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An Investigation of the Outcomes of Psycho-Oncology Interventions

A Thesis presented as partial fulfilment of the requirements for the degree of

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ABSTRACT

Cancer can have a significant psychological impact on those diagnosed, and their families. The ability of psychotherapy to reduce this impact has been extensively studied internationally. However, New Zealand-based research in this area remains limited. The present study aimed to investigate the effectiveness of psycho-oncology interventions, provided by a New Zealand psycho-oncology service, in reducing distress and improving quality of life for cancer patients and their families/whanau. Eighteen clients (patients/family members) of the service (intervention group) were recruited and matched for initial distress and wellbeing with patients/family members located in an area without a psycho-oncology service (control group). Wellbeing, wairua (spirituality), distress, impact and coping were measured pre- and post-therapy, and at follow-up. In addition, eight intervention group participants were interviewed to examine their experiences of cancer and the psycho-oncology service. Possible key factors influencing the effectiveness of service interventions were also investigated. The results showed that participants who had access to the psycho-oncology service showed significant improvements in all outcome measures by the end of therapy. The majority of these were maintained 3 months later. Improvements were also observed in the control group. Reasons for accessing therapy centred on diagnosis/prognosis concerns, communication with family, and talking to a non-family member about their worries. Although clients had no specific expectations prior to therapy, previous psychotherapy experiences influenced their perceptions of its potential effectiveness. Therapists' personal and professional qualities were also viewed as crucial. Five key themes were identified as most beneficial - receiving individualised support, talking to someone who was not family, receiving expert/professional support, regaining a sense of control, and service availability/flexibility. Overall, psycho-oncology interventions had a significantly positive impact on clients' lives, and were viewed as being extremely beneficial for those experiencing cancer-related distress. This research provides a unique contribution to the limited psycho-oncology research in New Zealand.

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CHAPTER ONE

The Impact of Cancer

*“We are not ourselves when nature, being oppressed,
commands the mind to suffer with the body”*

(King Lear, Act II, Scene IV; Shakespeare)

Cancer affects everyone – young and old, rich and poor, men, women and children. ‘Cancer’ is a generic term used to describe a collection of over 100 diseases in which abnormal cells multiply and spread throughout one or more organs of the body. No two cancer types are the same, each with varying rates of disease progression, and prognoses (Ministry of Health, 2003). Although historically cancer was considered a fatal disease, many different cancer treatments now exist which have been shown to be effective in eliminating or slowing disease progression, such as surgery, radiotherapy and chemotherapy, hormone therapy, and immuno- and gene therapies.

1.1 Cancer Prevalence/Mortality

In 2002, the International Agency for Research on Cancer’s GLOBOCAN project estimated (worldwide, per year) 10.9 million new cases of cancer, 6.7 million deaths, and 24.6 million persons living with cancer (Parkin, Bray, Ferlay & Pisani, 2005). Worldwide, lung cancer was the most commonly diagnosed (1.35 million new cases per year), followed by breast (1.15 million) and colorectal cancer (1 million) (Parkin et al., 2005). The most common causes of cancer death were lung cancer (1.18 million), stomach cancer (700,000), and liver cancer (598,000) (Parkin et al., 2005). Due to its high incidence and relatively good prognosis, breast cancer was reported as the most prevalent cancer worldwide (17.9%) (Parkin et al., 2005). An estimated 4.4 million women who were diagnosed with breast cancer were alive 5 years post-diagnosis, compared to just 1.4 million with lung cancer (Parkin et al., 2005). Statistics indicate that on average, worldwide, there is approximately a 10% chance of being diagnosed with cancer before the age of 65 (Parkin et al., 2001).

According to the GLOBOCAN 2002 data, Australia and New Zealand were recorded as having the second highest incidence rate of cancer in the world. In New Zealand, 17,943 new cancer registrations were recorded, of which 1207 were Maori (13.5%), and 432 were Pacific Islanders (4.9%) (New Zealand Health Information Service, 2006). In 2002, 7,800 people died from cancer, making it the leading cause of death in New Zealand (New Zealand Health Information Services, 2006). The New Zealand cancer death rate has been reported to be higher than countries such as Australia, Canada, Britain and the United States (Gavin, Marshal, & Cox, 2001).

Although the incidence of all adult cancer is expected to increase, official figures from the Cancer: New Registrations and Deaths (2002) data report that overall cancer death rates are declining (New Zealand Health Information Services, 2006). Improvements in early detection and treatment mean that an increasing number of people are surviving cancer. However, in addition to the difficulties people with cancer and their families face during diagnosis and treatment, surviving cancer brings with it unique challenges.

1.2 Psychological Impact of Cancer on Patients

When someone is diagnosed with cancer, its impact extends beyond the physical effects of the disease. Cancer can cause considerable distress, impacting significantly on a person's quality of life, psychologically, emotionally, socially, spiritually and functionally. Distress has been defined by the National Comprehensive Cancer Network as *"a multi-factorial unpleasant emotional experience that may interfere with a person's ability to cope effectively with cancer, its physical symptoms and treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis"* (Holland, Andersen & Breitbart, et al., 2010, p. 450). Distress can be related to many different issues, such as physical problems relating to an illness or disability, psychological problems, and/or family and social concerns (e.g., employment).

1.2.1 Prevalence of Distress

The empirical literature has consistently reported a high prevalence of psychiatric illness amongst a variety of cancer patient populations. Early prevalence studies of psychological distress indicated that 25-30% of individuals with newly diagnosed and recurrent cancer experienced significantly high levels of emotional distress (Derogatis et al., 1983; Farber, Weinerman & Kuypers, 1984; Zabora, Brintzenhoffsoc & Smith, 1996). One of the earliest and most widely cited studies by Derogatis et al. (1983) reported that almost half (47%) of those with cancer met the diagnostic criteria for a psychiatric disorder. In a large study with 4496 patients, Zabora, Brintzenhoffsoc, Curbow, Hooker and Piantadosi (2001) found significant distress in 35.1% of their participants. Most recently, a study of 3000 cancer patients found 37% met criteria for significant distress (Carlson & Bultz, 2003).

1.2.2. Psychosocial Problems

People with cancer experience many different psychosocial difficulties related to their diagnosis, treatment and survival. Some of the most frequently cited problems are discussed below.

1.2.2.1. Anxiety

One of the major areas of distress for people with cancer is the feeling of uncertainty and fear about the future (Bottomley & Jones, 1997). Anxiety is one of the most common psychological difficulties that people experience when diagnosed with cancer. An early study reported that approximately 20-25% experienced anxiety (Derogatis et al., 1983), with similar findings reported in more recent studies (Stark et al., 2002; Zabora et al., 2001).

People with cancer may experience anxiety at different stages of their cancer journey. At the time of diagnosis, anxiety may arise about telling family and friends, or about their survival (Bottomley, 1997). At the time of treatment, there may be anxiety about undergoing surgery, as well as experiencing the side effects of chemotherapy or radiotherapy (Beckman, Bernheim & Zittow, 1986; Cox & Fallowfield, 2007). There may also be anxiety about pain, fear of

disability or disfigurement, or loss of desirability (Pitceathly & Maguire, 2003; Portenoy, Thaler, Kornblith et al., 1994).

Fear of recurrence is also a great source of anxiety for many cancer survivors. Lampic et al., (1994) assessed anxiety and cancer-related worry in 197 cancer patients attending follow-up visits, and found that one fifth of survivors exhibited moderate to severe anxiety. Forty-six percent of patients were afraid of a recurrence and 33% were concerned about their doctors overlooking symptoms of new cancer. Thomas, Glynne-Jones, Chait and Marks (1998) found that 31% of long-term cancer survivors experienced significant anxiety (as measured by the Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983), and that patients in long-standing remission exhibited similar rates of anxiety to patients with active disease.

As those with cancer reach the advanced stages of the disease, they may become fearful for their family's future, or experience fears of being abandoned by family and medical staff (Chochinov, 2001). Physical symptoms such as pain, shortness of breath and loss of body functions may cause great distress. Many may also fear the process of dying and death itself (Fawzy, 1999; Holland, 1989).

1.2.2.2. Depression

Depression is another common psychosocial difficulty people with cancer experience. However, it is often not identified as such because the symptoms of depression often mirror cancer-related symptoms, such as fatigue, weight loss, loss of appetite or sleep disruption (Derogatis & Melisaraatos, 1983). Also, many are reported to hold the belief that it is only natural that people with cancer should feel 'down' (Chochinov, 2001). As a result, depression in individuals with cancer has been described as being under-diagnosed and under-treated (Massie & Holland, 1984). Depression has been found to be strongly associated with the cancer diagnosis, with prevalence rates of depression ranging from 1% to 53% (Bukberg, Penman & Holland, 1984; Derogatis et al., 1983; Massie, 2004). Differences in prevalence rates may be attributed to a number of factors including variations in study methods, as well

as differences such as cancer site, age, cancer stage, time since diagnosis, and type of treatment (Pasquini & Biondi, 2007). Despite these variations, the most commonly reported prevalence rates of major depression range from 20–25%, increasing with higher levels of physical disability, advanced illness, and pain (Carlson et al., 2004). The importance of detecting and treating depression in individuals with cancer is that the presence of comorbid illnesses may complicate the treatment of both depression and cancer, resulting in poor adherence to treatment recommendations and poorer outcomes of both conditions (Massie, 2004).

Types of cancer shown to be most associated with depression include oropharyngeal, pancreatic, breast and lung cancer, with less depression seen in patients suffering from colon, gynaecological cancer and lymphoma (Massie, 2004). Factors that have been found to influence the development of depression include a prior history of depression (Aass, Fossa, Dahl & Moe, 1997), type of cancer (Massie, 2004), poorly controlled pain (Spiegel, Sands & Koopman, 1994), undergoing chemotherapy or major surgery (Molassiotis, Akkers, Milligan, Goldman & Boughton, 1996), and reduced ability to continue daily life activities (Aass et al., 1997).

1.2.2.3. *Psychosexual Difficulties*

Although anxiety and depression are the main psychological problems faced by people with cancer, sexual functioning and maintaining intimate relationships are also very important (Clark et al, 1997; Lamb, 1995; Wilmoth, 2001). Many people experience emotional and physical difficulties related to changes in their bodies and have concerns about their ability to function sexually, both during and after cancer treatment (Gallo-Silver, 2000). Cancer treatment can play an important role in changing sexual behaviours. Many chemotherapeutic drugs reduce sexual desire (Pennan et al., 1984); surgery, radiation burns or hair loss can also have an influence on a person's sexual behaviour (Schover, 1987; Wilmoth, 2001).

The most significant cancers affecting sexual behaviour are gynaecological cancers. In a qualitative study by Stead, Fallowfield, Brown and Selby (2001),

women with ovarian cancer reported changes in their level of sexual desire, anxiety about sexual activity (e.g., fear of recurrence), relationship concerns (e.g., fear of rejection) and distress regarding potential loss of fertility. Physical problems or psychological distress resulted in a reduction in the frequency of sexual activity. Hawighorst-Knapstein et al. (2004) found that for women who had undergone surgery for cervical cancer, sexual difficulties had the greatest impact on their quality of life. Women also perceived themselves to be less attractive and self-confident following surgery compared to how they felt prior to surgery. Wilmoth (2001) reported that of particular concern to women post breast cancer treatment was the adjustment to breast removal or change in its appearance; coping with the physical and psychological aspects of an accelerated menopause; loss of sexual sensations and decreased sexual desire; and loss of womanhood.

Men also experience many sexual problems due to cancers of the prostate (Ofman, 1994), penis (Romero et al., 2005) and testicles (Arai, Kawakita, Okada & Yoshida, 1997). The most common sexual problems for men include loss of desire for sex, erectile dysfunction, and reduced or poor self image (Chapple & Ziebland, 2002; Clark et al., 1997; Ofman, 1994). Hormone therapy has been found to have a profound effect on men's libido, body shape, and impotence (Chapple & Ziebland (2002). A study by Schover (1992) found that undergoing radiotherapy resulted in erectile dysfunction in 25% of men. Arai, Kawakita, Okada and Yoshida (1997) found that 25-50% of men who underwent chemotherapy, radiotherapy, or surveillance therapy reported some type of sexual difficulties. According to Schover (1992), with most treatment methods, only 20% of men remain sexually functional.

1.2.2.4. Cancer Treatment

Surgery

For many people with cancer, treatment involves surgery, and the psychological consequences of undergoing surgery can be significant. Many experience anxiety and fear in anticipation of surgery (Deane & Degner, 1998; Hughson, Cooper, McArdle & Smith, 1988). Increased distress prior to surgery has also been linked to poorer post-treatment outcome (Croog, Baume &

Nalbandian, 1995; Scott, Clum & Peoples, 1983). Montgomery and Bovbjerg (2004) found that pre-surgery distress contributed to patients' post-surgery nausea, discomfort and fatigue, and that pre-surgery expectations were significant predictors of pain intensity, pain discomfort, and fatigue. Other patients may have fears regarding pain, concerns about the anaesthesia and the possibility of side effects (Chung, Ritchie & Su, 1997; Gray, Fitch, Phillips, Labrecque & Klotz, 1999), death, loss of body parts (Hughson et al., 1988; Pitceathly & Maguire, 2003), as well as concern for their family (Bottomley & Jones, 1997). For some, the fear of surgery can be so great that they may postpone surgery, seek non-surgical alternatives, or refuse treatment (Fawzy, 1999).

Chemotherapy & Radiotherapy

Chemotherapy is one of the main treatments for fighting cancer and it involves subjecting patients to high levels of toxic drugs in the attempt to prevent the spread of cancer. Unfortunately, this aggressive method of treatment can also cause significant amounts of emotional distress. Physical side effects of the treatment including nausea, vomiting, hair loss, loss of taste, appetite, and sexual function may all contribute to a sense of helplessness and loss of control (Brinkley, 1983; Carey, & Burish, 1988; Pandey et al., 2006). Chemotherapy involves numerous cycles of drug administration, therefore, for many individuals, knowing in advance that they are going to be unwell may produce 'conditioned vomiting', needle phobia and even refusal of treatment (Brinkley, 1983). In a survey by Coates et al. (1983), vomiting and nausea were found to be the two most distressing side-effects experienced by patients receiving chemotherapy, and had the most impact on quality of life and compliance with treatment. Love, Leventhal, Easterling and Nerenz (1989) found that the distress, difficulty and disruption experienced as a result of chemotherapy resulted in almost half (46%) of the patients considering quitting treatment. Most indicated experiencing emotional distress (90%), and disruption in social life (75%) and work life (81%). These levels of distress, difficulty and disruption were reported to have increased as treatment progressed.

The thought of radiotherapy treatment can also create feelings of fear and anxiety amongst people with cancer (Beckman et al., 1986). Many find radiotherapy to be very emotionally upsetting. Some find the equipment to be intimidating, others are distressed by seeing others with advanced cancer, or fear the treatment might cause long-term physical harm. Many patients who feel sick during their radiotherapy experience conditioned reflex nausea on re-entering the treatment facility (Hughson et al., 1987). Fritzsche, Liptai and Henke (2004) found that 18% of those undergoing radiotherapy experienced anxiety or depression and 11% had maladaptive coping styles. Fifty one percent of patients were considered to have mental disorders, of which 33% were regarded as having a mental disorder requiring psychotherapeutic or psychopharmacological treatment.

1.2.2.5. Cancer Pain

Second only to the fear of death, pain is perhaps the most feared consequence of cancer (Ahles, Ruckdeschel & Blanchard, 1984). For those diagnosed with cancer, the onset of pain may be the first sign of cancer, may be emotionally draining, or be so acute that it leaves the sufferer totally debilitated (Ahles et al., 1984). The type, intensity, and location of pain can vary according to the type of cancer, the extent of disease progression and type of treatment used (Ahles et al., 1984). Up to three quarters of chronic pain syndromes result from the direct effects of the tumour (neuropathic pain). Others are related to therapies administered to manage the cancer (nociceptive pain), or disorders unrelated to cancer or its treatment (Portenoy et al., 1994).

Pain is considered to be multidimensional, with complex interactions between physiological, psychological, cognitive, social and other factors (Ahles, Blanchard & Ruckdeschel, 1983). Uncontrolled pain can have a hugely negative impact on the individual with cancer and their family (Portenoy et al., 1994). Pain related to cancer or its treatment affects 50-90% of those with cancer (Portenoy et al., 1994). Zaza and Baine (2002) conducted a review to assess psychosocial factors associated with cancer pain - in particular psychological distress, social support and coping. Fourteen out of 19 studies

found a significant association between chronic cancer pain and psychosocial distress, with higher levels of distress being associated with higher levels of pain. Seven out of eight studies reported finding a significant association between social activities and/or social support and cancer pain. Higher levels of pain were associated with reduced social activities, less social support, and a reduction in social functioning.

1.2.2.6. *Work and Family Role Changes*

As a result of a cancer diagnosis there are often changes in employment roles within the family, and for most patients, the diagnosis and treatment of cancer means that they have to temporarily or permanently stop work (Bloom et al., 1988; Houts, et al., 1986). In a review by Spelten, Sprangers and Verbeek (2002), the rate of returning to work for cancer survivors varied from 30-93%, with an average of 62%. Factors influencing their decision to return to work include financial pressures, a desire for normality or distraction from their illness, feelings of responsibility or loyalty to the workplace, support from the workplace (i.e., flexibility, reduced workloads), or physical health (Bouknight, Bradley & Luo, 2006; Kennedy, Haslam, Munir & Pryce, 2007; Main, Nowels, Cavender, Etschmaier & Steiner, 2005). For those unable to return back to work, many face financial loss, social isolation and a reduction in self-esteem (Barofsky, 1989). Even those who are able to return to work face difficulties, such as problems with employers/co-workers, diminished work capacity, personal changes in attitudes to work, and feelings of social withdrawal (Berry, 1993; Brown & Tai-Seale, 1992; Kennedy et al., 2007; Maunsell et al., 1999).

Role changes within the family are an inevitable part of adjusting to cancer. However, these changes in family dynamics can cause a great amount of anxiety (Northouse, 1995). For women, the role of mother is a significant caretaking role which often involves balancing meeting their own needs and their family's needs (Spira & Kenemore, 2000). In a study by Fitch, Bunston and Elliot (1999), women with cancer felt that changes in their role as mother often created tensions, particularly relating to their inability to do what was normally done in the past. They struggled with having no energy to do

anything, but feeling that things should be done (e.g., housework), and having to rely on friends and family.

Men experience similar challenges as they attempt to control the effects cancer has on their roles as working men, husbands, and fathers. Elmerger, Bolund and Lutzen (2002) found that men struggled with the change in their self-image. The role of a hard-working man had been replaced by the role of a weak father at home. This shift in self-image was described as a burdensome experience. Men's views of themselves as a father also changed; with many feeling that their authority within the family had weakened.

1.2.2.7. *Interpersonal Communication*

Often people with cancer experience poor interaction and communication with others (Lichter, 1989), including family, friends, and medical professionals. Poor communication between patients and doctors has been found to have a significant and negative effect on the patients' ability to cope with cancer (Faulkner & Maguire, 1994). Lerman et al. (1993) found that a significant proportion of patients (84%) had difficulties communicating with their oncology team. A large discrepancy has also been found between what health professionals think is necessary information and what patients actually want to know (Fallowfield, Ford & Lewis, 1994; Jenkins, Fallowfield & Saul, 2001); with many patients wanting more information than they are given. Poor communication with health professionals can also have a long-term effect on patient outcome. In Lerman et al's (1993) study, communication problems were associated with increased anxiety, depression, anger, and confusion at the 3-month follow-up. Kerr, Engel, Schlesinger-Raab, Sauer and Holzel (2003) found that poor communication had an effect on functioning, symptoms, body image, and lifestyle up to four years post-diagnosis.

A cancer diagnosis can also lead to communication problems between patients and their family/whanau. Studies have found that although family members feel that communication about cancer is one of their most urgent needs (Kilpatrick, Kristjanson, Tataryn & Fraser, 1998), family members do not talk as much and often hold back more than the patient (Cooper, 1984). Some family

members refuse to discuss the cancer for fear that it will upset the patient (Boehmer & Clark, 2001; Dunkel-Schetter, 1984). Chekryn (1984) found that 40% of patients and 30% of spouses in their study did not discuss their fear of recurrence of cancer, and that as patients neared the end of life, families found talking about death and dying particularly difficult. Zhang and Siminoff (2003) found that two thirds of families experienced communication problems which were associated with avoidance of psychological distress, desire for 'mutual' protection, and belief in positive thinking.

1.3 Psychological Impact of Cancer on Family Members

Although the psychosocial impact of cancer on patients has been thoroughly documented, the psychosocial impact that cancer has on family members is a relatively neglected aspect in the treatment of cancer. For the majority of people with cancer, partners and other members of the family act as key supports, enhancing the cancer patient's ability to adapt to their illness and treatment. However, like patients, family members can differ in their ability to cope with the impact of a cancer diagnosis and their ability to fulfil the patient's needs (Cassileth et al., 1985). Most family members are able to adjust. However, some studies have reported that 20-30% of carers of cancer patients experience high levels of emotional distress or psychiatric morbidity (Compas et al., 1999; Hagedoorn, Buunk, Kuijer, Wobbles & Sanderman, 2000). In some studies, patients and their spouses have shown significant and similar levels of distress (Compas et al., 1999; Northouse & Stetz, 1989). While some studies have shown that post-diagnosis, distress levels in carers reduce over time (Hoskins, 1995), others have shown that it increases (Ell, Nishimoto, Mantell & Hamovitch, 1988; Given & Given, 1992). This is thought to be a result of carers putting their own worries and problems on hold while they focus on the patient's needs (Vess, Moreland, Schwebel & Kraut, 1988).

A review by Pitceathly and Maguire (2003) found that female carers and those with a history of psychiatric morbidity were more vulnerable to experiencing high levels of distress or developing an affective disorder. In addition, those who had a more negative view of the patient's illness and the impact it had on

their lives were also more likely to experience psychological difficulties. Carers were more likely to become more distressed and develop psychiatric morbidity as the illness progressed and treatment became palliative.

1.4 Summary

Cancer is a worldwide disease, with over 10 million new cases of cancer identified each year, 6.7 million deaths, and 24.6 million persons living with cancer. Unfortunately New Zealand has one of the highest incidence and death rates for cancer in the world. Cancer not only causes physical distress, but also psychological distress. Research has shown that a significant proportion of people with cancer suffer from psychosocial difficulties including anxiety, depression, sexual difficulties, distress relating to cancer treatment such as surgery, chemotherapy and radiotherapy, as well as adapting to changes in roles, and interpersonal communication difficulties. The diagnosis and treatment of cancer also has a great impact on the family, with many family members experiencing similar levels of distress to those seen in people with cancer.

CHAPTER TWO

Factors Influencing the Impact of Distress

“The human spirit is stronger than anything that can happen to it.”

(C.C. Scott)

Not everyone reacts to cancer in the same way, and the degree to which cancer impacts on individuals can be influenced by a number of medical, demographic and psychosocial variables.

2.1 Medical Factors

2.1.1 Cancer Site

Cancer can develop almost anywhere in the body. Although a cancer diagnosis, irrespective of location, causes a great deal of emotional turmoil, for some, the location of the tumour means facing additional and distressing challenges. Differences in the availability of treatment options, prognoses, impact on physical/sexual functioning, or appearance can all contribute to increased psychological distress. Zabora et al. (2001) found that patients with lung, brain, Hodgkin’s disease, and pancreatic cancer reported higher levels of distress than patients with colon, prostate and gynecological cancers. They suggested that lung cancer might cause greater distress because of the poorer prognosis, and the feeling that they might be somewhat responsible for their diagnosis due to lifestyle choices (e.g., smoking). Brain and pancreatic cancers were also considered to have poorer prognoses as treatment at those sites was relatively ineffective. Koster and Bergsma (1990) reported that individuals with head and neck cancer experienced more emotional distress than other types of cancers because they were less able to hide the effects of treatment, for example, may have had significant changes in speech, ability to swallow and taste, as well as changes in physical appearance.

2.1.2 Cancer Stage

Over the cancer trajectory, patients are confronted with many challenges. As already highlighted, particularly challenging and distressful times include being

informed of the diagnosis, receiving and completing treatment, recurrence, and surviving cancer. Although these phases are indicative of increased distress levels, some researchers have found that the degree of distress experienced depends on whether patients are in the early or latter stages of cancer. Some studies have reported that people newly diagnosed with cancer experience more adjustment difficulties than those further along the cancer continuum (Fallowfield, 1990). However, others have found that patients with more advanced cancer have more adjustment difficulties and higher levels of distress than those in the earlier stages of cancer. For example, Cassileth et al. (1985) found that patients receiving palliative care had significantly higher levels of anxiety, mood disturbance and poorer overall mental health compared to those in the earlier stages of cancer. Similar findings were also reported for the family members of these cancer patients. Reasons for the higher levels of distress in the latter stages of cancer included reduced hope of recovery and focus on comfort rather than cure or remission.

2.2 Demographic Factors

2.2.1 Age

Research has consistently shown that younger people with cancer experience more psychological distress than those who are older (Harrison & Maguire, 1995; Politi, Enright & Weihs, 2007; Thewes, Butow, Girgis & Pendlebury, 2004). A study examining the functional impact of breast cancer at diagnosis found that women under 41 years of age experienced the greatest decline in health-related quality of life compared to middle-aged (41-64yrs) and older women (≥ 65 yrs) (Kroenke et al., 2004). This was evident across multiple areas, including physical roles, bodily pain, social functioning and mental health. Vinokur, Threatt, Vinokur-Kaplan, and Satariano (1990) followed women during their first year post-diagnosis and found similar results - younger women (≤ 60 yrs) experienced significantly greater deterioration in mental health and wellbeing than older women. Zabora et al. (2001), however, found that it was not only the young (< 30 years) that experienced greater distress, but also those over the age of 80.

A number of possible age-related reasons for greater psychological distress in younger women have been suggested. Some researchers have stated that greater distress levels in younger women may reflect a higher number of potential losses in their lives, including careers, social life, family life, and fertility (Mor, Malin & Allen, 1994; Siegel, Gluhoski & Gorey, 1999). Other studies have reported that for women diagnosed at a very young age, the presentation of their cancer tends to be more advanced and symptoms are often more aggressive (Kroman et al., 2000; Walker, Lees, Webb & Dearing, 1996). Baider, Ever-Hadani, Goldzweig, Wygoda and Peretz (2003) suggested that women of different ages might experience cancer differently. For example, cancer is more common in older women, therefore, perceived as being less traumatic or threatening.

Other studies have revealed that women of different age groups may employ different methods of coping with cancer. In some studies (e.g., Halstead & Fernsler, 1994) older women demonstrated a greater ability to cope with cancer by using already learned coping strategies, whereas younger women tended to use less effective ways of coping. Goodwin et al. (2004) found that young age was significantly associated with greater distress, greater anxious-preoccupied and reduced fatalistic coping, and reduced emotional and cognitive functioning up to 1 year post-diagnosis. Compas et al. (1999) also found that during the early stages of cancer, younger women experienced greater distress and had a tendency to engage in less adaptive ways of coping than older women.

2.2.2 Gender

Findings comparing levels of psychological distress amongst men and women with cancer have been mixed. Some studies has shown that women experience more emotional distress (e.g., Cella et al., 1987; Katz, Irish, Devins, Rodin & Gullane, 2003; Keller & Henrich, 1999), whereas others have reported that men are more distressed and that their lives are more disrupted by the experience (e.g., Pettingale, Burgess, & Greer, 1988). Some studies have found no gender-related differences in psychological distress (Carlson, et al., 2004; Marks, Richardson, Graham, & Levine, 1986). Gender differences in

distress amongst family members, however, appear to more consistent, with female partners exhibiting higher levels of distress than male partners or patients. Hagedoorn et al. (2000) found that 35% of female partners compared with 12% of male partners scored above the cut-off for depression on the Centre of Epidemiological Studies Depression Scale – CES-D. Kornblith, Herr, Ofman, Scher, and Holland (1994) found that wives were significantly more distressed than their ill husbands. Other researchers have similarly found higher levels of distress in wives of male cancer patients than in the men themselves (Baider, Koch, Esacson, & De-Nour, 1998; Drabe et al., in press).

Research suggests that differences in gender-related distress may be related to differences in coping styles and social support. More effective coping styles such as problem-solving have been shown to be used by men, whereas women tend to use more emotion-focused ways of coping (Fife, Kennedy & Robinson, 1994; Hoekstra-Weebers, Jaspers, Kamps & Klip, 1998). Gender difference may also reflect social norms regarding accessing social support. Women are more likely to express concerns to others, whereas men tend to be more reluctant to admit and report distress (Kornblith, Herr, Ofman, Scher & Holland, 1994; Roth et al., 1998). Differences also exist with regard to the amount of social support available to men and women. Women typically rely much more on resources both inside and outside of the family and have a broader social network, whereas men tend to rely primarily on their partner (Antonucci & Akiyama, 1987; Boehmer & Clark, 2001; Keller & Henrich, 1999).

2.2.3 Race

Incidence and mortality rates for cancer have been shown to differ significantly amongst different ethnicities. For example, Black Americans have higher incidence and mortality rates than non-Hispanic White ethnicities (Ries et al., 2003). In New Zealand, Maori are 18% more likely than non-Maori to be diagnosed with cancer, and have a 93% higher mortality rate (Robson, Purdie, & Cormack, 2006). Given the higher incidence and mortality rates amongst these populations, one might expect them to have poorer psychological outcomes. New Zealand research examining psychological distress amongst

the Maori population is very limited. However, one study of a breast cancer screening mammography programme found that levels of anxiety were related to ethnicity. Maori and Pacific Island women were reported to experience significantly higher levels of anxiety about developing cancer, while waiting for mammography appointments, and receiving results, than New Zealand European and Asian women (Brunton, Jordan, & Campbell, 2005). Levels of anxiety were also reported to be related to level of education, family history of breast cancer, stress levels during screening, and experience of pain during the procedure.

Some other studies have found some race-related differences in distress levels. Zabora et al. (2001) found that African American cancer patients experienced a higher level of distress than Caucasian patients; but the difference was small. However, most studies have failed to find a difference in distress levels based on race (Friedman et al., 2006). Rodrigue (1997) examined race differences in psychological adjustment to cancer and found no significant differences between African Americans and Caucasians. However, African Americans were more likely to use avoidant coping strategies in dealing with their illness. They also reported more cancer-related disruption in family relations, and reported having smaller social support networks.

2.3 Psychosocial Resources

Psychosocial resources are the internal and external support structures that individuals have, or perceive to have, available to them in dealing with particular situations. Psychosocial resources that have been found to have a particular impact on how a person copes include stress appraisal, self efficacy, coping strategies and social support.

2.3.1 Appraisal & Self Efficacy

The impact cancer has on people can be greatly influenced by how an individual or family copes with the challenges they face. How one copes with an event such as a cancer diagnosis, is thought to depend somewhat on how the individual interprets or appraises the stressful event (Franks & Roesch,

2006). Appraisal is defined as *“an individual’s perception or judgement of an event that determines the stressfulness of the situation in terms of personal significance”* (Franks & Roesch, 2006, p. 1028). Appraisal has been described as a two-step process in which the individual first appraises the significance/impact of the stressful event, and second, appraises the availability of resources for dealing with the stressful situation (Lazarus & Folkman, 1984).

Studies have shown that the appraisal process plays a significant role in the adjustment to cancer. For example, those with a negative appraisal of their illness have been shown to exhibit higher levels of psychological distress (Gallagher, Parle & Cairns, 2002; Whitaker, Watson & Brewin, 2009). Studies have also shown that a spouse’s ability to cope has been linked to their appraisal of their partner’s illness. Spouses who are more optimistic appear less depressed and more psychologically adjusted (Given et al., 1993). However, carers who perceive the cancer to be more serious (Compas et al., 1999), the treatment more stressful, or have more illness-related concerns (Lewis, Woods, Hough & Bensley, 1989) are more likely to be emotionally distressed.

The second phase of the appraisal process focuses on self efficacy, or the confidence a person has in their ability to perform in a particular situation (Bandura, 1989). According to Social Cognitive Theory (Bandura, 1997), self efficacy refers to having a sense of control over one’s environment and behavior. Self efficacy has also been shown to influence a person’s adjustment to cancer (Cunningham, Lockwood & Cunningham, 1991; Lev & Owen, 1996; Kreitler, Peleg & Ehrenfeld, 2007). Kreitler et al. (2007) found that self efficacy reduced perceived stress and increased quality of life. Self efficacy had a significant positive effect with regard to overall quality of life, family functioning, cognitive functioning, physical wellbeing, body and self image, sense of control, and coping.

2.3.2 Coping

Coping has been defined as *“a cognitive and/or behavioural attempt to manage (reduce or tolerate) situations that are appraised as stressful to an individual”* (Franks & Roesch, 2004, p. 1028). Many different types of coping strategies have been identified. However, they tend to fall into one of two groups. Coping strategies described as active, adaptive, problem- or approach-focused, are those in which individuals *“accept and actively attempt to deal with their situation”* (Kershaw, et al., 2004, p 140). Coping strategies described as avoidant and maladaptive, are those in which individuals *“try to avoid dealing with problems by cognitively and physically distancing themselves from the situation”* (Kershaw et al., 2004, p 140).

Numerous studies have highlighted the significant role coping plays in the psychosocial adaptation to chronic illness (e.g., Dunkel-Schetter Feinstein, Taylor & Falke, 1992; Heim, Valach & Shaffner, 1997; Livneh, 2000). Cancer, in particular, has been frequently cited as requiring a number of coping strategies to deal with the many challenges experienced (Livneh, 2000). Research has found that the type of coping strategy used is related to psychological adjustment (Dunkel-Schetter et al., 1992). Livneh (2000) found that individuals who used engagement-oriented coping strategies such as problem-focusing, having a fighting spirit, positive re-interpreting of problems, and seeking social support had better psychosocial outcomes. Those who used disengagement-oriented coping strategies such as wishful thinking, self blaming, and having a fatalistic attitude had poorer psychosocial adaptation to cancer (Heim, Valach & Schaffner, 1997). Similar findings regarding the benefits of active versus avoidant coping strategies have also been reported by other researchers (Compas, Worsham, Sydney & Howell, 1996; Zabalegui, 1999).

Coping strategies used to manage distress have also been shown to differ between patients and family members. Kershaw, Northouse, Kritpracha, Schafenacker and Mood (2004) found significant differences between patients with advanced cancer and family caregivers. Individuals with cancer were reported to use more emotional support, religion, positive reframing, self-

distraction, venting, and humor, whereas family caregivers used more alcohol and drugs. Ben-Zur et al. (2001) found that female patients used more active coping strategies than their husbands, but a similar number of avoidant coping strategies. Dodd and colleagues (1992) reported slightly different findings. In their study both groups used similar active coping strategies. However, patients were reported to use a greater variety of coping strategies than their caregivers. Some studies have examined whether differences in coping styles between patients and family members influenced how each other coped. Hannum et al. (1991) found that husbands' coping strategies were the best predictors of wives' psychological distress. However, Ptacek et al. (1994) and Ben-Zur, Gilbar and Lev (2001) found no connection between the coping of one spouse, and the coping of the other.

A cancer diagnosis often raises many existential issues and can challenge an individual's sense of meaning in life. In times of significant distress and trauma, many turn to their spiritual or religious beliefs for comfort. Religious or spiritual faith has been shown to provide women with breast cancer the emotional support necessary to deal with their cancer. Women have described being able to rely on their faith, that they felt taken care of, received companionship, guidance, comfort, strength, a sense of wellbeing, and alleviation of fear (Feher & Maly, 1999). Faith has also been reported to provide social support through interaction with the church, volunteer work, and prayer, as well as providing them with the ability to make meaning of their day-to-day lives (Feher & Maly, 1999).

The role spirituality plays in the psychological adjustment to cancer has been found to be significant, with results indicating that spirituality/religiosity is associated with better quality of life and well-being, and less distress (Chibnall, Videen, Duckro & Miller, 2002; Kim, Heinemann, Bode, Sliwa, & King, 2000; Nelson, Rosenfeld, Breitbart, & Galietta, 2002; Riley et al., 1998; Rippentrop, Altmaier, Burns, 2006). Research has also shown religious and spiritual beliefs to be associated with active rather than avoidant coping strategies among people with cancer (Baider et al., 1999; Holland et al., 1999). A recent review, however, found that although most studies found a positive relationship

between spirituality and wellbeing, the poor quality of the studies reviewed prevented a definitive conclusion being reached regarding the benefits of spiritual beliefs in coping with cancer (Visser, Garssen & Vingerhoets, 2009).

2.3.3 Social Support

The relationship between social support and psychosocial adjustment to cancer has been well established, with numerous studies highlighting the beneficial effects of social support (Arora, Rutten, Gustafson, Moser, & Hawkins, 2007; Bloom, Stewart, Johnston, Banks & Fobair, 2001; Dunkel-Schetter, 1984; Helgeson & Cohen, 1996; Shelby, et al., 2008). Social support is often provided by a wide variety of people, including family and friends, work colleagues, community groups or professionals (e.g., doctors, nurses). Social support has been described as multi-dimensional, with each dimension serving different purposes. House (1981) conceptualised social support as consisting of four types: *emotional support* (empathy, love, trust, and caring), *informational support* (advice and problem-solving strategies), *instrumental support* (tangible aids and services e.g., transportation, money), and *appraisal support* (information that is useful for self-evaluation, constructive feedback). However, the meaning, and the importance placed on social support is highly subjective, and can vary according to personal and cultural factors (Ashing, Padilla, Tejero, & Kagawa-Singer, 2002; Baider & De-Nour, 1987; Baron-Epel, Granot, Badarna, & Avarami, 2004; Helgeson & Cohen, 1996; Henderson, Gore, Davis, & Condon, 2003; Kagawa-Singer & Wellisch, 2003; Lugton, 1997; Moore, 2001).

The extent to which social support influences adjustment also depends on the quality of the support. While most people with cancer report that friends and family are very supportive and helpful in ameliorating the impact of distress, sometimes the support offered is not always considered helpful. This often occurs as a direct result of 'others' misconceptions about the cancer patient's needs and desires (Peters-Golden, 1982). Minimising the problem, being forced to be cheerful, avoidance, being told not to worry, receiving medical care without emotional support, and insensitive comments from friends are all behaviours that people with cancer most often consider to be unhelpful (Dakof

& Taylor, 1990; Dunkel-Schetter, 1984, Gottlieb & Wachala, 2007). However, sometimes the perceived helpfulness of support can differ depending on the source of support. People with cancer may find advice and information from experts to be helpful, but the same 'support' may be considered unhelpful when offered by family or friends (Dunkel-Schetter, 1984). As already highlighted, the level of support provided by friends and family may also vary depending on their ability to cope with the patient's diagnosis (Cassileth et al., 1985).

2.4 Summary

Everyone reacts differently when faced with a cancer diagnosis and the impact it has on individuals can vary. Research has revealed that many internal and external factors play a role in determining the extent of that impact. Medical factors such as cancer site have been shown to influence the degree of distress experienced. For example, cancers with significant additional stressors such as limited treatment options, poor prognoses and more physical impairment cause greater distress than those that do not. Although particular stages of cancer appear to significantly heighten levels of distress (e.g., diagnosis, treatment, recurrence and terminal), whether one stage causes greater distress than another is less clear. Demographic variables such as age and race have been shown to impact on distress, with younger, Non-Caucasian individuals experiencing more distress than those who are older or Caucasian. However, the impact of gender on distress levels is less clear, particularly amongst cancer patients. Amongst family members, however, females appear to experience greater levels of distress than male family members. Psychosocial resources which are available, or perceived to be available to people with cancer, and their families, such as social support, and stress appraisal, self efficacy and coping, also play a significant role in the adjustment to cancer. Higher levels of adequate social support, increased belief in one's abilities to cope and the use of problem-focused coping strategies have been found to greatly reduce the impact of cancer.

CHAPTER THREE

Cancer & Psychotherapy

'Turn your face to the sun and the shadows fall behind you'

(Maori Proverb)

The majority of people affected by cancer are able to cope without specific psychological interventions, finding strength in themselves and in close friends and family. However, a small minority, will, at some stage of the disease, show psychological symptoms or signs of distress requiring psychosocial intervention (Bolund, 1990).

3.1 *Psycho-Oncology*

Psychosocial interventions are common in the area of mental health (Roth & Fonagy, 1996) and have been around for a very long time. However, the need for psychosocial intervention for health-related illnesses such as cancer has only been recognised relatively recently. Up until the 1800s, cancer was equated to death. There was no known cause or cure. Often doctors did not inform patients that they had cancer because of the distress it would cause. If patients were told, they were encouraged not to reveal their illness to others because of the stigma attached to it (Holland, 2002). In the early 20th Century, as the treatment of cancer improved with the introduction of surgery, radiation and chemotherapy, so too did the attitudes towards cancer. Post World War II, the American Cancer Society began organising self-help groups for people with cancer, despite scepticism from the medical profession. However, over time, the benefits of social support for this population began to gain credibility. However, it was not until the mid-1970s that the field of psycho-oncology was born (Holland, 2002); finally recognising the specific psychological needs of those living with cancer. Psycho-oncology is considered to be a subspecialty of oncology, dealing with the psychological reactions of individuals with cancer and their families at all stages of disease, as well as the psychological, social and behavioural factors associated with the development of cancer and survival (Holland, 2002).

3.2 *Psycho-Oncology Interventions*

A variety of psychological interventions have been developed over the years to help those with cancer, and their families. These interventions have been broadly categorized into education, cognitive-behavioural training (individual or group), individual supportive therapy and group supportive therapy (Carlson et al., 2004). Although these interventions can be provided in isolation, the needs of people with cancer can vary markedly depending on factors such as cancer type, stage, social support, and coping abilities. Therefore, more often than not, a combination of behavioural, educational and supportive interventions is provided. Psychosocial interventions may be offered formally by health care professionals (e.g., nurses, doctors, social workers, psychologists) or informally by lay persons (e.g., volunteers, cancer survivors). Other interventions may be provided by a variety of self-help groups or cancer support organisations.

3.2.1 *Education*

It was Francis Bacon, in 1597, who said “*scientia potentia est*”, which in modern times has been paraphrased as “knowledge is power”. For those diagnosed with cancer, their world can suddenly become filled with the unknown. Questions may arise regarding prognosis, treatment, side effects, quality of life, and coping. Those diagnosed with cancer, and their families, may also feel a sense of helplessness and loss of control. Interventions which are education-oriented are designed to help reduce the sense of helplessness due to uncertainty and lack of knowledge (Fawzy, Fawzy, Arndt & Pasnau, 1995), replacing it with a sense of mastery and control. Depending on the client’s needs, education may focus on disease and treatment information, information about coping, and/or emotional issues (Fawzy et al., 1995). Studies have shown that receiving educational information can increase knowledge, decrease anxiety, depression, treatment problems and life disruptions (Devine, 2003; Devine & Westlake, 1995; Jacobs, Ross, Walker & Stockdale, 1983; Pruitt et al., 1993).

3.2.2 Cognitive-Behavioural Training

Cognitive-Behavioural Training (CBT) aims to reduce psychological stress and the physical difficulties that people with cancer often experience. CBT involves a variety of cognitive and behavioural techniques such as problem solving, stress management, cognitive restructuring, coping skills training, progressive muscle relaxation and guided imagery (Fawzy et al., 1995). Numerous studies have shown the benefits of individual and group CBT in reducing distress and improving coping amongst individuals with cancer and their families (Baider, Uziely & De-Nour, 1994; Telch & Telch, 1986). CBT has also been shown to be particularly effective in alleviating the biological and psychological effects of chemotherapy (Burish & Lyles, 1981; Lyles, Burish, Krozely & Oldham, 1982; Morrow & Morrell, 1982; Vasterling, Jenkins, Tope, & Burish, 1993). Some studies have shown individual and group CBT to be more effective than individual or group supportive therapy (Bottomley, Hunton, Roberts, Jones & Bradley, 1996; Edelman, Craig & Kidman, 2000; Sherman et al., 2004; Telch & Telch, 1986).

3.2.3 Individual Supportive Therapy

Most of the psychological help available to people with cancer is supportive, non-directive counseling combined with information giving and practical advice and guidance (Moorey et al., 1998). One-to-one counseling, focusing on expressing feelings, reducing denial, dealing with unfinished business and establishing a sense of control over their environment, has been shown to improve quality of life for people with cancer in the terminal stage (Linn, Linn & Harris, 1982).

3.2.4 Group Supportive Therapy

Group supportive therapy is less structured, and often facilitated by non-professionals. Supportive group therapy provides individuals with valuable social support, and the opportunity to adjust to their cancer situation through shared experiences, exchanging information, reducing social isolation and improving interpersonal communication (Bottomley, 1997). Studies have shown that women involved in group supportive therapy experienced reduced tension, fatigue, reduced pain, less depression and fewer maladaptive coping

responses (Cunningham & Tocco, 1989; Spiegel, Bloom, Kraemer & Gottheil, 1989). Supportive group interventions have been found to be of more benefit to individuals with cancer than no treatment.

3.3 Psychotherapy Across the Cancer Continuum

As research has highlighted, the cancer journey is a rollercoaster of physical and emotional challenges. The diagnosis/pre-treatment phase, during and immediately post-treatment, and advanced disease or near death have been reported as being particularly distressing times for patients and loved ones. As such, psychosocial interventions tend to be offered during these particular stages of the cancer continuum (Schneiderman, Antoni, Sabb & Ironson, 2001) and some types of interventions may be particularly beneficial depending on which stage the cancer patient is at (Fawzy, 1999).

Research has shown that providing brief, structured, psycho-educational interventions may be most beneficial during the diagnosis/pre-treatment stage when there is a strong need for information. Fawzy, Fawzy and Canada (2001) found that newly diagnosed malignant melanoma patients who received a psycho-educational intervention showed significantly lower levels of anxiety, depression and general psychological distress at the six month follow-up. Similar benefits of education have been reported by Fawzy, Cousins, Fawzy, Kemeny, Elashov and Morton (1990), and Fawzy, Fawzy and Hyun (1993). Research has also shown that providing educational information at the early stages can lead to greater treatment compliance (Richardson, Shelton, Krailo & Levine, 1990).

Techniques such as relaxation, stress management and cognitive coping have been suggested as being most useful for individuals undergoing extensive treatment such as chemotherapy or radiotherapy (Bottomley, 1997, Fawzy, 1995). Redd, Montgomery and DuHamel (2001) reported that behavioural interventions were effective in controlling anticipatory nausea and vomiting in patients undergoing chemotherapy. They also found behavioural interventions combining a number of different behavioural methods (distraction, modeling,

relaxation, contingency management, and cognitive restructuring) reduced anxiety and distress associated with invasive medical treatments.

For those with more advanced cancer, supportive-based interventions may be more helpful (Bottomley, 1997). Spiegel and Glafkides (1983) found that individuals with advanced breast cancer benefited from open discussions about death and adjustment to metastatic disease. A review by Sherman (2004) revealed that individuals with cancer who participated in supportive therapy had better outcomes than those in the control groups, with respect to emotional distress (Classen et al., 2001; Goodwin, et al., 2001), coping (Spiegel, Bloom & Yalom, 1981) and a sense of purpose in life (De Vries et al., 1997).

3.4 The Efficacy of Psychotherapy

There is a significant amount of literature examining whether psychotherapy interventions are beneficial or efficacious (see Tables 5.1-5.3 in Lambert & Ogles, 2004). *“An intervention has proven efficacy if it is responsible for observed changes in the outcome of interest”* (Manne & Andrykowski, 2006, p.98). To be able to draw conclusions across all the literature, researchers have focussed on results from meta-analyses. Statistical techniques such as meta-analyses are often used to collate and summarise research findings, providing a systematic overview of quantitative research. This type of review is considered to have the advantage of being systematic and objective, thereby reducing bias (Arnqvist & Wooster, 1995). Meta-analysis involves the calculation of effect sizes from studies that have already been published. An effect size indicates the strength of the relationship between two or more variables and allows for direct comparisons of effects across different studies examining the same topic (Tatrow & Montgomery, 2006). The consistent finding across the literature is that, on average, people who receive psychotherapy have better outcomes than those who do not receive psychotherapy (Lambert & Ogles, 2004). Can similar conclusions be drawn with regard to the efficacy of psychological interventions for people with

cancer? A number of meta-analyses have specifically examined the efficacy of a variety of psycho-oncology interventions for individuals with cancer.

Trijsburg, Van Knippenberg and Rijpma (1992) found different interventions to be beneficial for different cancer-related problems. 'Tailored counselling' (counselling and support) contributed to improvements in distress, self-concept, locus of control, fatigue and sexual problems; 'structured counselling' (education and behavioural instructions) showed positive effects in reducing depression and distress, while behavioural interventions and hypnosis alleviated specific symptoms such as anxiety, pain and vomiting.

Meyer and Mark (1995) conducted a meta-analysis on 45 randomised controlled trials (RCTs) which compared a group of adults with cancer receiving psychosocial, behavioural or psycho-educational interventions with a group receiving no psychosocial intervention. They found small to moderate effect sizes for emotional adjustment (.24), functional adjustment (.19), treatment and disease-related symptoms (.26), medical measures (.17), compound and global measures (.28). They concluded that psychosocial interventions did have positive effects on emotional adjustment, functional adjustment, and treatment and disease-related symptoms in adults with cancer.

Devine and Westlake (1995) examined the effects of psycho-educational therapy on psychological wellbeing, physical wellbeing and cancer-related knowledge. Psycho-education was divided into three general categories – education, non-behavioural/non-cognitive counselling, and behavioural/cognitive counselling. Across all types of psycho-education, there were statistically significant beneficial effects for all seven outcome variables – anxiety, depression, mood, nausea, vomiting, pain and knowledge.

Sheard and Maguire (1999) examined the effect of psychological interventions of anxiety and depression in people with cancer and found moderate effect sizes in favour of treatment versus no treatment for anxiety, but not

depression. These effects were greatest when interventions were targeted to those suffering significantly from psychological distress.

Luebbert, Dahme and Hasenbring (2001) examined the benefits of relaxation training on treatment-related symptoms and emotional adjustment in non-surgical patients. Effect sizes were calculated for treatment-related symptoms (nausea, pain, blood pressure, pulse rate) and emotional adjustment (anxiety, depression, hostility, tension, fatigue, confusion, vigor, overall mood). Relaxation training had a significant effect on all treatment-related symptoms and 3 of the 7 emotional adjustment variables (anxiety, depression, hostility). Relaxation was also found to be equally effective for patients undergoing different medical procedures (e.g., chemotherapy, radiotherapy, bone marrow transplantation).

Devine (2003) examined 25 intervention studies to determine the effectiveness of psycho-educational interventions on adults with cancer pain. When analyzed across all studies, a statistically significant beneficial effect on pain was found. Relaxation-based cognitive-behavioural interventions were effective in reducing pain shortly after treatment. However, no conclusions were made regarding their long-term benefits. Education about using pain medication and supportive counseling was also found to have a small to moderate effect on pain reduction.

Rehse and Pukrop (2003) examined 37 studies evaluating the effectiveness of psychosocial interventions on quality of life (QOL). Psychosocial interventions were found to have a positive impact. Variables that influenced the effectiveness of therapy included length of intervention - those longer than 12 weeks were significantly more effective than interventions less than 12 weeks; quality of the therapist-client relationship - better quality relationships (i.e., stability, trust) increased the effectiveness of psychotherapy; and mode of therapy - educational programmes were more beneficial than social support, coping training and psychotherapy.

Osborn, Demoncada and Feuerstein (2006) investigated the effects of CBT and education on depression, anxiety, pain, physical functioning and quality of life in adult cancer survivors. Although CBT was not effective in managing pain or improving physical function, it was effective for the short-term management of anxiety and depression and quality of life. CBT also had long-term effects on quality of life. Education was effective in managing pain for up to eight months. However, it did not have any effect on quality of life.

3.5 *Psychotherapy & Cancer Survival*

Psychosocial factors are believed, by many, to be linked to the development and progression of cancer either directly or indirectly (Doan, Gray & Davis, 1993; Lemon, Edelman & Kidman, 2003), for example, preventive health-related behaviours (e.g., breast exams, pap tests, changes to diet and smoking behaviour), delays in seeking treatment, compliance with treatment regimens, coping behaviour, availability of social support, and family communication. Research has also shown that psychological interventions can have a significantly positive effect on many physical symptoms of cancer such as pain (de Wit et al., 1997) and fatigue (Yates et al., 2005), as well as possible side effects of treatment, for example, nausea (Redd, Montgomery & DuHamel, 2001) and lymphodema (Maguire et al., 1983). More recently, Andersen et al. (2007) conducted a study to examine whether psychological interventions influenced health status (medically rather than subjectively), and to identify the mechanisms by which this might occur. They found that psychological interventions improved health via behavioural change (e.g., lowering symptomatology and increasing functional status) rather than by improving functional immunity.

Some researchers argue that psychosocial interventions can extend the life of people with cancer. Spiegel, Bloom, Kraemer and Gottheil (1989) were among the first to report such a finding, claiming that women in their study with metastatic breast cancer who had received supportive-expressive group psychotherapy lived twice as long as women in the control group. To determine whether differences in medical treatment or differences in cause of

death could explain Spiegel's original findings, Kogon, Biswas, Pearl, Carlson and Spiegel (1997) examined the medical charts of participants in Spiegel's original study. They found no significant differences with regard to cancer treatment between the control and treatment groups. Fawzy and colleagues (1993, 2003) also reported that group CBT reduced the risk of death by seven-fold amongst patients with malignant melanoma, and at 10 years, reduced risk of death by three-fold.

Despite these findings, a large number of studies have failed to replicate Spiegel's results. Goodwin et al. (2001) compared women with metastatic breast cancer who received weekly supportive-expressive group therapy with a control group who received no such intervention. When age and stage at diagnosis, time since first metastases, and treatment variations were taken into account, they found that supportive-expressive group therapy did not prolong survival. A meta-analysis by Smedslund and Ringdal (2004) examining the effects of psychosocial interventions on cancer survival found that neither randomised controlled trials (RCTs) nor non-randomised controlled trials showed an overall treatment effect. Kissane et al. (2004) conducted a clinical trial in which women with early stage breast cancer receiving adjuvant chemotherapy were randomly assigned to either 20 weekly sessions of group therapy and 3 relaxation classes, or to the control group (3 relaxation classes only). They found no difference in mean survival times between the two groups. A systematic review by Chow, Tsao and Harth (2004) also found that across all cancers, there was no statistically significant difference in the overall survival rates at one- and four- years post-diagnosis.

In a recent review, Coyne, Stefanek and Palmer (2007) argued that the survival research conducted to date was fraught with a variety of methodological problems. Concerns raised included failing to have survival as a primary end-point, confounding co-interventions, poor analyses, and failing to use an intention-to-treat methodology. Coyne and colleagues also argued that meta-analyses may not be an appropriate method for summarising and evaluating survival studies, claiming that many researchers had made compromises in order to reach their conclusions (e.g., ignoring confounds,

equating as-treated and intent-to-treat, and accepting variations in follow-up times). Coyne et al. concluded that: *“Given the limitations, there is no reason to assume that psychotherapy promotes survival. The lack of evidence for a mechanism by which psychotherapy should influence survival serves to strengthen this scepticism”* (p. 387).

3.6 Is Psychotherapy as Efficacious as Initially Thought?

The results of the meta-analyses discussed earlier in this chapter indicate that a variety of psychotherapeutic interventions are beneficial for the cancer population. However, recently a number of researchers have argued that psychotherapy may not be as efficacious as past researchers (e.g., Mark & Meyer, 1995) have asserted. Newell, Sanson-Fisher and Savolainen (2002) argue that to date, reviews investigating the efficacy of psychotherapy for patients with cancer have lacked methodological rigour. Examining studies relating to psychosocial, side effect and survival outcomes, they concluded that only tentative recommendations could be made about the effectiveness of psychological therapies for improving cancer patients' outcomes. Lepore and Coyne (2006) reported that the frequent use of a narrative approach in reviewing literature distorted the results by including low quality trials (Moher et al., 1998), unlike the systematic approach which focuses on evidence provided by randomised controlled trials. Of the 36 articles reviewed, Lepore and Coyne (2006) reported that 72% did not select studies using basic methodological criteria (e.g., randomisation), only 25% followed the gold standard of reviewing only RCTs, and only one study reviewed just adequate quality RCTs (i.e., Newell et al., 2002). Lepore and Coyne concluded that there was *“no convincing evidence of broadly effective psychological interventions for reducing a wide range of distress outcomes in cancer patients”* (p. 90).

As reviews become more advanced, researchers claim to be finding weaker evidence for the efficacy of psychosocial interventions to reduce distress in people with cancer. However, Coyne, Lepore and Palmer (2006) argue that even these more advanced reviews may be overly positive in their conclusions

as reviewers continue to accept flawed studies. In an examination of a selection of RCTs from 'top tier' journals, Lepore and colleagues found evidence of confirmatory bias, selective reporting of the most favourable outcome measures, failure to disclose null results and dropping of data from patients least likely to benefit from the interventions. Carlson and Bultz (2004), however, point out *"in the context of these recent reviews, it is useful to consider that a lack of adequate evidence of efficacy does not constitute evidence of lack of efficacy. Objectively considered, research in psychosocial oncology strongly suggests the efficacy of targeted interventions but methodological rigor has been insufficient to reach unequivocal conclusions."* (p. 839).

3.7 RCTs versus Clinical Practice

To date, most of the research examining the beneficial effects of psychotherapy has focused on whether or not psychotherapy is efficacious. These studies have predominantly involved randomised controlled trials (RCTs), as they are generally considered to be the most thorough methodology for evaluating an intervention's efficacy. Randomised controlled trials involve the random allocation of patients into different treatment conditions whilst controlling for factors which are likely to influence outcome (Roth & Fonagy, 1996).

However, many researchers believe RCTs to be the wrong methodology for empirically validating psychotherapy as it is practiced in the field. Some argue that RCTs lack external validity (Howard, Moras, Brill, Martinovich & Lutz, 1996) and do not focus on the types of clients seen, or therapies used in practice (Parloff, 1979; Persons, 1991). Seligman (1995) argues that efficacy studies exclude a number of crucial elements that characterise psychotherapy as it is conducted in the clinical setting. Unlike interventions in efficacy studies, psychotherapy in clinical practice is not of fixed duration. Psychotherapy in the clinic is self-correcting, with therapists choosing alternative techniques if improvements are not observed. Patients often actively seek treatment, choosing their therapist as opposed to being given a clinician and treatment

programme. Patients attending clinics usually have multiple problems not single disorders; and in clinical settings the focus is on improving the patient's general functioning, as well as addressing the specific, presenting symptoms. This is unlike efficacy studies which tend to focus only on the specific disorder/symptoms. Research findings inform clinical guidelines to ensure clinicians 'do the right thing'. However, Roth and Fonagy (1996) state that there is a need to establish "*whether the right thing has been done, whether it has been done right, and whether it resulted in the right outcome*" (p 55).

3.8 The Effectiveness of Psychotherapy

Efficacy studies examine how well psychotherapy works under special, experimental conditions. However, as Bower (2003) reported, "*a demonstration of efficacy within an RCT does not mean that the treatment can be transported directly to routine clinical practice and assumed to have the same effects. Rather, this must be demonstrated, by undertaking systematic research into outcomes based on those routine settings.*" (p.332). In order to assess how therapy works in practice, naturalistic experiments, or effectiveness studies are required (Howard et al., 1996). Effectiveness studies are designed to evaluate how well psychotherapy works in the field. These types of studies place emphasis on external validity, trying to ensure that findings are generalisable to other clinicians, other clinical settings and patient groups. Subjects are not randomly assigned to groups; therefore comparison groups may differ on many variables. Clinical scientists argue that these potential threats to internal validity leave any observed results open to multiple interpretations.

Leichsering (2004) argues that because quasi-experimental studies do not use random assignment, they use other processes to show that alternative explanations of the effect are implausible. These include the identification and study of plausible threats to internal validity, the use of additional design elements or of statistical controls, and pattern matching. Leichsering proposes that the gold standard of effectiveness studies is a prospective quasi-experimental study of '*high clinical representativeness*'. These are

characterised by non-random comparison groups, the matching of groups, clear descriptions of treatments, participants and their selection, the use of reliable and valid diagnostic procedures and outcome measures, the use of additional design elements, coherent pattern matching, the reporting of drop-outs, pre-and post-assessments, follow up studies, and reporting of relevant statistical data.

To date, there has been very little research examining the effectiveness of psychotherapy as it is practiced in the 'real world'. However, a few studies have examined the differences in efficacy and effectiveness studies. Weisz, Weiss and Donenberg (1992) examined four meta-analyses in child and adolescent research. They compared the effect sizes of treatments conducted in research settings with those conducted in clinic settings and found that most clinic studies did not show significant effects. Shadish and colleagues (1997; 2000) conducted two secondary meta-analyses to examine the benefits of therapy conducted in conditions that were representative of clinical conditions. Their first meta-analysis (1997) examined 54 studies from 15 previous meta-analyses that differed in the degree to which they were conducted in clinically representative conditions. They found that the effects for the clinically representative sample were the same as in the original meta-analyses. Their second meta-analysis (2000) included a larger sample of studies (90) along with a number of improvements to their methodology. As found in their earlier meta-analysis, similar effects were found between those studies that were representative of clinical conditions and those that were not, suggesting that psychological therapies were just as effective in clinic settings as they were in research settings.

Seligman (1995) reported several findings based on responses from readers in a consumer report regarding the effectiveness of psychotherapy. People receiving mental health treatment reported benefiting from treatment; longer term therapy was more beneficial than shorter term therapy; there were no differences found between psychotherapy alone or psychotherapy and medication; psychologists, psychiatrists and social workers performed equally well; family doctors performed as well as mental health professionals in the

short term, but worse in the long term; clients who carefully selected therapists and actively participated in therapy did better in treatment; and no specific modality of therapy was more effective than any other mode of treatment. Although Seligman noted a number of methodological flaws in the survey, Lambert and Ogles (2004) argued that it still provided valuable information from an externally valid sample of psychotherapy clients. Similar patterns were observed in a replication study in Germany, suggesting that the data from the US report had more global applications (Hartmann & Zepf, 2003).

Ryan, Nitsun, Gilbert and Mason (2005) conducted a study examining the effectiveness of short-term, focal, integrative psychotherapy provided by health and primary care services for women with psychological difficulties following childhood sexual abuse. Outcomes were also compared based on individual or group therapy. Results showed that both individual and group patients made statistically and clinically significant improvements after treatment, and that the majority of these gains were maintained at follow-up.

Most recently, Beatty and Koczwara (2010) examined the effectiveness of a cognitive behavioural stress management programme for women with breast cancer in a clinical setting in Australia. Clinical changes in distress, coping, and social support were assessed pre- and post-therapy, as well as at a 1-month follow-up. Results showed a clinical improvement over time in PTSD symptoms and social support, but not for cognitive avoidance. Although some clients were reported to have recovered at follow-up, two clients with the greatest initial distress, who had experienced large improvements in depression, anxiety and PTSD at post-treatment, were reported to have returned to baseline levels at follow-up. Qualitatively, clients reported that learning relaxation techniques, cognitive restructuring, and gaining social support were the most beneficial aspects of the programme.

Despite these few studies, there continues to be a lack of research examining whether the benefits of psychotherapy observed in a controlled research setting are replicable in clinical practice.

3.9 Summary

Although the majority of people affected by cancer are able to cope without specific psychological interventions, a minority will at some stage experience distress significant enough to warrant psychosocial intervention. In the 1970s, the field of psycho-oncology was developed, recognising the specific psychological needs of people with cancer, and their families. Many types of interventions have been developed, the most common being education, cognitive behavioural training, individual supportive therapy, and group supportive therapy. A number of meta-analyses have found psychotherapeutic interventions to be efficacious, showing improvement in distress, physical symptoms and quality of life. However, some recent studies have questioned the quality of such meta-analyses, citing a lack of methodological rigour. Some researchers also argue that randomised controlled trials are the wrong methodology for empirically validating psychotherapy as it is practiced in the field stating that they lack external validity, do not focus on the types of clients seen, or therapies used in practice. A small number of studies have looked at the effectiveness of psychotherapy as it is provided in clinical settings, but to date, results have been mixed. More research examining the effectiveness of psychotherapy in clinical practice is needed.

CHAPTER FOUR

Factors Influencing Psychotherapy Outcome

“What treatment, by whom, is most effective for this individual with that specific problem, and under which set of circumstances?”

(Paul, 1967, p. 111)

Psychotherapy research has made significant progress in the last 20 years, with several hundred studies demonstrating the efficacy of numerous types of therapy. Meta-analyses have revealed that on average, 63% of people who receive psychotherapy improve, compared with 38% receiving either placebo or minimal treatment (Hoglund, 1999). However, despite having established that psychotherapy ‘works’, the question *“Why, and how does psychotherapy work?”* still remains unanswered.

4.1 The Great Debate

The reason this question has been difficult to answer is that researchers have been unable to consistently find differences in effectiveness between the different therapeutic interventions (Andersen & Lambert, 1995; Stiles, Shapiro & Elliot, 1986; Wampold et al., 1997). Some experts (e.g., Lambert, 1992; Wampold, 2001) argue that the lack of difference between the different therapies is because the key ingredients in therapeutic change are not the specific techniques used within each therapy, but rather the common (or non-specific) factors that exist across all therapies. Such common factors may include the therapeutic alliance, corrective experiences, insight, opportunity to express emotions, acquisition of a sense of mastery, and therapist qualities such as attention, empathy, and positive regard (Wampold, 2001). While these authors believe that only non-specific factors are of any real importance in producing therapeutic change, many other researchers argue that the specific techniques employed within each psychotherapy approach contribute significantly to the effects of a caring and supportive psychotherapeutic relationship (e.g., Chambless & Ollendick, 2001). These contrasting arguments have led current researchers to look at variables that influence the

effectiveness of psychotherapy. Not everyone responds the same way to psychotherapy, therefore, identifying factors that influence the effectiveness of a therapy intervention will increase clinicians' understanding of why people respond differently to different treatments and help to ensure that people get the most out of treatment (Johansson & Hoglend, 2007).

4.2 Factors Affecting Psychotherapy Effectiveness

In psychotherapy research, the predominant focus has been on providing evidence of the efficacy of interventions, focusing on the client's diagnosis and techniques of therapy. However, Clarkin and Levy (2004) argue that the focus on treatments has meant little attention has been paid to other important factors such as client and therapist variables, and the therapeutic relationship. In everyday clinical practice, these variables must also be considered when providing a treatment intervention (Clarkin & Levy, 2004).

4.2.1 Client Variables

No two clients are the same; each client possesses different characteristics which could potentially influence the therapeutic process and outcome (Clarkin & Levy, 2004). Some studies suggest that client characteristics are better predictors of outcome than the interventions themselves (Ablon & Jones, 1999; Zuroff et al., 2000). Lambert (1992) claimed that client variables and influences outside of therapy could account for as much as 40% of client improvement in psychotherapy. Client variables such as socio-demographic variables (e.g., age, gender, ethnicity), personality variables (e.g., outcome expectancy, self efficacy), interpersonal variables (e.g., interpersonal relatedness), and social support have all been examined in relation to their potential influence on treatment outcome. In the field of psycho-oncology research, the impact of such variables have also been considered and are discussed below.

4.2.1.1 Socio-Demographics

Although client age and gender have been shown to moderate the impact of distress amongst cancer patients, these variables do not appear to influence

treatment outcome (e.g., Baider, Uziely & DeNour, 1994; Johnson, 1982; MacDonald, 1994; Petry, Tennen & Affleck, 2000). Helgeson, Cohen, Shultz, and Yasko (2000) found no association between age, education, income and treatment outcome in individuals with cancer. Studies examining the role of gender in influencing treatment outcome have found results to be weak and contradictory (Baider, Uziely & De-Nour, 1994; Forester, Kornfield, Fleiss & Thompson, 1993). However, a recent meta-analysis by Heron (2009) found that psychological interventions were most beneficial for those who were least likely to use it (e.g., males). Although studies indicate that clients from an ethnic minority attend fewer therapy sessions compared to Caucasian clients (Greenspan & Kulish, 1985), studies have shown that race-related client and therapist variables such as race matching between client and therapist, do not impact on therapy outcome (Jones & Zoppel, 1982). At present, there are no New Zealand data available examining differences in psychotherapy outcome between Maori, Pacific Island and Pakeha clients.

4.2.1.2 Initial Distress

Research has shown that a client's initial level of cancer-related distress influences treatment outcome (i.e., those who experience higher levels of distress benefit more from therapy) (Sheard & Maguire, 1999). Unlike most other studies, Sheard and Maguire screened for baseline distress, including only those with significant levels of distress. They found that screening had a significant impact on outcome. Studies that did not screen for anxiety produced an overall effect size of .33, whereas studies that did, produced an effect size of .93. Similar results were found for depression, with non-screened studies producing an effect size of .16, and screened studies producing an effect size of .85. Classen et al. (2001) and Boesen et al. (2005) also found that patients with greater levels of distress showed greater improvement than those who began treatment with less difficulty. Nezu and colleagues (2003) found large effect sizes for cancer patients with significant levels of distress. These findings were confirmed most recently in a meta-analysis by Schneider et al. (2010). Pre-intervention distress levels were found to significantly moderate intervention effects. When pre-intervention distress levels were low, interventions had very little effect on anxiety and depression. However, when

initial distress levels were high, interventions had a significant impact on anxiety and depression. These findings occurred irrespective of variations in intervention type, setting, dose, and whether interventions were specifically for distressed patients. Overall, the findings from these studies suggest that interventions should be specifically targeted at those at risk, or with high levels of psychological distress.

4.2.1.3 Personality Factors

Outcome Expectancy

Expectations can regularly shape our experiences and perceptions (Greenberg, Constantino & Bruce, 2006). Therefore, it is possible that expectations individuals have about whether they are likely to benefit from psychotherapy may influence how successful the treatment will be (Lambert, 1992; Noble, Douglas & Newman, 2001). Psycho-oncology studies have shown that this is indeed the case. Cunningham, Lockwood and Edmonds (1993) and Graves and Carter (2005) found that people with cancer who had different expectations about therapy, experienced different quality-of-life outcomes. The majority of studies in a review by Dew and Bickman (2005) showed that outcome expectancies were significantly related to outcomes, particularly when client improvement (i.e., decrease in distress) was the outcome of interest (Borkovec & Costello, 1993; Meyer et al., 2002; Safren et al., 1997; Sotsky et al., 1991).

Recently, Kerry (2009) conducted a study examining clients' pre-treatment expectations of psychotherapy. Results indicated that clients had specific expectations about their therapist, as well as their role as the client. Clients also had expectations about the structure of therapy (e.g., frequency and number of sessions), disclosed expectations for in-session tasks and therapy outcomes. Clients also reported how their respective sources of knowledge had informed their expectations for therapy. When a client dealing with cancer has positive outcome expectancies, they may have a greater sense of hope that they will improve. However, they may have negative outcome expectations such as adverse thoughts about the future, consequences of treatment and/or illness; negative ideas concerning body image and sexuality;

and pessimistic attitudes about returning to work, which reduces their sense of hope (Graves, 2001). Interventions that focus on restructuring these negative self-statements are reported to help clients alter their unrealistic and negative outcome expectations (Graves, 2003), leading to improvements in functioning (Moorey & Greer 1989).

Self Efficacy

As discussed earlier, self efficacy is an individual's belief in their ability to successfully achieve a particular goal. Because self efficacy can be learned, psychotherapy interventions have been designed to increase self efficacy and to enhance psychological adjustment (Lev et al., 2001), by providing people with cancer with information, and teaching and providing feedback on the use of positive coping strategies (Graves, 2003). Studies have shown that psychological interventions which focus on enhancing an individual's self efficacy and sense of control have more positive outcomes. Cunningham, Lockwood and Edmonds (1991) found a strong positive correlation between self efficacy and quality of life. Lev, Paul and Owen (1999) found that without intervention, a cancer patient's perception of self efficacy and adjustment decreased significantly over time and that self efficacy significantly influenced patients' quality of life. Scheier et al. (2005) found that interventions primarily benefited women by enhancing their self efficacy expectations, reducing some of their cancer concerns, reducing intrusive thoughts about the illness, and by buffering their self-concept perceptions. Graves (2003) conducted a study to examine whether interventions with a greater number of Social Cognitive Theory (SCT) components (i.e., self efficacy, self-regulation) resulted in better quality of life outcomes in people with cancer than interventions with limited or no SCT components. Significantly large effect sizes were observed in interventions that had more SCT components, suggesting that using SCT-based interventions maximizes improvement in quality of life for people with cancer.

4.2.1.4 Social Support

Social support has been found to be a strong variable in treatment outcome (Clarkin & Levy, 2004) with a number of studies showing that the provision of

adequate social support improves client outcome (Longabaugh, Beattie, Noel, Stout & Malloy, 1993; Moos, 1990). For people with cancer, and their families, psychological interventions can provide emotional, informational and instructional support. For those who have limited support from friends and family, therapy can provide an opportunity to share worries and fears. Communication problems within families of cancer patients are common (Lichter, 1989). Therefore, therapy may help to facilitate improved communication between the patient and family members, so that greater levels of emotional support can be provided within the family.

Badger, Braden, Longman and Mischel (1999) found that women with cancer who participated in a telephone interpersonal counselling programme showed significantly more improvement over time in the quality of their interpersonal relationships than those in the control group. Therapy may also reduce feelings of isolation by encouraging people to activate their own support systems (Dimsdale et al., 1979), or referring them to various cancer support groups or community resources. Social support groups have been shown to provide people with cancer with the opportunity to share experiences, exchange information, reduce social isolation and improve interpersonal communication (Bottomley, 1997). A client's subjective sense of support has also been shown to be particularly important. That clients are aware that psychological support is available if they need it may, in itself, serve to reduce feelings of distress.

Although many interventions have been designed to improve social support for those who are lacking in it, there is no agreement as to which form of intervention is the most effective, or whether social support interventions actually improve support (Hogan, Linden & Najarian, 2002). For example, in a review by Sherman et al. (1994), only three out of ten studies examining the benefits of social support for cancer patients reported improvement in various aspects of social support (Esplen et al., 2000; Helgeson et al., 1999; Richardson et al., 1997).

As most social support interventions typically involve a mixture of emotional, informational, and/or instrumental support, it can be difficult to examine the unique contribution of support provided by professionals (Hogan, Linden & Najarian, 2002). Helgeson, Cohen, Shultz, and Yasko (2000) found that women with cancer who had limited social support and fewer personal resources benefited the most from educational groups compared to women with greater social support and personal resources. Peer discussion groups were also helpful for women who lacked social support, however, were harmful for those with high levels of support. Similarly, Manne and colleagues (2005) found that a group intervention was more beneficial for women with cancer who rated their partners as unsupportive prior to the intervention, than women who rated their partners as supportive. These studies are consistent with other research findings (e.g., Sheard & Maguire, 1999; Classen et al., 2001; Boesen et al., 2005; Schneider et al., 2010) demonstrating that interventions are most effective when they are specifically provided to those most in need.

4.2.1.5 Coping Styles

The implementation of different coping styles can also influence the way clients respond to different treatments (Beutler et al., 2004). Fawzy et al. (1990) evaluated the effects of a 6-week structured intervention (education, problem-solving skills, stress management and psychological support) on psychological distress and coping methods in people with cancer. After 6 weeks, the intervention group showed greater use of active-behavioral coping than the control group, and at the 6-month follow-up, the intervention group was using significantly more active-behavioral and active-cognitive coping than the control group. Fawzy (1995) reported that positive changes in self-appraisal, increases in personal resources and active (e.g., behavioural/cognitive) rather than passive approaches can improve one's ability to cope with stressors. Therefore, psychological interventions for cancer patients that focus on promoting 'active coping' may be beneficial.

4.2.2 Therapist Variables

When psychotherapy research was in its infancy, therapist variables were considered to be very important for gaining an understanding of treatment

outcomes. However, in the past 20 years there has been a shift in focus from examining specific therapist characteristics to effects of treatment on outcome (Bergin, 1997; Beutler, 1997). Meta-analyses that have examined therapist trait characteristics such as age, sex and race have found very small effect sizes, indicating that they are poor predictors of outcome (e.g., Beutler et al., 2004; Bowman, Scogin, Floyd & McKendree-Smith, 2001). The influence therapist factors such as type of training and experience have on treatment outcome have also been examined. Although some studies have suggested that more experienced therapists can produce greater reductions in anxiety and depression amongst those living with cancer (e.g., Sheard & Maguire, 1999), overall, studies have also found that therapist training, skill, experience and style contribute little to outcome (Bowman et al., 2001; Shapiro & Shapiro, 1982; Sherman et al., 1994).

4.2.3 The Client-Therapist Relationship (Therapeutic Alliance)

The therapeutic alliance refers to the collaborative nature of the client-therapist relationship, their agreement on goals and tasks and the bond that develops during therapy (Kazdin, 2007). Within the psychotherapy literature, the therapeutic relationship is considered to play a central role in intervention effectiveness (Brent & Kolko, 1998; Horvath & Symonds, 1991). A positive therapeutic relationship has been thought to increase a client's involvement and investment in an intervention and therefore, may increase the chances that specific intervention techniques will be effective (Addis, Wade & Hatgis, 1999). Research examining the therapeutic alliance has covered a wide range of interventions including behavioural (DeRubeis & Feeley, 1990), cognitive (Rounsaville et al., 1987), gestalt (Horvath & Greenberg, 1989), and psychodynamic (Saunders, Howard & Orlinsky, 1989).

Unfortunately there has been limited research examining the effect of the therapeutic relationship in the context of individuals with cancer. However, a systematic review by Schnur and Montgomery (2010) examining the role of therapeutic alliance in therapy outcome amongst people with cancer, continued to provide support for the benefits of a positive client-therapist relationship on treatment outcome. Frank (1961, in Lambert 2004) considered

the client's confidence in their therapist and treatment to be the critical determinant of outcome. In a qualitative study, Littauer, Sexton and Wynn (2005) asked clients which therapist qualities they felt were most important with regard to the therapist-client alliance. Qualities given highest priority were: the therapist behaving in a confidence-inspiring and calming manner; having a plan for therapy; being accepting and understanding; and being able to listen and be attentive as well as question and comment. Another qualitative study by MacCormack et al. (2001) investigated cancer patients' experiences of psychotherapy and found that most important to them was the opportunity to enter into a relationship with a therapist whom they could safely share their thoughts and feelings with, someone who seemed genuinely interested in understanding their cancer experience.

4.2.4 Therapy Variables

4.2.4.1 Therapy Type

A wide variety of interventions have been found to be effective in improving psychological adjustment to cancer. As discussed earlier, whether these types of intervention differ in terms of their effectiveness has been an ongoing debate. Despite studies showing variations in treatment effectiveness, Lambert and Ogles (2004) argue that there continues to be little consistent evidence that one type of psychotherapy has clinically significant superiority over another. Although limited, psycho-oncology research has provided results consistent with this view. Devine and Westlake (1995) conducted a meta-analysis and found that all types of therapies produced moderate to large effect sizes (Cohen's $d = 0.4-.74$), concluding that one type of therapy was just as effective as the other.

4.2.4.2 Therapy Delivery

In the general psychotherapy literature, studies have shown that a significant proportion of clients demonstrate significant improvements within the first 10 sessions, and that this continues to increase as therapy sessions increase. Although limited, psycho-oncology studies have also shown similar findings. In a meta-analysis, Rehse and Pukrop (2003) found that duration of therapy was a significant factor in treatment outcome, with interventions longer than 12

weeks being significantly more effective than interventions of shorter duration. Cunningham, Edmonds, Jenkins and Lockwood (1995) also found a 6-week group therapy programme to be more effective in reducing distress than a weekend version. However, this was not maintained at follow-up.

Luebbert, Dahme, and Hasenbring (2001) examined intervention intensity as a potential factor influencing treatment outcome. Results revealed a benefit for low intensity interventions compared to high intensity interventions (i.e., relaxation training of less than 2 hours tended to have a higher average effect on anxiety than relaxation sessions greater than 2 hours). Shapiro et al. (1994) found that when patient impairment was relatively high, longer-term treatment was most effective. However, when impairment was low, the intensity of treatment had no significant effect on outcome. Meta-analyses have provided varying results regarding the influence of treatment format on outcome. Systematic reviews by Sheard and Maguire (1999) and Ross, Boesen, Dalton and Johansen (2002) have indicated that the effect sizes for both group- and individually-delivered interventions are similar. However, not all studies have found similar results. Graves (2003) found that group treatments had larger effect sizes than individual treatments; whereas Tatrow and Montgomery (2006) found that clients were significantly better off with individual therapy formats.

4.3 Assessing Psychotherapeutic Change

Many methods for assessing psychotherapeutic change in clients have been developed over the past few decades. However, in current psychotherapy literature, the most commonly used approach has been quantitative (Klein & Elliot, 2006). Although this type of research provides valuable information, it has been argued that by relying purely on quantitative methods, a complete picture of psychotherapeutic change cannot be obtained (Gordon, 2000). Klein and Elliott (2006) claim that valuable contributions toward understanding psychotherapy change can be gained from both quantitative and qualitative methods. Kazdin (2007) suggests that qualitative research can gather a rich and detailed account of the therapeutic process, including who changed, how change occurred, and identifying who did not change and why.

Up until recently, there has been relatively little investigation into clients' experiences of therapy in general (Paulson, Everall & Stuart, 2001). However, there is growing awareness of the importance of obtaining clients' perspectives of therapy (McLeod, 1990; Howe, 1993). Clients' perceptions provide a valuable and unique contribution to understanding the therapeutic process, particularly as they often differ from the therapists' perceptions (Bachelor, 1991; Elliott & James, 1989). From the cancer patient's point of view, being in an environment with someone who is supportive and understanding has been reported as being the most crucial factor for a good outcome (MacCormack et al., 2001). Therapists, however, have been reported to attribute success more to technique (Feifel & Eels, 1963).

Studies that have been conducted have shown that cancer patients' perceptions of counselling services are generally very positive. In a study by Ohlen, Holm, Karlsson and Ahlberg (2005), the majority (84%) of patients with cancer felt that the counselling service met their expectations. Many reported improved understanding of their own reactions and feelings, experienced a distancing from their cancer, had increased pleasure in life and more ability to take action, and were less frightened. Boulton et al. (2001) reported that a significant proportion of clients with cancer (90%) in their study felt that counselling had been beneficial for their emotional wellbeing. Counselling had allowed clients to work through their thoughts and feelings, to come to terms with their cancer, and regain a sense of control in their lives.

However, not all aspects of therapy have been reported as being beneficial. Paulson, Everall and Stuart (2001) found that not all aspects of therapy are reported as being beneficial. They conducted a qualitative study examining clients' perceptions of experiences which they believed hindered therapy. Three core aspects of therapy that clients identified were: counsellor behaviour, external and structural barriers, and client variables. For example, negative counsellor behaviours, insufficient direction, and lack of responsiveness were considered to be impacting negatively on therapy. External barriers to feeling understood included perceptions of a power differential; and cultural, age and religious differences. Internal barriers

identified by clients as impacting on therapy were their own lack of readiness and low motivation.

Despite progress within psychotherapy research, there is still a great need for researchers to examine factors responsible for therapeutic change (Kazdin, 2007). In addition to client and therapist variables, many psychosocial interventions in clinical settings incorporate components of psycho-education, relaxation training, cognitive-behavioural techniques, and social support (Compas et al., 1998), making it very difficult to determine which aspects of therapy contribute to improved patient outcomes (Owen, Klapow, Hicken & Tucker, 2001). Ongoing research in this area will hopefully continue to shed light on just how psychotherapy works and which key factors contribute to a positive therapeutic outcome.

4.4 Summary

Although numerous studies have established that psychotherapy works and is more beneficial to those who receive it than those who don't, the question still remains – why and how does it work? Due to the difficulties in identifying consistent differences in outcome across a wide range of therapies, two contrasting arguments have emerged regarding which aspects of therapy are most responsible for therapeutic change. This has led current researchers to look at potential variables that may influence the effectiveness of psychotherapy. In the psychotherapy literature, potential factors that have been given consideration have been client variables, therapist variables, and client-therapist relationship variables. Within the field of psycho-oncology, a number of studies have examined factors such as mode of treatment, therapist factors, demographic and medical factors, personal and social factors, self efficacy, outcome expectancy, coping, and social support. Although determining whether a variable has an influence on treatment outcome is typically conducted quantitatively, qualitative methods have also been considered important. Researchers are becoming increasingly aware of the importance of gathering information about the psychotherapy process from the client's perspective. Despite psychotherapy research having made some

progress in outcome research, there is still a great need to study the factors responsible for therapeutic change in the field of psycho-oncology.

CHAPTER FIVE

Rationale & Methodology

5.1 *Rationale*

Psycho-oncology research is still in its infancy compared to other areas of psychological research. There remain many unanswered questions regarding the psychological impact of cancer on patients and their families, and more so, the ability of psychological interventions to reduce this impact. Given the increasing numbers of those affected by cancer worldwide, it is crucial that attempts are made to answer many of these questions. The current study hopes to make a valuable contribution, not only to the current psycho-oncology literature as a whole, but also more specifically to cancer-related research within New Zealand. Specific rationales for the current study are outlined below.

A large proportion of the psycho-oncology literature to date has focused on the impact of cancer on the patient. However, research examining the impact of cancer on family members is relatively sparse. Research that has been conducted has revealed that the diagnosis and treatment of cancer has just as much impact on the family as it does on the cancer patient (Compas et al., 1999; Northouse & Stetz, 1989). Like patients, families can differ in their ability to cope with the impact of a cancer diagnosis (Cassileth et al., 1985). Therefore, this study will provide further valuable information regarding the impact of cancer on family members/whanau.

Researchers have repeatedly stressed the need for rigorous, evidence-based evaluations of psychotherapeutic interventions. Randomised controlled trials (RCT) are generally considered to be the most thorough methodology for evaluating an intervention's effectiveness. However, many researchers believe RCTs to be the wrong methodology for empirically validating psychotherapy as it is practiced in the field (e.g., Fensterheim & Raw, 1996; Persons & Silbershatz, 1998; Seligman, 1995). It is argued that RCTs lack ecological validity (Howard et al., 1996) and do not focus on the types of clients seen, or

therapies used in practice (Parloff, 1979; Persons, 1991). Conducting quasi-experimental studies, however, enables the assessment of how therapy works in practice (Howard et al., 1996). This study will gather valuable information regarding the effectiveness of psycho-oncology interventions as they are conducted in clinical practice.

The debate about the efficacy of psychotherapeutic interventions in alleviating psychological distress in people with cancer continues (Coyne, Lepore & Palmer, 2006). One of the main contributory factors for this is that researchers have not yet been able to consistently identify the key factors responsible for the positive outcomes observed following treatment. It is argued that to understand the relationship between treatment and outcome, it is crucial to examine factors which can influence outcome (Shadish & Sweeney, 1991). This study will attempt to address this issue by examining the factors influencing the effectiveness of the interventions provided by a psycho-oncology service. Although the majority of research in this area has predominantly been quantitative, many researchers (e.g., Howe, 1993; McLeod, 1990) have highlighted that obtaining clients' perceptions of their psychotherapy experience is an important way of gathering this information. Therefore, this study will seek to obtain valuable qualitative information with regard to the interventions provided by a psycho-oncology service.

In 2003, the New Zealand Cancer Control Strategy (Ministry of Health, 2003) recognised that psychosocial support was a crucial element in delivering quality cancer care to patients and their families. In 2006, Surgenor, Costello and McKellow conducted a national stocktake of psychosocial cancer services in New Zealand for the Ministry of Health. They found that while there was wide provision of general emotional, cultural and complementary support services, there was a lack of specialist psychological and mental health support. The need for supportive care for people with cancer has more recently been acknowledged, with the Ministry putting forth "*Guidance for Improving Supportive Care of Adults with Cancer in New Zealand*" (Ministry of Health, 2010). However, despite this growing recognition of the importance of psychosocial support in New Zealand, the majority of research examining the

effectiveness of psychotherapy in alleviating psychological distress in people with cancer has been internationally based. To the author's knowledge, only one study examining cancer patients' needs and experiences of supportive health care services in New Zealand has been published (Walton, Reeve, Brown & Farquhar, 2010). Therefore, in keeping with the goals of the New Zealand Cancer Control Strategy and the more recent clinical guidelines, this research will provide much needed New Zealand evidence-based research regarding improving quality of life for those with cancer, their family and whanau.

In 2006, with funding from the MidCentral District Health Board, the Massey University School of Psychology began delivery of New Zealand's first integrated psycho-oncology service. The psycho-oncology service is a specialised psychological intervention service for people with cancer and their family/whanau experiencing significant distress. The service works in conjunction with other psycho-social services (e.g., social workers, specialist and oncology nurses, chaplains, the New Zealand Cancer Society, and the Child Cancer Foundation). Clients living in the MidCentral DHB catchment are referred to the psycho-oncology service from the Regional Cancer Treatment Service. However, cancer patients and their families from other DHBs which are serviced by the RCTS are able to access the psycho-oncology service if they have been referred to Palmerston North for medical treatment (e.g., radiation therapy). Clients can receive individual, group and/or family sessions that can be accessed from a variety of locations, including the university psychology clinic, local hospital, and in the community. The service receives clinical contributions from four qualified and registered clinical psychologists drawn from a pool of psychologists at the university psychology clinic, two of whom are solely contracted to the service. The aims of the service are to improve clients' quality of life by reducing distress, assisting with coping strategies, improving adjustment, and promoting active choice and participation in treatment. Intervention strategies implemented by therapists include Cognitive Behavioural Therapy (CBT), supportive and expressive therapies, behavioural techniques (e.g., relaxation), training in problem-solving,

assertiveness, and coping. Some demographic information regarding service use is outlined in Table 1.

Table 1: Psycho-Oncology Service Demographics (2006-2010)

Ethnicity				Gender		Client	
NZ European	NZ Maori	Non NZ European	Pacific Islander	Male	Female	Patient	Family Member
81%	12%	5%	2%	37%	63%	72%	28%

While this service is based on international research and guidelines, much of this has not been tested with the New Zealand population. As a result, the present research study will examine the effectiveness of the interventions provided by the service; and to investigate whether the psycho-oncology service achieves its aim of improving quality of life for those affected by cancer in New Zealand. The results of this study will also provide information that can be used by other DHBs in the implementation of similar services throughout the country.

5.2 Methodology

5.2.1 Aims

- To assess the effectiveness of the interventions provided by a psycho-oncology service in reducing distress levels and improving quality of life in those affected by cancer
- To investigate clients' experiences of cancer and their perceptions of the psycho-oncology service
- To identify factors which influence the effectiveness of interventions provided by the psycho-oncology service

5.2.2 Objectives

The objectives of the study were:

- To determine the impact of psycho-oncology interventions on clients' levels of psychological distress by comparing them with those who have not received interventions from a specialist psycho-oncology service, at initial assessment, end of therapy and at follow-up.

- To explore clients' experience of their cancer journey, including the impact of the cancer diagnosis, most difficult aspects, distress management, coping strategies, and social support.
- To examine clients' perceptions of the psychological support they received from the psycho-oncology service.
- To explore possible factors influencing the effectiveness of the interventions provided by the psycho-oncology service.

5.2.3 Consultation

5.2.3.1 *Waikato District Health Board & Regional Cancer Centre*

Due to the nature of this study, it was not appropriate to randomise participants. Therefore, it was necessary to find a sample of cancer patients/families that did not have access to a psycho-oncology service, to enable a comparison with those who did have access. The Waikato District Health Board was approached with regard to providing a control group for the study. Extensive communication also took place with staff at the Regional Cancer Centre, within the Oncology Department at Waikato Hospital. A research assistant was employed, funded by the study, to help one other oncology staff member with the identification of potential study participants from the hospital database. Regular consultation was held with members of the Regional Cancer Centre prior to each mail-out to ensure that any study participants who had died were not contacted.

5.2.3.2 *Maori Kaumatua*

Discussions with Maori were undertaken in the development of the research. There was regular consultation with a Maori senior clinical psychologist, who had extensive links with Maori within the community, regarding terminology used in the measures. The research team also consulted with the local Kaumatua at each location regarding the research. The feedback from Kaumatua in both study locations was positive, and their full support was offered. As a result of the consultation, some additional questions were included in the demographic section.

5.2.4 Ethical Approval & Considerations

Ethical approval for this study was granted by the Multi-Region Ethics Committee. All potential participants received a written explanation of the study and were given the opportunity to discuss the study with the researchers if they wished. Written consent was obtained prior to entering the study. Anyone not wishing to participate was assured that their normal care would not be affected in any way. Complete confidentiality of all information was assured. If they wished to discuss any emotional issues raised during the interview or questionnaire, the researcher provided them with the contact details of the psycho-oncology service and Cancer Society. Participants were also told that they could end their participation in the study at any stage.

5.2.5 Study Design

Due to the nature of the psycho-oncology service, it was not considered appropriate to conduct a randomised controlled trial. The service is contracted to provide psychological support for people distressed by cancer. Therefore, it was not considered appropriate to deny some clients access to the service for research purposes. Also, research indicates that RCTs (i.e., randomising participants into treatment and non-treatment groups) may not be an appropriate method for empirically validating psychotherapy as it is practiced in the field. Therefore, this study used a mixed-method design. The first phase used a non-equivalent, two group (treatment, control) pre-post experimental design; the second phase involved conducting qualitative interviews. The quantitative research involved using standardised measures to obtain quantitative data from cancer patients and family members who received psychological support from the psycho-oncology service and comparing it with patients and families members who received standard care in a setting without a psycho-oncology service. Intervention group data from the quantitative phase of the study was then used to inform the selection of participants for qualitative interviews. The qualitative research involved using semi-structured interviews with a small sample of cancer patients and family members who received psychological support from the psycho-oncology service.

5.2.6 Phase 1

5.2.6.1 Sample

The intervention group consisted of people who had been diagnosed with cancer, and family members of those who had been diagnosed with cancer, who had received psychological interventions from the psycho-oncology service. The control group included people who had been diagnosed with cancer, and family members, who had received standard care in a setting without a psycho-oncology service. Both groups received similar medical care i.e., standard protocols for cancer treatment throughout New Zealand. However, they differed in that the control group did not have access to funded specialist psycho-oncology interventions, and for any psychological support that was required, the patients and/or family members would have had to seek this out and fund it themselves.

The sample size for this study was estimated based on the intervention and control groups having a mean difference of 5 (SD = 7) on the main outcome measure (Outcome Rating Scale; Miller & Duncan, 2000, see Appendix D). This mean difference was based on the Reliable Change Index (RCI). It was calculated that to achieve an effect size of .8, a minimum sample size of 22 participants in each arm would be required. Based on a recent study by Baken, Woolley and Kent (2008), a response rate of approximately 40-50% for each mail-out was anticipated. The current study had three mail-outs over a five month period. Therefore, it was expected that by the end of the data collection period, a high percentage of the original sample would have dropped out. To ensure that there remained a sufficient sample size at the end of the data collection period, it was estimated that 600 invitations would need to be distributed to the control group population.

5.2.6.2 Participant Recruitment

The intervention group were recruited from within the psycho-oncology service. The psycho-oncology service administrator identified from the service database, all eligible clients who met the inclusion criteria for the study. Three months following the cessation of therapy, the administrator sent each eligible client a letter inviting them to participate, as well as a study pack containing an

information sheet, consent form, demographics form, outcome measures, Client Satisfaction Questionnaire - 8 (CSQ-8, Attkisson & Zwick, 1982) and additional satisfaction questions (see Appendices A-F). Those who wished to take part in the study completed the forms and returned them to the researcher.

The control group were recruited from the Regional Cancer Centre (Oncology Department, Waikato Hospital). A research assistant and one hospital staff member identified all eligible clients from the database who met the inclusion criteria. Potential participants were initially sent an invitation letter from the Regional Cancer Centre (see Appendix G) on behalf of the researcher, informing them about the research project, as well as a study pack for themselves, and one for a family member or support person (see Appendices C & H-K). Those who wished to take part in the study completed the forms and returned them to the researcher.

5.2.6.3 Inclusion Criteria

For potential participants to be eligible to participate in the study they had to be a patient or family member of someone diagnosed with cancer, they had to have been informed of the diagnosis, and be over 18 years of age. For the intervention group, participants also had to have had two or more sessions with the psychologist and completed measures on at least two occasions (to enable before and after comparisons). To reflect the type of clients seen in the psycho-oncology service, the inclusion criteria were not limited by cancer type, stage or other demographic variables. Similarly, both patient and family member data were included as this reflected the nature of the clients seen.

5.2.6.4 Exclusion Criteria

Intervention group participants were excluded from the study if the clinical psychologist felt that the client was too unwell, or too cognitively impaired. It was not possible to determine the cognitive functioning of potential participants for the control group. The decision of whether potential control group participants were well enough to be sent a study pack was based on a

recruitment procedure designed by the Regional Cancer Centre (see Appendix L).

5.2.6.5 Procedure

Intervention Group

As part of standard practice of the psycho-oncology service, clients complete the very brief Outcome Rating Scale (Miller & Duncan, 2000), Distress Thermometer (Roth et al., 1998), Impact Thermometer (Akizuki, Yamawaki, Akechi, Nakano & Uchitomi, 2005), Coping Thermometer, and the Target Issues and Health questions at the beginning of each therapy session. However, at times the psychologist may decide that it is not in the best interests of the client to complete the measures during the first session. This includes if clients are perceived to be too distressed or too ill, there are cultural reasons, or the belief that completing the questionnaire may negatively impact on developing rapport. In these situations, the clients are asked to complete the outcome measures at their second session. Three months after therapy ended, clients were recruited into the study. Participants gave written consent for the researcher to obtain a copy of the outcome measures completed during therapy that were on their clinical file. These outcome measures, along with those completed at the time of study recruitment, were scored and entered into the computer for data analysis. Clients also gave consent for the researcher to access their referral letter to identify what led them to seek support and obtain service information from the cover of their file (e.g., no. of sessions). The researcher did not have access to session notes.

Control Group

Participants who chose to take part in the study completed and returned the study pack they received at the time of recruitment (Time 1). Participants were then sent the outcome measures and some additional demographics questions (see Appendix J) a second time, in line with the average course of therapy for the intervention group. From information provided by the psycho-oncology service, this was calculated to be approximately 2 months (Time 2). At the 3-month follow-up, those who completed the second mail-out were sent a third

and final mail-out (demographics (see Appendix J) and outcome measures) (Time 3).

5.2.6.6 Measures

The effectiveness of psychotherapy in improving quality of life has been well documented (Meyer & Mark, 1995; Rehse & Pukrop, 2003). However, the majority of studies rely on multiple assessment measures which, whilst providing valid and reliable outcome results, are often lengthy and complex. Studies have shown that the use of such assessment measures is often not practical in a clinical setting (Miller & Duncan, 2000; Brown, Dreis & Nace, 1999). This research attempted to resolve this issue by using a number of brief validated measures to investigate the effectiveness of the psycho-oncology service interventions. During therapy sessions, outcome measures were estimated to take 2-3 minutes to complete. It was estimated that it would take approximately 5-10 minutes for participants to complete their study pack. The majority of outcome measures administered in this study (except the CSQ-8 and demographic information) were chosen during the development of the psycho-oncology service, as a research component was part of the service delivery contract.

Outcome Rating Scale (ORS)

The Outcome Rating Scale (see Appendix D) is a 4-item visual analogue scale designed for use by clinicians to assess change in clients following psychological intervention (Miller & Duncan, 2000). Clients are asked to mark on a 10cm rule, how they feel they have been doing in the last week including the present day, in four different areas of their life: individual, interpersonal, social, and overall. Marks to the left represent lower levels; marks to the right represent higher levels. The distance to each mark, on each of the four items, are measured with a ruler to the millimetre and totalled to provide an overall score (maximum score of 40). ORS items were scored by the researcher. However, to ensure reliability of item measurement, a large random sample of ORS ($n = 98$) were also scored by a second independent rater. Inter-rater reliability (intra-class correlation coefficient) was found to be significant, $F(97, 97) = 11, p = .000$.

The psychometric properties of the Outcome Rating Scale have been examined in a number of studies. Miller, Duncan, Brown, Sparks and Claud (2003) reported internal consistency reliability (0.93) for an overall ORS score as well as for subscale scores. Concurrent validity (.58) between the ORS and Outcome Questionnaire-45 (OQ-45, Lambert, Hansen, et al., 1996) was calculated using Pearson's product moment correlations (Cohen & Cohen, 1983). Test-retest reliability between the first and second session was .66. A similar study by Miller, Duncan, Brown, Sorrell and Chalk (2004) found test-retest reliability to be .53. These lower test-retest scores are reported to be expected in measures sensitive to small changes over time (e.g., ORS and OQ-45, Miller et al., 2003; Vermeersch, Lambert & Burlingame, 2000). Miller et al. (2003) found the ORS to be sensitive to changes over time, distinguishing between the clinical and non-clinical sample. The mean ORS score at baseline for the clinical sample was 19.6 (SD = 8.7), and 25.7 (SD = 8.7) post intervention ($p < .00001$). For the non-clinical sample, the mean score at baseline was 27.9 (SD = 6.8) and 29.4 (SD = 7.0) post intervention ($p > .1$).

A clinical 'cut off' indicates the boundary between a normal and clinical range of distress (Jacobsen & Traux, 1991). To calculate a clinical cut-off for the Outcome Rating Scale, Miller and colleagues used a method described by Jacobsen and Traux (1991) in which a large sample was used (34,790). Based on this method, Miller and colleagues obtained a clinical cut-off of 25 on the Outcome Rating Scale, with scores of 25 and above indicating the non-clinical range.

An increase in ORS scores over time would suggest treatment has been effective. However, in order to determine whether change in scores can be attributed to therapy, and not other external factors (e.g., natural changes over time, measurement error), the difference between scores must exceed a statistical index called the Reliable Change Index (RCI). When a change in score exceeds both the RCI and crosses the clinical cut-off, this change is considered to be 'clinically significant' (Jacobsen & Traux, 1991). Miller et al. (2003) reported an internal consistency coefficient of .93 which resulted in a

RCI of 5. In a larger study, alpha coefficients of .79 and .78 were calculated, resulting in RCIs of 6.7 and 6.8 respectively (Miller, Duncan, Brown, Sorrell & Chalk, 2004). In the current study, the RCI was calculated to be 5, similar to that of Miller et al. (2003). However, given the small sample size of the current study, it was decided that an RCI of 7 would also be used as a more stringent criteria.

Wairua

A measure of wairua (spiritual health) was included in the study following consultation with a Maori clinical psychologist (see Appendix D). Other elements of the Te Whare Tapa Wha Maori model of health (Durie, 1985), for example, physical (tinana), family (whanau) and mental (hinengaro) aspects of health, were already included in the outcome measures. In keeping with the format of the Outcome Rating Scale, the wairua measure asked participants to indicate with a mark on a 10cm rule, where they felt their wairua was over the previous week (including that day). Marks to the left indicated lower levels of wairua, marks to the right indicated higher levels. As many participants may have been unfamiliar with the term wairua, in discussion with the Maori clinical psychologist, alternative English words or phrases were included that conveyed a similar meaning (e.g., 'sense of meaning', 'purpose', 'belief', and 'spiritual wellbeing').

Distress Thermometer (DT)

The Distress Thermometer (see Appendix D) is a widely used screening tool for detecting psychological distress in people with cancer (Roth et al., 1998), and more recently it has also been found to be a valid measure for screening for distress in the family members of people with cancer (Zwahlen, Hagenbuch, Carley, Recklitis & Buchi, 2008). The Distress Thermometer is a very brief, 1-item measure which asks respondents to rate their level of distress over the previous week on a thermometer-like visual analogue scale. Scores range from 0 ('no distress') to 10 ('extreme distress'), with a midpoint score of 5 indicating 'moderate distress'. Previous research has identified a cut-off score of 4/5 on the Distress Thermometer as indicating significant distress. The two-number expression for the cut-off is used for clarification

purposes. That is, 4/5 indicates that the threshold for clinical versus nonclinical distress lies between these two numbers (i.e., ≤ 4 = nonclinical distress, ≥ 5 = clinical distress), thus avoiding the ambiguity potentially caused by using a single number (e.g., 5) (McDowell, 2006). Akizuki and colleagues (2003) found that a cut-off of 4/5 was best able to correctly identify clinically distressed clients (sensitivity = .84, specificity = .61) when compared with the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Similar findings regarding an optimal cut-off of 4/5 have also been reported (Gessler et al., 2008; Zwahlen, Hagenbuch, Carley, Recklitis & Buchi, 2008). There is still, however, some debate as to which cut-off score is appropriate, with some studies showing that a cut-off score of 3/4 provides greater sensitivity and specificity (Jacobsen, Donovan, Trask, Fleishman, Zabora, Baker & Holland, 2005; Gill, Grassi, Travado, Tomamichel & Gonzales, 2005). Referrals into the psycho-oncology service were based on clients having a distress score of 5 and above (i.e., 4/5), therefore, a cut-off score of 4/5 was used in the current study.

The validity of the Distress Thermometer (DT) has been investigated in a number of studies and a recent review of these studies, as well as other ultra short screening measures, was conducted by Mitchell (2007). Of the 38 studies reviewed, 19 examined the validity of the Distress Thermometer alone. The findings from these studies were pooled together and analysed. Results of the review indicated that the Distress Thermometer was modestly accurate at detecting distress (sensitivity = 78.3, specificity = 66.5) and depression (sensitivity = 78.3, specificity 66.8), but less accurate in detecting anxiety (sensitivity = 77.3, specificity = 56.6) (Mitchell, 2007). The Distress Thermometer was included in the present study because of its brevity, and relatively strong psychometric properties. In addition, because the Distress Thermometer was already being used as a screening tool by the psycho-oncology service, it was seen as a suitable measure for matching the intervention and control group samples.

Impact Thermometer (IT)

The Impact Thermometer (IT) (see Appendix D) was designed by Akizuki, Yamawaki, Akechi, Nakano, and Uchitomi (2005) to examine the impact that distress has on people with cancer. The IT asks respondents to rate how much their distress has impacted on them in the last week. It is similar in format to the DT, with higher scores indicating a less favourable status. Akizuki and colleagues found that the combination of the DT and IT improved the validity in their sample. Using cut-off points of 3/4 on the 'distress' score and 2/3 on the 'impact' score produced a sensitivity and specificity of 0.82 and 0.82, respectively. They concluded that the ability of the Distress and Impact Thermometer to screen for adjustment disorder and major depression was comparable to that of the Hospital Anxiety and Depression Scale (HADS). Baken, Woolley and Kent (2008) found that the IT alone was just as accurate as the DT alone in detecting anxiety, depression and distress, and that when the two measures were combined they performed better than each measure on its own.

Coping Thermometer (CT)

The Coping Thermometer (see Appendix D) was designed for the purpose of this study and follows the same design as the DT and IT. Respondents were asked to rate on a thermometer-like 11 point Likert scale (0-10), their level of coping over the previous week. Unlike the Distress and Impact Thermometers, a higher score indicated better functioning (e.g., higher levels of coping). No psychometrics properties are available for the Coping Thermometer.

Client Satisfaction Questionnaire-8 (CSQ-8)

The Client Satisfaction Questionnaire is an extensively used measure of client satisfaction with mental health services. The CSQ-8 (Attkisson & Zwick, 1982) (see Appendix E) is an eight-item version of the Client Satisfaction Questionnaire (Larsen, Attkisson, Hargreaves, & Nguyen, 1979), and consists of eight Likert type items with four possible responses. The CSQ-8 includes items such as "Have the services you received helped you deal more effectively with your problems?" and "How satisfied are you with the amount of help you have received?" Scores range from 8-32, with higher scores

indicating greater satisfaction. The CSQ-8 has been reported to have high internal consistency, with alpha coefficients ranging from .87 in a sample of 3,120 clients from a number of different mental health services (Nguyen, Attkisson & Stegner, 1983) to .93 in a sample of community mental health centre clients (Attkisson & Zwick, 1982). As evidence of concurrent validity, scores on the CSQ-8 have been found to be highly correlated with clients' ratings of global improvement of symptomatology and therapists' ratings of clients' progress (Lunnen & Ogles, 1998). Lunnen and Ogle (1998) also found that CSQ-8 scores were correlated with dropout rates (i.e., clients who reported lower satisfaction had higher dropout rates). Deane (1993) examined client satisfaction with psychotherapy services in New Zealand. As well as clients reporting high levels of satisfaction with services (mean = 27.21, sd = 5.17), results revealed positive correlations between satisfaction and symptom change on both therapist- and client-rated outcomes measures.

Target Issues

Clients seeking psychological support often have specific concerns that are addressed in therapy (e.g., communication, self esteem). Therefore, a measure was developed to examine changes over time in these specific areas of concern (see Appendix D). As only the intervention group received regular psychological support, this measure was only administered to them. The format for this item was the same as the DT and IT, with clients rating how well they had been doing with regard to the 'target issue' over the past week. Clients placed a mark on a 10cm rule, with 'low' and 'high' indicators at opposite end-points. As this item was developed specifically for the study, no psychometric properties are available for this item.

Self-Rated Health

Clients' self-rated perception of their health has been argued to be an important outcome in the evaluation of treatments (Fayers & Sprangers, 2002). One of the most frequently used measures of self-rated health is a single question asking clients to rate their health on a scale from excellent to poor. This brief measure is reported to provide a useful summary of clients' perceptions of health, as well as a means of predicting morbidity and mortality

(Idler & Benyamini, 1997). Studies indicate that despite its brevity, the single self-rated health question has been shown to have adequate reliability and validity (Cunney & Perry, 1991; De Salvo, Fisher, Tran, Bloser, Merrill & Peabody, 2006).

Many studies have used a global or holistic definition of health used by the World Health Organisation, which incorporates physical, psychological and social states (Idler & Benyamini, 1997). In the current study, the psychological and social aspects of wellbeing were covered in other outcome measures; therefore, the focus of this item was on clients' perceptions of their physical health (see Appendix D). Participants were asked to rate their current physical health on a 5-point scale, 'Excellent' (5), 'Very Good' (4), 'Good' (3), 'Fair' (2), and 'Poor' (1), with higher scores indicating better health.

Demographic Information

Demographic information was collected on age, gender, education, occupation, ethnicity, living arrangements, cancer type, stage of cancer, relationship to diagnosed person, level of social support and previous use of psychological services (see Appendix C). In addition to providing valuable information about the participant population, it enabled the two groups to be compared with regard to group matching. Some additional demographic questions were also collected at Time 2 and 3 for the control group (see Appendix J).

5.2.6.7 Analysis

Group Matching

As discussed earlier in this chapter, it was considered inappropriate to conduct a randomised controlled trial and instead the intervention and control groups were matched as much as possible. The matching of groups has been reported as being one of the critical features in quasi-experimental study designs to ensure that the gold standard in effectiveness studies is reached (Leichsering, 2004). As stated earlier, the referral criterion for the psycho-oncology service required that clients were experiencing significant distress (i.e., scores of 5 or higher on the Distress Thermometer). Studies have shown

that initial distress levels moderate outcomes of psycho-oncology interventions (i.e., those who are more distressed have been found to benefit more from treatment) (Sheard & Maguire, 1999; Schneider et al., 2010). Therefore, it was crucial that the two groups be as matched as possible on this variable. Previous research has stated that scores of 5 and above are indicative of significant distress. Therefore, participants in this study whose distress scores fell below 5 were not included in the data analysis. As indicated by Miller and Duncan (2004), limited improvements in ORS are expected if at intake, scores are close to the clinical cut-off. Therefore, participants with ORS scores on or above the clinical cut-off were also excluded from the analysis. The two groups were also compared with regard to demographic variables. Group differences at baseline are reported in the following chapter.

Missing Data Values

Due to the nature of recruitment and the collection of data over time, there was some missing data within the control group, but not the intervention group. Therefore, a Missing Values Analysis was conducted to determine whether this missing data had any significant effect on test results. Estimated missing data values were calculated and added to the original data set. Statistical analyses were conducted on the complete data set, which were then compared to the analyses from the original data set. Analyses revealed that the addition of the estimated missing values altered the significance of some test results. However, on examination of these new results, it appeared that these changes in significance were attributable to the significant increase in the number of control group cases now included in the analyses. As similar sample sizes allowed for a more accurate comparison between groups, a decision was made to not include the estimated missing values into the original data set.

Statistical Significance

Assumptions of the statistical analyses were assessed and found to be satisfied (Tabachnick & Fidell, 2001). In the initial analyses, independent t-tests were conducted to test for differences between those who completed the study and those who dropped out. Where possible, Pearson's chi square analyses were also conducted to test for group differences in demographic

variables. Independent t-tests were then conducted to test for differences in dependent variables between the intervention and control groups at baseline (pre-therapy), post-therapy, and follow-up. Two by two repeated measure ANOVAs were conducted to determine whether changes in outcome measures over time differed by treatment group. Paired t-tests were then conducted to examine the impact of treatment on outcome measures within each group. For pre-post therapy ORS data only, effect sizes were also calculated. The calculation of Cohen's 'd' (Cohen 1977) effect sizes using repeated measures were computed for the ORS (Time 1-Time 2) using an effect size statistic developed by Faul, Erdfelder, Lang, and Buchner (2007). Cohen's rule of thumb states that an effect of less than .20 is small, equal to .50 is medium, and greater than .80 is large. Analyses were also conducted to examine whether any differences in outcome measures existed between cancer patients and family members.

Clinical Significance

In addition to identifying whether there were any statistically significant differences in the Outcome Rating Scale (ORS) between the two groups, further analyses were conducted to determine whether the changes observed had any clinical significance. The Reliable Change Index (RCI) and clinical cut-off were used to determine the percentage of study participants who reached a clinically significant change.

5.2.7 Phase 2

5.2.7.1 Sample

A sample of clients from the intervention group were selected based on outcome results of the measures, half who showed the most change in ORS scores at follow-up, and half who showed the least change. The final sample size was based on what Glaser and Strauss (1967) referred to as 'theoretical saturation' (i.e., a point at which interviews no longer appear to generate new information).

5.2.7.2 Participant Recruitment & Procedure

Halfway through Phase 1 recruitment, potential participants for the intervention group were invited to take part in a semi-structured interview with the researcher. Waiting until halfway through recruitment was decided because it allowed the researcher to determine the average change scores within the sample from which to identify high- and low-change participants, and also avoid a long delay between completion of Time 3 questionnaires and the interview. The interviews were conducted in addition to completing the outcome measures, to examine potential factors influencing the effectiveness of their therapy. Identifying all clients' preference to be interviewed upon initial contact avoided contacting participants a second time and additional mail-outs in the future. Once written consent had been obtained, interviews were conducted either at the psychology clinic, or in the family home depending on the participant's preference. Interviews with clients took approximately one hour and were audio-taped.

5.2.7.3 Interview Schedule

A semi-structured audio-taped interview was used to explore clients' perceptions and experiences of their cancer journey, their perceptions and experiences of the service, and identify factors influencing intervention outcome. Interviews followed a topic guide to ensure a number of important subjects were covered (see Appendix M). Areas of particular interest were the impact of the diagnosis, use of coping strategies and distress management; perceptions and experiences of social support, and key aspects of the service found to be most and least beneficial.

5.2.7.4 Analysis

Interviews underwent an in-depth thematic analysis to explore the clients' experiences of cancer, and their perceptions of the psycho-oncology service. Thematic analysis is widely used as a method for analysing qualitative data (Braun & Clarke, 2006). Because it is a flexible methodology, it is not linked to specific theories. The current study takes an exploratory approach and is an attempt to develop an understanding of the participant's experiences of cancer and of the psycho-oncology interventions they received. Therefore, an

inductive approach was employed, an approach often favoured by clinical psychologists (Boyatzis, 1998). Similarities exist between using an inductive form of thematic analysis and grounded theory in that the themes that are identified are linked to the data (Braun & Clarke, 2006). Interviews were transcribed verbatim by the researcher. Transcripts were then examined four times, enabling the researcher to develop a thorough understanding of the transcripts and to extract themes. Transcripts were then examined by the supervisor to enable cross-checking and comparisons of identified themes.

A brief set of analyses (independent sample t-tests) were conducted to examine possible statistical differences between the high- and low-change groups over time. Examination of qualitative data was also undertaken to determine possible explanations for differences in treatment outcome between the two groups.

CHAPTER SIX

Phase One Results

One of the key aims of this study was to examine the effectiveness of psycho-oncology interventions in reducing distress and improving quality of life amongst people with cancer, and their families. Participants who had access to the psycho-oncology service completed outcome measures at three time points. Their scores were then compared to the scores from a group of participants who did not have access to the service. This chapter reports on the response rate and drop out analysis, final sample size, demographic characteristics of the two groups, group differences in outcome measures at baseline (pre-therapy), post-therapy and 3-month follow-up, as well as patient versus family member results.

6.1 Response Rates

For the intervention group, study invitation packs were distributed to eligible clients until the required sample size was reached. Over the course of the recruitment period (one year) 40 clients were eligible to participate in the study. Of those invited, 24 responded (60% response rate). For the control group, 300 people with cancer were sent a study pack, as well as a study pack for a family member. Of the 600 study packs distributed, 189 people consented to participate in the study (31% response rate).

6.2 Dropout Analysis

Because the intervention group were recruited at Time 3, no participants dropped out over the course of the study. Of the 189 control group participants who completed questionnaires at Time 1, 71% (n=134) completed questionnaires at Time 2; and of that group, 80% (n=107) completed questionnaires at Time 3. Reasons for dropping out were not obtained, as it was not considered appropriate. This was because participants were at various stages of their cancer journey and it was possible that they may have dropped out due to feeling unwell (e.g., chemotherapy or recurrence) or worst

case, may have died. At Time 2, 2 control group participants had died and at Time 3, 5 had died. Independent t-tests revealed no significant differences in initial ORS ($t = -1.42$, $p = .161$), distress (DT) ($t = .79$, $p = .433$), impact (IT) ($t = .63$, $p = .533$), coping (CT) ($t = .46$, $p = .645$) wairua ($t = -.66$, $p = .510$) or self-rated health ($t = .22$, $p = .824$) between those who completed the study, and those who did not. No drop-out patterns were observed amongst demographic variables such as gender, cancer type or cancer stage. However, there was a difference in the ethnicity, with 63% of NZ/Maori participants dropping out at Time 2 compared to only 25% of NZ/Pakeha.

6.3 Final Sample Size

Of the 24 intervention group participants who agreed to take part in the study, three had completed their Time 1 questionnaires during their second therapy session and subsequently had initial distress scores (DT) below 5 (indicating that they were not significantly distressed). Therefore, their data was excluded from the analysis. Three participants were also excluded because their initial ORS scores were above the clinical cut-off of 25. Therefore, the final sample size for the intervention group was 18. Of the 189 control participants who consented to participate, 109 reported distress (DT) scores of less than 5. Additionally, 35 had ORS scores above 25. Therefore, these two groups were excluded from the analysis, leaving the control group with a final sample size of 45. Of the 18 intervention group participants, two were a couple (i.e., husband and wife). Within the control group, 14 participants were couples.

6.4 Demographic Characteristics

The demographic characteristics of participants included in the final analyses are summarised in Table 2. The average age of participants across both groups was approximately 51 years of age. The majority of intervention and control group participants were female and of New Zealand European descent. Eleven percent of the control group identified themselves as NZ Maori, and within this group, only 8% reported that they were still living in their original hapu area.

Table 2: Demographic Characteristics by Treatment Group

	Intervention			Control		
	Patient (n = 10)	Family Member (n = 8)	Total (n = 18)	Patient (n = 30)	Family Member (n = 15)	Total (n = 45)
Age (years)	54	45	50	55	47	52
Gender %						
Male	10	25	17	33	13	27
Female	90	75	83	67	87	73
Ethnicity %						
NZ European	100	62	83	84	87	85
NZ Maori	0	0	0	10	13	11
NZ Maori/European	0	13	6	3	0	2
Non NZ Ethnicity	0	25	11	3	0	2
Cancer Type %						
Breast	60	25	44	40	13	31
Lymphoma	0	0	0	7	20	11
Prostate	10	0	6	10	20	13
Bowel	0	25	11	16	20	18
Brain	0	13	6	7	7	7
Other	30	37	33	20	20	20
Cancer Stage %						
Treatment	30	12	22	22	31	25
Post Treatment	60	25	44	63	38	55
Recurrence	0	25	11	4	23	10
Palliative Care/Hospice	0	13	6	11	8	10
Deceased (F/M only)	10	25	17	0	0	0
Educ. Qualifications %						
No formal	20	13	17	29	36	31
Trade	20	13	17	4	14	2
Secondary	0	12	5	24	7	24
Tertiary	60	62	61	43	43	43
Living Arrangements %						
Spouse/partner only	60	62	61	53	60	56
Spouse & children	10	25	17	16	27	20
Alone	20	13	17	7	0	4
Children only	10	0	5	7	0	4
Other	0	0	0	17	13	16

Breast cancer was the most common cancer, although other frequently reported cancers included lymphoma, prostate, bowel, and brain cancer. Cancers that were reported by less than 5% of the sample (e.g., thyroid, lung, bladder cancer) were grouped as 'Other'. The majority of intervention and control group patients had been diagnosed within 2 years of the study commencing and approximately 50% reported that they, or the cancer patient, were in the post-treatment phase of their cancer journey. Similar percentages of intervention and control group participants reported experiencing recurrence and being in palliative/hospice care. Within the intervention group, 17% of participants were clients whose family member had died of cancer.

The majority of participants had tertiary qualifications (intervention = 61%, control = 43%). A higher percentage of the control group had secondary

qualifications (24%) compared to the intervention group (5%). The intervention group had a higher percentage with trade qualifications (17%), compared to 2% of the control group. Seventeen percent of the intervention group and 31% of the control group had no formal school qualifications. The majority of the intervention (61%) and control groups (56%) were living with either their husband/wife or de facto partner. A similar percentage of the intervention group (17%) and control group (20%) reported living with their partner and children. A higher percentage of the intervention group lived alone (17%) compared to 4% in the control group. A similar percentage of the intervention (5%) and control group (4%) lived with their children only. Sixteen percent of the control group lived with a range of other family members (e.g., children, siblings, parents).

Due to insufficient numbers in each cell, it was not possible to conduct Pearson's chi-square analyses to statistically determine group differences in demographic data. Qualitatively, there appeared to be very little difference between the two groups with regard to age, gender, ethnicity, cancer stage or type. However, there were differences with regard to living arrangements and education with more of the intervention group living alone, and possessing formal school or trade qualifications than the control group.

6.4.1 Social Support

6.4.1.1 Perceptions of Overall Support

Participants were asked to rate the level of overall support they had received from family, church, professionals (e.g., psychologist, social worker), and 'others' (e.g., friends). Approximately half (53%) of the intervention group respondents reported that the level of support had been 'excellent', 41% reported it was 'good', and 6% said it had been 'poor'. By comparison, 40% of the control group rated the support as 'excellent', 49% reported it was 'good', and 12% said it was poor. A Pearson's chi-square analysis was conducted, and showed no significant difference in perceived social support between the intervention and control group, $F(2,58) = 1.15$, $p = .562$.

6.4.1.2 *Support Information*

Participants were also asked to indicate who provided social support, the level of support, and how helpful they perceived it to be.

Family: A very high proportion of intervention (94%) and control group (91%) respondents reported receiving high levels of support (i.e., 'quite a bit' or 'a lot') from their families and felt that the support was 'quite' or 'very' helpful.

'Other' (e.g., friends, colleagues, other health professionals): A similarly high percentage of the intervention group (83%) and control group (84%) reported receiving high levels of support from friends, work colleagues, other health professionals (e.g., doctors, nurses), and organisations (e.g., Cancer Society). The majority of the control (83%) and intervention groups (77%) perceived that support to be 'quite' or 'very' helpful.

Professionals: All participants in the intervention group had received professional support. The majority (78%) reported that the level of support was high and most (89%) found the support to be 'quite' or 'very' helpful. Within the control group, 45% reported receiving support from professionals, but only 19% described this as a high level of support. Of those who did receive support, 83% reported it as being 'quite' or 'very' helpful. Twenty-nine percent of the control group reported receiving 'no support' from professionals. However, it is possible that respondents meant that they had not received support from professionals, rather than having found them unsupportive. Sixteen percent of the control group had left the 'professional' question blank. However, as they had completed all the other sections, it was assumed that this meant that they had not been involved with professionals. Therefore, blank responses were recorded as 'not applicable' (N/A).

Church: As with the 'professional' question, a significant number of respondents had left the 'church' question unanswered. As they had completed all the other sections, it was assumed that this meant that they did not attend church. Therefore, blank responses were recorded as 'N/A'. Twenty-eight percent of the intervention group and 18% of the control group

reported receiving support from the church. The majority had found the church's support 'quite' or 'very' helpful.

6.4.2 Previous Psychotherapy Experience

Within the intervention group, nearly one third (28%) had received psychological support unrelated to the cancer diagnosis prior to therapy, compared to only 5% of the control group. Twenty-eight percent of the control group had received psychological support for cancer-related issues prior to the study. However, 83% of the control group stated that they would have accessed a specific psychological service for those affected by cancer, had it been available. Twenty-five percent of the control group who completed measures at all three time points indicated that they had sought some form of psychological support related to their cancer diagnosis over the course of the study period. However, it is possible that a greater number of the control group participants sought psychological support at some point during the study. However, this information was not able to be obtained as they had not completed the final set of questionnaires at Time 3 (when this question was asked).

6.4.3 Psycho-Oncology Service Satisfaction

Feedback from the intervention group regarding service satisfaction indicated that they were very satisfied with the service they received. The mean score for the CSQ-8 was 29.2 (SD = 3.06), with scores ranging from 23 to 32 (maximum possible score = 32). All clients (100%) gave a rating of 3 or more on all but one of the eight items, indicating a high level of satisfaction with the service (one client rated a 2, indicating "Only a few of my needs have been met"). All respondents said that they would access the service at a later date if necessary, and would recommend the service to a friend.

Clients also identified aspects of the service they found most and least helpful. Responses were broken down and grouped based on thematic content, with some responses fitting into multiple themes. As shown in Table 3, being in a safe, non-judgemental and supportive environment, as well as feeling heard and acknowledged were the two most reported benefits of the service (n = 7).

Clients also valued being able to talk openly and honestly with someone not emotionally connected to them (n = 6). Service availability and flexibility was also important (n = 5), as well as the professionalism of the staff (n = 4). Receiving individualised care, learning techniques to reduce distress and having friendly staff were also reported to be helpful by some (n = 3), as well as contact with other services and support for family members. The majority of clients did not comment on, or indicate that there was a least helpful aspect of the service. However, discussion of irrelevant topics, location, filling in questionnaires, and scheduling were raised by a small number of clients.

Table 3: Most & Least Helpful Aspects of the Psycho-Oncology Service

	Response Themes	No. of Clients
Most Helpful	Safe, non-judgemental and supportive environment	7
	Feeling heard and acknowledged	7
	Freedom to talk openly and honestly	6
	Availability/flexible of service	5
	Professional care	4
	Individualised care/meeting needs	3
	Providing information and techniques to reduce distress	3
	Friendly, helpful staff	3
	Contact with other services	1
	Support for family members	1
Least Helpful	N/A or no response	9
	Nothing	5
	Location	1
	Discussing irrelevant topics	1
	Filling in questionnaires	1
	Scheduling during work hours	1

Clients were also asked how service provision could be improved. Nine clients indicate that there was nothing the service could have done better. Nine clients did not comment. However, as they had answered previous questions, blank responses were taken to mean they could not think of ways the service could be improved. Some clients suggested working within a timeframe, or improving location, and one indicated that although a phone-call was helpful for them post-therapy, others may need more than a phone call. Clients were also given the opportunity to make additional comments about the service. All

comments were positive, and some of these are provided below:

“Being able to use this service saved my sanity at an incredibly difficult time for me. Being in a safe, caring environment allowed me to explore and develop how to cope with this life changing event.” (Cancer Patient)

“I want to give my most grateful thanks for this service. How valuable it was to both myself and my family... Using the scale of wellbeing etc was a good focus to review how I was feeling and how I had progressed backwards and forwards”. (Cancer Patient)

6.4.4 Self-Rated Health

Participants were also asked to rate their level of health pre-therapy, post-therapy, and at follow-up. The mean self-rated health scores for the intervention and control group at Time 1, 2 and 3 are shown in Figure 1.

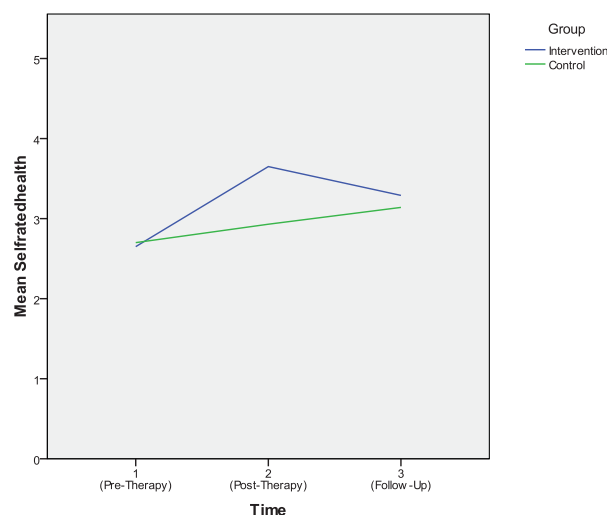


Figure 1: Change in Mean Self-Rated Health Scores over Time

An independent t-test showed no significant difference in mean self-rated health scores at baseline (pre-therapy/Time 1), with the intervention group having a mean score of 2.65 (1.06), and the control group having a mean of 2.70 (.82) ($t = -.20$, $p = .839$). At Time 2, the intervention group had a mean score of 3.65 (.93) and the control group had a mean score of 2.93 (.92). A

2x2 repeated measures ANOVA revealed an interaction effect for time*group, $F(1, 40) = 6.42$, $p = .015$, indicating that changes in mean self-rated health scores from Time 1 to Time 2 differed significantly between the intervention and control group. Paired t-tests revealed that there had been a significant improvement in mean self-rated health scores for the intervention group ($t = -3.30$, $p = .005$), but not for the control group ($t = -.27$, $p = .788$). At follow-up (Time 3), the mean self-rated health score for the intervention group was 3.29 (1.10), and 3.14 (.79) for the control group. An ANOVA analysis showed an interaction effect for time*group, $F(1, 34) = 7.83$, $p = .008$, indicating that changes in mean self-rated health scores from Time 2 to Time 3 differed significantly between the intervention and control group. Paired t-tests revealed a significant reduction in mean self-rated health scores for the intervention group ($t = 3.00$, $p = .009$). However, there was no change for the control group ($t = -1.68$, $p = .110$).

Analyses were also conducted examining overall change in self-rated health from pre-therapy (Time 1) to follow-up (Time 3). An ANOVA analysis failed to show an interaction effect for time*group, $F(1, 34) = .985$, $p = .328$, indicating that changes in mean self-rated health scores from Time 1 to Time 3 did not differ significantly between the intervention and control group. However, paired t-tests revealed that, overall, there had been a significant increase in mean self-rated health scores for the intervention group ($t = -2.18$, $p = .044$), but no change in self-rated health for the control group ($t = -1.84$, $p = .083$).

6.5 Main Outcome Measures

6.5.1 Group Differences at Each Time Point

Analyses of the difference in means were calculated to determine whether there were any significant differences in dependent variables between the two groups at each time-point. As shown in Table 4, at baseline (i.e., pre-therapy/Time 1), there were no significant differences between the intervention and control group. However, at the end of therapy (Time 2), there was a significant difference between the two groups across all outcome measures, with the intervention group showing significantly higher levels of wellbeing,

wairua and coping, and lower levels of distress and impact than the control group.

Table 4: Analysis of Mean Differences in Dependent Variables Pre-Therapy (Time 1), Post-Therapy (Time 2) and Follow-up (Time 3)

	Group	Mean (SD)	Mean Diff.	T	Sig (2-tailed)
Pre-Therapy (Time 1)					
ORS (Outcome Rating Scale)	Intervention	16.46 (5.44)	-2.13	-1.52	.134
	Control	18.59 (4.78)			
Wairua (Spirituality)	Intervention	4.33 (2.35)	-.82	-1.33	.189
	Control	5.14 (1.81)			
DT (Distress)	Intervention	7.05 (1.63)	.70	1.86	.068
	Control	6.36 (1.23)			
IT (Impact)	Intervention	6.50 (2.09)	.39	.72	.478
	Control	6.11 (1.47)			
CT (Coping)	Intervention	4.53 (2.54)	-1.17	-1.82	.082
	Control	5.70 (1.58)			
Post-Therapy (Time 2)					
ORS (Outcome Rating Scale)	Intervention	30.26 (6.92)	5.96	2.93	.005
	Control	24.30 (6.86)			
Wairua (Spirituality)	Intervention	7.62 (1.59)	1.52	2.67	.011
	Control	6.10 (2.25)			
DT (Distress)	Intervention	3.17 (2.23)	1.61	-2.44	.018
	Control	4.78 (2.25)			
IT (Impact)	Intervention	2.44 (1.95)	-2.41	-3.53	.001
	Control	4.86 (2.48)			
CT (Coping)	Intervention	8.11 (1.32)	1.39	2.96	.005
	Control	6.72 (1.73)			
Follow-up (Time 3)					
ORS (Outcome Rating Scale)	Intervention	27.38 (8.97)	-1.82	-.735	.467
	Control	29.20 (6.88)			
Wairua (Spirituality)	Intervention	5.80 (2.64)	-1.60	-2.05	.048
	Control	7.40 (1.97)			
DT (Distress)	Intervention	4.24 (2.73)	.319	.399	.692
	Control	3.92 (2.36)			
IT (Impact)	Intervention	3.59 (2.58)	.130	1.69	.867
	Control	3.46 (2.32)			
CT (Coping)	Intervention	7.24 (2.36)	-.140	-.224	.825
	Control	7.38 (1.64)			

At follow-up (Time 3), there was no significant difference in wellbeing, distress, impact or coping between the two groups. However, there was a significant difference in wairua, with the intervention group having significantly lower levels of wairua than the control group.

6.5.2 Change over Time

The following results are presented in three sections. The 'Pre-Post -Therapy' section reports on the change in outcome measures from the beginning (Time 1) to the end of therapy (Time 2). The 'Post-Therapy - Follow-up' section reports on the change from the end of therapy (Time 2) to the 3-month follow-up (Time 3). The 'Pre-Therapy - Follow-up' reports on the overall change over time from the beginning of therapy (Time 1) to the 3-month follow-up (Time 3).

Mean scores for each outcome measure were analysed in a 2x2 repeated measures ANOVA with time (pre-post, post-follow-up or pre-follow-up) as the within-subjects factor and treatment group (intervention/control) as the between-subjects factor. Paired t-tests were also conducted to examine the impact of 'treatment' on outcome measures by comparing mean scores at the three different time-points (i.e., pre-post, post-follow-up, and pre-follow-up) within each treatment group. These results are shown in Table 5 below.

Table 5: Paired T-Test Results for Each Outcome Measure for Three Time Comparisons.

	Group	Pre-Therapy/ Post-Therapy (Time1/Time2)		Post-Therapy/ Follow-up (Time2/Time3)		Pre-Therapy/ Follow-up (Time1/Time3)	
		t	Sig (2-tailed)	t	Sig (2-tailed)	t	Sig (2-tailed)
ORS (Outcome Rating Scale)	Intervention	-7.14	.000	1.49	.155	-4.74	.000
	Control	-3.70	.001	-2.97	.007	-6.30	.000
Wairua (Spirituality)	Intervention	-4.74	.000	3.36	.005	-1.93	.076
	Control	-2.14	.043	-1.83	.084	-4.00	.001
DT (Distress)	Intervention	4.83	.000	-1.41	.176	3.46	.003
	Control	3.70	.001	1.43	.165	4.61	.000
IT (Impact)	Intervention	5.15	.000	-1.60	.129	3.88	.001
	Control	3.09	.000	3.07	.005	5.14	.000
CT (Coping)	Intervention	-5.88	.000	1.29	.214	-2.94	.010
	Control	-2.66	.012	-2.82	.010	-3.84	.001

6.5.2.1 Pre - Post Therapy (T1–T2)

Outcome Rating Scale (ORS)

An ANOVA analysis revealed an interaction effect for time*group, $F(1,46) = 44.11$, $p = .000$, indicating that changes in mean ORS scores differed significantly between the groups. As shown in Table 5 and Figure 2, mean ORS scores for both groups significantly improved between Time 1 and Time 2. However, the intervention group showed greater improvement in ORS than the control group.

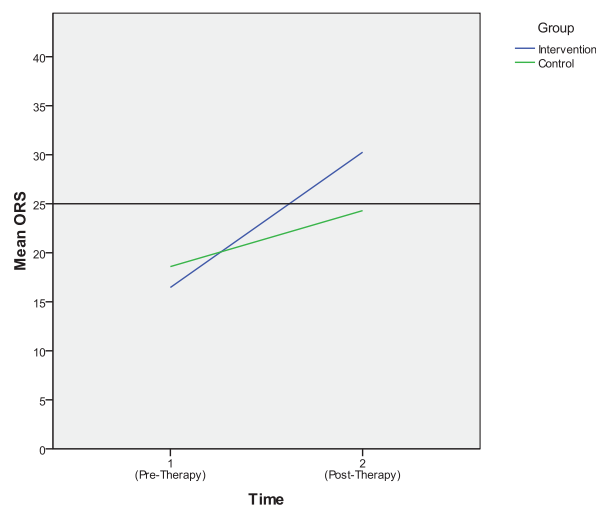


Figure 2: Change in Mean ORS Scores over Time (T1-T2)

To examine whether changes observed were clinically significant, further analyses were conducted. Change that both exceeds the Reliable Change Index (RCI) and crosses the clinical cut-off is considered to be reliable and 'clinically significant' (Jacobsen & Traux, 1991). Accordingly, mean change scores between Time 1 and Time 2 were compared to the RCI of 5 and 7. Over the course of therapy, the intervention group showed a mean increase in ORS of 13.8, (well above the RCI of 5, and the more stringent RCI of 7), compared to the mean increase of 6.2 for the control group (above the RCI of 5, but not 7).

The percentage of individuals crossing the clinical cut-off (25) at Time 2 was also calculated. At the beginning of therapy, neither group was on or above the clinical cut-off (>25). However, by the end of therapy, 89% of the

intervention group had ORS scores of 25 or more, compared to 38% of the control group. Therefore, based on Jacobsen and Traux's description of clinically significant change, by the end of therapy 83% of the intervention group had achieved clinically significant change, compared to only 35% of the control group. When the larger RCI was used (i.e., 7), 83% of the intervention group and 31% of the control group showed clinically significant change.

Calculations of Cohen's '*d*' effect sizes using repeated measures were computed using an effect size statistic developed by Faul, Erdfelder, Lang and Buchner (2007). Effect sizes were in the medium range for the control group ($d = .69$) and in the large range for the intervention group ($d = 1.68$).

Wairua

An ANOVA analysis revealed an interaction effect for time*group, $F(1,39) = 19.93$, $p = .000$, indicating that changes in mean wairua scores over time differed significantly between the groups. As shown in Table 5 and Figure 3, mean wairua scores significantly improved between Time 1 and Time 2 for the intervention group, while there was no change for the control group.

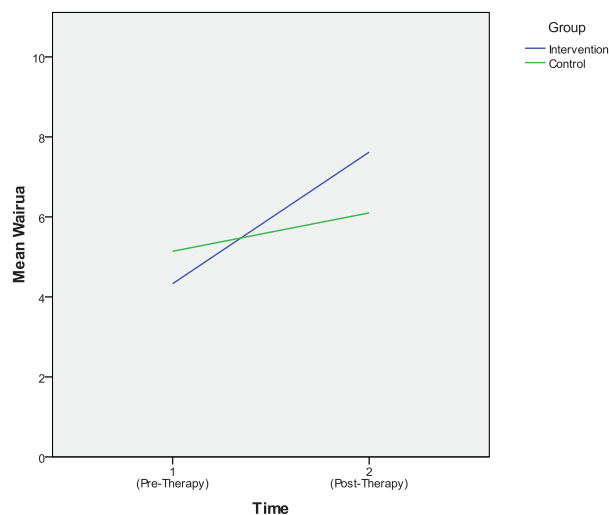


Figure 3: Change in Mean Wairua Scores over Time (T1-T2)

Distress (DT)

An ANOVA analysis showed an interaction effect for time*group, $F(1,49) = 32.52$, $p = .000$, indicating that changes in mean DT scores from Time 1 to Time 2 differed significantly between the groups. As shown in Table 5 (p. 81) and Figure 4, while distress decreased significantly for both groups, the intervention group showed greater reduction in distress than the control group. At Time 2, 22% of the intervention group had DT scores of 5 or more, compared to 56% of the control group (suggesting that the majority of the control group were still significantly distressed).

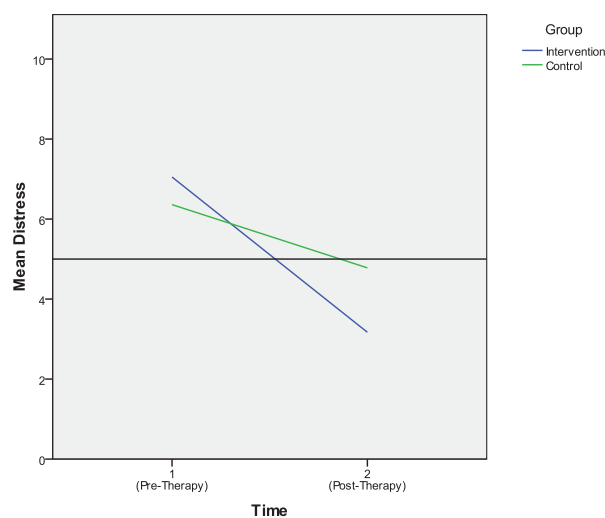


Figure 4: Change in Mean Distress Scores over Time (T1-T2)

Impact (IT)

An ANOVA analysis showed an interaction effect for time*group, $F(1,48) = 28.87$, $p = .000$, indicating that changes in mean IT scores from Time 1 to Time 2 differed significantly between the groups. As shown in Table 5 (p. 81) and Figure 5, while impact was significantly reduced for both groups, the intervention group showed a greater reduction in impact than the control group (where there was still a moderate degree of impact).

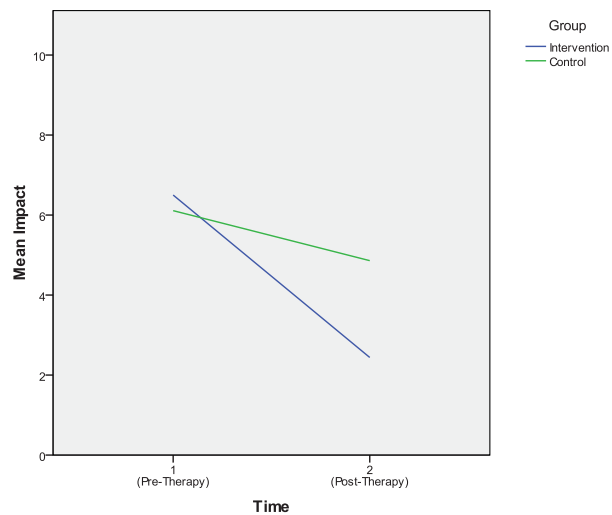


Figure 5: Change in Mean Impact Scores over Time (T1-T2)

Coping (CT)

An ANOVA analysis revealed an interaction effect for time*group, $F(1,49) = 27.62$, $p = .000$, indicating that changes in mean CT scores from Time 1 to Time 2 differed significantly between the groups. As shown in Table 5 (p. 81) and Figure 6, while coping significantly improved for both groups, the intervention group showed a greater improvement in coping than the control group.

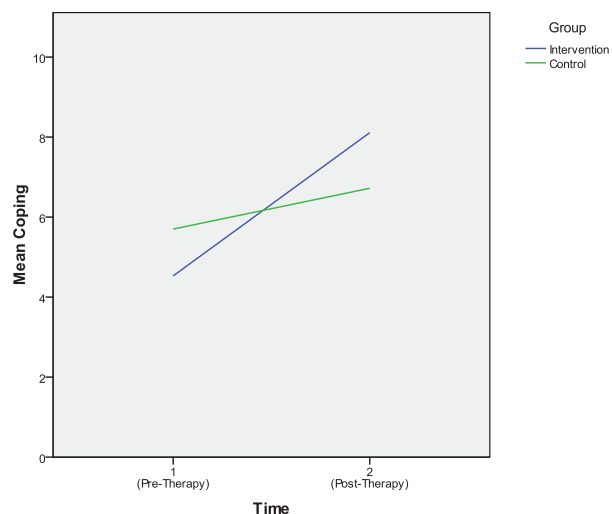


Figure 6: Change in Mean Coping Scores over Time (T1-T2)

6.5.2.2 Post Therapy – Follow-Up (T2-T3)

The paired t-test results for each group comparing means post-therapy (Time 2) to follow-up (Time 3) are shown in Table 5 (p. 81).

Outcome Rating Scale (ORS)

An ANOVA analysis showed an interaction effect for time*group, $F(1, 38) = 8.79$, $p = .005$, indicating that changes in mean ORS scores from Time 2 to Time 3 differed significantly between the two groups. As shown in Table 5 (p. 81) and Figure 7, ORS scores improved significantly for the control group, while there was no change for the intervention group.

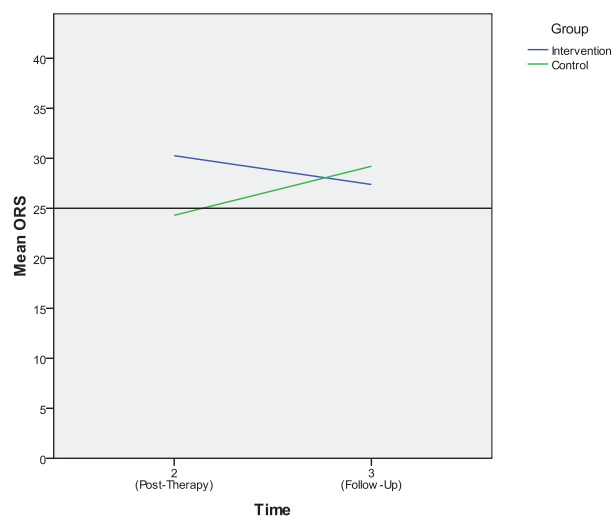


Figure 7: Change in Mean ORS Scores over Time (T2-T3)

At the 3 month follow-up, the percentage of participants showing clinically significant change had increased for the control group (from 31% at T2 to 77% at T3), but had dropped for the intervention group (from 83% at T2 to 47% at T3). However, 3 of the 9 intervention group participants who did not show 'clinically significant' change at Time 3, had very low ORS scores at Time 1 (i.e., 6) and had Time 3 ORS scores just below 25 (i.e., 24.1). Therefore, despite failing to meet criteria for 'clinically significant change', scores had improved considerably for these participants.

Wairua

An ANOVA analysis revealed an interaction effect for time*group, $F(1, 32) = 13.15$, $p = .001$, indicating that changes in mean wairua scores from Time 2 to Time 3 differed significantly between the groups. As shown in Table 5 (p. 81), a significant reduction in the mean wairua score was seen for the intervention group. Although Figure 8 suggests an increase in wairua for the control group, this change was not significant.

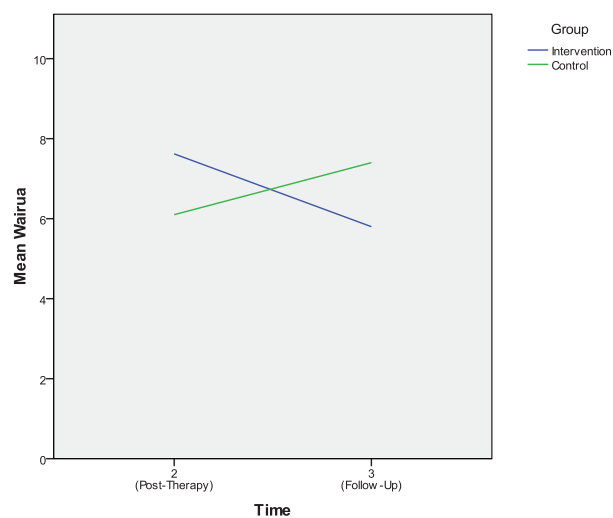


Figure 8: Change in Mean Wairua Scores over Time (T2-T3)

Distress (DT)

An ANOVA analysis showed an interaction effect for time*group, $F(1, 39) = 4.30$, $p = .045$, indicating that changes in mean DT scores from Time 2 to Time 3 differed significantly between the groups. Although in Figure 9, distress scores appeared to increase for the intervention group, and decrease for the control group, as shown in Table 5 (p. 81) there was no significant change in DT scores for either group. For the intervention group, the percentage of participants who had distress scores of 5 or more (i.e., significantly distressed) had risen from 22% at Time 2 to 59% at Time 3. However, for the control group, there was very little change (i.e., 56% at Time 2, to 50% at Time 3).

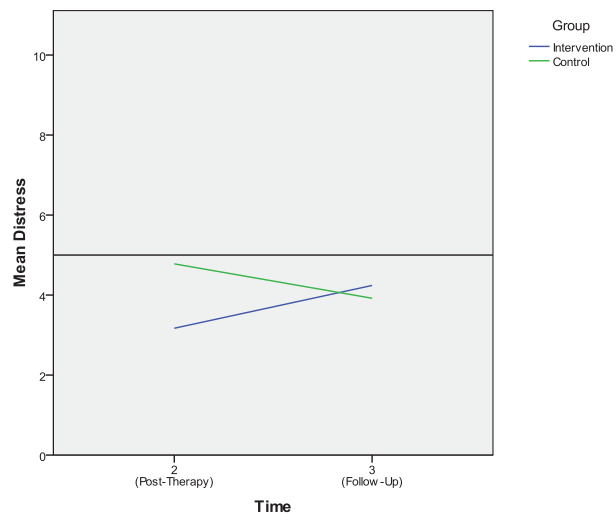


Figure 9: Change in Mean Distress Scores over Time (T2-T3)

Impact (IT)

An ANOVA analysis showed an interaction effect for time*group, $F(1, 39) = 9.40$, $p = .004$, indicating that changes in mean IT scores from Time 2 to Time 3 differed significantly between the groups. Although in Figure 10, mean IT scores appeared to increase for the intervention group, as shown in Table 5 (p. 81), this change was not significant. However, the control group did show a significant decrease in the impact of their distress.

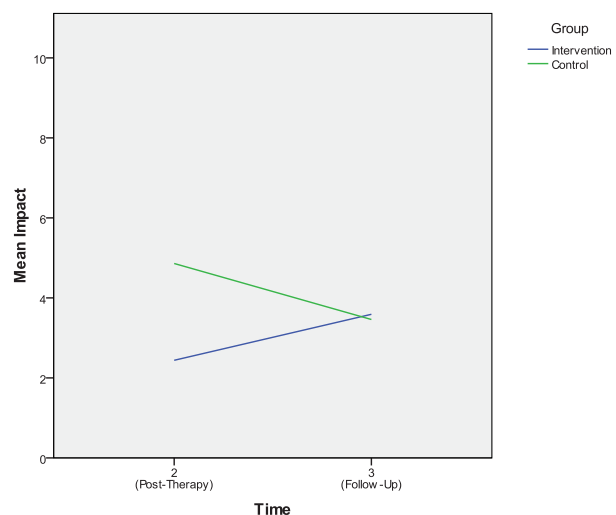


Figure 10: Change in Mean Impact Scores over Time (T2-T3)

Coping (CT)

An ANOVA analysis showed an interaction effect for time*group, $F(1, 39) = 6.88$, $p = .012$, indicating that changes in mean CT scores from Time 2 to Time 3 differed significantly between groups. Although in Figure 11, coping scores appeared to decrease for the intervention group, as shown in Table 5 (p. 81), this change was not significant. However, coping improved significantly for the control group.

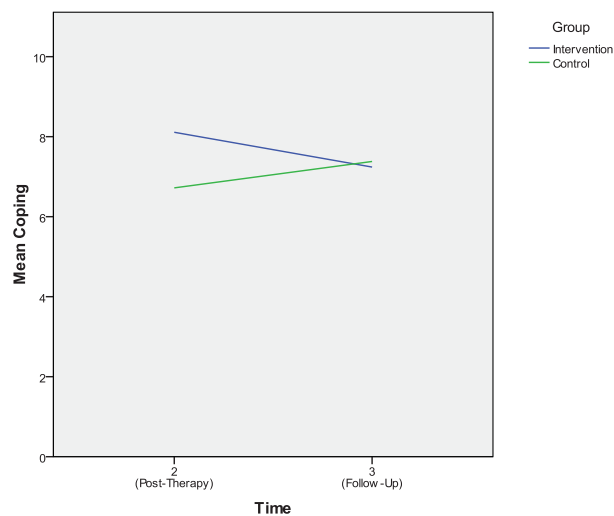


Figure 11: Change in Mean Coping Scores over Time (T2-T3)

6.5.2.3 Pre-Therapy – Follow-Up (T1–T3)

The paired t-test results for each group comparing means at pre-therapy (Time 1) to follow-up (Time 3) are shown in Table 5 (p. 81).

Outcome Rating Scale (ORS)

An ANOVA analysis failed to show an interaction effect for time*group, $F(1, 38) = .02$, $p = .897$, indicating that change in mean ORS scores from Time 1 to Time 3 did not differ significantly between the groups. As shown in Table 5 (p. 81) and Figure 12, overall both groups showed a significant improvement in ORS, and had scores above the clinical cut-off (25) (i.e., reporting levels of wellbeing similar to the general population).

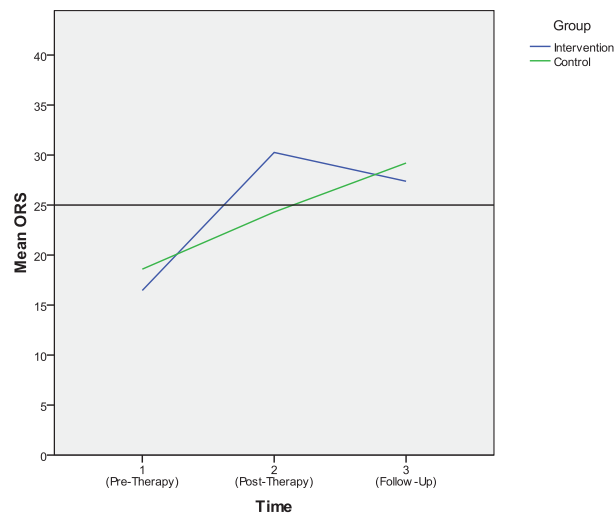


Figure 12: Change in Mean ORS Scores over Time (T1-T3)

At the 3-month follow-up (Time 3), mean ORS scores for the intervention group had increased by 11.0 points, and the control group by 11.3 points, from baseline (Time 1), with both change scores above the RCI of 5 and 7.

Wairua

An ANOVA failed to find an interaction effect for time*group, $F(1, 30) = .27$, $p = .606$, indicating that changes in mean wairua scores from Time 1 to Time 3 were not significantly different between the two groups. However, as shown in Table 5 (p. 81) and Figure 13, wairua rose significantly over that time-frame for the control group, but not for the intervention group.

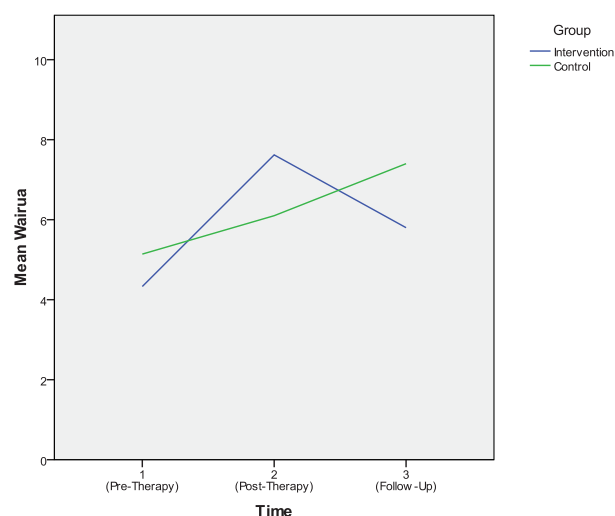


Figure 13: Change in Mean Wairua Scores over Time (T1-T3)

Distress (DT)

An ANOVA analysis found no interaction effect for time*group, $F(1, 39) = .11$, $p = .746$, indicating that changes in mean DT scores from Time 1 to Time 3 did not differ significantly between the two groups. As shown in Table 5 (p. 81) and Figure 14, overall both groups showed a significant drop to non-clinical levels of distress.

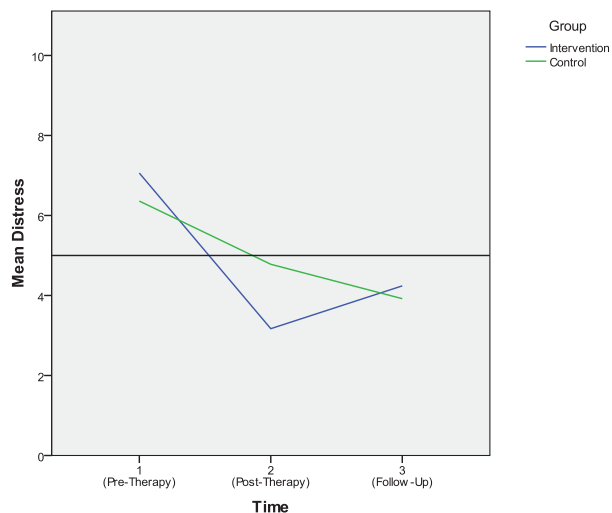


Figure 14: Change in Mean Distress Scores over Time (T1-T3)

Impact (IT)

An ANOVA analysis failed to show an interaction effect for time*group, $F(1, 39) = .05$, $p = .822$, indicating that changes in mean IT scores from Time 1 to Time 3 did not differ significantly between the two groups. As shown in Table 5 (p. 81) and Figure 15, overall mean impact (IT) scores significantly decreased for both the intervention and control group.

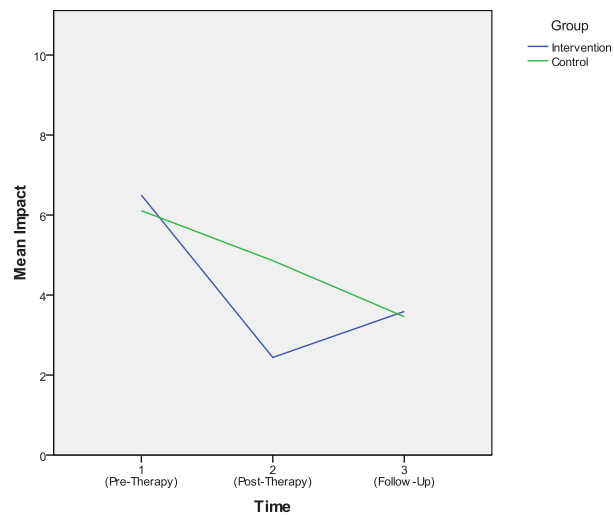


Figure 15: Change in Mean Impact Scores over Time (T1-T3)

Coping (CT)

An ANOVA analysis found no interaction effect for time*group, $F(1, 39) = .93$, $p = .340$, indicating that changes in mean CT scores from Time 1 to Time 3 did not differ significantly between the two groups. As shown in Table 5 (p. 81) and Figure 16, overall both the intervention and control group showed significant improvements in their ability to cope between Time 1 and Time 3.

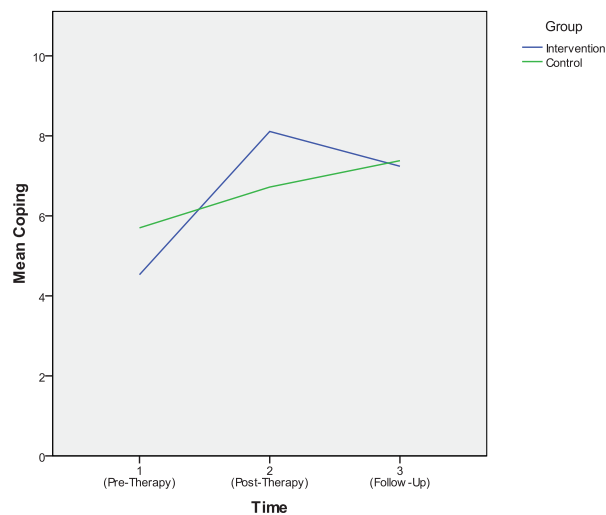


Figure 16: Change in Mean Coping Scores over Time (T1-T3)

6.6 Target Issues

Data was gathered on specific target issues that clients wished to discuss with the therapist. However, an insufficient number of participants completed this questionnaire item to warrant analysis.

6.7 Patients with Cancer versus Family Members

Analyses were conducted to examine possible differences in outcome measures between patients with cancer and family members. Analyses revealed that for the intervention group, there was no significant difference in mean scores for ORS, DT, and IT measures between patients and family members at Time 1. However, there was a significant difference in wairua, with patients reporting high levels of wairua ($M = 5.22$, $SD = 1.99$) than family members ($M = 2.83$, $SD = 2.26$) ($t = 2.21$, $p = .044$). There was also a significant difference in coping, with patients reporting higher levels of coping ($M = 5.70$, $SD = 2.31$) than family members ($M = 3.00$, $SD = 2.09$) ($t = 2.57$, $p = .021$). For the control group, there was no significant difference between patients and family members on any outcome measures pre-therapy (Time 1). Post-therapy (Time 2) and at follow-up (Time 3), there was no significant difference between patients and family members for any of the outcome measures, for the intervention or the control group.

6.8 Summary of Part One Results

Part One presented data on demographic information and the difference in outcome measures over time for the control and intervention group. Overall, social support for both groups was high, particularly from family and friends. A similar percentage of intervention and control group participants had accessed psychological support in the past. However, a significantly higher percentage of the control group indicated that they would have accessed specialised psychological support had it been available. The intervention group reported high levels of satisfaction with the support from the psycho-oncology service. The intervention group showed significant improvements in self-rated health over the course of therapy, however, this was not maintained at follow-up. There was no change in self-rated health over time for the control group.

Over the course of therapy (i.e., Time 1 – Time 2), the intervention group showed statistically and clinically significant improvements in ORS and distress, and statistically significant improvements in wairua, impact and coping. The control group also showed statistically significant improvements in ORS, wairua, distress, impact and coping. However, mean changes in ORS, and distress were not clinically significant, and wairua, impact and coping scores were still moderate. ANOVA analyses indicated that across all outcome measures, the intervention group made a significantly greater improvement over the course of therapy, than the control group.

At follow-up (Time 3), intervention group mean scores for all outcome measures appeared to have reduced. However, the majority of these changes were not statistically significant (except wairua). At Time 3, although mean scores for the control group appeared to increase, the majority of these changes were not statistically significant. Overall, from pre-therapy to follow-up (Time 1-3), both groups showed significant improvements over time. The intervention group made significant improvements across all outcome measures, except wairua. The control group showed significant improvement across all measures. Overall, there was very little difference in outcome measures over time between patients and family members (intervention or control group). However, pre-therapy, patients in the intervention group reported higher levels of wairua and coping than family members.

CHAPTER SEVEN

Phase Two Results

From Phase 1, 8 of the 18 intervention group participants were selected to be interviewed in depth about their experiences of their cancer journey, and their experiences and perceptions of the psycho-oncology service. Four participants were chosen who made the least change in ORS from baseline to follow-up (low-change), and four who made the most change (high-change). The majority of participants interviewed were female (n = 7) cancer patients (n = 6) of New Zealand Pakeha/European ethnicity (n = 7) with breast cancer (n = 7).

The results of Phase 2 are presented in two parts. Part A presents the experiences of cancer and perceptions of the psycho-oncology service of all 8 interviewees (irrespective of grouping, i.e., high- vs low-change). Part B presents possible key factors responsible for the effectiveness of the psycho-oncology service interventions by examining the differences between those who made the greatest change in ORS and those who did not, quantitatively as well as qualitatively.

7.1 Part A: Clients' Experiences of Cancer & Perceptions of the Psycho-Oncology Service

7.1.1 Cancer Journey Experiences

Cancer patients and family members were invited to share their experiences of their cancer journey. Questions focused on what impact the diagnosis had on them, what they found particularly difficult, how they managed their distress, what coping strategies they used, and how much support they felt they had received from family, friends, and others in the community. The following results reflect the responses from all clients. Illustrative quotes reflecting the key themes are presented in italics.

7.1.1.1 Impact of Diagnosis

For individuals with cancer, the impact of receiving the diagnosis was devastating for most and for many, was still ongoing. They spoke of feeling very lost, being unable to plan for a future, or think about future events, and having to deal with the grief associated with the loss of their sex life. Many described being in total shock, particularly with regard to the way they were informed of their diagnosis, and others struggled to cope with feelings of guilt.

“It was devastating because it meant for a year I had been living with this, not knowing and I hadn’t done anything about it. I could have gone back earlier. Part of me had to deal with the regret of my own inaction.” (Cancer Patient)

“At the time you just go, do what you have to do, deal with it. I can deal with it. Yeah. So you operate on automatic until at some point further down the track you go, I lost a breast! You know, and um, and that had a significant impact later.” (Cancer Patient)

For family members, although the diagnosis was devastating for them, there was a feeling that they had to hold it together for their family’s sake. For one family member, their way of coping was to remain focussed on the current issues and not dwell on the future. Although they were aware that it would be something they would have to deal with at a later stage.

“ It might be a year, it might be 18 months, it might be 2 years after that, that finally I get time to sit there and go ok I don’t have to do anything for anyone anymore, then, I’ll have to deal with it.” (Family Member)

“It devastated me, but I had to be strong for my brothers and sisters because they like fell apart.” (Family Member)

7.1.1.2 Most Difficult Aspects

For cancer patients, aspects of their cancer journey reported to be most difficult centred on struggling to cope with their family's grief, confronting their own fears about cancer, and the loss of peace of mind and constant unknown. For some family members, seeing the physical impact that the cancer treatment was having on their family was difficult. Others were concerned about how best to support their sick spouse and children.

"The thing that stressed me the most was if I crash, where does she get her support from?" (Family Member)

7.1.1.3 Distress Management

A small number of cancer patients reported that over time their levels of distress had decreased as they came to accept their illness. However, for the majority, distress levels had increased. Some patients reported that initially they had been so focused on getting through their treatment, that the impact of what was happening had not sunk in. It was not until they finished treatment that their distress levels increased. For some patients, the unexpected long-term side effects of their treatment had also increased levels of distress.

"While having the main treatments, during that six months I was just getting through them....it was quite a busy time really getting through them and doing what I needed to, and all the appointments and everything like that. So, in some ways the distress became worse later I think." (Cancer Patient)

The majority of those with cancer felt that their mood was mostly affected by tiredness or when they were stressed about particular things. Some reported getting stressed and upset more easily. Hormones were also reported to affect mood. For many, being able to remain at work allowed them to keep their minds busy. However, when they were no longer able to work, distress levels increased as they spent increasing amounts of time at home alone. For one family member, how the ill family member was coping directly affected their level of distress.

“The thing that’s made it easier for me is [wife] being able to handle it better and especially since [she’s] been coming here [psycho-oncology service], it’s been much easier for [her] to deal with things and get some perspective... And then of course my stress levels go down because I’m not required as much as support.” (Family Member)

7.1.1.4 Coping Strategies

Patients and family members reported using a variety of coping strategies to manage their distress. Avoidance strategies were employed by a number of individuals. These strategies had predominantly been employed prior to accessing the psycho-oncology service and many recognised that these had not been helpful. For some, however, these strategies were still being used. Many spoke of being in denial, of feeling somewhat detached from what was happening to them, as if it were happening to somebody else. One individual reported intentionally avoiding the emotional and distressing aspects of cancer by focussing on the practical aspects, or focusing on other personal/family issues. Others reported that they had tried to avoid thinking about it, retreated inside themselves and bottled their feelings up, blamed others, or hoped that it would go away.

“Once I got out of control I just hid myself away. I didn’t really have anything to stop myself getting out of control. I just had a way of stopping myself getting further out of control, which didn’t actually help at all.” (Family Member)

Others, however, reported being determined to face the cancer head on from the outset.

“One thing that has always been how I’ve dealt with any situation is I don’t hide. Honesty and truth for me has always been something I’ve faced head on. And so I think it helped because I just wouldn’t hide from it.” (Cancer Patient)

Other coping strategies used by some patients and family members included spending time in the garden, making time for themselves, or talking with other people. For a small number of people, spirituality played an important part of their cancer journey and in helping them to cope. These particular individuals had reported having some difficulties with support from family. Some reported reconnecting with their spiritual side following their diagnosis and that now it was a great source of strength for them. Others also noticed that their spiritual beliefs had become stronger over the course of their illness.

“That’s how I coped. Just turning to prayer, yeah, and the support of the church. I just felt that it was only through the prayer that got me through really.” (Cancer Patient)

For other individuals, there was an acknowledgement that a holistic approach to their healing was necessary. Meditation was also used to enhance their spiritual and emotional wellbeing.

“I actually realised I needed whole healing. It wasn’t just physical healing that needed to go on, there was emotional and spiritual and mental healing as well.” (Cancer Patient)

7.1.1.5 Social Support

Overall, patients and family members viewed social support as being vitally important in helping them to cope throughout their cancer journey. The types of support offered by various people in their lives, as well as the helpful and sometime unhelpful aspects of social support are discussed below.

Partners/Spouses

Cancer patients reported receiving a lot of emotional and practical support from their partners. However, many stated that often the level of support they received from them was insufficient, or that they were unable to rely on their partners because they themselves were not coping well with the diagnosis. Many reported that it had been very difficult to talk to their partners about what they were going through.

"It was good to have somebody like [psychologist] to talk to, because I couldn't talk to him because he just wasn't coping with it." (Cancer Patient)

Often how the person coped with their diagnosis/prognosis differed from their partners, with some preferring to share their feelings and thoughts with others, while their partner did not want to talk to anyone. Some family members reported choosing not to share their feelings with their ill partners for fears of upsetting them more.

Friends/Family/Whanau

Patients and family members reported receiving a great deal of support from their friends and family/whanau in the form of practical support (i.e., housework/transport), and/or emotional support. The majority of practical support included arranging help around the home, cooking meals, cleaning, driving them to and from treatment or doctor's appointments, or even taking over their work for them. Emotional support involved visits, phone calls, receiving flowers or gifts, being understanding and caring, listening to them and providing encouragement, talking with them on a daily basis, keeping them involved in social activities, providing them with company, love, laughter and support.

"I often laugh about this, cos you couldn't move for flowers. And I've got my garden full of them!" (Cancer Patient)

Just knowing that the extended family was there and available if needed was a great sense of comfort to cancer patients and family members. Family members also helped financially, by increasing their workload so the ill family member was able to stop work.

Although the majority of individuals reported extremely positive support from friends and family, some reported being very disappointed in the lack of support they received from some close family members.

"I can't really talk to him, because he's quite determined now that I am over the breast cancer, I'm better and I'm going to live a normal life, and you know. So he doesn't want to hear anything else."
(Cancer Patient)

Colleagues

Overall, patients and family members reported receiving excellent support from work colleagues. Many were given time off work during treatment, were allowed to have flexible work hours, and workloads were adjusted so that they were able to continue working. Being allowed to transition back into work without the pressure of taking on too much was appreciated. Some people were surprised by the supportive response from colleagues who did not know them well.

"The boss was quite happy, "Just go, take as much time as you need". And that's been good. Without that, if I had a job and they said, "Well you've used up all your sick pay, you've got to use your annual leave", I'd probably have left the job and that would have increased stress a lot." (Cancer Patient)

However, not all patients and family members found their workplace to be a supportive environment. Some reported that employers and colleagues had not provided them with adequate support, causing added distress.

"I got a very bad reaction from my boss..... she didn't cope at all well with it I didn't feel. And her support was minimal." (Cancer Patient)

"There was a lack of support from some of my colleagues, but some support from others. It wasn't across the board. That was quite hard to deal with. I just felt that I couldn't share it at work, I had to leave it at the door and pick it up when I went home."
(Cancer Patient)

Medical Professionals

Overall, patients and family members were happy with the support they received from medical professionals (i.e., GPs, oncology staff, breast care, hospice and district nurses). Those who accessed the Cancer Society found their practical support, social support networks, advice, and literature very helpful. Hospice Nurses provided help with pain medication and talked through issues. A number of patients found the Breast Cancer Support Nurses extremely helpful, reporting that they could discuss medical concerns with them, as they often explained things more easily. They also appreciated the nursing staff making them aware of other services that were available or putting them in direct contact with the psycho-oncology service. Social workers also provided emotional support, as well as practical advice and information. Many found that medical staff was very supportive in providing medical advice. And although some reported that they also received emotional support from them, many felt that there was only so much they could offer.

“They do as much as they can but they’re sort of in a position where, they can be supportive, but they can’t, there’s a limit to how helpful they can be because they can’t change things” (Cancer Patient)

The majority of cancer patients interviewed reported experiencing a significant amount of help and support from medical staff involved in their care. However, some did experience, and continued to experience difficulties with the medical profession with regards to their cancer journey. A number of cancer patients felt that although they were given some basic information about what treatment would entail, there was other information which would have been very beneficial (e.g., side effects of treatment, and explanations about CT/MRI scans). Some felt a sense of being kept out of the loop, or that it was assumed that they knew everything they needed to know.

“I never saw my CT scans or my MRI scan. I didn’t understand what it meant. And it wasn’t well explained” (Cancer Patient)

Three patients were disappointed with the attitudes and behaviour of some medical staff. In particular, the lack of bedside manner, lack of any emotional support, poor explanations, and inappropriate discussions in front of other patients.

"I still don't feel I can ask [doctor] a question..... [doctor] pulls faces when I ask a question. I don't think [doctor] means to though cos, it's just like, for [doctor] it's not important. And the questions that I'm asking, [doctor] may not feel are relevant or necessary. But I don't know that!" (Cancer Patient)

Two cancer patients reported being significantly distressed about the way they had been informed of their cancer diagnosis. The manner in which they were told was considered to lack warmth and caring. Also, that they had not been given any prior indications that they may have had cancer was reported to be very distressing.

"[Doctor] just said I've got cancer and more or less walked out the door.... If you had any idea, you'd take someone with you, wouldn't you?.... [Doctor] just walked in, took a look at the thing and left. I still, when I think about that, I think that was the worst thing that happened to me the whole time." (Cancer Patient)

"When my doctor called me to say he wanted to see me, he didn't hint that he was going to drop this on me. Didn't say I should bring a support person. And he just said "I'm really sorry to tell you, you've got cancer". I was there on my own, I was given this diagnosis and I got out and drove home" (Cancer Patient)

Church

Some patients and family members received support from their church during their cancer journey. Church members offered practical support in the form of gardening, cooking meals, visits and phone calls, but also provided spiritual support through prayer. For some individuals, they reported that their faith and

connection with the church was what helped them get through the difficult times.

“I’ve said flippantly that I’ve been getting by on morphine and prayer and virtually that’s what it’s been.” (Cancer Patient)

7.1.2 Experiences & Perceptions of the Psycho-Oncology Service

Qualitative data regarding clients’ (i.e., patients and family members) experiences and perceptions of the psycho-oncology service were also obtained. Clients spoke of their reasons for seeking help, and what their expectations of therapy were, as well as their perceptions of their therapist. Clients also discussed which aspects of therapy they found to be most and least beneficial.

7.1.2.1 Reasons for Seeking Help

The reasons for accessing the psycho-oncology service varied among clients. For many, it was dealing with the diagnosis and prognosis and what that meant to themselves and their family/whanau. Others sought help to cope with the stress associated with treatment and pain. One client struggled with how to cope with the reactions of others, and in the process uncovered unresolved grief issues; some were distressed about the pain associated with dying, and grief over loss of sexuality/femininity. Improving communications with family members was also important, as well as being able to unburden and to talk to someone who had helped others living with cancer.

7.1.2.2 Expectations of Therapy

The majority of clients reported that they did “not really” have any expectations of therapy. However, previous experience of therapy (unrelated to cancer) appeared to influence their perceptions of the potential effectiveness of therapy. Three clients reported having had positive experiences with therapy in the past. They had a general idea of what would be offered and felt that therapy would be beneficial. Three clients had had negative experiences with psychological services. Two of these clients reported being initially sceptical about whether therapy would be helpful. The third client felt that in previous

therapy sessions elsewhere, ideas had been imposed on them. However, having met and felt comfortable with the psycho-oncology service therapist, they felt that they “had a good chance”. This client also recognised that it was something important that they needed to do for themselves.

“ I didn’t really know what it would be like, but I knew that I thought it was really important, because of my own experiences and feeling the whole emotional and mental sort of areas of my life were not catered for in any way in the treatment system, but knowing that they needed to be.” (Cancer Patient)

Clients who had not accessed psychological support services before had a number of different expectations. For one, there was an expectation that it would deal more with the emotional side of cancer rather than the physical side. Others saw it as an opportunity to talk to someone in confidence, and with someone who had an understanding of cancer and other cancer-related services.

7.1.2.3 Therapist Qualities

Therapist qualities played a central role in how clients perceived their overall psycho-oncology experience. All clients highlighted personal qualities of the therapist as important, describing them as being extremely supportive, sympathetic, empathetic, calm, restful, easy to talk to, and quiet in manner. Some reported that they enjoyed talking to and felt connected with their therapist. Many described feeling comfortable around their therapists; that they felt able to speak honestly and openly, able to share their feelings, and discuss things they did not feel able to discuss with anyone else. Clients felt that the therapists really listened to them and gave them their full attention without judgement.

Clients commented not only on their therapist’s personal qualities, but also their professional qualities. Clients reported having a sense of trust in what the therapist was doing. Therapists were described as competent and skilled professionals, who provided honest and practical support. Some clients

reported feeling that they were not just another client, but a person whom the therapist genuinely cared about.

7.1.2.4 Most Beneficial Aspects of Therapy

Five main themes were identified as being most beneficial to clients: individualised support, talking to someone who wasn't family, expertise and structure, regaining a sense of control, and availability/flexibility.

Theme 1. Individualised Support

Many clients valued that therapy specifically focussed on their individual needs rather than a 'one size fits all' approach. They reported that the therapist appeared to understand how they felt and had the time for them, and worked around their needs as they perceived them to be. Clients who had not had positive experiences with therapists in the past commented that they appreciated being spoken to in a way that was on their terms, someone who did not just state what was needed, but listened to what best fit their needs.

"[Therapist] is right on board with what I'm going through and what I've been through, and what we talked about before without constant referral to notes.....I found that really good, that yes, it's not as if [therapist] is scratching through their notes and thinking well who are you and what are you about?" (Cancer Patient)

Clients also felt that therapy was individualised not just with respect to themselves, but to their family as a whole. If others within the cancer patient's family also needed support, this could be addressed in therapy. Patients recognised that their diagnosis had had a huge impact on their children and partners, and therefore valued that family members were able to receive support as well as themselves. Communication within the family was reported to have improved, enabling them to better support each other. Patients appreciated that additional family members who had attended therapy, had felt involved in the treatment process.

“My husband appreciated that he felt acknowledged and included and could address the areas necessary. So it was not just my problem” (Cancer Patient)

Theme 2. Talking to Someone Who Wasn't Family

The majority of clients felt that a crucial aspect of therapy was being able to talk to someone who was not a relative, and who they could talk to without judgement. Because there was no emotional attachment to the therapist, they felt they could talk without fear of hurting them. Many felt that other family members were unsure of how to help them, or would try to give advice which was unhelpful.

“ I often feel when I try to talk to people, within my own family or friends that as I said, it's a like, they try to make it better for me or they try to steer me away, or say “oh you're such and such”. “[therapist] just let me say and be.” (Cancer Patient)

“You talk to someone you don't know differently to someone you do know. And you can say things that might be hurtful to people who in no way in the world want to hurt you, but, and I think it was talking to someone else.” (Cancer Patient)

A number of cancer patients reported receiving a great deal of emotional and practical support, specifically from their partners. However, at times the level of support partners provided was not sufficient. Some felt unable to rely on their partners at all because the partners were not coping well with the diagnosis. For others, their partners were at different stages of coping or acceptance than they were, so they had difficulty talking to them about their concerns.

“My husband's whole part of the journey was very much, very much behind me, quite a few steps behind. And, so it was good to have somebody like [therapist] to talk to, because I couldn't talk to him because he just wasn't coping with it.” (Cancer Patient)

Often how the cancer patient coped with their diagnosis/prognosis differed from their partners, with some preferring to share their feelings and thoughts with others, while their partner did not want to talk to anyone. Family members reported choosing not to share their feelings with their ill partners for fear of upsetting them more. They also struggled with having a need to be supported. There was a sense that they needed help, but that they should be the strong person in the family and hold everything together.

“I’m a husband and a father and it’s my job to be supportive and it’s their job to support me, but I don’t want to put a burden on them when they’re under stress already, so it’s good to have something outside that you can lean on.” (Family Member)

Theme 3. Expertise/Structure

Having support from someone with expertise in the field was particularly important for a number of clients. They felt that the therapists were well prepared and focussed, and provided support in a professional and safe manner. That the therapist often spoke frankly about issues without ‘beating around the bush’ was important for some clients. Clients valued that the therapists helped them to process their own thoughts and realise things for themselves, asking questions that allowed them to think. The therapist was also able to provide something that they could not get from just talking with family and friends, reassurance that they were coping ok and were not doing anything wrong. Some felt that the strategies they had in place were working well, but that it had been helpful to talk through their coping strategies with someone else and receive feedback.

“It’s good to have someone behind you who knows, or has got experience. I think that’s the key. Your family can be supportive, your friends can be, but they don’t have the experience, the specialist experience in this situation to be able to say to you, this is the kind of outcome you can expect from this kind of, this way of looking at things, or even just to say, “you’re doing well.” (Cancer Patient)

Clients appreciated being given practical advice, or specific information about cancer concerns (e.g., about the dying process or what happened at hospices). Therapy provided them with structure for dealing with their worries, providing them with reading material, teaching them coping strategies, such as breathing techniques, or helping them to resolve issues and reframe thoughts.

“It gave me, yeah, a process to go through instead of just getting caught in a loop....it structured how I could process through... it was a clear focussed, structured service” (Cancer Patient)

For some clients, the professional connections that the therapists had with other health professionals working with people with cancer were particularly important.

“The interconnectedness of the different services, the fact that they’ll say, well maybe I can’t help you there, but try ringing this person, or try contacting these people. That’s been really useful because there is no ‘one stop shop’.” (Family Member)

Theme 4. Regaining a Sense of Control

The majority of clients reported that they felt they had no control over their cancer, in a physical sense, but that they had control over how they responded, and how they dealt with it. For some, their sense of control came from their faith and spiritual beliefs. Others made changes in their lifestyle, modifying diet, and increasing exercise. However, a number of clients reported struggling with the sense of loss of control over their lives.

“That’s something I searched for, why? Why did I get it? Not to imply that somebody else should have got it instead of me, but what went wrong within me? Can I do something to make sure that it won’t happen again? And I couldn’t.” (Cancer Patient)

"For a while there, I almost introduced myself, the two connected, "Hi, I'm [name], I've got breast cancer. That was my name! And I didn't want that, I didn't want it to be so dominant that I disappeared." (Cancer Patient)

Many clients reported that the therapists enabled them to regain a sense of control over their lives, giving them the skills to cope, to become more secure in their own feelings. Despite having tried to have a sense of control, many realised that they were not able to do it on their own.

"I was a piece of grass swirling around in a tornado...After seeing [therapist] I felt like I was a brick on the ground in the tornado." (Family Member)

For some, therapy helped them to be able to 'get their life back', by enabling them to get back involved in daily activities, be around other people, go shopping for clothes, or feel good enough about themselves to buy makeup or have their hair coloured. Often the process of going through therapy allowed clients to talk about their concerns and then process them on their own in between therapy sessions, enabling them to have a sense of control over how they managed their distress.

"It [therapy] made me realise that I had to figure out ways, I kind of just expected it would all be handed to me on a silver platter. I had to work at it myself. I still didn't have any control over [cancer], but I had control over the way I felt about it." (Family Member)

Therapy also helped focus clients on the present, and to live in the moment.

"Today is good. And a lot of the counselling was getting my head into that... I don't have tomorrow, I have today and that has always been my attitude. But boy did it focus it! And it clarified things." (Cancer Patient)

Talking to the therapist helped some clients identify what changes they needed to make or how they were viewing/interpreting their situation. Other clients recognised that it was important for them that they learnt how to change themselves rather than being changed by the therapist. Being given the tools to use if they needed them was helpful.

“The fact that [therapist] tried to make it so I actually had to think of a way to fix it, not that they were going to wave their magic wand and fix everything.” (Family Member)

Theme 5. Availability/Flexibility

That the service existed was very important for a number of clients. They were extremely grateful that there was a service specifically set up for those coping with cancer. Many had accessed other local community organisations that provided advice and the opportunity to meet others in similar situations. However, many felt that those services were not able to help them with the specific emotional concerns they had. Having access to a free service was also very important for many clients. Many had struggled to pay medical bills and indicated that they would not have been able to afford to pay for the service.

“I’ve had to pay for everything I’ve done...so it’s been an enormous cost. I felt that this [service] was a gift.” (Cancer Patient)

“There’s four of us, there’s no way we could afford for four of us on our wages to access a service like that if we had to pay for it. ...I don’t think you can underestimate what the value of that is when you’re under stress”. (Cancer Patient)

Clients appreciated that there was flexibility around when and where therapy could take place (e.g., home visits). A number of clients were grateful that if they needed to, they were able to return at a later date, that there was no time limit. Just knowing that the service was there if they needed them in the future, reduced clients' distress.

“There was no limit.....I could come as often and we sorted out when I needed to drop from weekly to fortnightly to monthly to hey, we don’t need to do this anymore. But it was in my time, I felt. I was not pushed, say “Well you’ve only got 6 visits and you’ve got to pay for it.” (Cancer Patient)

“It was my lifesaver. It saved me emotionally and mentally, that’s not actually being too exaggerated. I would have survived, but I think I would still be trapped in a lot of fear that I had. I would not be as strong and determined as I am and as clear and as focused as I am. And my biggest worry is that this service won’t be here when I need it again.” (Cancer Patient)

7.1.2.5 Least Beneficial Aspects of Therapy

The majority of clients were unable to identify aspects of therapy which were not helpful. One client felt that at times the therapist would discuss issues that they did not feel were relevant (e.g., historical family events). Despite the psycho-oncology service being available from a number of locations, for some clients having to travel just outside of the city to the psychology clinic was raised as an inconvenience.

“It would be much easier if I didn’t have to trot out to Massey. I mean, the location of the service is, I found that difficult to access when I was working.” (Cancer Patient)

7.2 Part B: Possible Factors Influencing the Effectiveness of Psycho-Oncology Service Interventions

The second part of Phase 2 was to identify possible factors influencing the effectiveness of the interventions provided by the psycho-oncology service, by comparing those who made the most change in ORS at follow-up with those who made the least change.

7.2.1 Quantitative Group Differences

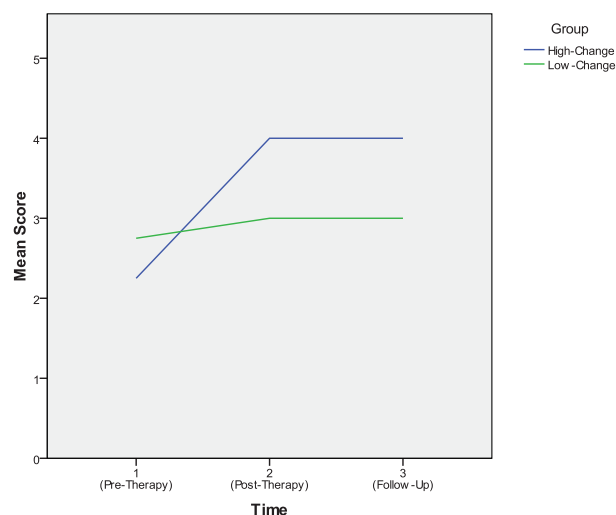
7.2.1.1 Demographics

As shown in Table 6, there was very little difference between the groups with regard to gender, ethnicity, living arrangements, education and cancer type at baseline (pre-therapy/Time1). There was also little difference in the average number of sessions, with the high-change group having an average of 10.5 sessions, and the low-change group having an average of 8.75 sessions. However, the two groups did differ with regard to cancer stage. Three of the four low-change clients were in the treatment stage and one was in the post-treatment stage, whereas all of the high-change group were in the post-treatment stage.

Table 6: Demographic Characteristics of High- and Low-Change Groups

	High Change (N = 4)	Low Change (N = 4)
Relationship to diagnosed %		
Patient	75	75
Family Member	25	25
Age (years)	57	45
Gender %		
Male	25	0
Female	75	100
Ethnicity %		
NZ European	100	75
NZ Maori/European	0	25
Cancer Type %		
Breast	75	100
Ovarian	25	0
Cancer Stage %		
Treatment	0	75
Post Treatment	100	25
Educational Qualifications %		
No formal qualifications	25	25
Trade	25	0
Tertiary	50	75
Living Arrangements %		
Husband or Wife only	75	75
Spouse & children	25	25

Figure 17 shows the change in mean self-rated health scores for the high- and low- change groups over time. Although from the figure, groups appeared to differ, independent t-tests revealed no statistically significant differences between the two groups at Time 1 ($t = -.739$, $p = .488$), Time 2, ($t = 1.464$, $p = .203$), or Time 3 ($t = 1.095$, $p = .315$).



*Figure 17: Change in Mean Self-Rated Health Scores over Time
(High- versus Low-Change)*

7.2.1.2 Main Outcome Measures

Statistical analyses were conducted to examine whether there were any significant differences in outcome measures between the two groups, pre-therapy, post-therapy, or at follow-up. Independent sample t-tests revealed no significant difference in mean ORS scores between the two groups at Time 1 ($t = -7.26$, $p = .50$) or Time 2 ($t = .18$, $p = .86$). However, there was a significant difference between the two groups at Time 3 ($t = 4.49$, $p = .021$). As shown in Figure 18, the high-change group continued to show improvements in ORS, with mean scores increasing from 30.38 (11.31) at Time 2 to 37.03 (.19) at Time 3. However, the low-change group dropped from 29.33 (2.74) to 21.00 (7.14) (i.e., falling below the clinical cut-off of 25).

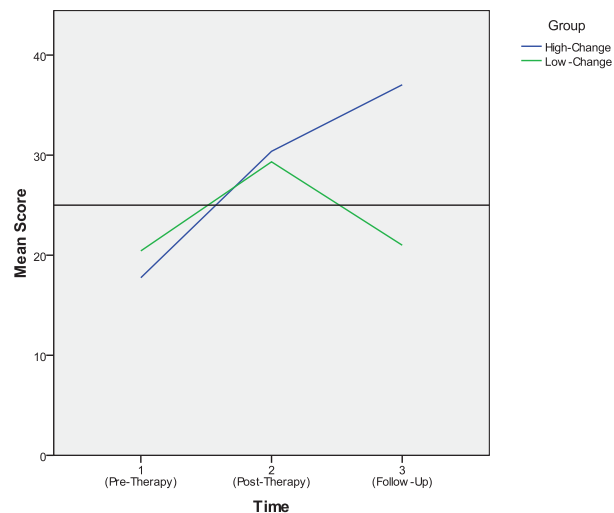


Figure 18: Change in Mean ORS Scores over Time
(High- versus Low-Change)

The change in mean scores over time for wairua, DT, IT and CT are shown in Figures 19-22. Analyses revealed that there were no statistically significant differences in mean scores between the two groups at Time 1 or Time 2. At Time 3, however, there was a statistical difference in mean wairua scores ($t = 3.28$, $p = .031$). The mean wairua score for the high-change group increased from 7.77 to 8.70, whereas for the low-change group, mean scores dropped from 7.73 to 5.93.

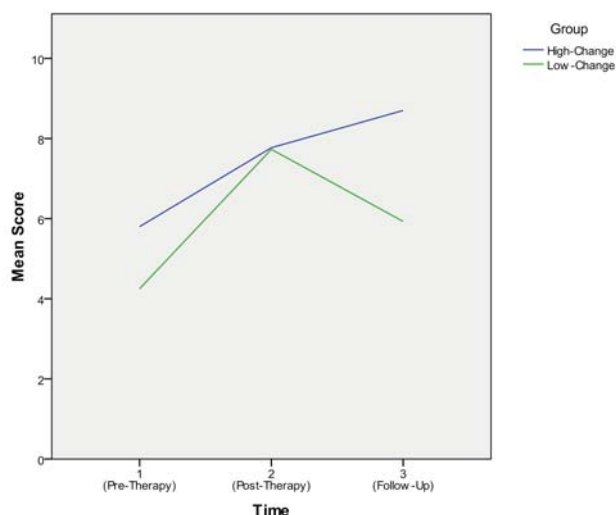


Figure 19: Change in Mean Wairua Scores over Time (High- versus Low-Change)

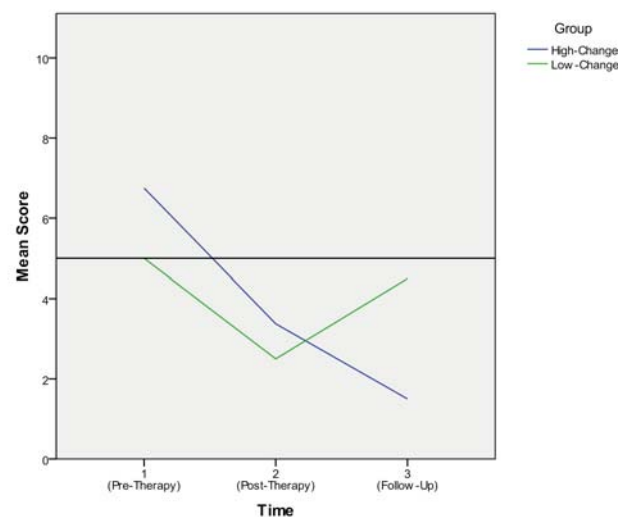


Figure 20: Change in Mean Distress Scores over Time (High- versus Low-Change)

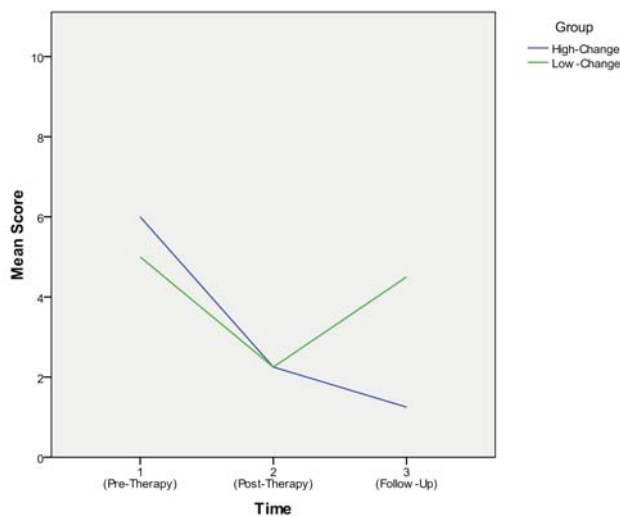


Figure 21: Change in Mean Impact Scores over Time (High- versus Low-Change)

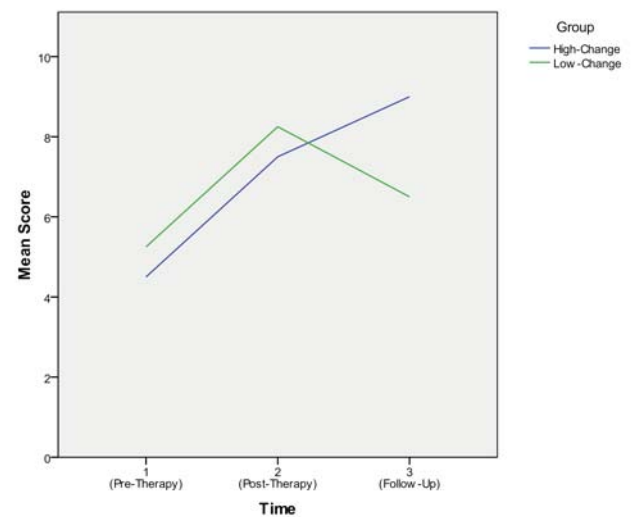


Figure 22: Change in Mean Coping Scores over Time (High- versus Low-Change)

From Time 2 to Time 3, mean changes in distress (DT) ($t = .651$, $p = .059$) and impact (IT) scores ($t = -2.41$, $p = .052$) were approaching significance. At the follow-up (Time 3), 3 out of the 4 low-change group participants had distress (DT) scores above the clinical cut-off (i.e., had clinical levels of distress). These three clients were actively in treatment. Although the high- and low-change groups appeared to show different levels of coping at Time 3, this difference was not significant ($t = 1.608$, $p = .194$).

7.2.2 Qualitative Group Differences

To investigate possible explanations for the differences in outcome measures at follow-up, qualitative analyses of client interviews were undertaken. Therapist qualities, therapeutic alliance, and client factors such as outcome expectancy, self efficacy/sense of control, coping strategies, social support, benefits of therapy, and current life stressors (including health) were considered as possible variables influencing ORS ratings at Time 3 (i.e., 3 month follow-up).

Clients' perceptions of their therapist, and their relationship with the therapist did not differ between those who made a greater change in ORS and those who did not. Clients in both groups reported finding the therapists to be very helpful and extremely supportive and caring. The aspects of therapy clients

found most beneficial were also similar between the two groups. Benefits centred on having someone to talk to and helping them to work through their concerns, as well as facilitate understanding of their situation. The groups did not differ in terms of their expectations of therapy, or their sense of control over their situation. All clients acknowledged that cancer was not something they could control, but that they did have control over how they felt about it. Coping strategies did not differ among the two groups. This is consistent with the finding that statistically, the two groups did not differ with regard to coping at follow-up. The majority of clients in both groups engaged in active-focused coping strategies post-therapy, remaining positive about life, and engaging in problem-solving. Many also accessed additional resources within the community, and made an effort to fill their life with positive and fun activities.

However, there were some noticeable differences between the two groups. All clients in the high-change group reported high levels of social support from friends and family, and that since accessing the service they were more able to ask for help from others. Although some of the low-change group also reported having a lot of support from different people (friends, family, work, community organisations), one client reported having no support from family, and that talking to the therapist had been the only support they had received. Another client reported having some family support, but that they were still reluctant to share emotional concerns with friends and others in the community. They stated that they had received the necessary social support from the psycho-oncology service.

Although statistically there was no significant difference between the two groups with regard to self-rated health, qualitatively, a number of clients in the low-change group reported struggling with physical difficulties relating to their cancer diagnosis. These low-change clients were still receiving treatment, or were in the more advanced stages of cancer. Difficulties reported included loss of sexual arousal, early menopause, increased tiredness, pain, and decreased energy. By comparison, clients in the high-change group reported feeling relatively healthy, with no significant physical difficulties impacting on their life.

Perhaps the most noticeable difference between the two groups was that compared to the high-change group, each of the low-change clients had experienced significant additional challenges post-therapy. Two clients had to cope with the recurrence of cancer, another had experienced difficulties in their living situation, and another was struggling to cope with the ongoing impact of treatment and its side effects. For one client, although they reported that they had been doing well, the week they completed the follow-up ORS, they had noted on the questionnaire that they had had a visit to the specialist that had been stressful.

7.3 Summary of Phase Two Results

Interviews were conducted with a small sample of the intervention group regarding their experience of cancer and their perceptions of the psycho-oncology service. Results revealed that the diagnosis of cancer had a huge initial impact, and although distress decreased over time for some, for the majority, distress levels increased. Prior to therapy, clients used a variety of coping strategies including avoidance, engaging in pleasurable activities, and spirituality. Social support was also viewed as a vitally important coping tool. Although clients had no specific expectations prior to therapy, previous psychotherapy experiences influenced their perceptions of its potential effectiveness. Therapists' personal and professional qualities were viewed as crucial. Five key themes were identified as most beneficial - receiving individualised support, talking to someone who was not family, receiving expert/professional support, regaining a sense of control, and service availability/flexibility. Exploration of possible explanations for group differences in ORS outcome at follow-up indicated that differences existed at follow-up only, not post-therapy. Variables such as perceptions of therapy or the therapist, sense of control or coping strategies did not differ between the low and high-change groups. However, the low-change group experienced significant life events post-therapy (e.g., recurrence, ongoing treatment side effects), and reported more difficulties with health, and less social support.

CHAPTER EIGHT

Discussion

8.1 Outline & Aims

This chapter discusses the major outcomes and findings of this study, which investigated the effectiveness of psycho-oncology interventions in reducing distress and improving quality of life; explored clients' experiences of cancer and their perceptions of the support they received; and explored possible factors influencing the effectiveness of psycho-oncology interventions. The implications of these results will be discussed in relation to current psycho-oncology clinical practice, both within New Zealand and overseas. Finally, the limitations of this research will be identified and discussed as well as future recommendations for research.

8.2 Phase 1: Major Outcomes & Findings

The aim of the first phase of this study was to assess the effectiveness of the interventions provided by a New Zealand psycho-oncology service in reducing distress levels and improving quality of life in those affected by cancer. Participants with and without access to a psycho-oncology service were asked to complete outcome measures (e.g., wellbeing, wairua, distress, impact and coping) at 3 time points: pre-therapy, post-therapy, and 3-month follow-up.

8.2.1 Immediate Treatment Outcomes (T1-T2)

Participants who had access to the psycho-oncology service (intervention group) made statistically, and more importantly, clinically significant improvements in wellbeing and distress over the course of therapy. Statistically significant improvements in wairua, impact and coping were also observed. Although some researchers have been sceptical about the efficacy of psychological interventions for cancer patients/families (e.g., Lepore & Coyne, 2006), the findings of the current study are in line with the large number of efficacy studies highlighting the benefits of psychological interventions (Meyer & Mark, 1995; Devine & Westlake, 1995; Sheard &

Maguire, 1999; Luebbert et al., 2001; Devine, 2003; Rehse & Pukrop, 2003; Osborn, Demoncada & Feuerstein, 2006). The results of this study are also consistent with two effectiveness studies (Ryan, Nitsun, Gilbert & Mason, 2005; Beatty & Koczwara, 2010) demonstrating that psychological interventions provided in a clinical setting are also effective in reducing distress and improving wellbeing.

Those who did not have access to the psycho-oncology service (control group) also made significant improvements in all outcome measures. Some improvement in outcome measures by the control group is likely to occur due to natural changes over time (maturation). However, the significant improvement observed may be explained by the fact that individuals in the control group were 'treatment as usual', rather than 'no-intervention', or 'wait-list-controls' as typically seen in randomised controlled trials. Although the control group did not have access to the psycho-oncology service, some participants had accessed other psychological support over the course of the study, as was evident from information collected at follow-up. Had the control group not had access to any psychological support, significant improvements in wellbeing, distress, wairua, impact and coping may not have been observed.

Despite the fact that, on average, both groups improved, a number of important differences in results existed between the two groups. First, across all measures, the intervention group showed significantly greater improvements in scores than the control group. That is, the intervention group improved at a much faster rate than the control group. Second, although the control group showed an improvement in scores, over half were still clinically distressed at the 'end of therapy'. Third, despite improvements, a greater proportion of the control group indicated that their distress was still having a significant impact on them. And finally, although statistically there were improvements in coping, clinically, the control group showed little improvement in their ability to cope with their distress over time, compared to the intervention group.

Clients' satisfaction with the psycho-oncology service was also obtained from the intervention group. Mean scores compared well with the comparison norms reported by a New Zealand study by Deane (1993). This suggests that people using the psycho-oncology service are at least as satisfied as people who use other psychological services.

This study is one of very few to attempt to evaluate psychotherapy interventions within the clinical setting; therefore, the ability to make direct comparisons with other research is somewhat limited. To enable some comparison between the findings of the present study, and other studies, effect sizes were calculated for the main outcome measure (ORS). Effect sizes were large for the intervention and medium for the control group. The effect size for the intervention group was significantly larger than that of the control group, and the average effect size calculated in many meta-analyses in this area (Cwikel, Behar & Rabson-Hare, 2000; Devine & Westlake, 1995; Rehse & Pukrop, 2003). As Sheard and Maguire (1999) found, larger effect sizes were produced when initial distress score were taken into consideration, which may explain the larger effect sizes in the present study.

8.2.2 Treatment Outcomes at Follow-up (T2-T3)

One of the aims of psycho-oncology interventions is to teach clients skills to manage their distress, and help them develop more effective coping strategies, which can be implemented beyond the therapeutic environment. Consistent with this, the majority of participants who had access to the service maintained high levels of wellbeing and coping, and low levels of distress and impact after therapy had ended. These findings are consistent with other effectiveness studies showing that the gains achieved during therapy were maintained (Ryan, Nitsun, Gilbert & Mason, 2005), as well as efficacy studies demonstrating the short and long-term effectiveness of psychotherapy (Osborn, Demoncada & Feuerstein, 2006).

Although across all measures, intervention group scores appeared to drop slightly at follow-up, for the majority these changes were not statistically significant. This is in contrast to findings by Beatty and Roczwara (2010) who

found that for some clients, gains achieved immediately post-therapy were no longer evident at follow-up, and had, in fact, returned to baseline levels of distress. In the present study, a small reduction in scores is not surprising. During therapy, the intervention group received intensive emotional and social support, advice and feedback; a level of support over and above what patients would typically receive from their family or community. Therefore, when this high level of support was no longer provided, levels of wellbeing would be expected to reduce slightly. Further increases in wellbeing would also not be expected, as at the end of therapy, intervention group scores were higher than those obtained by the non-clinical group in Miller et al.'s study (2003). Those who did not have access to the psycho-oncology service continued to show significant improvements in wellbeing, impact and coping, but not in distress and wairua. Although the change in distress was not significant, the average distress score at follow-up fell within the non-clinically distressed range. Continued improvements in the control group may, again, be due partially to access to psychological support over this period, in combination with natural change over time.

8.2.3 Overall Treatment Outcomes (T1-T3)

Overall, participants who had access to the psycho-oncology service made significant improvements in wellbeing, distress, impact, and coping from the beginning of therapy to 3 months after therapy ended. However, for wairua, despite significant improvements being observed during therapy, there were no significant improvements overall. Those who did not have access to the psycho-oncology service showed significant improvements across all outcome measures. Although it appears that both groups made similar gains after 5 months, it is important to note that the control group took considerably longer (i.e., 5 months) to reach the level of wellbeing, wairua and distress obtained by the intervention group in 2 months. Even after 5 months, the control group had not reached the level of coping and impact achieved by the intervention group in 2 months. That is, the control group were significantly impacted by their distress and less able to cope for a much longer period of time. Furthermore, research suggests that the most significant improvements are typically observed in the early stages of therapy (i.e., first 2-3 sessions) (Howard,

Kopta, Krause & Orlinsky, 1986). Therefore, it is possible that the significant improvements in the intervention group observed at Time 2, in fact, occurred earlier (i.e., in less than 2 months).

8.2.4 *Psychological Interventions & Self-Rated Health*

In addition to improvements in outcome measures, participants who had access to the psycho-oncology also showed a significant improvement in self-rated health over the course of therapy. By comparison, those who did not have access to the psycho-oncology service did not show any improvements. At the 3-month follow-up, self-rated health scores had decreased for the intervention group, but remained unchanged for the control group. Research has suggested that a correlation exists between perceived health and emotional wellbeing (Brown, McMillan & Milroy, 2005, Tessler & Mechanic, 1978). Therefore, one could argue that the change in self-rated health observed in the intervention group during therapy was due to changes in emotional wellbeing. That the control group failed to show an improvement in health, despite an improvement in emotional wellbeing, might suggest that perceived health and emotional wellbeing are not connected. However, this finding may be explained by the fact that although distress levels improved, the majority of the control group were still 'clinically distressed'.

Alternatively, it could also be argued that the improvement in wellbeing and distress was due to an improvement in health. This may have occurred independently of psychological intervention, for example, reduction in tumour size following medical treatment, side effects of treatment may have subsided or been better managed with pain medication. However, health improvements may also have occurred, in part, as a result of psychological intervention. Psychological interventions have been shown to improve health by reducing physical symptoms such as pain (Devine, 2003), nausea (Redd, Montgomery & DuHamel, 2001) and fatigue (Yates et al., 2005), as well as facilitating improved communication between patients and health professionals so that physical concerns are addressed more readily (e.g., Harrington, Noble & Newman, 2004). Psychological interventions have also been shown to increase compliance with medication or acceptance of treatment (Richardson,

Shelton, Krailo & Levine, 1990) or reduce symptoms by recommending regular exercise (MacVicar et al., 1989). Although there are a number of possible explanations, it is not clear which factors were responsible for changes in self-rated health based on results from the present study. A randomised controlled trial may have been more able to accurately determine the factors responsible for these changes.

8.2.5 Cancer Patients versus Family Members

To examine whether patients and family members experienced similar levels of distress, wellbeing, wairua, impact and coping, data from patients and family members was compared pre- and post-therapy, as well as at follow-up. On the whole, levels of wellbeing, wairua, distress, impact and coping did not differ significantly between cancer patients and family members. This finding is consistent with a number of studies highlighting the significant impact a cancer diagnosis can have not just on the patient, but others in the family (Compas et al., 1999; Northouse & Stetz, 1989). Although some studies have reported that distress in family members increases over time (e.g., Given & Given, 1992), consistent with Hoskins (1995), distress levels of family members in the present study decreased over time.

Although there were no significant differences between patients and family members overall, patients in the intervention group reported higher levels of coping and wairua prior to therapy than family members. Although one might predict that those with the disease would have the most difficulty coping, these findings are less surprising when considering the feedback from some patients stating that they and their partners had very different ways of coping, and were also at different stages of coping. Such differences in coping styles have been reported in earlier research. For example, Ben-Zur, Gilbar and Lev (2001) found that patients tended to use more effective coping strategies (e.g., problem solving) than their spouses. Cooper (1984) reported that family members did not talk as much and would often hold back more than the patient. According to Fife, Kennedy and Robinson (1994) and Hoekstra-Weebers, Jaspers, Kamps and Klip (1998), gender differences could also account for these coping differences. However, this was not the case in the

present study, as the majority of participants were female. Alternatively, there may have been differences in social support, with family, community and professional support being more readily available to cancer patients than their families (Northouse, 1988; Northouse, Templin, Mood & Oberst, 1998; Payne, Smith & Dean, 1999). Reports of higher wairua amongst patients may also partially explain their higher levels of coping. For many patients, a cancer diagnosis may cause them to question their meaning in life, and be fearful of the possibility of death, more so than for a family member. As such, they may be more likely to turn to spiritual support and guidance. Spiritual support has been reported to enhance coping, despite significant distress (Brady, Peterman, Fitchett, Mo & Cella, 1999).

8.3 Phase 2: Major Outcomes & Findings

The second phase of this study was two-fold. A small sample of intervention group participants was interviewed to examine their experiences of their cancer journey and the psycho-oncology service. Interviews were also examined to identify possible factors influencing the effectiveness of the psycho-oncology interventions they received.

8.3.1 The Cancer Journey

Being informed of their cancer diagnosis had a significant psychological impact on patients and family members in the present study. Feelings of anxiety were particularly common. Throughout the psycho-oncology literature, anxiety has been recognised as one of the major 'side effects' of a cancer diagnosis (e.g., Bottomley & Jones, 1997; Derogatis et al., 1983; Zabora et al., 2001). In this study, patients' anxiety mainly centred on their and their family's future. For family members, however, the focus of their anxiety was more on the present and getting through each day. This may reflect the fact that carers often put their own worries and concerns about the future on hold while they focus on the patients' current needs (Vess, Moreland, Schwebel & Kraut, 1988).

The unsupportive manner in which some patients in the present study were informed of their diagnosis left them unable to communicate openly with their

doctors during subsequent visits. They reported being reluctant to ask questions and discuss concerns with their doctor for fear of looking stupid or wasting the doctor's time with unnecessary worries. Poor communication between health professionals and patients with cancer has been shown to have a significant impact on a patient's ability to cope (Faulkner & Maguire, 1994; Kerr, Engel, Schlesinger-Raab, Sauer & Holzel, 2003). Fallowfield and colleagues (1994, 1999), and Jenkins, Fallowfield and Saul (2001) found that clinicians often underestimated the amount of information that patients required, and only disclosed certain information if asked by patients.

Cancer patients and family members in the present study used a variety of coping strategies to manage their distress prior to accessing the service. Avoidant coping strategies were employed by a number of individuals (e.g., denial, distancing), however, these were acknowledged as having been unhelpful. This finding is in keeping with previous research showing such coping strategies to be detrimental in the psychological adjustment to cancer (e.g., Heim, Valach, & Schaffner, 1997). Some clients had also engaged in coping strategies such as talking with friends and family and thinking positively, which have been shown to help reduce distress (Compas et al., 1996; Zabalegui, 1999; Livneh, 2000). However, that these clients were still experiencing significant distress suggests that these coping strategies alone were not sufficient, or were perhaps not addressing the key issues which ultimately led them to seek support.

Spirituality and religious beliefs also provided a strong source of strength for a small number of clients and there was an acknowledgement that a holistic approach to their healing was necessary. Previous research has revealed that spirituality can be a strong and effective coping strategy in times of distress, providing emotional as well as social support (e.g., Chibnall, Videen, Duckro & Miller, 2002; Nelson, Rosenfeld, Breitbart, & Galletta, 2002; Rippentrop, Altmaier, & Burns, 2006). Interestingly, in the present study, those who reported relying on prayer and spirituality to "get them through," were also those who reported having a lack of support from, or had difficulty sharing concerns with, family. Therefore, for these clients, prayer and a connection

with the church appeared to provide an outlet for expressing and sharing feelings, which has been shown to increase psychological wellbeing (Bottomley, 1997).

Social support was considered to be very helpful by the majority of clients. Most reported receiving high levels of social support from a variety of sources, which made their day-to-day lives more enjoyable and manageable. Research has consistently shown that social support can play a significant role in helping people with cancer cope with their diagnosis (Arora et al., 2007; Bloom et al., 2001; Dunkel-Schetter, 1984; Helgeson & Cohen, 1996; Shelby et al., 2008), by sharing work and home demands, providing a 'listening ear', and helping them remain actively engaged in social and community activities. As previously identified by House (1981), in this study different types of social support were provided by different groups of people. For most, friends and family provided satisfactory levels of emotional and instrumental (i.e., practical) support. However, the ability of some partners/spouses to provide sufficient levels of emotional support was greatly influenced by their own coping ability. Workplace support helped alleviate stress associated with financial matters and allowed clients to maintain a sense of purpose by continuing to work (Bouknight, Bradley & Luo, 2006; Kennedy, Haslam, Munir & Pryce, 2007; Main et al., 2005). Support from medical professionals predominantly involved providing medical information, with many clients acknowledging that there was only so much emotional support health professionals were able to offer.

8.3.2 Perceptions & Experiences of the Psycho-Oncology Service

Reasons for accessing the psycho-oncology service centred on coping with the diagnosis/prognosis, dealing with the impact of treatment and improving communication within the family. These reasons for seeking help are consistent with many studies examining the cancer patients' and families' need for support (Pandey et al., 2006; Portenoy et al., 1994; Kilpatrick et al., 1998; Hawighorst et al., 2004). Although the majority of reasons were cancer-related, some found that therapy brought up past issues which needed to be addressed, unrelated to their diagnosis. Similarly, Salander (2009) found that

33% of people with cancer sought help for issues not connected, or only somewhat connected, to the cancer disease.

Consistent with findings from Ohlen (2006), the majority of clients interviewed in the present study did not have any particular expectations of therapy. This finding is in stark contrast to the results from Kerry's study (2009), in which participants reported very specific expectations, not only about the therapist, and their role, but also the structure of therapy. It is also interesting that clients in the present study did not report specific expectations even though they had previous experience of therapy. This may be due to the possibility that clients perceived specialised psycho-oncology support to be very different from previous therapy experiences and therefore were unsure what to expect. Clients were also significantly distressed at the time of intake, and were extremely grateful that the service was available and was free. Therefore, some may not have felt that it was appropriate to hold any particular expectations. Although no specific expectations were reported, there was a general expectation that it would be beneficial. This was particularly evident amongst those who had had positive experiences of psychotherapy in the past. Positive expectations of therapy have been shown to have a positive impact on therapy outcome (Lambert, 1992; Noble, Douglas, & Newman, 2001). Therefore, it is possible that having these positive beliefs contributed to the success of therapy seen in the current study.

All clients in this study felt that having a good relationship with their therapist was a crucial aspect of therapy. Working through their difficulties with someone who was both personable and professional was extremely important. A strong therapeutic relationship has consistently been shown to be a significant contributor to positive therapy outcomes (Brent & Kolko, 1998; Horvath & Symonds, 1991; Littauer, Sexton & Wynn, 2005, MacCormack et al., 2001). That clients valued having a good connection with their therapist is also consistent with a number of other themes identified by clients as being important aspects of therapy. Many of these themes centre around one overarching positive experience - of the therapist 'really being there for them'.

Clients valued that therapy was individualised, and that therapists focussed on the client's needs as the client perceived them to be. The importance of therapists being flexible and following the client's agenda rather than their own has been identified as being important in a number of studies (e.g., Taylor & Ingleton, 2003; Trijsburg et al., 1992). It was also important to clients that consideration was given to other family members, that the family was able to be involved and receive support if necessary. The involvement of other family members in therapy, as well as offering them individual support, has been found to benefit the entire family. For example, Martire et al. (2004) found that including spouses in therapy had a positive effect on depression in people with cancer, and that among family members, positive effects were found for caregiver burden, depression, and anxiety. MacCormack et al. (2001) found that clients valued family participation in therapy sessions, and stated that therapy would have been more helpful had there been sessions set aside for family members who were not coping. Having to support non-coping family members was an additional burden that many people with cancer could not deal with. Consistent with findings from Boulton et al. (2001), some family members in the current study indicated that therapy provided an opportunity for them to recognise that their own emotional needs were just as important as those of the patient.

Being able to talk with someone who was not family was very important to clients. The importance of having external support in addition to family has been well documented (Walker et al., 2000; MacCormack, et al., 2001; Boulton et al., 2001). Many patients and family members are scared of causing further distress by burdening each other with their concerns, and being able to talk freely to an independent person can be a huge relief for many individuals. Often family members are experiencing similar levels of distress to that of the patient, and therefore are not be able to provide the necessary emotional support (Hagedoorn, Buunk, Kuijer, Wobbles & Sanderman, 2000). In addition, certain types of emotional support provided by friends and family (e.g., reassurance such as "you'll be fine" or "it'll all work out") are not perceived as helpful by those with cancer (Dunkel-Shetter, 1984).

Clients valued receiving advice and support from someone with expertise, someone who could cope emotionally with whatever issues they raised (unlike family/friends). Clients valued that they could share their experiences with someone who had knowledge in the area, and who would respond honestly. Being 'frank' and answering questions without hesitation has been shown to enhance trust (Wright, Holcombe & Salmon, 2004). Similarly, Bischoff and McBride (1996) noted that clients found it reassuring to be able to confide in someone who was an expert at solving problems. Although this would suggest that clients prefer a somewhat less collaborative approach to therapy, as Bischoff and McBride highlighted, it is likely that placing trust and value in such 'expertise' would first require a strong therapist-client relationship, in which the client felt a sense of empathy, understanding and mutual respect.

Clients reported that therapy helped them to regain a sense of control in their lives. Although it is unclear exactly what clients meant by a 'sense of control', theory suggests that self efficacy is a large part of it. Self efficacy is well recognised as enhancing psychological wellbeing (Cunningham et al., 1991; Lev & Owen, 1996; Kreitler et al., 2007). Boulton et al. (2001) found that as a result of therapy, clients had an increased sense of control, and subsequently developed a new attitude towards life and felt more positive about how to approach their future. In the current study, self efficacy was not only enhanced through the teaching of self-coping strategies, but also through the process of therapy itself - therapy was collaborative, rather than instructive. Clients recognised that they played an important role in therapy, identifying and working through their concerns rather than just being the passive recipient of information and advice.

Finally, clients valued that the psycho-oncology service existed. While support from other community services was helpful, it often did not meet clients' specific emotional needs. Wilkinson et al. (2007) also found that clients were extremely appreciative that specialised psycho-oncology services were available. In this study, having access to a free service was also very important, as many clients had struggled to pay medical bills and indicated that they would not have been able to afford to pay for the service. Clients also

valued that the service was not time-limited. Results from previous studies have indicated that when the number of sessions is limited, clients are often left 'hanging' (MacCormack et al., 2001). Boulton et al. (2001) also found that many clients felt they would have benefited from more sessions than were available.

8.3.3 Key Factors Influencing Intervention Outcomes

The second part of Phase 2 was to identify possible factors influencing the effectiveness of the interventions provided by the psycho-oncology service. Participants who had made the greatest and least change in ORS at follow-up were interviewed. Quantitatively, there were no significant differences between the high- and low-change groups in outcome measures pre- or immediately post-therapy. However, the two groups differed significantly at follow-up. Average scores in the high-change group remained in the non-clinical range. However, for the low-change group, average scores fell back into the clinical range of distress, a similar finding to that of Beatty and Koczwara (2010). Although it is difficult to make any solid conclusions given the small sample size, consistent with previous research (Baider, Uziely & DeNour, 1994; Johnson, 1982; MacDonald, 1994; Petry, Tennen & Affleck, 2000), demographic characteristics such as client age, gender and race did not appear to influence treatment outcome at follow-up. Qualitatively, no differences in perceptions and experiences of the psycho-oncology service were reported. This is supported by the quantitative data indicating that at the end of therapy there were no significant differences in outcome between the two groups.

Contrary to previous research highlighting the effect of self efficacy and expectation on treatment outcome (Cunningham, Lockwood & Edmonds, 1991; Cunningham Lockwood & Edmonds, 1993; Graves & Carter, 2005) these factors did not appear to play a major role in treatment outcome in the present study. Rather, external factors unrelated to service provision (e.g., recurrence, ongoing treatment side effects, lack of social support, and deterioration in physical health), appeared to play a significant role in determining level of distress and wellbeing at follow-up. This is consistent with

earlier research examining factors influencing treatment effectiveness. As Lambert (1992) stated, client variables and influences outside of therapy may account for as much as 40% of client improvement. A further explanation for these findings is discussed in the limitations of the study.

8.4 Implications of Findings

The findings from this study have a number of implications for current psycho-oncology practice. These are each discussed below.

8.4.1 The Benefits of Psychotherapy & Service Provision

The results of this study indicate that psycho-oncology interventions are likely to be beneficial for New Zealanders affected by cancer. The impact of a cancer diagnosis is significant and long-lasting, causing high levels of distress and poor quality of life. Unfortunately, specialist psycho-oncology services are limited in New Zealand. However, the findings from this research indicate that there may be value in providing psycho-oncology services throughout New Zealand. Although many community services and organisations exist throughout the country, providing varying degrees of social and emotional support, the results from the present study and others (e.g., Surgenor et al., 2006) indicate that the specific emotional needs of those with cancer, and their families, are still not being sufficiently met. This study revealed that a high percentage of people without access to specialist psychological services are experiencing significantly high levels of distress, and suggests that this distress may be reduced more quickly and effectively if such services were available. Furthermore, the feedback from those who did not have access to specialist psychological support was that they would have accessed it, had it been available.

Feedback from study participants indicates that psycho-oncology services need to be easily accessible. Many people with cancer, and their families, face increased financial stress due to reduced ability to work and treatment costs. Paying for additional services (e.g., private psychological services) is usually not possible. The provision of government-funded or subsidised psycho-

oncology services would increase access and may ultimately reduce the need for more costly health-related services, for example, hospital, medicines (e.g., for pain, nausea). Psycho-oncology services also need to be flexible, with regard to locality, as patients may be too ill to travel from home or hospital. Given the nature of cancer, it is also important for clients to feel able to contact services again in the future if necessary (e.g., disease progression, recurrence, bereavement). As this study highlighted, it may also be valuable for psycho-oncology services to maintain strong links with other cancer-related services, and encourage good communication between clients and their health professionals.

8.4.2 Strengthening the Therapeutic Relationship

The qualitative results from this study indicate that what clients tend to value the most in therapy is a strong therapeutic alliance - an opportunity to express emotions and increase self efficacy, coupled with therapist qualities such as warmth and understanding. It is important to continue to recognise that although specific therapeutic techniques are effective in reducing distress and improving quality of life, from the client's perspective, at the heart of therapy is the therapist-client relationship. If a personal and mutually respectful connection is not established and maintained between the clinician and the client, no amount of techniques will be effective. Clients may disengage through lack of contribution to therapy sessions, non-completion of homework, or stop accessing therapy all together. It is also important that interventions remain focused on the client's needs. This may be best achieved by obtaining feedback from the client at the end of each therapy session. Duncan and colleagues (2000; 2004) have found that clients show significant improvements in outcome from treatment when therapists have access to immediate, in-therapy feedback from clients regarding the process and outcome of therapy.

8.4.3 Holistic Approach to Therapy

8.4.3.1 Supporting Family Members

Although psychological support for people with cancer is greatly acknowledged, support for family members is less so. This study indicates that in New Zealand, cancer has an equally significant psychological impact on

family members as it does on patients, and that how each person in the family copes significantly impacts on the other family members. In this study, incongruencies existed between how patients and family members coped (e.g., communication versus non-communication), which limited their ability to support each other. The results also revealed that those who were more distressed 3 months after therapy had ended, had less support from other family members. Therefore, there is value in providing psychological support family members, so that all members of the family are able to support each other effectively once therapy has ended.

8.4.3.2 Quality of Life

Cancer affects many facets of an individual's life, functionally, physically, socially, emotionally, and spiritually, and it is important that all these different aspects of wellbeing are addressed within a psycho-oncology framework. As this study has highlighted, psychotherapy can have a positive impact on perceived physical wellbeing, spiritual wellbeing, as well as emotional wellbeing. Therapy may also raise some non-cancer related issues, and it is important that these are addressed, as they are likely to have a negative impact on the cancer journey. In New Zealand, a holistic approach to health is increasingly being acknowledged as beneficial by the general population, and has long been seen as crucial by many non-Pakeha ethnic groups. Therefore, it is important that psycho-oncology services strive to provide support that attends to all aspects of wellbeing, to ensure that the needs of all New Zealand individuals are acknowledged and supported.

8.4.3.3 Beyond Therapy

The findings of the current study have shown that the majority of psycho-oncology service clients maintained low levels of distress and wellbeing 3 months after therapy had ended. For this group, having strong family and community support networks appeared to play an important role in helping to maintain high levels of wellbeing post-therapy. However, for some clients, distress levels were again in the clinical range. Significant life events such as recurrence, poor communication with family and health professionals, and lack of social support, appeared to contribute to this increase in distress.

Therefore, it may be beneficial to not only focus on the client's primary reason for seeking support, but also to consider other difficulties (poor social support, communication) which may influence the long-term effectiveness of therapy. For example, ensuring that clients are aware of and feel able to link in with other community support services once therapy has ended; and ensuring that clients feel better able to communicate with other health professionals and family members. Research has shown that group therapy can be beneficial for those with limited social support (Helgeson, Cohen, Shultz, & Yasko, 2000; Manne et al., 2005). Therefore, the provision of group therapy, in addition to individual and family therapy should be considered when providing psychological support services.

8.5 Study Limitations & Recommendations for Future Research

The aim of this study was to investigate the effectiveness of psychological interventions as they were offered in clinical practice. Because it was not appropriate to deny clients access to the service for research purposes, the study sample was not randomised, raising the possibility of problems with internal validity. Despite a number of measures being put in place to reduce threats to internal validity, it is possible that some threats still remained. The two treatment groups differed significantly with regard to sample size, which may have affected the significance of test results due to differences in error variance. Because overall sample sizes were small, study results may not be generalisable to all service users, or to the general cancer population, and should therefore be interpreted with caution. Some participants were also part of a couple, therefore, their data may not be considered to be independent. Although living in the same dwelling, it was anticipated that each participant would complete their own questionnaire independently, without collaboration with their spouse. However, it is possible that some responses given were influenced by the emotions and experiences of the other spouse. This is important because it could be seen to breach one of the assumptions of the statistical processes used. It is possible that the improvements in both groups over time may have been influenced by other factors in addition to treatment

condition. For example, because the intervention group were recruited post-therapy, it is possible that the study sample may have been affected by self-selection bias. That is, clients who benefited from therapy chose to participate in the research, and those who had not, did not. Also, as discussed earlier, the control group was 'treatment-as-usual', rather than 'non-treatment'. Therefore, some participants in the control group received psychological support during the course of the study. Although unlikely, it is also possible that there was a potential time bias, which could have introduced differences in cancer treatment that participants received. This is because the intervention group were recruited post-therapy (T3), with retrospective data being collected at T1 and T2. Whereas the control group were recruited at study commencement (T1), and were followed prospectively (T2 & T3).

Participants in this study were predominantly women with breast cancer. Therefore, it is unknown whether psychological support was just as effective for males or women with other cancers. This is unfortunate, as a recent meta-analysis by Heron (2009) reported that psychological interventions were most beneficial for those who were least likely to receive it (e.g., males and clients with non-breast cancers). This finding suggests that had clients in these groups been more evenly represented in the present study, those in the intervention group would have shown even greater effect sizes. Maori and Pacific Island clients were also under-represented in the study, which is unfortunate given the higher rates of cancer in this population. Further research needs to be conducted within these populations.

In addition to exploring changes in distress over time, this study also attempted to look at possible factors influencing outcome. Research has suggested that clients' perceptions of the therapeutic experience may differ from that of the therapists' (Weiss, Rabinowitz & Spiro, 1996). Therefore, interviewing the therapists would have provided important data regarding therapist views of the key aspects of psychotherapy within this specialised clinical setting. Both factors, effective techniques combined with a good therapeutic relationship, have been shown to maximise the effectiveness of therapy (Lambert, 2004). Clients may benefit from effective techniques without any conscious

awareness of what is being used. However, therapists who have been schooled in utilising certain techniques may, at times, not consciously focus on relationship factors, which are also important in ensuring an effective intervention (Lambert, 2004). Additionally, clients' perceptions of their therapy experience were also obtained three months post-therapy. Therefore, it is possible that clients' recall of events became less specific over time, instead providing a more global account of their experience. Future research may benefit from talking with clients immediately after therapy has ceased, or during the course of therapy, as more specific technique-related elements of therapy may be identified by clients.

In hindsight, the method for choosing the high- and low-change groups may not have been the most appropriate. Differences in ORS change scores over time were examined at follow-up. Although this provided a unique look at the extended effectiveness of psychological interventions, analyses showed no statistical or qualitative differences between the two groups at the end of therapy. Had low and high-change groups been identified at the end of therapy rather than at follow-up, it is possible that more therapeutic rather than external factors may have been identified as being responsible for treatment outcome. Additionally, rather than comparing those who made the most and least change over time, it may be more clinically beneficial for future studies to compare those who showed a clinically significant change with those who did not, and examine possible explanations for this.

8.6 Conclusions

The goal of this present study was to provide valuable New Zealand-based data regarding the impact of cancer on patients and their families, and the effectiveness of psycho-oncology interventions in reducing this impact. The results of this study suggest that the provision of psycho-oncology interventions may significantly, and quickly, reduce the distress experienced by those affected by cancer, as well as enhance their quality of life. Unfortunately, the results of this study also suggest that a large percentage of the New Zealand cancer population are experiencing significant emotional

distress, but do not currently have access to the necessary psychological support.

Not only have these results provided support for the benefits of psycho-oncology interventions for New Zealanders with cancer, and their families, they have also contributed valuable data to the small number of international studies exploring clients' perceptions of therapy. Clients provide crucial information regarding the success of support services. Only by continuing to explore clients' perceptions of the therapeutic experience can we truly begin to provide therapy that best meets their needs.

This study has also contributed valuable data to the currently sparse psycho-oncology literature regarding the effectiveness of psychological interventions as they are practised in clinical settings. Although randomised controlled trials have shown psychotherapy to be effective in reducing distress and improving quality of life, it is important that there is clinical evidence to support this.

Finally, this research has been a forerunner for the changes recommended in the Supportive Care Guidelines put forth by the New Zealand Ministry of Health (2010). The Guidelines state that "evaluation should be an integral part of new service models and in determining the effectiveness of programmes/interventions" (p. 2). In keeping with this statement, the present study has provided empirical and clinical evidence that psycho-oncology interventions provided by a New Zealand psycho-oncology service are quite an effective and a valued part of supportive care for people with cancer, and their families.

Despite its limitations, it is hoped that the results from this study will not only inform the practice of clinicians providing psychological support for people with cancer and their families in New Zealand, but may also guide the decision-making of those responsible for ensuring that the goals of the Cancer Control Strategy and the Supportive Care Guidelines are fulfilled. In summary, the results of this research provide a unique contribution to the limited psycho-oncology research in New Zealand. It is hoped that these findings will help

contribute to ongoing research aimed at ensuring that over time, more New Zealanders with cancer, and their families, are able to access the benefits of psycho-oncological interventions than are currently available through publicly funded providers.

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APPENDICES

Appendix A: Information Sheet (Intervention Group)



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An Investigation of the Outcomes of the Psycho-Oncology Service Interventions

INFORMATION SHEET

Introduction

You are invited to participate in a research project conducted through Massey University. The Psycho-Oncology Service, available within the MidCentral District Health area, provides specific psychological support to those affected by cancer. The aim of this study is to determine how effective the Psycho-Oncology Service is in alleviating distress and improving wellbeing, and also to identify factors that might influence how effective the support is. By obtaining this information, the service can make improvements, ensuring that clients receive psychological support that is best tailored to their needs. As the Psycho-Oncology Service is the first of its kind in New Zealand, this study will also provide information for other DHBs to consider, when they look at whether they are going to provide such a service. This invitation has been sent to you by the Psycho-Oncology Clinic administrator. Only if you consent to take part in this research will the researchers know who has been contacted.

Why have I been chosen?

All clients over 18 years of age, who have received support from the Psycho-Oncology Service on at least two consecutive occasions, are invited to take part in the study. The study is seeking 240 participants.

Do I have to take part?

Your participation is entirely voluntary (your choice). If you choose not to take part this will not affect any contact you have with the Psycho-Oncology Service. We recognise that cancer can be associated with physical illness and would encourage you not to complete the questionnaire if you do not feel up to it. If you decide to participate, you have the right to:

- decline to answer any particular question
- withdraw from the study at any time, without giving a reason
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used without permission
- if interviewed, ask for the audio tape to be turned off at any time during the interview
- receive a summary of the project findings when it is concluded

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone: (NZ wide) 0800 555 050; Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT); Email (NZ wide): advocacy@hdc.org.nz

If I choose to take part, what do I have to do?

As part of standard practice within the Psycho-Oncology Service most clients are asked to complete a sheet of rating scales at the beginning of each session. If you choose to participate you would give consent for the researcher to obtain a copy of your rating scales that are on your Psycho-Oncology Service file. On receiving this invitation and consenting to participate, you would also complete the same sheet of rating scales, a demographics sheet and a brief satisfaction questionnaire, returning them to the researcher in a prepaid envelope provided. By looking at your rating scales completed during and after therapy, we can see if the support you received from the service has contributed to any improvement in your level of wellbeing over time. To determine which issues are most

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important to those dealing with cancer, the researcher would also like to find out what lead you to seek support (from your referral letter), and obtain service information from the cover of your file (e.g., no. of sessions, type of therapy). The researcher will not have access to your session notes.

In addition, the researcher would like to talk with a small number of people about their experience accessing the Psycho-Oncology Service, the support they've received and how they have coped. The interview allows us to look more closely at factors that might influence how well a person copes with any distress they experience during their or their family member's cancer journey, and how effective the psychological support was that they received from the service. If you give consent, you may be asked to take part in one interview (approx. 1 hr). You are under no obligation to take part in an interview if you choose to complete the rating scales. The interview could either take place at your home, at the Psychology Clinic, or an alternative location, whichever you prefer.

Will my taking part in this study be kept confidential and anonymous?

Your name and contact details will be separated from your rating sheets, interview transcripts, demographic information and satisfaction questionnaires by the researcher. Any answers you give will be treated with confidence by the research team. All data relating to the research will be kept in a locked office and will only be accessed by the research team. Data will be stored for 5 years, after which time it will be destroyed.

What will happen to the results?

You and your family will not be identified in any report or publication. Group information will be used to inform the Psycho-Oncology Service about the quality of the psychological support they provide, and enable them to look for ways to make improvements. The results will also provide information for other DHBs to consider, when they look at whether they are going to implement such a service. The information will inform the international psycho-oncology community through articles and presentations at conferences and a report will be given to the MidCentral District Health Board. The results of the study will also be published as the researcher's Doctoral Thesis.

If a participant would like a summary of the research findings they can indicate this on the consent form. The consent form will be separated from the completed questionnaires to preserve the confidentiality and anonymity of the participants. We cannot indicate at this stage how long it will take to send you this summary as it is unclear how long it will take to gather enough responses.

Who are the researchers?

This research project is being conducted by Philippa Croy, a Doctorate of Clinical Psychology student, with support from the Psycho-Oncology Service and the MidCentral District Health Board. The supervisors for this research are Cheryl Woolley, Dr Don Baken and Dr Janet Leatham. They are all clinical psychologists and staff members of the School of Psychology at Massey University.

If you have any questions or concerns regarding this project please contact Philippa Croy.

Philippa Croy
School of Psychology
Massey University
Private Box 756
Wellington
Ph:
Email:

If you would like to contact the Psychology Clinic for any other reason, please contact:

Ph: (06) 350 5196
Fax: (06) 350 2264
Email:

This study has received ethical approval from the Multi-region Ethics Committee which reviews National and Multi regional studies.

Appendix B: Consent Form (Intervention Group)



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An Investigation of the Outcomes of the Psycho-Oncology Service Interventions

CONSENT FORM

- I have read and understand the information sheet for volunteers taking part in the study designed to investigate the outcomes of the Psycho-Oncology Service interventions. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I agree to participate in this study under the conditions set out in the Information Sheet.
- I am happy to be contacted about an interview. Yes / No
- I agree to the interview being audio taped. Yes / No / NA
- I would like to be sent a summary of the results when the study is complete. Yes / No

Full Printed Name: _____

Signature: _____ Date: ____/____/____

Address: _____

Phone No: _____

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So that we can know a little about those who have taken part in our study, please answer as many of the following questions as possible. If there are any you do not want to answer, please leave them blank.

	D	D		M	M	19		
	Day			Month		Year		

	Male	<input type="checkbox"/>
	Female	<input type="checkbox"/>

What is your relationship to the diagnosed person? (Please tick one box)

Self	<input type="checkbox"/>
Other (Please state below)	<input type="checkbox"/>

Pakeha / New Zealander of European descent ☐

NZ Māori ☐

Iwi _____ Hapu _____

Pacific Islander ☐

Asian ☐

Other (please state below) ☐

My legal husband or wife ☐

My partner or de facto, boyfriend or girlfriend ☐

My son(s) and/or daughter(s) ☐

My mother and/or father ☐

My sister(s) and/or brother(s) ☐

Other (Please state: e.g. grandparents, flatmates etc) ☐

None of the above – I live alone ☐

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

Q 7 What is the highest qualification that you've completed? (Please tick one box)

No school qualifications	<input type="checkbox"/>
NZ School Certificate	<input type="checkbox"/>
NZ Sixth Form Certificate	<input type="checkbox"/>
NZ University Entrance	<input type="checkbox"/>
NZ A/B Bursary or University Scholarship	<input type="checkbox"/>
Tertiary Qualification	<input type="checkbox"/>
Trade Qualification	<input type="checkbox"/>

Q 8 What is/has been your occupation? _____

Q 9 Which type of cancer were you/your family member diagnosed with? _____

Q 10 In what year were you/your family member diagnosed? _____

Q 11 Which stage of the Cancer Continuum best describes your/your family member's situation?

Diagnosis	<input type="checkbox"/>
Treatment (please state type) _____	<input type="checkbox"/>
Post Treatment	<input type="checkbox"/>
Disease Recurrence	<input type="checkbox"/>
Palliative Care	<input type="checkbox"/>
Hospice	<input type="checkbox"/>

Q 12 Have you seen a professional for psychological support in the past, for reasons unrelated to the cancer diagnosis?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

Q 13a Since the cancer diagnosis, how much support (emotional and/or social) have you received from the following people? (Please tick all that apply)

	No support	A little bit of support	Quite a bit of support	A lot of support
Your Family/Whanau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your Church	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professionals (e.g., Social Worker, Psychologist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix D: Outcome Measures (Intervention Group)**Outcome Rating Scale (ORS)**

Name _____ Age (Yrs): _____ Sex: M / F
 Session # _____ Date: _____
 Who is filling out this form? Please check one: Self _____ Other _____
 If other, what is your relationship to this person? _____

Looking back over the last week, including today, help us understand how you have been feeling by rating how well you have been doing in the following areas of your life, where marks to the left represent low levels and marks to the right indicate high levels. *If you are filling out this form for another person, please fill out according to how you think he or she is doing.*

Individually
 (Personal well-being)

I-----I

Interpersonally
 (Family, close relationships)

I-----I

Socially
 (Work, school, friendships)

I-----I

Overall
 (General sense of well-being)

I-----I

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Please Turn Over

Sense of Meaning/Wairua
(purpose, belief, spiritual wellbeing)

(low) I-----I (high)

If you and your psychologist have agreed on an issue that is the focus for your therapy, indicate on this scale how well you have been doing with regard to this issue in the past week, including today.

Target Issue = (_____)

(low) I-----I (high)

In general, would you say your physical health is:

(Please circle one)

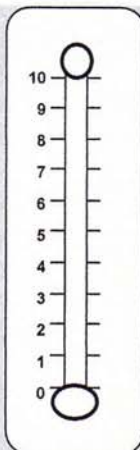
Excellent Very good Good Fair Poor
1 2 3 4 5

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

Extreme Distress

Moderate Distress

No Distress

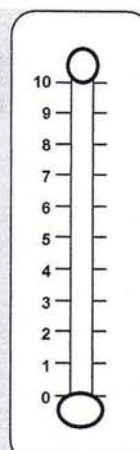


Please circle the number that best describes how much impact this distress (mamae) has had on your life in the past week including today.

Extreme Impact

Moderate Impact

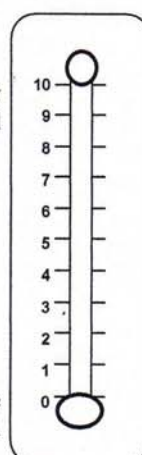
No Impact



Please circle the number that best describes how well you have coped in the last week including today

Coped Very Well

Did Not Cope At All




Version 2 01.11.07

Appendix E: Client Satisfaction Questionnaire -8 (CSQ-8)

(Permission to include a copy of the CSQ-8 in the appendix was obtained from the author).

CSQ-8 UK English

	CLIENT SATISFACTION QUESTIONNAIRE CSQ-8
---	--

Please help us improve our service by answering some questions about the help that you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.* We also welcome your comments and suggestions. Thank you very much. We appreciate your help.

CIRCLE YOUR ANSWERS

1. How would you rate the quality of service you received?

4 <i>Excellent</i>	3 <i>Good</i>	2 <i>Fair</i>	1 <i>Poor</i>
--------------------	---------------	---------------	---------------

2. Did you get the kind of service you wanted?

1 <i>No, definitely not</i>	2 <i>No, not really</i>	3 <i>Yes, generally</i>	4 <i>Yes, definitely</i>
-----------------------------	-------------------------	-------------------------	--------------------------

3. To what extent has our service met your needs?

4 <i>Almost all of my needs have been met</i>	3 <i>Most of my needs have been met</i>	2 <i>Only a few of my needs have been met</i>	1 <i>None of my needs have been met</i>
---	---	---	---

4. If a friend were in need of similar help, would you recommend our service to him or her?

1 <i>No, definitely not</i>	2 <i>No, I don't think so</i>	3 <i>Yes, I think so</i>	4 <i>Yes, definitely</i>
-----------------------------	-------------------------------	--------------------------	--------------------------

5. How satisfied are you with the amount of help you received?

1 <i>Quite dissatisfied</i>	2 <i>Indifferent or mildly dissatisfied</i>	3 <i>Mostly satisfied</i>	4 <i>Very satisfied</i>
-----------------------------	---	---------------------------	-------------------------

6. Have the services you received helped you to deal more effectively with your problems?

4 <i>Yes, they helped a great deal</i>	3 <i>Yes, they helped somewhat</i>	2 <i>No, they really didn't help</i>	1 <i>No, they seemed to make things worse</i>
--	------------------------------------	--------------------------------------	---

7. In an overall, general sense, how satisfied are you with the service you received?

4 <i>Very satisfied</i>	3 <i>Mostly satisfied</i>	2 <i>Indifferent or mildly dissatisfied</i>	1 <i>Quite dissatisfied</i>
-------------------------	---------------------------	---	-----------------------------

8. If you were to seek help again, would you come back to our service?

1 <i>No, definitely not</i>	2 <i>No, I don't think so</i>	3 <i>Yes, I think so</i>	4 <i>Yes, definitely</i>
-----------------------------	-------------------------------	--------------------------	--------------------------

WRITE ANY COMMENTS OVERLEAF

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--	---

TMS.002



CLIENT SATISFACTION QUESTIONNAIRE

Various forms of the CSQ are available to serve a range of program evaluation and research applications within health, human services, public benefit, and governmental service programs.

Choose a version of the CSQ that best fits your specific application:

CSQ-8

CSQ-3

CSQ-18A

CSQ-18B

CSQ-31

Assistance in making your choice can be found at www.CSQscales.com.

The CSQ-8 is available in 16 languages. The CSQ-3 and CSQ-18B are also available in selected languages.

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Appendix F: Additional Satisfaction Questions

Satisfaction Questionnaire continued.....

1) What was most helpful about the service?

2) What was least helpful about the service?

3) Was there anything about the service that you felt could have been better?

4) Any other comments:

Appendix G: Invitation Letter from the Regional Cancer Centre (Waikato)



Waikato District Health Board
HEALTH WAIKATO DIVISION

Regional Cancer Centre
Department of Oncology
Waikato Hospital
Private Bag 3200 Waikato Mail Centre
Hamilton 3240 New Zealand

Dear Sir/Madam,

This covering letter is to confirm that the Waikato Hospital Oncology Department has agreed to participate in the POS study. The information pack contains information about the study which we would like you to read and consider participating in.

It is through research from willing patients like yourself that further gains can be made in improving our services to the community that we serve.

This study has ethical approval from the Multi Region Ethics Committee in Wellington. We wish to assure you that all material received will be treated in the strictest confidence and no identifying names or personal details will be kept with any information you provide.

We would like to invite you to read the information enclosed and if you have any questions you can contact Philippa Croy Main Investigator (Massey) or Wendy Thomas Clinical Nurse Manager- Oncology Clinical Trials at Waikato Hospital on 07 839 8976. Thank you

Kind Regards

Wendy Thomas
Clinical Nurse Manager
Oncology Clinical Trials
Regional Cancer Centre
Waikato Hospital
Private Bag 3200 Waikato Mail Centre
Hamilton 3240 New Zealand
Ph 07 8398976

Appendix H: Information Sheet (Control Group)



Massey University

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673
www.massey.ac.nz
<http://psychology.massey.ac.nz>

An Investigation of the Outcomes of the Psycho-Oncology Service Interventions

INFORMATION SHEET

Introduction

You are invited to participate in a research project conducted through Massey University. Studies have shown that receiving psychological support can reduce distress and improve quality of life for those affected by cancer. Last year, the MidCentral District Health Board decided to fund the development of a Psycho-Oncology Service which provides specific psychological support to those affected by cancer. The aim of this study is to determine how effective this type of service is in alleviating distress and improving quality of life, and also to find out what key things makes the service effective. Although the Psycho-Oncology Service is the first of its kind in New Zealand, this study will provide information for other DHBs to consider, when they look at whether they are going to provide such a service.

Why have I been chosen?

To find out whether people benefit from this type of service, we need to compare those who live in an area with a Psycho-Oncology Service, with those who live in area that does not. As the region you live in does not currently have a Psycho-Oncology Service, we would like to invite people over the age of 18 years who have been either diagnosed with cancer or who have a family member who has been diagnosed with cancer, to take part in the study. Two identical study packs have been enclosed, one for you to complete, the other for either a family member or support person to complete. The study is seeking 240 participants.

Do I have to take part?

Your participation is entirely voluntary (your choice). We recognise that cancer can be associated with physical illness and would encourage you not to complete the questionnaire if you do not feel up to it. If you decide to participate, you have the right to:

- decline to answer any particular question
- withdraw from the study at any time, without giving a reason
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used without permission
- be given access to a summary of the project findings when it is concluded

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone: (NZ wide) 0800 555 050; Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT); Email (NZ wide): advocacy@hdc.org.nz

Version 4 21.05.08

If I choose to take part, what do I have to do?

On receiving this invitation and consenting to participate, you will be asked to complete one sheet of rating scales that asks about your level of wellbeing over the past week, and a demographics sheet (takes approx. 5 min). On two more separate occasions you will be sent the rating scales again. Completed forms are returned to the researcher in a prepaid envelope provided.

Will my taking part in this study be kept confidential and anonymous?

Your name and contact details will be separated from your rating sheets and demographic information by the researcher. Any answers you give will be treated with confidence by the research team. All data relating to the research will be kept in a locked office and will only be accessed by the research team. Data will be stored for 5 years, after which time it will be destroyed.

What will happen to the results?

You and your family will not be identified in any report or publication. Group information will be used to inform the Psycho-Oncology Service about the quality of the psychological support they provide, and enable them to look for ways to make improvements. The results will also provide information for other DHBs to consider when they look at whether they are going to implement such a service. The group information will also be presented in articles, at conferences, and a report will be given to the MidCentral and Waikato District Health Boards. The results of the study will also be published as the researcher's Doctoral thesis.

If a participant would like a summary of the research findings they can indicate this on the consent form. The consent form will be separated from the completed questionnaires to preserve the confidentiality and anonymity of the participants. We cannot indicate at this stage how long it will take to send you this summary as it is unclear how long it will take to gather enough responses.

Who are the researchers?

This research project is being conducted by Philippa Croy, a Doctorate of Clinical Psychology student, with support from the Psycho-Oncology Service and the MidCentral District Health Board. The supervisors for this research are Cheryl Woolley, Dr Don Baken and Dr Janet Leathem. They are all clinical psychologists and staff members of the School of Psychology at Massey University.

If you have any questions or concerns regarding this project we would invite you to contact Philippa Croy. Her contact details are:

Philippa Croy
School of Psychology
Massey University
Private Box 756
Wellington
Ph:
Email:

This study has received ethical approval from the Multi-region Ethics Committee which reviews National and Multi regional studies.

Appendix I: Consent Form (Control Group)



Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North 4442
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673
www.massey.ac.nz
<http://psychology.massey.ac.nz>

An Investigation of the Outcomes of the Psycho-Oncology Service Interventions

CONSENT FORM (Rating Scale)

- I have read and understand the information sheet for volunteers taking part in the study designed to investigate the outcomes of the Psycho-Oncology Service interventions. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I agree to participate in this study under the conditions set out in the Information Sheet.
- I would like to be sent a summary of the results when the study is complete. Yes / No

Full Printed Name: _____

Signature: _____ Date: ____/____/____

Address: _____

Version 2 01.11.07

Appendix J: Additional Demographic Information at T2 & T3 (Control Group)**Time 2:**

Q 1 Have you seen a professional for psychological support in the past, for reasons related to the cancer diagnosis?

	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

Q 2 If there was a service available in your area which offered psychological support to those dealing with cancer, would it have been something you might have accessed?

	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

Time 3:

- Q 1** Since this study began (Aug 08), have you seen a professional for *psychological* support for reasons related to the cancer diagnosis?

	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

- Q 2** At present, how much support (emotional and/or social) are you receiving from the following people? (Please tick all that apply)

	N/A	No support	A little bit of support	Quite a bit of support	A lot of support
Your Family/Whanau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your Church	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professionals (e.g., Social Worker, Psychologist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Q 3** How helpful is their support? (Please tick all that apply)

	N/A	Not at all helpful	Somewhat helpful	Quite helpful	Very helpful
Your Family/Whanau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your Church	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professionals (e.g., Social Worker, Psychologist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Q 4** In general, how would you describe the level of support (emotional and/or social) you are currently receiving?

	Poor	<input type="checkbox"/>
	Good	<input type="checkbox"/>
	Excellent	<input type="checkbox"/>

- Q 5** Please describe the type of support you have received from each of the people you ticked in Q 2

Appendix K: Outcome Measures (Control Group)**Outcome Rating Scale (ORS)**

Name _____ Age (Yrs): _____ Sex: M / F Session # _____ Date: _____ Who is filling out this form? Please check one: Self _____ Other _____ If other, what is your relationship to this person? _____
--

Looking back over the last week, including today, help us understand how you have been feeling by rating how well you have been doing in the following areas of your life, where marks to the left represent low levels and marks to the right indicate high levels. *If you are filling out this form for another person, please fill out according to how you think he or she is doing.*

Individually
(Personal well-being)

I-----I

Interpersonally
(Family, close relationships)

I-----I

Socially
(Work, school, friendships)

I-----I

Overall
(General sense of well-being)

I-----I

Institute for the Study of Therapeutic Change

www.talkingcure.com

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Please Turn Over

Sense of Meaning/Wairua
(purpose, belief, spiritual wellbeing)

(low) I-----I (high)

In general, would you say your physical health is:
(Please circle one)

Excellent	Very good	Good	Fair	Poor
1	2	3	4	5

Please circle the number that best describes how much *distress* (mamae) you have been experiencing in the past week including today

Extreme Distress

Moderate Distress

No Distress

Please circle the number that best describes how much *impact* this distress (mamae) has had on your life in the past week including today.

Extreme Impact

Moderate Impact

No Impact

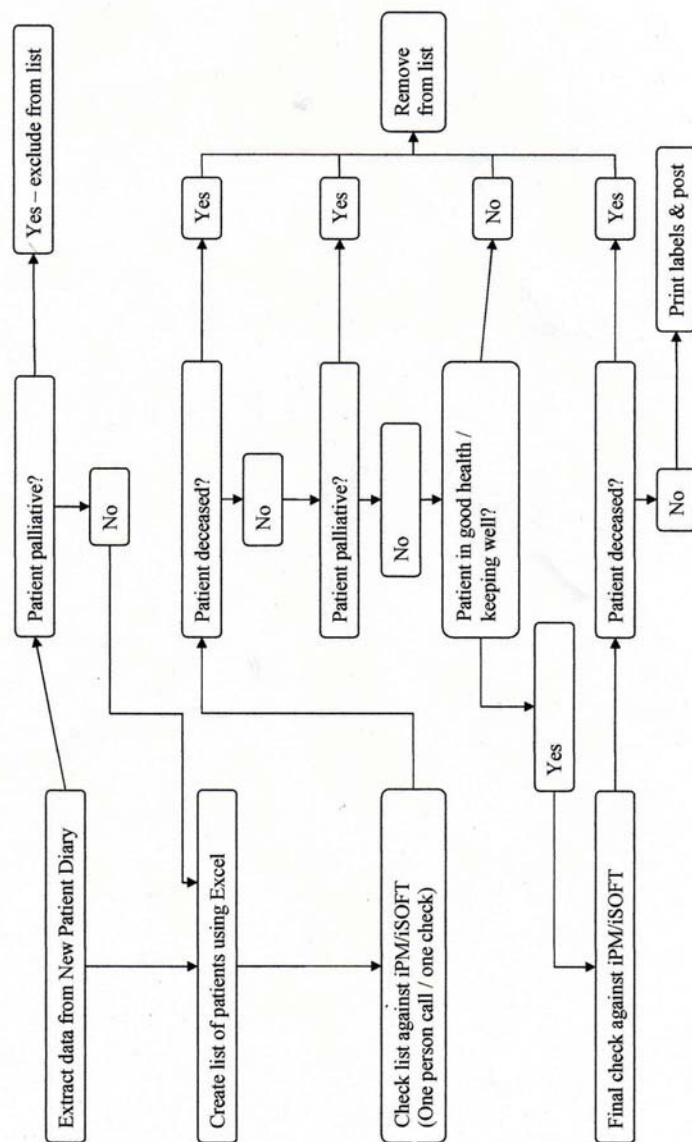
Please circle the number that best describes how well you have *coped* in the last week including today

Coped Very Well

Did Not Cope At All

Appendix L: Recruitment Procedure (Control Group)

Psychosocial Oncology Study Process Flowchart



21 August 2008

Appendix M: Interview Topic Guide

Interview Schedule - Prompts

Introduction

- Rapport building/rationale for study

Cancer history

- How long ago were you (they) diagnosed? Cancer type? Currently in treatment, stage of treatment? Other health issues?

Coping

- What impact did your (their) diagnosis have on you? (emotionally, physically, spiritually)
- Which aspects of your (their) diagnosis have you found most difficult to deal with?
- Has your level of distress changed over the course of your (their) illness? Please explain.
- Over the course of your (their) illness, have you noticed any particular things that have had an impact on your mood? Please explain.
- Prior to accessing the psycho-oncology service, how had you been trying to manage your distress? Please explain
- How would you describe your ability to manage your distress since accessing the service?
- (If there has been a change) What do you do differently? What do you think has been responsible for this change? (If not) Why do you think that is?

Experiential Avoidance

- Prior to accessing the service, were there things you did to avoid dealing with your (their) illness? (thoughts, behaviours) Please explain
- Since accessing the service, has this changed? Please explain.
- (If there has been a change) What do you do differently? What do you think has been responsible for this change? (If not) Why do you think that is?

Social Support

- What social support have you had available to you since your (their) diagnosis? (friends, family, doctors, church, professionals)
- Was the support helpful or unhelpful?
- Have you noticed any change in social support since accessing the service?

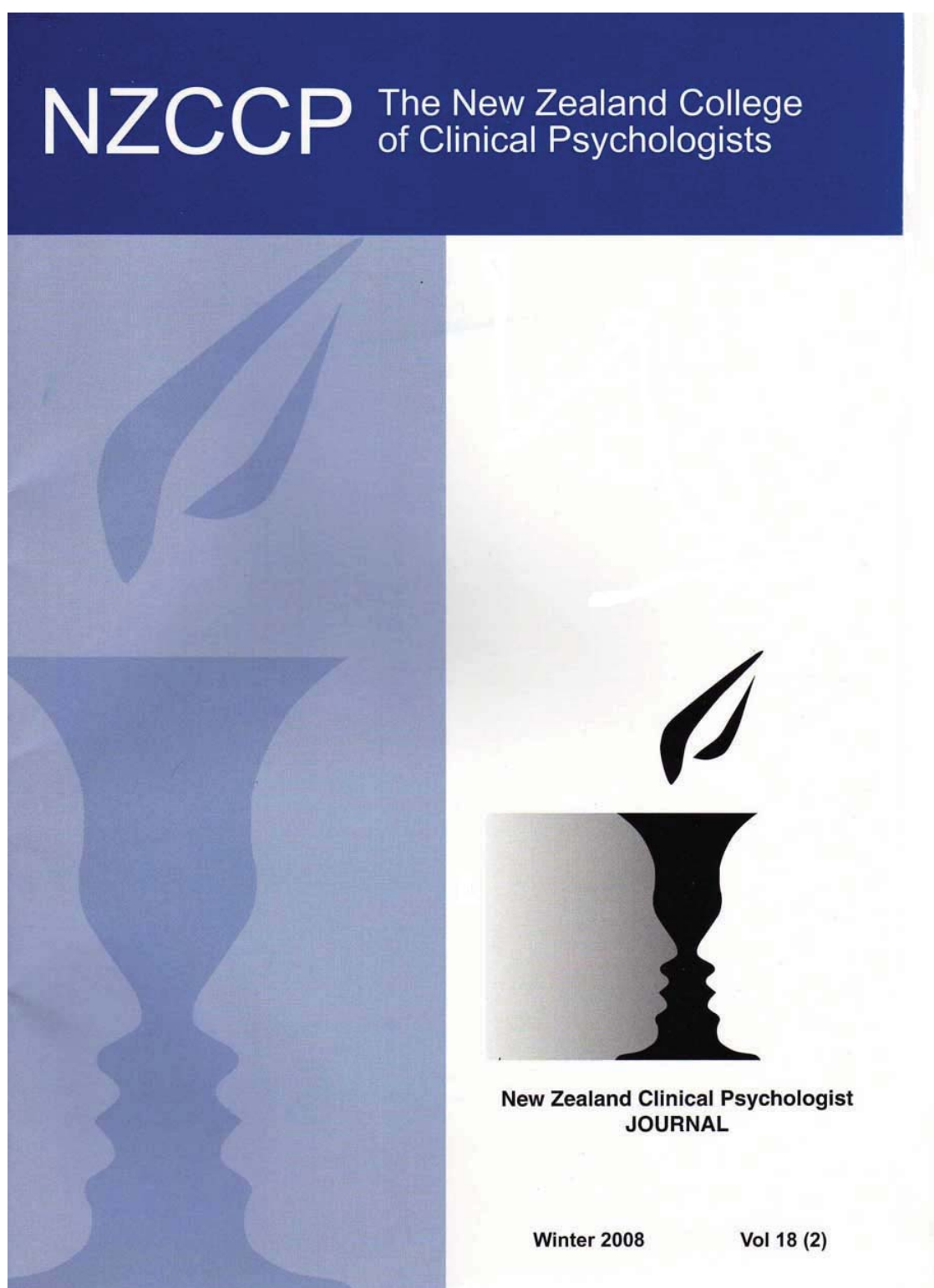
Perceived Control

- Prior to accessing the service, did you feel that you had a sense of control over your illness? Please explain.
- Since accessing the service, has this changed? Please explain
- (If there has been change)- What do you think has been responsible for this change? (If not) Why do you think that is?

Service Provision

- Had you sought psychological support for your distress prior to accessing the service? Please explain.
- What led you to access the psycho-oncology service?
- What expectations did you have of the service, were they met? Please explain.
- What aspects of the service/intervention did you find most helpful/least helpful? Please explain.
- What were your perceptions of the psychologist you worked with? Please explain
- What do you feel were the main things that were responsible for any changes in your level of distress or wellbeing since accessing the service?
- What would have made the therapy more helpful?

Appendix N: Journal Article



often due to negative symptoms associated with schizophrenia, poor ability to self-monitor, and antisocial attitudes. The question arises whether the clinical impressions gained regarding the relative success of the cognitive rehabilitation programme is dependent on homework between sessions and active application of the skills taught. Further, if this is the case,

were there additional factors noted that motivated those involved to continually achieve this level of participation other than enjoyment of the game-like activities? In sum, I enjoyed the read and look forward to hearing about future research regarding cognitive rehabilitation with forensic patients.

How Effective Are Psycho-Oncology Interventions in Improving Wellbeing and Reducing Distress in New Zealand Cancer Patients and their Families?

Phillipa Croy

Abstract

The diagnosis and treatment of cancer are sources of considerable psychological distress. Although a significant body of research has found psycho-oncology to be beneficial in reducing distress and improving wellbeing, few of these studies examine the effectiveness of psychotherapeutic interventions as they are practised in the field. This article provides a brief overview of the issues that face those living with cancer and discusses the different methodologies used in evaluating the effectiveness of psychotherapeutic interventions in reducing distress and improving wellbeing. Finally, the rationale for conducting research examining the effectiveness of psycho-oncology interventions in New Zealand is also discussed.

In 2002, New Zealand and Australia were recorded as having the second highest incidence of cancer in the world. In New Zealand, there were 17,943 new cancer registrations recorded, and 7,800 deaths from cancer, making it the leading cause of death in New Zealand (New Zealand Health Information Services, 2006). The New Zealand cancer death rate is now higher than countries such as Australia, Canada, Britain, and the United States (Gavin, Marshal, & Cox, 2001). Improvements in early detection and treatment mean that an increasing number of people are surviving cancer. However, in addition to the difficulties cancer patients and their families face during

diagnosis and treatment, surviving cancer brings with it its own challenges.

When someone is diagnosed with cancer, its impact extends beyond the physical effects of the disease. Cancer can cause considerable distress, impacting significantly on a person's quality of life psychologically, emotionally, socially, spiritually and functionally. Research has shown that a significant proportion of cancer patients suffer from psychosocial difficulties. Anxiety and depression are two of the most common psychological manifestations that patients experience when diagnosed with cancer, with approximately 20-25% of patients

Phillippa Croy is a Doctorate in Clinical Psychology Candidate at the School of Psychology, Wellington Campus of Massey University. Contact details: Phillipa Croy p_croy@yahoo.com

experiencing clinical levels of anxiety and/or depression (Stark et al., 2002).

Dealing with cancer also has a significant impact on sexual functioning and maintaining intimate relationships (Wilmoth, 2001). For many cancer patients, treatment involves surgery, and the psychological consequences of undergoing surgery can be significant. Patients can experience anxiety and fear in anticipation of surgery, which has been linked to poorer post-treatment outcome (Croog, Baume, & Nalbandian, 1995).

Many factors associated with receiving chemotherapy and radiotherapy have been shown to contribute to a patient's emotional distress. These include having to face the reality that their disease is severe and potentially fatal, receiving insufficient information about the aims of the treatment and the possible outcomes, as well as the physical side effects of treatment (Pandey et al., 2006). Pain related to cancer or its treatment is also a significant contributor to psychological distress, affecting 50-90% of cancer patients (Portenoy et al., 1994). As a result of a cancer diagnosis, many families experience financial difficulties. There are often changes in employment roles within the family, and for most patients the diagnosis and treatment of cancer means that they have to temporarily or permanently stop work (Bloom et al., 1988). Poor communication between patients and doctors has also been found to have a significant and detrimental effect on patients' ability to cope with the cancer (Faulkner & Maguire, 1994), as well as a long-term effect on patient outcome. The diagnosis and treatment of cancer also has a great impact on the family, with many family members experiencing similar levels of distress to those seen in cancer patients (Compas et al., 1999). Although the psychosocial impact of cancer on

patients has been thoroughly documented, the psychosocial impact that cancer has on family members is a relatively neglected aspect in the treatment of cancer.

Most people affected by cancer are able to cope without specific psychological interventions. However, a number of people will at some stage of the disease display psychological symptoms or signs of distress requiring psychosocial intervention. A significant body of literature has examined whether psychotherapy interventions such as education, cognitive-behavioural training, individual supportive psychotherapy, and group therapy are beneficial, or 'efficacious'. The consistent finding across the literature is that on average, people who receive psychotherapy have better outcomes than those who do not receive psychotherapy (Lambert & Ogles, 2004). These efficacy studies have predominantly involved randomised controlled trials (RCTs), as they are generally considered to be the most thorough methodology for evaluating an intervention's efficacy. However, many researchers believe RCTs to be the wrong methodology for empirically validating psychotherapy as it is practised in the field (Persons & Silbershatz, 1998). Whereas efficacy studies examine how well psychotherapy works under special experimental conditions, effectiveness studies are designed to evaluate how well psychotherapy works in the field. To date, there has been very little research examining the effectiveness of psychotherapy as it is practiced in the real world.

Despite having established that psychotherapy 'works', why and how it works is less clear. Recently, researchers have begun to focus on investigating variables that might influence the

effectiveness of psychotherapy, i.e., moderators and mediators. Moderators address *when* or *for whom* a treatment is more strongly related to an outcome; mediators establish *how* or *why* a particular variable predicts or causes an outcome (Frazier, Tix, & Barron, 2004). Not everyone who receives psychotherapy benefits from it. Therefore, identifying factors that influence the effectiveness of a therapy intervention will hopefully increase our understanding of why people respond differently to different treatments and help to ensure that people get the most out of treatment (Johansson & Hoglend, 2007).

As the research has highlighted, the diagnosis and treatment of cancer are sources of considerable psychological distress. However, despite the significant impact cancer has on patients and their families, it has only been in the last 30 years that the specific psychological needs of those living with cancer has been recognised (Holland, 2002). Meta-analyses have concluded that in laboratory-like settings (efficacy studies), many psychological interventions reduce cancer patients' distress and physical symptoms and improve quality of life (Fawzy, 1999). However, to the author's knowledge, no research has yet been published in the psycho-oncology literature examining the effectiveness of psychotherapy as it is practised in the field. Although research shows that clients receiving psychotherapy do better than clients not receiving psychotherapy, there are still many unanswered questions regarding why and how therapy works.

In 2003, the Ministry of Health and the New Zealand Cancer Control Trust developed the New Zealand Cancer Control Strategy (Ministry of Health, 2003). Among their objectives and goals were a) to improve the quality of life for

those with cancer, their families and whanau through support, rehabilitation, and palliative care; b) to improve the delivery of services across the continuum of cancer control through effective planning, co-ordination, and integration of resources and activity, monitoring, and evaluation; and c) to improve the effectiveness of cancer control in New Zealand through research and surveillance. Recently Surgenor, Costello, and McKellow (2006) conducted a national stocktake of psychosocial cancer services in New Zealand for the Ministry of Health. They found that while there was wide provision of general emotional, cultural and complementary support services, there was a lack of specialist psychological and mental health support.

In 2006, the Massey University Psychology Clinic (Turitea) began delivery of New Zealand's first integrated Psycho-Oncology Service. The aim of the service is to improve the client's quality of life by reducing distress, providing coping strategies, helping them manage any physical difficulties, and assisting them to cope with any treatment side effects. While this service is based on international research and guidelines, to date, much of this has not been tested within the New Zealand population. As a candidate for Massey University's Doctorate in Clinical Psychology, my research will focus on assessing the effectiveness of the interventions provided by the Psycho-Oncology Service. This research will also aim to identify the mediating and moderating factors which influence the effectiveness of these interventions. In keeping with the goals of the New Zealand Cancer Control Strategy (Ministry of Health & New Zealand Cancer Control Trust, 2003), this research will also provide much needed New Zealand evidence-based data regarding the use of

psychotherapeutic interventions with cancer patients, their families and whanau.

Acknowledgements

Thanks to the MidCentral and Waikato District Health Boards for their support of this project.

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Appendix O: Conference Abstracts



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PSYCHOSOCIAL | **ONCOLOGY NEW ZEALAND** | CONFERENCE

16th - 18th November 2008 • Palmerston North Convention Centre

Winds of Change: Ideas • Innovation • Initiatives

Handbook

An investigation of the outcomes of psycho-oncology service interventions

Philippa Croy¹, Cheryl Woolley², Don Baken² & Janet Leathem³



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When someone is diagnosed with cancer, its impact extends beyond the physical effects of the disease. Cancer can cause considerable distress, impacting significantly on a person's quality of life psychologically, emotionally, socially, spiritually and functionally. The aim of this study is to investigate the effectiveness of a New Zealand psycho-oncology service in alleviating distress and improving quality of life for cancer patients and their family/whānau. This research will also attempt to identify moderating and mediating factors that might influence the effectiveness of psycho-oncology interventions. Twenty-five psycho-oncology service clients were recruited and matched for initial distress, age and gender, with twenty-five patients located in an area without access to the Psycho-Oncology Service. The intervention group completed validated scales measuring wellbeing and distress at 3 time points, (pre-therapy, post -therapy, 3-month follow-up). The control group also completed these measures following the same time line as the intervention group's therapy. A sample of psycho-oncology clients who showed least and most improvement over time were interviewed to examine potential factors influencing the effectiveness of their therapy. In keeping with the goals of the New Zealand Cancer Control Strategy, this study will provide much needed New Zealand evidence-based research regarding improving quality of life for those with cancer, their family and whānau. It will also provide valuable information that can be used by other DHBs in the implementation of similar services throughout the country. An overview of research to date and initial findings will be presented.




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clients' lived experiences of using the Psycho-Oncology Service (POS) at Massey University. The psychological impact of a cancer diagnosis may include anxiety, pain, depression, delirium and fatigue (Holland, 2003), effects which may also be seen in the cancer patient's family/whānau. Thematic analysis was applied to semi-structured interviews involving former POS clients with colorectal, breast or gynaecological cancer and family/whānau clients. These clients represented the largest attending groups with typically higher initial distress levels. Participants told their own story from before their diagnosis to end of therapy covering areas of "Cancer Experience", "Life Impact" and "Experience with the POS". This study adds to limited New Zealand and International research regarding psychological interventions provided for cancer patients and their families. The results of the study formed part of a planned evaluation of the POS and will help to refine and improve interventions

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4.00pm

Providing Clinical Health Psychology Services in a Primary Health World: The establishment of the Massey University Health Conditions Psychology Service.

Maria Berrett & Sarah Malthus

Senior Clinical Psychologist and Service Co-Ordinator, Health Conditions Service, Massey University.

Individuals with long term health conditions are at greater risk of emotional and behavioural problems, including mental health issues such as anxiety, depression, risk taking behaviours, body image and eating disorders, as well as social difficulties (for example, Barlow & Ellard, 2006; Berge & Patterson, 2004; Weiser, 2008). These psychological issues can impact on an individual's ability to cope with their physical condition. Family members of an individual with a chronic health condition are also at risk of psychological distress. To date, there has been a notable absence of psychological support services, both for individuals and their families affected by chronic illness. A new MidCentral Health initiative focussed on the provision of psychological services for adults, children and their families with chronic illness has recently been established at Massey University's Palmerston North Psychology Clinic. These Services are among the first of their kind in New Zealand, and have implications for the management of individuals with chronic health conditions in the primary health sector. This paper will outline the aims and establishment of the Services and discuss professional and clinical issues arising in the development of the service.

4.20pm

Tailoring interventions when working with children and young people with long term and life limiting conditions.

Dr Kirsty Ross

Massey University Health Conditions and Psycho-Oncology Services

The rates of serious health conditions, including cancer, have been rising in recent times (New Zealand Health Information Service, 2006). Alongside higher prevalence rates for many health conditions, survival rates from illnesses that were once considered fatal are improving. Consequently, many diseases are increasingly being thought of as long term or chronic conditions. With this, come issues of survivorship and adjusting to living with a chronic health condition. Chronic illness and cancer have a profound effect on the physical, emotional, and psychological wellbeing of individuals. Children and young people are especially vulnerable for emotional and behavioural problems, due in part to disruption in normal developmental tasks (Berge & Patterson, 2004; Blackman & Gurka, 2007; Burns, Sadof & Kamat, 2006; Erickson, Patterson, Wall & Neumark-Sztainer, 2005; Hysing, Elgen, Gillberg, Lie & Lundervold, 2007). Psychosocial interventions have an enormous contribution to make in the quality of lives of children and young people with cancer and long term health conditions, both psychologically and physically. This paper discusses the work with children and young people being carried out by the Massey University Health Conditions & Psycho-Oncology Services. Case studies will be used to illustrate the unique characteristics of working with children with chronic and life threatening illnesses. Particular focus will be placed on tailoring interventions to the child and family's circumstances.

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4.40pm

An Investigation of the Outcomes of Psycho-Oncology Service Interventions

Philippa Croy

Cheryl Woolley

Dr. Don Baken

Prof. Janet Leathem

all Massey University

Background: Cancer has a significant impact on families; however research examining the effectiveness of psychotherapy for New Zealand cancer patients and their family/whānau remains limited. Aim: This study investigates the effectiveness of a New Zealand psycho-oncology service in reducing distress/improving wellbeing for cancer patients and their family/whānau; and attempts to

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identify key factors influencing the effectiveness of psycho-oncology interventions. Method: Twenty-five Psycho-Oncology Service clients were recruited and matched for initial distress with patients/family members located in an area without access to the Psycho-Oncology Service. Participants' levels of wellbeing and distress were measured pre- and post-therapy, and at 3-month follow-up. A sample of Psycho-Oncology clients who showed the least and most improvement over time was interviewed to examine their perceptions and experiences of the service. Results: Compared to the control group, Psycho-Oncology clients showed significant reductions in distress and improvement in wellbeing over time. Interviewed clients reported extremely positive feedback regarding the service.
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5.00pm

Meta-analysis of moderators of psycho-oncology therapy effectiveness: "It's the sick who need a doctor"

Heather Heron

Student, Massey University School of Psychology, Palmerston North

Dr Don Baken

Massey University Psycho-oncology service, Palmerston North

Dr Shane Harvey

Director, Massey University Psychology Clinic, Palmerston North

Variables moderating the effectiveness of psycho-oncological therapies for adults have not been comprehensively investigated until now. This meta-analysis investigated sociodemographic, psychological, medical and therapy related variables from controlled trials using outcomes of anxiety, depression, and general distress. An extensive search resulted in a dataset comprising 150 controlled studies, including RCTs, naturalistic experimental designs, unpublished studies and additional unpublished data provided by authors. Preliminary analyses of validity threats exposed two trial design confounds which were taken into account in substantive analyses. Broad therapy types (education, relaxation, CBT, expressive-supportive therapies) were assessed for impact and trajectory of effect, and a sense of their roles and value in relation to each other and to distressed patients and patients generally was obtained. These results, plus findings that patients with cancer at sites other than the breast, possibly at more serious stages, and with demographics that suggest relative social isolation (poor, older, single, men), will be presented. Funded by the Cancer Society of New Zealand
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Counselling Psychology Stream

Chair: Bill Farrell

11.30am – 1.10pm

Te Manawa 1

11.30am

Counselling families in partnership with Child Youth and Family when children have been removed from the home: A co-gender approach.

Wendel Foerster

NZ Psychological Society

Yvonne Perkins

NZ Association of Counselling

Counselling families in partnership with Child Youth and Family when children have been removed from the home: a Co Gender approach. One of the greatest tragedies for parents is the loss of a child or children. Having children put in Care by a Child Protection Agency is an example of such an experience. Using a case example, this paper will explore the complexities, challenges, and rewards of working alongside Child Youth and Family to restore a safe environment for children who have been removed from home. Particular emphasis will be given to how we as counsellors can engage with families while maintaining strong relationships with Social workers through this process.
Email: wendelandjulia@gmail.com

11.50am

Educating counselling psychologists - the graduates view

Brent Gardiner

School of Arts, Development and Health Education, Massey University

Associate Professor Jeannie Wright

School of Arts, Development and Health Education, Massey University

This paper reports on research which aimed to consult students who had completed the postgraduate counsellor education programme at Massey University. They were asked about how different elements of that counsellor education prepared them for continuing development as reflective practitioners, professional employment, gaining professional membership and appropriate progression in the field. The study used mixed methods. Firstly, an online questionnaire survey was sent out to 75 graduates of the programme and secondly, telephone semi-structured interviews were conducted. The qualitative data derived from both the online questionnaire and the 3 telephone interviews were analysed using Interpretative