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**A Qualitative Study Exploring Factors
Impacting the Therapeutic Outcome and
Experiences of Clients using a
Psycho-Oncology Service**

A thesis presented in partial fulfilment of the requirements for the degree of

Doctorate

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Clinical Psychology

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ABSTRACT

Current research shows that people coping with cancer benefit from psychological interventions. This qualitative study aimed to explore and identify factors which may affect the experiences and therapeutic outcomes of clients using the Massey University Psycho-Oncology Service (POS) in New Zealand as a case study. It is hoped that the current study will add to the limited psycho-oncology literature from New Zealand and also to the international knowledge base.

The findings presented in this study arise from the thematic analysis of semi-structured interviews with 24 participants who were recruited for the study. They included women with breast or gynaecological cancer and family/whānau clients who attended Massey's Psycho-Oncology Service as well as psychologists of the Psycho-Oncology Service and people affected by cancer who were not clients of the Service.

Four main themes were identified. These were *Meaning of cancer – creating distress*, *Dealing with it – reducing distress*, *Experience of POS*, and *Being a psycho-oncologist*. Factors that emerged which may impact the outcomes and experiences of clients using POS included client expectations, inclusion of family members in therapy, a strong therapeutic relationship and the personal connection that the POS psychologists expressed sharing with clients, their work and the team.

This study was limited by low participant numbers. No clients came forward who were dissatisfied with the Service meaning that factors which may have negatively impacted outcomes could not be identified. Findings and implications are discussed.

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TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
TABLE OF CONTENTS	iv
LIST OF FIGURES	ix
LIST OF TABLES	x
LIST OF APPENDICES	xi
CHAPTER 1: INTRODUCTION	1
1.1 Background	1
1.1.1 A brief history of cancer	1
1.2 Cancer Statistics	4
1.2.1 Worldwide.....	4
1.2.2 New Zealand	5
1.3 Study Rationale	6
1.4 Thesis Overview.....	8
1.5 Summary	9
CHAPTER 2: THE PSYCHOLOGICAL IMPACT OF CANCER.....	10
2.1 Distress.....	10
2.2 Impact at diagnosis.....	11
2.2.1 “Being traumatised”- anxiety	11
2.2.2 Depression at diagnosis.....	13
2.3 Impact during Treatment.....	14
2.3.1 Pain and fatigue.....	15
2.3.2 Neuropsychological effects.....	16
2.4 Impact of Survival	17
2.5 Impact of Cancer Recurrence	19
2.6 Palliative /Terminal Phase.....	20
2.7 Impact for Family/Whānau	21
2.8 Impact of Breast Cancer	22

2.9 Impact of Gynaecological Cancers	24
2.10 Coping with Cancer –What Impacts Distress?	25
2.10.1 Responses which may reduce distress	26
2.10.1.1 Seeking information	26
2.10.1.2 Lifestyle changes.....	27
2.10.1.3 Having a positive attitude, being optimistic.....	28
2.10.1.4 Social support.....	30
2.10.1.5 Self-efficacy	32
2.10.2 Responses which may increase distress	33
2.10.2.1 Protective buffering and social constraints	33
2.10.2.2 Cognitive avoidance	34
2.11 Summary	34
CHAPTER 3: PSYCHOLOGICAL INTERVENTIONS FOR CANCER	36
3.1 Is Psychological Intervention Helpful For People Affected by Cancer	36
3.1.1 Supportive therapy- group.....	38
3.2 Cognitive Behavioural Therapy (CBT)	39
3.2.1 Education.....	40
3.2.2 Relaxation	41
3.2.3 Hypnosis.....	42
3.3 Interventions for Breast Cancer	43
3.4 Interventions for Gynaecological Cancers.....	46
3.5 Family Interventions	47
3.6 Factors Affecting Psychological Interventions	49
3.6.1 Client Factors	50
3.6.1.1 High baseline distress	50
3.6.1.2 Social support	50
3.6.1.3 Client expectations.....	51
3.6.1.4 Financial problems.....	52
3.7 Therapeutic Alliance	52
3.8 Therapist Variables	54
3.9 Summary	56

CHAPTER 4: PSYCHO-ONCOLOGY	57
4.1 The Development of Psycho-oncology	57
4.2 Development of the First Specialist Psycho-Oncology Service in New Zealand	58
4.2.1 Population served	60
4.2.2 Referral process	62
4.3 Summary	66
 CHAPTER 5: METHODOLOGY	 67
5.1 Design	67
5.1.1 Rationale for participant groups	68
5.2 Participant Recruitment.....	69
5.2.1 Former POS clients–(breast/gynaecological and family/whānau)	69
5.2.1.1 Participant inclusion criteria	70
5.2.1.2 Participant exclusion criteria.....	70
5.2.2 Non-intervention group.....	71
5.2.2.1 Participant inclusion criteria	71
5.2.2.2 Participant exclusion criteria.....	71
5.2.3 Psycho-Oncology Service clinicians.....	71
5.2.3.1 Participant inclusion criteria	72
5.2.3.2 Participant exclusion criteria.....	72
5.3 Participants.....	72
5.3.1 Participant details	72
5.3.2 Semi-structured interview	73
5.3.3 Interview process	75
5.3.4 Saturation	76
5.4 Analysis.....	77
5.4.1 Rationale for using thematic analysis	77
5.4.2 Analysis process.....	78
5.4.2.1 Phase 1: Familiarising yourself with your data.....	78
5.4.2.2 Phase 2: Generating initial codes	79
5.4.2.3 Phase 3: Searching for themes	79
5.4.2.4 Phase 4: Reviewing themes.....	79
5.4.2.5 Phase 5: Defining and naming themes.....	80

5.4.2.6 Phase 6: Producing the report	80
5.5 Ethical Considerations	80
5.5.1 Ethical issues addressed	80
5.6 Reflexivity Statement	81
CHAPTER 6: FINDINGS.....	83
6.1 Meaning of Cancer – Creating Distress	84
6.1.1 Cancer means death.....	84
6.1.2 Loss	87
6.1.2.1 Loss of a future.....	87
6.1.2.2 Loss of control	89
6.1.2.3 Loss of body image	92
6.1.2.4 Loss of connection	95
6.1.2.4.1 Disconnection from intimate relationship.....	96
6.1.2.4.2 Disconnection socially	99
6.2 Participant Group Differences.....	101
6.2 Summary	102
CHAPTER 7: DEALING WITH IT- REDUCING DISTRESS	103
7.1 Taking control	103
7.1.1 Finding knowledge.....	103
7.1.2 Healthy behaviours.....	105
7.1.2.1 Exercise	105
7.1.2.2 Diet.....	107
7.2 Being positive	108
7.3 Support	111
7.3.1 Family/friends	111
7.3.2 Spouse/partner.....	114
7.3.3 Medical staff.....	115
7.3.4 Other support services.....	116
7.4 Participant Group Differences.....	118
7.5 Summary	120

CHAPTER 8: EXPERIENCE OF POS	121
8.1 Pre-Service Use Expectations	121
8.1.1 Perceptions of psychologists	121
8.1.2 Someone to talk to.....	124
8.2 Feeling Safe.....	125
8.2.1 Professional	126
8.2.2 Not someone I know	127
8.2.3 Safe, nurturing environment.....	129
8.3 Feeling Connected.....	132
8.4 Reconnecting.....	135
8.5 Effects of the Research Interview	138
8.6 Participant Group Differences.....	139
8.7 Summary	140
CHAPTER 9: BEING A PSYCHO-ONCOLOGIST.....	141
9.1 Connections.....	141
9.1.1 Connecting with the work	141
9.1.2 Connecting with the client	142
9.1.3 Connecting with the team	144
9.2 Challenges	145
9.2.1 Therapeutic challenges.....	146
9.2.2 Personal challenges	150
9.3 Participant Group Differences.....	151
9.4 Summary	152
CHAPTER 10: DISCUSSION.....	153
10.1 Major Findings	153
10.1.1 The meaning of cancer –creating distress	153
10.1.2 Dealing with it – reducing distress.....	154
10.1.3 Experience of POS	155
10.1.4 Being a psycho-oncologist.....	155
10.2 Factors Affecting Therapeutic Outcomes	156
10.2.1 Client expectations.....	156

10.2.2 Connection with the psychologist -the therapeutic relationship	157
10.2.3 Team environment	158
10.2.4 Seeing the whole family.....	158
10.3 Comparison of Cancer Journeys	159
10.4 Clinical Implications	160
10.4.1 Benefits of a dedicated Psycho-Oncology Service	160
10.4.2 Working with the whole family	161
10.5 Study Limitations	162
10.6 Recommendations for Future Research	164
10.7 Conclusion	166
REFERENCES.....	169
APPENDICES	215

LIST OF FIGURES

FIGURE 1: Temporal trajectories of psychological health in cancer survivors	17
FIGURE 2: Map of MidCentral District Health Board Region	61
FIGURE 3: Psycho-Social Referral Decision Tree.....	64

LIST OF TABLES

TABLE 1: Massey Psycho-Oncology Service percentage of referrals by known cancer site/type: April 2006-June 2013.....	62
TABLE 2: Massey Psycho-Oncology Service percentage of referrals by known referral stage: April 2006- June 2013	63
TABLE 3: Cancer participant details.....	74

LIST OF APPENDICES

APPENDIX A: Ethics Approval Letter	215
APPENDIX B: Semi-structured Interview - Former POS Clients with Cancer	216
APPENDIX C: Semi-structured Interview - Former Family/whānau POS Clients.....	218
APPENDIX D: Semi-structured Interviews -NI Group.....	220
APPENDIX E: Semi-structured Interview– POS Clinicians	222
APPENDIX F: Transcriber Confidentiality Form	223
APPENDIX G: Letter of Invitation to Participate – Former POS Clients.....	224
APPENDIX H: Information Pack – Former POS Clients.....	225
APPENDIX I: Newspaper Advertisement for NI Group	228
APPENDIX J: Information Pack - NI Group.....	229
APPENDIX K: Letter of Invitation to Participate – POS Clinicians.....	232
APPENDIX L: Information Pack– POS Clinicians	233
APPENDIX M: A Thematic Map of the Analysis.....	236
APPENDIX N: An Audit of Outcomes (Cover).....	237
APPENDIX O: Conference Abstracts	238

CHAPTER 1

This chapter begins by defining cancer and looking at the history of the illness to modern day in terms of detection and treatment. Cancer statistics are highlighted both worldwide and in New Zealand. The rationale for this qualitative study, exploring factors which may impact the therapeutic outcomes and experiences of clients using a Psycho-Oncology Service, is discussed and an overview of the thesis is provided.

1.1 Background

Cancer is a term used to describe a number of diseases in which cells in the body multiply in an uncontrolled way and invade surrounding tissues and organs. Cancer can be seen as a consequence of the natural regeneration of cells in all complex animals, a process which normally occurs in a controlled manner with cell growth ceasing at a specific chemical signal (Gabriel, 2007). Every cancer has specific characteristics which distinguish it from other cancers and cancer cells may metastasise (spread) through the body via the blood and lymphatic systems.

1.1.1 A brief history of cancer.

Cancer is not a historically recent disease. However, until recent times, history has largely ignored the psychological and emotional impact of the disease and instead focused solely on the physical nature of cancer. The first documented cases of cancer were by the ancient Egyptians in 3000BC but it was the Greek physician Hippocrates in 400BC who devised the term cancer from the Greek word “karkinos” meaning crab, referring to the shape of the tumours he saw (Sudhakar, 2009).

In 168BC the Roman physician, Galen, proposed that if cancer was detected early it could be cured by cutting or cauterising around the tumour (American Cancer Society, 2012). It was during the 18th century that physicians and scientists such as Paul

Ramazzani, John Hill and Percival Potts related lifestyle, tobacco use and occupation respectively, to the increased risk of developing cancer (Sudhakar, 2009). However, the fear remained that cancer was a contagious disease and hospitals to treat cancer were therefore built away from cities (American Cancer Society, 2012). It appears the very act of physical treatment being isolationist in nature at this time, may have encouraged the development of maladaptive psychological functioning and entrenched societal stigma.

The development of pathological histology in the nineteenth century saw the discovery of cancer metastases and the treatment of breast cancer by radical mastectomy (Sudhakar, 2009). In 1895, the discovery of X-rays by Wilhelm Conrad Roentgen (1845-1923) made the detection of cancer easier and in 1899 Tage Sjogren (1859-1939) pioneered the use of X-rays to successfully treat cancer (Sudhakar, 2009). During the 18th and 19th century, the philosophical influence of that time (influenced by Descartes) magnified the separation of mind and body.

From the 19th century, cancer discoveries continued to develop based primarily on physiological components, with psychological aspects still largely ignored. Major physical breakthroughs in cancer treatment were developed in the first half of the 20th century. The discovery by Charles Huggins in 1939 that certain cancers grew in the presence of specific hormones, laid the groundwork for hormonal treatment (American Cancer Society, 2012). In 1946, Louis Goodman reported the use of nitrogen mustards as the first chemotherapeutic agents against Hodgkin's Disease, lymphosarcoma, and leukaemias (American Cancer Society, 2012).

The latter half of the 20th century saw an increased understanding of DNA and the way in which genetic mutations, through exposure to radiation, chemicals or viruses can lead to the development of cancer. Significantly, the 1970s saw the naming of

specific cancer genes termed oncogenes and tumour suppressor genes (American Cancer Society, 2012). Oncogenes are mutated genes which cause normal cells to grow uncontrollably becoming cancer cells. Tumour suppressor genes slow down mitosis, repair DNA errors and control programmed cell death and it is errors in these tumour suppressing genes which may allow cancer to develop. Cancer genes have also been found to pass through family lines and in 1990 a major breakthrough occurred in the identification of breast cancer susceptibility genes, BRCA1 and BRCA2 (Sudhakar, 2009).

It is only since 1960 that cancer screening tests were widely adopted, the first being the cervical smear originally developed by George Papanicolaou in 1923 (Sudhakar, 2009). Cervical screening led to a 70% reduction in cervical cancer deaths in the USA. Mammograms to detect breast cancer were also developed in the 1960s but not recommended as a regular cancer screening tool until 1976 (American Cancer Society, 2012).

In terms of treatment breakthroughs, the late 20th century saw a number of physical advances and continued dominance of treatment concentrating on the physiological aspects of cancer treatment. While surgery, radiation therapy and chemotherapy continue to be the primary treatments, other options such as bone marrow transplants and hormone therapy have been added. If detected early, cancers such as breast, colorectal and cervical cancers now have high cure rates, particularly if detected before metastases have occurred.

The 21st Century has seen significant advancement in cancer research. Major on-going research includes the complete genome mapping of a number of cancers by the Cancer Genome Atlas Project (TCGA) a project which began in 2006 (Hudson et al., 2010). The goal of this project is to improve identification, treatment and prevention of

cancer through specific identification of mutated genetic code of diseased cells (Hudson et al., 2010). Epidemiologic research continues to identify factors that increase cancer risk and in 2008 the World Health Organisation (WHO) recognised over 100 chemical, physical, and biological carcinogens (Ferlay et al., 2010). Research into the improvement and development of new cancer treatments continues with particular focus on tailoring treatment specifically to suit the genetic makeup of each individual's cancer (Varmus, 2006).

1.2 Cancer Statistics

1.2.1 Worldwide.

Despite advances in the detection and treatment of cancer, this illness still remains one of the leading causes of death worldwide. In 2010 cancer accounted for 21% of all non-communicable deaths, second only to cardiovascular disease (Jemal, Siegel, Xu & Ward, 2010). In 2008 the yearly worldwide incidence of cancer cases was estimated to be 12.7 million with 7.6 million cancer deaths (Ferlay et al., 2010). The lifetime risk of developing any cancer is currently estimated as one in three with this predicted to increase to one in two by 2015 as a result of ageing populations, recent trends in smoking and the rise of unhealthy lifestyles (Jemal et al., 2009).

Different cancer types have varying prevalence, with lung, breast, colorectal, stomach and prostate cancers accounting for more than half of those diagnosed annually. Lung cancer is documented as having the highest mortality rate and in 2008 accounted for 18% of global cancer deaths (Jemal et al., 2011). Breast cancer is the main cause of death from cancer for women worldwide, with 1.3 million women being diagnosed each year and a mortality rate of approximately one third of those diagnosed. The incidence of colorectal cancer is rare in non-developed countries but in the

developed world this disease affects over 940,000 people annually worldwide, with nearly 500,000 deaths (Jemal et al., 2010).

1.2.2 New Zealand.

New Zealand is reported as having the fourth highest cancer rate in the world (Ferlay et al., 2008). At time of writing the latest published cancer statistics cited cancer as the leading cause of death for New Zealanders, with 8437 people dying in 2009 (Ministry of Health [MOH], 2012). In the 10 year period to 2009 cancer deaths increased by 9.9% although the rate of death decreased by 16.2% to 126.8 per 100,000 population. Figures show that there is a large disparity in cancer rates between Māori and non-Māori. Cancer is the leading cause of death in Māori women, being 78% higher than for non-Māori and is the second highest cause of death in Māori men (MOH, 2003).

The highest recorded death rate for both sexes in 2009 was for lung cancer (18.9% of cancer deaths), followed by colorectal and prostate cancer for men and breast and colorectal cancer for women. In fact, for women, breast cancer continued to be the most frequently registered cancer in New Zealand, with an incidence level of 28.4% in 2009 (MOH, 2012). Gynaecological cancers, (uterine, cervical, ovarian and vulval) account for 10% of cancers in New Zealand and 10% of cancer deaths (MOH, 2002). Death rates from cancer, however, continue to decline, with the latest report from Otago University (Soeberg et al., 2012) stating that overall death rates for cancer in New Zealand had fallen by 26% each decade for the last two decades. It is advances in the detection and treatment of cancer which have enabled people to survive for longer periods free of cancer (Winer et al., 2009).

1.3 Study Rationale

There is no doubt that advances in medical treatment focused on treating and curing cancer have developed exponentially over the last couple of centuries. Cancer, in many instances, is curable, yet for most people today, a cancer diagnosis still coexists with overwhelming fears, burdens and psychological distress. Many still face a journey where their life span is shortened by their cancer. As evident in the history of treatment development, psychological factors and impact of cancer have been largely ignored historically until relatively recent times.

The last four decades has seen an extensive body of literature studying the psychological impact of cancer, with the consensus being that a cancer diagnosis may generate significant psychological distress. Massie and Holland (1989) assert that people living with cancer face what they term the “5Ds” in that they may confront the potential of death, increased dependence on others, disability, disfigurement and the disruption of life plans. Holland (2003) states that the psychological impact of a diagnosis of cancer may include anxiety, pain, depression, delirium and fatigue.

There are numerous Randomised Clinical Trial studies which have investigated the effects of specific mediating and moderating variables on therapeutic outcome for non-cancer clients. Kazdin (2007, p. 1) states that “after decades of psychotherapy research, we cannot provide an evidence-based explanation for how or why even our most well studied interventions produce change, that is, the mechanism(s) through which treatments operate”. The literature indicates that people with cancer do gain benefit from psychological intervention (Andrykowski & Manne, 2006; Heron, 2009; Meyer and Mark, 1995; Sheard & Maguire, 1999).

Psycho-Oncology is still a young field and since the 1970s the majority of research has focussed on the psychological impact of cancer and the effects of psychological interventions (Holland, 2002).

While internationally, researchers are exploring what impacts the efficacy of psychological interventions generally, individual clinicians and services also spend time trying to answer this question for their specific setting so that they can improve the services they provide. To date, one study by Croy (2010) has evaluated the outcomes of interventions by the Massey Psycho-Oncology Service in New Zealand as part of a large, formal evaluation of the Service. Croy's (2010) study combined quantitative and qualitative methodology in which only a small sample of participants were interviewed. Croy (2010) specifically targeted those former POS clients with the greatest changes in distress versus those with the least changes in distress after psychological therapy. The aim of the current qualitative study is to explore what factors may impact the therapeutic outcomes and experiences of clients using a Psycho-Oncology Service.

It is important for the future development of specialised cancer services that research is aimed at specific cancer groups (Koch & Kralik, 2009). The current study does this as it expands on the previous research by Croy (2010) in specifically targeting the Service's largest attending referral groups, with the highest reported levels of initial distress. These groups were women (breast and gynaecological cancers) and family/whānau members. As recommended by Croy (2010), this study also explored the experiences, thoughts and feelings of the Service's clinicians in relation to providing therapy to people coping with cancer and how they might impact client outcomes. In addition, the cancer experiences of patients and family/whānau members who reported not making use of specialised psycho-social support was explored. This fourth non-intervention (NI) group was interviewed in order to gain a better understanding of their

lived experience of coping with cancer in order to explore why they did not use the POS and to allow comparison with POS clients' cancer journeys.

The aim of this study was to answer the research questions:

- What factors impact the therapeutic outcomes and experiences of clients¹ using a Psycho-Oncology Service.
- How does the cancer experience of people who did not use specialised psycho-social support services compare with clients who used a Psycho-Oncology Service.
- How does the experience of being a psychologist working with people affected by cancer impact clients and clinicians.

It is hoped that this current study will add to limited psycho-oncology literature from New Zealand. International research in this area is also lacking, so findings will add to the international knowledge base with regard to what factors may impact the therapy outcomes of people using Psycho-Oncology Services. The findings of this study may also be useful in the development of other specialist Psycho-Oncology Services in New Zealand and provide information that could be applied by other services in the psycho-oncology field. In addition it may also help to refine and improve the interventions offered by the Massey Psycho-Oncology Service.

1.4 Thesis Overview

This thesis is comprised of 10 Chapters. Chapter 1 provides an historical background to cancer including recent data on the incidence and survival of cancer and provides a study rationale. Chapters 2 and 3 review the literature relating to the psychological impact of cancer and psychological interventions and factors affecting

¹ Throughout this thesis the term "client" refers to people seen by the Massey Psycho-Oncology Service who either had cancer or were a family/whānau member of a person with cancer.

therapy. The development of Psycho-Oncology worldwide and in New Zealand is discussed in Chapter 4. Chapter 5 outlines the study methodology including method rationale, description of procedure and analysis. The findings and discussion are contained in Chapters 6 to 10 with recommendations for clinical practice and further research being summarised in Chapter 10.

1.5 Summary

This chapter provided a background into the definition and history of cancer. Cancer is an illness which has been recognised since ancient times and is actually several distinct diseases each with specific characteristics. In 2008 the prevalence was estimated to be 12.7 million with 7.6 million cancer deaths worldwide. Statistics show that cancer still remains one of the leading causes of death worldwide (Ferlay et al., 2010). New Zealand has the fourth highest cancer rate in the world (Ferlay et al., 2010) and cancer is cited as the leading cause of death for New Zealanders, with 8437 people dying in 2009 (MOH, 2012). Throughout history, medical advances have continued to be made in detecting and treating cancer which has meant that the cancer mortality rate is now declining. However, it is only relatively recently that research relating to the psychological impact of a cancer diagnosis has been advanced. The aim of this qualitative study was to explore the lived cancer experience of clients using a Psycho-Oncology Service, people who chose not use psycho-social support and psycho-oncology clinicians in to order identify what factors may impact the psychological therapy outcome and experiences of using such a Service.

Literature Review

CHAPTER 2

THE PSYCHOLOGICAL IMPACT OF CANCER

This chapter reviews the literature concerning the psychological impact that cancer may have on a patient. Impact is discussed along the cancer continuum, from diagnosis to long-term survival and terminal phase. In addition the impact for a cancer patient's family/whānau is discussed and the specific effects for people with breast and gynaecological cancers are considered. Coping with cancer is discussed in terms of what impacts both positively and negatively on distress. Both quantitative and qualitative studies are reviewed in order to provide a broad account of the literature.

2.1 Distress

Cancer is not a discrete, short lived illness. In the 1930s a person with cancer had a 1:4 chance of surviving for 5 years, however, with advancements in cancer detection and treatment, survival rates now average 2:3 (Jemal et al., 2004). Since the formal development of psycho-oncology there has been an extensive body of literature exploring the psychological impact of cancer with the consensus that a cancer diagnosis may generate significant psychological distress. In a concept analysis of psychological distress, Ridner (2004) defines this construct as: "the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person" (p. 539). In relation to cancer, the term "distress" encompasses an array of psychological responses which may manifest as disorders at clinical or sub-clinical levels at varying times along a patient's cancer journey. Distress may interfere with a patient's ability to cope with their cancer

treatment and can vary from feelings of vulnerability, fearfulness and sorrow to depression, anxiety, feelings of isolation or spiritual crisis (Holland, 1999).

High levels of psychological distress have been found to affect over one third of all cancer patients (Derogatis et al., 1983; Zabora, Brintzenhofesoc, Curbow, Hooker & Piantadosi, 2001). The major transition points on the cancer continuum are considered times when patients are at significant risk of high levels of distress (Bush, 2009). Crisis points include diagnosis, treatment, end of treatment, recurrence of cancer, and the terminal phase (McCormick & Conley, 1995).

The National Comprehensive Cancer Network (Holland & Bultz, 2007) has proposed that the level of “emotional distress” be considered the “sixth vital sign” of a patient’s well-being. The term “emotional distress” has been utilised with the aim of reducing the stigma often related to psychological disorders (Holland & Bultz, 2007).

2.2 Impact at Diagnosis

2.2.1 “Being traumatised”- anxiety.

Despite improved survival rates, the belief that cancer is incurable perpetuates to some extent and this illness can still generate a considerable fear and anxiety response in people (Holland, 2002). There can be substantial delay before a cancer diagnosis is confirmed and in a review of distress during the diagnostic process Brocken and colleagues (Brocken, Prins, Dekhuijzen, & van der Heijden, 2012) found that pre-diagnostic anxiety may have a prevalence of between 33-60%. However, a rapid reduction in distress is seen following a benign result.

In qualitative studies exploring cancer patients’ beliefs and knowledge about cancer, the view that cancer is a terminal illness predominates (e.g. Chrz, Cermák, & Plachá, 2006; Landmark & Wahl, 2002; Shahid & Thompson, 2009; Sheikh & Ogden, 1998). Hence, those whose diagnosis is positive for cancer can experience severe

distress and may initially be left in a state of shock, feeling stunned and lost (Greer, 2002). In their qualitative study of 27 newly diagnosed cancer patients, McCaughan and McKenna (2007) described this stage of initial reaction to diagnosis as “Being Traumatized”. They regard this as this a period of introspection in which newly diagnosed cancer patients take time to process what is happening to them. Typically a cancer diagnosis adversely impacts not only quality of life but can cause the temporary or permanent abandonment of future plans that bring life meaning (Scheier & Bridges, 1995). The prevalence of anxiety after diagnosis varies and those with lung, gynaecological, or haematological cancers tend to report the highest anxiety levels (Linden, Vodermaier, MacKenzie, & Greig, 2012). In a recent study of newly diagnosed cancer patients over a period of five 19.0% of patients showed clinical levels of anxiety with 22.6% having sub-clinical symptoms (Linden et al., 2012).

American psychiatrist, Lawrence Goldie, equates the trauma of cancer diagnosis to that of “shell shocked” veterans of World War II, in producing both physiological and psychological pain (Goldie, 2005).

In 2000 the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000) re-defined trauma criteria for acute stress disorder (ASD) and post-traumatic stress disorder (PTSD) to include the diagnosis of life threatening illnesses such as cancer. There is however, some contention regarding the inclusion of cancer as a traumatic stressor. Critics of its inclusion claim that the enduring nature of the disease does not fit with a single traumatic event (Van der Kolk & McFarlane, 1996) and that the threat is not externally induced (Green et al., 1998). In addition, reported PTSD symptoms may in fact be the side effects of cancer treatment or fit better as symptoms of anxiety or depression (Cordova & Andrykowski, 2003; Green et al., 1998). However, Rustad, David and

Currier (2012) argue that multiple studies using the PTSD Checklist Civilian Version support PTSD as a conceptualisation of distress for cancer patients. In May 2013 the Diagnostic and Statistical Manual of Mental Disorders (5th ed., DSM-5; American Psychiatric Association, 2013) moved PTSD from the class of anxiety disorders into a new class of "trauma and stressor-related disorders." There is still a requirement for exposure to a traumatic or stressful event as a diagnostic criterion.

The published prevalence rates for both ASD and PTSD in cancer patients vary considerably as research methodologies are not consistent in terms of design, assessment tools and cancer type (Kangas, Henry & Bryant, 2002). The literature reports the presence of ASD in cancer patients ranging from 5% to 33% (Kangas et al., 2002), with PTSD rates at 0% to 32% (Kangas, Henry & Bryant, 2005). Characteristics of ASD and PTSD include avoidance and avoidant behaviours, re-experiencing of the traumatic event through intrusive thoughts and dreams and intense psychological reactions to anything cueing the event. These symptoms may have considerable impact on the behaviours of those with cancer. Symptoms of avoidance may result in patients failing to participate fully in their cancer treatment as they associate the hospital with the trauma of diagnosis (McGarvey et al., 1998). In addition, dissociative responses may result in important information being missed during medical appointments and patients may feel disconnected from family members at a time when they most need their support (McGarvey et al., 1998).

2.2.2 Depression at diagnosis.

In a meta-analysis of over 100 studies looking at the prevalence of depression in cancer patients, Massie (2004) found that although rates of depression ranged from 0% to 58%, it was evident that cancer is associated with a high incidence of depression. Literature examining the incidence of depression for those newly diagnosed with cancer

is limited. Bucherri (1998) found that 44% of men newly diagnosed with lung cancer were moderately to severely depressed. However, this group included early to late stage diagnosis. Consistent with all cancer research, prevalence figures for depression at diagnosis vary and are impacted by methodology. Linden et al. (2012) found that at diagnosis, 12.9% of patients had clinical symptoms of depression with 16.5% describing sub-clinical symptoms.

Studies suggest that the early diagnosis of depression is critical as depression may have a negative impact on a patient's quality of life, cancer progression and mortality (Spiegel & Giese-Davis, 2003). Depression can be missed at diagnosis as the emotional and physical presentation such as fatigue, weight loss, reduced appetite and sleep disruption can be mistaken for cancer symptoms (Fallowfield, Ratcliffe, Jenkins & Saul, 2001). The effects of untreated depression can result in poorer outcomes for cancer patients who may not adhere to their treatment (Massie, 2004).

2.3 Impact During Treatment

As discussed in the introduction, cancer results from cells in the body multiplying in an uncontrolled way. A person with cancer faces not only being unable to control his own body but they can feel powerless to control the impact of the illness on their life as a whole. A feeling of loss of control can be generated though the uncertain outcome of a cancer diagnosis and particularly where cancer patients may perceive that decisions are being made about their health by people in authority (Williams & Koocher, 1998). In addition, patients tend to be offered very little preference for treatment, preference of appointment times or choice of medical staff. From interviews exploring the experiences of people with chronic health conditions, who had also been clients of Massey University Psychology Clinic, Dempster (personal communication, 24 June, 2013) found that people felt depersonalised within the hospital system and

described themselves as being on a factory production line. Where feelings of loss of control are persistent it can bring about feelings of helplessness, hopelessness and depression in the patient (Greer & Moorey, 1997).

The treatment of cancer may include surgery, chemotherapy, radiation, immunotherapy and bone marrow transplant and each of these treatments can impact a cancer patient both physically and psychologically (Schroevers, Ranchor & Sanderman, 2004).

2.3.1 Pain and fatigue.

For people with cancer, pain and fatigue can be a direct result of their tumour or can arise as a secondary effect of treatment such as radiation, chemotherapy and surgery.

In a meta-analysis of over 52 cancer pain studies van den Beuken-van Everdingen et al. (2007) found that the prevalence of pain was over 50% in pooled cancer patients. An international study involving 1095 patients being seen for severe cancer pain, found that 20.8% of patients had one or more pains caused directly by cancer therapies (Caraceni & Portenoy, 1999). A significant relationship has also been found between the higher expression and intensity of physical pain and the presence of mood disorders (Delgado-Guay et al., 2009) and in a systematic review of the literature Laird, Boyd, Colvin and Fallon (2009) assert that there is evidence to claim a causal relationship between pain and depression in cancer patients. Pain can also increase psychological distress in cancer patients. In a review of the impact of cancer pain on psychological distress Zaza and Baine (2002) found that 14 of the 19 reviewed studies showed a significant association between increased pain and increased distress.

The National Comprehensive Cancer Network (NCCN) defines cancer related fatigue as “a persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning” (Mock et al., 2003, p. 309). Fatigue is considered to be the most prevalent symptom reported by cancer patients (Carlson et al., 2004; Lawrence, Kupelnick, Miller, Devine, & Lau, 2004; Stone, Richards, & Hardy, 1998). In a study of 379 cancer patients, it was reported that 76% experienced fatigue with 30% suffering on a daily basis (Curt, Breitbart & Cella, 2000). Of those reporting fatigue, 90% felt that it prevented them from living a normal life including impacting on daily routines, and reduced participation in social activities with 75% of those employed reducing their hours of work (Curt et al., 2000). In a review of the literature regarding the prevalence of fatigue in breast cancer patients undergoing chemotherapy, de Jong et al. (2002) found that the overall prevalence was 48%.

2.3.2 Neuropsychological effects.

Traditional chemotherapy is administered in cycles, a treatment period followed by a recovery period, then another treatment, and so on. In their meta-analysis of the neuropsychological effects of chemotherapy on women with breast cancer, Stewart, Bielajew, Collins, Parkinson, and Tomiak (2006) found that the reported areas of cognitive decline differed. The areas which were affected most negatively were short-term memory, language and spatial ability. O’Shaughnessy (2003) reported that cognitive decline is over twice as likely to occur in women who have chemotherapy treatment than those who do not. In a qualitative study women’s perception of the cognitive effects of chemotherapy, Munir, Burrows, Yarker, Kalawsky, and Bains (2010) found that there was a clear awareness of cognitive decline which affected their confidence and ability to work. Being unable to work can add to distress as there is likely to be added financial burden due to cost associated with treatment (Heron, 2009)

Chemotherapy destroys cancer cells because it is specifically targeted at killing rapidly dividing cells. However, the toxic effects also destroy other rapidly dividing cells such as those in blood, mouth, intestinal tract, nose, nails, vagina, and hair. This toxic effect causes many physical side effects such as hair loss, nausea, vomiting, and diarrhoea and associated psychological morbidity such as increased distress, anxiety and depression in cancer patients (Pandey et al., 2006).

2.4 Impact of Survival

There appears to be no consensus within the literature which provides a clear definition of a “cancer survivor”. The National Cancer Institute (2011) proposes that someone be termed a cancer survivor from diagnosis through their remaining life. However, medically survival rate is typically defined as the percentage of those people who are still alive five years from diagnosis. Andrykowski, Lykins and Floyd (2008) convey psychological health in cancer survivorship as both a dynamic and fluid concept and propose several outcomes over time, represented in Figure 1 (p. 17).

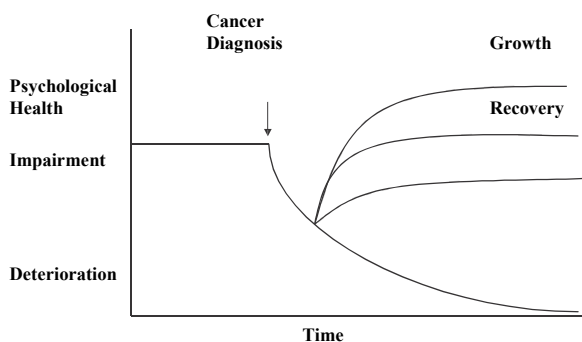


Figure 1. Temporal trajectories of psychological health in cancer survivors. (From Andrykowski et al., 2008, p. 196)

The transition from treatment to cancer survivor is frequently a time when a cancer patient’s distress levels may increase significantly (Andrykowski, et al., 2008). Stanton et al. (2005) describe the “myths of treatment completion” in their review of

adjusting to cancer survivorship. These include “I should be celebrating, I should feel well, I should be the pre-cancer me and I should not need support” (p. 2609). Rather than being a time of increased hopefulness, the end of treatment can be predominated by fear of recurrence (Arnold, 1999; Stanton et al., 2005; Wenzel et al., 2002) and experiencing the loss of social support from friends and family who are unaware of the patient’s continued needs (Stanton et al., 2005).

In their study of 1721 cancer survivors Herschbach et al., (2004) established that, in fact fear of cancer progression was the most prevalent cause of distress. The impact of physical side effects such as pain and fatigue also persists for many survivors particularly in the first 5 years since diagnosis (Shi, Qiu & Yu, 2011). In the long-term, the physical symptoms and limitations experienced by cancer survivors are generally comparable to those without cancer, although for those between 45-65 years of age symptoms may still be significant (Schroevers et al., 2004). The continuation of pain and fatigue has been correlated with difficulty in returning to work which can in turn perpetuate distress because of subsequent financial strain, loss of normal role and also loss of social contact (Spelton et al., 2003). Survivors can be left with a feeling of being alone and an increased awareness of their own mortality, although positive aspects are also evident (Foster, Wright, Hill, Hopkinson & Roffe, 2009). Younger survivors, in particular those under 65 years, may ascribe positive changes to their cancer journey, experiencing a greater appreciation for life and relationships, feel strengthened and expressing that they no longer take life for granted (Shroevers et al., 2004).

A number of studies have shown that the prevalence of depression declines for most cancer survivors with levels in the long-term (>5 years) generally matching the prevalence of the general population at approximately 15% (Shroevers et al., 2004; Burgess et al., 2005). In the long-term, incidence of depression is greater for cancer

survivors who continue to cope with significant unmanaged pain or fatigue (Ciaramella & Poli, 2001; Sellick, & Crooks, 1999). The long-term effects of depressive symptoms are considered to be a predictor of shortened survival time (Brown, Levy, Rosberger & Edgar, 2003). In a recent review of literature Mitchell, Ferguson, Gill, Paul, and Symonds (2013) found that for cancer survivors and their partners, anxiety rather than depression can persist up to 10 or more years after diagnosis.

2.5 Impact of Cancer Recurrence

Cancer recurrence is distinct from cancer progression. Progression refers to the spread of the cancer or it getting worse and occurs within 3 months of treatment (American Cancer Society [ACS], 2013). The risk of cancer recurrence is related to a number of factors, including cancer type, duration of disease free interval and age at diagnosis (ACS, 2013).

There appears to be scant research investigating the psychological impact of cancer recurrence. This may be due to assumptions that the impact of cancer recurrence and progression are synonymous or that the psychological response will mimic that of initial diagnosis (Stein, Syrjala, & Andrykowski, 2008). Indeed the initial response to cancer recurrence mimics that of initial diagnosis in that cancer patients may feel shocked and devastated (Stein et al., 2008). However, for those where there has been a long period of time before recurrence the impact can be greater than the initial diagnosis (Vivar & McQueen, 2005). Recurrence has been correlated with a poorer quality of life than those with initial cancer diagnosis, including poorer physical and emotional health and greater distress (Northouse, 2002).

2.6 Palliative /Terminal Phase

Despite the modern advances in cancer detection and treatment, unfortunately many of those diagnosed with cancer will die from their illness. Patients living in the final phase of life are likely to experience the grief of facing loss of future and the separation from family and friends (Pasacreta & Pickett, 1998).

As with other areas of cancer research, end of life studies suffer from inconsistent methodologies. Ryan and colleagues (2011) maintain that research with populations at the end of life offers increased challenges for recruitment and purport that many studies are not open regarding the characteristics of their population sample. The prevalence of psychological morbidity with those who are terminally ill shows conflicting results. Lichtenthal et al., (2009), claim that the incidence of mental disorders do not change for those approaching death, except for younger adults. However, an increase in existential and physical distress is typically experienced.

A feeling of high spiritual well-being is seen as important to those who are terminally ill. Poor control of physical and psychological symptoms of distress appear to be correlated with lower levels of spiritual well-being (Kandasamy, Chaturvedi, & Desai, 2011; Lichtenthal et al., 2009). In a qualitative study of 26 men with terminal heart disease or cancer participants talked about “actively dying” meaning that they would continue as much as they could with doing things they always enjoyed (Vig & Pearlman, 2003). The men’s main concerns were related to becoming dependent and burdening family during the course of dying and death. In an large survey of over 2000 people which included people with cancer, bereaved family members, oncology staff and cancer volunteers, Steinhauser and colleagues (Steinhauser et al., 2000) found that the factors considered most important were symptom control, preparing for death and spending time with loved ones.

2.7 Impact for Family/Whānau

Unquestionably the impact of a cancer diagnosis is not isolated to the patient.

She just sat on my dad's hand on the sofa and said, 'There's no easy way to tell you, I've got cancer.' I just lost it. I just burst into tears and then my mum did, and then my dad did. It was just the most terrible thing in the world. (17 year old girl)

(Forrest, Plumb, Ziebland & Stein, 2006, p. 3)

This quote from Forrest and colleagues' exploration of children's perceptions of their mother's breast cancer clearly reveals the distress that a cancer diagnosis can have on a family. Family therapists Veach, Nicholas and Barton (2002), consider that the level of impact a cancer diagnosis has on a family is related to the family life cycle stage, identifying the differences in family structure, size, and coping patterns according to stage of family development. Within the family, fear of loss predominates, together with loss of physical contact, greater emotional distance, uncertain future, the burden of additional responsibilities and family role changes. (Borneman et al., 2003; Veach et al., 2002). Maternal depression has been linked to poor family functioning regardless of whether the mother is the person with cancer (Schmitt et al., 2008).

Many couples confront cancer as a team and adjustment to cancer by one partner affects the other (Northouse, Templin & Mood, 2001). Hagedoorn and colleagues' (Hagedoorn, Buunk, Kuijer, Wobbes & Sanderman, 2000) study of 172 couples indicated that women actually experience more distress than their partners whether they have cancer or not. Data show that 18-30% of a cancer patient's adult relatives suffer from depression (Edwards & Clarke, 2004) and maternal depression has been linked to poor family functioning regardless of whether the mother is the person with cancer (Schmitt et al., 2008). Edwards and Clarke (2004) also established that cancer type influenced the levels of psychological distress. The partners of patients with colorectal

or prostate cancer were seen to have higher distress levels than the patient, with the opposite being true for breast cancer. The lowest anxiety levels were found in families where colorectal cancer was diagnosed (Edwards & Clarke, 2004). Northouse et al. (2000) suggest "...even though patients and their family caregivers share the same cancer experience, their ways and times of responding to it may differ, due in part to their different roles (i.e. patient vs. caregiver) and in part to their...responses as males and females" (p. 283).

A diagnosis of cancer may also have an impact on communication between partners' and their intimate relationships. In reviewing the impact of cancer on partners' coping and distress Carlson, Bultz, Speca, and Pierre (2000) concluded that effective communication clearly benefits the psychological adjustment of both partner and cancer patient. Poor family communication has also been related to behavioural and emotional problems in school aged children and Schmitt et al. (2008) suggest that depression screening should be routine for both parents.

2.8 Impact of Breast Cancer

As previously stated, breast cancer is the most frequently diagnosed cancer for women. However, as mortality rates continue to decline for those with breast cancer, more women are forced to cope with the psychosocial impact of their diagnosis and treatment. A diagnosis of breast cancer can produce considerable psychological distress (Zabora et al., 2001). Incidence of both mood and anxiety disorders are consistently found to be higher than the general population, particularly in the first year post diagnosis (Derogatis et al., 1983; Grabsch et al., 2006; Härter et al., 2001). Studies have shown that breast cancer can have greater impact for younger women, particularly those who were pre-menopausal or with no children at diagnosis, where chemotherapy can induce early menopause (Avis, Crawford, & Manuel, 2005; Northouse, 1994). In a

study of 549 women with newly diagnosed breast cancer, Fobair et al., (2006) found that 50% of women younger than 50 years of age had problems with poor body image. Breast cancer may impact a woman's sense of self and daily functioning as well as her family and social life (Loveys & Klaich, 1991). Women with breast cancer may face a number of physical challenges including coping with menopausal symptoms from the effects chemotherapy, hair loss, pain, fatigue and insomnia (Ferrel, Grant, Funk, Otis-Green & Garcia, 1997).

One of the greatest concerns for women diagnosed with breast cancer is the potential loss of a breast (Ashing-Giwa et al., 2004). In Ashing-Giwa and colleagues' qualitative study of 102 breast cancer survivors this distress is clearly expressed by a participant who stated: "...but your body is missing something. You'll never be the same. You feel as if you're beneath others, you don't feel worthy" (Ashing-Giwa et al., 2004, p. 422).

Concerns over their sexual attractiveness, feelings of low self-esteem and believing themselves to be less feminine are frequently observed in women with breast cancer (Fobair, et al., 2006). Sexual problems have been shown to be associated with greater body image concerns (Fobair, et al., 2006). In the Australian study by Kissane et al., (1998) nearly 33% of the women felt less attractive, had lost interest in sexual activity and had considerable distress concerning hair loss. Hair loss is, in fact, considered by women as one of the most difficult side effects of chemotherapy to cope with. A woman's hair is a symbol of her identity, sexuality and personality (Freedman, 1994; Lemieux, Maunsell, & Provencher, 2008). Freedman (1994) found that hair loss may be considered worse than loss of a breast. The following quote from Landmark and Wahl (2002), illustrates this: "It's got worse and worse, I'm losing my hair, it's thin and ragged but I'm glad I've kept going. It's a constant battle" (p. 116).

2.9 Impact of Gynaecological Cancers

The most common gynaecological cancers are those of the ovaries, cervix and endometrium (lining of the uterus). The clinical presentation of each is distinct and also varies in management and prognosis (Beaver & Booth, 2007). As with other cancers, anxiety and depression predominate with data suggesting that up to 70% of women may experience severe symptoms (Petersen & Quinlivan, 2002). In a study of 83 women with gynaecologic cancer it was found that there was a 23% incidence of depression and a 24% incidence of adjustment disorder with depressed mood (Evans et al., 1986).

Women with these cancers often have to face the removal of organs resulting in sterility, which for some women equates to a loss of femininity (Juraskova, et al., 2003). From Juraskova and colleagues study of women following gynaecological surgery, a 41 year old woman states: “These are my reproductive organs . . . this is my womanhood . . . this is what we are all about . . . and if they would have said: *‘We have to take your breast away, that wouldn’t have worried me.’*” (Juraskova et al., 2003, p. 271)

The consequences of surgical treatment of gynaecological cancer may cause physiological effects such as vaginal dryness, early menopause or infertility (Royal College of Radiologists et al., 2007). Many women fear that intercourse may be painful or will cause recurrence or damage (Frumovitz et al., 2005). Andersen (1993) found that 50 % of women with gynaecological cancer report sexual morbidity during the first 12 months post-treatment with up to 40% having persistent sexual problems. The impact of early menopause can be devastating for couples who have not completed their families. In a qualitative study exploring the experience of 18 Chinese women who had gynaecological cancer, many participants concerns included marital problems, worries about the future of their children, concerns about sexuality and loss of fertility

(Molassiotisa, Chan, Yam, Chan, & Lam, 2002). The sense of loss of an important life experience is highlighted by the following comment:

I was worried that I won't have any children anymore... If I had complete removal of the [sexual] organs, then I wouldn't have any chance of having children and it means that I will miss out on something.
(K.I.L.) (Molassiotisa et al., 2002, p. 119)

The loss of being able to have a child also impacts the male partner. For men not being able to have a child can create a sense of loss, depression and social isolation (Hadley & Hanley, 2011). Even where the man is fertile, he can experience a sense of powerlessness and lose his sense of self-esteem and respect (Imeson & McMurray, 1996).

2.10 Coping with Cancer –What Impacts Distress?

Lazarus (1993, p. 237) defines the coping response as consisting of “cognitive and behavioural efforts to manage psychological stress” and states that an illness such as cancer may pose different threats and therefore require different coping strategies throughout the course of the illness. In their critique of classifying coping Skinner and colleagues (Skinner, Edge, Altman & Sherwood, 2003, p. 217) state “the fundamental problem in identifying core categories is that “coping” is not a specific behaviour that can be unequivocally observed or a particular belief that can be reliably reported. Rather, it is an *organizational construct* used to encompass the myriad actions individuals use to deal with stressful experiences”. Patients’ level of distress may also be greater in those who perceive their cancer to be an acute disease rather than a chronic illness (Rabin, Leventhal & Goodin, 2004).

Patterns of coping with cancer have been identified in preference to specific coping styles, in addition it has been found that cancer site, time since diagnosis and

type of cancer threat may not be significantly related to specific coping patterns (Dunkel-Schetter, Feinstein, Taylor and Falke, 1992; Link, Robbins, Mancuso, Charlson, 2004). The following section reviews the coping behaviours commonly utilised by those dealing with cancer which have been found to either reduce or perpetuate distress.

2.10.1 Responses which may reduce distress.

Research has demonstrated having a greater perception of control tends to be correlated with improved psychological adjustment (Lowery, Jacobsen & DeCette, 1993; Taylor, Helgeson, Reed & Skokan, 1991). Williams and Koocher, (1998) discuss the use of action-oriented response, in which those diagnosed with cancer use behaviours that include seeking out cancer related information or change their lifestyle by exercising or improving their diet. These active behaviours are considered to be reliant on a person's problem-solving skills and are typically related with someone possessing an internal locus-of-control (Williams & Koocher, 1998).

2.10.1.1 Seeking information.

Information seeking refers to efforts to learn more about a stressful situation or condition, and studies indicate that the majority of cancer patients desire information about their illness (Jenkins, Fallowfield & Saul, 2001; Meredith et al., 1996). Although cancer patients do receive information about their diagnosis from medical staff often it is at a time when they are in a state of shock and unable to process the information being provided. In addition time constraints can make it difficult for medical staff to spend the time providing the information necessary.

Maslow (1963) asserts that we may seek or avoid knowledge in order to reduce anxiety. A study of the outcomes of a consumer health information service found

receiving information reduced anxiety in 52% of participants but increased the anxiety of 10% (Pifalo, Hollander, Henderson, Desalvo & Gill, 1997). It has been suggested that the need for information varies throughout the cancer experience. In a qualitative study, Leydon et al. (2000) interviewed 17 women with breast cancer and found that there was a need for basic information on diagnosis and treatment but information was not wanted at all stages of their illness. However, a detailed methodology and data collection process were not provided in the study which makes it difficult to judge the validity of their conclusions.

People coping with cancer have been found to use a variety of information sources. In a review of information seeking in patients with colorectal, breast and prostate cancer over 50% used medical staff, personal contacts and the media (Nagler et al., 2010). The Internet was used by nearly one third of cancer patients although they still utilised offline sources to learn about their disease. Although the Internet can be a useful and easily accessed information source it is not always helpful. In their qualitative study examining women with epithelial ovarian cancer, Power, Brown and Ritvo (2008) participants commented:

I013: I'd started looking up on, you know, on the Internet, and then what I'm doing is scaring myself.

I017: I went on the Internet for things, but then I found out things that I didn't want to know, so I stopped doing that. (p. 372)

2.10.1.2 Lifestyle changes.

Health professionals and public health messages advocate the beneficial role of a healthy lifestyle to people diagnosed with cancer. Making lifestyle changes in response to their diagnosis has been attributed to cancer patients regaining a sense of control over their illness (Maunsell, Drolet, Brisson, Robert & Deschênes, 2002). Approximately

two thirds of cancer patients have been found to make changes in physical activity or diet in response to their diagnosis with more choosing dietary changes or adding dietary supplements (Patterson et al., 2003). In a study of 250 women with newly diagnosed breast cancer, Maunsell and colleagues (2002) found that 41% reported making some dietary changes in the year after their diagnosis. Significantly there was nearly twice the reduction in psychological distress for those women who altered their diets.

A number of systematic reviews have found evidence that exercise improves mood and quality of life for cancer patients (e.g. Bicego et al., 2009; Courneya, 2003; Beesley, Eakin, Janda, Battistutta, 2008). Courneya (2001) reviewed the bio-psychosocial effects of exercise for cancer patients during treatment and although the number of studies was small (n=11) he concluded that positive emotional benefits were seen with reduction in anxiety, anger and depression, improved body satisfaction and general quality of life. A recent New Zealand review by Szymlek-Gay, Richards, & Egan, (2011) found that most cancer survivors are interested in increasing physical activity but that tailoring exercise programmes to the specific needs of the patient is essential to maintain adherence. The fact that the exercise interventions varied greatly in intensity and type may imply that the improvement in psychological distress was linked to an aspect of coping such as regaining control.

2.10.1.3 Having a positive attitude, being optimistic.

There is a difference between having a “positive attitude” and “positive thinking”. De Raeve (1997) states that a positive attitude is “a state of mind that permits the seeing of things in an optimistic way positive thinking emphasizes the cognitive rather than affective dimension of mental life” (p. 250). The literature has shown that a positive attitude can reduce levels of distress for people with cancer. In a study of 80 women, all one year post-diagnosis of primary or recurrent breast cancer

Cohen, (2002) found that a positive attitude was linked to greater use of problem focussed coping, particularly for the women with primary breast cancer, which resulted in reduced levels of distress. In a qualitative study of 11 patients being treated for cancer, Wilkes and colleagues (Wilkes, O’Baugh & Luke, 2003) found that patients defined a positive attitude as getting through another day and taking control. Patients reported that they felt that the need to be positive or fight with the aim of beating the cancer rather than it beating them (Wilkes et al., 2003).

An additional aspect of a having a positive attitude is that patients may find benefit from their illness. In studies of women with breast cancer the ability to find benefit or positive aspects of their cancer journey within one to five years after diagnosis or treatment was predictive of low distress and fewer depressive symptoms and positive affect four to seven years later (Bower et al., 2005; Carver & Antoni, 2004).

Optimism can be described as the expectation of a good or positive future (Scheier & Carver, 1992). In a study of 439 cancer patients Dunn et al., (2011) found that benefit finding was in fact linked to having greater feelings of optimism. Being optimistic about a positive outcome to their cancer diagnosis has been shown to lower distress, and improve emotional well-being particularly at time of diagnosis and for the following 12 months (Carver et al., 1994; Epping-Jordan et al., 1999; Matthews & Cook, 2009; Stanton & Snider, 1993). In fact, Epping-Jordan et al. (1999) found that low optimism was predictive of symptoms of anxiety and depression at diagnosis and 6-month follow-up for those with early stage breast cancer. Miller, Manne, Taylor, Keates, and Dougherty (1996) also found a sense of optimism to be inversely related to distress for those with last stage cancer, although their study did not show the effect of this over time. It is thought that having a sense of optimism focuses people on achieving

their goals which is then associated with positive behaviours (Carver, Lehman, & Antoni, 2003) and adaptive coping (Carver et al., 1993; Chang, 1998; Stanton & Snider, 1993). This optimistic attitude linked to behaviour is seen in the following quote from Power et al. (2008) qualitative study of coping in women with uterine or ovarian cancer. One woman stated:

I014: So, as I say, I feel very optimistic and very confident at this stage. I feel extremely positive myself and I think that makes a big difference as to how you handle things. ...You have to look at the positive outcomes and work towards that, and so I think that's really helped me tremendously. (p. 376)

2.10.1.4 Social support.

Social support may include the provision of both emotional and instrumental support which can benefit those affected by cancer by reducing distress, improving interpersonal relationships and restoring a sense of control (Helgeson & Cohen, 1996). Emotional support includes verbal and non-verbal expressions of caring, providing a “listening ear” or being encouraging, and comforting (Finfgeld-Connett, 2005; Helgeson & Cohen, 1996). Instrumental support consists of providing practical help such as transport, money, or doing household chores.

After the death of a spouse or partner this can be a time when people can receive a great deal of both emotional and practical social support. Anusic and Lucas (2011) revealed that levels of social support before the death of a spouse did not increase well-being post-loss but in fact those who are gather social support after their spouse's death appear to cope better with their loss.

Social support may buffer some of the negative effects of illness by reducing symptom distress (Lewis et al., 2001) and enabling individuals to gain additional coping resources (Wellisch, 1985). In a longitudinal study of women with breast cancer,

Helgeson, Snyder, and Seltman (2004) found that the group who were least distressed at the end had greater social support than the group whose distress increased over time. Manning-Walsh's (2005) postal survey of 100 women with breast cancer found that there was a positive correlation between support from family and friends and reduction in symptom distress although this was only assessed in the short term. However, the type of people within the support network appears to be less important than the personal qualities of those within the network (Finfgeld-Connett, 2005). What appears to be critical is the perception that the support provides "unconditional positive regard, availability, reliability, and trustworthiness versus kinship or other traditional interpersonal links" (Finfgeld-Connett, 2005, p. 6).

It is important to note that cancer patients may still feel isolated and disconnected from friends and family without cancer, even while feeling fully supported by them. In a qualitative analysis of correspondence (n=21,806) to a newsletter for those effected by ovarian cancer by women with ovarian cancer between 1994 and 2000 Ferrell et al. (2003) found that some women felt alone in their cancer fight. One woman stated: "In spite of all the supportive people I have around me and all the love, I do feel somewhat alienated from all the folks around me who are not fighting cancer" (p. 652).

Some people find benefit from talking to others who are also on their own cancer journey. In a review of peer support groups studies, Dunn et al. (2003) found that being able to compare one's own experience with others can be helpful in validating and normalising emotions as well as providing information about treatment, well-being and coping strategies.

In addition to the psychological benefits of social support, in a meta-analysis of 122 studies, DiMatteo (2004) found that there were significant impacts of social support on adherence to medical treatment. It was found that receiving practical support

increased the likelihood of adherence by 3.6 times and emotional support reduced the chance of non-adherence by 1.3 times. Family cohesiveness was also important and those who perceived themselves to be in a close, nurturing family were 3.03 times more likely to adhere to medical treatment whereas those living in conflict were 1.53 times more likely to be non-adherent (DiMatteo, 2004). There was no detail provided in the review concerning the type of medical conditions that the studies included. However, it may be probable that those with cancer would also be more likely to adhere to treatment where there was good social support available.

2.10.1.5 Self-efficacy.

Over 30 years ago, Bandura (1977) introduced the concept of self-efficacy perceptions to describe a person's belief in their abilities to adapt to a new stressful event and take effective action to create desired outcomes. Self-efficacy has been shown to impact on health behaviours and the way in which a person adapts to illness and treatment. In a six year study, involving 2288 community-dwelling residents (age 55–85), Bisschop, Kriegsman, Beekman, & Deeg, (2004) found that self-efficacy was a protective factor for depression in cancer patients. In addition, higher levels of self-efficacy were seen to buffer the impact of stress related to thoughts of cancer recurrence (Bisschop et al., 2004).

Self-efficacy has also been found to positively affect the quality of life of family caregivers. A study of 189 women with recurrent breast cancer and their family caregivers showed that caregivers with greater self-efficacy reported lower hopelessness, more positive appraisal of their caregiving, and better quality of life (Northouse et al., 2000). Level of self-efficacy also contributes to trait anxiety and a study of caregivers for family with advanced cancer found that caregivers with low self-efficacy are more likely to have high anxiety than self-efficacious caregivers

(Mystakidou et al., 2012). Additionally, Benight, Flores, and Tashiro (2001) analysis of self-efficacy in relation to the distress over their husbands' death by cancer, showed that widows with a strong sense of self-efficacy suffered less emotional distress and better physical health.

2.10.2 Responses which may increase distress.

2.10.2.1 Protective buffering and social constraints.

The social-cognitive processing model proposes that open communication within a supportive environment facilitates processing and emotional adjustment following a traumatic event such as a cancer diagnosis (Lepore et al., 1996). Protective buffering is self-imposed and refers to hiding cancer-related thoughts and concerns from one's spouse or partner in order to reduce one's partner's upset and burden (Coyne & Smith, 1991). As a result, partners and patients who engage in protective buffering are less likely to openly communicate their own concerns and distress to each other, which may result in negative emotional adjustment (Coyne & Smith, 1991; Suls, Green, Rose, Lounsbury, & Gordon, 1997). Interestingly Manne et al., (2007), in a study of 235 couples coping with breast cancer, found that protective buffering was predictive of greater distress for couples where their relationship satisfaction was high before the cancer but had no impact on distress where relationship satisfaction was low. Thus, couples who may have been communicating well before a cancer diagnosis feel greater distress by the sudden loss of connection concerning the illness.

Social constraints are externally imposed and refer to “any social condition that causes trauma survivors to feel unsupported, misunderstood, or otherwise alienated from their social network when they are seeking support and attempting to discuss their trauma” (Lepore & Ituarte, 1999, p.168). Behaviours which may inhibit open communication can include minimisation, forced cheerfulness, avoidance, withdrawal,

and criticism. Research on various cancer populations has indicated that social constraints imposed by one's partner or family/friends are associated with poor emotional adjustment for the patient (Carlson, Bultz, Speca, & St. Pierre, 2000). However, where social constraint is low, the impact between disease-related intrusive thoughts and subsequent distress among cancer patients is reduced (Lepore, 2001).

2.10.2.2 Cognitive avoidance.

Cognitive avoidance coping can be defined as those “responses aimed at denying or minimizing the seriousness of a crisis or its consequences,” (Cronkite & Moos, 1995, p. 578).

Creamer and colleagues' cognitive processing theory suggests that avoidance mediates the association between intrusions and psychological adaptation. Avoidance increases distress because thoughts and memories are not confronted directly and thus are not processed sufficiently (Creamer, Burgess & Pattison, 1992).

Studies of cognitive avoidance and impact on distress have been contradictory, with some research showing that cognitive avoidance may result in less mood disturbance and less anxiety (Orr, 1986 ; Watson et al., 1984). However, in a meta-analysis of 43 studies of coping with cancer, Suls and Fletcher (1985) noted that cognitive avoidance may reduce distress in the short-term but resulted in increased distress over time. Costanzo, Lutgendorf, Rothrock & Anderson (2006) studied the impact of coping strategies for 64 women with gynaecological cancer and found the use of cognitive avoidance was associated with poor outcomes on multiple facets of mood and quality of life.

2.11 Summary

This chapter reviewed the psychological impact of cancer. A cancer diagnosis generates a significant array of psychological responses and psychological distress

which can occur at varying times along a patient's cancer journey. In addition, the impact for a cancer patient's family/whānau was discussed. Within the family fear of loss predominates, together with loss of physical contact, greater emotional distance, uncertain future and the strain of additional tasks (Borneman et al., 2003; Veach et al., 2002). Both breast and gynaecological cancers can produce significant distress especially in the first year of diagnosis. Anxiety and depression predominate with concerns about body image, menopause effects and sexual functioning at the fore.

Coping with cancer is discussed in terms of what impacts both positively and negatively on distress. Both quantitative and qualitative studies are reviewed in order to provide a broad account of the literature.

CHAPTER 3

PSYCHOLOGICAL INTERVENTIONS FOR CANCER

Over the last 30 years there has been an abundance of research on the effectiveness of psychological interventions for people experiencing the impact of a cancer diagnosis. The answer to the question “what works for whom?” is problematic for those with cancer as it is such a diverse condition. Andersen (1992) asserts that cancer should be viewed as separate diseases as each has different development and outcomes. This chapter reviews the literature regarding psychological interventions which have been developed for patients with cancer and their families. These include Cognitive Behavioural Therapy (CBT) which may incorporate Education, Relaxation, and Hypnosis to help with problem solving, coping and the side effects of treatment (Knight, 2004). Interventions may be conducted in individual sessions or as Supportive and Expressive group therapy. Specific interventions for those with breast and gynaecological cancer and family members are also reviewed.

3.1 Is Psychological Intervention Helpful for People Affected by Cancer?

Some researchers have challenged the need for psychological interventions for those coping with a cancer diagnosis (e.g. Coyne & Lepore, 2006). Zabora et al., (2001) found that two thirds of cancer patients with distress will actually adapt to their diagnosis without the need for psychological therapy. However, it is argued that one third of cancer patients will not adapt to their diagnosis without help. In addition, Ell, Nishimoto, Morvay, Mantell and Hamovitch (1989) found that patients with lung, colorectal or breast cancer show no psychological adaptation to their diagnosis over time.

Meta-analyses of psychological interventions have shown effect sizes ranging from 0 to 0.31 (Rehse & Pukrop, 2003). However, there appears to be little consistency in methodology, session numbers, timing or objective of intervention (Dale, Adair, & Humphris, 2010; Owen et al., 2001). Coyne and Lepore (2006) conclude from their meta-analysis, that in fact, psychological interventions for people with cancer are ineffective for distress and not accepted by patients. These findings are criticised by Andrykowski and Manne (2006), and from their own systematic review they assert that the “preponderance of evidence” is that psychological interventions are effective, especially where distress is elevated. Meta-analyses by Sheard and Maguire, (1999) and Heron (2009) also support Andrykowski and Manne (2006) in finding that for people affected by cancer who have high levels of distress, psychological intervention was effective.

Andrykowski and Manne (2006) also criticise Coyne and Lepore’s use of accrual, retention and completion rates as measures of patients’ acceptance of interventions believing that evidence for acceptability should come from asking patients directly (Andrykowski & Manne, 2006). When patients are directly asked about their experiences of receiving psychosocial support, the majority of research shows that they find therapy beneficial. In a partially qualitative study by Boulton et al. (2001) 142 clients responded to a survey about their counselling experiences. Over 90% of participants stated that they found counselling helpful and that their emotional health was improved. Having someone to talk to, whom they did not know and whom they could openly express their feelings to without fear of upsetting them, was considered particularly important.

In a more recent study by Croy (2010), former clients of the Massey University Psycho-Oncology Service reported that receiving psychological support was extremely beneficial. One cancer client commented:

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) (Croy, 2010, p.78).

It should be noted that clients choosing to seek psychosocial support do not always want help with issues related to their cancer. Salander (2010) found, in a study with his own outpatients between 1993 and 2013, that although the most common motive to see a psychologist was to cope with anxiety and worry about their cancer, over one third desired help with relationship and family issues.

3.1.1 Supportive therapy- group.

Professional led group counselling has been empirically demonstrated to be effective in both reducing distress and improving the quality of life for those with cancer (Clark, Bostwick & Rummans, 2003; Gottlieb & Wachala, 2007; Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb & Spiegel, 1999). Group therapies may include psycho-education, relaxation, problem solving and CBT or mindfulness strategies (Clark et al., 2003). Support groups enable cancer patients to interact with peers at a time when they may feel socially isolated by their disease, facilitating needed emotional support and the sharing of information (Gore-Felton & Spiegel, 1999).

In 1981 Spiegel and colleagues (Spiegel et al., 1981) conducted a landmark study comparing the quality of life outcomes for 58 women with metastatic breast cancer who had either care as usual or care as usual plus weekly group psychosocial intervention. The 12 month long study concluded that the women in the weekly support

group experienced less tension, anxiety, and fatigue and had more energy than those who only received care as usual.

The attendance of cancer patients to group therapy is not greatly utilised, with rates reported being between 5% to 31% (Blake-Mortimer, et al., 1999). In a comparison of people who attended group interventions with those who did not, Grande, Myers & Sutton (2006) found that group participants tend to be disproportionately represented by single, educated, younger females and non-attendees were more likely to have the support of a significant person. The low utilisation of group therapy may be due to various factors. A study by Ussher, Kirsten, Butow, and Sandoval (2008) in which they interviewed 87 cancer support group attendees who dropped out and 26 people who had never attended such groups, found that non-attendees reported coping by not talking about their cancer or commented that they already had enough support. In addition, not all people affected by cancer feel psychologically able to take part in group therapy or they may not be able to attend at specific times due to the impact of work or treatment schedules or may be too physically unwell (Clark et al., 2003; Ussher et al., 2008).

Few studies have compared the efficacy of group interventions with individual therapies. In their meta-analysis of psychological therapies for cancer patients, Newell, Sanson-Fisher and Savolainen (2002) concluded that group therapies may be effective in the medium term whereas individual therapies produce both short and long-term effects.

3.2 Cognitive Behavioural Therapy (CBT)

For people coping with cancer, CBT can offer help with problem-solving skills, the identification of distorted thinking, and modifying beliefs and behaviours. Cognitive and behavioural techniques can show those affected by cancer how to identify and

challenge negative automatic thoughts underlying their anxiety and depression (Greer et al., 1992; Greer, 2008).

Meta-analysis of psychological interventions has shown that emotional distress and pain can be reduced with psychological therapies and that CBT is superior to no treatment (Sheard & Maguire, 1999; Moorey & Greer, 2002; Tatrow & Montgomery 2006).

Cognitive behavioural therapy has been found effective with regard to improving coping skills, and has been seen to be particularly beneficial for those who have responded to their cancer diagnosis with feelings of helplessness/hopelessness (Greer, 2008). Patients are encouraged to participate in activities that provide a sense of achievement and pleasure in order to regain a feeling of being in control of their lives (Greer et al., 1992). The therapist may help the client to focus on areas of their life unaffected by cancer and helps them to be aware of their personal strengths (Greer, 2008). Cognitive behavioural therapy may include Education, Relaxation and Hypnosis.

3.2.1 Education.

Patient education intervention (PE) is intended to provide cancer patients with information and knowledge in order to increase their understanding of their illness and to provide a sense of control over the illness experience. In a meta-analysis of 116 studies, significant beneficial effects were found for outcomes of anxiety, depression, mood, nausea, vomiting, pain, where PE was integrated with psychological interventions (Devine & Westlake, 1995). In contrast, Osborn, Demoncarda and Fuerstein (2006) found that PE did not produce significant positive outcomes for symptoms of depression, anxiety, pain and QOL. The different findings in these studies may be due to the fact that Osborn et al., (2006) results were based on a meta-analysis of only 4 studies in which only 17% received PE and all were breast cancer participants.

In a group intervention study involving 312 women with early stage breast cancer, Helgeson and colleagues reported that the Education-based group interventions helped with the initial adjustment to their illness (Helgeson, Cohen, Schulz & Yasko, 1999). Immediately after the intervention, the women assigned to the education group were found to have higher self-esteem, improved body image and less uncertainty about their illness than those not in the education groups. In addition, they were more likely to discuss the illness with family and friends. The benefits of education continued in the 6 months post intervention with the education group experiencing greater personal control, and fewer intrusive thoughts about their cancer. This study was conducted with women who were highly educated who may have benefited more than those with less education. In addition, no comparison was made with individual education intervention and therefore group dynamics may have impacted the results (Helgeson et al., 1999).

3.2.2 Relaxation.

Relaxation therapy involves techniques which elicit a relaxation response of the autonomic nervous system, resulting in the normalising of blood supply to the muscles and a reduction in oxygen consumption, heart rate, respiration and skeletal muscle activity. The techniques used to relax patients vary but may include deep breathing, guided imagery, progressive muscle relaxation (PMR) and biofeedback.

Relaxation techniques have been extensively utilised with cancer patients and have been found to generate significant psychological and physical benefits (Luebbert, Dahme & Hasenbring; 2001 Wallace, 1997). Relaxation techniques have shown some promise for treating cancer pain (Carroll & Seers, 1998) and also helped with emotional responses to chemotherapy and radiation treatments (Roffe, Schmidt & Ernst, 2005). However, individual difference variables may impact the effectiveness of relaxation

interventions including imaging ability, outcome expectancy and number of concurrent symptoms (Kwekkeboom, Hau, Wanta & Bumpus, 2008).

Luebbert et al. (2001) reviewed the effectiveness of relaxation training in reducing symptoms of cancer treatment. Of the 15 studies reviewed, which consisted of predominantly female participants (M=64.4%), 87.5% used PMR and 11 studies (73%) of the interventions were PMR combined with guided imagery. Two studies used only hypnosis. All studies showed significant beneficial effects for cancer treatment related symptoms such as nausea, pain, pulse rate and blood pressure with effect sizes ranging from 0.45 to 0.55. In addition significant improvement was shown for both depression and anxiety although the effect sizes were not large varying from 0.08 to 0.54. It was noted that a greater reduction in anxiety resulted when relaxation training was given before medical treatment (Luebbert et. al., 2001).

3.2.3 Hypnosis.

A number of systematic reviews using hypnosis with cancer patients have indicated significant benefits in reducing both chronic and acute pain (Bardia, Barton, Prokop, Bauer & Moynihan, 2006; Rajasekaran, Edmonds & Higginson, 2005; Richardson, Smith & Pilkington 2006). Hypnosis can also be helpful in reducing the side effects of treatment. However, all cite methodological limitations including low participant numbers, lack of standardised hypnotic interventions and lack of long-term follow-up. Lioffi and White (2001) conducted a study of 50 palliative care cancer patients who were randomly assigned to have standard care or standard care plus hypnotherapy. They demonstrated that physical distress and also depression and anxiety scores were significantly reduced in the hypnotherapy group. However, neither of the measures utilised in this study had been validated for patients with advanced cancer. In addition, only those well enough to complete the questionnaires were selected and so

results could not be generalised to the whole palliative care population. A semi-structured interview was also used in which participants commented on the helpfulness of hypnotherapy in improving self-efficacy and reducing distress.

I felt more in control of myself and the situation and my problems seemed more manageable after my hypnosis. It has helped a lot with my anxiety. I feel much less anxious now. And my husband has noticed the difference (Lioffi & White, 2001 p. 155).

However there was some feeling of being dependent on the therapist as expressed in the comment: “I wish you could teach me how to do it myself or with my wife’s help” (Lioffi & White, 2001 p. 155).

3.3 Interventions for Breast Cancer

Cancer intervention studies appear to predominantly draw on women with breast cancer as study participants. However, studies to assess interventions targeting the specific impact that breast cancer has for women are limited. Sharpley and Christie (2006) established that for women with breast cancer, somatic symptoms of anxiety and depression may reduce over time but cognitive symptoms, such as feelings of helplessness and feeling unable to cope can actually remain stable.

There is mixed evidence that group psychological interventions are effective at reducing the psychological impact for women with breast cancer. The literature indicates that psycho-education groups provide more benefit for women with breast cancer than peer-group support (Helgeson & Cohen, 1996). A meta-analysis of 56 RCTs with groups that included women with breast cancer, showed that the greatest effect size was seen in psycho-educational interventions preferably provided prior to surgery and by medical staff. Psycho-education delivered information about the nature of the cancer and its medical treatment including side effects of chemotherapy

(Zimmermann, Heinrichs & Beaucom, 2007). Hegelson et al. (2000) found that only those who had low social support benefitted emotionally from peer-discussion groups and in fact those with good social support showed no benefit. They suggested that there may be reluctance in peer group members to share and express feelings. In a review of group therapies by Edwards, Hulbert-Williams and Neal (2008), which included 511 women with metastatic breast cancer, they concluded that there was not enough evidence to support the long-term benefits of group psychological therapies. However, Heron (2009) found that breast cancer studies often included many women who were not distressed which meant that any intervention would be ineffective for distress.

As previously discussed, for peri-menopausal women, chemotherapy may induce sudden menopause with symptoms that may interfere with sexual functioning. In a psycho-educational intervention for 72 women with breast cancer (which included intervention targets of emotional distress, sexual functioning and relationship functioning), Rowland et al. (2009) found that there was improvement in relationship adjustment and communication and increased satisfaction with sex compared to those who had printed material only. However, emotional functioning did not differ between groups.

Vos et al. (2006) hypothesised that the timing of group intervention may impact outcome. They compared a group education intervention provided to 67 women with early stage breast cancer with one group beginning within 4 months and a second beginning 7 months after surgery. The intervention groups consisted of a psychotherapy group which incorporated CBT components and a social support group, both over a period of 12 weeks. They found that the earlier intervention group had significantly less distress 6 months later compared to the later intervention group. However, social interaction decreased. All women regardless of time of enrolment showed improved

body image and increased recreation activities. The study was limited in that no follow up data was recorded after 6 months.

As discussed, one of the common side effects for those being treated for breast cancer is sudden menopausal symptoms including hot flushes (i.e. the sudden feeling of heat in the face, neck and chest). Relaxation therapy has been found to be of benefit in reducing the frequency and severity of hot flushes. In a randomised control trial of 150 women with primary breast cancer who experienced hot flushes, Fenlon and colleagues (Fenlon, Corner, & Haviland, 2008) found that the group who received one session of relaxation therapy plus a CD to follow at home had a significant reduction of reported hot flushes after 1 month than the no intervention control group. In addition, distress was reduced significantly after one month compared to the control. The effect was not sustained however and no difference between control and intervention was seen at 3 months. The lack of effect post three months may have been due discontinuation of using relaxation by the intervention group at the conclusion of the study.

Specific support groups have also arisen to help women affected by a cancer diagnosis. The “Look Good, Feel Better” workshops run by the NZ Cancer Society, originated in the USA (Taggart et al., 2009). The aim was to help women cope with appearance-related treatment side-effects to improve their quality of life, body image and self-esteem by enhancing their appearance. Research has shown that these workshops have significant benefit for women with poor body image and low self-esteem in increasing social interaction and reducing anxiety, however, they do not appear to strengthen social support (Taggart et al., 2009).

3.4 Interventions for Gynaecological Cancers

As previously highlighted, gynaecological cancer and its treatment can create diverse psychological problems which may include coping with sudden onset of menopausal symptoms, loss of fertility, pain, sexual problems and relationship difficulties. While there is limited research that has evaluated interventions designed for those with gynaecological cancer the following reviews suggest that individual, supportive counselling may be particularly effective, giving time for women to reflect their specific concerns and obtain adequate information.

In a systematic of psychosocial interventions for those with gynaecological cancer, Hersch, Juraskova, Price, and Mullan, (2009) analysed twenty-two studies which included 1926 participants. They found that CBT was effective for helping to reduce the emotional distress but there was limited evidence for positive effects on self-esteem and body image. In relation to sexual functioning, Hersch et al. (2009) found counselling had positive results but CBT had mixed results for improving sexual relationships. This is in contrast to research by Newell, Sanson-Fisher and Savolainen (2002) who reported in a review of that no intervention was effective at improving sexual functioning or marital relationships. However, they considered the effectiveness of therapist-delivered, individual interventions incorporating education and counselling, were encouraging and should be explored further (Newel et al., 2002).

Research by Petersen and Quinlivan (2002) evaluated the effectiveness of a one-hour relaxation and counselling interview versus control, involving 53 gynaecological cancer patients. The counselling interview was conducted by the patient's senior doctor, with the interview consisting of listening to a tape of five minutes of relaxation music followed 20 minutes of relaxation exercises. The remaining 30 to 35 minutes allowed the patient to discuss their illness and to ask questions. Petersen and Quinlivan (2002)

found that intervention patients had significant reductions in anxiety and depression symptoms compared to the control group. They also reported that patients commented that they found benefit in “spending time with a doctor in a context without the pressure of time constraints” (Petersen & Quinlivan, 2002, p. 393).

In an intervention comparison study, involving 353 women with gynaecological cancer, Manne and colleagues (Manne et al., 2007) compared a coping and communication enhancing intervention (CCI) with supportive counselling (SC) and usual care (UC). They found that at the 6 and 9 month follow up, those women assigned to CCI or SC had fewer depressive symptoms than UC participants (Manne et al., 2007).

3.5 Family Interventions

Findings from the Western Australia Cancer and Palliative Care Network (Department of Health, Western Australia, 2008) show that, despite recognising that the spouse of someone diagnosed with cancer can have high needs, they typically get little support from the medical team. Research into the effectiveness of family interventions for cancer patients is limited (Northouse, 2005) and many have no stated theoretical framework (Martire, Lustig, Schulz, Miller & Helgeson, 2004).

In an RCT involving 134 cancer patients, Northouse, Kershaw, Mood and Schafenacker, (2005) evaluated the effectiveness of a five session family intervention for patients with advanced breast cancer and their family caregivers. It was reported that patients in the intervention group had significantly less hopelessness and less negative appraisal of illness than controls. Caregivers reported significantly less negative appraisal of caregiving. However, the intervention effects were not sustained beyond three months. Northouse et al. (2005) proposed that the family intervention may

maintain positive long-term effects if longer sessions were provided over a more sustained time period.

Sherman and Simonton (2001) consider that for families affected by cancer, interventions should be aimed at the specific areas namely “(a) enhancing communication and emotional contact, (b) accommodating structural changes within the family, (c) facilitating a sense of meaning, and (d) addressing mortality issues” (Sherman & Simonton, 2001, p. 193) and these should be related to the phase of illness that the patient is in.

As part of a meta-analysis of 70 family intervention studies for patients with chronic illness in which five were cancer studies, Martire, et al. (2004) found that family therapy was effective in reducing depression and feelings of burden for both the patient and caregiver where the focus was on relationship difficulties. They also noted that family interventions were not associated with any negative psychological outcomes for either the cancer patient or family members. For women with early stage breast cancer Baucom et al. (2009) demonstrated that, for those who received relationship enhancement couple therapy there was greater improvement in general relationship and sexual functioning than couples in treatment. The sample of 14 couples was small however, and therefore the effect sizes found could have been due to chance. However, in an earlier study by Scott et al. (2004) ninety-four married women with early stage cancer and their partners were randomly assigned to couples-based coping training (Can-COPE), individual coping training, or a medical education control. The CanCOPE intervention was found to produce significant improvements in supportive communication and sexual adjustment. Couples also experienced reduced psychological distress and with the conclusion that supporting couples in therapy rather than just the individual was more effective in helping couples contend with cancer.

The previous studies support the recommendation by Schmitt et al. (2008) who consider that at least one family session should be routinely offered to families of cancer patients. Shands et al. (2006) propose that research should be conducted into couple's core concerns about cancer in order to facilitate couples in therapy to identify their issues more easily. It is also important for families affected by cancer that already existing relationship stressors are recognised. The literature shows that where there is existing family dysfunction, the addition of further significant stress to a family's life, such as cancer, can create an increased possibility of the illness being exacerbated (Thoits, 2010).

3.6 Factors Affecting Psychological Interventions

There is much debate within the literature regarding factors which may impact or influence the outcome of psychological interventions. However, studies of specific factors affecting the outcomes of therapies for cancer patients are limited. Although the literature largely concentrates on the effectiveness of specific psychotherapies for cancer patients, there is substantial research evidence that their effectiveness is roughly equivalent and it is argued that the factors which affect therapy outcomes are client and therapist variables (Brown, Dreis, & Nace, 1999; Castonguay & Beutler, 2006; Norcross, 2011). Lambert and Barely (2001) describe these variables as typically comprising extra-therapeutic factors (or client factors) such as social support and baseline distress, client expectations, specific therapy techniques, and common factors found in most therapies including the therapeutic alliance and therapist variables. Client and therapist factors impacting psychological interventions are discussed in the following sections.

3.6.1 Client factors.

According to Asay and Lambert (1999), client or extra-therapeutic factors account for 40 per cent of outcome variation, expectancy and technique each account for 15% and common factors account for 30%. Client factors impacting therapy are numerous and may include the client's personal strengths and weaknesses, motivation, values, skills, experiences, perseverance, resources, attitude towards the value of counselling, therapy expectations, social support, and potential for change. They also include level of initial distress, spontaneous remission, and fortuitous events in the client's life (Morawetz, 2002).

3.6.1.1 High baseline distress.

As previously indicated, not all cancer clients become highly distressed by their diagnosis and those who are not distressed are unlikely to gain benefit from psychological intervention. Screening for distress prior to accessing specialised services is therefore essential in order for support to be provided to those who need it. In a review of the effectiveness of psychological interventions for cancer patients Heron (2009) states that high baseline distress predicted better outcomes for the use of CBT. Other studies have also indicated that those with lower psychological morbidity do not benefit greatly from psychological interventions (Naaman, Radwan, Fergusson & Johnson, 2009; Ross et al., 2002; Schneider et al., 2010; Sheard & Maguire, 1999).

3.6.1.2 Social support.

The impact of social support from peers or family has been found to benefit therapeutic outcomes. Conrad-Garrisi (2011) proposes that "social support is pivotal in the recovery process in that it, (a) provides a method to obtain supportive resources, (b) an opportunity to develop reciprocal relationships, and (c) a sense of identity and connection with others, as opposed to being isolated and alone" (p. 6).

Those who report being highly satisfied with their support networks are more likely to be goal and success orientated and be more hopeful about outcome and less depressed (Corrigan & Phelan, 2004). Thrasher et al. (2010) found that social support significantly improved outcomes for PTSD interventions which involved cognitive restructuring and exposure. It was suggested by Thrasher et al. (2010) that those with poor social support were less able to cope with the demands of PTSD therapy and that a good social network may provide a buffer to treatment stress.

3.6.1.3 Client expectations.

Studies have consistently shown that clients who have greater positive expectations for therapeutic benefit of their therapy are more likely to have improved outcomes than clients who are less optimistic (Dew & Bickman, 2005; Greenberg et al., 2006). Patient expectations prior to psychotherapy have been linked to positive therapy outcome and to the quality of the therapeutic relationship, irrespective of therapy type (Constantino, Arnou, Blasey & Agras, 2005; Gibbons et al, 2003). In a re-analysis of data from the National Institute of Mental Health Treatment of Depression Collaborative Research Program, Meyer et al. (2002) determined that high expectation of therapy outcome predicted a greater active engagement in therapy by participants. These findings were supported by Gibbons et al. (2003) who found that patients who enter therapy with more hope about the therapeutic process may have a greater likelihood of easily engaging interpersonally with the therapist, however, those who are more negative about the value of psychotherapy might tend to be interpersonally distant.

A review of studies relating to the impact of expectations on treatment outcomes has shown that “natural and “induced” positive expectations can improve therapeutic outcomes (Greenberg et al., 2006, p. 658). Pre-session information which clients are exposed to about the therapist may also influence the opinion of the therapist’s

expertise. Greenberg (1969) showed prior information in which the therapist is introduced as “warm” or “experienced” can positively influence clients’ experience of therapy. In a study of client’s pre-session perception of the therapist Claiborn and Schmidt (1977) found that perceived expertness was greater when the therapist’s knowledge, skills, and successful reputation were highlighted rather than the therapist's similarity to the client and enthusiasm to help.

3.6.1.4 Financial problems.

A diagnosis of cancer results in most patients and families being subjected to additional costs. Many cancer patients face the costs in visiting their GP, paying for prescriptions and other medications, which they may need to sustain their treatment. In addition, a major burden for cancer patients can be those related to travelling to treatment. Financial stress related to having cancer is consistently linked to an increased risk of adverse psychological outcomes (Kayser et al., 1995; Sharp, Carson and Timmins, 2013). In a UK based study many patients claimed that financial concerns were second only to pain as a cause of stress (Quinn, 2002). Lower income is typically linked with poorer health outcomes but it also reduces people’s ability to cope with the consequences of ill-health (Heron, 2009). Those in lower socio-economic groups can therefore encounter greater difficulties coping with a cancer diagnosis and the subsequent treatments may also result in difficulty returning to work. Psychological interventions may be less effective where a patient and their family are facing high levels of financial stress which is not being addressed (Francoeur, 2001).

3.7 Therapeutic Alliance

A consistent finding from the literature is that both the client and the therapist consider the quality of the therapeutic alliance to be predictive of positive treatment outcome (Black, Hardy, Turpin, & Parry, 2005).

The therapeutic alliance is a construct which is generally described as the interactive, collaborative elements of the therapeutic relationship in the context of a positive attachment (Constantino, Castonguay, & Schut, 2002). Two views regarding the process in which the therapeutic alliance impacts therapy outcomes have been posited (Castonguay, 2003; Crits-Christoph, 2001). One opinion is that the alliance between client and therapist is itself therapeutic as it provides a model of a positive relationship experience for the client. The other view proposes that a strong therapeutic bond generates a trust and belief in the therapeutic techniques used by the therapist (Crits-Christoph, & Gibbons, 2001). Research has, however, shown that the quality of the therapeutic alliance is considered to contribute only moderately to therapeutic change but that it still strongly predicts patient therapy outcomes (Crits-Christoph, Gibbons, Hamilton, Ring-Kurtz & Gallop, 2011; Horvath & Bedi, 2002; Horvath & Symonds, 1991).

In their review of the therapeutic alliance research for those with cancer, Schnur and Montgomery (2010) comment that despite the extent to which the therapeutic alliance is considered to be a common factor in therapy “the study of the therapeutic relationship appears to be quite *uncommon* in the cancer therapeutic literature” (Schnur & Montgomery, 2010, p. 246). They conclude however, that the cancer literature is consistent with general research showing that the therapeutic alliance is associated with beneficial therapeutic outcomes. Andrews (2000) reported that over 80% of the positive outcomes of therapy may be due to the therapeutic alliance.

In a qualitative study MacCormack, et al. (2001) interviewed 14 participants (four males and ten females) between the ages 30 to 72 years. The aim was to explore and compare the experiences of two groups of cancer patients diagnosed with metastatic disease who had been offered either CBT or relaxation therapy. Their results showed

that the type of intervention was not critical to the patients' experience of therapy. In fact, MacCormack, et al. (2001) state "it was often difficult to tell from their transcripts which form of intervention participants had received" (p. 59). The common theme that emerged was that participants expressed feeling safe to share their cancer experience with someone whom they felt genuinely wanted to understand them who honestly cared (MacCormack, et al., 2001).

For those working with people in palliative care there can be a sense of deeper connection with the client. In a study looking at the views of six hospice workers including nurses and social workers Callahan (2012) found that a sense of spiritual sensitivity was identified as creating deeper relationships with dying patients.

3.8 Therapist Variables

The therapist brings their own unique characteristics to the therapeutic relationship. Miller, Hubble and Duncan (2008) suggest that 'Who provides the treatment is a much more important determinant of success than what treatment is provided' (p. 15). In their review of 24 studies between 1988 and 2000, Ackerman and Hilsenroth (2003) noted a number of specific therapist personal qualities which influenced the therapeutic alliance. These included the therapist's ability to express empathy, to communicate clearly, be connected with the client, work collaboratively and being competent. Other personal factors included being flexible, warm, genuine, respectful, friendly, trustworthy, interested and alert (Ackerman & Hilsenroth, 2003). The claim that the therapist is the key to successful client outcomes, rather than the treatment, is supported by a number of authors (e.g. Blow, Sprenkle and Davis, 2007; Spinelli, 2001). Blow et al. (2007) assert that the focus of research should be on the therapist qualities including, how they make decisions in therapy and how they move therapy forward.

The client's perception of the therapist as an empathetic person has also been shown to affect intervention outcome (Horvath & Luborsky, 1993). In Mac Cormack et al. (2001, p. 56) participants commented 'He was safe and easy to talk to. So I could say anything and be honest with how I felt'. Another said, 'I could open up, not be ashamed of my feelings, and you knew she really cared'. Croy (2010) compared the overall outcomes of two groups of cancer patients, one group received psychological intervention (n=18) and the matched control group received care as usual. All intervention participants showed improvement at the end of therapy and although Croy (2010) does not attribute this improvement to the therapeutic relationship it was reported that the intervention group perceived their therapists as "very helpful and extremely supportive and caring" (Croy, 2010, p. 116).

Despite an extensive search of the literature, the author and the Massey University Library Service were unable to find any studies which specifically interview and explore the experience of psychologists working with adults affected by cancer. One related article by Susan Hendrick (2013) was a personal description of her experiences of working with people coping with cancer. She stated "My experience is that *who* the therapist is matters less than *how* the therapist is" (Hendrick, 2013, p. 31). She reported several qualities she felt were needed by clinicians unique to working in oncology which included, the desire to work in the field, have patience and courage, be willing to step out one's comfort zone and being comfortable in the medical environment. Hendrick (2013), comments that the assessment of clients in the psycho-oncology setting, "is clearly oriented toward meeting the patient as a *person*, relying on the counsellor-client relationship as the primary therapeutic tool" (p. 35).

In a qualitative study exploring the views of four occupational therapists working in a hospice, one of the themes which emerged was that of "journey with the

patient” (Rahman, 2000, p. 810). The participants expressed that their work in caring for patients who were dying was meaningful and reflected on feeling connected at a deeper level with their patients (Rahman, 2000).

A recent study exploring the experiences and training needs of 786 psycho-oncology professionals from 63 countries, including 322 psychologists, was completed by Weiner et al. (2012). However, the survey only included those working in the paediatric oncology field. The study found that the clinicians surveyed used a range of therapeutic approaches and found their work to be highly meaningful. Challenges identified included difficulties with professional relationships, unsatisfactory supervision and need for further specialist training (Weiner et al., 2012).

3.9 Summary

This chapter reviewed the use of psychological interventions for those with cancer. Research into the effectiveness of psychological interventions has shown that therapies are roughly equivalent in their effectiveness. Psychological therapy includes CBT which may incorporate Education, Relaxation, and Hypnosis to help with problem solving, coping and the side effects of treatment. Interventions may be conducted in individual sessions or as group therapy. Specific interventions for those with breast and gynaecological cancer and family members were also reviewed. Assay and Lambert (1999) propose that client or extra-therapeutic factors account for 40 per cent of outcome variance. Expectancy and technique each account for 15% and common factors account for 30%. The literature relating to client factors, the therapeutic alliance and therapist variables were discussed in terms of their possible impact on the outcomes of psychological interventions for people with cancer.

CHAPTER 4

PSYCHO-ONCOLOGY

4.1 The Development of Psycho-oncology

Psycho-oncology is a multidisciplinary field which involves the psychological, social, and spiritual support of people affected by cancer. This holistic approach has been developed to address the recommendation of support for the whole person throughout their cancer journey (WHO, 2002). Psych-oncology is still a fairly young discipline with formal development of the psycho-oncology field originating in the United States in the 1970s. However, it is only since the 1990s that psycho-oncology has had a recognised role in providing specific therapies for oncology patients (Holland, 2003).

In 1913 the American Cancer Society began the first formal educational programmes aimed at reducing the fear of cancer. However, the first psychological responses to cancer were only formally documented in the 1950s following the improved survival rate of cancer patients (Holland, 2002). Prior to the 1970s cancer patients were not usually told of their diagnosis as it was believed that it would cause them to lose hope and that they would be unable to cope (Holland, 1999). Family members may have been informed; however, a cancer diagnosis would rarely be talked about outside of those closely related to the patient (Holland, 2002). A survey of doctors in 1961 (Oken, 1961) revealed that over 90% of the profession believed that patients should not be made aware of their cancer diagnosis, but over the next 17 years this view changed to one of candour to enable the cancer patient to make informed choices about their treatment (Novack et al., 1979).

In 1975 the first national research conference on psycho-oncology was held in San Antonio, Texas, USA and this event is cited as being pivotal to the formal start of

psycho-oncology (Holland, 2003) and in 1997 the first clinical practice guidelines were published by the National Comprehensive Cancer Network (Grassi & Watson, 2012).

There is now a growing recognition that psychosocial care is an important component of the comprehensive care of people diagnosed with cancer. Over the past 20 years numerous psycho-oncology services have arisen worldwide, in a variety of different forms. Numerous guidelines have also been developed providing recommendations for psychosocial screening, evaluation, treatment, and follow-up that are presented primarily in the form of clinical pathways (Grassi & Watson, 2012).

4.2 Development of the First Specialist Psycho-Oncology Service in New Zealand

In 2003 the New Zealand Ministry of Health published its Cancer Control Strategy which included the goal to reduce the incidence and impact of cancer in New Zealand (Ministry of Health, 2003). In 2004 the MidCentral District Health Board (MCDHB) developed a major cancer services plan which included the establishment of an integrated Psycho-Oncology Service. The Psycho-Oncology Service at Massey University in Palmerston North, New Zealand was established in partnership with the MCDHB in January 2006. The aim of the service was to provide free, equitable and culturally aware psychological support for cancer patients and their families/whānau from the MCDHB region. The partnership with Massey University was intended to benefit cancer patients and their family/whānau members through improved mental health (MCDHB, 2012).

The recommendation from Holland (2003) has been that psycho-oncology services should be situated in within or adjacent to the medical oncology clinics. Holland (2003) asserts that “the need to refer a cancer patient to a psychiatric clinic away from the cancer clinic, and especially to a place marked “psychiatric,” loses many people who still feel the stigma of psychiatric care” (p. 260s). However, the Department

of Health, Western Australia (2008) proposes that the hospital should not be considered as a suitable setting for the provision of psychosocial services. They state that “Cancer care should be provided in settings that are family friendly and that recognise the special needs of families with young children or specific cultural background (p. 13). The Massey POS is physically located in the Massey Psychology Clinic at Massey University, approximately 15kms from medical oncology services at Palmerston North Hospital. Despite being remote from the hospital, the Service clinicians are considered an integral part of the multi-disciplinary oncology team within the MidCentral Health district.

At the time of data collection for the current study, the Psycho-Oncology Service at Massey University was staffed by four Senior Clinical Psychologists making up a total of 2.5 FTE. One clinician specialised in supporting children affected by cancer and there was a dedicated Maori psychologist. In addition, since 2007, intern psychologists have contributed to the Psycho-Oncology Service as part of their training. Besides the provision of psychological services a team member, in partnership with the School of Psychology’s academic staff, conducts research in psych-oncology and supervise the research of post-graduate students.

The POS team also provides continuing education to other health professionals and they regularly meet with oncology clinicians from the hospital as part of the multi-disciplinary oncology team. Significant benefits have been found in working as part of a team within an oncology setting. Previous research has suggested that mutual support may protect against the challenges of working in with people dealing with cancer (Penson et al., 2000). In a qualitative study with social workers, physicians and nurses (n=21) working in oncology, Rohan and Bausch (2009) found that being part of a team was important to the clinicians. One physician stated: “Part of what we all use each

other for is, you know, the camaraderie. We all enjoy what we do, and it's nice to kind of share some of the experiences together and also to deal with the problem [together]".

Laura, 33 (Rohan & Bausch, 2009, p. 97)

The overall view is that the oncology team environment can provide mutual respect, understanding and good communication in a setting that allows team members to share the emotional burden and responsibility of working in oncology (Penson et al., 2000; Rohan & Bausch, 2009).

4.2.1 Population served.

In 2006 the National Census showed MCDHB region (Figure 2, p. 61) had a population of approximately 158,000 people with the majority residing in Palmerston North, (MCDHB, 2012) this population is expected to rise by 8% by 2026 (Central Region District Health Boards, 2012). Of those resident in the MCDHB region 86% were below 65 years of age, 51.5% were female and Maori made up 17.3% of residents. In the period from June 2006 to June 2013, 73% of the Psycho-Oncology Service referrals were for patients and 27% were for family members. Within these groups 64% were female, 11.3% Maori, 1.4% Pacific Island, 83.2% NZ European and 4.1% Other Non-European. The figures indicating that nearly twice as many women accessed the service are consistent with previous research on mental health service utilisation (Burgess et al, 2009; Mehta & Hamel, 2011; Smith, Braunack-Mayer & Wittert, 2006). The utilisation of the Psycho-Oncology Service by Maori, although disproportionately less than the area population, has gradually increased since the service commenced in 2006. The Psycho-Oncology Service is expanding and strengthening its relationships with the wider community to include marae and Māori and Pacific communities. The Service also uses a support framework that acknowledges Te Whare Tapa Whā model of health.

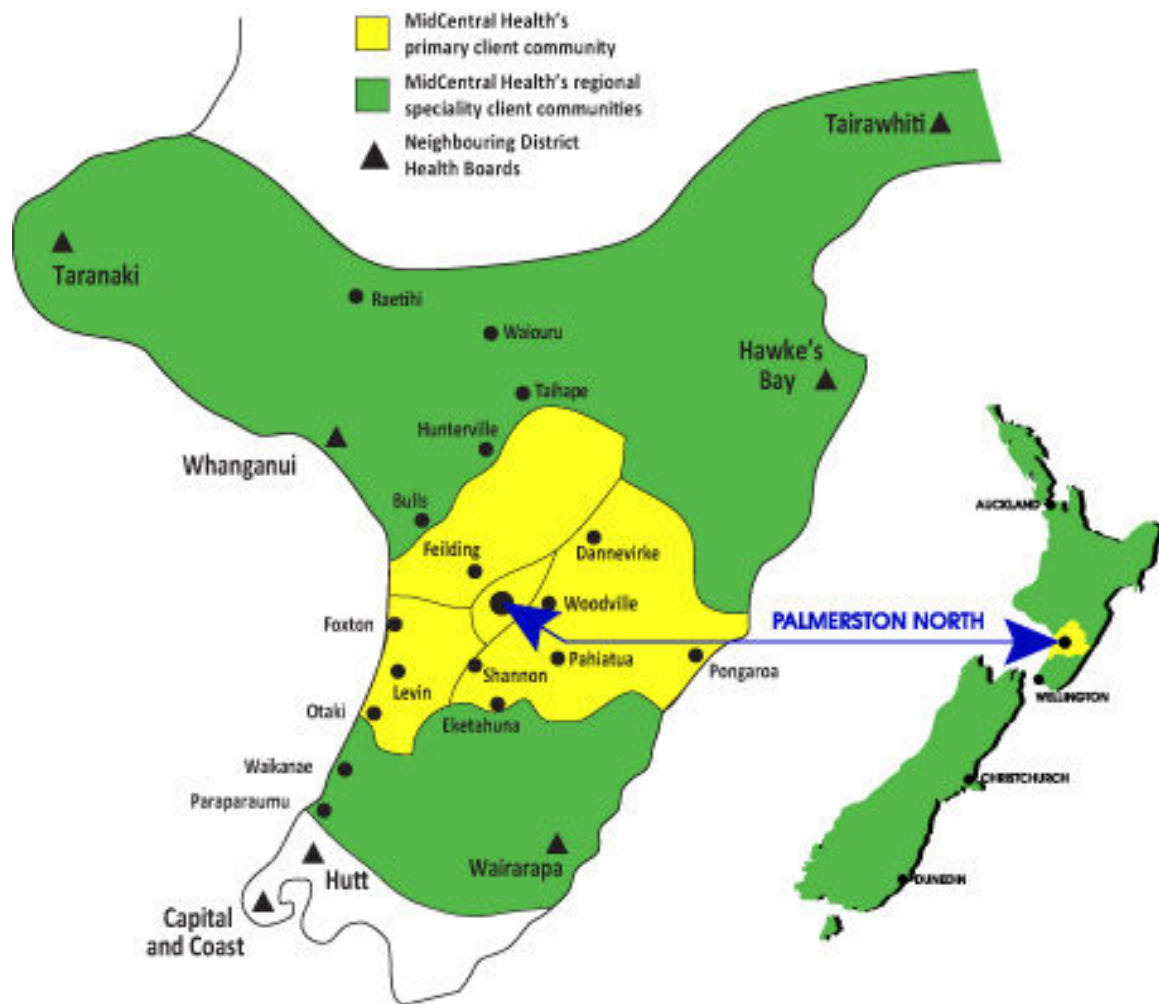


Figure 2. Map of MidCentral District Health Board region:

(Adapted from MCDHB, 2009)

Table 1 (p. 62) reports POS client statistics for known cancer site/type. Due to commercial sensitivity only client percentages are shown. Breast cancer represented 23% of known cancer site referrals which is a reflection of breast cancer registrations rates (Cancer Society of New Zealand, 2004). Table 2 (p. 63) shows client statistics for stage of treatment.

Table 1

*Massey Psycho-Oncology Service percentage of referrals by known cancer site/type:
April 2006-June 2013*

Cancer site/type	% of Clients
Breast	23.0
Colorectal	14.5
Lymphoma	7.0
Lung	6.1
Gynaecological	6.0
Prostate	5.7
Brain	5.4
Head & Neck	5.2
Unknown	3.8
Leukaemia	3.6
Oesophageal	3.0
Renal	2.9
GIT	2.6
Melanoma	2.6
Blood	2.3
Bone	1.4
Urological	1.4
Testes	1.1
Pancreas	1.0
Endocrine	0.9
Liver	0.5
TOTAL	100

4.2.2 Referral process.

The Psycho-Oncology Service has a close relationship with the Regional Cancer Treatment Service at Palmerston North Hospital from where the majority of referrals are received. Cancer patients and family/whānau may also be referred to the Psycho-Oncology Service by surgical staff and by other cancer support services. Medical staff, particularly oncology nurses are encouraged to routinely screen for distress using the Cancer Related Distress Screen (CRDS).

Table 2

Massey Psycho-Oncology Service percentage referrals by known referral stage: April 2006- June 2013

Referral Stage	% of Clients
Diagnosis	9.1
Treatment	64.3
Post treatment	13.0
Recurrence	4.6
Preventative	0.3
Palliative	7.9
Unknown	0.8
TOTAL	100

The CRDS was adapted from the National Comprehensive Cancer Network Distress Screen the DIS-A (NCCN, 2006) and includes the Distress Thermometer (DT) (Roth et al., 1998) and Impact Thermometer (IT) (Akizuki, Yamawaki, Akechi, Nakano, & Uchitomi, 2005) plus questions about problems with Spiritual (Taha Wairua), Physical (Taha Tinana), Family (Taha Whānau) and Emotional (Taha Hinengaro) areas. The validity of the CRDS in identifying significant symptoms of anxiety, depression and general distress was assessed by Baken and Woolley (2009) who found that using scores from both the DT and IT was superior to using either thermometer alone. Where distress levels on the DT are at 5 or above a referral can be made to the Psycho-Oncology Service. The Psycho-Oncology Service liaises with other psychosocial support services such as Social Workers, Specialist nurses, Oncology nurses within RCTS, Te Whare Rapuora, Chaplains, Cancer Society, Child Cancer Foundation, Arohanui Hospice and other services in the area. Figure 3 (p. 64) shows the Psycho-Social Referral Decision Tree developed in 2008 by POS in collaboration with social workers from MCDHB.

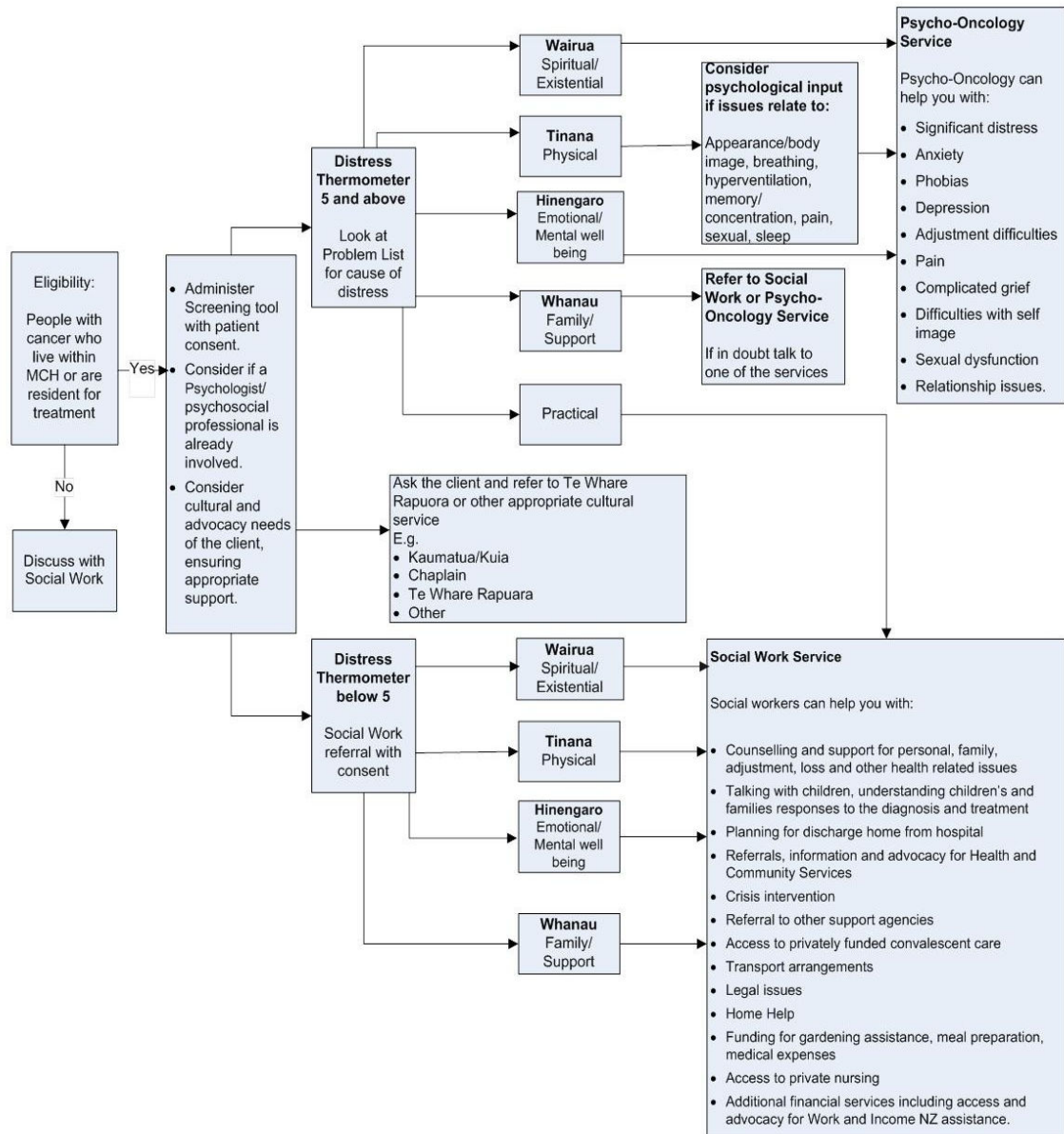


Figure 3. Psycho-Social Referral Decision Tree (Kent, E., & Wood, S., 2008)

Clients predominantly come to the Massey Psychology Clinic in Palmerston North. However, they may also be seen by clinicians at other locations including Addis House (Cancer Society), Arohanui Hospice, home visits, in the hospital and outlying regional hospitals.

Reasons for referral to POS include anxiety, depression, adjustment problems, pain, grief, difficulties with self-image, sexual dysfunction, relationship issues, and difficulties around treatment decisions (L. Kent, personal communication, 10 February,

2009). The Psycho-Oncology Service offers individual and family/whānau interventions including Cognitive Behavioural Therapy (CBT), supportive and expressive therapies, behavioural techniques plus training in problem solving, assertiveness and coping. More recently clinicians have used adjunct therapies such as hypnosis to relieve pain and menopausal symptoms.

Clinicians at POS regularly monitor the effects of therapy. There is clear evidence in the literature that therapists who obtain feedback from their clients during therapy generate improved client outcomes. In a study of over 3,000 cases at a single practice, the on-going use of outcome information over 12 months resulted in a 150% improvement in overall effectiveness (Miller, Duncan, Brown, Sorrell, & Chalk, 2003). The Outcome Rating Scale (ORS) was developed to help clinicians assess change in clients following psychological intervention (Miller et al., 2003). The ORS is a brief visual analogue measure which asks clients to rate their functioning in the last week across three life domains, as well as overall. The client places a mark on a 10 cm line to indicate how well they have been doing socially, interpersonally and individually over the last seven days. Marks on the left of line indicate they have been doing less well whilst marks on the right indicate greater levels of well-being.

In addition, the Session Rating Scale Version 3 (SRS V.3.0) is also utilised. The SRS V.3.0 is a brief measure of therapeutic alliance developed by Johnson, Miller and Duncan (2000). The SRS V.3.0 is a four-item visual analogue measure completed by the client at the end of a therapy session. It measures the client's perception of the relationship with the therapist, level of agreement on therapy goals, agreement on the therapeutic approach and an overall score for the session.

Chapter 3 reviewed a number of evidence based studies which highlighted the benefits of psychological interventions for people experiencing the distress of a cancer

diagnosis and treatment. In order to ensure that Massey Psycho-Oncology Service provides effective treatments for its clients, internal reviews are regularly conducted and this study will add to data already gathered and expand on the work done by Croy (2010).

4.3 Summary

This chapter explored the development of psycho-oncology as a discipline and Psycho-oncology Services worldwide. It described the development of the first specialised Psycho-Oncology Service (POS) at Massey University in New Zealand. This Service was developed through collaboration of MidCentral District Health Board with Massey University Psychology Clinic, based in Palmerston North. The client statistics of POS were reviewed showing that the largest client groups are women with breast cancer and family members. The development of the referral processes to POS was reviewed including comment on the use of validated client distress and outcome screens used by the Service.

CHAPTER 5

METHODOLOGY

5.1 Design

The methodology chosen for this study was a qualitative thematic analysis. Merriam (1998) defines qualitative research as “an umbrella concept covering several forms of inquiry that help us understand and explain the meaning of social phenomena with as little disruption of the natural setting as possible” (p. 5). According to Denzin and Lincoln (2000) the defining characteristics of qualitative research include its ability to capture the individual’s perspective. It is concerned with the richness of data and allows the examination of the constraints of everyday life. Qualitative methods provide the opportunity to develop a descriptive, rich understanding and insight into an individual's attitudes, beliefs, concerns, lifestyle, culture and behaviour (Needleman & Needleman, 1996). Elliot, Fischer and Rennie state that “the aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage, and live through situations” (1999, p. 216).

The use of quantitative methods dominated psychological research for many decades and it was not until the 1980s and 1990s that qualitative methods emerged to challenge the positivist approach (Howitt, 2010). Quantitative approaches are generally based on the view that observed phenomena can be represented by mathematical relationships and the conditions under which the phenomena are observed are controlled as much as possible to eliminate influencing variables.

Historically, quantitative methodology has been used in research regarding which factors impact therapeutic outcome (Hubble, Miller, & Duncan, 1999). However, researchers have stressed the importance of obtaining clients’ experiential knowledge of psychotherapy in order to gain a better understanding of the therapeutic process (Elliot

& James, 1989; Howe, 1993; Rodgers, 2002). In examining qualitative studies of clients' therapy experiences, Rodgers (2002) states that qualitative methodology "is highly desirable in fields such as counselling and psychotherapy which are intimately involved with real people in real situations, not abstracts and concepts" (p. 28). The use of a qualitative approach in this study is consistent with the needs in this area of research. This study allowed participants to provide their perceived experiences with cancer, psychotherapy and managing the distress experienced in detail and in an holistic context. In a study of the impact of qualitative interviews for patients with cancer Colborne and Sque (2005) found that the interview process had therapeutic consequences and so themes relating to this aspect of the research were also identified.

5.1.1 Rationale for participant groups.

In 2005, the American Psychological Association (APA) published a policy statement which said "Evidence-based practice in psychology (EBPP) is the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (American Psychological Association, 2005).

In order to obtain data that would be most representative of the Massey POS, the current study specifically targeted the Service's largest attending referral groups of females (breast and gynaecological cancers), those with colorectal cancer and family/whānau members. For the female group it was important to look at ways in which having breast or gynaecological cancer differed particularly in relation to the possible impact of cancer on the women's sexuality, sense of being a woman and body image. In addition, the groups chosen were also those with the highest initially reported pre-therapy distress levels and therefore likely to have experienced the best therapy outcomes (Heron, 2009).

The intention to include clients with colorectal cancer in this study was with the aim to explore and compare the thoughts and experiences of male and female cancer clients with the same cancer type. However, in the first six months of the study there were no colorectal clients who qualified for inclusion and a decision was made at that point to exclude this group as it was not anticipated that participant recruitment would take a further three years. In addition, ethics requirements meant that because of the earlier Massey POS study by Croy (2010) that clients previously contacted for that research could not be contacted for this current study. This resulted in a reduced population from which to draw participants.

This study explored the experiences of POS clients, those affected by cancer who chose not to use POS and also the experiences of POS clinicians. Clients experience therapy as part of a dyadic relationship with a clinician and therefore in order to provide a more complete study of the therapeutic process, it was felt essential to also explore the views and thoughts of the therapy experience with the cancer client from the clinicians' paradigm. Interviewing the POS clinicians not only integrated the "clinical expertise" but McLeod (2001) also asserts that "It is this descriptive material that can help the practitioner to develop a wider 'repertoire' of practical knowledge, of what is possible, and what might happen, in different clinical situations" (p. 8). The inclusion of a Non-Intervention (NI) group was considered essential in order to allow comparison of the experiences of people with cancer who had used professional psychosocial support with those who had not.

5.2 Participant Recruitment

5.2.1 Former POS clients (breast/gynaecological cancer and family/whānau)

The Service administrator identified clients whose files were closed and who met inclusion criteria for the study from the Clinic database. A letter of *Invitation to*

Participate (Appendix G) was mailed to them. If the return slip was sent back by a date specified in the letter, an *Information Pack*, (Appendix H) which included a participant Information Sheet and a Consent Form was then posted to them. One week after being sent an Information pack respondents were telephoned by the Principal Investigator to enable them to ask questions about the study and, if agreeable, to arrange the interview.

5.2.1.1 Participant inclusion criteria.

The criteria for inclusion in the study required that former POS clients be aged 18 years and above, diagnosed with breast cancer, gynaecological cancer or a family/whānau member of a person diagnosed with cancer. All former clients who were invited to participate had to have had completed more than one session of therapy. It was considered that a single session would not allow a client to have enough experience of the Service to comment adequately. In addition their final therapy session had to have occurred no more than 18 months prior to invitation. Due to initial difficulties in recruitment of former clients with a final therapy session of no greater than 3 months it was decided to extend this time-frame to 18 months in order to enable invitations to be sent to a larger sample of former clients.

5.2.1.2 Participant exclusion criteria.

Participants were asked to self-exclude if they felt that they were not well enough to participate. Participants were also excluded if they were considered by the Principal Investigator to be suffering from cognitive impairment caused by medication or treatment. It was important for the study that participants were able to concentrate, understand or follow the questions being asked. In addition clients were excluded if they had a recent diagnosis of new cancer occurrence. It was felt that the interview process may exacerbate any distress already present due to cancer recurring.

5.2.2 Non-intervention group.

To recruit non-intervention participants, an advertisement was placed in a regional newspaper (Appendix I) for one night. Potential participants were asked to make contact through a Freephone number. Those who responded were contacted by the Principal Investigator and were posted an *Information Pack* (Appendix J). One week after being sent the Information Pack respondents were telephoned by the Principal Investigator to enable them to ask questions about the study and, if agreeable, to arrange the interview.

5.2.2.1 Participant inclusion criteria.

The inclusion criteria for the NI group was that they had to be adults who had either been diagnosed with cancer during the last 18 months or who were a family/whānau member of someone diagnosed with cancer.

5.2.2.2 Participant exclusion criteria.

Exclusion criteria included those who had attended any counseling or psychological service related to their cancer experience. Participants were also excluded if they were considered by the Principal Investigator to be suffering from cognitive impairment caused by medication or treatment or felt they were too unwell to participate. In addition clients were excluded if they had a recent diagnosis of new cancer occurrence.

5.2.3 Psycho-Oncology Service clinicians.

Clinicians working for the Psycho-Oncology Service were recruited for interview in order to provide their perspective and experience of working with people coping with cancer. A letter of *Invitation to Participate* (Appendix K) was sent to them. If the return slip was sent back, an *Information Pack*, (Appendix L) including a Participant Information Sheet and Participant Consent Form was then posted to them.

One week after being sent an Information pack, respondents were contacted by the Principal Investigator to enable them to ask questions about the study and, if agreeable, to arrange the interview.

5.2.3.1 Participant inclusion criteria.

The inclusion criteria for Clinicians was that they had to be fully registered Clinicians. They also had to have worked for POS for more than one year. It was important for the Clinicians to have had a reasonable amount of experience in the Service to enable them to compare initial experiences of working with cancer clients with later ones.

5.2.3.2 Participant exclusion criteria.

Exclusion criteria were that the Clinicians were not intern status nor had worked for POS for less than one year.

5.3 Participants

5.3.1 Participant details.

A total of 24 participants were recruited for this study. Three groups of participants were recruited from the Psycho-Oncology Service. Two groups were former adult clients of the Service consisting of women with breast ($n=4$) or gynaecological ($n=2$) cancer plus family /whānau clients ($n=9$ of which 4 were male). Demographic data was provided by the administrator from the Massey Clinic client database with client consent. The age range for these two client groups was between 19 – 69 years and each had attended more than one session with the Psycho-Oncology Service. A third group comprising Psycho-Oncology Service clinicians ($n=4$) was also interviewed each of which had worked for POS for over 5 years. A fourth group of people affected by cancer who had not used any professional psycho-social support

($n=5$) was also interviewed of which three were male. Table 3 (p. 74) provides details of cancer participants and pseudonyms have been used to maintain confidentiality.

The participant numbers in this study were limited both by time restrictions and difficulty in participant recruitment. For the Psycho-Oncology Service client groups, 89 invitations were posted with an uptake of only 15 participants over a period of three years. With limited time available to conduct this investigation, it was not possible to recruit additional participants.

5.3.2 Semi-structured interview.

All participants were interviewed by the researcher within a semi-structured framework. The semi-structured interview allows the interviewer to elaborate on the original response or to follow a line of inquiry introduced by the interviewee (DiCiccobloom & Crabtree, 2006).

The interview questions were constructed with respect to Te Whare Tapa Wha model of health. Te Whare Tapa Wha means “the house of four sides” and was proposed by Professor Mason Durie (Durie, 1994). This model brings together Taha Tinana (the physical), Taha Hinengaro (the mental or emotional), Taha Whanāu (the social or family) and Taha Wairua (the spiritual) dimension of health and healing. Durie (1994) states that if one of the sides is damaged or missing then a person would become unwell. This is a holistic approach to health and mental wellbeing and was chosen as a guide to the interview questions and because of its cultural appropriateness to the New Zealand situation. The questions were developed to allow participants to have the flexibility to tell their own story, to include their feelings and experiences about cancer from before they or their family/whānau were diagnosed with the disease and through their current cancer experience and therapy (for former Service clients).

Table 3
Cancer Participant Details

Name	Age	Cancer Type	Participant Group²
Meg	50-60	Son - Brain Tumour	POS-family
Gary	>60	Wife -Colorectal Cancer	POS-family
Peter	40-50	Wife – (Sarah) Ovarian Cancer	POS-family
Dave	>60	Wife died of Bowel Cancer	POS-family
Susan	18-30	Mother – Breast Cancer	POS-family
Paul	50-60	Wife (Ellen) –Breast Cancer	POS-family
Jane	40-50	Husband – Metastatic Squamous cell cancer	POS-family
Frank & June ³	40-50	Son died from Neurofibromatosis Cancer aged 18	POS-family
Lorraine	40-50	Breast Cancer	POS
Karen	40-50	Breast Cancer	POS
Claire	40-50	Breast Cancer	POS
Ellen	50-60	Breast Cancer	POS
Sarah	30-40	Gynaecological Cancer	POS
Jill	40-50	Gynaecological Cancer	POS
Jim	50-60	Colon Cancer	NI
Grace	50-60	Husband Gastrointestinal Cancer	NI
Brian	50-60	Prostate Cancer	NI
Rose & Bill ³	>60	Ovarian cancer	NI

² POS-family = Family/Whānau POS Client; POS = POS Client with Cancer;
 NI = Non-intervention participant.

³ Indicates a couple interviewed together.

The quality of interview material was assessed by reviewing the initial three interviews. The intention of this assessment was so that changes could be made to the interview guiding questions if it was found that the information gained from the first three interviews was not seen to be adequate to answering the research questions.

For the POS groups the semi-structured framework (Appendix B and C) covered areas of:

- Cancer Experience
- Life Impact
- Experience with the POS

For the NI group the semi-structured interview (Appendix D) covered areas of:

- Cancer Experience
- Life Impact
- Support

Semi-structured interviews were also conducted with the Service clinicians (Appendix E). The areas covered included:

- Initial involvement with psycho-oncology.
- Differences in working with cancer clients.
- Therapeutic and personal challenges.
- Ending therapy decisions.
- Perception of what affects client outcomes.

5.3.3 Interview process.

The interviews for Clinicians and some client participants were conducted in a private room at either the Massey University Psychology Clinic or, where appropriate, in their home. A \$25 fuel voucher was provided to cancer participants and family

members to cover their time and/or travel costs. The interview length was approximately one hour with the option to re-interview at a later date.

Where both the cancer patient participant and their family member were being interviewed, the option to be interviewed together was available. This option was taken up by two couples while the remaining participants chose to be interviewed separately. Both former POS and NI participants were advised that if the interview process created subsequent distress then the participant would be offered the use of the Service. It is not known whether any participants used this option.

The interviews were audio taped with participant consent and later transcribed verbatim by professional transcribers who completed a confidentiality form (Appendix F). On return the interview was listened to again along with the transcript to ensure correct transcription. Participants were offered the opportunity to review and comment on a copy of the finished transcripts. Those who chose to review their interviews were given two weeks to respond with any changes or additional comments. No interviews were returned.

5.3.4 Saturation.

The appropriate sample size for a qualitative study is considered to be that where addition of more participants would add no further new information to the research, considered the point of saturation (Glaser & Strauss, 1967). There is however, little to guide the researcher regarding the number of interviews which are likely to provide saturation (Guest, Bunce & Johnson, 2006). In their study of 60 interviews, Guest et al. (2006) found that saturation was achieved after 12 interviews.

An exploration of average sample size of 568 qualitative PhD studies indicated the average sample was 31 (SD=18.1). However, it is recognised that funding and time pressures are factors which may restrict the ability to reach saturation (Mason, 2010).

For this study the richness of the data was strengthened by the inclusion of family members, clinicians and those who had not used the Service. However, it must be considered that saturation may not have been achieved in the present study.

5.4 Analysis

5.4.1 Rationale for using thematic analysis

Thematic analysis (TA) was used to analyse the participant interviews in this study and present themes (patterns) that relate to the data. Thematic analysis is widely applied to qualitative information obtained in psychology research. It has, however, been judged as requiring less knowledge of the complexities of theoretical foundations of qualitative research than other techniques (Howitt & Cramer, 2008). Where some contend that TA should be considered part of analytic method, researchers Braun and Clarke (2006) argue that TA is actually a method in its own right. Thematic analysis is able to depict the data in detail and manages diverse subjects through interpretations (Boyatzis, 1998). It is considered that TA offers a flexibility of approach and does not need to be tied to specific theoretical frameworks (Braun & Clarke, 2006).

Analytical methods such as Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA) were considered. However, GT aims to generate theory from the data to understand how people make sense of their experience (Suddaby, 2006) and relies on theoretical sampling, which is established during data collection (Glaser & Strauss, 2009). Although TA and IPA are epistemologically similar, major differences occur in the initial stages of coding since IPA uses multiple re-readings to make wide-ranging and unfocused notes which are quite different to the open coding of TA. In addition, in contrast to TA, “IPA aims to capture and explore the meanings that participants assign to their experiences” (Reid, Flowers & Larkin, 2005, p. 20).

Thematic Analysis was considered appropriate for the data that would arise from the interviews as it can be applied independent of specific theory and epistemology. Themes emerging from interviews could be collated in order to develop a collective experience and this would be able to highlight similarities and differences across the data set. In addition, as the current study formed part of a larger evaluation it was important to be able to use a comparable method of analysis.

In this study, an inductive, semantic and realist approach to thematic analysis was carried out. An inductive or 'bottom-up' approach meant that the themes identified were directly linked to the data (Boyatzis, 1998). In a semantic approach, themes were identified within the explicit or surface meanings of the data without looking for anything beyond what was said (Braun & Clarke, 2006). Finally, a realist approach allowed the development of theories regarding motivations, experience, and meaning in a straightforward way, assuming a unidirectional relationship between meaning, experience and language (Braun & Clarke, 2006).

5.4.2 Analysis process.

The analysis of interviews followed the six step format as discussed by Braun and Clarke (2006, p. 16). All interviews were digitally recorded and transcribed verbatim for thematic analysis (TA).

5.4.2.1 Phase 1: Familiarising yourself with your data.

The first phase of the analysis involved becoming familiar with the data. Immediately following the interview observations were made with regard to the initial impressions of the interview and of the participant. Then each participant interview was listened to as soon as possible after the interview had been completed. Once each transcribed

interview was received it was checked against the digital recording for ‘accuracy’ and to re-familiarise with the data.

5.4.2.2 Phase 2: Generating initial codes.

In the second phase interview data was imported into the software programme, NVIVO 8.0 by QSR International. This software is used worldwide in qualitative research to aid the process of coding data. It allows the researcher to highlight key points and assign visual ‘codes’ to them. In addition a memo feature allows observations and ideas to be attached to data. The initial coding stage was performed as transcribed interviews were received.

5.4.2.3 Phase 3: Searching for themes.

In phase three, the codes identified were analysed and combined to form overarching themes. These codes were double checked by the Primary Supervisor who had also read through the transcripts. At this stage a sense of the significance of individual themes was developed and a view of main overarching themes and sub-themes within them.

5.4.2.4 Phase 4: Reviewing themes.

In phase four there were two levels of reviewing and refining the themes. Level one involved reviewing the coded data extracts in which all collated extracts were read for each theme and considered whether they formed a coherent pattern. A Thematic Map of the analysis was then created (Appendix M). In level two the validity of individual themes in relation to the data set was considered and whether the thematic map “accurately” reflected the meanings apparent in the whole data set. At this point the themes were checked for validity with the author’s Primary Supervisor who reviewed the transcripts in relation to the thematic map.

5.4.2.5 Phase 5: Defining and naming themes.

In phase five the “essence” of each theme was identified by deciding what aspect of the data each theme captured. The “story” that each theme told was considered within the overall data “story” and in relation to the research questions. As part of the refinement, sub-themes were also refined.

5.4.2.6 Phase 6: Producing the report.

The final phase of producing the findings, involved selecting extracts which vividly represented the themes as they related to the aims of the current study.

5.5 Ethical Considerations

A meeting was held with Kaumatua of Te Whare Rapuora/Māori Health Unit of MidCentral District Health to discuss the study’s cultural responsibility to tāngata whenua and the study was fully endorsed by that group. Ethics approval was then sought and granted from the Central Regional Ethics Committee (CEN/08/03/008).

5.5.1 Ethical issues addressed.

There was a possibility that participants may have become distressed during or following the interview discussion. Participants were advised that they could stop the interview at any time should they feel too distressed to continue. Although many of the participants did become visibly upset during the interview process, when asked by the interviewer if they wished to stop, all expressed the desire to continue. All clients were given contact details for the Psycho-Oncology Service to enable them to access support should distress occur following the interview. In consideration of participants’ privacy, it is not known whether any participants called the Psycho-Oncology Service following their interview. Throughout the interviews the researcher was sensitive to what the participants did or did not want to discuss.

It was also considered that there were ways in which participants may have benefited from participating in the study. Participants may have felt affirmed in that their participation is contributing to the development of improved therapies for subsequent clients of the Psycho-Oncology Service. Additionally, positive outcomes may have arisen from them being able to reflect on and express their opinions regarding factors which have impacted their therapeutic journey. The interview may have also further enhanced their sense of empowerment as being active agents in their own therapy (Opie, 1992, Colborne & Sque, 2005).

5.6 Reflexivity Statement

This reflection statement is an acknowledgement that my past experiences, beliefs, values and knowledge affect all parts of the research. It particularly required an exploration of my own experiences with, and attitudes about, cancer.

My first memories of cancer were at the age of 11 years when my grandfather, who had retired only 3 months earlier, died from lung cancer. I had only recently got to know him well, having lived previously in another country, and this still feels like a huge loss to me. In my mid-teens my Grandmother, with whom I had a very close relationship, was diagnosed with oesophageal cancer. This was in the early 1980s, a time when families often chose not to tell their loved one they had cancer. My Grandmother's children made the decision not to tell my Grandmother, who then went through major surgery to remove the tumour without knowing her true diagnosis. She survived for another 20 years without needing any further treatment and only found out that she had had cancer when her GP unknowingly revealed it.

At the age of 18 I began training to become a nurse and of course came into contact with many people with cancer during this time. I remember distinctly the tragic

image of an older man who had to have a tracheotomy following throat cancer surgery. He was so addicted to cigarettes that he would smoke through his tracheotomy hole. Cancer, therefore, had become synonymous for me with loss, fear and horror. However, despite these initial experiences, when I had to confront the possibility of having cancer in my late twenties I do not recall feeling fearful nor overly distressed while waiting for the diagnosis. I did not have cancer, but being required to have regular check-ups impacted my life for many years. I believe that this has enabled me to connect with some of the experiences that participants expressed.

During my Clinical Psychology internship and in the subsequent two years I have worked for a significant period as a member of the Psycho-Oncology Service team. This dual role, being a clinician conducting research, may of course had an impact on the collection and the analysis of the qualitative data. I was not a neutral observer but an active POS team member which may have affected how I viewed the data and also how POS clinicians responded in interview. However, I believe that working with clients of the service has given me a greater insight into the feelings described by both clients and Clinicians in the Service.

CHAPTER 6

FINDINGS

This chapter and the following three present the findings from the interview data. All themes identified resulted from interviews with the four groups of participants, *former Psycho-Oncology Service (POS) Cancer Clients, former POS Family/whānau Clients, Non- intervention (NI) Group and POS Psychologists*. Having conducted a thematic analysis, and keeping the research questions in mind, the following patterns emerged with four main themes and accompanying sub-themes (Appendix M for full thematic map).

Meaning of Cancer – Creating Distress

Cancer means death

Loss

Dealing With It – Reducing Distress

Taking control

Being positive

Support

Experience of POS

Pre-Service Use Expectations

Feeling Safe

Feeling connected

Reconnecting

Effects of the research interview

Being a Psycho-oncologist

Connections

Challenges

The themes and sub-themes are discussed in this and the following chapters making reference to the literature where appropriate, and comparing themes and sub-themes across participants in each group interviewed. Pseudonyms are used throughout to maintain participant anonymity. It was felt necessary to provide names to enable the reader to connect more closely with those interviewed and to identify them as real people rather than quotes linked only to a number or gender.

6.1 Meaning of Cancer – Creating Distress

The literature shows that those with high baseline distress benefit most from psychological interventions (Naaman et al., 2009; Ross et al., 2002; Schneider et al., 2010) and this is also true for those with cancer (Heron, 2009; Sheard & Maguire, 1999). For the purpose of the current study it was important to explore what aspects of the cancer participants' journey may have contributed to their distress.

When asked about their thoughts of cancer prior to their own current experience, it was clear that for all cancer participants the word “cancer” created a significant fear response. Participants used words like *scary, horror, fear, death, dying, the end* and *a secret* to describe their thoughts about the word cancer. The meaning of “cancer” for the majority of those interviewed was that it had clearly become a word which primes a distress response. Sub-themes which emerged were *Cancer means death* and *Loss*.

6.1.1 Cancer means death.

Receiving a diagnosis of cancer can create a significant distress response both for those with cancer and for family/whānau. Despite advances in cancer treatment and the continual increase in cancer survival rates, the perception that cancer is still incurable persists (Chrz, Cermák, & Plachá, 2006; Holland, 2002; Landmark & Wahl, 2002; Shahid & Thompson, 2009; Sheikh & Ogden, 1998). For the majority of participants interviewed this was clearly evident. All but two of the participants had past

experiences of knowing people who had been diagnosed with cancer. The interviewees had varied cancer experiences ranging from their own children dying of cancer to only having knowledge from the media. Two of the participants expressed having no thoughts about cancer until they or their family member had been diagnosed but for others however, the feeling was that cancer is something to be afraid of. The following quotes are illustrative of participants' responses when asked what their thoughts about cancer were prior to their current experiences.

Former POS clients, Lorraine and Paul, expressed that before their cancer diagnosis they believed that having cancer meant death.

....that's scary, cancer usually means dying. (Lorraine- POS)

.....you know, you knew it was a dreaded disease, it was terminal... (Paul- POS family)

The view that a cancer diagnosis means dying was also expressed by NI participants. Jim's thoughts also purveyed the vision of a horrible death and like Grace and Brian they had believed that cancer was a fatal illness.

My feelings would be, um, definitely in the doom and gloom side of things.....basically, if someone said you had cancer, you had had it.... probably the horror of the end point. Um, probably because that's, probably what sticks in your mind. (Jim - NI)

Oh, that it was a death sentence. (Grace - NI)

..my viewpoint of cancer was that that it was, basically, if someone said you had cancer, you had had it. It was, it was, it was fatal, basically. (Brian - NI)

For husband and wife participants, Peter and Sarah, their perceptions of cancer came only from what they had read or what had they were aware of through the media and society in general. They had not had any previous

experience of cancer within their group of family and friends. It is apparent from this comment that society still disseminates the message that cancer is a terminal illness.

I obviously knew a lot about cancer, enough to know that it was bad, you know ... it was obviously a lot of societal knowledge about what cancer is, even though I hadn't really thought about it that much until then.

(Peter – POS family)

....that it was usually a terminal illness um and that came from the stories that you read and even stories that said “miraculous cure” you'd think, that puts it into the miracle side as opposed to a high proportion of people surviving.

(Sarah - POS)

For two participants however, their thoughts about cancer prior to their own experience were less distressing.

Bill was a survivor of prostate cancer and his previous experience appeared to have shaped his perception of the illness and therefore his wife being diagnosed with ovarian cancer seemed to be less distressing for him.

Another hiccup in life. It's another hiccup in life. (Bill - NI)

Frank and June's son passed away at the age of 18 years from cancer which was developed through him having the genetic condition neurofibromatosis 1 (NF1) in which tumours develop on nerves that can turn cancerous. They had spent much of their time coping with medical crises related to the NF1 and the expectation that their son may die and so this seemed to impact Frank's attitude towards cancer. For Frank cancer was perceived as another problem that one can be faced with in life, something that was not planned but had no specific meaning for him.

Nothing. ...Just no, it would be like a road accident, or like um. Any sort of problem.No, nothing. (Frank - NI)

6.1.2 Loss.

The current study further identified a number of ways loss was experienced with four main areas of loss identified; those of *Loss of a future*; *Loss of control*, *Loss of body image* and *Loss of connection*.

This study found that the sub-theme of *Loss* was significant for all cancer participant groups interviewed. This result is in keeping with previous research by Veach et al. (2002) and Borneman et al. (2003) who found that for families and caregivers the fear of loss predominates including the loss of physical contact, emotional closeness and future plans. In the current study facing the loss of a future emerged particularly for family members who feared the death of their loved one. Three family participants were aware that their loved one's prognosis was not favourable and that they were facing the loss of their spouse or child.

6.1.2.1 Loss of a Future.

The loss of a future was particularly significant for family members where the prognosis was perceived by the participant as poor. For family members the cancer diagnosis may mean that they are potentially facing a future without their spouse or child. For parents facing the loss of a child is particularly devastating as seen in the quotes below.

Meg's adult son was diagnosed with a brain tumour shortly after she had treatment for her own breast cancer. Her professional knowledge of cancer meant that she believed there was only one outcome for her son which was that he would die. When facing the loss of her child Meg was not only facing spending her future without him but she was also coping with the distress of her son losing his future life experiences.

The biggest impact for me is I know the prognosis. And no matter how positive I am or what I say and what I tell people I still know the prognosis. (Meg – POS family)

Meg's experience of her son's cancer was extremely distressing. However, her own cancer had less impact and she described it as being "nothing" because she did not perceive that it would lead to her losing her life.

..in fact well I sometimes forget that I've had cancer.....so I knew what I had was something and nothing really, that's what I tell myself and I believe that. (Meg – POS family)

Gary and his wife had been married for over 40 years. He felt that his purpose in life was being with his wife and that the uncertainty of his wife's prognosis meant that he felt he had lost his purpose in life.

Um, the biggest impact would be, not not having a future..... ah you know your kind of your purpose in life has gone. (Gary – POS family)

Loss of a future for people affected by cancer did not only correspond with loss of life but also the loss of potential life where fertility is lost due to treatment. The women in the current study did not highlight fertility as an impact for them. Two of the three participants with gynaecological cancer were over 40 years old and already had children and therefore fertility may no longer have been important to them. Loss of fertility in their partner can also impact men. For men facing a childless future there can be a sense that life has no purpose and even where the man is fertile, he can lose his sense of self-esteem, respect, and power (Imeson & McMurray, 1996). For Peter, being a middle aged man, his loss of a future was not only aligned to facing the potential death of his partner, but also a loss of meaning in his life, facing a future without having his own children.

..this has ruined my life, not ruined it but devastated all the hopes and dreams I had for a child and I found it very difficult,....I feel really pissed off. I think if anything it's contributed to depression.if you think what's the meaning of life and for me it was very much bound around you it was raising a family, you know raising kids and devoting your life to them and that's not happening. (Peter – POS family)

Sarah did express some distress about her loss of fertility however she had described thoughts of having a family at the time of her cancer diagnosis as being a vague future plan.

.....and so therefore because all of a sudden we won't able to have family together it was sort of like well, you know that sort of vague vision that I had for the future was an impossibility (Sarah - POS)

Although Peter did initially actively explore the options available to them, such as surrogacy and adoption but felt these were not realistic for them because of Sarah's cancer diagnosis as making these unavailable.

I think she was not very interested until she realised she couldn't have them, there's no guarantee that we'd be able to adopt because the courts have to approve all adoptions and you know if the mother has got long-term cancer they're not likely to approve it. (Peter – POS family)

6.1.2.2 Loss of Control.

Feeling a loss of control was significant for many participants and was felt by both family members and the person with cancer. For family members, the effect of their partner's cancer diagnosis meant that their time was often taken up with treatments and tests with little notice prior to appointments. The impact of treatment also prevented plans being made for future events as they faced not knowing if their partner would be well enough. This theme has also been documented by Borneman et al. (2003). Jane

expressed feeling frustrated at the inability to plan for future holidays as she did not know whether her husband would be well enough and had no control over this.

I think one thing with cancer you just live one day at a time. Well that's how I feel, I don't know if that's the right way to see it but you can't plan that in November you're gonna go on a bus trip or whatever you know what I mean?

(Jane – POS family)

Despite participants praising medical staff, most still felt that they had little control over medical decisions and the timing of treatment. Their experience of “Loss of control” is explained in literature as a loss of internal locus of control, where decisions affecting them are perceived to be being made by people in authority (Williams & Koocher, 1998). A number of participants commented on the loss of control over the medical process. Both Grace and Lorraine compared their experience to feeling like they were a part in a factory production line, as if they had no choice to stop or affect the cancer treatment process. Grace a NI family member alludes to the feeling being disconnected and lonely within the hospital process.

*The hospital was so rushed and the doctors nurses was so rushed that, that, then I realised that, you know, most of the patients are our age now aren't they, the baby boomer generation, so that, so that's to be expected but when it, when it happens it's, it's an awful experience because you feel quite lonely in amongst this rush, it's like being on a production line because that's how it is, we're the component on the production line..***(Grace - NI)**

...so it was like living in a three-week period, I had been diagnosed, in hospital, had the mastectomy and through the treadmill and spat out kind of thing...

(Lorraine – POS)

This concept of the hospital environment instilling a feeling of being a part in a factory was also found by Dempster (personal communication, 24 June, 2013) who

explored the experiences of former Massey Psychology Clinic clients with chronic health conditions.

Being unable to have control over finances impacted both the person with cancer and family members. Some participants were forced to take time off work and faced reduced income due to treatment demands. Family members had to face financial loss where a partner with cancer had to give up work. These findings are supported by research which has highlighted financial stress as being a factor in not only coping with a cancer diagnosis (Heron, 2009) but also impacting the effectiveness of psychological interventions as despite therapy, financial burden may sustain psychosocial and functional problems (Francoeur, 2001).

For family client Jane, her husband's inability to work as he became too unwell meant that they faced financial loss. For Jane, this loss of income had a significant impact and meant that she had to face the loss of her home and former lifestyle.

.....and we had a big character house with big character gardens which we'd won lots of prizes with in garden competitions and things and then all of a sudden that was all taken away from you because in the end Jim couldn't work cos he was having all that radiotherapy and he was really quite sick and that's when we sold that and come to here. So it was actually quite a big change of lifestyle really and I think probably the biggest thing was being on two incomes and then just living off mine.Well, I mean, well, like I'd go and buy 3 lots of blouses and... you know... that sort of thing and now you can't do that. (Jane – POS family)

A diagnosis of cancer can add to financial stress and loss of control experienced with the recurrent need to have to pay for prescriptions plus travel and treatment. Karen felt that her costs were not high in comparison to others she had known go through cancer however, but she still struggled with the expense of her illness.

...it was pretty, pretty hard. Just, just the prescriptions and things. And I'm lucky, I didn't have, I just had very small costs compared to other people's cancer treatments. But yeah, it was still hard, having to have that time off work, couldn't, couldn't even get a travel allowance, you know, to come in for chemo.

(Karen – POS)

We had to draw in our belts when we came back, till we get over it. **(Meg – POS family)**

Not all participants who experienced loss of income struggled financially but they still experienced loss of control. Jim had saved for retirement and was able to leave work, being mortgage free. However, his wife did continue to work and for Jim the loss of control was the feeling of no longer having the role of being the main breadwinner and supporting his family financially.

I was working full time. Right up to the colonoscopy.So I had quite a reasonable income off that, which suddenly chopped.Um, yeah, I went down to nothing. Um, [his wife] kept working her job, and I think, her thought was, well I can sort of try and um, minimise this financial impact. So, that was sort of, that was quite hard to get my head around. Because I suppose the male was sort of, you know, you've got to provide your home. **(Jim - NI)**

6.1.2.3 Loss of body image.

Loss of body image was clear from interviewing those with breast and gynaecological cancers. As identified in the literature review, breast and gynaecological cancers can have a substantial impact on a woman's feelings about her body (Ashing-Giwa et al., 2004; Fobair et al., 2006).

Former POS client Lorraine expressed feelings that the loss of their breast was a devastating. Although she felt others would not notice her missing breast it was a constant visible reminder of cancer to her.

I mean everyone likes their bodies but I particularly liked my boobs [Laughs] and it was you know I was devastated to think that I had to lose one and that I wasn't gonna have one there for a certain amount of time.it was just the fact that you look in the mirror and you had this flat, flat side here with a nice sort of scar across it and a little scar under your arm where they'd taken the lymph nodes and that and I didn't like to look at it. Um, sure you could be dressed and have your prosthesis on and your clothes and lots of people couldn't tell, they wouldn't know one or the other but the fact was I knew and I didn't like it. (Lorraine – POS)

For Karen the loss of one of her breasts was an aspect of her cancer treatment which clearly created distress for her and like Lorraine she felt that it was a reminder that she had had cancer.

Sort of publicly, it's it's, probably affected me more than anything. Because you know, you watch what you're wearing after having a mastectomy.It's more the physical than the mental side, it just reminds you all the time. (Karen – POS)

Loss of body image had a significant impact not only for those clients who had disfiguring surgery but also for those who were affected by the side effects of medication. For those with gynaecological cancer the physical effects were not as visible but the impact of treatment still manifested physically. For participants with gynaecological cancer loss of self also occurred where treatment caused women to put on or lose weight.

Prior to her cancer diagnosis Sarah had no specific thoughts or concerns about how she looked. She had been able to manage her weight without conscious effort however, following her cancer treatment and due to the effects of medication, Sarah put weight on. She suddenly became more focused on her body and more aware of the physical image she presented to the world.

really body image has never ever concerned me before but all of a sudden all of that sort of stuff became like, but yeah I look terrible in this and I can't play sport any more um yeah so all of the sudden what had never been a process and never a concern of me with myself or anyone else, had become more of a concern. (Sarah – POS)

Jill became very unwell after her cancer surgery and this resulted in her losing a great deal of weight. Working as a hairdresser, an industry in which “beauty” is the goal, her body image was a part of her work. She not only had to face her cancer but also face others comments about her “sick body”. People were negative and she began to see herself in the same light. Jill used terms that depict her being at “war” with her body and her own thoughts as she tried to gain weight.

So I was just like a walking insect stick, and I looked, I had from my clients, from my hairdressing clients “Oh, you look so ill, you look so frail, you look so thin” and I looked very, very anorexic, and that used to upset me, you know, ‘cos I used to look in the mirror and I’d think “Oh, you just look so gaunt, you look so...”, you know?.....And I’d try to eat more, you know, to try and plump up my face and get some meat on my bones and it was just a real battle, a real, real battle, so that was sort of like a little bit of an internal sort of struggle that I went through for a long, long time. (Jill - POS)

From the literature the author anticipated that loss of hair would have been a concern for the cancer participants. Contrary to studies by Freedman (1994) and Landmark and Wahl (2002), hair loss was not experienced as especially distressing in the current study, but was viewed as expected and accepted by participants. It may be that over the last 11 years there has been significant improvement in wigs or that hair loss is more generally accepted with public cancer fundraisers such as head shaving.

6.1.2.4 Loss of connection.

Finally, loss of connection emerged where some participants' response to the cancer meant they became disconnected from their loved ones and also socially isolated. It was clear in many interviews that cancer created loss in personal relationships. Sub themes of *Disconnection from Intimate Relationships* and *Disconnection Socially* were identified.

6.1.2.4.1 Disconnection from intimate relationship.

The interviews revealed that coping with a cancer diagnosis caused deterioration in some participants' relationships, either from the strain of coping with treatment side effects or through lack of communication. This supports previous research in which a cancer diagnosis may result in greater emotional distance within family relationships (Borneman et al., 2003; Veach et al., 2002). The use of protective buffering (Coyne & Smith, 1991) was evident for some participants, where they tried to reduce the stress and burden on their family by hiding their own thoughts and feelings.

Family members often have to face changes in loved ones due to the side effects of treatment. Gary found that his wife's memory was significantly impacted by her chemotherapy which created a strain in their relationship.

We've had a lot of emotional problems between us through this, its, ummm, yer its strained our relationship a lot but I've found it very hard with her memory, she repeats a lot which I just answer the appropriate thing... (Gary – POS family)

Peter expressed feeling powerless to help Sarah with her cancer and in keeping his marriage together.

....we were arguing a lot, little things, stupid, mainly stupid things and sort of accuse and re-accuse and the marriage was going south quite quickly and um and, and I realised I couldn't help her with the cancer and I couldn't keep our relationship together. So for me it wasn't so much dealing with cancer, it was dealing with the sudden deterioration in our relationship cos I didn't you know want to um lose her... (Peter – POS family)

Both Jane and her husband were clients of POS. However they were not seen together at any point in their therapy. Jane reflected that her husband commented she was “not on the bus” he was driving. Being “Driver of the Bus” refers to an ACT metaphor concerning not allowing your anxieties or your thoughts to control your behaviour. Unfortunately, as Jane had not been present in any of her husband’s POS sessions she misinterpreted this as meaning he wanted to cope with his cancer journey without her support.

He said, “It’s like this, I’m on a bus and I’m on a journey” and he said, “I’m the driver of the bus and I decide who gets on the bus and who gets off it.” So I thought to myself, “oh well fair enough if he doesn’t wanna talk about it...” So that’s... So me being me, the next time he went I said to him, “Well, am I on the bus or am I still at the bus stop?” and he just said, “Oh, you’re at the bus stop.” And that was... that was it. So that was his way of dealing... you know... (Jane – POS family)

This added to the strain that Jane’s husband’s cancer diagnosis had already made on their relationship. Sarah explained also that she did not want her cancer diagnosis to add to her husband’s stress but this created a distance in their relationship. She explained that they used to talk about everything but they were unable to be open about her cancer diagnosis. This revealed the use of protective buffering described by Coyne and Smith (1991) in which Sarah felt that she did not want to burden Peter by talking about her cancer. This disconnection felt from their previously good relationship is

supported by Manne et al., (2007), in which protective buffering creates higher distress for those with good relationships pre-cancer.

I didn't want to worry him anymore so I probably didn't want to talk to him about those fears and my feelings cos if I did that would add to his stress and I'd say, well I don't want to add to his stress, so therefore I just won't talk about it or deal with it with him, which ends up adding a different dimension which is I don't want to talk about it, this stuff and it's kinda like oh okay whereas, before we'd been quite open in conversation and talked about all sorts of things, all of a sudden we had a much more closed conversation. (Sarah – POS)

The perceived contrast in attitudes that Peter felt he and Sarah had towards her cancer diagnosis, also created disconnection in their relationship. Peter commented that he was more negative about Sarah's prognosis and he wanted to talk with her about the possibility of her dying. However, Peter sensed that Sarah wanted to maintain a positive outlook for her future and so she was actually preventing him talking about her possible death from her cancer.

Sarah's got a very positive aspect on things and she now it's sort of treating it as a long-term illness and refuses to accept that she'll ever die, um whereas I'm just assuming it's a matter of time and, and that difference of view between us does create difficulties between us being able to talk about it because we can't talk about the possible eventuality of her dying or prepare for it in any way. It's just not a subject that we are allowed to talk about, it is complete taboo, so yeah. (Peter – POS family)

So, for Sarah her reasoning for not talking with Peter about her cancer was related to reducing his distress about the possibility she would not survive her illness. However, this was clearly felt by Peter as actually increasing his distress and mistaking her refusal to talk as trying to be positive. This couple show how disconnection within their relationship prevented Peter and Sarah from communicating effectively and openly

about their thoughts and emotions. They were essentially walking on different paths within their cancer journey, disconnected from each other.

In contrast to the research (e.g. Andersen, 1993; Kissane et al., 2004; Fobair, 2006) only two former POS participants described sexual disconnection from their partner or spouse. For the majority interviewed cancer participants' sexual relationships appeared to be relatively unaffected which may have been a reflection of the small sample size or because it was a difficult topic to for them to discuss in the research interview. Although Lorraine perceived that her cancer had not impacted her sex life significantly, she felt that her partner would say it had and she linked this to feeling less attractive because of her surgery.

Did it affect our sex life, possibly, if you ask [partner] he'll probably say yes. Um yeah it probably did a little because I didn't feel attractive so um yeah not nice.

(Lorraine – POS)

Paul expressed feeling that he and Ellen's sexual relationship had been impacted and although initially intimating that this was not significant went on to describe it as "the crux" of their problem.

A little, initially a little bit yeah, I suppose but yeah, it's, it has, yeah, a little bit of sexual relationship side too I suppose yeah, and that was generally the, the crux, the crux of it yeah. (Paul – POS family)

For NI participant, Jim, there was some difficulty with sex but this was not attributed to his cancer and he and his wife used humour to cope with his colostomy during intimate times.

I'd say it's not as great as what it was. Maybe because I'm 60 now, might have something to do with it. Nah. No, not really. Um, so oh, we'd joke about it a hell of a lot. You know, we'd cuddle up and you'd hear this plasticity, scrunchity sort of, well sometimes it had sharp edges, and there'd be a bit of a yelp, and like yeah. Um, but I think we joked a lot about it. And, and we laughed about it.

(Jim - NI)

6.1.2.4.2 Disconnection socially.

The effect of social constraints (Lepore & Ituarte, 1999) perpetuated distress in a number of participants. Cancer participants spoke about avoiding talking with friends in case they were seen as over preoccupied with their cancer or thought they may burden their friends with their distress. For family members and cancer clients, treatment, such as chemotherapy, created a self-enforced social isolation in order to avoid possible infection from other people, including their friends. This occurred at a time when personal social contact with friends may have been most needed rather than just phone calls or emails. Although all participants talked about the support they had from friends, a number of them chose not to be open with friends about their cancer experience. They all talked about not wanting to burden others with their distress.

I um, I didn't tell any, my friends, um, because at the time we were going through exams, and everybody was quite stressed, and I didn't want to put that on anybody else?..... (Claire - POS)

Claire clearly felt that talking with her friends at the time about her mother's breast cancer was inappropriate and she appeared to have been more concerned about their stress than her own needs.

Karen was also concerned that the consequences of talking to her friends and family about her breast cancer would alienate her from them.

Yeah, you didn't sort of want to feel like you were burdening them, just talk to your friends and family too much. Talk about the same thing too much, they'd probably get sick of you. (Karen – POS)

Despite loving and supporting her husband through his cancer journey Jane felt annoyed by him at times but she felt unable to share this within her social network due to worry of being perceived negatively.

But like one of our friends or one of [husband's] relations or something you feel a bit guilty about saying that, thinking, "Well what would they think of me, thinking like that?" (Jane – POS family)

Sarah also did not want to burden family and friends but in her comment below she highlights the physical impact of her cancer on her ability to maintain and develop support networks.

....friends and family, they, I mean they're genuinely concerned that you don't want to make them more concerned. Ah so therefore you, you ah don't necessarily want to tell them everything cos yeah although you know you share some things but, you wouldn't say what, I didn't want to ah burden them....and ah without having that energy I found socialising with people very hard. We were relatively new to New Zealand anyway, so we didn't have that many strong relationships with that many people so therefore when you're just developing relationships it takes a lot more energy, so we probably felt that it affected it quite dramatically. (Sarah – POS)

Bill also raised the issue of needing to be socially isolated in order to reduce the chance of bringing back potential infections to his wife who would be vulnerable following her chemotherapy.

I didn't go to the Probus meetings at all. Or to the luncheons or anything like that because I felt that, you know, I could easily end up picking up something unknowingly. Well a lot of the time, we didn't feel overly like doing much. (Bill –NI)

The perception of “being alone” in their cancer journey has been identified by studies of women with gynaecological cancer (e.g. Ferrell et al., 2003) despite feeling well supported by friends and family. Jill’s comment clearly reflects similar feelings in that although she did feel supported by friends and family, she also felt that cancer was an illness which you went through alone.

But on a whole, as a whole, you can have the best and most loving, caring family and friends in the world, and all the support, but when you're going through cancer, you go through it alone. It's more, it's so personal, having cancer, and having to deal with the effects of it is so personal, that it's, it's only really you, it's you alone.... (Jill - POS)

The theme of social disconnection developed for a number of participants as an effect of their choice to abide by social constraints (Lepore & Ituarte, 1999). The choice to avoid usual social gatherings was related to concern over avoiding infection or because of the physical impact of treatment fatigue. The cancer journey was also perceived as something which was purely personal and thus some cancer patients felt this was something they were going through alone.

6.2 Participant Group Differences

Cancer clearly created some degree of distress for all participants interviewed coping with a cancer diagnosis. The breast and gynaecological POS participants highlighted the specific loss relating to body image which did not emerge for the other groups interviewed. Although the NI group consisted of participants who also had cancers which could affect body image, such as having a colostomy or dealing with urinary incontinence, it was not an area that was highlighted as an issue for them. The issues they dealt with were considered temporary impacts in that the colostomy had been reversed and the incontinence had resolved. However, loss of a breast and effects of sudden menopause are permanent. Social isolation was experienced by both those diagnosed with cancer and family members from both POS and NI groups. The emotional impact of cancer for family members is well documented and this study highlights that there is also a social impact where family isolate themselves to support their partner.

6.3 Summary

This chapter examined the theme of *Meaning of cancer –increasing distress* and the sub-themes of *Cancer means death* and *Loss* which emerged in relation to the meaning that cancer had in the lives of the participants and the way in which it created distress in their lives. The idea that cancer is still incurable perpetuates in today's society (Holland, 2002; Landmark & Wahl, 2002; Chrz, et al., 2006; Shahid & Thompson, 2009) and it was indeed evident in the thoughts of most participants, that cancer meant death. The sub-theme of *Loss* emerged for many participants and was seen to impact in different areas of their lives which is supported by work by Veach et al. (2002). Facing the loss of a future emerged particularly for family members who feared the death of their loved one. Other participants felt a loss of control in being unable to plan for the future, control medical decisions or finances. For those with breast or gynaecological cancers loss of self, relating to their body image, was clear. Finally loss in relationships emerged where participants' response to the cancer meant they disconnected from their loved ones in order to protect themselves or their loved one and also became socially isolated from friends and family.

CHAPTER 7

DEALING WITH IT- REDUCING DISTRESS

The negative impact of cancer was evident for the cancer participants interviewed and they used a number of strategies to help cope with their distress. Many participants conveyed coping with their cancer in quite active terms such as “battle through”, “fighting”, and “getting through”. The most frequently used phrase was “dealing with” which related to many aspects of their cancer including the actual diagnosis, impacts of treatment, relatives and friends. The three sub-themes which emerged were *Taking Control*, *Being Positive* and *Support*.

7.1 Taking Control

The interviews demonstrated that participants utilised a variety of different strategies to help them deal with their cancer diagnosis. Prior studies have noted the importance of having a perceived sense of personal control in reducing psychological distress (Taylor, Hegleson, Reed & Skokan, 1991; Lowery, Jacobsen & DeCette, 1993). Participants expressed two distinct coping behaviours in which they actively took control of their cancer journey. These were *Finding Knowledge* and *Healthy Behaviours*.

7.1.1 Finding knowledge.

In line with other research (Meredith et al., 1996), participants in this study felt the need for more information about their cancer and actively sought the knowledge they needed (Nagler et al., 2010). The sub-theme *Finding knowledge* emerged as an active form of control with participants finding helpful information from various sources such as friends in the medical field, others who had coped with cancer, medical staff and the internet. In reviewing the literature it was evident that not having

knowledge or the feeling of not being given enough information can create or exacerbate distress in those coping with a cancer diagnosis (Pifalo et al., 1997). A number of the participants in this study felt that they were not provided enough information by medical staff but most felt that this was due to how busy the medical staff was.

Family member, Grace, reported feeling quite uninformed about her husband's cancer but felt comfortable actively seeking details from medical staff.

I made sure I kept in touch with the doctor and the hospital and made sure that I was up front, in their face, I really made a nuisance of myself.... (Grace - NI)

Grace also actively sought information from the internet however but was left feeling overwhelmed by the volume and variety of information she found. This is similar to the qualitative findings by Power et al. (2008) where some participants also described finding the internet discouraging and frightening. So while the internet can be a helpful source of information, the amount of information available can be overwhelming at times and therefore creating added distress.

Um, it was probably a week, the doctor said it was called a GIST so I looked that up on the internet, far too much information ohhh, and, and all the possibilities of where it could go in his body and what it could do and, maybe that wasn't a good idea to look it up but I had to know..... I would have liked to have known that I'm sure, because then we can deal with it rather think think what if, what if and then information about it given to me in such a way that I can handle it rather than going to the internet and finding all these different..., they even gave pictures on the internet and I was able to ask (husband) which one was it because they showed him a photo as they were looking down, you could see it. (Grace - NI)

Brian was provided with some information but he felt that the few, undetailed pamphlets he was given were inadequate and like Grace used the internet to inform himself about his cancer.

But I got no information from him [oncologist] what-so-ever. Yeah. Got the pamphlet, little pamphlet and that was it, um, which told me nothing. Was just, the basic, where the prostate is, what it does, um, and that was about in the, about four things that what can be done, the surgery all that. But only little paragraphs of ten or twelve lines each, basically nothing. I picked everything up off the world wide web, off the internet. (Brian - NI)

Lorraine actually expressed feeling quite well informed by medical staff about her breast cancer, but unlike Grace she did not always want to ask questions of her doctor and she was able to utilise the knowledge of a friend who used to be a nurse.

...my friend, who is an older lady and she is a nurse, or ex-nurse as well, so um she was, she was great cos I could kind of run things by her if I didn't feel like talking to the doctors. (Lorraine – POS)

7.1.2 Healthy behaviours.

In the theme “Healthy Behaviours” additional active forms of control emerged in which cancer participants described making efforts to improve their health by exercising or changing their diets. Lifestyle changes are highlighted in the literature as a response utilised by cancer patients to regain control (Maunsell et al., 2002; Williams & Koocher, 1998).

7.1.2.1 Exercise.

Exercise has been linked with the reduction in psychological distress and improved quality of life for those with cancer (Courneya, 2001; Courneya, 2003; Beesley et al., 2008; Bicego et al., 2009). In this current study being diagnosed with cancer or having a family member with cancer generated, in a number of participants,

the motivation to review their lifestyle. Some participants reported increasing their own physical activity and also observing activity changes in their family members.

Brian made a significant effort to start being active following his cancer treatment and began to exercise regularly during the week.

But um, fitness wise, I've been um trying to keep active. Um. I've taken up swimming I do about 40 lengths of (name) pool every, every Sunday. Um, and sometimes on Fridays because I have Fridays off, I work four days a week. Um but having said that I haven't been for a swim on Friday now for about four weeks, because other things have been on Fridays, so, that's sort of taken up that time. But I do like bike rides, I go bike riding, I usually do that on Saturday morning. (Brian - NI)

Claire explained that she had begun increasing her activity after her cancer diagnosis. She chose to incorporate her decision to be active with her children's activities thus also providing her with treasured moments with her sons.

Yeah, oh I never, I never sit around, I wouldn't, oh, I did once, I sat down and watched a DVD during the day. I've changed that, I did the paper round this morning, with my sons. (Claire - POS)

Family members remarked on seeing changes in their loved ones relating to attitudes towards improving their health.

Um well the physical side, she's started to exercise. She does ah virtually daily on the exer-cycle and on the gym here um she does it at her own pace, (Gary – POS family)

She exercises very regularly, and she's goes, you know, to the gym, and she makes sure that she does that, she has to do to it 3 times a week. (Susan – POS family)

7.1.2.2 Diet.

Changing their diet was also a way in which participants reported that they could gain a sense of control over cancer. Altering diet is considered one of the major lifestyle responses to cancer (Patterson et al., 2003) and has been shown to significantly reduce distress (Maunsell et al., 2002). In this current study participants researched dietary information and chose to cut out or increase different food groups with some making the changes for their partner with cancer. They reported using information from books and the internet to determine how they should alter their diets to improve their own or their partner's health.

Gary indicated that he and his wife were working together to both eat in a way that they felt was more healthy. This was not however, just about a choosing "healthy" foods, as Gary highlights that also additional scrutiny is required in assessing how his wife responds to her food.

I feel that uuum, uuum some of the causes are though our food chain, uuum, and lifestyle, so you know I feel proper nourishment and general exercise alleviate a lot of our diseases. ah we've read up and looked at our diet and we are both um working on our diet to make sure that's healthy without being ridiculous you know. Basically our vegies and meat, our choice of there's no fat in our meat things like that. And taking note of what affects her because she has a lot of trouble with her bowels ah so we have got to watch that so we are looking very carefully so yeah (Gary – POS family)

Brian talked about cutting out specific food groups and reducing his intake of others. Interestingly he talked about a "fear" of using milk and has changed to drinking soy milk. For Brian, the cancer created an impetus to make health changes.

Biggest area of impact would be possibly diet. I've sort of um, I've cut out a lot of dairy. Stuff, I cut out, um, I won't say I've cut out completely red meats, but I've probably don't need to eat meat as much as I did. Um, I still like steak, and things like that. But ah, I suppose with dairy produce is the main part which I've cut out on. Like I'm scared of using milk on Weetbix, I use um, soy milk. Um. And um, which intrigues the family, because I'm so anti soy product beforehand because of the, it's a long and involved story. Um and um, um, sugar. ... Not that I ate much sugar, but sweet, sweetened things and that, I don't sort of go by now. Um, like I wouldn't dream of putting sugar on Weetbix for example. I don't think I put sugar on my Weetbix beforehand either, but, I certainly am conscious of that sweetening thing of the sugars too. (Brian - NI)

Susan described ways in which she had seen that her mother had become more mindful about what she ate and had increased intake of specific foods.

I think she's a lot more conscious of her health, and she's quite fastidious about the things that she feels are helping her like lots of tomatoes you know, the foods that are supposed to be good for you and um, you know, not having takeaways too often, and things like that. (Susan – POS family)

7.2 Being Positive

Having a positive attitude regarding the outcome of their cancer diagnosis emerged as helping some participants cope with their distress. This supports findings by other studies which show that a positive attitude about a cancer diagnosis can reduce distress levels (Cohen, 2002). The cancer participants described being determined to cope, not hiding their diagnosis and expressing certainty of survival to others. Having a positive attitude was evident within all groups of cancer participants.

I choose, I chose that "I'm not going to let this destroy me", because it just about did in lots of ways. Yeah. (Jill - POS)

Don't hide. But be proud of it. And much the same as this, I think. I find the same sort of thinking to it. It's nothing to be ashamed of, why hide it? Um. Um. I think that's by far the better way to sort of approach things. (Brian - NI)

We told them as straight forward as we could, and I always said to them, no, I'm not going to die. So get that out of your head. (Bill - NI)

Being positive was also reflected in finding aspects of their lives which they felt had been enhanced by having cancer. Research has demonstrated that benefit finding after a cancer diagnosis can reduce distress and depressive symptoms and increase positive affect (Carver & Antoni, 2004; Bower et al., 2005).

Several cancer participants found that their cancer journey helped them become more connected with their partner, family or friends. Although Peter had expressed his distress at the fact that his relationship with Sarah was deteriorating he was still able to see her in a positive way.

I mean I've probably fallen in love with her more and more as it is gone by because you know you realise through seeing her deal with it what a beautiful person she is (Peter – POS family)

Others noticed that there was a change in relationship within their family towards their loved one with cancer.

I noticed that they're [their children] not talking to him [her husband] so disrespectfully anymore. Like they get impatient because he doesn't hear them, ... they don't seem to be showing that, which is good, I like that. Perhaps, perhaps appreciation, I, I did enjoy how the children would ring up a lot to see how he was getting on, I enjoyed that, the attention, yeah, yeah, I think when you're sick you do enjoy the attention (Jill - POS)

Interestingly Jim expressed finding that one of the positive aspects of his cancer diagnosis was feeling more connected to others and experiencing a deeper relationship

with others, in particular his brother whom he had felt distanced from before his diagnosis.

Part of that, and we've become very, very much closer, now, as brothers, because of this cancer situation.Oh, there's lots, there's lots of positives, really. Really, really great positives. Yeah, relationships with people, um, yeah, you probably talk a lot more in depth with people, than you do, ah, without it. I think every person has a cancer experience. (Jim - NI)

Two cancer participants, Lorraine and Jim also revealed positive behaviours as a response to their diagnosis by deciding to volunteer to help others also affected by cancer. Lorraine reflected that volunteering at a local Cancer Society programme, which aimed to help women improve their self-image, also helped her to feel good about herself and put her cancer experience in perspective.

I actually volunteer at that now [Look Good, Feel Better]. Um I found that that was really, really good and it just made you feel better about yourself and made you aware that there were other people out there u and also aware that there are other people out there that, while you'd had cancer and you shouldn't dismiss it, there are people out there you know that have got the lot of a more rockier road than what you are on so it made you think "hang on get a grip", sort of thing [LAUGHS] (Lorraine – POS)

Jim chose to "give back" by also helping others with cancer in a practical way at the local hospital.

....I would like to give something back again. We, (other cancer patients), we at the moment are up at the hospital on Monday afternoons. They've started a shuttle, little shuttle service around the car park. Means people who've got to park right out by Tremaine Avenue don't have to walk back, especially the elderly. And we decided to do that as a thank you. (Jim - NI)

Being positive was reflected in some participants' attitude towards their cancer diagnosis. Having a positive attitude has been shown to reduce distress and attributed to having a fighting spirit (Cohen, 2002; Wilkes et al., 2003). Additionally, finding positive aspects of their cancer journey helped develop greater connections with loved ones and some also found benefit connecting with other cancer patients through volunteer work.

7.3 Support

A number of studies have reported that social support is effective at reducing symptoms of distress for people coping with cancer (Wellisch, 1985; Lewis et al., 2001; Helgeson, Snyder, and Seltman, 2004).

7.3.1 Family/friends.

All cancer participants described receiving a variety of support from friends and family. This included phone calls, emails or receiving cards from family who did not live nearby, support at doctors' appointments, being there to listen and taking them out.

This comment from Gary clearly expresses how much he valued and felt supported by being able to share the experience of having a family member with cancer that he and his friend shared.

A lot of our friends have been very good. Ah, a friend of my wife's she ah she had lost her husband about 14 years ago to cancer and ah she would talk ah you know and we'd discuss our experiences you know which is brilliant, ah it is like she is walking the path with me. But ah now her second husband has got leukaemia, just been diagnosed, so ah we'll both be there for her. (Gary – POS family)

Lorraine described support from family and friends but also felt affirmed that her work clients were thinking of her.

So um I had lots of support from family and friends, yeah, and clients at work, that was really interesting, that was kind of cool as well. It was just that knowing that they were thinking about you or whatever and they'd send a little card or whatever. So, very supported through the whole, the whole thing. (Lorraine – POS)

Meg talked about sharing her son's cancer journey and providing support for her son by attending his medical appointments. She felt that as she had considerable cancer knowledge she was able to help explain to her son and family what the doctor was communicating.

Yer, mmm. I've been with him, I've only missed one doctor's appointment, um while he had his treatment and (father) went with him for that. But I'll go with him. He's gained a lot from the fact that I've gone with him, to all his appointments that I talk things over with him so that he can formulate the questions that he needs to ask the doctor and I tried where possible not to preempt him when we are in the doctor's room. I've explained to him what his medications are, why the doctor did this and why the doctor did that and what he's likely to feel as a result of doing this or doing that. Ah, I've just tried to be there for him really and ah make his life is as pleasant as it possibly can be at the present, yer. (Meg – POS family)

Clare explained how much she and her husband valued the support from friends who had coped with the experience of having a daughter diagnosed with leukaemia. She describes people “being there for us”.

That friendship has been very valuable....and her husband actually and my husband get on quite well too.....,and her daughter went through leukaemia,... when she was fourteen, and she's now twenty, and she's got through it all. So that mum's been through a lot and she really looked after me and made, made a big effort to, um come with me to appointments...or, do all the support she could, so she's been outstanding. In fact I have had other outstanding friends too, so people have just been um, you know there for us. And other friends and I just talk like lots. (Claire - POS)

Friends and family also provided practical support including making meals, helping with housework and providing transport to medical appointments and encouraged socialising.

Immediately after the death of his wife from bowel cancer Dave found the thought of being alone intolerable and appreciated his family staying with him and also that friends provided support by taking him out or providing a meal. This is related to findings by Anusic and Lucas (2011) in which well-being is increased for those who are widowed when they have social support after the death rather than before.

I got lots of support [from family] they stayed quite a while cos I couldn't be by myself. Friends would call me and take me out to the local, I'd go down there and play darts....a lot of friends stopping in with food and that. (Dave – POS family)

Unlike some of the views of participants in the previous Chapter Jim perceived that friends wanted to know what he was going through and he was happy to be talk about his cancer journey with friends. In addition, his friends appeared to adjust their lives to suit his treatment symptoms so that they could remain connected to him.

And um, and when they say to you, you know, how are you feeling, they really want to know. They don't want the glossed-over version. If you're feeling like crap, they want to know you're feeling like crap. Um. And they'll say things like, oh, well, instead of going out, look we'll come and have dinner at your place. And then, if you want to crash, you crash. (Jim - NI)

Susan talked about experiencing a change in roles. She found that providing practical support helped her cope with her mother's cancer diagnosis although she clearly recognises that this may have been a way to avoid her feelings related to the cancer. Here the provision of support to the cancer patient benefited both the patient and the person providing the care in a form of symbiotic connection.

Like, I think it quite helped me, because you know, I knew I was doing something that was helping, I wasn't just trying to be emotionally supportive or something, where that can be, am I even doing anything, but practically you could see that it was going, you know, that housework was getting done so I know that I'm helping. So it was like my role, I felt through the whole thing was just, support in that way and whatever else was needed. I, I think it was good for me, but (chuckles) um, I suppose then I wasn't wasn't really thinking about, about how I was feeling. (Susan – POS family)

7.3.2 Spouse/partner.

Participants talked about the importance of the support they received from their partner or spouse and a number of them expressed the way in which they were able to mutually support each other.

I suppose that just somebody there to um, to talk to, to just, to talk things over, a shoulder to lean on um, yep just a moral support beside her I, I would gather, do the little things that she couldn't do, yeah I would think, er yeah,she was always there (for Paul) yeah, no I think just that we supported each other, just as I said. (Paul – POS family)

Rose expressed the thought that she would have been unable to cope without the support from her husband Bill. However, his reply showed the gratitude he felt that she had supported him when he had prostate cancer a number of years earlier.

Ah. Mentally or emotionally yes, you are, and you're very dependent on the support that you do receive from your husband.. If I didn't have him, I don't know how I would have coped. (Rose - NI)

Well I mean she's looked after me so for so long that, well it was my turn to look after her sort of thing (Bill - NI)

It is recognised that interviewing some couples together may have prevented either partner openly communicating negative feelings about the other. However,

evidenced from the previous dyad, the joint interview could also be viewed as a strength. It was clear during the interviews that couples were able to reflect on each other's discourse and this provided an added richness to the data that may not have emerged if they had been interviewed separately.

Of the six POS women diagnosed with breast or gynaecological cancer, five of them expressed feeling cared for and supported by their partner or husband. Claire and Lorraine both expressed worries that their partner would react negatively about their loss of a breast.

I feel, my husband's really supportive, and that cos I know, I do know somebody else who's had their husband, he's really quite unpleasant about the mastectomy, and the scar. And everything, what she looks like. He's really good and supportive, and you know, he worried about me of course. But he hasn't been, there's no way he'd make a nasty joke or anything about it, you know what I mean?(Claire - POS)

However, both women found that their husbands were supportive in spite of their surgery. Lorraine's partner provided humorous practical support when she began to lose her hair.

You know he's [partner] been great through this whole, I mean there's a little sense of humour, he went and bought his dust buster when I was losing my hair {Laughter} because he'd vacuum the pillow every morning to pick up my hair that had fallen out and little things like that. So um, yeah it probably made us closer in the sense that he was always there for me so that I knew I could rely on him and he wasn't going to run off and disappear because I didn't have a boob anymore. (Lorraine – POS)

7.3.3 Medical staff.

Although most participants expressed concern over the lack of adequate information they still felt supported by medical staff. Studies show that 50% of cancer

patients are comfortable asking for information about their illness from medical staff (Nagler et al., 2010.)Most of those interviewed had praise for the support they received from their hospital specialists and nursing staff and GP.

Lorraine described feeling that her female GP, who had also gone through cancer, was able to provide her with both practical and emotional support.

My GP I found that she was really supportive and it wasn't always you know I'd go there and she'd say you're doing really great and she'd give me a hug and any time to call me just call me which I thought was really nice and she'd talked to me about wigs and stuff like that and about so I found that really good and I felt quite comfortable seeing her you know I didn't feel like if I just need to go in and have a bit of a chat and get a bit a bit of um not sympathy but you know set me on the straight and narrow or whatever and that she was really supportive and she wasn't you know like when I said I was feeling a bit down or whatever she wasn't dismissive of it she said well look it's natural and it happens to most people. (Lorraine – POS)

Peter felt that he was less involved with the hospital staff than his wife Sarah. His perception was that Sarah had a close relationship with her medical team and that this had actually influenced their decision to stay in New Zealand.

Yeah I mean [Sarah] has had a closer relationship with them and she actually knew one of those nurses through her teaching job she teaches her child. To be honest the main factor and not returning to Sydney has been because she has really um thought that the staff at the hospital have been excellent so we've been very happy with that, so having that continuity of people that she knows with her treatment is very important to her, it's a big factor in staying here. (Peter – POS family)

7.3.4 Other support services.

When asked what support services participants had used, other than POS, three of the women diagnosed with cancer had used the Look Good, Feel Better Service

offered by the local Cancer Society. The Look Good, Feel Better Service offers women diagnosed with cancer free makeover workshops with the aim to improve their quality of life, body image and self-esteem by enhancing their appearance during and after treatment. Research has shown that, for women with poor body image and low self-esteem, these workshops improved self-image, social interaction and reduced anxiety, but did not strengthen social support (Taggart et al., 2009).

In addition to providing them with free makeup and lessons to improve their looks, Lorraine, Sarah and Rose found benefit in being able to share the experience with people at various stages of their cancer journey. Lorraine found benefit in her perception that she was less affected by her cancer than others, while Sarah and Rose were comforted by feeling that others were going through the same journey.

Yeah that was good. The Look Good, Feel Better thing was great um and I actually volunteer at that now um I found that that was really, really good and it just made you feel better about yourself and made you aware that there were other people out there that, while you'd had cancer and you shouldn't dismiss it, there are people out there you know that have got the lot of a more rockier road than what you are on so it made you think "hang on get a grip", sort of thing {Laughs} (Lorraine – POS)

I went to a couple of things at the Cancer Association, the Look Good Feel Better which was almost kind of, as I sat there I thought, apart from the good thing that there was a range of people who were affected by cancer, for memy looks and my makeup and stuff had never really bothered me, although practical advice of how to draw an eyebrow and stuff was really good, so um. And there was like massage therapy there so that was, that was quite good to have those kind of services. (Sarah – POS)

Although Rose had not used POS and would not have done even if offered it she still reached out to support provided by another agency beyond her own social network and her husband.

Well I, I was amazed at what you came home with, actually. The generosity of the firms that donate the makeup and um, the people who come around to help on that day. No, you came away feeling better, you saw other people who were in various stages of treatment. And thought oh, well, we're all in much the same boat. (Rose - NI)

In summary, all groups found that they benefited from both the emotional and practical support they received or provided. They described friends and family as sharing their journey in feeling that they could talk with them about their cancer experiences. Participants also felt supported practically with friends and family attending hospital appointments, cooking meals and taking them out. Support from partners was particularly valued especially by those with breast cancer who held concerns that losing their breast would negatively affect their relationship. All groups reported having emotional and practical support from family/whānau, friends and Services outside POS. However, as discussed in Chapter 6, despite feeling happy with the support of their social network the research by Ferrell et al., (2003) did show that there can still exist a feeling of disconnection from others who do not have cancer.

7.4 Participant Group Differences

No differences emerged between groups regarding how participants coped with their or their family member's cancer diagnosis. Participants from all cancer groups felt that they needed further information about their illness and made active efforts to research their cancer and also made lifestyle changes. All cancer participant groups expressed feeling supported by family, friends and other support services. It would

seem, however, that the former POS clients' social support may not have been sufficient to meet their emotional needs at the time they sought help from POS. Research by Finfgeld-Connett, (2005) revealed that the important aspects of effective support are that the cancer patient feels the person providing the support is trustworthy, reliable and available. All NI participants apart from Grace commented that they would not have used POS if offered it. Grace stated that she would have liked to have used the Service and also reflected in her interview that she did not greatly discuss her husband's cancer diagnosis with others. All other NI participants expressed feeling they had adequate support from family and friends. Rose commented on past experiences helping them cope with her diagnosis and conveyed connecting more as a family at times of stress.

Well. I sort of haven't taken part in everything. We have moved around, and we've learnt with the moves that we've turned into ourselves, as a family. When you move, you uproot yourselves, I mean, the first time, well I was quite upset when we moved. Um. But we've found that as a family, I think we sort of turn to each other. Ahm, and I think that's probably what we've done when [Bill].was diagnosed with prostate cancer as well. (Rose - NI)

Jim described developing his own support group by reaching out and connecting to other men and women who had cancer.

I think um, friends critical part. Friends, the hospital staff and this sort of funny network that developed, of people with cancer. (Jim - NI)

Interviewer: Like your own, own support group?

Yes. Yeah, we, we sort of I don't think we intentionally set out to form it, but it happened. And then others came on board, like [name]... um. She said I wish that I had people close by me that I could talk with and um, so I said well just don't hesitate to pick up the phone, and, and that's what happened. (Jim - NI)

7.5 Summary

This chapter examined themes which emerged relating to the ways in which participants dealt with their cancer diagnosis that reduced their distress. The three sub-themes which arose were *Taking Control*, *Being Positive*, and *Support*. Some participants felt that they were not provided enough information regarding their cancer and so took control by actively seeking out information either from others or by written media and the internet. The sub-theme of *Healthy behaviours* emerged as a means of control for some participants who gained control over their cancer, by exercising or changing their diets. Having a positive attitude toward their diagnosis helped some participants cope with their distress and they reported being determined to cope and expecting to survive. In addition this positive attitude allowed participants to see positives aspects of their cancer journey in developing closer relationships, with improved communication with loved ones and friends and in helping others. All groups found that they received both emotional and practical support from different sources including family/whānau, friends, other support services and medical staff although some NI participants actively sought the support they needed. Their social networks, including family, acted as a buffer to the distress that the participants were experiencing which is consistent with previous research findings (e.g. DiMatteo, 2004; Dunn et al., 2003; Finfgeld-Connett, 2005; Lewis et al., 2001).

CHAPTER 8

EXPERIENCE OF POS

This chapter explores the participants' experiences of using the POS and the support experiences of those participants who had not used POS. This chapter reports on four sub-themes, *Pre-Service Use Expectations*, *Feeling Safe*, *Feeling Connected*, and *Reconnecting*. All former POS clients interviewed for this study expressed feeling that the Service was beneficial to them and improved their ability to cope with their cancer journey. In line with Croy (2010), former POS participants in the current study were unable to recall specific types of psychological therapy that they received. This may be related to the fact that the participants were interviewed up to 18 months post-therapy or may be that they were unaware of what specific techniques were being used with them due to their lack of knowledge and understanding of the process of psychotherapy.

8.1 Pre-Service Use Expectations

Clients' expectations regarding therapy have been established in the literature as an important aspect affecting therapeutic outcome (Gibbons et al., 2003; Constantino et al., 2005). The majority of participants in the current study entered therapy with positive attitudes towards clinical psychologists and the therapeutic process and most had no specific goals for therapy. Two sub-themes were identified in this theme, *Perceptions of Psychologists* and *Someone to talk to*.

8.1.1 Perceptions of psychologists.

Psycho-Oncology participants were asked about their feelings and thoughts about psychologists before using the Service and non-intervention (NI) participants' perceptions were also explored. Two POS participants expressed having no expectations

about psychologists before using the Service and four family members had extremely negative views of the profession. All others interviewed including NI group participants commented positively about psychologists and therefore this did not appear to be a reason they would not have used POS. In addition, research by Croy (2010, p. 105) also found that former POS clients considered the psychologists to be “competent and skilled professionals”, but this was identified as clients’ post-therapy views rather than prior expectations. All POS participants commented that the psychologists of POS were professional and they felt that they had specialist knowledge.

Those who commented negatively held their views for differing reasons. Jill’s negative view originated not from her own experiences but from her perception of how little she felt therapy had helped friends.

Yeah, I’d heard from other people that had gone to counselling and a couple of people that I’ve sort of, not known closely, but sort of known, and it was like, I didn’t have a very good perception of counselling, or even the people that had been counselled. That had been going for years and years and years, and it’s like “I don’t see any change in you”, and you know, like “what is this all about” so I didn’t have a very good image of people going to counselling to be honest with you. (Jill - POS)

However, for Peter his negativity was related to the stigma that he felt was attached to people who used psychology services. Although, clearly his experience of POS changed that view for him.

Beforehand, I, I, you know you had this feeling about it you went and saw one of these people you were a seriously sick mentally person and it was a bit of a stigma or embarrassment to go to see them but I don’t think that anymore. I definitely wouldn’t hesitate to go and see somebody anymore. (Peter – POS family)

Susan's opinion was also negative and she talked about preconceived ideas regarding the therapy process which she acquired from seeing American movies. She expressed her concerns that she would be part of a group or be analysed and judged with the strong feeling that she would be forced to talk against her will.

Probably not overly favourable. Um, yeah, everything you know like in movies and I know the American thing, you know, like group therapy and oh, you know, I really wouldn't like that, and I really wouldn't like if they forced you to do, you know or open up what you wouldn't want to and that was what I kind of thought might happen. Like that, if I thought about them, if I thought about it at all, you know, that was quite definitely how I felt. (Susan – POS family)

Paul felt that not needing to see a psychologist was aligned to his attitude about his own needs. He described himself as being arrogant in his thoughts that psychologist were not needed in his life.

Um probably a little, a touch of arrogance that yeah psychology, who would need a psychologist? Yeah, I, because I don't feel that er you should, you know. I, being a positive sort of guy I suppose, I don't um, I don't get down and, so I, yeah because "I can't see the benefit of them and I don't have problems worrying me" too, so as I said arrogant, I sort of think that, what place they got – none. (Paul – POS family)

From the interviews it was apparent that people had negative views of psychologists and therapy for a variety of reasons which included social stigma and personal perceptions of need. However, it would appear their need for help may have outweighed their negative views of therapy. This relates to research by Vogel et al. (2003) in which help-seeking behaviour is described as an interaction between expected outcome and risk of talking about the distressing event. Once they experienced the Service, those with negative views expressed finding it helpful.

8.1.2 Someone to talk to.

Participants were also asked about what they thought they needed help with when they first used POS. The majority of those interviewed had no expectations or specific goals for therapy and commented that they just wanted to talk with someone. This is consistent with previous research findings (e.g. MacCormack, et al., 2001; Boulton et al., 2001; Salander, 2010) in which the most beneficial element of therapy expressed by clients was to just talk and feel heard.

Peter was aware that he needed to talk with someone about his distress and expressed some annoyance with feeling that his needs were ignored by medical staff and that Peter and Sarah both had to ask for him to be referred.

I think I just needed somebody to talk to and yeah and I'd changed jobs as well, there was a lot of issues going on and things got a lot harder because of that,, it was definitely needed yeah. (Peter – POS family)

Sarah interestingly commented that that she initially attended POS because of Peter's distress rather than her own worries.

I think initially I was thinking it was more for Peter than me but um initially I think they wanted to clarify a few thoughts in my head and ah yeah really I just needed an opportunity to talk to someone about a few worries and concerns and things like that.....I thought well it's a free service so it doesn't hurt to go and just see what's going to happen and whether or not it helps me or not and it did help. (Sarah – POS)

Peter also explained that because he and Sarah were unable to talk to each other in private, that having time with the POS clinician together encouraged them to communicate with each other and allowed them to develop their own strategies to improve their relationship.

.... I think I think mainly it was the fact that we [Peter and Sarah] couldn't talk about it and we needed a third person there to talk about the issues, we would never talked about it privately and the ideas we came up with were things, you know they were just common-sense little things so yeah. (Peter – POS family)

Meg felt that just talking with a POS clinician helped her and sort through her thoughts and feelings about her son's cancer.

.....Well she [psychologist] just let me talk actually and in between times I did a fair bit of thinking...(Meg – POS family)

Gary had mentioned that he had tried to solve his problems by reading but found that this was not as useful as he hoped and he needed to talk though his issues.

Some of the problems we were having I read, but ah you can only read so much, you do need help, you need to discuss with someone. (Gary – POS family)

Therapeutic techniques were not remembered but the importance of having someone to talk to and the therapeutic relationship appeared to be a key factor in therapy outcome. This mirrors research by MacCormack et al., (2001) in which it is stated “indeed, it was as if their therapists’ ‘being’ and not their ‘doing’ was the most helpful element” (p. 58).

8.2 Feeling Safe

All POS participants commented positively about their experience with POS. A theme of the Service *Feeling safe* emerged from the interviews. The concept of safety was expressed in emerging of sub-themes perceiving the psychologist as a professional in their field, as not someone they knew and as creating a safe, nurturing environment.

8.2.1 Professional.

Most POS participants commented on their perception that the Service offered the opportunity to talk with psychologists who were trained professionals with specific experience in helping people with cancer. The fact that the Service clinicians were viewed positively is important as it this may increase their expectation of a good outcome. This follows research showing that optimism concerning the therapeutic process or view of the psychologist as expert in their field is more likely to create interpersonal engagement with the psychologist (Gibbons et al., 2003). For many the sense that the POS was a specialist service provided them with a sense of security and confidence prior to using the Service.

Meg had prior experience of the positive impact that POS had for the people she nursed with cancer. She felt safe to talk about her own cancer experience because she felt that the POS team would have specialist knowledge.

*I think if you're a member of the psycho-oncology team you must have a bit of knowledge there and um, I think I found it easier to maybe describe how I felt to someone who I knew had some knowledge than it would have been to talk to someone who perhaps had no knowledge, no medical knowledge I mean or no psych knowledge, like a priest or um I can't think who else would talk to. **Meg***

Peter would clearly not have seen a psychologist whom he did not believe had specialist cancer knowledge.

*...imagine if they had given us two or three private consultants and we had to choose one of them, that'd be terrible, you know I wouldn't want to do it. The fact that the people here are getting a continual stream of cancer patients, I imagine they are dealing with similar issues or whatever and over-time they'll get better and better at assisting..... **(Peter – POS family)***

Claire also commented that knowing the psychologists were trained specifically for the work they do was important.

Then it truly, someone who's trained to listen, and to and to get to the heart of the matter can really make a big difference. (Claire - POS)

Training was also an area that Jill commented on. Jill expressed feeling that because of the training her psychologist was professional and could be trusted.

.... I knew that she was also, I knew she's a professional. Yeah, because I knew that she'd had the training. Yeah. I had confidence in her and the little bit of confidence that I had in myself which wasn't very much, and also there was that trust, I actually did trust her, Yeah, I just knew that I could trust [the psychologist], Yeah, she's very professional, very friendly, and just the way that she counselled me was really, it was quite unique really. (Jill - POS)

In summary, the POS psychologists were viewed as professional in light of their specialist training and long-term experience with this client group. This instilled a sense of trust and confidence in the POS participants' for the Service clinicians giving them a feeling that they the Service was a safe place for them to be. These findings are consistent with the literature showing that positive feelings about the clinician prior to therapy can help to develop a strong therapeutic relationship which is linked to improved client outcomes (Claiborn & Schmidt, 1977; Greenberg, 1969; Greenberg et al., 2006).

8.2.2 Not someone I know.

A clear sub-theme related to feeling safe was being able to talk with someone the participant did not know. Nearly all POS participants reported that being able to talk with someone who was not a family member, friend or work colleague was critical to their experience with POS. The comments made highlight a sense of feeling safe that

they could share their thoughts and feelings and leave them behind with the clinician, aware that it was confidential and their problems would stay private.

Meg had spoken about the strain of being the person whom her family turned to for information about her son's cancer because of her professional knowledge and of having to be strong emotionally for her son. She comments here that it was important for her that she was able to speak with someone who was not related or connected with her or her family.

Someone outside family and outside work, not a friend, not a colleague, somebody that I wasn't related to in any way whatsoever....had no emotional ties, any sort of relational ties to me or [son] yeah it was somebody neutral, somebody completely independent. (Meg – POS family)

Jane expresses the same idea but comments that she felt able to talk to the psychologist about topics she felt unable to discuss with people she knew.

I thought it was good going to someone that you didn't know. Completely didn't know you, or you didn't work with or wasn't family or friends.... It was just going to talk to someone that didn't know you and that you could just tell them how you felt. It's like there's some things that you probably couldn't say to other people and you could just get them off your chest you know. (Jane – POS family)

Lorraine also stressed the importance of being able to be open, particularly emotionally, with the psychologist. She expressed the idea of being able to walk away giving the impression that she was leaving her problems behind when she left which is an additional benefit of talking with someone not in your social network.

I had like, going to the clinic is not the first time I've been to see a psychologist. Um, so generally on one hand I know that they are actually great and they really helpful ..., you've got someone different to talk to um there's no relationship there

as such like in family and friends, you can go, you can cry your eyes out, you can tell them what ever and you can walk away and you know that it's all just safe and secure and um so yeah I had no problems in that sense. (Lorraine – POS)

For Karen the ability to talk with someone she did not know was related to her perception that she believed she was burdening her friends and that they were tired of listening to her talk about her cancer journey. In essence in speaking with a POS clinician she was safe from the anxiety that she may get negative response from friends or family she talked to about her cancer journey.

I didn't know, because I'd never sort of talked to a psychologist or anything before I think just having someone there to talk to. Yeah, you didn't sort of feel like you were burdening them, just talk to your friends and family too much, talk about the same thing too much, they'd probably get sick of you, hearing about you. So it's nice to have someone to talk to that wasn't going to get sick of hearing about it. (Karen – POS)

As illustrated, the Service was viewed by participants as a safe place in which they felt the freedom to talk about aspects of their cancer journey they had felt unable to discuss with family or friends. Participants reported that being able to talk with someone not related to them and whom they did not know was important and this parallels findings by Croy (2010), Boulton et al., (2001) and MacCormack et al., (2001).

8.2.3 Safe, nurturing environment.

The environment at Massey POS was considered to be safe and nurturing by POS participants and some found value in not being at the hospital. This is a significant finding as it contradicts with previous psycho-oncology service international recommendations which state that psycho-oncology services should be seen as an integral part of the oncology team and situated within the hospital with the aim at reducing the stigma associated with seeing a psychologist (Holland, 2003). However,

this current study's findings are aligned with the opinion of the Department of Health, Western Australia (2008), that the setting of psycho-oncology services should be family and culturally friendly. They also assert that “the physical environment should recognise the right of individuals to privacy and confidentiality when discussing personal issues” (p. 13). The Massey POS is considered to be an integral part of the MidCentral District Health Oncology team while being outside of the hospital itself. An aspect of feeling safe that was expressed by many POS participants was the feeling of nurturing that they felt in coming to the Massey Clinic. It was clear by their following comments that for some their initial feeling of well-being actually originated from their encounter with administration staff before their meeting with the psychologist.

Clients were made to feel welcome and “cared for” and both Lorraine and Sarah express their appreciation of being made welcome at reception.

No, no the service was fantastic. I loved going to get my cup of tea when I went into the waiting room {Laughter}, “would you like a cup of tea, yes please, thank you very much” no, no problems at all... .. it was nice but like the atmosphere was nice um receptionists were, were great you know and yeah, my cup of tea when I got in was very welcome. (Lorraine – POS)

The receptionist is always friendly and “can I get you a cup of tea” and I think that's really important its welcoming but at the same time not too intrusive. (Sarah – POS)

Jill commented directly that she felt her mental health was improved by seeing the psychologist outside the hospital. Compared to the Massey Clinic Jill did not feel that the hospital was a comfortable or safe place for her to be.

Even though the hospital is there for your good, yeah, there is something about being in a hospital environment that is, that you, you didn't, you know, you don't

really want to be there {laughs} So being out of that environment is probably a little bit more helpful, for your mental health. (Jill - POS).

Susan talked about being in the POS environment as if she felt protected and safe from the world outside.

Yeah, they're quite good supportive, kind of a safe environment, you know?even though it's on campus, it's kind of like when I come here, everything is outside, when I'm here everything's kind of safe when I'm here. (Susan – POS family)

For Peter the knowledge that what he said to the psychologist was confidential provided a feeling of safety to him, to the extent that he considered talking with the psychologist was as comfortable as talking to his parents.

It probably is actually yeah when I think about it it is, because although you say you don't want to talk about it you do want to talk about it and this is why this has been so good because you can talk about it. There are certain things that I couldn't even talk about but I did, I was able to talk about it with [the psychologist] knowing that it was confidential. There are some things ah, I shared just about everything with my parents, my own parents but only because I am very close to them but I can imagine some other people wouldn't even tell their own parents, so you know. (Peter – POS family)

Most participants felt that having appointments away from the hospital was not a problem although some did find it difficult to find the Massey Psychology Clinic at their first appointment. Gary actually found additional benefit of being at the Massey location as he and his wife took the opportunity to spend time together on nearby walks in an environment which enabled them to spend time together and nurture their relationship.

The good part was afterwards we would drive back through the esplanade just see the blossoms and that um occasionally we would go for a walk there [at Massey] so that was good. (Gary – POS family)

The sub-theme of *Feeling Safe* highlighted participants' views that POS offered a Service that was staffed by clinicians who were professional and trained at what they do. They had a perception from prior knowledge about the Service provided by the medical staff who referred them and from information leaflets, that the psychologists had expertise and were professional in the area of helping people affected by cancer. This relates to research by Gibbons, 1969 and Claiborn and Schmidt (1977) linking pre-session information to positive views of the therapist. Cancer participants also felt that talking to someone they did not know was beneficial similar to findings by Croy (2010), Boulton et al., (2001) and MacCormack et al., (2001). The Service was also perceived by former POS clients as a safe and nurturing place to be.

8.3 Feeling Connected

The therapeutic relationship between client and clinician was represented in the theme of *Feeling connected*. Participants described their relationship with the POS psychologists in mostly positive terms. Their reflections of their therapeutic relationship included relating well, not feeling judged and being able to talk openly. They described personal qualities of the psychologists in terms of being gentle, helpful, empathetic, easy to talk to and someone they could relate to. These are qualities that may contribute to developing a good relationship with the client and for the client a sense of feeling connected to the clinician. The participants in the study by Croy (2010) also reported similar descriptions of the Massey POS psychologists. This finding is expected given that the psychologists seen in this study and Croy's research were the same. However, research literature specific to cancer therapists is lacking. It is unclear what therapeutic traits can be developed through specialist training to meet cancer clients' needs or if therapists with certain traits are drawn to work in this field.

The impression that the POS participants felt a connection with the psychologist was apparent throughout the interviews. Lorraine commented on feeling it was essential that she could relate well to the psychologist she saw and connected this to the Service being helpful.

I think that you need to work with someone that you can relate to quite well[psychologist] was just absolutely fantastic and really, really lovely and yeah so, so I found it very helpful. (Lorraine – POS)

Paul found that the psychologist he saw developed a connection with him describing them as “linked”.

They, they were easy to talk to, yeah and very er, attentive, they were um, yeah they seem to get in on the um, on your wavelength very easily yeah, yeah they, they linked up quite well yeah (Paul – POS family)

Gary had reported that he did not feel a connection with the first psychologist he saw but found that it was straightforward for him to change. This shows the value of a team service to the client where other psychologists are available if the relationship may not be working.

I've always felt that it's very like a family doctor. Some you can relate to and some you can't, it's how you deal with the individual that makes the difference. I think at Massey because there is several there you can find the psychologist that is tailored to you. I feel that's a bonus. (Gary – POS family)

Meg described feeling that she was an equal in the relationship she had with her psychologist and felt listened to and not judged. She already knew her psychologist from seeing her work with others with cancer and therefore, in contrast to other participants, for Meg having a prior connection already was important. This may possibly be a reflection of Meg's awareness of good outcomes for patients she knew who had seen the POS clinician rather than that she knew the clinician. In connection

with previous research (e.g. Claiborn and Schmidt, 1977; Greenberg et al., 2006), Meg viewed the psychologist as an expert in their field due to pre-session information.

I felt that [the psychologist] was someone I was able to talk to, on an equal basis. I didn't feel that ah I didn't feel that she was a doctor and I was a patient. I just felt that [the psychologist] was someone who was there to listen to what I had to say and be non-judgemental and maybe give me a few things to think about that I hadn't thought about from what I told [the psychologist]. Yer it was just a wee bit easier than with a complete stranger. You didn't feel that you had to go right back to basics with her I mean I don't think she knows me from any of the other nurses that work there but there was just a footing there that wouldn't have been there if I'd been, if she'd been a complete stranger mm. (Meg – POS family)

Susan remarked that she initially did not want to use POS and like Meg seeing a stranger seemed difficult to her. She described feeling forced to go and her reluctance appeared to arise from the fact that she found it difficult to talk to anybody about her problems. However, it is clear that she felt able to talk with her psychologist and she attributed this to their personality and behaviour towards her.

I, I don't know, because I think I had always been quite reluctant to use the service, that's why I was pushed to. Yeah, yeah, I had that big push to come and I, I don't know, I think it's because I haven't really, I don't really talk to people about things very much. Like normally I don't think I'd feel comfortable talking through them with somebody I didn't know? It was, really good like I, I liked coming in to see her and I, I did like her and her manner and everything and personality. And it was like and just coming in and talking to her. No, she was really good, and really supportive and quite interested in what I was doing and how I was going and very concerned that you know, and not just you know this is my job and I have to "what have you been doing and tell me about this", and she was quite actually interested in connecting with me. I'm quite surprised that I didn't think, you know, that a stranger, that I'd you know, feel that comfortable, but I did, I, I really enjoyed coming in and I think that was a lot her manner with me. (Susan – POS family)

Within the sub-theme of *Feeling connected* participants spoke of their therapeutic relationship with the POS clinician. They talked about feeling connected or “linked” and it is interesting to note the value that clients placed in their relationship with the POS psychologists.

8.4 Reconnecting

The importance of family members attending at least one session with the cancer clients was advocated by MacCormack et al. (2001) and Schmitt, et al. (2008), the benefit being that the needs of all members of the family are recognised. In fact Martire and colleagues (Martire et al., 2004) found that family interventions are not associated with any negative psychological outcomes for either the cancer patient or family members.

For the couples who attended POS it was clear that although most had separate sessions they also valued seeing the psychologist together. They felt that being seen as a couple helped them to reconnect and improve their relationship.

Sarah valued being seen together, although it was clear that for her and Peter to be able to initially work on their personal issues alone later enabled them to connect in joint therapy sessions to work on aspects of their relationship.

Yeah, and it just happened that it was, that it became the right time because Peter and I were able to clarify things separately and then come together rather than try from the beginning to clarify things together first. I think if we'd gone initially together, I still would have, I probably would have clammed up a lot more because I still wouldn't have wanted Peter to hear some of my deeper concerns. ... like and my concern was mainly him so I probably would have said 'oh, yeah but what about Peter, you know. Peter I'm worried about this and I'm worried about this about Peter and dah, dah, dah, dah, dah' so yeah. It was good to have that opportunity to be flexible and I think it was so good to have where it wasn't just focused around the patient. (Sarah – POS)

With the relationship stuff we broke it down into why is it happening a number of reasons and then came up with the specific kind of, developed specific little plans to deal with things and a key outcome there is there has been a decrease in the number of arguments, I mean if they do happen we don't hold on to them, we just deal with them a lot quicker, yeah it is much, much better now um and an ability to talk a bit more openly about things when we need to. Yeah it's been good. (Peter – POS family)

Paul and Ellen found that their relationship improved, for Paul it helped them reconnect sexually but for Ellen it was feeling that she now understood Paul's behaviour and she perceived that he had become more affectionate.

Well I suppose they um, they sort of um, um got us through the, this, the sexual relationship part, yeah, I think that was the, the most helpful yep. (Paul – POS family)

I found those joint sessions with, because we had one or two I'm not sure, with [the psychologists], they were really good and one of them, well it all was good, I think that one of the lights that clicked on for me...and how we talked, I have got a much better appreciation of how it might be, be to feel how [husband] feels and to be, to be a male and the kind of male things that, you know. But I, I can understand him a bit more now and um we're and you [husband] are, are more affectionate now I think, in a way. (Ellen)

Susan expressed being helped to communicate her feelings and connect to her mother by asking for her mother to attend one of her sessions with her.

And I wanted her to come along to that one so that I could, you know, talk to her because I didn't feel up to able to talk to her just at home, or well, with my whole family around...and everything, so, um. It was really good being able to have her bring her in and talk to her in that way with [the psychologist]... there to help us go through that kind of thing. (Susan – POS family)

Susan also felt that benefit of feeling comfortable opening up to the psychologist spread to her friendships. She chose to talk with her friends without the thought that they were judging her. This may be connected to the theory that a good therapeutic relationship can be a model for other relationships (Crits-Christoph, 2001).

...kind of feel, I kind of feel with my friends that I like I could tell them things more, I didn't feel like they were like going to judge me about them. Thinking about me, you know, I didn't have all of those thoughts, I could open up and say, and with one of my friends I just, I had to come to the point where I was having lunch her, and said I have to go now. And I said oh, you're going, and normally I like, I wouldn't want anybody to know that I was crying, and I just said to her I'm going to psycho oncology today to deal with. (Susan – POS family)

The previous comments clearly demonstrated the benefit that some participants found in having family members attending therapy with them for some sessions. The benefits were for themselves, the relationship with their partner or loved one and for their interactions with friends.

Family participant Jane and her husband did not attend any joint therapy sessions. From Jane's interview it was apparent that both she and her husband had found POS helpful in working on their personal cancer related problems. However Jane still felt disconnected from her husband and this was referred to in Chapter 6 in which the ACT "Driver of the Bus" metaphor was misinterpreted. For this couple it is clear that the way Jane's husband communicated what he learned in session would have been better shared with the psychologist there to explain. In the following comment Jane reflects that she did not know what her husband's thoughts were and did not feel able to talk with him.

...but he's never been a very good communicator and the kids have said that. Cos his whole family are like that and yeah, you don't know what goes on in his mind... You know?... and you don't... So I just leave it at that you know, I don't pressure him into...you know... talking about things. (Jane – POS family)

There is of course a benefit for clients to have individual sessions where they may be able to talk about issues relating to other family members or work on specific personal issues (Salander, 2010). However, the current study revealed that where family members attended at least one therapy session with their partner or family member the relationship benefited, supporting recommendations by Schmitt, et al. (2008) that there should be at least one therapy session which includes family members. Participants expressed feeling able to understand and be able to talk more openly with their loved one, which contrasted with one participant who, having not attended with her husband, felt more isolated from him.

8.5 Effects of the Research Interview

During the interviews it became apparent that for both POS and NI participants an unexpected theme emerged in which they reflected that the interview itself had provided a therapeutic benefit. Similar results have been observed in qualitative research and the findings in this current study are consistent with the research by Colborne and Sque (2005) in which the interview allowed the processing of the participants beliefs and knowledge. For two of the NI participants, the interview prompted their own reflections on their cancer journey, particularly in relation to communication with their partners.

When Jim was asked whether his wife was aware of his concern for her wellbeing he reflected the need to talk further with her.

Yeah, and she's, she's aware that I'm concerned of what has happened to her. Um, to the depth. Ah, I dunno, we're both sort of we're still busy people, and I just wonder perhaps that sort of is a side. Be interesting after this, I might go back and talk to her a bit more. (Jim – NI)

In response to asking what she felt were her husband's thoughts and feelings about his cancer, Jane also felt encouraged to talk further with him.

..actually I probably should go home and ask him, whether he's you know, still feels, you know whether he still has feelings about what happened with the operation and everything (Jane – POS family)

Both NI and POS participants felt that there was value in the research interview in helping them further process their thoughts about their cancer journey. Jim and Claire expressed that the research interview process had helped them to clarify their thoughts.

It's just been a pleasure to actually to do it, because, yeah, it helps put building blocks into my brain in the right way round too so, and to go back over it. There's probably things that I haven't thought about for ages. (Jim - NI)

Oh, it's my pleasure, truly. And thank you too, because it's, I think it's good for me to sort of get it out clearly, yes. (Claire - POS)

Again this theme revealed the value that just talking had for some of those interviewed. For those NI participants who conveyed a benefit from the research interview this may have helped them to appreciate positive elements of using professional support services.

8.6 Participant Group Differences

No difference was noted in the perceptions of the POS participants with regard to their experience with the Service. As discussed, although they had positive attitudes towards psychologists, all NI group except for Grace stated that they would not have used POS if they had been given the option. Three of the four NI group participants

expressed finding adequate support through their cancer journey from family and friends.

8.7 Summary

This chapter explored the themes which emerged from participants' thoughts and feelings about using POS. Four sub-themes emerged of *Pre-Service Expectations*, *Feeling Safe*, *Feeling Connected* and *Reconnecting*. The majority of former POS clients started therapy with positive attitudes towards psychologists. However, four had quite negative prior perceptions, although their attitudes changed after using the Service. Most participants who used POS had no specific goal for therapy and expressed just wanting to have someone to talk to. It emerged that some family members attended as a way to encourage their loved one to use the Service but also found benefit themselves. It was clear that all POS participants felt a sense of safety in using the POS. They felt the psychologists were professional and felt safe talking to someone they did not know. They also found the Massey Clinic environment a safe and nurturing place to be and found value in not being seen at the hospital. The sub-theme of *Feeling Connected* highlighted the positive and strong bond that the former POS clients expressed they had with the psychologists they saw. The benefit that family members found in attending together was explored in the sub-theme *Reconnecting*. Finally the emergence of some participants finding benefit from the research interview was commented on.

CHAPTER 9

BEING A PSYCHO-ONCOLOGIST

This chapter explores the themes that arose from interviews with four clinical psychologists working in the Psycho-Oncology Service at Massey University. For the purpose of maintaining anonymity they are identified as P1, P2, P3 and P4. As previously discussed, the author was unable to locate any previous studies in which clinical psychologists working in adult oncology were interviewed about their thoughts, feelings and perceptions of their work. Therefore, the interviews with this small sample of psycho-oncologists appear to be unique in the field of psycho-oncology research. Some literature of relevance was discussed in Chapter 4 and where relevant, sub-themes identified in this current study are compared to those. Two main sub-themes emerged from the interviews *Connections* and *Challenges*.

9.1 Connections

The sub-theme of *Connections* encompassed much of what was spoken about in the interviews with the four POS clinicians. Three sub-themes related to connections evolved relating to the work, the clients and each other.

9.1.1 Connecting with the work.

One of the qualities identified by Hendrick (2012) for working in the oncology field was the desire to do so and this was identified in this study under the theme “*connecting with the work*”. All clinicians interviewed had worked in other areas of psychology before coming to work in POS and they all spoke about their work with POS as being very different. Each of the psychologists interviewed talked about the satisfaction they found in working with people affected by cancer. This was similar to the finding by Weiner et al. (2012) in which the paediatric psycho-oncologists felt their work was meaningful.

At the time of the interview P1 had been with POS for three years and expressed a strong commitment to the work and its value.

...and now I don't think I'd want to do anything else....I believe very strongly in what we are doing here, and I still feel that it's really important...(P1)

For P3 the work at POS provided a personally rewarding and meaningful environment to work in and provided the opportunity to see beyond the mental health issues to the strengths that people had when coping with cancer.

I love POS so muchI find it one of the most uplifting areas to work in because you see such strength and beauty and kindness in people. I feel like the work's been maybe far more meaningful, maybe far more rewarding, that's maybe my personal, you know as much as people say "oh it must be a hard area to work in", you know not for me, you know it's sad and it wakes you up and stuff but maybe that's what makes it more meaningful at all levels it's because there are some really sad outcomes and you're human.... (P3)

P2 perceived that they had a greater ability to effect change because clients had made the choice to come to POS and so were motivated to do the work necessary.

Um, so my experience is that, the POS clients are much keener, as in like, they're there because they want to be there, um the majority of the time, you get the odd one who's been arm twisted to, to come, um but generally they want to be there. Generally the, it's about um, often it's about what's happening now for them that they come in as a person of strength who's going, just through a difficult time and so all you've really got to do is focus on now, um so what you find is, you find that you can actually make quite a lot of change. (P2)

9.1.2 Connecting with the client.

In commenting on therapeutic techniques for people with cancer, Hendrick (2012) asserted that it was important in the oncology field that the client-therapist

relationship be considered the primary therapeutic intervention. In Rahman's (2000) qualitative study with hospice occupational therapists the theme of a deep connection with the client was identified. Similarly, all POS psychologists interviewed for the current study described feeling a deeper therapeutic connection with the clients they saw.

It was considered that because the clients they saw were suddenly faced with an illness that could potentially be life threatening or mean the loss of a loved one, that the POS clients were more open. The POS clinicians perceived that they were then able to get to the important issues in therapy faster. The comment from P1 conveys this as a very strong connection with the client's life and their cancer journey.

It's a different feeling of working. Ah. But it does mean that I don't know whether you get more involved, but you, it almost feels like you're part of their life more than any other job I've ever done. Um, not in the sense that you become part of the family, or anything like that, but you just, you witness more....you are there, the most traumatic part of someone's life...and you walk the journey with them..... and that's where you become, not more involved in their life, but it's a closer, different therapeutic relationship because you have to share that stuff with someone. Because they're facing death sometimes. (P1)

For P3 working with POS clients brought issues of spirituality to the forefront of therapy, which was clearly an extremely important part of the work for this clinician. The value of acknowledging the existential aspects of their work with clients helped to develop what was considered a stronger therapeutic connection. This sense of spiritual connection is reflective of the findings from Callahan's (Callahan, 2012) research with hospice workers in which spiritual sensitivity was identified as creating deeper relationships with dying patients.

.....and I think it's different because you have to deal with spiritual issues...somehow we get onto an area of spirituality, what meaning, what does their life stand for, it just seems that it comes up without having to dig for it when working with POS clients..... it's just naturally a part of the territory when you work in this area whereas um I think in other areas that I've worked atit's not even in the forefront..... It's definitely being more connected and being able to get down to the real stuff...I guess in other places you're still spending a lot of time digging, where in this area you haven't got too much time to dig, you've got to get to what's important because you might not be here tomorrow. (P3)

P4 also expressed the concept of connecting with the client and felt that this enabled them to explore deeper issues and to get to problems more quickly than with non POS clients. In addition, it was perceived that working as a member of a team allowed clients to be matched to the psychologist in terms of gender or ethnicity, where possible. This concept was supported by former POS client Gary as discussed in Chapter 8.

Being more connected and able to get to the deeper stuff.....get to what's important quicker. We have a lovely mix in our team of genders and ethnicities and um styles, so that allows us to match [clients] where we can. (P4)

9.1.3 Connecting with the team.

Being a member of a team of psychologists working with cancer clients was seen as extremely important. Each clinician felt that the team added to their ability to create better client outcomes. They experienced peer support that was additional to usual professional Supervision, where the team members could debrief about difficult experiences or discuss client cases. The value of team support in oncology settings has been identified in previous research in which mutual support may protect against the challenges of working in an oncology setting (Penson et al., 2000; Rohan & Bausch,

2009). This theme of connecting with the team was in contrast to that found by Weiner et al. (2012) in which paediatric psycho-oncologists expressed feeling they had little time for collegial interaction and inadequate supervision. This difference may be related to the fact that the Massey POS team comprised of fellow psychologists rather than being a multi-disciplinary team.

Both P3 and P1 expressed the benefit of being able to talk with peers who work in the same field and how that can positively impact the way they worked with clients.

Working on your own yeah and not having anyone to debrief with ...would be very difficult and very hard, especially in this area um, I mean I could do it, I'm sure anyone could but ah yeah, I think it's good to have that peer backup or the peer decision makingjust having a think, the question about how do you close cases off, we often spend time discussing how we might do that, you know like the cases that have being going on and on or how can we dwindle that down, you know I don't think you'd get that if you were by yourself, you'd just keep going and going until your supervisor said "enough".(P3)

..you know, you need to have the team support. You need to go and review cases with them. And we've done that a few times, and I've found that enormously helpful. (P1)

For P2 it was the connection was the feeling of being mutually respectful about the work they did with clients, despite working in different ways.

It's just a fantastic place to work, the team is very respectful of each other and even though we work in quite different ways our training allows us to respect and understand each other..... (P2)

9.2 Challenges

The psychologists were asked about the challenges they experienced in working with people coping with cancer. Therapeutic challenges were process and Service

related and all talked about the challenge of ending therapy within the remit of the Service as a brief intervention service of up to six sessions.

9.2.1 Therapeutic challenges.

When the POS psychologists were asked about particular forms of therapy they used for clients with different cancer types, all reflected that they used an “eclectic approach”, making use of specific aspects of different therapies to suit the client’s identified needs. This was similar to the comments made by psychologists surveyed by Weiner et al. (2012) in which they reflected using a range of therapies. The POS psychologists did not make therapy distinctions between the needs of clients with different cancer types, rather they reflected that they treated clients as individuals with unique therapeutic needs.

P2 talked about the challenges that the referrers unintentionally introduced to the Service where they would be unaware of what was possible to accomplish in specific periods of time.

So a couple of things come to mind one of those is the, the fact that sometimes the expectations of the referrers..., or our perceived expectations is a little difficult. So sometimes, . for example somebody with a phobia like a claustrophobia or a needle phobia will be referred .. like the week before they have their treatment. So with the traditional CBT approaches ... they take sort of like months to work and yet we’re expected to deliver.that was particularly difficult as a new service, ..they (referrer) hadn’t had psychologists involved at all before, so they didn’t know and we were also trying to show that we were useful..... which was um, a challenge both, both to the Service, and to us as psychologists and to us as people it’s always nice to be able to deliver, so that’s been the reason why um, [psychologist] and I have um explored things like hypnosis looking for, for techniques to take, take on those challenges you know, because there are some other techniques which can speed those processes up..... (P2)

At the time when POS was a new Service P2 expressed feeling additional stress to deliver good outcomes for clients referred and subsequently this resulted in POS psychologists looking at alternative evidence supported approaches to usual therapies. This need for additional training was also reflected in Weiner et al.'s (2012) survey of paediatric psycho-oncologists.

One identified challenge was that some clients took the opportunity to use the Service to deal with unresolved personal issues not directly related to cancer. This was similar to findings by Salander (2010) in which it was identified that one of the most common reasons for seeking counselling for cancer patients was the desire to discuss interpersonal relationships not obviously related to the cancer diagnosis.

P2 explored the challenge of recognising that once a client is seen at the Service there are times when previous issues, unrelated to their cancer, come to the surface and are impacted by or impact on their illness. They accepted that the need to continue sessions beyond the six expected is considered a balancing act.

....so ours is a short to medium term service yeah, I describe it as a wee bit like digging a hole in the sand right and when you dig a hole in the sand um, more sand pours into the hole and um you've got to dig a slightly bigger hole to stop, to get a degree of solidity, to stop the sand building in, er pouring in and so that then becomes a difficult judgement. So, our service is there to deal with cancer related distress um. but ... people do come along with on-going issues, so they might come along with a marriage issue which has actually been there for quite a while, it's just flared up now um, or they might come along with some distress now but actually that's based on um ways of being which have been around for quite a long time and um you can't just get in there and do the two, three session fix you know, just listening and, and a chance to talk isn't just what that person needs.... so while our service averages around six to seven sessions you know, each of us have clients which have, sort of gone well beyond that, ...you know that's that balance isn't it, ..we're in this to help people um so we want to stay

around and help people um we, we don't want to finish with somebody and just have them fall over again in a month's time and come back, so, we need to stay in there but at the same time, every six sessions we spend with that longer person, time person, there's another person who might not get to access the service, so it's that constant weigh up, so you're doing it as a service. (P2)

This clinician remarked on the feeling that other issues unrelated to cancer cannot be totally ignored, especially when failing to deal with them may exacerbate on the present illness or prevent them dealing with it. This is important given that research has indicated that when life stressors or negative events, co-occur within a year, there is an increased possibility of exacerbated illness, disability or death Thoits (2010).

P1 also remarked on the challenge of clients who clearly have major historical life issues such as domestic violence and the difficulty of knowing that the issues they bring are not directly related to cancer but that sometimes there can be no other agencies for them to access the help they need. In such a case helping the client becomes the priority rather than applying the Service client criteria.

Basically, though, there are a lot of people who are only just hanging on for whatever reason, and then cancer comes along. And all the other things that were happening beforehand, which were just being managed, or sometimes not being managed very well, becomes much, much bigger, and much, much more difficult to handle. So, um, I guess the way I figure it out, if the current functioning is cancer related or not, is to look for well what were you like before the cancer came along? What was going on in your life? But it's a real grey area, it's not always easy to figure out. um you know, and cancer's sometimes the straw that breaks the camel's back, you know in terms of managing something into not managing at all. I guess the pre-functioning, the pre-cancer issues, make dealing with the cancer very, very difficult. So in order to be able to manage the cancer better it's very hard not to look at those pre-existing issues, because otherwise you're just skimming the surface, and you're kind of doing a superficial patch-up job basically.So sometimes with the really well functioning prior to the illness... you can see the effect that it's had and chosen a

more discrete way. So those are the six therapy session people who are actually are quiteit's ah manageable yeah, yes, it more clear cut, .and then you've got these really, really messy situations, it's just all the on-going things for a very long time. If I had said strictly, domestic violence, emotional abuse, is not cancer related, I really wouldn't have made any difference. (P1)

All clinicians reported using the ORS as a guide to when it was time to end therapy with a client but also felt that it was a mutual decision. P2 reflected that recognising when to end therapy can vary and that they used a variety of outcomes to recognise when no further therapy would benefit the client. This reflects an element of doing POS work in that you do what you have to in the time available to do it.

...sometimes the client just decides it's time to end therapy, so they say, yep that's good, got enough, sometimes um, it's just about um, that they live out of the area and so they, they're going home. Um, I use the outcome rating scale a lot and so, um myself and the client are looking at progress over time and um you know, the, the scores means and stuff and so when they get into an area which suggests they're operating um similarly to um, to the rest of the population then it's, it's a sign but often they, they'll be talking about it you know and you can see the change in the way they're sitting and they're talking about, you know, no longer feeling anxious or their mood improved or become more active or that their problems with the family have resolved and, and so it becomes quite evident um that, that the problem that they came for isn't a problem anymore, people come with an issue and you work on the issue and then the issue isn't an issue any more, yeah it's time to move on, I mean it's not time to look for another issue. (P2)

P1 expressed finding the ORS useful in helping to identify the appropriate time to end therapy however, they noted that because of the nature of cancer, a client can be seen to be doing well but then there may be a reoccurrence or progression of the cancer creating additional distress. A recurrence of cancer where there had been positive

expectations of cure can create distress that is similar or greater than that at first diagnosis (Stein et al., 2008; Vivar, White & McQueen, 2005).

That is something else that I struggle with. Um, and I think that, I try to go on ORS as much as possible. Um, the number of times that I've got to a point that I've thought they're [client] functioning really well, and then there'll be some set-back, and everything just crashes again. ... That's happened to me a number of times, and it's been around people who've been in remission and their cancer's come back, and it's not looking good at all, and they're highly distressed about it. Um, I think that mmm, that's happened a number of times, with me.... (P1)

The POS clinicians identified a number of challenges they experienced identified within therapy and the therapeutic process. These were what issues to focus on when non-cancer problems arose and also when to end therapy given that cancer is a long term condition which can have significant changes in its course.

9.2.2 Personal challenges.

Working with people with cancer offers very different personal challenges in that clients do die and working with people who are terminal can be particularly difficult where the client is known well and a strong therapeutic relationship has been developed. The POS psychologists talked about coping quite well with this aspect of their work.

P1 expressed feeling that they coped well with seeing clients who were terminally ill. Their coping mechanism was reflected as both strength and a weakness. This clinician identified that being able to step back emotionally from clients' distress helped them to personally cope with oncology work. However, they also acknowledged that this may impact the therapeutic relationship if it was perceived by the client as being uncaring.

I think I handle it quite well, yeah I think I, I think I do. I think it's probably a strength and a weakness of me and the way I work and you know, I think that um, as a strength I don't think that I, I don't get I get hugely emotional affected by, by my work. I like to think um, but yeah, you get tearful on the odd occasion.I like to think that, that because of that I can stay in this field for quite a long time and um I can um, and so I can build lots of knowledge and expertise over time because I can be here for quite a while. Um, one of the weaknesses is I think that sometimes, because I, I can have that ability to, to be a little dissociated from the experience, just, just step off, you know sometimes that can, might be read as disinterest, I don't, I just, just a couple of times, you know I just wonder, I just wonder if sometimes it comes.. (P1)

P3 felt that often they were unaware that the client was terminal as they lacked the medical knowledge that others in the POS team had. They reflected that their way of coping may be an expectation that clients would survive.

I cope pretty well. Sometimes I don't know that they're [client] terminal and its quite good not having too much medical knowledge. Sometimes I have a case where everything is fine and then they're dead.I always dread ringing. I just see that in everyone there is the potential for a good outcome. Maybe that's my coping mechanism, ignorance can be bliss. (P3)

9.3 Participant Group Differences

As discussed, the POS psychologists clearly expressed feeling a deep connection with their clients who may be facing their own mortality or the early death of a loved one. This existential aspect of their work helped some clinicians to feel that the conversations they had with clients were more meaningful and spiritual. However, the depth of this spiritual aspect of their cancer journey was not reflected by the POS participant groups. This may have been a reflection of culture given that no participants who identified as Maori or Pasifika were interviewed. For Maori and Pasifika cultures spirituality or wairua is an integral part of their culture and of the Maori model of

health, Te Whare Tapa Wha (Durie, 1994) as previously discussed. When asked about spirituality, the cancer participants interviewed mentioned religion but not existential spiritual aspects of their cancer journey possibly because of the more secular nature of western culture or it may be that those who maintain a positive attitude relating to their prognosis do not look at existential issues.

9.4 Summary

This chapter explored the experience of four clinical psychologists working in the Massey Psycho-Oncology Service. The theme of “Connections” emerged with the clinicians expressing the deep satisfaction they found in working with people with cancer. This theme also extended into the stronger therapeutic connection they experienced with this client group in comparison with clients from other services. This connection was also felt within the POS team where their being able to talk with their peers and have ready support positively impacted client outcomes. Challenges were explored and the psychologists identified the therapeutic challenges of what were the issues to focus on when non-cancer problems arose and also bringing therapy to a close. Personal challenges were related to working with clients who may be dying and how to protect themselves from the inevitable distress that this would create.

CHAPTER 10

DISCUSSION

This chapter discusses the outcomes of the current study which explored the experiences of former clients of the Massey Psycho-Oncology Service (POS) who were coping with breast or gynaecological cancer or were family/whānau members of clients coping with cancer. The study also interviewed people with cancer who had received no specialist psycho-social support so their journeys could be compared to those of former POS clients. To further seek to understand the factors that affect outcomes, the psychologists of the Service were interviewed so their perspectives could be explored. Thematic analysis was used to explore participants' lived experience of cancer. Factors which may have impacted POS psychological interventions were analysed and discussed. Implications for clinical practice in New Zealand and internationally are elucidated. Study limitations are identified and finally recommendations for future research are suggested.

10.1 Major Findings

The aim of this study was to explore and identify factors which may impact the experiences and therapeutic outcomes of clients in New Zealand using the Massey University Psycho-Oncology Service (POS) as a case study. Major themes identified were *Meaning of Cancer – creating distress*, *Dealing with it – reducing distress*, *Experience of POS* and *Being a Psycho-Oncologist*.

10.1.1 Meaning of cancer – creating distress.

It was important to explore the relationship that people affected by cancer had with the illness and not just their experience with POS. This was not only respectful of the clients' cancer journey but allowed key issues that impacted them to emerge thus

allowing future Services to focus on them. Taking an holistic view of their cancer journey also allowed participants to uncover what cancer meant to them before they were personally affected by it. Sub-themes identified which emerged were *Cancer Means Death* and *Loss*. The sub-theme, *Cancer Means Death* highlighted the fact that for most of those interviewed there was an innate belief that a diagnosis of cancer was a death sentence which generated considerable distress for the majority of cancer participants. The distress response was also embodied for some participants within the sub-theme of *Loss*. Specific areas of loss reflected by participants were *Loss of future*, *Loss of control*, *Loss of Body Image* and *Loss of Connection*. Distress was seen to be generated for participants by the specific, unique relationship that each had with cancer, the meaning that it had for them as an illness and the way this impacted their lives.

10.1.2 Dealing with it – reducing distress.

It was also important to identify the manner in which people affected by cancer were able to reduce the distress caused by this illness. This is helpful for psychologists working with people affected by cancer as it provides them with knowledge regarding the ways people affected by cancer cope with distress. This is knowledge which may then be shared with clients. Sub-themes of *Taking Control*, *Being Positive* and *Support* were explored. In essence, the theme of *Dealing With It - Reducing Distress* was related to the way in which cancer participants sought to cope with the distress they experienced from the meaning and impact that being affected by cancer had on their lives. Most cancer participants actively used their own emotional, practical and personal support resources to change their relationship with this illness in order to reduce distress and cope with a perceived loss of future, control, body image, and connection with others.

10.1.3 Experience of POS

For some people affected by cancer, in spite of using good coping responses they still felt the need for professional psychosocial support. In this theme the relationship that POS participants had with POS, from both the breast/gynaecological cancer and family/whānau groups, were explored. Sub-themes of *Pre-Service Use Expectations, Feeling Safe, Feeling connected, Reconnecting* and *Effects of the Research Interview* were found. Throughout this theme of *Experience of POS* the concept of relationships was clear. Positive expectations and a sense of trust in the Service helped to develop a good initial relationship with the clinicians. This was continued through having a sense of the Service and the clinicians as being safe, and in turn this encouraged a strong relationship to further develop with the clinicians. In addition, for couples, their own relationships improved because of connecting together within therapy and with the clinician. The author endeavoured to develop a relationship during the interview process and this may have been why some participants felt a benefit from the interview itself.

10.1.4 Being a psycho-oncologist

Four of the Service clinical psychologists were also interviewed in order to determine their experiences of the therapy story. In the theme of *Being a Psycho-oncologist* two sub-themes emerged *Connecting* and *Challenges*. Reflected within this theme of *Being a psycho-oncologist* it was apparent that the concept of relationships was a connection throughout the findings. The clinicians described the meaningfulness of their relationship with their work, their clients and with the team. This is consistent with previous research (e.g. Callahan 2012; Penson et al., 2000; Rohan & Bausch, 2009, Weiner et al., 2012) in which working in an oncology setting can deepen relationship connections.

10.2 Factors Affecting Therapeutic Outcomes

A number of factors emerged from the themes within participant interviews which may have impacted therapeutic outcomes. These were identified as *Client expectations, The therapeutic relationship, and Team environment*.

10.2.1 Client expectations.

As previously discussed most study participants clearly had positive expectations of the Service prior to seeing the POS psychologist. Previous studies (e.g. Greenberg et al., 2006; Claiborn & Schmidt, 1977; Greenberg, 1969; Gibbons et al., 2003; Constantino et al., 2005) have shown that clients feelings of confidence and trust in the psychologist prior to therapy can positively impact the therapeutic relationship and outcomes for clients. This differs from the findings of Croy (2010) who concluded expectation “did not play a major role in treatment outcome” (p131) for clients of POS. It is unclear why Croy’s (2010) research findings differed from the current study. Although not attributed to improved outcome Croy (2010) did state that participants had a “general expectation that it [therapy] would be beneficial” (p. 128). The current study findings for this group of participants did indicate that pre-therapy expectations may have been a factor in positive therapeutic outcomes and this is consistent with previous research in which improvement is more likely for those clients with more optimistic or positive expectations (Lambert, 1992; Dew & Bickman, 2005; Greenberg et al., 2006).

Participants conveyed having confidence in POS, expressing an understanding that the psychologists were trained and had specialist knowledge in treating people coping with cancer. The fact that the Service was linked to Massey University, may have created a feeling for clients of being connected to a place of knowledge, a place which is respected in the local community. The positive attitude POS participants had prior to their therapy appeared to also be reinforced on their first POS contact. They

found that the administration staff were welcoming and clinic environment was perceived as safe and nurturing. With the Service being able to allow clients flexibility of appointments and being concerned about “matching” the client to the clinician, clients may also have experienced a renewed sense of being in control within their cancer journey. Having an improved sense of personal control may reduce feelings of helplessness and hopelessness and improve well-being (Greer & Moorey, 1997; Kandasamy, Chaturvedi, & Desai, 2011; Lichtenthal et al., 2009).

10.2.2 Connection with the psychologist- the therapeutic relationship.

All former POS clients interviewed expressed feeling comfortable and safe seeing POS clinicians. A small minority expressed negative attitudes about psychologists prior to using POS but all found the Service beneficial and believed that the psychologists were helpful and professional. Only two participants had felt that they were not well matched to their initial psychologist. But they found that it was easy to change clinician, finding benefit of the team structure in the ease of transition. This ability to change clinician once again provided POS clients with a sense of control over their therapy, which was missing during their hospital treatment.

One of the unique aspects of this study was being able to interview the POS psychologists. All expressed feeling a deeper connection with their cancer clients, than other client groups they had previously worked with, finding that getting to the core of issues was an easier process than with clients in other settings with different problems. Previous areas of practice may have been less conducive to a strong therapeutic alliance, but even for work environments where mental health issues may be comparable, the psychologists felt there was a more profound connection working with POS clients. This is important as research has consistently identified therapeutic outcome as linked to the strength of the therapeutic alliance (Schur & Montgomery, 2011) and that

therapeutic alliance is a critical factor for those clients with cancer (MacCormack et al., 2001). Blow, Spenkle and Davis (2007) claim that “it is in the therapeutic relationship that therapists either make or break therapy” (p. 306). The current study suggests that the Service psychologists’ enthusiasm for the work they do and the feeling that their work had meaning, may have fostered a stronger and faster therapeutic alliance with the POS participants.

10.2.3 Team environment.

The team environment was described as being beneficial by all POS psychologists interviewed. They felt being able to discuss clients and issues they may have in a supportive and mutually respectful workplace benefitted client outcomes. This is consistent with previous research which found that teams whose members are available to support each other may offer protection against the challenges intrinsic in working in oncology (Penson et al., 2000; Rohan & Bausch, 2009). As previously discussed, the team environment also meant that clients were able to transfer easily to a different psychologist if needed. It meant they were able to do this without having to face engaging a new psychologist themselves, having their notes transferred, and maybe going on another waiting list.

10.2.4 Seeing the whole family.

The cancer clients and family members who were seen together at some point during therapy at POS clearly found this beneficial. They voiced being able to connect with their partner or family member in a deeper way due to improved communication and a better understanding of each other. As previously discussed, the current study supports prior findings (e.g. Baucom et al., 2009; Schmitt et al., 2008; Scott, Halford &

Ward, 2004) which show that therapy outcomes for couples and families are improved by the provision of family inclusive therapy sessions.

10.3 Comparison of Cancer Journeys

The cancer participant groups were compared within the findings chapters. The journey for those who had sought professional psychosocial support did not differ clearly from the NI group. Participants from both groups expressed a similar innate belief that cancer was terminal and also experienced the distress of similar losses. The POS participants conveyed feeling happy with the social support they experienced as did the NI group. NI group participants actively sought peer support from friends and family who had experienced the same cancer. However, most POS participants received rather than actively sought support and therefore this may not have been the type of support they required thus leading them to still need specialist support. This is consistent with research by Finfgeld-Connett (2005) showing that it is specific qualities of support that are need. Two of the Non-intervention couple, Bill and Rose, had previously coped with Bill's prostate cancer and so were able to draw on that past positive experience and mutual support while coping with Rose's ovarian cancer. Non-intervention group family member Grace, was the only NI participant who did not actively seek social support and did comment that she would have used POS if it had been offered. The process of actively seeking social support may have led to a greater sense of control by the NI group and provided them with all the support they needed.

10.4 Clinical Implications

The Massey Psycho-Oncology Service clearly provided a service which benefited those who used it, and findings from this study suggest a number of clinical implications for psycho-oncology practice. The current study was clinically important in that it identified several areas which created distress for the cancer participants. This will enable POS clinicians to enter initial therapy sessions with clients having knowledge of areas of possible distress to explore. Other clinical implications of the *Benefits of a dedicated Psycho-Oncology Service* and *Working with the whole family* are discussed in the following sections.

10.4.1 Benefits of a dedicated Psycho-Oncology Service.

As previously stated, the general recommendation for psycho-oncology practice is for a dedicated psychologist to be part of a multi-disciplinary oncology team within a hospital (Holland, 2003). Holland (2003) states that the purpose of this policy is to reduce the stigma often associated with seeing a psychologist. This study showed that a dedicated Psycho-Oncology Service can work effectively in conjunction with the hospital despite being off-site from a medical facility. The initial therapeutic relationship benefitted from clients' perception that they were using a Service which was dedicated to support people on their cancer journey. They perceived the POS psychologists as being professionally trained and experienced in helping people with cancer. Still being associated with the hospital team and with Massey University may have been enough to reduce any stigma of seeking "help" with their mental health. In addition the benefit of the Massey POS model is that it is client focussed and not process focussed. The Service included the availability of several psychologists with different genders, cultural affiliations and methods of working therapeutically. This allowed the opportunity to "match" clients with a psychologist as much as possible and

if problems did arise with the therapeutic relationship, an easier transition to a new clinician could occur for the client. Being part of a team also benefited the Service psychologists who felt that they could more easily discuss aspects of client care with each other, something that would be much more difficult if working alone.

Being away from the environment of the hospital allows clients to feel removed from the medical setting which participants in this study found beneficial to their mental well-being. The hospital environment is not always conducive to developing a strong therapeutic relationship and the hospital can be a reminder of their connection with cancer and treatment. However, the author acknowledges that there are times when through necessity, POS psychologists must conduct therapy at the hospital.

10.4.2 Working with the whole family.

Massey POS psychologists routinely ask about the distress of family members. It is important for those working with people diagnosed with cancer to recognise the detrimental impact that cancer can also have on family members. The benefit of working holistically with the family was clear in the participant interviews. The current study and previous research (Baucom et al., 2009; Schmitt et al., 2008; Scott et al., 2004) highlights the benefit that seeing family members together can have on relationships. Family members expressed feeling a greater connection and being able to communicate better with their loved one. Where possible and appropriate therefore, professionals working with people with cancer should encourage family members to attend therapy both separately and in joint sessions.

10.5 Study Limitations

The aim of the current study was to explore and identify factors which may have affected the therapeutic outcomes and experiences for those clients with breast cancer, gynaecological cancers and family/whānau members. As with all research there are several limitations to the current study.

Although it was hoped to interview POS clients who identified as Maori or Pacific Island, unfortunately there was no representation from either of these ethnic groups. At the time of data collection the number of Maori and Pacific Island clients was low and therefore there was an even more limited sample to draw from. Ethnicity was not intended as the chosen focus for the current study.

The numbers of participants for the breast (n=4) and gynaecological cancer groups (n=2) was low and the author feels that it is unlikely that saturation was reached for this group. However, time constraints limited the opportunity to rectify this, and the participants who agreed to be interviewed took three years to recruit. There were no former POS clients with cancer and only one in the family group who were under the age of 30 years. This means that the views of younger adults would not have been fully represented and for some groups, such as those with gynaecological cancer, additional themes particularly relating to impact such as loss of fertility and future family would likely have been found.

As previously explained it had been intended to include clients with colorectal cancer in the study in order to explore and compare the thoughts and experiences of male and female cancer clients with the same cancer type. However, due to difficulty in recruiting this group it was excluded from the study. Thus, the experiences of former male POS clients with cancer were not explored and so findings cannot be expanded to this group.

Ethics requirements meant that all participants were offered the option of having a support person present when interviewed and as a result of this some couples chose to be interviewed together. As previously discussed in Chapter 7, interviewing some couples together may have prevented either participant from disclosing information about the other openly. However, it was noted that couples who were interviewed together reflected on each other's discourse thus providing a richness to the data that may not have emerged if they had been interviewed separately.

All POS participants were recruited post psychological therapy and therefore it is possible that the study was affected by a self-selection bias, meaning that only those clients who felt positive about their POS experience agreed to participate. Therefore, the experiences of former clients who may have had a less favourable perception of the Service are not known. Also, participants were recruited up to 18 months post-therapy which may mean that they were not able to remember specific aspects of therapy which they found more or less helpful.

It was coincidental that the POS participants were drawn from those who had only attended the POS clinic. Given that clients are sometimes also seen in their own homes or in hospital wards, it was not possible to directly compare the impact of how "where" therapy is conducted may have had on therapy outcome.

The participants were drawn only from the MidCentral District Health Board Area in New Zealand. New Zealand has a small population and the location of this study is from a small city, in a relatively rural based population area. It did not include population from any of the larger cities. Also, it did not include participants who may have sought counselling services or sought help privately within the same geographical location of POS. This means that it was not possible to compare the experiences and outcomes of former POS clients with those who used other professional support.

Therefore caution should be used in applying these findings in other settings without additional research.

10.6 Recommendations for Future Research

The findings of the current study draw attention to a number of areas which may be addressed by future research.

The current research suggested that those who chose not to seek professional psychosocial support relating to their cancer diagnosis felt adequately supported by their social support network. However, some of these participants actively sought the support they needed. As discussed, former POS clients also expressed feeling supported by friends and family. Therefore, qualitative research exploring the differences in social support received, or sought, between these groups may be able to further elucidate if there were any differences in the nature of this support which would explain this phenomenon in more depth.

Future research should aim to include the views of those adults with cancer under the age of 30 years and also the experience of children and adolescents who have used the Service. In addition, research concentrating on the experience of male clients is essential given that this group has been found to be more likely to benefit from psychological interventions provided they overcome their barriers to seeking help (Heron, 2009).

The psychologists interviewed in this study had only been working in POS for approximately three years at the time of interview. It would be interesting to explore the ways in which their feelings and thoughts about working in POS and experiences with clients may have changed during the last four years. The current study was specifically looking at factors influencing outcomes of those using Massey POS and therefore it was reasonable to interview only the psychologists of that Service.

However, given this is such an under researched area, exploring the thoughts and feelings of psychologists working in other oncology settings is necessary in order to gain a broader picture of their experiences. It would be particularly valuable to develop an online survey for oncology psychologists, initially accessing the Australasian network, with a view to expanding our knowledge of what these clinicians see as the essential and most helpful strategies for working with cancer clients and examining whether these are reflected in, or differ from, the views of the clients themselves. Given the relatively higher rates of cancer, the views of Māori and Pacific Islanders should be represented in New Zealand cancer research. Therefore, a further qualitative study exploring the cancer journey and POS experience of specific cancer groups within these populations should be conducted. The fact that some Maori and Pasifika clients tend to avail themselves of the Service at a much later stage in their cancer journey, in fact in some cases terminal, does raise questions about what the Service might offer to clients at different stages in their cancer journey.

This study examined two specific groups of former POS clients, breast/gynaecological cancer and family/whānau members, as they were the largest POS client groups within this Service. The study of other cancer groups is also important in order to gain a wider understanding of how POS and other cancer services globally and in New Zealand can better support the needs of diverse groups affected by cancer. Given the limitations imposed by the small sample size, it was useful to explore these concepts in more depth prior to developing a larger quantitative study which would have the potential to add to our knowledge of this area by creating a multi-location study capable of accessing larger numbers of participants.

In addition to the qualitative research conducted to explore the impacts and needs of various groups using the Service, information from the literature and insights

obtained from the current study could also be used to develop an online survey questionnaire. This would enable a larger group of cancer patients to be canvassed with a view to exploring more fully the needs of people dealing with a cancer diagnosis.

10.7 Conclusion

The aim of the current study was to identify factors which may impact the therapeutic outcomes and experiences of two groups of clients, females with breast or gynaecological cancer and family/whānau using the Massey Psycho-Oncology Service (POS) in New Zealand as a case study. In addition, clinical psychologist working in POS and a group of people affected by cancer who had not used any professional support were interviewed. Previous research by Croy (2010) studied a broader overview of the Service and did not look at specific cancer groups. In addition Croy (2010) did not explore the experiences of POS clinicians and this was a recommendation by Croy (2010) for future research.

This study added to a larger planned evaluation of the Massey Psycho-Oncology Service in New Zealand which have included Baken and Woolley (2009), Baken, Woolley, Croy, and Nixon, (2009, see Appendix N) and Croy, (2010). It is hoped that the current study will also add to that of Croy (2010) to enable POS to help refine procedures and interventions targeted at specific client groups and the unique needs of the New Zealand population. Further, that the findings of this study will aid in the development of other specialist Psycho-Oncology Services and provide information that could be applied by other services in the psycho-oncology field in New Zealand.

The current research also adds to the international knowledge base with regard to clients who use Psycho-Oncology Services although, as discussed, the small participant numbers make it difficult to apply findings outside of the study setting. This study is unique in exploring the experiences of psychologists working with people

affected by cancer and also in examining the journeys of those who used psychosocial support with those who did not.

In summary, the major findings were that for the cancer participants interviewed, distress developed through inherent beliefs that cancer is a terminal illness. Distress was also created through facing loss of a future, loss of control, loss of body image and disconnection from intimate and social relationships. Cancer participants used a variety of coping strategies to reduce their cancer related distress. In order to attempt to regain control over their illness a number of participants reported using active coping skills such as seeking out information or adopting healthier behaviours including exercise and dietary changes. The interviews showed also that some cancer participants adopted a positive attitude and were also able to see positive aspects of their cancer journey. All cancer participants reported receiving both emotional and practical support from their partner/spouse, family and friends, medical staff and other support agencies. The non-intervention group who did not use POS however, seemed to adopt a more active seeking of social support. For the participants who were former clients of POS there was a pre-Service expectation that the Service had psychologists who were specially trained and knowledgeable in working with people affected by cancer. Most of them had no specific goals for therapy but just wanted to talk with someone. The former POS clients talked about their experience of the Service as finding it a safe and nurturing place to be. They found the POS psychologists to be professional and felt the benefit of talking to someone they did not know. The POS clients talked about feeling a sense of connecting with the clinicians and it emerged that the relationship with the clinician was the main recollection about their therapeutic experience. This is in line with research (e.g. Andrews, 2000; MacCormack et al., 2001; Croy, 2010) referred to earlier which emphasises the importance of the therapeutic relationship in working in a

psychotherapeutically effective manner. Those POS participants who had been seen with a family member during therapy at POS found that communication improved and they described reconnecting with their loved one. The benefit of talking to someone about their cancer journey emerged within all cancer participant groups and in line with research by Colborne and Sque (2005), some participants experienced the research interview itself as being beneficial. The interviews with the POS psychologists revealed that they felt strong connections with their work and found meaning and value in it. They also described feeling that the therapeutic relationship was deeper with their cancer clients. The model of the Service having a team of psychologists was seen to benefit both the psychologists and the clients. The POS psychologists found that working in oncology produced both therapeutic and personal challenges.

The aim of this study was to explore factors which may impact the therapeutic outcomes and experiences of clients using a Psycho-Oncology Service. The factors which emerged from the themes within participant interviews were identified as positive client expectations, a strong therapeutic relationship, and the benefit of providing psychological interventions in a team environment.

It is hoped that on-going research into additional areas, including long-term survivorship brought about by continuing improvements in cancer diagnosis and treatment, will lead to on-going improvements in designing interventions which will benefit the psychological as well as the physical well-being of people dealing with a diagnosis of cancer, be they children, adolescent, adults or older adults. In addition, research into the training needs for specialist psycho-oncology clinicians may contribute to their ever increasing effectiveness and improved holistic interventions for cancer patients.

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APPENDICES

Appendix A: Ethics Approval Letter



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

21 July 2008

Ms Colette Nixon
53 Wyndham Street
Ashhurst
4810

Dear Colette,

A qualitative study to explore factors which may impact the effectiveness of interventions provided by the Psycho-Oncology Service at Massey University.
Ms Colette Nixon, Dr. Don Baken
Massey University
CEN/08/03/008

The above study has been given ethical approval by the Chairperson of **Central Regional** Ethics Committee under delegated authority.

Approved Documents

Information sheet and consent form version 5.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **28th June 2009**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **June 2009**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Emalene Pearson
Multi-region Ethics Committee Administrator

Email: emalene_pearson@moh.govt.nz

Appendix B: Semi-structured Interview –Former POS Clients with Cancer**A study of factors which may affect how clients with breast or gynaecological cancer and family members respond to therapy provided by the Psycho-Oncology Service at Massey University.****Interview Questions – *Client with cancer***

Interview will begin with:

- Introductions / Whakapapa
- Explanation of study
- Answering of any questions
- Outline areas to be discussed –**Cancer experience –Life Impact–PO Service**
 - = *interviewer’s prompt only.*

Cancer Experience

1. If you look back to before you were diagnosed with cancer, what do you recall were your thoughts or experiences of this disease?
2. If you were looking back from the time before you were diagnosed up until today, what can you tell me about your own cancer experience? (Thoughts / Feelings / Expectations / Behaviour)
 - Initial diagnosis
 - Prognosis
 - Treatment options
 - Communication / relationship with medical staff
 - Communication / relationship with family / whanau / friends / work colleagues
 - Family reactions / behaviour/ coping skills

Life Impact

3. In what ways has having cancer affected your life?
 - Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality – body image (Tinana)
 - Relationships – family – friends – work (Whanau)
 - Financially
 - Socially
 - Area of most impact?

Interview Questions -cont

4. How do you feel that having cancer has affected your family / whanau?
 - Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality (Tinana)
 - Relationships – family – friends – work (Whanau)
 - Financially
 - Socially
 - Area of most impact?
5. What support have you had you had from partner / family / whanau / friends/other sources?

P-O Service

6. When you were first offered the use of the PO Service what were you hoping that they could help you with?
 - Was the help with this a service that they couldn't find elsewhere?
7. When seeing the psychologist what were the issues you worked on?
 - Coping strategies used in previous stressful experiences - has seeing the psychologist changed these?
8. How would you describe your experience using the PO Service?
 - Appointment times
 - Venue
 - Travelling
 - Relationship with your psychologist
 - Problems
9. In what ways has seeing the psychologist been most helpful during your cancer experience?
10. What were your thoughts or feelings about psychologists before attending PO Service?
 - How have they changed, if at all, since meeting with the psychologist?

Appendix C: Semi-structured Interview–Former Family/whānau Clients with Cancer

**A study of factors which may affect how clients with
breast or gynaecological cancer and family members respond to therapy
provided by the Psycho-Oncology Service at Massey University.**

Interview Questions– *Family/Whānau Client*

Interview will begin with:

- Introductions/Whakapapa
- Explanation of study
- Answering of any questions
- Outline areas to be discussed –**Cancer experience –Life Impact–PO Service**
 - = *interviewer’s prompt only.*

Cancer Experience

11. If you look back to before (*cancer patient name – [CP name]*) was diagnosed with cancer, what do you recall were your thoughts or experiences of this disease?
12. If you now look back from the time before [*CP name*] was diagnosed up until today, what can you tell me about your cancer experience? (Thoughts / Feelings / Expectations / Behaviour)
 - Initial diagnosis
 - Prognosis
 - Treatment options
 - Communication / relationship with medical staff
 - Communication / relationship with [*CP name*] / friends / work colleagues
 - [*CP name*]'s reactions / behaviour/ coping skills

Impact

13. In what ways has [*CP name*] having cancer affected your life?
 - Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality (Tinana)
 - Relationships – family – friends – work (Whanau)
 - Financially
 - Socially
 - Area of most impact?

Interview Questions continued

14. How do you feel that having cancer has affected [CP name]?
- Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality – body image (Tinana)
 - Relationships – family – friends – work (Whanau)
 - Financially
 - Socially
 - Area of most impact?
15. What support have you had you had from [CP name] /family/whānau/friends/other sources?
16. What help do you feel [CP name] has needed from you most during this time?

P-O Service

17. When you were first offered the use of the PO Service what were you hoping that they could help you with?
- Was the help with this a service that they couldn't find elsewhere?
18. When seeing the psychologist what were the issues you worked on?
- Coping strategies used in previous stressful experiences - has seeing the psychologist changed these?
19. How would you describe your experience using the PO Service?
- Appointment times
 - Venue
 - Travelling
 - Relationship with your psychologist
 - Problems
20. In what ways has seeing the psychologist been most helpful during your experience with [CP name] having cancer?
21. What were your thoughts or feelings about psychologists before attending PO Service?
- How have they changed, if at all, since meeting with the psychologist?

Appendix D: Semi-structured Interview – NI Group**Interview Questions – *No Intervention*****What factors may impact the wellbeing of people affected by cancer?**

Interview will begin with:

- Introductions / Whakapapa
- Explanation of study and Answering of any questions
- Outline areas to be discussed:
 - Assessment of distress levels at diagnosis and current distress levels
 - Using Distress Thermometer
 - Cancer experience
 - Life Impact
 - Support
 - = *interviewer's prompt only.*

Cancer Experience

22. If you look back to before you were diagnosed with cancer, what do you recall were your thoughts or experiences of this disease?
23. If you were looking back from the time you were diagnosed up until today, what can you tell me about your own cancer experience? (Thoughts / Feelings / Expectations / Behaviour)
- Initial diagnosis
 - Prognosis
 - Treatment options
 - Communication / relationship with medical staff
 - Communication / relationship with family / whānau / friends / work colleagues
 - Family reactions / behaviour/ coping skills

Life Impact

24. In what ways do you feel that having cancer has affected your life?
- Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality – body image (Tinana)
 - Relationships – family – friends – work (Whānau)
 - Financially
 - Socially
 - Area of most impact?
25. How do you feel that having cancer has affected your family / whānau?
- Spiritually (Wairua)
 - Emotionally – fear – anger (Hinengaro)
 - Physically – sexuality (Tinana)
 - Relationships – family – friends – work (Whānau)
 - Financially
 - Socially
 - Area of most impact?

Support

26. What support have you had you had from partner / family / whānau / friends?
- How helpful was this?
27. What support have you had you had from other sources
- Self-help groups / Cancer Society / other?
 - How helpful was this?
28. What other help/support would you have liked to have had?
29. Were you aware of the Psycho-Oncology Service?
- Was a referral offered to the POS?
 - If *yes* - why did you not use the POS?
 - If *no* - would you have liked to have been referred?
30. Is there anything else you would like to add?

Appendix E: Semi-structured Interview POS Clinicians**Interview Questions – *Psychologist*****A study of factors which may affect how clients with breast or gynaecological cancer and family members respond to therapy provided by the Psycho-Oncology Service at Massey University..**

Interview will begin with:

- Introductions / Whakapapa
- Explanation of study
- Answering of any questions
- Outline areas to be discussed
- = *interviewer's prompt only.*

Cancer Experience

1. What prompted you to be involved with the POS?
2. How long have you been seeing clients for the POS?
 - Ratio of POS to non POS clients?
3. In what ways is your experience helping a POS client different from helping a non POS client?
4. What therapeutic techniques do you use for POS clients?
 - Family involvement in therapy?
5. What specific therapeutic challenges have you found when working with a POS client?
 - Therapeutic relationship
 - Poor response to therapy
 - Poor prognosis
 - Other professionals
 - Any other
 - How were these handled?
6. What personal challenges have you encountered working with POS clients?
7. How do you decide that it is time to end therapy?
8. Is there anything that you would like to add?

Appendix F: Transcriber Confidentiality Form

A study of factors which may affect how clients respond to therapy provided by the Psycho-Oncology Service at Massey University.

Confidentiality Agreement Transcription Services

I, _____, transcriptionist, agree to maintain full confidentiality in regards to any and all audio recordings and documentation received from Colette Nixon related to the above named doctoral study.

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of digitally recorded interviews, or in any associated documents;
2. To not make copies of any computerised files of the transcribed interview texts, unless specifically requested to do so by Colette Nixon;
3. To store all study-related digital recordings and materials in a safe, secure location as long as they are in my possession;
4. To return all digital recordings and study-related documents to Colette Nixon in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the digital recordings and/or files to which I will have access.

Transcriber's name

(printed) _____

Transcriber's signature

Date _____

Appendix G: Letter of Invitation to Participate – Former POS Clients**AN INVITATION TO PARTICIPATE
IN A RESEARCH STUDY****A study of factors which may affect how clients with
breast or gynaecological cancer and family/whānau clients respond to therapy
provided by the Psycho-Oncology Service at Massey University.**

The Psycho-Oncology Service is in the process of inviting former clients to take part in a study of their experience of using the Service. The study is being conducted through interviews by Colette Nixon who is a post-graduate student. Any information, which you provide, is with the assurance that any material which could personally identify you, including your name, will not be used in any report of this study or be seen by Psycho-Oncology Service staff.

If you are interested in finding out more, please fill out the slip below and return it to the Psycho-Oncology Service in the Freepost envelope enclosed by.....

Remember that you have the right not to take part. You are in no way committing yourself by returning the slip.

If you do reply, an Information Pack will be posted to you. You will then be contacted by the Principal Investigator so you can talk to her in more detail about the study and its procedures, and discuss any questions that you may have. At that point, if you agree to participate, your interview will be arranged for a time that suits you. Your interview would take place in a private room at either the Psycho-Oncology Service Clinic or at Addis House (Cancer Society, Palmerston North). Alternatively, where appropriate, a meeting can take place in your home or in a suitable, mutually agreed venue. A \$25 fuel voucher will be provided at your interview to cover your time / travel costs.

Thank you for considering this invitation.

Yours sincerely

Gail Shirley , Administrator
Psycho-Oncology Service
Massey University
Ph: (06) 3505196

I am considering participating in your study and would like you to contact me to discuss it further.

Name: _____

Contact phone number/address: _____

Appendix H: Information Pack – Former POS Clients
(Information Sheet and Consent Form)

INFORMATION SHEET

9th March 2009

**A study of factors which may affect how clients with
breast or gynaecological cancer and family/whānau clients respond to therapy
provided by the Psycho-Oncology Service at Massey University.**

Principal Investigator

My name is Colette Nixon and I am a mature postgraduate student completing a Doctorate in Clinical Psychology at Massey University. My supervisor is Cheryl Woolley (Senior Lecturer and Clinical Programme Co-ordinator in Psychology at Massey University). This study has received ethical approval from the Central Regional Ethics Committee.

About the Study

The aim of this study is to understand the experience of being a client of the Psycho-Oncology Service (POS). In particular, I am looking at what factors may have positively or negatively affected your experience with the POS. To do this I would like to informally interview some people so that they can tell me what a diagnosis of cancer and having use of the POS has meant to them. I will ask some questions during the interview but will also be guided by what have been important issues for you. I am interested in hearing about personal experiences of cancer, using the POS and anything that may have helped in coping or coming to terms with having cancer. Examples of issues I want to discuss are your personal cancer experience, how having cancer has affected your life and how you hoped the POS could help you.

The interview will take about 60 to 90 minutes and may be done over one or two sessions depending on individual wishes. The interview will take place in a private room at either the Psycho-Oncology Service Clinic or at Addis House (Cancer Society, Palmerston North) at a time that suits you. Alternatively, where appropriate, a meeting can take place in your home or in a suitable, mutually agreed venue. You have the right to have a friend, family or whānau support during the interview. A \$25 petrol voucher will be provided to cover your time / travel costs.

Your interview will be audio-taped and transcribed by a professional transcriber for later analysis by me. The tapes will be stored securely in a locked filing cabinet, only be accessible to myself. To ensure confidentiality your name will only be known to myself and your interview audiotape and transcript will be identified by code. Your name will not be used in any analysis or publication of findings. All tapes, transcripts and data will be destroyed after 10 years; however you can have your tape returned to you if you wish.

You are invited to take part in this study but participation is entirely voluntary. If you do not feel well enough to take part please feel free to decline participation. If you agree to take part, it will be under the conditions set out in this information sheet. You may have a friend, family or whānau support help you understand this study and any other explanation you may require. You are encouraged to ask questions about the study.

If you choose to take part, you have the right to refuse to answer any questions. You have the right to ask for the tape to be switched off at any time during the interview. If you do agree to take part you are free to withdraw from the study at any time without having to give a reason and this will in no way affect your future or continuing health care. You have the right to stop the interview should you feel any distress during the interview and you have the right to re-access the Psycho-Oncology Service. Should you feel distressed following the interview you can contact the Psycho-Oncology Service on (06) 3505196.

Any information, which you provide, is with the assurance that any material which could personally identify you, including your name, will not be used in any report of this study or be seen by Psycho-Oncology Service staff. If you wish you will be provided with a transcript of your interview. If you wish you may be provided with a summary of your answers to ensure that your experience has been interpreted in a way that you agree with.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Sylvia Rumball, Assistant to the Vice-Chancellor (Ethics & Equity), telephone 06 350 5249, e-mail humanethicsouthb@massey.ac.nz”.

If you would like any further information or have any questions about the study please do not hesitate to contact me at the address above, or phone (06) 3505196. If you leave a message with your phone number I will return your call as soon as possible. My supervisor may be contacted at the same number.

Thank you

Colette Nixon

CONSENT FORM

A study of factors which may affect how clients with breast or gynaecological cancer and family/whānau clients respond to therapy provided by the Psycho-Oncology Service at Massey University.

I have read the Information Sheet dated 9th March 2009 for volunteers taking part in the study designed to study factors which may affect how clients of the Psycho-Oncology Service at Massey University respond to therapy. I have had the details of the study explained to me and have had an opportunity to discuss this study. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I have the right to withdraw from the study at any time and to decline to answer any particular questions 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 understand that if I feel distressed during the interview that I have the right to stop the interview.

I understand that if I feel distressed during the interview, or at any time afterwards, I have the right to access help through the Psycho-Oncology Service at Massey University.

I agree to provide information to the researcher on the understanding that my name will not be used in any publications.

I consent to my interview being audio taped YES/NO
I understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

I wish to receive my transcript following interview YES/NO

I wish to receive a copy of the results YES/NO
I understand that a significant delay may occur between data collection and publication of the results.

I _____ (full name) hereby consent to take part in this study

Date: **Signed:**

Researcher's Full Name: Colette Nixon **Contact Phone Number:** 06 3505196
Project explained by: Colette Nixon **Project Role:** Principal Investigator

Signed: **Date:**

Appendix I: Newspaper Advertisement for NI Group**What factors may impact the wellbeing of people affected by cancer?**

Massey University invites you to take part in a study looking at what affects the wellbeing of people with cancer and their family/whānau members.

If you decide to take part you will be asked to come to an informal interview which will take approximately 60 minutes.

We would like to hear from 10 adults who have either been diagnosed with cancer during the last 18 months or who are a family/whānau member of someone diagnosed with cancer. It is important for this study that you have *not* attended any counseling or psychological service related to your cancer experience.

A \$25 fuel voucher will be provided to cover your time / travel costs. If you would like find out more about this study please contact:

Colette Nixon
School of Psychology
Massey University
Tel: (0832)73403

**This study has been approved by the Central Regional Ethics Committee
CEN/08/03/008**

Appendix J: Information Pack –Non Intervention Group
(Information Sheet and Consent Form)

INFORMATION SHEET

11th September 2009

What factors may impact the wellbeing of people affected by cancer?

Principal Investigator

My name is Colette Nixon and I am a mature postgraduate student at Massey University, completing a Doctorate in Clinical Psychology. My supervisor is Cheryl Woolley (Senior Lecturer and Clinical Co-ordinator in Psychology at Massey University). This study has been approved by the Central Regional Ethics Committee.

About the Study

As part of this study I am interested in hearing about your personal experience cancer. In particular, I am looking at factors which may have positively or negatively affected how you have coped. Examples of issues I want to discuss are your personal cancer experience, how cancer has affected your life and what support you have received.

The interview will take about 60 minutes and may be done over one or two sessions depending on individual wishes. Your interview will take place in a private room at either the Psycho-Oncology Service Clinic, Massey University or at Addis House (Cancer Society, Palmerston North). Alternatively, where appropriate, a meeting can take place in your home or in a suitable, mutually agreed venue. A \$25 fuel voucher will be provided at your interview to cover your time / travel costs.

You have the right to have a friend, family or whānau support during the interview. The interview will be recorded and transcribed by a professional transcriber for later analysis by me. The recordings will be stored securely, only accessible to myself. To ensure confidentiality your name will only be known to myself and your interview recording and transcript will be identified by a code. Your name will not be used in any analysis or publication of findings. All tapes, transcripts and data will be destroyed after 10 years.

You are invited to take part in this study but participation is entirely voluntary. If you do not feel well enough to take part please feel free to decline participation. If you agree to take part, it will be under the conditions set out in this information sheet. You may have a friend, family or whānau support help you understand this study and any other explanation you may require. You are encouraged to ask questions about the study.

If you choose to take part, you have the right to refuse to answer any questions. You have the right to ask for the recorder to be switched off at any time during the interview. If you do agree to take part you are free to withdraw from the study at any

time without having to give a reason and this will in no way affect your future or continuing health care. You may stop the interview at any time should you feel any distress and you have the right to access the Psycho-Oncology Service. Should you feel distressed following the interview you can contact the Psycho-Oncology Service by phoning 06 350 5196.

Any information that you provide is with the assurance that your name will not be used in any reports. No material which could personally identify you will be used in any reports in this study. If you wish you will be provided with a transcript of your interview to enable you to add any further information and to check that it accurately reflects your feelings and opinions.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate at Advocacy Network Services Trust: Free Phone: 0800 555 050, Free fax: 0800 2782 7678, email: advocacy@hdc.org.nz

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Sylvia Rumball, Assistant to the Vice-Chancellor (Ethics & Equity), telephone 06 350 5249, e-mail humanethicsouthb@massey.ac.nz".

If you would like any further information or have any questions about the study please do not hesitate to contact me at the address above, or phone 3505196. If you leave a message with your phone number I will return your call as soon as possible. My supervisor may be contacted at the same number.

Thank you

Colette Nixon

CONSENT FORM

What factors may impact the wellbeing of people affected by cancer?

I have read the Information Sheet dated 11th September 2009 for volunteers taking part in the study designed to study factors which may affect the wellbeing of cancer patients or their family/whānau. I have had the details of the study explained to me and have had opportunity to discuss this study. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I have the right to withdraw from the study at any time and to decline to answer any particular questions 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 understand that if I feel distressed during the interview that I have the right to stop the interview.

I understand that if I feel distressed during the interview, or at any time afterwards, I have the right to access help through the Psycho-Oncology Service at Massey University.

I agree to provide information to the researcher on the understanding that my name will not be used in any publications.

I consent to my interview being audio taped. YES/NO

I understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

I wish to receive a copy of the results YES/NO

I understand that a significant delay may occur between data collection and publication of the results.

I wish to receive a copy of my transcript YES/NO

I _____ (full name hereby consent to take part in this study)

Date:

Signed:

Researcher's Full Name: Colette Nixon

Contact Phone Number: 06 350 5196

Project explained by: Colette Nixon

Project Role: Principal Investigator

Signed:

Date:

Appendix K: Letter of Invitation – POS Clinicians**AN INVITATION TO PARTICIPATE
IN A RESEARCH STUDY****A study of factors which may affect how clients with
breast or gynaecological cancer and family members respond to therapy
provided by the Psycho-Oncology Service at Massey University.**

As a psychologist who has been a member of the Psycho-Oncology Service (POS) at Massey University, you are invited to take part in a research study. The study is being conducted through interviews by Colette Nixon, a 2nd year DCLinPsych student. No material which could personally identify you, including your name, will be used in any report of this study or seen by Psycho-Oncology Service staff. An Information Pack is enclosed which tells you about the study and what it will involve for people who participate.

If you are interested in finding out more, please fill out the slip below and return it in the envelope provided to the Psycho-Oncology Service administrator by.....

Remember that you have the right not to take part. You are in no way committing yourself by returning the slip.

If you do reply, you will be contacted by Colette so you can talk to her in more detail about the study and its procedures, and discuss any questions that you may have. At that point, if you agree to participate, your interview will be arranged for a time that suits you. Your interview would take place in a private room at the Psycho-Oncology Service Clinic.

Thank you for considering this invitation.

Yours sincerely

Gail Shirley , Administrator
Psycho-Oncology Service
Massey University
Ph: (06) 3505196

I am considering participating in your study and would like you to contact me to discuss it further.

Name: _____

Contact phone number/address: _____

Appendix L: Information Pack –POS Clinicians
(Information Sheet and Consent Form)

INFORMATION SHEET

12th September 2009

**A study of factors which may affect how clients with
breast or gynaecological cancer and family members respond to therapy
provided by the Psycho-Oncology Service at Massey University..**

Principal Investigator

My name is Colette Nixon and I am a postgraduate student completing a Doctorate in Clinical Psychology at Massey University. My supervisor is Cheryl Woolley (Senior Lecturer and Clinical Programme Co-ordinator in Psychology at Massey University). This study has been approved by the Central Regional Ethics Committee.

About the Study

As part of this study I am interested in the experience of psychologists who help clients with cancer. In particular, I would like to learn about any challenges you may have faced helping POS clients and also to compare your therapeutic experiences of POS clients and those without cancer. I will ask some questions during the interview but will also be guided by what have been important issues for you.

The interview will take about 60 minutes and may be done over one or two sessions depending on individual wishes. The interview will take place in a private room at the Psycho-Oncology Service Clinic. You have the right to have a friend, family or whānau support during the interview.

Your interview will be recorded and transcribed by a professional transcriber for later analysis by me. The recordings will be stored securely, only accessible to myself. To ensure confidentiality your name will only be known to myself and your interview recording and transcript will be identified by code. Your name will not be used in any analysis or publication of findings. All recordings, transcripts and data will be destroyed after 10 years.

You are invited to take part in this study but participation is entirely voluntary. If you agree to take part, it will be under the conditions set out in this information sheet. You are encouraged to ask questions about the study.

If you choose to take part, you have the right to refuse to answer any questions. You have the right to ask for the recorder to be switched off at any time during the interview. You have the right to stop the interview at any time. If you do agree to take part you are free to withdraw from the study at any time without having to give a reason.

Any information that you provide is with the assurance that your name will not be used in any reports. No material which could personally identify you will be used in any reports in this study. You will be provided with a transcript of your interview to enable you to add any further information if you wish and to check that it accurately reflects your feelings and opinions.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate at Advocacy Network Services Trust: Free Phone: 0800 555 050, Free fax: 0800 2782 7678, email: advocacy@hdc.org.nz

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Sylvia Rumball, Assistant to the Vice-Chancellor (Ethics & Equity), telephone 06 350 5249, e-mail humanethicsouthb@massey.ac.nz".

If you would like any further information or have any questions about the study please do not hesitate to contact me at the address above, or phone (06) 3505196. If you leave a message with your phone number I will return your call as soon as possible. My supervisor may be contacted at the same number.

Thank you

Colette Nixon

CONSENT FORM

A study of factors which may affect how clients with breast or gynaecological cancer and family members respond to therapy provided by the Psycho-Oncology Service at Massey University.

I have read the Information Sheet dated 12th September 2009 for volunteers taking part in the study designed to study factors which may affect how clients of the Psycho-Oncology Service at Massey University respond to therapy. I have had the details of the study explained to me and have had an opportunity to discuss this study. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that taking part in this study is voluntary (my choice) and that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

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 provide information to the researcher on the understanding that my name will not be used in any publications.

I consent to my interview being audio-taped. YES/NO

I understand that I have the right to ask for the audio-tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

I wish to receive a copy of the results YES/NO

I understand that a significant delay may occur between data collection and publication of the results.

I wish to receive a copy of my transcript YES/NO

I _____ (full name) hereby consent to take part in this study

Date:

Signed:

Researcher's Full Name: Colette Nixon

Contact Phone Number: 06 3505196

Project explained by: Colette Nixon

Project Role: Principal Investigator

Signed:

Date:

Appendix M: A Thematic Map of the Analysis

Meaning of Cancer – Creating distress

- Cancer means death
- Loss
 - Loss of a future
 - Loss of control
 - Loss of body image
 - Loss of connection
 - Disconnection from intimate relationship
 - Disconnection socially

Dealing With It- Reducing Distress

- Taking control
 - Finding knowledge
 - Healthy Behaviours
 - Exercise
 - Diet
- Being positive
- Support
 - Family/friends
 - Spouse/partner
 - Medical staff
 - Other support services

Experience of POS

- Pre-Service Use Expectations
 - Perceptions of psychologists
 - Someone to talk to
- Feeling Safe
 - Professional
 - Not someone I know
 - Safe, nurturing environment
- Feeling connected
- Reconnecting
- Effects of the Research Interview

Being a Psycho-oncologist

- Connections
 - Connecting with the work
 - Connecting with the client
 - Connecting with the team
- Challenges
 - Therapeutic challenges
 - Personal challenges

Appendix N: Audit of Outcomes (Cover)



Painting kindly supplied by Sarah Platt, Artist

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16th - 18th November 2008 • Palmerston North Convention Centre
Winds of Change: Ideas • Innovation • Initiatives

Handbook

Appendix O: Conference Abstracts

A qualitative study exploring factors impacting effectiveness of POS interventions for clients with colorectal or breast cancer and their families/whānau

Colette Nixon¹, Cheryl Woolley² & Don Baken²

¹*Colette Nixon is a doctoral candidate, Clinical Psychology, Massey University, Turitea Campus, Palmerston North*


²*Psychology Clinic, School of Psychology, Massey University, Turitea Campus, Palmerston North*


In January 2006 a specialist Psycho-Oncology Service (POS) was established by the MidCentral District Health Board in partnership with Massey University. This paper will present the initial findings from a qualitative study exploring clients' lived experiences of using the POS at Massey University.

Approximately 16,000 people develop cancer each year in New Zealand and by 2011 this level is predicted to increase to 22,000 (Gavin & Marshall, 2001 as cited in Cancer Society of New Zealand, 2004). The psychological impact of a diagnosis of cancer may include anxiety, pain, depression, delirium and fatigue (Holland, 2003). The impact of a cancer diagnosis is not isolated to the patient; research has shown that 18-30% of a cancer patient's adult relatives suffer from depression (Edwards & Clark, 2004).

The initial findings presented arise from the thematic analysis of interviews with former POS clients. Client interviews were confined to those with colorectal or breast cancer and family/whānau members. This study will add to the limited pool of New Zealand and International research in evaluating what factors may have an effect on the psychological interventions provided for cancer patients and their families. The results of the study will help to refine and improve interventions offered and forms part of a planned evaluation of the POS.

pnixon9@slingshot.co.nz






The New Zealand
Psychological Society
Te Rōpū Mātai Hinengaro o Aotearoa

**The New Zealand Psychological Society
Annual Conference 2009**


**Conflict...Process...Resolution
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Catherine Love &
Moe Milne
Kerry Chamberlain
Michael Corballis
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Palmerston North Convention Centre
Thursday 27th - 30th August 2009

Programme & Abstracts, Thursday 27th August 2009

of easy and difficult trivia statements. Previous research has shown that when people read high contrast statements, they are more likely to think those statements are true. We sought to replicate this effect. In a second study, we investigated whether photos would produce the same effect, and paired statements with a related photograph or with no photograph.

12.10pm

Does briefly seeing a photograph change beliefs about people's childhood experiences?

*Robert Michael
Gregory Franco
Stefanie J. Sharman
all Victoria University of Wellington*

We investigated two techniques for increasing people's confidence that they had certain childhood experiences. First, to investigate the effects of processing fluency on beliefs about childhood experiences, we paired brief descriptions of possible childhood experiences with a related photograph or with no photograph. Second, to investigate the effects of base rate information, we asked some people but not others to read a newspaper article claiming that 90% of NZ children experienced a fake skin sample test. People who read the newspaper article were more confident that they had actually had a skin sample taken in childhood. We discuss the role of frequency information in the development of false beliefs.

12.30pm

What's in a name?

*Emily Miller
Eryn J. Newman
Maryanne Garry
all Victoria University of Wellington*

We wondered if processing fluency would affect how people judge unknown others based solely on their names. We manipulated how easy it was to pronounce names from various countries. We hypothesised that, regardless of country of origin, people with names that were easy to pronounce would be judged as good people who had done good works.

12.50pm

Tell me again and maybe I'll believe you

*Thomas Huthwaite
Eryn Newman
Jeffrey L. Foster
Maryanne Garry
all Victoria University of Wellington*

*Elizabeth Loftus
University of California-Irvine, USA*

Repeater: We asked people to watch a simulated crime, and then read three police reports ostensibly written by three different previous participants, or one participant who wrote all three. These reports misled people about some details of the witnessed crime. Our primary aim was to see if [a] people would be swayed by these misleading details when they were repeated three times than when they appeared only once, and [b] people would be more influenced by repeated details attributed to three different people than repeated details said by the same person.

Clinical Health Symposium

*Chair: Janine Van Blerk
Massey University*

3.40pm – 5.40pm
Meeting Room

The Massey University Psycho-Oncology Service has been running for three and a half years, providing psychological support services for cancer patients and their families in the MidCentral Health region. This symposium aims to firstly present the latest research findings about the factors impacting on the effectiveness of psychological interventions for cancer patients, followed by research on the psychological outcomes for clients of the Psycho-Oncology Service at Massey University. Following on from the success of the Psycho-Oncology initiative, MidCentral has more recently established the Health Conditions Psychology Services for Adults and Children and their families at Massey University. The aims and issues around the establishment of the Health Conditions Services will be discussed, followed by a presentation on the work with children and young people carried out by the Massey Psycho-Oncology and Health Conditions Services.

3.40pm

A qualitative study exploring factors which may impact the effectiveness of interventions provided by the Psycho-Oncology Service at Massey University for clients with colorectal, breast or gynaecological cancer and family/whānau members.

*Colette Nixon
Don Baken
Cheryl Woolley
all Massey University*

This paper presents the initial findings exploring

THURSDAY

Programme & Abstracts, Thursday 27th August 2009

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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
Email: nixonz@xnet.co.nz

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.

Email: K.J.Ross@massey.ac.nz

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



Programme & Abstracts, Sunday 21st

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Afternoon 3.00pm - 6.30pm and posters

ICJP symposium continued

3.00pm - 4.00pm - Coronet level 4

The legal liability of Psychologists flowing from disclosure or non-disclosure of confidential personal information received in a clinical environment.

Richard Niven
Departmental Solicitor, Department of Corrections

Duty to disclose, is this a soft or hard duty? How does the Privacy Act impact on this duty? Psychologists rely on the confidence of their clients for the efficacy of their work. The confidence flows from the promise of confidentiality. While some or even most clients attend a psychologist reluctantly, all accept that they must do so. Clinical success depends on full disclosure by the client to the psychologist and a belief that any disclosure will remain confidential. The law limits this. This paper will explore the impact of the Protected Disclosure law and show that its impact is actually very limited. It will examine the Tarasoff decision in a New Zealand context and examine practical examples. The presentation will examine what a court may expect to be considered when disclosure is made and the impact of the Privacy Act when a decision is made to release personal information to the Police (and if a decision is made not to release personal information to the Police) and the hoped-against eventuality actually occurs. Finally, examples of what a Psychologist needs to advise a client at the commencement of treatment in relation to possible disclosure, the nature of any forms to be signed and any additional advice a client may need to receive on this issue will be discussed.

Richard.Niven@corrections.govt.nz

Massey University

Clinical Health Symposium

Chair: Cheryl Woolley, Senior Lecturer, School of Psychology, Massey University, Palmerston North
4.30pm - 6.30pm - Coronet level 4

MidCentral DHB in partnership with the Massey University Psychology Clinic (Manawatu Campus) has established two psychological intervention services to provide psychological support for patients and their families in the MidCentral Health region. The Psycho-Oncology Service caters for the needs of people with cancer, while the Health Conditions Service provides

psychological interventions for adults and children with chronic health conditions.

The first two papers are presented by clinical doctoral candidates whose research focuses on the effectiveness of the Psycho-Oncology Service for people living with cancer. The second cluster of papers report on research which developed manualised treatment programmes, one for children and one for adults.

Finally, a brief discussion of the benefits of building capacity in research and practice, while enhancing the training needs of clinical psychology students, will conclude the current symposium.

c.c.woolley@massey.ac.nz

4.30pm

A qualitative study exploring factors impacting the effectiveness of the Psycho-Oncology Service at Massey University: Experiences of women with breast or gynaecological cancer and family/whānau clients

Colette Nixon¹, Cheryl Woolley², and Don Baken³

¹ Doctor of Clinical Psychology candidate, School of Psychology, Massey University

² School of Psychology, Massey University, Palmerston North

³ Psychology Clinic, School of Psychology, Massey University, Palmerston North

In January 2006 a specialist Psycho-Oncology Service was established by the MidCentral District Health Board (MDHB) in partnership with Massey University. The goal of the Psycho-Oncology Service is to provide free, equitable and culturally aware psychological support for cancer patients and their families/whānau from the MDHB region. The findings presented in this paper arise from the thematic analysis of semi-structured interviews with women with breast or gynaecological cancer and family/whānau clients who attended Massey's Psycho-Oncology Service. Psychologists of the Psycho-Oncology Service and people affected by cancer who were not clients of the service were also interviewed. This study highlights factors impacting the effectiveness of psychological interventions provided for a sample of female cancer patients and family/whānau clients. This study was completed in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology.

nixons97@gmail.com

5.00pm

An investigation into the outcomes of Psycho-Oncology Service interventions

Philippa Croy¹, Cheryl Woolley², Don Baken³, and Janet Leatham¹

¹ Doctor of Clinical Psychology candidate, School of Psychology, Massey University