The caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting.

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A thesis submitted for the degree of Master of Health Sciences (Nursing - Clinical)

at the University of Otago, Dunedin, New Zealand.

October 2018.
Abstract

Background

Haematopoietic stem cell transplant (HSCT) - also known as 'bone marrow transplant' or 'stem cell transplant' - is an intensive treatment which may be used to treat patients with blood cancer such as leukaemia, lymphoma and myeloma. The HSCT process is complex. The treatment carries the risk of multiple physical complications including significant patient morbidity and mortality. Caregivers, who are often the patients' family members or close friends, perform an essential role in supporting the care and recovery of patients undergoing HSCT treatment. Due to its complexity, HSCT is only provided at tertiary hospitals located in main city centres, which means patients and their caregivers living in provincial New Zealand must relocate in order to access HSCT treatment. HSCT can be a demanding process, not only for the patient, but also their caregiver. Caregivers can experience significant psychological, physical, and social challenges as a result of the HSCT experience.

Aim

The aim of this research was to explore the experience of haematopoietic stem cell transplant (HSCT) from the perspective of the caregiver within the provincial New Zealand setting.

The purpose of this study is to:

- contribute to an improved understanding of the HSCT caregiver experience for those who live in provincial New Zealand.

- provide information to underpin the future development of evidence based nursing interventions, and models of care across the multidisciplinary health care team, in order to address the specific needs of HSCT caregivers.

- identify potential areas for further research.
Research Design

The research design is a qualitative descriptive study using interviews underpinned by a narrative inquiry methodological approach. A sample of eight participants who fulfilled the role of caregiver to a patient undergoing HSCT were interviewed within the time period of six months to five years post-transplant. Data analysis examined the interview narrative, utilising both a narrative and thematic analysis approach.

Study Findings

Eleven themes emerged from the participants' narratives describing their caregiver experience. The notion of the experience as a journey, was woven throughout the caregiver narratives, and emerged as an overarching theme of the study findings. A degree of inter-relatedness was identified between the themes, and highlights the complex challenges faced by caregivers during the HSCT experience.

The findings reveal the breadth of the caregiver journey, and how the experience continues to influence the lives of caregivers across the HSCT trajectory during the weeks, months and years following transplant. The findings illustrate the broad impact which relocation exerts upon the HSCT caregiver experience within the provincial New Zealand context. Furthermore the findings provide compelling insight into the depth of responsibility caregivers perceive they have.

Discussion

The study findings convey the scope of the caregiver role, and the impact the HSCT experience has upon the lives of caregivers. The experience of relocation has wide reaching practical and emotional implications for caregivers, who find themselves disconnected from their everyday lives and separated from the support of family and friends. Caregivers need to balance the duty of caring for the HSCT patient, with a range of other commitments which occur in their everyday lives 'outside' the immediate transplant setting.
The intensity and selflessness of caring for another person can result in caregivers neglecting their own self-care needs, which places them at risk of becoming overwhelmed with the responsibilities associated with the caregiver role. Therefore it is essential that health care teams and support agencies are aware of the significant impact which HSCT can exert upon the lives of caregivers, in order to recognise and plan services to address the support needs of this vulnerable population.

The study findings express a clear message for health services to increase their focus toward the provision of information and support strategies aimed specifically at HSCT caregivers. The study findings will be made available to key stakeholders, to provide evidence based insight which may be used to inform the development of nursing interventions, and comprehensive strategies across the multidisciplinary health care team, which are tailored to meet the needs of HSCT caregivers in the New Zealand setting.
Acknowledgements

The journey towards completing this research would not have been possible without the incredible support I have received along the way.

The academic and clinical expertise of Associate Professor Philippa Seaton, Dr Sandy Richardson, and Dr Sean MacPherson from the University of Otago was invaluable to this research project. This thesis would not have been completed without their astute guidance, enthusiasm and unwavering support.

Grateful thanks to Leukaemia and Blood Cancer New Zealand, and the two DHB haematology departments who supported recruitment to this research study. Thank you for recognising the value in understanding the challenges faced by the caregivers who support our HSCT patients.

Thank you to the three regional branches of the Cancer Society who supported this research project by providing a meeting space to conduct several of the interviews for this study.

I extend thanks to my colleagues and professional networks who have supported my research journey. This study was made possible with the support of my employer - the Hawkes Bay District Health Board; and Health Workforce New Zealand who provided assistance with my university fees.

This thesis would not have been possible without the caregivers who participated in the study. They shared their personal stories openly and generously, and displayed a genuine desire to contribute to this research project, with the hope that the findings may help HSCT caregivers in the future.

This research project was inspired in part by the intersection of my own clinical practice, with the experience of two families who hold a personal connection to me. I continue to be in awe of the courage, strength and family bonds that are supporting these people through their HSCT journey.
To my friends and family who have supported me during this study - I truly cannot thank you enough. I am so grateful to those people who have kept in contact to check in on my progress, and encouraged me to 'keep my eyes on the prize'. Special thanks to Marcia & Kate - your encouragement, epic manuscript reading skills (!) and genuine interest in this research project has been an incredible support.

To my parents - Fay and Des, and my parents in-law - thank you for the numerous child minding sessions that have enabled me to attend supervisory meetings, conduct interviews, and keep on writing. To my sister Natalie - thank you for listening attentively to what I know is a foreign topic for you, and for your eagle eyed proof-reading skills. Grateful thanks to my brother-in-law Anthony, for generously providing your time and expertise to assist with formatting the final manuscript.

Finally to my husband Regan, and our three girls - thank you for sharing me with this research project for the past two and a half years. To Chloe, Ayva Lola and Matilda - Mama has 'finished her university'! (for now...)
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Chapter 1: Introduction and Background

Introduction

Haematopoietic stem cell transplant (HSCT) - also known as 'bone marrow transplant' or 'stem cell transplant' - is an intensive treatment which may be used to treat patients with blood cancer such as leukaemia, lymphoma and myeloma. The HSCT process is complex. The treatment carries the risk of multiple physical complications including significant patient morbidity and mortality, in addition to a range of potential psychosocial challenges - such as relocation for treatment, financial concerns, relationship changes, and mental health distress.

Blood cancer is the fifth most common type of cancer diagnosed each year in New Zealand (Ministry of Health, 2016a). New Zealand is experiencing a significant increase in the volume of HSCT's being performed each year (Ministry of Health, 2011). Factors which are contributing to this increase include treatment advances which have increased the potential age of eligibility for HSCT and the country's ageing population, whereby cancer is overwhelmingly diagnosed more in older people. In New Zealand nearly 7 out of 10 of all new cancer cases in 2013 were diagnosed in the population aged 60 years and older (Ministry of Health, 2016a). The most recent available data indicates that in 2016, 308 patients received a HSCT in New Zealand (Australasian Bone Marrow Transplant Recipient Registry, 2016). The number of HSCT's undertaken in New Zealand has nearly doubled over the past decade and is projected to increase by approximately 25 additional transplants each year, subject to available resources (Australasian Bone Marrow Transplant Recipient Registry, 2016; Ministry of Health, 2011).

HSCT patients are required to have a designated caregiver to support them through the HSCT process and post-transplant recovery phase. This is often a family member or close friend. The extreme nature of HSCT can be a demanding experience not only for the patient, but also for their caregiver (Fife, Monahan, Abonour, Wood & Stump, 2009). The aim of this research was to explore the experience of HSCT from the...
perspective of the caregiver, with a particular focus on the characteristics of this experience within the provincial New Zealand context.

The importance of addressing the support needs of the caregiver within the framework of comprehensive cancer care has particular resonance within the New Zealand context. Due to the service configuration in New Zealand, many patients and families face additional challenges associated with the requirement to relocate away from home for HSCT treatment. In response to the particular importance of family/whanau and community to Māori and Pacific people, the needs of family/support persons are addressed within the national development strategy for supportive cancer care (Ministry of Health, 2010). It is therefore imperative that the experience of the HSCT caregiver be examined within the New Zealand context, in order to identify the support needs required by the HSCT caregiver population. The findings from this examination may subsequently serve to inform the development of strategies and interventions across the HSCT care trajectory in order to provide comprehensive care to patients, family and caregivers whom are affected by blood cancer.

This chapter presents an overview of haematopoietic stem cell transplantation (HSCT) in order to provide background information and context of the role of the HSCT caregiver. The role of the HSCT caregiver is outlined and an illustration of how this translates to the New Zealand context is presented.

**Haematopoietic stem cell transplant (HSCT)**

HSCT is used in the treatment of blood cancers, including leukaemia, lymphoma and myeloma, as well as some non-malignant haematological conditions. HSCT may also be used to treat other conditions such as immune disorders and a small group of solid tumour types (Wingard, 2007). However, these contexts lie outside the scope of this study which focuses specifically on the role of HSCT in the treatment of blood cancers.

HSCT involves the delivery of high dose chemotherapy followed by the replacement of abnormal bone marrow with an infusion of healthy haematopoietic stem cells (Copelan, 2006). Haematopoietic stem cells are capable of maturing into all types of blood cells. This ability is harnessed by the HSCT process to renew and replenish a person's damaged bone marrow (Richardson & Atkinson, 2006).
There are two main types of HSCT: autologous and allogeneic. An autologous HSCT (auto-HSCT) is where the transplanted stem cells are obtained directly from the patient themselves. The stem cells are harvested from the patient, stored (preserved and frozen), then re-infused after the patient receives high doses of chemotherapy. The patient's bone marrow which has been damaged by the high dose chemotherapy treatment is 'rescued' by the returned stem cells (Kisch, 2015).

An allogeneic HSCT (allo-HSCT) involves stem cells that have been donated to the patient from another person. Allogeneic transplantation is more complex and high risk than an autologous transplant (Richardson & Atkinson, 2006). The aspect that distinguishes an autologous from an allogeneic transplant is the immunosuppression required for an allogeneic transplant. Immunosuppression is pivotal in an allo-HSCT to mitigate the potential complications caused by the different immune systems that exist between patient and donor (Copelan, 2006; Wingard, 2007).

During HSCT the patient undergoes 'conditioning therapy' which involves the administration of high dose chemotherapy and sometimes includes total body irradiation (TBI) treatment. The objectives of conditioning are to eliminate residual disease, encourage immunosuppression and create space in the bone marrow for the donor cells to engraft (Gyurkocza & Sandmaier, 2014; Richardson & Atkinson, 2006). Following the completion of the conditioning phase, the donor stem cells are infused into the patient at the time point referred to as 'Day 0'. The engraftment phase follows, where it can take 10 to 28 days for the new cells to engraft and generate new mature blood cells. This is a high risk period where the patient may experience severe side effects including: nausea, diarrhoea, mucositis, fatigue, graft versus host disease and an extreme risk of infection due to immunosuppression (Copelan, 2006; Kisch, 2015; Murray, 2015).

In recent years HSCT treatment has evolved to include reduced intensity conditioning (RIC) and non-myeloablative transplants. This approach has reduced the overall toxicity of treatment that in turn has made it possible to perform HSCT in older people and for patients with co-morbid health conditions (Gyurkocza & Sandmaier, 2014; Kisch, 2015).

It is imperative that tissue matching between the patient and the donor is assessed prior to embarking on an allogeneic HSCT to determine if an adequate match exists - this is
known as HLA (human leukocyte antigen) tissue typing. HLA matching is not necessarily absolute - it can be described in the context of HSCT as involving 'degrees of risk'. In general the closer the HLA match is, the greater the chance the HSCT will be successful (Hansen, Petersdorf, Martin, & Anasetti, 1997). An HLA mismatch can lead to the donor cells attacking the patient's own cells resulting in an immune response which may cause a cascade of serious side effects, known as Graft versus Host disease (GVHD) (Koh & Chao, 2008).

GVHD elicits an inflammatory reaction which may involve the skin, liver and gastrointestinal tract. GVHD may be classified as acute (develops less than 100 days after transplant) or chronic (develops from three months post-transplant onwards). Acute GVHD varies in severity, however it can be life threatening and is associated with significant morbidity and mortality in allogeneic HSCT (Copelan, 2006). The effects of chronic GVHD may be long term and may involve more body systems than acute GHVD, hence it can have a significant ongoing impact on a patient's quality of life (Brammer & Holtan, 2015).

The immunological differences between patient and donor tissue can however be harnessed in a positive way. This is known as the Graft versus Tumour (GvT) effect, whereby specialised immune cells (T cells) in the donor tissue recognise malignant cells in the patient (host) and attack and destroy these cancerous tumour cells. Hence there is a fragile balance between achieving an optimal GvT effect while trying to reduce the risk of GVHD (Copelan, 2006; Richardson & Atkinson, 2006).

The donor for an allo-HSCT may be a matched relative (usually a sibling) or a matched unrelated donor (MUD). There is a 25% chance of each patient's sibling being an HLA match (Koh & Chao, 2008). Approximately 15-30% of patients have a matched related donor available, and 30-70% of people have a MUD donor match available (Nowak, 2008). Certain minority ethnic groups however can find it more difficult to find a MUD donor. The probability of a MUD match for these patients can be as low as < 10 % (Hansen, Petersdorf, Martin, & Anasetti, 1997). This is an issue relevant to the New Zealand population, where it has been demonstrated that New Zealand Māori and Pasifika peoples have a reduced chance of finding an unrelated bone marrow transplant donor, compared to Caucasian New Zealanders. This is due to differences in HLA genetic variation and distribution between these ethnic groups plus an under-

Fortunately advances in transplant procedures have enabled patients who have been unable to find an adequate donor match to receive an allo-HSCT, by using a haploidentical related donor. In a haploidentical HSCT the donor is a relative (often a parent, sibling or child) who has a partial tissue match (approximately a 50% match) to the patient (Koh & Chao, 2008).

Overall mortality from transplant complications is approximately 1% for autologous HSCT. Allogeneic HSCT is a particularly high-risk treatment associated with approximately a 15-20% risk of patient mortality attributable to the significant complications associated with this type of treatment (Ministry of Health, 2011). HSCT is a physically and emotionally demanding treatment which causes a profound psychological and social impact over a sustained period of time upon both the patient and their family (Kisch, 2015; McGrath, Holewa & Etcheverry, 2011).

The HSCT caregiver

The caregiver role
Caregivers have been identified as playing an integral role in the care of the patient across the HSCT trajectory (Gemmill et al., 2011). The HSCT caregiver role is often assumed by people who have a significant relationship to the patient, such as partner/spouse, relative or friends, and provide physical assistance and emotional support to the patient (Hudson & Payne, 2009). Caregivers are a dedicated presence providing support in the form of emotional support and assistance with daily cares for up to 24 hours a day during the inpatient phase of care, leaving the bedside only for short rest or meal breaks (Foster et al., 2005). Allo-HSCT patients are required to be accompanied by a caregiver and to remain together nearby the treatment centre for up to 100 days post-transplant. Similarly, patients who have undergone an auto-HSCT are required to have a caregiver with them 24 hours a day for approximately two to four weeks once discharged from hospital (Boyle & McCord, 2015).

During the recovery phase following HSCT, patients may initially be discharged to an accommodation facility close to the hospital where the transplant took place, and
monitored as an outpatient, before eventually being discharged home. In addition to
providing support whilst the patient is in hospital, it is vital that caregiver support is
available once the patient has been discharged from being a hospital inpatient. The
caregiver provides a safety mechanism to identify the development of potential
complications which may occur, such as the risk of severe infection (Fife et al., 2009).

Impact on the HSCT patient
The presence of a committed caregiver has been shown to reduce patient distress
following HSCT, and even influence patient survival outcomes (Rini et al., 2011; Foster
et al, 2005; Foster et al, 2013). A study by Rini et al. (2011) examined 230 patients
following HSCT. They found those patients who had a dedicated and committed
caregiver during and after HSCT experienced less psychological distress up to three
years following HSCT.

A study by Foster et al. (2005) demonstrated that patients who had a caregiver staying
with them during the acute hospital phase of allogeneic HSCT were three times more
likely to survive one year post transplant. This prospective study followed up 164
patients, who received an allogeneic HSCT, over a four year period (Foster et al., 2013).
Study results confirmed an overall increase in long term survival for HSCT patients
who had a dedicated caregiver during the acute hospital phase of HSCT (Foster et al.,
2013). Furthermore the study results indicated that overall survival and relapse-free
survival rates were improved when a caregiver visited for >3 hours per day, for >75%
of the patient’s total overall hospital stay. A limitation of this research may include the
absence of data on how many of these patients had caregiver support beyond the acute
hospital stay period. However, the importance of the HSCT caregiver role as a
significant prognostic indicator is certainly clinically significant.

Impact on the HSCT caregiver
HSCT caregivers face the dichotomous challenge of coping with the responsibilities of
supporting the physical and emotional well-being of the patient, whilst at the same time
experiencing significant emotional, social and physical effects of the HSCT experience
themselves. A qualitative study by Williams (2007) conducted in the United States,
showed that HSCT caregivers felt they needed to prioritise the patient’s needs above their own. This neglect of self-care may contribute to the HSCT caregiver experiencing difficulties in maintaining their other life roles, such as being a parent, employee, and friend, and could ultimately lead to problems meeting their own personal needs and a reduction in quality of life (Deniz & Inci, 2015).

There is an expanding shift in HSCT service delivery, seen both internationally and here in New Zealand, from post-transplant care that occurs exclusively as a hospital inpatient, to a model of care that is becoming increasingly outpatient based (Ministry of Health, 2011). This practice change could heighten the involvement of HSCT caregivers, and in doing so, may raise the health care team’s expectations of the role, with increased responsibilities being placed upon HSCT caregivers. (Beattie & Lebel, 2011; Wilson, Eilers, Heermann & Million, 2009).

HSCT should be regarded as a trajectory that extends beyond the transplant itself, to include the recovery period. The length of this period can vary widely and may indeed involve the patient experiencing long-term effects for several years following their transplant. This requires a sustained commitment from the caregiver to support the ongoing physical and psychosocial needs of the patient such as fatigue, ongoing infection risk, symptom management, depression, family role adaptation and financial concerns (Gemmill, Cooke, Williams & Grant, 2011; Von-Ah, Spath, Nielsen & Fife, 2015). The impact on the HSCT caregiver should therefore not be underestimated. The caregiver who often is caring for their spouse or close family member, whilst experiencing the uncertainty of their loved one having a cancer diagnosis, may themselves experience significant psychological and psychosocial effects from the HSCT caregiver experience (Bishop et al., 2007; Brown & Stetz, 1999).

*Interventions to support the HSCT caregiver*

There is an increasing awareness of the importance of the health care team, and in particular nursing, to address the support needs of the HSCT caregiver (Page & Adler, 2008; Applebaum & Breitbart, 2013; Ministry of Health, 2010; Stetz, McDonald & Compton, 1996). The nursing model of care incorporates holistic and family centered care (Sabo, 2011). This can be seen within the bone marrow transplant (BMT) setting where the nursing staff are at the core of providing round the clock care and support to
both the patient and their family. The central role of the nurse-patient-family relationship within this practice setting, suggests nurses are ideally positioned to assess, implement and evaluate the support needs of the HSCT caregiver throughout the HSCT trajectory (Applebaum & Breitbart, 2013; Sabo, 2011).

Williams (2003, p. 679) describes the caregiving partnership as a 'caregiving dyad' between carer and patient "who are intertwined in the process of meeting the needs of the illness experience." According to Williams, understanding the elements which initiate, support and maintain the relationship across the illness trajectory are key to enabling nurses to effectively apply interventions to support these relationships between patient and caregiver (Williams, 2003). Williams (2007) formulated a conceptual model of informal caregiving dynamics that she applied and validated within the bone marrow transplantation setting. The model proposes three elements along the illness trajectory: commitment, expectation management, and role negotiation. Williams (2007) suggests that health care teams, and in particular nurses can utilise this model to understand the dynamics of the HSCT caregiving relationship in order to recognise when it may be appropriate to engage with the patient and/or caregiver to support and optimise the ongoing caregiving relationship.

**HSCT in New Zealand**

In New Zealand HSCT must be undertaken by specialist services, located at tertiary hospitals in main city centres. This means, that relocation for treatment is required for those people who live outside these areas. Auto-HSCT services are provided at Auckland, Waikato, Palmerston North, Wellington and Christchurch hospitals. Allo-HSCT services are provided at Auckland, Wellington and Christchurch hospitals.

A study by McGrath and Holewa (2011) is the sole example of research to date that examines the experience of treatment for haematological malignancy specifically within the New Zealand context. The findings from their qualitative study demonstrate how relocation for specialist treatment significantly challenges and impacts upon the lives of patients and their carers.

It is also salient to note the absence of literature and epidemiological data available regarding ethnicity and HSCT in New Zealand. The Australasian Bone Marrow
Transplant Recipient Registry (ABMTRR) is the sole collective repository for HSCT performed in New Zealand, and does not publish ethnicity data within its annual report (Australasian Bone Marrow Transplant Recipient Registry, 2016).

The intention of the current study presented in this thesis, is to build upon the work of existing research, with a distinct focus on the caregiver experience within provincial New Zealand. This inquiry builds upon data from overseas studies to examine the role of the HSCT caregiver.

**Study purpose**

The aim of this study is to explore the HSCT caregiver experience for those people who are required to travel away from home and relocate to one of the main New Zealand city centre hospitals for treatment. The purpose of this study is to: i) contribute to an improved understanding of the HSCT caregiver experience for those who live in provincial New Zealand; ii) provide information to underpin the future development of evidence based nursing interventions, and models of care across the multidisciplinary health care team, to address the specific needs of HSCT caregivers; iii) identify potential areas for further research.

**Research question**

This research aims to answer the question, ‘What is the caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting?’

**Thesis outline**

The thesis is presented in the following chapters: The role of the HSCT caregiver, clinical context of HSCT, and HSCT service delivery within the New Zealand setting has been outlined in Chapter One.
A review of the extant literature pertaining to the HSCT caregiver experience, is provided in Chapter Two. The review findings serve to inform the research inquiry into the experience of HSCT caregivers within the provincial New Zealand context.

The research process undertaken to conduct the study is presented in Chapter Three. This chapter describes the research design, including the narrative inquiry methodology which underpins the research study. The research methods employed to examine the research topic, including: data collection, data analysis, and ethical considerations are also discussed.

Chapter Four presents the research findings obtained from narrative analysis and thematic analysis of the interview data.

Chapter Five provides a discussion of the research findings. The significance of the findings, their clinical implications, the study's limitations and potential directions for future research are explored.
Chapter 2: Literature Review

Introduction

Research within the context of haematopoietic stem cell transplantation (HSCT) has extended to examining the experience of HSCT caregivers, in order to identify just what this experience 'looks' like and what support needs exist for this group of people. This chapter provides a review of the literature that explores the experience of the HSCT caregiver. The key facets of the HSCT caregiver experience identified within the literature will be described and discussed.

The purpose of this review is to: i) provide an overview of the literature which examines HSCT caregiver experience, ii) review and synthesize the research available to-date on the HSCT caregiver population, iii) identify potential areas for further research.

Review Framework

A narrative review using a systematic approach has been chosen for this literature review. This review framework has been selected in order to provide a comprehensive overview of the breadth of literature pertaining to the HSCT caregiver experience. A systematic approach underpins this narrative review in order to enhance methodological rigour and to promote the application of critical thinking. This narrative review is therefore intended to serve as a platform to inform the reader and provide the background for the research study within this overall thesis, which examines the HSCT caregiver experience within New Zealand.

A narrative review method provides a comprehensive overview of a given topic, and allows a broader range of elements within a subject to be incorporated than may be possible within a systematic review, which by its structured design is specifically focused around a narrowly defined research question and the use of strict procedures for data extraction and analysis (Ferrari, 2015).

As the descriptor 'unsystematic narrative review' suggests - the narrative review approach is sometimes considered the antithesis of a systematic review (Green, 2006,
This is largely due to the absence of explicit steps to methodically search, critically appraise and synthesize literature findings which are essential to the systematic review process. Narrative reviews typically do not state specific literature search strategy or follow strict methodological procedures, nor do they explain how decisions were made about the relevance and validity of the included studies (Collins & Fauser, 2005). Consequently, the process of critical appraisal, whilst not precluded by the narrative review process, is not necessarily applied within its methodology (Green, 2006). Variation in the format and methodology of narrative reviews, in addition to a lack of scholarly guidelines for writing quality narrative reviews is noted within the literature (Ferrari, 2015; Green, 2006).

The broad scope and lack of procedural structure within a traditional narrative review approach does therefore present limitations to this choice of research design. These can manifest as a lack of rigour, validity and/or bias within the narrative review approach (Collins & Fauser, 2005). However, to overcome these risks it is suggested that narrative reviews incorporate a systematic approach, and 'borrow' methodological elements from the systematic review process (Ferrari, 2015; Murphy, 2012). Utilising a systematic approach to reviewing literature is important in order to promote clarity, auditability and validity (Booth et al., 2016). These systematic elements should include a literature search strategy which is explicit and reproducible by others, and which outlines inclusion and exclusion criteria. It may also include other systematic procedures, such as the application of critical assessment in order to evaluate the quality and validity of literature included in the review (Green, 2006; Murphy, 2012).

Overall this hybrid type of approach harnesses the flexibility and broad scope of a narrative review, while incorporating the methodological rigour of a systematic approach, to ultimately enhance the overall rigour of the narrative literature review process.

**Scope of the Review**

The focus of this review is to examine the HSCT caregiver experience, and explore the impact and challenges faced by HSCT caregivers. The guiding question for this review is "what is the caregiver experience of haematopoietic stem cell transplant?" A
secondary focus of this review is to identify examples of interventions designed to support the HSCT caregiver population.

Method

Literature Search

Search strategy
A literature search across the following electronic databases was performed for the time period from 1995 to 2017 using CINAHL (via EBSCO), Google Scholar, Medline (via Ovid), PubMed, and Scopus. The electronic search strategy incorporated the following keywords using the appropriate Boolean operators (AND, OR): haematopoietic stem cell transplant(ation), bone marrow transplant(ation), caregiver, carer, informal caregiver, family, spouse, experience, quality of life, psychosocial impact, physical impact, support strategies, support interventions. Related terms were included to optimise the range of the search results. A manual search of references within published articles was performed as a further method of identifying relevant literature.

The date range of articles published in the years from 1995 to 2017 was chosen to maximise the yield of search results within this niche research topic; and to include the evolution of study findings over the span of the past several decades, during which time research activity examining the role of HSCT caregiver has continued to develop, in response to a growing awareness across the health care landscape regarding the importance of the HSCT caregiver role.

Inclusion criteria
Studies were included if they examined one or more of the following domains: i) the psychosocial impact experienced by HSCT caregivers, ii) the physical impact experienced by HSCT caregivers, iii) family dynamics of HSCT patients, or iv) interventions to support HSCT caregivers.

The domain of family dynamics was included because the role of HSCT caregiver is often performed by close relatives/family members of HSCT patients, e.g. spouse,
sibling, parent, or child. Published studies using qualitative, quantitative, or mixed methods were included.

Exclusion criteria
Studies were excluded if they examined HSCT in children (aged <15yrs), or HSCT for conditions other than haematological malignancy. This is due to the differences that exist within these particular clinical contexts. Articles published in languages other than English were excluded due to the potential financial costs associated with translation services within the resource limitations of this study project. Grey literature was not included, in order to limit the focus of literature review to research-based evidence.

Exceptional criteria
Two articles were included which did not exclusively examine the context of HSCT caregiver experience (McGrath, 2000; McGrath & Holewa, 2011). These two qualitative studies focus on the experience of patients and their caregivers following relocation for 'specialised haematological treatment'. Although specialist treatment may predominantly include HSCT - it may however also encompass intensive inpatient chemotherapy without transplantation. These aforementioned studies are predominantly patient focused, however do include some caregivers within their study sample. It was decided to include these two articles within the data analysis because they are among the few studies undertaken within an Australasian context that include HSCT caregivers. Furthermore, the article by McGrath and Holewa (2011) is to the author's knowledge, the only study to date to examine the experience of relocation for the treatment of haematological malignancy within New Zealand. Therefore the inclusion of this particular study in this literature review is highly pertinent to the research inquiry presented within this thesis.

Data evaluation
The search strategy identified a total of 525 articles, which was then reduced to 312 after duplicates were removed. The articles within the search results were screened,
based on the previously outlined inclusion and exclusion criteria, to determine if they met the scope and eligibility criteria of the literature review.

The titles and abstracts of the 312 articles were screened - resulting in 44 eligible articles. An in-depth review of the full text content screened these 44 articles, which excluded a further 19 articles - resulting in a final sample of 25 studies which met the criteria for inclusion in the review. The data evaluation process is outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram presented in Appendix One (Moher, Liberati, Tetzlaff & Altman, 2009).

Data analysis

The selected articles were arranged into three groups according to research methodology: quantitative, qualitative, and mixed method studies. Data within each group were extracted and assembled into a matrix which displayed the studies included in the literature review, according to: author, date/country, study aim/purpose, study design/sample characteristics, method, key findings, limitations (see Appendix Two).

Data summary

This narrative review included twenty-five articles within the data analysis. All 25 articles were primary research studies: qualitative studies (n= 6), quantitative studies (n=15), and mixed method studies (n=4). The studies took place in seven different countries: United States (n=16), Turkey (n=4), United Kingdom (n=1), Canada (n=1), France (n=1), Australia (n=1), and New Zealand (n=1).

The type of sample within the studies varied to include HSCT caregivers and HSCT patients both singularly and in combination: caregiver only studies (n=16), patient/caregiver dyadic studies (n=5), and both patients AND caregiver studies (n=4).

The studies examined allogeneic and autologous HSCT contexts both singularly and in combination: allo-HSCT (n=9), auto-HSCT (n=1), allo-HSCT & auto-HSCT (n=11). Four studies did not specify what specific type of HSCT context was being examined.


**Critical assessment**

Critical assessment of the 25 articles was undertaken using the JBI critical appraisal tool/s framework (Joanna Briggs Institute, 2016). Commentary on the assessment findings is included in the limitations column within the study matrix presented in Appendix Two.

**Data synthesis**

By utilising the guiding review question of "what is the caregiver experience of haematopoietic stem cell transplant?" - the data was analysed through an iterative reading and note taking process to enable patterns and relationships from within the data to be identified.

As a result of this process the following key themes emerged: *the HSCT caregiver role; the impact on the HSCT caregiver; and support for the HSCT caregiver*. These themes were utilised as a framework for analytic purposes and also served as a method of structuring the presentation of the literature review findings.

**Related Literature Reviews**

This literature review builds upon the study findings summarized within existing systematic reviews relating to the HSCT caregiver population, by Beattie and Lebel (2011); Gemmill, Cooke, Williams and Grant (2011); Wulff-Burchfield, Jagasia and Savani (2013); and scoping review by Applebaum et al., (2016). Each of these review articles focus on particular aspects of the HSCT caregiver role, including psychosocial challenges, support interventions, long-term effects, and the outpatient HSCT setting. The literature review presented in this thesis examines the topic through a broad lens by considering the overall HSCT caregiver experience, and provides an updated review of the current research activity pertaining to the HSCT caregiver population.

The reviews by Beattie and Lebel (2011) and Gemmill et al. (2011) examine research undertaken on the experience of both allo-HSCT and auto-HSCT caregivers. Beattie and Lebel (2011) summarised that caregiver distress can be equal to or greater than patient distress. They identified several items predictive of caregiver distress including:
female gender, high subjective burden and high patient symptom distress. Distinct concepts inherent to the HSCT caregiver experience were identified across these two review studies including: uncertainty/fear of the future, prioritisation of own needs, role preparedness, role adaptation, quality of life, and demands of care. Gemmill et al. (2011) identified education, psychosocial support interventions, and self-care strategies as having potential to support the HSCT caregiver.

The concept of allo-HSCT as a trajectory that includes both the acute transplant period and beyond the transplant itself into the long-term was examined in the review by Wulff-Burchfield et al. (2013). They summarised that significant caregiver burden across the transplant trajectory exists, and how the late effects of HSCT and changes in quality of life post-transplant impacts not only the patient, but also the caregiver. The need to assess caregiver distress at critical points across the HSCT trajectory in order to identify caregivers who may need assistance was subsequently highlighted. Furthermore, they suggest that health care teams have an obligation to provide care not only to the transplant recipient (patient) as an individual, but also to the caregiver by addressing the support needs of the 'recipient-caregiver' as a combined unit (Wulff-Burchfield et al, 2013, p. 472).

A scoping review by Applebaum et al. (2016) sought to examine the experience of caregiver burden within the specific setting of outpatient based HSCT. They examined a sample of studies which included both allo and auto HSCT contexts - noting the types of caregiver burden being investigated and the assessment tools used to measure the degree of burden. They demonstrated a wide variation in how burden is assessed and measured across different studies, and how this in turn presents a challenge in evaluating burden and measuring the effectiveness of interventions to mitigate caregiver burden. Applebaum and colleagues observed an absence of research studies examining the specific context of outpatient HSCT - thus identifying a potential gap in our collective knowledge and understanding of how the growing shift towards outpatient HSCT management may impact the HSCT caregiver experience.

These review articles contribute overall to the current knowledge of the HSCT caregiver experience. They provide an overview of the HSCT caregiver role by amalgamating the key findings of existing research, which may also be useful in identifying areas to focus future research. The review articles indicate several areas whereby future research
inquiry may best be directed including: investigation into the HSCT caregiver experience within the outpatient setting, risk factors of HSCT caregiver distress, and the clinical application of support interventions for HSCT caregivers.

**Results**

**The HSCT caregiver role**

Within the literature there is some variability of the term used for, and definitions of, the 'caregiver' role. The terms caregiver, carer, support person, informal caregiver, and family caregiver are used interchangeably. The role of caregiver is typically performed by the patient's spouse/partner, parent, sibling, child or friend (Cooke et al., 2011; Fife et al., 2009).

The care requirements of HSCT patients are complex and may include physical, psychological, social and spiritual aspects of care (Gemmill et al., 2011). Consequently, this means the scope of the HSCT caregiver role and its associated tasks are many and varied. In addition to the provision of emotional and psycho-social support, this may include (but is not limited to) practical tasks such as medication administration, assistance with personal cares (showering, dressing, mobilising), temperature monitoring, monitoring for potential complications (e.g. infection, GvHD), provision of transport, and co-ordination of follow-up appointments (Applebaum, et al., 2016).

Several studies have reported that when the extent of caregiving activities increases, the HSCT caregiver experiences higher care burden and decreased quality of life (Akgul & Ozdemir, 2014; Cooke et al., 2011).

Performing the role of HSCT caregiver can be a particularly demanding experience. HSCT caregivers provide care and support in a similar manner to caregivers of other cancer patients, however, the elements that distinguish the HSCT caregiver role from other cancer caregivers are the complexity and intensity of the treatment itself, the relocation for several months away from home required for treatment, and the significant chronic long term effects involved in recovery which can last for many years post-HSCT (Beattie & Lebel, 2011; Wulff-Burchfield et al., 2013).
HSCT caregivers provide support across the transplant trajectory which can include pre-transplant, hospitalization phase, post-hospital discharge (including outpatient care), and may also extend into the long-term recovery phase during the months and years following HSCT (Bishop, Curbow, Springer, Lee & Wingard, 2011).

The value in considering the caregiver perspective across the HSCT transplant trajectory was acknowledged in a study by Von Ah, Spath, Nielsen and Fife (2015). Von Ah and colleagues sought to better understand the HSCT caregiver experience across the trajectory by interviewing a sample of fifteen auto-HSCT and allo-HSCT caregivers at two separate time points: during hospitalisation and four months post-discharge home. Among the themes identified were uncertainty, and the need for information (particularly in the early HSCT phase). Juggling multiple roles, for example being the organizer/clinician/interpreter, and finding balance between caregiver commitments and 'other' aspects of everyday life such as employment, and family responsibilities were reported throughout the HSCT trajectory.

A study by Sabo, McLeod and Coubain (2013) examined the experience of spousal HSCT caregivers up to one year following HSCT. They identified the following themes within HSCT caregiver experience: the need for hope and reassurance, uncertainty, and waiting. Their overall findings suggest that HSCT caregivers may be vulnerable to caregiver burden and psychological distress throughout the HSCT trajectory.

The enduring effects of HSCT upon the caregiver are acknowledged by Bishop et al. (2011) who sought to understand the lasting life changes for patients and their caregivers following auto-HSCT and allo-HSCT. In this study, 30 patient/caregiver dyads were interviewed at an average time point of 13 years post HSCT. Spouses reported higher negative changes than those reported by patients. The HSCT caregivers cited lingering issues of burden including: anxiety, depression, relationship challenges, and intimacy problems. In a reassuring shift, several positive dyadic themes were reported within this study, including an increased appreciation for family and relationships, hope for the future and the development of a positive outlook on life.

The responsibilities of the caregiver role may change from when the patient is in hospital receiving inpatient care from the clinical team, to the point at which the patient is discharged home and/or transitions to outpatient care. The support function of the caregiver role becomes imperative at this point in order to support the patient to carry
out activities of daily living and as a crucial safety mechanism to monitor the side effects and complications patients may experience after undergoing HSCT (Fife et al., 2009). As a consequence, the expectations and degree of responsibility placed upon the caregiver role can increase markedly during this time. This is particularly pertinent to understanding the HSCT caregiver experience as a whole, and at a time when outpatient and ambulatory models of care are being increasingly applied to the context of HSCT (Applebaum et al., 2016; Grimm, Zawaki, Mock, Krumm & Frink, 2000).

A study by Grimm et al. (2000) is one of the few studies which examine the HSCT caregiver experience specifically within the outpatient-based HSCT setting. Their longitudinal study used a mixed-methods, descriptive design to compare the emotional responses and needs of HSCT caregivers in inpatient versus outpatient settings. They reported higher patient care related needs in the outpatient caregiver cohort, however they found that outpatient caregivers experienced less mood disturbance than inpatient caregivers at the point of discharge. Furthermore, the authors found no significant differences in emotional responses or psychosocial needs between the two cohorts at six months and one year following HSCT. Limitations of this study include a small convenience sample size (n = 43) and incomplete data across some data points. Perhaps most importantly, however, is how this potentially counterintuitive finding disputes the assumption that outpatient-based HSCT may heighten caregiver burden and distress. This insight serves as a useful demonstration of how further examination of the caregiver experience of outpatient-based HSCT is required.

Impact on the HSCT caregiver

Psychological impact

The challenges associated with HSCT can present psychological issues for both patients and their caregivers. The scope, intensity and sustained nature of caregiving duties mean that the experience can profoundly affect those who perform the HSCT caregiver role. Significant psychological morbidity among HSCT caregivers, such as emotional distress, anxiety, depression, and cognitive disturbance, is reported across the literature (Armoogum, Richardson & Armes, 2013; Aslan et al. 2006; Cuhadar, Tanriverdi, Pehlivian, Kurnaz and Alkan, 2016; Foxall & Gaston-Johansson, 1996; Jim et al., 2014; Sabo et al., 2013; Simoneau et al., 2013). The terms burden and distress are used within
the literature to describe the negative impact and personal effects experienced by caregivers in response to caring for the HSCT patient (Foxall & Gaston-Johansson, 1996).

A study by Cuhadar et al. (2016) sought to evaluate the psychiatric symptoms and resilience of allo-HSCT and auto-HSCT patients and their family carers during the acute transplant period. Psychiatric symptoms reported by caregivers included depression, anxiety, emotional distress and obsessive compulsive symptoms. Their study revealed that the incidence of psychiatric symptoms among HSCT caregivers was equal to that of the patient cohort. The notion of psychological resilience as the ability to successfully overcome negative conditions when faced with stressful life events was examined. The study results demonstrated that higher levels of resilience lowered the degree of psychiatric symptoms experienced by the HSCT caregivers.

The psychological impact of HSCT upon caregivers is not limited to the acute transplant period. A study by Bishop et al. (2007) which examined long term quality of life in the years following HSCT revealed that spousal HSCT caregivers were 3.5 times more likely to experience depression than matched peer-nominated controls. Perhaps even more pertinent was that they found partners/spouses were less likely than survivors to access mental health support for depression.

**Physical impact**

Prioritising patients’ needs above their own is recognised as a way self-care deficit can be created by HSCT caregivers. This can manifest in a variety of ways including: decreased physical activity, sleep problems, mental health concerns, and fatigue (Foxall & Gaston-Johansson, 1996; Ross, Yang, Klagholz, Wehrlen & Bevans, 2016).

A study by Armoogum et al. (2013) describes the supportive care needs of HSCT caregivers up to two years post-transplant. Looking after their own health needs such as exercising, sleeping and eating properly was cited as the fifth most common unmet need (33%) by the sample of 98 caregivers surveyed in this study.

Ross et al. (2016) examined health behaviours in a sample of 78 allo-HSCT caregivers. The authors demonstrated poor health behaviours such as lack of exercise, and poor nutrition/diet, in addition to fatigue, and poor sleep quality within the HSCT caregiver
population. Studies have demonstrated that caregivers can experience physical challenges throughout the HSCT trajectory. Simoneau et al. (2013) examined 109 allo-HSCT caregivers immediately prior to transplant (Day 0) and found that all participants demonstrated difficulties with both sleep quality and duration associated with anxiety and fatigue in the peri-transplant period. Furthermore, the long-term physical consequences of the caregiver role were observed by Bishop et al. (2007) who reported spousal HSCT caregivers continued to experience fatigue, cognitive dysfunction and sexual issues years after the transplant took place. These physical manifestations were also found to be inherently related to depression within the study population - further demonstrating the depth of chronic strain experienced by those who perform the HSCT caregiver role.

Social impact
The impact of performing the role of HSCT caregiver upon the social aspects of a person's life can be far reaching. Social aspects of caring for a family member undergoing HSCT may include: changes in marital and family dynamics, disruptions in daily life and an overall immense sense of responsibility associated with providing physical and emotional care (Polomeni, Lapusan, Bompoint, Rubio & Mohty, 2016). Research suggests that spousal HSCT caregivers may even experience a poorer quality of life than HSCT patients themselves (Bishop et al., 2007). The notion of social isolation and a loss of identity has been described by HSCT caregivers as they experience a sense of disconnect from their everyday lives. HSCT caregivers have been reported as having less time to pursue their own social activities (Aslan et al., 2006). They may find themselves in the midst of an incredibly intense experience whilst 'normal' life continues to carry on around them - and perhaps most profoundly - without them. This disruption to work and family life may contribute to feelings of 'loss of identity' and 'being overlooked'; whereby the shared social network of both patient and caregiver may be perceived as being more concerned with the wellbeing of the patient, than that of the caregiver (Jim et al., 2014).

The effect of caregiving upon relationships is noted, particularly as the role of HSCT caregiver is most often performed by the patient's spouse (Fife, Monahan, Abonour, Wood & Stump, 2009; Sabo et al., 2013). It is recognised that caregivers can experience
significant changes in their relationship with the patient as a result of the transplant process (Foxall & Gaston-Johansson, 1996; Jim et al., 2014). A study by Deniz and Inci (2015) revealed higher caregiver burden and reduced caregiver quality of life scores when the HSCT caregiver was the patient's spouse. Wilson, Eilers, Heermann and Million (2009) examined the spousal caregiving experience among a study sample of 11 auto-HSCT and allo-HSCT caregivers who were providing care to their spouse undergoing HSCT. Caregivers were interviewed at multiple time points within the 100 day acute transplant period. Wilson and colleagues found that the caregiver role often evolved across the HSCT transplant trajectory - from being at their spouse’s bedside to providing emotional and physical care both during hospitalization and upon discharge. The study results revealed a set of caregiving themes within the realm of the caregiver/patient relationship. These included: knowing the person, protecting, providing care, and balancing me/us.

The impact upon spousal relationships can be long-lasting and pervasive. Spousal HSCT caregivers have reported long terms effects in the years following HSCT such as fear/anxiety of recurrence, sadness at limitations upon what the couple can do due to the patient's enduring physical health problems, and grief for the loss of shared future life plans (Bishop et al, 2011).

Financial impact

It can be incredibly challenging for the HSCT caregiver to balance caregiver commitments with the demands of their own daily lives. One example of this is how the HSCT caregiver role may impact on the person’s ability to work, resulting in a loss of earnings. This may occur at a time when household income may already be reduced abruptly - particularly if their spouse is the HSCT patient, and when additional expenses may occur associated with the HSCT experience. This is examined in a study by Meehan et al. (2006) that investigated 40 caregivers of patients undergoing autologous HSCT in the United States. Meehan and colleagues demonstrated significant financial and time commitment required by the caregiver associated with accommodation, food and petrol costs, childcare, travel time and loss of earnings whilst accompanying the patient in hospital, away from home.
A study by Simoneau et al. (2013) illustrated the changes in employment status for 109 allogeneic HSCT caregivers in the United States. Study results revealed that full time employment status decreased from 51% before becoming a HSCT caregiver to 27% whilst being a caregiver; and those taking leave from work during caregiving increased from 2% to 25%. It is perhaps no surprise then that the low income status has been found to adversely relate to levels of burden experienced by HSCT caregivers (Akgul & Ozdemir, 2014; Deniz & Inci, 2015).

Majhail et al. (2013) suggest that certain factors may contribute to the amount and type of additional costs incurred during HSCT. This includes the travelling distance to the transplant centre, the type of HSCT - where auto-HSCT patients may be discharged home sooner than allo-HSCT patients, and the availability of financial support and resources to both the HSCT patient and their caregiver. Their study of 30 allo-HSCT patient/caregiver dyads in the United States found that substantial costs were incurred to patients/caregivers during the acute transplant period (defined as the three month period immediately following allo-HSCT), and that those who relocated away from home and required temporary accommodation experienced significantly higher expenses than those who did not.

This is echoed in an Australian study by McGrath (2000) which explored the financial impact of relocation for the treatment of haematological malignancies. Participants described increased financial demands which impacted both patients and their carers who had to relocate for treatment. Additional costs incurred during relocation included: accommodation, shopping, telephone calls and the cost of maintaining their own home in their absence such as lawn mowing, pet care, and childcare. This extra expenditure was described in tandem with a decrease in available finances available to both patient and caregiver due to loss of income and/ or reduced hours of employment, the exhaustion of leave entitiles, and use of financial savings (McGrath, 2000). Within the New Zealand setting McGrath and Holewa (2011) also describe considerable evidence of the financial stressors experienced by patients and their caregivers during relocation for treatment of haematological malignancy; such as accommodation, travel (e.g. petrol), food costs, phone call charges and parking fees.

Much of the research on the financial impact of HSCT has been limited to the acute transplant period - however a pilot study in the United States by Denzen et al. (2016)
explores the long term financial impact of allo-HSCT upon 30 patients and caregivers up to two years following transplant. The study utilised a questionnaire, diary and phone interview at multiple time points (6, 12 18, & 24 months post allo-HSCT). 54% of patients who had previously been employed had not returned to work by two years following their transplant. This meant their spouse, who as previously acknowledged, is often also the person in the role of HSCT caregiver was the sole household income earner. Although this study by Denzen and colleagues is limited by a small sample size and limited generalization due to reduced study participation in the later transplant trajectory phase, the overall findings indicate that continued and significant long term financial burden can be experienced by patients, caregivers and their families following allo-HSCT.

Support for the HSCT caregiver

Assessment
The findings of several research studies support the role of assessment within the HSCT caregiver population and advocate its application into clinical practice (Armoogum et al., 2013; Aslan et al., 2006; Cooke et al., 2011; Cuhadar et al., 2016; Sabo et al., 2013; Simoneau et al., 2013). Armoogum et al. (2013) surveyed the supportive care needs of HSCT caregivers and reported high unmet need across psychological, social, financial and education/information domains. As a result of these findings, the authors suggest the application of an early 'needs assessment' for HSCT caregivers at the time of first contact with the clinical team, in order to determine those people who are most in need of support.

As a consequence of their investigation into the psychiatric symptoms of HSCT family caregivers, Cuhadar et al. (2016) suggest that family members of HSCT patients should be evaluated for psychiatric symptoms in order to identify those at risk of impaired coping and resilience during the transplant process.

The results of a study by Sabo et al. (2013) highlight the way in which the psychosocial impact of HSCT upon spousal caregivers is not limited to the acute transplant phase, but can also continue to be experienced into the long-term following transplant. The authors suggest that the health care team, and nurses in particular need to incorporate
psychosocial assessment of the HSCT caregiver at repeated intervals pre and post-transplant in order to guide the delivery of support interventions and ultimately promote HSCT caregiver well-being.

**Interventions and resources**

There is an emerging body of research examining interventions and resources to support the HSCT caregiver population. HSCT caregivers have been reported as experiencing unmet education, information and support needs (Aslan et al., 2006; Jim et al., 2014). A study by Bevans et al. (2014) harnessed a problem solving therapy approach in the form of three 1-hour education sessions held with 71 allo-HSCT caregivers. These sessions were conducted weekly following transplant during the first three weeks of the patient transition from inpatient to outpatient care. Participants reported an increased in self-efficacy (defined as confidence in performing the HSCT caregiver role) and a reduction in stress following participation in the education sessions.

As previously outlined allo-HSCT caregivers can experience high levels of stress, anxiety and depression as a result of the intense commitment and level of care required over a sustained period of time throughout the transplant trajectory. A randomized controlled trial study by Laudenslager et al. (2015) acknowledged the unique support needs of the allo-HSCT caregiver population and applied a psychosocial intervention in the form of a series of eight - one on one stress management sessions across the 100 day transplant period to a sample of 148 allo-HSCT caregivers. Participants were randomly allocated either to the intervention group or the 'treatment as usual' (TAU) group. The sessions followed the PEPRR model (Psycho-Education, Paced Respiration and Relaxation) which included education modules on stress, physical emotional health, coping skills, communication and fatigue/sleep management. This was delivered in tandem with the application of a biofeedback device designed to train breathing patterns to invoke relaxation. The PEPRR intervention was shown to significantly lower HSCT caregiver depression and overall distress levels at 3 months post-transplant compared to TAU.

The way in which caregivers are provided information and education about the HSCT process was explored in a study by Aslan et al. (2006). Aslan and colleagues surveyed 58 caregivers of allo-HSCT and auto-HSCT patients and discovered that they accessed a
wide range and combination of information sources to contribute to their knowledge and understanding of the HSCT process, including doctor/nurse, dietician, books, internet, and other HSCT patients. 67% reported they were satisfied with the information they were given - and the majority reported that they preferred the mode of face-to-face communication with a healthcare professional. The study participants indicated an information gap exists regarding the need for more information on the specific care requirements and caregiver responsibilities required following the patient's discharge home.

The importance of the healthcare team as a support and information resource, as well as the provision of information provision continuing into the post-discharge phase was raised in a study by Fife et al. (2009). A sample of 192 allo and auto-HSCT caregivers were surveyed at different time points across the HSCT trajectory - including one month following discharge home. The ongoing provision of information and support from the healthcare team were particularly associated with significantly lower levels of HSCT caregiver distress following discharge. Thus, suggesting a valid indication for post-discharge follow up with HSCT caregivers by the healthcare team.

At a time where our lives are increasingly connected, informed and influenced by the internet, it would be remiss to not consider the role of social media and technology as a potential platform to support HSCT caregivers. A study by Jim et al. (2014) described how caregivers found email, blogging and social networking helpful activities during HSCT. In addition to this Jim and colleagues also recommended that HSCT caregivers access internet based information and resources provided by established blood cancer specific organisations.

In addition to formal support strategies, the literature also discusses some of the more self-directed ways in which HSCT caregivers seek to cope with the challenges of the HSCT experience. The use of personal routine, individual social supports, focusing on one day at a time, having a positive outlook, and envisioning the future are reported as among the types of coping strategies employed by HSCT caregivers (Jim et al., 2014; Wilson et al., 2009). The provision of complementary psychosocial interventions such as music therapy, mindfulness, and yoga for HSCT caregivers has also been suggested as having potential to promote psychological well-being and resilience within this population (Cuhadar et al., 2016).
Summary

The studies examined within this review include both allo-HSCT and auto-HSCT caregiver populations; the rigour and long-term effects associated with allogeneic HSCT in particular, is noted. Two of the twenty-five articles evaluated interventions to support the HSCT caregiver population (Bevans et al., 2014; Laudenslager et al., 2015). Nine articles related specifically to the experience of spousal and/or family HSCT caregivers (Bevans et al., 2007; Bishop et al., 2011; Cuhadar et al., 2016; Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Polomeni et al., 2016; Sabo et al., 2013; Von Ah et al., 2015; Wilson et al., 2009).

Quality assessment identified overall limitations in the generalizability of study findings due to small sample size, and demographically homogenous sampling. In addition to this, several of the studies were limited by the application of a solitary time-point of measurement within the HSCT trajectory, or a lack of clarity on what point in time within the trajectory was being evaluated.

The literature acknowledges the range of people who may perform the caregiver role; however, an emphasis on family caregivers, and in particular spousal HSCT caregivers was observed within this review. Examination of the patient/caregiver dyad appeared to be usefully employed when investigating the long term changes experienced by patients and their spousal caregivers, and in those studies which sought to evaluate the financial impact of HSCT. Research on the financial implications of HSCT was limited to the United States (3) and Australia (1). It may be useful to conduct future research into the financial impact upon HSCT caregivers in a range of other country settings, whereby international comparisons on the experience of health services and support available to HSCT caregivers could potentially be made.

Discussion

The review findings illustrate how the transplant experience can significantly impact the lives of HSCT caregivers. Individuals within this population can experience psychological symptoms such as anxiety and depression, and physical symptoms such
as insomnia and fatigue. In addition to this, they may also experience significant changes in the psychosocial structure of their lives. This can include changes in relationships, family dynamics, employment and financial status. It was observed that these negative symptoms are described collectively throughout the literature as 'distress' and/or 'burden'. The specific and individual definitions of which are debated within the literature, however, these lie outside the focus of this review. The development of a 'burden of care' and self-care deficit among HSCT caregivers was described within the literature - whereby the caregiver places the needs of the patient before their own, leading to the detriment of their own well-being through the experience of distress and/or burden.

There is a paucity of research evidence available on the caregiver experience specifically within the outpatient/ambulatory setting. The literature appears unified in its concern that the growing shift to this model of care within HSCT may increase the responsibility of the caregiver role and could heighten its associated stressors. However, the current research appears unclear specifically how and to what degree this may affect the HSCT caregiver experience, and furthermore what type of support interventions could be tailored to best support the needs of caregivers within the outpatient/ambulatory HSCT setting.

Of note within the literature is a focus on viewing the HSCT experience as a broad trajectory. The evolution of the caregiver experience, and the differences which exist during the different phases of the transplant process are widely acknowledged across the studies included in this review. This can be observed within several of the studies which evaluated the HSCT caregiver experience at multiple time points during the transplant process. Furthermore, the research findings within this review elucidate the significant long term impact experienced by those who take up the HSCT caregiver role. This includes the enduring effects the transplant process can have on the HSCT caregiver's finances, relationships, psychological and physical well-being.

The review findings reveal how the needs of the HSCT caregiver can indeed change over time. This may be helpful in providing evidence to guide the timing and provision of support strategies. There appears to be agreement across the research literature that consideration of the HSCT caregiver is crucial, and that psychosocial assessment of the caregiver should be carried out at different time points in order to assess changes over
time. This is consistent with the findings and recommendations for clinical practice suggested within the existing literature reviews pertaining to the HSCT caregiver experience.

The ability to recognize caregiver distress and respond appropriately is fundamental to the provision of safe and effective care, and consistent with the collective professional responsibility of the health care team. However, this must be reinforced by the clinician's ability to provide support, and is therefore dependent on available resources. Research has begun to examine the effectiveness of interventions to support the HSCT caregiver and demonstrates the potential to improve well-being within this population. Further research is required to examine the type, timing, and mode of delivery of support interventions and resources which could be applied to clinical practice in order to support the HSCT caregiver.

**Conclusion**

This chapter has provided a narrative review of the literature that explores the experience of the HSCT caregiver. It is clear that the complexity of care required over a sustained period of time, in order to support the HSCT patient during their transplant and recovery, means the caregiver role is an essential component of the HSCT process. The scope of the HSCT caregiver role, its challenges and enduring impact on the lives of the people caring for those undergoing HSCT has been described.

There is a sizeable body of literature on the HSCT caregiver experience. However, detailed exploration of the types of interventions and resources to support this population is in its infancy, and is not well understood. The review findings demonstrate how there may be merit in focusing future research on support interventions for HSCT caregivers, and examination of the HSCT experience specifically within the outpatient/ambulatory setting. Overall the literature review presented in this chapter provides compelling evidence to underpin the purpose of this thesis which is to explore the caregiver experience of HSCT in New Zealand.

The following chapter outlines the methodology and research process followed to undertake the research project of this thesis. The research design, methodology, data collection, data analysis and ethical considerations will be described and discussed.
Chapter 3: Methodology and Methods

Introduction

This chapter describes the research process undertaken to conduct this study which explored the caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting. A description of the research design, including the methodology and methods, is presented.

Whilst there is a sizeable body of international literature on the HSCT caregiver experience there have been no published studies to date that specifically investigate the HSCT caregiver experience within New Zealand. Therefore an exploratory research design was chosen to investigate this topic within the provincial New Zealand context.

Methodology

Narrative inquiry is a way of understanding experience (Clandinin & Connelly, 2000). It recognises that stories have the ability to transform experience into a communicable representation, in order to provide insight about lived experience (Thorne, 2000). Narrative inquiry acknowledges the chronology of personal stories, whereby it "describes human experience as it unfolds through time" (Clandinin & Rosiek, 2007, p.40). It is a research methodology which promotes the collection of personal stories and rich descriptions of experience, and enables an exploration of what this means from the perspective of the individual (Connelly & Clandinin, 1990).

A narrative inquiry approach to research, considers how people's stories are influenced by their past experiences as well as their present life situation, including a person's social network, and the dynamics of their own living and working spaces (Lindsay, 2006). The methodology also acknowledges the researcher as a participant in listening to the stories being told, and how these stories are consequently shaped by the interaction between the researcher and the participant (Clandinin & Connelly, 2000; Lindsay, 2006; Haydon & Van Der Riet, 2014).
The philosophical foundation of narrative inquiry is based on the notion of experience by philosopher, John Dewey. Dewey's philosophy asserts that experience is continuous over time, and interconnected across personal, social and physical environments (Clandinin & Rosiek, 2007; Lindsay & Schwind, 2016; Wang & Geale, 2015).

This study utilises the framework of Connelly and Clandinin (1990) both of whom are educational researchers who pioneered the narrative inquiry approach as a research methodology (Wang & Geale, 2015). Their framework builds upon the Deweyan philosophy of experience, and establishes a three-dimensional schema of 'common places' that includes: temporality, sociality, and place as concepts inherent to the notion of experience, to be considered within a narrative inquiry research approach (Connelly & Clandinin, 1990; Connelly & Clandinin, 2007; Wang & Geale, 2015). These common places distinguish narrative inquiry from other qualitative research methodologies, and served as a conceptual framework to guide the application of this research methodology within this study (Lindsay & Schwind, 2016).

This study used a narrative inquiry research methodology to explore the experience of HSCT caregivers in provincial New Zealand, by considering the past, present and future of the storyteller (temporality); the social context of the story - including the storyteller's interactions with other people (sociality); and recognising the situational context of the story (place), including how the physical situation and environment has affected the experience/s of the storyteller (Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Haydon & van der Riet, 2014; Wang & Geale, 2015).

Narrative inquiry can be studied from a wide range of perspectives, which means no single defined approach exists (Elliot, 2005; McCance, McKenna & Boore, 2001; Sandelowski, 1991). With no perspective mutually exclusive to another, the researcher can harness the versatility of a narrative inquiry approach, by deciding how to shape the research method in order to address the aim/s and intention of their own particular study (Clandinin & Connelly, 2000; Elliot, 2005; McCance et al., 2001).

Narrative inquiry research can focus on the content of the narrative for example, what the story told; or on the form and structure of narrative, or how the story was told. (Elliot, 2005). Research that utilises narrative inquiry methods can also be descriptive or explanatory (Polkinghorne, 1988). Descriptive narrative research reveals how individuals describe their own experience of life events. It may describe either
individual or group narratives of particular life episodes, and what function that episode of life experience has within an individual's own life (Sandelowski, 1991).

Explanatory narrative research is retrospective and examines past events which are linked together in narrative form in a story. Explanatory narrative inquiry attempts to reveal an individual's perceptions of their experience, and provide insight into the reasons why life events have happened. The explanatory approach seeks clarity on the significance of events by looking back and re-telling stories of past experience (Polkinghorne, 1988; Sandelowski, 1991).

The research study presented in this thesis explores the HSCT caregiver experience using the three-dimensional framework of temporality, sociality and place, and predominantly utilises a content focused, descriptive narrative inquiry research approach. In response to the overall intention of this research, which is 'to gain an understanding of the HSCT caregiver experience in provincial New Zealand' - aspects of the explanatory narrative inquiry perspective, as well as an awareness of the narrative structure have also been harnessed where applicable, to underpin the overall research methodology of this study.

Narrative inquiry is not focused on generalisation but is said to "sing up many truths and narratives" (Byrne-Armstrong, 2001, p. 112). Trahar (2013) asserts a social justification for utilising narrative inquiry as a research methodology as a way of enabling "...silenced voices to be heard..." (Trahar, 2013, p. xiv). The narrative inquiry research methodology "allows researchers to present experience holistically in all its complexity and richness" (Duff & Bell, 2002, p.209). It is these qualities which contribute to the narrative inquiry methodology being an effective way to seek insight into experiences of healthcare (Hardy, Gregory & Ramjeet, 2009; Haydon & van der Riet, 2014; Lindsay & Schwind, 2016; Riley & Hawe, 2004; Wang & Geale, 2015). The personal stories revealed in the narratives of health care consumers, enables health consumers to have a voice, and provides opportunity to inform the practice of health care professionals, by identifying challenges associated with the health care experience (Lindsay & Schwind, 2016; Sparkes, 2005).

It is the multi-faceted lens of narrative inquiry with its distinct focus on 'experience', which resonates with the study objective of elucidating an understanding of HSCT caregiver experience within the context of provincial New Zealand; thus providing a
clear rationale for the selection of narrative inquiry research methodology to underpin this study.

**Recruitment**

The nationwide professional networks of the researcher were harnessed to assist with identifying potential eligible study participants to approach and invite participation in the study. This included connecting with clinical haematology teams at hospitals across two District Health Boards (DHB's), and the support services team of Leukaemia & Blood Cancer New Zealand (LBC). The two DHBs were chosen based on being located in the North Island, and South Island respectively, in an effort to promote participant representation from areas which New Zealand based HSCT caregivers have to travel from. Given that LBC is the leading organisation in New Zealand providing support to patients and their families affected by blood cancer, the researcher recognised that connecting with LBC would be a key enabler for study recruitment.

The researcher contacted clinical leads within each of the DHB haematology departments, and the support services manager at LBC in order to seek their formal approval to support study recruitment. Each organisation was provided with copies of the supporting documents for the study (see Appendices Three, Four & Five). Locality assessment was undertaken, whereby the research proposal was considered by each organisation, with opportunity provided for any queries to be discussed with the researcher. Feedback from all of the organisations was uniformly positive. They each endorsed the study's objectives and provided written approval to support recruitment to the study.

Study recruitment was supported by DHB haematology nursing staff, and LBC's nationwide network of support services coordinators, who identified potential participants from their own patient/client population based upon the study inclusion and exclusion criteria. The DHB haematology nurses and LBC support service co-ordinators contacted potential participants to introduce the study, and then provided interested individuals with a copy of the study advertisement (see Appendix Three). The involvement of these representatives finished at the point of dissemination of the
recruitment information, which meant they did not have any way of knowing who subsequently agreed to participate in the study.

The study advertisement included the contact details of the researcher, and invited individuals to make contact either by phone or email if they wished to find out more about participating in this study. Following a phone conversation with the researcher, those who remained interested in participating were provided with the study information sheet (Appendix Four) and consent form (Appendix Five). After allowing time to read and consider the information, the researcher then contacted potential participants to answer any further questions and to discuss informed consent.

The study participants

A convenience sample (Polit & Beck, 2017) of eight participants were recruited to take part in the study. The study participants were caregivers of adult patients (patient aged 18 years >) with haematological malignancy, who had undergone HSCT between six months and five years ago. The role of caregiver was defined as the person (e.g. spouse/partner, family member or friend), aged 18 years or over, who performed the primary caregiver role during the HSCT trajectory, who either lived with the patient and/or regularly assisted with medical tasks/activities of daily living during the transplant trajectory.

The following eligibility criteria for the study were developed:

**Inclusion criteria**

- Caregiver aged > 18 years
- Caregiver to an adult HSCT patient (aged > 18 years )
- Patient has undergone HSCT (allogeneic or autologous) for haematological malignancy within the previous five years.
- Lives > 100km from the treatment centre
- Ability to understand and complete the written informed consent.
- Ability to communicate effectively in English during the interview process.
Exclusion criteria

- Caregiver aged < 18 years
- Caregiver to a HSCT patient aged < 18 years
- HSCT for a non-haematological condition
- HSCT occurred more than five years ago
- HSCT occurred less than 6 months ago
- Lives < 100km from the treatment centre
- Unable to understand or complete the written informed consent
- Unable to communicate effectively in English during the interview process
- Bereaved caregiver (patient is deceased)

The study sample included caregivers of allogeneic and autologous HSCT patients. However preference was given to caregivers of allogeneic HSCT patients due to the complexity and intensity of this particular treatment modality. Bereaved caregivers were excluded from this study in order to prevent causing potential harm to individuals who may find the process of recalling the HSCT experience where the patient has since died, particularly distressing. HSCT for conditions other than haematological malignancy, and in the paediatric setting (patient aged < 18 years) were excluded due to the differences that exist within these particular clinical contexts.

The timeframe of between six months and five years following HSCT was chosen to optimise the likelihood of obtaining adequate participant numbers of HSCT caregivers, whilst promoting participant safety and data quality within this research study. This prevented participants being interviewed during the acute transplant phase (up to six months post HSCT) whereby both caregiver and patient remain particularly vulnerable to physical and emotional stressors.

An upper limit of two years post HSCT was initially specified in the inclusion criteria for participation in the study. However during the course of the recruitment process, interest was received from people whose HSCT journey exceeded this timeframe. After
speaking with these caregivers it became clear that the experience of HSCT was so profound, that their memories would last a lifetime. Furthermore they were able to recollect the details of their experience with incredible clarity even when the HSCT had taken place several years prior. As a consequence, the inclusion criteria for participation in the study was revised, and the timeframe increased to include the period up to five years following HSCT. This revision was approved by the University of Otago Human Ethics Committee (Health) - see Appendix Six.

The study participants were recruited from across New Zealand. All participants needed to fulfill the study criteria of being provincially located - meaning that they did not live in the city where the hospital transplant service is located. Therefore, for some of the patient's treatment, they were required to live away from home and relocate to the city-based hospital location where the HSCT took place. Within this study this is defined as living a distance of greater than 100 kilometres from the hospital transplant service.

Given the relatively small niche study population - recruitment was focused on obtaining adequate participation without preference given to participant ethnicity. Therefore strategies to specifically recruit Māori participants were not applied. However it is salient to note the subsequent study findings, do highlight the merit of future research to examine the HSCT caregiver experience from a Hauora Māori (Māori health) perspective (Durie, 1998).

Consent

Written informed consent was a requirement for all participants in this study. A copy of the consent form is provided in Appendix Five. The consent process was undertaken in accordance with the requirements and recommendations of the University of Otago Human Ethics Committee (Health), in addition to consultation with the University of Otago - Kaitohutohu Rangahau Māori /Māori Research Advisor. Emphasis was placed upon voluntary participation and confidentiality in the study. Participants were assured no identifiable information would appear in any spoken or written report, or publication associated with the study. Further details of the ethical considerations within the study are provided later in this chapter (see 'Ethical considerations').
Participants were provided with two copies of the consent form. Those who chose to participate in the study completed both consent forms. Participants were able to keep one copy for their own records, and were asked to forward the remaining copy to the researcher via the prepaid envelope provided.

Data collection

Data collection was achieved through in-depth qualitative interviews underpinned by the principles of narrative inquiry. Narrative inquiry research methodology acknowledges the role of the researcher as they listen to the participants' stories, and places importance on how the narrative is co-constructed by the collaborative and interactive partnership between the researcher and the participant (Duff & Bell, 2002; Lindsay, 2006; Mishler, 1986). The partnership dynamic is highlighted by Clandinin and Huber (2010) who state that "narrative inquiry is a process of entering into lives in the midst of each participant's and each inquirer's life" (p. 445). The researcher was mindful of the responsibility involved in being entrusted with the participant's stories, and ensured the contributions of each participant were supported and respected throughout each stage of the research process.

Padgett (2016) defines reflexivity as "the ability to critically examine one's self" (p. 18). As a registered nurse working within the clinical specialty of malignant haematology, the researcher applied reflexivity to examine how her own beliefs and assumptions regarding the experience of HSCT caregivers, may influence data collection. The interview process avoided the use of leading questions, to encourage participants to share their stories, and ensure their own voices were heard.

The way the participant is supported during the research process can affect the construction and usefulness of the narrative (Mishler, 1986). The researcher ensured that at the beginning of each interview session each participant was provided with a reminder of the aims of the study, as well as an outline of the interview plan including: the question format, audio recording process and expected duration of the interview. Participants were reminded they were able to decline to answer any questions and/or stop the interview at any time if they felt they did not wish to continue.
Study participants were interviewed at a single time point ranging from six months to five years post-transplant within the patient's HSCT trajectory. The interviews were carried out face to face - either in person in a private meeting room with the researcher and participant present in person, or via online video conference using Skype. The option of a 'virtual' face to face interview was included following a request by one of the study participants to be interviewed via Skype. An application to consider the Skype video conference option was submitted to the University of Otago Human Ethics Committee (Health), and was subsequently approved (see Appendix Seven). Two of the study interviews were conducted via Skype. The option of conducting the interviews online enabled the researcher to reach caregivers who were remotely located, whilst maintaining privacy and overall data quality. This was important as the hallmark of this study was to examine the experience of HSCT caregivers who were provincially located.

Consistent with a narrative inquiry approach, a semi-structured interview approach was adopted. This allowed for flexibility in the interview process in response to the participant's story of their own individual experience (McCance et al., 2001; Mishler, 1986, Riessman, 1993). Open ended prompting questions were developed from themes identified within previous research studies, in addition to addressing areas that enabled exploration of the HSCT caregiver experience from a uniquely New Zealand context. A copy of the interview question template is included in Appendix Eight.

The interviews were structured so as to keep the duration to approximately one hour. This was in an effort to minimise strain on the participant, whilst providing adequate time to generate the narrative data required in order to explore the research topic. The interviews were audio recorded on an external recording device. The video-conference interviews via Skype were conducted in a private space, and audio recorded in the same manner as the in-person interviews, in order to provide privacy within the online environment.

'Memo' notes were written by the interviewer both during and immediately following the interview. These written memos were used to "record anything that attracts the researcher's attention." (Burnard, 1991, p. 462). The memo notes consisted of observations such as the participant's body language, overall impressions, and notes on practical aspects of the interview including the physical set up of the interview room,
the interview question template, the audio recording process, and/or ideas about the interview data collected thus far.

The recorded interviews were subsequently transcribed verbatim into a typed transcript by the researcher. All data has been kept in a locked filing cabinet, or in a password protected computer in a locked office. In the interests of confidentiality, the audio recorded interview data (which may be potentially more identifiable from voice or spoken details) was erased on completion of the study. As per the Otago Human Ethics Committee (Health) requirements - no written data will be destroyed until 10 years after the closure of the study. Data will be securely kept in password protected, locked storage until this time.

Data analysis

The literature pertaining to narrative inquiry reveals a diverse range of data analysis approaches used in narrative research (Bamberg, 2012; Clandinin & Rosiek, 2007; Hardy, Gregory & Ramjeet, 2009; Mishler, 1986; Polkinghorne, 1995; Riessman, 1993; Sandelowski, 1991). There is however an absence of clear guidance on when to use, or not use, particular data analysis approaches in narrative inquiry research (McCance et al. 2001). According to Mishler (1986) this prevents narrative researchers being restricted to only using certain approaches, and highlights the importance of selecting a data analysis approach based on its suitability to the design and aims of a research study (Bamberg, 2012; McCance et al. 2001; 1986). The idea of using a range of analytic approaches is supported by Guest, MacQueen, and Namey (2012) who assert that good research design uses a data analysis approach which combines analytic techniques and elements from across different research perspectives.

In order to determine the analytical framework for this study the researcher regularly went back to the aims of this study, which sought to examine the experience of HSCT caregivers in provincial New Zealand, to consider which analytical techniques would be suitable to guide the data analysis within this study.

After considering the different approaches presented within the literature, features within the analytical approaches of several authors whose studies involved narrative data, stood out to the researcher as being compatible with the design and aims of the
research study presented within this thesis. These included Hunter’s (2009) analysis of narrative interview data using a combined approach of narrative analysis and thematic analysis; Emden's (1998) narrative analysis technique of core story creation; Burnard’s (1991) thematic analysis of narrative interview data; and Gibson and Brown's (2009) methods of thematic analysis.

Riley and Hawe (2004) provide a comparison of narrative analysis and thematic analysis, and suggest that the two approaches are interconnected, with an interest in 'themes' being common to both narrative and thematic data analysis approaches. This is echoed by Gibson and Brown (2009) who explain that narrative analysis is focused on working out the discursive themes across interview data. These authors go on to state that narrative analysis and thematic analysis are approaches which are equally concerned with the differences, similarities, and relationships present within data (Gibson and Brown, 2009, p. 127-129).

The researcher subsequently recognised the thematic focus of these two analytic approaches would support the aim of this research study, and reveal the diversity of the HSCT caregiver experience in New Zealand, conveyed by the participants within the narrative interview data. Hence a combined approach of narrative analysis and thematic analysis was used to conduct the data analysis within this study. This was underpinned throughout by the previously outlined analytic lens of narrative inquiry research methodology, whereby the data was examined overall to consider the dimensions of temporality, sociality and place within the interview narratives.

**Stages of data analysis**

The procedural steps undertaken by the researcher are best described as a series of stages that when combined, form the data analysis process (Burnard, 1991). In a real sense, the first stage of data analysis within this study began during the participant interviews, as the researcher began thinking about the data being collected and writing memo notes (see: data collection), and during the interview transcription process.

The audio recorded interviews were transcribed verbatim and typed up by the researcher. The transcription process provided the opportunity to repeatedly listen to and read the interview narratives. The specific techniques used for data analysis
developed as the interview data was carefully read and re-read, which in turn helped to shape the data analysis process (Guest, et al., 2012).

The second stage of data analysis involved reading and re-reading the interview transcripts with the aim of becoming "immersed in the data" (Burnard, 1991, p. 462). The transcripts were read repeatedly, focusing on a different element each time. The transcripts were read for 'typo' errors, and for a general sense of content - then read again to identify and highlight 'quotable' quotes which the researcher identified as having potential to be used when writing up the results (Hunter, 2009). At this point, copies of the interview transcripts were provided to the four participants who had indicated they wished to assist by checking the transcripts for accuracy (see: section on Rigour below). All of the participants indicated that the typed transcripts provided an accurate record of their interview.

Stage three began by reading the interview transcripts once again, this time focusing on narrative structure, and 'how' the participant's told their stories. The researcher then utilised a blend of Emden's (1998) method of core story creation, and Hunter's (2009) technique of story reduction, to construct a summary of each participant's interview narrative. The summary process involved moving fragments of each participants' narrative around, in order to reduce the content into one coherent story that summarised each interview narrative. Key quotes were identified to reflect elements central to each core story, using the participants' own words. A total of eight summaries were constructed - one for each corresponding interview transcript.

As per Emden's (1998) application of core story, the researcher returned the narrative summary to each of the four participants who chose to take part in the member-checking process (see: section on Rigour below). The participants were asked to comment on whether they felt the narrative summary reflected their caregiver experience. The researcher also sought clarity around some sections of the interview transcript and narrative summary pertaining to two of the participants. The researcher harnessed this opportunity to check the context and intended meaning within these particular sections with the two participants.

The overall response from those who engaged in this member-checking process was uniformly affirmative. One participant chose to provide email feedback that served to reinforce some of the ideas contained within her original interview. All four participants
remarked that the narrative summary captured the stories they had shared within the interview, and reflected their overall HSCT caregiver experience.

The fourth stage of data analysis consisted of a thematic analysis of the interview narratives. Consistent with the exploratory principles of narrative inquiry, the interview data was analysed inductively to allow themes to emerge from the participant's stories (Polkinghorne, 1988; McCance et al., 2001). The researcher applied a coding process to the interview transcripts, whereby a set of 'codes' were created to label categories which described a range of thematic features that emerged from within the participant's narratives (Gibson & Brown, 2009; Guest et al, 2012). Coding of the data was an iterative process where the interview transcripts were read and re-read again, which in turn meant the coding structure evolved with the cyclical nature of the procedure (Gibson & Brown, 2009).

The approach of Hunter (2009) was utilised to code the interview transcripts by examining individual sentences, paragraphs, separate narratives within each interview, narrative structure, and the overall interview narrative. It was important at this point to avoid the pitfalls of analysing sections of interview data, where there is a risk of context and meaning being lost when interview sections are cut into pieces. For this reason, the researcher kept master copies of the original complete interview transcripts, and was mindful to refer back to these transcripts, as well as the original audio recordings during the data analysis process (Burnard, 1991).

Stage five involved examining the list of codes and grouping them together into a 'coding tree'. This process created a structure of categories to describe the codes which were emerging from the interview narratives (Gibson & Brown, 2009). The aim of this process was to reduce the number of codes by collapsing them into broader categories (Burnard, 1991).

The sixth stage of data analysis involved repeated examination of the participants’ interview narratives, in what Hunter (2009) describes as 'continuous interrogation' of the data. Each participant's interview narrative was individually scrutinized in a vertical manner, to scope its narrative content in order to further refine and develop the evolving categories within the coding tree.
This led into the seventh stage of data analysis which consisted of a horizontal analysis across all eight interview transcripts, in order to examine the relationships and patterns that existed among the coding categories. Gibson and Brown (2009) term this process 'relational analysis', and it was this stage which ultimately revealed the thematic dynamics present within the narrative data generated by the interviews with the study participants (Gibson and Brown, 2009, p. 138).

Themes emerged from the relationships identified between categories, and from the pattern of similarities and differences observed across the participants’ narratives (Gibson & Brown, 2009; Hunter, 2009). Fragments of themes were identified within some of the categories, and ultimately formed the sub-themes within the structure of the overall study findings (Emden, 1998).

Stage eight examined all eight interview narratives according to the coding categories - which by this point had evolved into a hierarchical structure of themes, categories and codes. In an effort to be as thorough as possible, the researcher undertook a self-described 'sifting' of the data. This involved word searches of the interview transcripts, pertaining to keywords associated with the themes and sub-themes which had been identified. Sifting the data in this manner enabled narrative content related to the thematic features identified within the interview data to be found, which, without this procedural step, may have been overlooked.

Supplementary data was examined in the penultimate stage of data analysis. This involved reviewing the demographic data and memo notes collected during the interview process (see: data collection).

The final stage of data analysis was an iterative process which involved repetition of the preceding stages where necessary, and multiple reconfigurations of the analytic components. The aim of this stage was to achieve a final thematic structure that represented the narratives of the eight HSCT caregivers who participated in this study.

It is important to highlight that the analytic lens of narrative inquiry was continually applied throughout all the stages of data analysis in order to examine the dimensions of temporality, sociality and place within the interview narratives.

The final stage of data analysis was undertaken in tandem with the writing up process, which meant the overall data analysis and writing of the study findings became
interwoven (Hunter, 2009). This stage also included cross-checking with a member of the supervisory team, who read the interview transcripts, and then reviewed the thematic structure within the study findings (see: Rigour).

A set of eleven themes were identified within the interview data, which enabled the participant's narratives of their HSCT caregiver experience to be captured. The researcher initially queried whether the number of themes was too large, and was concerned this may infer analysis of the interview data was somehow deficient. However upon reflection the researcher considered the number of themes depicted in the study findings reflects the complexity of the caregiver experience, and breadth of the HSCT journey, rather than inadequacies intrinsic to the overall data analysis. The eleven themes also allow the trajectory of the participant’s journey to be presented in such a way, that if the number of themes were reduced in perhaps a stricter thematic analysis, the depiction of some of the more narrative elements within the interview data may have been muted.

A degree of inter-relatedness between themes within the study findings was identified, which meant determining 'where does this quotation best fit?' was a recurring challenge faced by the researcher. The researcher chose to weave the eleven themes together into a coherent sequence in order to preserve the narrative essence of the stories which the participants had shared, and to mirror their collective and individual journeys within those stories.

**Ethical considerations**

The relational aspect of narrative inquiry, whereby research participants share stories of their own personal experience with the researcher, heightens the researcher's responsibility to pay attention to the ethical concerns within narrative research studies (Clandinin & Huber, 2010). Written informed consent from the study participants was obtained prior to commencing the study with the caveat that participation in the study may be discontinued at any time, without causing disadvantage of any kind to the caregiver or to the patient whom they cared for. To avoid potential conflict of interest, the study was undertaken outside the researcher's own geographical DHB of
employment location so that the researcher was not directly involved in the care of any patient for whom a participant was a caregiver.

Anonymity and confidentiality are necessary aspects of the research process, in order to respect the personal stories which are made visible in the presentation of narrative inquiry research (Clandinin & Connelly, 2000; Clandinin & Huber, 2010). This study focuses on haematological malignancy within a provincial New Zealand setting - which represents a unique and specific group of people within the population. McGrath and Holewa (2011) suggest that there may be a high degree of interconnectedness and familiarity within the New Zealand population, hence there was particular ethical concern to protect the identity of participants within this study. For this reason - demographics (including geographical location) were provided in broad terms only, in an effort to preserve participant confidentiality. Non-identifiable, numerical labels were used to attribute quotations in the presentation of study findings to maintain privacy throughout the study.

The experience of caring for a person (often a family member) with a serious and life threatening cancer diagnosis and sharing this journey can be emotionally challenging. It was therefore important that the ethical principles of justice and beneficence were upheld within this study, and that participant safety was paramount. Consequently this study strived to prevent harm to the participant throughout the research process. Wang and Geale (2015) suggest the researcher should prepare a plan in advance to manage the potential for participants to become emotionally distressed while being interviewed. The participants were informed that they were welcome to bring a support person to accompany them during the interview. This was reinforced by the researcher throughout the interview planning process, however all participants chose to attend the interview on their own. In addition to this, the participants were advised they could stop the interview, or withdraw from the study, for any reason at any time without causing disadvantage of any kind to themselves or to the patient for whom they were a caregiver.

As a registered nurse working within the specialty of malignant haematology, the researcher who conducted the interviews demonstrated competence in advanced communication skills, which included being appropriately skilled to recognise signs of distress. If indicated, the researcher/interviewer was able to utilise her knowledge and
professional networks to connect the participant with appropriate support agencies/resources (e.g. psycho-oncology services, Leukaemia and Blood Cancer New Zealand, DHB haematology service, or GP) in an appropriate and timely manner. The researcher encountered two participants in particular, who appeared to be struggling emotionally following their HSCT experience. Whilst there was no urgent concern for the well-being of either of these two participants in relation to the interview, the researcher felt it was appropriate to encourage them to connect with their local psycho-oncology service, and/or Leukaemia and Blood Cancer New Zealand, and therefore provided these two participants with the contact details for these services accordingly.

Consideration of how the collaborative relationship between the researcher and participant ends at the completion of the study is also particularly important within the context of health research where participants may have revealed their vulnerability by sharing their personal stories (Hardy et al., 2009). At the conclusion of each interview session the researcher explained the expected timeframes to completion of the study. The participants were provided with an outline of the next steps including data analysis, the report writing process, and dissemination of results. Following each interview each participant was invited to contact the researcher via email or phone if they wished to add, change or discuss any aspect of their contribution to the study. Finally, each participant was asked if they wished to receive a copy of a summary of the research findings, once the final study report was available - to which all the participants responded, yes.

**Ethical approval**

Ethical approval was obtained from the University of Otago Human Ethics Committee (UOHEC) (Health). The initial application to the UOHEC (Health) was granted 'conditional approval' (see Appendix Nine) subject to the following:

- provision of locality assessment documentation
- clarification of the recruitment process, interview questions and proposed data analysis methods
- consideration of the handling of health information and patient consent
 provision of the outcome of the Māori consultation process

 revision to the length of time the data will be stored at the completion of the study - to a period of ten years.

Changes were made to the information sheet and consent form as suggested. The application for ethical approval was re-submitted, along with the additional information requested. Full ethical approval from the UOHEC (Health) was granted on the 13th September 2016 (see Appendix Ten). Two applications were submitted to the UOHEC (Health) to consider amendments to the study: the updated inclusion criteria was subsequently approved on 22nd March 2017 (see Appendix Six); and the Skype video conference option was approved on the 18th December 2017 (see Appendix Seven).

Māori consultation

As part of the overall ethical approval process, consultation was also undertaken with the University of Otago Kaitohutohu Rangahau Māori /Māori Research Advisor. This process was integral to examining the cultural safety of this research study which examines the HSCT caregiver experience within New Zealand. The researcher acknowledges the inequalities relating to Māori cancer outcomes, and the need to uphold the principles of the Treaty of Waitangi in order for this research study to be effective and relevant to Māori (Ministry of Health, 2010b; Ministry of Health, 2016a; National Lymphoma Tumour Standards Working Group, 2013). The Treaty of Waitangi principles of partnership, participation and protection underpin the responsibility of researchers to conduct research that addresses inequalities, and which may contribute to useful and relevant outcomes for Māori. Therefore in research that has the potential to involve Māori, is of interest to Māori, and is important in terms of reducing inequalities - Māori must be considered (Hudson, Milne, Reynolds, Russell, Smith, 2010).

The notion of consent was raised during Māori consultation (see Appendix Eleven). This included discussion on the right of self-determination and autonomy of the HSCT caregivers, who could exercise these rights in choosing whether they participated in this research study. Of particular note is the recommendation by the University of Otago Kaitohutohu Rangahau Māori /Māori Research Advisor that caregivers consult with
their whānau - including the patient, before consenting to participate in this research study. Furthermore it was recommended that information be explicit on who to contact if participants wished to opt out of the study at any time. The study advertisement, information sheet and consent form were subsequently updated to reflect these recommendations (Appendices Three, Four, & Five).

**Rigour**

The following processes for maintaining rigour in qualitative studies were consistently adhered to within this study. A transparent and explicitly outlined research process, adherence to the philosophical perspective, thorough data collection and analysis strategies all contribute to the rigour of this research study (Stephens, 2005). This study was underpinned by Lincoln and Guba's (1985) principles of trustworthiness which include: credibility, transferability, reliability and confirmability.

The researcher checked for accuracy by seeking clarification with two of the participants, regarding several statements contained within their interview transcripts and narrative summary. Member checking was also harnessed as a method of establishing credibility by promoting truthfulness within the study findings (Lincoln & Guba, 1985; Thyer, 2010). A copy of the interview transcript and narrative summary were returned to each of the four study participants who wished to take part in the member checking procedure. The participants were given the opportunity to provide written and/or verbal feedback to the researcher. The four participants who engaged in this member-checking process all expressed that the narrative summary reflected their HSCT caregiver experience. The application of these review and feedback procedures enabled clarification of anything that was unclear or ambiguous, and therefore contribute positively to the overall credibility and reliability of the study findings (Guest et al., 2012; Shenton, 2004).

An audit trail was maintained by the researcher to enable the decisions made regarding the research design, data collection and data analysis process to be described. This provided transparency across the research process, and promoted transferability by enabling other researchers to review the trustworthiness of this study, and/or replicate it's research procedures in future studies (Guest, et al., 2012; Thyer, 2010).
The recruitment process, study sample and data collection were described in order to provide the context, characteristics and boundaries of the study. The participants' quotations were individually labelled within the presentation of the study findings to demonstrate representation from across the study sample within the study findings. Information regarding the characteristics of the study participants was provided in broad terms only in order to strike a balance between maintaining anonymity, and providing a level of detail sufficient to enhance the context of the study findings to the reader (Guest et al., 2012). Description of the study sample also provides sufficient information for the reader to establish confidence in the reliability, and potential transferability of the research findings to other study settings and/or caregiver populations (Lincoln & Guba, 1985; Shenton, 2004).

The audio recorded interviews were transcribed verbatim by the researcher, and the participant's own words were utilised extensively within the study findings. The value of using verbatim quotes can be seen in the way quotes are able to connect the participants' own experiences to the researcher’s interpretation of that experience as depicted within the study findings (Guest & MacQueen, 2008). The use of quotes within qualitative research "lays bare the emergent themes for all to see" (Guest et al, 2012, p. 99). Hence the inclusion of the participant's own words within the study findings serves to further promote reliability and confirmability within this research study.

The researcher harnessed cross-checking within the data analysis process to promote reliability of the study findings. Cross-checking is a technique where researchers use other team members to review and confirm their data analysis (Thyer, 2010). Within this study, a member of the supervisory team was provided with the interview transcripts and asked to independently review whether their own assessment corroborated with the thematic structure within the study findings. The feedback was largely in agreement with the existing thematic structure. Several suggestions were offered, and adjustments made by the researcher accordingly. Overall, the cross-checking process generated discussion between the researcher and supervisor, which enhanced confirmability and reliability within the data analysis process.

One way of establishing confirmability is to apply reflexivity to ensure the study findings are shaped by the participants and not the pre-conceptions or bias of the researcher (Lincoln & Guba, 1985; Shenton, 2004). The researcher applied reflexivity
throughout the research process, by reflecting on her own pre-existing knowledge of the research topic gained through her professional experience working as a registered nurse with HSCT patients and their families. The researcher considered how her own assumptions may influence the research process, and was careful to not let her prior knowledge cloud the representation of the participants own experience. As a consequence the researcher was mindful of balancing the potential for bias, with the merits associated with having the professional insight to enable a rich inquiry into the research topic. The research study was subsequently designed to include the strategies as outlined above, to foster trustworthiness and overall rigour within this research study.

**Summary**

This chapter has described narrative inquiry as the research methodology chosen for this research study. The research design including recruitment, data collection and data analysis have been discussed. In addition to this, the ethical and cultural considerations which underpin this research project have been examined. The following chapter will present the research findings from this study.
Chapter 4: Study Findings

Introduction

This chapter presents the research findings obtained from the interviews with the HSCT caregivers who participated in this study. To maintain confidentiality and preserve anonymity the participant's names, geographical location and/or other features of their narrative deemed to be potentially identifiable have been withheld.

Consistent with a narrative inquiry approach, the research findings present the study participant's stories, and reflect the way in which the interview narratives were explored using Clandinin and Connelly's (2000) three-dimensional framework of narrative inquiry. This lens examined the interview narratives both individually and collectively to consider the past, present and future (temporality); personal and social (sociality); and situational (place) dimensions of the HSCT caregiver experience. A combined approach of narrative analysis and thematic analysis was utilised within this study (see Chapter 3: Methodology).

Eleven themes emerged from the analysis of the interview transcripts:

- The journey
- 'Being there'
- Duty and responsibility
- Relocation
- Life outside
- Relationships: 'together and apart'
- Fear and Worry
- Coping: 'getting on with it'
- Support
- Learning
- The journey to a 'new normal'

These themes were woven across the participants’ narratives, and illustrate the journey of the HSCT experience for the eight caregivers who participated in this study. Where stated, sub-themes are identified within some of the core themes and are included in order to depict the complexities within the HSCT caregiver journey.

The order in which the themes are presented are intended to be consistent with a narrative representation of the participant's 'journey'. The notion of the caregiver
experience across the HSCT trajectory is introduced by the first theme - The Journey. Being there in the HSCT caregiver role and the associated sense of duty and responsibility are then described to provide a foundation to discuss the challenges associated with relocation. Thereafter, the commitments relating to 'life outside' the immediate transplant setting are presented. The complex relationship dynamics at the centre of each caregiver's experience are revealed, and further explored in relation to the fear and worry associated with caring for a loved one undergoing HSCT treatment. The themes which follow, illustrate a range of coping and support strategies utilised by the caregivers, and the journey of learning. The thematic presentation of the study findings culminates with a description of the experience following HSCT, and examines the journey back to everyday life for the caregivers who shared their stories in the course of this research study.

**Study participants**

A total of eight participants were recruited to the study. All the participants were female, and all specified their ethnicity as New Zealand European. The age of the participants ranged between 30-39 years (n=1), 50-59 years (n=2), and 60-69 years (n=5). The study participants were caregivers to patients who had undergone either allogeneic HSCT (n=7), or autologous HSCT (n=1). The majority of the study participants were spousal HSCT caregivers - with the relationship between the caregiver and the HSCT patient including spouse (n=5), parent (n=2), and sibling (n=1).

The distance from the participant's home to the city based transplant hospital ranged from 105 kilometres to 650 kilometres - with an average distance of 282 kilometres. The majority of the participants travelled to the transplant hospital by car, with the exception of one caregiver who travelled by air. The driving time ranged from 90 minutes to 9 hours - with an average driving time of 3.5 hours. Study participants were based across New Zealand - with representation from North Island (n=5) and South Island (n=3) locations.

In order to demonstrate representation across the study sample, quotations from the participants are labeled numerically from C1 to C8 (e.g. Caregiver 1...) and presented in superscript at the end of each quotation.
Findings

The journey

The study participants shared their stories of the challenges and triumphs they faced during their HSCT experience. The distinct notion of the experience as a journey - both in a geographic and metaphorical sense, was woven throughout the caregiver interview narratives, and emerged as an overarching theme of the study findings.

Relocation away from home during the HSCT experience took the participants not only to a different city, but on a journey which involved social isolation, fear and worry, altered relationships, and the acquisition of new knowledge. This journey took place whilst balancing the duty and responsibilities of being there in the multiple guises of the caregiver role, with the demands of life outside the transplant setting. The caregivers required support in order to cope with the stressors associated with the HSCT experience. This was of particular importance as the participants described the enduring strain associated with the caregiver journey which extended into the long term following HSCT. The exploration of this journey through the participants’ narratives, therefore reveals the complexities of the HSCT experience which feature across the themes presented within the study findings.

All of the caregivers interviewed within this study described how their role as caregiver was not limited to the transplant period, but also included caring for the patient from the point of diagnosis and during their initial chemotherapy treatment which preceded the HSCT. The caregivers reported that this first treatment phase lasted anywhere from three to six months, and how, because of their provincial location, chemotherapy was not necessarily available locally. Hence this meant that some of the caregivers had already had to travel away from home in order to support the patient receiving chemotherapy, even before they had embarked upon the HSCT treatment process which followed.

Caregivers described relocating away from home while they accompanied the patient during the HSCT and post-transplant recovery phase up until day 100. The term 'day 100' was used by several of the caregivers referring to the recovery goal used by clinical teams, that signals the approximate timeframe for when the patient is typically well
enough to be fully discharged and return home. The caregivers interviewed within this study reported being away from home between three weeks and four months, according to the patient's recovery progress.

Participants were interviewed for this study between 8 months and 4 years following the date of transplant. The study participants were able to recollect the memories of their HSCT experience with ease, irrespective of how long it had been since the HSCT occurred. One caregiver remarked: "I will never forget those days."\(^{C4}\) The significance of the HSCT journey upon the caregivers’ lives, was perhaps expressed most clearly when it emerged from the narratives that the date of the HSCT was firmly imprinted in the memory of each caregiver. One caregiver observed: "pretty much cos that's the anniversary isn't it? It just sticks in your head because it's such a big event."\(^{C7}\) One participant could even recall the exact time of the HSCT: "... then on the 10th of March at two o'clock they re-introduced the stem cells back."\(^{C1}\) Another caregiver reflected: "we'll never forget that date."\(^{C5}\)

'Being there'

The notion of 'being there' was a theme that emerged from the study participants’ descriptions of what their role as an HSCT caregiver actually 'looked' like. Providing care for the HSCT patient involved a multiplicitous approach. Three sub-themes were identified which explain how 'being there' as the caregiver, involved assuming overlapping roles of being: the carer, the advocate, and the clinician.

A striking feature of the caregiver role was just how much time was spent by the caregiver being physically present with the HSCT patient whom they were supporting. "I just stayed with [patient] all day. I would go home for lunch sometimes, then go back in the afternoon, then home for tea and then back after tea."\(^{C7}\) The study participants described how they were almost continually at the patient's bedside. They would visit the patient daily whilst they were in hospital, often staying all day with few breaks. "I would sit with [patient] from 9 am til about 6 at night."\(^{C1}\) One caregiver described long days spent with the patient. "....'cos you are in the hospital from 7 til 11 at night.... you kinda just zip out make yourself a sandwich.... [patient] was sleeping most of the time
and didn't want me to leave the room...." C5 Another caregiver likened the routine to going to work each day: "pretty much it was just like doing a job really." C6

The caregivers described how the daily visiting pattern continued for the duration of the patient's hospital stay which varied in length according to the patient's post-transplant recovery but lasted approximately between two and six weeks. Caregivers discussed how after this time patients entered a transitional phase where they were discharged from hospital to a nearby accommodation facility, where the caregiver was already staying. It was at this point that the medical follow up for the patient became outpatient based - requiring daily visits to the hospital for monitoring. Caregivers reported that they often accompanied the patient on these visits. "We were pretty busy getting backwards and forwards to the hospital most days." C7 The study participants reported that this outpatient phase lasted anywhere from three to four weeks, and in some cases up to several months.

Several caregivers remarked that they periodically stayed overnight with the patient while they were in hospital. This occurred if the patient was having a "rough time" C3, or "didn't want to be alone." C5 One caregiver recalled staying the night in response to the patient becoming incredibly unwell: "I know one night I spent with [patient], [the patient] was really really low, and I thought 'you're so sick, I don't know if you're going to come out the other side of this', and I thought, I'll just stay here....." C8 Another caregiver recalled: "I got a call from [patient] at two in the morning and [the patient] said 'I've been sick can you come?.... [patient] didn't like to be on [their] own." C4

Staying the night at the hospital sometimes meant the caregiver relinquished their own sleep, in order to be at the patient's side: "when [patient] asked me to stay, I just stayed, you know....I just slept in the lazy boy - not that I really slept." C5 The act of providing care simply by being with the patient at their bedside was summed up by one caregiver who explained: "it's just being there with [patient]." C5

The carer

Several caregivers described how they assumed some of the daily care tasks in hospital such as making the patient's bed and helping with personal cares such as toileting and showering. There was variation reported by the caregivers in terms of the type of practical tasks they were required to carry out when caring for the HSCT patient. The
degree to which the caregivers assisted with daily care tasks varied according to the patient's level of physical recovery. "... [patient] was so sick - she was never really...not unwell... [patient] was always connected to a machine, so to get up to go to the toilet in the middle of the night you had to unhook the machine so [patient] could wheel it into the toilet and then help her back in.....if she wanted a drink and was in isolation she couldn't go and get her own water, so yeah little things like that - she was never actually well enough to go do things for herself." \(^{C8}\)

However, some of the participants described how they were not required to provide personal care to the patient during their recovery: "[patient] managed to shower himself all the time, he didn't need any help there at all." \(^{C1}\) Another caregiver explained: "[patient] was so independent he was able to have a shower all by himself.....no I didn't do anything at all that you could class in that category." \(^{C6}\)

Several participants noted the ward nurses had high workloads, and suggested how in some circumstances this limited the attention of nursing staff. One participant recalled: "...they [the nurses] must have been so so busy, the whole time when we were down there not one nurse made [the patient's] bed... I was doing all that, changing the bed.... I learnt where the linen cupboard was and all that stuff, they just didn't have the time, and sometimes [patient] would want to have a shower and they'd say 'oh we'll come in' but there wasn't anybody available, so I'd be the one that even had to do all those sort of things for [patient], and clean the bathroom up... I'm not complaining... but they were the situations that the nurses were under." \(^{C8}\)

Another participant described how she provided care to the patient, in response to a perceived lack of support from the nursing staff. "... but virtually it was up to me to make sure [patient] had a shower each day and change the bed, she did have some good nurses, but like going to the toilet - I don't know if [patient] was on her own, if she buzzed them..... if they'd be there to help her, like if I wasn't there? I think... I just got used to doing it all... it was just the norm." \(^{C4}\)

Several caregivers recounted how they assisted the patient with personal care such as taking the patient's temperature and providing mouth cares. "Yes, I made sure I did [the patient's] mouth cares, 'cos otherwise they got ulcers and I know two people who did get mouth ulcers." \(^{C3}\) Another participant explained how she acted as a prompt to remind the patient to do things by saying: "...make sure you do your mouthwashes, make sure
you've eaten, make sure you've taken your pills..." C5 The nurturing and guidance aspects of the role was noted by one caregiver: "I just sort of took on the mothering...not that he was like a child... but you know what I mean, you just do those things, you just do what had to be done....you had to take over things to make sure when he was to do it - his medication and charts..." C7

Some caregivers described how their role was motivational, by encouraging the patient to maintain activities of daily living, and to achieve small goals as their recovery progressed: "I just had to remind him to look after himself basically, and also to get him to do stuff [laughs], you know instead of not doing anything, even if it's just get up and take ten steps." C5 Another caregiver recalled: "I would get things organised for his shower each day....it was about making the time to have a shower, he felt so much better getting up... just getting his hair washed and things - that daily shower, it was a big achievement." C7

The participant narratives revealed how the care they provided included supporting the patient's nutritional needs during their recovery following the transplant. One caregiver identified changes in the patients' taste and appetite associated with treatment, and described how she made a particular effort to prepare food according to his changing dietary preferences. "I think his taste buds got damaged so you just had to try and tempt him with certain foods." C7 This was described by another caregiver who observed: "because what they like today isn't what they like tomorrow!" C2

Many of the caregivers described cooking meals for the patient while they were staying at the accommodation facility during the outpatient phase. "I stayed with him that whole time and cooked tea every night, got the groceries...got whatever he needed." C3 One caregiver also described how she provided alternative food choices while the patient was an inpatient and not tolerating the hospital food: "it was just easier in the end, to cook meals and take them up to the ward." C8 Some caregivers also described how they were mindful to make safe food choices for the patient while they recovered from low immunity: "you had to be careful what [patient] ate.... so you had to be careful where you could go.... a treat for us was McDonalds but you had to make sure it was freshly cooked." C4

The act of caring was not only limited to the patient whom the caregiver was the main carer for, but in some cases extended to helping others. Several participants explained
that they assisted other patients and families both in the hospital environment and whilst living in the accommodation facility. One caregiver remembered spending time with another patient: "I would go and sit with her [another patient] sometimes because her family couldn't be there all the time, and I could see she was on her own and felt sorry for her." Another caregiver described providing support to other patients and families despite feeling tired herself: "well I stepped in of course, because you can't see people suffer without stepping up... but actually your tank's pretty bloody low... and when you've got eighteen families staying in the one place - the nurturing process is a bit full on! (laughs)... sometimes when it's hard going with [patient] you haven't got enough emotional energy left over." 

The advocate

Many of the caregivers recalled examples of acting as the advocate for the patient during the HSCT experience. Caregivers described speaking on behalf of the patient, when they were too unwell to speak for themselves. "I was her advocate, because you know ... she didn't have the strength to do it." Another caregiver remembered supporting the patient when he became depressed being in isolation following his transplant - "...he got really down, he kind of stopped talking in a way - but he'd still talk to me though, so I would just have to try and ask them [the health care team] questions on his behalf." This caregiver went on to describe a situation where she felt she needed to defend the patient's behaviour toward some of the health care team: "...he got very grumpy and probably a little bit angry with some of the nurses and doctors....he was just fed up with not being able to leave, so I had to sort of try and portray to them not to take it personally....I felt like I needed to sorta tell them, look he's just had enough, so he's not having a go at you, it's just the situation." 

One caregiver told of a situation when she was the voice for the patient when her pain was not being adequately managed: " normally I'm quite a shy person but... when you watch [patient] going through what she is.... see her wince in pain... you sort of think ... you've got to speak up. 'cos virtually she [patient] would leave me to speak for her, she’d say something to me and I'd have to go sort it out for her, because she just wasn't up to it to say things... she'd sit there and suffer... and be too scared to say anything so I would have to."
Another caregiver described a situation where she had to advocate for the patient as they navigated the hospital emergency department, in order to be seen in a timely manner. “I had a card so that he didn't have to wait in the waiting room, and I'd show them the card...there was only once when we were told to sit down and I had to go and say look he shouldn't be sitting here, he needs to go straight in, he's not allowed to be amongst people that are sick...so they came out and got him.”

One of the participants recalled taking the patient into the hospital emergency department, and expressed a perceived risk of being judged negatively by others when advocating for the patient: “you know the system going through ED...you know what it's meant to be like and you know that most of the time it doesn't happen that way... you know that you have to have your shit together to kind of get what he [patient] needs, in the shortest amount of time...so you have to learn to manipulate the system, because it looks as if you are just pushing in... I thought - how do I advocate for the patient while they are vulnerable, yet not come across as being complaining, and being labelled as such?”

The clinician

Several caregivers described scenarios where they had been involved in providing specific clinical care. One caregiver remembered being asked by nurses to monitor the patient's intravenous infusion: "sometimes if they [the nurses] were so busy they'd come in and ask you to watch the um..... the dripping...... and do the counting for them, so that they knew she was getting the right amount and that it wasn't going to fast or too slow, and one nurse showed me how to move the thing [the roller clamp on the intravenous line] if it was a little bit too fast ....” When the interviewer asked this particular caregiver how she felt about doing that she replied, "ummm... a little nervous to start with, but again like I said - you get on and do it ......it's just...... that's what you're there for, and they [the nurses] were just so damn busy.”

One of the study participants expressed concern at the responsibility of performing clinical tasks. This caregiver recalled being distressed when asked by the health care team to give the patient an injection: "at one stage she had to have injections in her stomach and they were going to try and make me do those, like on weekends out or
something....but I thought that's something they should be doing 'cos I hated doing it, I was like 'no, no'." C8

Several caregivers described their involvement in providing intravenous central line care. One caregiver recalled how she would remind the nursing staff when one of the lumens in the patient's central line wasn't working. "I don't know how many times - it was more than once... I'd have to say 'no, remember it's on her chart, not that one, because that one's the blocked one, you've got to do this one first and then do the unblocking of the other one'. C4

Another caregiver reported feeling overwhelmed and lacking knowledge on what steps to take when technical problems or complications arose with the patient's central line. This caregiver described an occasion where: "we got the book from [the hospital] saying 'you're going to be in charge of your own Hickman line'...you know flushing it, doing your own bloods and things...... so I tried to flush it and none of the three ports would flush....so you've got this great tunnelled Hickman and I'm thinking...well I don't know?... I'm not familiar with these... and it's not working...and he's just had a central line infection and it's started going red again now too!... and I'm thinking ...aaargh!" C2

Duty and responsibility

The narratives of the study participants revealed a strong sense of duty among the caregivers interviewed for this study. A duty of care to ensure the well-being of the HSCT patient featured throughout the caregiver journey. An absolute commitment to the caregiver role, as well as an implicit devotion to the person whom they were caring for emerged from the interview narratives, and consequently feature across several of the themes within the study findings, including perhaps most notably the themes of: "being there", and relationships: 'together and apart'.

The caregivers described a distinct sense of responsibility associated with role - particularly regarding the need to keep the patient safe once they had been discharged from hospital. The study participants described how the move to outpatient care was entirely dependent on having a caregiver present with the patient "24/7" C2. They reported being told by the hospital team that if the patient did not have a caregiver
available - then the patient would have to remain in hospital until they were well enough to return to their own home.

Several caregivers spoke strongly of a duty of care, and of a sense of obligation not to leave the HSCT patient for any length of time. "[patient] wasn't allowed to be left alone...and I didn't want to go home, well I mean I desperately wanted to go home..... so yeah even as desperate as I was to come home, I didn't want to leave [the patient], so it wasn't an option... it just wasn't an option." C6 Another caregiver described the emotional challenge of being away from the patient who remained in hospital: "I couldn't leave.....I felt guilty when I went away because she was in hospital going through it, I found it really hard... I'd go away and have a coffee or go and potter around the shops but yeah it was very hard to go away and enjoy myself when you knew she [the patient] was not feeling well." C8

One caregiver spoke of a sense of wanting to help, and to feel useful. "I kind of felt well this is my job, this is something I can do...to make sure that he can take this myriad of pills and things and his temperature on time..." C6 Another caregiver remarked: "to make [the patient's] life comfortable you'd have climbed the bloody walls if [patient] asked you to! [laughs]...and I think for me that's how I saw my role, that's what I was there for." C4

Caregivers described how they provided a continual presence with the patient once they were discharged to outpatient care. The caregivers explained how their role during this time served as a safety mechanism to monitor the patient who remained at risk of becoming suddenly and seriously unwell. "You can't leave [the patient] alone, so unless he was admitted - I had to be with him 24/7." C2 One caregiver perceived her responsibility during this time to include documenting the patient's progress in order to update the health care team: "I took his temperature every day... and I wrote everything down in a notebook... I'd write everything in a book - his temperature... what it was, how he felt..... I'd take it in with me every time we went back to the hospital every day to let the doctors know how he'd been." C1

Several caregivers described feeling a personal duty to keep the patient safe once they were discharged from hospital. "Yeah well he's so vulnerable, and I know how vulnerable he is, therefore I have to do something to prevent it." C2 Others expressed a
strong sense of overall responsibility "...when someone's life is on the line, you know that you are responsible for looking after them." C4

This duty and responsibility was echoed by one study participant who explained that the patient whom she had been looking after had subsequently become critically ill with a serious infection as a delayed transplant complication, several months following his HSCT. Guilt and regret were a recurring feature within the narrative from this caregiver. She described her own 'failure' to recognise signs that the patient was becoming seriously unwell, which prevented accessing early medical help: "it was just a real bad move on my part, failing to realise he was getting so badly sick, and then sitting and waiting and doing nothing." C3 It was clear that a sense of personal responsibility and an enduring duty to care continued to weigh heavily on this caregiver: "I know - I should have done things differently..." C3

Many of the participants spoke of taking the patient's temperature and being vigilant to recognise signs of infection during the outpatient phase. This was illustrated by one caregiver who explained "and we all get told if they have a temp of 38... over to ED [emergency department]... straight into the ward...to get treated really quickly, it's really important...and we all have to buy our own little thermometers...we get good at taking them every minute [laughs]...so that meant I was taking his temperature every time he breathed! [laughs]" C2

The participants’ narratives revealed the caregivers felt a heightened sense of responsibility to keep the patient safe once they were discharged from hospital. Several participants described their reaction to the patient being discharged to outpatient care. 
"...well that was scary, cos you lost your constant contact with most of them up at the hospital then...and I was thinking, yeah okay you guys have had [patient] for the last few weeks and now you're leaving her with me, what am I supposed to do with [patient]? What if something happens?" C4 Another described her panic. "Oh I felt sick! I thought 'well what on earth do I do with this person now?'" C3

One caregiver expressed anxiety regarding the responsibility of managing the risk of infection: "I became OCD... everything had to be cleaned, because he had no white cells, and if he got an infection it was my fault...so everything was clean, everything was sterile, and I actually kept people away - he didn't want visitors, but actually I kept others away as well, because of the risk of infection." C2 Another caregiver recalled
feeling under pressure to react appropriately if the patient became unwell: "well what am I meant to be looking for? ... and what have we done wrong if we don't get [patient] back to the hospital quick enough?"\(^\text{C4}\)

However, some caregivers did not find the level of responsibility once the patient had been discharged to outpatient care quite so daunting: "...it didn't freak me out...yeah I felt comfortable."\(^\text{C5}\) Another caregiver explained: "I felt that I sort of pretty much knew what I was looking for and what I was doing."\(^\text{C6}\) One caregiver described that she felt the discharge experience was straightforward after receiving adequate preparation from the health care team. "...they explain it all to you - so that was all easy enough."\(^\text{C7}\)

**Relocation**

The requirement for patients and their caregivers to relocate to city centres in order to access hospitals that provide HSCT services, featured across the study participants’ narratives. Travel and isolation were identified as two sub-themes which emerged in relation to the experience of relocation for the caregivers interviewed in this study. The study participants described the extent of travel required, as well as some of the logistical relocation challenges they encountered during their HSCT journey. The participants’ narratives also revealed how separation from home lead to a sense of isolation for some of the HSCT caregivers.

All of the study participants described staying at accommodation facilities which were located close to the hospital campus, and provided financially subsidised accommodation for those HSCT patients and their caregivers who had relocated away from home. The caregivers overwhelmingly expressed positive sentiment regarding the accommodation facilities: "oh that's an amazing facility, so close to the hospital and so central to everything....to have that was just incredible... we were lucky we had that."\(^\text{C6}\); "it was brilliant...absolutely a god send, it really was..."\(^\text{C4}\); "it was great! ...such a good place and it's just so lovely inside, it's like a hotel."\(^\text{C3}\); "it was lovely at [accommodation facility], and they are really lovely people there that run the place."\(^\text{C7}\)

The value of these facilities was highlighted by several caregivers: "if that wasn't there I guess you'd be stuck in a motel and that would be quite restrictive, not to mention expensive...we were so lucky we had that."\(^\text{C6}\) Another caregiver remarked how vital she
felt the accommodation facility was: "like without that ... with everything else you had to deal with.... I can't even imagine what it would be like...that is like the base hub for you to be."\textsuperscript{c5}

Several caregivers spoke of the camaraderie which existed among the caregivers and patients staying at the accommodation facilities: "yeah I would have called it more like a family home with lots of family that you didn't know when you got there but you certainly did by the time you left!\textsuperscript{c4}"; "the people that were there were just amazing, and we were all going through similar stuff at the same time.\textsuperscript{c5} One participant explained: "as a carer you need to share your stories, and other families need to share that with you.\textsuperscript{c4}" Another caregiver spoke of a sense of shared experience: "everyone was sort of in the same boat there.\textsuperscript{c2}

Study participants reported forging lasting friendships with other caregivers and patients that they met, and in some cases whom they remain in contact with: 'we got so friendly with everyone that we all had communal meals, it was awesome...we did some really cool stuff together, and we still keep in touch with one couple.\textsuperscript{c4}

However not all of the study participants enjoyed the dynamics of a shared living environment. Several caregivers commented how the communal space meant it was inevitable they were sometimes exposed to negative HSCT patient stories. Such as when other caregivers and families were discussing patients who were critically unwell. "You can hear what others are saying... I knew when someone wasn't doing very well or even dying...and it did make you feel a little scared.\textsuperscript{c5} One caregiver described that she used avoidance behaviours to shield herself from these situations: "you kind of just went 'vroom' straight into your bedroom and kind of holed up there.\textsuperscript{c2}

Whilst sharing the experience with others could be supportive, one caregiver remembered feeling guilty that the patient she was caring for was recovering from her HSCT so well, while others around her were not: "because we all compared the patients’ results...but when [patient] was the only one of the group who was doing really well - then you feel guilty, so after that I didn't tell them.\textsuperscript{c4}

The study participants outlined some of the practical challenges they faced during their time away from home. Several caregivers discussed the importance of having access to a vehicle: "our [family relative] had a spare vehicle and they brought that up for us to
go get groceries and stuff, but it wasn't for the first couple of weeks... so yeah trying to walk to the supermarket and drag groceries back was a bit tough...we would have been lost without the car". Another caregiver remarked: "I wouldn't have wanted to be there without the car - [accommodation facility] does actually have a vehicle for you to use, you have to just book it... I didn't use it, but I think it's probably quite helpful for others." C6

Having a vehicle meant that the caregivers required car parking. Some of the caregivers explained how they benefited from complimentary car parking available at some of the accommodation facilities: "there is parking at [accommodation facility]...I had my own car park and I just walked over to the hospital, and I never had to pay for a park." C6

Another participant recalled: "... there was a carpark underneath the house, and then across the road there was a free carpark that we used." C7

Several study participants described creative solutions for car parking challenges. One caregiver explained: "we had to use the car parking building at [city hospital]...we might get onto the 8th or 9th floor, but at 6 o'clock I'd go and move the car down to about the 3rd floor as close to the door as possible and I'd just stay there.... oh and if you moved the car in the morning before 8 am you got it a bit cheaper which was a bonus! [laughs]" C1

Another caregiver described receiving some helpful parking advice: "I also found out through another stem cell patient I met up on the ward... that if I went to the ward office desk I could get a $7 a week pass for parking rather than pay per day...cos you sometimes don't get told these things." C1

Several caregivers noted the challenges of learning to navigate their new city surroundings: "you get a map and you think 'oh how are we gonna find our way around all this?!" C7

Another caregiver noted: "one thing I felt was the most challenging after he came out of hospital was that it was me who had to do the driving around [the city]and I didn't know[the city] at all! [laughs]...but I do now!" C6

**Travel**

Being provincially located meant all the study participants were required to travel in order to accompany the patient during the HSCT process, which took place at tertiary hospital sites located in main city centres. The caregivers who participated in this
study were located a significant distance from the transplant hospital. The distance from the participant's home to the city where the transplant took place, ranged from 105 kilometres to 650 kilometres - with an average distance of 282 kilometres. Most of the caregivers travelled by car, with the exception of one participant who travelled by air whilst accompanying the HSCT patient who they were caring for at the time.

Despite the sizeable travelling distance the caregivers interviewed in this study expressed resilience and overall positivity toward their travelling experience: "we couldn't have been further away really!...but that's just how it was, no point moaning about it! [laughs]" C6; "you just do it, yeah you've got no choice so you just do it." C5; "it was tiring - but the road was quite good, it was good that they were also doing the new motorway at the time...we've done so much travelling for his treatment now that we've just got used to it really." C1

The study participants described receiving financial support from National Travel Assistance (NTA) - a government funded scheme, to assist with their travel costs. "You get travel assistance...like you get petrol money - so much per kilometre." C5; "we did get transport money, someone switched us onto the national travel scheme." C2 One caregiver explained how they claimed for their travel costs to be reimbursed through the NTA scheme: "you filled in a form and sent the receipts and you had to get the office lady in the ward each time to stamp it." C1 Several caregivers described the process as straightforward: "it's relatively easy, you get a form stamped at every hospital visit, fill out the form initially, and prove your bank account and send it off." C5; "I just asked at the hospital and a lady at the desk there gave me all the forms, I didn't have any difficulty with that." C6

Caregivers reported variation in the degree of their entitlement via the NTA scheme. "I got reimbursed to a certain degree... I got reimbursed for my fuel and accommodation but only to a degree... I didn't get it all, I had to fund a bit of that myself." C6 Some caregivers reported receiving NTA support for both travelling, and accommodation costs, whereas others did not: "I could apply for money for petrol, but I couldn't get money for board because I didn't qualify apparently." C1 Similarly, another caregiver recalled: "they wouldn't give us money for going back to [transplant hospital], because I couldn't have money for both travel and accommodation." C2
Two of the study participants reported receiving help from a travel co-ordinator based at the hospital: "we had communication with the travel co-ordinator at the hospital, she helped tell us what help qualified for." C6 One caregiver remarked that it was helpful to have someone else organising the travel details: "the hospital travel person booked our flights and paid for it for us, they just sent the tickets through and told us when to be there...yeah they were good that way, because I think you've got enough on your mind without having to worry about booking flights you know?" C7

The requirement for travel was not limited to the immediate transplant period, but also extended into the long term phase of the HSCT trajectory. Several study participants described an ongoing travel commitment, associated with wanting to support the patient by accompanying them to their follow-up appointments with the health care team at the transplant hospital.

Depending on their location and the structure of local health services, some of the study participants described a continued need to travel to the transplant hospital for these appointments for up to twelve months following the HSCT. One caregiver recalled: "so for [six months]... we were going over to [city transplant hospital] once every three weeks." C1

One caregiver who lived a particularly large distance from the transplant hospital, expressed her frustration at being ineligible for NTA support for her to accompany the patient to his follow up appointments - she shared this reflection: "they wouldn't fund me to accompany him...they said because it's a follow up appointment I wasn't funded...he was going back quite regularly...and was quite keen for me to go with him, because he was quite worried that he wouldn't perhaps pick up on everything, you know two heads are better than one to pick up on information they talk about in the appointment, and so I did pay for myself just a couple of times and I flew up with him...the ludicrous thing is... had we driven - they would have paid the petrol for the car, but who wants to do that? It's a huge drive for a half hour doctor's appointment!...whereas we could fly there and back in one day...yeah I found that a wee bit irritating." C6
Isolation

The participants’ narratives revealed how relocation away from home contributed to the HSCT caregivers experiencing feelings of isolation. One participant suggested the sense of isolation was lessened because they were fortunate to know people living in the city where the transplant took place: “we were lucky though we had friends in [city] and my [family relative] was living there..." C4. However this experience was the exception among the study group, as the remaining participants reported not having the same level of social support nearby. One caregiver remarked: "we didn't know anyone in [city] at all." C6 Another caregiver explained "it was just the two of us.... we were just completely isolated from everybody and everything." C8

Being away from home meant isolation from family and friends. Separation from loved ones was exacerbated by the restrictions placed on visiting due to the patient being low in immunity and at risk of infection. "...as the carer you had to keep in mind that you couldn't be around your grandkids and you had to keep away from other family if they were unwell....they were also told that they couldn't come down and see us...so there were times where we saw none of them." C4 The lack of interaction with other people was echoed by another caregiver who reflected: "I think I just felt a little bit isolated sometimes... not seeing people, like I normally would." C6

Many of the study participants stated they did not have the opportunity to have a trip home during the patient's HSCT and outpatient recovery phase. "I don't think I came home at all in those entire four months." C2 With the exception of three caregivers who explained they were fortunate to have another family member to come and be with the patient for a period. This respite enabled the main caregiver to travel home for a short break.

The angst of being separated from home for a prolonged period was highlighted by several caregivers. One caregiver commented: "the hardest thing was actually a Friday night... cos everyone was going home for the weekend but it was too far for us to go home... so it became just another weekend stuck there" C8

Another caregiver described her surprise at experiencing profound homesickness: "I actually was quite astounded with how desperately homesick I got... I was really really
homesick, which sounds stupid! ...but if someone had said to me 'hey you can jump on a plane and go home for three or four hours then come back'...if it was practical I'd have been there! I would have done it!... I didn't expect to feel like that. C6 When questioned whether these feelings were worse at any particular time during the transplant experience she replied: "no.... just the whole thing!... and it just got worse as every day went by!" C6

The value of maintaining social connections to alleviate the isolation of being away from home was illustrated by one caregiver who described how their relatives were able to visit over the festive period during the outpatient recovery phase: "...they [family relatives] had Christmas day with us in [accommodation facility] - so that was nice, and because we had two bedrooms they were allowed to stay there ...there was a wee cost, but it wasn't anything major and it was company... someone else for us to talk to." C7

In addition to the isolation associated with relocation away from home, the participants’ narratives also revealed how some caregivers felt isolated within the accommodation facilities which they were staying in. Caregivers described shared hostel type living arrangements, as well as self-contained apartment style spaces provided within the accommodation facilities. The study participants indicated that room allocation was based on a degree of patient/caregiver preference, but was mostly random and in accordance with the room availability within each facility at a given time. Some caregivers spoke about how the configuration of the apartment units contributed to feeling alone: "you can get apartments there, which was handy... but it also meant that we were quite isolated, because you cooked for yourself and you were in your own little apartment, so you never really saw anyone or anything...we did feel isolated." C7

Another caregiver remarked: "we didn't have much to do with other people because everyone was busy doing their own things, coming and going at different times." C6 One caregiver explained how living in an apartment space separated her from the company of others: "I think elements of [the accommodation facility] were really good, but I did miss the socialisation." C8

One caregiver remarked how isolation worked to her advantage, and explained that she preferred the apartment units because it meant she could be on her own and thus avoid the pitfalls associated with a shared living space: "they were fabulous, cos you could go
into your own unit and you could close yourself off, which was perfect...but when it's communal lounge, and it's communal kitchen and it's communal stress levels...and as soon as you go into the kitchen or dining room or lounge you're bombarded with all of that! ...and that becomes an added burden."\textsuperscript{C2}

Several caregivers described how they felt socially isolated due to the age difference between themselves and others who were also staying at the accommodation facility. One caregiver remarked: "we were like the youngest people there... the hard thing is that most of the people are a lot older ...like we connected with people down there to a point, but not people of our own age - because they weren't really around."\textsuperscript{C5}

Similarly another caregiver explained: "it would have been nice to talk to other people, the people that were there were a little bit older ... which probably didn't help, yeah... it was hard."\textsuperscript{C8}

The study participants expressed an overall sense of isolation during their transplant journey associated with relocation, and separation from social support networks. This was poignantly summarised by one caregiver who suggested a sense of isolation inherent to the HSCT experience itself: "unless you've been through it you really have no idea."\textsuperscript{C8}

'Lif e outside'

A theme which ran strongly throughout individual stories as well as collectively across the participants’ narratives was that of 'life outside'. This term pertains to elements of the caregiver's life which existed outside the physical HSCT setting, but which exerted a significant influence upon their experience across the HSCT trajectory.

Redundancy, major illness, moving house, divorce and new jobs are some examples of the significant life events that caregivers reported happening in the midst of the HSCT transplant experience. The impact of experiencing multiple stressors whilst being a HSCT caregiver was summed up by one participant who reflected: "when it's so intense - you don't kind of realise it and recognise it... you're dealing with family and friends and stuff at home and maybe your job...so actually when other things and people are coming in and making demands on your energy and your emotions...it can be too much."\textsuperscript{C2}
A set of four sub-themes related to ‘life outside’ were identified within the participants’ narratives: employment, home, family, and finances. In combination with the participants’ own words, these sub-themes illustrate how everyday life outside the transplant setting intersects with the HSCT experience, and how these two facets interact to shape the overall HSCT caregiver experience.

**Employment**

Balancing employment commitments during the HSCT experience was noted as a concern which was common to all the study participants: "it's so hard when you've gotta work at the same time." All of the caregivers reported that they were employed at the time the HSCT took place. This meant that caregivers had to take leave from their job in order to take on the role of HSCT caregiver. Several participants described their employers as supportive: "they were really supportive, they were very very good, they basically held my job open for me, there was never a question that I wasn't going to be able to go back to work... right from the moment he was diagnosed they were just totally supportive." Another caregiver described: "my work was really good, they let me have the time off and they just got someone to replace me."

For some caregivers, this was the second time they had needed to take leave, after previously taking time off in order to be with the patient during their initial chemotherapy. One participant described difficulty when trying to negotiate leave with her employer: "... the second time they made it hard... I kind of asked again for leave without pay but they wouldn't give it to me...you feel really guilty about taking time off."

Three of the study participants were self-employed at the time of HSCT, and described how they too experienced employment related challenges. One caregiver explained how having three months off meant she needed to hire and train a new staff member to provide cover in her absence. Another caregiver reported that in order to accompany the patient through his transplant, she was forced to sell her owner-operator business at short notice.

Several caregivers described how they were able to work remotely and continue their job whilst they were away from home performing the HSCT caregiver role. "I worked while I was there though...if [patient] was sleeping for three hours straight there was nothing for me to do in that time, so I just worked... I'd just sit in the room with my
laptop and work and that was really good." One caregiver explained how the lack of an internet connection at the hospital's accommodation facility thwarted her attempts to work whilst away from home. "I tried to do a bit of one aspect of my job on my own laptop.... but the one thing [accommodation facility] doesn't have is free Wi-Fi... I would have had to buy data and it was too expensive, and in the end I just couldn't keep doing the work.......I would have loved to have done it, just to fill in the very long days, but I just couldn't." 

Home

Being out of town for a prolonged time while accompanying the patient during HSCT meant that caregivers were still responsible for their own domestic commitments even while they were away from home. This was expressed by one caregiver who recalled: "when you're living away from home... you've got home still ticking over." Garden maintenance, pet care, mail collection and household bill payments were some of the continued responsibilities which the caregivers in this study described. The support of family and friends to provide assistance with these tasks featured across the participants’ narratives: "my friend’s husband came round and mowed our lawns...and the neighbours across the road kept an eye on the house and collected the mail."; "my son used to come down...and collect the mail, if he didn't do it then his wife did."; "luckily we have neighbours from heaven, who adore the cat, and looked after that for us." 

Receiving support from others was sometimes reliant on the caregiver's ability to ask for help, according to one study participant who explained: "people do say 'well let us know if there's anything we can do to help', and I find myself thinking I'd love someone to just go whizz around my garden, but I just couldn't ask! (laughs) you know if someone had said I'm just going to your house and I'm going to go tidy your garden'... I'd say 'oh thank you!'(laughs)...but I just couldn't - I just couldn't ask..."

Family

The arrival of new grandchildren born while the caregivers were away from home during the HSCT was reported by several study participants. One caregiver explained how she didn't have the opportunity to meet the new baby: "we had a grandchild born the day before we went up there [to the transplant hospital], my daughter... would send me photos of the baby... so I didn't feel I missed out on too much...but you know...you
sort of did..." Caregivers expressed how they felt torn being unable to be in two places at once, and felt like they were missing out on being with family during a special time. "I wanted to support her [daughter who had recently given birth], but I couldn't really...I felt like I had to be strong to support her...I missed out on a lot of that...I sort of felt that the baby just appeared when we got home, all of a sudden we just got this new baby when we got home - I missed all that, but never mind... never mind..." The study participants spoke of the wider family responsibilities they had to leave behind at home, and how other people - often other family members, took this on in their absence. Several caregivers described having elderly parents whom they cared for. “We were isolated while we were away having his transplant, my mother's still living and I couldn't be in contact with her the same, I had to rely on our children to go visit her and see what was going on and that sort of thing." Another described how she took on additional responsibilities to support her elderly parents, while looking after the patient during his HSCT. " They're in a rest home here, they're quite elderly in their 80's.....but with both of them with dementia, I have to do all their financial stuff so I have to pay all the bills and all their appointments and everything.... but I've had to do all that on my own while [the patient] has been in hospital- so it's been quite full on....I'm going to take most of that on now 'cos he [the patient] needs to focus on his recovery." Caregivers who had young children at home to look after discussed some of the practical challenges and emotional impact of leaving them at home. A reliance on grandparents and wider family to provide childcare was described. "...so basically my parents took on the full time role of looking after our kids." Another caregiver explained how she felt upset at being unable to continue assisting with the care of her grandchildren: "I did miss my grandchildren terribly though...because normally I pick them up every day from school usually, and they come to our house until tea time.... and I couldn't do that when we were away in [city]." One participant became tearful when expressing the emotional challenge of balancing the dual role of acting as the HSCT caregiver at the same time as being the mother of a young family. "... juggling the kids and [the patient]... it's the kids....that's the part that makes me cry." Concern for children during the HSCT journey also extended to adult offspring. One caregiver referred to her adult children: "we tried hard not to burden
them with worrying about it all, we just didn't want to burden them with that.....they knew obviously that [patient] was sick - but you try to protect your kids.”

One caregiver reflected on her experience, and shared how in the midst of becoming a HSCT caregiver, she had faced her own health challenges: "...it was quite a major....I was in the hospital for a few weeks just before [the patient] was diagnosed.... so yes.....it was a bit shocking and then after we went off to [city] for his transplant.”

Several caregivers spoke of being aware that family and friends were waiting at home for updates on how the patient was progressing. One caregiver explained how she tried to protect a close family member by sparing them from worry: "we tried to be careful......we tried not to tell [family member] too much when [the patient] was really sick...because we didn't want to worry him.”

One caregiver described how sometimes the concern from family members was a ‘double edged sword’ C6. This participant recalled a time when family members were visiting from overseas: "...it was lovely to see them, I mean they came over especially for [patient]... but it was also difficult, cos they kind of expected to be entertained.”

Caregivers described it as reassuring that others were concerned and thinking of the patient, but they were mindful to keep the task manageable. The use of social media and technology (for example, text messaging and emails) were mentioned as helpful tools to achieve this. One study participant explained: "with the family we kinda had this messenger thing on Facebook where we were all a group...so instead of messaging them individually I would just send one message and it would go to all of them.” Another caregiver explained her strategy was to restrict the number of people that she kept in contact with: "I kept in touch with immediate family pretty closely, just a phone call or text or something.....but beyond that I didn't involve too many other people.”

**Finances**

The HSCT journey created financial challenges for some of the caregivers within this study. "The whole financial thing is quite stressful... it's quite a financially challenging time.” Being displaced from home during the relocation period, meant that caregivers faced dual living costs - both at home and away: "because we were running two households, basically here [at home] and in [the city]... [we were] still paying the
house bills, while I had my expenses like groceries while I was away too, so it wasn't easy." C8 Another caregiver reflected on her outgoing living costs: "when you're living away from home... you know the power bill at home still has to be paid even though you aren't there, our phone bills kept coming... and because you're living away from home and spending extra money- it made things expensive." C2

The study participants described additional costs associated with being away from home: "because I was cooking for us both, and still going out and doing stuff... you know we had to do stuff to keep occupied, and that all unfortunately cost money...you couldn't not do something...you had to go and do things." C8 Caregivers incurred mobile phone charges trying to keep in touch with people while they were away: "you were trying to keep online, but there was no free WiFi or anything... that was like $8 for an hour, so you were forever trying to keep in touch with folk... but you couldn't use phone's at the hospital or [accommodation facility] because they were all toll barred, so you clocked up a lot of dollars in phone calls and data on your cellphone." C2

One study participant who owned her own business described the financial implications of her HSCT experience: "we decreased our pay from the business to us - to just cover our expenses....it made finances very tight, but we made sure we had enough to cover all the necessities... everything that had to be paid, like mortgage and household bills." C5

The negative financial effect was heightened by a reduction in income, as a result of having to take an extended time off work to care for the patient during the transplant period. "Because neither of us at that point were working... I'd exhausted all my leave, [the patient] had exhausted all his leave he had owing, but the bills still kept coming at home, plus you're still funding yourself to live away from home, so that was challenging." C6

For some of the study participants the financial impact was compounded when the caregiver was caring for their spouse - whereby both partners were unable to work, and as a consequence neither were being paid: "when you are trying to live on a budget ...and both of you had no income... that was made even harder because you had added costs at the same time." C2 Another caregiver described having to adapt to a reduced joint household income: "you had to get your mind set on that there's no wages coming in for either of you... so you had to be careful with what you were buying." C7
One of the study participants expressed a sense of privacy regarding money matters, and sensitivity when discussing the financial impact of the HSCT experience with others. This particular caregiver shared: "I felt like that was kind of something that I had to keep to myself, because I sort of didn't want to discuss money stuff with other people necessarily….. or burden [patient] with that for him to worry we've got no money coming in!" C6

Several participants reported taking on debt as a consequence of the financial pressure associated with their HSCT experience: "it was sort of costing me money that I didn't have at the time….I think I lived on my credit card for a little bit." C8 Another caregiver described needing a financial loan after exhausting their savings: "it hasn't been easy... we've had to take out another mortgage." C4

The financial toll of the HSCT experience was far-reaching, and affected the long term financial position of several study participants. One caregiver shared her experience: “we had to sell our business and our house... yeah we've gone backwards really... so yeah financially it's been hard." C4 One caregiver described how she was still feeling the financial effect 12 months following HSCT: "I had to take a year off work ...so I did lose.... like a whole year off work basically, so I still feel we're on a catch up mode." C8

The study participants reported mixed success in seeking financial support from the government agency - Work and Income New Zealand (WINZ). One caregiver who did receive financial support stated: "they gave us an extra benefit...but it wasn't much to live on!" C7 However many of the caregivers interviewed reported being ineligible for financial help. "We weren't eligible for anything." C2, "we got absolutely nothing..." C4, "no WINZ support at all, we didn't qualify for anything there." C5, "I enquired at WINZ before we left for [city], and was told we wouldn't get anything...they didn't want to help me at all." C6

Several participants described the process of applying for financial support challenging: "so we had this information and we ended up going to WINZ...which took a hell of a lot of time and effort...you know going to the bank and getting statements and getting information from there and there and me having to do all this while [the patient] was sick, and then to be told actually 'you're not eligible'!" C2 One caregiver recalled: "they [the hospital transplant team] told us to go to WINZ, which we did and we went through
the whole process, which was a lot to do but after doing all that... they said that we weren't entitled to anything whatsoever." \[C4\]

Another caregiver shared her experience: "I spent an excruciating hour and a half with a very patronizing man at WINZ...we have a few assets and I got asked ...have you got a holiday home? well we do have a holiday home, he told us to rent that out to make yourself money, and I thought you nit wit - you have no idea how difficult that is, but we didn't qualify for anything according to him... he basically said 'use your savings, sell your assets and come back to us when you run out of money'. \[C6\]

**Relationships: 'together and apart'**

The impact of the HSCT experience on the caregivers’ relationships with the people around them was visible across the participants’ narratives. The study participants described an emotionally charged experience, which resulted in both positive and negative effects upon their key relationships.

The caregivers in this study were all immediate family members of the patient. Many of the participants spoke of the emotional challenges associated with caring for their loved one undergoing HSCT. This was highlighted by one participant who observed: "well it brought the two of you together, but it was also capable of pushing you apart at times." \[C1\] One caregiver who had cared for their spouse reflected on the toll which illness and HSCT had upon their relationship: "so the person you meet and you fall in love with and you get to know ... disappears... suddenly you've got this stranger who you don't really recognise... who relies on you 100 %, and you're thinking 'shit... who is this?' you know?" \[C2\]

Another caregiver recalled struggling with angry outbursts from the patient during his recovery, and the strain this placed on their relationship: "he was quite awful really...any little bit that upset him he would go off the tree like really really badly... [a friend] rang me once to see how he was and I said, 'I'm just about ready to pack my bags and leave' ...it.... it just wasn't him." \[C1\]

Another caregiver described the pressure which the HSCT experience placed upon other family relationships: "sometimes I didn't even feel like I could talk to my [partner]"
about it, because [partner] had a different view...he wanted to know facts and figures and I didn't want to know those sort of things, I sort of had a positive outlook... I didn't want to know the chances of things...we were on different wavelengths, which was difficult at times...how he dealt with it was different to how I dealt with it."C8

Many of the caregivers remarked how the HSCT process caused the patient to experience mood swings, depression, and at times anger directed at the caregiver themselves. The memory of the relationship difficulties between themselves and the patient was vividly recalled by one caregiver: "he's just said horrendous horrible things to you and you just want to slap his face and leave, and actually you feel like you are trapped there and that was incredibly hard, so any conflict in the relationship was a lot more difficult to resolve or kind of cope with...you didn't want to be anywhere around him ...".C2

Some of the caregivers explained how they coped with bearing the brunt of the patient's mood swings, by recognising it was a consequence of illness and treatment. "Well it was just the medication and side effects though, [patient] is not a grumpy person, he had a lot to deal with as well... you've got to understand that when people have had a lot to deal with it's gotta come out somewhere."C7 This was echoed by a participant who stated: "when [patient] got angry she was very apologetic afterwards, but from time to time [the patient] got upset and directed it at me...and it just wasn't worth having a disagreement because it wasn't her... you just get on with it, you just have to recognise it's part of it."C8

One caregiver explained how she tolerated the patients' mood swings: "... given the situation that he's in I couldn't take offence to anything he was throwing at me, cos he's fighting for his life...so he could pretty much throw anything at me... to a degree ... and I would just take it...but then I'd also know that he's only taking it out on me because I'm the closest person to him, so he's going to take it out on me."C5

The ongoing challenge of coping with the patient's mood fluctuations was described by one caregiver who explained the enduring emotional effects of caring for her family member during HSCT: "I spent some real bad black days with [patient]... I probably haven't dealt with them, but it's just too bad... it's what it was...and even now sometimes when [patient] has grumpy moods... I look at [patient] and think I've got to walk away
otherwise I will explode... I've put up with so much from [patient] in the past year, I just have to walk away... otherwise I'm just gonna lose it, and I don't want to do that. "C4

Despite the difficult emotional challenges, the study participants also spoke of the positive influence the HSCT experience had upon their relationships. A sense of partnership and being drawn closer together as a result of the HSCT experience featured across the caregiver narratives. One caregiver explained her attitude toward caring for her family member as: "we're here to do a job, and we're in it together." "C1 Another caregiver remarked: "I saw him experience some very vulnerable things that he would never ever want anyone to know or see, so I think that's sort of brought us even closer together, which is nice... "C5

One caregiver described feelings of shared accomplishment alongside the patient during his HSCT: "I couldn't say it's brought us closer, cos we were a pretty strong unit together anyway, but it's an experience that we went through together... we both felt the highs and the lows and the sense of achievement when things were going really well... I sort of felt well we've done this together."C6 The sentiment of togetherness was poignantly expressed by one caregiver who had experienced her own life-threatening health complications prior to her family member's HSCT: "I said to [patient] obviously I was meant to come back and look after you, so we could go through this together..."C7

Fear and Worry

Feelings of fear and worry were expressed across the narratives of the study participants, and featured in descriptions of the caregiver experience throughout the HSCT trajectory.

The study participants described concern for the patient undergoing HSCT treatment: "I was worried if he was going to be able to tolerate the chemo... I thought in my mind that he would, but... you have that concern and feel a bit apprehensive."C1 Caregivers worried when the patient became unwell and experienced treatment complications: "any time something went wrong I always worried."C3 An incessant state of worry was succinctly expressed by one caregiver who stated: "I just worried the whole way through."C8
One caregiver described worrying about the patient's recovery progress following HSCT: "I was worried that he wasn't going to respond... the main worry was that he was going to die through some part of it, and as he reached each milestone... each week was like a milestone... got through that one... and he should be picking up... he should be picking up soon..." Caregivers expressed a profound sense of worry regarding the patient's ability to survive the HSCT process: "I worried that he would die, and I would be left on my own." Worry associated with the fear of a negative patient outcome was reported by several caregivers: "it was life threatening... we were worried sick because we didn't know what the outcome was gonna be..."; "you know this could go all horribly wrong and the worst could happen.

Several caregivers described experiencing anxiety following HSCT when the patient was discharged from hospital. This transition point was tinged with fear for some of the caregivers. One participant explained: "we've had all this time with the hospital cocoon around us - as carers as well, and relying on you guys[health care team] to do it for us, but when they said go home that's it - it was like - there's the cut off - that's it! [slaps hand for effect]... and that's scary." In some instances this was associated with concern around accessing urgent medical care from the transplant team if the patient became unwell: "you didn't want to venture too far from the hospital." This was amplified when the patient was discharged fully to return home - a significant distance from the city transplant hospital: "it was a little bit more scarier in the sense that we were back here and also we were two hours away from [transplant hospital]."

The study participants expressed a sense of enduring worry, which extended into the long term post-transplant period: "you do worry a lot, it was and still is quite hard... I don't think it's any easier now." The long term side effects of the HSCT worried one caregiver: "he wasn't really right in the head afterwards... as if the chemo had left him a bit slow... it was a bit of a worry to think well is he going to come right?"

Fear of disease recurrence was described by several caregivers: "you still have that sort of fear in the back of your head that it might come back." One caregiver described an ongoing sense of responsibility and anxiety that the patient could become unwell again: "if it happens again, I'll have to go through it all again... [patient] said to me the other day that she had a temperature and I thought...'oh god, here we go again'... you know it's just not going to go away... it's just the way it is..." The recent positive news of her
family member's remission one year post transplant was overshadowed by ongoing fear for this particular caregiver, who expressed guarded optimism for what the future may hold: "it is good news, but I know [patient] is not out of the woods by any means... but we'll take everything we can get." C4

One study participant was the caregiver as well as the stem-cell donor for the patient's allogeneic HSCT. This caregiver described a particular lingering sense of concern for the patient's ongoing well-being following his transplant: "well as his donor I am very personally invested for sure!...and of course I do worry, so I've written him out a big set of rules 'you're not doing this, and you're not doing that!'...and I say 'I'll be watching over your shoulder!'" C2

Worry for other family members was also expressed. One caregiver explained her concern at the impact the transplant had upon her children: "like I worried about [the patient] as well, but it's thinking about the kids and worrying how all this affected them." C5

Coping: 'getting on with it'

Despite describing significant challenges associated with the role of HSCT caregiver, several study participants initially struggled to answer, when questioned on how they coped with HSCT caregiver experience. One caregiver responded by suggesting there was no alternative but to cope: "well this was just something we just had to get through, there wasn't a choice." C7

Another caregiver alluded to the personal toll of keeping the emotional strain to herself: "you learn to internalise, which is not healthy...yeah you learnt to really internalise it, you learnt to suck up shit that you probably shouldn't really." C2 Coping by relying on oneself was echoed by one caregiver who responded by saying: "well you just get on with it." C8 One participant minimized her own distress and questioned her own coping ability: "I think there's people having a far worse time out there than me, you sort of think well how do other people cope?... they just get on and do it ...so I tell myself 'stop being dumb!'" C4
The study participants went on to describe a range of methods which they utilised to cope with the challenges they faced during the HSCT experience. Maintaining perspective was a useful strategy for one caregiver: "you know that it isn't going to last forever you know?... that once he got through that bad time...nothing’s forever."C7

While other participants focused on positive thinking: "I think it's the sort of thing you just have to go through and get through the best way you can, you've just got to get on and go for the ride and hope for the best."C6; "... we tried to stay positive all the way through... you know... that we were going to get home."C8

Enduring the HSCT journey itself was viewed by one participant as contributing to her ability to cope, as she described how she became toughened by the experience: "well it made me stronger for sure - which no doubt helped, I think I'm just a bit tougher now."C5

Utilising self-control as a coping mechanism was noted by several caregivers. One caregiver described how she coped with the patient's mood swings: "I had to learn to be very tolerant and walk away and bite my tongue quite a bit."C8 Another caregiver spoke of balancing her own emotions when caring for her family member: "he was freaking out, so I couldn't freak out...yeah so when he's freaking out, I can't look like I'm freaking out too...even though I would have been - but I couldn’t let him know that I was."C5

The enormity of the experience and the need to re-prioritise was recognised by one caregiver who reflected: "there's so much on your plate when you're going through that...so my way of coping was clear anything off your plate that you can clear off and just let everything go, so you can just cope with today... sometimes just this five minutes, sometimes an hour at a time...but you know it's that intense that you almost just can't cope with anything else."C2

Several caregivers spoke of practical coping measures and the importance of doing 'normal' things as a distraction from the hospital focus: "I'd go to town and go to a shopping mall....just to walk around... I wasn't going to be buying anything... just to walk around you kind of felt a little bit normal...you know?... it was important to have just a normal daily thing to do in between the hospital visits."C6 Another caregiver enjoyed going out for meals: "there was a nice coffee shop I'd go over and have a nice
coffee there...but towards the end I just got so tired of cooking for myself that once a week I took myself down to a restaurant and just had a nice steak. 

The ability to work remotely was a key coping strategy for one caregiver: "I think if I didn’t have that I would have probably lost the plot... it was just an outside focus, so I didn’t have to focus on hospital stuff the whole time...if I didn’t have that, I had all that time on my hands just to sit there and think about what was going on, so it gave me a way of thinking about other stuff...definitely it was a huge help... mentally and financially." 

Several study participants recognised the importance of self-care while they were away from home during the HSCT recovery period. One participant explained how she tried to keep up her normal exercise regime: "I tried to go for a couple of runs (laughs!)...cos I like to run..." Several caregivers noted that it was difficult at times to look after their own nutrition. "I went down to the cafe and brought all my meals, I just didn’t have the energy to cook for myself... sometimes I was too tired to eat anyhow." Another caregiver described how she neglected her own dietary needs: "I was starting to get a little bit tired no doubt...I think people did notice that I’d lost a lot of weight, but it was hard to stay motivated to eat sometimes." 

One caregiver noted an increase in her alcohol intake whilst performing the role of HSCT caregiver: "I would have a couple of wines just to zone out, not every night... not every night, but usually I sort of have a wine in my normal life... I have a wine like on a Friday or something, but there at [accommodation facility] I’d have a wine like every second night, so it was sort of a lot more wine than I’d usually drink if I’m honest." 

Support

The importance of having support available to mitigate the challenges of the HSCT journey featured across the study participants’ narratives. The caregivers described their experience of receiving informal support provided by friends and family, in addition to the assistance offered by more formal support mechanisms such as cancer related non-government organisations (NGO's) and the health care team. Hence three sub-themes were identified relating to the descriptions of support provided by the caregivers.
interviewed in this study: informal support, support from NGO's, and support from the health care team.

**Informal support**

The study participants described the value of family and a supportive social network: "close friends really - they were quite supportive, and you need that...and even work colleagues were supportive to a degree." One caregiver described how when separated from family by distance, regular phone contact was an important way of coping: "my mum and dad I'd talk to every day - sometimes twice a day... three times a day...they were my main lifeline most days"

One caregiver described how she found it particularly helpful to speak with someone else going through a similar experience: "generally people don't understand - you have some friends that were really good... but I spoke to a mother of another stem cell transplant patient and she was really good because she actually understands."

Several caregivers explained how well-meaning comments from other people intending to offer support, were in fact sometimes unhelpful. One caregiver described her inflammatory reaction to a remark from one of her friends: "some people just don't get it... a friend of mine said to me: 'oh yes I know about that... my friend had breast cancer - she had chemo', and that really annoyed me... I was like 'nah... you have no idea what we're going through here, you just don't get it all!'...a stem cell transplant is so much more major - you know?" Another study participant highlighted the need to receive support from others which was positively focussed: "well we both got to the point when we got out of the hospital that we both said 'if anyone says to us again 'oh well it's early days yet' - we're going to rip their ears off!...because we thought 'well yes it's early days - but you know, isn't he doing well?'"

One support strategy experienced by some of the study participants, was the ability to share the caregiver role. Alternating caregiver duties with other family members provided some respite for the main caregiver and was seen as a practical way in which others could help: "his mum and I alternated looking after him after he sort of got out of the transplant from hospital and started doing better...cos she wasn't really working so we were able to alternate." Another caregiver was able to use the opportunity for a
special trip away: "my brother stayed and let me head away to [town] to visit my daughter and new granddaughter for a couple of days just before Christmas - which was so so nice."\(^{C7}\)

**Support from NGO's**

The study participants described several platforms which offered formal support during their HSCT experience. These included the non-government funded organisations (NGO's): Leukaemia and Blood Cancer New Zealand (LBC) and the Cancer Society. All the caregivers reported being aware of the existence of these NGO's, however the degree to which they chose to engage with these groups for support varied.

Some of the study participants described how they felt they did not require the support offered by the NGO groups: "like I went on the LBC website and had a look at things... I think there are some things... with them and also the Cancer Society that I chose not to engage in by my choice, I think cos we had so much good support, family and friends that we didn't need to use those services."\(^{C5}\)

Several of the caregivers described receiving initial contact from the NGO's at the beginning of their HSCT journey, however no further follow up: "I had contact from them - they just popped in to say hello, and then I saw them once at the hospital in [city hospital] but that was only once... I never saw them again... I suppose had I wanted to contact them I could have."\(^{C6}\) Similarly another participant stated: "we met a nice person from Blood and Leukaemia [LBC] they gave us a $10 petrol voucher.... but we didn't see them after that...but I think it was up to us to make further contact if we needed them."\(^{C2}\)

Several caregivers stated they did not feel like engaging with the NGO's. One caregiver described an aversion to group sessions, and recalled attending a workshop run by one of the NGO's: "we went once to the Cancer Society, cos it was across the road and the nurses told us to go over there and just see what's available for us, but they [the other workshop participants] were all doom and gloom....we were looking at each other thinking 'can we go'? [laughs]... we never went back again cos it was all.... oh so depressing!"\(^{C4}\) Another caregiver stated she didn't feel the NGO support groups would be particularly helpful for her: "I suppose had I wanted to... they had coffee mornings..."
but that was no interest to me... I didn't want to walk a few blocks away to have coffee with people when I wanted to spend my time with [patient] in hospital. \( ^{C6} \)

Several caregivers explained they were uncertain what type of support the NGO's provided. "I didn't really know what kind of support they offered? \( ^{C2} \) One caregiver described being unsure how the NGO groups could help her, and commented: "yeah I found it hard to kind of figure out - well what can they do to help me?... practically there was really nothing they could do - we just had to get through on our own. \( ^{C6} \)

Some of the study participants described receiving NGO support in the form of grocery and petrol vouchers. One caregiver also recalled: "the leukaemia people [LBC]... gave us a token thingee that meant you could watch TV in hospital instead of paying the $8 a day or something horrendous it was at the hospital....distraction therapy was absolutely vital for us so that was a god send. \( ^{C2} \)

Other study participants described the support provided by the NGO's as incredibly beneficial: One caregiver stated: "yeah the LBC support groups are great, and I've got some great friends I've made there who text me and say 'do you want to meet for a coffee'?" \( ^{C1} \)

Another caregiver described ongoing support from the NGO's following HSCT: "the Cancer Society have been really good, they're still in touch with us...the lady from there has brought around some baking and invited us to dinners and things like that, which we go to now and then, and we were going to meetings... with the Leukaemia Foundation [LBC]. \( ^{C7} \)

**Support from the health care team**

The caregivers interviewed for this study all expressed gratitude towards the health care team they had been involved with. Throughout the interview narratives the study participants acknowledged the willingness of the doctors and nurses in the transplant team to answer questions as the caregivers progressed along the HSCT pathway alongside the patient. "They made you not scared to ask questions you know...no question was a stupid question or a dumb question. \( ^{C5} \); "they really were open to all your questions...we could have asked anything, there was never a time I felt I couldn't..."
ask somebody something...yeah they were really good."³⁶⁶; "we'd ask questions... they were happy to help."³⁴⁸

Whilst feedback regarding the health care team was positive overall, several study participants identified an imbalance of support and education, which was aimed more at the patient, than the caregiver. One caregiver stated: "[the health care team] could be a little bit more inclusive of the caregivers... they give so much information to the patient."³⁴⁴ This was echoed by another study participant who noted: "there is a lot of support for the patient, but there probably could be better support for the caregiver."³⁴⁷ One caregiver described how she felt there was a lack of support aimed specifically at caregivers from the health care team: "there was nobody for the carer...everyone was revolved around [patient], but no one actually sat down and said what the whole process was for the carer."³⁴⁸

The study participants were asked if the health care team in the hospital had connected them with a social worker. Three participants recalled receiving input from a social worker. One caregiver described receiving assistance with financial issues: "if I had a question about what we were entitled to financially I went to the social worker."³⁴⁸ Another caregiver who did not qualify for financial support explained: "the social worker meant well, but wasn't able to actually deliver anything."³⁴² Several caregivers said they were not offered contact with a social worker. One participant explained they had declined a referral to a social worker: "No... I didn't have a social worker, I don't think I would have found it particularly helpful to be honest, I knew where to go and what I had to do, I navigated it myself."³⁶⁶

One participant described having an opportunity to meet with a psychologist, at an appointment she attended along with the patient as part of the formal pre-transplant preparation: "we also had a psych consult...and that was actually helpful, kind of focusing on the coping mechanisms."³⁴² This caregiver went on to suggest: "I think the psych consult you need probably more than half an hour...and more counselling for individual partners."³⁴²

Several of the participants described how their GP was a source of support. Caregivers who experienced this were referring to their family GP - whereby they shared the same family doctor as the patient. "I have a very good rapport with our GP, we text each other and I let him know how [patient] is, I did that when we were away having the
transplant, and I'm still able to do that now we are back home, which I find really helpful." Another caregiver described the supportive role of their family GP: "our family doctor...he's been great ... I guess that's because he knows the whole story, I don't have to repeat everything to him because he's been part of it all since the start... he's even rung me throughout the whole process every now and again just to see how we've been going and coping with it all." Several caregivers described being connected to a nurse specialist within the bone marrow transplant (BMT) team, and the importance of such role serving as a single point of contact for the caregiver. "[BMT nurse specialist] is amazing... she's such a lovely lady, and like she used to say to me 'if there is anything you want to know or anything you're not sure about just ring me.' ... she gave me her cellphone number, I don't think I had to use it that much... she'd just pop in and out, she'd just tell us what was happening... what time he was booked in for things... she was really my main contact." Another participant noted how the transplant nurse specialist recognised the support needs of the caregiver: "she [BMT nurse specialist] was amazing... she'd say 'right [patient] is having a sleep, and you are coming with me'... and we'd go and have a coffee and a chat... she meets you when you first go down [to the hospital] she had a chat with [patient] and said I'm here for you and your carer too', and she'd just pop in every two or three days to see how you were." Several study participants remarked how the health care team were accessible to contact. One caregiver explained that she appreciated having the ability to contact the haematologist and BMT nurse specialist directly: "we have their phone numbers to use if we need to, and I have, but you try not to abuse that ever." Another caregiver described how the health care team provided ongoing support to the patient and caregiver following discharge home, even up to one year following HSCT: "the [haematology consultant] and [BMT nurse specialist] were really good... we had [BMT nurse's] cellphone number, so we'd just text or email... even now that's what we do, there's always someone there if we have a question." The importance of continued access to and support from the health care team following the patient's discharge home was underlined by one study participant who explained: "the beneficial thing that is that they make you feel like there's a real safety net there."
The importance of feeling connected to the transplant team following discharge home for provincially located caregivers was highlighted by one participant, who recalled an occasion where she experienced difficulty contacting the health care team. This caregiver also expressed a perceived barrier toward contacting the haematology consultant directly: "...you can't ring [haematologist] cos he's right up the top...we tried to ring [BMT nurse specialist] at one stage when [patient] was getting really crook, but it was a day we couldn't get hold of her...".C3

One caregiver shared the experience interacting with the health care team, from the perspective of being a health care professional as well as a HSCT caregiver. She described being welcomed by the haematology consultant, and the value of having her health care background acknowledged: "I said, 'I'm a [health care professional]...he said 'oh fabulous - welcome to the team!'... it was great to hear, like we're all in this together and we've all got our part to play, it was like .... 'I may be the head of the transplant team, but I want input from both of you'...so that was kind and he was willing to listen to what was important for [patient] but also my viewpoint... anything that I contributed was actually valued and not kind of 'oh you're being a pain in the arse'...which that's what you often get... so you often don't admit that you're a [health care professional] (laughs)... but [haematologist] was just fabulous.".C2

Learning

As the study participants described heading into the unknown territory of the HSCT journey, the theme of 'learning' emerged from across the interview narratives: "it was all a learning curve the whole way through, you didn't know what to expect next really.".C8

The caregivers described finding themselves on a journey of learning that some would rather not be on, as they accompanied their loved one who was facing cancer diagnosis and treatment: "yep we learnt all the stuff that we never really ever wanted to know! [laughs]".C6 The study participants described transitioning from lay person to HSCT caregiver, acquiring new knowledge along the way: "we didn't know much about leukaemia or bone marrow transplants or any of that stuff to begin with of course - it was a foreign language.".C4 One caregiver described how they learnt to ask questions,
and clarify meaning as they learnt new concepts: "I'd say... what's that in English?...what does that mean?"C1

Medical terminology featured across the interview narratives as the study participants described learning about the patient's diagnosis and treatment, as well as practical steps on how to navigate the HSCT experience. It became evident that the study participants had picked up an impressive array of medical knowledge during their experience. One caregiver recalled: "you learnt to say: 'neutropenic! febrile! rigors! 39 degrees! haematology!'"C2 Another caregiver remarked: "it got to the point where you knew the routine and medical stuff as good as the nurses just about![laughs]"C4 One caregiver recalled feeling a gradual accumulation of expertise and understanding: "you felt quite expert as time went on... you began to be able to understand what it was all about."C7

The study participants described being informed by a range of information resources. Members of the patient's health care team - doctors and nurses in particular, were reported as being a main source of information. One caregiver noted that learning to trust the health care team was implicit to the education process: "what they said was gospel and we went with it... because we knew nothing, and we felt hey you're the experts...and we trust you.... we have to trust them!...there's no other option"C4

Several caregivers described attending an initial hospital appointment which included meeting the clinicians in the transplant team, such as the haematologist and a nurse specialist. The participants recalled how this visit involved a verbal education session with the patient and the caregiver about the HSCT process, including treatment goals and survival statistics: "Doctor [haematologist] said 'I want you to remember a four letter word... C.U.R.E.'...and we just thought 'right we've been told it's a cure – let's do it!'"C3 Another caregiver remembered: "the doctors quoted percentages of survival ...it was truthful.... it was upsetting... but it was the truth, so they had to tell us."C7

Written information appeared to be the dominant form of information. Many of the caregivers described being given a folder from the transplant team which contained booklets and other reading material to help prepare for the HSCT process. "We got a stem cell transplant folder, it was really brilliantly laid out, I think there were seventeen chapters in it... it went over the basics really really well."C2
The internet was noted by one participant as a source of HSCT information - with the caveat from the health care team to only visit websites containing trustworthy information: "I quickly realised that reading stuff on the internet was not the right thing to do, and they [the health care team] told us the correct websites to only use." C5 One caregiver described how fellow HSCT caregivers were also a valuable information resource: "I learnt a lot from another caregiver as well, because there are a lot of things that get passed along from one person or another." C8

The volume and pace of the education process led to some participants feeling overloaded with information: "you get all this different information all at once." C8; "it was a lot of information to take in." C6 One caregiver commented that it was sometimes difficult to retain information: "I think you're in a world where you don't quite take it in sometimes." C8 The rapidity of the education process for HSCT was overwhelming for one caregiver who remembered: "everything happened so fast, and you got told so much information all in one go... so it was all pretty much a blur at the start..." C7

One study participant suggested it may be beneficial for the health care team to re-visit some of the education topics as the caregiver's understanding becomes clearer over time: "they actually need to come back and see you in again in few weeks’ time and go through the whole process again, cos then you can start putting it together and actually start linking it together to start understanding what it meant." C8

Several participants noted the value of the education process to prepare the caregiver by setting expectations for the HSCT experience: "there was never a time in the whole process that I thought - well no one told us about that, it was pretty comprehensive...we knew pretty much both knew what we were in for." C6 Another caregiver remarked: "so as far as the education goes... for me personally as the carer - I thought that it was brilliant, I went in there probably not really understanding it, but when things happened - they'd talked about it, so it was not a huge surprise." C4 The importance of having a plan was noted by one study participant who stated: "one thing that was really helpful was when we got our whole itinerary of what was going to be happening you know sort of..... day by day, so we kind of knew what to expect then." C7

However some aspects of the HSCT education process did not suit everyone's learning styles. One caregiver commented how they had difficulty with the written information component: "there was a lot of written information, screeds of it ...and I have to be
honest - I didn't read much of it... I think I'm probably more of a person that's like - tell me about it...I don't want to read about it. "

Another caregiver explained that she preferred to receive as little information as possible: "there were a few times I wished they didn't tell us so much, because we had asked not to be told too much, just what we needed to know."

One caregiver explained that she felt she didn't receive much information about the HSCT process, and wondered if it was because the health care team assumed she had existing knowledge from caring for the patient during prior chemotherapy cycles: "every time [patient] had chemo they give you the side effects and everything, but not so much in the transplant...I can't remember getting much information at all actually...maybe they assumed I knew it all by that stage?"

**Participant's recommendations**

During the interview process the study participants were asked to reflect on the experience and knowledge they had gained during their HSCT experience. The study participants were asked: "what things can the hospital team do to help prepare and support the caregivers of people going through a stem cell transplant?" and, "what advice do you have for someone who is just about to head into this process of being a caregiver for someone undergoing a stem cell transplant, including what tips would you have for them on how they might best get through the experience as the caregiver?"

The participant responses are summarised and presented in Appendix Twelve and Appendix Thirteen.

Some of the participants required encouragement to share their own specific caregiver perspective, when they were asked - "what advice did they have for people about to become HSCT caregivers on how best to get through the transplant experience as the caregiver?" Despite the specificity of the question, several participants provided responses which were entirely patient focused, and offered suggestions on how caregivers could best support the patient.

It is worth noting that some study participants demonstrated a tendency to focus on the patient details and journey at times during their interview. In order to obtain insight into the HSCT experience from the perspective of the caregiver, several study participants
required periodic, and sometimes repeated encouragement from the researcher during the interview to re-align the focus toward themselves.

A strong sense of duty and responsibility to assess and monitor the patient was reflected in the response of one participant who suggested prospective caregivers should "learn to read the patient's body and symptoms." A sense of heightened responsibility experienced by caregivers at the point of discharge was expressed by several participants. One caregiver expressed the importance of having a clear action plan in place if the patient became unwell after being discharged from hospital. Similarly another participant stated: "be careful when you get home - know what patient symptoms to look out for, who and when to call for help."

Some participants provided a more caregiver focused perspective in their advice to new HSCT caregivers on how best get through the transplant experience. Several participants recommended coping strategies for the caregiver including knowing when to seek support from others. Some participants provided advice on how to learn about the transplant process. Variation in personal learning styles could be seen in the responses of the participants. One participant recommended: "read as much information as you can." While another caregiver stated: "don't go on the internet...keep as blind as you can." These opposing statements highlight the complexity of learning needs within the HSCT caregiver population.

When the participants were asked 'what things can the hospital team do to help prepare and support the caregivers of people going through a stem cell transplant?' The study participants overwhelmingly expressed a desire for the health care team increase the focus on providing support and information to the HSCT caregiver. This was summed up by one participant who suggested: "provide better support for the caregiver - don't just focus on the patient." Several participants recommended specific education strategies, including the need to provide education and support for caregivers to enable a safe transition home for the patient following discharge. One study participant suggested HSCT caregivers should have the opportunity to meet with a psychologist. Several caregivers stated the health care team should maintain their current education process for HSCT caregivers, including the provision of an education folder containing written information.
The journey to a 'new normal'

The challenge of transitioning back to normal life following HSCT featured across the interview narratives. The study participants explained how the overall HSCT experience exerted an enduring impact, and continued to influence their daily lives. "I still feel like I'm on a rollercoaster ride..."⁴ The word 'normal' was used by the participants throughout the interview narratives, to describe the return to everyday life following HSCT. However what emerged from the participants' narratives was the sense of a journey toward a 'new normal', whereby life was not quite the same as it had been prior to embarking on the HSCT caregiver journey. This was summed up by one participant who described how she was feeling eight months following her family member's HSCT: "life feels normal - but it's kind of not..."⁵ Another caregiver reflected on the long term changes since the transplant: "...it's almost like nothing is the same anymore sometimes."⁴

The caregivers within this study were interviewed between eight months and four years following the date of transplant. One caregiver noted the gradual transition back to everyday life following the HSCT, and shared this reflection: "we're coming up one year since the transplant, and to be honest it's been a blur...I don't think I even remember much of last year...sometimes it feels like it just didn't happen... because we're kind of getting back to normal which feels odd after going through such a major experience ...my friend brought it up with me the other day- - she said, "hey you know you called round the other day and we didn't once talk about [the patient's] cancer"...and I was like "oh my gosh, we didn't."⁵

Several study participants described how their personal HSCT journey had shaped their attitude toward the overall experience: "it sounds really weird but I think we actually had quite a positive experience out of a really terrible situation and a positive outcome."⁶ One study participant explained how the experience changed her outlook on life: "I'm sure anyone who has gone through a life threatening situation like we did, finds that you don't sweat the small stuff now really."⁶

One study participant acknowledged the personal concessions she had made in order to be the HSCT caregiver. This caregiver shared the complexity of emotion she was
continuing to experience following HSCT, including uncertainty regarding the future: "sometimes I feel a little bit bitter, not so much towards [patient] but the whole situation...you know like we've given up a really good life, so I could be there to look after [patient], and I'm sitting here thinking what on earth is going to happen for us now?" C4

A sense of good fortune after obtaining a positive outcome for the patient following the transplant, was a shared sentiment expressed by several caregivers: "we were just so lucky, everything went so well" C3; "[the patient] is doing so well, it couldn't have gone better really, we were very lucky." C6; "we felt really lucky." C2; "you had your moments obviously where you though that this could have all gone really badly, but we were incredibly lucky that it didn't." C7

The study participants described how moving forward with their lives following HSCT continued to be challenging. One participant described ongoing anxiety and uncertainty about the future: "some days we don't even think about it, but it's always there in your mind you know? The worry that obviously things could change and all this could come back." C6 Another caregiver described how the HSCT experience had a radical impact upon her own life, and continued to do so, even when interviewed twelve months after the transplant: "this whole experience has just... turned our world upside down...and even now one year on...it's just huge..." C4

One caregiver who was interviewed four years after the transplant described the emotional strain of watching the patient whom she was caring for struggle with the long term health consequences following the transplant: "he got really quite depressed, he'd say: ... 'if this is the quality of my life then I don't want to be alive', and that's really hard to see as a caregiver...and his [family member]" C2

One study participant shared how the HSCT patient whom she was a caregiver for was now several years following the transplant, experiencing further health complications as consequence of their HSCT treatment. This caregiver explained that further treatment was required, which meant relocation once again to the city based hospital for several weeks. "... things were back to normal til we've just come to this bump in the road again...it's a bit like 'here we go again' all over again....but we'll get there." C1
The long term psychological impact of the HSCT caregiver experience was demonstrated by one study participant, who shared the ongoing challenges she was continuing to experience one year after her family member's HSCT: "I'm still not over it... so it's all these things sitting in the back of my head and... I just feel silly that these things still worry me really."\textsuperscript{C4}

**Summary**

The study participants shared the personal stories of their HSCT experience. A set of eleven core themes emerged from the participants’ narratives, which although are each distinct, demonstrate a degree of inter-relatedness across the study findings, which illustrates the complexities of the HSCT caregiver journey.

Analysis of the narratives reveals the caregiver journey and the associated social, emotional, psychological, and practical challenges experienced by those interviewed within this study. The study findings highlight how the HSCT journey profoundly affects the lives of the participants, whose stories give voice to the experience of HSCT caregivers within the context of provincial New Zealand.

The following chapter will present a discussion of the study findings with a particular focus on the implications for clinical practice within the health care team.
Chapter 5: Discussion

Introduction

Haematopoietic stem cell transplantation (HSCT) is a physically and psychologically demanding treatment used in the treatment of haematological malignancies. Caregivers, who are often the patients' family members or close friends, perform an essential role in supporting the care and recovery of patients undergoing HSCT treatment. The research literature demonstrates that the transplant experience can significantly impact the lives of HSCT caregivers. The sustained commitment on behalf of the caregiver to provide patient care and support across the HSCT trajectory, means the challenges associated with the HSCT caregiver role can extend into the weeks, months and even years following transplantation.

Because HSCT is such a complex and specialised treatment modality, this line of treatment is only provided at tertiary hospitals located in main city centres. As a consequence, patients and their caregivers who live in provincial New Zealand must relocate in order to access HSCT treatment. Relocation can significantly heighten the stressors associated with the HSCT experience. Living away from home for several months can contribute to significant challenges for HSCT caregivers. Caregivers must deal with the emotional strain of caring for their loved one, including the uncertainty which surrounds the transplant outcome. All whilst separated from their usual familial and social support networks.

This chapter provides a discussion of the research findings from this qualitative study, which explored the caregiver experience of HSCT for haematological malignancy within the provincial New Zealand setting. The significance of the study findings are discussed, alongside commentary relating to the relevant existing literature. Suggestions on how key learnings from this study may be applied are included throughout the chapter, and further explored in relation to the clinical implications of the study findings. The chapter concludes with an overview of the study's limitations, and potential directions for future research.
The purpose of this study was to: i) contribute to an improved understanding of the HSCT caregiver experience for those who live in provincial New Zealand; ii) provide information to underpin the future development of evidence based nursing interventions, and models of care across the multidisciplinary health care team, in order to address the specific needs of HSCT caregivers; iii) identify potential areas for further research.

The study findings convey the scope of the HSCT caregiver role, and the impact the experience had on the lives of the study participants. Eleven themes emerged from the interviews, capturing the narrative of the HSCT caregiver journey. A degree of inter-relatedness exists between the themes, and serves to highlight the myriad of challenges and complexities associated with the HSCT caregiver experience.

Several particularly significant findings were identified from this study. These include the trajectory and complexity of the caregiver journey and the broad impact which relocation exerts upon the HSCT experience within the provincial New Zealand context. Furthermore the study revealed compelling insights into the depth of responsibility caregivers perceive the HSCT caregiver role to include.

**Temporality, sociality and place**

The analytic lens of narrative inquiry, and more specifically, the dimensions of temporality, sociality and place (see Chapter 3: Methodology and Methods) display a distinct synergy across the participants' interview narratives. Temporality resonated across the study participants’ descriptions of the HSCT caregiver journey. This dynamic which pertains to the past, present and future of the storyteller, intersected with the conceptualisation of the caregiver experience as a journey through time, across the HSCT trajectory.

The way in which 'place' influences the caregiver journey, is perhaps most clearly articulated by the theme of relocation. The impact of relocation is visible across the participants' narratives, and is represented thematically across the study findings. The thematic elements identified within the findings demonstrate how the social dynamics present within the caregiver journey interact with the situational environment to shape the overall HSCT caregiver experience.
The interaction between temporality, sociality and place can be observed in the challenge of balancing 'life outside' with relocation away from home, and is particularly visible in the way these elements converge across the HSCT trajectory, within the caregiver journey.

**The caregiver journey**

'Journey' has been defined as "an act of travelling from one place to another", or "a long and often difficult process of personal change and development" (Oxford Dictionaries, 2018). This definition is echoed by the caregivers who were interviewed in this study. The caregivers described the HSCT caregiver experience as a journey - a geographical journey involving relocation, as well as an experiential journey where they faced significant challenges across the HSCT trajectory.

The interview narratives convey how the caregivers’ lives were ultimately changed as a result of their HSCT experience. The notion of evoking change over time in the lives of those caring for their loved ones through HSCT, therefore led to a sense of 'journey' emerging as an over-arching theme of the study findings.

The study participants depicted their caregiver journey as being inclusive of the patients' diagnosis and initial treatment, continuing into the transplant phase, and then into the weeks, months and years of post-transplant recovery. The expansive timeframe associated with the HSCT journey for the caregivers in this study is consistent with the extant international literature which conceptualises the caregiver experience as spanning the HSCT trajectory (Armoogum et al. 2013; Aslan et al., 2006; Bishop et al., 2011; Cooke et al., 2013; Jim et al., 2014; Sabo et al., 2013; Von Ah et al., 2015; Wulff-Burchfield et al., 2013).

The stories which the study participants shared exposed the ongoing challenges associated with the caregiver journey, including what can become life-long changes for some caregivers. The findings echo the evidence generated by several overseas studies which demonstrate the type of long term effects experienced by caregivers in the years following HSCT. These include: psychological morbidity (depression, anxiety), fear and worry regarding disease recurrence, ongoing financial concerns, and altered family relationships (Armoogum et al., 2013; Bishop et al., 2007; Bishop et al., 2011; Young,
2013; Zabora et al., 1992). Therefore the findings of the current study, add to the existing body of knowledge, by reinforcing the potential for caregivers to experience long lasting challenges following HSCT, and highlights the need to consider the long-term support needs of the caregiver population.

The study findings suggest several points along the HSCT journey where caregivers may experience particularly high information and support needs. The transition phase where patients move to outpatient care can increase caregiver anxiety regarding the heightened responsibility of their role. Similarly the point at which patients are discharged home can be particularly distressing for some caregivers, as they become separated from the perceived safety of the hospital 'cocoon'. These transition points are congruent with the wider literature which have identified similar transition points associated with higher information and support needs among HSCT caregivers (Aslan, 2006; Ross et al., 2016; Von Ah et al., 2015).

The study findings suggest this angst may be amplified for caregivers and patients who have had to relocate, due to the geographical distance which separates patients and their caregivers from the city based specialist transplant clinicians once they have returned home. It is therefore imperative the support needs of caregivers across the entire HSCT journey are not under-estimated, nor overlooked by health care teams.

**The caregiver**

The caregivers interviewed in this study displayed unwavering dedication to the role of caregiver. The study findings demonstrated how performing the caregiver role, involves balancing the demands of everyday life within the emotionally charged setting of supporting their loved one going through HSCT, and how this can take a physical, emotional and psychological toll on the caregiver. This insight is consistent with existing literature in the broader context of cancer caregivers, which also depicts the potential for significant and wide reaching effects upon the lives of those people who undertake the caregiver role (Soothill et al., 2001; Stenberg, Ruland, & Miaskowski, 2010)

Concepts such as caregiver distress and burden within the HSCT caregiver population, have been identified and explored within the research literature (Akgul & Ozdemir,
Therefore time Having throughout patient, tendency potentially centric each A a sense needs recently an exhaustion” stress relation authors recognised stress and trauma (Armoogum et al., 2013; Bishop et al., 2011; Cuhadar et al., 2016; Ross et al., 2016; Sabo et al., 2013). The cumulative effects of the HSCT journey have been shown to contribute to the development of long-term psychological challenges for some HSCT caregiver’s (Armoogum et al., 2013; Bishop, 2011; Sabo et al., 2013; Wulff-Burchfield et al., 2013).

Although the term 'compassion fatigue' has predominantly been limited to the context of stress and trauma experienced by health professionals, Lynch and Lobo (2012) recognised how the concept also relates to the experience of informal caregivers. The authors applied the concept to family caregivers to describe how "a caregiving relationship founded on empathy potentially results in a deep psychological response to stress that ultimately progresses to physical, psychological, spiritual, and social exhaustion" (p. 2128). Gentry (2002) acknowledges the personal sacrifice of caring for another person, and states: "anyone who has sat at the bedside of a seriously ill or recently bereaved loved one knows the toll involved in devoting singular attention to the needs of another suffering person" (p. 37). Similarly Skaff and Pearlin (1992) refer to a sense of 'role engulfment', whereby the demands of caring for another person may reach a tipping point where the carer becomes overwhelmed by the caregiver role.

A striking aspect of the caregivers' narratives in the current study, was how focused each participant was upon the HSCT patient for whom they were a caregiver. Patient centric responses were evident in the early stages of the interview, where they could be potentially dismissed as merely establishing the context of the interview. However, the tendency for some participants to periodically neglect their own perspective, also featured during the latter interview stages. The caregiver's persistent focus toward the patient, typified a sense of selflessness and profound altruism, which was woven throughout the participants' narratives.

Having such intense and devoted focus upon the patient, and for a sustained period of time during the HSCT trajectory, can for some caregivers become overwhelming. It is therefore imperative that health care teams are aware of the potential for caregivers to
become overwhelmed with the stressors associated with HSCT, and are able to recognise when caregivers may require additional support.

**Expectations of the caregiver role**

The study findings reflect a perception of extreme responsibility associated with the caregiver role, which can become overwhelming for some caregivers. This has particular relevance for provincially located caregivers within the outpatient context and following discharge home, whereby caregivers may experience significant anxiety around the responsibility of their role once separated from the proximity to the health care team.

This insight provides compelling evidence for health care teams to reflect on how expectations on the scope of the caregiver role are established. It is important to point out there are multiple dynamics present which influence these expectations. The study findings reflect how expectations can be shaped by an individual's personality, and coping mechanisms. Expectations may also be self-imposed by caregivers themselves, through a profound sense of duty toward the patient, or via what they perceive is expected of them by the health care team.

Role expectations can also be imposed on caregivers by the health care team, albeit consciously or otherwise. The study findings highlight how health care teams can be at risk of making assumptions regarding the capability of individual caregivers. For example, when a caregiver has a background of being a health professional. This particular scenario has a raft of implications - the exploration of which is outside the scope of this thesis. However the notion of capability in general has relevance to discussion regarding how expectations are established.

The study findings suggest how the health care team - doctors and nurses in particular, should consider how the scope of each caregiver role is established. Expectations regarding the scope of the role may be best negotiated in partnership with the caregiver. In an individualised process that recognises the prior knowledge, transferable skills and strengths of each caregiver, whilst acknowledging their capability, knowledge gaps, and individual concerns.
The experience of relocation

This is the first study, to the author's knowledge, to specifically examine the experience of HSCT from the perspective of caregivers within the provincial New Zealand context. Relocation for treatment is certainly not limited to the New Zealand setting. Studies exist which consider relocation for haematological treatment within Australia (McGrath, 1999; Maurice & Foreman, 2006). Both of these studies demonstrate the stress of relocation is a deeply challenging experience for the caregiver population. Furthermore, the body of international research literature acknowledges the significant impact which relocation elicits upon the physical and psychosocial well-being of the HSCT caregiver population (Applebaum et al., 2016; Beattie & Lebel, 2011; Gemmill et al., 2011; Wilson et al., 2009).

The configuration of HSCT services in response to the country's geography and population distribution, mean that most HSCT patients in New Zealand do not live nearby hospital transplant centres (Ministry of Health, 2011). This is compounded in the South Island, where only one third of the HSCT patient population live in the same city as the hospital transplant centre (Ganly, as cited in Ministry of Health, 2011).

The study findings highlight how being away from home for an extended period of time presents practical and psycho-social challenges for HSCT caregivers. Relocation causes caregivers to become separated from their usual support networks, whilst dealing with the practical and emotional demands of caring for the HSCT patient. This separation is consistent with the sense of 'dislocation' experienced by HSCT caregivers as a result of relocation, in a study by Wilson et al. (2011).

The findings of the current study resonate with the caregiver insights provided by McGrath and Holewa's (2011) study which examined the New Zealand experience of relocation for the treatment of haematological malignancy. Their study was principally patient focused, and was not limited to HSCT, however the overall study findings revealed considerable burden and psycho-social distress associated with relocation.

A subsequent report by McGrath, Holewa and Etcheverry (2011) compares the experience of relocation for specialist treatment of haematological malignancies in Australia, to the experience in New Zealand. However, it is interesting to note the
juxtaposition of the report's findings, with those of the current study. The report suggests the geographical size of New Zealand dictates smaller travel distances, which enables most caregivers to travel home with some regularity. Furthermore, the report describes how New Zealand's comparatively small size means caregivers are likely to have pre-existing social connections in larger cities, and familiarity with the tertiary hospitals and cities where HSCT services are provided.

This contrasts with the findings of the current study, which reveal caregivers struggled with social isolation and navigation in an unfamiliar city environment where they knew nobody; and experienced profound homesickness as a result of being unable to travel home. One reason for these contrasting findings may be that McGrath and Holewa's (2011) study sample was focused on 'specialist treatment for haematological malignancies'. It is unclear how many of the participant's interviewed in their study were involved specifically in HSCT. It is conceivable that caregivers of patients involved in treatment modalities other than transplantation, such as intensive chemotherapy, may have more opportunity to travel home than those involved in HSCT, due to the intense hospitalisation and length of patient recovery particularly associated with transplantation.

The current study findings, depict the accommodation facilities associated with each of the main city hospitals, as a vital resource for HSCT caregivers in New Zealand. Several Australasian research examples provide evidence concurring with this sentiment, and assert that the provision of accommodation is an essential resource for HSCT patients and their caregivers who need to relocate for treatment (McGrath & Holewa, 2011; McGrath, 1999, 2015). In light of the increasing rates of HSCT in New Zealand, it will be crucial to consider resource planning for accommodation facilities, in order to address the future needs of the caregiver population (Australasian Bone Marrow Transplant Recipient Registry, 2016; Ministry of Health, 2011).

The study findings reveal how certain room types (self-contained apartments versus shared living spaces) appeared to suit some caregivers, and not others. This preference was largely dependent on individual personality. Some caregivers sought the social stimulation and camaraderie of other people in the shared accommodation areas, whereas others found solace in the isolation and independent living within the apartment units. It was unclear if people were asked their room-type preference by the
accommodation facility staff when the rooms were allocated. Understandably room allocation is subject to availability at any given time. The study findings suggest that room-type may have a significant impact upon the HSCT experience, and indeed may influence the coping ability of some caregivers during their HSCT journey. This insight suggests it would be worthwhile for accommodation facilities to enquire what people’s preferences are, and to take this into account wherever possible when allocating rooms.

**Employment**

The findings of the current study are consistent with existing research which indicates relocation can significantly restrict the ability for HSCT caregivers to continue their employment (Simoneau et al., 2013). There are several research examples which suggest having a supportive employer, and flexible work options may decrease the impact of relocation on employment for HSCT caregivers (Meehan et al., 2006; Majhail et al., 2013; McGrath, 2000; McGrath & Holewa, 2011).

Creative solutions such as working remotely via laptop computer can enable people to continue to work whilst away from home. This may have benefits for caregivers across the HSCT trajectory, however will be limited to those caregivers whose job type means this is an option. Working remotely may enable caregivers to receive a continued source of income at a time of potential financial stress, and to connect with the world outside the immediate transplant setting.

The benefits of continuing to work may not be limited to income and employment however. The insights shared by the study participants indicate that being able to connect with life outside the immediate transplant setting may reduce feelings of isolation, by maintaining an aspect of normal routine. Furthermore, the current research findings suggest that continuing to work may also serve as a periodic distraction to the intense emotional experience associated with the HSCT caregiver experience.

Working remotely may also support caregivers during their transition back to normal life following HSCT, by assisting caregivers to maintain links with their employer. Keeping in contact with the workplace could ease the process of resuming their pre-transplant employment role once caregivers return home following transplant.
Flexible work options should be considered on an individual basis, and in negotiation between HSCT caregivers and their employers. Caution should be exercised, so that such strategies remain an option to ameliorate some of the stressors which HSCT caregivers may experience, and not a mechanism whereby less supportive employers could attempt to deny caregivers leave by insisting on remote working options. Such a scenario has the potential to heighten employer expectations of caregivers and negate the potential to positively influence the HSCT caregiver experience.

**Financial support**

The study findings illustrate how the transplant experience can exert a significant financial impact upon some caregivers. Relocation for treatment may result in additional expenses and dual costs involved with living away from home, whilst meeting existing household bills. This insight fits with the findings of several other studies, which have demonstrated how increased living costs associated with relocation can compound the financial challenge for caregivers (McGrath, 2000; Meehan et al., 2006). A study by Majhail et al. (2013) found that financial pressure is heightened for caregivers who are caring for their spouse, whereby overall household income is reduced while the patient and their caregiver are both unable to work. The current study revealed financial repercussions may also continue into the long term beyond HSCT. This is consistent with the findings in a study by Denzen et al. (2016) who revealed how the financial burden upon caregivers can continue for several years following HSCT.

Whilst not all caregivers in the current study indicated they experienced financial hardship as a result of their HSCT experience - those who did express financial challenges, described difficulty in navigating the process of seeking financial support. Several caregivers perceived attitudinal barriers during the process of seeking financial support via Work and Income New Zealand (WINZ). The study findings share a degree of commonality with those of Jorgensen, Parsons, Jacobs & Arksey (2010), whose study explored the unmet needs of informal caregivers for people with disabilities in New Zealand. Their research revealed it is common for caregivers to experience difficulty when trying to find information about how to apply for financial assistance. Furthermore, those authors exposed valuable caregiver insight into the specific experience of dealing with WINZ. They reported how caregivers experienced difficulty
when completing paper work, were required to repeat information and had to organise multiple visits to WINZ offices in order to apply for financial support.

The findings from the current study, resonate with those of Jorgensen et al. (2010) which suggest information provided to caregivers can at times be fragmented, whereby discrete silos of information are held across the health care team, WINZ and other agencies. Caregivers can feel overwhelmed with the bureaucracy involved in navigating financial support. A co-ordinated approach between services is necessary to enable caregivers to obtain the support they require while they traverse the financial challenges of the HSCT journey.

**Balancing 'life outside'**

The conceptualisation of 'life outside' within the current study, acknowledges that nothing exists in a vacuum. All manner of life events including (but not limited to) redundancy, new relationships, severe illness, sporting commitments, the arrival of grandchildren continue to occur - only for caregivers, it is happening simultaneously with the practical and emotional demands associated with the HSCT journey.

The study participants explained how relocation away from home meant they had to be organised in order to manage 'life outside' the immediate transplant setting. This referred to the caregivers' commitments back at home, and included tasks such as organising household bill payments, garden maintenance, and seeking assistance from family and friends to help with childcare. This study finding fits with the notion of HSCT caregivers being 'the organiser' - identified in a study by Von Ah et al. (2015). Their study revealed how caregivers felt primarily responsible for organising patient, household and family activities across the HSCT trajectory, including the post-transplant phase once they had returned home following transplant.

Caregivers in the current study described a range of behaviours that helped them cope with the stress associated with the HSCT experience. Some caregivers went out for coffee, or shopping, while others tried to exercise or catch up with friends. Whatever the chosen activity, they were all motivated by the need to seek a sense of normality, and find balance between the demands of transplant and 'life outside'. This finding resonates with several examples within the existing literature. Wilson et al. (2009) suggest a
conceptual model where the caregiver is at the centre of several separate, yet inter-related 'worlds', whereby ordinary life and transplant life intersect. The authors describe how caregivers try to balance these two worlds within the context of their own relationship with the patient. Similarly, Von Ah et al. (2015) illustrate how caregivers strive to 'find balance' between their responsibilities as a caregiver and with commitments such as family and employment which exist outside the transplant setting.

Family commitments were identified among the concerns of caregivers within the current study. This was not limited to those with young children, but also extended to caregivers who were grandparents - including one participant who played a lead role in supporting her elderly parents. This is indicative of the changes to conventional family roles present within today's society, whereby people may still be involved in caring for younger or older generations within their wider family, long after they relinquish child care duties of their own.

The study findings contribute to existing knowledge regarding the significant and often competing demands which the HSCT journey places upon caregivers. This insight highlights a key implication for health professionals, whereby those who view the caregiver solely through the lens of the immediate transplant context, will neglect to recognise the complex support needs of this population.

The consideration of family within the HSCT caregiver journey, resonates within the New Zealand context, whereby caregiving exists in the context of relationships between family and whanau (Goodhead & McDonald, 2007). Research evidence suggests it is essential that health care teams understand family issues, and personalise family care in order to adequately consider the needs of caregivers within the HSCT setting (McGrath, 2015; Young, 2013; Zabora et al. 1992). It is therefore pertinent for health care teams to consider the familial dynamics of HSCT caregivers when assessing the support requirements of this population.

**Technology and connectivity**

The study findings raise considerations associated with the application of technology during the HSCT caregiver journey. These aspects hold particular relevance for provincially based caregivers who relocate away from home. Internet connectivity and
the use of technology is a key enabler in maintaining social interaction. The study findings demonstrate how technology solutions could mitigate some aspects of isolation that accompany the HSCT caregiver experience.

Examples of the use of technology taken from the literature, and supported by the author's findings, include enabling caregivers who have relocated away from home to: work remotely, remain in contact with family/friends, access education resources, and participate in supportive care networks provided via online platforms (Gemmill et al., 2011; Jim et al., 2014; Klemm & Wheeler, 2005). The findings of the current study suggest that whilst not all HSCT caregivers seek information this way, some are certainly comfortable accessing information in electronic format.

Innovative approaches are needed to harness the benefits which technological solutions can provide to address the education and support needs of the HSCT caregiver population. Breen’s (2015) research project recognised the growth in computer literacy, and societal shift toward online information. This insight was applied to the development of a multi-platform strategy that included the use of social media, live video streaming and online education manuals, tailored to the education and support needs of HSCT caregivers.

Despite developments in technology and society's penchant toward electronic communication, research over the past decade into the application of these advances in the context of online support interventions for cancer caregivers, remains scant (Klemm & Wheeler, 2005; Kaltenbaugh et al., 2015; Kent et al., 2016). Stenberg et al. (2010) signal the need for an internet based support system for cancer caregivers, based on similar systems which exist for cancer patients. A report by Kent et al. (2016) explored the clinical priorities for informal cancer caregiving, and suggests the use of technology to support the informal cancer caregiver population should be promoted.

The findings from the current study suggest that a lack of internet connectivity, and/or prohibitive costs associated with accessing the internet, may be a potential barrier preventing HSCT caregivers from accessing information, and maintaining important family, social and vocational connections outside the immediate HSCT setting. Therefore within the New Zealand context, it is fundamentally essential that a reliable, and ideally cost-neutral internet connection is available in hospitals and accommodation facilities, in order to meet the needs of the HSCT caregiver population.
The New Zealand context

The findings from the current study add to the existing body of knowledge pertaining to the HSCT caregiver population, by examining the caregiver experience through a New Zealand specific lens. The study findings provide insight into the ways in which the HSCT caregiver experience is nuanced by the geographical, social and cultural characteristics intrinsic to the New Zealand setting.

Goodhead and McDonald’s (2007) literature review revealed a dearth of research relating to informal caregivers specifically within the New Zealand cancer care context. It appears local research since the publication of this report, remains relatively scant. However, it would be unfair to represent the New Zealand health care landscape as completely devoid of acknowledgement toward the role of caregivers.

New Zealand has several strategy documents that refer to populations which require caregivers. These include the: New Zealand Health Strategy: Future Direction, The New Zealand Carers' Strategy Action Plan 2014-2018, New Zealand Disability Strategy 2016-2026 (Ministry of Health, 2016b; Ministry of Social Development, 2014, 2016). These documents are written in the context of those caring for people with disabilities, the elderly, or living with long-term illness. The specific mention of cancer is absent throughout these documents. However, this is probably appropriate given that these represent high-level strategy type documents, and that cancer is now recognised as a long term health condition which certainly fits under the umbrella term 'long-term illness' (Ministry of Health, 2009).

Several documents do exist, in which their aims can be viewed as broadly encompassing the caregiver population within the New Zealand cancer care context. These include the New Zealand Cancer Control Strategy, and the New Zealand Cancer Plan: Better, faster cancer care 2015–2018 (King, 2003; Ministry of Health, 2014). The Standards of Service Provision for Lymphoma Patients in New Zealand, and Standards of Service Provision for Myeloma Patients in New Zealand, both include a focus on supportive care within the malignant haematology setting (National Lymphoma Tumour Standards Working Group, 2013; National Myeloma Tumour Standards Working Group, 2013).
The *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*; and *Model of Care for the Psychological and Social Support Initiative* demonstrates an encouraging shift towards addressing the psychological and supportive care needs of New Zealander's affected by cancer (Ministry of Health, 2010, 2017). What is striking however, is that these documents do not explicitly address the needs of caregivers within the cancer context. Direct reference to the caregiver population within these documents is scant at best. Instead, consideration of caregivers is framed within broad aspirational goals that aim to improve access to information and support resources for people affected by cancer as well as their families and whānau.

A study by Jorgensen et al. (2010) examined the characteristics of New Zealand informal caregivers and their unmet needs. Their study sample was limited to caregivers of people with neurological conditions such as dementia and stroke, and developmental disorders. The study findings reveal significant psycho-social effects including mental health and financial implications associated with performing the role of informal caregiver.

New Zealand research examining the caregiver experience within the clinical context of HSCT is limited. McGrath and Holewa's (2011) examination into the New Zealand experience of relocation for haematological treatment is the sole example of research specific to this setting and locale that is currently available. Their research differs from the study within this thesis, however, it does examine a related study population. McGrath and Holewa's study explores specialist haematological treatment which includes, but is not limited to, HSCT. Furthermore, their study was predominantly patient focused, although the research did include some caregivers within its purposive study sample.

The research study presented in this thesis, acknowledges the limited literature and epidemiological data available regarding ethnicity and HSCT in New Zealand. As previously outlined, the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) is the sole collective repository for HSCT performed in New Zealand, and does not publish ethnicity data within its annual report (Australasian Bone Marrow Transplant Recipient Registry, 2016). It is not known if this data is collected and/or collated at either a local or national level in New Zealand. Investigation to gain this data is likely to be manual and rely on self-reporting via hospital admission forms.
Inequities exist in the setting of haematological malignancy between Māori and non-Māori within the New Zealand population. The report Unequal Impact II (Ministry of Health, 2010b) shows both a higher Myeloma registration rate and death rate for Māori females compared with non-Māori females. The lymphoma death rate is higher for Māori than non-Māori (Ministry of Health, 2016a). This likely reflects the poor access among Māori to appropriate and timely management (National Lymphoma Tumour Standards Working Group, 2013). When viewed alongside the study findings presented within this thesis - the inequalities related to Māori cancer outcomes and the limited availability of domestic HSCT ethnicity data, signal further investigation is required in order to address the disproportionate impact of blood cancer upon Māori communities.

In summary, examination of the aforementioned body of literature leads to an overall impression that the connection between caregivers and the specific context of cancer within the New Zealand landscape, has not been articulated at a national level, nor explored in any great depth to date.

**Implications for practice:**

Among the salient points raised from this exploration into the caregiver experience of HSCT within the provincial New Zealand context, is the importance of raising the profile of the needs of the HSCT caregiver population. The learnings taken from the findings of this study may be used to inform practice development initiatives within health care teams, and ultimately integrate a caregiver focus within the service delivery of HSCT in New Zealand. Therefore, disseminating the findings of this research project across the relevant services and stakeholders will be an important step in promoting awareness of the needs of the HSCT caregiver population.

The research evidence within the context of HSCT, underscores the need for health care services to demonstrate a shift towards recognising the unmet needs of the caregiver population (Akgul & Ozdemir, 2014; Armoogum et al., 2013; Grimm et al., 2000; Jim et al., 2014; Williams, 2007). This is a sentiment also shared within a broader cancer context. A report from the United States by Kent et al. (2016) discusses the priorities for informal cancer caregivers and recommends: further investigation into the prevalence and burden of cancer caregiving; the inclusion of support for caregivers within the
formal health care setting; and the development and evaluation of interventions aimed at improving caregiver outcomes.

The caregivers within the current study expressed a need for HSCT education to be an inclusive process that addresses the information needs of the caregiver as well as those of the patient. The study findings are consistent with existing research which articulates the need for health care teams to increase their focus upon the support and information needs of the HSCT caregiver population (Aslan et al., 2006; Gemmill et al., 2011; McDonald, Stetz & Compton, 1996; Metoyer, 2013; Williams, 2007).

The current study portrays diversity within the experiences of caregivers across the transplant journey. Hence a 'one size fits all' approach to address the information and support needs of this population, is inadequate. Instead, education and support resources should be individually tailored to the needs of each caregiver. The study findings are consistent with existing research evidence which suggests education interventions aimed at the HSCT caregiver population should include information to help people prepare for the caregiver role, and advice on self-care strategies (McDonald et al., 1996; Metoyer, 2013; Williams, 2007).

However, before the needs of caregivers can be fully addressed, health care teams need to determine what each caregivers' actual needs are. Detailed examination of specific assessment tools and support interventions lie outside the scope of this thesis. However, the conceptualization of the caregiver experience as a journey that spans the HSCT trajectory has the potential to be applied within the context of health assessment among the caregiver population. Particular time points across the trajectory appear to be associated with higher information and support needs among HSCT caregivers. Health care teams should harness this evidence to implement assessment strategies at different time points along the transplant trajectory. This will provide the opportunity to focus interventions and guide the allocation of resources, in response to the individual and dynamic needs of the HSCT caregiver population.

The study findings suggest a need for health services to be underpinned by models of health care that are congruent with the broad range of challenges faced by HSCT caregivers in order to support this population effectively. The bio-psychosocial model of health has been effectively applied in the context of cancer care, and includes
consideration of biological, psychological, spiritual, social and environmental processes relating to the patient and their family (Loscalzo, Clark, Pal & Pirl, 2013).

Within the New Zealand context, Te Whare Tapa Wha is a model that represents the Maori health perspective and considers the interaction between taha wairua (spiritual); taha hinengaro (thoughts and feelings); taha tinana (physical); and taha whanau (family) (Durie, 1998). A Whanau Ora model underpins the recently developed national standards for service provision for haematological malignancies (National Lymphoma Tumour Standards Working Group, 2013; National Myeloma Tumour Standards Working Group, 2013). This multidimensional approach recognises the interdependence of people. Whanau Ora considers health as not limited to physical symptoms, but as part of the collective social context of a person (Durie, 1998; Kidd, Gibbons, Lawrenson, & Johnstone, 2010). This is consistent with the focus of this research study, which by addressing the experience of the caregiver, demonstrates responsiveness to patient whanau centred care. Whilst not the specific focus of this thesis, it is salient to note these theoretical models of health which resonate with the study findings, and should therefore be considered when planning health care services to address the needs of the HSCT caregiver population.

The holistic ethos of nursing, and its resonance with a family centred approach suggests nurses are ideally placed to recognise and respond to the supportive care needs of caregivers (Grant & Ferrell, 2012). It is recognised that oncology nurses spend more time with patients and family caregivers than other members of the health care team (Given & Northhouse, 2011). Given the significant challenges which the HSCT experience may place upon caregivers, it is essential that nurses working in the setting of HSCT, expand their role to encompass the information and support needs of the caregiver population.

Spirituality was not the focus of this particular study, nor did this aspect emerge from the study findings. However it is important to note that spirituality is acknowledged within the extant literature relating to the HSCT caregivers, specifically in relation to how spiritual connectedness can influence how caregivers cope with the broad challenges inherent to the HSCT experience. (Bishop et al., 2011; Fife et al., 2009; Gemmill et al., 2011).
Therefore a shift toward addressing the supportive care needs of the HSCT caregiver population needs to harness a multi-disciplinary approach. The value of incorporating clinicians from social work, psychology and other allied health disciplines is evident in response to the complex psychosocial needs which exist among the HSCT caregiver population.

Consideration should also be given to the role which primary care can play in supporting the well-being of the HSCT caregiver population. The historical and ongoing relationship which GP's have with their patients, suggests GP's may be well positioned to recognise and respond to signs of caregiver distress.

The health service climate has seen a burgeoning focus on the delayed effects of transplant for HSCT patients (Bhatia et al., 2011; Mosher et al., 2009). Services dedicated to 'late effects' have been designed to primarily monitor patients for the development of physical side effects related to the toxicities of treatment, but also include a focus on long term psychological or psychosocial effects of treatment (Brown et al., 2015; Mosher et al., 2009; Savani et al., 2011; Stein, Syrjala & Andrykowski, 2008). Indeed, the related literature and findings of the current study underline a gap in current models of care, whereby services to address the delayed effects of HSCT upon the caregiver population are presently absent.

This insight highlights an opportunity to develop models of care which apply the principle of 'late effects' by extending its application to the context of the HSCT caregiver population. The enduring relationship between GP's and their patient population, suggests the connection with primary care may be a particularly useful space to monitor caregivers for signs of serious long-term effects associated with the transplant experience.

The overall study findings and supporting literature underscore the merit of raising awareness of the types of challenges caregivers may experience along the HSCT trajectory, across the entire multidisciplinary team. This may then enable members of the health care team to more readily recognise and respond to signs of distress among the HSCT caregiver population.
Recommendations

- The importance of recognizing the unmet needs of HSCT caregivers should be promoted across health care services - including primary care settings.

- Caregivers should be included as part of the HSCT education process, in order to address the information and support needs of the caregiver as well as those of the patient.

- The support needs of HSCT caregivers should be assessed at regular intervals across the transplant trajectory.

- Information and support should be tailored to the individual needs of HSCT caregivers.

- HSCT education should include information to help prepare caregivers for the transplant experience, including self-care strategies.

- Nurses working in the setting of HSCT should incorporate the support and information needs of caregivers within their practice.

- A multi-disciplinary approach that includes social work and psychology disciplines should be utilized to address the complex psychosocial needs of HSCT caregivers.

- Models of care should be developed to include opportunities to address the late effects of HSCT upon the caregiver population - with a particular focus upon collaboration with GP's within the primary care setting.

Limitations and Strengths

The study is limited by a small sample size, and homogenous ethnicity and gender characteristics within the study sample. The small sample size used in the current study limits the ability to infer relationships between demographic characteristics (for example: caregiver age, relationship to patient, or type of HSCT) and the likelihood of caregivers experiencing stressors, such as financial burden, or psychological distress.
A gender bias exists, in that all study participants were female. The gender representation is, however, not unexpected given the preponderance of female caregivers within the HSCT setting (Applebaum et al., 2016). The inclusion of a male perspective in future research may provide opportunity to gain a broader insight into the HSCT caregiver population, and help identify if any gender specific issues exist.

All the participants in the current study identified as New Zealand/European. The lack of ethnic diversity within the study sample was the result of recruiting a small sample size, within a niche population. Furthermore, it is important to note that there is no ethnicity information for the HSCT patient, or HSCT caregiver population readily available. Therefore it is a challenge to know with any real accuracy, what study sample composition would be ethnically representative of the HSCT caregiver population in New Zealand. Future research into New Zealand's HSCT caregiver population, may be able to recruit a study sample that is larger in size and more ethnically diverse, in response to the growth in the ethnic diversity of New Zealand's overall population (Statistics New Zealand, 2014).

The size and homogeneity of the study sample limits the ability to generalise the study findings to the overall HSCT caregiver population. It is important to note however, that consistent with the premise of a qualitative research approach, the intention of this study was not to establish generalisation across the study population, but rather to contribute to an improved understanding of the HSCT caregiver experience in provincial New Zealand (Beanland et al., 1999). The sample size is appropriate for the methodology chosen for this study, whereby interviewing a sample of eight participants allowed a rich description of the HSCT caregiver experience in New Zealand to be explored. The study findings have generated useful insight which can be considered within the context of the HSCT caregiver population, and includes aspects which may also be applicable to other caregiver populations.

**Potential directions for future research**

The study findings identify several potential areas where future research into the HSCT caregiver population could be directed. The current study identified the scenario whereby the caregiver was also the patients' HSCT donor. This is most likely to occur
with siblings, and further highlights the complex relationship dynamics that are present within the caregiver-patient dyad. An extreme sense of responsibility, in tandem with intense personal guilt if things go wrong, provides compelling insight into the challenges faced by those caregivers who are also the transplant donor. Opportunity exists to conduct research aimed at further investigating the unique experience and challenges associated with this combined caregiver/donor role.

The study findings illustrate a diverse range of personal preferences, learning styles, and psycho-social support needs present within a relatively small group of eight HSCT caregivers. Future research involving a larger study sample is needed to understand how the caregiver experience is influenced by different socio-economic, cultural backgrounds and characteristics such as gender and age. Such investigation may assist in identifying 'at risk' groups and inform the allocation of resources to support the HSCT caregiver population.

Further research is required to validate the use of assessment tools within the HSCT caregiver population, in order to provide beneficial evidence to inform models of care to address the needs of this specific population. There is opportunity for future research to evaluate the application of support interventions for HSCT caregivers within the New Zealand setting. Particular focus should be given to evaluation of the timing of such interventions within the HSCT trajectory.

The study findings highlight particular anxiety for caregivers associated with the responsibility of the role once the patient moves to outpatient care, and when they are discharged home. Coupled with the trend toward outpatient models of care, this insight signposts the need to focus future research upon examining the caregiver experience specifically within the HSCT outpatient setting.

Conclusion

The aim of this research study was to explore the experience of HSCT from the perspective of caregivers within the provincial New Zealand setting. The study findings reveal caregivers face a complex journey at a time of incredible worry for their loved one who is undergoing treatment for life-threatening illness.
The experience of relocation away from home has wide reaching practical and emotional implications for caregivers, who find themselves disconnected from their everyday lives and separated from their usual family and social supports. Caregivers must balance the duty of caring for the HSCT patient, with their other 'outside' commitments.

For many of the caregivers, HSCT represents the next stage of what may have already been several years of supporting the patient through treatment, since the point of initial diagnosis. Caregivers play an essential role in supporting the patient throughout the transplant trajectory. The value of the caregiver role is particularly visible at the point where the patient transitions to outpatient care, and eventually returns home. In the outpatient setting, health care teams are reliant on the capability of caregivers to problem solve, to recognise if patients are becoming unwell and to respond accordingly by alerting the medical team in a timely manner. The scope of the caregiver role, therefore places an incredible sense of responsibility upon caregivers who perform this vital role.

The potential for long term challenges which may extend into the years beyond the immediate transplant period, is apparent by the financial hardship, relationship strain, and psychological distress experienced by some caregivers, as they strive to return to 'normal' life following HSCT. The study findings signpost a gap in health services may currently exist in the recognition of these significant 'late effects' within the caregiver population.

The information and support needs of the caregiver population are diverse and vary between individuals, in response to the dynamic course of the HSCT journey. The study findings express a clear message for health services to increase their focus toward the provision of information and support strategies aimed specifically at HSCT caregivers.

There is opportunity for future research to explore the effectiveness of specific support strategies and interventions aimed at the needs of the HSCT caregiver population. Indeed further research is required to examine how the shift toward outpatient models of care within the HSCT setting, may impact the caregiver experience.

The study findings highlight the need for synergy between government level strategy, service provision and resource allocation, in order to deliver effective support services.
to the HSCT caregiver population within the New Zealand setting. Although the findings of this study are limited in their application beyond the setting of haematopoietic stem cell transplantation in New Zealand, they do provide compelling insight which may also be relevant to other caregiver populations.

The overall study findings provide valuable insight into the symbiotic relationship between caregiver and patient, which exists at the centre of each caregiver's HSCT journey. The profound connection present within each caregiver/patient dyad, is reflected in the sense of commitment inherent to the caregiver experience. The intensity and selflessness of caring for another person can result in caregivers neglecting their own self-care needs, which places them at risk of becoming overwhelmed with the responsibilities associated with the caregiver role. Therefore it is essential that health care teams and support agencies are aware of the significant impact which HSCT can exert upon the lives of caregivers, in order to recognise and plan services to address the support needs of this vulnerable population.
References


Foster, L. W., McLellan, L., Rybicki, L., Dabney, J., Copelan, E., & Bolwell, B. (2013). Validating the positive impact of in-hospital lay care-partner support on patient...


Murphy, C. (2012). Writing an effective review article. *Journal of Medical Toxicology, 8*(2), 89-90. doi: 10.1007/s13181-012-0234-2


Thorne, S. (2000). Data analysis in qualitative research. *Evidence-Based Nursing, 3*(3), 68-70. doi: 10.1136/ebn.3.3.68


APPENDICES

Appendix One: PRISMA 2009 flow diagram

Records identified through database searching (n = 521)

Additional records identified through other sources (n = 4)

Records after duplicates removed (n = 312)

Records screened (n = 312)

Records excluded (n = 268)

Full-text articles assessed for eligibility (n = 44)

Full-text articles excluded (n = 19)

Studies included in review synthesis (n = 25)

## QUALITATIVE STUDIES

<table>
<thead>
<tr>
<th>Author, date</th>
<th>Country</th>
<th>Study aim/purpose</th>
<th>Study design, sample characteristics</th>
<th>Method</th>
<th>Key findings</th>
<th>Limitations</th>
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<tbody>
<tr>
<td>Bishop et al, 2011</td>
<td>United States</td>
<td>To understand the lasting life changes after HSCT for patients and their spousal caregivers.</td>
<td>Qualitative design. 30 patient /spouse caregiver dyads Allo-HSCT &amp; Auto-HSCT</td>
<td>Interviews. Administered at average time point 13 years post HSCT.</td>
<td>Spouses reported higher negative changes: fear/anxiety, lingering health effects (intimacy), caregiver burden. Positive spousal themes: appreciation re: family/relationships</td>
<td>Small sample size. Unclear at what time point in the trajectory the focus groups took place.</td>
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<tr>
<td>Jim et al, 2014</td>
<td>United States</td>
<td>To examine quality of life post HSCT from the caregiver's perspective.</td>
<td>Qualitative design. 16 caregivers Allo-HSCT</td>
<td>Focus groups</td>
<td>Themes identified: loss of identity, lack of preparedness, anxiety, relationship changes, emotional challenges.</td>
<td>Small sample size. Unclear at what time point in the trajectory the focus groups took place.</td>
</tr>
<tr>
<td>McGrath, 2000</td>
<td>Australia</td>
<td>To explore the financial impact on families who relocate for specialist treatment for haematological malignancies.</td>
<td>Qualitative study design. 10 patient/caregiver dyads</td>
<td>Interview. Audio recorded, open-ended questions. Administered within the first 100 day post HSCT period</td>
<td>Additional costs during relocation identified: food shopping, telephone calls, loss of local family and social support networks, accommodation, petrol/travel, home maintenance during absence. Other factors: loss of income, use of employment leave allocation.</td>
<td>Small sample size. Sampling bias - convenience sample through a single support provider.</td>
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<tr>
<td>McGrath, Holewa, &amp; Etcheverry, 2011</td>
<td>New Zealand</td>
<td>To understand the experience of relocation for treatment for patients with haematological malignancy and their carers.</td>
<td>Exploratory qualitative design. Purposive sample 62 participants (46 patients; 16 caregivers)</td>
<td>Interview Open-ended questions via telephone.</td>
<td>Themes identified: 'travel based relocation', the ability to return home, having to put 'life on hold', carer issues, support needs. Challenges re: the adjustment required when relocating to metropolitan centres for patients and caregivers from provincial locations.</td>
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<tr>
<td>Wilson, Eilers, Heermann &amp; Million, 2009</td>
<td>United States</td>
<td>To explore the experience of HSCT spousal caregivers.</td>
<td>Descriptive qualitative design. 11 caregivers <em>Allo-HSCT &amp; Auto-HSCT</em></td>
<td>Interviews Repeated from the point of hospital admission to discharge (within the 100 day acute transplant period)</td>
<td>Overall themes identified: uncertainty, forming a positive outlook, envisioning the future. Caregiving themes: knowing the person, protecting, providing care, balancing me/us.</td>
<td>Small sample size. Acute HSCT phase only.</td>
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<tr>
<td>Author, date</td>
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<tr>
<td>Akgul and Ozdemir, 2014</td>
<td>Turkey</td>
<td>To identify caregiver burden and influencing factors in HSCT caregivers.</td>
<td>Descriptive, cross sectional</td>
<td>Questionnaires: Zarit Burden Scale; Caregiver questionnaire. Administered 2-12 months post HSCT</td>
<td>Lower education &amp; income status was associated with increased caregiver burden. The extent of caregiver duties increased caregiver burden. Changes in relationships affected burden levels.</td>
<td>A single measurement of burden at only one time point across the trajectory was used.</td>
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<tr>
<td>Armoogum, Richardson &amp; Armes, 2013</td>
<td>United Kingdom</td>
<td>To describe the supportive care needs of HSCT caregivers.</td>
<td>Quantitative, cross-sectional survey research design.</td>
<td>Survey Questionnaire Administered within 2 years post HSCT. Supportive Care Needs Survey Partners &amp; Carers (SCNS-P &amp; C) General Health Questionnaire (GHQ12)</td>
<td>When the caregiver had a high level of un-met needs the incidence of psychological morbidity also increased. Reported caregiver un-met need: worries about cancer recurrence, impact on caregiver employment, financial support, caregiver physical health (sleeping, eating), emotional support.</td>
<td>Broad time period (2 years post HSCT) measured - variability within this period.</td>
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<td>Aslan et al, 2006</td>
<td>Turkey</td>
<td>To identify the needs of lay caregivers throughout the HSCT trajectory.</td>
<td>Quantitative design</td>
<td>Survey: Psychological and Social Needs Scale</td>
<td>Psychological and social needs/issues identified. Most caregivers preferred face-to-face education from a health professional. Information deficit identified regarding homecare after discharge.</td>
<td>Limited by recall bias, and single data collection point (day 100+ post HSCT).</td>
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<tr>
<td>Bevans et al, 2014</td>
<td>United States</td>
<td>To determine the effect of a problem-solving education (PSE) intervention on self-efficacy and distress in allo-HSCT caregivers.</td>
<td>Longitudinal repeated measure design.</td>
<td>Intervention: Three, 1-hour problem-solving education sessions. Held during the first 3 weeks of transition from hospital to outpatient care. Questionnaire, pre and post the intervention were administered.</td>
<td>PSE improved caregiver self-efficacy and reduced caregiver levels of distress and fatigue.</td>
<td>Limited generalizability.</td>
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<tr>
<td>Author, date</td>
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<td>Bishop et al, 2007</td>
<td>United States</td>
<td>To examine the health-related quality of life and post traumatic growth (PTG) of HSCT spouses/partners compared with survivors and survivor-matched controls.</td>
<td>Longitudinal, cross-sectional design</td>
<td>Questionnaires&lt;br&gt;177 partner/spouse: patient pairs&lt;br&gt;Allo-HSCT &amp; Auto-HSCT&lt;br&gt;A set of 26 questionnaires administered to measure: physical functioning/well-being, psychological adjustment, social functioning, dyadic adjustment, spiritual well-being, post-traumatic growth Measured at 6.7 years (average) post HSCT</td>
<td>HSCT partners/spouses reported higher levels of fatigue, depression, sleep and sexual problems than controls.&lt;br&gt;HSCT partners/spouses reported less PTG than survivors.&lt;br&gt;Partner/spouse depression rates were 3.5 times higher than control subjects.&lt;br&gt;Depressed partners/spouses were less likely than depressed survivors to access mental health support.</td>
<td>Study findings are limited to spousal/partner HSCT caregivers i.e. non-spousal caregivers are not included.&lt;br&gt;There is a wide time range in survey administration 1.9 to 19.4 years post HSCT - this may lead to recall bias and could limit generalizability of findings.</td>
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<td>Cooke et al, 2011</td>
<td>United States</td>
<td>To describe the allo-HSCT caregiving experience.</td>
<td>Descriptive, correlational design</td>
<td>Questionnaire&lt;br&gt;Administered 3-12 months post HSCT.</td>
<td>Caregiver quality of life (QoL) scores decrease when caregiver problem solving, emotional challenges and caregiving increase. QoL decreases when the caregiver experience becomes less predictable.</td>
<td>Small sample size. Potential demographic bias between the two recruiting hospital sites.</td>
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| Cuhadar et al, 2016 | Turkey  | To evaluate the psychiatric symptoms and resilience of HSCT patients and their family carers. | Quantitative cross-sectional descriptive design  
Purposive sample  
51 patients  
45 family caregivers  
*Allo-HSCT & auto-HSCT* | Survey  
Brief symptom inventory (BSI)  
Resilience Scale for Adults (RSA)  
Administered at the point of hospitalization for HSCT. | Caregiver themes identified: anxiety, depression, obsessive compulsive symptoms.  
Caregiver psychiatric symptoms of equal incidence as that of patients.  
Higher resilience shown to lower the degree of psychiatric symptoms in both patients and caregivers. | Limited by small sample size, cross-sectional design, pre-HSCT/early HSCT phase only. |
| Deniz & Inci, 2015 | Turkey  | To identify the burden of care and quality of life of HSCT caregivers.           | Quantitative design  
123 caregivers | *Questionnaires:* Zarit Burden scale; Caregiver Quality of life index cancer scale | Higher care burden scores associated with: increased age, male gender, low income, spousal relationship, disruption to work and family life. | Unclear at what time point in the trajectory the questionnaires were administered. Unclear what type of HSCT the sample consisted of. |
| Fife et al, 2009   | United States | To examine adaptation of family caregivers during the acute phase of HSCT. | Quantitative, prospective study design  
192 caregivers  
*Allo and Auto HSCT* | *Questionnaire:* Self-report surveys administered at: pre-HSCT, during hospitalization, & 1 month post discharge | Emotional distress decreased across the HSCT trajectory.  
Caregiver resilience (coping skills) was associated with lower emotional distress.  
Continued support from health care providers was significantly associated with less emotional distress post-discharge. | |
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<tr>
<td>Foxall &amp; Gaston-Johansson, 1996</td>
<td>United States</td>
<td>To describe the burden of care and health outcomes of HSCT family caregivers.</td>
<td>Descriptive, correlational research design, with repeated measures. Convenience sample of 24 caregivers</td>
<td>Questionnaire: Measurements of burden, state-anxiety, depression, symptom distress and fatigue Administered pre-HSCT, 5 days, and 20 days post HSCT.</td>
<td>Caregiver burden themes: financial concerns, emotional distress, worry about the future, strained relationships. Health outcome themes: anxiety and depression were more prevalent pre-HSCT, than by day 20. Caregiver distress and fatigue was most strongly experienced at day 5 post HSCT.</td>
<td>Limited by a small convenience, homogenous sample in a single centre study. Unclear what type of HSCT the sample consisted of.</td>
</tr>
<tr>
<td>Grimm et al, 2000</td>
<td>United States</td>
<td>To compare the emotional responses and needs of HSCT caregivers in inpatient versus inpatient/outpatient (IPOP) settings.</td>
<td>Longitudinal, descriptive outcomes study design Convenience sample 43 caregivers (IPOP =17, inpatient unit = 26) Allo-HSCT &amp; Auto-HSCT</td>
<td>Survey &amp; Questionnaire: Caregiver Needs Survey (CNS) Profile of Mood States (POMS) Administered at: Pre-admission, day -1, day +21, day of discharge, 6 months post HSCT, &amp; 12 months post HSCT.</td>
<td>Both groups showed less mood disturbance by 6-12 months post HSCT. IPOP caregivers: less mood disturbance before discharge. High levels of information and psychological needs satisfaction at day +21.</td>
<td>Limited by use of small convenience sample &amp; incomplete data across some data points.</td>
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<td>Author, date</td>
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<td>Laudenslager et al, 2015</td>
<td>United States</td>
<td>To test the theory that stress management adapted for allo-HSCT caregivers would reduce stress, compared to treatment as usual (TAU).</td>
<td>Randomized controlled trial 148 caregivers Allo-HSCT</td>
<td>Intervention: PsychoEducation, Paced Respiration and Relaxation (PEPRR). Eight - one on one stress management sessions delivered across the 100 day HSCT period.</td>
<td>The PEPRR intervention significantly reduced caregiver stress and anxiety in the 100 days post HSCT period compared to TAU.</td>
<td>Demographically homogenous sample.</td>
</tr>
<tr>
<td>Meehan et al, 2006</td>
<td>United States</td>
<td>To evaluate the time commitment and financial requirements of auto-HSCT caregivers during the inpatient hospitalization phase.</td>
<td>Quantitative prospective study design with repeated measures 40 caregivers Auto-HSCT</td>
<td>Survey Completed daily throughout the acute hospital stay period (median length of stay 22 days, range: 17-41 days)</td>
<td>Travel based relocation Loss of income Expenses: accommodation, petrol, meals, childcare</td>
<td>Limited by single centre study - single location where many caregivers stay in the patients room. This may underestimate financial requirements and travel time required. Self-reporting survey may present recall bias and variable compliance with daily survey completion exists.</td>
</tr>
<tr>
<td>Ross et al, 2016</td>
<td>United States</td>
<td>To examine the relationship between health behaviours and sleep quality and fatigue in HSCT caregivers.</td>
<td>Single group; Cross-sectional design 78 caregivers Allo-HSCT</td>
<td>Questionnaire completed by caregiver just prior to hospital discharge</td>
<td>High levels of caregiver distress. Low levels of caregiver physical activity. Poor sleep quality and fatigue.</td>
<td>Small sample size. Limited to hospital phase of HSCT trajectory.</td>
</tr>
<tr>
<td>Author, date</td>
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<td>Simoneau et al, 2013</td>
<td>United States</td>
<td>To describe the peri-transplant psychological status of allo-HSCT caregivers.</td>
<td>Quantitative study design&lt;br&gt;109 caregivers&lt;br&gt;Allo-HSCT</td>
<td>Questionnaires&lt;br&gt;Multiple self-survey instruments were used to measure: mood, stress, sleep, health (physical &amp; mental), and burden.&lt;br&gt;Administered immediately prior to HSCT (day 0).</td>
<td>Younger caregiver age was related to greater distress. Caregivers experienced significant distress and anxiety pre-HSCT. Examples: avoidance behaviour, intrusive thoughts and sleep difficulties</td>
<td>Limited by lack of ethnic and socio-economic diversity in study sample. Study data collection limited to pre-HSCT phase.</td>
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### MIXED METHOD STUDIES

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<tr>
<th>Author, date</th>
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<tr>
<td>Denzen et al, 2016</td>
<td>United States</td>
<td>To assess financial impact of allo-HSCT on patients and families from 3 months to 2 years post HSCT.</td>
<td>Mixed methods&lt;br&gt;30 patient &amp; caregiver dyads&lt;br&gt;Allo-HSCT</td>
<td>Questionnaire, diary, phone interviews (at 6,12,18,24 months post HSCT)</td>
<td>Continued significant long term financial burden post HSCT.</td>
<td>Small sample size. Recall bias (income reporting), limited generalisation of results due to reduced study participation in the later trajectory phase.</td>
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<tr>
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| Majhail et al, 2013 | United States | To evaluate patient/caregiver out-of-pocket costs in the first 3 months post allo-HSCT. | Mixed methods 30 patient:caregiver dyads  
*Allo-HSCT* | Survey, diary, phone interviews  
Survey administered at pre-transplant baseline, fortnightly diary during first 3 months of transplant phase, and interview at 3 month post-HSCT time point. | Patient/caregiver dyads who had to relocate away from home incurred significantly higher costs. Loss of household income was a universal concern pre and post HSCT. | Limited by small sample size, higher than national median household income and under-representation of ethnic minorities within the study sample.                                                                                                                                                                                                                                             |
| Polomeni et al, 2016 | France       | To examine the impact of allo-HSCT on patients and close relatives quality of life. | Mixed method 29 patients 48 relative caregivers  
*Allo-HSCT* | Questionnaire & phone interview | Relative’s main concerns: changes in marital/family dynamics; changes in daily routines, responsibility for being main carer (emotional & physical). | Small sample size - limit the generalisation of results. Unclear at what time point in the trajectory the data collection took place.                                                                                                                                                                                                                                               |
| Sabo, McLeod & Couban, 2013 | Canada       | To explore the impact of caring on the psychosocial health of HSCT spousal caregivers. | Mixed method, exploratory study design 12 caregivers  
*Allo-HSCT & Auto-HSCT* | Questionnaire and interviews  
Administered at four time points: pre HSCT, 6 weeks, 6 months, & 1 year post HSCT. | Themes identified: need for hope/reassurance, uncertainty, & waiting. Depression, low QoL scores. Caregiver burnout highest in the first 30 days post HCT. | Small sample size, homogenous sample.                                                                                                                                                                                                                                                                                                                                                       |
Appendix Three: Study advertisement

The caregiver experience of bone marrow transplant in New Zealand

Have you been a caregiver for someone who has had a bone marrow transplant (also called ‘stem cell transplant’) for the treatment of blood cancer?

We are seeking people to participate in a research project which I am completing as a student researcher, for my Masters in Health Science degree at the University of Otago.

The study aims to:

- improve the understanding of how being a caregiver affects people’s lives - especially when they live outside the main city centre areas (in provincial New Zealand).
- provide the opportunity to contribute to improvements in health care services for patients & families with blood cancer.

Who are we asking to take part?

- People aged 18 years or older, who have been the caregiver for a person who has undertaken a bone marrow transplant (also called: ‘allogeneic or autologous stem cell transplant’) for the treatment of blood cancer within the past six months to five years.
- people who have supported the patient as a caregiver during their transplant and recovery. A caregiver may be a spouse/partner, family member or friend.
- People who live at least 100 km away from the main city hospital where the bone marrow transplant took place. This is so we can explore what the experience is like for people who have to relocate away from home for treatment.

What will you be asked to do?

If you participate you will be asked to take part in a face to face interview with the researcher. The interview will last approximately one hour. You may choose to have a support person with you during the interview.

Participation in this study is voluntary (your choice). You may withdraw at any time. Participation in this study is confidential. Identifiable information will not appear in any spoken or written report of this study.

We recognise that the transplant journey is a personal experience for both you and the person who you are caring for (the patient). We encourage you to speak with the patient, and your whanau/family before you consent to participate in this study.

For more information please contact:
Anita Wootton, Student Researcher, 021 269 2184, smjan901@student.otago.nz
or, Dr Philippa Seaton, Principal Investigator, 03 364 3858, philippa.seaton@otago.ac.nz

This project has been reviewed and approved by the University of Otago Human Ethics Committee, (Health). Reference: H16/083
Appendix Four: Study information sheet

The caregiver experience of
bone marrow transplant in New Zealand

Information Sheet

This is an information sheet for a research project I am completing as a student researcher, for my Masters in Health Science degree at the University of Otago. You are invited to participate in this study which is looking at the experience of people who have been a caregiver for a patient who has had a bone marrow transplant (also called 'haematopoietic' stem cell transplant) for the treatment of blood cancer.

This study is looking at the way this experience affects people who live further than 100km from the city hospital where the transplant took place (Auckland, Hamilton, Palmerston North, Wellington or Christchurch hospitals). We hope that this study will help us better understand the caregiver experience, how we can support individuals and families through this process, and contribute to developing improvements in health support services.

Introduction

Thank you for showing an interest in this study. Please read this information sheet carefully. Take time to consider and if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research study?

The aim of this study is to explore the experience of haematopoietic stem cell transplant (HSCT) for the treatment of blood cancer, from the perspective of caregivers who live in provincial New Zealand.

Participation in this study is voluntary (your choice). You may withdraw at any time without any disadvantage to you OR the patient you are a caregiver for.

Participation in this study is voluntary (your choice). You may withdraw at any time without any disadvantage to you OR the patient you are a caregiver for.
What is the purpose of this study?

- to improve the understanding of how being a HSCT caregiver affects people's lives - especially when they live outside the main city centre areas (in provincial New Zealand).
- to provide information and evidence to improve and develop health and support services for HSCT caregivers, patients and their families.
- to identify potential areas of further research.

Will it cost me to participate in this project?

There is no cost to participate in this study.

Will I get paid to participate in this project?

There is no payment offered to people who participate in this study.

Who are we asking to take part in the project?

- People aged 18 years or older, who have been the caregiver for a person who has undertaken a haematopoietic stem cell transplant for the treatment of blood cancer within the past six months to five years. This may be either an allogeneic (donor), or an autologous (self) transplant.

- A caregiver can be a spouse/partner, family member or friend who has supported the patient as the main caregiver during their transplant and recovery. The caregiver either lives with the patient and/or regularly assisted with activities of daily living during and immediately after the transplant.

- We are seeking participants who live at least 100 km away from the transplant hospital (either Auckland, Waikato, Palmerston North, Wellington or Christchurch) where the bone marrow transplant took place. This is so we can explore what the experience is like for people who have to relocate away from home for treatment.

If you participate, what will you be asked to do?

If you participate you will be asked to take part in a face to face interview with the researcher. This will take place in a location that ensures your conversation is private.

Participation in this study is voluntary (your choice). You may withdraw at any time without any disadvantage to you OR the patient you are a caregiver for.
You may choose to be interviewed in your home or another suitable place. You can discuss suitable options for the interview location with the researcher.

The interview will last approximately **one hour**. The researcher will use some pre-written questions to guide the conversation. The interview will be **recorded** using a digital audio recorder. The researcher will also write some notes on paper during the interview.

You may choose to have a **support person** with you during the interview.

The interviewer will not be previously known to or involved in the clinical care of you (the participant) or the associated patient.

Participation in this study is **voluntary** (your choice). **You may withdraw at any time.**

**Is there any risk of discomfort or harm from participation?**

You may find that remembering and talking about the transplant experience, and what this means to you, could be emotional at times. You can decline to answer particular question(s), stop the interview, or **withdraw from the study for any reason at any time**. **This will not disadvantage you or the patient you are a caregiver for, in any way at any time.**

The interviewer (student researcher) is a registered nurse with experience in cancer nursing. If you are upset by talking about this experience, the interviewer can provide you with the contact details for support services such as, Leukaemia and Blood Cancer NZ, Cancer Society, your GP or medical specialist if further support is required.

**What information will be collected, and how will it be used?**

The interview will be sound recorded using a digital audio recorder. The researcher will also write notes during and after the interview. The researcher will analyse this information to write up a research report (thesis) which will be submitted to the University of Otago. A summary of this report will be provided to all participants at the completion of the study. The overall study findings will be presented by the researcher at professional conferences. Study findings may also be submitted for publication to academic journals.

**What about information privacy?**

No detail that could personally identify you (or the patient you are caregiver for) will be used in any reports associated with this study. Completed consent forms will be held in a locked filing cabinet which is only accessible by the student researcher and the principal researcher/supervisor. Data collected will be stored on a password protected computer. All data collected will be held for ten years before being destroyed.

Participation in this study is **voluntary** (your choice). **You may withdraw at any time** without any disadvantage to you OR the patient you are a caregiver for.
The student researcher will be the only person who transcribes the recorded audio interview into a typed written script. This will also help to keep the identity of the participant's confidential.

We recognise that the transplant journey is a personal experience for both you and the person who you are caring for (the patient). We encourage you to speak with the patient, and your whanau/family before you consent to participate in this study.

If you agree to participate, can you withdraw later?

Participation in this study is voluntary (your choice). You may withdraw from participation in this study at any time - without any disadvantage to yourself or the patient you are a caregiver for. To withdraw your participation at any time please contact the research team by using the contact details shown below.

Questions?

If you have any questions now or in the future, please feel free to contact:

Student Researcher
Anita Wooton
Centre for Postgraduate Nursing Studies - University of Otago
Phone: 021 269 2184
smian01@student.otago.ac.nz

Principal Investigator/Supervisor
Dr Philippa Seaton
Centre for Postgraduate Nursing Studies - University of Otago
Phone: 03 364 3838
philippaseaton@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee (Health), Ref: H16/083. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone: +64 3 479 8226 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Participation in this study is voluntary (your choice). You may withdraw at any time without any disadvantage to you OR the patient you are a caregiver for.
**Appendix Five: Consent Form**

### The caregiver experience of bone marrow transplant in New Zealand

**CONSENT FORM FOR PARTICIPANTS**

Please circle your response, sign & return in the pre-paid addressed envelope provided.

<table>
<thead>
<tr>
<th>Statement</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have read and I understand the information sheet for participants taking part in the study titled The caregiver experience of bone marrow transplant in New Zealand.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that consent to participate is for this study only. I understand this involves a face to face interview with the researcher which will be audio recorded, and that I am welcome to bring a support person with me to the interview.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand if I feel uncomfortable during the interview at any time - I may decline to answer particular question(s) and/or withdraw from the study at any time without causing disadvantage of any kind.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I have had the opportunity to consider and to talk with the patient and my whanaunuku/family about my choice of participating in this study.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I confirm that I meet the criteria to participate in this study - which are explained in the information sheet.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that my participation in this study is entirely voluntary, that I am free to withdraw at any time and that this will not cause disadvantage of any kind to me or the patient whom I am a caregiver for.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand that my participation in this study is confidential. Identifiable information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of this study.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand there is no payment offered for participation in this study.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand that data from this project will be placed in secure storage for ten years after the completion of this project.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand that as a participant of the study I will receive a summary of the study findings.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I confirm that all my questions about this study have been answered to my satisfaction. I understand I am able to request further information at any stage. I know who to contact if I have any questions about this study or if I wish to withdraw at any time.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I ___________________________ (Full name, please PRINT CLEARLY) hereby consent to take part in this study.

Signature (participant): ___________________________ Date: ______________

Signature (student researcher): ___________________________ Date: ______________

For further information please contact: Dr Philippa Seaton - Principal Investigator on 03 364 3658 or email: philippaseaton@otago.ac.nz

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Appendix Six: Ethics Committee letter - inclusion criteria amendment approval

Dr P Seaton
Centre for Postgraduate Nursing Studies (Chch)
72 Oxford Terrace, Levels 2 and 3
University of Otago, Christchurch

Dear Dr Seaton,

I am again writing to you concerning your proposal entitled “The caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting”, Ethics Committee reference number H16/083.

Thank you for your request for amendment of 20th March 2017.

The Committee accepts and approves the requested changes to the inclusion criteria and thanks you for providing the revised documentation.

Your proposal continues to be fully approved by the Human Ethics Committee. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing. I hope all goes well for you with your upcoming research.

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

cc. Dr P Seaton, Director, Senior Lecturer Centre for Postgraduate Nursing Studies (Chch)
Appendix Seven: Ethics Committee letter - Skype amendment approval

Dr P Seaton  
Centre for Postgraduate Nursing Studies (Chch)  
72 Oxford Terrace, Levels 2 and 3  
University of Otago, Christchurch  

Dear Dr Seaton,

I am again writing to you concerning your proposal entitled “The caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting”, Ethics Committee reference number H16/083.

Thank you for your request for amendment of 13th December 2017 notifying the Committee of changes to the above project. You note that some participants have expressed a wish to be interviewed via online conferencing, such as Skype rather than in person.

The Committee accepts and approves the amendment.

Your proposal continues to be fully approved by the Human Ethics Committee. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing. I hope all goes well for you with your upcoming research.

Yours sincerely,

[Signature]

Mr Gary Witte  
Manager, Academic Committees  
Tel: 479 8256  
Email: gary.witte@otago.ac.nz

cc. Dr P Seaton  Director, Senior Lecturer  Centre for Postgraduate Nursing Studies (Chch)
Appendix Eight: Interview question template

Interview Framework

A semi-structured interview approach using prompting questions will be utilised. Potential questions which may be posed include:

**Demographic questions**

- **Age**
- **Patient diagnosis**
- **Transplant date**
- **Employment status**

**Relationship to participant**

- **Transplant type**
- **Distance to transplant centre**
- **Sole caregiver or shared duties?**

**HSCT related questions**

- ‘How are you connected to [x] (patient)?’ / ‘What is your relationship to [x] (patient)?’
- ‘Tell me about your experience of caring for X during his/her transplant?’
- ‘Where did you stay while the patient was in hospital?’
- ‘How long did you stay with the patient while they were in hospital?’
- ‘Tell me about the information (education) you received to prepare you before the transplant?’
- ‘What things have been the most challenging parts of the transplant experience for you?’
- ‘Tell me about the support you had available to you during and after the transplant process? - nurses, social worker, LBC/CS, GP, doctors’
- ‘Tell me about the experience of travelling away from home during the transplant process?’ - parking, accommodation, frequency of trips
- ‘Tell me about the financial impact of the transplant process?’ - parking, accommodation, loss of income, household costs (groceries, childcare)
- ‘What were your concerns/worries/fears before the transplant?’
- ‘What were your concerns/worries/fears during the transplant?’
- ‘What are your concerns/worries/fears following transplant?’
- ‘What positive changes have occurred from being X’s [patient’s] caregiver?’
- ‘How have things changed for you since X’s [patient’s] transplant?’
- ‘What things could the hospital team do to help prepare and support caregivers of HSCT patients?’
- ‘What advice/information would you give someone else who is about to become the carer of a patient undergoing HSCT?’

Do you wish to be sent a copy of the final research report?
Appendix Nine: Ethics Committee letter - conditional approval

H16/083

25 July 2016

Dr P Seaton
Centre for Postgraduate Nursing Studies (Chch)
72 Oxford Terrace, Levels 2 and 3
University of Otago, Christchurch

Dear Dr Seaton,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled “The caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting”.

As a result of that consideration, the current status of your proposal is:- Conditional Approval

For your future reference, the Ethics Committee’s reference code for this project is:- H16/083.

The comments and views expressed by the Ethics Committee concerning your proposal are as follows:-

Locality Assessment

Please provide a copy of the locality assessment from the DHB, and the approval from Leukemia and Blood Cancer NZ regarding recruitment, for our records.

Methodology

The Committee would be grateful if you could provide clarification of the following points:
- how will participants be approached?
- please provide an outline of the interview questions to be posed.
- how will the narratives be analysed?

Ethical concerns
The Committee noted that the patient being cared for does not appear to have been considered. The caregivers may need to discuss details about the patient and their health status and may disclose health information. In this case, should the patient be asked for their consent for the issues relating to them to be included in the study? The Committee wondered whether this had been raised during Maori consultation. Please advise whether Maori consultation has been completed, and if so whether this issue was discussed. How will this issue be managed?

Storage of data

The Committee considered that as the data collected potentially contains health information, that data should be stored for ten years. Please ensure this is added to the Information Sheet.

Before approval of the research to proceed can be granted, a response must be received addressing the issues raised above. The Committee expects that these comments will be addressed before recruitment of participants begins. Please note that the Committee is always willing to enter into dialogue with applicants over the points made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood. Please provide the Committee with copies of the updated documents, if changes have been necessary.

Yours sincerely,

[Signature]

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8258
Email: gary.witte@otago.ac.nz

c/o Dr P Seaton, Director, Senior Lecturer, Centre for Postgraduate Nursing Studies (Christ)
Appendix Ten: Ethics Committee letter - full approval

Dr P Seaton
Centre for Postgraduate Nursing Studies (Chch)
72 Oxford Terrace, Levels 2 and 3
University of Otago, Christchurch

13 September 2016

Dear Dr Seaton,

I am again writing to you concerning your proposal entitled “The caregiver experience of haematopoietic stem cell transplant for haematological malignancy within the provincial New Zealand setting”, Ethics Committee reference number H16/083.

Thank you for your letter of 7th September 2016, with revised documentation attached, addressing the issues raised by the Committee.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:
Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

The Human Ethics Committee (Health) asks for a Final Report to be provided upon completion of the study. The Final Report template can be found on the Human Ethics Web Page [http://www.otago.ac.nz/humanethics/committees/HumanEthicsCommittee.html](http://www.otago.ac.nz/humanethics/committees/HumanEthicsCommittee.html).

Yours sincerely,

[Signature]

Mr Gary Witte
Manager, Academic Committees
Tel: 478 8256
Email: gary.witte@otago.ac.nz

cc: Dr P Seaton, Director, Senior Lecturer, Centre for Postgraduate Nursing Studies (Chch)
Appendix Eleven: Maori Research consultation letter

4 August 2016

Dr Philippa Seaton
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch

Mā te rangahau Hauora e tautoko te whakapiki ake te Hauora Māori. All health research in Aotearoa New Zealand benefits the Hauora (health and wellbeing) of tangata whenua.

Tēna kōe Philippa,

Thank you for taking the time to meet with me at my office at the University of Otago, Christchurch on the 11th August 2016, to discuss your research study titled:

A Qualitative Descriptive Study Exploring the Caregiver Experience of Haematopoietic Stem Cell Transplant for Haematological Malignancy Within the Provincial New Zealand Setting

I understand that this research is self-funded and that Ms Anita Wootton, a Master’s student completing the requirements for this degree, will be involved in the project.

Commentary on Proposed Research Project
Leukaemia is a group of cancers that affect the blood and bone marrow. All leukaemias start in the bone marrow where developing blood cells undergo a malignant (cancerous) change. Lymphomas are cancers of the lymphatic system and myeloma is a cancer of plasma cells. Haematopoietic stem cell transplant (HSCT), also called bone marrow transplant, is a complex and intensive process which may be used in the treatment of patients who have a blood cancer such as leukaemia lymphoma or myeloma. Patients require a caregiver to be with them and to remain near the treatment hospital for up to 100 days’ post-transplant. In New Zealand, HSCT is provided at specialist treatment services in main city hospitals only (Auckland, Hamilton, Palmerston North, Wellington and Christchurch). This means that relocation for HSCT treatment is required for those living outside these areas. The aim of this study is to examine how relocation for HSCT treatment impacts upon the lives of caregivers within New Zealand, and to identify the needs required for this population. It is anticipated that 8-10 caregivers will be recruited nationally and interviewed in person. Study participants will be recruited drawing from the professional networks of the research team.

Māori Health Gain
Cancer touches all whānau. Much progress has been made in surrounding the knowledge of cancers, in that a third are preventable, a third are treatable, and a third can be managed well. Yet the impact of this disease on the peoples of Aotearoa is uneven and inequitble. While cancer mortality is decreasing among non-Māori, it is increasing among Māori. Growing evidence indicates that disparities in cancer outcome have less to do with the biological aspects of the disease, but more to do with the type and timeliness of care that these populations receive. For Māori the rate of cancer is only a fifth higher overall than among non-Māori however, most cancers kill Māori at a significantly higher rate than they do non-Māori.
This study addresses the experience of the whānau caregiver, thus allowing Māori perspectives and narratives on patient and whānau centred care, to be captured in a meaningful way. It is anticipated that this study will contribute to informing the development of evidence based nursing interventions and models of care, across the multi-disciplinary health team to address the specific needs of HSCT caregivers. This provides the appropriate context to the importance of this research toward improving Māori health in the future and reducing health inequalities between Māori and non-Māori.

Consent
Issues regarding informed consent for Māori participants who are recruited to this study were discussed. With this in mind, you must ensure that Māori participants are explicitly aware that consent is for this project only. We discussed the rights to self-determination (tino rangatiratanga) regarding whānau caregivers and their autonomy to choose whether they participate or not in this research study. Because this research involves whānau who have received HSCT, it is recommended that caregivers consult with their whānau prior to consenting to participate in this research study. In addition, should any Māori participants wish to opt out of the study, you must provide information as to who they should make direct contact with to arrange this. This information should be clearly set out in the study information sheet.

Ethnicity
Whilst this research does not specifically target Māori, you have indicated that Māori may have a presence within the recruitment population. This number should be reflective of the Māori population using specialist treatment HSCT services. You will also need to consider how ethnicity data will be collected for this study. It is recommended that ethnicity data is collected in accordance with the Ministry of Health guidelines, which involves the use of the Census 2013 question. If a participant identifies as Māori, but this is not recorded in their records, this should be rectified. This may be likely to occur given the poor ethnicity data collection in hospital protocols and databases.

Partnership
As you are aware Hauora Māori involvement for this study would ensure that tikanga Māori frameworks are considered and integrated into the project. With regard to Māori involvement in your study, I have recommended that further consultation be undertaken with respective Hauora Workers in their regions who may be already working alongside whānau are bone marrow transplant recipients. It is hoped that their involvement will support whānau participation in this research. You have also indicated that you will be seeking resources to support this involvement.

Potential Further Support Resources
Further resources that you might want to access to strengthen your responsiveness to Māori within your research are: 1. HRC’s Ngā Pōu Rangahau Hauora Kia Whakapikir Ake Te Hauora Māori 2004-2008, 2. The Health Research Strategy to Improve Māori Health and Well Being 2004-2008. For regional data relating to Māori in each District Health Board (DHB) region, the District Health Board (DHB) Māori Health Profiles (2015) published by the Ministry of Health New Zealand will help to create a picture of the health status of a DHB’s population at a given time. The reference that is available is 3. Hauora Māori Standards of Health IV: A Study of the Years 2000-2005 by Bridget Robson and Ricci Harris, Māori Health Research Unit, Wellington School of Medicine, University of Otago, Wellington. All provide Māori specific information on a range of health issues. The recent publication Tūtau Kahukura: Māori Health Chart Book 2015, Ministry of Health, 2010 (3rd edition) is an update relating to the socio economic determinants of health, health status and service utilisation of the Māori population. Further references are available from the HRC’s Guidelines for Researchers on Health Research Involving Māori (page 22), www.hrc.govt.nz
Dissemination of Results
As stated in the HRC’s Guidelines for Researchers on Health Research Involving Māori, it is important that research results contribute to Māori health gain. This should occur not only in an academic forum, but also within the community from where the data is drawn. Looking to the future, I would recommend that you utilise your Hauora Māori networks to assist you in identifying an appropriate Māori forum where the findings from your research may be shared. I also understand that you will be looking to develop a whānau friendly newsletter providing a summary of the study findings to all study participants, as well as presenting the results to the Leukaemia and Blood Cancer New Zealand group. As such, these avenues may allow an opportunity for the consideration of Māori feedback into any discussion going forward.

Ngā manaakitanga o te wā,

Karen Keelan
Kaitohutohu Rangahau Māori/Māori Research Advisor
Appendix Twelve: Caregiver responses - suggestions for the health care team

"What things can the hospital team do to help prepare and support the caregivers of people going through a stem cell transplant?"

<table>
<thead>
<tr>
<th>Suggestions for the Hospital Team</th>
<th>Related Theme/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide better support for the caregiver - don't just focus on the patient.</td>
<td>Support</td>
</tr>
<tr>
<td>Connect the patient with other caregivers - as a means of support and sharing of information and experiences.</td>
<td>Support, Learning</td>
</tr>
<tr>
<td>Consider repeating education topics after a few weeks, to allow caregivers time to understand it more.</td>
<td>Learning</td>
</tr>
<tr>
<td>Provide an opportunity for the caregiver to have an individual psychology consultation.</td>
<td>Coping, Support, Fear &amp; Worry</td>
</tr>
<tr>
<td>Keep doing the education folder - it's really good and the information is done really well.</td>
<td>Learning</td>
</tr>
<tr>
<td>Give the caregiver more information when the patient is discharged - about when the symptoms will appear, and when the side effects appear - what do we do?</td>
<td>Duty &amp; responsibility, Learning, Fear &amp; Worry</td>
</tr>
<tr>
<td>They need to include the caregivers more.</td>
<td>Support</td>
</tr>
<tr>
<td>Don't give us all the scary information, and just use simple language.</td>
<td>Learning, Fear &amp; Worry</td>
</tr>
<tr>
<td>Just keep doing what they are doing.</td>
<td>Learning, Support</td>
</tr>
<tr>
<td>Have someone who can actually sit down and go through the process with the caregiver - not just the patient.</td>
<td>Learning, Support,</td>
</tr>
<tr>
<td>When the patient is discharged - give the caregiver time to transition, and provide some key points to look out for.</td>
<td>Duty &amp; responsibility, Support, Learning</td>
</tr>
</tbody>
</table>
"what advice do you have for someone who is just about to head into this process of being a caregiver for someone undergoing a stem cell transplant? what tips would you have for them on how they might best get through the experience as the caregiver?"

<table>
<thead>
<tr>
<th>Advice</th>
<th>Related theme/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make time for yourself.</td>
<td>Coping</td>
</tr>
<tr>
<td>Set up a deal with a friend before the transplant...tell that person:</td>
<td>Coping, Support</td>
</tr>
<tr>
<td>I'm going to need your help and this is the sort of help I'm going to need.</td>
<td></td>
</tr>
<tr>
<td>Keep focused on the goal of cure for the patient.</td>
<td>The journey, Relationships, Coping</td>
</tr>
<tr>
<td>Don't go on the internet - keep as blind as you can.</td>
<td>Learning</td>
</tr>
<tr>
<td>Read as much information as you can.</td>
<td>Learning, Duty and responsibility</td>
</tr>
<tr>
<td>Don't be afraid to ask questions.</td>
<td>Support, Learning, 'Being there'</td>
</tr>
<tr>
<td>Be careful when you get home - know what patient symptoms to look out for, who and when to call for help.</td>
<td>'Being there', Support, Learning, Duty and responsibility, The journey to a 'new normal'</td>
</tr>
<tr>
<td>Listen to and absorb as much information as possible.</td>
<td>Learning, Duty and responsibility</td>
</tr>
<tr>
<td>Learn to read the patient's body and symptoms - because they may not tell you, or might even try to hide what is wrong.</td>
<td>Learning, Relationships, Duty and responsibility</td>
</tr>
<tr>
<td>Empathise with the patient, but don't over sympathise with them.</td>
<td>'Being there', Relationships</td>
</tr>
<tr>
<td>Keep the patient motivated by having a positive attitude.</td>
<td>'Being there', Relationships</td>
</tr>
<tr>
<td>If you feel like you aren't coping, then ring someone.</td>
<td>Coping, Support</td>
</tr>
<tr>
<td>Don't be afraid to ask whoever you need to for help - when you need it.</td>
<td>Coping, Support</td>
</tr>
<tr>
<td>Be positive, and keep your patience.</td>
<td>'Being there', Coping</td>
</tr>
<tr>
<td>Don't be selfish, just roll your sleeves up and do what you can.</td>
<td>'Being there', Relationships, Duty and responsibility</td>
</tr>
</tbody>
</table>