira Harrison-Woolrych	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Fiona McCrimmon	Lay (the law)	27/10/2015	27/10/2018
Dr Anna Paris	Lay (other)	24/08/2017	24/08/2020
Dr Nicola Swain	Non-lay (observational studies)	27/10/2015	27/10/2018
Dr Devonie Waaka	Non-lay (intervention studies)	13/05/2016	13/05/2019
Dr Mathew Zacharias	Non-lay (health/disability service provision)	27/10/2015	27/10/2018

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

Appendix 2.2: Invitation letter

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES
SCHOOL OF NURSING

Deborah Raphael
Telephone: 923-6661
Email: d.raphael@auckland.ac.nz
Postal Address:
Private Bag 92019
Auckland 1142, NZ.

Dear.....

My name is Deborah Raphael and I am a PhD student conducting research in the area of haematological (Blood) cancer survivorship. I am looking for blood cancer survivors to complete a questionnaire that explores how survivors are coping physically and emotionally after cancer treatment.

Fortunately, because treatment has improved, and cancers are often caught early, more people are surviving cancer. However, research has shown that some survivors who have finished treatment may be left with physical, psychological and social problems. These problems are not always recognised, and therefore survivors may not receive the support they need. This research seeks to explore what life is like for blood cancer survivors in New Zealand. We want to understand what support you have found useful in your cancer journey, how you are feeling since finishing treatment, and if you feel the need for more support.

I am looking for volunteers who have finished their primary treatment for a blood cancer, and are currently considered in remission or cured. The questionnaire would take approximately 10-20 minutes to complete. I have enclosed a Participant Information sheet that provides more information about the study.

If you are interested in participating, please complete the enclosed questionnaire and mail back to me in the postage paid envelope provided, or you can complete the questionnaire online by typing the following URL into your web browser: https://goo.gl/wU8igm

If you would like more information, please contact me by phone on **09 923 6661** or email me at **d.raphael@auckland.ac.nz**.

Thank you for your help

Yours faithfully,
Deborah Raphael

Approved by the Southern Health and Disability Ethics Committee on 12/10/17. (Ref: 17/STH/184)

Appendix 2.3: Participant information sheet

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES
SCHOOL OF NURSING

Wellbeing in Haematological Cancer Survivors after Treatment
For further information contact:
Deborah Raphael
PH: 923-6661
email: d.raphael@auckland.ac.nz

Participant Information Sheet

Project Title: The Wellbeing of Haematological Cancer Survivors after Treatment

Researchers: Professor Merryn Gott (Principal Investigator) and Deborah Raphael (PhD Student) from the School of Nursing at the University of Auckland.

You are invited to take part in a study looking at how people are coping once they have **finished treatment** for a haematological (blood) cancer. This questionnaire is part of my PhD study. You have received this information because you have been identified through the New Zealand Cancer Registry as having been diagnosed with a blood cancer in the past.

Please take a moment to read the following information and discuss it with friends or relatives if you wish. Contact us if there is anything that is not clear or you would like more information about. Thank you for taking the time to read this information sheet.

Access to Participant Information

As mentioned above you were identified from the New Zealand Cancer Registry (NZCR). The NZCR only provides information to researchers after the study has been assessed and approved by the New Zealand Health and Disability Ethics Committee. After ethical approval the NZCR provided names, ages, addresses, type of cancer, and date originally diagnosed. Information provided by the NZCR is private and confidential and will only be used for this study.

What is the purpose of the study?

The study aims to explore whether you have had any concerns since you have finished your treatment. The questionnaire will look at your experiences as a cancer survivor to help understand how survivors are coping post-treatment

Furthermore, the overall results from this questionnaire will also be fed back to health and care professionals and people responsible for making policies in this area, in order to inform them about the needs of cancer survivors and the support they need

What happens if I decide to take part?

If you decide that you would like to take part you will be given this information sheet to keep and will be asked to sign a consent form at the beginning of the questionnaire. The study involves completing a questionnaire and mailing it back or completing the survey online if you prefer. The survey includes questions about how you are feeling emotionally and physically since your treatment ended. It also contains questions about support you are currently receiving and what support may be useful to you. The questionnaire will take approximately 10-20 minutes to complete. A prepaid self-addressed envelope will be provided for you to return the questionnaire if you choose to complete the hard copy. We would also like to record some simple information about you such as your gender, age, ethnicity and some other demographic information.

To complete the questionnaire online please type the following URL into your browser address bar:
https://goo.gl/wU8igm

Your participation is voluntary

Your participation is entirely voluntary (your choice). You do not have to take part in the study. You can withdraw your participation up until you submit the questionnaire. **You may skip any questions in the questionnaire that you do not wish to answer**. . If you do agree to take part, **you are free to withdraw your participation at any time** without giving a reason. If you do not wish to participate in the survey you don't have to give a reason.

How will the information be stored?

All identifying information (including contact information) will be kept on a secure password protected computer at the School of Nursing, the University of Auckland and deleted after six years. Paper questionnaires will be stored in locked filing cabinets in the Nursing School for six years and then securely destroyed. Online questionnaires will be stored on a secure server on the web-based software known as Qualtrics. No material that could personally identify you will be used in any publication or presentation related to this study.

What is the time-span for the study?

The study is expected to start in August 2018 and will continue to August 2019.

The risks of the study

There may be a risk for some people that the topics in the questionnaire will raise some issues that cause some distress or discomfort. However, if the questionnaire makes you feel uncomfortable or upset in any way you can stop at any time. Should you need extra support after taking part in this study, please refer to the list of contacts at the end of this form. There is a small risk that particular participants could be identified by demographic information, however to prevent this results will only report summary data and no data on individual participants.

The benefits of this study

The information you chose to share with us will help to gain a better understanding of your experiences as cancer survivor. By participating in this study, you can help health professionals understand the needs of cancer survivors. This study will also give you a chance to voice your opinion and share your experiences of health care services.

What will happen to the results of the study?

The results will form part of my PhD thesis and will be reported in professional and academic journals as well as academic and health professional conferences, locally and internationally. The results would be distributed to local DHBs and other health care providers. You will have an option to see a summary of the results if you wish by accessing a website dedicated specifically to this research project, details of this are on the questionnaire.

Who is organising the research?

The research is based at the School of Nursing at the University of Auckland. The study has received ethical approval from the Health and Disability Ethics Committee.

Contact for further information, or to raise concerns or complaints

If you require any further information, or if you feel any distress from completing the questionnaire and would like to discuss it, then please contact:

PhD student: Deborah Raphael ☎ 09 923 6661 ✉ d.raphael@auckland.ac.nz

Principal Investigator: Merryn Gott ☎ (09) 9231655 ✉ m.gott@auckland.ac.nz

Co-Investigator: Rosemary Frey ☎ (09) 9231353 ✉ r.frey@auckland.ac.nz

Head of School: Professor Alexandra McCarthy ☎(09) 373 2897
✉ alexandra.mccarthy@auckland.ac.nz

If you want to talk to someone not involved in the study, you can contact a health and disability advocate (with the choice of a Maori advocate if you prefer) on:
Phone: 0800 555 050
Email: advocacy@hdc.or.nz

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:
Phone: 0800 4 384427
Email: hdecs@moh.govt.nz

Other Support

If you feel the need to speak to someone about any emotional or psychological issues you may be experiencing (because of the topics in the questionnaire, or existing issues) please consider contacting one of the services in the list below.

All the following services are free.

Lifeline: Phone 0800 543 354 | www.lifeline.org.nz.

Lifeline provides free, private telephone counselling 24 hours a day, 7 days a week.

Samaritans: Phone 0800 726 666 at any time | www.samaritans.org.nz.

Samaritans offer non-judgemental, confidential support to anyone in emotional distress and are available 24 hours a day.

Depression Helpline: Phone 0800 111 757 | Text 4202 | www.depression.org.nz

Talk to a trained counsellor who can discuss your situation and find you the right support. Available 24 hours a day, 7 days a week.

Cancer Information Helpline: Phone 0800 226 237 | info@cancersoc.org.nz

This Helpline is available Monday to Friday (9-5pm) and you can speak to an experienced cancer nurse.

Approved by the Southern Health and Disability Ethics Committee on 12/10/17. (Ref: 17/STH/184)

Appendix 2.4: Questionnaire

The Wellbeing of Haematological Cancer Survivors after Treatment

You are invited to take part in a study looking at how people are coping once they have finished treatment for a haematological (blood) cancer. This questionnaire is part of my PhD study. You have received this information because you have been identified through the New Zealand Cancer Registry as having been diagnosed with a blood cancer in the past.

The study aims to explore whether you have had any concerns since you have finished your treatment. The questionnaire will look at your experiences as a cancer survivor to help understand how survivors are coping post-treatment. The information you chose to share with us will help to gain a better understanding of your experiences as cancer survivor. By participating in this study, you can help health professionals understand the needs of cancer survivors. **This study will also give you a chance to voice your opinion and share your experiences of health care services.**

Please take a moment to read the accompanying **participant information sheet** and discuss it with friends or relatives if you wish. Contact us using the details on the last page of the questionnaire if there is anything that is not clear or if you would like more information. If you prefer to complete online, please type the following URL into you browser: https://goo.gl/wU8igm

Instructions

As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes. **If you would rather not answer one of the questions, please go on to the next one**.

By filling out the questionnaire and ticking the box below you are indicating that you have read the information provided above, and have voluntarily agreed to take part in this research.

I AGREE TO PARTICIPATE

☐Yes
☐No

Thank you very much for assisting us with this important project. Could you please answer a couple of brief questions before beginning?

1. Have you finished your main/primary treatment for your haematological cancer?
☐ Yes – go to question 2
☐ No – We're sorry but you don't qualify for this survey. Thank you for your time

2. Have you been told by your doctor that you are you currently in remission, or cancer free, or cured?
☐ Yes – go to Section A
☐ No - We're sorry but you don't qualify for this survey. Thank you for your time

Section A. Some questions about you:

1. What is your gender?
☐ Male
☐ Female
☐ Transgender
☐ Other……

2. What is your age?_____

3. Which ethnic group do you most identify with?
☐ New Zealand European
☐ Māori
☐ Pacific
☐ Asian
☐ Middle Eastern/Latin American/African
☐ Other……

4. Were you born in New Zealand?
☐ Yes- go to **Q5**
☐ No – go to **Q4a**

4a. Is English your first language?
☐ Yes- go to **Q5**
☐ No – go to **Q4b**

4b. How many years have you lived in New Zealand?
☐ Less than 12 months
☐ 1-3 years
☐ 4-10 years
☐ More than 10 years

5. What is your current partnership status?
☐ Married/Civil Union
☐ De facto union
☐ In a relationship
☐ Single
☐ Divorced
☐ Separated
☐ Widowed

6. Do you have children?
☐ Yes- go to **Q6a**
☐ No- go to **Q7**

6a. How many children do you have (including adult children)?

Sons_____

Daughters_____

6b. Please enter the age(s) of your child/children in the space below.
Sons_____

Daughters_____

7. Who do you live with most of the time?
☐ Alone
☐ With spouse/partner only
☐ With spouse and child/other relative
☐ With spouse and non-relatives
☐ With child (not spouse)
☐ With other(s) not spouse or children
☐ Other ……..……

8. What is your current employment status?
☐ Full-time employment (30 hours or more per week)
☐ Part-time employment
☐ Unemployed *(incudes those currently looking for work)*
☐ Currently not working/on sick leave because of cancer-related issues
☐ Retired

9. What type of haematological cancer were you diagnosed with?
☐ Non-Hodgkin's Lymphoma
☐ Hodgkin's Lymphoma
☐ Acute Lymphoblastic Leukaemia
☐ Acute Myeloid Leukaemia
☐ Chronic Lymphocytic Leukaemia
☐ Chronic Myeloid Leukaemia
☐ Multiple Myeloma
☐ Other…….

10. What type of treatment did you receive for your cancer? (Tick all that apply)

☐ Chemotherapy
☐ Radiotherapy (Radiation)
☐ Surgery
☐ **Bone marrow transplant/Stem cell transplant**
☐ Other

11. How long ago did you finish your main/primary treatment (not including follow appointments)?

Year(s)…….Months……..

12. What are your top three <u>physical</u> or <u>psychological</u> health concerns currently? *(They do not have to cancer-related)*

1. …….

2. ……..

3. ……..

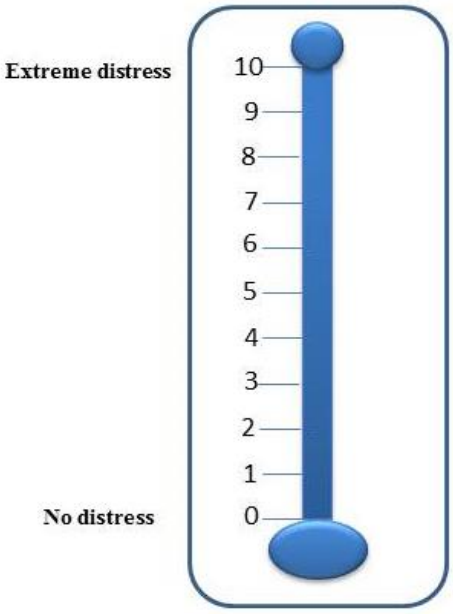
<u>Section B.</u>

The following questions ask about how you have been feeling during the **past 30 days**. For each question, please tick the number that best describes how often you had this feeling.

1. During the past 30 days, about how often did you feel ...

	For each question 'tick' by the number you feel best describes your answer	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
a.	...nervous?	1	2	3	4	5
b.	...hopeless?	1	2	3	4	5
c.	...restless or fidgety?	1	2	3	4	5
d.	...so depressed that nothing could cheer you up?	1	2	3	4	5
e.	...that everything was an effort?	1	2	3	4	5
f.	...worthless?	1	2	3	4	5

2. Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the **past week including today**



3. Please indicate if any of the following has been a problem for you in the **past week including today**. Be sure to circle **YES** or **NO** for each.

Child care	**Yes**	**No**	**Changes in urination**	**Yes**	**No**
Housing	**Yes**	**No**	**Constipation**	**Yes**	**No**
Insurance/financial	**Yes**	**No**	**Diarrhoea**	**Yes**	**No**
Transportation	**Yes**	**No**	**Eating**	**Yes**	**No**
Work/school	**Yes**	**No**	**Fatigue**	Yes	No
Treatment decisions	**Yes**	**No**	**Feeling swollen**	**Yes**	**No**
Depression	**Yes**	**No**	**Fevers**	**Yes**	**No**
Fears	**Yes**	**No**	**Getting around**	**Yes**	**No**
Nervousness	**Yes**	**No**	**Indigestion**	**Yes**	**No**
Sadness	**Yes**	**No**	**Memory/concentration**	**Yes**	**No**
Worry	**Yes**	**No**	**Mouth sores**	**Yes**	**No**
Loss of interest in usual activities	**Yes**	**No**	**Nausea**	**Yes**	**No**
Dealing with children	**Yes**	**No**	**Nose dry/congested**	**Yes**	**No**
Dealing with partner	**Yes**	**No**	**Pain**	**Yes**	**No**
Ability to have children	**Yes**	**No**	**Sexual**	**Yes**	**No**
Family health issues	**Yes**	**No**	**Skin dry/itchy**	**Yes**	**No**
Spiritual/religious concerns	**Yes**	**No**	**Sleep**	**Yes**	**No**
Appearance	**Yes**	**No**	**Substance abuse**	**Yes**	**No**
Bathing/dressing	**Yes**	**No**	**Tingling in hands/feet**	**Yes**	**No**
Breathing	**Yes**	**No**			

Other Problems: *(please write below)*

Section C.

These questions ask for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	<u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
b	Climbing <u>several</u> flights of stairs	☐ 1	☐ 2	☐ 3

3. During the past <u>4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	<u>Accomplished less</u> than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b	Were limited in the <u>kind</u> of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Have you felt downhearted and depressed?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Section D.

The next questions are from a scale used in many studies and are about how you have been feeling lately concerning your health in the future. For each question, please choose the best answer to describe how you have felt

	Not at all	A little bit	Somewhat	Very much
1. I worry about future diagnostic tests				
2. I worry about another type of cancer				
3. I worry about my cancer coming back				
4. I worry about dying				
5. I worry about my health				

Section E.

Instructions: Now we'd like to ask you some questions about your social network and social relationships. We are interested in how you feel about the following statements. Read each statement carefully. **Tick the box** that indicates how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

<u>Section F:</u> Psychological/emotional support you received during treatment.

1. Did you receive **any psychological** or **emotional support** from the following health professionals and support services during your **treatment period**?

	Yes	No	What type of support did you receive?	How frequently was this support given?
Haematologist				
GP				
Nurse				
Psychologist or counsellor				
Social worker				
Support group				
Online resources				
Other ……..				

2. Did you feel like you needed **more psychological** or **emotional support** from health professionals and other support services **during your treatment period**?

- ☐ Yes
- ☐ No

3. Would you have liked any **psychological** or **emotional support** from the following health professionals and support services during your **treatment period**?

	Yes	No	What type of support would you have liked?	How frequently would you have liked this support?
Haematologist				
GP				
Nurse				
Psychologist or counsellor				
Social worker				
Support group				
Online resources				
Other ……..				

Section G: Psychological/Emotional Support Post-Treatment

1. Have you received **any psychological** or **emotional support** from the following health professionals and support services since your primary **treatment ended**?

	Yes	No	What type of support have you received?	How frequently was this support given?
Haematologist				
GP				
Nurse				
Psychologist or counsellor				
Social worker				
Support group				
Online resources				
Other ……..				

2. Do you feel like you need **more psychological** or **emotional support** from health professionals and other support services since your primary **treatment ended**?

☐ Yes
☐ No

3. What **psychological** or **emotional support** would be helpful for you in the post-treatment period?

	Yes	No	What type of support would you like?	How frequently would you like this support?
Haematologist				
GP				
Nurse				
Psychologist or counsellor				
Social worker				
Support group				
Online resources				
Other ……..				

Section H. Post-Treatment Care

This section addresses the care you have received since you finished your primary/main treatment (i.e. follow-up you have received once you were in remission).The questions are about your level of satisfaction with your overall experience of **follow-up care**, including care from the **hospital** and from your **GP surgery**

Please score your satisfaction on a scale one to five, where 5 = totally satisfied and 1 = not at all satisfied and tick in the appropriate box	**Not at all satisfied** 1	2	3	4	**Totally satisfied** 5	Not applicable
Q1. How satisfied are you with the way any <u>physical</u> problems or symptoms have been addressed? *e.g. pain, numbness, fatigue or other physical problems*						
Please use this space if you wish to make any comments to explain your satisfaction levels:						
	Not at all satisfied 1	2	3	4	**Totally satisfied** 5	Not applicable
Q2. How satisfied are you with the way any <u>emotional/psychological</u> problems have been addressed? *e.g. anxiety , fear, worry, anger, depression, coming to terms with thinking of yourself in a different way*						
Please use this space if you wish to make any comments to explain your satisfaction levels:						
	Not at all satisfied 1	2	3	4	**Totally satisfied** 5	Not applicable
Q3. How satisfied are you with the way any <u>relationship</u> problems have been addressed? *e.g. family arguments, difficulty in talking about relationships, intimacy issues, lack of interest in sex, feeling unloved or unlovable*						
Please use this space if you wish to make any comments to explain your satisfaction levels:						
	Not at all satisfied 1	2	3	4	**Totally satisfied** 5	Not applicable
Q4. How satisfied are you with the way any <u>social</u> problems have been addressed? *e.g. return to work, benefits, insurance, returning to your normal activities*						
Please use this space if you wish to make any comments to explain your satisfaction levels:						
	Not at all satisfied 1	2	3	4	**Totally satisfied** 5	Not applicable
Q5. Overall, how satisfied are you with the <u>general support and care</u> you have received since your initial diagnosis and treatment for cancer?						

Please use this space if you wish to make any comments to explain your satisfaction levels:

Section I

Listed below are a few statements about your relationships with others. How much is each statement TRUE or FALSE for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
1. I am always courteous even to people who are disagreeable.					
2. There have been occasions when I took advantage of someone.					
3. I sometimes try to get even rather than forgive or forget.					
4. I sometimes feel resentful when I don't get my own way.					
5. No matter who I'm talking to, I'm always a good listener.					

Is there anything that you would like to say or aspects of your post-treatment care or support that have not been covered?

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Thank you for being part of this study. The information you have shared is much appreciated and is very important as it will help us find out how life is in the post-treatment period for New Zealanders diagnosed with haematological cancers

If you would like to view a summary of the findings from this study please have a look at the following website, results will on this site from around March 2018:

wellbeinghaematologicalcancersurvivors.wordpress.com

Available Support

If you would like to speak to anyone about the issues raised in this survey the following services may be of help.

All the following services are free.

Lifeline: Phone 0800 543 354 | www.lifeline.org.nz.

Lifeline provides free, private telephone counselling 24 hours a day, 7 days a week.

Samaritans: Phone 0800 726 666 at any time | www.samaritans.org.nz.

Samaritans offer non-judgemental, confidential support to anyone in emotional distress and are available 24 hours a day.

Depression Helpline: Phone 0800 111 757 | Text 4202 | www.depression.org.nz

Talk to a trained counsellor who can discuss your situation and find you the right support. Available 24 hours a day, 7 days a week.

Cancer Information Helpline: Phone 0800 226 237 | info@cancersoc.org.nz

This Helpline is available Monday to Friday (9-5pm) and you can speak to an experienced cancer nurse.

Contact for further information, or to raise concerns or complaints

If you require any further information, please contact:

PhD student: Deborah Raphael ☎ (09) 923 6661✉ / d.raphael@auckland.ac.nz

Principal Investigator: Rosemary Frey ☎ (09) 9231353 ✉ r.frey@auckland.ac.nz

Co-Investigator: Merryn Gott ☎ (09) 9231655 ✉ m.gott@auckland.ac.nz

Head of School: Professor Alexandra McCarthy ☎(09) 373 2897
✉ alexandra.mccarthy@auckland.ac.nz

If you want to talk to someone not involved in the study, you can contact a health and disability advocate (with the choice of a Maori advocate if you prefer) on:
Phone: 0800 555 050
Email: advocacy@hdc.or.nz

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:
Phone: 0800 4 384427
Email: hdecs@moh.govt.nz