Dealing with Distress for Cancer Patients: Using brief Dialectical Behaviour Therapy skills groups for patients with cancer

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Abstract

The global incidence of cancer is rising due to the ageing of the population and population growth (Conley et al., 2016). In New Zealand, cancer is the leading cause of death (Ministry of Health, 2018b). The literature suggests that quality of life is enhanced by psychosocial treatments. Dialectical Behaviour Therapy (DBT) (Linehan, 2014a) is a psychological treatment for emotional dysregulation and complex presentations that has been well researched, but there is little literature related to its use for cancer patients.

This mixed-methods pilot study examined whether DBT groups are an effective psychological intervention in reducing distress, increasing resilience and increasing quality of life for cancer patients. The quantitative component measured the outcomes of distress, quality of life, and resilience using the Distress Anxiety Stress scale (DASS-21), the European Organisation for Research and Treatment of Cancer Quality of Life C30 Questionnaire (EORTC QLQ-C30 Version 3) and the Connor-Davidson Resilience Scale (CD-RISC) respectively. The qualitative component sought participants' experiences of the group programme through interviews and an Appreciative Inquiry process, creating an opportunity for participants to identify what worked well and suggest modifications to improve the programme. Qualitative data were audio-recorded and transcribed and then analysed using Braun and Clarke's (2012) thematic analysis process.

There were two conditions in this study that were presented as single-case designs due to the small sample size (n=6). Condition One involved two cancer patient participants, who suggested the modification of including supporter/ family members in the group.

Condition Two involved four cancer patient participants, two of whom also had family members attend.

Condition One results indicated some improvements in distress scores (as measured by the DASS-21) by one participant whilst resilience scores improved for the other participant. Additionally for both participants, some EORTC QLQ-30 functioning and symptom scores also improved. The participants found learning and using the skills taught in the group helpful. Findings for the second condition (modified group) showed improvements in distress, a consistent positive long-term impact on quality of life (global health) and fatigue, and relatively consistent impacts on physical function, role function, pain, and dyspnoea. Although resilience and depression (as well as emotional and cognitive functioning) improved during the time of the group, these variables were not maintained at follow-up for all participants. During interviews, participants reported the helpful effect the group had on general psychosocial stressors. Several modifications of the group programme are recommended, including the involvement of careers/support people as part of the DBT programme; the use of a manual; and using non-psychologists to facilitate the group programme to allow for wider community reach. Future research could include trials with a larger and more diverse group of participants, measuring outcomes on support/carer participant's anxiety and/or stress, and the benefits of a follow-up group and web-based support.

Abbreviations used in this thesis

AI	Appreciative Inquiry
BDI	Beck Depression Inventory
BPD	Borderline Personality Disorder
BSI-18	Brief Symptom Inventory-18
CBT	Cognitive Behaviour Therapy
CD RISC 25	Connor Davison Resilience Scale
DASS-21	Depression, Anxiety and Stress Scale- 21
DBT	Dialectical Behaviour Therapy
DHB	District Health Board
DT	Distress Thermometer
EORTC QLQ-C30	European Organisation for Research and Treatment of Cancer Quality of Life C30 Questionnaire
FRC	Fear of recurrence of cancer
HADS	Hospital Anxiety Distress Scale
NCD	Non-communicable disease
SCL-90	Symptom Checklist-90
WHO	World Health Organization

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Trish Du Villier

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Ethics Approval

Approval for this research was granted by the Central Health and Disability Ethics Committee (HDEC reference 17/CEN/65) and the Auckland University of Technology Ethics Committee (AUTEC, reference number 17/229)

Chapter 1 Introduction

Cancer touches everyone, young and old, rich and poor, male and female and is one of the leading causes of death in the world (World Health Organization, 2017). Cancer is also the leading cause of morbidity and mortality in New Zealand and the prevalence of cancer is steadily increasing. As a small country with a predominantly public health system, New Zealand is subject to the increasing cost and impact of cancer (Ministry of Health, 2011a). In 2011, the average cost of cancer treatment per person for the period from one year prior to diagnosis to five years post-diagnosis was $20,372.50. By 2021, the total cost of cancer treatment is predicted to be $117 million higher than the 2011 cost (Ministry of Health, 2011a).

Along with its physical impacts, cancer has significant psychological impacts (such as distress, anxiety, and depression) which can in turn affect treatment adherence and outcomes. Evidence-based psychological treatments can have positive impacts for people who develop symptoms of distress and anxiety. The positive impact not only applies to those suffering mental health issues but also to the distress and anxiety of people suffering cancer.

Emotion dysregulation is the term used to describe the inability to manage the intensity and duration of negative emotions such as fear, sadness or anger (Franco, 2018). Dialectical Behaviour Therapy (DBT) is a psychological intervention for mental health service users that was developed to address problems of emotional dysregulation (Anderson, Jensik, Peloza, & Walker, 2013; Feigenbaum et al., 2011; Linehan et al., 2006; Linehan et al., 2015; Sobhi, & Sahrzad, 2014). DBT consists of several parts including group and individual therapy. Research has shown that for some people with mild to moderate mental health issues, a brief modified version of

DBT groups (that can be delivered by non-psychologists in the community) is an effective and less expensive option than one-to-one individual therapy by a psychologist (Zhao, 2006).

This study aimed to investigate if a brief DBT intervention (similar to those that have been used in mental health settings) would benefit cancer patients by reducing distress and improving resilience and quality of life. It also aimed to explore how Brief DBT could be modified for cancer patients to potentially achieve better results.

In this chapter, I describe my interest in translating a brief DBT programme that I have run in a community mental health service to the cancer domain. I also discuss principles of equity and empowerment that underlie this research.

1.1 Situating this study

I graduated as a Clinical Psychologist in 1983. At that time, mental health was seen as a very separate domain to physical health and few psychologists worked in physical health services. Patients' mental health records were kept separate from their physical health records, partly because of the stigma of mental illness.

As part of my final year of training, I spent several months in the Liaison Psychiatry department at Auckland Hospital, working with patients who were hospitalised with physical illnesses and who were having some psychological difficulty. This was challenging work as patients could be hostile to the idea of seeing a psychologist when they were hospitalised for a physical complaint. One patient who stands out in my mind was refusing to take the medications prescribed and I was assigned to talk to her and assess why. Initially she was chatty and engaged, but when she realised I was a psychologist, she became angry and refused to talk to me, hid under her blankets and

demanded that I leave, because she was “not crazy”. She thought that talking to a psychologist stigmatised her as having a mental illness.

Since graduating, I have had a 35 year career in mental health and have worked with people with many mental health diagnoses, some of whom had physical comorbidities that affected their mental health status, and vice versa. A central part of their presentation often involved anxiety, depression and emotional dysregulation. I have also observed that cancer patients have some of the same issues that mental health service users have with regulating emotions such as anxiety.

Over my career, the walls between physical health and mental health have started to come down. Physical health services such as cardiology, lung and kidney transplant, pain management, and oncology have recognised that psychology can play a part in treatment and recovery, and psychologists are now employed in these and other areas to make their contribution as part of a multidisciplinary team. There are currently over 20 psychologists employed in physical health services in the Auckland District Health Board (Stewart, 2008). Early in my career, there were few treatments to address the needs of service users with complex trauma histories, emotional dysregulation and suicidal behaviour. No effective medications were available and they were often high users of resources such as emergency departments and inpatient psychiatric units. The treatments existing at that time often made their problems worse. In 1993, a treatment called Dialectical Behaviour Therapy (DBT) was developed to address the needs of this group of service users. In 2000 I was trained in DBT by the training institution set up by the developer of the treatment, Dr Marsha Linehan (Behavioral Tech, 2017). Since then I have delivered this model of therapy as an individual therapist and as a group skills facilitator, receiving on-going supervision and training.

Over the last 19 years, I have developed and utilised a shortened form of DBT for people in mental health services who present with less extreme difficulties and therefore do not require the full DBT treatment. This brief DBT skills training group intervention consists of six sessions run twice weekly, thus taking only three weeks. The full DBT protocol takes a full year of weekly individual therapy, group sessions and telephone coaching to complete. An evaluation of the Brief DBT Groups I developed showed a significant reduction in anxiety and hopelessness for mental health service users, who gave very positive feedback on aspects of the group and reported that participation was beneficial (Zhao, 2006).

I have been directly affected by cancer as my grandmother, aunt, mother, mother-in-law, two sisters-in-law and two cousins have all had cancer diagnoses. My experience of facilitating brief DBT groups and my family's history of cancer, together led me to consider whether this therapy would have application to the distressing situation of experiencing cancer and the treatment that in itself is also stressful.

1.2 Principles underlying this research

As a therapist, I have often seen clients feel empowered by being able to use and master skills that led to better outcomes, including increases in self-esteem and competence. The first principle behind this research was to empower people with cancer to have greater control over their lives and emotions even when they have a life threatening disease. Consequently, I wanted the principle of empowerment to inform the research by selecting a methodology that is strengths-based and empowering for participants.

The second principle that I wanted to drive this research was to enable equal access to psychological therapy irrespective of where a person lives. The New Zealand Ministry

of Health has emphasised that the country's cancer programme is nationally based and aims for all New Zealanders to have the same access to high quality care. This national cancer programme should include psychological care (Ministry of Health, 2019b). This means that interventions need to be able to be delivered in places close to where people live. Therefore, this led to this research taking place in a local community centre away from a hospital. A manual was developed in order for the programme to be consistent with teaching skills that are the same no matter where in New Zealand the group is delivered.

There is increasing pressure on the psychology workforce (Pather, 2016) due to population increases, increased provision of psychology services in Primary Care, increased talking therapies in mental health services, and expansion into physical health areas. This means that in order to improve access, psychological interventions need to be able to be delivered by non-psychologists. The brief DBT Groups allow up-skilling and training of non-psychologist clinicians, such as nurses, in the delivery of a brief evidence-based intervention, leading to more group facilitators able to provide access to more people with cancer. This would also allow psychologists to focus delivery on people identified as having more severe problems and needing more intensive one to one therapy.

1.3 Aims and research questions that this study sought to address

The aims of this pilot study were to investigate whether attending brief DBT groups would reduce distress, increase quality of life and increase resilience for cancer patients. It also aimed to explore if the standard DBT groups used for mental health patients could be modified for cancer patients and to investigate if these were more effective than unaltered groups.

The research questions were:

1. Do cancer patients who attend standard non-modified brief DBT groups experience decreased distress, increased quality of life and increased resilience?

2. Do cancer patients who attend brief DBT groups, which are modified for cancer patients, achieve better results on measures of distress, quality of life and resilience than patients who attend standard DBT groups?

1.4 Summary

This chapter has outlined the aim of this research, which was to modify an intervention that I have used in the mental health area for cancer patients. In this chapter I have also described the reasons for my personal interest in this area, cancer having affected my family, and the rationale for translating Brief DBT, as used in the mental health field, to assisting with treatment of cancer. This chapter also describes the principles of empowerment and equity that are strong values for me and have informed the methodological choices made in developing this research.

1.5 Overview of the chapters in this thesis

This chapter introduced the aims of the research, my interest in this area, and the key principles of empowerment and equity that influenced the research methodology.

Chapter Two comprises a more detailed literature review of the areas of distress, resilience and quality of life as well as psychological interventions for cancer with a focus on group interventions.

Chapter Three discusses the qualitative and quantitative approaches that make up this mixed methods pilot study and the rationale for choosing each methodology to answer different parts of the research questions.

Chapter Four describes the methods used for this study including the two conditions and the Appreciative Inquiry Focus groups

The results of Condition One are described in Chapter Five, which includes individual and combined findings for the unmodified group.

The Appreciative Inquiry Focus Group findings for the unmodifed group are presented in Chapter Six. This chapter describes the modification of including family/ support people as participants in the group and other modifications suggested by participants in Condition One.

Chapter Seven describes the results of Condition Two, the modified group that included two support carers.

Chapter Eight describes the findings of the Appreciative Enquiry focus group following the attendance at the modified group- Condition Two.

The discussion of how this study fits with the literature in this area, strengths and limitations and suggestions for practice and future research are presented in Chapter Nine.

Chapter 2 Literature Review

2.1 Introduction

Despite cancer being a major non-communicable disease (NCD), resources are scarce for people in New Zealand to receive psychological support once out of the early treatment and diagnostic stage. This chapter provides the background to this study by presenting the literature about cancer and the relationship of cancer to psychological factors including distress, resilience, and quality of life. Psychological group therapies and the evidence for the effectiveness of DBT are then introduced, first in a mental health context and then pertaining to its use with cancer patients. The use of psychological approaches in cancer management in New Zealand is also discussed.

2.2 Literature review strategy

Searches for this literature review were conducted through EBSCO Health Database, ERIC via OVID and Proquest, PubMed, Psychinfo, Medline, and Google Scholar. Searches were limited to research articles post 2000 and included only studies in English. Search terms included psychological groups for cancer, psychological treatments for cancer, psychosocial treatments, group therapy, distress, resilience, quality of life and cancer. Literature regarding Dialectical Behaviour Therapy was searched using the search terms: Dialectical Behaviour Therapy, Dialectical Behavior Therapy, and DBT.

2.3 Biomedical, epidemiological, and economic aspects of cancer

The human body is made up of many millions of cells. Normally cells grow and divide to form new cells. As cells die, are damaged or grow old, new cells replace them where they are needed. When some of the body's cells start to divide abnormally without stopping and spread to the surrounding tissue, this is known as cancer. Cancer is the

name of a collection of over 100 related non-communicable diseases and are caused by genetic changes to the ways human cells function and grow. Cancers can start in any area of the human body (National Cancer Institute, 2015). Cancers present a major obstacle to national development due to the treatment costs, lost productivity due to illness and death, and because they absorb scarce resources and entrench poverty (World Health Organization, 2009) for a country. The global total annual economic cost of cancer was estimated as $US1.16 trillion in 2010 (Stewart & Wild, 2014).

The global incidence of cancer is rising due to population growth and the aging of populations (Conley, Bishop, & Andersen, 2016). In 2008, there were 13 million new cases of cancer worldwide. This number rose to 17 million new cases by 2018 and is projected to be over 21 million new cases by 2030 (Cancer Research UK, 2019; Magnusson, Gostin, & Studdert, 2011). In New Zealand, cancer is the leading cause of morbidity and mortality (Ministry of Health, 2018b), accounting for one-third of all deaths with 24,086 new patients registered on the New Zealand Cancer Registry in 2016 (Ministry of Health, 2018c, 2019c).

In New Zealand, the most common type of cancer registrations over the five years between 2008 to 2012 were prostrate, breast, colorectal, melanoma and lung cancers which together account for 63 per cent of cancer registrations (Health Quality and Safety Commission, 2020). Costs are calculated for one year prior to diagnosis and five years post diagnosis, based on the mean price of services such as Primary Care consultation, laboratory testing, public hospital discharge, outpatient attendance and so on for ten different cancers. The calculated price of registered cancers in New Zealand in 2011-2012 was $880 million (Ministry of Health, 2019c). This was 6.3 per

cent of a total Vote Health budget of $13,953 million making the cost of cancer service provision a significant part of the New Zealand health budget (Ministry of Health, 2011b) and therefore making the allocation of resources an important consideration.

Since 2000, early detection and improvements in treatment survival have meant that people live longer following a cancer diagnosis. Between 1995-99 and 2010-14 survival trends remained flat internationally, however, after 2000 five year survival increased by five per cent in countries such as Denmark, the United Kingdom and the Netherlands and by 11 per cent countries such as the United States and Germany (Allemani et al., 2018). The New Zealand cancer mortality rates are also slowly reducing. Five year survival rates improved from 57.7 per cent in 1998-1999 to 63.3 per cent in 2011 (Ministry of Health, 2015). Research, lifestyle changes, screening tests such as mammography and colonoscopy, campaigns such as Quitline (Homecare Medical, 2017), developments of newer treatments such as immunotherapy, and improvements in managing side effects of existing pharmacological and other therapies have all contributed to the improved survival rates (Markham et al., 2020). Even with the advances in medical treatments listed above, the psychological impacts of cancer can still be distressing and overwhelming for cancer patients. Increases in survival have meant that there is now a large population of cancer survivors who undergo distress. Increased resources for psychological interventions for dealing with this distress are required due to the increased numbers of these patients.

2.4 Psychosocial aspects of cancer

Basic functions such as body temperature, pulse and respiration, which are routinely measured by medical professionals, are known as vital signs. Psychosocial distress is regarded as the sixth vital sign of cancer (after body temperature, pulse, blood

pressure, respiratory rate and pain: Health Outcomes International, 2011). Prevalence studies show that about 30 per cent or more of all people newly diagnosed or with recurrent cancer, develop significant psychological distress. This rate may vary according to the type of cancer; for example, a large study by Zabora, Brintzenhofeszoc, Curbow, Hooker, and Piantadosi (2001), of 4496 cancer patients with over 14 different cancer diagnoses found that the overall prevalence rate of distress varied from 29.6 per cent for gynaecological cancers to 43.4 per cent for lung cancer, with an overall rate of 35.1 per cent. A recent study by Carlsona et al. (2019) found a prevalence rate of distress of 46 per cent amongst 4664 cancer patients in over 55 cancer treatment centres in the United States and Canada.

Psychological trauma is linked to exposure to a traumatic stressor (Giesseler, Gaertner, Thaden & Theobold, 2018). According to the Diagnostical and Statistical Manual for Mental Disorders (DSM) version three (American Psychiatric Associaton, 1980) and subsequent versions including the currently used DSM version five (American Psychiatric Association, 2013), cancer is included in the definition of a traumatic stressor. A traumatic stressor is defined as "any event (or events) that may cause or threaten death, serious injury or sexual violence to an individual, a close family member, or a close friend." (American Psychiatric Association, 2013, p.271). A diagnosis of cancer meets the criteria of a traumatic event for some people. Krupnik (2019), defines trauma as "a stress response to an event (which) must meet a necessary condition that the event be outside of the person's normative life experience, and a sufficient condition that the response include a breakdown of self-regulatory functions" (p. 259). Trauma may lead to post traumatic stress disorder (PTSD), acute post traumatic stress, anxiety or depression. However not every person

diagnosed with cancer develops a traumatic reaction, there is evidence according to Marzilano, Tuman and Moyer (2020), that some people especially those with more advanced cancer, may make positive changes following a traumatic event described as Post Traumatic Growth (Tedeschi & Calhoun, 2004).

People can experience a range of reactions when they hear that they have a diagnosis of cancer and through the treatment process. The stressful event in the case of cancer may be protracted and continuous. Unlike other trauma's where the PTSD symptoms may include re-experiencing the trauma, the traumatising aspects of the experience of cancer may also be future orientated such as intrusive worry waiting for test results (Green et al., 1998).

Reactions may include intrusive thoughts, avoidant behaviours, sleeping difficulties, heightened arousal, shock, fear, hopelessness (National Cancer institute, 2019). For example, the greatest psychological difficulties reported by breast cancer patients are anxiety, distress, anger, feeling a burden, need for help, and greater body vigilance (Jones, Hadjistavropoulos, & Gullickson, 2014; Schubart et al., 2014). For cancers generally, the most common concerns reported were fear of recurrence, eating/weight issues, sleep problems, fatigue, anxiety, living with uncertainty, managing stress and pain (Ness et al., 2013; Schubart et al., 2014).

Although not all cancer survivors need psychological support, anxiety, depression, post-traumatic stress disorder and quality of life effects have been shown to be significant for many (Mehnert & Koch, 2008; Philip & Merluzzi, 2016). The effects may occur with either a surviving or a palliative prognosis. Mental health issues such as depression and anxiety can be present prior to, or as a result of, physical illnesses such as cancer. Many authors such as Kolappa, Henderson, and Kishore (2013) believe that

physical health interventions for non-communicable diseases (NCDs) should always include mental health treatments.

Increasing numbers of cancer patients survive, having completed treatments such as surgery, radiotherapy and/or chemotherapy which may cause debilitating side-effects such as hair loss, nausea and vomiting, fatigue and memory problems (National Cancer Institute, 2018b). Survivors report both positive (e.g., personal growth, well-being and post-traumatic growth) and negative (e.g., distress including Post Traumatic Stress Disorder) responses to this experience (Andrykowski, Lykins, & Floyd, 2008). Survivors may experience distress and impairment in physical and social functioning, which also causes distress. Cancer survivors may also experience on-going psychological issues such as fear of recurrence (FCR – also known as the Damocles syndrome) or fear of secondary malignancies as well as survivor guilt and sadness from surviving whilst others did not (Almeida, Elliott, Silva, & Sales, 2019; Cupit-Link, Syrjala, & Hashmi, 2018; Harpham, 2018).

Gender differences in psychological effects of cancer have been found regardless of type of tumour. Studies by both Bergerot et al. (2013) and Guo et al. (2013) found that female patients reported more symptoms, more distress, anxiety and depression and had a lower quality of life than male patients. Bergerot et al. (2013) hypothesised that this may be because women find it easier to express and communicate their emotions. Koyama et al. (2016)'s study using 101 Japanese cancer patients found that female patients were more likely to have distress related to changes in appearance, family issues such as feelings of responsibility for children and grandchildren and sexuality issues whilst male patients were more likely to have spiritual pain. The psychological

effects may be accounted for by the likelihood that women are better at expressing how they feel and gender roles rather than biological gender differences.

Research has shown that approximately 30 per cent of a rising number of survivors experience significant distress, be it as a result of the diagnosis or treatment and on-going adjustments. It is recognised that interventions to assist with the mental health impact of cancer are a part of cancer treatment. There are a growing number of survivors who will require access to an effective psychological intervention to go alongside their physical treatment needs.

The following sections will discuss in more detail three specific aspects of the psychological responses to cancer: Distress, resilience, and quality of life, that are the particular focus of this study.

2.4.1 Distress

Distress refers to "an unpleasant emotional experience of a psychological, social or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, or its treatment." (Dekker et al., 2017, p. 1027). The term 'distress' is commonly used rather than 'depression' to describe patients' emotional reaction because it is difficult to distinguish some symptoms of depression (such as poor appetite and poor sleep) from the symptoms of cancer or side effects of the treatment (Schubart et al., 2014). As distress is a mental health issue this distinction is useful as it helps target interventions to mental health needs rather than possible physical side effects of chemotherapy (for example, poor appetite).

Dekker et al. (2017) make the distinction between adaptive and maladaptive distress. Adaptive distress facilitates adjustment to important events. For instance, fear causes

physiological changes that prepare and support behavioural responses such as seeking support. Maladaptive distress includes emotional inertia, emotional instability, lack of emotional regulation, and other emotional responses that interfere with the patient's ability to deal with cancer (Dekker et al., 2017). This study will focus on teaching of behavioural skills to change maladaptive distress responses to more adaptive ones.

Patients' adaptation to the diagnosis of cancer is significantly influenced by pre-existing psychosocial factors such as a person's level of resilience, their social supports, optimism, self-confidence, and adaptive coping strategies (Min et al., 2013). Higher distress is positively correlated with younger age, more extensive surgery, single relationship status, concerns about eating and weight, sleep problems, fatigue, pain, reoccurrence of a cancer, and poorer problem solving skills (Schubart et al., 2014). The location and prognosis of cancer also predicts more distress (Zabora et al., 2001). In a five-year study of women with breast cancer, Hopwood, Sumo, Mills, Haviland, and Bliss (2010) found that patients with anxiety or depression at baseline were likely to continue to have anxiety and depression over time. The patients who were more distressed within the first two weeks of diagnosis continued to be the most distressed (Zabora et al., 2001). Tang, Castle, and Choong (2015) also found that distress increased over time for patients with extremity sarcomas. Therefore, this suggests that patients who are likely to be distressed can be identified as distressed early. Research indicates that these patients do not improve over time without intervention.

This study used the notion of distress to distinguish the mental health aspect of the cancer participant's experience. The research on distress identifies two kinds of distress - maladaptive and adaptive. Maladaptive distress responses include emotional

dysregulation, which has been the target of the intervention used in this research. Significant distress can be identified early and can increase if not treated.

2.4.2 Resilience

Definitions of resilience vary from it being seen as a stable personality trait, also called resiliency or trait resilience (Luthar, Cicchetti, & Becker, 2000), to an interactive dynamic process (Prince-Embury, 2013). In this study, resilience is defined using Eicher, Matzka, Dubey and White's (2015) conceptualisation of resilience as an active process measured by a person's capacity to cope with adversity (in this case, a cancer diagnosis, symptoms and treatment). Resilience is an important protective factor against distress (Seiler & Jenewein, 2019). Higher psychological resilience predicts decreased risk of emotional distress (Min et al., 2013). An integrative literature review by Eicher et al. (2015) concluded that the dynamic process of facing cancer diagnosis and treatment was impacted by the patient's resilience, social factors such as family supports and interpersonal relationships. It was also impacted by biological factors, for instance, hormone levels, developmental changes in brain structure and function and personal factors such as hope, self-esteem, cognitive appraisal and active coping.

Resilience is modifiable through psychological interventions (Seiler & Jenewein, 2019). Some psychological interventions that are important for enhancing resilience include coping strategies such as social support seeking and problem solving. A review of research on resilience and posttraumatic growth by Seiler and Jenewein (2019) identified several studies where patients with serious illnesses (including cancer) who used adaptive coping strategies were found to have better quality of life and less distress and increased likelihood of Post Traumatic Growth (Gori, Topino, Sette &

Cramer, 2021). The adaptive coping strategies found to enhance mental health included seeking social support and religious or problem focussed coping.

Similarly, a study by Manne et al. (2015) of 281 women with gynaecological cancers found that greater resilience was linked to greater quality of life. Coping strategies including cultivating a sense of peace and meaning in life accounted for 63 per cent of the relationship between resilience and quality of life. Of interest to the current research is that psychological resilience is modifiable with psychological interventions. The literature suggests that increasing adaptive coping strategies, which can be taught, leads to more resilience. The intervention in this research specifically uses coping strategies and therefore is arguably likely to enhance resilience.

2.4.3 Quality of life

The final outcome of any cancer depends on medical care, cancer type and stage; however, preserving the patients' quality of life and diminishing the burden of the illness as much as possible over the course of the illness, treatment, aftercare and life with cancer has become a major objective of treatment internationally (Sibeoni et al., 2018). The World Health Organization (1993) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (p. 153).

Higher levels of optimism, higher perceived social support and active coping are significantly associated with better quality of life (Applebaum et al., 2014). Popa-Velea, Diaconescu, Jidveian Popescu and Trutescu's (2017) study of 178 participants with a

variety of cancers, measured quality of life, resilience and active coping and found that by modifying resilience, psychological interventions, can have a positive effect on quality of life. This outcome is also supported by a review and meta-analysis of 2117 patients with colorectal cancer (Son, Son, Kim, and Lee, 2018) which found a significant benefit to quality of life from psychosocial interventions.

Increased quality of life is therefore influenced by increased resilience, which is modifiable by psychological interventions including active coping. Because preserving and improving quality of life is a focus of both the physical and mental health aspects of cancer care, the researcher considered that measuring quality of life was important in evaluating the effectiveness of the intervention.

In summary, the literature suggests that early identification of maladaptive distress is useful as patients who demonstrate distress early remain distressed without intervention. Resilience is modifiable by psychological interventions including active coping strategies. Higher resilience predicts reduced risk of distress and impacts positively on quality of life.

The next section will review the research in the area of the psychosocial impacts of cancer on people diagnosed with cancer and reviews the literature on these patients' psychological needs.

2.5 The development of a focus on meeting cancer patients' needs for psychological assistance

In 2009 the World Health Organization developed a global action strategy to prevent and control four prominent non-communicable diseases including cancer (World Health Organization, 2009). This strategy was criticised for not including mental health aspects of cancer patient's treatment (Kolappa et al., 2013). Kolappa and colleagues

called on member states of the World Health Organization to do away with what they considered the artificial boundary between physical and mental health (Kolappa et al., 2013).

Historically New Zealand has been slow to include psychological care as part of cancer care. The UK National Health Service cancer plan in 2000 identified psychological support as an integral aspect of good cancer care (Department of Health, 2000). Similarly, Australia and Canada included psychological needs and interventions in their clinical practice guidelines and strategies (Health Canada, 2002; National Health and Research Council, 1999). Although the New Zealand Health Strategy published in 2000 included reducing the incidence and impact of cancer, it did not explicitly identify the need to address the psychological impacts or developing a strategy and structure to address the psychological needs of cancer patients (King, 2000).

Guidelines for cancer treatment developed by the National Institute for Clinical Excellence (National Institute for Clinical Excellence [NICE], 2004) in the UK recommended assessment of psychological distress and support needs, and access to appropriate psychological support services as part of the treatment. The NICE (2004) guidelines also recommended a stepped care approach where the level of intervention provided was matched to the severity of need. According to these guidelines, the use of psychological therapies has generally been aimed at two places: Firstly at mild to moderately distressed patients, which can often be delivered in group interventions; and secondly at patients with severe symptoms of distress, who require individual therapy, typically by a psychologist (NICE, 2004).

In 2006 the first psycho-oncology service, resulting from a partnership between The Mid-Central District Health Board and Massey University was started based at Massey

University Psychology Clinic at Palmerston North . Clinics expanded to locations around the Mid-Central region including Feilding. Horowhenua and Tararua. Links with the University enabled this unique service to provide a psychology service as well as research the effectiveness of psycho-oncology interventions (Massey University, 2008).

It was not until 2014, that recognition of cancer survivors' needs for mental health input led to the New Zealand Government targeting sustainable funding to increase psychological resources for cancer patients. The government provided funding to increase the numbers of both psychologists and social workers employed in Oncology (Ministry of Health, 2014). This funding developed into the Psychological and Social Support for Cancer Initiative in New Zealand (Greensmith et al., 2017).

The statement of principles which guide the implementation of the Psychological and Social Support for Cancer Initiative recommends a stepped care approach, identification of need through screening, and availability of equitable, evidence based options which also meet the needs of people living in rural and remote areas (Greensmith & Bell, 2015). A stepped care approach in New Zealand would utilise a therapy group for patients with mild-moderate distress and would free psychologists to deal with those who experience more severe distress and need individual interventions, this is in line with the NICE (2004) guidelines. The group therapy to be used in New Zealand would need to address patients' distress in the mild-moderate range and be able to be delivered in both rural and urban areas so that it was equitable. The opportunity to develop a group programme that would fit these requirements is one of the drivers for this study.

2.6 Formats for psychological therapies for cancer patients

Psychological therapies can be delivered in several formats. Patients can be seen individually,. For example, Lo et al. (2013) developed brief individual psychotherapy for patients with advanced cancer which had a small effect size and achieved encouraging results which need further research. Therapy can also be delivered to couples; for instance, Baucom et al. (2009) developed a couples based psychological intervention which involved women with breast cancer and their partners which has also shown promise in improving individual and couples functioning. Families have also participated in therapy; for example Kazak et al. (1999) developed a family based intervention for adolescent cancer survivors and their families where results showed a decrease in post-traumatic stress and anxiety symptoms. Therapy can also be delivered in groups; for example, Classen et al.'s (2001) study which developed a supportive-expressive group therapy for patients with metastatic breast cancer which demonstrated a reduction in traumatic stress symptoms. The mode of delivery can also vary and includes face-to-face, over the telephone, using self-study (for example, through manuals or self-help books) or via the internet. The literature therefore indicates that there have been a range of formats for delivery of psychological therapies that have been found to be effective for cancer patients. In the research study reported here, a group therapy format delivered face-to-face was used.

2.7 Facilitation of psychological therapies

Counsellors, psychiatrists (Chujo et al., 2011), nurses (Anderson et al., 2013), social workers (Sautier et al., 2014) as well as psychologists have delivered psychological interventions (Omylinska-Thurston & Cooper, 2014; Yavuzsen et al., 2012) for cancer patients. Of the two studies that used the same intervention as this research (Dialectical Behaviour Therapy (DBT) with cancer patients, neither had groups run by a

clinician trained in the therapy. Hejazi et al. (2014) did not clearly identify who administered the DBT intervention and in Anderson et al's (2013)study, the group was facilitated by plastic surgery nurses. Both Anderson et al (2013) and Hejazi et al (2014) found that DBT led to improvements in the measures tested. In the present study, a Clinical Psychologist specifically trained in DBT delivered the intervention. The researcher considered that delivery by an expert within this research context maximised the chances of accurately representing the DBT model of therapy. If DBT proved useful in this study, the evidence developed could then inform delivery by less expert clinicians using a manual developed as part of this study.

2.8 Psychological group therapies in the mental health setting

Group psychotherapies are a common modality for delivery of treatment and are defined as "two or more individuals who are connected by or within social relationships" (Forsyth, 2014, p. 4). According to Yalom and Leszcz (2005) who have reported extensively on the benefits of group therapy, groups often support the installation of hope, allow members to experience their universality and similarity to others, and enable efficient sharing of information. Members can be altruistic and help others, as well as learn from watching how others tackle problems (Yalom & Leszcz, 2005).

Group treatments also represent a more cost-effective way of delivering therapy than individual therapy sessions because multiple individuals can receive treatment at once and therapists may require less training since the treatment may follow a well-specified protocol (Blackford & Love, 2011).

Groups can be classified according to group leadership style and therapeutic goals. Groups range from highly specific therapeutic goals with high levels of leader-

directedness (such as problem solving or skills based psychotherapy groups), to groups with nonspecific goals and little direction from leaders, (such as support groups). Support groups provide a psychosocial network where there are opportunities for sharing of problems and experience, whereas problem solving/skills based groups often focus on shared learning and modelling by the group leader teaching specific information and having specific goals (Montgomery, 2002).

In keeping with the research that active problem solving is useful for modifying resilience, DBT, the group intervention in this study is a problem solving/skills based group. One of the main modes of therapy used in DBT is behavioural skills teaching and coaching in groups. DBT skills groups focus on teaching active skills and strategies balanced with mindfulness and acceptance of reality (Swales, 2019). The teaching of skills in groups also represents the most cost efficient way of imparting DBT skills and knowledge whilst also allowing group members to observe and learn from other group members in the same situation as themselves.

2.9 Models of group therapy

Groups can also be categorised according to the orientation or model that they use. There are a number of schools of thought, some of which will be briefly discussed here. and. Psycho-analytic approaches derived in the late 19th and early 20th century developed from Freudian psychoanalysis (Freud, 1922). This model focuses on the individual's internal conscious and unconscious emotional life which are made up of the person's character structure, psychological defence patterns and other factors which are based on their relationships in the past particularly early child rearing practices (Neukrug, Brace-Thompson, Maurer, & Harman, 2015). The group process focusses on observing exchanges in the present that relate to past conflict and

analysing the context and relationships between individuals and with the group leader. Psychotherapy groups using this model are generally low structure with emphasis on insight and high attention to transference and issues such as analysing resistance (Price, Hescheles & Price, 1999).

Interpersonal therapies are grounded in the concept of attachment theory that suggests that distress is caused by relational challenges that remind the individual of early disruptions with key attachment figures. The focus of the therapy is on getting the individual's interpersonal needs met rather than altering how they think. This model has many components such as doing homework, role playing and modelling which are similar to Cognitive-Behavioural therapies; however, the focus is on interpersonal relationships and achieving interpersonal objectives (Neukrug et al., 2015).

Family Systems Theory developed by Murray Bowen in the 1960's focuses on common patterns in human emotional systems namely families. Whilst in Freud's psychoanalytic tradition, psychopathology is related to early life experience with one's parents, from a Family Systems perspective, Freud's concept cannot account to the cause of the symptom's occurance. Family System's theory conceptualises symptoms as reflecting a disturbance in the balance of emotional forces in the person's most important relationship systems most often the family system (Kerr, 2013) . The goal of therapy is to reduce anxiety by facilitating awareness of the functioning of the family system and to increase differentiation so that the individual can function autonomously (Brown, 1999). The therapist uses questions to encourage a multi generational lens to connect the client's present relationship problems with the ways previous generations have dealt with similar issues. The therapist's position is of a

calm interested investigator so that the family can learn about itself as an emotional system (Brown, 1999).

In Aotearoa/ New Zealand Te Whare Tapa Whā developed by Mason Durie (1985) represents one of the developing models of health that provides a Māori perspective. The model, describes health as being made up of four dimensions or cornerstones using the metaphor of a meeting house (wharenui). Health is made up of taha wairua (spirituality), taha hinengaro (mental health), taha tinana (physical health) and taha whānau (social relationships). The goal of therapy is attending to each of these dimensions to achieve well being.

Behavioural (and its later development Cognitive Behavioural Therapy (CBT)) theory began with the work of J. B. Watson (1913) and the theories of operant conditioning developed by Skinner (1938) and others. The early behaviourists did not consider thoughts or emotions; however, during the 1950's and 1960's it was considered that cognitions and behaviour affect emotions and personality. CBT applied behavioural principles to cognitions, was easily researched and showed that CBT techniques could be effective with a number of issues such as anxiety and depression in a relatively short period of time (Neukrug et al., 2015).

2.9.1 Dialectical Behaviour Therapy

It is this researcher's observation from clinical practice that the diagnosis of a life threatening illness such as cancer, which is outside of an individual's usual experience and ability to cope, appears to lead to some of the same kinds of dysregulation, distress and anxiety seen in patients diagnosed with Borderline Personality Disorder (BPD). BPD is a mental health diagnosis which includes emotional dysregulation and behavioural control issues as core problems and often involves the individual having

undergone psychological or physical trauma (Swales, 2019). . Dialectical Behaviour Therapy (DBT) is a form of Cognitive Behaviour Therapy (CBT) specifically developed to target emotional regulation and distress tolerance (Linehan et al., 2006) for people diagnosed with BPD or emotional dysregulation.

Emotional dysregulation is defined by Neacsiu, Eberle, Kramer, Wiesmann, and Linehan (2014) as "lacking the skills necessary to regulate emotions or using maladaptive strategies to regulate emotions" (p. 40). Elements of DBT include the meditative practice of mindfulness, skills that help with accepting situations, breathing, relaxation, and problem solving. DBT as a treatment consists of both individual and group skills components; however, the group component alone has been found to be effective in reducing emotional dysregulation (Linehan et al., 2015). DBT is taught using a manual and the group protocols can be taught by non-psychologists (Feigenbaum et al., 2011), an important consideration when picking this intervention for this research.

Behaviours that interfere with the quality of life of people with emotional dysregulation are one of the main targets of therapy in DBT. There have been a few studies regarding DBT and quality of life for mental health populations; for example, Swales, Hibbs, Bryning, and Hastings (2016) found that for 43 adolescents with a Borderline Personality diagnosis attending DBT treatment, health related quality of life was improved between admission and discharge but not to statistically significant levels. In a study of 30 patients with Irritable Bowel Syndrome, Mohammadi and Azizi (2017) found that those patients in the DBT groups had significantly improved quality of life compared to controls.

Research with DBT with a mental health population

To date there have been 20 published randomised controlled trials (RCTs), six published quasi experimental trials, and other unpublished trials that demonstrate the efficacy of DBT for people with BPD, compared with treatment as usual (for example, Linehan et al., 2006; Linehan, Dimeff, Koerner, & Miga, 2014; Linehan et al., 2015). Washburn, Rubin and Zhou (2018) have published benchmarks for outpatient DBT in adults with BPD. Self-reported aggregated within–group effect sizes were 0.99, 95% confidence interval (0.29, 0.57) for depression in comparison with treatment as usual effect sizes of 0.86, 95% confidence interval (0.71, 1.01) for depression.

DBT has also been used trans-diagnostically for other presentations that include emotional dysregulation, high risk of suicide, substance misuse, and other chronic disorders. DBT has been reported as efficacious in treating eating disorders (Federici, Wisniewski, & Ben-Porath, 2012), problem gambling (Christensen et al., 2013), bipolar disorder (Goldstein et al., 2015) and Attention Deficit Hyperactivity Disorder (ADHD) (Cole et al., 2016; Fleming, McMahon, Moran, Peterson, & Dreessen, 2015).

A pilot randomised controlled trial using DBT skills for people with various mental health issues (non-BPD) conducted by Neacsiu et al. (2014) found that DBT was superior to an activities based support group in significantly decreasing emotional dysregulation and anxiety at one year follow-up. Decreases in depression were significantly greater for the DBT group during the study, but not at follow-up (Neacsiu et al., 2014). Participants in DBT are more likely to complete treatment than participants in other therapies (Linehan et al., 2006). This is of particular interest with cancer patients, because high drop-out rates are common in research studies of cancer

patients using psychological interventions (Hui, Glitza, Chisholm, Yennu, & Bruera, 2013).

The researcher's work delivering the brief DBT groups (developed in the United States) at a publically funded community mental health service in New Zealand, is focussed on helping mental health service users develop emotional regulation skills. The full DBT protocol involves a year long programme of both individual and group therapy; many overseas studies have adapted the protocol to make it briefer and remove some of the skills. The DBT treatment group reported by Neacsiu et al., (2014) involved skills training alone over a 16-week period. Booth, Keogh, Doyle, and Owens (2012) adapted DBT to a six-week group-only intervention in a psychiatric inpatient setting where patients generally have shorter lengths of stay and therefore have limited time in which they can participate. The results of Booth et al's study achieved positive results in distress tolerance over a three-month follow-up period. Fleming et al. (2015) also adapted DBT to an eight-week group-only intervention for college students with ADHD and found greater treatment response rates and improved quality of life than the control group.

I have facilitated a brief DBT group in a community mental health service in Auckland, New Zealand for 20 years. Zhao's (2006) research study with a mixed population of mental health service users who attended the groups facilitated by me found significant improvements were achieved for 66 matched pre and post group pairs on the Beck Anxiety Inventory (BAI) (Beck & Steer, 1993a) and 65 paired results on the Beck Hopelessness Scale (Beck & Steer, 1993b) ($r = .60$ and $.44$ respectively: $p < .001$).

In summary, the research shows that DBT is an effective intervention for emotional dysregulation and distress not only for BPD mental health service users but also with

other patients with a mental health diagnosis. DBT has been adapted in shortened forms in several settings and the skills training groups alone have been found to be effective without the individual therapy component. The brief DBT group run by the researcher has also demonstrated improvements in anxiety and hopelessness. In the following section, the research is presented on psychological interventions for cancer patients.

2.10 Psychological interventions for cancer patients

2.10.1 Screening

Using screening to identify need

Early screening for cancer patients is important as higher initial distress can predict lingering distress many years later (Zabora et al., 2001). Identifying which cancer patients experience elevated levels of distress is important because without screening, a large number of patients decline or do not participate in psychological interventions as their level of distress is not high enough for them to see the value of seeking help or they may be reluctant to admit they are distressed (Roth et al., 1998). Screening also allows treatments to be targeted to those who most need it. Treatment benefit from psychological interventions for patients identified by screening is three times higher than for unscreened patients (Sanjida et al., 2018),. Therefore; in the current research a screening tool was used to identify those potential participants who were distressed.

Screening tools

The use of a psychological screening measure to identify distressed patients is one of the basic standards of cancer care in many countries including the US (American College of Surgeons, 2015; Institute of Medicine of the National Academies, 2008), Australia (Butow et al., 2015; Cancer Australia, 2014) and New Zealand (Greensmith & Bell, 2015). The alternative to using a screening tool to identify distress is to have every

patient psychiatrically evaluated. This has been found to be less successful; for example, Roth et al's (1998) study found 12 out of a group of 29 men with prostrate carcinoma either missed the interview or refused to be interviewed. According to Roth et al, psychiatric evaluation of people with a physical health issue may trigger shame, anti-psychiatric biases and has a much higher cost in terms of use of resources and time. Therefore, finding a screening tool that is fast to administer and does not have these disadvantages was a consideration for the current research.

In New Zealand, screening is recognised as important to ensure that patients with significant support needs can be better identified. However, some clinicians do not feel confident identifying distress and worry that they have no way of addressing (Central Cancer Network, 2015). Associate Professor Lois Surgenor, a clinical psychologist, (personal communication, September 15, 2015) stated that a large issue for the few psychologists working in oncology in New Zealand is the over-referral of mild to moderate cases, and an under referral of severely distressed patients. Patients with initial distress have on-going distress (Bjordal & Kaasa, 1995; Ganz et al., 2013; Uchitomi et al., 2003). One of the implications of screening to identify those people who are distressed is that the distress will be addressed via the provision of service aimed to address it. Currently there is a lack of treatment options. One of the aims of this research is to develop a group intervention which will enable more people who are identified as mild to moderately distressed to receive psychological treatment, freeing psychologists to focus on more severely distressed individuals thereby better using resources.

Initial screening measure selection

Psychological assessment measures to identify distressed patients for psychological intervention need to be brief, reliable and valid, and need to be able to differentiate depression symptoms from the effects of cancer symptoms (Hejazi, Sobhi, & Sahrzad, 2014). Many researchers have used rating scales such as the Hospital Anxiety and Depression Scale (HADS) (Omylinska-Thurston & Cooper, 2014; Sautier, Mehart, Hocker, & Schilling, 2014) or the Beck Depression Inventory (BDI) (Hejazi et al., 2014; Yavuzsen, Karadibak, Cehreli, & Dirioz, 2012) that include symptoms such as tiredness and lack of appetite that may result from cancer or its treatment rather than from depression. Measures like the HADS may identify anhedonia which may be present due to physical illness rather than depression in patients with advanced cancer (Lloyd-Williams, Friedman, & Rudd, 2001). As an initial screen, a number of researchers have used simple Likert scales to measure distress such as a Distress/Emotions Thermometer (Anderson, Jensik, Peloza, & Walker, 2013; Sautier et al., 2014; Schubart et al., 2014). Alternatively, they have focused on anxiety, such as the Salkovski Health Anxiety Inventory (Jones et al., 2014), the State Trait Anxiety Inventory (Kovacic, Zagoricnik, & Kovacic, 2013); quality of life, such as the Quality of Life Questionnaire (Chujo, Kigawa, & Okamura, 2011); and/or measures of resilience such as the Connor-Davidson Resilience Scale (Min et al., 2013). Many of these instruments are commonly used and are brief to administer.

The literature indicates that previous studies have used a variety of tools as an initial screen. The distress thermometer was chosen for this research. Baken and Wooley (2011) validated the distress thermometer for a New Zealand population in a study using 200 patients from a New Zealand central regional cancer treatment service. They also supported the cut-off scores of four suggested in the lierature. The choice of the

distress thermometer is also in line with the Psychological and Social Support for Cancer Initiative for New Zealand's (Greensmith et al., 2017) recommendation of a distress thermometer (Butow et al., 2015; Kelly, McClement, & Chocinov, 2006) as one of the two possible best options for a validated initial brief screening tool. In the following section, the research regarding the strategies that have been found to be useful for distressed cancer patients is presented.

2.10.2 Psychological strategies identified as useful for cancer patients

A number of different strategies have been found to be helpful for distressed cancer patients. These strategies include mindfulness (Shennan, Payne, & Fenlon, 2011), relaxation training (Sautier et al., 2014), yoga/relaxation (Kovacic, Zagoricnik, & Kovacic, 2013), problem solving (Nezu, Nezu, & Saber, 2013), stress management (Yavuzsen et al., 2012), cognitive behaviour therapy (Heinrichs et al., 2012; Watson, White, Lynch & Mohammed, 2017) and coping strategies (Chujo et al., 2011). Acceptance is also seen as an important skill (Hulbert-Williams et al., 2015). Teaching patients active coping strategies rather than passive avoidance is most effective (Hulbert-Williams et al., 2015). Delivery of interventions has been via individual (Nezu et al. 2013), couple (Heinrichs, 2012), family (Nezu et al., 2013) and group formats (Shennan et al., 2011), and in person and via telephone (Watson et al., 2017). The current research used a group format that will be discussed in the next section.

2.10.3 Group psychological therapies for cancer patients

Description and outcomes of psychological group therapy for cancer patients

Group interventions have been used for cancer patients (Lachman, 2002) and have been identified as helpful in reducing distress, anxiety and hopelessness and increasing quality of life (Yavuzsen et al., 2012). Different group formats have been found to be

helpful. Some of the group formats have included supportive-expressive therapy (Classen et al., 2001), mindfulness based interventions (Shennan et al., 2011), relaxation and psychosocial support (Sautier et al., 2014), education, physiotherapy and stress management (Yavuzsen et al., 2012), problem solving therapy (Nezu et al., 2013), stress coping plus relaxation (Chujo et al., 2011), relaxation alone (Kovacic et al., 2013), written and verbal disclosure support (Carmack et al., 2011) and group coping skills, (Telch & Telch, 1986). Acceptance and Commitment Therapy (Hulbert-Williams et al., 2015) and DBT (Anderson et al., 2013) have also been found to be useful. As the current research involved teaching group based DBT skills, some examples of individual studies, reviews, and meta-analyses that are of particular relevance are described below.

The results of a study by Telch and Telch (1986) which compared three conditions, (group coping skills instruction, support group therapy and no treatment) found consistent positive treatment gains for patients with a variety of cancer diagnoses attending the coping skills group compared to the support group (little improvement) and the no intervention group (deterioration in psychological functioning). The coping skills group outlined by Telch and Telch appeared to have many elements that are consistent with the behavioural skills-based content of DBT groups. The coping skills group consisted of six sessions held weekly (up to two hours duration) and emphasised homework, goal setting, behavioural rehearsal and coaching. Coping skills taught included relaxation and stress management, communication skills, problem solving, feelings management and planning pleasant activities. These interventions were similar to the behavioural skills-based content of the groups in the current study,

which suggests that skills based intervention like DBT may be efficacious for cancer patients.

Early studies, such as one by Speigel, Kraemer, Bloom, and Gottheil (1989) claimed that psychological interventions increased survival. However Speigel et al's (1989) study with 86 women participants with metastatic breast cancer had methodological anomalies. The anomolies included unintentional bias because the control group in this study died at a faster rate than the normal population of recurrent breast cancer patients whilst his treatment group lived as long as what would be expected in a general population of women with metastatic breast cancer (DeAngelis, 2002). Speigel's results have not been replicated; for example, a study by Goodwin et al. (2001) of 235 women with metastatic breast cancer found that the same intervention used by Speigel did not prolong survival but did improve mood and perception of pain. The aim therefore of psychological interventions with people with cancer is not necessarily to prolong life but to increase quality of life.

A randomized control trial by Guo et al. (2013) of patients with various cancers undergoing radiotherapy showed that group therapy of eight to twelve hours for groups of five to eight people involving psycho-education and Cognitive Behaviour Therapy, including coping styles and supportive-expressive therapy, did not affect survival rates but did improve anxiety, depression and quality of life especially in female patients. Similarly, Hulbert-Williams, Storey, and Wilson (2015) reviewed research on psychological group interventions for patients with cancer, and concluded that quality of life is improved (less pain, better mood, reduced constipation, and improved body image) rather than length of survival.

The target population for which DBT was developed are people with Borderline Personality Disorder who are at high risk of suicidal thoughts and actions. Cancer patients also have four times more risk than the general population of completing suicide (Zaorsky et al., 2019). DBT group therapy focusses on patients developing a "life worth living" (Linehan, 2014a, p. 15) and includes using skills to focus on improving quality of life.

A number of group formats have been found to improve quality of life of cancer patients including teaching active coping. Telch & Telch's study (1986) which used a group coping skills condition that had many elements similar to DBT skills groups suggested that DBT may benefit cancer patients. Although psychological interventions may not increase survival, quality of life has been found to improve. One of the specific focuses of DBT is on the area of quality of life.

Description and outcomes of DBT group therapy for cancer patients

The database searches described at the beginning of this chapter identified only two studies of the use of DBT for people with cancer. Both studies had small numbers of participants. Hejazi et al's (2014) study of 30 women with breast cancer reported significant improvements in anxiety and depression.

Anderson et al. (2013) reported a pilot study involving 17 women participants with early stage breast cancer. Results for the pilot showed that after eight weeks of DBT, insight and behaviour changes were reported by the participants. However, there were attendance and compliance issues. A second study also reported in Anderson et al. (2013) of 14 women with early stage breast cancer showed statistically significant improvements in the post intervention measures of distress, biothermal measures and pulse as measured by a biofeedback log using a Mann-Whitney Rank Sum Test and the

somatisation measure of the Brief Symptom Inventory 18 (Derogatis & Fitzpatrick, 2004) which is not reported in detail. Biothermal measures improved significantly from pre-test (M=1.23, SD=.49) to post-test (M=2.39, SD=1.00), t(34)=6.14, p<.001. Pulse also improved significantly between pre-test (M=94.92, SD=11.43) and post-test (M=82.33, SD=8.71), t(35)=5.25, p<.001. Distress level as measured by a Distress Thermometer also improved significantly from pre-test (M=6.82, SD=2.00) to post-test (M=3.36, SD=1.65), t(47)=9.29, p=<.001. DBT skills were taught in both individual and group sessions.

Both Anderson et al's (2013) and Hejazi et al's (2014) studies using DBT with cancer patients have some methodological issues. For example, in Hejazi et al's study DBT was delivered in the Persian language; as DBT was developed in English in the United States, there may be cultural differences as to how the treatment was delivered which may have made a difference to the outcomes and their generalisability to New Zealand. The exact skills taught are also not specified in Hejazi et al's study so adherence to the DBT model is difficult to determine; the English version of Hejazi et al's study also leaves out some statistical information and results tables.

Anderson et al's study used biofeedback reports of pulse and biothermal measures as an outcome measure. Biofeedback itself is a treatment for anxiety, is not part of DBT and may have influenced the results. The treatment in Anderson et al's study was led by plastic surgery nurses not specifically trained in DBT. Therefore, although Anderson et al and Hejazi et al have found positive results, the factors outlined above highlight the need to investigate the utility of DBT for people with cancer in New Zealand further. In the next section the research regarding factors such as client characteristics and participation in research by cancer patients are presented.

2.10.4 Factors impacting on outcomes in psychological interventions for cancer

Based on past research, a number of factors including client characteristics, participation by clients and retention of clients in the therapy have impacted on psychological therapies for cancer. In the following section each of the factors is considered and discussed.

Client and intervention characteristics

Past research has been impacted by low participation rates of cancer patients. The intention of the current research was to maximise the chances of participation of participants by considering the factors known from past studies to make participation more likely. A meta-analysis by Sanjida et al. (2018) found that poorer outcomes (demonstrated by low effect size) for anxiety reduction were predicted by patient characteristics including lack of distress at baseline, lack of screening, diagnosis of breast cancer, female patients, or newly diagnosed patients. Intervention characteristics that predicted better outcomes included low dose interventions, lower duration, low number of sessions and low total hours. Eyles et al. (2015) also found that long interventions, such as, eight weeks with interventions such as Mindfulness Based Stress Reduction therapy (MBSR), with too much practice at home were not well accepted by cancer patients. The factors identified by Eyles et al. (2015) and Sanjida et al. (2018) highlight the importance of aspects such as screening for distressed participants, making psychological intervention sessions short (with a low number of sessions) and making practice at home brief in order to achieve the best outcomes.

A study by Chujo et al. (2011) comparing cancer patients who chose to participate in group interventions with non-participants found differences in constipation, body image and future perspective. Participants reported a higher quality of life and

described a desire to deal with psychological distress as their main reason for participating. Time needed to attend was not an obstacle to attendance. There were no significant intergroup differences for initial stress levels – non-participants still had stress but did not want to talk to others and wanted to avoid hearing bad news. Other factors considered by the researcher in relation to the current research discussed below are participation and retention of participants.

Participation and retention

Recruiting and retaining patients in oncology clinical trials is frequently mentioned as difficult, leading to studies that are underpowered, prematurely stopped, or biased due to drop out. Hui et al. (2013) reported that attrition rates range from 34 per cent to 80 per cent, with more symptoms at the time of enrolment and a higher education level predicting more likelihood of dropping out. Hui et al. (2013) also recommend that studies be as short as possible, that they minimise the study burden, and support the patients. Schellekens et al. (2016) reported that amongst palliative care and survivor patients, anticipatory fear of meeting other patients was a frequent reason for dropping out of therapy, typically taking at least two sessions for the fear to diminish. Patients feared having to face the suffering of others and expressed reluctance to face the possible negative course of the disease in palliative patients which may make them feel worried about their own prognosis. In addition, patients reported that they feared becoming distressed through identifying with others suffering as well as fear of feeling survivor guilt when comparing their own experience with others who may have a worse prognosis.

According to studies by Sautier et al. (2014) and Kelly, Tyrka, Price and Carpenter, (2008) there are several factors which increase the likelihood of participation in patient

support groups for cancer survivors. Patients who were younger, unemployed, less educated, and who had a higher emotion coping style were more likely to participate. A higher emotion coping style is where coping is aimed at changing emotional responses to a stressor by use of strategies that include venting, self-blame, positive reappraisal and rumination. Patients who had more treatments and a stronger desire to deal with psychological distress were also more likely to participate. Patients also participate more if they perceive that the intervention will be helpful (Sautier et al., 2014).

Factors known to increase retention and participation were considered by the researcher. Strategies such as making sure the intervention was brief (which fits with brief DBT groups), screening for distress, informing participants of the helpfulness of DBT for other diagnoses, as well as informing participants about the positive results in past research studies, were used to try and enhance involvement in the study. The next section, describes current psychosocial resources for cancer in New Zealand.

2.11 Psychosocial resources for cancer in New Zealand

Despite cancer being common, resources in New Zealand are scarce for people to receive psychological support, particularly after the early diagnostic and treatment stage. Psychosocial services in the public healthcare sector are currently based in the six national cancer centres (Smith, Esplin, Cherrington, Boyle & Prince, 2018). These centres are in the Auckland, Canterbury, Capital and Coast, MidCentral, Southern and Waikato District Health Boards (Ministry of Health, 2019a). Tumour standards are descriptions of internationally accepted levels of service that cancer patients should have access to. They enable variation in levels of care to be identified and treatment gaps to be addressed (Ministry of Health, 2019d). Standards support consistent,

equitable treatment which is person centred and allows system integration. Treatment for cancer in New Zealand is organised by tumour standards which includes brain, breast, gynaecological, haematological, head and neck, lower gastrointestinal, lung, sarcoma, upper gastrointestinal, urological and other cancers as part of the Ministry of Health's Faster Cancer Treatment initiative (Ministry of Health, 2018a). Internationally, setting tumour standards is accepted as the way of driving quality healthcare improvements. Provisional standards based on national and international guidelines have been developed by working groups and consumer health representatives in New Zealand. These standards were then informed by wider consultation with key stakeholders and professional organisations (Ministry of Health, 2019d). Equitable and coordinated access to supportive care in accordance with the 2010 guidance for improving supportive care (Ministry of Health, 2010) forms part of the standards for each tumour group (Ministry of Health, 2013). Referrals from general practitioners (GPs) or surgeons in the Northern region are seen at Auckland City Hospital, Oncology Department. Treatment may include surgery, chemotherapy and/or radiation therapy (Healthpoint, 2019). Following treatment, patients are discharged home with follow up by their GP and regular monitoring by the cancer centre.

Patients receive psychological services from psychologists based in Oncology services. Some patients also receive psychological support through the Cancer Society which is a non-governmental organisation reliant on community support and donations (Cancer Society, 2015). People with cancer may also join specific support groups such as Breast Cancer Support (Breast Cancer Support, 2019).

Evaluation of the Psychological and Social Support Initiative funded by Ministry of Health in 2014 (Ministry of Health, 2014a) by Smith et al. (2018) indicated that 83 per

cent of referrals to psychologists working in Oncology Departments are made at the front of the pathway (during suspicion of cancer, diagnosis, or treatment) with few referrals being made post-treatment or at recurrence. Smith et al. (2018) considered that this may in part be due to scarcity of the psychology workforce generally compounded by the lack of availability of expertise in working with the level of high distress of the cancer population as well as New Zealand wide difficulties recruiting. The most recent Cancer Action Plan (2019-2029) (Ministry of Health, 2019c) once again prioritises equity of cancer care and a sustainable skilled workforce.

The resources for psychosocial support are limited in New Zealand with standards being provisionally developed to ensure equity of access for all New Zealanders. The standards for all tumours include psychosocial support. Support is provided via psychologists based in national cancer centres as well as the Cancer Society and other support groups. The limited workforce to provide the psychosocial support that is outlined in the standards is currently focussed on the front part of the cancer pathway (suspicion of cancer, diagnosis and treatment). There is a gap in effective group interventions for mild to moderately distressed people with cancer, especially post treatment. This gap means that there is currently a lack of equitable, available psychosocial treatments and a lack of workforce to provide it. The current research may fill this gap by providing a group intervention that can be administered by non-psychologists.

2.12 Summary

The global incidence of cancer is rising due the aging of the population and population growth (Conley et al., 2016). In New Zealand cancer is the leading cause of death (Ministry of Health, 2018b), but, as medical treatments become more successful and

people with cancer survive longer, there is an increasing burden on the New Zealand public health system. In 2011-2012, the calculated price of treatment for the population of people diagnosed with cancer from a year prior to diagnosis to five years post diagnosis was $880 million (Ministry of Health, 2019c). Treatment of cancer is therefore a significant cost to New Zealand and should be the most effective, best practice allowing the best quality of life possible for cancer patients.

Psychosocial distress is a vital sign of cancer (Health Outcomes International, 2011). About 46 per cent of cancer patients suffer significant distress (Carlsona et al., 2019) which can be due to the cancer itself, changes in role and lifestyle or the medical treatment and its side effects (Schubart et al., 2014). These can be overwhelming for some cancer survivors. Distress can sometimes be adaptive as it can facilitate adjustment. In this study, distress is taken to mean maladaptive, emotional reactions that interfere with the ability to cope (Dekker et al., 2017). Reducing the level of distress, in part through building resilience, is important for improving the quality of life for people at all stages of living with cancer (Popa-Velea et al., 2017). Resilience is modifiable through psychological interventions and adaptive coping strategies that enhance mental health, increase quality of life and reduce distress (Seller & Jenewein, 2019). Although psychological groups for cancer do not increase survival, they can be aimed at reducing distress and increasing and improving quality of life (Hulbert-Williams, Storey, & Wilson, 2015). The focus of the current study is on the development of a group treatment that taught adaptive coping strategies that were likely to improve distress by increasing resilience and therefore quality of life.

There have been a number of formats used for psychological therapies for cancer patients such as individual or group based therapies. This research used a group

therapy delivered face-to-face facilitated by an expert which was thought to be the best way to maximise the chances of accurately representing the DBT model of intervention. The outcomes could then inform delivery via a manual by less expert clinicians. Internationally, psychosocial treatments have been part of cancer treatment since the early 2000's (Department of Health, 2000). In 2014, the New Zealand government targeted funding for psychosocial support via the Psychological and Social Support Initiative. This initiative advocates a stepped care approach whereby patients who have mild to moderate distress would attend a group treatment (Greensmith et al., 2017). There is currently a lack of workforce resource and ability to meet the needs of mild to moderately distressed cancer patients (Smith et al., 2018). There is also a commitment by the New Zealand Government to equity and best practice tumour standards (Ministry of Health, 2019c). Additionally there are a rising number of cancer survivors (Health Quality and Safety Commission, 2020). The current research investigated a group therapy that could fill the gap in treatment provision for this mild to moderate group.

DBT (Linehan, 2014a) is a treatment for emotional dysregulation and complex presentations that has been well researched with over 20 RCTs in mental health settings; however, there is little literature related to its use for cancer patients. It is a problem solving skills-based group rather than a support group, and includes some of the strategies found to be helpful for cancer patients such as relaxation, mindfulness and problem solving (Sautier et al., 2014; Shennan et al., 2011). The literature above suggests that DBT might assist people with cancer in managing their distress and improving their quality of life. Brief DBT skills groups are short-term, involving six sessions for a total of three weeks. Short interventions have been shown to be the

more effective for cancer patients (Eyles et al., 2015). Participation and retention of cancer patients in clinical trials has been a consistently discussed problem in cancer research (Hui et al., 2013). Patients who are distressed and have a desire to deal with the distress are more likely to participate (Sautier et al., 2014). Screening to identify need is a basic standard of cancer care in many countries (Greensmith & Bell, 2015). Screening is important in terms of participation and retention. Screening also targets treatment because patients who become distressed initially are more likely to remain distressed (Zabora et al., 2001). The current study therefore used a Distress Thermometer (Roth et al., 1998) as a screening tool as recommended and used by the Psychological and Social Support Initiative (Smith et al., 2018).

The present study aimed to extend knowledge both about how to adapt DBT for cancer patients and the outcomes of doing so. This study also allowed the opportunity for skills and interventions from mental health to be used in a physical health area.

Studies by Anderson et al. (2013) and Hejazi et al. (2014) suggest that brief DBT skills groups may reduce the distress felt by some cancer patients. However the Anderson et al. (2013) and Hejazi et al. (2014) studies had several limitations that reduce the ability to generalise the findings because: trained DBT therapists were not used; particular DBT skills were not identified; and the New Zealand context was not accounted for. The present study will address these limitations by using an expert therapist in DBT (the researcher), and developing of a tailored intervention based on focus group feedback from participants.

The literature suggests that quality of life is enhanced by psychosocial treatments. This pilot study will identify whether this could include brief DBT groups. This study will add

to the body of knowledge about whether DBT groups are likely to increase resilience and therefore improve participants' capacity to deal with general adversity.

At present, there is a gap in psychological treatment provision following interventions for cancer such as surgery, chemotherapy or radiotherapy when patients are discharged to either GP care or in remission or in palliative care. This research focuses on this group.

Chapter 3 Methodology

3.1 Introduction

The present research aims to determine whether brief DBT groups decrease distress, improve resilience and improve quality of life for cancer patients. This study also seeks to understand how to tailor brief DBT groups to cancer patients. This chapter describes the philosophical approach, methodological considerations, and rationale for the use of a mixed-methods research methodology to allow both of these major research questions to be explored. The quantitative methodology using a stepped wedge design and qualitative methodology of Appreciative Inquiry focus groups used in this study are described. Quantitative methods have traditionally dominated health and social science research but in the last 20 years mixed methods research has become popular because it can allow a richer and more multi-faceted exploration of complex phenomena (Tariq & Woodman, 2013). Mixed methods approaches aim to gain the best from both the positivistic approaches often associated with quantitative methodologies and the more post-positivist approaches (including acknowledgement that researchers are affected by their social, cultural, and political contexts) often associated with qualitative methodologies.

3.2 Definition and philosophical underpinnings of Mixed Methods

A mixed methods approach allows researchers to collect and analyse quantitative data (e.g., from rating scales or performance instruments) as well as qualitative data (e.g., collected by interview, observation and/or focus groups). Research designs detail the method for conducting a study. A mixed methods design will lead to organisation of the research procedure so that both forms of data are gathered. The mixed methods approach also allows consideration and integration of the findings of both types of

data so that an integrated and coherent exploration of the research questions can be made (Creswell & Plano Clark, 2018). A mixed methods methodology allows a problem to be investigated using the participants' descriptive experience as well as through numerical values (Grant & Giddings, 2002; Morgan, 1998). Sale, Lohfeld, and Brazil (2002) considered that using the quantitative and qualitative paradigms in the same study is useful because the combination allows data to be considered from several perspectives, and allows a commitment to rigour, and conscientiousness and critique in the research process.

The philosophical standpoint of positivism underlies the quantitative paradigm. Positivism values objectivity and is embedded in modern scientific thinking, dating back to philosophers such as Pythagoras who lived in 600BC (Grant & Giddings, 2002). The quantitative scientific method considers that the only way of knowing something about the world is to investigate it empirically. Objective reality, gathered from sensory experience or by instruments, and counted, is considered the only truth. The role of the researcher is to measure and analyse data collected in quantifiable pieces that will allow the use of statistical tools (Sofaer, 1999).

By contrast, qualitative data consists of textual, verbal or visual data (Hammarberg, Kirkman, & de Lacey, 2016). Narratives and words may be gathered via methods that include focus groups, case studies, individual interviews, and observations. Data may be recorded in notes, audio or video recordings and must be transcribed verbatim to be analysed (Sutton & Austin, 2015). Qualitative methodologies are based on the post-positivist paradigm developed out of the critiques of positivism by philosophers such as Popper (1959) and Kuhn (1962). The post-positivist paradigm argues that there are multiple truths and that reality exists but we cannot perfectly know these so we must

examine them broadly and critically to understand truth and reality as well as possible (Guba & Lincoln, 1994; Smith, Sparkes, Phoenix & Kirkby, 2012).

For the last 150 years, positivism has been the dominant influence in scientific research including research in the social sciences and psychology (Ponterotto, 2005). Observation via quantitative methods relies on deriving causal explanations from actions that coincide reliably. In the social sciences however many phenomena being studied in healthcare are dynamic, complex social processes such as beliefs and values, which influence human behaviour. In the context of social sciences the focus of research may be on humans whose behaviour is not locked into acting predictably and whose behaviour may change due to particular circumstances (Gamlen & McIntyre, 2018). Social, political, organisational and economic contexts are also relevant (Curry & Nunez-Smith, 2015). Post positivism thus represents a diverse, less unified approach to research (Gamlen & McIntyre, 2018). In seeking to understand social action, qualitative methods allow explanations and understanding from the people involved themselves. Previous reliance on quantitative methods has moved to the inclusion of both qualitative and quantitative methods in psychology research, for example embedding qualitative approaches into RCTs (Plano Clark et al., 2013).

It is argued by authors such as Heale and Forbes (2013) that the reason for using mixed methods is that combining two or more methods of gathering data on the same phenomenon (known as triangulation) allows the phenomenon to be understand more thoroughly and a richer view to be developed. Other authors, such as Sale et al. (2002) acknowledge a criticism of this view; that qualitative and quantitative methodologies represent two different paradigms, they do not study the same phenomena, and represent what are essentially two conflicting world views. Even if one agrees with Sale

et al. that qualitative and quantitative methods are in conflict, mixed methods research can set aside this clash in paradigms in favour of being pragmatic and allowing investigation from the two paradigms.

3.3 Study design and quantitative and qualitative methodology

This pilot study investigated DBT groups for cancer patients. The research questions explored were: Do cancer patients who attend standard non-modified brief DBT groups experience decreased distress, increased quality of life and increased resilience? Secondly, do cancer patients who attend brief DBT groups, which are modified for cancer patients, achieve better results on measures of distress, quality of life and resilience than patients who attend standard DBT groups?

Quantitative and qualitative approaches were both seen as appropriate for addressing these questions. The first question, regarding the outcomes of DBT groups for people with cancer, mainly lends itself to quantitative exploration. Qualitative data however, could also add the participants' subjective opinion and understanding of using skills in regards to their experience of distress, resilience and quality of life. The second question involving modification of the DBT group to meet the needs of people with cancer lent itself to qualitative exploration due to the need to explore development of new material not known prior to the process and to develop more complex, dynamic and richer descriptions of the phenomena than numerical ones (Creswell & Plano Clark, 2007).

3.3.1 Quantitative pilot study methodology

Measurement of the effect of brief DBT groups on distress, quality of life and resilience can best be addressed using quantitative techniques. The independent variable was

the DBT group intervention. The dependent variables were distress, quality of life, and resilience.

Reliable and valid results using statistical tools generally require large sample sizes and use of techniques such as randomisation and blinding. To undertake a Randomised Control Trial (RCT) with enough statistical power to achieve 80 per cent power, (alpha = 0.05, assuming a standard deviation of 27 and accounting for drop-out) 96 participants for an experimental group and another 96 for a control group would be required (J. Pearson, personal communication, June 9, 2016, based on formulae developed by Twisk (2013).

Within the limited time and resources of this doctoral research, it was predicted it would be difficult to recruit this number of participants. The time-consuming nature of the intervention and the necessity for small group sizes limited the number of participants who could undertake the intervention. Patient recruitment difficulties and high drop-out rates for cancer patients are widely identified as a significant challenge (Anderson, Jensik, Peloza, & Walker, 2013; Feigenbaum et al., 2011; Lachman, 2002; Omylinska-Thurston & Cooper, 2014; Sautier, Mehart, Hocker, & Schilling, 2014). Many studies report small numbers of participants completing, typically 8 to 17 participants. Therefore, a pilot study using a quasi-experimental design researching within subject change was planned instead.

Pilot studies allow researchers to explore issues within constraints such as time, resources, patient recruitment, management or process difficulties, and statistical uncertainty (for example, limited data from which to estimate the potential treatment effect and variance that is required for accurate power calculation) (Leon, Davis, & Kraemer, 2011). According to Leon et al. (2011), a pilot study is “a requisite initial step

in exploring a novel intervention or an innovative application of an intervention" (p. 1) although its limited statistical power from a small sample size may limit its ability to test hypotheses. Pilot studies can be run with smaller sample sizes to test out components and with the intention of running a larger study (Arain, Campbell, Cooper, & Lancaster, 2010). The pilot study reported here could be scaled up to comprehensively explore whether DBT groups tailored to cancer patients improve distress, resilience and quality of life. Knowledge from this pilot could help develop a larger RCT and increase the probability of it being successful.

RCTs are commonly considered the 'gold standard' of research to produce the best evidence and the most scientifically rigorous way of testing a hypothesis (Akobeng, 2005). However when it is not possible to undertake an RCT due to random assignment being difficult or impossible or where the timeframe or other constraints limit the possibility of more robust research designs (Grant & Giddings, 2002) then quasi-experimental designs are often used in medical and psychological research. In the current research, a stepped wedge quasi-experimental design was selected.

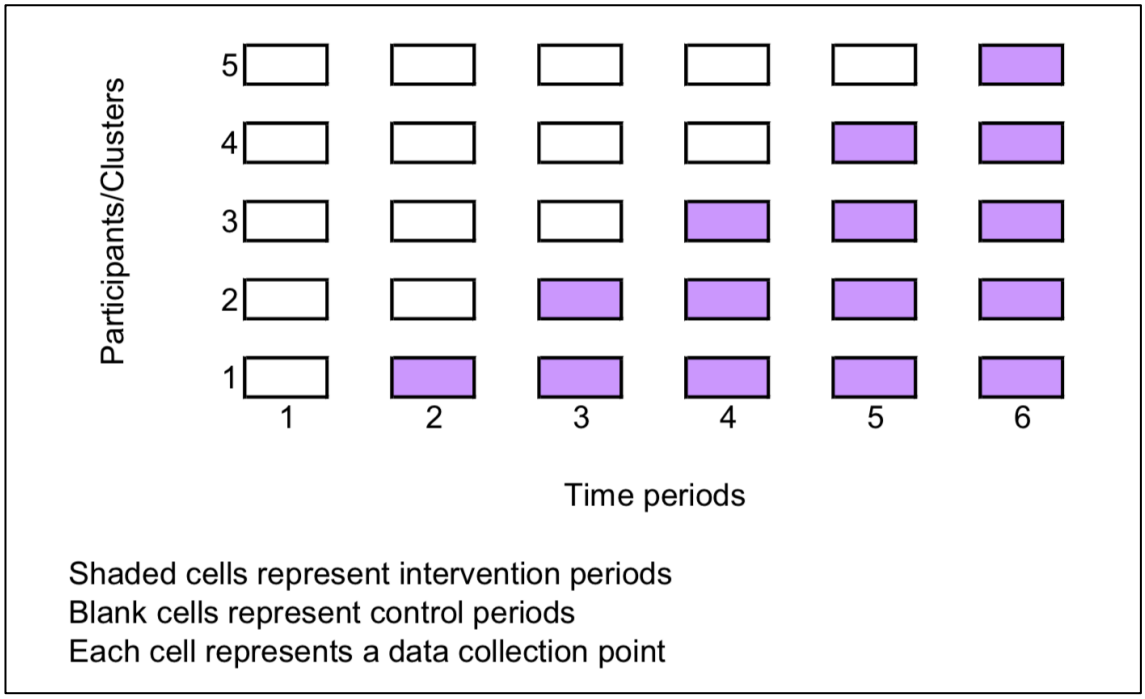

Figure 3.1.1: Example of a stepped wedge research design (Brown & Lilford, 2006 p.2)

In a stepped wedge design, the intervention is progressively rolled out to small groups of participants so that over time more and more of the participants have undertaken the intervention and eventually all participants have received the intervention. Participants constitute the control condition prior to undertaking the intervention. This design has been used in various countries to evaluate interventions including vaccinations, educational programmes, screening and treatment for tuberculosis and human immunodeficiency virus (HIV) (Brown & Lilford, 2006). The stepped wedge design addresses the practical issue of needing to recruit participants over time and the constraints of having one facilitator for the groups (Brown & Lilford, 2006). In stepped wedge designs, the intervention generally stays the same; however, given that part of the purpose of this study was to further tailor the intervention to the needs of cancer patients, some development of the intervention was undertaken. As the later groups effectively had this tailored variation of the intervention, all groups did not received exactly the same intervention so the design does not strictly fulfil the

definition of a stepped wedge design (Hemming, Haines, Chilton, Girling, & Lilford, 2015). That all participants do receive the intervention over time prevents ethical objections that might arise if patients are not provided an intervention that is anticipated to be beneficial.

3.3.2 Qualitative methodology

Understanding how the DBT group intervention could be tailored to the needs of the cancer population could best be addressed using qualitative techniques. In choosing the specific qualitative method, understanding the broad sweep of cancer patients' own experience and engagement in the intervention process, and supporting their empowerment, were important considerations. A smaller sample size than is required for statistical analysis of quantitative data is generally appropriate and reliable for qualitative research methodologies (Sale et al., 2002).

Appreciative Inquiry (AI) was the qualitative methodology chosen for this study. First proposed by Cooperrider and Srivastva (1987) and initially applied in organisational settings, the roots of AI are in the Action Research (AR) paradigm, which holds that it is not possible to analyse human phenomena in an abstract, disconnected way to produce objective findings. Human organisations are social constructs produced, repeated and altered by human interactions.

Action Research deliberately induces change in whatever is being researched (Van Brabant, 2015). The original model of AR was deficit-based - focussed on problems and using a consultant expert to identify action for change (Boyd & Bright, 2007). Participatory Action Research (PAR) represents a further step from AR where the researcher and the participants partner with each other in using participatory research

strategies to produce knowledge, reflect on data, and guide change (Bergold & Thomas, 2012; Van Brabant, 2015).

PAR was developed by Lewin (1951). The fundamental principles of PAR involve having a democratic context and a feeling of safety, trust, participation, and empowerment by the people directly affected who give their knowledge to the process of understanding (Bergold & Thomas, 2012). The researcher is an active participant in the research, helping the other participants to generate conversations that create aspirations and elicit alternatives for change (Zandee, 2014). Appreciative Inquiry is a PAR process that focusses on strengths and on shifting conceptions from the normal process or situation towards an improved state (Boyd & Bright, 2007; Hennessy & Hughes, 2014).

The Appreciative Inquiry methodology takes a collaborative, positive, curious, open-minded stance and invites bold, imaginative, generative thinking. The inquiry itself is a vehicle for change and occurs in a cycle with different parts. These parts are

- Discovery: where the positive qualities are discussed
- Dream: where participants use their imaginations to picture the future positively
- Design: where participants move to concrete designs for action, and
- Delivery: a collective reflection that leads to transformative action (Cram, 2010).

According to Rogers and Fraser (2003), AI is particularly suited to programme evaluation. The researcher chose AI as the qualitative methodology because she already had experience using this methodology and had observed that it was strengths based and empowering. AI would likely allow participants to join with the researcher in considering what alterations could be made to better tailor the DBT group for cancer patients. AI would allow the researcher to be a curious participant and join with the participants collaboratively. The researcher had learned from clinical experience that

the positive stance of AI would likely increase participation for the participants and that the process would likely be a positive experience for them. AI was also a good fit with the principle of empowerment which was an important consideration in this research as outlined in Chapter one.

3.4 Summary

This chapter has presented an overview of the methodologies employed that have informed the development and design of this study. A mixed methods methodology incorporating quantitative and qualitative parts was chosen in order to answer the research questions as to the efficacy of DBT groups for reducing distress, improving resilience and quality of life and then to tailor the group better for cancer patients. Due to the potentially small number of participants and the limited time available, a full RCT was not undertaken and a pilot study was carried out using a stepped wedge design. Mixed methods research pragmatically allows the data obtained using one methodology to complement data obtained in the other methodology to explore complex sets of research questions.

The use of quantitative techniques to assess outcomes of the group intervention before and after the tailoring of the intervention for people with cancer is desirable. However, the small numbers of available participants meant that insufficient statistical power limited the study.

Qualitative techniques were chosen to guide the development of the DBT programme to better fit the needs of cancer patients. Appreciative Inquiry was chosen as it allowed the researcher to participate alongside other participants in collaboratively guiding how the DBT group could be altered to better meet the needs of cancer patients in an empowering and positive manner. The next chapter will describe in

detail the methods of the study including recruitment of participants and collection and analysis of data.

Chapter 4 Methods

4.1 Introduction

This chapter describes how the methodological considerations set out in the last chapter were applied. Starting with the ethical considerations that were addressed (including consultation with Māori), this chapter discusses how participants were recruited into this study, the inclusion criteria and how potential participants were screened prior to taking part. The quantitative instruments used and the methods used to gather qualitative data are described, as is the process by which this study was undertaken. Details of the DBT intervention group sessions are then presented. Finally, the process of analysis for both the quantitative data and the qualitative data including ensuring rigour is discussed.

4.2 Ethics

This research aimed to add to knowledge and produce beneficial results utilising an intervention study (National Ethics Advisory Committee, 2012). As with all research, there was a responsibility to conduct the study within ethical guidelines and standards. Ethics approval was gained from both the Central Health and Disability Ethics Committee (HDEC reference 17/CEN/65) (see Appendix C) and the Auckland University of Technology Ethics Committee (AUTEC, reference number 17/229) (see Appendix A). Post-approval alterations to the original protocols were approved. These involved: adding Facebook, Hospice and local newspapers to the recruitment sources; changing the brochures and posters; including support people in the groups; and holding feedback sessions and readministering measures several months after the group ended; (Appendix C). The Auckland District Health Board Research Office (reference number 7511), and the Waitematā and Auckland District Health Boards Māori

Research Committee granted locality approval, as the original intention was to recruit patients from the Auckland District Health Board (Appendix D). The study was registered on the Australian and New Zealand Clinical Trials Register (Registration number ACTRN12617000187347p).

4.2.1 Participant safety

The participants in this research were cancer patients who might have been physically unwell and/or traumatised. As part of protecting potentially vulnerable individuals, close consideration was given to potential harm or upset to the participants. As with any psychological intervention, there is potential for participants' signs and symptoms of distress to be exacerbated. All participants were given an information sheet (Appendix H) that informed them they could withdraw at any time, for any reason. Participants were also informed that they could apply for compensation from ACC if any injury resulted from the study. Their ongoing medical treatmentremained in place.

4.2.2 Researcher safety

The groups in this study occurred in a local community hall. To ensure the safety of the researcher/facilitator of the group and the research assistant who also attended the groups, a researcher safety protocol was developed (Appendix E) and the supervisor of this research was notified by text at the start and again at the end of each session. The researcher and assistant were able to contact others via mobile phone if needed.

4.2.3 Informed consent

The first right of the New Zealand Health and Disability Code of Consumers Rights (Code of Rights) is the right to respect (Health and Disability Commissioner, 2019), and this requires participation in research to be a free, informed decision. This is particularly important for vulnerable people with serious illnesses (National Ethics

Advisory Committee, 2012). Potential participants were contacted by phone, given information about the group, and invited to participate if they met the inclusion criteria. If they agreed, participants were mailed or emailed a Participant Information Sheet that included a consent form (Appendix H). Written consent forms were collected prior to the start of the first group.

4.2.4 Data storage

Data and consent forms including printed transcripts are stored in a locked filling cabinet in the researcher's office, so only the researcher had access to the data collected. The research supervisor will keep data and consent forms in a locked filing cabinet for 10 years. Thereafter all the information will be destroyed or deleted. Digital recordings such as the record of the focus groups were kept in a password-protected computer until the study was completed and then they were deleted.

4.2.5 Confidentiality

Breaches of privacy and confidentiality are considered to be harmful (Health and Disability Commissioner, 2019). In this study, participants' names were replaced with a letter identifier and in transcripts or other presentations of results any potentially identifying information was altered to maintain confidentiality. The research assistant and the person who transcribed the qualitative data signed confidentiality agreements (Appendix I).

4.2.6 Māori consultation

To ensure cultural respect and safety and to honour the principles of participation, protection and partnership enshrined in the Treaty of Waitangi, which is New Zealand's founding document between Māori and the English crown, two kaumātua (Māori elders) at Auckland District Health Board were consulted about the study. The

kaumātua did not recommend any changes to the study. The Waitematā and Auckland District Health Boards Māori Research Committee approved the study (Appendix D.2). Facilitation of groups was according to the Guidelines for Cultural Safety outlined by the New Zealand Psychologists Board, which includes for example, psychologists acknowledging the beliefs and practices of people who differ from themselves and psychologists empowering the users of the service to express their perceived levels of risk or safety (The New Zealand Psychologists Board, 2009).

4.3 Participants

4.3.1 Recruitment strategy

To enable a study to be adequately powered to test the hypotheses, 96 participants would have been required. As this was a pilot study, my aim was to recruit a total of 60 participants, 30 in each of the two treatment conditions (see Figure 4.1) via Nurse Specialists at the Oncology Department of Auckland City Hospital distributing brochures advertising the study (Appendix F). No participants were recruited within the timeframe of this research via this avenue so re-application for ethics approval was undertaken to recruit via local newspapers, Facebook and Hospice New Zealand. A Facebook page and webpage were developed (Appendices G.1 and G.3). Messages advertising the study were posted on Facebook pages for the New Zealand Gynaecological Cancer Foundation, Breast Cancer Network New Zealand, Head and Neck Cancer Support Group, Prostate Cancer Foundation of New Zealand, Leukaemia and Blood Cancer New Zealand, Breast Cancer Cure, the Cancer Society of New Zealand, Melanoma New Zealand, Bowel Cancer New Zealand, Breast Cancer Foundation New Zealand and Lung Foundation New Zealand. The administrators of each page were contacted via Facebook private message to seek permission and request that posts be placed advertising the study with contact details for the

researcher. All the above Facebook page administrators accepted the posts (Appendix G.2). Brochures were left with Hospice West Auckland but no participants were recruited through Hospice. Potential participants were requested to phone the researcher if they were interested in finding out more about the study.

4.3.2 Participant selection strategy

When a potential participant contacted the researcher by Facebook Messenger, text, or telephone, they were telephoned and the study was described and additional demographic and clinical data such as age, gender, education, type and stage of cancer, any other medical disorders, and their current treatment regime was collected (Appendix J). Participants' eligibility for inclusion was also ascertained, including administering the Distress Thermometer (Ransom, Jacobson, & Booth-Jones, 2006) (Appendix K). Inclusion criteria for the study were: Adults aged 18-65 years old with a diagnosis of cancer; a score of four or above on the Distress Thermometer; the ability to read, write and understand English (due to participating in the group, reading the manual, and completing the homework requiring literacy in English). Exclusion criteria for the study were: involvement in current psychological treatment or counselling (as this would confound the results); current terminal disease phase; and in currently palliative care (as this may cause distress and survivor guilt for other participants (Wertich, 2017).

Eligible participants were mailed or emailed the patient information sheet, the initial measures and information about the dates, times and place of the group and consent forms (Appendices H and O). For participants in Condition One (immediate start), written consent was gained via a return addressed envelope before the first group. For participants in Condition Two (delayed start), written consent was gained via a return

addressed envelope prior to the start of the three week no intervention control period. Potential participants who did not meet the criteria for inclusion in the study but still wished to participate, were directed to other sources of support such as Warmline, a peer mental health telephone support helpline (Lifeline Aotearoa, n.d.). Participants who attended at least four sessions out of six were considered to have completed the group and their data was used. Data collected for potential participants as well as participants who did not complete at least four groups was not used and was destroyed.

4.4 Measures

4.4.1 Quantitative measures

Quantitative measures used in this study are outlined below. The Distress Thermometer was used as a screening tool, and the remaining three measures were used to explore whether brief DBT groups decreased distress and increased resilience and quality of life. These self-rated, pencil and paper measures were readily available at low cost, have been used in previous research with cancer patients (for example , Hegel, Collins, Kearing, Gillock, Moore & Ahles, (2008); Anderson et al. (2013) and have been found to be reliable and valid. The measures took a total 20-30 minutes per participant at each point that they were administered.

1. The Distress Thermometer

The Distress Thermometer (DT) developed by Roth et al. (1998) was used as a screening tool in this study (Appendix K). A distress thermometer is a single 10-point visual analogue scale. It was first recommended in the United States National Comprehensive Cancer Distress Practice Guidelines in 2003 (National Comprehensive Cancer Network, 2003). This tool was validated by Ransom et al. (2006) for prostate

cancer patients and Hegel et al. (2008) for newly diagnosed breast cancer patients. Mitchell (2010) reported that the efficiency in terms of cost effectiveness and brevity of the DT is better than the Hospital Anxiety Distress Scale (HADS) (Zigmond & Snaith, 1983), with comparable overall accuracy. A meta-analysis by Ma et al. (2014) noted comparisons between the DT and the HADS, the Brief symptom Inventory-18 (BSI-18)(Derogatis, 1992), Diagnostic and Statistical Manual of Mental Disorder, fourth edition criteria for depression (American Psychiatric Association, 2000) and other questionnaires as reference standards. These authors report pooled results for 42 studies with 14,808 patients showed a sensitivity of 0.81, (95 per cent confidence interval 0.79-0.82) and pooled specificity of 0.72 (95 per cent confidence interval 0.71-0.72) at the cut-off score of four for the Distress Thermometer. Ma et al. (2014) suggested a cut off of four out of a possible ten as recommended and optimal, and this cut-off was used for the inclusion criteria in this study.

A study by Tang, Zhang, Pang, Zhang and Song (2011) of 106 Chinese patients with diverse types and stages of cancer found a test re-test correlation coefficient of 0.80, ($P<0.01$) which suggested the test is stable. A cut-off score of four maximised the sensitivity against the HADS to 0.80 and 0.87 against the Symptom Checklist-90 (SCL-90) (Derogatis, 1975) in a sample of 574 patients. Receiver Operating Characteristic (ROC) analysis indicated that Area Under the Curve (AUC) of 0.80 sensitivity and 0.70 specificity against the HADS and an AUC of 0.83 for sensitivity and 0.72 against the SCL-90. Jacobsen et al. (2005) found similar results in a study of 380 ambulatory cancer patients from ROC analyses for the Distress Thermometer and HADS and BSI-18 of 0.80 and 0.78 respectively. These results indicate that the Distress Thermometer has high diagnostic accuracy and differentiates distressed patients from those who are not

distressed (Jacobsen et al. 2005; Tang et al. 2011) and has been validated in New Zealand (Baken & Wooley (2011).

2. The Depression Anxiety Stress Scale (DASS-21)

The DASS-21 scale was developed in Australia by Lovibond and Lovibond (1995) as a shortened version of their original 42 item test to measure depression, anxiety and stress. The researcher purchased this questionnaire from the authors to use in this study and as it is restricted by copyright, it is not copied in the Appendix.

There are seven items in each of the three subscales. Each item is rated over the past week on a four-point (0-3) Likert scale rating from "Did not apply to me" to "Most of the time". Scores on the 21-item scale are doubled giving a score of severity ranging from zero to 42 for each of depression, anxiety and stress to allow for comparison with the original 42-item scale. The depression scale items measure hopelessness, the level of lack of positive feeling, and self-esteem; for example, *I can't seem to experience any positive feeling at all*. Items in the anxiety scale measure physical arousal, worry about panic and fear such as, *I felt I was close to panic.* The stress scale measures tension, reactivity and agitation; for example, *I found it hard to wind down* (Gloster et al., 2008). The normative sample was a non-clinical group of 2914 university students and white and blue collar workers in the age range 17 to 69. Levels of severity ranging from normal to extremely severe (Appendix L.1) were developed (Lovibond & Lovibond (1995). Cutoff scores indicating reliable change indices for populations including a non psychiatric population are detailed in Ronk, Korman, Hooke, and Page (2013) (Appendix L.2).

The DASS-21 has shown good internal consistency and construct validity on a large sample of United Kingdom adults, with Cronbach's alpha of .88 (95 per cent CI 1⁄4 .87–

.89) for the Depression scale, .82 (95 per cent CI 1⁄4 .80–.83) for the Anxiety scale, .90 (95 per cent CI 1⁄4 .89–.91) for the Stress scale, and .93 (95 per cent CI 1⁄4 .93–.94) for the Total scale (Henry & Crawford, 2005). Two studies, both by Brown, Chorpita, Korotitsch & Barlow (1997) found that the DASS-21 was temporally stable with test-retest correlations showing no changes in scores over time. In a factor analysis using a cohort of 123 patients with traumatic brain injury Wong, Dahm and Ponsford (2013) found a test-retest reliability of .99. Studies have also found that the DASS-21 can distinguish between depression, physical arousal and psychological agitation (Antony, Bieling, Cox, Enns, & Swinson, 1998). Welfare-Wilson and Newman (2013) demonstrated a significant change over a three-month period in DASS-21 scores for clients undertaking a CBT intervention in a mental health population, showing the DASS-21 is sensitive to therapeutic change.

The DASS-21 has been used in previous oncology research (Anderson et al., 2013; Beatty & Scott, 2013; Lawrenson, Brown, Obertova, Lao & Conaglen, 2014; Tang, Castle & Choong, 2015). It may be particularly useful as it does not assess somatic items and is therefore less likely to unintentionally inflate depression or anxiety scores through measuring cancer symptom severity rather than psychological distress. The DASS-21 has been used in a large study of prostate cancer which included 106 New Zealand men (Lawrenson et al., 2014). The Cancer Society of New Zealand (Auckland Branch) routinely uses the DASS-21 to assess distress (A. Legatt, personal communication, April 18, 2016).

3. The European Organisation for Research and Treatment of Cancer Quality of Life C30 Questionnaire (EORTC QLQ-C30 Version 3)

Version 3 of the EORTC QLQ is the most recent version of a quality of life questionnaire developed specifically for cancer (Aaronson et al., 1993). It is a health related quality of life measure focusing on aspects of quality of life related to cancer disease and treatment. The researcher purchased this questionnaire from the authors to use in this study and as it is restricted by copyright, it is not copied in the Appendix. The EORTC QLQ-30 is one of the most widely used cancer-specific quality of life questionnaires (Luckett et al., 2011). It is a patient reported measure made up of 30 items assessing functioning and symptoms over one week. It is brief, taking approximately 11 minutes to complete and is easy to administer. The EORTC QLQ-C30 questionnaire consists of a Global Health/Quality of Life score, five functional scales (physical functioning, role functioning, emotional, cognitive and social functioning) and nine symptom scales, that assess symptoms such as pain, nausea, fatigue, appetite loss and constipation. Financial difficulties are also assessed as part of the symptom scales. (Aaronson et al., 1993).

The EORTC-C30 consists of a general, core form and is supplemented by tumour-specific forms for example, for lung cancer or breast cancer. The general form asks a broad range of questions relevant to cancer patients no matter which specific cancer they have. Only the general form was administered in this study so that the data collected would be consistent between participants. The scores for each scale range between 1 and 100. Higher scores on the functional scales represent higher functioning and lower scores on the symptom scales represent fewer symptoms (Kuijpers et al., 2016). A table of reference values gives means and standard deviations of each scale for comparison with a sample of 23,553 patients. For example, the mean

global health status score for patients with cancer is 61.3 (SD 24.2) (Fayers et al., 2001; Scott et al., 2008). Cocks et al. (2012) systematically reviewed published literature and expert opinions and published guidelines for improvements or reductions in subscale scores to indicate trivial, small or medium significant changes.

Tan et al. (2014) validated the general questionnaire and the breast cancer specific form, and found that the general questionnaire had a Cronbach's alpha coefficient of 0.846 suggesting good internal consistency. A study of test/retest reliability by Hjermstad, Fossa, Bjordal and Kaasa (1995) using 190 cancer outpatients found high Pearson's correlation coefficients for all functional scales ranging from .82 for cognitive and role functioning to .91 for physical function. The global quality of life r value was .85 and symptom scales ranged from .63 to .86. Spearman rank correlations were in the same range for all dimensions.

Over 2,200 studies using this scale have been registered (Fayers et al., 2001). New Zealanders were included in pooled data analysis of 6024 patients who were part of 25 randomised control trials (Quinten et al., 2015).

4. The Connor-Davidson Resilience Scale (CD-RISC)

In this study resilience was measured with the CD-RISC, a 25-item questionnaire developed by Connor and Davidson (2003). It uses five-point Likert scales to measure dimensions such as hardiness, support/purpose, persistence and faith. Total scores range from one to 100 with higher scores indicating higher resilience. The mean resilience score in a normal population is 80.4 (Standard deviation 12.8). Individuals scoring greater than 92 are considered resilient (Connor & Davidson, 2003; Min et al., 2013). The researcher purchased this questionnaire from the authors to use in this study and as it is restricted by copyright, it is not copied in the Appendix.

The CD-RISC was developed with a general population sample of 577 people (Connor & Davidson, 2003). The authors have identified a five-factor structure: The notion of personal competence and standards, tolerance of negative affect and trust in one's own instincts, acceptance of change, feeling in control and spiritual influence. It has good internal consistency (Cronbach's alpha is .89 with item-total correlations of 0.30 to 0.70). In a review of 19 resilience measurement scales, Windle, Bennett, and Noyes (2011) found that the CD-RISC received the best psychometric ratings of the scales reviewed particularly in regard to construct validity. Connor and Davidson (2003) reported a high test-retest reliability of .87. Karairmak (2002) reports convergent validity for 246 participants with other scales such as the Ego Resilience Scale (Block & Kremen, 1996), Pearson r= .68, p<.001 and positive affect scores of the Positive and Negative Affect Schedule (Watson, Clark & Tellegen, 1988) Pearson r= .69, p<.001. Connor and Davidson (2003) used clinical samples from the general population (n= 577), primary care outpatients (n= 139), psychiatric outpatients in private practice (n= 43), participants in a study of generalised anxiety disorder (n= 25) and participants in two trials of post-traumatic stress disorder (n= 22). The CD-RISC has shown sensitivity to therapeutic change, with CD-RISC scores increasing significantly with overall clinical improvement (Connor & Davidson, 2003). The CD-RISC has been used with a wide number of clinical samples. A Turkish version used with 246 earthquake survivors in Turkey found a Cronbach's alpha of .92 (Karaırmak, 2010) and a study of 160 older American Indians found a Cronbach's alpha of .93 (Goins, Gregg, & Fiske, 2012). Other research using the CD-RISC has included Māori adolescents (Earthquakes Professionals Research Group, 2012) and New Zealanders who were in the Christchurch earthquakes (Marie, 2014).

4.5 Procedure: Research

The following figure summarises the design of this study.

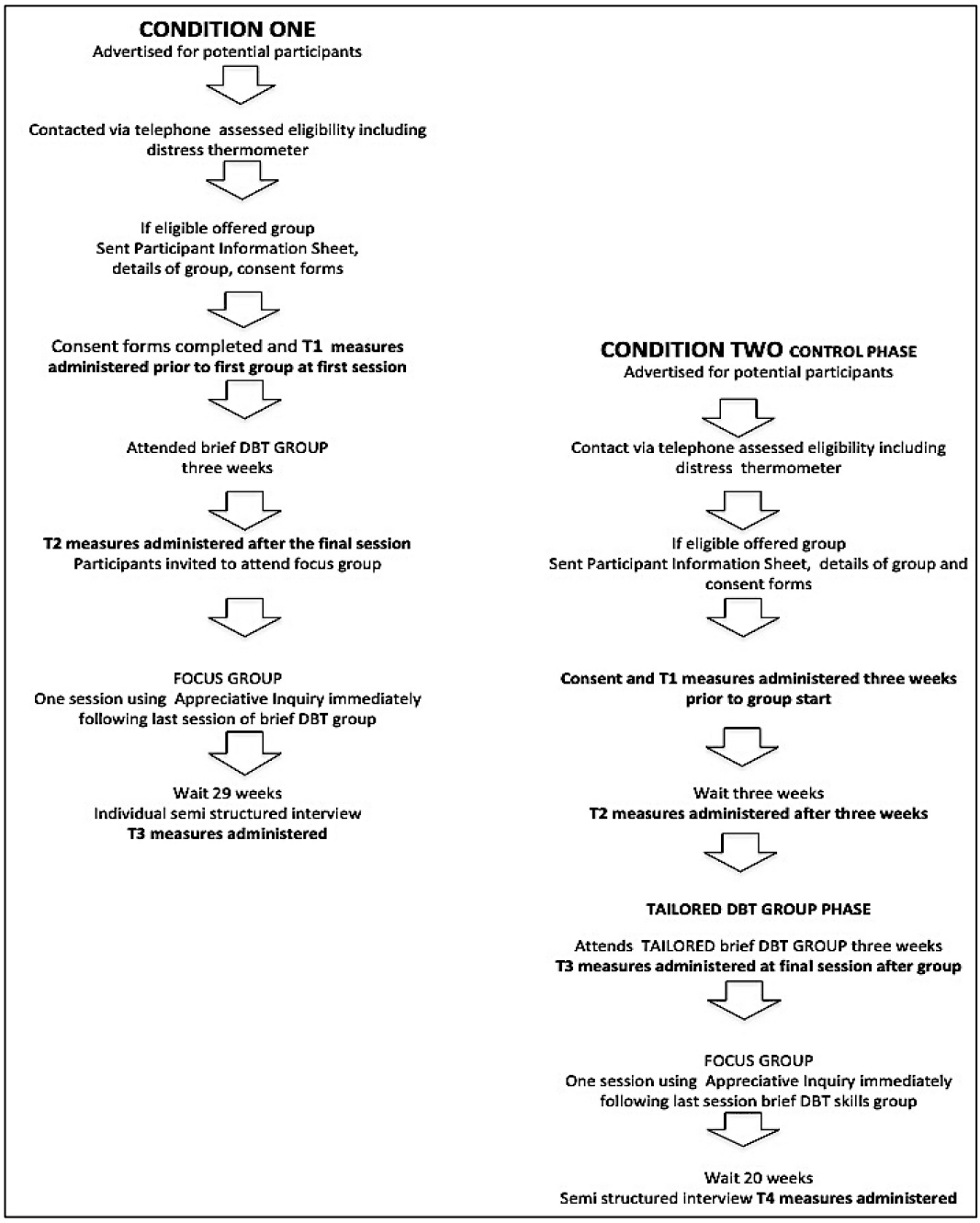

Figure 4.1: Flowchart of this study

As indicated in Figure 4.1, this study had two arms: Condition One and Condition Two, constituting the stepped wedge design as outlined in the methodology chapter. This is also represented in the diagram in Figure 4.2. that shows the stages of the study over time.

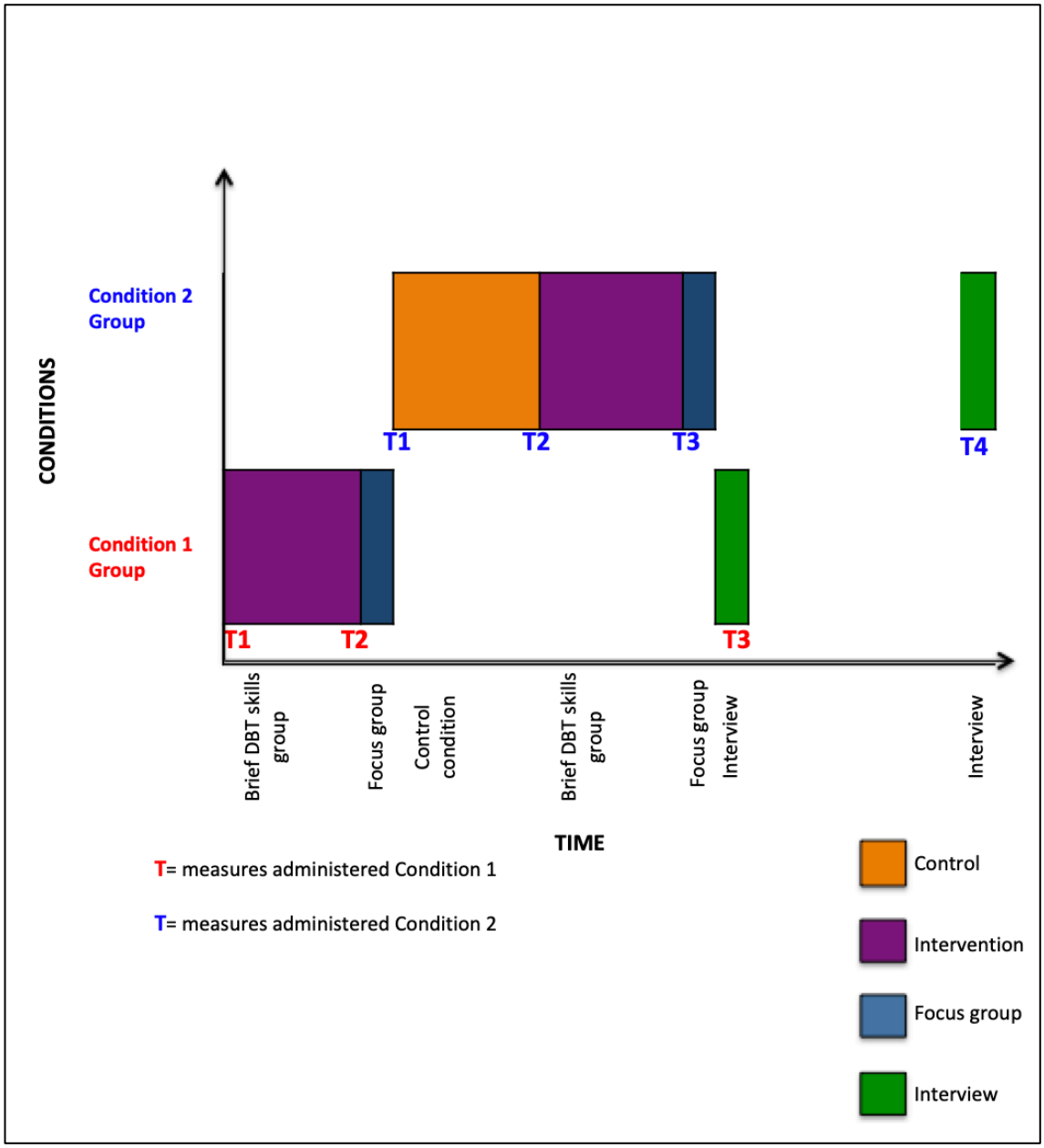

Figure 4.2: Parts of the study showing timing of measures and stepped wedge design

In Condition One participants attended the standard six-session DBT group. The participants then provided feedback using an Appreciative Inquiry process and then took part in individual semi-structured interviews 29 weeks (Condition One) and 20 weeks (Condition Two) later. The different lengths of time between the intervention ending and the follow-up interviews was due to the unexpected personal circumstaces of the researcher. In Condition Two, there was a control phase of three weeks where no intervention was undertaken. Participants then attended the DBT group with

modifications suggested by participants in Condition One. The participants who took part in the modified DBT group then participated in an Appreciative Inquiry session at the end of the group sessions. The modified DBT participants also took part in semi-structured interviews at follow-up. The following details the process for the one group in Condition One and the one group in Condition Two.

4.5.1 Condition One

Engagement

Engagement processes for participants were as described in the Recruitment Strategy and Selection Strategy sections above. Measures for Condition One groups were completed just prior to the first session.

Intervention

Following the administration of the measures, participants attended the DBT group. Two sessions of the DBT group were held each week for a three-week period, one session on a weekday and the other on a Saturday to ensure the least disruption for participants who worked. Sessions were two hours long. The researcher (a Clinical Psychologist) facilitated the groups. A research assistant helped the researcher by collecting consent forms and measures, distributing manuals, and preparing tea at the break. At the first session each participant received a manual containing all the material covered in the group including practice worksheets for homework. The manual is included in Appendix R. Each session consisted of a mindfulness exercise, review of last sessions learning and any practice, a 10-minute tea break, then learning and review of new skills. Three to four skills were taught in each session. The skills taught in each session are outlined in Appendix P. A variety of skills were taught in order to be as widely applicable as possible to the different needs of different participants. At the end of the final session, participants were asked to complete the

same three quantitative measures as they had prior to the group starting. This was the second measurement point for Condition One.

Focus group

Participants were then invited to attend a 30-minute focus group using an Appreciative Inquiry process run by the researcher to gather data regarding how the group could be tailored to better fit cancer patients. Attendees were asked a series of open questions following a cyclical process directed towards modifying the group content or process. This session was held in the same community hall as the group and followed the final DBT group session. The focus group session was recorded digitally, uploaded to a password-protected computer and later transcribed verbatim by an independent transcriber. Input from focus group participants was identified on the transcript using the same identifier previously used for their quantitative data and demographic information. In the Appreciative Inquiry, the researcher asked a series of open questions in a cycle (Cram, 2010).

Figure 4.3 Appreciative Inquiry cycle (Cram, 2010)

Appreciative Enquiry questions are listed in Appendix M and follow the Discovery, Dream, Design and Destiny cycle above.

Discovery- where positive qualities and strengths are discussed. Questions were asked about which skills were helpful and effective. For example, can you tell me about which skill you have learnt that you think has been the most helpful or effective and how you have used it?

Dream- participants use their imaginations to picture the future positively. Questions asked in this phase included, if you were starting a group like this, what changes in content do you think would improve the group and make it more useful for people with cancer?

Design- participants move from articulated dreams to concrete designs for action. An example of a question asked in this phase was, is there anything about the structure or format that we could change

Destiny/ Delivery- a collective reflection that leads to transformative action. Questions asked in this final phase included, are there any steps that you think I need to take next?

Follow-up

Participants were phoned and invited to a final individual interview session 32 weeks after the start of the study (29 weeks after the end of the group). The interviews were held at the same community hall location as the groups were held. The quantitative measures were again administered at the beginning of this interview. With only one opportunity to interview the participants at the end of the follow-up period, a semi-structured style of interview is particularly useful (Cohen & Crabtree, 2006). Semi-structured interviews allow for a more conversational style and broader discussion, and also allow the interviewer to follow up on new areas of interest as they arise (Bernard, 1988) while consistently exploring key topics. See Appendix N for the questions asked in the semi-structured interviews.

4.5.2 Condition Two

Modification of DBT group

During the month prior to recruitment for Condition Two, data from the Appreciative Inquiry cycle in Condition One were transcribed and themes analysed to determine what changes were needed for the group intervention. Specific changes made to the DBT Group format are outlined in Chapter Five.

Engagement

Potential participants in Condition Two were recruited one month after the end of the Condition One group. Engagement processes were the same as described in the Recruitment Strategy and Selection Strategy sections above. Each potential participant was sent the same information as in Condition One and asked to return the completed measures to the researcher. This was the first data point for the quantitative measures for Condition Two. After a few days, if the researcher did not receive the information, a text reminder was sent.

Three weeks later, one week prior to the first group meeting, participants who had sent completed consent forms and the pre-measures were contacted and sent the same set of measures again with a reminder about the first group meeting. This was the second data point for Condition Two.

Intervention

Condition Two participants attended the modified group facilitated by the same researcher as in Condition One. As there were over 10 potential participants, two groups were organised for Condition Two. These groups ran concurrently for one session; however, all attendees at one of the groups either did not attend or discontinued after one group (see Chapter Seven) and therefore only one group ran. The structure of the group sessions and number of groups was the same as Condition One. At the end of final session of the six group sessions, the participants again completed the quantitative measures. This was the third data point for Condition Two.

Focus group

After the final group sessions, Condition Two participants were invited to attend a focus group using Appreciative Inquiry, the same as Condition One, and using the same process and cycle of questions detailed above.

Follow-up

Twenty-six weeks after being recruited to Condition Two (which was twenty weeks following the completion of the DBT group), Condition Two participants were approached by text and phone and invited to attend an individual semi-structured interview which took place at the same community hall venue where the group had been held. The questions asked were the same as in Condition One and data was again recorded and later transcribed and analysed for themes. Participants again completed the quantitative measures. This was the fourth data point for Condition Two.

Following the interviews the researcher met with all the participants in small groups and talked about how participants had used the skills; coaching was provided to address any areas of difficulty participants were having.

4.6 Procedure: Intervention

The intervention carried out in this study involved attendance at a six-session group DBT programme, which used a manual to increase the consistency of content amongst the groups. The course manual was based on the DBT manual and worksheets developed by the originator of DBT, Marsha Linehan (2014a, 2014b) and adapted by the researcher.

DBT skills groups focus on teaching skills in four modules that are taught consecutively to help improve participants' ability to regulate their emotions, effectively problem solve, or accept their current situation. These modules are Mindfulness, Distress

Tolerance, Emotion Regulation and Interpersonal Effectiveness. Skills from the Mindfulness, Distress Tolerance and Emotion Regulation modules were taught in the intervention in this study. The skills taught were chosen on the basis of known effectiveness with cancer patients, such as mindfulness (Anderson et al., 2013; Johns et al., 2016) and relaxation (Kovacic et al., 2013; Sautier et al., 2014). The skills selected were also guided by research-based protocols by Linehan (2014a) that suggest which skills to teach in shorter versions of her treatment. Each participant received a manual that included all the skills taught plus worksheets for home practice. See Appendix P for a table of skills taught and handouts for each session.

At each session, a mindfulness exercise was facilitated by the researcher, followed by review of homework, a tea break of 10 minutes, then new teaching of skills for that session followed by instructions concerning the homework.

The modifications made to the intervention for Condition Two (as a result of the feedback from participants in Condition One) are described in detail in Chapter Five.

4.7 Data analysis

4.7.1 Quantitative analysis

Quantitative data was scored by the researcher and interpreted according to the manuals of the three measures. Data for Condition One was collected at three time points and at four time points for Condition Two.

I planned to undertake statistical analysis using the software package SPSS version 22.0 and a significance level of $p<.05$, which would have tested whether data had a sufficiently normal distribution for use of parametric statistics. It was intended that hypothesis One (that participating in the DBT intervention improves distress and

resilience) be tested by comparing the change in the two groups between TI and T2 (see Figure 4.1). If there was a significant interaction effect over time in the test scores between Condition One (spanning the unmodified DBT intervention) and Condition two (spanning the control phase) using a two way repeated measures analysis of variance (ANOVA) (or non-parametric equivalent), this would have indicated a significant difference between the intervention and a treatment-as-usual control.

It was also intended that hypothesis two (that modified DBT would be more effective than the standard DBT) be tested comparing the change between T1, T2, and T3 for Condition One (spanning the untailored DBT intervention and through to follow-up) and T2, T3, and T4 for Condition Two (spanning the tailored DBT intervention and through to follow-up), potentially using a 2x3 repeated measures ANOVA. A significant interaction effect in this analysis would indicate different outcomes from the two interventions, and/or different degrees of maintenance of treatment outcomes.

Statistical group level analysis was not undertaken because of the small sample size and because this was a pilot study, whose primary aim was to indicate whether the groups may have had an effect on the variables of distress, resilience and quality of life preliminary to a larger study where larger numbers of participants would allow more clear cut statistical analysis. Each participant's results were analysed and are presented as single case studies. Visual analysis of the raw data is presented in both table form and as graphs and analysed which allowed both visual analysis recommended by Kratochwill et al. (2010) and replication as recommended by Manolov, Gast, Perdices, and Evans (2014). Some data, for example the DASS-21 was also compared to norms derived by the test developers detailed in the manual for that questionaire (Lovibond & Lovibond 1995). According to Krasny-Pacini and Evans (2018), single case

experimental designs are useful when piloting new interventions, when there are time limitations, and when working with a small number of participants, as was the case in this study. This format was also recommended by Dr Alain Vandal, Department of Biostatistics and Epidemiology, Auckland University of Technology, who provided statistical support for this study.

Participant results were graphed and compared with their other results at different time points thus enabling comparisons between each individual's scores at different data collection points.

4.7.2 Qualitative analysis

There is a range of techniques for analysing qualitative data obtained through the focus group and semi-structured interviews. Schmidt (2004) points out there is an interplay of theoretical knowledge and literature with exploration in the field, so methods of analysis can only be partially designed before data collection, in part because the development of analytical categories is in response to the material collected.

For both the focus group process and semi-structured interviews, data was audio recorded and later transcribed by an independent transcriber. Thematic analysis was used to understand the data using the six-phased process outlined by Braun and Clarke (2006, 2012). The data from the interviews and focus groups was read and re-read and audio recordings were listened to repeatedly. Notes were made using several larger headings. Consideration was given to how to categorise each piece of data into codes and organise the data into small chunks. Emergent themes within the data were identified and data were combined under themes whilst also considering the research questions and how the themes answered these. The supervisors gave input to develop

the themes. Each theme was named as it related to the data. These themes are noted in the reporting of the results in the next three chapters.

Rigour of qualitative analysis

The English Oxford Living Dictionary defines the term 'rigour' as describing the quality of being thorough and accurate in the research process and outcomes (Oxford University Press, 2019). There have been debates in the research literature about how to apply the concepts of reliability and validity to the research process and interpretation of qualitatively derived data (Cypress, 2017). Reliability is the ability to repeat or replicate a finding and validity is concerned with the accuracy and truth of the findings. The degree of confidence or trustworthiness in the results is based on the quality, authenticity and truthfulness of the research findings. Trustworthiness in qualitative research is analogous to reliability and validity (Cypress, 2017). In order to protect against researcher bias, lack of reproducibility and lack of generalisability I have considered the four aspects of trustworthiness identified by Lincoln and Guba (1985) to demonstrate rigour: credibility, transferability, dependability and confirmability.

Credibility

Credibility is the precise and truthful representation of the participants' experience (Cypress, 2017). This research was planned using rigorous methods of data collection and analysis. Patton (1999) believes that there are three important areas to be considered concerning credibility. Firstly, that there have been rigorous methods for gathering high quality data that is carefully analysed. Secondly, that the researcher has credibility, in terms of training, status and presentation. Thirdly, that there is a philosophical appreciation of the value of qualitative inquiry. Strategies for achieving

credibility in qualitative research include prolonged engagement, persistent observation and peer debriefing (Lincoln & Guba, 1985).

I have many years of experience as a DBT therapist. I have also studied research methods and as a Clinical Psychologist, I am trained to make observations of people. In this study, as facilitator of the group I spent time with the participants getting to know and build rapport and trust with them, initially over the build-up prior to the group starting via phone and text, then in the three weeks of the group where I saw participants twice weekly and then at follow-up. I was able to make persistent observations of participants as they engaged in the group, on seeing them again at follow-up, learning something of their context at home when they reported through practice of skills at home and their homework back in the group. The strategy of debriefing by participation in regular supervision involving discussion about the research process, research findings and questioning of my analyses further enhanced credibility of the process and results. I audio recorded the interviews and focus groups and was able to replay them as well as repeatedly revisiting the transcribed data to check themes as I carried out my analysis. In reporting the results, I have used verbatim quotes transcribed from the interviews and focus group sessions in order to bring the participants voices to the research. These strategies are consistent with those outlined by Noble and Smith (2015) for enhancing the credibility of qualitative research.

Transferability

Transferability is a way of achieving a type of external validity (Lincoln & Guba, 1985). Transferability is described by Lincoln and Guba (1985) as a 'thick description' or detailed account of phenomena in enough detail that conclusions drawn from the

research are transferable to other contexts and people. This study is a pilot so conclusions may not be generalisable to the whole population, but a detailed account of the research methods and processes as well as demographic information about the participants has been presented so that the conclusions drawn may be evaluated in terms of their transferability to other contexts.

Dependability

Dependability entails demonstrating that the findings of the research are repeatable and consistent (Guba & Lincoln, 1994). This can be achieved by having an audit trail by which another researcher can follow the decision making of the researcher (Thomas & Magilvy, 2011). The methods used in this research have been noted in detail in this chapter. Supervision provided external auditing of my interpretations and conclusions and how these were supported by the data.

Confirmability

The degree to which the findings of a study are shaped by the participants and are independent (rather than the result of researcher bias or interest) is known as confirmability (Lincoln & Guba, 1985). Confirmability occurs when credibility, transferability and dependability have been addressed (Thomas & Magilvy, 2011). Thomas and Magilvy (2011) suggest that research must also be reflective, maintaining a sense of openness to emerging results. This is based on the idea that knowledge is situated and the effects of the researcher need to be assessed in a process known as reflexivity (Malterud, 2001). Throughout this research, I paid systematic attention to the research process especially my own perspective and preconceptions as the researcher and how my perspective and preconceptions affected the research as

outlined in Chapter 1. I kept a journal of field notes regarding my thoughts and observations during the research.

4.8 Summary

Undertaking research in real-life settings with people with significant difficulties often requires practicality and adaptability to meet the emerging situation. The methods for this study were somewhat impacted by the unexpected lack of availability of potential participants from the expected referral sources. This led to the changes in recruitment strategies and analytic approaches described in this chapter.

This chapter described the methods used for each phase of this stepped wedge pilot study that was undertaken. The ethical considerations, approaches to participant safety, informed consent and consultation with Māori were outlined. The recruitment process, inclusion criteria and participant selection strategies were described. The mixed-method (quantitative and qualitative) research design and approach used in this study is reflected through discussion of the quantitative measures used and their analysis, and the qualitative approaches taken to analyse the interviews and focus groups. The DBT intervention was described as well as aspects of the study that ensured rigour were presented. The next chapter presents the results of Condition One, the group with the unmodified DBT intervention, including the results of the measures used and an analysis of the themes from the interview data.

Chapter 5 Results: Condition One- unmodified group

5.1 Introduction

The results for this research are presented in four chapters. Chapter Five presents the quantitative findings of Condition One, the unmodified group. Chapter Six presents the qualitative findings and thematic analysis of the focus groups used to modify the group for cancer patients. Chapter Seven presents the findings from the second condition, which was the modified group and Chapter Eight presents the analysis of the data obtained in the focus group following the second condition.

This chapter presents the findings from Condition One, which was the group that received the original DBT skills programme as designed for mental health service users without modification for cancer patients. Firstly, quantitative data from the Depression Anxiety Stress Scale (DASS-21), the Connor- Davidson Resilience Scale (CD-RISC), and the European Organisation for Research and Treatment of Cancer Quality of Life Scale (EORTC QLQ-C30 Version 3) are presented. Secondly, qualitative data from individual semi-structured interviews at follow-up is presented.

5.2 Participant characteristics

Nine potential participants contacted the researcher. Three respondents were excluded because they were older than 65. One respondent was excluded due to being below the threshold of four out of ten on the Distress Thermometer and was directed to the Warmline telephone counselling support line. One respondent was due to go overseas when the group was scheduled and so was unable to participate. Two potential participants were unable to participate by the time the group started due to deteriorating health. The two remaining participants completed all group sessions for Condition One. It was not possible to continue with further recruitment due to the

time limits for this study. Demographic data for the participants are shown in Table 5-1.

Table 5-1: Demographic data of participants in Condition One

Participant	Gender	Age (in years)	Education	Ethnicity	Type of cancer	Other medical disorders	Self-rating on Distress Thermometer	Number of groups attended
A	Female	47	Polytechnic	NZ European	Breast stage 3	Diabetes	4	6
B	Female	50	University	NZ European	Brain tumour		8	6

5.3 Quantitative results for Condition One participants

The quantitative results for each participant in Condition One are presented as single case designs.

5.3.1 Participant A

Participant A was a 47-year-old New Zealand European female who had treatment for stage three breast cancer. She had diabetes and worked fulltime in a leadership position. Participant A had received significant burns as a result of radiotherapy. During the time of the study, she was not having any treatment for cancer but was being monitored regularly. She was single and had family support. After attending the group her work underwent a restructure which Participant A found very stressful.

Table 5-2 presents the data for Participant A at pre-, post- and follow-up.

Table 5-2: Quantitative data Participant A

Test	Subscale	Score and when administered		
		Session 1 (week 1)	Final session (week 3)	Follow up (week 32)
DASS-21	Anxiety	6[a]	8[b]	10[c]
	Stress	12[a]	8[a]	18[b]
	Depression	2[a]	2[a]	2[a]
	Total	20	18	30
CD RISC 25	Resilience	61[d]	76[b]	75[b]
EORTC QLQ-C30	QL (Global health)	66.7	83.3.	66.7
Functional scales				
	PF (Physical)	93.4	100.0	93.4
	RF (Role functioning)	83.4	100.0	66.7
	EF (Emotional functioning)	75.0	83.4	75.0
	CF (Cognitive functioning)	83.4	83.4	83.4
	SF (Social functioning)	100.0	100.0	83.4
Symptom scales				
	FA (Fatigue)	22.3	11.0	22.3
	NV (Nausea and vomiting)	0	0	0
	PA (Pain)	0	0	33.3
	DY (Dyspnoea)	33.3	0	0
	SL (Insomnia)	0	0	33.3
	AP (Appetite loss)	0	0	0
	CO (Constipation)	0	0	0
	DI (Diarrhoea)	33.3	0	0
	FI (Financial difficulties)	0	0	33.3

Note: On measures high scores indicate: DASS-21 = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DASS-21: [a] Normal range, [b] Mild range, [c] Moderate range
CD RISC 25: [d] within the range of Patients with Generalised Anxiety Disorder, [b] within the range of Primary Care patients

Graphical representations of the results detailed above separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning results, and EORTC QLQ-C30 symptom results are presented below.

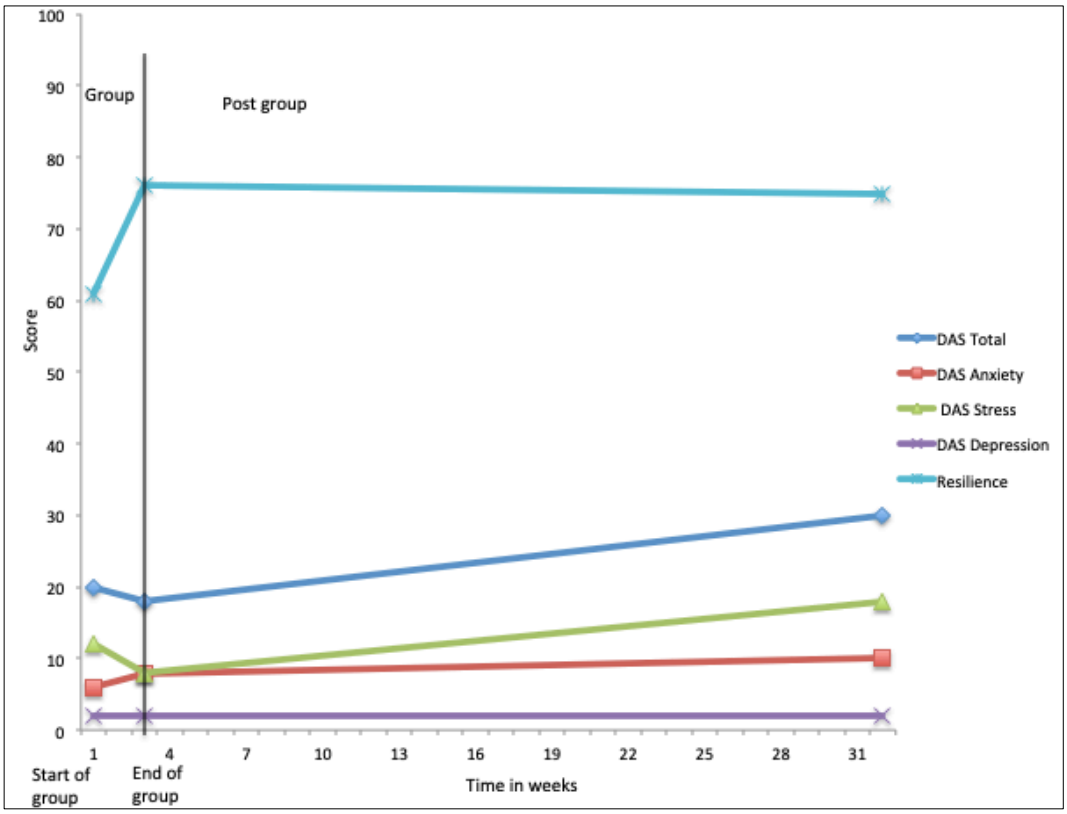

Figure 5.1: Participant A- DASS-21 and resilience results pre-start of DBT group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.1 shows the DASS-21 and CD RISC 25 (resilience) results for Participant A at pre-, post-, and follow-up. The DASS-21 scores for this participant indicate that at the start of the group sessions, she was in the normal range for depression, anxiety and stress. Her total score on the DASS-21 improved slightly during her participation in the group with depression and stress continuing within the normal range. Participant A's anxiety increased to within the mild range (8-9) at the end of the group and worsened to the moderate range (10-14) by follow-up. Although Participant A's score for stress improved by the end of the group it got worse again at follow-up reaching a mild level (15-18) which increased her total DASS-21 score. Participant A's DASS-21 scores therefore showed no reliable change according to Ronk et al's (2013) criteria during her attendance at the DBT group or at follow-up.

Participant A's resilience scores increased during her attendance at the group and remained within one point of her improved resilience at follow-up 29 weeks later. Her resilience score was within the range usually found in patients with generalised anxiety disorder at the beginning of the group, moved to within the range seen in primary care by the end of attendance at the group, and continued in this range (Connor & Davidson, 2003).

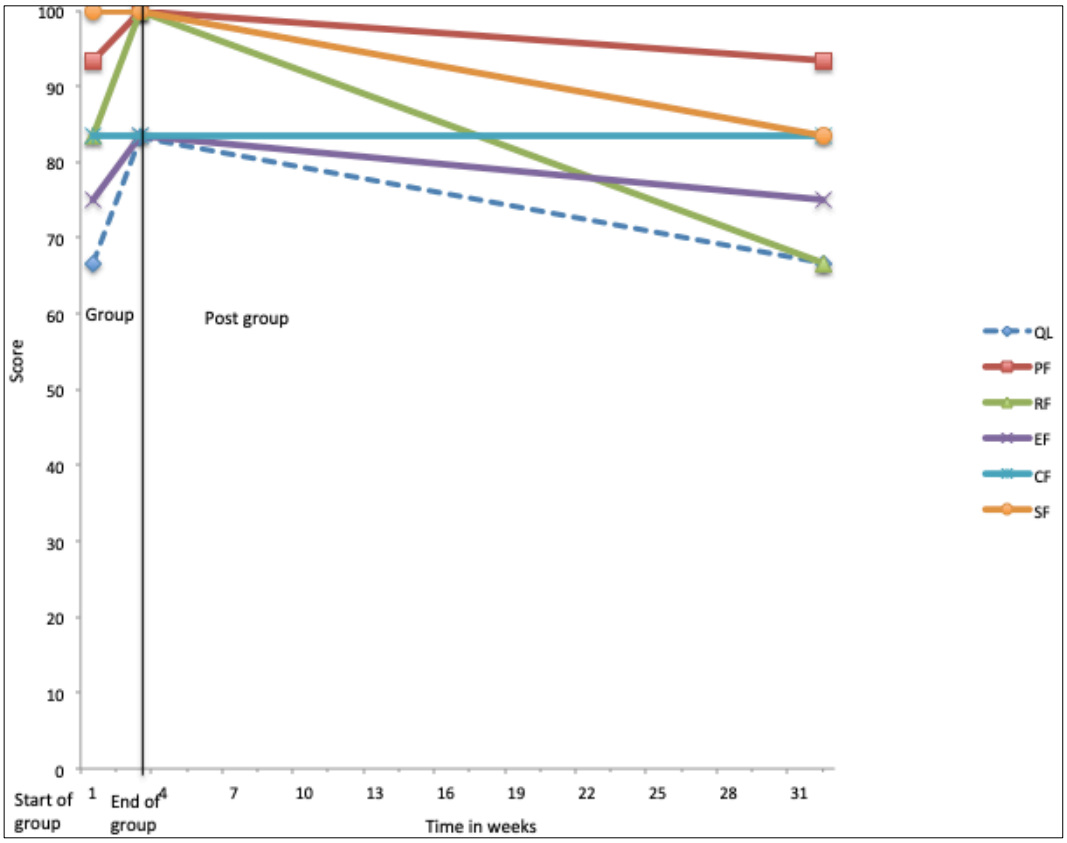

Figure 5.2: Participant A- Global health and functioning results pre-start of DBT group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.2 shows the results for Participant A on the EORTC QLQ-C30 global and other functioning results at pre-, post-, and follow-up. Participant A's QL (quality of life) score as measured by the EORTC QLQ-C30 improved by over 16 points during the time of her attendance at the group, which indicates at least a medium clinically meaningful

difference (Cocks et al., 2012). Her score however reduced again to pre-group levels at follow up. Three of the five functional scales (PF, RF, EF scores) showed a small clinically meaningful improvement of over 5-10 points during the group, indicating that physical functioning (activities such as walking, carrying, eating, using the toilet), role functioning (limitations in work, daily activities, hobby and leisure time), emotional functioning (concentration, worry, irritability, depression) all improved. These gains were not maintained at follow-up except for her CF (cognitive functioning) score, which did not change throughout the measurement period. RF (role functioning) reduced by a large difference of 33.3 points at follow-up. SF scores (social functioning) also remained the same at the maximum score of 100 before and during the group however reduced at follow-up.

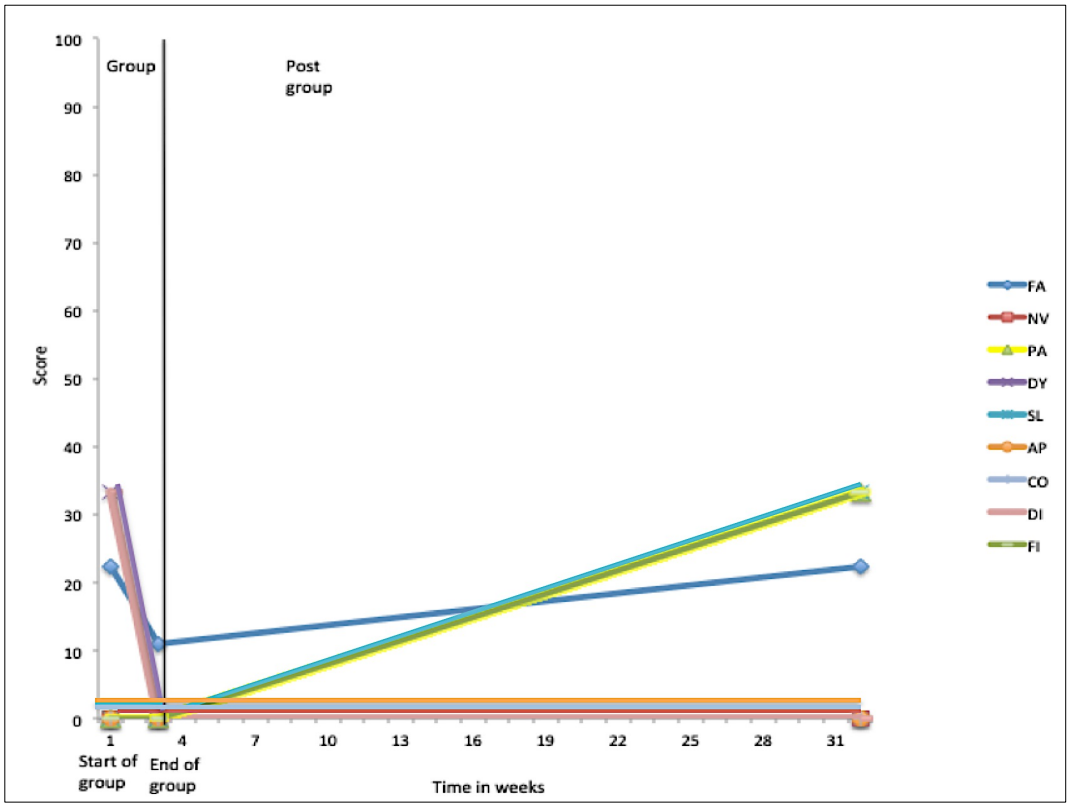

Figure 5.3: Participant A - Symptoms results pre-start of DBT group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.3 shows the results for Participant A on the EORTC QLQ-C30 symptom scales at pre-, post-, and follow-up. Participant A's scores on measures of FA (fatigue), DY (dyspnoea) and DI (diarrhoea) indicated poor functioning at the beginning of the group. At the end of the group, Participant A no longer had these symptoms except for FA (fatigue) which decreased but not to zero. All these changes were clinically significant. At follow-up, Participant A's scores on symptoms of PA (pain), SL (insomnia) and her FI (financial difficulties) had all gone up by clinically significant amounts meaning a deterioration in her symptoms. Her FA score (fatigue) also went up to pre-group levels.

In summary, Participant A's scores indicated improvements in stress, resilience, global health/quality of life and a reduction in symptoms between the start and the end of attending the group. However, at follow-up resilience was the only measure where these gains were sustained and may indicate the impact of the work restructure on Participant A .

5.3.2 Participant B

Participant B was a 50-year-old New Zealand European woman. She was a single parent of one child and the caregiver for her elderly mother. She had worked in a professional job prior to having a brain tumour and was not working at the time of this study. She expressed anxiety about the possibility of recurrence of cancer and reported being particularly anxious at her yearly oncology appointments.

Table 5-3 presents the data for Participant B at pre-, post- and follow-up.

Table 5-3: Quantitative data Participant B

Test	Subscale	Score and when administered		
		Session 1 (week 1)	Final session (week 3)	Follow up (week 32)
DASS-21	Anxiety	16[d]	2[a]	4[a]
	Stress	30[d]	14[a]	16[b]
	Depression	16[c]	12[b]	14[c]
	Total	62	28	34
CD RISC 25	Resilience	55[e]	56[e]	49[e]
EORTC QLQ-30	QL (Global health)	50.0	83.3	66.7
Functional scales				
	PF (Physical functioning)	73.3	80.0	80.0
	RF (Role functioning)	83.4	66.7	66.7
	EF (Emotional functioning)	41.7	75.0	66.7
	CF (Cognitive functioning)	33.3	66.7	50.0
	SF (Social functioning)	33.3	83.3	50.0
Symptom scales				
	FA (Fatigue)	56.7	20.0	53.3
	NV (Nausea and vomiting)	0	0	0
	PA (Pain)	16.7	16.7	16.7
	DY (Dyspnoea)	33.3	0	0
	SL (Insomnia)	66.7	33.3	33.3
	AP (Appetite loss)	0	0	0
	CO (Constipation)	33.3	33.3	33.3
	DI (Diarrhoea)	0	0	0
	FI (Financial difficulties)	100.0	33.3	100.0

Note: On measures high scores indicate: DASS-21 = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DASS-21: [a] Normal range, [b] Mild range, [c] Moderate range, [d] Severe range .
CD RISC 25: within the range of [e] Post Traumatic Stress Disorder patients.

Graphical representations of the results detailed above separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning results, and EORTC QLQ-C30 symptom results are presented below.

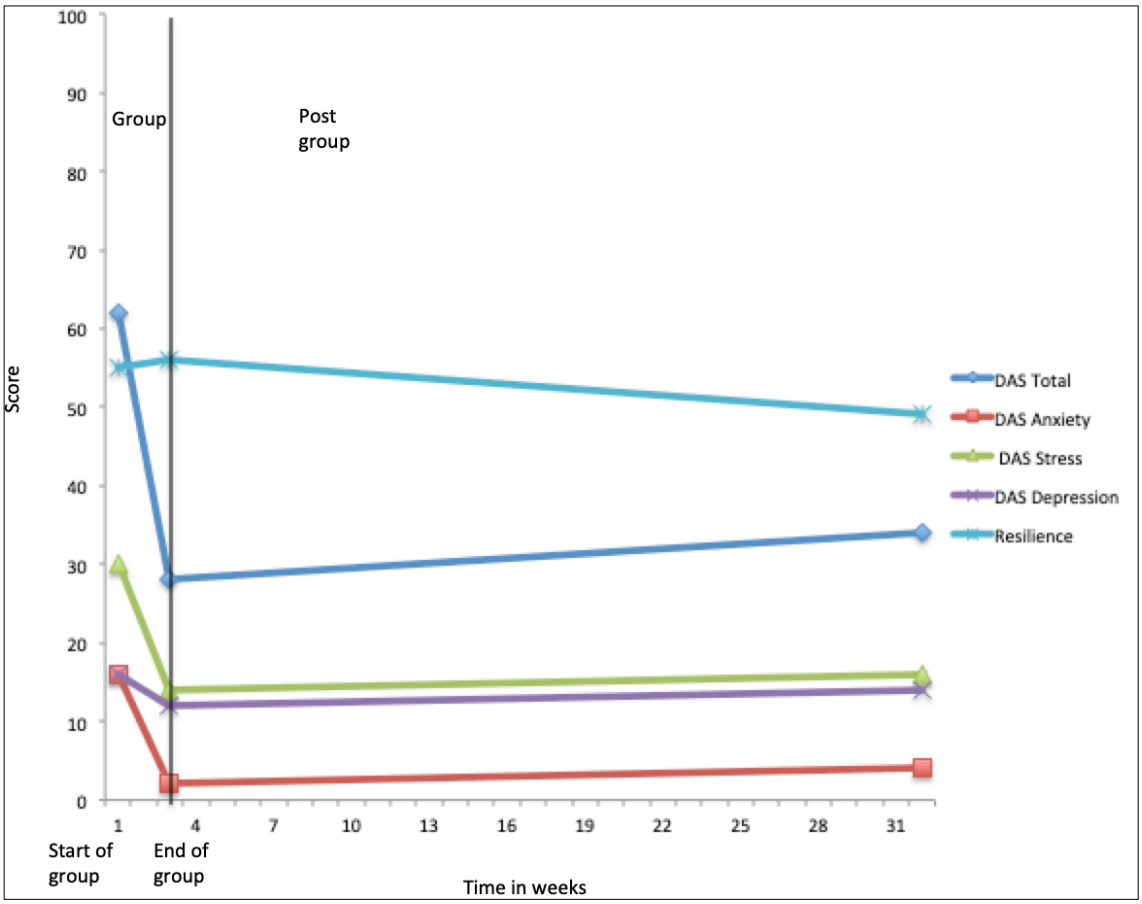

Figure 5.4: Participant B- DASS-21 and resilience results pre-start of DBT group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.4 shows the DASS-21 and CD RISC 25 (resilience) results for Participant B at pre-, post-, and follow-up. Participant B's DASS-21 results prior to starting the group indicated severe stress (range of 26-33) and anxiety (range of 15-19) and moderate depression (range of 14-20). At the end of the group sessions, Participant B's stress and anxiety had reduced to within the normal range and her depression had reduced to the mild range. When assessed at week 32, Participant B's anxiety level remained within the normal range, her stress scores were in the mild range and her depression was moderate. Participant B's attendance at the DBT group led to improvements in anxiety and stress which were reliable changes according to Ronk et al. (2013) (Appendix L.2). Participant B's resilience was within the range of patients with Post

Traumatic Stress Disorder at the beginning of attending the group and did not significantly change during group or at follow-up (Connor & Davidson, 2003).

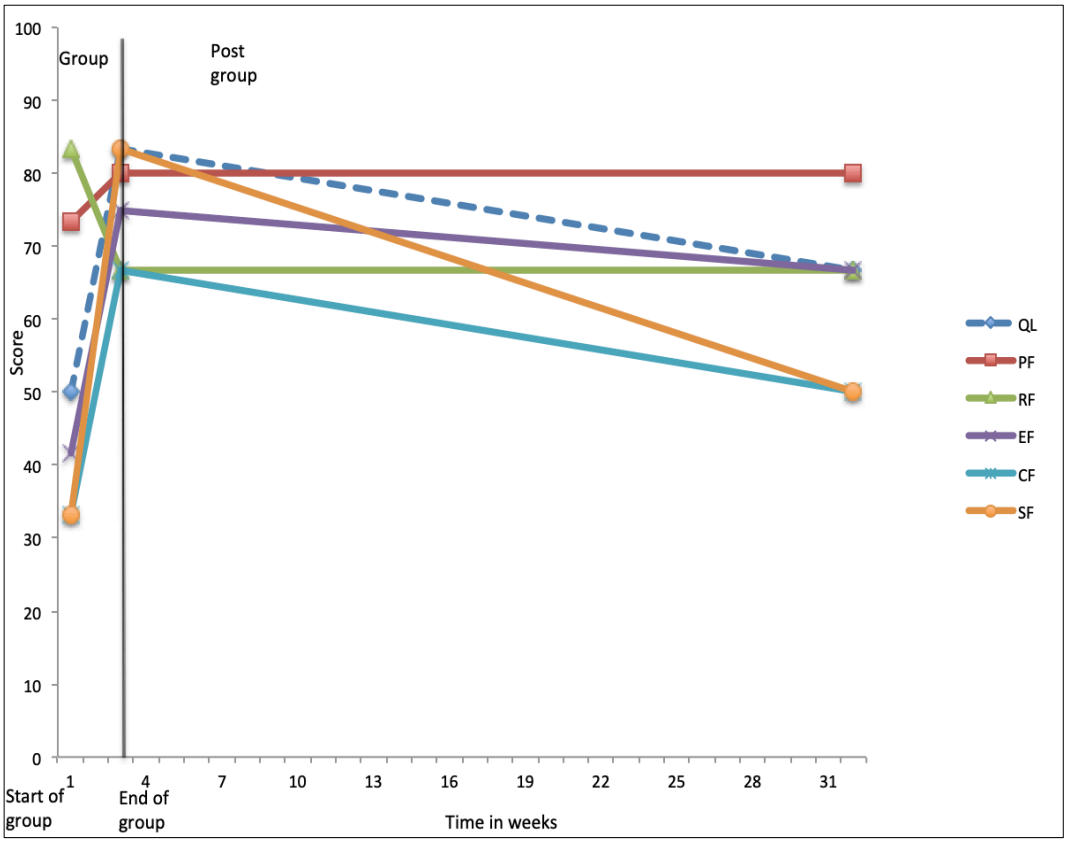

Figure 5.5: Participant B- Global health and functioning results pre-start of DBT group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.5 shows the results for Participant B on the EORTC QLQ-C30 global and other functioning results at pre-, post-, and follow-up. Scores on functional scales for Participant B all showed medium to large improvements of more than 10 points between pre-group measures and end of the group measures except for RF (role functioning – daily activities, leisure and hobbies). SF scores (social functioning: physical condition or treatment interfering with family life and social activities) showed the largest improvement (over 50 points), followed by CF (cognitive functioning: memory and concentration), EF (emotional functioning: tension, worry, irritability and

depression) scores, and QL (global health/quality of life), which also improved by over 30 points each. These are considered clinically significant according to Cocks et al. (2012).

At follow-up, Participant B's scores on QL (global health), SF (social functioning), CF (cognitive functioning) and EF (emotional functioning) scores all deteriorated but still maintained improvements over pre-group levels. Overall, there was a clinically meaningful improvement in her quality of life (QL score) even 29 weeks following attendance at the group of over 16 points. Physical functioning (PF) improved and then stayed the same at follow-up. Role Functioning (RF) having reduced post-group, remained the same at follow-up.

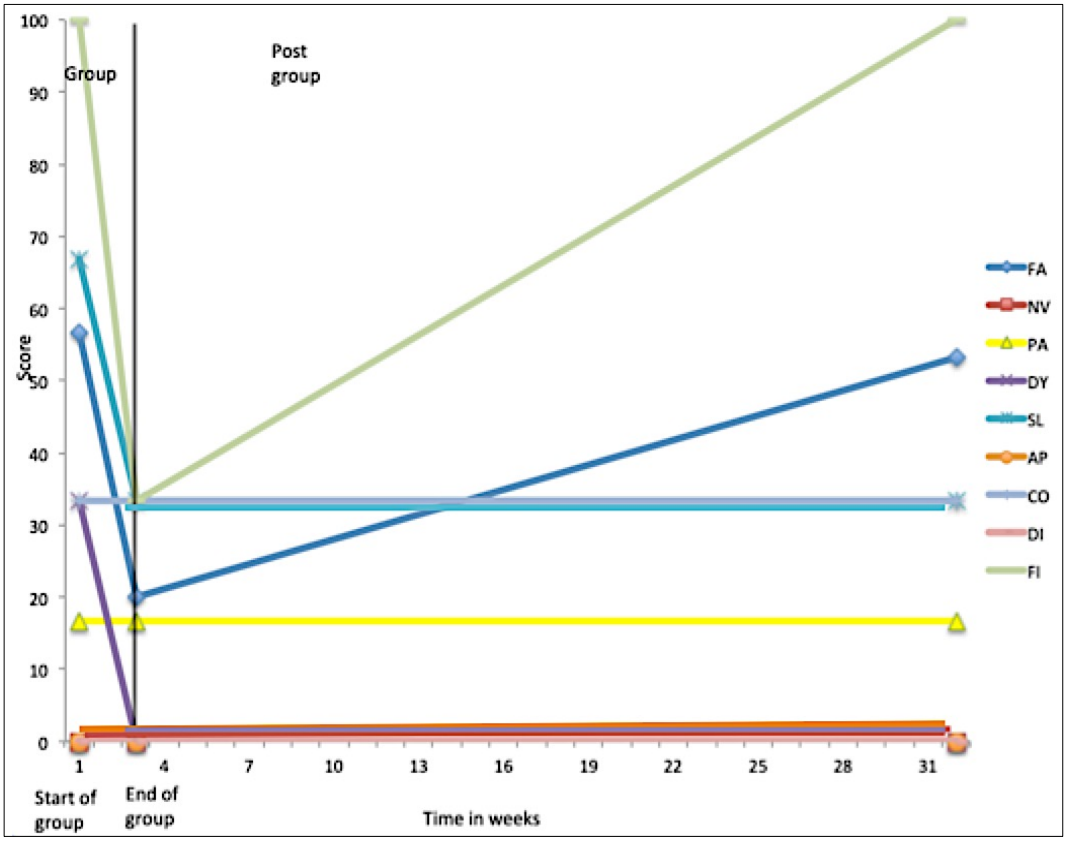

Figure 5.6: Participant B- Symptoms results pre-start of DBT group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 5.6 shows the results for Participant B on the EORTC QLQ-C30 symptom scales at pre-, post-, and follow-up. Participant B scored in the elevated (poorer status) range on six out of the nine symptoms measured. Participant B's scores on FI (financial difficulties), SL (insomnia), FA (fatigue) and DY (dyspnoea) improved by clinically meaningful amounts during group attendance with FA and FI scores showing worsening symptoms again at follow-up. SL and DY scores stayed at improved levels at follow-up. PA (pain) and CO (constipation) remained the same levels throughout the study.

In summary Participant B's scores for anxiety and stress improved reliably from severe to normal or mild and were maintained at week 32. Resilience stayed the same during the group and then decreased at follow-up. Quality of life, functioning and symptoms improved by clinically meaningful amounts during group and reductions at follow-up were still improvements on pre-group scores except for financial difficulties.

5.4 Combined quantitative results for Condition One

Table 5-4 summarises for both participants whether clinically significant improvement was achieved between baseline and the post-group measure and between the baseline and follow-up (that is, whether a clinically significant improvement was sustained).

Table 5-4: Summary of therapeutic change and maintenance of gains for participants Condition One

	Significant improvement start of group- to post-group		Improvement sustained or increased to follow-up	
	Participant		Participant	
Test/ Subscale	**A**	**B**	**A**	**B**
DASS-21				
Anxiety	X	✓	X	✓
Stress	X	✓	X	✓
Depression		✓		X
Total	X	✓	X	✓
CD RISC 25				
Resilience	✓	X	✓	X
EORTC QLQ-30				
QL (Global health)	✓	✓	X	✓
Function				
PF (Physical function)	✓	✓	X	✓
RF (Role function)	✓	X	X	X
EF (Emotional function)	✓	✓	X	✓
CF (Cognitive function	X	✓	X	✓
SF (Social function)		✓	X	✓
Symptoms				
FA (Fatigue)	✓	✓	X	X
NV (Nausea & vomiting)				
PA (Pain)		X	X	X
DY (Dyspnoea)	✓	✓	✓	✓
SL (Insomnia)		✓	X	✓
AP (Appetite loss)				
CO (Constipation)		X		X
DI (Diarrhoea)	✓		✓	
FI (Financial difficulties)		✓	X	X

	Significant improvement start of group- to post-group		Improvement sustained or increased to follow-up	
	Participant		Participant	
Test/ Subscale	**A**	**B**	**A**	**B**
KEY	Significant change achieved	✓	Gain maintained or improved at follow-up	✓
	Change not possible		Improvement not possible	
	No significant change	X	Improvement not maintained	X

Note: Significant change achieved = Clinically significant improvement between pre- and post-group measure.
Change not possible = Symptom/function already in normal range – no significant improvement possible.
No significant change = No clinically significant improvement from pre- to post-group measure.
Gain maintained or improved at follow-up = follow-up score as good as post-group score OR significantly improved from pre-group measure
Improvement not possible = score was within normal range or no symptoms so no scope for improvement from pre-measure to follow-up
Improvement not maintained = Improvement made over course of group not maintained to follow-up

One of the aims of this study was to determine if attending a brief DBT group decreased distress, increased resilience and increased quality of life for these participants. Table 5-4 indicates a variable pattern of outcomes across the participants and it is difficult to draw any conclusions due to there being only two participants.In terms of distress, as measured by DASS-21 scores, results indicated improvements in total DASS-21 scores for both participants and anxiety, stress and depression for Participant B whilst attending the group. Twenty-nine weeks following the group ending, results between the two participants also varied. At follow-up, anxiety and stress increased again for Participant A, who experienced a restructure of her job and reported at interview that this was stressful. For Participant B however, although anxiety and stress increased at follow-up, her levels were far improved from the severe levels she experienced prior to the group and these changes were considered reliable (Ronk et al. 2013).

Participant A's resilience increased during the time of the group remaining improved at follow-up. However Participant B's resilience did not significantly improve and reduced to levels below pre-group measures at follow-up. Quality of life as measured by global functioning indicated improvements for both participants during the time they participated in the group. Functioning in most of the areas measured by the EORTC QLQ-30 improved for both participants, except for role functioning (limitations on work and daily activities) for Participant B. At follow-up, most of Participant B's functioning scores stayed at improved levels compared with pre-group scores. Although her emotional, cognitive and social functioning reduced, this was not to pre-group levels. During the group, symptoms also improved for Participant A and mostly improved for Participant B, except for pain and constipation, which stayed the same. However, at follow-up there was more variation between participants with some symptoms such as pain not changing, insomnia improving and constipation also staying the same for Participant B: whereas fatigue, pain, insomnia became worse at follow-up than at pre-group for Participant A. Financial difficulties increased to pre-group levels for both.

The following is the presentation of qualitative findings for both participants in Condition One. The names of skills taught in the group mentioned by the participants are presented in bold.

5.4.1 Combined qualitative data at follow-up

At follow-up, which was 32 weeks from the start of the group and 29 weeks after the group ended, each of the participants took part in an individual semi-structured interview conducted by the researcher to gather data regarding their experience of the group and to understand whether they had continued using the skills learned. The

following are findings derived from recorded transcripts of the interviews. Questions that guided the interviews are outlined in Appendix N. The three themes, *Using skills*, *Looking after me* and *Being with others*, describe the impact of attending the group. These themes were derived from the participants pooled data according to the method described by Braun and Clarke (2006, 2012).

Theme one: Using skills

This theme captures participants' views of the skills they gained from the DBT group and used day-to-day, and which skills they found particularly useful. This theme consisted of three sub-themes: *Having and using DBT skills, The happier me, and Calming down. Having and using DBT skills* captures the use of particular skills such as paced breathing. Both participants could identify and name particular skills learned in the group that were useful to them and that they still used 29 weeks later. Participant A described how use of the skills had affected her life by helping her to reach her goal of increased fitness, leaving her feeling happier – an example of *The happier me,* sub-theme. The third sub theme *Calming down* describes how Participant B was able to regulate her feelings of anxiety and worry.

Having and using DBT skills

Participant A stated she used breathing to "switch off" after work and used mindfulness to be more self-aware. This indicated that Participant A was able to grasp these skills and apply them effectively. She reported that following attendance at the group, she coped with stress differently than in the past, and this led to better outcomes for her. When asked if she thought attendance at this group has led to any changes for her, Participant A stated, "Oh yeah, on how I've coped, completely."

Paced breathing enabled Participant A to slow down her anxious breathing, reducing the physical effects of anxiety even though her stress increased with her work restructuring at the time.

> *I definitely use that **paced breathing** app. If I have had a really long day at work of being able to switch off quicker before getting into the evening routine. **Mindfulness** is what I really have been focussing on because I realised that if you are self-aware of what is happening that's the first step and before I was so busy being in the emotion of being stressed and anxious that I wasn't able to cope with it as well, so the **mindfulness** and learning to look after myself better.*

This participant described the previous five months as being very stressful due to changes and conflicts at work. She attributed the use of the skills and attendance at the group as having changed her ways of coping. She gave an example of when she was anxious about a meeting she prepared by writing down what she wanted to say. This illustrated that Participant A was coping ahead with a potentially stressful situation by rehearsing her response, which was another skill that was taught in the group.

> *I wrote down before going into the meeting so that I was mentally prepared **(coping ahead)**, and I knew what I was trying to achieve, and it ended up being a really good outcome, actually.*

Participant B reported that the most important factor in her improvement was that she knew that she had skills such as breathing to use to counteract worry and make effective decisions that helped reduce stress.

> *I think not worrying so much about things and remembering that I can breathe to get into that **wise mind** state/position where you make **effective** decisions instead of sitting there worrying and thinking "What is going to happen?" Getting yourself, all stressed out in that type of situation, but you know you have got something there to help you.*

Participant A said that she had learned to be more self-aware, which led to her using skills, which in turn impacted positively on her life.

> *Well just being self-aware (**mindful**) and learning these skills, because if you don't know it you can't apply it, and if you can't apply it you can't cope, and if you can't cope then everything falls over.*

An example of how Participant A was more self-aware was her response to the restructure at her work.

> *Oh, that whole dealing with the conflict at work situation. If I hadn't been through what we had talked about in those sessions, I wouldn't have thought about acknowledging that I was anxious and worried about the situation **(acceptance)**.*

The happier me.

When asked if she thought the group had made any difference to her quality of life Participant A said that it "definitely" had. In the quote below, Participant A indicated that although her work restructure after she attended the group was stressful, she felt less stressed and happier.

> *There was someone I hadn't caught up with for a couple of months and they said, "You look so happy" and it's just because I don't have the stress... I am really pleased I've learnt this stuff. Because I kind of feel now if I get any further strong life lessons, I've certainly got a lot more **skills** now.*

Participant A reported that attending the group also led her to work towards her goal of increasing her fitness. She had completed a quarter marathon walk. She had injured herself and had started thinking negatively, but was able to observe her own thinking and used the problem solving skills she learned in the group to adapt and find a successful alternative strategy.

> *And then I have been trying to get fitter and I did ten kilometres, quarter marathons they call them, walking event and injured my (self), so I have had to adjust to that as well which was a little bit stressful in the beginning. And I*

have had to learn how to adapt and do different exercises, which has brought me to yoga.

Calming down

Participant B reported she had learned a series of skills in the group that she could use in stressful situations rather than engage in ineffective worrying.

Teflon mind (a mindfulness skill) and paced breathing (which teaches participants to slow down their breathing to reduce the physical sensations of anxiety) were named as skills taught in the group and which Participant A thought were the most useful skills she had learned.

*I still use the **Teflon mind** skill. The **breathing** has been really helpful I've noticed when I do get worried about things, I stop myself and then use the breathing skills and try and calm myself, and it does work.*

Theme two: Looking after me

The second theme of *Looking after me* links to the first theme of using DBT skills in that participants described the impact of using these skills. This theme is made up of four sub themes: *Developing boundaries and saying no*, *Physical resilience*, *Taking the bull by the horns* and *sorting it out, and Helping others as well as me.*

Developing boundaries and saying no

Being able to observe oneself and identify your own stress and anxiety are fundamental skills taught in the DBT group. Participant A was able to identify when she was getting stressed and intervene by saying no to requests that were likely to increase her stress. By prioritising her own health and self-care at work, Participant A demonstrated that she had learned to take care of her own health first. In the past, in a work situation, she would have put her own needs second and worked harder when asked. Participant A identified this as an outcome of having come to the group.

My health is too important, and I've gone and said to whoever "If I need temps in or if, look, I just can't get this done, so who else can we look at to getting it done?" And I have just said "No" more.

Physical resilience

When asked if she had noticed any difference in her resilience since attending the group, Participant A stated that she thought she had been more resilient as she had not been sick over winter.

A lot of people in the building have got sick, and more than once or twice, and it's not just the odd cold there have been flu's and everything. I haven't got sick this year, and I have been through a really stressful year and I am, like, "this is good."

Taking the bull by the horns and sorting it out

Being active and not avoiding is a central principle of DBT that was taught in the group. Participant B commented several times that since the group, she handled stress actively rather than passively sitting and worrying.

*Yeah, I feel like I have got something to fall back on with these **skills** and I feel like I am taking the bull by the horns a bit more instead of sitting back and waiting for it to resolve itself. I think it's no use doing that, just get on in there and sort it out.*

Participant B stated that as soon as she noticed herself worrying, she focussed on problem solving, as taught in the group, so that she could deal with stressors, and engaged in more problem solving in her daily life. In the group, she had also learned mindfulness skills and was more able to observe her own behaviour.

So, I have gotten into a routine now of dealing with things, pretty much as soon as I know it is wrong, I will try and make a plan to get it resolved.

Observing and describing are parts of mindfulness skills taught in the group. Participant B observed that worry affected her life and she used the skill of observe and describe to notice a process which she called a worry "spiral".

> *I think differently I suppose, yeah I think that worry side of things was really hard for me and I would just go into a spiral and spiral downhill.*

She was able to identify and then problem solve by stopping this spiral of worries before she became overwhelmed.

> *But now I know something clicks in where I think oh I can do this or I can do that **(problem solving**).*

Helping others as well as me

Both participants made comments about either teaching others the skills they had learned or contributing to knowledge in this area. Participant A said

> *I've certainly got a lot more skills now and I find in work I'm the person that people come to now, for a lot of stuff. That I must have this label that says "come and ask me, I really want to help you". Because I've shared what I've learned, because I like to share what I have learnt to the people around me.*

Participant B said that she primarily attended the group so that she could learn strategies for herself, but was also interested in helping others through her participation in this study.

> *I suppose the main reason I did it was so I could learn strategies for myself but also to maybe to help other people by our experience in the future.*

Theme three: Being with others

The third theme of *Being with others* concerned the participants' experience of being in the group and meeting others with shared experience. This theme captures the participant's experience of seeing the other participant learning and coping. Being with others in a group allows group members to observe others changes and how they have learned. Participant A said that she had observed the other group member she met. She had seen the other participant's coping abilities, and this inspired her.

I am highly impressed, I mean it's not nice going through cancer for anybody, but I've always believed that having xxxx cancer would be horrific to go through, a whole lot worse, you know but everybody's really got on with it.

5.4.2 Integration of qualitative and quantitative results

Participant A's quantitative scores showed positive change and improved functioning, as well as improved quality of life during group attendance. Follow-up scores on quantitative tests indicated the treatment gains were not maintained, except for improvements in resilience. This participant reported that she was physically more resilient and hadn't been sick over winter, and was also mentally more resilient in being able to say no and deal with work conflicts in a different way than she had previously. Her report of increased resilience was reflected in her resilience scores, which increased during the time of attendance at the group and were maintained 29 weeks later.

A restructure at her work following attendance at the group had been very stressful for Participant A. Although DASS-21 stress scores increased from the normal range to the mild range at follow-up, this increase for Participant A may have been higher had she not learned skills in the group, which she said, had improved the way she coped with stress. Skills, especially mindfulness and paced breathing, had been used to deal with work conflict and Participant A was able to say "no "when demands she thought were too high were placed on her. As well as giving examples of how the skills acquired in the group had been used to improve how she coped, Participant A also felt positive about teaching the skills to others.

For Participant B, quantitative data generally indicated improvements in stress, anxiety, depression, resilience and quality of life measures of functioning and symptoms during attendance at the group. The improvements reduced at follow-up

but generally did not go back to pre-group levels. Participant B stated that she felt she was slowing down and felt increased pressure due to family members relying on her. Scores showed increased fatigue (higher FA scores) and financial difficulties (increased FI scores) and limits to daily activities, work or hobbies as reflected in decreases in her RF (role functioning) score by a clinically measurable amount and was noticeable as the only measure not improved. Qualitative data indicated that Participant B thought that the biggest effect of attending the group was the change in the way she dealt with worry. Previously she had felt overwhelmed and gone into what she described as a 'spiral of worries'. Attendance at the group had led to her using the skills of Teflon mind and paced breathing to counteract anxiety. She had also learned to actively problem solve. These changes were reflected in reductions from severe anxiety pre-group to the normal range by the end of the six sessions. Similar changes were noted in stress scores. These gains were maintained 29 weeks later.

Outcomes from Condition One indicated that the brief DBT group intervention, even as developed primarily for mental health clients, might be of value in assisting cancer patients in the New Zealand context. This was justification for proceeding to the next stage of the planned study, namely utilising an Appreciative Inquiry approach to explore how the brief DBT group could be modified to potentially better meet the needs of cancer patients. Results and discussion of this exploration are reported in the next chapter.

5.5 Summary

In this chapter, results for the participants in Condition One were presented as single case designs. The key results were that distress, namely stress levels, resilience and quality of life improved during the three weeks of participation in the group.

Quantitative outcomes generally showed improvement 29 weeks later compared with levels before the start of the group; however, improvements were reduced from the levels reached at the end of the group. Qualitative findings for the participants indicated that they found the skills helpful. Both participants reported that paced breathing was a skill they found the most beneficial. These results indicated that DBT was seen as applicable and relevant for these cancer patients. In the next chapter- Chapter Six, the results of the Appreciative Inquiry focus group to alter the group for cancer patients will be presented.

Chapter 6 Findings: Appreciative Inquiry Condition One- modifying the group

6.1 Introduction

The second aim of this study was to tailor the DBT group, originally developed for mental health service users, for use by cancer patients. This was done with focus groups, using an Appreciative Inquiry methodology in which participants were asked to consider if/what modifications should be made to the group to tailor the programme for cancer patients. The first focus group was held after the final session of the Condition One group, and the findings from that group were used to guide modification of the programme used with the Condition Two group. A second focus group was held after the final session of Condition Two group and suggestions from that group can be used to guide future development of this type of programme. The AI session was conducted following the Discovery, Dream, Design, Destiny cycle (Cram (2010). This chapter describes these findings, presented according to the phases of the AI process.

Below are the findings from the AI focus group for Participants A and B.

6.2 Findings Appreciative Enquiry

6.2.1 Discovery phase

In this phase, participants were asked about which skills they had found most useful and where they had used these skills effectively. Three themes were identified: *Focusing on your breath, Flicking that feeling away and other skills,* and *Practising at home and other helpful aspects of the group.*

Theme one: Focussing on your breath

Paced breathing, which involves slowing down and counting the breath, was taught in the second session and was mentioned as the most helpful skill by both participants. They stated that paced breathing acted as a distraction from the emotion they were feeling, such as sadness and anxiety, whilst also helping them to reduce their physical arousal. Participant A said:

> *And that brings my mind in tune with my body and then I can notice what's going on. . . Yeah it removes the emotion of what you're feeling at the time because you have to* ***focus on your breathing*** *so you're not focusing on being offended, hurt, and sad or any of that stuff, and so when you stop having those feelings you calm down. Then you can be more* ***effective****.*

Participant B stated:

> *Yeah for me the* ***paced breathing*** *is a good one. Sometimes I find I wake in the middle of the night and worry about things, and the paced breathing has allowed me to kind of flick those feeling away and to actually get myself back to sleep again and calm myself down, so that has been a very helpful technique.*

Theme two: Flicking that feeling away and other skills

Different skills were taught in each session of the group with the expectation that participants practiced them at home. Both participants named skills besides paced breathing that they had learned and now used because of attending the group. These skills included progressive muscle relaxation, thinking of the pros and cons, Teflon mind, and being non-judgemental.

Participant A identified progressive muscle relaxation (PMR) as a particularly useful skill. Learning PMR allows people to better notice when their muscles are tense and to relax and reduce the tension in muscle groups throughout their body.

> ***Progressive muscle relaxation****. . . It really helps just to relax down at the end of a busy working day. But even if you turn it around it can set your day up if you use it first thing in the morning and so that is something I am now doing very regularly.*

Thinking of the pros and cons (positives and negatives) of a situation or a course of action allows more balanced decision-making. Participant A said:

> *I like the **pros and cons**. Why I like it is because it can be applied in so many different situations, not just about going through the cancer journey and having to make all those decisions. I used it for looking at what I'm eating and what are my best food choices, and by going through those steps I'm more aware of what I'm eating now and putting in my mouth and I think that's kind of important and quite helpful.*

Teflon mind and being non-judgemental are skills taught as part of the skill of mindfulness, which was taught in the first session. These skills permit the person to separate themselves from their emotion, which then allows the emotion to reduce. Participant A said:

> *Family members were getting into a bit of a debate and winding almost all of us up in the lounge and I just used the **Teflon mind** there. Someone said "What are you doing?" And I said, "I'm just letting go of everything you guys are saying because it is not helping the situation." And that just brought a whole end to what was going on in that conversation.*

Participant B said:

> *I like the **Teflon mind**, I think that's a very quick skill, you can **observe and describe (mindfulness)** the feeling and then it's something you can go straight to and it's just there to try and flick that feeling away.*

The ability to put judgements and personal interpretations aside allows emotions to be more easily regulated. Taking a non-judgemental stance allowed participants to take control of their emotions as identified by Participant B:

> *I think I've found (being) **non-judgemental** very useful, especially with an older mother and a young son and having cancer myself. It does actually help you to stop those feelings getting out of control of when judging someone, and it does bring you back to a calmer place once you realise you are being judgemental.*

Theme three: Practicing at home

Participants regarded practicing the skills outside of the session as helpful. The three-week (six sessions) length of the group, allowed for two to three days of practice between sessions which, being just a few days, meant that participants were willing to practice skills at home because this was not seen as too long a time period. This was also identified as helpful. Participant A stated:

> *So actually, being asked to go and do the homework and doing it and noticing the differences and reaping the benefits straight away was the best thing for me. I like the fact that this has been set up to be done in three weeks. At first it seemed like it was a bit of a commitment to make, being twice a week, but then before I knew it, it's finished, so it's raced by, but I liked it being for a total of three weeks.*

6.2.2 Dream phase

In this phase, participants were asked what changes would improve the group. Both participants suggested the theme of *Bringing a support person along.*

Theme: Bringing a support person along

A support person/carer attending with the participant was thought to be the most useful change that needed to be made. A cancer diagnosis not only affects the patient, but also their families, whānau and support people. Participant B said:

> *Bringing a support person along, because they are going through as much stress as we are, and for both of you to be able to have skills to get through that stress.*

Both participants focussed on the importance of family and support people learning how to manage their own stress and learning how to support the family member with cancer as well. Participant A said:

> *You need the support person totally to get through, and so they need to be able to have good stress management skills as well.*

The participants considered that their carers and support people needed help also, and thought that attending group together would help both. Participant B said:

> *I would say one group all together because it is good for the both the caregiver and the person with cancer to understand what both are going through and knowing the skills which both parties can use.*

6.2.3 Design phase

In this phase participants were asked to talk about what concrete changes could be made to modify the group for cancer patients. Two themes emerged: *Increasing access* to the DBT group, and *Follow-up groups to increase/maintain gains.*

Theme one: Increasing access

This theme captured the participants' ideas about increasing access to this therapy. Two sub themes: *People in the country get to access the group, and Offer it at diagnosis and be flexible* emerged. Both participants thought that the group was useful and that others in New Zealand, especially in the regions outside of big cities, should be able to access it. Participant A:

> *I just want it to be throughout New Zealand so the people in the country get to access it as well. . . Almost compulsory!*

Participant B:

> *It needs to be available to everybody.*

Both participants thought that the programme would be most useful for people with cancer around the time of, or shortly after diagnosis. Participant B:

> *Personally, I think at the beginning, but it may be a bit too much to deal with at that time, the middle Yes, I would say perfect timing.*

Both participants also pointed out that cancer patients cope differently at the beginning of their treatment and some may not be ready to be part of a group. Participant A's comments are below:

> *What I'd like to suggest is that the person is given the option right from the beginning and [they] make the decision. [Some can] just respond in a different way and be quite capable of dealing with it and then there's others, like myself, that wouldn't have been able to deal with it right at the beginning.*
> *I think some sort of assessment or understanding of the stuff in here should happen right at the beginning and perhaps you make it optional so the person can choose to come back later on, when they have got through the surgery and the chemo and they know how they are going to respond because you just don't know.*

Reasons for offering the group at diagnosis included being able to make the decisions regarding treatment, which need to be made at the beginning of treatment without feeling overwhelmed; helping communication with the medical team and how the team deal with the person; and also helping the person have lower stress levels. However, participants also acknowledged that it might be too difficult for the patient to be in a group at the time of diagnosis as it might be too much to deal with while having treatment. Participant B stated:

> *I feel like the end is a very important time as well because this is the time you have been through all the treatment and there are no more doctors - maybe just every six months or a year, and you're on your own and now you need to navigate yourself forward, and to have these type of skills to move forward is very important and to make decisions about your life going forward these skills are very helpful.*

Having the option to learn skills near the end of the treatment may also be useful because of the reduction in supports once cancer treatment is over and the person returns to their GP's care.

Theme two: Follow-up groups to increase/maintain gains

This theme captured participants' suggestions about other aspects that may help to reinforce the skills and therefore the usefulness of the group. Both participants agreed that a follow-up session would be useful. Participant A said:

> *Maybe have one session where we get together with all of the groups so that we can network for a start, because that's quite important to have a wider cancer network support and be able to discuss what we've learnt, it could be quite beneficial.*

Although being in a group that also includes palliative care patients, may be challenging because cancer patients who have survived may feel guilty, Participant A thought a mixed group might be a good idea.

> *I sometimes feel guilty that I am a survivor especially when you see young children, you know other people who have got the terminal diagnosis. . . I think it could be quite interesting, I think my learning may be greater because I would hear their side of the story and their journey, so I could learn from them, so they could help me. I don't know if I could help them in return, but I would like to.*

6.2.4 Destiny phase

In this phase, suggestions were made about the next actions. The theme of *Using social media to maintain skills* captured participants' ideas about how to maintain the knowledge and skills learned in the group. Both thought that having some reminders of skills or a Facebook group would be helpful.

> *Maybe some kind of social media, some tips to follow up, like how we continue to practice and reminders maybe about some of these techniques just reminders, "Are you doing this, what are you finding helpful or have you tried this."* Participant B
>
> *That's a cool idea.* Participant A

They also thought that if others wanted to follow the conversation without signing in or having to participate, that would acceptable and might be helpful to others. Participant A said:

> *Those that don't want their story to be told can still follow and read the story without signing up so it could be really helpful. I think it's a really cool idea.*

6.2.5 Summary of Appreciative Inquiry session

Through the process of Appreciative Inquiry, participants identified paced breathing as the most useful skill. In the Discovery phase, they named several other skills such as Teflon mind, thinking of the pros and cons, progressive muscle relaxation as useful skills that they had practiced at home. They found that having to practice skills at home by doing homework was helpful. The timing of the group, twice a week for three weeks, suited them and feedback about content of the group was positive as well. In the Dream phase where further developments of the group were considered, participants suggested including support people as an addition to the current package. Having a follow-up session was also suggested. In the Design phase, both participants agreed that it would be good to offer the group at the time of diagnosis in order to help the patient and their support people deal with the decisions about treatment they needed to make. However, they were also unsure if every patient would be ready for that. The participants suggested giving patients the option of attending the group that they could take up later if they wanted. One participant thought a mixed group with survivors and palliative patients would be all right. Finally, in the Destiny phase, the suggestion was made of on going coaching and sharing of tips for coping through social media.

The following section presents the changes made to the programme as a result of suggestions made in the focus group following Condition One.

6.3 Changes to the programme for Condition Two as a result of the Appreciative Inquiry Focus Group

The Appreciative Inquiry findings after the final session of Group One indicated that major changes to the content or format of the group were not necessary, so the content of sessions remained the same. The feedback was that a support person attending would be useful, so participants for Group Two were invited to bring along a support person to participate in the group with them. The manual was distributed to cancer patients and support people at the beginning of the group, and support people participated in the group and homework exercises the same as the cancer patients.

No other substantive changes were made to tailor the group programme to be specifically for people with cancer.However, as the facilitator was more aware of issues related to cancer, such as anxiety about having to make decisions about cancer treatment, more cancer related examples were used when discussing DBT skills. Participant's suggestions about increasing access and equity of access to this kind of intervention for people with cancer were beyond the scope of this study.

6.4 Summary of the findings of the Appreciative Inquiry- Condition One

The focus group following Condition One that considered how to modify the group for cancer patients indicated the content and the timing of the group was acceptable to cancer patients and suggested inclusion of family/whānau/support people in the group as well as the patient. The participants identified paced breathing as to most useful skill they had learned. They stated that they found doing homework between sessions useful and also commented about increasing access and maintaining gains.

The next two chapters discuss the quantitative and qualitative outcomes of the Condition Two, the group that was modified for cancer patients as informed by the

Appreciative Inquiry described in this chapter. Chapter Seven which follows, details the results for Condition Two the modified group where support people were invited to participate in the group alongside cancer patient participants. Chapter Eight presents the results of the Appreciative Inquiry session held at the end of the final group in order to identify any changes for future brief DBT groups.

Chapter 7 Results: Condition Two- modified group

7.1 Introduction

In this chapter, results for the modified group developed out of the Appreciative Inquiry focus group, reported in the last chapter, are presented. Inclusion of support people/carers in the same group was the main modification made. Results are presented as single case studies for the four participants of the modified group. Due to the small number of participants, statistical analyses were not undertaken. The results comprise quantitative data for each participant. Qualitative data, consisting of the common themes emerging from the post-group interviews of Condition Two participants, are also are presented in this chapter.

7.1.1 Potential participants who did not continue in the study

Seventeen potential participants telephoned the researcher and agreed to participate in this research. Ten potential participants did not attend or return their forms. Of these ten, three had to return to work and were not able to take time off, one had shift work, one had no childcare, and one had chemotherapy treatment during group time. Two potential participants were overseas when the groups were held. Two others did not participate for unknown reasons.

In Condition Two, three participants completed pre-measures and the quantitative measures gathered in the first group, attended only one group and did not complete the entire programme or complete the follow up measures and therefore their data was not included in the study as they did not complete the programme. Reasons given by these three participants for discontinuing were that driving to the venue was too difficult, one potential participant's son became ill and she had to stay home with him,

and another potential participant started a round of chemotherapy treatment and became too unwell to travel to the group.

Four participants were fully enrolled in this study and completed the group. Two participants had support people who were able to attend, one participant attended with her husband and one with her sister.

7.2 Participant characteristics

Table 7-1 Demographic data of Participants in Condition Two

Participant	Gender	Age (in years)	Education	Ethnicity	Type of cancer	Other medical disorder	Self-rating on Distress Thermometer	No. of groups attended
C	Female	61	University	NZ European	Breast stage 3	Bursitis	8	5
D	Female	54	University	European	Breast stage unknown	Fibromyalgia	5	5
E	Female	46	High School	NZ European	Bowel Ovarian	Peritoneal disease	8	6
F	Female	64	University	NZ European	Brain tumour	Arthritis in one knee	5	6

7.3 Results for Condition Two participants

Results are presented as single case studies, with a table summarising patterns of change in the quantitative data across all four cases shown after the individual cases. Quantitative measures were conducted at four points in this part of the study: two measurement points prior to the intervention, one at the conclusion of the group, and one at follow-up. The DASS-21, CD RISC 25 and EORTC QLQ-30 were administered pre-group three weeks before the group started (listed as Pre in the results table for each participant) and the same measures were re-administered at the start of the first group (listed as First in the results tables). The measures were administered along with

an Appreciative Inquiry Focus Group at the end of the group sessions (listed as Final in the results tables), and participants again completed the quantitative measures plus an individual semi-structured interview at follow-up (listed as Follow-up in the results tables). Follow-up had been intended for four months after the group ended, but a family illness and bereavement for the researcher necessitated delaying the follow-up to 20 weeks after the group ended. As all participants could not come on the same day for the follow-up session, the session was repeated. Three participants from Condition Two attended individual semi-structured interviews with the researcher, which were recorded and transcribed. One participant, Participant D, felt unwell and her interview was recorded via telephone.

7.3.1 Participant C

Participant C was a 61-year-old New Zealand European woman who had worked as a teacher but was not currently working. She was treated for breast cancer and underwent chemotherapy during the time when the group was being run, starting just prior to session one. She was unable to attend one session as she was having treatment at that time. Chemotherapy finished shortly after the group and she was not receiving treatment at follow-up. Participant C had hypothyroidism and bursitis in her right elbow. She attended the group with a support person, her husband, who was also not working and who attended all sessions.

The quantitative results for Participant C are presented in the following table.

Quantitative results

Table 7-2: Quantitative Data for Participant C

Test	Subscale	Score and when administered			
		Pre (week 1)	First (week 3)	Final (week 6)	Follow up (week 26)
DASS-21	Anxiety	10[c]	20[e]	20[e]	2[a]
	Stress	22[c]	10[a]	0[a]	0[a]
	Depression	4[a]	12[b]	12[b]	8[a]
	Total	36	42	32	10
CD RISC 25	Resilience	72	66	81	83
EORTC QLQ-30	QL (Global health)	16.7	33.3	0	75.0
	Functional scales				
	PF (Physical functioning)	14.0	74.0	40.0	57.0
	RF (Role functioning)	0	34.0	0	66.7
	EF (Emotional functioning)	25.0	75.0	20.0	75.0
	CF (Cognitive functioning)	0	17.0	17.0	50.0
	SF (Social functioning)	0	0	34.0	50.0
	Symptoms scales				
	FA (Fatigue)	100.0	76.0	100.0	66.7
	NV (Nausea and vomiting)	100.0	33.3	100.0	16.7
	PA (Pain)	83.3	33.3	100.0	50.0
	DY (Dyspnoea)	33.3	33.3	100.0	0
	SL (Insomnia)	66.7	33.3	33.3	0
	AP (Appetite loss)	100.0	66.7	100.0	0
	CO (Constipation)	100.0	33.3	100.0	0
	DI (Diarrhoea)	100.0	0	33.3	33.3
	FI (Financial difficulties)	66.7	100.0	66.7	33.3

Note: High scores indicate: DASS-21 = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DASS-21: [a] Normal range, [b] Mild range, [c] Moderate range, [d] Severe range, [e] Extremely severe range

Graphical representations of the results detailed above separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning results, and EORTC QLQ-C30 symptom results are presented below.

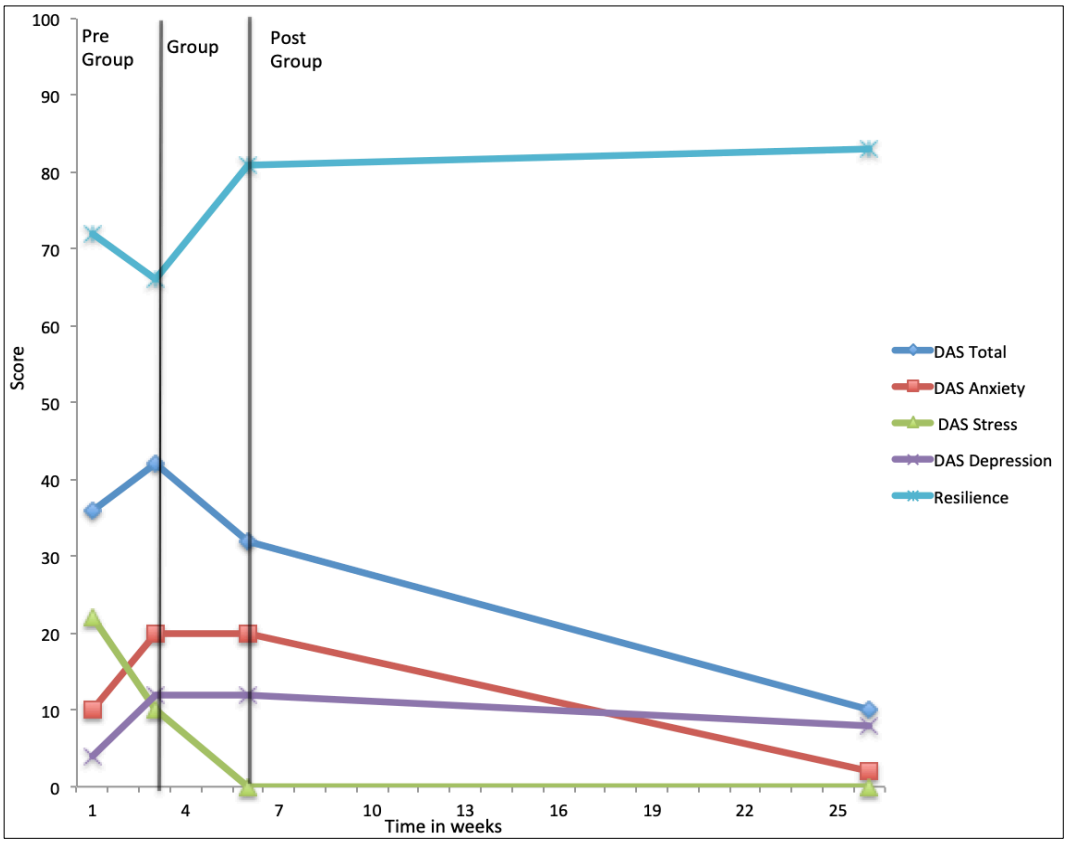

Figure 7.1: Participant C- DASS-21 and resilience results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 7.1 shows that DASS-21 results for Participant C showed considerable variability prior to the start of the intervention, with anxiety, depression, and the total score showing substantial increases up to week three (the start of intervention). The increases were within reliable ranges according to Ronk's (2013) criteria (Appendix L.2). Anxiety ranged from moderate to extremely severe before the group started. Paradoxically, stress levels decreased over the time from pre-group to the start of the intervention. Depression was also in the mild clinical range. The elevated levels on these measures may be consistent with Participant C undertaking chemotherapy over the course of the group.

Stress levels decreased over the time of the group and were maintained at the lower level through to follow-up. Anxiety did not change over the time of the group, but

decreased through to follow-up. Depression did not change over the time of the group but did improve to the normal range at follow-up. The DASS-21 total score reflected the changes above, decreasing slightly over the course of the intervention, but showing a larger change improving more at follow-up. Resilience showed a clinically significant increase over the course of the intervention and this increased further to follow-up, finishing within the normal range for the general population (Connor & Davidson, 2003).

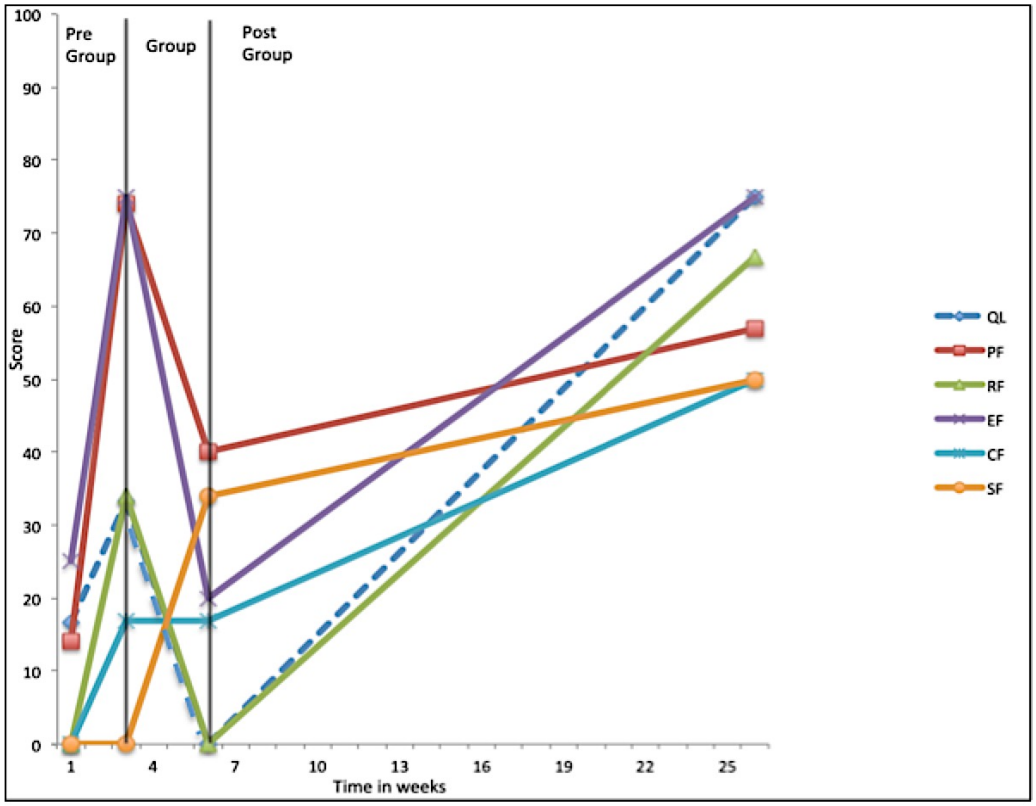

Figure 7.2: Participant C- Global health and functioning results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Scores on the EORTC QLQ-C30 functioning scales shown in Figure 7.2 also showed large variability prior the start of the group. Except for cognitive function (CF) (unchanged) and social function (SF) (improved), all other functioning scales showed

deteriorations over the time of the group, which coincided with the participant receiving chemotherapy. By follow-up all scales showed significant improvements in function, typically to above baseline levels, although not necessarily to above the three-week (start of group) levels.

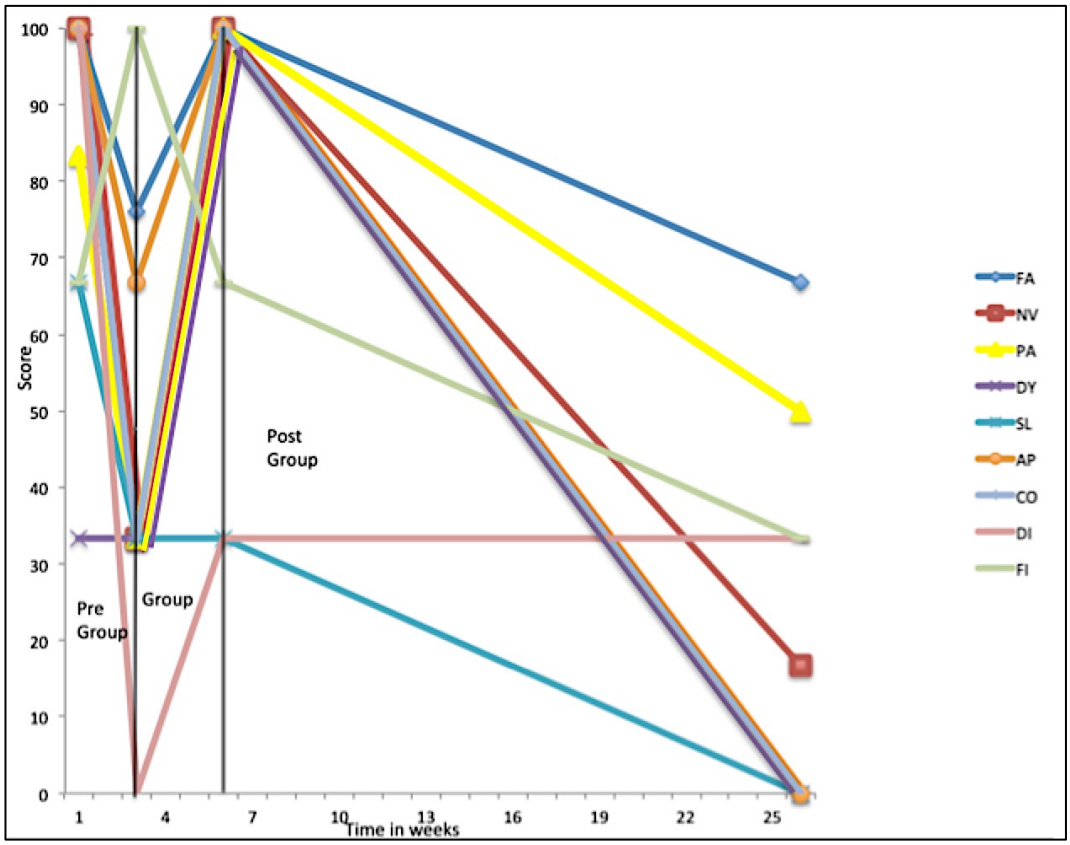

Figure 7.3: Participant C- Symptoms results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

The EOTC QLQ-C30 symptoms scales as shown in Figure 7.3 also showed wide variability in the pre-group period prior to the start of treatment, with all except financial difficulties showing a decrease between baseline and the three-week point at which the intervention started. All symptoms except for insomnia (SL) got worse over the course of the intervention, but by follow-up (after the end of chemotherapy), most

had improved to levels well below the level at the start of the group. Participant C having chemotherapy whilst attending the group likely influenced all symptom scores.

In summary, Participant C attended the group with her husband who also learned the skills. During the time of her attendance, her symptoms, including fatigue, nausea and pain increased, as did her anxiety, which may be explained by her receiving chemotherapy while she attended the group. Even though Participant C was having chemotherapy, her stress scores reduced, and resilience measures increased.

7.3.2 Participant D

Participant D was a 54-year-old married New Zealand European mother of two children with disabilities with a diagnosis and treatment for breast cancer. She had completed active treatment for cancer. She also suffered from fibromyalgia, which increased her pain levels and affected her ability to work. During the period when the group was running, she was on leave from her professional work. Participant D returned to work soon after the group ended.

Quantitative results

Table 7-3: Quantitative Data for Participant D

Test	Subscale	Score and when administered			
		Pre (week 1)	First (week 3)	Final (week 6)	Follow up (week 26)
DASS-21	Anxiety	12[c]	4[a]	2[a]	16[d]
	Stress	16[b]	30[d]	8[a]	16[b]
	Depression	32[e]	26[d]	4[a]	12[b]
	Total	60	60	14	44
CD RISC 25	Resilience	74	71	81	75
EORTC QLQ-30	QL (Global health)	33.3	50.0	41.7	75.0
	Functional scales				
	PF (Physical)	47.0	66.7	86.7	80.0
	RF (Role functioning)	33.3	33.3	100.0	66.7
	EF (Emotional functioning)	66.7	33.3	58.4	66.7
	CF (Cognitive functioning)	66.7	50.0	83.3	50.0
	SF (Social functioning)	50.0	66.7	83.3	50.0
	Symptoms scales				
	FA (Fatigue)	53.3	53.3	44.3	44.3
	NV (Nausea and vomiting)	33.3	16.7	0	0
	PA (Pain)	50.0	33.3	50.0	16.7
	DY (Dyspnoea)	33.3	0	0	0
	SL (Insomnia)	33.3	66.7	66.7	33.3
	AP (Appetite loss)	0	0	0	0
	CO (Constipation)	0	33.3	0	0
	DI (Diarrhoea)	0	0	0	33.3
	FI (Financial difficulties)	66.7	66.7	33.3	33.3

Note: High scores indicate: DASS-21 = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DASS-21: [a] Normal range, [b] Mild range, [c] Moderate range, [d] Severe range, [e] Extremely severe range

The following graphs present the results detailed above, separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning, and EORTC QLQ-C30 symptoms.

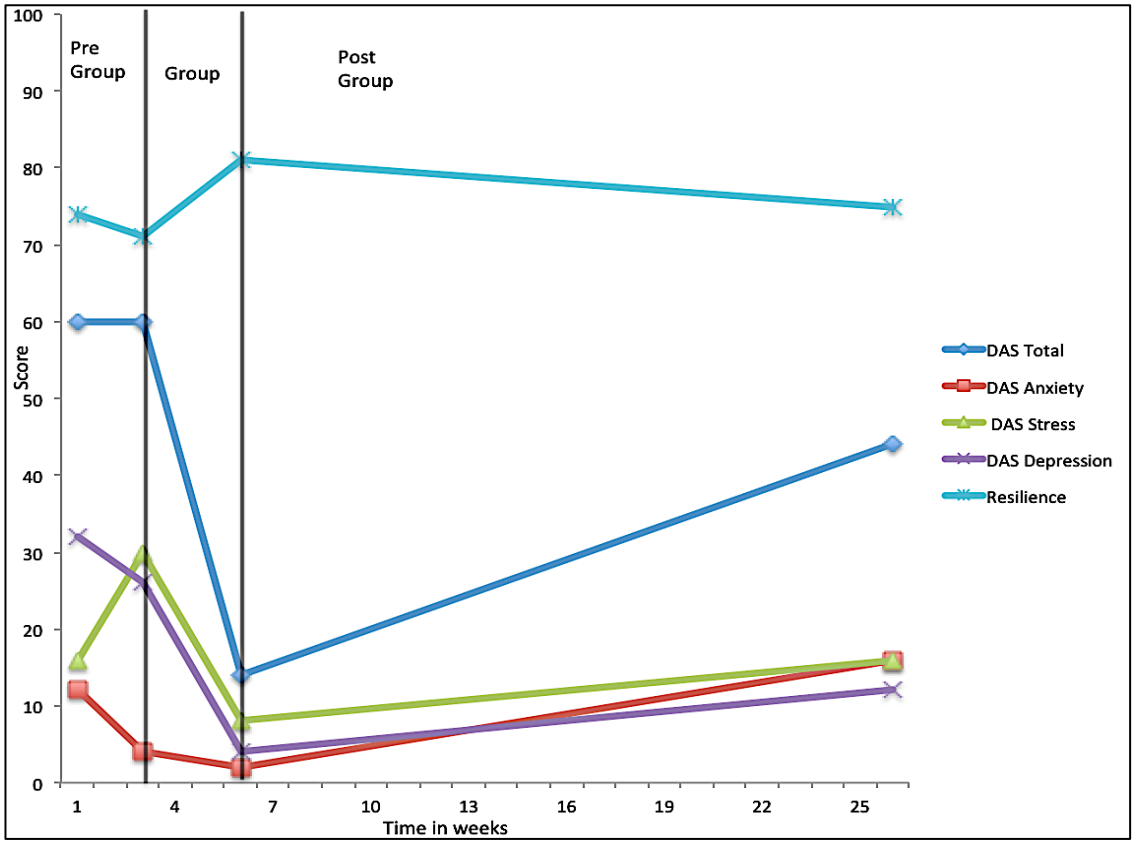

Figure 7.4: Participant D- DASS-21 and resilience results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 7.4 shows Participant D's DASS-21 and resilience scores. Participant D's depression score pre-attendance at the group was in the extremely severe range (score of 28 or more), dropping into the severe range (score of 21-27) prior to the group starting. Her score for anxiety was in the moderate range (score of 10-14) and her score for stress was in the mild range (score 15-18) prior to attending the group. All three measures showed improvements that represented reliable change to within the normal range from pre- to post-group. However, all measures except depression returned to close to baseline levels at follow-up. At follow-up scores indicated a return to severe stress (score 26-33) and mild anxiety (score 8-9). At follow-up depression was in the mild range (score 11-13), much lower than pre-group levels.

Participant D's resilience scores prior to attending the group fell within the range for the general population (Connor & Davidson, 2003). Resilience scores increased somewhat during the group sessions and although they reduced slightly, they stayed within the general population range at follow-up.

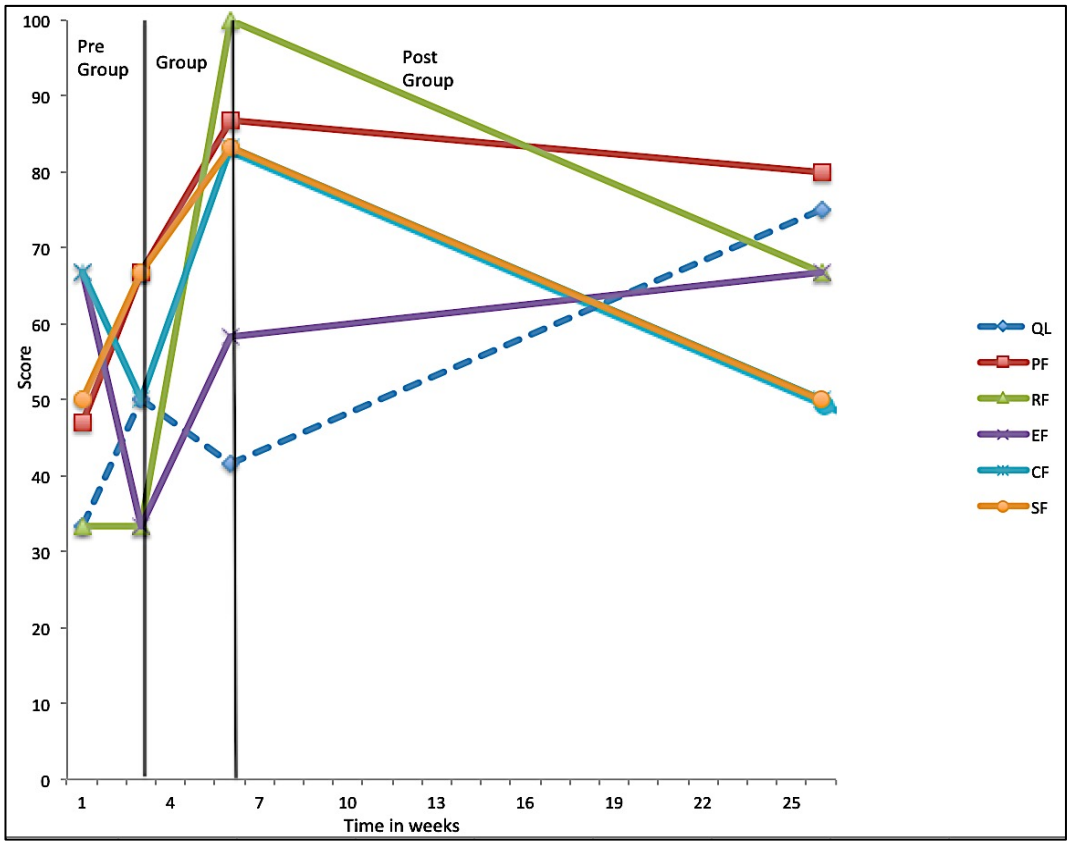

Figure 7.5: Participant D-Global health and functioning results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

As can be seen in Figure 7.5 substantial variability was again seen in most measures between the baseline and three week measurements, with all but RF (role functioning) showing clinically significant changes in the three weeks before the group started. All functioning scores except QL (global function) showed medium or above clinically significant improvements (Cocks et al., 2012) of ten points or more between start of group and post-group measures. Even though PF (physical function) and RF (role

function) scores reduced at follow-up, medium to large clinically significant improvements from baseline were maintained to follow-up for PF (physical function) and RF (role function), but was not maintained for CF (cognitive function) or SF (social function). Emotional functioning (EF) also improved at follow-up but not by a clinically significant amount. Global Health (QL) showed a small deterioration over the intervention, and showed an above medium significant improvement from post-group to follow-up.

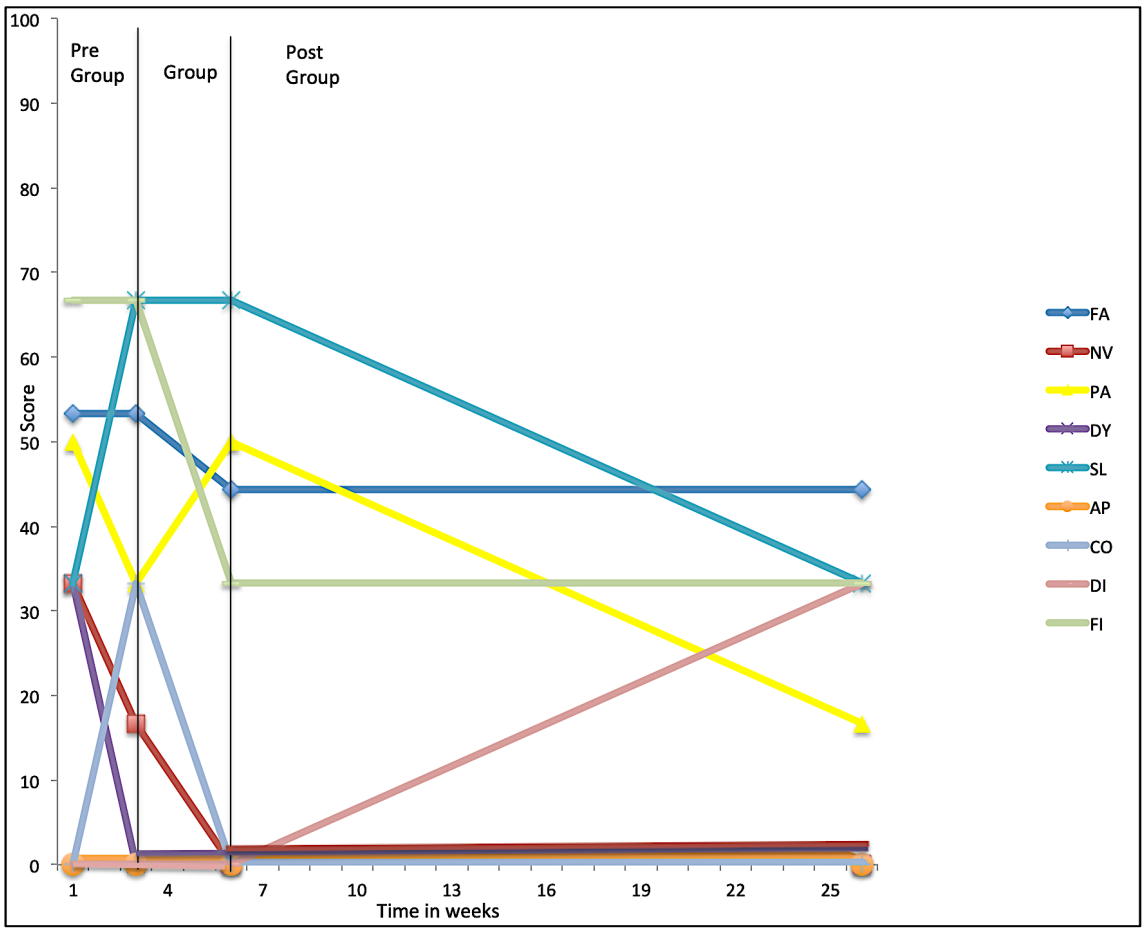

Figure 7.6: Participant D- Symptoms results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Participant D's EORTC QLQ-30 symptom score measures as seen in Figure 7.6 showed substantial variability between baseline and the three-week measure. Fatigue (FA),

nausea and vomiting (NV), constipation (CO) and financial difficulties (FI) improved from the group start to post-group and this was maintained to follow-up. Pain (PA) reduced prior to the group starting and then increased during the group to post-group but had a medium to large significant improvement by follow-up. Insomnia (SL) did not improve over the course of the intervention and was at the baseline level at follow-up. Diarrhoea (DI) was not a concern for Participant D prior to or during the group, but became a concern by follow-up.

Summarising Participant D's quantitative data, Participant D showed improvements in mood measures between pre- to post-group but the improvements for anxiety and stress were not maintained to follow-up. Most aspects of function improved pre- to post-group, with some of these being maintained to follow-up, and while global health (QL) did not improve over the intervention, substantial improvements were seen by follow-up. Most of the problematic symptoms identified at pre-group did show improvements by post-group and/or follow-up.

7.3.3 Participant E

Participant E, was a 46-year-old New Zealand European single mother of two daughters who had treatment for bowel and ovarian cancer and peritoneal disease. She was not working whilst attending the group. Participant E reported extreme anxiety at oncology appointments and had previously taken two support people along with her because she was so overwhelmed. At her oncology appointment prior to attending the group, she had been so overwhelmed that she was not able to recall what the Oncologist said.

Quantitative results

Table 7-4: Quantitative Data for Participant E

Test	Subscale	Score and when administered			
		Pre (week 1)	First (week 3)	Final (week 6)	Follow up (week 26)
DASS-21	Anxiety	8[b]	4[a]	4[a]	14[c]
	Stress	10[a]	8[a]	2[a]	14[a]
	Depression	14[c]	16[c]	2[a]	18[c]
	Total	32	28	8	46
CD RISC 25	Resilience	41[e]	41[e]	64	43[e]
EORTC QLQ-C30	QL (Global health)	66.7	66.7	83.3	83.3
	Functional scales				
	PF (Physical)	80.0	86.7	93.4	100.0
	RF (Role functioning)	66.7	83.3	100.0	100.0
	EF (Emotional functioning)	50.0	58.4	83.3	17.0
	CF (Cognitive functioning)	83.3	66.7	100.0	66.6
	SF (Social functioning)	83.3	100.0	100.0	100.0
	Symptoms scales				
	FA (Fatigue)	53.3	53.3	43.3	33.3
	NV (Nausea and vomiting)	0	0	0	0
	PA (Pain)	50.0	0	0	16.7
	DY (Dyspnoea)	33.3	0	0	0
	SL (Insomnia)	33.3	33.3	0	0
	AP (Appetite loss)	0	0	0	0
	CO (Constipation)	0	0	0	0
	DI (Diarrhoea)	33.3	0	33.3	33.3
	FI (Financial difficulties)	33.3	66.7	0	66.7

Note: High scores indicate: DASS-21 = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DASS-21: [a] Normal range, [b] Mild range, [c] Moderate range, [d] Severe range, [e] Extremely severe range
CD RISC 25: [e] within the range of Patients with Post Traumatic Stress Disorder

The following is a presentation of graphic representations of the results detailed above separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning results and EORTC QLQ-C30 symptom results.

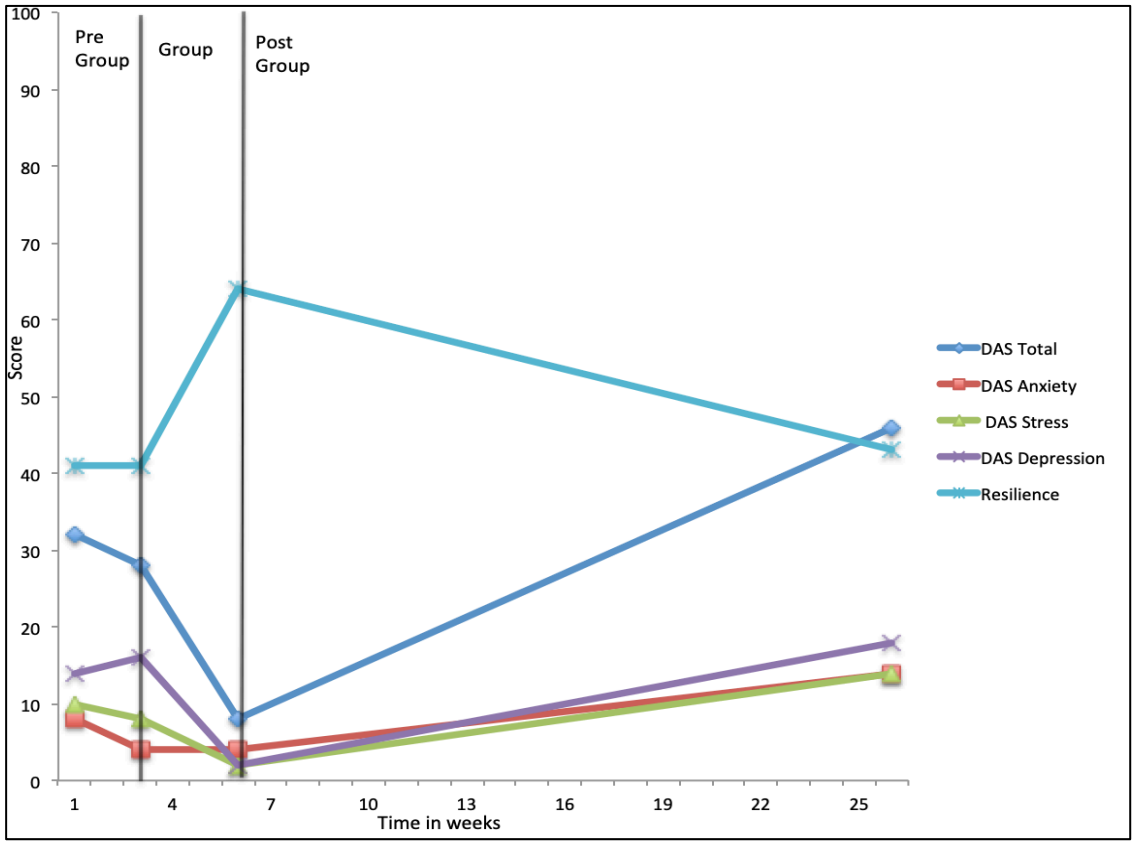

Figure 7.7: Participant E- DASS-21 and resilience results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

As can be seen in Figure 7.7, Participant E's scores for depression, anxiety and stress did not demonstrate any reliable change over the baseline period (the three weeks prior to the group starting) but stress and depression scores did show reliable improvements between the start and end of the group (Ronk et al.,2013). These improvements were not sustained at follow-up. In the pre-group baseline period Participant E's DASS-21 scores indicated mild anxiety which reduced to normal prior to the group starting. Over the time of the group no change to anxiety occurred (it remained in the normal range). Depression scores also improved from moderate in the baseline period to normal by the end of the group. Total DASS-21 scores also showed an improvement over the time of the group from the baseline period moving down from 28 at the start of the group to eight by the end (higher scores indicate higher

difficulties). However, once again this was not sustained at follow-up. Resilience scores indicated no change in resilience over the control period where resilience scores were in the same range as patients with Post Traumatic Stress Disorder (Connor & Davidson, 2003). There was however, a significant improvement whilst attending the group with resilience improving to the level of the general population .This also was not sustained at follow-up where resilience reduced to pre-group levels.

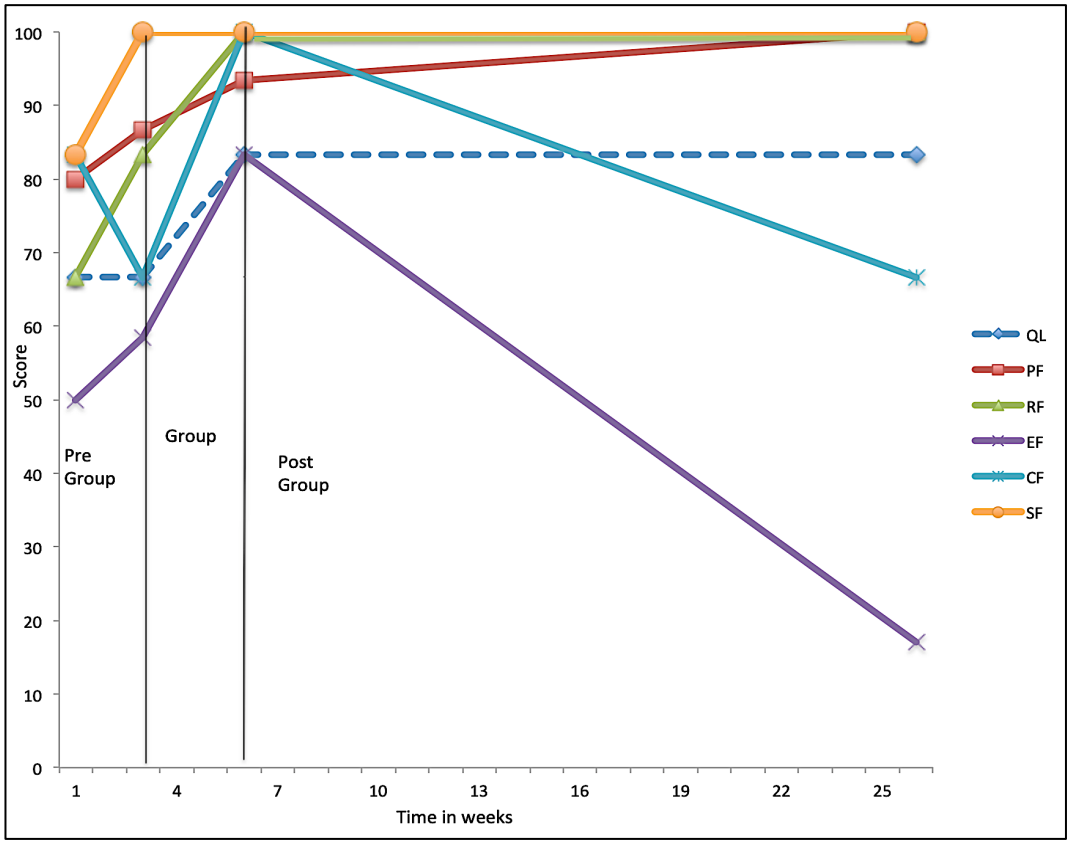

Figure 7.8: Participant E- Global health and functioning results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

For Participant E all measures of functioning as measured by the EORTC QLQ-30 except for CF (cognitive functioning) improved significantly during the pre-group phase as indicated in Figure 7.8. These improvements continued or were maintained during the group.

CF (cognitive functioning) scores reduced in the pre-group period. This trajectory of reducing CF changed to an over 30 point medium to large clinically significant increase during the time Participant E attended the group. Gains were maintained at follow-up for SF (social functioning), RF (role functioning), PF (physical functioning) and general QL (global health).

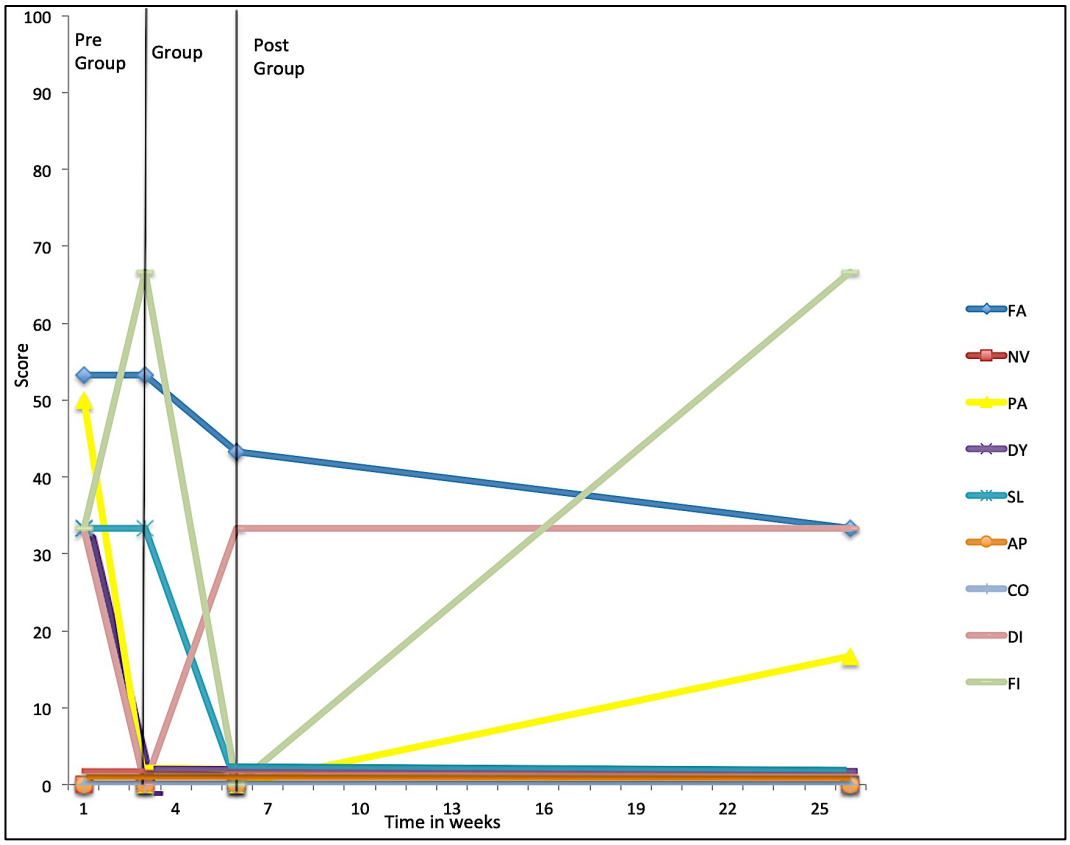

Figure 7.9: Participant E- Symptoms results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 7.9 shows EORTC QLQ-C30 results for Participant E who experienced the symptoms of fatigue (FA), pain (PA), dyspnoea (DY), diarrhoea (DI), insomnia (SL) and financial difficulties (FI) in the pre-group period. By the end of the group all symptoms except for DI improved. At the follow-up point even though PA (pain) increased, fatigue (FA), insomnia (SL) and dyspnoea (DY) had reduced by medium or more

clinically meaningful amounts. Financial difficulties (FI) and diarrhoea (DY) showed no sustained improvement.

In summary, in the pre to post-group period most of Participants E's results showed improvements in mood. Anxiety, depression and stress showed improvements in the pre-group to post-group period. Resilience, global health and functioning also improved. During attendance at the group, symptoms of fatigue and insomnia in particular reduced, having been at the same level for the three weeks pre-group. Follow-up measures showed that the gains Participant E had made whilst attending the group reduced again, depression and anxiety returning to moderate levels and resilience, emotional and cognitive functioning reducing below pre-group levels. At follow-up however, Participant E's quality of life scores, social, physical and role functioning scores remained improved as did her fatigue, pain, dyspnoea and insomnia.

7.3.4 Participant F

Participant F, was a 64-year-old female former journalist who is New Zealand European and had a diagnosis of brain cancer. Her sister, who was her main support person, accompanied her. Participant F was not able to drive so her sister was her driver. She had also developed severe arthritis in her leg that affected her mobility. The arthritis worsened during the time she participated in the study.

Quantitative results

Table 7-5: Quantitative Data for Participant F

Test	Subscale	Score and when administered			
		Pre (week 1)	First (week 3)	Final (week 6)	Follow up (week 26)
DASS-21	Anxiety	4[a]	6[a]	6[a]	2[a]
	Stress	0[a]	6[a]	6[a]	4[a]
	Depression	14[c]	6[a]	2[a]	10[b]
	Total	18	18	14	16
CD RISC 25	Resilience	73	66	82	77
EORTC QLQ-30	QL (Global health)	66.7	66.7	91.7	83.3
	Functional scales				
	PF (Physical)	53.3	66.7	73.7	40.0
	RF (Role functioning)	66.7	83.3	100.0	33.3
	EF (Emotional functioning)	66.7	100.0	91.7	66.7
	CF (Cognitive functioning)	50.0	50.0	66.7	50.0
	SF (Social functioning)	100.0	100.0	83.3	100.0
	Symptoms scales				
	FA (Fatigue)	33.3	22.3	0	20.0
	NV (Nausea and vomiting)	0	0	0	0
	PA (Pain)	33.3	16.7	33.3	66.7
	DY (Dyspnoea)	0	0	0	0
	SL (Insomnia)	0	66.7	0	0
	AP (Appetite loss)	0	0	0	0
	CO (Constipation)	0	0	0	0
	DI (Diarrhoea)	0	0	0	0
	FI (Financial difficulties)	33.3	33.3	0	0

Note: High scores indicate: DAS = poorer status, CD RISC 25 = higher resilience, EORTC – Functional Scales = better function, EORTC – Symptom scales = more difficulty.
DAS-21: [a] Normal range, [b] Mild range, [c] Moderate range, [d] Severe range, [e] Extremely severe range

The following is a presentation of graphic representations of the results detailed above separated into DASS-21 and CD RISC 25, EORTC QLQ-C30 global and other functioning results and EORTC QLQ-C30 symptom results.

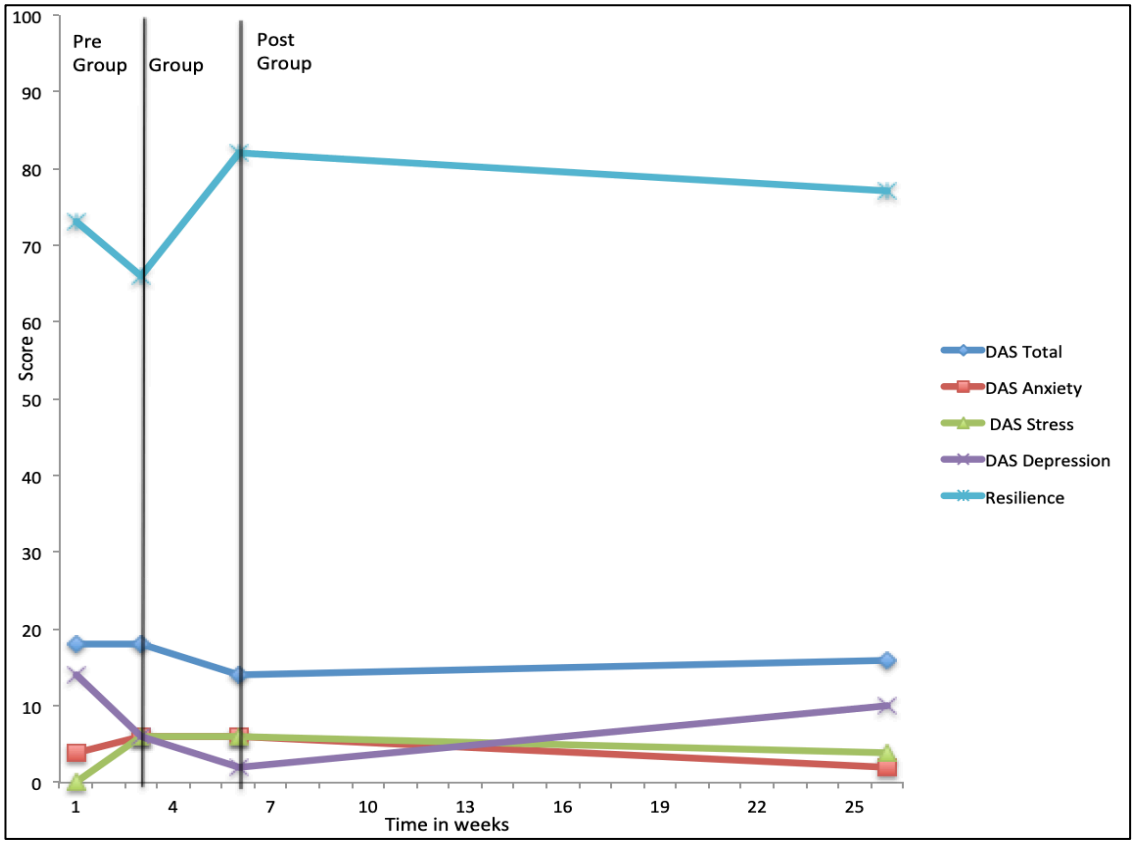

Figure 7.10: Participant F- DASS-21 and resilience results at three weeks pre start of DBT group, at start of the group, post-group and at follow-up

Note: DASS-21 Higher score = more severe symptoms. Resilience: Higher score = greater resilience
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

As shown in Figure 7.10, DASS-21 scores for Participant F indicated anxiety and stress within the normal range in the period before starting the group and stayed within that range throughout the study (Appendix L.1). Participant F had moderate depression in the pre-group period that improved prior to the group starting and improved further to the normal range during group. At follow-up Participant F scores indicated mild depression.

In the pre-group period, Participant F's scores indicated that her resilience was reducing. This trend reversed during attendance at the group and at follow-up Participant F's resilience was in the range of the general population (Connor & Davidson, 2003).

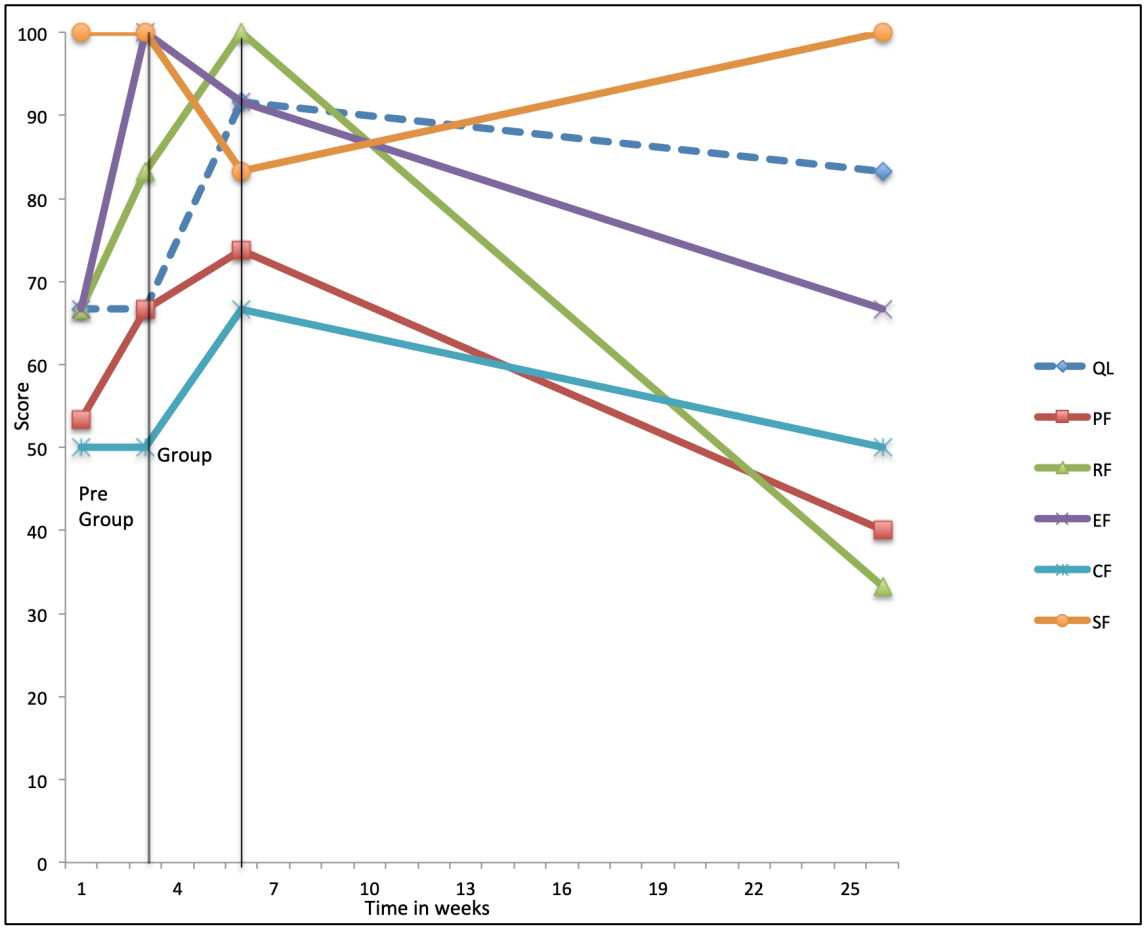

Figure 7.11: Participant F- Global health and functioning results at three weeks pre start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations: Quality of life score= QL; Physical functioning= PF; Role functioning= RF; Emotional functioning= EF; Cognitive functioning= CF; Social functioning= SF
EORTC QLQ-C30: Higher score = better function
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

Figure 7.11 shows that in the pre-group to post-group period Participant F's functioning showed medium to large significant improvement except for social functioning (SF) and emotional functioning (EF). Scores on global functioning (QL) and cognitive functioning (CF) showed no change in the three week pre-group control period. However, in the time of attending the group both improved by medium or more clinically significant amounts. During the group, Participant F's physical functioning (PF) made small improvements. Participant F's role functioning (RF) however increased by a medium to large clinically measurable amount.

At follow-up, gains in functioning were not sustained except for Participants F's general global health, which was higher by a clinically significant amount at follow-up compared to pre-group levels.

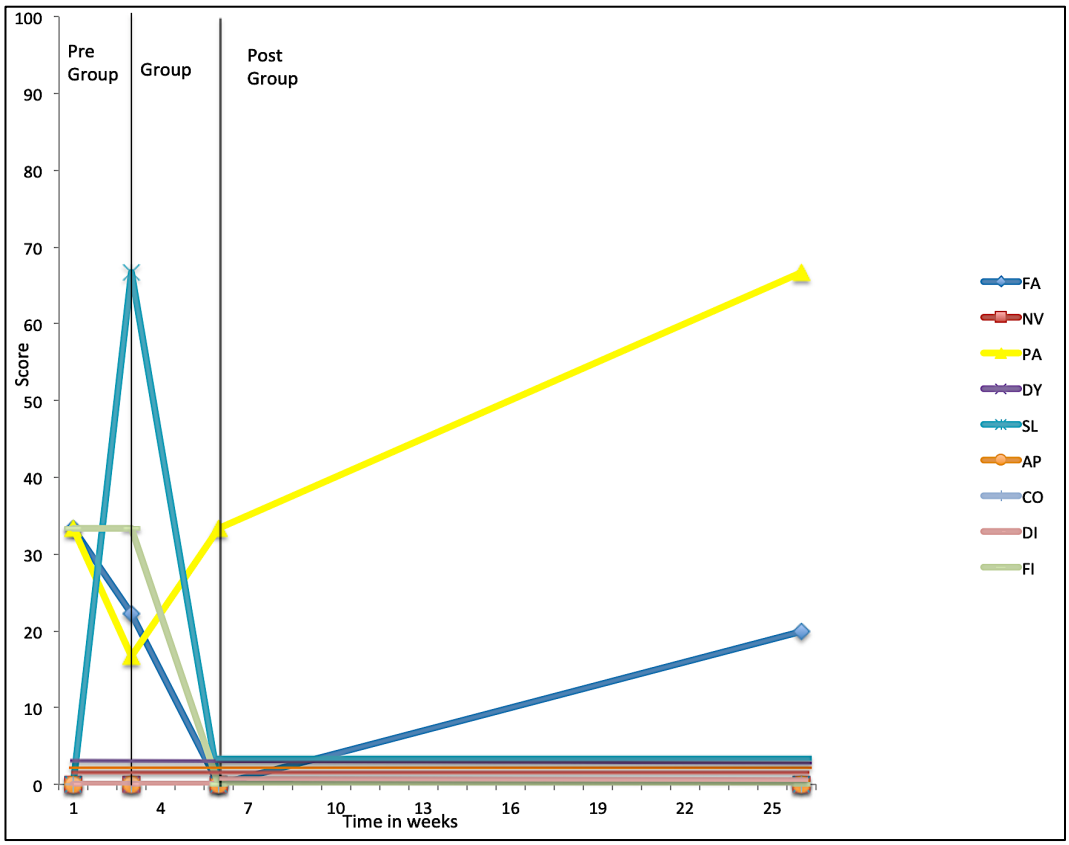

Figure 7.12: Participant F- Symptoms results at three weeks pre-start of DBT group, at start of the group, post-group and at follow-up

Note: Abbreviations of symptoms: Fatigue= FA; Nausea and vomiting= NV; Pain= PA; Dyspnoea= DY; Insomnia= SL; Appetite loss= AP; Constipation= CO; Diarrhoea= DI; Financial difficulties= FI
EORTC QLQ-C30 Symptoms: Higher score = more severe symptoms
Shapes on each scale indicate measurement points ie X , ▲, ♦, ■.

EORTC QLQ-C30 results as shown in Figure 7.12 indicate that Participant F's symptoms in the pre-group period were pain (PA), fatigue (FA) and financial difficulties (FI). At the beginning of the group, she also had insomnia (SL) which also reduced to zero by the end of the group and follow-up. All symptoms (except pain) reduced whilst attending the group. At follow-up, Participant F's pain and fatigue (having reduced), increased again, although not to pre-group levels.

To summarise, Participant F's results indicate that prior to the group she had moderate depression. Functioning improved from pre-group to post-group with her general global functioning improvement being sustained at follow-up. In spite of Participant F's increased pain (PA) score over the time of the group (and at follow-up) as well as increased fatigue, her depression reduced during group attendance and at follow-up remained at a mild level. In terms of resilience, Participant F 's scores indicated reducing resilience prior to the group. During group attendance this reversed, and resilience increased. Although resilience reduced again at follow-up, this was not to pre-group levels.

7.4 Combined quantitative results for Condition Two

Table 7-6 summarises (for all participants) whether clinically significant improvement was achieved between baseline and the post-group measure and between the baseline and follow-up (that is, whether a clinically significant improvement was sustained).

Table 7-6: Summary of therapeutic change and maintenance of gains for participants-Condition Two

	Significant improvement start of group- to post-group				**Improvement sustained or increased to follow-up**			
	Participant				Participant			
Test/ Subscale	**C**	**D**	**E**	**F**	**C**	**D**	**E**	**F**
DASS-21								
Anxiety	X	✓	✓		✓	X	X	
Stress		✓				✓	X	
Depression	X	✓	✓	✓	✓	✓	X	X
Total	✓	✓	✓	✓	✓	✓	X	X
CD RISC 25								
Resilience	✓	✓	✓	✓	✓	X	X	X
EORTC QLQ-30								
QL (Global health)	X	X	✓	✓	✓	✓	✓	✓
Function								
PF (Physical function)	X	✓	✓	✓	✓	✓	✓	X
RF (Role function)	X	✓	✓	✓	✓	✓	✓	X

	Significant improvement start of group- to post-group				Improvement sustained or increased to follow-up			
	Participant				Participant			
Test/ Subscale	**C**	**D**	**E**	**F**	**C**	**D**	**E**	**F**
EF (Emotional function)	X	✓	✓	✓	✓	X	X	X
CF (Cognitive function	X	✓	✓	✓	✓	X	X	X
SF (Social function)	✓	✓		X	✓	X		✓
Symptoms								
FA (Fatigue)	X	✓	✓	✓	✓	✓	✓	X
NV (Nausea & vomiting)	X	✓			✓	✓		
PA (Pain)	X	X		X	✓	✓	✓	X
DY (Dyspnoea)	X				✓	✓	✓	
SL (Insomnia)	X	X	✓	✓	✓	X	✓	
AP (Appetite loss)	X				✓			
CO (Constipation)	X	✓			✓			
DI (Diarrhoea)	X		X		X		X	
FI (Financial difficulties)	✓	✓	✓	✓	✓	✓	X	✓

KEY	Significant change achieved	✓	Gain maintained or improved at follow-up	✓
	Change not possible		Improvement not possible	
	No significant change	X	Improvement not maintained	X

Note: Significant change achieved = Clinically significant improvement between pre- and post-group measure.
Change not possible = Symptom/function already in normal range – no significant improvement possible.
No significant change = No clinically significant improvement from pre- to post-group measure.
Gain maintained or improved at follow-up = follow-up score as good as post-group score OR significantly improved from pre-group measure
Improvement not possible = score was within normal range or no symptoms so no scope for improvement from pre-measure to follow-up
Improvement not maintained = Improvement made over course of group not maintained to follow-up

Table 7-6 indicates a highly variable pattern of outcomes across the four participants. The most consistently observed short-term improvements that were maintained longer-term were physical function (PF), role function (RF), fatigue (FA), and financial situation (FD). The most consistently observed short-term improvements that were not maintained longer-term were in depression, resilience, and cognitive function. Whilst short-term gains in Quality of Life (Global Health) were variably observed, all

participants reported longer-term improvements in this at follow-up. Improvements in pain were also noted more at follow-up than post-group. The types of symptoms that were present varied widely across participants, which is unsurprising given the heterogeneity of cancer types and stages of treatment. Changes in symptoms post-group and at follow-up also varied widely, with no clear pattern evident.

7.5 Combined qualitative data for Condition Two

At follow-up 20 weeks after the group ended, participants for Condition Two took part in an individual semi-structured interview conducted by the researcher to gather data regarding their experience of the group, whether they had continued using the skills, and whether DBT groups are effective for cancer patients. The following findings are derived from recorded transcripts of individual interviews with three participants who were interviewed in person and one participant (Participant D) who was interviewed by phone. Questions that guided the interviews are presented in Chapter 4. Findings from interviews with each of the participants in Condition Two were pooled and coded according to the methodology described by Braun and Clarke (2006, 2012). Additional comments of interest not directly relevant to the research questions are also presented. Names of skills learned in the DBT group are highlighted in bold. Three themes relating to the above questions were identified: *Learning DBT skills* , *Applying skills* and *Being with others in a group*,

Theme one: Learning DBT skills

The theme, *Learning DBT skills* captured participants experiences about the skills they had learned and used most. *The skills that I have used most* sub theme captured the participants views on which skills they learned in the group and found most helpful and used 20 weeks after the group ended. The second sub theme of *Learning a variety*

of skills captures participants' views about each cancer patient being different and having different needs.

The skills that I've used most

Of the skills learned during the group sessions, paced breathing was the skill most commonly mentioned as being used and useful. Participants also reported using progressive muscle relaxation, mindfulness skills, doing pleasant events, cope ahead and acceptance skills. Participant C stated:

> *The **breathing** would be the one I've used the most, yeah, the breathing and **mindfulness** that's been the more consistently out of everything.*

Participant D indicated that she had learned and used paced breathing and progressive muscle relaxation skills.

> *I would say that the **breathing** is the main one that I use. . . . At night before I go to sleep when I feel my heart is pounding and I think I probably employ it more then . . . to quiet my mind before I go to sleep.*
> *Have you used any other skills?* Researcher
> *Um the tensing and untensing, the **relaxation**.*

Participant F also identified paced breathing as the skill she continued to use at the 20-week follow-up point.

> *The count **(paced breathing)** when my problems occur. Teen age child with problems in the home. So, your skills are helping with that, also the countdown (**paced breathing**) and relaxing **(progressive muscle relaxation)** and thinking of other things **(distraction**)*.

Participant C was able to name and describe how she had used many skills learned in the group, but it was also apparent that she learned how to observe herself better.

> *The breathing, the **paced breathing** I have done that many, many times and do that regularly. I have taken up yoga to enhance the breathing . . . so I have a clearer head, which is really interesting. Yeah. The **Teflon** effect- that's has just been an absolute amazing -don't fuss the small stuff let it slide. So that been really beneficial.*

Breathing, open hands, and half-smile are acceptance skills that are part of the Distress Tolerance module of DBT.

> *I'm sitting there with **breathing, open hands and half smile**. Half smile, open hands, calm.* Participant E

Learning a variety of skills

A variety of skills were taught in each session of the group in order to be as widely applicable as possible to the different needs of different participants. This sub theme captures participants' comments about this. Participants pointed out that for them the value of learning a variety of skills was because individuals were different, had different needs and were at different stages of cancer treatment. People also reacted differently to a cancer diagnosis and treatment. For example, Participant C commented that

> *I think (teaching a variety of skills) was good because we all had cancer at different levels and stages and in human nature people are going to react to their journey differently and even the impact of cancer on your life and how that happens. . . you can't really cater for individual need so you are having to do across the board to try to meet everybody's needs.*

Theme two: Applying skills

The theme of *Applying skills* captured participants experiences about applying the skills that they had learned to situations which resulted in increased self-care, assertiveness, being more active and, particularly, responding to anxiety provoking situations. This theme is divided into the areas of *Empowering me to make choices, keeping active and busy, Calming myself down,* and *Coaching other people too.* These subthemes capture the different aspects of application of skills learned in the group. This indicates that as well as simply learning skills, participants had applied them to various aspects of their lives and were using them to have positive effective outcomes.

Empowering me to make choices

This sub theme captures the use of skills to make important decisions about treatment. Participant C gave several examples of how she had used what she had learned in the group to make decisions. For example, Participant C discovered that she and members of her family had a gene mutation known as BRCA (Breast Cancer) genes (National Cancer Institute, 2018a) which indicated higher chances of developing cancer than the normal population. Participant C applied the DBT skills of check the facts and acceptance leading to problem solving in this situation, as illustrated in the example below.

> *I think it is a whole process you know coming to the class and having the diagnosis for myself and for my family. . . So yeah, I think it has empowered me to be there for them rather than the 'poor woe is family' sort of thing. These are the facts so what are we going to do**. (Check the facts** and **problem solving skills).***

Another example, also reported by Participant C, was that she was able to use what she learned in group to empower herself in decision making and choosing which treatments to have or not.

> *I've used the **pros and cons** model and I felt that was really grounding and informative because my initial reaction was to go with the suggestion (of further cancer treatment) but after I weighed up the pros and cons then I decided that no it was going to be of little benefit to me so that was really good.*

The focus of DBT skills is to help people learn to regulate their emotions, Participant C was able to use skills to regulate her emotions so that rather than making decisions based on how she felt, she was able to make decisions based on her needs. For example, she was also able to listen to her family regarding her return to work.

> *Probably, without really thinking about it, using the **wise mind** more rather than the emotional mind. I used to go more on my emotions, without thinking it through properly yeah taking a **step back** and giving myself a hug basically*

and then saying "Let's look at this realistically.. . . Yes, I listened to my body and to my loved ones and instead going back full time I have gone back just three days per week.

Keeping active and busy

Participants' descriptions of how the group contributed to them being more motivated and engaging in activities is the focus of this sub theme. PLEASE (which is an acronym for treat PhysicaL illness, balanced Eating, Avoid mood altering drugs, balanced Sleep, get Exercise) skills were taught in the group about the importance of self-care including the value of exercise. As a result of coming to the group Participant F was motivated to get dressed by mid-morning rather than spend days in her pyjamas.

I said myself, "Well this is what you got to do now. Breakfast is breakfast, but morning tea is clothes. So, get up and get dressed and get yourself motivated."

Participant F gave the example that in the past she had used the pain in her leg as an excuse to avoid going out. It was helpful for Participant F to apply the skill of opposite action and acceptance to her issues with arthritis in her leg. Doing this helped her remain active.

*The only thing with me is the stupid arthritis in my leg, but I'm using your methods **(acceptance)** and saying "I haven't got a stupid leg. We are going down the road so I will get my stick," and we will get the stick and I will do the walk down. I will get there a bit puffed and bothered, but I leave to have plenty of time so when I get there I calm down, so it's not just cancer, your systems help with life.*

As a result of the group, Participant F was more active and had not allowed the leg pain to stop her activities, for instance, by getting her sister to drop her off near the door of the shopping centre.

It (attending the group) has helped me do things… Because I'm doing it, whereas before I would say, "M, my leg hurts today. I don't want to go shopping today. Can we do it another day?" Whereas now, I am saying, and M knows it, so she will find a closer (car) park and say, "Go on then, jump out." and (she will) go park (the car).

Calming myself down

Participants described anxiety as an emotion they found difficult to deal with. A common comment made by participants was about experiencing anxiety, becoming overwhelmed and having to calm down in order to, for example, cope at work or deal with Oncology appointments. Paced breathing was one of the skills that participants used to cope with anxiety. For example, Participant E calmed herself at work prior to her oncology appointment using paced breathing and practiced doing that ahead of time -the skill of cope ahead.

The sub theme of *Calming myself down* ties into the theme of *Applying skills* by capturing participants descriptions of dealing with anxiety in specific situations such as at work or prior to going to sleep.

Subsequent to her attendance at the group, Participant E returned to work where she applied skills at stressful times. Participant E used paced breathing to reduce the physical effects of stress.

> *Any sort of appointments I use it for and actually sometimes when I am getting stressed at my desk, I sometimes use that. I say, "**Calm breathing**." I do use it at work.*

Participant D also applied paced breathing to calm her mind so that she could sleep.

> *At night before I go to sleep when I feel my heart is pounding and I think I probably employ it more then. . .*

One of the skills taught was to write a plan how to cope ahead in a stressful situation. Participant E explained:

> *So I'm using those **skills** when I am actually sitting in the waiting room trying to calm myself down, because my anxiety is through the roof, but because most of my appointment times seem to be in the early afternoon so all the time during the morning I am sitting at my desk trying to calm myself with my **breathing**.*

Participant E reported that she used skills that week (20 weeks after the group) when going to see her Oncologist for her regular check-up. She started using breathing earlier the same day, as well as in the waiting room before her appointment.

> *(I have used skills) just to calm myself down because otherwise I know I would be so emotional, extremely emotional and it is just trying to bring myself centred and not to let go even before I've stepped in the room. . .Well I have only been to two medical assessments since the group has ended and I have used them.*

Coaching other people too

Participants did not simply learn and apply skills for themselves- they also coached others in using them. This was also discussed in Condition One where a participant coached her workmates. Participant E gave an account of having passed on the skills she learned to her sister-in-law who also had medical appointments which were anxiety provoking. Participant E coached her sister-in-law in Distress Tolerance skills as well as using them herself.

> *I've even told my sister-in-law to do the same thing. Saying "**Open hands, half smile,** get yourself through it," and she said, "It worked." . . .so when she goes to her medical assessments and waiting for her result I say, "Do this," and I taught her.* Participant E

Theme three: Being with others in a group

This theme captures participants' experience of being in a group. The subthemes that make up this theme are *Tips from others: learning how other group members cope in the same situation,* which captures participant comments about learning from other group members and getting support. This sub theme also ties in with the other sub theme of *Being with people who actually get what it's like* which captures participants descriptions of feeling a commonality with people going through the same thing as them.

Tips from others: Learning how other group members cope in the same situation.

Learning skills in a group setting was seen as valuable. For example, Participant E felt she could learn from how other people coped in situations which were similar to hers. She said:

> *Someone might turn up (to group) and they have this issue all the time where they immediately think of "Oh God I have a pain in my toe and think, "Is it Cancer?". What do they do to get them through and whether relevant to be brought in, you know, just that sort of thing, just sharing their experiences and how one copes with these experiences.*

Meeting others with similar issues helped Participant F understand why her daughter insisted she did tasks for herself rather than her daughter doing them for her.

> *Yes, a couple of the ladies saying what they do, and one lady had her (support person) . . .and he said "No." My daughter says "No, you can get up and put the rubbish out mum, you can. What did the lady tell you at the meeting?" Motivate yourself. It's not just mind, it's your functioning as well.*

Being with people who actually get what it's like.

This subtheme describes the participants' descriptions of the value of attending a group with other people who also have had a cancer diagnosis. Participant D stated:

> *So, it was nice to be in the company of people who understood the journey.*

All of the participants made comments about noticing how other group members coped, sharing experience and finding this helpful and supportive indicating that even though the group was skills/learning type group it still provided a supportive environment.

Participant E stated:

> *And that's why I did enjoy it - because I looked at it as a mini support group even though it had a different purpose. We're kind of the same people facing the same issues and even just sharing a laugh about it sometimes was actually really beneficial.*

Below is Participant D's description of how she found attending the group helpful and supportive.

> *I thoroughly enjoyed it and I think what was nice was being in the company of other people going through that journey and being open and honest with each other and people who actually get what it's like, because in the real world people don't give a fig really, they pretend that they have some concern about cancer but in reality they don't really want a bar of it or they are not interested, to be fair. So, it was nice to be in the company of people who understood the journey.*

Additional findings of interest

Following are some comments of interest that did not directly relate to the research questions posed for this study.

Changing relationships between my support person and me.

The main finding of the Appreciative Inquiry phase for Group One suggested that having a support person attend would be useful. The comments below were of interest because they indicate possible effects on the relationship between participants and their support person/carers.

Both participants who attended with support people said it was useful for the support person's own learning and allowed the support person to understand the participant's experience better. Both participants mentioned that the support person could coach the participant to look in the manual or think about what the group facilitator might say and remind them of skills they could use without the support person needing to directly advise or instruct the participant.

For example, Participant F had memory problems associated with her brain cancer, so being reminded to access the manual was helpful to bring to mind the content of the sessions.

> *M says now, "What would Trish say?" and I said, "It's funny you should say that, I have just been looking up my pages.". . . if I'm not careful I'll forget what you've told me, so I have my little notebook.*

Participant F's sister attended the group as her support person. Participant F's sister prompted her to look at the manual and referred to the facilitator rather than directly instructing the participant. Referring to the facilitator helped Participant F to maintain her sense of autonomy and sustained their relationship.

> *Because she knows what I did with you and she would say "Now what would Trish say?" Instead of her saying "Have you done your exercises, have you relaxed, have you taken your medication?" Instead of her having to say that she just gently says "Now what would Trish say". . . And it is a reminder to me to go back and to say, "Oh I don't know, I better go back and look it up".*

Participant C's husband also attended the group and learnt and practised the skills alongside her. Participant C underwent chemotherapy during the group, which may have affected her ability to learn and remember the content of the group sessions. His attendance was helpful as he could prompt her to look at her manual and remind herself of the skills the group had covered.

> *The last six months there is not a heck of a lot that I recall. It was like my brain just closed on down into survival mode basically and its more as I have got a few more brain cells lined up that I've been able to recall and re read the information. Yeah and it was so good having my husband there and he'd say, "Let's see what Trish said?" so having support in the class certainly made a big difference.*

No time for skills

At the first group session participants were orientated to the need to practice by doing homework. Dialectical Behaviour Therapy is a behavioural treatment and therefore practice by behavioural rehearsal and repetition in less stressful situations is a focus to help participants integrate the skills into their behavioural repertoire. Although Participant D reported that she used some of the skills she learned in the group, she

thought that she had not used them as much as she should have. Participant D returned to work following group attendance. She could see the value of integrating skills more into her life, but with juggling work and two children with special needs at home, she felt that she had not had time since the group ended to practice skills or look after herself and focus on her own needs.

> *With all the skills I've learned, they just fall to the wayside because you are just reacting to lots of stuff. . . I think what has happened since then is I've gone back into the stream of life and I haven't actually taken any time for myself like I'm meant to do, you know, just with my commitments.*

Participant D blamed herself for not using the skills she had learned in the group because she was so busy.

> *I think I have been a bit of a failure. . . I am thinking how stupid I am because I think the skills are there, I know them, but I just get caught up in reacting to situations and I just think there is so much on my plate.*

The fear of cancer

Participant E was able to use skills in the situations she had prepared for, such as oncology appointments, but there were times, such as in the middle of the night, when she became overwhelmed with anxiety and fear and was not able to use skills possibly due to of the high level of her fear and distress. This may be because this group as a standalone treatment was designed for those with mild to moderate levels of distress.

> *I mean it gave me those skills to handle the medical assessments but as in coping with this disease long term, not necessarily. I don't know if there is actually anything that is going to be able to help with this long term. . . I don't think learning anything can help you prepare or help you deal with this, I don't. Ok because it's just you can prepare but when you get bad news, you can deal with it at that point and time, but that doesn't help in the middle of the night, or it doesn't help when you have your death wall right there.*

Participant E's comments are of interest because although this participant had moderate levels of anxiety and depression, the comments indicate that her the levels

of distress may be higher than the levels targeted by attending this brief DBT group alone without additional supportive therapy.

7.6 Summary

This chapter presented the results of the modified group, which was the second arm of the study. The modification suggested by the participants in Condition One was that support people should attend the group, and two participants in Condition Two attended with their support people: One brought her husband and another brought her sister. All other aspects of the group remained the same except that some of the examples used for practicing skills were made more relevant to likely situations that cancer patients might encounter. For example, for learning the skill of cope ahead of time, the example of going to an oncology appointment was used.

Quantitative data showed a variable pattern of shorter and longer-term gains for participants, but with all participants showing some short and/or longer-term benefits in domains such as mood and stress, resilience, function, or symptom severity. The variation is consistent with the heterogeneity of the type of cancer, stage of disease, type of current treatment, and other individual differences. Qualitative data was indicative of the intervention having a role in the gains observed, as participants described the skills as being useful and making a difference for them.

It was also noted that the experience of living with cancer could include times of intense distress that can be overwhelming. The brief six session group researched in this study may be insufficient to deal with more high or intense, overwhelming distress.

Those participants who bought a support person along reported that it was useful having the support person there. The usefulness included the support person being better able to understand the person's experience and being better able to offer constructive help to that person. The support person is able to remind and reinforce the skills that the person with cancer has learnt as part of the group in situations where they do not remember to use them, and this may improve the relationship between the person with cancer and the support person. The next chapter, Chapter Eight presents the findings of the Appreciative Inquiry focus group for Condition Two participants.

Chapter 8 Findings: Appreciative Inquiry- Condition Two

8.1 Introduction

Following participation in the modified group (which included two supporter/whanau participants), the cancer patient participants attended a focus group session to identify any further modifications which might be considered for furture brief DBT groups for cancer patients. This chapter presents the findings of this focus group captured in themes derived from recordings and trascriptions of the focus group session. The methodology used for this focus group was Appreciative Inquiry, which was the same methodology used for the focus group following Condition One.

8.2 Findings Appreciative Inquiry

The Appreciative Inquiry focus session was held immediatiely after the final session of the group. One participant was unable to attend this session due to work commitments. The findings from the post-completion focus group for Condition Two are presented in the Discover, Dream, Design, and Destiny phases (Cram, 2010) as described in Chapter Six. The themes and sub themes were, as much as possible, named using the participants' phrases and descriptions.

8.2.1 Discovery phase

This phase involves appreciating successes. Three themes captured the participants' opinions. The first theme, *Skills,* captures participants' views of the skills they found most helpful. Within this theme, there were four sub themes: *Paced breathing, Other skills, Other aspects of learning skills, and Situations where skills were useful,* each describing facets of skill use. The second theme *Being in a group* concerned the group process itself and consisted of two sub-themes: *Aspects of the group itself* and *Being with others and shared experience.* The third theme was *The value of a support person*

coming, which had two sub-themes: *Helping me,* and *Helping them and helping them to help us.*

Theme One: Skills

Paced breathing

As was the case with Condition One, the skill that was mentioned as being the most used and effective was paced breathing.

> *I like the **breathing** and I find the breathing relaxes me and if I find I have a conversation with a family member and it is getting a bit aggro I breathe and go "Yes, okay."* Participant F

Paced breathing was also used in combination with other skills such as observe (Teflon mind).

> *In my family I live with my daughter and grandson and we've had a few altercations . . . So, I sit there and do my **breathing** and its coming off the **(Teflon)** raincoat.* Participant F

Other skills

Participants were able to identify Teflon mind (Observe), Relaxation, Mindfulness and Acceptance as skills that they had learned, used, and found effective. Participant C commented:

> ***Teflon**, I think I used to play with it but now I'm more **mindful** of that technique and the body awareness relaxation technique (**progressive muscle relaxation**). That's been really helpful especially if I've had unexplained pain somewhere, I can just concentrate on it and then let it go (**acceptance**). I have found that's really helpful and the **pros and cons** - that's also been very beneficial.*

Two participants had stress and three had anxiety above normal levels at some point in the study. The skills mentioned by the participants, especially paced breathing, progressive muscle relaxation, and mindfulness (of which Teflon mind is a part) are useful for reducing the physical sensations associated with anxiety and stress.

The skill of being able to observe without getting caught up in the emotion (Teflon mind) was also identified as useful by Participant E.

> *The most helpful thing for me has been **Teflon (mind**); I have used that so many times . . . to control my responses to regards to what I am hearing.*

Other aspects of learning skills

Learning a variety of skills was also seen as useful because of individuals' different circumstances. Participants C and E commented on this:

> *Everybody interprets things slightly different and one skill may work better for you, and they may have picked up another skill that works better for them.* Participant C

The participants identified that being able to give a technique a name and using the metaphor of non-stick Teflon was helpful.

> *I have got a lot out of this course, I previously tried to not let things get to me but just assigning a name to **Teflon** has really helped.* Participant E

Situations where skills were useful

Participants reported having used skills in challenging situations, such as when feeling nauseated, feeling like stopping treatment, or if they risk getting upset with other's well-meant suggestions. Participant C described using skills in this situation:

> *I guess I was quite sick this last time round and when I was vomiting, I was thinking "This is not worth it." So I did, in-between mouthfuls, the **pros and cons**. "You know they are putting heaps of money into me, people putting heaps of time into me. If I give up there's no win for anybody at all." And just not buying into everybody else's... they are experts of cancer, lots of your visitors come around and they know what you should be doing, and you just put **Mona Lisa smile (half smile)** on and say, "I will look into that one."*

Participant E found that applying skills helped her to let go of trying to control other people's behaviour and accept that they will do things that she might not approve of or agree with. Having this set of helpful skills allowed her to teach her daughter the

same skills. Knowing skills and being able to teach others was a way of empowering and restoring the power balance for participants who may have felt that they had reduced power due to their illness and having to rely on others.

> *My situation where I've applied the **Teflon** is when my daughter is telling things to me that I could imagine myself getting upset about. Just taking it on board and just letting it go and realising that I cannot control every situation **(acceptance)**. And every time I can actually find them getting upset, something maybe about school or something that has been said to them, I always say to them, "**Teflon, Teflon**," and they have taken it on board.*

Participants mentioned examples of changes they had made as a result of using the skills they learned in the group such as increasing exercise as part of self-care (PLEASE skills (see Appendix N, Session Two content). Participant F described changes she had made:

> *I have rung up friends and said "Come on, I am ready to go. Are you ready to go?" And they've swallowed on the end of the phone and said, "Is this you?" And I say, "Come on". So, two days ago I did an hour and a half out. I haven't done that in three years.*

Participant C gave the example below of being more focussed on the present and mindful, managing stress in a more accepting way and asserting her own needs more effectively.

> *After doing this I've really taken time to really **observe. . .** and just be **in the present.** For example, you know when I had to go for my tattoo the other day, I had to wait for three hours, she was running behind schedule and I was just sitting in the chair and just thinking. "You know what? I can't do anything about it, I want to get this done, so let's just chill out, you know" **(acceptance skills).***

Theme two: Being in a group

This theme captures participants' experience of being in a group of others with the same experience. The sub theme of *Aspects of being in a group* included their views on

the operation of the group. The sub theme of *Being with others with shared experience* captures participants' reflections on meeting others with cancer.

Aspects of the group itself

Participants reported that coming twice a week allowed practice to feel more manageable rather than having to practice for a whole week. Some reported it was more difficult to make time twice weekly, but doing so enabled more momentum and halved the total length of the group as discussed by Participant C:

> *I think coming the twice a week was perhaps a contributing factor because weekly that's quite long.*

All participants commented on how they had enjoyed the group and found it useful for them and planned to continue using the skills. An example is Participant F's comment:

> *I have thoroughly enjoyed it, I'm going to miss it, but I will not stop. It's here now, Thank you.*

Being with others with shared experience

Being with others who were living with cancer was identified as helpful and supportive as expressed by Participant C:

> *You aren't strangers any longer, you are here for a common factor and as a group you are learning as well as supporting.*

Participants commented that getting to know others with cancer and hearing about their experiences helped them feel more supported, normalised their experience, and supported their learning skills. Participant E felt less isolated:

> *I actually think it has been really helpful coming to group sessions, because it has really helped me knowing I am not the only one, and what I am going through, and how I am feeling, and how I am reacting is actually completely normal. There are just tools out there that can help me get through it.*

Theme three: The value of a support person coming

This theme captured participants' views on attending with a support person/carer. Two participants brought support people/carers to the groups. Both commented on this, as did one who did not bring a support person but could see the value of doing so. Aspects of having a support person attend were described in two sub themes: firstly *Helping me* and secondly, *Helping them and helping them help us.*

Helping me

Comments were made that having a support person attend helped the participant to feel more relaxed and encouraged them to use skills. Participant C commented:

> *Being in a group has been really awesome. Being able to bring a support person and have other support people around, it's actually been really relaxing.*

Participant F also commented on this:

> *And it is not just a sympathy thing. "Oh, you're all right, sister, brother, uncle, mum. Remember do your **breathing** exercises, come on, we will both do them together."*

Helping them and helping them help us

Participants commented that the support person could also benefit. The participants were all aware of how caring for them affected their support people. Participant F was supported by her sister:

> *Even my support has learnt and is encouraged. We are totally en vogue on the phone, every day, but it's great to meet everyone. . . You don't have to tell (your support person) everything, they are seeing it, they are seeing the other recipients and they talking to the other support people. . . in their own situations and their own lives they have got family get together and hassles. . . And they have to stop everything to look after us, but then they have to go back to their own family. So, I think this is helpful for them too.*

Being in the group also was seen as useful to normalise the cancer patient's reactions so that support people could better understand the participant. Even though

Participant E did not have a support person attend, she commented that she thought it would be beneficial:

> *If I had had a support person here it would have been great; because you know when you go into those appointments they can foresee, because of the discussions we've had, perhaps, how I am going to react and how they can actually help me get through that period of time.*

8.2.2 Dream phase

In this phase, participants were asked what changes they would make if they were starting a group like this to make it even more useful for people with cancer. Two themes were captured in this phase, *Additions to the group and other improvements,* included participants' suggestions as to additional ways of tailoring the group to cancer patients. The second theme in this section was *Increasing access and when to offer the group.*

Theme: Additions to the group and other improvements

This theme captured suggestions about how to modify the group for cancer patients. Two subthemes, *Add in cancer knowledge and scenarios*, and *Teach skills and support family/whānau/support* emerged.

Add in cancer knowledge and scenarios

Participants suggested adding some cancer specific information to the content of the group or having facilitators with cancer expertise. Participant F commented:

> *Maybe different notes on different conditions. Or if you've got, like you've just had your test and a thing comes through. "Can I bring my test results and say there something wrong with my blood and it says blah blah. Could you help me with that?" But when it's all just cancer surely, we can just talk about that condition. And what we can think of to help with that?*

In order to practice using skills in real situations, one of the group sessions involved roleplaying a visit to the Oncologist, which was usually a scenario that several

participants found anxiety provoking. Coaching and role-play with teaching specific skills such as cope ahead and paced breathing for this scenario, enabled several participants to then use the skills in the real situation. Being able to practice may have enabled participants to feel more in control. Participant C suggested that role-play was helpful and should be used more:

> *Maybe even some role play in group, a situation or given a scenario how will you react and as a support person how can you support, that kind of thing maybe*.

During the group Participant E's oncology visit scenario was used as an example of how to apply skills which Participant E found useful:

> *We sort of did that . . . I was very upset that time. . . and it worked, and that turned into my counselling session*.

Teach skills and support family/whānau/support people

Participants felt the skills learned would be useful for everyone not just cancer patients. They thought that the skills were particularly important for their family/supports. As Participant E's comments indicate:

> *I mean I think you can consider it being very successful, I mean it isn't just for cancer patients; this is for other people. This is why I was trying to encourage my daughter to come, because I think she could have got a lot out of this if she had come.*

Participants talked about how their diagnosis did not just involve them but has also affected their family and supports. Participant C stated:

> *Definitely some good life skills and everybody won't, hopefully, get a cancer diagnosis in their life, but there will be some emotional trauma that these skills will help with, and to help the family, because nobody does anything on their own in a journey - it affects everybody actually.*

Support for family and support people was a common topic. How or when to offer the group for family members, so that they could have support as well, was discussed by several participants including Participant F:

> *So, if there was a half hour or this time is for you to sit down there and talk. . . and she can say that. "Mum was shitty, and I didn't know what to do, what do I do?" And the other support people could say "Oh yeah that's happened to me and I told them to do their breathing or I said let's talk it over."*

Participant C made the suggestion of an evening session for family so that they could receive support without the participant present:

> *The other thing I think is to maybe to have an evening session for partners to come or your kids if they are at school.*

Theme: Increasing access and when to offer the group

Participants suggested that more people should have access to such groups because they stated that they had found it useful for them and wanted others to have the opportunity to learn the skills and attend the group. As commented by Participant C:

> *Maybe money is a factor too for some people, and if there was some way for the doctor to say, "Hey there's this group going on." Or the Cancer Society "You might be interested, and you could pop along and say, "Hey that's not for me or yeah that's ok." But if you are having to have to pay a couple of hundred dollars twice a week to go, that's a lot of money if you aren't working.*

When to target the group intervention was also discussed. All agreed that offering the group from the beginning, just after diagnosis, or later, would be helpful because reactions to the diagnosis and treatment vary. All felt that cancer patients should be able to take up the chance to participate when they were ready. Participant C's comment is an example:

> *When you are first diagnosed, you are just coming to terms with it and you're just thinking "My goodness, my life is going to be cut short. How do I deal with that?" and just trying to keep the family together and keeping everything as*

normal as possible until you need to start treatment or have an operation. I felt so exhausted the whole time. For me the timing right now is right.

8.2.3 Design phase

Theme one: Considerations for delivering the group

In this phase, a theme of *Considerations for delivering the group* that reflected additional factors relevant to setting up a DBT group, emerged, with two sub-themes: *Time the group so that it does not interfere with work* and *Discuss normal reactions to cancer*.

Time the group so it does not interfere with work

Participants commented that the timing and structure suited them, but it was good to accommodate workers as well as non-workers, as taking time off work was a potential problem. One participant told their employer that they were working from home in order to come. Participant E said:

> *One of the things I'd like to say is not to have during the day of a week day. I've had to say to people I am going to work from home today. . . but not really.*

Many of the participants indicated that they had financial difficulties and so being able to work was important, especially as they already had to take time off to attend treatment and for their recovery. A comment by Participant F:

> *If you are going to have a group that don't work, then that's okay. But if you want workers with non-workers I think the group needs to run outside of work hours.*

Discuss normal reactions to cancer

Participants thought that including information on how people react to cancer for instance by pushing others away, would be helpful for support people to understand. Participant C said:

What we could do to let our families in? How can we let them support us? When we were trying to be the strong ones keeping our families together, putting a smile on our face do all the normal things and it was your own personal battle. Yeah, and the moment they walk out of the door, falling to pieces, totally. If there was some way to be able to adjust that, that I think would be really beneficial for the families or your very close friends, whoever are your support people, who want to truly support.

Pushing people away in the early stages of a cancer diagnosis was a common reaction that participants suggested needed to be normalised and talked about in the group. As stated by Participant F:

So maybe that is something that could be included in the course, you know, is how to let people in, you know. Because I certainly pushed people away, Yes, I only involved my sister I didn't involve my daughter, I didn't want to upset her and the family.

8.2.4 Destiny phase

In this phase, the theme of *Other considerations* includes participants' views on considering the weather/season when planning a group and on being in mixed groups of palliative and survivor patients.

Theme: Participants and timing- Separate groups for palliative and survivor patients and seasonal timing

The facilitator asked participants about how they would feel being in a group with palliative patients. Participant C stated that she would rather be in a group with cancer survivors the same as her:

*Yeah, I definitely think there needs to be two groups because our needs are so very different. You know having the **Teflon effect** will be planning your funeral kind of sort of thing. Exactly, that's a total different mind-set, yeah. The palliative care support people they have got an entirely different supportive role yeah*.

Participants thought they would get too upset being in a mixed group. Participant E held this view:

It's just like, too confronting right. It's like, I maybe, I'm still not clear, I still do think I have some cancer in my body but having somebody there that is terminal that is very confronting for me because I could just think "That could be me in a year." Do you know what I mean? I don't think I could deal with that.

The participants thought that consideration should be made about the weather when planning a group. This group ran in mid-winter and for a couple of sessions the weather was particularly stormy and cold. For participants who are physically vulnerable this is likely to be an important factor.

Participant E*: The weather, have it in the summertime.*

Participant F: *Then we will all be too hot.*

Participant E: *Cancer doesn't only come in summer.*

Participant F*: No unfortunately not. [Laughter]*

8.3 Summary of the findings of the Appreciative Inquiry- Conditions One and Two

In the focus groups following both Condition One and Condition Two, participants identified skills they used and situations where they had found the skills helpful. Specific skills such as paced breathing and Teflon mind, knowing the names of specific techniques, and learning a variety of skills were helpful aspects. Participants also used skills in challenging situations, found they could be more present and mindful, manage stress, and assert their own needs better. Participants suggested how the skills taught could be further tailored to cancer patients adding in specialist cancer knowledge, and roleplaying stressful situations such as a visit to the oncologist to practise coping strategies ahead of time.

Condition Two participants commented that having support people attend was useful both for the person with cancer and for the supporter. Supporting the supporter, giving them the skills to support the person with cancer, and learning the skills for the

supporter themselves was seen as valuable outcomes of the group. Having support people also hearing specific medical information regarding cancer, learning about how to deal with common scenarios such as preparing for a visit to the Oncologist, and learning about normal reactions to cancer such as pushing family away so that they could understand the cancer patient's reactions better, was seen as useful. Offering evening sessions would be important for family and support people, as well as for people with cancer who are working.

Participants also discussed increasing access to the group. Readiness to participate in a group was considered a very individual decision. The practical suggestion of scheduling the group to allow working participants to attend was also made. Separate groups for palliative and survivor groups were suggested due to their different needs. The following chapter, Chapter Nine presents the discussion of the findings of this study. Also presented are how these relate to the current research in the area of therapy groups for cancer patients, the strengths and limitations of the current research study and suggestions for both clinical application and future research.

Chapter 9 Discussion

9.1 Introduction

In this chapter the results of Condition One (the unmodified group) and of Condition Two (the modified group) are discussed, followed by a discussion of the findings of the Appreciative Inquiry focus groups. How the findings of this study relate to the literature is then discussed and this chapter concludes with presenting the strengths and limitations of this study, as well as recommendations for practice and further research.

This mixed methods pilot study aimed to test whether attendance at a brief Dialectical Behaviour Therapy (DBT) skills group could decrease distress, increase resilience, and increase quality of life for cancer patients. Results for Condition One indicated partial support for this aim. One of the two participant's total distress scores (total DASS-21) improved during her attendance at the group, whilst resilience scores improved for the other participant. Additionally, some EORTC QLQ-30 functioning and symptom scores also improved; however, the pattern of improvements was variable and because of the small sample size (N=2) contextual issues (such as one participant's work restructure) may have influenced results. Semi-structured interviews following Condition One indicated that the participants found learning and using the skills taught in the group helpful. Findings for the second condition following the Appreciative Inquiry focus group, showed improvements in distress as measured by DASS-21 total scores for all participants. There was variation between participants as to the specific areas of improvement.

Results for the EORTC QLQ-30 indicated a consistent positive long-term impact on quality of life (global health) and fatigue, and relatively consistent impacts on physical

function, role function, pain, dyspnoea and participants' perceptions of their financial difficulties. Although resilience and depression (as well emotional and cognitive functioning) improved during the time of the group, these variables were not maintained at follow-up for all participants. A second aim of this study was to use Appreciative Inquiry to gain feedback from participants in order to tailor the DBT group developed for mental health service users to cancer patients. Findings indicated that the main modification identified was that including caregivers/support people along side cancer patient participants would enhance the group.

9.2 Discussion of the findings for each part of this research

1. Condition One

Extensive recruitment efforts resulted in two participants completing the group. The results are presented as two single case designs. Although all results must be considered tentative, the main purpose of this part of the pilot study was to see if the brief DBT group was suitable for cancer patients and to allow the participants to be familiar enough with the group material and style to be able to give feedback in order to tailor the group for cancer patients. The results for the two participants on the quantitative measures used are discussed below and consideration of the variations of the patterns within the contexts and characteristics of the two participants is madethis may allow some tentative conclusions to be drawn.

DASS-21 results varied for both participants. Total distress for Participant B (which included stress, anxiety and depression) reduced after participation in the group; however, Participant A's improvements were not a reliable change. Participant B maintained their gains at follow-up. Participant B's moderate depression as scored on

the DASS-21 reduced during the group. Participant A did not have depression and there was no change during the course of the intervention and follow-up.

Participant A's resilience improved following participation in the group, and was maintained to follow-up. According to Ronk et al. (2013) Participant A's increase in stress at follow-up was a reliable change. This change is also understandable and a likely result of her work restructure. Although there is a slight increase in anxiety for Participant A, it is not a reliable increase. Therefore, Participant A had an increase in stress but also an improvement in resilience and she did not have a reliable increase in anxiety. This result could relate to the use of the skills taught in the group. Participant B on the other hand, did not face a significant increase in stress and maintained her gains in anxiety and stress at follow-up. Participant B showed little change in resilience over the programme and reduced resilience scores by follow-up. These results may be suggestive that the programme did help the participants to manage their mood better, although significant stressors would still understandably affect them. The results also indicate that people with both relatively low levels and higher levels of stress can benefit from the programme. The variability in resilience scores between the two participants in this condition suggests we can draw no conclusions about the impact of the programme on resilience based on these two participants.

Functioning in most areas measured by the EORTC QLQ-30 improved for both participants during the group with improvements being maintained for Participant B at follow-up. Symptoms measured by the EORTC QLQ-30 decreased during attendance at the group but this was not maintained at follow-up.

It may be hypothesised that the group would be most likely to bring about positive changes in the EF (emotional functioning), RF (role functioning), and possibly SF (social

functioning) scale of the EORTC QLQ-30 measure, with less change in the CF scale and PF scales (cognitive and physical changes are perhaps less likely to be effected by a DBT skills group). Overall, both participants showed improvements in emotional function following the group. However, for Participant A this was not sustained, which may have related to her job situation, whereas Participant B showed more sustained improvement. No other consistent patterns were evident between the two participants.

Some symptoms related to anxiety and worry such as fatigue, and dyspnoea also improved following the group. The improvement in dyspnoea was maintained for both participants, but the improvement in fatigue was not. Few other consistent patterns were noted, which may reflect the heterogeneity of symptoms that would be expected with different kinds of cancer, different stages of disease and treatment, and different psychosocial contexts.

Some of the background factors that need to be taken into account when considering the results include: Participant A's work stress from the restructuring between post-group and follow-up and that Participant B had an aging mother who increasingly relied on her. During the study, however neither participant had any significant changes in their cancer/disease status.

In summary, the results for Condition One (unmodified group) are tentative due to the small number of participants recruited who completed all groups. Results are displayed as single cases. The DASS-21, CD RISC 25 and EORTC QLQ-30 results indicated that there were some improvements between the start and end of the DBT group- namely some functioning and some symptom scores of the EORTC QLQ-30. DASS-21 scores improved during the group for one of the participants. In the semi-structured

interviews following attendance at the group, both participants talked about the helpful effect the group had on general psychosocial stressors rather than disease-related symptoms. This was consistent with the lack of change between pre- and follow-up on the cancer specific quality of life measures as measured by the EORTC QLQ-30.

Semi-structured interviews took place following attendance at the group, where participants were asked about their experience of the group. It is notable that both participants primarily talked about using the skills to deal with general life situations. This highlights the value of learning skills for dealing with day-to-day stressors, which ultimately are likely to improve quality of life and possibly the ability to deal with the stress of having cancer.

In the Using Skills theme the two participants reported using skills to reduce stress so they could problem solve. The way they did this could reflect their different initial levels of distress. Participant A, with lower initial levels of stress, according to her DASS-21 scores, used skills directly to problem solve work situations. Participant B, with higher initial levels of stress used skills to calm down, before being able to use the problem-solving skills.

The outcome of the findings in Condition One

As this was a pilot study and there were a small number of participants, statistical analysis of the quantitative results was not undertaken. However, based on the results of Condition One, and supported by the literature review (Chapter Two), there was seen to be enough evidence of the potential benefit for the use of a DBT-based group to justify moving to the subsequent stages of study. This involved identifying how the

group could be tailored to the specific needs of cancer patients and then running and evaluating the modified brief DBT group.

The next section discusses the findings of the two Appreciative Inquiry sessions and their implications for modifying the programme to best serve the needs of people with cancer.

2. Condition Two

As well as offering a change by having carers/support people attend and participate, Condition Two also had a three-week control period. A substantial degree of variability was noted in many of the measures for many of the participants between the week one measure and the week three measure (also pre-group). As there was no group intervention between them, these were both baseline measures so the variability indicates either that the measures are not stable or that the condition of the participants was not necessarily stable. This needs to be considered in interpreting results. The small number of participants in this pilot meant that group level statistical analysis was not carried out to identify any pattern of changes in particular variables across the participants. A larger future study might indicate a more consistent therapeutic effect of the intervention.

DASS-21 total scores for all participants showed an improvement from the start of the group to post-group, with variation between participants as to the specific areas of improvement. One participant scored within the normal range for depression at the start of the group which did not change during the time of this study. However, the other participants (who scored as depressed) improved according to their DASS-21 depression scores over the time of the group. Resilience scores as measured by the CD RISC 25 also improved for all participants from the start of the group to post-group.

This was maintained at follow-up for two participants. Potential therapeutic gain was obtained from the group even when it is undertaken concurrently with stressful medical procedures, for example chemotherapy in the case of Participant C.

Results for the EORTC QLQ-30 indicated a consistent positive long-term impact on quality of life (global health) and fatigue, and relatively consistent impacts on physical function, role function, pain, dyspnoea and participants' perceptions of their financial difficulties. Interestingly, resilience, stress and depression (as well emotional and cognitive functioning) did improve during the time of the group. However, none of these variables showed long-term patterns of improvement. This may in part relate to the heterogeneous sample in terms of diagnosis, contextual factors and current disease and treatment experience.

It is possible that the relatively limited long-term impact on mood and function variables may suggest that a somewhat longer programme is needed. This would assist to consolidate the short-term impacts observed. Alternatively, as suggested by the participants, further follow-up "booster" sessions may be beneficial to help consolidate abilities and skills and may be important to strengthen and sustain the therapeutic effect.

Feedback from the post-group interviews from Condition Two indicated that the inclusion of a support person benefited both the patient and the support person. For the patient, they felt better, the support person understood their experience and situation better, and the support person was able to remind them to use the skills when, for reasons either related to the cancer or otherwise, the patient may forget the skills or forget to practice them. For the support person, (having shared the learning of the content) they could often refer to that content or the group leader rather than

appearing to be controlling or unsympathetic; thereby protecting the relationship with the person they are supporting. These findings indicate that inclusion of a support person in this group is a valuable innovation that would be important to factor into any similar initiatives in the future.

Participants identified that generalisation of the use of the skills beyond the sessions and the time the group was running could be a challenge. This was attributed to factors such as being too busy to use the skills, focusing on other's needs rather than looking after self, poor memory leading to forgetting of the skills (or forgetting to use them at appropriate times), and feeling overwhelmed by emotions that were too strong for the skills to help manage. Practicing the skills as homework and troubleshooting problems with homework or skills practice at home within the DBT group sessions are ways the skills are generalised and strengthened, from learning in the group context to the context of participants' own lives and in being able to use them when overwhelmed (Chapman, 2006). For some participants, especially when the level of distress is high, the three-week period that the group was run for was not sufficient for strengthening skills use enough for the participant to be able to use the skills after the group ended. Strategies such as follow-up "booster" sessions, social media-based support (as suggested by the participants in Condition One) may be some possibilities for increasing generalisation. Environment cues for the use of skills in daily life (for example fridge or wall posters, or purse flash cards) which supplement the manual material are other possibilities.

Although participants commented that they used "Teflon mind", a metaphor for the "Observe and Describe" component of mindfulness skills (similar to the Acceptance and Commitment Therapy concept of diffusion), comments were made that there

were times when emotions became so overwhelming that skills were very difficult to use. This may suggest that lengthening the group and strengthening the mindfulness and related components to enable more coaching and practice of skills that deal specifically with weathering times of feeling emotionally overwhelmed may be of value.

Summary of findings of Conditions One and Two

In Condition One, the DASS-21, CD RISC 25 and EORTC QLQ-30 results indicated that there were some improvements between the start and end of the DBT group; namely, stress, some functioning and some symptom scores of the EORTC QLQ-30. In the semi-structured interviews following attendance at the group, both participants talked about the helpful effect the group had on general psychosocial stressors rather than disease-related symptoms.

Condition Two involved a control period of three weeks prior to the start of the group intervention plus the modification of having two supporter/participants attend the group with cancer participants. Overall, total DASS-21 scores for all participants improved during the time of the group. There was variation in which scores improved for different participants. Based on EORTC QLQ-30 scores, the most consistently observed short-term improvements that were maintained longer-term were physical function (PF), role function (RF), fatigue (FA), and financial situation (FD). Over the time of the group there were improvements in depression, resilience, and cognitive function; however, these were not maintained longer-term. All participants reported longer-term improvements in global health/quality of life at follow-up. Improvements in pain were also noted more at follow-up than post-group.

The types of symptoms that were present varied widely across participants, which is unsurprising given the heterogeneity of cancer types and stages of treatment. Changes in symptoms post-group and at follow-up also varied widely, with no clear pattern evident. Individual semi structured interviews at the end of the group indicated that paced breathing was the most useful skill learned. Participants also reported that they applied skills to empower themselves, help others, and calm themselves down. Comments on the usefulness of being with others going through the same experience were also made.

Focus groups to identify how the programme could be modified for people with cancer were held after both Condition One and Condition Two. The following is a discussion of the findings from these focus groups.

3. Appreciative Inquiry

The numbers in Condition One were particularly small, so the findings may not be representative of people with cancer. It is notable that the findings of the Condition Two Appreciative Enquiry, which involved a larger group of different people, generated similar themes, providing some assurance that the process of identifying useful modifications to the programme was robust.

Changes were suggested when Condition One was completed, and these were utilised to guide modification of the programme for Condition Two. The main substantive change between Condition One and Condition Two was that, for Condition Two each participant was invited to bring along a support person, and this person participated in all programme activities alongside the person with cancer. The other change identified by the facilitator during Condition One (and later also identified by the Condition Two participants) involved practicing skills using cancer-based situations to illustrate how to

apply skills. Some changes were identified at the end of Condition Two and may be used to guide the development of future initiatives. These are discussed together below.

Access to the intervention for people with cancer and others

Participants in both groups thought it was important that access to this kind of programme be improved for people with cancer. This indicates that they found it valuable.

Participants in both groups identified the value of their support people and other family members learning the same skills, so that support people could assist the person with cancer but also to help with their own life challenges, which included both challenges related to caring for a person with cancer and challenges that are more general (for example dealing with work issues).

Participants in both groups thought that the group programme should be available at any stage from diagnosis onwards, but as patients have different coping styles and needs, flexibility was important so that the timing could match individual need. Participants thought that some people would find it useful to access this kind of programme soon after diagnosis. One of the barriers to increased flexibility as suggested by the participants in this study is the lack of resources. This lack of resources means that many cancer patients cannot access publicly funded psychological treatments. At present availability of psychological treatments for cancer patients is focussed at the beginning of cancer diagnosis and treatment pathway.

Key therapeutic components

Part of the analysis of the AI focus groups was to identify components of the programme found particularly useful by participants, because this identified specific

skills that were regarded as most useful and therefore should be an even stronger focus in the programme tailored for cancer patients.

The skills identified included distress-reducing skills such as paced breathing, progressive muscle relaxation, Teflon mind and being non-judgmental. These techniques assist people to reduce their physiological and cognitive arousal and to reduce painful, sustained, and non-productive emotional states. The skills identified also included alternative problem-solving skills such as pros and cons. These skills empower patients to find solutions for solvable problems rather than ruminating over, but not finding solutions to, troublesome situations.

Very similar sets of skills were described as most useful by the Condition One and Condition Two participants, suggesting that DBT skills do have broader applicability for people with cancer.

Participants frequently talked about gaining considerable support from contact with other group members who were undergoing similar experiences. In future groups this component could be strengthened by encouraging members to have on-going contact after the end of the group. Ongoing contact would allow members to continue to be able to support each other and encourage each other to continue practising the skills. This is not explicitly encouraged in DBT groups with mental health service users and there are group guidelines which limit group members having private relationships and potential discussion of suicidal or self-harm behaviour with each other (Linehan, 2014a). These guidelines are not particularly relevant to cancer patients and having supportive relationships which extend past the attendance at the brief DBT group would likely be useful to cancer patients.

Content areas

Normal reactions to cancer

Discussing normal reactions to cancer was identified as another content area that could be enhanced in future programmes. This is consistent with the focus on normalisation and validation of emotions in DBT. Seiler and Jenewein (2019) point out that one of the factors which facilitate resilience in cancer patients is the ability to make meaning from the experience, which is an adaptive adjustment process. Research indicates that searching for meaning is only helpful when meaning is found rather than non-productive rumination (Seiler & Jenewein, 2019). Normalisation and validation of cancer patients' reactions to their diagnosis and treatment may aid in increasing resilience.

Including supporter/carers as participants along with cancer patients

Seal, Murray, and Seddon (2014) advocate for interventions for carers of cancer patients. The experience of caring can lead to dissatisfaction with the role due to lack of confidence and discomfort in the carer's ability to provide the care, which in turn has impacts on the patient.

Participants in Condition Two were very aware of the impact that supporting them had on their carer/supporters lives and commented that the DBT group provided significant people in their life with the support they needed, without placing undue stress and distress on them.

The present pilot study is in line with Stenberg, Ruland, and Miaskowski's (2010) systematic review of the effects of caring for a cancer patient. This found that there are complex problems, responsibilities and burdens for carers which include mental health, physical, social and economic issues in being a family caregiver for a cancer

patient. An analysis of the academic literature from 2002 to 2012 by Barello, Graffigna and Vegni (2012) showed that better outcomes for patients are achieved by increased patient engagement. For patients with cancer, strengthening the relationship with informal caregivers has been associated with increased positive outcomes and engagement. A study of 50 cancer patients from Northern Italy by Saita, Acquati, and Molgora (2016) ncluded a support person using a cancer dyads group. The study found that cancer patients had reduced levels of anxious preoccupation (as well as improvements in other measures), which strengthened the relationship with their support person when compared to a control group receiving psychosocial care as usual. Such is the association between support people and the cancer patient that studies, (for example, Bultz, Speca, Brasher, Geggie, and Page, 2000) have shown that cancer patients also benefit from interventions such as a brief psycho-edication programme that are provided for their support people, even if the cancer patient themselves has not been the direct recipient of the intervention.

Involving cancer specialists

Participants in Condition Two suggested a potential area for further development of DBT groups included adding more specific information about cancer by cancer specialists. Although this idea is in keeping with the idea of normalising reactions to cancer, there are potential pitfalls. Being able to have cancer specialists attend the group is unlikely as there is a current shortage of skilled workforce in the cancer area (Ministry of Health, 2019c) and the medical oncology workforce is already working beyond their capacity (Bidwell et al., 2013). Having specialists in DBT groups may also take the focus off the core purpose of the group, which is to learn skills. It may also set a more passive and didactic tone rather than the active and experiential tone which is what DBT groups aim to do. In addition, information that is relevant to some

participants may not be relevant to others, leaving false (and possibly distressing or confusing) impressions. It is however relevant to coach cancer participants in how to access information from experts as part of the DBT group.

Delivery approaches

In the AI focus group, how to deliver the information most effectively was also considered. A strong recommendation from the focus group participants was to include support people in the DBT group. This was seen as a way to provide support for the supporters, ensure that they also knew the types of skills that the person with cancer was using, and they could potentially support and coach the person with cancer during times of difficulty using the same skills. Having a shared language and knowledge about coping strategies may also be helpful. Two participants in Condition Two did bring support people and found it useful, and one other reported that they would have liked to. The participants who had support people attend commented that the support person coached them to re-read their manual or to consider what the facilitator would say in a situation, rather than directly telling the participant what to do. This indicates that the support people also gained skills such as being less judgmental, which aided in the development of a more collaborative, equal relationship that respects the participant's sense of autonomy and compensates for the reductions in role functioning that come with being in a patient role.

It was also suggested that having a brief, twice-a-week group with a strong emphasis on practice at home was a useful format for people with cancer. Comments from participants suggested that the brief format was useful and that a longer course would not have been attended. This suggests that keeping the course short and intensive is preferred.

Follow-up sessions were also suggested. These would assist cancer patients to maintain their skills, develop new skills, learn effective ways of managing on-going challenges, and gain support from each other. There was some discussion about inclusion of people in the palliative phase of treatment in these groups; however, an overall consensus seemed to be that participants would prefer that palliative care patients are not included. This is in keeping with Schellekens et al. (2016) report about anticipatory fear of meeting other patients being a frequent reason for dropping out of therapy.

Follow-up sessions were discussed in the context of enhancing on-going social support. Grassi, Spiegel, and Riba (2017) consider that this is not just the concern of oncology or palliative care but also of primary care which has a role in follow-up. General Practitioners who follow-up cancer patients once they have finished cancer treatment could provide a pathway to refer to groups directly if these groups were provided on a regular basis.

Social media was proposed as a way of assisting people to continue to use and enhance their techniques and to obtain support in an on-going way. There are many social media based support groups for cancer patients; for example, Facebook support pages like Breast cancer support- I got this (Breast cancer support, 2020) which has 12,399 followers. DBT skills also have been coached via apps (for example, DBT coach (Swasth Incorporated, 2020) and via Facebook pages (such as DBT skills and support, 2020). This would enhance both the support and skills use/coaching elements of the group and is worthy of further investigation.

9.3 How the outcomes of this study relate to the literature

9.3.1 Distress, resilience and quality of life

Interventions such as stress management (Yavuzsen et al., 2012), mindfulness (Shennan et al., 2011), coping skills (Telch & Telch, 1986) and DBT (Anderson et al., 2013) have led to improvements in dealing with distress for cancer patients. This pilot study supported the literature on the use of psychological therapy to support cancer patients to deal with and reduce distress. As the numbers of participants in this study were so low, caution is needed when interpreting the results. The aspects of distress which changed most for participants during the DBT group in this study were stress and depression. This supports the findings by Guo et al. (2013), who also found that coping styles therapy and supportive-expressive therapy improved depression, especially in female patients.

There was not enough data in the present study to support the effect of DBT for anxiety. Sanjida et al. (2018) suggested that low anxiety at baseline is a common reason for low effectiveness of psychological interventions on anxiety. The current study supports this. In the current study, of the six participants in both conditions, three had anxiety levels at higher than normal at pre-treatment, however, for two of these participants' anxiety levels had reduced to normal during the control phase. By the time the group started, all participants except one in each condition had anxiety at normal levels. This may have been the reason for variation in terms of the results for anxiety.

Neacsiu et al. (2014) used a sixteen week stand-alone DBT skills group with trans diagnostic mental health service users and found that DBT groups did reduce anxiety. At follow-up however, some of these gains were reduced. These authors hypothesised

that this is because of the loss of motivational support and skills guidance after the group ended, which resulted in participants becoming less effective in their use of skills and therefore losing the impact on anxiety that existed when they attended the group. In this current study, as only one participant had a higher than normal level of anxiety at the start therefore no conclusions can be made. Neacsiu et al.'s (2014) hypotheses were not explored by the current study. Future studies should consider selecting participants with moderate or higher anxiety in order to explore whether DBT groups reduce anxiety for cancer patients.

In this study, resilience improved for most participants during attendance at the group and remained higher than pre-group levels at follow-up despite decreasing from levels attained during the group. These results are similar to a study by Lee and Mason (2019) who found that one to four group sessions of DBT with college students led to clinically significant improvements in resilience and general mental health. The coping strategies taught in DBT may have led to increased resilience in keeping with the findings of Seiler and Jenewein (2019), who found that resilience is modifiable and that the teaching of coping strategies is effective in increasing resilience. However, once the group is finished it may take booster sessions or a longer group to maintain the improvements in resilience longer term.

Improvements in global functioning/quality of life scores for most participants between the start of the group and the final session are in line with Anderson et al.'s (2013) study using DBT. They also found improvement in quality of life and distress levels using DBT. These results are also in keeping with a review by Galway et al. (2012) of over 30 trials. Galway et al. (2012) found small improvement effects of psychosocial interventions on illness related quality of life measures. As well, Guo et al. (2013)

found improvements in depression, anxiety and quality of life using psychosocial interventions as measured by the EORTC QLQ-C30, (the same measure used in this study). The most common symptoms experienced by participants were fatigue, sleep problems, pain and financial difficulties, many of the common characteristics of cancer patients who are distressed. This result is consistent with research by Schubart et al. (2014) who studied the emotional difficulties of patients with breast cancer. In the present study fatigue and sleep problems generally reduced for those who experienced them during the group, which may have been an impact of the DBT skills taught in the group. The skills acknowledged in other studies as being helpful for example, mindfulness (Shennan et al., 2011), relaxation (Sautier et al., 2014) and coping strategies (Chujo et al., 2011; Telch & Telch, 1986) were also identified by participants in this study as being beneficial.

Paced breathing was taught in the second session and was the skill most mentioned by participants as being helpful. This finding is in line with Szulczewski's (2019) study of 16 participants who were trained in paced breathing. Training in paced breathing was found to decrease hyperventilation and increase relaxation, pleasantness, vigour and alertness, and reduce arousal symptoms, anxiety, depression, anger and confusion (Zaccaro et al., 2018).

Although this was a small pilot study, the results were in line with the literature in the area of DBT being a useful intervention for a number of areas of difficulty for cancer patients such as stress, resilience and global functioning. The results were in line with past research both in the use of DBT (Anderson et al., 2013) and with other interventions such as mindfulness (Shennan et al., 2011) with cancer patients.

9.4 Strengths of this study

This study used a mixed methodology to answer two research questions. The quantitative results allowed direct evaluation of the effectiveness of the brief DBT group on distress, anxiety and depression. The findings from the semi-structured interviews added a richness to the results by exploring the description of the participants experience such as being with others going through the same experience. The Appreciative Inquiry component of the study also allowed an exploration of the ways in which the group could be tailored to cancer patients. The methodologies and methods combined to allow findings that could not have been achieved by using either qualitative or quantitative methods alone. Appreciative Inquiry as a methodology allowed an atmosphere of positive participation for the participants so that they could express themselves, focused on positive improvements and allowed suggestions for change in an efficient forward moving manner.

The mixed methods design also allowed a two-step process, firstly to determine the effectiveness of DBT for cancer patients and modifications of the group and then testing this modification in the second arm. The stepped wedge design allowed Condition Two participants to act as their own control. Having a control condition allowed the researcher to conclude that for two participants, global functioning for the three weeks prior to the group did not change, but did increase by a clinically significant amount during the group.

This study included a follow-up period in the study design, which is essential to determine if the results are maintained. In a review of the literature, I was only able to find two studies using brief DBT for cancer patients. Both used pre and post-intervention measures with no follow-up (Anderson et al., 2013; Hejazi et al., 2014).

Including a follow-up component is a strength of the current study. Furthermore, neither study used a DBT trained therapist to facilitate the groups. This is the first study that has been conducted with participants who have a cancer diagnosis where a DBT trained therapist has facilitated the groups. My familiarity with the material and experience as a therapist allowed me to choose which skills to teach from the 24 session full DBT skills programme, to teach the skills adherently and confidently, create a pleasant, positive and relaxed learning experience for participants and to create a collaborative therapeutic alliance.

The present study found that including carers in the face to face group had benefits for cancer patients and is an additional strength of this study. A review of the psychotherapeutic interventions for support/carers by Applebaum and Breitbart (2013) found that of the 49 interventions reviewed, most were delivered individually to care givers or in dyads of carer plus patient and only eight percent (four studies) were delivered in groups composed of both carers and patients. Of these studies, none of the problem solving/skill building interventions identified by Applebaum and Breitbart (2013) involved mixed groups of caregivers and patients. In the present study both cancer patients and their support/caregivers were together in the same group, participating with others who were going through the same experience, with an intervention which may potentially strengthen the relationship and be beneficial to both (Bultz et al., 2000).

The alteration suggested by the participants and made to the DBT group (which expanded it to include carers/support people) is ideally suited to whānau based involvement and participation as recommended in the New Zealand Cancer Action Plan 2019-2029 (Ministry of Health, 2019c) as a cancer diagnosis and treatment does

not only affect the individual but also impacts their family. Including support people is also consistent with the holistic notion of health as a family concern rather than an individual one held by Māori and Pacific people and models such as Te Whare Tapa Whā (Durie, 1985) and the individual as part of a larger family system (Brown, 2013). It is also in keeping with the future direction and principles of the New Zealand government's cancer plan (Ministry of Health, 2019c).

A further strength of this study was that in this study the groups were run within the participant's community rather than in a hospital setting which may enable generalisation of the findings for community settings in New Zealand.

9.5 Limitations of this study

In the following section, the limitations of this study are discussed. Accessing cancer patients and recruitment issues presented the biggest obstacles in this research and led to a small number of participants. Other challenges included the confounding effects of the therapeutic relationship and the homogeneity of the participants within a small sample. All participants were New Zealand European women aged 46 to 64. As significant numbers of cancer patients in New Zealand are Māori or Pacific people, future research would need to consider a more diverse group of participants.

The findings of this study were presented as six single case reports which limits the conclusions that can be drawn from the study. Because of the limited data set, group level statistical analyses were not carried out on the quantitative measures used. Additional confounding factors were that one participant was attending chemotherapy during the group; the side effects include nausea and vomiting which may have affected EORTC QLQ quality of life symptom scale results as well as the other measures.

The biggest challenge in this study was recruitment of participants. This is a frequent challenge mentioned in the research on cancer (Hui et al., 2013). Accessing potential participants proved to be extremely difficult. Recruitment was envisaged to be via the Oncology Services at Auckland City Hospital. Meeting with treatment providers was challenging and time consuming and there were multiple researchers trying to gain access to patients/participants at the same time. The Oncology Department also has high staff turnover and several staff members, for example the Nurse Unit Manager, left their role necessitating the researcher establishing new relationships with new staff in order to solicit assistance. Participant recruitment therefore shifted to Facebook support group pages which yielded nine potential participants for Condition One and seventeen potential participants for Condition Two. Future researchers should consider how to access to participants. Researchers who are based in an Oncology departments or part of a support group networks such as The Cancer Society are likely to encounter fewer difficulties with recruitment.

This study faced a high dropout rate which is in keeping with other research with this population which indicates drop out and attrition rates between 34 and 80 percent (Hui et al., 2013). Once potential participants had been identified, 13 out of 17 (76 per cent) who initially indicated they would participate decided not to go ahead due to various reasons including becoming unwell, travelling overseas and transport difficulties. Several participants withdrew after attending one group, for example, due to having chemotherapy treatment and getting ill and not being able to drive. This affected the number of groups that could be run. The difficulties in accessing, recruiting and retaining cancer patients for participation a study such as this one are a realistic representation of the complications of offering group treatment to this

population. These findings are potentially useful for future research or clinical application.

Due to the recruitment challenges outlined above, four post approval protocol amendments needed to be made to the Health and Disability Ethics Committee in order to expand the sources for recruiting potential participants. This involved changing the recruitment brochure to include support people and using social media to assist with recruitment. Each of these amendments took several weeks for approval. This also delayed the start of recruitment thus shrinking the timeline for the research. As a result of this reduced timeframe and attrition of potential participants, a very small number of participants took part in this study and only one Condition Two group was run. As a single case design pilot (even though a control period was used in the second condition (Condition Two), baseline data was generally unstable with two measurement points. Future studies should consider a longer baseline period with more measurement points as suggested by Kratochwill et al. (2010) which would provide a more stable baseline from which to draw more confident conclusions.

One of the participants of this study was undergoing chemotherapy during the time of the group. Future research should consider having a more homogenous group and excluding people having chemotherapy because it is hard to distinguish the symptoms of anxiety and distress from some side effects of chemotherapy treatment (Pearce et al., 2017). The cognitive effects of chemotherapy may prevent participants from gaining the most out of the group.

The factors of group cohesion, social support and rapport were not assessed in this study. Future research may include consideration of therapist-rated rapport and group cohesion which is related to positive outcomes with psychotherapeutic interventions

(Schnur & Montgomery, 2010). Group cohesion (feeling involved and supported by the group) predicted reduced emotional distress in a randomised control study by Andersen, Shelby, and Golden-Kreutz (2007) of 227 women with breast cancer. Several participants in this study also talked about the support gained from being with others who shared the same experience. Future studies should consider the influence of social support in DBT groups for cancer.

The measure of quality of life used in this study was the EORTC QLQ-C30. This is a cancer specific measure of self percieved health status. The term quality of life as opposed to health related quality of life, may be misleading as the EORTC QLQ-C30 measures people's perception of how well they carry out predefined activities and functions and their experience of symptoms over the past week. These descriptors are only one aspect of quality of life and may be influenced by factors other than those considered to be part of health (for example, material circumstances), (Karimi & Brazier, 2016). Apart from the ongoing debate about the use of terms such as quality of life and health related quality of life and their overlap, Carr and Higginson (2001) argue that health related quality of life measures are not patient centred because they do not measure what constitutes quality of life for all patients. Rather, they describe what health professionals or society believes constitutes quality of life for people who have cancer which may have little importance or validity for the person themselves and therefore not indicate change in areas important to the person. Although the EORTC QLQ-C30 is a widely used measure, it is not based on a conceptual definition of quality of life. The brief version of the quality of life profile developed by the World Health Organization (WHO), the WHOQOL-BREF (World Health Organization, 1996) may have been a better consideration as it is based on the WHO's conceptualisation of

quality of life, is more positively phrased and is more generic in content than the EORTC QLQ-C30 (de Mol et al., 2018). These aspects may make the WHOQOL-BREF more patient centred and a better measure of change brought about by a psychological intervention such as a DBT group.

DBT as a therapy has a strong emphasis on adherence to the treatment model and principles (Miga, Neacsiu, Lungu, Heard, & Dimeff, 2019; Swales, 2010). Future research should consider measuring adherence to the DBT model. In the next section recommendations for practice based on this study are made.

9.6 Recommendations for practice

The findings of this pilot study indicated that brief DBT groups are a useful intervention for cancer patients. DBT is a mental health intervention and participants gave suggestions about how the group could be better tailored to cancer patients. The recommendations and suggestions for future practice are identified below.

9.6.1 Including carers/whānau

A recommendation from this study is to include having cancer patients and support people in groups together. One of the areas of development of DBT has been to include families and carers of patients in the treatment by including family members in groups either separately or together with their family member (Fruzetti, Santisteban, & Hoffman, 2007; Hoffman, Fruzetti, & Swenson, 1999; Miller, Glinski, Woodberry, Mitchell, & Indik, 2002). A diagnosis of cancer not only involves the patient but also impacts family and supports. Consideration should be given to running groups outside of work hours such as in the evening and providing an extra session just for support people/carers (without the cancer patient present), so that support people can gain

support for themselves. This is also relevant for Māori, Pacific Peoples and those from collectivist cultures.

9.6.2 Separate groups for palliative and survivor patients

Separate groups for palliative and survivor participants (as suggested by the participants in the present study) is recommended as this is most likely to create a safe and validating learning environment and minimise distress more likely to occur in a mixed group.

Facing a shared experience in a skills group may lead to a sense of connection and community which helps the participants feel less isolated (Lacovino & Reesor, 2008). Conversely, a fellow participant's death may lead to increased powerlessness, helplessness and grief as well as lead to an increase in death anxiety (Glaser, Knowles, & Damaskos, 2019), or survivor guilt (MacDonald, 2015).

9.6.3 Additions to the DBT group content

Participants in the present study suggested that medical information regarding cancer could be added to the content of the group. This is in keeping with recommendations in the 2008 report by the Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, Adler, and Page, (2008) on Cancer Care for the Whole Patient which concerns the need for information expressed by cancer patients. The report concluded that there is little evidence that providing information affects patient outcomes. However, Epstein and Street (2007) consider that there are benefits to improving patients' participation in their care such as increasing knowledge and satisfaction with decision-making. Increasing the medical information given regarding cancer should be via the examples used in teaching the skills within the group in order to minimise interference with the skills focus of the group.

9.6.4 Duration

It is recommended that the group be brief rather than the standard 24-weeks of DBT as developed for mental health service users with Borderline Personality Disorder. The three week duration of the group in the present pilot study (with a total of six sessions occurring twice weekly) was an added element to this DBT skills training, which was a replication of a similar brief DBT group run for mental health service users (Zhao, 2006) facilitated by the Researcher. Participants' comments indicated that the element of meeting twice weekly for three weeks suited cancer participants needs and were also in keeping with Eyles et al. (2015) findings that commitment to eight weeks of participation was too long and a reason for non-participation. The duration of three weeks was enough to allow changes in resilience, depression, stress and some functioning scores to be seen in this small sample. No participants who had attended more than two sessions dropped out over the three weeks. However, conversely, it may be that three weeks was not long enough for sustaining improvements. Participants suggested that a follow-up session would be helpful and that this may be in the form of separate sessions for cancer participants and carer/supporters. This would still be within the bounds of a brief intervention and be a commitment short enough to prevent non-participation (Eyles et al., 2015). Future research may clarify the usefulness of this approach.

Additionally, the brief three week duration of the this DBT intervention allows the group to meet the needs of participants at different stages of their cancer journey so could be offered on diagnosis however participants could start at any time that suited them. As well, participants could do the programme more than once or use it as a stepping stone to other psychological interventions such as the use of Eye Movement

Desensitisation and Reprocessing (EMDR) for trauma (Pomeri, La Salvia, Carletto, Oliva & Ostacoli, 2021).

9.6.5 Using a manual

Although there are those in favour and against manual based treatments (Mansfield & Addis, 2001), in this case, dissemination of this treatment (especially to non-psychologists) aids the consistency of structure which may be helpful for non-psychologists who facilitate these groups. In the present study, participants commented that having a manual which they could refer to after completing the group was useful. In addition, it was useful for caregivers/supporters to refer participants to the manual. Therefore, it is recommended that the groups follow a manual and that this be given to all participants as part of their attendance.

9.6.6 Other suggestions

In this study, the DBT group was run in a local community hall rather than in a hospital. This is in keeping with the principle of equity of access identified in a number of Ministry of Health action plans (Ministry of Health, 2010). The most recent New Zealand Cancer Action Plan 2019-2029, (Ministry of Health, 2019c) identifies equity as a central principle and specifies that New Zealanders should experience the best treatment no matter where they live. Running groups in patients' local communities allows greater access to psychological treatment especially in regions outside of big cities. However, issues regarding participation and drop out still need to be addressed.

In Condition Two of this research, examples of cancer relevant situations where skills could be used were included. Findings by Cameron et al. (2005) suggest that a greater focus on cancer related (rather than generalised) distress and anxiety may influence greater participation. It is recommended that future DBT groups include skills targetted

at fear of recurrence of cancer (FRC) as it may reduce the impact of FRC for cancer patients.

MacDonald (2015) suggested that FRC is one of the issues of survivorship. Hall (2019) reported that 30 to 70 percent of survivors report moderate to high levels of fear of cancer recurring. Appointment anxiety, fear of facing routine appointments is linked to fear of recurrence (Annis, 2019).

In a review of studies on FRC, Simard et al. (2013) reported that carers have higher FRC than patients. Of the research reported by Simard et al. (2013) there was only one study directly focussed on FRC and psychological group therapies. Participants in the Condition Two group of the present study experienced high anxiety in oncology appointments and suggested that role-play and planning ahead for specific difficult situations (such as an appointment with the Oncologist), as well as the addition of cancer related scenarios, would be helpful. Although this is recommended, the focus of the group needs to stay on learning DBT skills.

A further suggestion that the group be offered at diagnosis, is in keeping with the recommendations of those working in the New Zealand government's Psychological and Social Support Initiative who recommend screening for psychological difficulties around the time of diagnosis and at the front of the patient pathway (Greensmith et al., 2017).

Making use of social media to maintain connections with group members and remind them of skills were also suggestions made by participants and this may improve outcomes. There are already a wide number of DBT resources including slideshows, articles and relevant material available online (Schmidt & Russo, 2019). The use of

technology to improve psychological support is also mentioned in the service design documents for the New Zealand Psychological and Social Support Initiative (Greensmith & Bell, 2015 ; Greensmith et al., 2017). Internet based follow-up may help maintenance of skills and allow patients to overcome barriers such as feeling unwell and increase access (Butow et al., 2015).

To implement a programme of DBT groups in local communities for cancer patients would require a robust business case to address challenges. The business case should address funding, finding suitably trained clinicians to provide leadership, training and supervision of group facilitators and linking in to General Practitioners and cancer centres to locate participants early in their treatment. The next section recommends areas for further research as a result of this study.

9.7 Recommendations for research

This was a pilot study with six participants, which suggested that brief DBT groups might be a useful intervention for cancer patients to reduce distress, increase quality of life and increase resilience. This study also included suggestions about tailoring the group to cancer patients. Future research to further test this DBT programme with a larger number of participants on which statistical analyses could be made is recommended; however, as identified the practical issue of recruiting enough participants would need to be carefully considered.

The only studies using DBT with cancer patients (Anderson et al., 2013; Hejazi et al., 2014) did not have follow-up measures. In the present study, there were follow-up measures taken. Gains in global functioning above pre-group levels were maintained at follow-up. However, although gains were made during attendance at group in depression and distress, these gains were not maintained at follow-up. This highlights

the importance of the inclusion of follow-up measures in future research to ascertain whether any gains made were sustained.

It may be useful for future studies to investigate the treatment duration. For example, increasing the number of sessions may benefit some, although Eyles et al. (2015) indicated that eight weeks is too long. An adherence measure would also ensure that although the group was tailored to cancer patients it maintained enough DBT components to be adherent to the DBT model.

In terms of the New Zealand setting, future research should include more culturally diverse participants. Registration rates of cancers in Māori adults in New Zealand are significantly higher compared non-Māori in New Zealand (Ministry of Health, 2018d). Thus, the benefits of such a programme should be explored in partnership with Māori.

Although Pacific peoples have a lower incidence of cancer than Europeans do, some types of cancer, (for instance, breast cancer, gynaecological and gastrointestinal cancers) have higher incidences. As well, Pacific people have more difficulties accessing care (Ministry of Health, 2014b). It is recommended that a larger study with a more diverse group of participants including Māori and Pacific people and their whānau and support people would add an increased relevance to the New Zealand context. Basing the groups in community settings may reduce some of the barriers to attendance.

This pilot study indicated that brief DBT groups may be an effective way of reducing distress, increasing quality of life and increasing resilience for cancer patients. The modifications suggested for cancer patients including the addition in the groups of supporters/carers, possible follow-up groups and use of web based additional coaching and support of patients in using skills could form the basis of a larger trial which might

include a more diverse, larger number of cancer survivors and the measurement of outcomes for supporter/carers.

9.8 Conclusion

The present mixed methods pilot study set out to investigate the application of a mental health intervention (DBT) to the physical health context of cancer. This study represents a possible direction for psychological treatment of cancer patients who have moderate distress. The main modification made to the brief DBT group was to include whānau/ carers as participants along with cancer patient participants.

Brief DBT intervention groups may represent a useful addition to cancer patients treatment once they have completed surgery, chemotherapy or other treatments in a cancer centre and return to their community. As expressed by Participant B in the following quote.

> *You have been through all the treatment and there is no more doctors maybe just every six months or a year and you're on your own and now you need to navigate yourself forward and to have these type of skills to move forward is very important and to make decisions about your life going forward these skills are very helpful.*

There were two parts to the research question. Firstly, do brief DBT groups reduce distress, increase resilience and quality of life for cancer patients, and secondly, to investigate how the group could be better tailored to a cancer population. Both were answered by this study.

The literature on the effectiveness of psychological interventions for this patient group was supported by the present study. Also (in keeping with the literature), stress and depression were the aspects of distress that changed during attendance at the group. At follow-up, depression was the measure that maintained improvement. Resilience

also improved for most participants, a result which was also consistent with Lee and Mason's (2019) study using brief DBT with college students.

The improvement in quality of life found in this study is in keeping with results by Anderson et al (2013) using DBT with cancer patients. However, some of the gains in resilience and global functioning, which were maintained at follow-up represent a new finding with a cancer population. In terms of specific skills, paced breathing was mentioned at interview as the most helpful skill, a result also found by other researchers when they explored increasing relaxation and reducing arousal (Zaccaro et al., 2018).

The modification, which resulted from the Appreciative Inquiry focus group was to include support people/carers. This was also consistent with previous research on the association between cancer patients and their supporters.

The focus groups and interviews conducted as the qualitative parts of this study allowed the participants to voice their experience of the groups and provided a valuable insight into the experience of DBT for the participants. They reported that the groups not only allowed them to learn useful skills but also provided support.

It is recommended that future directions for research include trials with a larger and more diverse group of participants, using non-psychologist facilitators, measuring outcomes on support/carer participant's anxiety and/or stress, adding a follow-up group and web based support. Successful larger trials of brief DBT groups held in the participant's community would potentially allow many more cancer patients access to brief psychological group therapy in keeping with the stated direction of cancer treatment in New Zealand.

In closing, one of the quotes from Participant C highlighted the value of attendance at the brief DBT groups.

> *I think that's the beauty as a group . . . you feel for one another and I think it is nice that the barriers are broken down, you aren't strangers any longer, you are here for a common factor and as a group you are learning as well as supporting.*

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Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. http://dx.doi.org/10.1111/j.1600-0447.1983.tb09716.x

Appendices

Appendix A: AUT Approvals

A.1 Confirming candidature

POSTGRADUATE

AUT

University Postgraduate Centre
Private Bag 92006 Auckland 1020
+64-9-921-9907
postgraduate.centre@aut.ac.nz

Ref: 9810267

16 November 2016

Trish Du Villier

Dear Trish,

Re: Confirmation of Candidature

Congratulations!

I am pleased to inform you your PGR9 was approved by the Faculty of Health & Environmental Sciences and was noted at the University Postgraduate Board at their meeting held on 15 Nov 2016. You have now completed all conditions placed on your provisional admission to your programme, and the Board will now confirm your candidature in the Doctor of Health Science.

The completion of this milestone marks a significant point in the career of every doctoral student, and represents the successful passage from provisional to confirmed candidature. It demonstrates your maturity as a doctoral researcher capable of contributing an original contribution to your field of enquiry. It also demonstrates that your project is of a suitable scope and standard for your degree, and that you have the capacity, resources, and potential to complete your research at the required level.

Data Collection

If your research does not require ethics approval, you may now begin data collection. If your research does require ethics approval, you may begin data collection once you have ethics approval.

Expected Submission Date

Currently, we are expecting that you will submit for examination on 19 Mar 2019. We are currently updating our records and if you feel this is incorrect, please contact your faculty contact person listed below.

Business Cards

As a recognition of this milestone, the University would like to provide you with your own AUT business cards for you to use when attending conferences and networking with other researchers. We have attached the 'AUT Business Card Order Form' for you to complete and return by email only (no hard copies required) to Scott Pilkington (scott.pilkington@aut.ac.nz).

The University will cover this initial printing expense, however, reprints will be at the candidate's expense. Please contact the University Postgraduate Centre when a reprint is required.

Faculty Contacts

Your primary supervisor is Kirk Douglas Reed

Your secondary supervisor is Margaret Roberts

Your third supervisor is Duncan Babbage

Your supervisory team mentor is Clare Hocking

The Associate Dean (Postgraduate) is Erica Hinckson, ext 7224

Your faculty doctoral contact person is Beibei Chiou, ext. 7020, fhesdm@aut.ac.nz

University Postgraduate Centre Contact

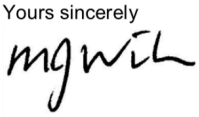
Your enrolment contact at the University Postgraduate Centre is Scott Pilkington, ext. 9378, scott.pilkington@aut.ac.nz

Congratulations Again

On behalf of all staff involved in the programme we would like to acknowledge the challenge of undertaking research at this level as well as the commitment and application which are required to pass this significant milestone in your research career.

If you have any questions, please feel free to contact me.

Yours sincerely



Martin Wilson
Manager, University Postgraduate Centre
martin.wilson@aut.ac.nz
+64-9-921-9999 ext 8812

cc: Kirk Douglas Reed, Margaret Roberts, Duncan Babbage, Clare Hocking, Beibei Chiou H4, Scott Pilkington

A.2 AUTEC approval

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

5 July 2017

Kirk Reed
Faculty of Health and Environmental Sciences

Dear Kirk

Ethics Application: 17/229 **Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?**

I wish to advise you that a subcommittee of the Auckland University of Technology Ethics Committee (AUTEC) has **approved** your ethics application.

This approval is for three years, expiring 4 July 2020.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Non-Standard Conditions of Approval

1. The footer details on the Information Sheet need completing.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: lavenir@slinshot.co.nz

Appendix B: Peer Review

SCIENTIFIC PEER REVIEW: Instructions to the researcher

Introduction

Scientific peer review (hereafter referred to as peer review) in the context of human research refers to the scientific validity of the research project and is a vital step in research project development. Peer review is a requirement of ethical approval and can enhance research project development in a variety of ways through providing an objective perspective from an informed reader.

It is a requirement of the Health and Disability Ethics Committees that all research projects involving humans undergo peer review.

Standards for peer review

Peer reviewers will consider the following points in order to determine scientific validity. Your proposal/application should ensure these are addressed.

1. ***The relative merit of the research***: consideration of whether the proposed work is important, worthwhile and justifiable. The research should address a health issue that is important for health and/or society. The aims, research questions and hypotheses should build on and address gaps in existing knowledge.

2. ***The design and methods:*** consideration of the quality of study design and the robustness of the methods used. This might include study methodology, a description of sample recruitment and characteristics (including number, gender and ethnicity where relevant) and proposed methods of data analysis. An indication of timelines for the research should be included.

3. ***The feasibility of the research:*** consideration of whether the overall strategy, methodology and analyses are well reasoned and appropriate to achieve the specific aims of the project. The review will determine whether the research has the likelihood, on balance, of improving scientific knowledge, concepts, technical capacity or methods in the research field, or of contributing to better treatments, services, health outcomes or preventive interventions. The research should be achievable within the specified timeframe and the researcher/research team must have the appropriate experience and expertise to undertake the research.
4. ***Peer review delivers an informed opinion:*** An effective peer review process provides perspectives from subject matter experts. It may be suitable for informed perspectives to be sought from individuals in the same organisation as the researcher, as long as the requirements of freedom from bias, equity and fairness can be met. An appropriate peer is one who can deliver an informed opinion on some or all of a proposal. Reviewers will be knowledgeable about the topic and/or context for the research, have the appropriate expertise relative to the breadth and scope of research under review and, as a result, will be well placed to make a statement as to whether the research in question has

verifiable scientific merit. Peer review of scientific validity may include consideration of cultural relevance and appropriateness.

5. ***Peer review delivers an objective opinion:*** Those acting in the capacity of reviewers are charged with delivering a balanced and considered analysis of the research. Generally, the success of the peer review process is determined by the extent to which these evaluations can be considered free of bias, equitable and fair. Objectivity can be compromised if peer reviewers have conflicts of interest, and so appropriate peer reviewers typically will not be materially connected to the researcher(s) in a way that might undermine objectivity, and be free from either positive or negative inducements.

6. ***A consensus opinion on scientific validity is formed:*** An HDEC will need to receive assurance that the peer review process has delivered support for the scientific validity of the proposed research. When a peer review process has engaged a range of experts, there needs to be a process that leads to a consensus opinion about the quality of the research.

SCIENTIFIC PEER REVIEW:

Date __14 December 2016

Research Title: Applying a mental health intervention to a physical health area: Is dialectical Behaviour Therapy helpful for cancer patients?

_____

Co-coordinating Investigator _Dr Kirk Reed

_____

Peer Reviewer Name: Dr Sandra Bassett

_____

Peer Reviewer Position_Senior Lecturer, School of Clinical Sciences, Faculty of Health and Environmental Sciences, Auckland University of Technology

_____

Independent from study? Yes

Peer Reviewer signature 

Recommendation: Approve / Revise minor / Revise major / Decline

REVIEW GUIDELINE	GUIDELINE PROMPTS	COMMENTS
Relative merit of the research	• Important, worthwhile and justifiable. • Addresses a health issue that is important for health and/or society. • Aims, research questions and hypotheses build on and address gaps in existing knowledge.	This research is worthwhile and justifiable. If the Dialectical Behavioural Therapy (DBT) is found to be effective for distressed people with cancer then it is non-invasive method of reducing their symptoms of distress and improving their quality of life. The research question is appropriate for the qualitative part of the proposed study, but cannot be answered by the quantitative study. The research questions for the quantitative arm of the data analysis along with the aims and hypotheses are appropriate for the study. The hypotheses are statistically testable. The significance of the study is clearly outlined, with the long term outcome being that people who are not psychologists could conduct these programmes. This outcome has the potential to reduce the health care costs for these people.
Design and methods	• Quality of study design • Robustness of the methods used. • Includes a description of sample recruitment and characteristics (including number, gender and ethnicity where relevant) proposed methods of data analysis. • Timelines for the research included	Overall the design of this study is robust with the inclusion of a qualitative arm and a quantitative arm. A demographic and relevant medical history characteristics questionnaire are now included. In addition, there is an outline of the method of data analysis for these characteristics. The percentage of attendance at the DBT sessions have now been included in the measures along with the proposed method of data analysis. The data analysis methods for the qualitative study are adequate. However, the data analysis for the quantitative study needs further clarification.

		The researchers have addressed the quantitative data analysis in a systematic manner in accordance with my recommendations for this analysis. requirements for quantitative data analysis.
Feasibility of the research	• Overall strategy, methodology and analyses are well reasoned and appropriate to achieve the specific aims of the project. • Likely to improve scientific knowledge, concepts, technical capacity or methods in the research field, or of contributing to better treatments, services, health outcomes or preventive interventions. • Achievable within the specified timeframe • Researcher/research team has the appropriate experience and expertise.	This research is feasible, and should be completed within the time frame provided. However, the researchers need to be aware of the possibility that it may take longer because of the unpredictable nature of clinical research. The quantitative research section now meets the required standard for outlining the design, measures and data analysis. This research has the potential to improve the care of people with cancer during their course of chemotherapy. In turn this should enable people with cancer to cope better with their treatment and their diagnosis.
Reviewer Independence /objectivity	• Peer review is considered free of bias, equitable and fair. • Objectivity can be compromised if peer reviewers have conflicts of interest, and so appropriate peer reviewers typically will not be materially connected to the researcher(s) in a way that might undermine objectivity, and be free from either positive or negative inducements. • If the peer reviewer is connected to the study please explain what measures are taken to mitigate conflict of interest.	I have peer reviewed this proposal in a scientific and unbiased manner. I have no conflicts of interest with this project.
Other comments	• Any reviewer observations that are not covered in the points above.	

Appendix C: Health and Disability Ethics Committees correspondance and approvals

C.1 Initial application

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS (384427)
hdecs@moh.govt.nz

28 March 2017

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

I confirm receipt of this application for HDEC review, which was submitted on 26 March 2017.

Arrangements for HDEC review

Your application has been assigned for HDEC review by the HDEC-Expedited Review pathway.

As this pathway involves a subcommittee of the Chair plus up to two other members, this application will not be assigned to the agenda of a meeting of the full HDEC. A member of the subcommittee may contact you by telephone to discuss this application before a decision is taken.

Timeline for giving a final opinion

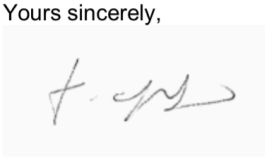
The 15-day clock for giving a final opinion on this application starts on 28 March 2017. This clock may stop once only, where the HDEC requires further information from you in order to make a final decision. You would then have up to 90 days to provide this further information, at which point the review clock would be re-activated.

No amendments to be made before HDEC approval

No amendments can be made to your application before it is approved, except where requested by the HDEC as a condition of approval. If you think you may need to amend your application during this time, we advise you to withdraw and re-submit it at a later date.

Please don't hesitate to contact us for further information.

Yours sincerely,



Tom Kent
Advisor
Health and Disability Ethics Committees
hdecs@moh.govt.nz

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

Appendix A
Documents submitted

Document	*Version*	*Date*
Protocol: Study protocol	2	22 January 2017
Evidence of scientific review: Peer review of protocol	16th Jan	16 January 2017
Survey/questionnaire: 1/3 questionnaires	DASS 21	22 January 2017
Survey/questionnaire: 2 of 3 questionnaires	CD-RISC rating scale	22 January 2017
Survey/questionnaire: questionnaire 3 of 3	QLQ-C30	24 January 2017
CV for CI: CV for Dr Kirk Reed	1	01 August 2016
Investigator's Brochure: Brochure for prospective participants	1	05 February 2017
Investigator's Brochure: Participants information for group and focus group and consent	1	05 February 2017
Investigator's Brochure: Participants information and consent (control)	1	05 February 2017
Application		

Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1) (c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (ethical/moral reasoning)	19/05/2014	19/05/2017

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

http://www.ethics.health.govt.nz

C.2 Approval

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

05 May 2017

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

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

Conditions of HDEC approval

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

Standard conditions:

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

2. Before the study commences at *any* locality in New Zealand, it must be registered in a clinical trials registry. This should be a WHO-approved (such as the Australia New Zealand Clinical Trials Registry, www.anzctr.org.au). However https://clinicaltrials.gov/ is acceptable provided registration occurs prior to the study commencing at *any* locality in New Zealand.

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

After HDEC review

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

Your **next progress report** is due by **04 May 2018.**

Participant access to ACC

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

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

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted

Document	*Version*	*Date*
Protocol: Study protocol	2	22 January 2017
Evidence of scientific review: Peer review of protocol	16th Jan	16 January 2017
Survey/questionnaire: 1/3 questionnaires	DASS 21	22 January 2017
Survey/questionnaire: 2 of 3 questionnaires	CD-RISC rating scale	22 January 2017
Survey/questionnaire: questionnaire 3 of 3	QLQ-C30	24 January 2017
CV for CI: CV for Dr Kirk Reed	1	01 August 2016
Investigator's Brochure: Brochure for prospective participants	2	29 April 2017
Investigator's Brochure: Participants information for group and focus group and consent	2	29 April 2017
Investigator's Brochure: Participants information and consent (control)	2	29 April 2017
Application		
Response to Request for Further Information		

Appendix B
Statement of compliance and list of members

Statement of compliance

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- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1) (c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
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Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (ethical/moral reasoning)	19/05/2014	19/05/2017

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

http://www.ethics.health.govt.nz

C.3 Amendment approvals

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

24 January 2018

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65/AM01**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

This amendment was reviewed by the Chairperson of the Central Health and Disability Ethics Committee and *provisionally approved* pending receipt of further information. This decision was made through the HDEC Expedited Review pathway.

The main issues considered by the HDEC in making this decision were as follows.

- Copies of proposed Facebook and newspaper advertisement require HDEC review.
- Tracking of changes made to the protocol document.

Further information requested

The further information requested in order for the Central Health and Disability Ethics Committee to make a final decision is as follows.

1. Please provide Facebook and newspaper advertisements for the Committee to review. A decision cannot be made without these first being reviewed.

2. Please provide a tracked changes version of the protocol document. Clearly showing the changes made will assist the Committee with their review.

Timeline for providing further information, and for giving a final opinion

You have 90 days to provide this further information. Your amendment will be considered to have been withdrawn if this information is not received on or before 24 April 2018. A new amendment would be required in this case.

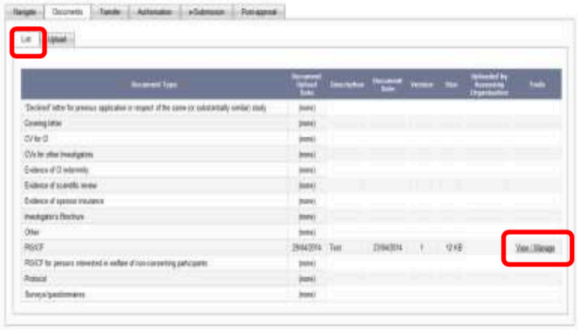
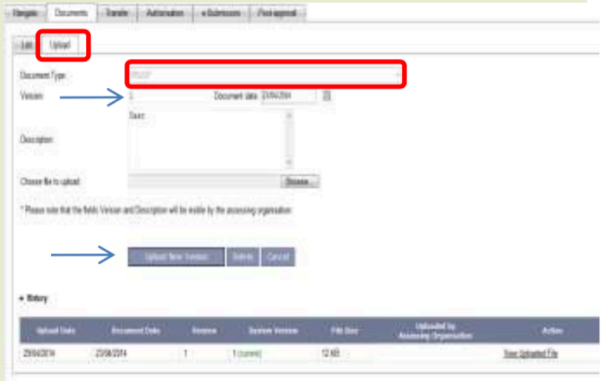
The 15-day clock within which a final decision must be made on this study is suspended as of the date of this letter. This clock, on which -21 days remain, will restart on the date on which **all** of the further information requested above is received by the Central Health and Disability Ethics Committee

Please remember to track changes made to new versions of documentation.

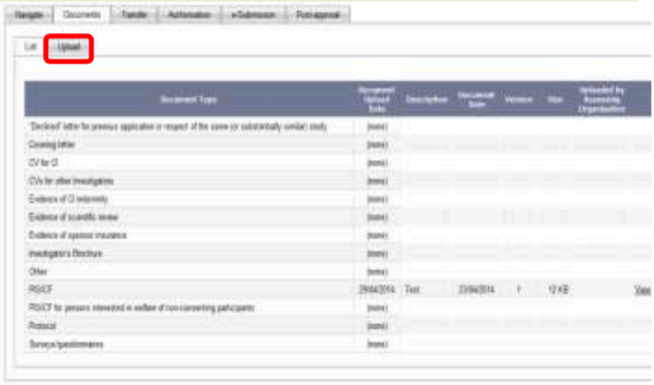
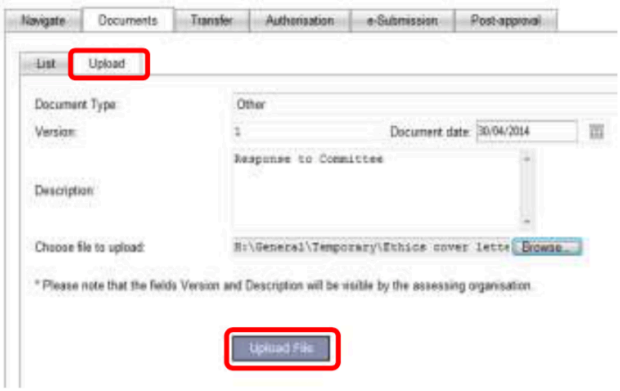
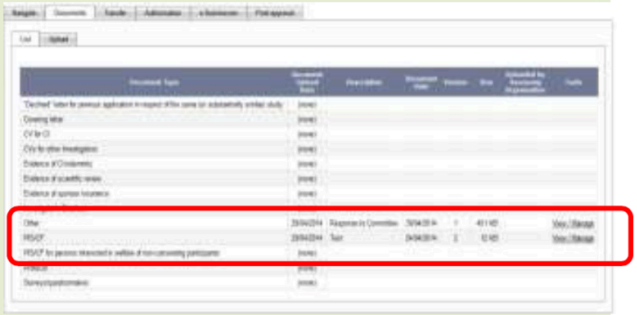
How to respond to a Provisional Approval for post approval submissions

You will need to submit your new or amended documents through Online Forms.

New versions of existing documents:

Steps	Screenshots
1. Select the corresponding PAF for this submission. 2. Go to the Documents Tab to upload the revised documentation requested by the secretariat	
3. To update versions of documents, go to the List tab. Select View/Manage to upload a newer version of the document. • For example you can upload new versions of the PIS/CF • Remember to track changes.	
4. When you click View/Manage for a particular document it will take you to the upload tab for that document. • Update the version number and document date. • Browse to find the new version of the file. • Click 'Upload New Version' • Once the upload is complete the history will populate with the new version.	

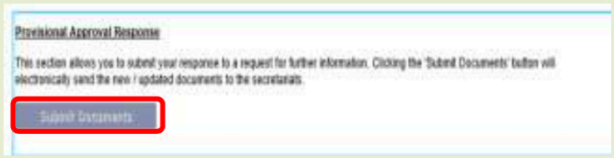
New documents:

Steps	Screenshots
5. For New documents, go to the upload tab. • For example you can upload a word document responding to questions raised by the Committee.	
6. Select the document type. Add a version number, document date and add a description if required. Browse your computer to find the new file and select Upload File.	
7. The new document will now be uploaded and visible on the List Tab. **Before submitting check to see all your documents are on the List tab and are displaying the correct version and document date.**	

To submit:

8. Once you have uploaded all new documents or updated all existing documents click the E-Submissions tab.

9. Scroll down until you see 'Provisional Approval Response'.



This button will only be able to be used when you have received a 'Provisional Approval' letter.

Please note: only click submit once.

Please don't hesitate to contact the HDEC secretariat if you have any queries. We look forward to receiving your response.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted

Document	Version	Date
Protocol: protocol with updated participant recruitment strategy and updated flow diagram of study	4	26 November 2017
Post Approval Form	01	-

Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020

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

http://www.ethics.health.govt.nz

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 Ethics
hdecs@moh.govt.nz

05 February 2018

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65/AM02**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

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

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

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted and approved

Document	Version	Date
Investigator's Brochure: brochure	Dec 2017	16 January 2018
poster	Dec 2017	16 January 2018
Post Approval Form	AM02	17 January 2018

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

19 February 2018

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65/AM01**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

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

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

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted and approved

Document	Version	Date
Protocol: protocol with updated participant recruitment strategy and updated flow diagram of study	4	26 November 2017
Post Approval Form	01	-
Protocol: tracked changes	copy	04 February 2018
print ad	1	04 February 2018
facebook post for relevant pages	1	04 February 2018
Facebook page for research	1	04 February 2018
video to go on facebook page for research	1	04 February 2018
website for study with private contact	1	04 February 2018
Response to Request for Further Information		

Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020

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

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

08 June 2018

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65/AM03**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

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

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

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted and approved

Document	Version	Date
Protocol: revised protocol	May18	19 May 2018
Investigator's Brochure: Participants sheet	Sheet2 version4	19 May 2018
Investigator's Brochure: New participants sheet for support/ family participants	Sheet 2 Support version1	19 May 2018
Post Approval Form	03	-

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

05 October 2018

Dr Kirk D Reed
AUT
Mail Code A11
Private Bag 92006
Auckland 1142

Dear Dr Reed

Re:	**Ethics ref:**	**17/CEN/65/AM05**
	Study title:	Applying a mental health intervention to a physical health area: Is Dialectical Behaviour Therapy helpful for cancer patients?

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

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

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

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

Appendix A
Documents submitted and approved

Document	Version	Date
Protocol: protocol altered with tracked changes	August 2018	26 August 2018
Investigator's Brochure	sheet 2 version 5 Aug2018	26 August 2018
Post Approval Form	AM05	26 August 2018

Appendix D: Locality approvals

D.1 Approval Auckland District Health Board

AUCKLAND
DISTRICT HEALTH BOARD
Te Toka Tumai

Auckland DHB
Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4949 Extn. 23854
Fax: 64 9 307 8913
Email: mwoodnorth@adhb.govt.nz
Website:
www.adhb.govt.nz/ResearchOffice

12th June 2017

Ms Trish Du Villier

Institutional Approval

Dear Trish,

Re: Research project A+ 7511 (Ethics: 17/CEN/65) Dialectical Behaviour Therapy (DBT) groups for cancer patients.

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee Dr Mary-Anne Woodnorth
Manager, Research Office
ADHB

c.c. Richard Sullivan

..../continued next page

AUCKLAND
DISTRICT HEALTH BOARD
Te Toka Tumai

POST-APPROVAL REPORTING

Your Ethical and Institutional approval is dependent on the Research Office (RO) having up-to-date information and documentation for your research and being kept informed of any changes to your study. It is **your responsibility** to ensure you have kept Ethics and the RO up to date and have the appropriate approvals. This applies even if ADHB is not the main site for the study.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after **2 reminders** it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your **Locality Assessment Approval has been withdrawn**. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the **ADHB project number**.

ETHICS		
HDEC Annual Progress Report	Use HDEC PAF form, complete and submit **BEFORE** anniversary date of original HDEC approval	o send copy of HDEC approved annual progress report letter to RO when received
Major amendments, design, CI, safety, temporary stops etc. (see HDEC SOP section 11 for definitions)	Write letter detailing changes, mark up changes in relevant documents. Use HDEC PAF form, complete and submit and obtain HDEC approval	o copy letter, changes to RO o send fully signed ADHB amendment form to RO o send copy of HDEC approval letter to RO when received
Financial amendments, including changes in study visits, tests, funding etc.	Liaise with research accountant and adjust budget accordingly. If financial amendment is related to a major amendment also follow requirements for a major amendment.	o Send revised budget using template to RO o send fully signed ADHB amendment form to RO
Minor amendments	Amendments that are minor in nature are reported to HDEC as part of the annual progress report. Only report minor amendments to the RO if proposed amendment will a) impact ADHB resources, e.g. staffing, facilities or consumables, b) potentially impact access to ADHB services for patients NOT in the study, c) require review of revised legal documents, d) involve ADHB service areas that have not previously authorised the research.	o If required send fully signed ADHB amendment form to RO
Serious study related adverse event reporting	If an ADHB patient enrolled in a research study is seriously harmed as a result of their participation in the study the SAE must be reported to the RO	o send the detailed, written SAE report to RO

AUCKLAND
DISTRICT HEALTH BOARD
Te Toka Tumai

High risk studies	Studies deemed by RRC to be of high risk must notify ADHB patient enrolments and SAEs to RRC	o notify RO when new ADHB patients are enrolled in the study o immediately notify RO of any SAEs for ADHB patients o send the detailed, written SAE report to RO when available
Notification of conclusion of study	Complete HDEC PAF form and submit	o Send HDEC approved notification of conclusion of study letter to RO o Inform RO if all finance elements also complete
Final Report	Complete HDEC PAF form, upload final report and submit	o Send final report and HDEC approved final report letter to RO o Inform RO when all finance elements also complete

LEGAL		
Contracts, Indemnities, Agreements, insurance certificates, amendments both financial and non-financial of above	All legal documents must be reviewed and approved before signing. Revise budget where relevant	o Send all legal documents to RO o Send revised budget using template to RO where relevant
FINANCIAL		
Budget maintenance	It is recommended that you review and update budgets at least quarterly	o Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to: ResearchOffice@adhb.govt.nz. All paper copies can be faxed to: 09 307 8913 or by post to: Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to http://www.adhb.health.nz/health-professionals/research/

D.2 Approval Waitematā and Auckland District Health Boards Māori Research Committee

He Kamaka Waiora
Waitematā and Auckland DHB
Level 2, 15 Shea Terrace,
Auckland 0740,
New Zealand
Private Bag: 93-503

20/04/2017

Dr Kirk Reed
Department of Occupational Science and Therapy
Auckland University of Technology
55 Wellesley Street
Auckland

Re: Applying a mental health intervention to a physical area: Is dialectical behaviour therapy helpful for cancer patients?

Thank you for providing the following documents the:

- RRC application
- Study protocol
- PIS/CF
- HDEC application

This local study explores whether cancer patients attending a brief Dialectical Behaviour Therapy group will experience decreased distress, enhanced quality of life, and resilience. There will be up to 60 participants recruited from within Aotearoa. The estimate of Māori participation is based on cancer registration data (2008 – 2012) specific to the Auckland DHB region. It is estimated that there may be approximately 9-10 Māori participants.

Māori responsiveness:

It is unlikely that the pilot study will provide any benefits to Māori as a distinct cultural population that engages with the services relevant to the health area under investigation. The study does not include sub-analysis by ethnicity as a method that would determinine if the mental health intervention is culturally as well as clinically effective. The study does include ethnicity data collection however, which can provide baseline data for future research that may be carried out with a focus on this type of intervention (see Te Ara Tika Maori Research Guidelines).

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee the study has been approved.

Heoi ano

Kim Southey
Kaupapa Māori Analyst
Waitematā and Auckland DHB
Level 2, 15 Shea Terrace, Auckland 0740,
New Zealand
Private Bag: 93-503
p: +64 9 486 8920
email kim.southey@waitematadhb.govt.nz

Appendix E: Researcher safety protocol

AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE (AUTEC)

Researcher Safety Protocol

DEFINITION & PURPOSE:

This is a guide to drafting a Researcher Safety Protocol and needs to be adapted for each research project.

Researchers need to assure their own safety as well as that of their participants and research assistants. The main purpose of a researcher safety protocol is to assess the level and likelihood of risk and to provide appropriate arrangements to minimise and manage those risks.

Situations in which researcher safety is likely to be at risk may include times when:

- *researchers are visiting the homes of others;*
- *researchers are undertaking sensitive research in a manner that puts them at personal risk;*
- *researchers are undertaking research in hazardous conditions;*
- *researchers are undertaking their research in a social or cultural setting with which they have minimal familiarity;*
- *researchers are involving people who pose a higher risk than would normally be the case (e.g. people with a known propensity for violence);*
- *the study impinges on the vested interests of powerful persons;*
- *the study is subject to the exercise of coercion or domination (e.g. where the research is about social conflict or where participants may face political threat, discrimination or stigma);*
- *there is an increased exposure to everyday risks (e.g. accidents, illness).*

Researchers may find it useful to read this research about levels of violence towards researchers in the field (QUALITI (NCRM) COMMISSIONED INQUIRY INTO THE RISK TO WELL-BEING OF RESEARCHERS IN QUALITATIVE RESEARCH by Bloor, M., Fincham, B., and Sampson, H.)

The following questions may be used to help write a protocol that is relevant to the context of the research.

Project title and brief description:

DBT groups for cancer patients

Supervisor

Dr Kirk Reed

Researcher

Trish Du Villier

Where is the research being undertaken?

What current travel warnings are in effect in the area in which the research will take place? None

At whose property will the research be undertaken? Te Atatu South Community Centre

Who is likely to be present at the research location?

- *Members of the public using other spaces in the facility*
- *Participants*

- *Research assistant*
- *Researcher*

What access permissions are needed to undertake the research at the chosen location? Contract and payments to Auckland City Council

What maps and guides has the researcher consulted to ensure familiarity with the locations? I have visited the location

What reliable local public transport is available? Buses

Which reputable taxi firms are easy to access? All

Where is it safe to use private cars and leave them in the area? Yes there is parking on site

What local rendezvous or contact points are available for researchers? Outside the hall

Who will be collecting the data and interacting with participants?

Who will be accompanying the researcher? Research assistant

How will the safety of any dependent children accompanying the researcher be assured? No children will be present

How will the safety of any translators, interpreters, intermediaries or transcribers be assured? None are required

How familiar is the researcher with the social or cultural context of the research ?

What level of familiarity does the researcher have with the social context of the participants and the research? Very familiar

What level of familiarity does the researcher have with the cultural context of the participants and the research? Very familiar

What language support is needed? None

What local tensions are there? None

What do local sources, such as the police or local leaders, say about risks in the research area? Area is safe

How safe are the activities in which the researcher is taking part?

Does the research involve sports or activities that may be hazardous in nature? No

Will sufficient qualified personnel be in attendance to supervise the activity or respond swiftly to any emergency? yes

What level of access to support is available?

Who will be available to provide assistance should it be required? Research assistant will be present, Supervisor is also available via cellphone

How will the researcher ensure that those providing support will be aware of any need that arises? Yes

What will those providing support do if it is needed? Call for assistance eg ambulance which is located on the same site, or police by phone

What emergency plans are in place? Who can help?

Who has been in touch with potential participants and what advice have they given? Participants have been advised of the location and where parking is

Who else is aware of the researcher's itinerary and research schedule? Supervisor is aware

How will the researcher keep key support people informed of what is happening? Researcher will inform supervisor at the start and end of each group session

How will key support people react if the agreed contact protocols are not followed? Supervisor will contact Researcher if he has not been contacted as specified.

Appendix F: Brochures

F.1 Brochure one

Dealing with Distress

6 Sessions for people who want to learn skills for dealing better with life's stressors

Image: Tom Curtis / FreeDigitalPhotos.net

Image: Simon Howden / FreeDigitalPhotos.net

We are looking for participants in research on Dealing with Distress groups for Cancer patients.

Participation in this research is additional to any treatment as usual.

Trish Du Villier

phone 021620044

trishdv@adhb.govt.nz

Health and Disability Ethics Approval number: 17/CEN/65

Dialectical Behaviour Therapy

Dialectical Behaviour Therapy was developed to help people who are distressed learn skills to regulate their feelings. It has been found to be helpful for patients with other stress related issues. The purpose of this study is to see if attending a brief Dialectical Behaviour Therapy group decreases distress, increases quality of life and increases resilience for cancer patients and we are interested in finding Cancer patients willing to participate in attending 6 group sessions with a psychologist as well as their usual treatment.

.

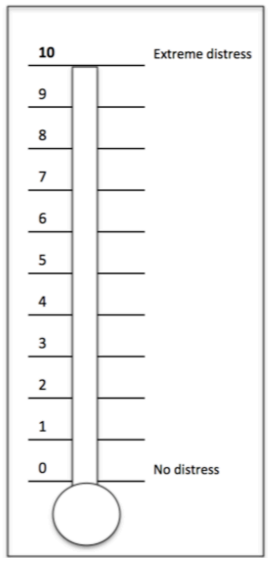
This study will involve you attending a group for 6 sessions lasting 2 hours each. Prior to attending the 6 groups and at the end you will be asked to complete 3 questionnaires. Please note: any questionnaires including the stress thermometer completed for this research are completely separate from any you might complete as part of your regular cancer treatment.

Eligibility

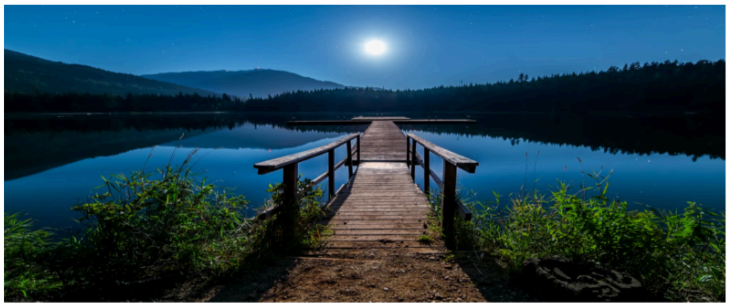
If you:

- *Are 18-65 years old*
- *Can read, write and understand English*
- *Have had no diagnosed psychiatric illness in the last year*
- *Score 4 or more on the stress thermometer (see right)*
- *Want the opportunity of participating in 6 groups to help you manage your distress*

THEN please call or text the researcher, Trish on 021 620044 to find out more.



F.2 Brochure two



AUT

Photos from www.Pexels.com

This research is partial fulfillment of a Doctor of Health Science Degree, School of Clinical Sciences, Auckland University of Technology.

Health and Disability Ethics Approval number 17/CEN/65

We are looking for 30 adults who have a diagnosis of cancer and who experience stress. You will be able to participate in **6 free psychotherapy groups** over a 3-week period.

Facilitated by a Clinical Psychologist, you will learn well-researched strategies to better deal with stress.

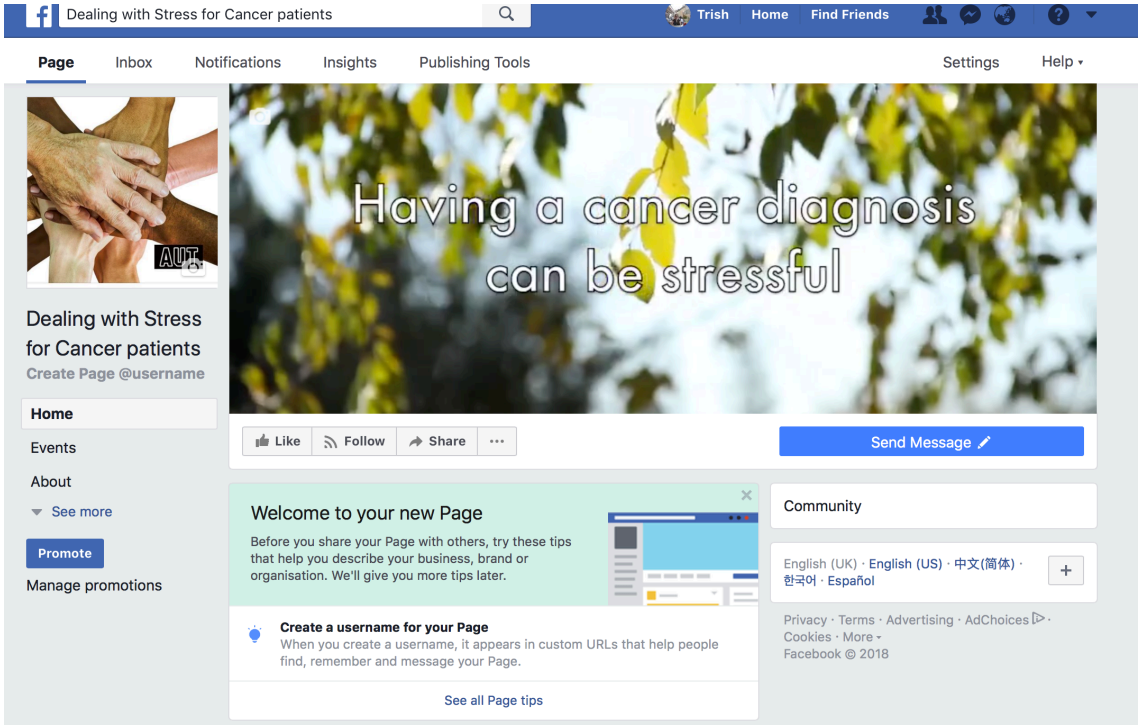
Groups will be run locally.

If you are interested or want to know more, text or call the researcher, Trish on:

021 620044

Appendix G: Advertising

G.1 Facebook page



G.2 Facebook posts

Direct message requests to Facebook page administrators

SEEKING RESEARCH PARTICIPANTS for a study on stress management for CANCER patients My name is Trish. I am a Clinical Psychologist and I live in Te Atatu, I am doing a Doctorate in Health Science at AUT. I am looking for participants to help me develop a FREE stress management group for Cancer patients which can be held in people's local area to help them deal with both the stress of a cancer diagnosis and the treatment.
I have a FACEBOOK page https://www.facebook.com/DealingwithStressCP where you can private message me or through my website https://lavenirnz.wixsite.com/website
If you know of anyone who may be interested please let them know. Thanks

Posts on Facebook pages

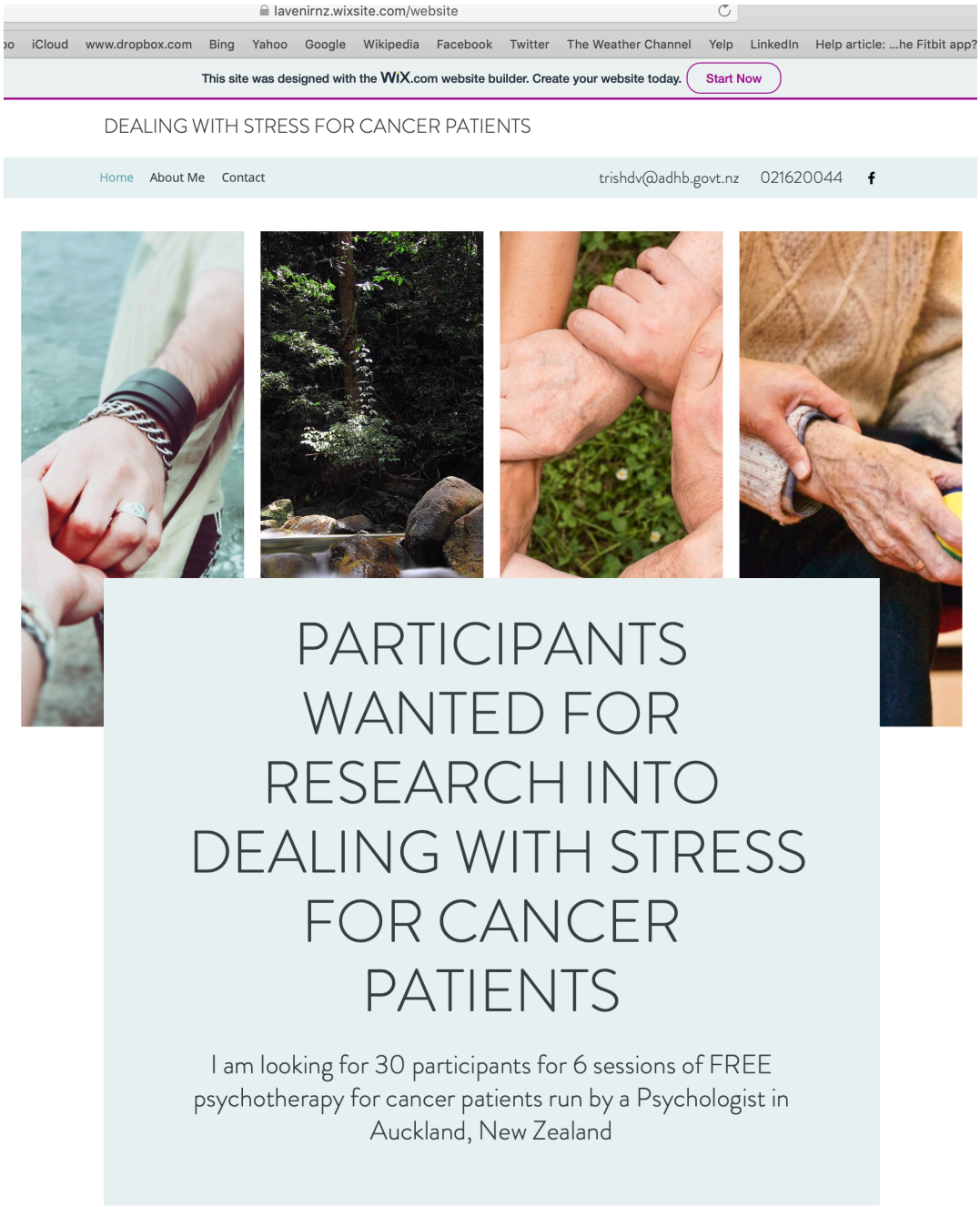
RESEARCH PARTICIPANTS WANTED
For a study on stress management for cancer patients.
FREE psychotherapy groups run in Auckland by a Psychologist.
Interested?
ring or text Trish 021620044
Faculty of Health and Environmental Studies

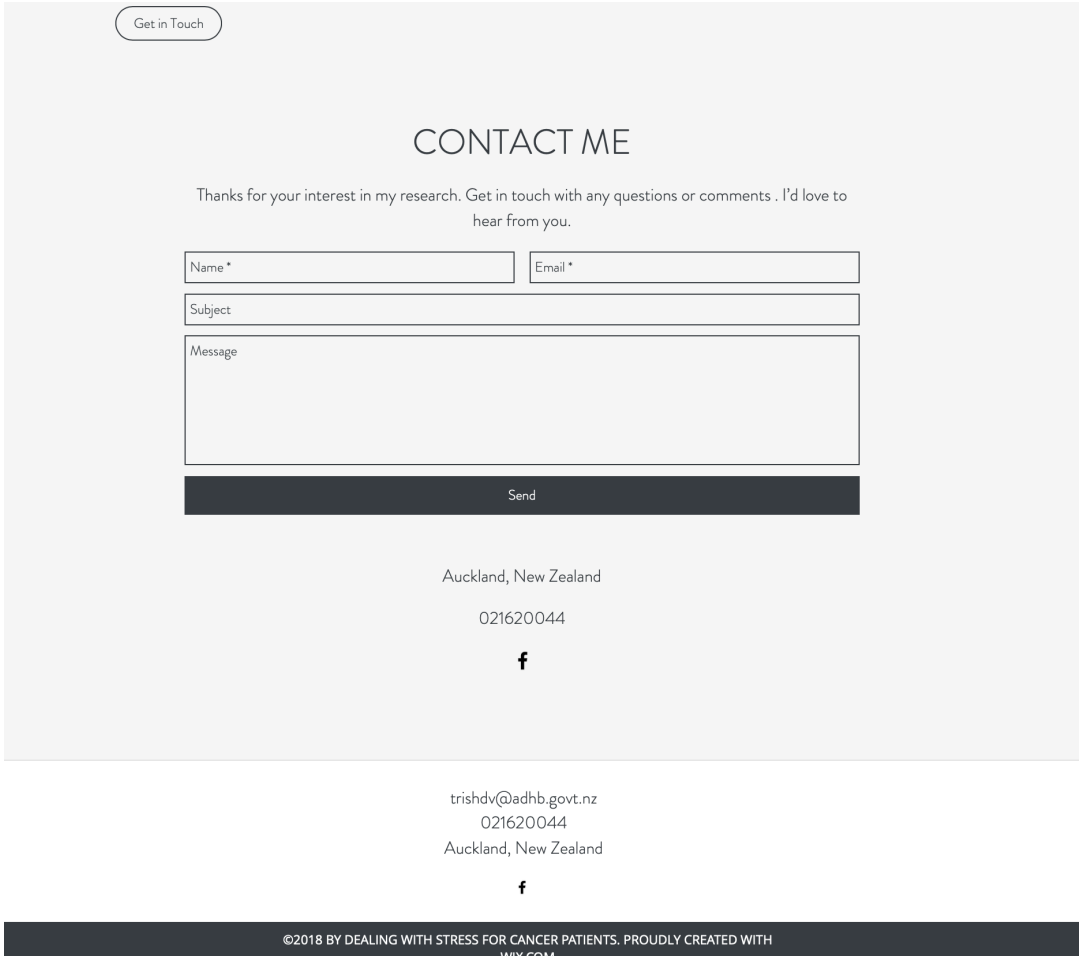
Like Comment

RESEARCH PARTICIPANTS WANTED
for a study on stress management for Cancer Patients
FREE psychotherapy groups run in Auckland by a Psychologist
Interested ?
Ring or text Trish 021620044 or https://lavenirnz.wixsite.com/website
Faculty of health and Environmental Studies

Like Comment

G.3 Webpage for the study





G.4 Print Advertising

G.5 Article in Stuff/ Western Leader

Auckland cancer patients sought after for university study

Danielle Clent · 11:02, Apr 27 2018

DANIELLE CLENT/STUFF

Senior clinical psychologist Trish Du Villier is looking for cancer patients to participate in a study she is conducting for research about stress levels.

An Auckland psychologist wants to find out if therapy used in the mental health sector can benefit cancer patients.

But she needs 30 participants to do so.

Trish Du Villier has been doing research for a Doctorate of Health Science for the past three years.

She previously provided therapy to mental health patients to help them deal with stress and distress, but now wanted to apply it to people with cancer.

READ MORE:
* **Student at forefront of cancer research**
* **Massey University's ground-breaking cancer research gets international funding**
* **Supporting palliative care and cancer research**

"I wanted to put my skills and my knowledge into that area," Du Villier said.

"To help people deal with the stress of having that diagnosis and knowing how to navigate their way through the treatment which is extremely stressful and difficult."

Du Villier said she had done a brief test run with a couple of cancer patients.

"They have found it super helpful," she said.

Now she was looking for cancer patients between the ages of 18 and 65 who experienced stress.

They would partake in about six free group therapy sessions focussed on learning skills such as relaxation and problem solving.

The aim of the study was to discover if this particular therapy was effective.

"What could happen is if this was really successful, because it's a manual, we could train people out in the community to deliver this and help a lot more people than are currently being helped," Du Villier said.

"It has potential to help a lot more people than are currently being seen by psychologists."

Du Villier said the group sessions would take place as close to home for the participants as possible.

This was to get them away from a hospital setting and make it accessible to them, she said.

If you are interested in being involved, contact Trish Du Villier on 021 620 044.

Stuff

G.6 Poster

RESEARCH PARTICIPANTS WANTED
for a study on stress management with cancer patients.

We are looking for 30 adults who have a diagnosis of cancer and who experience stress who would like to participate in **6 free psychotherapy groups** to learn how to deal with stress.

You will receive 6 x two hour groups over a three week period run by a registered Clinical Psychologist . Groups will take place locally in Te Atatu. You will learn strategies for reducing worry and dealing with stress.

If you are interested in participating and want to learn more please ring the researcher .

CALL or TEXT 021 620044

This research is part of the School of Clinical Sciences, AUT.
Health and Disability Ethics approval number 17/CEN/65

AUT

Appendix H: Participant Information Sheets and Consent Forms

H.1 Condition One participants

Participant Information Sheet 1

Study title: Dialectical Behaviour Therapy (DBT) groups for cancer patients

Locality: Auckland

Ethics committee ref.: 17/CEN/65

Lead investigator: **Trish Du Villier**

Contact phone number: 021620044

You are invited to take part in a study using Dialectical Behaviour Therapy groups to help cancer patients. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is [*6*] pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Dialectical Behaviour Therapy was developed to help people who are distressed develop skills to regulate their feelings. The purpose of this study is to see if attending a brief Dialectical Behaviour Therapy group decreases distress, increases quality of life and increases resilience for cancer patients.

There may be an oncology nurse participating in your group, this will be in order for the nurse to learn the skills as well as be able to provide coaching for you. A nurse may also participate in the feedback focus group.

The investigator is completing a Doctorate of Health Science at Auckland University of Technology (AUT), funding is through AUT. The investigator is also a Clinical Psychologist employed by Auckland District Health Board. The investigator Trish Du Villier can be contacted on 021620044 to answer any questions.

Northern Health and Disability Ethics Committee Approval number: 17/CEN/65

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been chosen for this study because you have a diagnosis of cancer and have scored 4 or more out of 10 distressed.
This study will involve you attending a group for 6 sessions. At the end you will be invited to attend a focus group to give feedback as to how to alter the group to better fit the needs of cancer patients.
The group will take 2 hours per day on two days per week. The group will be for 6 sessions therefore three weeks in total. When you have completed all 6 sessions you will be invited to attend a Focus group of 2 hours to give feedback.
Prior to attending the 6 groups and at the end you will be asked to complete 3 questionnaires that will take 30 minutes. The questionnaires will be administered by a research assistant and will measure distress, quality of life and resilience. . Four months after the end of the group you will be asked to complete the measures again and offered the opportunity to give feedback to the researcher.
The scores in the questionnaires will be de-identified before being analyzed.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Dialectical Behaviour Therapy has been found to be effective in teaching people skills in regulating their feelings. The benefits for participants are that you will learn skills that may be useful in dealing with distress, building resilience and quality of life. This will be in addition to any treatment you are currently receiving.

WHO PAYS FOR THE STUDY?

You will be provided with a manual that includes all the skills at no cost.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

WHAT ARE MY RIGHTS?

Your participation is voluntary and you are free to decline to participate, or to withdraw from the research at any practicable time, without experiencing any disadvantage
You have the right to access information about yourself collected as part of the study.
You will be told of any new information about adverse or beneficial effects related to the study that becomes available during the study that may have an impact on your health.
Your privacy and confidentiality will be maintained. All identifying information including this consent will be stored in a locked cabinet at AUT. All questionnaires will be de-identified before being analyzed.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Data will be stored digital data will be stored on a password protected computer, hard copy data will be stored in a locked filing cabinet and kept for ten years. It will not be used for any other purpose than this study and will be securely stored at Greenlane Clinical Centre, Auckland District Health Board. At the end of that time data will be securely destroyed.

This study is expected to take 2 years to complete. This will be documented in the form of a Doctor of Health Science thesis. At the completion of the study a brief report in plain English on the outcome of the study will be available to participants within 3 months of the thesis being completed.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

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

Trish Du Villier, investigator
Telephone number 021620044
Email trishdv@adhb.govt.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by telephoning 09 4868920 ext 3204

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

H.2 Condition Two Participants

Participant Information Sheet 2

Study title: Dialectical Behaviour Therapy (DBT) groups for cancer patients

Locality: Auckland

Ethics committee ref. 17/CEN/65

Lead investigator: **Trish Du Villier**

Contact phone number: 021620044

You are invited to take part in a study using Dialectical Behaviour Therapy groups to help cancer patients. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is [*6*] pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Research has shown that about one third of cancer patients experience significant emotional distress. Distress is a common concept used to describe patients' emotional reaction and can include anxiety, sadness and emotional pain. Sometimes these feelings can be overwhelming and it may be difficult for a person to control them. A person may also use strategies that are maladaptive for example avoiding people or getting angry at their family or others to deal with how they are feeling.

Dialectical Behaviour Therapy (DBT) is a kind of therapy that was developed to help people who are distressed develop skills to regulate their feelings. Skills to deal with upsetting and stressful feelings are taught in a group format with a trained facilitator. This type of therapy has been found to be helpful for people who are emotionally distressed. Elements of DBT include the practice of mindfulness, skills that help with acceptance of the reality of the situation, breathing, relaxation, problem solving and are taught in a group format. Research suggests that psychosocial interventions

exert a positive effect on quality of life for cancer patients. The research on DBT appears to indicate that teaching patients active coping strategies rather than passive avoidance is most effective. A person's adaptation to the diagnosis of cancer is significantly influenced by pre-existing psychosocial factors such as a person's resilience, their social supports, optimism, self-confidence and adaptive coping strategies. Resilience is a measure of stress coping ability and is another way of measuring a person's capacity to cope with adversity such as a cancer diagnosis. Higher psychological resilience predicts decreased risk of emotional distress. Many of the elements found to be helpful for cancer patients coping with the diagnosis and treatment are present in the content of DBT treatment groups. There have been two small international studies, which have shown positive results. The purpose of this study is to see if attending a brief Dialectical Behaviour Therapy group decreases distress, increases quality of life and increases resilience for cancer patients.

There may be family members or support people of participants participating in your group, this will be in order for the support person to learn the skills as well. Support people may also participate in the feedback focus group.

The investigator is completing a Doctorate of Health Science at Auckland University of Technology (AUT), funding is through AUT. The investigator is also a Clinical Psychologist employed by Auckland District Health Board. The investigator Trish Du Villier can be contacted on 021620044 to answer any questions.
Northern Health and Disability Ethics Committee Approval number: 17/CEN/65

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been chosen for this study because you have a diagnosis of cancer and have scored 4 or more out of 10 distressed on a distress thermometer .

This study will involve you completing some short questionnaires and then attending a group for 6 sessions three weeks later. The group will take 2 hours per day on two days per week. The group will be for 6 sessions therefore three weeks in total. The final session will involve a Focus group to provide feedback on your experience to the researcher.

Prior to attending the 6 groups and at the end you will be asked to complete 3 questionnaires that will take 30 minutes. The questionnaires will be administered by a research assistant and will measure distress, quality of life and resilience. You do not have to answer any questions if you feel uncomfortable about doing so. Four months after attending the group you will be asked to complete the measures again and offered the opportunity to give feedback to the researcher.
The scores in the questionnaires will be de-identified before being analyzed so that individual's scores are not known.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Dialectical Behaviour Therapy has been found to be effective in teaching people skills in regulating their feelings. The benefits for participants are that you will learn skills that may be useful in dealing with distress, building resilience and quality of life. This will be in addition to any treatment you are currently receiving.

WHO PAYS FOR THE STUDY?

There will be no cost to you apart from getting to and from the sessions. You will be provided with a manual that includes all the skills at no cost.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

WHAT ARE MY RIGHTS?

Your participation is voluntary and you are free to decline to participate, or to withdraw from the research at any practicable time, without experiencing any disadvantage

You have the right to access information about yourself collected as part of the study.

You will be told of any new information about adverse or beneficial effects related to the study that becomes available during the study that may have an impact on your health.

Your privacy and confidentiality will be maintained. All identifying information including this consent will be stored in a locked cabinet at AUT. All questionnaires will be de-identified before being analyzed.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Data will be stored digital data will be stored on a password protected computer, hard copy data will be stored in a locked filing cabinet and kept for ten years. It will not be used for any other purpose than this study and will be securely stored at Greenlane Clinical Centre, Auckland District Health Board. At the end of that time data will be securely destroyed.

Your participation is voluntary and you are free to decline to participate, or to withdraw from the research at any practicable time without experiencing any disadvantage.

This study is expected to take 2 years to complete. This will be documented in the form of a Doctor of Health Science thesis. At the completion of the study a brief report in plain English on the outcome of the study will be available to participants within 3 months of the thesis being completed.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

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

Trish Du Villier, investigator
Telephone number 021620044
Email trishdv@adhb.govt.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by telephoning 09 4868920 ext 3204

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

H.3 Condition Two Participant information for support people/family members

Participant Information Sheet 2 Support/ Family member

Study title: Dialectical Behaviour Therapy (DBT) groups for cancer patients

Locality: Auckland

Ethics committee ref. 17/CEN/65

Lead investigator: **Trish Du Villier**

Contact phone number: 021620044

You are invited to take part in a study using Dialectical Behaviour Therapy groups to help cancer patients. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is [*6*] pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Research has shown that about one third of cancer patients experience significant emotional distress. Distress is a common concept used to describe patients' emotional reaction and can include anxiety, sadness and emotional pain. Sometimes these feelings can be overwhelming and it may be difficult for a person to control them. A person may also use strategies that are maladaptive for example avoiding people or getting angry at their family or others to deal with how they are feeling.

Dialectical Behaviour Therapy (DBT) is a kind of therapy that was developed to help people who are distressed develop skills to regulate their feelings. Skills to deal with upsetting and stressful feelings are taught in a group format with a trained facilitator. This type of therapy has been found to be helpful for people who are emotionally distressed. Elements of DBT include the practice of mindfulness, skills that help with acceptance of the reality of the situation, breathing, relaxation, problem solving and are taught in a group format. Research suggests that psychosocial interventions

exert a positive effect on quality of life for cancer patients. The research on DBT appears to indicate that teaching patients active coping strategies rather than passive avoidance is most effective. A person's adaptation to the diagnosis of cancer is significantly influenced by pre-existing psychosocial factors such as a person's resilience, their social supports, optimism, self-confidence and adaptive coping strategies. Resilience is a measure of stress coping ability and is another way of measuring a person's capacity to cope with adversity such as a cancer diagnosis. Higher psychological resilience predicts decreased risk of emotional distress. Many of the elements found to be helpful for cancer patients coping with the diagnosis and treatment are present in the content of DBT treatment groups. There have been two small international studies, which have shown positive results. The purpose of this study is to see if attending a brief Dialectical Behaviour Therapy group decreases distress, increases quality of life and increases resilience for cancer patients.

This is the second part of this research study. During the first part feedback was received that suggested that having people who are family members or who support cancer patients also learn skills in order to both support the participants in this group in using the skills and for their own benefit may be useful. Therefore the participants were invited to ask a family member or support to attend as well.
The investigator is completing a Doctorate of Health Science at Auckland University of Technology (AUT), funding is through AUT. The investigator is also a Clinical Psychologist employed by Auckland District Health Board. The investigator Trish Du Villier can be contacted on 021620044 to answer any questions.
Northern Health and Disability Ethics Committee Approval number: 17/CEN/65

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

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This study will involve you completing some short questionnaires and then attending a group for 6 sessions The group will take 2 hours per day on two days per week. The group will be for 6 sessions therefore three weeks in total.

Prior to attending the 6 groups and at the end you will be asked to complete 2 questionnaires that will take 20 minutes. The questionnaires will be administered by a research assistant and will measure distress, and resilience. You do not have to answer any questions if you feel uncomfortable about doing so.
The scores in the questionnaires will be de-identified before being analyzed so that individual's scores are not known.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Dialectical Behaviour Therapy has been found to be effective in teaching people skills in regulating their feelings. The benefits for participants are that you will learn skills that may be useful in dealing with distress, building resilience and quality of life.

WHO PAYS FOR THE STUDY?

There will be no cost to you apart from getting to and from the sessions. You will be provided with a manual that includes all the skills at no cost.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

WHAT ARE MY RIGHTS?

Your participation is voluntary and you are free to decline to participate, or to withdraw from the research at any practicable time, without experiencing any disadvantage

You have the right to access information about yourself collected as part of the study.

You will be told of any new information about adverse or beneficial effects related to the study that becomes available during the study that may have an impact on your health.

Your privacy and confidentiality will be maintained. All identifying information including this consent will be stored in a locked cabinet at AUT. All questionnaires will be de-identified before being analyzed.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Data will be stored digital data will be stored on a password protected computer, hard copy data will be stored in a locked filing cabinet and kept for ten years. It will not be used for any other purpose than this study and will be securely stored at Greenlane Clinical Centre, Auckland District Health Board. At the end of that time data will be securely destroyed.

Your participation is voluntary and you are free to decline to participate, or to withdraw from the research at any practicable time without experiencing any disadvantage.

This study is expected to take 2 years to complete. This will be documented in the form of a Doctor of Health Science thesis. At the completion of the study a brief report in plain English on the outcome of the study will be available to participants within 3 months of the thesis being completed.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

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

Trish Du Villier, investigator
Telephone number 021620044
Email trishdv@adhb.govt.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@hdc.org.nz

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324

If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by telephoning 09 4868920 ext 3204

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 ETHICS
Email:	hdecs@moh.govt.nz

H.4 Consent form

Consent Form

Please tick to indicate you consent to the following *(Add or delete as appropriate)*

Please only include yes/no boxes if the statement is truly optional (i.e – that a person could still participate if they answer no).

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.		
I consent to the research staff collecting and processing my information, including information about my health.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I understand that there may be risks associated with the treatment in the event of myself or my partner becoming pregnant. I undertake to inform my partner of the risks and to take responsibility for the prevention of pregnancy.		
I agree to my (type of tissue) samples being sent overseas and I am aware that these samples will be disposed of using established guidelines for discarding biohazard waste.		
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of		

the information recorded for the study.	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	
I understand the compensation provisions in case of injury during the study.	
I know who to contact if I have any questions about the study in general.	
I understand my responsibilities as a study participant.	
I wish to receive a summary of the results from the study.	Yes ☐ No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

Appendix I: Confidentiality agreements

I.1 Transcriber confidentiality

Confidentiality Agreement

For someone transcribing data, e.g. audio-tapes of interviews.

Project title: :Is Dialectical Behaviour Therapy helpful for cancer patients?
Project Supervisor: ***Kirk Reed***
Researcher: ***Trish Du Villier***

- ○ I understand that all the material I will be asked to transcribe is confidential.
- ○ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ○ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: .....

Transcriber's name: .....

Transcriber's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Project Supervisor's Contact Details (if appropriate):

.....

.....

.....

.....

Approved by the Auckland University of Technology Ethics Committee on 5th July 2017

AUTEC Reference number 17/229

Note: The Transcriber should retain a copy of this form.

I.2 Research assistant

Confidentiality Agreement

For an intermediary or research assistant.

Project title: *Is Dialectical Behaviour Therapy helpful for cancer patients?*

Project Supervisor: ***Kirk Reed***

Researcher: ***Trish Du Villier***

- ○ I understand that all the material I will be asked to record is confidential.
- ○ I understand that the contents of the Consent Forms, tapes, or interview notes can only be discussed with the researchers.
- ○ I will not keep any copies of the information nor allow third parties access to them.

Intermediary's signature: .....

Intermediary's name: .....

Intermediary's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Project Supervisor's Contact Details (if appropriate):

.....

.....

.....

Approved by the Auckland University of Technology Ethics Committee on 5th July, 2017 AUTEC Reference number 17/229

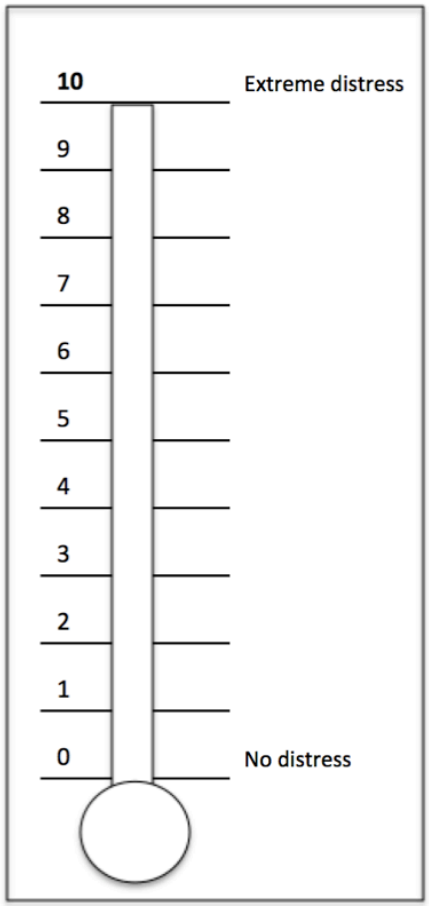
Note: The Intermediary should retain a copy of this form.

Appendix J: Phone call- Participants information sheet

Participants Information
Dealing with distress for cancer study

Name		
Does person fulfil selection criteria? 18-65, cancer diagnosis, read write English?, no diagnosed psychiatric illness last year, no current counselling		Score on DT
Participant number		
Date of birth		
Gender		
Highest education qualification		
Ethnicity		
Cancer stage and type		
Other medical disorder		
Current treatment		
Address for sending info		
Email		
Informed of dates ?		
Notes:		

Appendix K: Distress Thermometer



Roth et al. (!998)

Appendix L: Interpretations and cut-off scores for the DASS-21

L.1 DASS-21

Score Interpretation:

	Depression (D)	Anxiety (A)	Stress (S)
Normal	0 – 9	0 – 7	0 – 14
Mild	10 – 13	8 – 9	15 – 18
Moderate	14 – 20	10 – 14	19 – 25
Severe	21 – 27	15 – 19	26 – 33
Extremely Severe	28+	20+	34 +

Lovibond & Lovibond (1995)

L.2 Table 1: Cutoff scores from Table 2 Ronk et al. (2013 p.1107)

Cutoff Scores and Reliable Change Indices Necessary for Classifying Patient Change Using Three-Distribution Method Based on DASS-21 Scale Scores

	DASS-21 scale		
	Depression	Anxiety	Stress
Cutoff point separating:			
(a) normal range and outpatient range	9.03	6.27	12.27
(b) outpatient range and inpatient range	22.53	15.26	22.55
Minimum movement required for reliable change:			
(a) within normal range	3.86	3.85	4.90
(b) between normal and outpatient range	5.01	5.38	5.55
(c) within outpatient range	6.15	6.92	6.20
(d) between outpatient and inpatient range	6.28	8.08	6.36
(e) within inpatient range	6.41	9.23	6.52

Note. DASS-21 = 21-item Depression Anxiety Stress Scales (P. F. Lovibond & Lovibond, 1995). A change from the inpatient range to the normal range will always be reliable; therefore, these values are not presented here.

Appendix M: Questions asked in Appreciative Enquiry

Discovery- where positive qualities and strengths are discussed. The following were some of the questions asked in this phase.

- **Can you tell me about which skill you have learnt that you think has been the most helpful or effective and how you have used it?**
- **Is there somewhere that you have used it effectively in the last little while since you have learnt it?**

Dream- participants use their imaginations to picture the future positively. Some of the questions asked in this phase were as follows.

- **If you were starting a group like this, what changes in content do you think would improve the group and make it more useful for people with cancer?**
- **Are there any other changes that you would recommend, such as timing or frequency per week or design of the manual, so it would work better?**
- **For what part of people's cancer journey do you think this group would be most useful?**

3. Design- participants move from articulated dreams to concrete designs for action

In this phase, questions such as the following were asked of participants:

- **Do you think a follow up group might be useful?**
- **Is there anything about the structure or format that we could change?**
- **Is the timing right?**
- **Is there anything else that you think that I could do to improve the group or any skills that are not included or any additional content, to make the session more useful?**

4. Destiny/ Delivery- a collective reflection that leads to transformative action.

Questions asked in this final phase included:

- **Are there any steps that you think I need to take next?**

Appendix N: Questions asked in the semi-structured interviews

Questions asked included:

- **It has been a few months since you attended the group and I am interested in what effect, if any, attending has had. I am wondering which skills you still use?**
- **Can you give me an example of when you have used the skills effectively that you would not have done before coming?**
- **How have things been since I last saw you?**
- **Have you made any changes in your daily activity as a result of attending this group? Have you found the skills useful for dealing with that?**
- **Have you made any changes in your life or daily activities as a result of attending the group?**
- **Have you been looking at the book? (The group manual)**
- **Now that a few months have gone past, do you think that attending this group has made any difference to how you handle stress?**
- **(For those who improved) It seems from your test score on stress at the end of the group that things improved. What was the most important factor that you think led to the improvement? or**
- **(For those who did not improve) It seems from your test score on stress at the end of the group that things did not improve much. What was the most important factor that you think made that happen?**
- **Do you think you have noticed any difference in your ability to be resilient?**
- **Do you think that attending the group has made any difference to your quality of life or functioning? Are you functioning better, differently, the same, worse?**
- **Do you think that attending the group made a difference to how you experience your symptoms?**
- **Is there anything that you think I could do to improve the group or that would help you to use and maintain your use of the skills.**
- **Is there anything else that you would like to add?**

Appendix O: Information sent to participants

You are invited to participate in Stress Management for Cancer patients
6 sessions starting 5th June, 2018

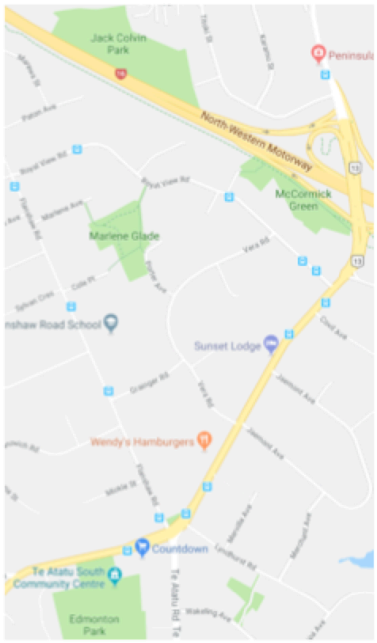
Dates:

Tuesday 5th June	10am-12pm
Saturday 9th June	12.30pm-2.30pm
Tuesday 12th June	10am-12pm
Saturday 16th June	12.30pm-2.30pm
Tuesday 19th June	10am-12pm
Saturday 23rd June	12.30pm-2.30pm

At: Te Atatu Community Centre

Address: 247 Edmonton Rd, Te Atatu South, Auckland 0610 -

From the North Western motorway: take the Te Atatu offramp in the direction Te Atatu South. At the third set of traffic lights, turn onto Edmonton Rd, you will see a Countdown supermarket on your left , after the driveway into the supermarket , turn down the driveway on your left that says **Lloyd Morgan Lions Club Park**. The community centre is the red brick building in front of you. You can park anywhere in the carpark.
Any problems call Trish 021 620044



Appendix P: Skills taught and handouts per session

Session	Module	Skills taught	*Handout from DBT Manual
One	Mindfulness	Mindfulness	M 1A
		Overview	M 2
		Wise mind	M 3
		What skills	M 4
		How skills	M 5
Two	Distress Tolerance	When to use crisis survival skills	D T 3
		Stop, Take a step back, Observe, Proceed mindfully (STOP Skills)	D T 4
		Distracting	D T 7
		Self- Soothing	D T 8
		Improving the Moment	D T 9
		Paced Breathing	D T 6
Three	Distress Tolerance	Pros and Cons	D T 5
		Radical Acceptance	D T 11
		Factors that interfer with being skilful	D T 11A
		Turning the mind	D T 12
		Willingness	D T 13
		Half Smile and Willing Hands	D T 14
Four	Emotion Regulation Distress Tolerance Emotion Regulation	Check the facts	E R 8
		Mindfulness of current thoughts	D T 15
		Accumulating Positive Emotions	E R 15
		Pleasant events	E R 16
Five	Emotion Regulation	Build Mastery and Cope Ahead	E R 19
		treat PhysicaL illness, balanced Eating, Avoid mood altering drugs, balanced Sleep, get Exercise (PLEASE skills)	E R 20
Six	Recap and Review		.

Note. M= Mindfulness, D T= Distress Tolerance, E R= Emotion Regulation.

* Handouts from Linehan, M. M. (2014). DBT skills training: Handouts and worksheets (Second ed.). New York, NY: Guilford Press.